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Original Paper

The Effectiveness of eHealth Technologies on Weight Management in Pregnant and Postpartum Women: Systematic Review and Meta-Analysis

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Abstract

Background: The emergence and utilization of electronic health (eHealth) technologies has increased in a variety of health interventions. Exploiting the *real-time* advantages offered by mobile technologies during and after pregnancy has the potential to empower women and encourage behaviors that may improve maternal and child health.

Objective: The objective of this study was to assess the effectiveness of eHealth technologies for weight management during pregnancy and the postpartum period and to review the efficacy of eHealth technologies on health behaviors, specifically nutrition and physical activity.

Methods: A systematic search was conducted of the following databases: MEDLINE, EMBASE, Cochrane database of systematic reviews (CDSR), Cochrane central register of controlled trials (CENTRAL), CINAHL (Cumulative Index to Nursing and Allied Health Literature), and PsycINFO. The search included studies published from 1990 to July 5, 2016. All relevant primary studies that involved randomized controlled trials (RCTs), non-RCTs, before-and-after studies, historically controlled studies, and pilot studies were included. The study population was adult women of childbearing age either during pregnancy or the postpartum period. eHealth weight management intervention studies targeting physical activity, nutrition, or both, over a minimum 3-month period were included. Titles and abstracts, as well as full-text screening were conducted. Study quality was assessed using Cochrane's risk of bias tool. Data extraction was completed by a single reviewer, which was then verified by a second independent reviewer. Results were meta-analyzed to calculate pooled estimates of the effect, wherever possible.

Results: Overall, 1787 and 176 citations were reviewed at the abstract and full-text screening stages, respectively. A total of 10 studies met the inclusion criteria ranging from high to low risk of bias. Pooled estimates from studies of the effect for postpartum women resulted in a significant reduction in weight (−2.55 kg, 95% CI −3.81 to −1.28) after 3 to 12 months and six studies found a nonsignificant reduction in weight gain for pregnant women (−1.62 kg, 95% CI −3.57 to 0.33) at approximately 40 weeks.

Conclusions: This review found evidence for benefits of eHealth technologies on weight management in postpartum women only. Further research is still needed regarding the use of these technologies during and after pregnancy.

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KEYWORDS

eHealth; technology; pregnancy; postpartum; weight

Introduction

Background

Mobile phones and other electronic health (eHealth) technologies are now ubiquitous in modern society, with over 90% of the Canadian population utilizing these continuously evolving technologies [1]. To put this in perspective, according to the United Nations (UN), of the world's 7 billion people, 6 billion have mobile phones, whereas only 4.5 billion have access to toilets [2]. The recent emergence of mobile and other eHealth technologies has resulted in an increased use of these tools in health prevention–, promotion-, and cessation-based intervention frameworks for varied clinical areas such as smoking cessation or medication adherence [3,4], and in diverse populations [5-7]. The mobile phone–based approach to health care problems offers health care providers several advantages as it: (1) enables remote data transmission from a participant's environment in an affordable and accessible manner, (2) reaches all segments of the population, including those of lower socioeconomic status, (3) can be semi- or fully-automated for efficient use of clinic resources, (4) can utilize a video or voice-over approach to communication for reducing barriers to access among those with lower literacy, and (5) can be delivered to people in any location with Wi-Fi service, making this approach viable even in rural areas. Finally, the availability, adaptability, and low cost of mobile technologies provide a promising format for delivering lifestyle intervention programs on a regular basis.

The global availability of mobile technologies [8] has created opportunities for mobile phones to potentially contribute to the United Nations Millennium Development Goals, advocated by the World Health Organization (WHO), of improving maternal and child health through the use of these emerging technologies in health care interventions [9]. More importantly, over 90% of millennial expectant women, between the ages of 18 and 32 years, in countries such as the United States, Canada, the United Kingdom, and China, were found to be regular mobile phone users [10,11], suggesting that these devices may offer an alternative approach for delivery of health-related information. Moreover, 96% of pregnant women in North America have indicated an interest in receiving guidance on prenatal care through their mobile phone [11], and 74% of postpartum women report interacting with weight management materials [12]. To date, however, there is a lack of comprehensive studies evaluating their impact during pregnancy or the postpartum period. Although not specifically focused on weight management, the Text4baby study, used a simple text messaging campaign aimed at changing attitudes and beliefs of economically disadvantaged pregnant women and new mothers [13]. The program was highly successful as measured by increased health literacy and preparedness for motherhood among participants. Widespread adoption of the Text4baby program following the initial evaluation suggests that such technologies have broad appeal and represent a viable model for delivery of interventions in the area of maternal and child health. To date, other interventions that have used mobile and other electronic technologies during these critical periods of a woman's life have targeted clinical areas relating to breastfeeding and general health [14], but have not examined other health behaviors in this population.

Other important clinical areas that may benefit from eHealth interventions include weight gain during pregnancy and postpartum weight loss. Both gestational weight gain (GWG) and postpartum weight retention are key contributors to the intergenerational cycle of obesity and cardiometabolic risk in the mother [15,16]. Pregnant women who exceed recommended GWG targets place themselves and their offspring at an increased risk of serious perinatal and future health complications [17]. Not only are these women highly susceptible to gestational diabetes, preeclampsia and other antenatal complications, but they are also at an increased risk of postpartum weight retention [18,19], which ultimately leads to higher rates of postpartum maternal obesity in the long term. It is critical to note, however, that pregnant and postpartum women often report receiving limited, if any, information from their health care providers on weight management during pregnancy and postpartum periods [20-22]. In fact, many health care professionals feel ill-equipped to deliver such counseling [23]. Although considerable systematic review evidence indicates that lifestyle interventions can successfully manage GWG and postpartum weight retention [24-28], when delivered in a personalized fashion, such individualized interventions are generally expensive and may lack scalability from a public health perspective. Consequently, in-person, provider-based delivery of weight management interventions is impractical in current prenatal and postnatal care environments because of the associated strains on the health care system and lack of health care resources. As such, effective real-world solutions are urgently needed to address the needs of women who are seeking personalized support, information, and guidance to assist them with management of their weight, especially those who are receptive to novel technology-based approaches [29]. Whereas eHealth technologies offer the potential to serve as low-cost, widely-available therapeutic tools to support lifestyle interventions for weight management during the pregnancy and postpartum periods, there remains a paucity of data supporting their efficacy and effectiveness during these periods [30]. As such, before the development and widespread implementation of eHealth technologies, a rigorous evaluation of the effectiveness of this delivery modality for health care interventions is required.

Objectives

The primary objective of this systematic review was to assess the effectiveness of eHealth technologies for managing weight (loss, gain, or maintenance) during pregnancy and the postpartum period. The secondary objectives were to assess the effectiveness of eHealth technologies on other clinical outcomes, including (1) glycemic parameters and (2) health behaviors (ie, nutrition and physical activity).

Methods

This systematic review was conducted following the preferred reporting items for systematic reviews and meta-analysis (PRISMA) guidelines [31].

Population

The population of interest included adult women of childbearing age (≥18 years) either during pregnancy or the postpartum period. Studies that did not explicitly specify the inclusion of pregnant or postpartum women were excluded.

Interventions and Comparators

This review investigated eHealth weight management interventions with a specific goal of targeting either GWG during pregnancy or weight loss during the postpartum period. Eligible eHealth technologies included the following: mobile phone (text-messaging or short message service [SMS] or mobile phone app), Web-based, email, personal digital assistant, handheld computer, home computer, or tablet app. The intervention must have included a health behavior component (nutrition or physical activity) in the eHealth technology. A minimum intervention duration of 3 months was required. The environment where the eHealth technology was implemented (eg, home-based and prenatal clinic) was not an eligibility criterion. Three different reference groups were considered as comparators: (1) in-person interventions, (2) other health technology interventions, and (3) no intervention (ie, standard care or usual health care environment).

Outcomes

The primary outcome was weight management with specific targets of GWG, measured in kilograms (kg) in pregnant women or weight loss (measured in kg) in postpartum women. In both populations, we also investigated changes in glycemic status (eg, fasting and 2-hour glucose levels), nutritional measures (eg, total energy intake), and physical activity (eg, minutes of physical activity).

Study Design

All relevant primary studies that involved randomized controlled trials (RCTs), non-RCTs such as clinical controlled trials (CCTs), pre-post studies, historically controlled studies, and pilot studies were included. All other study designs were excluded. All study protocols without preliminary results for data extraction were also excluded.

Databases and Search Criteria

A systematic computerized literature search was conducted of the following databases: MEDLINE, EMBASE, Cochrane database of systematic reviews (CDSR), Cochrane central register of controlled trials (CENTRAL), CINAHL (Cumulative Index to Nursing and Allied Health Literature), and PsycINFO. The search included studies published from 1990 to July 5, 2016. The starting year of 1990 was selected because of the rapid rise and acceptance of technological innovations after this date. No studies were excluded based on language. Reference lists and associated paper citations were reviewed to identify other potential eligible papers that may have been missed during the initial search. The search terms as designed for the MEDLINE database with medical subject headings (MeSH) and keyword searching are outlined in Multimedia Appendix 1. These terms were modified accordingly to search the other databases.

Study Selection

After searching the selected databases using the predefined terms, all identified citations were retrieved and screened by 2 independent reviewers in two stages. In the first stage of titles and abstract eligibility, each citation was independently screened by at least one reviewer. If one assessor excluded the paper, the second reviewer analyzed and verified the validity of the exclusion. Any disagreements between reviewers were resolved with a third reviewer. In the second stage, the full-text papers of all included studies were retrieved and screened for eligibility by 2 independent reviewers. Similarly, any disagreement regarding the status of a full-text papers was resolved by a third reviewer. For all eligible full-text papers, data extraction was completed by a single reviewer using standardized data collection forms, which were then verified by a second independent reviewer.

Data Extraction

Data extracted from the research included study, participant and intervention characteristics, and outcomes. Study characteristics were author, year, objective, design, setting, geographical region, period (ie, pregnancy or postpartum), duration of the intervention, sample size, participant inclusion or exclusion criteria, recruitment time points, methods of recruitment, details of the eHealth intervention and comparison, and statistical analyses used. Participant characteristics were age, pregnancy history, ethnicity, education, household income, and baseline anthropometric measurements. Intervention characteristics included type of eHealth technology, focus of the intervention (ie, nutrition, physical activity, or both), use of the eHealth intervention (ie, expected vs actual use), other components in addition to eHealth, communication strategy, detailed features, participant satisfaction, and participant- and investigator-reported benefits and limitations. Outcomes encompassed the type of assessment of outcomes (objective, subjective, or self-reported), clinical and laboratory measurements (baseline and end of study), and treatment effects.

Assessment of Risk of Bias

For included studies, the Cochrane Collaboration’s risk of bias tool was used [32] to assess the level of potential bias for each study based on six main methodological domains, which included the following: sequence generation, allocation concealment, blinding, incomplete outcome data, selective outcome reporting, and other sources of bias. Using this tool, each domain was scored as a low, unclear, or high risk of bias. The overall risk level was categorized based upon all six domains.

Data Analyses

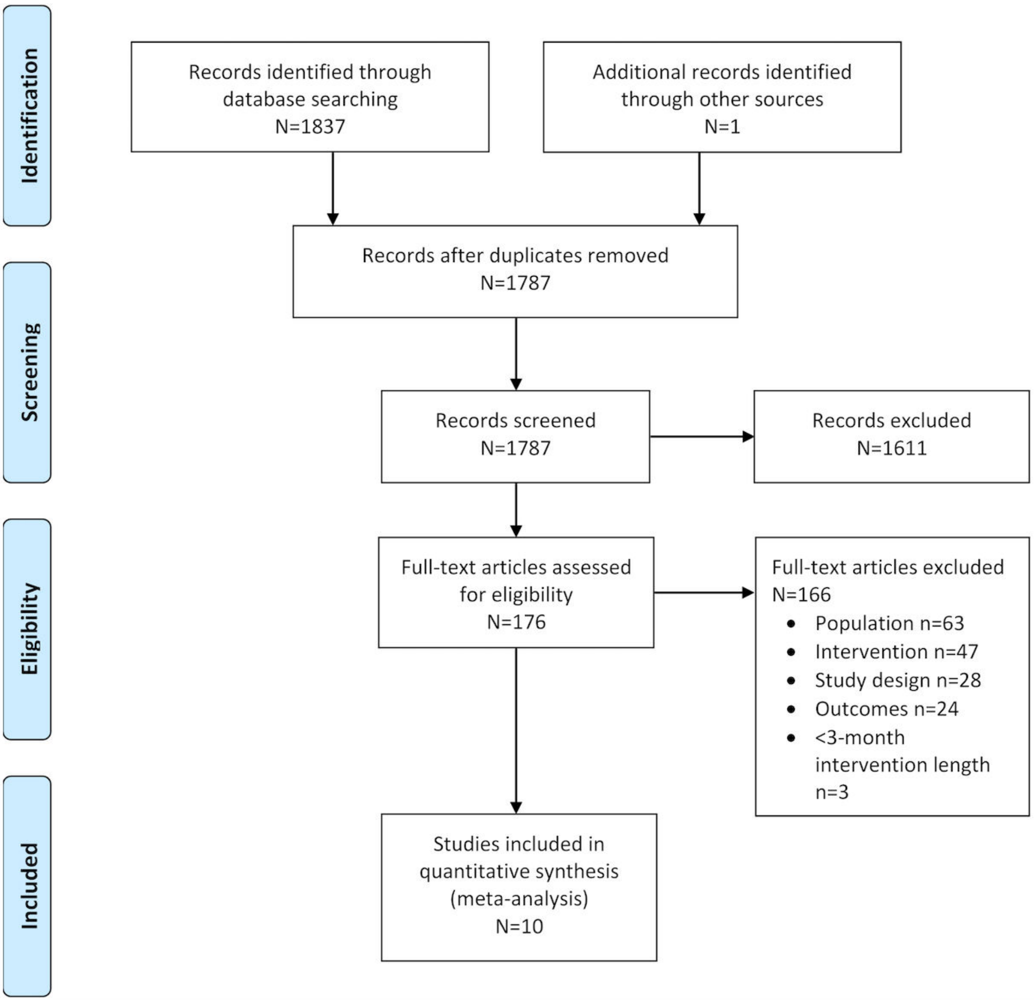
To perform meta-analysis, immediate posttreatment data (means and standard deviations) were utilized for continuous outcome measures, whereas number of events or prevalence was utilized for binary outcomes. The DerSimonian and Laird random effects models with inverse variance (IV) weighting method were utilized to generate the summary measures of effect in the form of mean difference for the continuous outcome measures and odds ratio (OR) for dichotomous outcomes. Mean differences in change scores were calculated using change from baseline data (ie, mean difference between pretreatment (baseline) and posttreatment (final or end point) values, along with the standard deviation (SD) for both intervention and comparison groups). For secondary outcomes such as glycemic parameters, daily energy intake, and daily servings, forest plots were created but no pooled estimates were provided, as the units of measurement, direction of effect, and outcome measures differed across studies. The Cochran's Q (alpha=.05) was employed to assess statistical heterogeneity, and I^2 statistic was used to quantify the magnitude of statistical heterogeneity between studies where I^2 >50% represented moderate and I^2 >75% represented substantial heterogeneity across studies.

Results

Study Selection

The literature search yielded 1837 citations from all of the databases, with one additional reference from gray literature (Figure 1; [31]). The removal of duplicate entries provided a total of 1787 citations. Next, 1611 citations were excluded after the screening of titles and abstracts, and an additional 166 citations were excluded at the full-text screening phase. In total, 10 studies (seven RCTs, one pilot RCT, and two CCTs) were included in the review.

Figure 1. The preferred reporting items for systematic review and meta-analysis (PRISMA) flow diagram on the effectiveness of electronic health (eHealth) technologies for weight management in pregnant and postpartum women.



Study Characteristics

Participant Characteristics

Of the included studies, seven were conducted in the United States of America [33-39], two were from Spain [40,41], and one study was from the United Kingdom [42]. The number of participants within each of the studies ranged from 18 to 104, with a total sample size of 525 participants. The dropout/loss to follow-up rate ranged from 2.0% to 39.1% in the intervention groups and 0% to 25.0% in the control groups. The intervention group participants were aged between 24 and 36 years, whereas the participants from the control groups were aged between 24 and 35 years. Several of the included studies [33,35,36,39,40,41] provided measures of prepregnancy body mass index (BMI) with values ranging from 26 to 30 kg/m^2 for the intervention groups and 25 to 30 kg/m^2 for the control groups. Participant ethnicity varied between the studies and study arms (white: intervention: 12.5%-100%; control: 13.3%-100%) [33-36,38-42]. Several studies reported on the level of education within their population ranging from 78% of the total sample having a secondary degree [36], to other studies reporting approximately 20% or above in the usual care and 21% or above in the intervention having a postsecondary education [34,37,38,40,41]. Additional details on the characteristics of each of the included studies can be found in Multimedia Appendix 2.

Intervention Components

Six studies conducted the intervention during pregnancy [35-37,40-42], whereas four studies focused on the postpartum period [33,34,38,39]. Of the studies that provided interventions during pregnancy, several used common eHealth technological elements such as text messaging or website support. In particular, Pollak et al [35] used a text-based intervention targeting four health behavior goals during pregnancy, including: (1) targeted daily walking to 10,000 steps, (2) avoid sweetened drinks, (3) eat at least 5 fruits and vegetables each day, and (4) eliminate fast food intake. Only the first two goals were implemented during the initial stages of the intervention (approximately 10 weeks) with all four goals utilized for the rest of trial (approximately 6 weeks). Participants received targeted text messages each week with regard to their current goals and monthly text-message reminders on the Institute of Medicine's (IOM) GWG guidelines. Carral et al [41] used a website specifically designed for monitoring people with diabetes during pregnancy that allowed for remote and bidirectional communication between health care professionals and patients, including relaying of messages and alerts for glucose monitoring. Herring et al [37] used text messaging, along with social media support groups and coaching to support women through nutritional and physical activity goals. The text messages were daily in frequency and personalized to each goal, building on skills and self-efficacy. The social media group was a forum to support and add further behavioral skills training. Perez-Ferre et al [40] used a telemedicine website and mobile phone app to support the transmission of glucose levels and for sending text messages. The website was used to monitor, adjust, and recommend insulin doses and goals. Smith et al [36] used a website that intervention arm participants would log on to review exercise and nutrition information. Specifically, this included recommendations, goal setting, problem-solving modules, a journal, a calendar, and a community forum for women to interact with other intervention arm participants. Finally, Soltani et al [42] used text messaging and self-monitoring diaries to support women through behavior modification for weight management, physical activity, and nutrition.

Of the studies that provided postpartum interventions, several eHealth strategies were used, including websites, biosensors/activity monitors (ie, pedometers), and text messaging. Colleran et al [33] utilized a Web-based dietary intervention to reduce dietary intake by 500 kcal/day below calculated energy requirements and compared results with recommendations provided on a weekly basis, along with providing strategies to assist women in meeting their outlined recommendations. Kim et al [34] employed a structured Web-based physical activity intervention in which participants received a pedometer and access to a Web-based curriculum. Participants were also provided with personalized step count goals, strategies for meeting these goals, as well as the opportunity to anonymously interact with other intervention group participants through a Web-based study-specific forum. Nicklas et al [38] modified the diabetes prevention program (DPP) to 12 core modules that provided women with the opportunity to track goals (ie, walking and weight), to share secure messages with health care professionals, and to view Web-based media files. Finally, Herring et al [39] piloted a Web-based and text messaging intervention that focused on six empirically tested weight-related behavior change strategies and monitored women via text messaging.

Among studies, the intervention content was provided at varying frequencies, including: daily [34,37], 3 times per week [35], weekly [33,38,40,42], every 2 weeks [39,41], or on an individualized basis [36]. All of the eHealth technologies employed a bidirectional communication modality with asynchronous or interactive communication between the health care professionals and participants. The duration of the interventions in the pregnancy interventions ranged from 6 to 26 weeks, whereas the postpartum interventions ranged from 23 to 52 weeks. All comparator or control groups received usual standard of care or a simplified educational version of the technology offered to the intervention group, which provided only general health information.

Risk of Bias in Included Studies

The results of risk of bias were determined using Cochrane Collaboration's risk of bias tool for the 6 methodological domains and the overall risk level (Table 1). Of the included studies, the overall risk of bias for seven studies was rated with an unclear risk of bias [33-35,36,38-40], two studies were rated with a high risk of bias [41,42], and one study was deemed to have low risk of bias [37].

Table 1. Risk of bias for included studies.

Study (year), country	Risk of bias					
	Sequence generation	Allocation concealment	Blinding of participants/ personnel	Selective reporting	Other	Overall
Carral (2015), Spain [41]	High	High	High	Low	Low	High
Colleran (2012), United States of America [33]	Unclear	Unclear	Unclear	Low	Unclear	Unclear
Herring (2014), United States of America [39]	Low	Low	High	Low	Low	Unclear
Herring (2016), United States of America [37]	Low	Low	Unclear	Low	Low	Low
Kim (2012), United States of America [34]	Unclear	Low	Low	Low	Low	Unclear
Nicklas (2014), United States of America [38]	Unclear	Low	Low	Low	Unclear	Unclear
Pérez-Ferre (2010), Spain [40]	Unclear	Unclear	Unclear	Low	Low	Unclear
Pollak (2014), United States of America [35]	Unclear	Unclear	Unclear	Low	Low	Unclear
Smith (2016), United States of America [36]	Low	Unclear	High	Low	Low	Unclear
Soltani (2015), United Kingdom [42]	High	High	High	Low	High	High

Synthesis of Results

Primary Outcome (Weight Management and Body Mass Index)

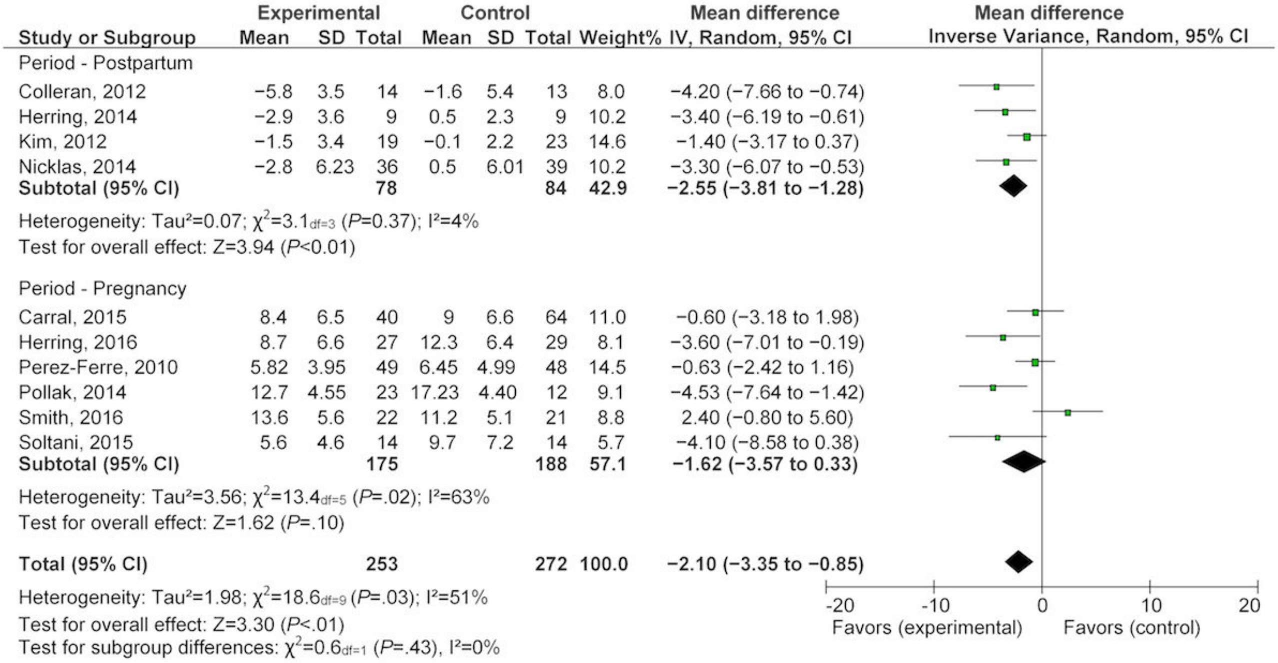
All 10 studies reported on participant weight management in terms of weight gain, loss, or maintenance. During pregnancy, six studies [35-37,40-42] that evaluated eHealth technology for weight management found a nonsignificant reduction in GWG, with a mean difference of −1.62 kg (95% CI −3.57 to 0.33) after exposure to the intervention (Figure 2). Four studies contributed to the pooled analysis for the postpartum eHealth technology weight intervention, showing a statistically significant difference in weight loss, with a mean difference of −2.55 kg (95% CI −3.81 to −1.28) after completing eHealth weight management interventions (Figure 2) [33,34,38,39]. The overall pooled analysis for any eHealth technology intervention in the combined population of interest resulted in a statistically significant reduction in weight, with a mean difference of −2.1 kg (95% CI −3.35 to −0.85; Figure 2). When examining the percentage of women gaining weight above recommendations, two studies [36,37] provided a nonsignificant OR of 0.76 (95% CI 0.13 to −4.59; Figure 3). However, the change in BMI in the pooled postpartum studies [33,34,38] showed a significant reduction with a mean difference of −0.87 kg/m^2 (95% CI −1.56 to 0.18; Figure 4).

Secondary Outcomes (Glycemic, Nutrition, and Physical Activity Parameters)

Three studies provided data for changes in glycemic parameters, two studies during pregnancy [40,41], and one study postpartum [34]. The pooled change in glycemic parameters during pregnancy as measured by glycated hemoglobin (HbA$_{1C}$) was an increase of 0.10 (95% CI −0.08 to 0.28; Figure 5). One study [34] that reported on glycemic parameters (fasting, 2 hour glucose, log fasting insulin) found that technology raised fasting glucose nonsignificantly by 0.09 mmol/L (95% CI −0.27 to 0.45) and 2-hour postprandial glucose by 0.06 mmol/L (95% CI −0.98 to 1.10). Finally, log fasting insulin decreased by −0.20 (95% CI −0.44 to 0.04; Figure 6). All glycemic changes were not statistically significant.

In addition, one study reported on nutrition status during pregnancy [36]. The study found that after exposure to a Web-based program, women reported a nonsignificant reduction in energy intake from carbohydrates (1.10%, 95% CI −4.24 to 2.04) and from fat (−0.90%, 95% CI −3.37 to 1.57), as well as a nonsignificant increase in energy intake from protein (1.40%, 95% CI 0.11-2.69; Figure 7).

Figure 2. Pooled analysis of eHealth technologies on weight management (kg) in pregnant and postpartum women.



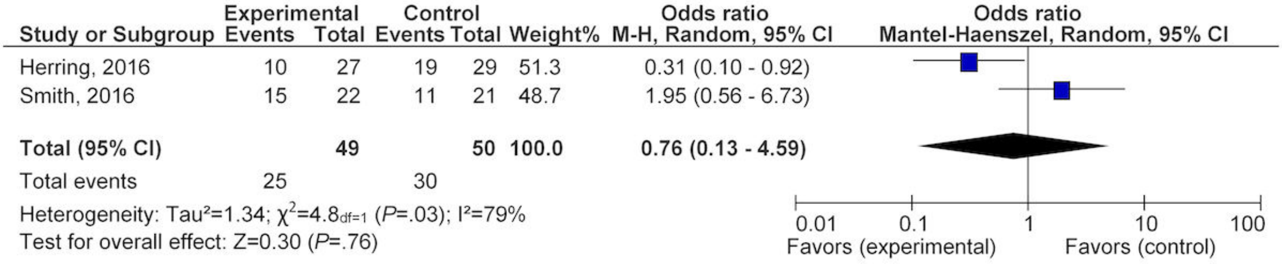
Study or Subgroup	Experimental Mean	Experimental SD	Experimental Total	Control Mean	Control SD	Control Total	Weight%	Mean difference IV, Random, 95% CI
Period - Postpartum								
Colleran, 2012	−5.8	3.5	14	−1.6	5.4	13	8.0	−4.20 (−7.66 to −0.74)
Herring, 2014	−2.9	3.6	9	0.5	2.3	9	10.2	−3.40 (−6.19 to −0.61)
Kim, 2012	−1.5	3.4	19	−0.1	2.2	23	14.6	−1.40 (−3.17 to 0.37)
Nicklas, 2014	−2.8	6.23	36	0.5	6.01	39	10.2	−3.30 (−6.07 to −0.53)
Subtotal (95% CI)			**78**			**84**	**42.9**	**−2.55 (−3.81 to −1.28)**
Period - Pregnancy								
Carral, 2015	8.4	6.5	40	9	6.6	64	11.0	−0.60 (−3.18 to 1.98)
Herring, 2016	8.7	6.6	27	12.3	6.4	29	8.1	−3.60 (−7.01 to −0.19)
Perez-Ferre, 2010	5.82	3.95	49	6.45	4.99	48	14.5	−0.63 (−2.42 to 1.16)
Pollak, 2014	12.7	4.55	23	17.23	4.40	12	9.1	−4.53 (−7.64 to −1.42)
Smith, 2016	13.6	5.6	22	11.2	5.1	21	8.8	2.40 (−0.80 to 5.60)
Soltani, 2015	5.6	4.6	14	9.7	7.2	14	5.7	−4.10 (−8.58 to 0.38)
Subtotal (95% CI)			**175**			**188**	**57.1**	**−1.62 (−3.57 to 0.33)**
Total (95% CI)			**253**			**272**	**100.0**	**−2.10 (−3.35 to −0.85)**

Period - Postpartum: Heterogeneity: Tau²=0.07; χ^2=3.1$_{df=3}$ (*P*=0.37); I²=4%
Test for overall effect: Z=3.94 (*P*<0.01)

Period - Pregnancy: Heterogeneity: Tau²=3.56; χ^2=13.4$_{df=5}$ (*P*=.02); I²=63%
Test for overall effect: Z=1.62 (*P*=.10)

Total: Heterogeneity: Tau²=1.98; χ^2=18.6$_{df=9}$ (*P*=.03); I²=51%
Test for overall effect: Z=3.30 (*P*<.01)
Test for subgroup differences: χ^2=0.6$_{df=1}$ (*P*=.43), I²=0%

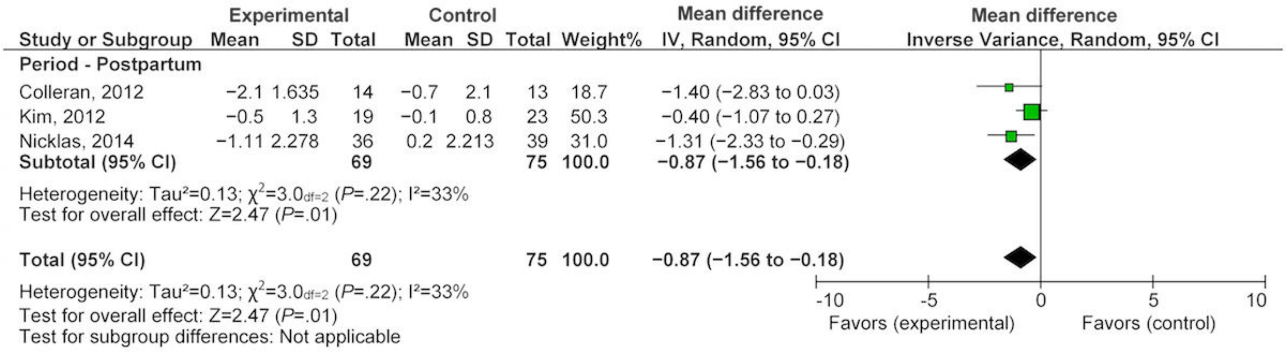
Figure 3. Pooled analysis of eHealth technologies on percentage of women gaining weight above IOM recommendations for pregnancy.



Study or Subgroup	Experimental Events	Experimental Total	Control Events	Control Total	Weight%	Odds ratio M-H, Random, 95% CI
Herring, 2016	10	27	19	29	51.3	0.31 (0.10 - 0.92)
Smith, 2016	15	22	11	21	48.7	1.95 (0.56 - 6.73)
Total (95% CI)		**49**		**50**	**100.0**	**0.76 (0.13 - 4.59)**
Total events	25		30			

Heterogeneity: Tau²=1.34; χ^2=4.8$_{df=1}$ (*P*=.03); I²=79%
Test for overall effect: Z=0.30 (*P*=.76)

Figure 4. Pooled analysis of eHealth technologies on body mass index (kg/m^2) in postpartum women.



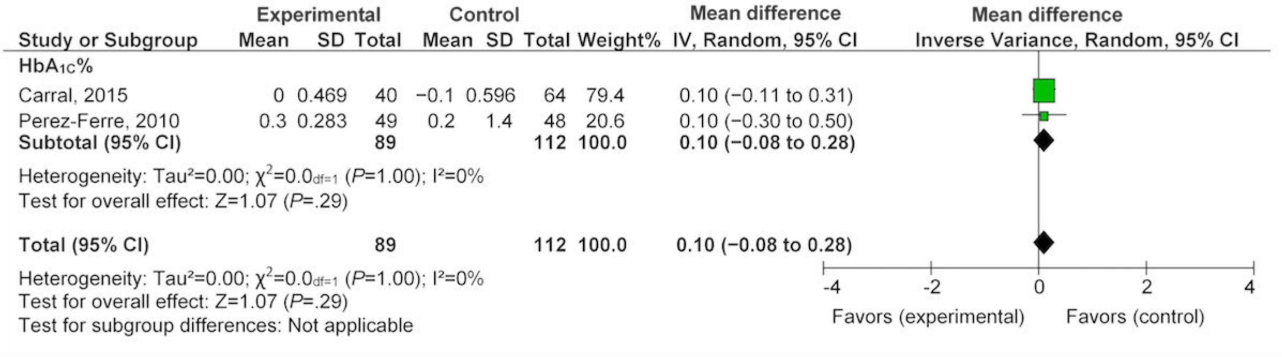
Study or Subgroup	Experimental Mean	Experimental SD	Experimental Total	Control Mean	Control SD	Control Total	Weight%	Mean difference IV, Random, 95% CI
Period - Postpartum								
Colleran, 2012	−2.1	1.635	14	−0.7	2.1	13	18.7	−1.40 (−2.83 to 0.03)
Kim, 2012	−0.5	1.3	19	−0.1	0.8	23	50.3	−0.40 (−1.07 to 0.27)
Nicklas, 2014	−1.11	2.278	36	0.2	2.213	39	31.0	−1.31 (−2.33 to −0.29)
Subtotal (95% CI)			**69**			**75**	**100.0**	**−0.87 (−1.56 to −0.18)**
Total (95% CI)			**69**			**75**	**100.0**	**−0.87 (−1.56 to −0.18)**

Period - Postpartum: Heterogeneity: Tau²=0.13; χ^2=3.0$_{df=2}$ (*P*=.22); I²=33%
Test for overall effect: Z=2.47 (*P*=.01)

Total: Heterogeneity: Tau²=0.13; χ^2=3.0$_{df=2}$ (*P*=.22); I²=33%
Test for overall effect: Z=2.47 (*P*=.01)
Test for subgroup differences: Not applicable

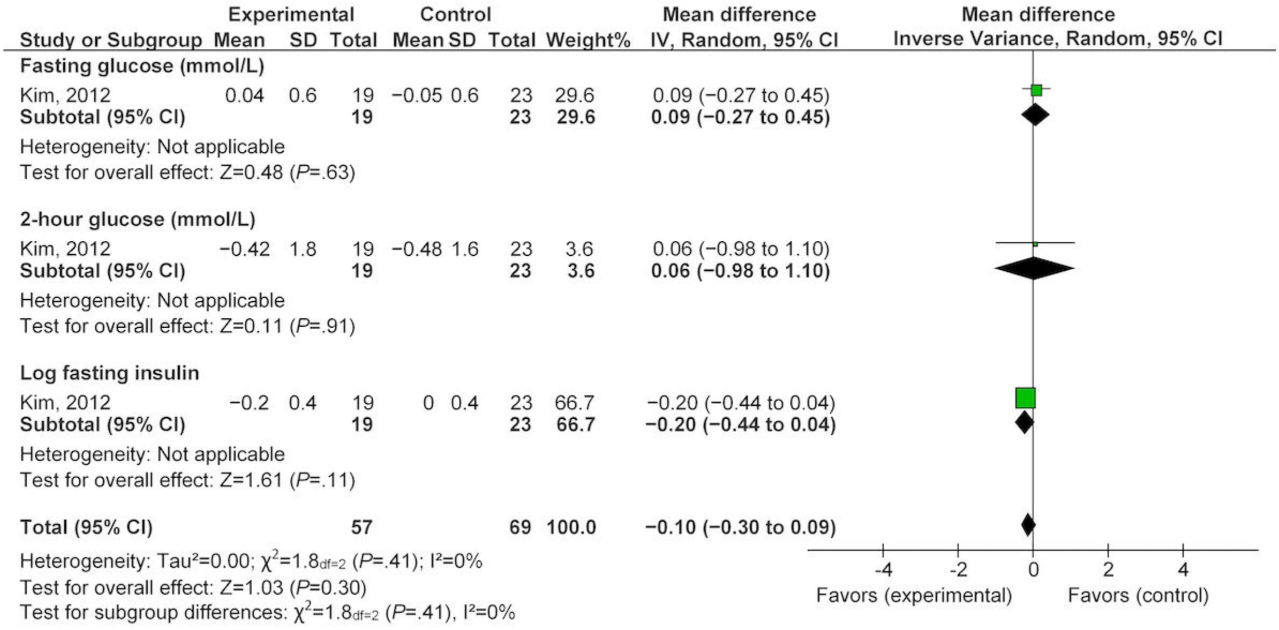
Another study reported on nutrition status changes postpartum after exposure to an eHealth technology intervention for 4 months [33]. This study found a statistically significant reduction in total daily energy intake of 442.0 kcal (95% CI −803.10 to −80.90). The same study found statistically significant reductions (Figure 8) in percentage of total daily intake of fat and added sugars by −4.90% (95% CI −7.84 to −1.96) and −5.70% (95% CI −8.66 to −2.74), respectively. Changes in the percentage of energy intake from carbohydrate significantly increased by 4.60% (95% CI 1.69-7.51), and the percentage of energy intake from protein decreased by −0.80% (95% CI −0.89 to 2.49), although this small change was not statistically significant (Figure 8). When examining daily servings of food groups, statistically significant reductions in the number of daily milk servings (−1.20, 95% CI −1.80 to −0.56) and daily servings of whole grains (−1.20, 95% CI −2.31 to −0.09) were noted [33]. However, daily servings of fruit, vegetables, oils or fat, and sweets were not significantly impacted by the 4-month exposure to the eHealth technology.

Figure 5. Effect of eHealth technologies on glycemic parameters in women during pregnancy.



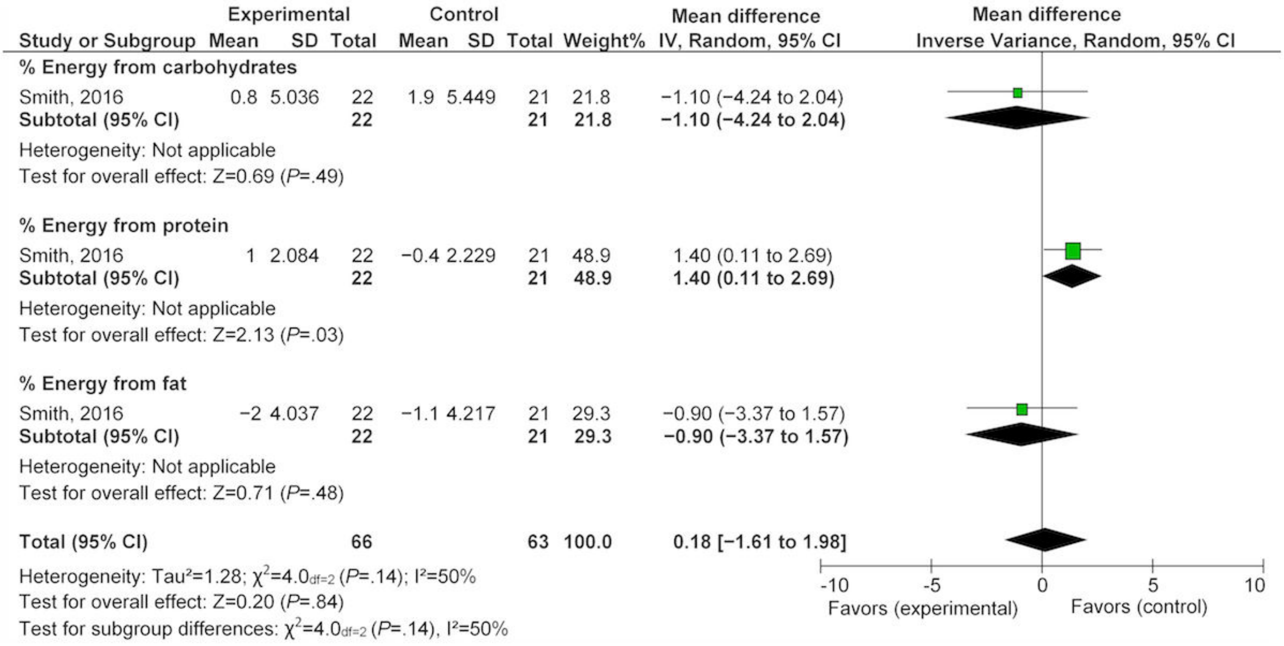
Study or Subgroup	Experimental Mean	Experimental SD	Experimental Total	Control Mean	Control SD	Control Total	Weight%	Mean difference IV, Random, 95% CI
HbA$_{1c}$%								
Carral, 2015	0	0.469	40	−0.1	0.596	64	79.4	0.10 (−0.11 to 0.31)
Perez-Ferre, 2010	0.3	0.283	49	0.2	1.4	48	20.6	0.10 (−0.30 to 0.50)
Subtotal (95% CI)			**89**			**112**	**100.0**	**0.10 (−0.08 to 0.28)**
Heterogeneity: Tau^2=0.00; χ^2=0.0$_{df=1}$ (*P*=1.00); I^2=0%								
Test for overall effect: Z=1.07 (*P*=.29)								
Total (95% CI)			**89**			**112**	**100.0**	**0.10 (−0.08 to 0.28)**
Heterogeneity: Tau^2=0.00; χ^2=0.0$_{df=1}$ (*P*=1.00); I^2=0%								
Test for overall effect: Z=1.07 (*P*=.29)								
Test for subgroup differences: Not applicable								

Figure 6. Effect of eHealth technologies on glycemic parameters in postpartum women.



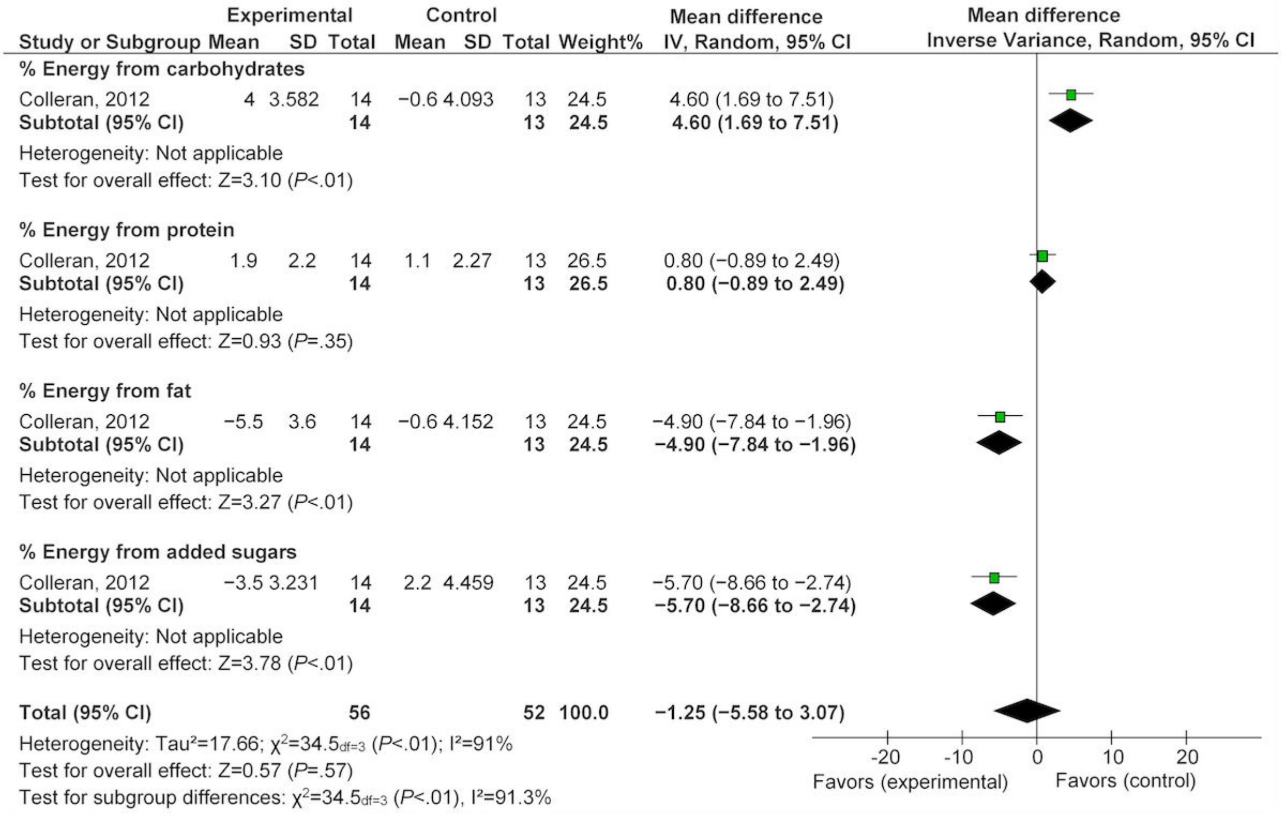
Study or Subgroup	Experimental Mean	Experimental SD	Experimental Total	Control Mean	Control SD	Control Total	Weight%	Mean difference IV, Random, 95% CI
Fasting glucose (mmol/L)								
Kim, 2012	0.04	0.6	19	−0.05	0.6	23	29.6	0.09 (−0.27 to 0.45)
Subtotal (95% CI)			**19**			**23**	**29.6**	**0.09 (−0.27 to 0.45)**
Heterogeneity: Not applicable								
Test for overall effect: Z=0.48 (*P*=.63)								
2-hour glucose (mmol/L)								
Kim, 2012	−0.42	1.8	19	−0.48	1.6	23	3.6	0.06 (−0.98 to 1.10)
Subtotal (95% CI)			**19**			**23**	**3.6**	**0.06 (−0.98 to 1.10)**
Heterogeneity: Not applicable								
Test for overall effect: Z=0.11 (*P*=.91)								
Log fasting insulin								
Kim, 2012	−0.2	0.4	19	0	0.4	23	66.7	−0.20 (−0.44 to 0.04)
Subtotal (95% CI)			**19**			**23**	**66.7**	**−0.20 (−0.44 to 0.04)**
Heterogeneity: Not applicable								
Test for overall effect: Z=1.61 (*P*=.11)								
Total (95% CI)			**57**			**69**	**100.0**	**−0.10 (−0.30 to 0.09)**
Heterogeneity: Tau^2=0.00; χ^2=1.8$_{df=2}$ (*P*=.41); I^2=0%								
Test for overall effect: Z=1.03 (*P*=0.30)								
Test for subgroup differences: χ^2=1.8$_{df=2}$ (*P*=.41), I^2=0%								

Figure 7. Effect of eHealth technologies on percentages of energy intake in women during pregnancy.



Study or Subgroup	Experimental Mean	Experimental SD	Experimental Total	Control Mean	Control SD	Control Total	Weight%	Mean difference IV, Random, 95% CI
% Energy from carbohydrates								
Smith, 2016	0.8	5.036	22	1.9	5.449	21	21.8	−1.10 (−4.24 to 2.04)
Subtotal (95% CI)			**22**			**21**	**21.8**	**−1.10 (−4.24 to 2.04)**
Heterogeneity: Not applicable								
Test for overall effect: Z=0.69 (*P*=.49)								
% Energy from protein								
Smith, 2016	1	2.084	22	−0.4	2.229	21	48.9	1.40 (0.11 to 2.69)
Subtotal (95% CI)			**22**			**21**	**48.9**	**1.40 (0.11 to 2.69)**
Heterogeneity: Not applicable								
Test for overall effect: Z=2.13 (*P*=.03)								
% Energy from fat								
Smith, 2016	−2	4.037	22	−1.1	4.217	21	29.3	−0.90 (−3.37 to 1.57)
Subtotal (95% CI)			**22**			**21**	**29.3**	**−0.90 (−3.37 to 1.57)**
Heterogeneity: Not applicable								
Test for overall effect: Z=0.71 (*P*=.48)								
Total (95% CI)			**66**			**63**	**100.0**	**0.18 [−1.61 to 1.98]**
Heterogeneity: Tau^2=1.28; χ^2=4.0$_{df=2}$ (*P*=.14); I^2=50%								
Test for overall effect: Z=0.20 (*P*=.84)								
Test for subgroup differences: χ^2=4.0$_{df=2}$ (*P*=.14), I^2=50%								

Figure 8. Effect of eHealth technologies on percentages of energy intake in postpartum women.



Study or Subgroup	Experimental Mean	Experimental SD	Experimental Total	Control Mean	Control SD	Control Total	Weight%	Mean difference IV, Random, 95% CI
% Energy from carbohydrates								
Colleran, 2012	4	3.582	14	−0.6	4.093	13	24.5	4.60 (1.69 to 7.51)
Subtotal (95% CI)			**14**			**13**	**24.5**	**4.60 (1.69 to 7.51)**
Heterogeneity: Not applicable								
Test for overall effect: Z=3.10 (*P*<.01)								
% Energy from protein								
Colleran, 2012	1.9	2.2	14	1.1	2.27	13	26.5	0.80 (−0.89 to 2.49)
Subtotal (95% CI)			**14**			**13**	**26.5**	**0.80 (−0.89 to 2.49)**
Heterogeneity: Not applicable								
Test for overall effect: Z=0.93 (*P*=.35)								
% Energy from fat								
Colleran, 2012	−5.5	3.6	14	−0.6	4.152	13	24.5	−4.90 (−7.84 to −1.96)
Subtotal (95% CI)			**14**			**13**	**24.5**	**−4.90 (−7.84 to −1.96)**
Heterogeneity: Not applicable								
Test for overall effect: Z=3.27 (*P*<.01)								
% Energy from added sugars								
Colleran, 2012	−3.5	3.231	14	2.2	4.459	13	24.5	−5.70 (−8.66 to −2.74)
Subtotal (95% CI)			**14**			**13**	**24.5**	**−5.70 (−8.66 to −2.74)**
Heterogeneity: Not applicable								
Test for overall effect: Z=3.78 (*P*<.01)								
Total (95% CI)			**56**			**52**	**100.0**	**−1.25 (−5.58 to 3.07)**
Heterogeneity: Tau²=17.66; $\chi^2=34.5_{df=3}$ (*P*<.01); I²=91%								
Test for overall effect: Z=0.57 (*P*=.57)								
Test for subgroup differences: $\chi^2=34.5_{df=3}$ (*P*<.01), I²=91.3%								

Finally, the pregnancy-specific study utilized the self-reported pregnancy physical activity questionnaire (PPAQ) for estimating physical activity levels during pregnancy [35]. No significant differences were found between the two groups in light or moderate physical activity as determined by the PPAQ at 32 weeks of gestation (moderate: 95% CI −3.5 to −0.3, *P*=.71; light: 95% CI −2.6 to 0.4, *P*=.08). A postpartum study that employed a Web-based self-report survey on physical activity habits [34] found no significant differences at baseline and follow-up with regard to the proportion of individuals within three activity categories (0 min/week, <60 min/week, and ≥60 min/week) for physical activity levels between the control and intervention groups, including any activity (baseline: *P*=.61; follow-up: *P*=.25), mild (baseline: *P*=.26; follow-up: *P*=.20), moderate (baseline: *P*=.81; follow-up: *P*=.51), and vigorous physical activity (baseline: *P*=.81; follow-up: *P*=.65). As a result of the heterogeneity of the measurement protocols between the pregnancy and postpartum studies, a meta-analysis was not conducted for the physical activity parameters.

Discussion

Principal Findings

Overall Effectiveness of eHealth Interventions in Pregnancy and the Postpartum Period

This review summarizes the most relevant/applicable trial evidence available to assess the effectiveness of eHealth technologies on weight management in pregnant or postpartum women. Notably, all of the included studies were recent (published between 2010 and 2016), which highlights the emerging use of this technology as a novel health care strategy, yet the low number of studies emphasizes the need for further evidence to support its efficacy for weight management in the clinical environment. To that end, the analysis of evidence within this review demonstrated that exposure to eHealth technology was associated with a nonsignificant benefit for weight management during pregnancy and a statistically and clinically significant weight reduction in the postpartum period. The pooled estimate for change in weight (kg) during pregnancy was −1.62 kg (95% CI −3.57 to 0.33), whereas the pooled estimate for change in weight postpartum was −2.55 kg (95% CI −3.81 to −1.28).

Components of Effective eHealth Interventions

The eHealth interventions that were effective in minimizing excessive weight gain (kg) during pregnancy comprised multiple components, including individualized text messaging and the use of social media [35,37]. Specific components that were effective in one study focused on a multimodal approach to eHealth, utilizing individualized text messaging for skills training and self-monitoring, private social media chat group for support, and individualized health coaching telephone calls [37]. Another study that was effective in reducing weight in pregnancy employed frequent text messaging (3 times per week), which focused on nutrition and physical activity by providing concise suggestions for modifying nutritional behavior (ie, avoid sweetened drinks) and increasing physical activity (ie, goal of 10,000 steps/day) [35].

Three studies demonstrated effectiveness in reducing postpartum weight with eHealth interventions. One study that included an eHealth solution (Web-based MyPyramid Menu Planner) with additional in-person counseling/support [33] had a greater reduction in weight and BMI as compared with the intervention that included only eHealth components (Web-based information, online forum, text messaging, and email) [34] implemented during the same period. Furthermore, another study found significant weight reduction when the eHealth intervention focused on both nutrition and physical activity (Healthy4Baby) [39]. Finally, one study modified the lifestyle-intensive DPP for postpartum women and also achieved a significant reduction in weight and BMI [38]. Overall, the multifaceted interventions (ie, targeting both physical activity and nutrition) with multiple and different modalities may be more effective than an eHealth-focused intervention targeting physical activity alone. More importantly, none of the studies performed an evaluation to separate the effects of personal contact with a health professional from the effects of the eHealth intervention alone. This information could help determine predictors of participant engagement or adherence with the eHealth technology. Further research is needed to determine the independent effects of these technologies on weight management for studies employing multimodal intervention methods.

Effective Components of eHealth Interventions

The growth in eHealth apps is related to the underlying presumption that their use will be associated with lower health care costs and improvements in health outcomes, particularly when focusing on the prevention of diseases and promotion of healthy lifestyles. Although eHealth technologies have the potential to improve prenatal health care delivery by providing frequent, interactive, and personalized information to broad populations in *real time*, there is a risk that the app may not be effective or could potentially result in harm to the mother and her unborn child. Thus, it is critical that eHealth intervention technologies be designed using an evidence-based approach and tested/evaluated with the addition of appropriate safeguards to ensure safety of the participants before being implemented into widespread use among the general population. This may include the performance of clinical trials that use a data safety and monitoring committee who will intervene in the occurrence of increased adverse events within a study.

Participant engagement is also critical to the success of any eHealth intervention. To date, technology-based weight management approaches have been well accepted in nonpregnant populations [7] and postpartum populations with up to 74% of postpartum women accessing and reviewing weight management materials immediately after receiving the resources in one study [12]. Studies have reported significant variability in the number of intervention participants that read and respond to study-based text messages, similar to the postpartum participants receiving eHealth interventions. Although the findings from this review suggest that multicomponent interventions (ie, combined focus on both nutrition and physical activity) resulted in more favorable weight management during pregnancy and postpartum, it is difficult to ascertain which component attributed to the observed effect or whether it is related to the entire “bundle” of interventions. Moreover, not all eHealth components are considered as useful or desired by participants within a weight management intervention. For example, only 14% of postpartum women utilized an online forum for interacting with other participants for peer support [34]. Consequently, before implementing an intervention of this type, investigators must carefully consider the design and features of the eHealth intervention for their target population. This includes ensuring the use of both effective and appropriate strategies and frameworks to provide reasonable engagement and adherence both in the short-term with long-term follow-up to determine whether these behaviors that are the targets of such interventions have lasting effects.

Recognizing the importance and value of patient engagement, the Canadian Institutes of Health Research (CIHR) examined a strategy for patient-oriented research (SPOR) where patients, researchers, health care providers, and decision makers work together to build a sustainable, accessible, and equitable health care system [43]. Applying this principle of patient engagement to the development of new eHealth apps is beneficial and necessary [44,45]. Including pregnant and postpartum women, whether during the initial app developmental process or through preliminary focus group trials, would provide tangible feedback during this critical period in areas such as GWG, physical activity, sleep, and nutrition. Ensuring that embedded tools and features are clear and easily accessible for various levels of literacy and digital experience is also a requirement [46]. For eHealth apps to gain traction and thus reach the widest audiences, endorsement from clinical stakeholders and health care providers will likely also be necessary [47].

Strengths and Limitations

This review was conducted through the use of a comprehensive search designed to identify high-quality evidence on eHealth technologies on weight management in pregnant and postpartum women. As eHealth technologies are a novel yet growing area, only 10 studies of relatively small sample sizes were eligible for inclusion. Given the limited number of participants, the meta-analyzed results, while promising, must be interpreted with caution until further studies are conducted. Seven of these included studies were “unclear” risk of bias because of poorly reported methodologies, two were deemed to have high risk of bias, and only one was low risk of bias. In addition, the studies were conducted in the United States, Spain, and the United Kingdom, which may potentially limit the generalizability to the rest of the world. This study is timely as, at present, there are four registered clinical trials investigating the use of eHealth technologies in targeting weight management or lifestyle behaviors in pregnancy (Trial registration: ClinicalTrials.gov NCT02229708, NCT01948323, NCT01461707, NCT01610752), which will help to further inform this important area.

Comparison With Existing Literature

O’Brien et al [30] previously conducted a technology-based systematic review in healthy pregnant women and reported that while these technologies have the potential to be helpful as a health care tool, further evidence in the form of RCTs is needed to determine the efficacy of mobile and other health technologies. However, this review included four ongoing studies (with no data) in addition to three published studies. Thus, a meta-analysis was not conducted as a result of the heterogeneity of their participant population. Lastly, a review of the quality of the evidence was not presented.

Conclusions

Enhanced prenatal care has been identified as one of the most important strategies for preventing obesity and future chronic diseases [48]. As the importance of excessive GWG and postpartum weight retention on cardiometabolic risks in mothers and their offspring gain more clinical attention, this review suggests that weight management in women during pregnancy and the postpartum period may be enhanced through the use of eHealth technologies. The widespread availability and adaptability of eHealth technologies provides a novel widely available platform for delivering information and guidance on weight management during these critical periods. As intensive in-person interventions are impractical within most health care systems, innovative and scalable approaches for the management of weight during these important life periods are needed [29]. Although eHealth technologies demonstrate a promising and pragmatic approach to delivering health care advice and support for weight management, more comprehensive research with larger sample sizes, comprehensive outcome measures, and longer follow-up periods, is required to determine the optimal levels of eHealth intervention support, intensity, and duration during pregnancy and the postpartum period. Moreover, further investigation is needed to determine whether the effectiveness of eHealth interventions is modified through in-person contact with a health care professional. Overall, further research is necessary before widespread adoption of these eHealth interventions.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Pregnancy technology and weight loss search strategy.

[PDF File (Adobe PDF File), 50KB - jmir_v19i10e337_app1.pdf]

Multimedia Appendix 2

Characteristics from the 10 selected studies summarizing the study objective, methods, participants, intervention, and risk of bias.

[PDF File (Adobe PDF File), 134KB - jmir_v19i10e337_app2.pdf]

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Abbreviations

BMI: body mass index
CCT: clinical controlled trial

CDSR: Cochrane database of systematic reviews
CENTRAL: Cochrane Central Register of Controlled Trials
CIHR: Canadian Institutes of Health Research
CINAHL: Cumulative Index to Nursing and Allied Health Literature
DPP: Diabetes Prevention Program
eHealth: electronic health
GWG: gestational weight gain
HbA1C: glycated hemoglobin
IOM: Institute of Medicine
MeSH: MEDLINE database with medical subject headings
OR: odds ratio
PPAQ: pregnancy physical activity questionnaire
PRISMA: preferred reporting items for systematic reviews and meta-analysis
RCT: randomized controlled trial
SMS: short message service
SPOR: strategy for patient-oriented research
SD: standard deviation
UNDP: United Nations Millennium Development Goals
WHO: World Health Organization

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Original Paper

Encouraging Physical Activity in Patients With Diabetes: Intervention Using a Reinforcement Learning System

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Abstract

Background: Regular physical activity is known to be beneficial for people with type 2 diabetes. Nevertheless, most of the people who have diabetes lead a sedentary lifestyle. Smartphones create new possibilities for helping people to adhere to their physical activity goals through continuous monitoring and communication, coupled with personalized feedback.

Objective: The aim of this study was to help type 2 diabetes patients increase the level of their physical activity.

Methods: We provided 27 sedentary type 2 diabetes patients with a smartphone-based pedometer and a personal plan for physical activity. Patients were sent short message service messages to encourage physical activity between once a day and once per week. Messages were personalized through a Reinforcement Learning algorithm so as to improve each participant's compliance with the activity regimen. The algorithm was compared with a static policy for sending messages and weekly reminders.

Results: Our results show that participants who received messages generated by the learning algorithm increased the amount of activity and pace of walking, whereas the control group patients did not. Patients assigned to the learning algorithm group experienced a superior reduction in blood glucose levels (glycated hemoglobin [HbA1c]) compared with control policies, and longer participation caused greater reductions in blood glucose levels. The learning algorithm improved gradually in predicting which messages would lead participants to exercise.

Conclusions: Mobile phone apps coupled with a learning algorithm can improve adherence to exercise in diabetic patients. This algorithm can be used in large populations of diabetic patients to improve health and glycemic control. Our results can be expanded to other areas where computer-led health coaching of humans may have a positive impact. Summary of a part of this manuscript has been previously published as a letter in *Diabetes Care*, 2016.

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KEYWORDS
reinforcement learning; physical activity; diabetes type 2

Introduction

Physical activity is highly recommended to patients with diabetes, as it is known that such activity leads to better control of glucose and other metabolic risk factors and improved quality of life [1]. Despite recommendations, most diabetic patients fail to perform regular physical activity [2]. A major objective of the caring medical team is to find better methods to encourage and incentivize physical activity in these patients.

Apart from the obvious aim of improving persuasiveness in the communication between the patient and the health care providers on the issue of exercise [3], there have been attempts to explore alternative approaches to improve adherence to physical activity in diabetic patients, including financial incentives [4] and community programs [5].

The smartphone revolution has brought entirely new opportunities for communicating with patients on a continuous basis and measuring movement, as well as other parameters, longitudinally.

A very large proportion (30%-70%) of the population in developed and developing countries owns a smartphone [6]. In the last decade, there have been multiple studies of mobile phone interventions using short message service (SMS) messages to improve health-related behaviors (reviewed in De Jongh et al [7]), and there are several previous studies that have tried to assess the effect of mobile phone apps in encouraging physical activity (reviewed in Bort-Roig et al [8]). These studies use random messages or a display that quantifies the amount of activity performed. None of these studies used a personalized learning algorithm to tailor messages to individuals. For example, two small-scale studies targeted patients with type 2 diabetes and took advantage of the ability of the patients' smartphone to recognize physical activity patterns [9,10], but the feedback was either the count of the number of steps walked, with no encouragement message, or a feedback provided by the nurse that cannot be scaled to a wide audience.

The impact of wearable activity monitors (such as Fitbit, Apple iWatch, and Microsoft Band) on encouraging exercise has not been assessed yet in an academic research setting.

The novel means of persistent communication afforded by smartphones, coupled with the ability to provide reinforcement to patients, as well as the almost immediate means to quantify its effect, has a potential to improve patient care on a wide scale, but the use of personalized SMS messages that take into account the actual quantified behavior that needs to be reinforced has not been reported yet.

Machine learning algorithms aim to discover a pattern, usually from previously-collected data. Reinforcement Learning (RL) algorithms [11], in contrast, are algorithms that learn by observing the result of an action taken by them and so can be applied in settings where data are scarce or varying. RL algorithms have been successfully applied in areas ranging from computer games [12] to health [13]. In the latter, Paredes et al [14] used RL to select interventions to assist mildly depressed individuals, showing that RL-selected interventions were more effective than those selected using other strategies. Adaptive experimental design [15] has been used to speed clinical trials and optimize treatment in a hospital setting [16].

The idea of highly personalized interventions for medical research has been suggested in the past, mostly to evaluate individual interventions without temporal correlations. Nahum-Shani et al [17] proposed using just-in-time adaptive interventions (JITAIs), which "adapt over time to an individual's time-varying status, with the goal to address the individual's changing needs for support." Whereas JITAIs were usually described in terms of predefined rules [18], Klasnja et al [19] suggested to implement them through microrandomized trials, where randomized interventions could be used to estimate the causal effect of interventions in JITAIs. In all these cases, interventions are commonly envisioned as a way to evaluate the effectiveness of single interventions. Here, we focus on learning a policy that will maximize physical activity when each person receives multiple interventions over time.

RL is frequently applied through algorithms, which assume that the states of the system and its environment can be deduced, such as Q-learning [20], or the ones that can also operate in a stateless environment such as temporal difference (TD, lambda) [12]. Both these algorithms can deal with discounted rewards in a principled manner. However, implementing these algorithms requires further assumptions (which can also be learned from the data) on the behavior of people, including, for example, the discount factor. In our implementation, described below, we chose a method which makes minimal assumptions on people's behavior and the change in them over time. The aim of this study was to assess the effectiveness of automatically tailored, personalized feedback in increasing the adherence of diabetic patients to a personal physical activity regimen recommended by their diabetes specialist. We used a smartphone app that measured physical activity (especially walking) and sent feedback, in the form of SMS messages, to users. A learning algorithm, trained using the RL framework, was used to predict the message most likely to increase activity on the following day. The primary outcome of this study was persistent improvement in physical activity. The secondary outcome was improved glycemic control.

Methods

Overview

We developed a mobile phone app that runs in the background of patients' smartphones and collects the amount of physical activity performed by patients. These data were transmitted to a central server.

Each morning an RL algorithm assessed, for each patient, which SMS message would likely increase the physical activity of the patient in the upcoming day, and that message was sent to the patient. Users were represented to the RL algorithm by their demographics, past activity, expected activity, and message history.

The effectiveness of each message was assessed the following morning by calculating the amount of activity the patient performed since the last message was sent to him or her, and this signal served as the reward for training the RL algorithm.

Patient Characteristics

Adult patients with type 2 diabetes were recruited for a 26-week-long study from the endocrinology and diabetes outpatient clinic at a tertiary hospital. Inclusion criteria were nonoptimal glycemic control (glycated hemoglobin [HbA1c] over 6.5%), a sedentary lifestyle with no dedicated physical activity up to the recruitment to the study, and ownership of an Android-based smartphone with a data connection (Wi-Fi at home or cellular data). Exclusion criteria were other types of diabetes and any disability that precludes walking for 20 min. The study was approved by the institutional review board of

Rambam Health Care Campus. All patients gave written informed consent. This trial was registered at ClinicalTrials.gov, registration number NCT02612402.

Note that HbA1c is the common measure for control of blood glucose level in people with diabetes. It refers to the levels of glycated hemoglobin, a form of hemoglobin that is measured to identify the average plasma glucose concentration.

At recruitment, all participants received information on the importance of physical activity and a personal prescription for an activity plan, including the number of sessions of activity per week and time span for each per session (ie, at least 2 hours of walking per week divided to 3 walking sessions per week). The target physical activity level was decided by the physician and the patient, taking into account the physical condition of the patient, medical disabilities, and significant schedule limitations.

A dedicated smartphone app was installed on the participant's mobile phone. This app used the phone accelerometer to sense when participants were performing physical activity (defined as walking or running for 10 min or longer) and transmitted this information once every 2.5 hours to a central server. The app was verified for its ability to measure walking when the mobile phone was on the participant's body, as well as in a bag or purse. Feedback was provided to patients through SMS messages.

To preserve battery life, the smartphone app sampled the accelerometer once every 3.5 min, and if walking was detected, kept monitoring the accelerometer until no walking was detected. Only contiguous walks of 10 min or more were collected, as shorter walks have a small effect on improvement in clinical outcomes. Patients were told at recruitment that only walks 10 min or longer will be counted and were asked to carry their cellphone during such walks.

Intensification of dietary or medical treatment was not restricted when this was considered appropriate by the medical team. The HbA1c measurements were performed by standard procedures before recruitment and every 3 months in the health maintenance organization lab of each subject. The patients filled a Quality of Life Questionnaire [17] before and after 6 months of participation in the study. They also filled a short questionnaire assessing satisfaction of the experience of using the app.

Types of Feedback Messages

Patients were randomized into a control arm and a personalized arm. The medical team was blinded to the type of messages each subject received. The control arm received identical unchanging once-weekly reminders to exercise. Patients in the personalized arm received daily feedback messages and weekly summaries.

We note that there are differences in both frequency and content between the messages for the control and treatment arms. For this reason, as will be explained below, two policies were used for the treatment arms, and these are further compared.

Following Elliot and Church [18], we sought to have three types of messages: mastery, performance-approach, and performance-avoidance, as well as a no-message condition. The daily feedback messages could be one of the following four messages (in parenthesis, the nomenclature of [18]):

1. Negative feedback: "You need to exercise to reach your activity goals. Please remember to exercise tomorrow" (Performance avoidance).
2. Positive feedback relative to self (referred herein as positive-self): "You have so far achieved N% of your weekly activity goal. Your exercise level is in accordance with your plan. Keep up the good work" (Mastery).
3. Positive feedback relative to others (referred herein as positive-social): "You have so far achieved N% of your weekly activity goal. You are exercising more than the average person in your group. Keep up the good work" (Performance approach).
4. No message

The percentage of the weekly goal ("N%") was given as an integer greater than or equal to zero, computed according to the length of activity so far, compared with the length of activity expected given the exercise plan of the individual.

In general, messages did not necessarily reflect reality. For example, patients were not divided into groups, as is implied in the positive-social message. Similarly, a negative message might be sent even though the patient has already achieved their activity goal. However, to allow the algorithm to learn a policy, we did not set constraints on the possible messages to be sent.

On most weeks, the weekly summary message was as follows: "Please remember to exercise this week to reach your activity goals." When patients reached a significant exercise achievement (as described below), and not more than once per 3 weeks, they could receive one of the following messages:

1. Maximal increase: Over the past week you increased your activity more than at any previous week.
2. Significant increase: Over the past week you increased your activity more than most previous weeks.
3. Maximal social: You won the first place! Last week you increased your activity more than any other participant in the experiment.
4. Significant social: Last week you increased your activity more than most participants of the experiment.

SMS messages were not sent to participants whose data were not received 12 hours or more before the current time to reduce the chance that the system would send a message based on incorrect data.

Feedback Message Policies

After an initial period of 3 months where feedback was sent according to a predetermined policy detailed below ("initial policy"), the decision on which daily feedback message to send was decided by a learning algorithm ("learned policy"). To allow the algorithm to collect information of outcomes to less likely feedback policies, exploration [19] was used for messages that were deemed less likely to succeed such that they were sent with significant probabilities, as detailed below. Figure 1 shows an outline of the two feedback policies.

The initial algorithm (herewith referred to as "Initial policy") was set so that no message was sent on 20% of days. For the remaining days, we drew a uniform random number between 0 and 1. If that number was larger than the expected fraction of weekly activity on that day, the user would receive the negative feedback message. Otherwise, they would receive one of the positive messages, with equal probability. This policy was based on the results of Elliot and Church [18] but also provided sufficient randomness for exploration.

After a sufficient number of instances were collected, we implemented a learned decision mechanism for deciding on the feedback message. This mechanism received, for each user, the following set of attributes:

1. Activity attributes:
    a. Number of minutes of activity in the last day.
    b. Cumulative number of minutes of activity this week.
    c. Fraction of activity goal.
    d. Fraction versus expected at this point in the week.
2. Demographics:
    a. Age
    b. Gender
3. Feedback attributes: Number of days since each feedback message was sent.

The attributes allowed the algorithm to model each person on each day through several aspects relevant to their behavior, including past activity (through the activity attributes), their demographics, and past interactions with the system (via the feedback attributes). The latter were added so that repeated messages could be used or avoided, if necessary, as determined by the learning algorithm.

Let $x_{i,t}$ denote a vector of the attributes above, for person i at time t, and let $y_{i,t}$ denote the change in activity from day t to day t+1, that is, the number of minutes of activity on day t+1 divided by those on day t. Following the Kesler construction [20], we augment $x_{i,t}$ with an action vector A such that the j-th element of A is equal to 1 if and only if message j was sent on day t.

The training data consisted of all previously collected $x_{i,t}$ and $y_{i,t}$ pairs. We trained a learning algorithm, specifically a linear regression algorithm with interactions, to predict $y_{i,t}$ from $x_{i,t}$.

The learning algorithm was rerun every day, and the most up-to-date model was used for prediction.

To predict the most appropriate action on day ρ, we applied the model to each $x_{i,\rho}$ and computed the resulting predicted $y_{i,\rho}$. We then performed Bolzmann sampling [20] with $T_{Boltzmann}=5$ on the outputs of the learning algorithm to choose the feedback message to be given. Thus, actions were chosen relative to their predicted effectiveness. This was done so that actions predicted not to be the best ones would still be tested, in addition to exploiting those actions predicted to be the best ones for the user. $T_{Boltzmann}$ was set based on the initial policy data so that each of the four messages was sent with a probability higher than 10%. We did not adjust this parameter during the experiment.

Figure 1. The two message policies.

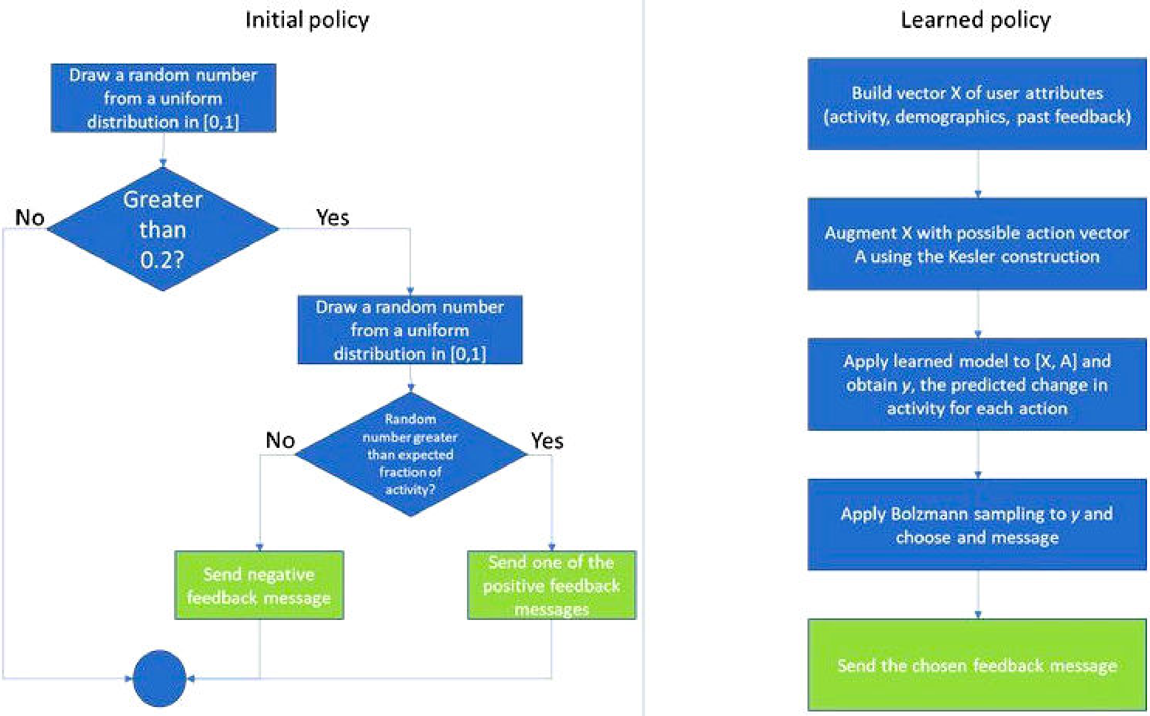


Table 1. Patient characteristics.

Characteristic	Treatment	Control
Number	20	7
Gender	8 female	1 female
Age in years, mean (SD[a])	58.7 (2.1)	55.1 (3.6)
Initial HbA1c[b] (%)	7.7	8.7

[a] SD: standard deviation.

[b] HbA1c: glycated hemoglobin.

There are many algorithms for addressing reinforcement learning problems. Most algorithms (Q-learning, TD learning, etc) rely on either having access to the true underlying state, or to high-quality features that represent the dynamics well. In our approach, we mostly tried to predict the effect of different actions on the immediate activity level given the current state of the patient rather than trying to change the patient's state. Thus, our policy is more of a “contextual bandit” type of algorithm [12]. Although we believe that introducing a state could be immensely useful, having statistical validity to it seems to require amounts of data beyond what we can expect.

Results

We report the characteristics of patients and their participation in the experiment, the effect of individual messages on user behavior, how the algorithm changed over time, and finally the two experimental outcomes—the change in activity made by participants during the experiment and the change in HbA1c during the experiment.

Patient Characteristics

A total of 27 patients were recruited, successfully installed the mobile app, and transmitted data for at least 1 week. Patient characteristics are shown in Table 1.

App Use and Physical Activity Measured

Target physical activity was on average 139 min (standard deviation [SD] 62) per week. The app continued to provide activity data for an average of 20 weeks (SEM 1.6). No statistically significant difference was observed between the treatment and control arms (ranksum, *P*=.30). Interrupted transmission was mostly because of the change of the mobile phone or phone number during the study. Analysis was done on all participants who successfully initiated app use, including the participants who did not complete the 26 weeks of the experiment. Thus, dropout was relatively late in the experiment.

All patients reported that they did not perform regular physical activity before recruitment, but there is naturally no objective accelerometer data for the amount of activity performed before recruitment. We decided that we could not separate the timing of providing the physical activity prescription from the recruitment process without causing any data collected in the first few weeks after recruitment to be biased.

Effect of Different Messages Over Time

We explored how each of the messages separately and how each two consecutive messages affected the change in the amount of activity and found significant differences in the reaction of participants to different messages and message sequences.

Figure 2 shows the average improvement in activity ($y_{i,t}$) for each of the four messages and the feedback effectiveness, which is the improvement in activity, weighted by the probability of each feedback message. The best increase in activity was found on the day after a positive-social message, whereas negative messages and positive-self messages led to a decrease in the amount of activity. This is congruent with experiments conducted by Elliot and Church [18]. The differences in the change of activity between the initial policy and the learned policy were statistically significant (analysis of variance, ANOVA; *P*=.004).

One of the attributes given as inputs to the learned policy was the time since each feedback message was sent. This provides a limited form of historical context to the policy, allowing feedback to be dependent between days. Figure 3 shows the average improvement in activity for feedback on day N, given the feedback on the previous day (N-1). We note that this figure is based on pairs of messages chosen by the algorithm and not random selection.

As the figure shows, for example, even though on average negative feedback produces a negative change in activity, negative feedback is correlated with a positive change in activity if given before a positive-self feedback. Similarly, positive-social feedback repeated day after day is correlated with a lower change in activity.

Differences in activity were statistically significant (ANOVA; *P*=.059 for the previous action and *P*=.02 for the current action, and *P*=.02 for the interaction of the two actions). Thus, time-dependent feedback is correlated with higher average change in activity.

Variability in Patient Response

The average improvement in activity varies among patients. To demonstrate this, we represented each user according to the average change in their activity following each daily feedback message (ie, a four-dimensional vector). We limit this analysis to 22 users in the treatment arm who received at least two different messages.

Figure 4 shows the results of clustering users using k-means with 3 clusters. As the figure demonstrates, one group of patients (cluster 1) reacted negatively to any feedback message. In contrast, patients in cluster 3 reacted positively to messages, especially positive-social or positive-self. This demonstrates the importance of individually tailored feedback delivered by our algorithm.

Users in the different clusters differed in their demographics. Table 2 shows the percentage of females and the average age of patients in each cluster. As the Table shows, cluster 3, where patients reacted positively to messages (Figure 4), is dominated by males. In contrast, cluster 2, where reactions to messages were overall weaker, comprises mostly women. Age variations are minor across clusters. Indeed, an ANOVA model with age and gender as independent parameters shows that age is not statistically significantly correlated with change in activity, whereas gender is (F=9.65, P=.002). Thus, there are significant correlates between patient gender and reaction to messages, demonstrating the importance of tailoring feedback according to these parameters and therefore providing them to the decision algorithm.

Table 2. Demographics of patients by cluster.

Demographic	Cluster 1	Cluster 2	Cluster 3
Female (%)	50 (2/4)	67 (6/9)	20 (1/5)
Average age, in years	57	54	56

Figure 2. Change in activity following feedback messages for the two feedback policies. Shown are the average improvement in activity for each of the four messages, as well as the feedback effectiveness, which is the improvement in activity weighted by the probability of each message.

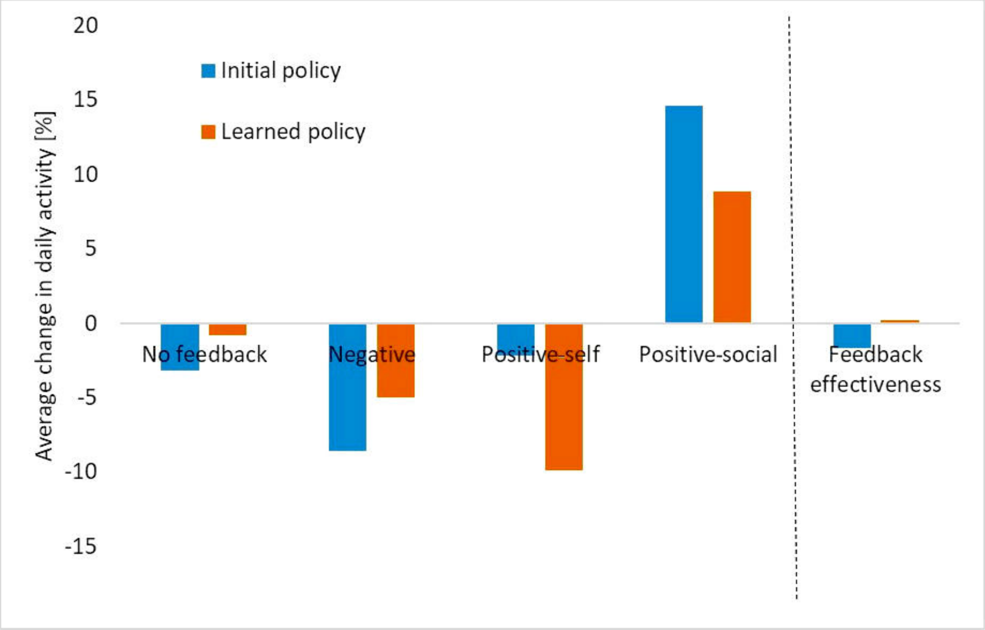
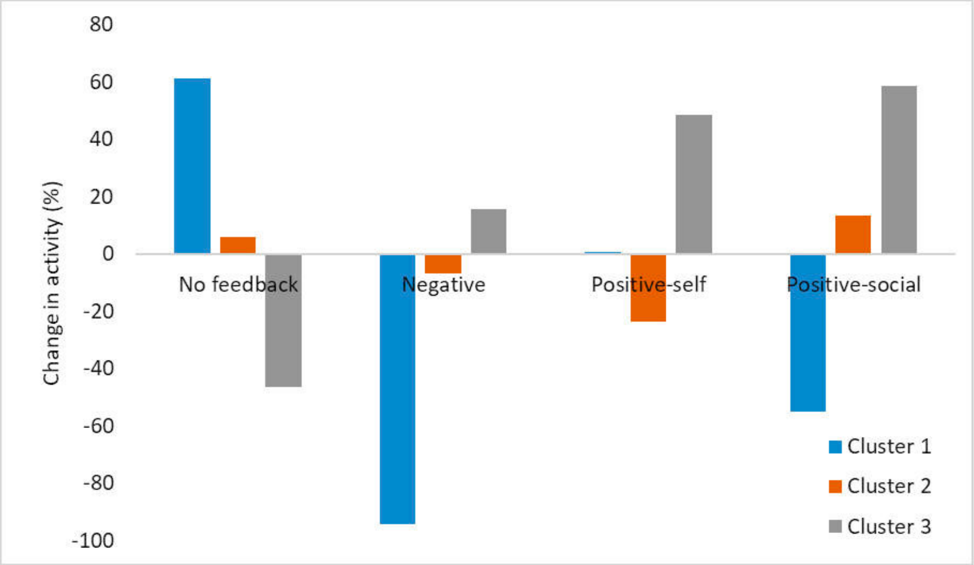


Figure 3. Change in activity as a function of feedback, grouped by current feedback. Each group shows the average change in activity following the current feedback (eg, feedback at time t), given the previous feedback given to the user (at time t-1).

Figure 4. Change in activity as a function of feedback message in each cluster. Cluster 1 comprised 4 patients, cluster 2 had 9 patients, and cluster 3 had 5 patients.



The Learning Process of the Algorithm Over Time

We investigated how the messages generated by the learning algorithm changed over time, as more information was collected on the response of the participants to feedback vis-a-vis their previous activity and demographics. Figure 5 shows how the learning algorithm gradually improves over time in predicting the amount of activity, demonstrating that much of the difference in exercise on a given day can be explained by the learning algorithm, which in turn indicates that much of patient behavior is predictable.

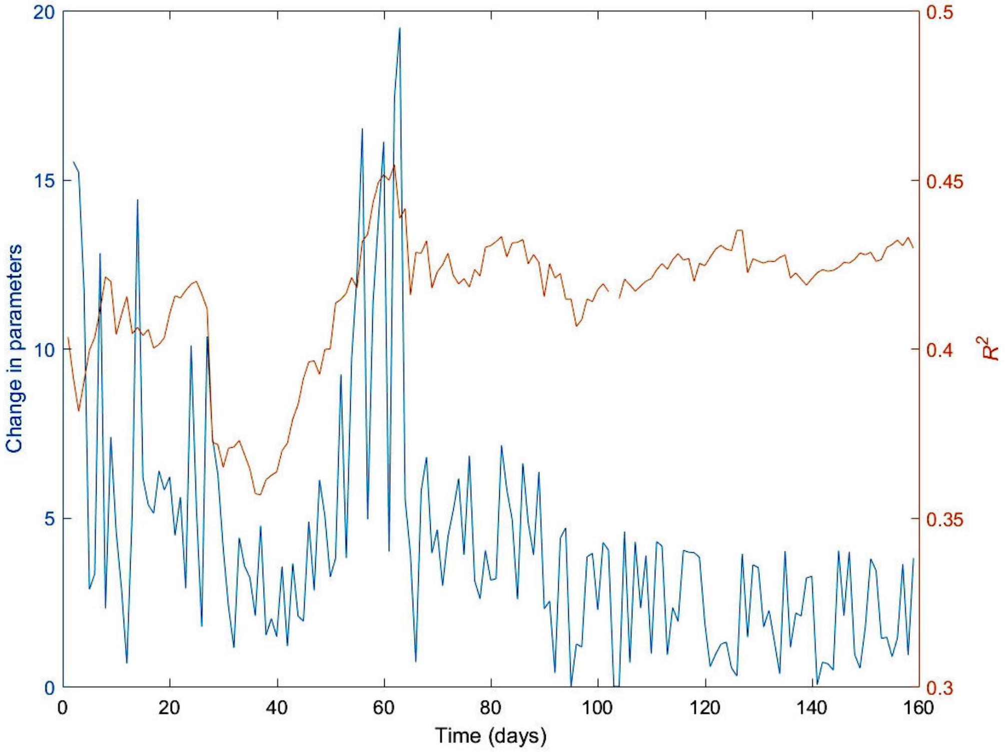
Figure 5 shows the change in parameters of the algorithm from one day to the next, calculated as the difference between the absolute values of the model parameters over successive days, and how much of the activity is explained by the predictions of the learning algorithm, as given by the adjusted R^2, over time.

First, we note that stability increases over time, as more data are collected. Second, R^2 initially increases, reaching approximately 0.43. This means that much of the difference in exercise on a given day can be explained by the learning algorithm attribute, indicating that to a large extent, patient behavior is predictable. We also note jumps in learning algorithm stability, for example, around day 60. These jumps seem to correspond to major adverse weather events and may be caused by new ways in which people behave because of these events, creating unexpected data that cause the algorithm to learn a new hypothesis. This demonstrates the necessity to collect longitudinal data over wide-ranging circumstances and possibly the need to include other variables such as weather and calendar events.

We analyzed the coefficients of the learned model to find the coefficients that affect the predictive ability of the learning algorithm. The coefficients that had statistically significant values (*P*<.05) in the linear model were as follows:

1. The interactions between daily activity in the day before feedback is given and
    a. the feedback message to provide.
    b. the activity performed so far.
    c. the time since each feedback message was given.
2. The interactions between the activity performed so far and the time since each feedback message was given.
3. The interactions between the fraction of activity performed so far and the time since each feedback message was given.
4. The interactions between the time since each feedback message was given.

Figure 5. Learning algorithm stability (change in parameters) and predictiveness over time. The horizontal axis is time as the learning algorithm was applied to the experiment. The left vertical axis and the blue lines denoted by plus signs shows the change in algorithm parameters from day to day, and the right vertical axis and full brown line shows the R^2 value of the model.



Improvement in Activity Quantity and Walking Rate

We modeled the change in activity performed by patients over time (presented as fraction of target activity) using linear regression. Figure 6 shows an example of the fraction of expected activity performed by one participant, together with the linear slope (which, for this patient, is equal to 0.0016) of this activity over the duration of the experiment.

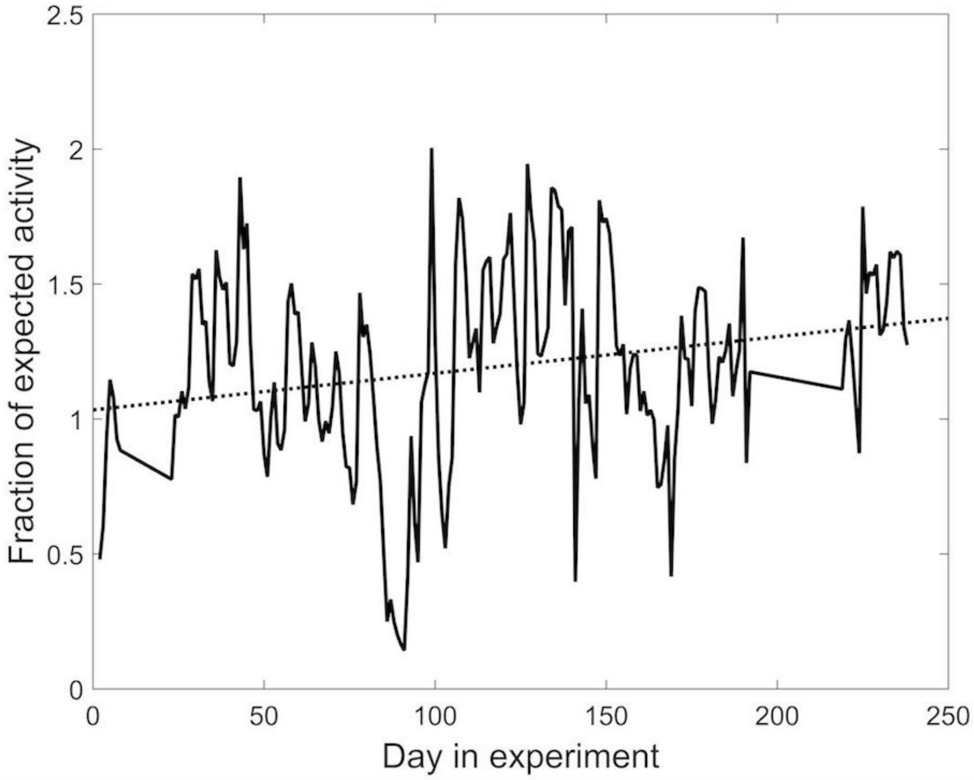
A linear function was fit for each participant separately, and the average slope for the participants in each policy group (weighted by the fit of the linear function) is shown in Table 3. As the table shows, the slope of the learned policy was superior to both the control population and the initial policy. Whereas the latter two show a negative change in activity, the learned policy shows a positive slope, implying in increase in activity over time.

Table 3. Rates of improvement in physical activity performed and in the rate of walking. The standard error of the mean is shown in parenthesis. The slope of change in activity is measured by a linear fit to the plotted amount of daily exercise over time. The slope of the rate of walking is the change in the number of steps per minute during walking over time.

Characteristic	Treatment		Control
	Initial	Learned	
Change in activity (minutes walking/day)	−0.001 (0.008)	+0.012 (0.002)	−0.004 (0.002)
Change in rate of walking (Hz/day)	−0.009 (0.005)	0.002 (0.005)	−0.010 (0.007)

The rate of walking (steps per minute) was measured throughout the experiment. We modeled the change in the average weekly rate of walking over time using a linear model by fitting a linear function to the rate of walking for each participant separately over time, and the average slope for the participants in each policy group (weighted by the fit of the linear function) is shown in Table 3. Patients in the control condition reduced their walking rate as the experiment progressed, consistent with the amount of walking they performed. In contrast, the personalized message population increased their walking rate over time significantly.

Figure 6. The change in activity (shown as the fraction of the expected activity) over time for one sample user. The dotted line shows the linear slope of the curve.



Change in Glycemic Control

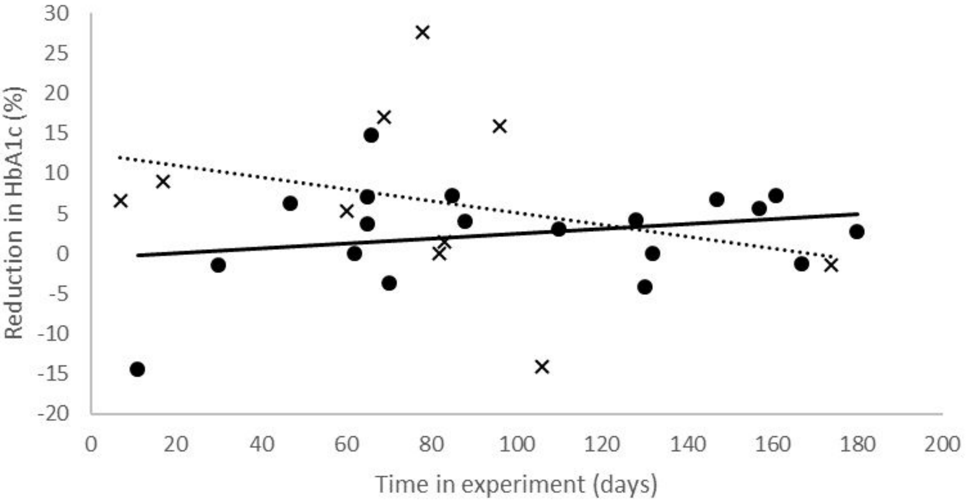
The initial HbA1c for all participants was 7.8 % (SD 1.0), and, on average, there was an improvement of 0.28 % (SD 0.84) in HbA1c for all patients. As mentioned, intensification of dietary or medical treatment was not restricted, so the change in HbA1c reflects a combination of the change in medical and dietary treatment and the change in exercise.

To assess the effect of variables of participation in the study on glycemic control, we constructed a linear model where the dependent variable is the difference between HbA1c levels at recruitment and the latest available measure of HbA1c. The independent variables are the number of days between measurements, initial HbA1c, and the activity target. Allocation to the personalized policy, higher initial HbA1c, and lower activity targets led to a superior reduction in HbA1c (R^2=0.405, P<.01).

Let HbA1c[t] be the blood glucose measure at time t. The relative reduction in HbA1c is given by (HbA1c[0] – HbA1c[t]) / HbA1c[0] where the beginning of the experiment is at t=0. The relative reduction as a function of the time in the experiment can be seen in Figure 7. The slope of a linear model for the treatment population is positive (0.05, R^2=0.07), whereas that of the control population is negative (−0.06, R^2=0.03), indicating that people in the treatment population experienced a reduction in blood glucose level the longer they participated and received messages determined by the personalized policy.

Thus, we conclude that receiving personal messages is associated with a statistically significant reduction in HbA1c levels. We note, however, that HbA1c values are known to suffer from significant intrasubject variability [21], and thus, future work will require larger cohorts to validate these findings.

Figure 7. Relative reduction in glycated hemoglobin (HbA1c) over time. Dots represent measurements from people allocated to the personalized policy, whereas crosses represent the control policy. The dotted line is a linear fit to the control policy data and the full line to the personalized policy.



Participant Satisfaction

The results of the patient satisfaction questionnaire are shown in Table 4. Interestingly, both control and learned policy group participants reported increasing their physical activity. The learned policy population reported that the SMS messages helped them increase and maintain the level of their activity significantly more than did the control population (*P*<.01). None of the participants in the control constant weekly reminder group felt that the SMS messages were helpful. Both groups said they received enough messages, though we interpret this result for the control population as unanimous lack of satisfaction with the unchanging wording of the feedback they received.

Table 4. Results of the patient satisfaction questionnaire. Only the response to the second question is statistically significantly different between control and personalized messages (chi-square test).

Question	Fraction answering “yes”		*P* value
	Treatment	Control	
Did you increase your level of physical activity since joining the experiment?	0.56	0.67	.73
Did the SMS[a] messages help you increase the frequency of physical activity?	0.80	0.00	.01
Did the SMS messages help you maintain your physical activity?	0.88	0.33	.07
Do you think you received enough messages to improve your activity?	0.78	1.00	.46

[a] SMS: short message service.

Discussion

Principal Findings

A large majority of patients with diabetes are resistant to the usual oral or written recommendations for physical activity they receive when encountering caregivers. Here, we developed a system that takes advantage of the continuous monitoring and communication afforded by smartphones to explore an alternative approach for improving adherence. In this pilot study, we evaluated the effect of feedback messages provided to patients directly by a mobile phone based on their success in obtaining physical activity goals, as measured by a computerized mobile app. This requires careful integration of hardware, software, and human guidance.

Our system used reinforcement learning to learn the feedback that will be most effective for each individual in any given situation, thus creating a highly personalized reminder service. Our results, as evident in the clusters of reactions to different feedback and the effect of message sequences, show the importance of tailoring messages to each individual and at each time.

We found that constant unvarying weekly reminders to perform physical activity are not effective in increasing activity and that patients were not satisfied with receiving them. On the other hand, changing the messages based on the activity performed as determined by the learning algorithm was effective in increasing both the length of time walked and the rate of walking. Indeed, the RL algorithm learned to sequence messages to improve efficiency.

Strengths and Limitations

In our approach, we learned a single model rather than a plurality of models. We ignored pertinent issues such as the sex and age of the user. It stands to reason that building multiple models from data (eg, one for women and one for men) could yield better results. Such an approach would require a larger population and would probably call for a different type of algorithm that takes into account contextual parameters as well to lead to much better performance [22].

Our approach is fairly unique in that we conducted training within an experiment. In RL terminology, this is called on-policy learning. In many treatments, one must follow an off-policy scheme: collect data using one policy (usually a historical policy) and try to learn a new policy without actually executing it. This leads to several problems such as large variance and bias, as exploration cannot be done where it matters most [23]. In our setting, this was not the case, and we had the luxury of training and using the same policy.

Patients were satisfied with the experience of using the app when they received personalized messages generated by the algorithm. The length of participation and allocation to the learned policy group for which the learning algorithm was used were correlated with superior improvement in HbA1c over competing policies, namely, weekly reminders and policies that do not take into account the specific context and attributes of each user.

Our results suggest that this novel concept for increasing physical activity can be implemented economically, efficiently, and effectively, leading to desired highly positive results. Notice that our approach not only allows for a predictive tool (going beyond current messaging systems) but also provides a method for personalized care.

The use of mobile phones as measurement tools is advantageous in that it does not require patients to maintain a separate device to participate in the experiment. It also has drawbacks in that measurements may be less accurate than those of dedicated devices and that patients may sometimes forget to carry them during exercise, leading to an underestimate of their exercise levels.

Conclusions

This small-scale study demonstrates the general concept that continuous monitoring and personalized guidance generated by a computer can have a significant impact on patient behavior. Unlike many current e-medicine systems that require input from the patient or the health care provider, the use of an automatic algorithm can be applied to very large groups of subjects. We plan to expand our result to the even more general concept that digitally generated health coaching of humans can have a positive impact. Further studies at larger scale and for longer periods are needed to evaluate whether the digital revolution and the potential to directly communicate with large groups of subjects and to assess the actual behavior reinforced can lead to a major improvement in their health-related behaviors or in their actual health.

Conflicts of Interest

None declared.

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Abbreviations

ANOVA: analysis of variance
HbA1c: glycated hemoglobin
JITAI: just-in-time adaptive interventions
RL: reinforcement learning
SD: standard deviation
SMS: short message service

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Original Paper

HealthyDads.ca: What Do Men Want in a Website Designed to Promote Emotional Wellness and Healthy Behaviors During the Transition to Parenthood?

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Abstract

Background: Up to 18% of men experience depression and/or anxiety during the transition to parenthood. Interventions designed specifically to promote the mental health of men during the transition to parenthood are scarce. Internet-delivered interventions may be acceptable and far-reaching in enhancing mental health, parenting knowledge, and healthy behaviors in expectant or new fathers.

Objective: To guide the development of Healthydads.ca, a website designed to enhance mental health and healthy behaviors in expectant fathers, a needs assessment was conducted to identify fathers’ perspectives of barriers to seeking help for emotional wellness, informational needs, and factors affecting the decision to visit such a website.

Methods: One hundred and seventy-four men whose partners were expecting, or had recently given birth, in 3 Canadian provinces (Quebec, Ontario, and Alberta) completed a Web-based survey inquiring about information needs related to psychosocial aspects of the transition to parenthood, lifestyle behaviors, parenting, and factors associated with the decision to visit a father-focused website.

Results: Most men (155/174, 89.1%) reported accessing the Internet to obtain information on pregnancy and spent an average of 6.2 hours online per month. Seeking information about parenting on the Internet was reported by 67.2% (117/174) of men, with a mean of 4.4 hours per month of online searching. Top barriers to seeking help to improve emotional wellness during the perinatal period were: no time to seek help/assistance (130/174, 74.7%), lack of resources available in the health care system (126/174, 72.4%), financial costs associated with services (118/174, 67.8%), and feeling that one should be able to do it alone (113/174, 64.9%). Information needs that were rated highly included: parenting/infant care (52.9-81.6%), supporting (121/174, 69.5%) and improving (124/174, 71.3%) relationship with their partner, work-family balance (120/174, 69.0%), improving sleep

(100/174, 57.5%), and managing stress (98/174, 56.3%). Perceiving the website as personally relevant (151/174, 86.8%), credible (141/174, 81.0%), effective (140/145, 80.5%), and having an easy navigation structure (141/174, 81.0%) were identified as important factors related to a first website visit. Providing useful (134/174, 77.0%) and easy to understand (158/174, 90.8%) information, which was also free of charge (156/174, 89.7%), were considered important for deciding to prolong a website visit. Providing the possibility to post questions to a health professional (133/174, 76.4%), adding new content regularly (119/174, 68.4%), and personal motivation (111/174, 63.8%) were factors identified that would encourage a revisit.

Conclusions: Our findings demonstrate that there is substantial interest among expectant and new fathers for using Internet-delivered strategies to prepare for the transition to parenthood and support their mental health. Specific user and website features were identified to optimize the use of father-focused websites.

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KEYWORDS

expectant fathers; mental health; needs assessment

Introduction

The transition to parenthood, while a positive and joyful life event for many expectant parents, can also be perceived as a stressful experience that negatively impacts psychological and marital resources for each partner in the couple relationship [1,2]. While numerous studies have been conducted to better understand and promote maternal adjustment during the perinatal period, fewer have targeted expectant fathers. However, expectant and new fathers are also at risk for increased emotional difficulties during the perinatal period. Two meta-analyses have found prevalence estimates between 8.4-10% for paternal antenatal and postpartum depression [3,4]. A recent review suggests that anxiety is also prevalent for men during the prenatal (4.1-16.0%) and postnatal periods (2.4-18.0%) [5]. Paternal emotional difficulties are related to unhealthy lifestyle behaviors (ie, greater use of alcohol and marijuana [6,7]), maternal postpartum depression [3], and a poorer quality and level of fathers' involvement with their infants [8-10]. Paternal depression occurring during pregnancy or in the early months of the infant's life may also negatively affect the child's behavioral, emotional, cognitive, and physical development [11-14]. Despite the prevalence and impact of emotional difficulties during the transition to fatherhood, few expectant or new fathers seek mental health services [15].

A qualitative study conducted to identify the needs of parents during the transition to parenthood found that even though men are now more involved in the antenatal care of their partners than in the past, men reported feeling frustrated by the lack of inclusion, involvement, and information specifically targeting fathers [16]. While this study provides a basis for understanding the gaps in care and needs of men during the transition to parenthood, more comprehensive studies are needed to obtain a better understanding of what men need and prefer, in order to guide and tailor the development of broad-reaching strategies aimed at better preparing men emotionally for the transition to fatherhood.

Despite men indicating a need for information and tools tailored to fathers to better prepare them for the transition, antenatal care and prenatal preparation programs do not systematically address the needs of expectant fathers [17]. In fact, stress management, lifestyle alterations, and relationship changes are often completely omitted from antenatal programs [17]. As a means to disseminate interventions designed to enhance, prevent, and treat mental health, the Internet has enormous appeal as it is anonymous, highly accessible (time and space), sustainable [18], and can be tailored to specific populations or groups [19]. For the majority of people in North America (estimated Internet usage in Canada is 86%) the Internet plays a pivotal role in work, education, and personal domains [20]. As many as 80% of Internet users in developed countries use this resource modality to search for health-related information, typically to find information on conditions, symptoms, and treatments [21,22]. An equally high proportion of men and women are also turning to the Internet to seek information on parenting [23].

A review of online parenting information concluded that many websites remain traditionally gender-biased, with most oriented towards the needs of mothers [23]. The needs of fathers during this life stage may be different from those of mothers. A meta-synthesis of qualitative studies related to early fathering revealed that men felt a strong sense of responsibility as fathers, but felt that they lacked the skills, experience, support, and recognition needed to be fathers [24]. The few studies conducted to date on the needs and knowledge gaps of men during this life stage suggest the importance of targeting fathers prenatally to facilitate their transition to fatherhood, and help them better prepare for the changes and stresses of becoming a parent [24,25]. While a number of Internet sites exist to address concerns related to expectant or new fathers [26,27], there is a lack of published data on their acceptability as a means of disseminating information and their efficacy in enhancing mental health, parenting knowledge, and healthy behaviors in expectant or new fathers.

While the Internet holds promise as a highly accessible and far-reaching mode of disseminating interventions, efficacy trials indicate that the actual uptake and sustained engagement with health interventions are low [28,29]. A sufficient amount of exposure to the intervention content is needed to positively impact the targeted intervention outcomes and initiate behavior change [30,31]. To optimize uptake and sustained use of an electronic health (eHealth) intervention, it is important to identify factors that are related to use in the target population. However, research examining the factors that influence visiting, extending a visit, and revisiting an electronically-delivered intervention remains sparse [32]. Some studies suggest that user (ie, education, age, motivation) and website characteristics (eg, credibility, ease of navigation) influence the use of eHealth interventions, and that the relative importance of these factors may vary depending on phase of exposure (ie, first visit vs revisit) [32]. Features such as the ability to monitor progress in behavior change and provision of tailored feedback have also been shown to increase revisits in studies with other populations [33,34]. Eliciting and incorporating the needs and preferences of the targeted intervention user have been emphasized as critical aspects of eHealth intervention development to optimize the intervention's usability and acceptability [35,36].

In preparation for the development of an acceptable and feasible evidence-based website (HealthyDads.ca) to enhance mental health and a healthy lifestyle for expectant first-time fathers, a Web-based needs assessment survey was conducted. This needs survey sought to determine: (1) barriers to seeking help to improve emotional wellness; (2) men's informational needs related to specific topics in the areas of mental health, parenting, and healthy behaviors; and (3) user- and Web-related factors associated with visiting a father-focused website.

Methods

Participants and Recruitment

Men were recruited between September 2014 and March 2015 by research staff, or via study flyers in the waiting rooms at university-affiliated obstetrician/gynecologist clinics, ultrasound clinics, and local prenatal classes in the Montreal, Toronto, and Calgary areas. Advertisements about the study were also placed on prenatal and parenting websites [37]. Potential participants were invited to participate in a Web-based survey and informed that the study aim was to learn more about the needs of expectant and new fathers to help the research team develop a new website tailored to men during the transition to parenthood. Eligibility criteria included: ability to understand English or French, partner currently pregnant (>13 weeks gestation) or delivered in the last 6 months, and Internet access.

The study protocol was approved by the McGill University Faculty of Medicine Institutional Review Board and the research ethics committees of the participating institutions (McGill University Health Centre, St. Mary's Hospital, St. Joseph's Health Centre, University of Toronto, and University of Calgary). All participants provided informed consent.

Men who indicated an interest in participating in the study were emailed a secure website address (a separate link for each participant) to access the Web-based survey. The survey was available in English and French, and was accessible through Fluid Surveys [38] via a password-protected log-in. Upon entering the log-in identifier number, participants viewed the cover page and a Web-based informed consent page describing the survey, with an option of consenting or declining to continue with the survey. Men who consented were then presented with a series of questions which took approximately 30 minutes to complete. Participants could exit the survey at any time. Upon completion of the Web-based survey, participants received a Can $10 gift card (eg, Amazon) to compensate them for their time.

Measures

The Needs Assessment Survey asked men to rate the importance and amount of information related to specific psychosocial aspects (ie, depressed mood, stress, work-family balance), parenting (ie, infant care, bonding), and healthy lifestyle behaviors (ie, sleep, physical activity, nutrition) that they would like to access through a Web-based site designed for expectant or new fathers. For items pertaining specifically to pregnancy (ie, *Information to help me learn how to support my partner during pregnancy/labor*), new fathers were asked to respond retrospectively to when their partner was expecting. Each item was rated on a 5-point Likert-type scale with higher scores reflecting greater importance and need for information. The survey also inquired about barriers to seeking help for emotional wellness, with each item rated on a 1 (not a barrier) to 5 (very much a barrier) scale. Using questions adapted from studies by Brouwer and colleagues [31,32,39], men were also queried about user- and Web-related factors associated with expectant fathers visiting a father-focused website. The topics and tools included in the survey were identified from the existing qualitative [16,40] and quantitative literature [23,41-43] (including our own study [44]), as well as the clinical expertise of our team.

Depressive symptomatology was assessed using the Patient Health Questionnaire-2 (PHQ-2). The PHQ-2 consists of 2 of the 9-items from PHQ-9; these include the frequency of depressed mood over the previous 2 weeks [45]. This scale is rated from 0 to 3 where 0= *not at all* and 3=n *early every day*. The validity of this 2-item scale has been verified in studies with men and women, and it is considered a useful tool [45,46].

The 4-Item Perceived Stress Scale (PSS-4) was used to assess perceived stress associated with daily life situations. The reliability and validity of the PSS-4 has been established with women during the perinatal period [47] and in diverse samples that have included men [48]. PSS-4 scores are obtained by reverse coding the positive items and then summing across all four items. Higher scores reflect higher degrees of perceived stress.

In addition to the questionnaires, demographic information (ie, age, marital status, ethnicity, education) was collected, along with monthly duration perusing the Internet to obtain information related to pregnancy and parenting.

Statistical Analyses

Statistical analyses were performed using the statistical software IBM SPSS version 20.0. The survey data were transferred from Fluid Surveys to SPSS. Descriptive statistics, including means, medians, and standard deviations (SDs) were calculated for all continuous variables, and percentages were calculated for categorical variables. Percent rating >3 for each barrier item (rating scale 1= *not a barrier*; 5= *very much a barrier*) to seeking help for improving emotional wellness was used to identify any barrier endorsed positively, regardless of severity, as very little is known in this area as it relates men during the perinatal period. Percent rating >4 for each item (rated on a 5-point Likert-type scale) related to information importance/amount and website-related usage factors was used to identify topics/factors most strongly needed or preferred, to allow us to best meet the needs of target users while being cognizant of project feasibility and budgetary constraints.

Chi-square tests were conducted to compare level of psychological distress with proportions of: (1) each barrier to improving emotional wellness, (2) preferences for website topics, and (3) factors related to website visits. Participants scoring above the cut-off on the PHQ-2 or in the top quartile on the PSS-4 were classified as distressed for these analyses. These results are presented in Multimedia Appendix 1.

Results

Characteristics of Study Participants

Of the 275 men who were eligible and agreed to be emailed a link to the Web-based survey, 203/275 (73.8%) accessed the link to start the survey. Among men accessing the survey, 29/203 (14.3%) did not complete the survey and 174/203 (85.7%) fully completed the survey and comprised the sample that was analyzed. As shown in Table 1, the mean age of our sample was 34.6 years (SD 4.5), with most men (132/174, 75.9%) in the 30-39-year-old age range. The majority of participants (155/174, 89.1%) had a University degree, with only 1.7% (3/174) having a high school diploma or less. Approximately 78.7% (137/174) of the men were Caucasian, and 86.8% (151/174) were employed. Most of the men who completed the survey had partners who were pregnant (141/174, 81.0%) and 19.0% (33/174) had an infant who had recently been born (mean age=11.7 weeks, SD 7.8). Among men whose partner was pregnant at the time of completing the survey, 77.9% (110/141) were expecting their first child.

Most men agreed that it is important to optimize one’s health during their partner’s pregnancy (150/174, 86.2%) to achieve and maintain good health prior to fathering (165/174, 94.8%), and that a father’s eating (166/174, 95.4%) and physical activity patterns (169/174, 97.2%) influence these health behaviors in his children.

Table 1. Characteristics of study participants.

Parameter	N=174
Age (years), mean (SD)	34.6 (4.5)
Education, % (n)	
High School or less	1.7 (3)
Grade 12/Vocational/Technical Program	5.2 (9)
Some College/University courses	3.4 (6)
University degree	89.1(155)
Ethnicity, % (n)	
Asian	7.5 (13)
Black	3.4 (6)
Caucasian	78.7 (137)
Other	10.2 (18)
Foreign born, % (n)	32.2 (56)
Married/Cohabitating, % (n)	98.3 (171)
Employment - Working, % (n)	86.8 (151)
Body mass index (kg/m^2), % (n)	
18.5-25	38.5 (67)
>25	61.5 (107)
Current Smokers, % (n)	10.3 (18)
Pregnancy Status, % (n)	
Partner currently pregnant	81.0 (141)
Recently delivered	19 (33)
Psychosocial, mean (SD)	
Patient Health Questionnaire-2	0.61 (1.0)
4-Item Perceived Stress Scale	4.2 (2.6)

Table 2. Barriers to improving emotional wellness during the perinatal period.

Help-Seeking Barriers	n (%)[a]
No time to seek help/ assistance	130 (74.7)
Lack of resources available in the health care system	126 (72.4)
Financial costs associated with services	118 (67.8)
Feeling that one should be able to do it on one’s own	113 (64.9)
Reluctance to talk to others about your moods or anxieties	107 (61.5)
Reluctance from family or friends to talk about emotional aspects of pregnancy/postpartum period	85 (48.9)
Fear that others will judge you	64 (37.0)

[a] Percent rating ≥3 for each barrier statement (1= *not a barrier*; 5= *very much a barrier*).

Most men accessed the Internet from their home (170/174, 97.7%) and 89.1% (155/174) reported accessing it to obtain information on pregnancy, with an average of 6.2 hours per month. Among those accessing Web-based pregnancy information, 42.6% (66/155) reported that the information was helpful. Seeking information about parenting on the Internet was reported by 67.2% (117/174) of men, with a mean of 4.4 hours per month of online searching related to this topic. Only 34.5% (40/117) found the Web-based parenting information helpful. Most users indicated that Web-based information related to pregnancy and parenting was not tailored specifically to fathers (121/154, 78.6%; and 87/117, 74.4%, respectively).

Psychological Well-Being

The mean score on the PHQ-2 was 0.61 (SD 1.0), with 16.7% (29/174) of participants scoring in the depressed range (score >2). The mean PSS-4 score was 4.2 (SD 2.6), with 26.3% (46/174) of men scoring in the top quartile (score >6) on this stress scale. Self-reported diagnosis of any psychiatric or psychological disorder was 6.9% (12/174). Prior treatment for an emotional problem was reported by 12.6% (22/174) of the sample, with psychotherapy (18/22, 81.8%) and medication (13/22, 59.1%) found as the two most frequently used modalities.

Barriers for Improving Emotional Wellness

The most frequently endorsed barriers to seeking help to improve emotional wellness for expectant and new fathers during the perinatal period (Table 2) were reported to be lack of time to seek help/assistance (130/174, 74.7%), lack of resources available in the health care system (126/174, 72.4%), financial costs associated with services (118/174, 67.8%), and feeling that one should be able to do it alone (113/174, 64.9%). Chi-square analyses indicated that compared to nondistressed participants, those who were psychologically distressed were more likely to endorse reluctance to talk to others about their moods or anxieties (71.9% vs 56.3%, *P*=.048), and reluctance from family or friends to talk about emotional aspects of pregnancy and the postpartum period (63.2% vs 41.9%, *P*=.008). No group differences were found for the other barriers. These results are detailed in Multimedia Appendix 1.

Information Needs

Information domains rated in terms of level of importance for a website to enhance emotional wellness, preparing to be a father, and healthy behaviors during the perinatal period (and amount of detail amount needed) are outlined in Table 3. The most highly rated topics were related to: (1) parenting/infant care (52.9-81.6%); (2) partner-oriented issues (66.1-71.3%); and (3) psychosocial topics including their own emotional adjustment, sleep problems, and stress-management (51.2-60.3%). Behavioral topics related to healthy eating and physical activity (42.5-50.6%) were rated as slightly less important. Specific questions in the parenting/infant care and partner-oriented domains that received the highest importance ratings were: how to settle a fussy baby (142/174, 81.6%), information related to baby care (130/174, 74.8%), ways to improve relationship with partner after baby’s birth (124/174, 71.3%), how to support their partner during pregnancy/labor (121/174, 69.5%), balancing work-family life (120/174, 69.0%), and supporting partner to start and maintain breastfeeding (115/174, 66.1%). The top three questions within the psychosocial domain with the highest ratings regarding importance of information were: information about fathers’ emotional adjustment following baby’s birth (105/174, 60.3%), tools to manage sleep problems (100/174, 57.5%), and stress-management tools (98/174, 56.3%).

Chi-square analyses indicated that compared to nondistressed participants, those who were psychologically distressed were more likely to endorse the following topics related to the psychosocial domain: stress-management tools (68.4% vs 50.4%, *P*=.025), strategies to improve mood/emotional well-being (68.4% vs 44.4%, *P*=.003), information about emotional adjustment during their partner’s pregnancy (63.2% vs 45.35, *P*=.027), and access to psychosocial resources (36.6% vs 23.9%, *P*=.045). No other group differences were found for the other topics within the psychosocial domain or questions in the parenting/infant care and partner-oriented domains. These results are detailed in Multimedia Appendix 1.

Table 3. The importance of information topics and amount of detailed information needed.

Survey Items	Importance of Information, n (%)[a]	Amount of Information, n (%)[b]
How to settle my baby when s/he is fussy	142 (81.6)	129 (74.2)
Information to increase my knowledge about how to look after my baby	130 (74.8)	121 (69.5)
Information to help me learn how to improve our relationship after pregnancy	124 (71.3)	105 (60.4)
Information to help me learn how to support my partner during pregnancy/labor	121 (69.5)	111 (63.8)
Balancing work-family life	120 (69.0)	95 (54.6)
Ways to support my partner start and maintain breastfeeding	115 (66.1)	90 (51.8)
Information about my emotional adjustment following the baby’s birth	105 (60.3)	79 (45.4)
How to bond with my baby	100 (57.5)	94 (54.1)
Tools to help manage sleep problems	100 (57.5)	81 (46.6)
Information to help me find out about what is offered for dads locally in my area	99 (56.9)	90 (51.7)
Stress-management tools	98 (56.3)	79 (45.4)
How to play with my baby	96 (55.2)	93 (53.4)
Access to parenting resources	94 (54.0)	74 (42.5)
Information to increase confidence in my role as a dad	92 (52.9)	74 (42.6)
Strategies to improve my mood (or emotional well-being)	91 (52.3)	69 (39.7)
Information about my emotional adjustment during my partner’s pregnancy	89 (51.2)	60 (34.5)
Strategies to help me become or stay physically active	88 (50.6)	73 (42.0)
Ways to stay motivated to exercise regularly after my partner has given birth	87 (50.0)	74 (42.6)
Information to help me learn how to cope with this huge change in my life	79 (45.4)	67 (38.5)
Tools to decrease anxiety or fear related to childbirth	76 (43.7)	65 (37.4)
Strategies to help me eat healthy	74 (42.5)	67 (38.5)
Tests to measure my mood/stress levels	66 (37.9)	54 (31.1)
Tips for getting help from my support system	65 (37.3)	50 (28.7)
Access to psychosocial resources	50 (28.7)	39 (22.4)
Information to help me learn more about my feelings about pregnancy	44 (25.4)	42 (24.3)
Chat rooms/social networking with other dads-to-be or new dads	42 (24.1)	31 (17.8)

[a] Percent rating ≥4 for importance of information topics (1= *not at all important*; 5= *very important*).

[b] Percent rating ≥4 for amount of information needed (1= *none*; 5= *detailed*).

Table 4. User and website factors reported as important when making a first-visit to a website for expectant fathers to promote their mental health and a healthy lifestyle.

Survey Items	n (%)[a]
Whether the visitor…	
Perceives the website as relevant for himself	151 (86.8)
Perceives the source (the organization that provides the intervention) of the website as credible	141 (81.0)
Knows that the website is effective	140 (80.5)
Is willing to spend time on visiting the website	137 (78.8)
Is motivated to visit a father-focused website	131 (75.3)
Has access to the Internet at a private location (eg, home, work)	127 (73.0)
Gets a positive recommendation about the website	125 (71.8)
Wants to improve his mental health and/or lifestyle	112 (64.4)
Has positive expectations of father-focused information delivered through the Internet	110 (63.3)
Has sufficient skills to use the Internet	73 (42.2)
Is referred to the Internet intervention by a health professional (eg, general practitioner, nurse)	67 (38.5)
Receives a reminder to visit the website	49 (28.1)
Receives an incentive for visiting the website	40 (23.0)
Whether the website…	
Has a navigation structure that appears to be easy to use at first sight	141 (81.0)
Is created by experts in parental well-being behavior change	134 (77.0)
Is based on scientific knowledge	131 (75.3)

[a] Percent rating ≥4 for importance (1= *not at all important*; 5= *extremely important*).

Factors Influencing Website Usage

The results for features perceived to be very/extremely important for determining whether an expectant father would make a first visit to a website designed to promote their mental health and healthy lifestyle are shown in Table 4. Visitor-related features for a first-time visit that were endorsed as very/extremely important by at least 75% of the sample included: perceiving the website as personally relevant (151/174, 86.8%), credible (141/174, 81.0%), and effective (140/174, 80.5%), as well as user's willingness (137/174, 78.8%) and motivation (131/174, 75.3%) to spend time visiting the site. Website-related features for determining a first visit that were identified as very/extremely important were reported to be: an easy navigation structure (141/174, 81.0%) and creation by experts in parental well-being and behavior change (134/174, 77.0%).

Table 5 displays the results for features perceived to be very/extremely important for determining whether an expectant father would continue to visit a website long enough to actively engage in, and process, the educational content provided on the website. Visitor-related features for a first-time visit endorsed as very/extremely important by at least 50% of the sample included the user wanting to improve knowledge in relation to the topics (134/174, 77.0%) and experiencing the website as rewarding (129/174, 74.1%). Website-related features for determining whether an expectant father would continue to visit a website long enough to actively engage in and process the educational content provided in the website included: easy to understand information (158/174, 90.8%), free of charge to use (156/174, 89.7%), having useful information for fathers to help them adjust and engage in healthy behavior (147/174, 84.5%), and website attractiveness (123/174, 70.7%).

The results for features perceived to be very/extremely important for determining whether an expectant father revisits a website designed to promote their mental health and healthy lifestyle are shown in Table 6. The most strongly endorsed visitor feature was commitment (111/174, 63.8%), while the most strongly endorsed website-related features were the possibility to post questions to a health professional (133/174, 76.4%) and providing new content on a regular basis (119/174, 68.4%). There were no significant differences in factors influencing website usage by psychological distress status. These results are presented in Multimedia Appendix 1.

Table 5. User and website factors reported as important in prolonging a visit to a website for expectant fathers.

Survey Items	n (%)[a]
Whether the visitor…	
Wants to improve his knowledge in relation to the topics of the website	134 (77.0)
Experiences the use of the website as rewarding	129 (74.1)
Likes receiving (tailored) feedback on the answers he provided on questions	84 (48.3)
Knows in advance how long it will take to go through the whole website	46 (26.4)
Experiences the use of the website as challenging	36 (20.7)
Whether the website…	
Provides information that is easy to understand	158 (90.8)
Can be used free of charge	156 (89.7)
Provides information that is perceived to be useful for dads to help them adjust and engage in healthy behavior	147 (84.5)
Is attractive for the visitor to use	123 (70.7)
Does not take much time to entirely complete	93 (53.5)
Provides brief textual information (ie, does not involve a great deal of reading)	87 (50.0)
Displays personal progress through the program (eg, progress bar page numbers)	68 (39.1)
Provides testimonials of successes of other dads who used it	66 (37.9)
Has a brief registration procedure (eg, the registration of log-in name and password)	63 (36.2)
Uses a short questionnaire for providing tailored feedback	62 (35.6)
Provides interactive features (eg, tests, forums, games)	57 (32.7)
Uses a virtual guide to guide a visitor through the website	41 (23.6)

[a] Percent rating ≥4 for importance (1= *not at all important*; 5= *extremely important*).

Table 6. User and website factors reported as important to revisit a website for expectant fathers.

Survey Items	n (%)[a]
Whether the visitor…	
Is committed to revisiting the website	111 (63.8)
Receives a reminder to revisit the website	35 (20.1)
Whether the website…	
Provides the possibility to post questions to a health professional	133 (76.4)
Provides new content on a regular basis	119 (68.4)
Uses an approach in which a new visit provides access to all modules or sections in the website	84 (48.2)
Provides the possibility for a visitor to monitor his progress in changing a behavior	80 (46.0)
Includes the option for the visitor to communicate with others (eg, chat rooms, blogs, forums)	53 (30.5)
Uses a modular approach in which a new visit provides access to the next module or section	36 (20.6)

[a] Percent rating ≥4 for importance (1= *not at all important*; 5= *extremely important*).

Discussion

Involving potential users in the early stages of intervention development may be key to optimizing the usage, adoption, and impact of eHealth technologies [36]. In preparation for the development of HealthyDads.ca, an electronically-delivered intervention to enhance the mental health and health behaviors of expectant fathers, this study investigated the needs and preferences of fathers towards an eHealth intervention designed to facilitate the transition to fatherhood.

The results of this study showed that expectant and new fathers spend a considerable amount of time on the Internet during their partner's pregnancy and the postpartum period to search for information on pregnancy (approximately 6 hours per month) and parenting (approximately 4 hours per month). While previous studies have reported on the frequency and patterns of Internet use for information-seeking related to pregnancy and parenting in expectant or new mothers [49-52], this is the first study to document frequency for expectant and new fathers living in Canada. The high use of the Internet as a resource for health-related information during pregnancy and the postpartum period for parents is consistent with findings from the general population [22]. A nationwide survey conducted in the United States found that 72% of Internet users reported searching online for health information of one kind or another within the past year [22]. While our findings support the feasibility of using Web-based educational strategies to reach large numbers of men during the transition to fatherhood, they also point to the need for more father-specific information, given that 3 in 4 men who used the Internet for this purpose reported that the content was not tailored to them.

Consistent with studies conducted with women during the perinatal period, we found that lack of time, lack of resources available in the health care system, and financial costs were common barriers reported by expectant/new fathers (regardless of their level of psychological distress) for seeking help to improve mental health during pregnancy and following the baby's birth [51,53,54]. The high percentage of expectant and new fathers reporting logistical barriers regarding when and where to obtain services during the perinatal period extends the findings of other Canadian studies with new parents that have examined barriers to accessing support services [55,56]. Delivering an intervention to expectant and new fathers over the Internet may help overcome these logistical barriers, given that Web-based interventions are far-reaching and accessible 24/7, allowing for access at the users' convenience. Moreover, given the frequency of Internet use by expectant fathers, a Web-based intervention tailored to the needs of men during this life stage may be a highly acceptable mode of delivering evidence-based strategies to promote mental health and better prepare men for fatherhood.

Fathers with elevated psychological distress were more likely to endorse reluctance to talk to others about their moods or anxieties, and reluctance from family or friends to talk about emotional aspects of pregnancy and the postpartum period as barriers to seeking help to improve mental health during pregnancy and following the baby's birth. It has previously been shown that men at higher risk of depression have more negative attitudes towards help-seeking [57]. These attitudinal barriers may relate to conformity to masculine norm expectations such as self-reliance and resisting displays of vulnerability [58,59]. These findings highlight the importance of incorporating strategies to preempt potential challenges to masculine identities when designing interventions to promote mental health in men, to ensure that they access such resources and remain engaged.

Our findings showed that men want a broad spectrum of Web-based information, including topics related to parenting/infant care (75-82%), supporting (121/174, 69.5%) and improving (124/174, 71.3%) relationships with their partners, work-family balance (120/174, 69.0%), managing stress (98/174, 56.3%), and improving sleep (100/174, 57.5%). The need for Web-based information and strategies to improve mood and coping skills, mobilize social support, and healthy eating were rated as somewhat less important. A study conducted in Australia that offered email and Web-based information tailored to expectant fathers on numerous topics found that fathers were more likely to choose topics related to father-infant interactions [41]. While this finding demonstrates the importance of involved fathering for men, it also suggests that men may be lacking (and therefore actively seeking) practical information on how to engage with their infants in caring and playful activities.

Men reported wanting information on how to support their partner during pregnancy and childbirth, reflecting the importance of an active role that expectant fathers play in their partner's pregnancy [60]. Uncertainty regarding how to support a pregnant partner has previously been reported by expectant fathers [61]. Increasing fathers' involvement during pregnancy can make the pregnancy seem more real to expectant fathers [61] and may also lead to better pregnancy outcomes through the reduction of maternal stress [62,63] and depression [64], and support for positive maternal behaviors [65]. Consistent with recent recommendations [40], our findings underscore the importance of including strategies to support their partner during pregnancy when developing father-inclusive antenatal programs. The degree of a father's involvement during pregnancy is likely influenced by the quality of the relationship with their partner [66], underlying the importance of incorporating strategies such as communication skills training in antenatal programs designed to better prepare couples for the transition to parenthood.

Overall, the informational needs of men in this study centered more on their infant and partner with less emphasis on their own emotional well-being, regardless of their psychological distress level. While these domains are key to the fathering role, they are optimized when fathers themselves are doing well emotionally and feel supported [67,68]. These results may indicate that men feel less of a need for Web-based information on topics related to their mental well-being compared to the parenting and partner domains. Men may also reflect stigma to endorse needs related to psychosocial aspects, or a lack of awareness, concerning the emotional challenges they can experience during the transition to fatherhood. Among the distressed expectant/new fathers in this sample, topics in the psychosocial domain that were most strongly endorsed included stress-management tools and strategies to improve mood/emotional well-being. Considering that subgroups of men struggle with depression, anxiety, and stress during the transition to fatherhood [3-5], father-specific or father-inclusive antenatal programs need to include knowledge and strategies that men can utilize (eg, relaxation techniques, sleep hygiene, physical activity) to optimize emotional adjustment during the transition to fatherhood.

Uptake and sufficient exposure to electronically-delivered interventions remains suboptimal [28,29,69] and requires consideration in the design phase of user- and Web-related factors to optimize usage [31]. The present study is the first to identify potentially important user- and website-specific factors related to uptake and exposure to an Internet-delivered intervention to enhance mental health and a healthy lifestyle in first-time expectant fathers. User-specific factors identified by expectant and new fathers related to making an initial visit to such a website included perceived personal relevance, credibility, effectiveness, time, and motivation. It is not surprising that perceived personal relevance was a top factor that was identified, as men in this study felt that existing websites were not tailored to fathers. Our findings related to the overall user aspects associated with an initial visit are consistent with recommendations made by Brouwer et al [32] who suggested that to impact these user factors, strategies such as targeted promotional information about the electronically-delivered intervention should occur prior to the initial visit to the website, to optimize adoption.

A clear navigation structure and credibility aspects related to the website development by experts with scientific-based content were strongly endorsed as important in deciding to make a first visit. An easy-to-navigate website has consistently been reported by users from all age groups as an important Web-related criterion to determine use [70,71], underscoring the importance of conducting usability testing with users during prototype development. Perceptions related to credibility of a website have been shown to influence judgements related to the quality and usefulness of the information on the website, as well as level of engagement [72,73]. Including a list of scientific resources used to develop the content, expertise of the team (ie, educational and research) contributing to the content of the website with their academic and/or clinical affiliations, as well as funding sources, may help to enhance the credibility of electronically-delivered interventions.

User factors related to wanting to improve knowledge and experiencing the website as rewarding were identified as factors important to prolonging a visit to the website. However, compared to user factors, website-related features were endorsed more strongly as important to prolonging a visit to a father-focused website. A website with easy to understand content, which was free of charge and contained information to help dads adjust and engage in healthy behaviors, with an attractive layout, were factors identified by fathers as important when deciding to prolong a visit. While it has previously been suggested that interactive website features such as tests, forums, and games improve adherence to eHealth interventions targeting mental health and lifestyle promotion [39,74], few respondents in the present study felt strongly about these components.

Fathers in the present study identified the possibility of posting questions to a health professional and regular new content as Web-related features, and personal commitment as a user factor, as being more strongly related to revisiting a website. The use of email reminders to prompt previous users to revisit the website was not highly regarded, even though studies have shown this to be a feature associated with increased usage of electronically-delivered interventions [75,76]. Very few respondents felt that a modular approach, in which a new visit provides access to the next module or section of a website, would entice them to revisit the website. This finding is in line with feedback from users of electronically-delivered interventions targeting expectant mothers [77], as well as those with other populations [78], indicating that users prefer flexibility and access to all modules with some guided features. The user- and Web-related factors identified in relation to uptake and degree of exposure point to the importance of pretesting newly designed Internet-delivered interventions with potential users to ensure that these aspects are optimized prior to the evaluation and implementation phases.

Overcoming barriers to access and strategies to fully engage men with health promotion interventions remains a complex and challenging problem. Identifying the needs of expectant and new fathers, and user- and Web-related factors associated with uptake, are important steps toward optimizing the usability and acceptability of our electronically-delivered program [35,36]. It is important to note that while we surveyed factors that potential users might consider when determining a first-visit, prolonging a visit, and revisiting a website targeting mental health and a healthy lifestyle for expectant fathers, eHealth studies targeting fathers that incorporate these features are needed to determine which of these factors actually contribute to uptake and increased exposure over time in this population. Electronic technology provides a means of creating and disseminating health promotion programs that can be enabled by a variety of channels, including social media, to better reach and engage hard-to-reach groups [79]. Novel ways of engaging men (eg, encouraging men to be agents in helping to promote and connect with other expectant fathers) may also facilitate uptake and use of father-friendly evidence-based electronically-delivered interventions.

Limitations

Several limitations of the study should be noted. Our survey was distributed to men who had Internet access and may not reflect the needs of men who are not online. However, this is likely to be a small minority given that 95% of Canadians under the age of 55 years have Internet access [20], with 83% having access at home [80]. Our sample size was comprised mostly of Caucasian, highly-educated men, with a high socioeconomic status. Thus, our sample cannot be considered representative of all men in the perinatal period, which limits the generalizability of our findings. The rate of elevated depressed mood in the present sample (29/174, 16.7%) was higher than what has been reported for paternal depression during the perinatal period (8.4%) [4]. It is possible that the responses to the survey are more representative of fathers who are experiencing emotional difficulties during the transition to parenthood. While we surveyed a broad range of user- and Web-related factors previously identified as important in determining a first visit, extending a visit, and revisiting Internet-delivered behavior change interventions [31], other user factors such as anxiety/worry about becoming a father and conformity to masculine gender norms may also influence the level of engagement. While our survey was offered in both English and French languages, the results do not reflect the needs of men who are not fluent in these languages. Given our relatively small sample size, our findings should be considered preliminary. The Can $10 incentive offered following survey completion may have impacted men’s inclination to participate and fully complete the survey. However, findings from Web-based surveys suggest that postpaid survey completion incentives do not substantially increase participation rates [81] or item nonresponse rates [82].

Implications and Conclusions

We have identified information topics that men find important to include, as well as user and Web-related features, which may enhance exposure to websites targeting fathers. Our findings indicate that during the perinatal period men want Internet-delivered information related to parenting, supporting their partner, and optimizing their emotional adjustment during the transition to parenthood. Gender-tailored elements to reduce stigma and overcome barriers to seeking and accepting help are also important to consider when developing interventions designed to promote mental health in men, such as HealthyDads.ca. Language around mental health and its treatments can itself be viewed as a barrier to engaging men [83]. We have taken steps to ensure that the language in the website is positive and friendly toward men. For example, cognitive-behavioral strategies to reduce mood, stress, and anxiety symptoms are termed *Mental Fitness Tools*. Activity or action-based strategies have also been shown to be useful when working with men [83]. Physical activity interventions, including those that are Web-delivered, have been shown to be acceptable and effective in enhancing mental health and increasing healthy behaviors in men [84-86]. We will provide men with a pedometer and they will have access to Web-based physical activity challenges designed to motivate the user to engage in regular exercise.

Similar to what has been suggested for women [87], a partner's pregnancy may be a "teachable moment" as men may be more open and interested in interventions designed to promote their own and their family's well-being and health. The findings from this needs assessment have guided the development of HealthyDads.ca, an evidence-based Internet intervention to enhance mental health and healthy behaviors for expectant first-time fathers. We are currently pilot testing this prototype to determine its acceptability and feasibility, which is an important step to undertake prior to conducting an evaluation of its effectiveness.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Additional tables by psychological distress status.

[PDF File (Adobe PDF File), 49KB - jmir_v19i10e325_app1.pdf]

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Abbreviations

eHealth: electronic health
PHQ: Patient Health Questionnaire
PSS-4: 4-Item Perceived Stress Scale
SD: standard deviation

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Original Paper

Characterizing Active Ingredients of eHealth Interventions Targeting Persons With Poorly Controlled Type 2 Diabetes Mellitus Using the Behavior Change Techniques Taxonomy: Scoping Review

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Abstract

Background: The behavior change technique taxonomy v1 (BCTTv1; Michie and colleagues, 2013) is a comprehensive tool to characterize active ingredients of interventions and includes 93 labels that are hierarchically clustered into 16 hierarchical clusters.

Objective: The aim of this study was to identify the active ingredients in electronic health (eHealth) interventions targeting patients with poorly controlled type 2 diabetes mellitus (T2DM) and relevant outcomes.

Methods: We conducted a scoping review using the BCTTv1. Randomized controlled trials (RCTs), studies with or pre-post-test designs, and quasi-experimental studies examining efficacy and effectiveness of eHealth interventions for disease management or the promotion of relevant health behaviors were identified by searching PubMed, Web of Science, and PsycINFO. Reviewers independently screened titles and abstracts for eligibility using predetermined eligibility criteria. Data were extracted following a data extraction sheet. The BCTTv1 was used to characterize active ingredients of the interventions reported in the included studies.

Results: Of the 1404 unique records screened, 32 studies fulfilled the inclusion criteria and reported results on the efficacy and or or effectiveness of interventions. Of the included 32 studies, 18 (56%) were Web-based interventions delivered via personal digital assistant (PDA), tablet, computer, and/or mobile phones; 7 (22%) were telehealth interventions delivered via landline; 6 (19%) made use of text messaging (short service message, SMS); and 1 employed videoconferencing (3%). Of the 16 hierarchical clusters of the BCTTv1, 11 were identified in interventions included in this review. Of the 93 individual behavior change techniques (BCTs), 31 were identified as active ingredients of the interventions. The most common BCTs identified were instruction on how to perform behavior, adding objects to the environment, information about health consequences, self-monitoring of the outcomes and/or and prefers to be explicit to avoid ambiguity. Response: Checked and avoided of a certain behavior Author: Please note that the journal discourages the use of parenthesis to denote either and/or and prefers to be explicit to avoid ambiguity. Response: Checked and avoided “and/or” and prefers to be explicit to avoid ambiguity. Response: Checked and avoided, and feedback on outcomes of behavior.

Conclusions: Our results suggest that the majority of BCTs employed in interventions targeting persons with T2DM revolve around the promotion of self-regulatory behavior to manage the disease or to assist patients in performing health behaviors necessary to prevent further complications of the disease. Detailed reporting of the BCTs included in interventions targeting this population may facilitate the replication and further investigation of such interventions.

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KEYWORDS

type 2 diabetes; telemedicine; mobile health; telehealth; eHealth; mHealth

Introduction

The global burden of diseases has shifted from communicable diseases to noncommunicable diseases (NCDs) due to interrelated nutritional, sociodemographic, and epidemiological transitions [1]. Deaths attributable to NCDs are expected to rise by 15% between 2010 and 2020 [2,3]. Type 2 diabetes mellitus (T2DM) is one of the major NCDs. Globally, around 415 million people are living with diabetes [4], and the global obesity epidemic [3] has increased its importance for global health. This number is expected to rise to 642 million by 2040. Hence, diabetes has become one of the largest global health emergencies of the 21st century [4].

As a result of advances in information and communication technology (ICT), mobile phones and the Internet are increasingly playing a role in interventions for health promotion and in those aimed at preventing and managing diseases [5]. These technologies may help patients perform behavior necessary for disease management and lifestyle modification and may support long-term treatment. Engaging patients in the care continuum using technological support to improve treatment outcomes and enhancing communication between patients and providers are effective interventions [6,7].

An increasing number of effective ICT applications are currently employed by health providers to improve health behaviors and manage disease outcomes in persons with T2DM [8-13]. Electronic health (eHealth) is the use of ICT for health [14]. Eysenbach defined eHealth as an “intersection of medical informatics, public health, and business, referring to health services and information delivered or enhanced through the Internet and related technologies” [15]. Applications such as telemedicine, videoconferencing, Web-based applications, tailored and untailored text messaging, mobile phone apps, biometric sensors, wearable devices, and Internet-based interactive support systems are currently used for the management of T2DM and to support the adoption of a healthier lifestyle [8,16-21].

Several outcome measures were employed in studies investigating the effectiveness of eHealth interventions targeting persons with T2DM [8]. Blood glucose and hemoglobin A_{1c}(HbA_{1c}) levels and the incidence of hypoglycemic events are often used as objective primary outcome measures in randomized controlled trials (RCTs) [22-27]. The frequency or rate of T2DM-related complications, adherence to self-care, and prescribed medications are also used to evaluate intervention effectiveness [28]. HbA_{1c} as an outcome measure is relatively well standardized and widely employed in research [8,28,29]. In contrast, measures for assessing changes in lifestyle, quality of life, and other psychosocial outcomes vary substantially [30]. In several studies, the Short Form Health Survey (SF-36) is used to measure quality of life [31,32]. However, other studies prefer using the Problem Areas in Diabetes Scale [20] or the Diabetic Quality of Life (DQoL) [33] questionnaire. Measuring the effectiveness of interventions requires identifying the outcomes of interventions and the tools used to measure the outcomes. Identifying the outcomes facilitates the comparison and syntheses of evidence across multiple interventions. While results of systematic reviews of randomized trials and observational studies suggest that participation in eHealth interventions leads to improvements in disease-related outcomes and health behaviors as well as a reduced risk for complications, the active ingredients of these interventions remain unclear [34,35]. The lack of homogeneity of measurements and the complexity of identifying and summarizing active ingredients of interventions make synthesizing and replicating the evidence a challenging task [35,36]. This is further complicated by poor descriptions of intervention content often available in scientific publications [37]. Therefore, adding to existing research findings, synthesis of evidence, and reliable implementation of interventions is limited [35,36].

Several models and taxonomies have been developed to help describe intervention content and simplify reporting of the effects of behavioral interventions. For example, using the Behavioral Change Wheel (BCW), researchers can organize content and components of behavioral interventions into 9 intervention functions: education, persuasion, incentivization, coercion, training, enablement, modeling, environmental restructuring, and restrictions [38]. The BCW model provides a systematic way of classifying behavioral change interventions using the 9 intervention functions and 7 policy categories. To translate the general intervention functions into specific techniques that were employed in a given intervention to change behavior, Michie et al [39] recommend the application of the Behavior Change Techniques Taxonomy Volume 1 (BCTTv1) (www.behaviourchangewheel.com/about-wheel). The Effective Practice and Organization of Care (EPOC) taxonomy [40] was used in a systematic review by Tricco and colleagues [41] to categorize and aggregate the effectiveness of 142 quality improvement studies in diabetes. Categories included education of patients, promotion of self-management, and reminder systems [41]. Both the EPOC taxonomy and the BCW model of intervention content evaluation are considered important hallmarks of a more reliable content analysis and the development and use of a common language for describing intervention components. However, a recent systematic review including 23 randomly sampled studies of 142 interventions demonstrated significant limitations of the EPOC taxonomy. Specifically, the level of detail with regard to content and the mode of delivery of interventions were not well represented when using the taxonomy [42]. Similarly, Drake and colleagues [43] called for a standardization of intervention content analysis. They pointed out difficulties they encountered when synthesizing the literature due to a lack of common language and a reliable model for analyzing intervention content [43]. Reliable content analysis of interventions and synthesis of evidence have been challenging due to poorly described behavioral interventions, a general inconsistency of terminologies across interventions, and the lack of replicable intervention content analysis methodology [36,44,45]. We believe that in comparison to the BCW model and the EPOC taxonomy, the BCTTv1 appears to be a more comprehensive, detailed, reliable, and useful tool in assisting researchers in retrospectively identifying the active ingredients of interventions, particularly behavioral interventions. The BCTTv1 includes 93 behavior change techniques considered to be effective for behavior change and 16 hierarchical clusters [44].

The BCTTv1 has been validated and is used to design and retrospectively evaluate and aggregate effect sizes of eHealth and other behavioral health interventions [46]. This is of particular importance because some evidence suggests that when theory in delineating intervention outcomes is used as a foundation for intervention design, the impact of interventions on those outcomes increases. Results of several studies suggest that eHealth interventions targeting persons with T2DM that are grounded in theory are associated with positive clinical, psychological, and behavioral outcomes such as reductions in HbA_{1c} levels, systolic blood pressure, cholesterol levels, and depression and increases in physical activity [47-51]. To our knowledge, the BCTTv1 has never been applied to evaluate eHealth interventions targeting persons with poorly controlled T2DM. Hence, this scoping review was initiated to identify relevant outcome measures reported in studies examining the effects of eHealth interventions in persons with poorly controlled T2DM and characterize the contents of the interventions targeting this particular population using the BCTTv1.

Methods

Framework

Throughout this paper, we follow the definition of eHealth by Eysenbach [15]. We use eHealth interventions in T2DM as a term to refer to all mobile Health (mHealth) interventions—those delivered via personal digital assistant (PDA), tablet, computer, Internet, and other forms of ICT—implemented to improve the management and outcomes of T2DM.

To address the objectives of this scoping review, we followed the 5 steps described in the framework by Arksey and O’Malley [52]: (1) identifying the research question, (2) identifying relevant studies, (3) selecting relevant studies, (4) charting data from the selected studies, and (5) summarizing and reporting the results [52]. Unlike systematic reviews, scoping reviews do not quantitatively aggregate the evidence but rather collate and summarize the evidence by mapping the related literature and examining the extent, breadth, nature, and characteristics of the available evidence [52]. Levac et al [53] recommended additional substeps to deal with the challenges encountered while conducting scoping studies. The details of the main challenges in each stage and the recommended substeps can be read elsewhere [53].

Stage 1: Identifying the Research Question

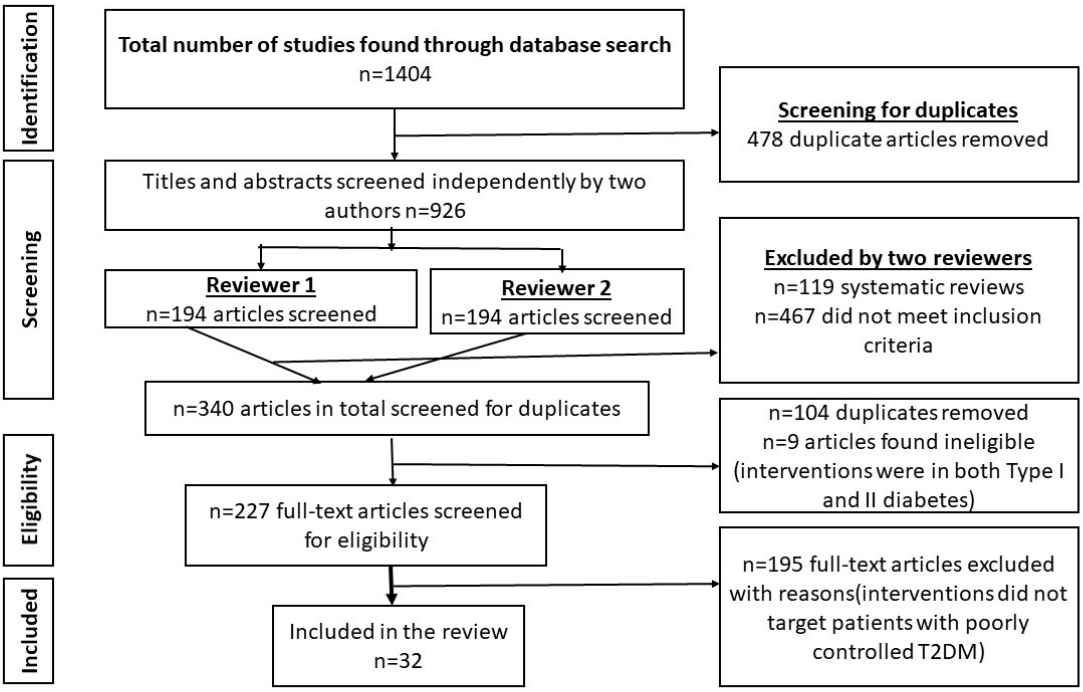
The research questions were developed after a rapid scan of the eHealth literature regarding the areas of prevention, self-management, and long-term medical care for persons with T2DM. We hypothesized that eHealth interventions play an important role in supporting patients who are under diabetic care. We also hypothesized that eHealth interventions targeting persons with T2DM include behavioral components. To search the relevant evidence for our hypothesis, we formulated the following research questions: Which outcome measures are used to assess the effectiveness of eHealth interventions in poorly controlled T2DM patients? What are the active ingredients of the eHealth interventions in poorly controlled T2DM?

Stage 2: Identifying Relevant Studies

PubMed, PsycINFO, and Web of Science were searched for relevant studies. During a preliminary search, we did not observe major differences in search results when using Excerpta Medica (EMBASE), Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Cochrane Library. Therefore, we concluded that PubMed and Web of Science covered the relevant articles. Articles containing results pertaining to eHealth interventions targeting patients with poorly controlled T2DM ($HbA_{1c} \geq 7.0\%$) published in peer-review journals from January 1990 to June 2016 were considered as potentially relevant for the review. To be included in the review, articles had to report findings of studies with quasi-experimental or pre-/post-designs or of RCTs and had to have a focus on eHealth interventions and poorly controlled T2DM. Articles were excluded if they were published in languages other than English, if only titles were available, and if they were study protocols for future or ongoing evaluations of eHealth interventions. The screening process and identification of the relevant studies are shown in Figure 1.

The key word search strategy employed to identify relevant literature is described in Multimedia Appendix 1. All search results of PubMed, PsycINFO, and Web of Science were exported to EndNote version X 7.3 reference software (Clarivate Analytics).

Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-analyses flowchart for database search and study selection.



Stage 3: Study Selection

Two authors (MK and TM) independently examined the titles and abstracts of eHealth intervention studies targeting persons with T2DM to assess their relevance for the review. We used the American Diabetes Association definition of poorly controlled T2DM as having an HbA_{1c} level of ≥7.0% [54,55]. In line with the framework by Arskey and O'Malley [52], a quality appraisal or quality assessment was not performed because it is not essential for scoping studies. Hence, methodological rigor of the published articles was not a criterion for inclusion or exclusion. The titles and abstracts previously selected by the 2 independent reviewers were merged and further screened for duplicates and following predefined inclusion criteria.

Stage 4: Charting of the Data

Preparation of the Data Extraction Form

Levac and colleagues [53] recommend cooperatively developing the data extraction form, an iterative data extraction process, independent extraction of data by multiple authors, and qualitative content analysis. Following this recommendation, a data extraction form was first prepared by MK and CP. The data extraction process and assurance of the quality of data was iterative with frequent updates of the extraction form and the data collected from the studies.

The data extraction spreadsheet (Multimedia Appendices 2 and 3) included the following items:

1. Authors, title, journal, year of publication, issue, volume, study location (identified by the corresponding author's address and/or the context of the study explained in the methodology)
2. Type of intervention, tailoring or individualization of the intervention, comparator (if any), duration of intervention, theories or models used for designing the intervention
3. Study population, size of the population
4. Aim of the study
5. Study design
6. Outcome measures, measurement tools
7. Results
8. Intervention active ingredients coded using the BCTTv1

Independent Data Collection by Reviewers

Three reviewers, MK, TM, and TL, independently collected the data using the extraction form. In addition, CP collected data from 5 randomly selected studies to check the quality of the data previously extracted by MK, TM, and TL. The reliability and quality of the extracted data was also ensured through subsequent meetings, cross-checking of the collected data, discussions to resolve disagreement in data extraction, rereading of the full texts of the papers, refining the extraction form, and revising the collected data.

Collaborative Exploration of the Interventions and Outcome Measures and Identification of the Active Intervention Ingredients

This was the main step for answering the research questions and required all reviewers to reach consensus regarding the classification of the type of intervention delivery and content and identification of the outcome measures. Here, the descriptive analytical narrative method was employed [53]. In addition, using thematic content analysis, type of intervention and outcome measures were exclusively categorized by content, nature of outcomes, and context/setting of implementation.

The descriptions of all interventions were analyzed, and active ingredients of the interventions were identified following the BCTTv1 by Michie and colleagues [44].

Emphasis was put on reaching consensus with regard to the labeling of the intervention components according to the taxonomy (Multimedia Appendix 3). MK and TL independently analyzed the contents of the interventions using the taxonomy. Analysis was followed by discussions between MK and TL regarding the coding. When there was disagreement, CP was consulted to reach consensus. Whenever we were indecisive in coding, we used the BCTTv1 coding rules supplement by Presseau and colleagues [42]. When the BCTTv1 and the coding supplement were not clear enough to characterize intervention content, the following 5 coding assumptions were used:

1. If an intervention included an educational component but sufficient detail on the themes and sequence of educational activities was not provided, the intervention was given the labels “information about health consequences” and “instruction on how to perform behavior.”
2. If an intervention included training without providing detail regarding the training, it was labeled as “instruction on how to perform behavior.”
3. If patients in a given intervention received blood glucose or blood pressure measurement devices, Internet services, software applications, computers, mobile phones, and/or airtime services, booklets, or leaflets, the intervention was labeled as “adding objects to the environment.”
4. If an intervention included warning or cautionary messages to raise patients’ consciousness regarding dangers of an unhealthy diet or sedentary behavior or clinical parameters reaching certain values (eg, elevated blood glucose, blood pressure), this was labeled as “salience of consequences.”
5. If motivational messages or calls or motivational interviewing were included in an intervention, the intervention was coded as “social support (emotional).”

Stage 5: Collating, Summarizing, and Reporting the Results

After charting the relevant data from the studies in spreadsheets, the results were collated and described using summary statistics, charts, figures, and tables. First, the types of eHealth interventions were charted into categories. Second, the outcome measures using studies examining the role of eHealth interventions in poorly controlled T2DM were categorized. Third, by exploring the contents of the intervention and cross-checking them with the definitions and examples of the 93 techniques in the BCTTv1, the active ingredients of the interventions were coded (Multimedia Appendix 3).

Results

Study Selection and Characteristics

Keyword searches in PubMed, Web of Science, and PsycINFO resulted in 624, 775, and 5 articles respectively (Multimedia Appendix 1), with a total of 1404 articles.

Removing the duplicates, subsequent screening, and eligibility assessment of the titles and abstracts led to 227 potentially relevant articles. Screening the full texts of these 227 articles and applying the eligibility criteria resulted in 32 studies [6,20,25,31-33,56-81] being included in the review (Figure 1).

Geographically, most of the studies included in the review were conducted in the United States (46.9%), followed by Canada (15.6%) and Europe (12.5%) (Figure 2).

Regarding the study design, 16 studies were RCTs, 4 were parallel and 3 cluster RCTs, 3 had pretest/posttest designs, 2 were 3-arm randomized trials, 1 was a prospective randomized trial, and 1 was a nonrandomized controlled intervention.

Among the 32 eHealth interventions investigated in the included studies, 24 (75%) were tailored to the health and behavioral characteristics of the individual patient. According to the evidence (seen in Figure 3), an increasing trend for individualization of intervention content was observed.

Only 8 interventions were designed following theories or models of behavioral change. The theories/models used for designing the interventions were cognitive behavioral therapy [31,78], the reach out problem-solving model [31,78], motivational interviewing [31,61,78], the universal model of behavioral change [6], Green and Kreuter’s PRECEDE-PROCEED model [63], the health belief model [20], the community model [32], and Wagner’s chronic care model [71].

Figure 2. Geographical distribution electronic health intervention studies in poorly controlled type 2 diabetes mellitus.

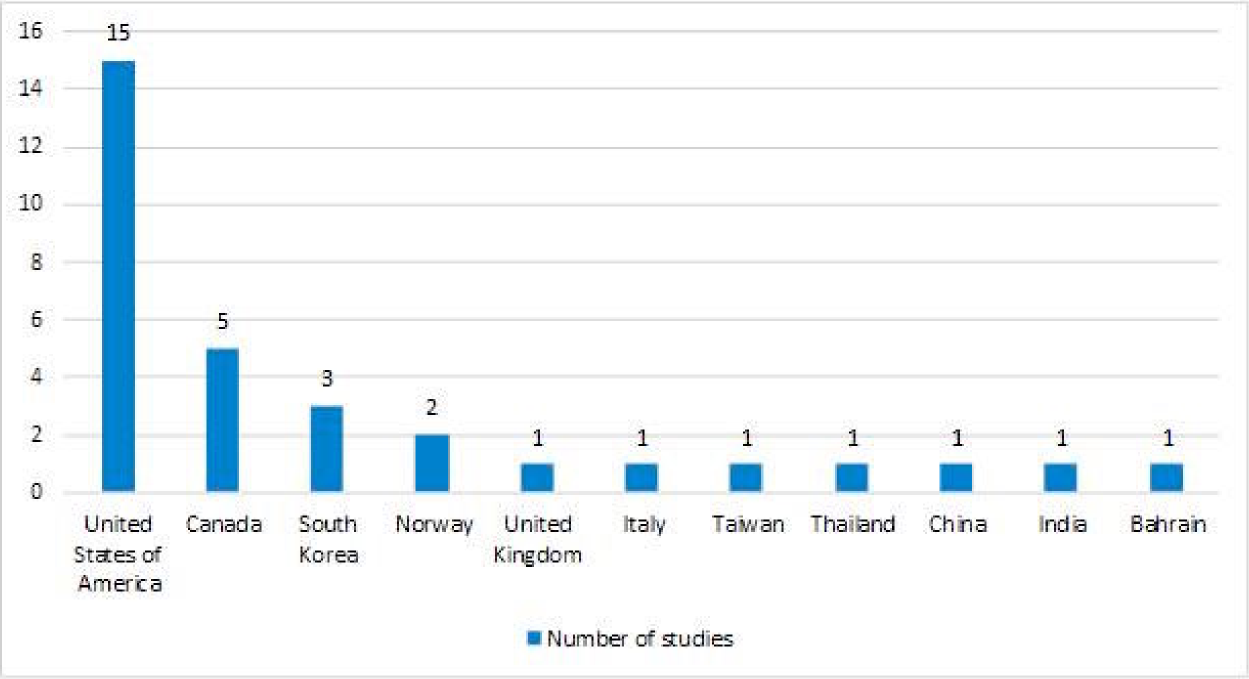
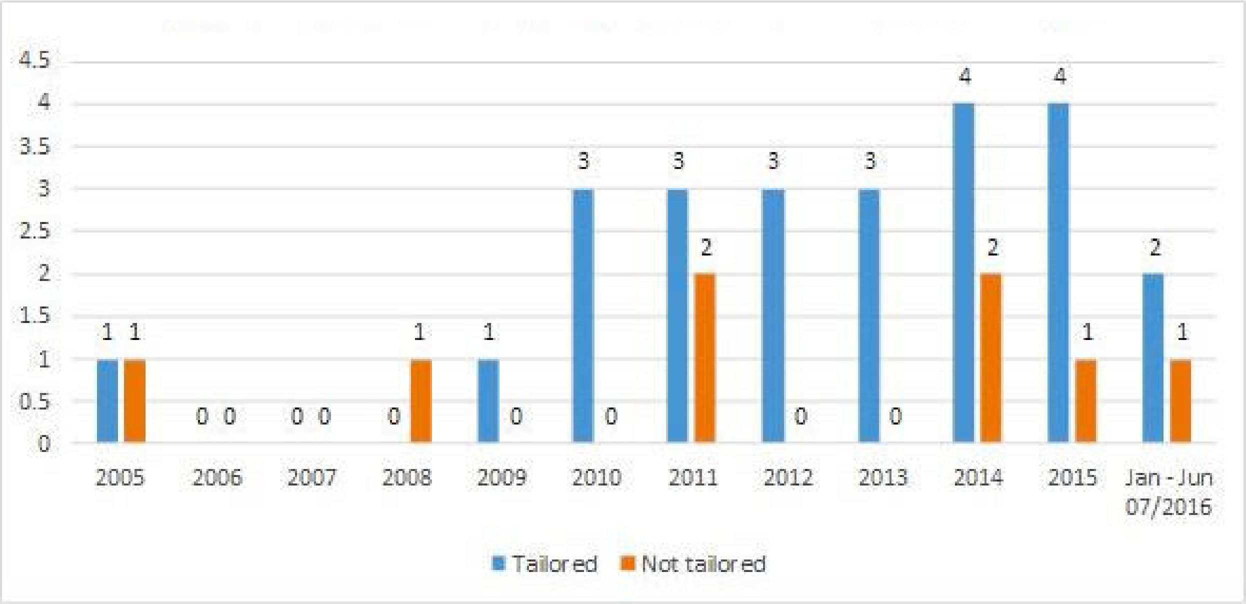


Figure 3. Distribution of tailoring in electronic health interventions.



Modes of Delivery of eHealth Intervention

Of the 32 interventions, 18 (56%) were PDA-, tablet-, computer-, or mobile phone–delivered or Web-based interventions [6,25,31,33,58,60,61,68-71,74-80], 7 interventions (22%) were telehealth interventions delivered via landline telephones [57,59,63,66,67,73,81], 6 (19%) used text messaging [20,56,62,64,65,72], and 1 employed videoconferencing [32].

Outcome Measures of eHealth Interventions in Poorly Controlled Type 2 Diabetes Mellitus

Changes in HbA_{1c} level were used as the primary outcome in the majority (28/32, 88%) of the studies. In addition, outcomes such as changes in lipid profiles (ie, total cholesterol, high-density lipoprotein [HDL], low-density lipoprotein [LDL], and triglyceride levels), changes in dose and quantity of antidiabetic drugs, use of drugs, adherence to treatment, and changes in diabetic knowledge were used as primary outcomes. Examples of secondary outcomes used in the interventions include patient satisfaction, medication adherence, performance of self-care tasks, and quality of life. The detailed list of primary and secondary outcomes employed in the included intervention studies are outlined in Multimedia Appendix 2. The outcome measures were broadly categorized and a framework was then developed (Figure 4) including all outcomes and suggesting pathways between different outcomes.

Figure 4. Outcome measures of electronic health effectiveness.

Acceptance and Use of Interventions

Outcomes included in this category were service satisfaction, remote home-monitoring device use, program compliance, patient interaction, perception of the program, and provider satisfaction.

Self-Management

This category included behaviors pertaining to disease self-management (ie, self-management score, summary of diabetes self-care activities, and performance of self-care tasks).

Outcome Measures

The outcome measures were the intermediate outputs that were considered to lead to the long-term effects of the interventions.

Cognitive and Psychosocial Outcomes

In the reviewed literature, diabetes knowledge, self-efficacy score, and knowledge about antidiabetic medications were used to assess the cognitive outcomes of eHealth interventions among poorly controlled T2DM patients. Outcomes such as depression, diabetic distress, social distress, social functioning, and changes in psychometric assessments were used to assess the effects of eHealth interventions on psychosocial outcomes.

Behavioral Outcomes Regarding Health and Self-Management Behavior

Outcomes including in this category were any changes in physical activity, dietary intake, general diet, medication adherence, use of prescribed drugs, average number of self-blood glucose tests, and self-reported foot care reported in the literature.

Glycemic Control Markers

Changes in glucose levels were measured by the mean HbA_{1c} change, achieving a fasting blood glucose of <120 mg/dL, postprandial blood glucose level of <180 mg/dL, HbA_{1c} <7%, fasting blood glucose levels of 80 to 130 mg/dL, HbA_{1c} fluctuation index, and percentage of patients with an HbA_{1c} <7% without hypoglycemia.

Biological Markers and Other Clinical Outcomes

Outcomes used to measure the effectiveness of eHealth interventions in poorly controlled T2DM patients included in this category were the following: blood pressure (systolic and diastolic); percentage of patients at the target blood pressure (130/80 mm Hg); change in diabetes symptoms; LDL, HDL, cholesterol, and triglyceride levels; change in incidence of hospitalization; emergency department utilization; self-reported hypoglycemia; incidence of symptomatic, asymptomatic, and nocturnal hypoglycemia; changes in dose or quantity of oral glucose lowering medications; and number of antidiabetic drug changes.

Body Composition Outcomes

Weight, weight loss, body mass index, waist circumference, whole body fat, android fat, and muscle mass were the main outcome measures reported in the literature and included in this category.

Long-Term Outcomes

Long-term effects of the intervention were quantified by changes in diabetic quality of life, bodily pain, general health, vitality, role functioning, general well-being, diabetes dependent impairment, and the cumulative incidence of diabetic complications, including incidence of microangiopathic complications (ie, diabetic retinopathy, diabetic neuropathy, diabetic nephropathy, diabetic foot ulcer, eye complications, macrovascular complications, microvascular complications).

In most of the studies (25 out of 32), a statistically significant change in HbA_{1c} percentage was used as a primary measure of eHealth intervention effectiveness in changing glucose levels in persons with poorly controlled T2DM. However, changes in diabetes knowledge [69], knowledge about antihyperglycemic medications, patient-reported medication decisional conflict [61], and cumulative incidence of diabetic complications [82] were also used as a primary outcome measures for assessing eHealth intervention effectiveness. In addition, achieving the target of fasting blood glucose <120 mg/dL, fasting and postprandial blood glucose levels [64], changes in physical functioning and role limitations [32], self-efficacy, medication adherence [20], proportion of patients achieving HbA_{1c} <7% without hypoglycemia [65], adherence to treatment prescriptions, and use of drugs [72] were used to determine intervention effects.

These outcomes were combined in the framework displayed in Figure 4. This framework was developed after careful examination of the nature of each outcome and hypothesizing its relationship in the pathway.

Characterizing the Contents of Interventions Using the Behavior Change Techniques Taxonomy Volume 1

The types of behavior change techniques (BCTs) identified in the selected interventions are described in Multimedia Appendix 4. All of the 32 interventions included multiple BCTs. Of the 16 overarching thematic categories, 11 (69%) were addressed in interventions: goals and planning, feedback and monitoring, social support, shaping knowledge, natural consequences, comparison of behavior, associations, repetition and substitution, reward and threat, regulation, and antecedents (Figure 5). No BCTs from the following 5 overarching categories were identified: comparison of outcomes, identity, scheduled consequences, self-belief, and covert learning. Of the 16 hierarchical clusters of the BCTTv1, feedback and monitoring was included in 27 of the 32 studies.

Figure 5. Frequency distribution of Behavior Change Techniques Taxonomy Volume 1 hierarchical clusters coded for 32 interventions.

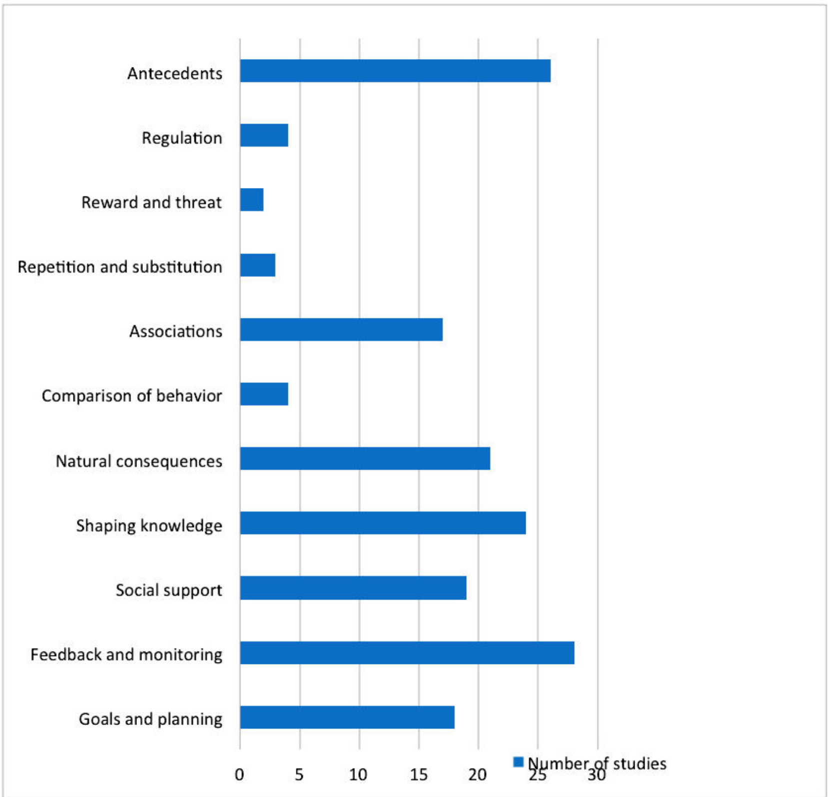


Table 1. Behavior change techniques and number of interventions that included specific behavior change techniques, Behavior Change Techniques Taxonomy Volume 1 hierarchical clusters, and intervention content examples.

BCT[a]	BCTTv1[b] hierarchical clusters	Examples extracted from descriptions of the interventions	Frequency	Studies that included the BCT
Instruction on how to perform a behavior (4.1)	Shaping knowledge	"Each participant received overall orientation on diabetes management (including how to inject insulin) as well as nutritional and exercise education" [64].	24	[6,20,25,31,32,56,58-60,64-66,68-75,77-80]
Adding objects to the environment (12.5)	Antecedents	"Participants were provided with wireless remote monitoring tools and enhanced patient portal functions to support self-management of diabetes" [6].	23	[6,20,25,31,32,56,57,60,61,64,65,67-70,73-79,81]
Information about health consequences (5.1)	Natural consequences	"If the sum of all high glycemic index foods in the previous 24-hour period is 5 or more servings, then it provided a more educational message regarding high and low glycemic index foods" [63].	21	[6,32,33,56-58,61,63-73,75,78]
Self-monitoring of outcomes of behavior (2.4)	Feedback and monitoring	"...Patients could view their trends over time and make associations between their behaviors and test results" [56].	19	[6,25,31,56,57,60,64,65,67-70,73-79]
Feedback on outcomes of behavior (2.7)	Feedback and monitoring	"If remote home-monitoring alerts are judged by the nurse to be significant, trigger an outbound call to the patient to arrange for a provider visit, additional services, or use of the emergency services, as needed" [81].	17	[6,25,31,56-58,65,67-70,73-76,79,81]
Prompts/cues (7.1)	Associations	"An alarm activates if the blood glucose level falls below 4 mmol/L" [74].	16	[6,33,56,62-64,67,68,71-76,81]
Goal setting (outcome) (1.3)	Goal and planning	"With health coaching assistance, clients determined health-related goals..." [80].	9	[6,20,25,31,59,61,64,66,71,80]
Social support (unspecified) (3.1)	Social support	"Internet browser was set to a diabetes education website designed for the study, containing links to several websites with vetted content related to diabetes self-management including sites that facilitated peer-sharing and mutual support" [68].	9	[33,56,57,60,62,67-69,80]
Action planning (1.4)	Goal and planning	"Patients received an electronic action plan every 2.5 months to support improved diabetes self-management and to serve as previsit summaries for physician office visits" [69].	8	[6,25,61,62,69-71,80]
Self-monitoring of behavior (2.3)	Feedback and monitoring	"The intervention contained email, text, and website with self-regulation, self-monitoring, and assessment functions...food/nutrition, exercise, emotion, and general health care were included" [33].	8	[32,33,60,69-71,78,80]
Social support (practical) (3.2)	Social support	"The nurse at the health office educated the patient face-to-face according to the physician's recommendations" [58].	8	[25,31,58,63,70,77,78,80]
Feedback on behavior (2.2)	Feedback and monitoring	"Care manager–participant contacts were used to review progress, reinforce nutritional and lifestyle modifications, and make medication changes" [68].	7	[31,62,63,68,69,74,77]
Social support (emotional) (3.3)	Social support	"Patients received phone calls from diabetic educators on days 3, 7, 14, and 60 after registration for specific barrier education, data explanation, and confidence establishment" [57].	7	[6,31,57,69,71,73,81]

BCT[a]	BCTTv1[b] hierarchical clusters	Examples extracted from descriptions of the interventions	Frequency	Studies that included the BCT
Biofeedback (2.6)	Feedback and monitoring	"...Patients were provided with special blood glucose testing before and after each exercise session" [80].	6	[56,59,64,69,71,80]
Goal setting (behavior) (1.1)	Goal and planning	"The message protocol included encouragement toward self-entered weight loss and exercise goals" [56].	5	[33,56,61,78]
Problem solving (1.2)	Goal and planning	"Text messages were sent to solve problems, support patients' needs, and improve skill..." [62].	5	[20,57,58,61,62,71]
Salience of consequences (5.2)	Natural consequences	"Education using animations of how diabetes affects how glucose is processed in the body and how different medication classes, foods, and physical activity affect blood sugar. When patients consume high glycemic index foods, they received a slightly more strongly worded message that also gave information about end-organ damage when diabetes remains uncontrolled." [61].	4	[20,61,63,73]
Demonstration of the behavior (6.1)	Comparison of behavior	"The exercise regimen consisted of a combination of aerobic and resistance exercises of 10-minute duration each, with 5-minute warm-up and cool-down periods... The subjects were encouraged to do this at home daily or on most days of the week" [32].	3	[32,61,64,79]
Discrepancy between current behavior and goal (1.6)	Goal and planning	"Interactive visual displays of facilitated tracking progress toward goals and correlated glucose control with medication compliance or lifestyle changes" [6].	2	[6,80]
Information about antecedents (4.2)	Shaping knowledge	"Patients were required to test glucose whenever they had symptoms related to hypoglycemia and to record their blood glucose readings" [59].	2	[59,77]
Social reward (10.4)	Reward and threat	"If the portion of high glycemic index foods is 0-1, they received a message of congratulations and encouragement to continue the same" [63].	2	[63,76]
Pharmacological support (11.1)	Regulation	"The diabetes status report displays diabetes-related medications—emphasizing the medications most important to risk reduction of diabetes complications" [73].	2	[58,73]
Reduce negative emotions (11.2)	Regulation	"Education on stress management and keeping well and healthy, participants were introduced to their self-care model and gained more confidence in the way they faced life stressors" [66].	2	[66,80]
Restructuring the social environment (12.1)	Antecedent	"...The intervention was designed to improve skills and action plans while contacting the team in anywhere and anytime manner" [62].	2	[62,80]
Review behavior goals (1.5)	Goal and planning	"...Participants set goals and develop specific action plans to address identified barriers or other concerns and identify specific questions and concerns to discuss with their doctor about their medications or making lifestyle changes"[61]	1	[61]

BCT[a]	BCTTv1[b] hierarchical clusters	Examples extracted from descriptions of the interventions	Frequency	Studies that included the BCT
Reduce prompts/cues (7.3)	Associations	“Patients stopped self-monitoring when target blood glucose levels were achieved and resumed self-monitoring prior to quarterly visits and if 3-monthly HbA_{1c} was >53 mmol/L (7.0%)” [25].	1	[25]
Behavioral practice/rehearsal (8.1)	Repetition and substitution	“The technique of progressive muscular relaxation was also taught in one of the sessions, with the advice of practicing this at home whenever the subjects encounter stress” [32].	1	[32]
Behavioral substitution (8.2)	Repetition and substitution	“...Provided education on common foods in their diet which have a high glycemic index, with low/moderate glycemic index food substitutes...” [63].	1	[63]
Habit formation (8.3)	Repetition and substitution	“For the duration of the project, a helper is available at all times in the community centers during the group sessions...” [32].	1	[32]
Graded tasks (8.7)	Repetition and substitution	“The insulin self-titration was based on an individualized stepwise treatment plan which contains a number of discrete successive medication doses (steps)...” [25].	1	[25]
Body changes (12.6)	Antecedent	“Progressive muscular relaxation was taught...” [32].	1	[32]

[a] BCT: behavior change technique.

[b] BCTTv1: Behavior Change Techniques Taxonomy Volume 1.

Of the individual 93 BCTs of the BCTTv1, 31 (33%) were employed in interventions to change behavior to manage poorly controlled T2DM. On average, 6.7 BCTs (SD 2.0) were included in interventions. The BCTs and the specific content of interventions with examples are displayed in Table 1. The maximum number of BCTs included in 1 intervention was 11 and the minimum was 3 (Multimedia Appendix 4).

Discussion

Principal Findings

The purpose of this review was to identify the relevant outcome measures reported in studies examining the effects of eHealth interventions in persons with poorly controlled T2DM and characterize the active ingredients of eHealth interventions among persons with poorly controlled T2DM using the BCTTv1.

Most of the studies (25 out of 32) measured the effectiveness of eHealth interventions using a statistically significant change in HbA_{1c} percentage as a primary outcome measure. This is similar to the review reported by Vorderstrasse and colleagues [29]. A review from the Cochrane Library by Pal and colleagues [27] found that all 16 RCTs included in its review used HbA_{1c} percentage as a primary outcome measure of effectiveness. Lipska and Krumholz [83] challenged this glucocentric approach, reporting that the effectiveness indicator of interventions in T2DM is moving away from the historic surrogate marker (ie, HbA_{1c}) to cardiovascular outcomes.

The identification of the active ingredients of the behavioral interventions is a basis for synthesizing evidence, building on evidence, and replicating interventions targeting behavioral change. The development and use of the EPOC taxonomy and BCW models contribute to the homogeneity in characterizing the contents of different interventions and in quantifying intervention effects (eg, by aggregating effect sizes). However, we observed that these 2 frameworks were not sufficiently comprehensive to characterize the content of interventions in detail. BCTTv1, in contrast, appeared suitable for in-depth analysis of the active ingredients of interventions. It offered a means of handling heterogeneity and provided a baseline for meta-analysis or the estimation of effect sizes for quantifying effects of behavior change interventions.

In our scoping review, only 31 (33%) of the 93 BCTs were identified in interventions. Similarly, Presseau et al [42] identified less than a quarter of the 93 BCTs in 23 interventions. BCTs such as credible source, reward (outcome), focus on past success remain underused in interventions. Innovative eHealth interventions employing these BCTs need to be tested with regard to their impact in changing patient behavior and affecting T2DM outcomes. Of the 31 BCTs identified in interventions included in this review, the most frequently used were instruction on how to perform behavior, adding objects to the environment, social support (practical), feedback on outcomes of behavior, self-monitoring on outcomes of behavior, and prompts/cues. Van Vugt and colleagues [49] identified BCTs such as providing feedback on performance of behavior, providing information on consequence of behavior, problem solving, and prompts/cues as the most commonly used BCTs in Web-based self-management programs for patients with T2DM. Pal [27] demonstrated that among the most frequently used BCTs, prompt self-monitoring of behavioral outcome and provide feedback on performance were reported to have significant effects on HbA_{1c} levels. However, frequency of inclusion of an individual BCT is neither proof for it significantly improving patient outcomes nor proof of a proper design of interventions [84].

Our study results suggest that, on average, 6.7 BCTs were included per each intervention. The evidence on whether including many BCTs in an intervention improves patient outcomes is not strong. Systematic reviews by Avery and colleagues [50] and Cradock [85] revealed that only 50% and 60%, respectively, of the most frequently used BCTs were associated with reductions in HbA_{1c}. An evaluation of diabetes-related apps by Hoppe and colleagues [86] indicated that diabetes mobile phone apps having more BCTs also had significantly higher functionalities and higher user ratings. However, which combination of BCT ingredients had a stronger effect and which BCTs were key moderators of effectiveness in poorly controlled T2DM needs to be further investigated. Customizing eHealth interventions to individual behavioral characteristics and disease progress increases the effectiveness of the intervention [87]. Tailoring or individualizing the communication between patients and providers has gained substantial attention in the past decade. In this review, we observed that more than 75% of the interventions were customized to the individual patient characteristics or needs. In addition, a generally increasing trend of tailored eHealth interventions was noted in the reviewed studies. Strategies used for tailoring vary across studies. Kim [64] and Wayne [80] used pragmatic approaches of tailoring and contextualized the intervention with respect to the individual patient. McFarland and colleagues [67] tailored the intervention to individualize the communication between patients and providers. First, patients self-monitored blood glucose levels by using monitors and transmitted their data using a messaging device. A registered nurse then downloaded the message and contacted the patient via telephone to evaluate whether there were any specific health concerns. Based on specific concerns (eg, with regard to adherence to certain medications or a dietary regimen or hypoglycemic events), patients were given recommendations regarding insulin dosage or lifestyle changes. Ralston and colleagues [71] tailored the Web-based intervention according to the clinical condition of each patient. Accordingly, the care manager responded to specific messages from each patient and reviewed the submitted blood glucose levels of each patient to adjust hypoglycemic medications as needed. Several studies suggest that tailoring may be an effective means of behavioral change and improving self-management skills [88-91]. Tailoring also helps initiate, enhance, and safeguard the partnership between the provider and the patient, increasing shared decision-making and person-centered care which ultimately facilitates the uptake of the desired behavior, such as healthy eating and improved physical activity [92]. However, a recent systematic review reported that there is lack of evidence to suggest tailored eHealth interventions are more effective than nontailored interventions [93]. Therefore, this issue obviously requires more research.

Despite a broad consensus that the use of theories or models to guide the development of interventions leads to greater impact of interventions, the current review showed that only 8 (25%) of the 32 eHealth interventions were theory-based. The finding of our review is consistent with the claim that undertheorization of eHealth interventions and underutilization or an inadequate application of behavioral science and health education theories is still a major issue in the eHealth intervention literature [38,47,84,85,94]. The evidence on effectiveness of designing and implementing interventions through the use of theories is mixed. Some evidence suggests that theory-grounded eHealth interventions are more likely to be associated with positive outcomes of patients with T2DM. Theories can enhance the uptake of the desired behavior by supporting providers and patients to collaboratively set targets, enhance the motivation of intervention participants, and provide a roadmap for behavior and treatment modification [47-51]. The impact and processes by which eHealth interventions influence outcomes are not directly comparable to the impact of pharmacological drugs that are administered into the body and bring a change within a certain period of half-life of the ingredient. eHealth interventions, in part, impact cognitive processes (eg, by improving knowledge) and may help intervention participants internalize the advantages of performing the target behavior, such as improving self-management, dietary, or physical activity behavior, leading to long-term maintenance of these behaviors. Behavior maintenance can then be subsequently linked with changes in biological markers and long-term changes in quality of life and a lower incidence in complications.

Limitations

Our scoping review had several limitations. The definition of poorly controlled diabetes was based on that of the American Diabetes Association. However, other guidelines, such as the one from the National Institute for Health and Care Excellence, consider an HbA_{1c} level up to 7.5% as a good indicator of glycemic control. This should be taken into consideration while interpreting our results. In some cases, it was challenging to crossmatch intervention contents described in the articles with the BCTs. For example, there were interventions that included motivational messages or calls to induce the uptake of a target behavior. However, motivation was not explicitly described in BCTTv1. In addition, there were interventions with poor descriptions. For instance, interventions provided education but there was no information available regarding the type of education. Coding the poorly described interventions was therefore challenging. Hence, we were forced to develop assumptions to deal with poorly described interventions. Another limitation of our scoping review was that the correlation between the 2 reviewers coding the BCTs was not systematically assessed. Rather, 2 coders independently analyzed contents of interventions, and where they disagreed, a third person was consulted to reach consensus.

Conclusion

For most interventions, changes in HbA_{1c} levels were reported as a primary measure of effectiveness. Overall, the BCTTv1 appeared practical and helped identify the active ingredients of interventions. Our results suggest that one-third of the 93 BCTs were employed in eHealth interventions targeting persons with poorly controlled T2DM.

Developing theory-based interventions and considering BCTs during the intervention design phase is desirable for obtaining effective interventions and transparently reporting the results of these interventions in the future and possibly in other chronic disease contexts.

Acknowledgments

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Authors' Contributions

MK conceived the idea, developed the design, conducted the systematic literature search, performed the title and abstract screening, extracted data from literature, conducted the data analysis, and drafted the manuscript. TPL was involved in the design, extracted the data, and participated in drafting the manuscript. TM conducted the abstract and title screening, participated in the extraction of the data, and drafted the manuscript. CRP was involved in the conception and design of the study and the extraction of the data and critically revised the manuscript. All authors read and approved the final version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Search keywords and output.

[PDF File (Adobe PDF File), 39KB - jmir_v19i10e348_app1.pdf]

Multimedia Appendix 2

Behavioral change technique data extraction form and data.

[XLSX File (Microsoft Excel File), 45KB - jmir_v19i10e348_app2.xlsx]

Multimedia Appendix 3

Extraction form and data.

[XLS File (Microsoft Excel File), 80KB - jmir_v19i10e348_app3.xls]

Multimedia Appendix 4

Behavior change techniques included in electronic health interventions targeting individual behavior change.

[PDF File (Adobe PDF File), 316KB - jmir_v19i10e348_app4.pdf]

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Abbreviations

BCTTv1: Behavior Change Techniques Taxonomy Volume 1
BCW: Behavioral Change Wheel
CINAHL: Cumulative Index to Nursing and Allied Health Literature
DQoL: Diabetes Quality of Life Questionnaire
EMBASE: Excerpta Medica database
EPOC: Effective Practice and Organization of Care
HbA1c: hemoglobin A1c
HDL: high-density lipoprotein
ICT: information and communication technology
LDL: low-density lipoprotein
NCD: noncommunicable disease
PDA: personal digital assistant
RCT: randomized controlled trial
SF-36: Short Form Health Survey
T2DM: type 2 diabetes mellitus

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Original Paper

Effect of a Website That Presents Patients' Experiences on Self-Efficacy and Patient Competence of Colorectal Cancer Patients: Web-Based Randomized Controlled Trial

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Abstract

Background: Patients often seek other patients' experiences with the disease. The Internet provides a wide range of opportunities to share and learn about other people's health and illness experiences via blogs or patient-initiated online discussion groups. There also exists a range of medical information devices that include experiential patient information. However, there are serious concerns about the use of such experiential information because narratives of others may be powerful and pervasive tools that may hinder informed decision making. The international research network DIPEx (Database of Individual Patients' Experiences) aims to provide scientifically based online information on people's experiences with health and illness to fulfill patients' needs for experiential information, while ensuring that the presented information includes a wide variety of possible experiences.

Objective: The aim is to evaluate the colorectal cancer module of the German DIPEx website krankheitserfahrungen.de with regard to self-efficacy for coping with cancer and patient competence.

Methods: In 2015, a Web-based randomized controlled trial was conducted using a two-group between-subjects design and repeated measures. The study sample consisted of individuals who had been diagnosed with colorectal cancer within the past 3 years or who had metastasis or recurrent disease. Outcome measures included self-efficacy for coping with cancer and patient competence. Participants were randomly assigned to either an intervention group that had immediate access to the colorectal cancer module for 2 weeks or to a waiting list control group. Outcome criteria were measured at baseline before randomization and at 2 weeks and 6 weeks

Results: The study randomized 212 persons. On average, participants were 54 (SD 11.1) years old, 58.8% (124/211) were female, and 73.6% (156/212) had read or heard stories of other patients online before entering the study, thus excluding any influence of the colorectal cancer module on krankheitserfahrungen.de. No intervention effects were found at 2 and 6 weeks after baseline.

Conclusions: The results of this study do not support the hypothesis that the website studied may increase self-efficacy for coping with cancer or patient competencies such as self-regulation or managing emotional distress. Possible explanations may involve characteristics of the website itself, its use by participants, or methodological reasons. Future studies aimed at evaluating potential effects of websites providing patient experiences on the basis of methodological principles such as those of DIPEx might profit from extending the range of outcome measures, from including additional measures of website usage behavior and users' motivation, and from expanding concepts, such as patient competency to include items that more directly reflect patients' perceived effects of using such a website.

Trial Registration: Clinicaltrials.gov NCT02157454; https://clinicaltrials.gov/ct2/show/NCT02157454 (Archived by WebCite at http://www.webcitation.org/6syrvwXxi)

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KEYWORDS

self-efficacy; colorectal cancer; patient competence; narrative information; Web-based experiential information

Introduction

Activating patients to become partners in their care has been a priority in health policy in many Western countries over the past years [1]. Increasing patient participation in health care rests, however, on at least three interrelated prerequisites. First, information on disease, treatments, and outcomes should be widely available. Second, health care providers should be able to effectively convey this information to patients and enable them to make informed decisions. Third, patients should be able to access, process, decide, and act on the health information relevant to them. As a consequence, interest has grown in concepts that describe patients' abilities to acquire and process health information, such as empowerment [2-5], health literacy [6-9], patient competence [10], and self-efficacy in coping with cancer [11-13] and other chronic diseases [14,15]. Obviously, the importance of these concepts can be rated even more highly if one considers the opportunities that the Internet provides for disseminating health information.

Although medical information on diseases, treatments, and outcomes that is based on available quality criteria [16-19] represents an important input into patients' informed (treatment) decision making, patients facing health care decisions also seek and use experiential information describing how other patients live with a disease [20-22]. This field of experiential knowledge and its presentation has recently received increasing attention in research on health information resources. Here again, the Internet provides a wide range of opportunities to share and learn about other people's health and illness experiences via blogs or patient-initiated online discussion groups, which may provide support from peers [5,23]. Some peer-to-peer online tools have been shown to increase patient empowerment in relation to information, mental health, and feeling supported [24,25], whereas others have revealed mixed or negative effects [5]. In addition, there exists a range of medical information devices that include experiential patient information, including decision aids [26] and other health information venues [27,28]. However, there is serious concern about the use of narratives in health information because they are powerful and persuasive tools and they may unduly influence health care decision making [29-33].

Against this background, this study asks whether a website that provides experiential information on living with colorectal cancer based on scientifically rigorous data collection and analysis positively influences self-efficacy for coping with cancer [11-15] and patient competence [10]. It aims to evaluate potential effects of a specifically designed website, while at the same time providing insight into factors contributing to changes in coping self-efficacy and patient competence that are increasingly attracting more research interest in psycho-oncology [10,34]. More specifically, we hypothesized that, compared to a waiting list control group, having access to and using a website presenting a broad range of individual experiences with colorectal cancer would increase patients' perceived self-efficacy for coping with cancer and patient competencies such as the ability to manage emotional distress arising in the context of cancer and its treatment or self-regulation as an ability to maintain a satisfactory equilibrium in interactions and affect [10].

Methods

Study Design

The study used a randomized two-group between-subjects design with repeated measures; participants were randomly assigned either to an intervention group that had immediate access to the colorectal cancer module for 2 weeks or to a waiting list control group that was given access to the module after completion of the study 6 weeks after randomization. Coping self-efficacy served as the primary outcome; patient competencies constituted the secondary outcome. Outcome criteria were measured in both groups at baseline before randomization and at 2 weeks (time 1). At 6 weeks after baseline (time 2), follow-up measures were taken to test for the short-term stability of the intervention. The trial was conducted before the website became available to the general public.

The study protocol was approved by the Charité Universitätsmedizin Berlin ethics committee (EA4/053/12) and was registered (clinicaltrials.gov NCT02157454). This trial is reported according to the Consolidated Standards of Reporting Trials (CONSORT) statement and the CONSORT-EHEALTH extension.

Intervention

The intervention of the study consisted of a website providing information of experiences by men and women diagnosed with colorectal cancer. The website is a section (module) of a German website krankheitserfahrungen.de, which aims to provide scientifically collected and analyzed experiences of health and illness to patients, health care providers, and the wider public.

The project team DIPEx Germany that runs the website is a member of the international research network DIPEx (Database of Individual Patients' Experiences) [35]. The website is hosted at the University of Freiburg. DIPEx aims to present online information on people's experiences with health and illness that have been systematically collected through qualitative interviews and analyzed with rigorous qualitative research methods. DIPEx intends to fulfill patients' needs for experiential information, while ensuring that the presented information includes a wide variety of possible experiences with the disease [36]. This is achieved by collecting illness experiences employing a maximum variation sampling strategy and using narrative interviewing techniques [37]. A researcher handbook details how the experiences are to be collected and analyzed. The handbook also ensures that funding for modules may only be provided by organizations with no involvement or financial interests in the content. This systematic and scientific approach and the transparency regarding funding distinguishes DIPEx markedly from peer-to-peer and other online support resources.

The content of the modules of the DIPEx website can be accessed via thematic pages (eg, "stoma" or "living with colorectal cancer") or by interviewed persons (person pages). The person pages can be searched applying a filter (eg, age or gender) for ease of navigation. These features of the website are positively viewed by users [37-39]. In particular, the feature that one may find others who are similar to oneself seems to help users find hope [37].

Sample Size and Power Calculation

In determining the necessary sample size for the trial, it was assumed that given a standard deviation of 18 [40,41], a difference of five scale points in self-efficacy for coping with cancer between the intervention group and the waiting list control group could be reasonably expected and should be detected with a power of .80 and a type one error probability of alpha=.05. For Cohen's *d* (between-group mean difference divided by SD) [42], this lies in the range of a small effect size (*d*=.20-.49). Based on these premises, a sample size of n=205 participants per group was deemed necessary.

Eligibility Criteria

Potential participants were considered eligible if they were German-speaking, 18 years of age or older, and had either been diagnosed with colorectal cancer within the past 3 years before enrollment or—independent of time since diagnosis—had metastasized colorectal cancer and/or a relapse of the disease, and who consented to participate online on the study website. Potential participants who indicated on the survey that the time since their diagnosis was more than 3 years and who indicated that they had no recurrence or metastases were excluded from the study.

Recruitment and Enrollment

A wide range of recruitment strategies was used. Many major websites related to colorectal cancer, such as felix-burda-stiftung.de and lebensblicke.de, were informed about the study and provided a link to the study website. Information on the study was posted regularly on a colorectal cancer Facebook group and on online colorectal cancer discussion groups. The study was presented in-person to support groups, in rehabilitation clinics, and to hospital staff for them to aid in recruitment. Some colorectal cancer centers also informed their patients about the study. Finally, the project was presented at information events for patients at hospitals and cancer meetings. Recruitment started in June 2014 and ended in August 2015.

Study participants had to enroll themselves through the study website, which also provided detailed information about the study. If participants then chose to enroll, this was considered as giving consent because they had previously been informed. After enrollment, participants were first asked to complete the baseline measures and were then randomized.

Data Collection

Online data collection at the three measurement points required patients to complete validated questionnaire measures of self-efficacy for coping with cancer, patient competence, depression, social support, health-related quality of life, and medical information received (Table 1). In addition, information on selected sociodemographic, illness, and treatment characteristics was obtained at baseline. Participants were also asked to provide information on their use of Internet resources addressing issues related to colorectal cancer. The pages that each participant visited on the intervention website were logged along with a time stamp, thus allowing a determination of the amount of time they spent on the website (in minutes), the number of sessions using the site, and the number of clicks produced (as an indicator of the number of subpages accessed). The analyses reported here focus primarily on the results regarding self-efficacy for coping with cancer and patient competence.

Primary Outcome: Self-Efficacy for Coping With Cancer

Self-efficacy for coping with cancer may be defined as a patient's confidence in his or her ability to perform coping behaviors in the context of cancer [13]. As the primary outcome of this study, self-efficacy for coping with cancer was measured using the German version of the brief form of the Cancer Behavior Inventory (CBI-B-D) [40,43]. Like the CBI-B, the original version of this instrument [11,13], the CBI-B-D consists of 14 items that describe coping behaviors in the context of cancer. Patients are asked to rate how confident they are in performing each of these behaviors on a nine-point scale ranging from "not at all confident" to "totally confident." A summary score is obtained across all 14 items, which can range from 14 to 126, with high values indicating high confidence in one's ability to perform the coping behaviors. The German version was created using a forward-backward translation approach. Reliability estimates for both the original and the German versions of the scale are generally high. Furthermore, the validity of the scale has been demonstrated in various studies of concurrent, predictive, or construct validity [11,13]. The CBI-B-D score was measured at baseline and at 2 and 6 weeks postbaseline.

Table 1. Data collection: measurements and time points.

Variables measured[a]	Baseline	2 weeks into study (postintervention)	6 weeks after randomization
Sociodemographics; illness and treatment characteristics; Internet use behavior	X		
Depression: PHQ-2	X		
Social support: SSUK-8	X		
Self-efficacy for coping with cancer: CBI-B-D (primary outcome)	X	X	X
Self-ratings of patient competencies: FEPK 2-57 (secondary outcome)	All 8 subscales	4 subscales	4 subscales
Information: EORTC QLQ-INFO25		X	
Ratings of personal reports of those affected by cancer		X	X
Quality of life: EORTC QLQ-C30		X	

[a] CBI-B-D: German version of brief form of Cancer Behavior Inventory; EORTC QLQ-C30: questionnaire to assess the quality of life of cancer patients by the European Organisation for Research and Treatment of Cancer; EORTC QLQ-INFO25: questionnaire to assess information given to cancer patients; FEPK 2-57: 57-item questionnaire on patient competence using five problem-focused and three emotion-focused subscales; PHQ-2: two-item Patient Health Questionnaire; SSUK-8: German brief version of the illness-specific Social Support Scale.

Secondary Outcome: Patient Competence

Following Giesler and Weis [10], patient competence in the context of cancer may be understood as a patient's ability to deal with the tasks and distress arising from cancer and its treatment, to be guided by his or her personal needs and goals, and to make use of support available from significant others or from the health care system as a whole. Based on this working definition of patient competence, as well as factor analysis, they constructed a self-rating measure of patient competence (FEPK 2-57) that assesses five problem-focused and three emotion-focused competencies. The measure contains 57 items each rated on a five-point scale intended to measure behaviors indicative of patient competence as determined in prior pilot studies. Items addressing emotion-focused competencies offer the additional response option of "not applicable to me." Subscale internal consistencies (Cronbach alpha) range from .64 to .87 (median .77) and may be judged as at least satisfactory. In this study, all these competencies were measured at baseline. At weeks 2 and 6, however, only the three emotion-focused competencies and one of the problem-focused competencies were measured as secondary outcomes because they were considered to best reflect the potential effects of the website.

The competencies measured at baseline and weeks 2 and 6 were "self-regulation" (ability to negotiate needed support and to allow for resting periods during the course of the day when needed), "managing distressing emotions" (ability to deal with cancer-related fears), "dealing explicitly with the threat posed to life by cancer" (being able to confront the idea that one might die), and "(low) avoidance" (ability not to engage in ruminating thoughts and avoidance behaviors) [10]. Problem-focused competencies measured only at baseline were "seeking information concerning disease and treatment," "being assertive in interactions with physicians," "striving for autonomous decisions," and "interest in social services." Scale scores for all competencies were formed by computing a participant's individual mean across the respective items. Scores can vary between 1 and 5, with higher scores indicating a higher level of self-rated competence.

Additional Measures

To allow a more comprehensive characterization of the participants, depression, social support, quality of life, and satisfaction with information received on the condition and its treatment were measured. Depression was measured at baseline using the two-item Patient Health Questionnaire (PHQ-2) [44,45]. Also at baseline, social support was measured by means of the SSUK-8 [46], the brief form of the German adaptation of the illness-specific Social Support Scale (SSUK) [47]. At 2 weeks, health-related quality of life was measured with the QLQ-C30, a reliable and valid instrument developed by the European Organisation for Research and Treatment of Cancer (EORTC) [48]. Finally, respondents' evaluation of disease and treatment information received was measured with the EORTC QLQ-INFO25 [49] at 2 weeks.

Data Analysis

Data analysis was performed using IBM SPSS versions 23 and 24. Baseline differences between the intervention and the waiting list group were analyzed by means of chi-square statistics for categorical variables or one-way analyses of variance (ANOVAs) in the case of continuous variables based on all participants with nonmissing data for a given variable. Effect sizes were estimated by computing phi coefficients or eta squared. Following Cohen [42], these may be categorized as small, medium, or large, with values of .10, .30, and .50 representing corresponding effect size thresholds for the phi coefficient, and values of .01, .06, and .14 representing those for eta squared.

For testing the hypothesized intervention effect on the primary and secondary outcomes, we preformed separate regression analyses of the postintervention (week 2) and follow-up (week 6) scores with the intervention dummy coded (intervention=0, control=1) and the respective pretest scores as an additional predictor, which is equivalent to a traditional analysis of covariance. These analyses were based on all randomized participants, using multiple imputation of missing values at baseline and at 2 and 6 weeks. We ran 10 multiple imputations with the full information maximum likelihood method when data were missing in single items or scales. Multiple imputation creates multiple datasets, in which the missing observations are imputed, using a stochastic algorithm that estimates values based on given information and creates different imputed values in each dataset. Statistics are performed separately for these datasets and coefficients are combined after having finished the analyses [50]. The assumption that data were missing completely at random could be retained after performing Little's missing completely at random test [51], which was not significant with $\chi^2_{31,997}$=27,222.8 (*P*>.99). The effect sizes of the predictors in the regression models are reported as beta weights for which the minima and maxima across the analyzed imputed datasets will be given. Following Cohen [42], values of .10, .30, and .50 for beta represent the thresholds for interpreting effects as small, medium, or large, respectively.

Results

Sample Characteristics at Baseline

The sample consisted of 212 randomized participants who completed the baseline survey. Figure 1 shows the participant flow.

The mean age of participants was 54.1 (SD 11.1) years and 58.8% (124/211) were female. Approximately 73.6% (156/212) of the study sample had read or heard stories and experiences of other patients online before that were unrelated to the intervention provided in the study. Most participants were recruited via the Internet (123/212, 58.0%), 33 (15.6%) were referred to the website by their physician, 25 (11.8%) were recruited via flyers, 8 (3.8%) had been informed by friends, and 23 (10.8%) provided no information about their recruitment path.

Figure 1. Flowchart of study participation.

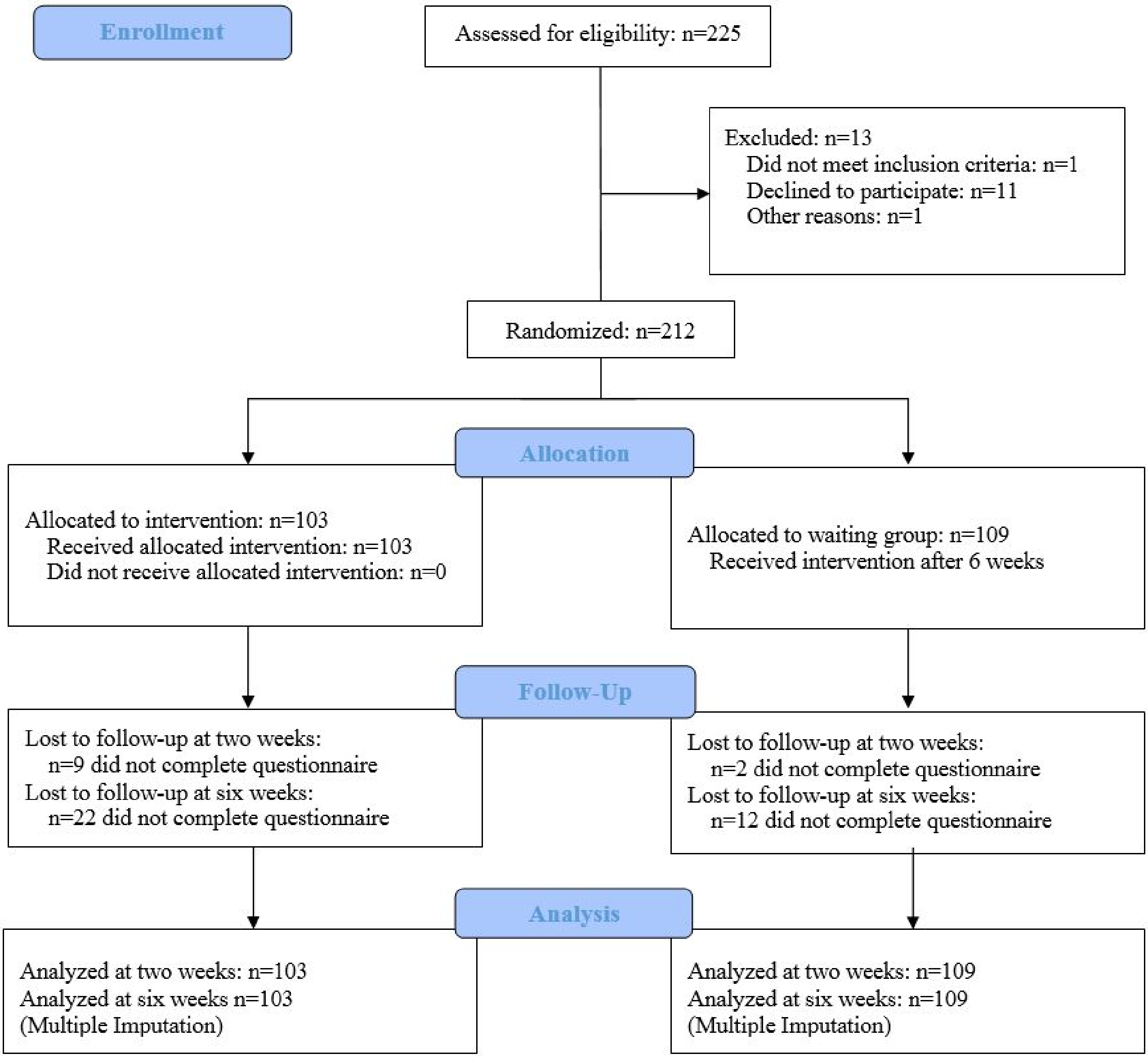

Table 2. Sociodemographic characteristics of participants in the intervention and control groups at baseline (N=212).

Sociodemographic characteristics	Intervention (n=102-103)	Control (n=107-109)	*P* [a]
Gender (n (%)			.17
Female	55 (53.9)	69 (63,3)	
Male	47 (46.1)	40 (36.7)	
Age in years, mean (SD)	54.5 (11.8)	53.6 (10.5)	.57
Family status, n (%)			.19
With partner	85 (82.5)	82 (75.2)	
No partner	18 (17.5)	27 (24.8)	
Children, n (%)			.70
Yes	78 (75.7)	80 (73.4)	
No	25 (24.3)	29 (26.6)	
Education (years), n (%)			.96
≥13	53 (52.0)	57 (53.3)	
10	39 (38.2)	39 (36.4)	
9	10 (9.8)	11 (10.3)	
Professional training, n (%)			.06
No degree	8 (7.8)	1 (0.9)	
Vocational training	55 (53.9)	53 (49.5)	
University degree	33 (32.4)	44 (41.1)	
Other	6 (5.9)	9 (8.4)	
Employment status, n (%)			.41
Employed	30 (29.4)	34 (31.2)	
Unemployed	4 (3.9)	2 (1.8)	
Sick leave	22 (21.6)	31 (28.4)	
Retired	29 (28.4)	32 (29.4)	
Homemaker	10 (9.8)	4 (3.7)	
Other	7 (6.9)	6 (5.5)	
Place of residence (number of inhabitants), n (%)			.83
<100,000	71 (68.9)	74 (67.9)	
100,000-1,000,000	16 (15.5)	20 (18.3)	
>1,000,000	16 (15.5)	15 (13.8)	

[a] *P* values for group comparisons are based on one-way ANOVAs for age and on chi-square tests for categorical variables.

As shown in Tables 2 and 3, there were no significant differences at baseline between intervention and control participants with respect to sociodemographic or illness and treatment characteristics. Similarly, there were no differences between the groups with regard to having sought health information online before entering the trial, including having read reports of other patients online (Table 4). Groups also did not differ significantly at baseline with respect to the primary and secondary outcomes and depression. However, participants in the control group tended to experience slightly less positive social support than those in the intervention group, with an effect size of eta squared=.02, which would qualify as small [42].

Table 3. Illness and treatment characteristics of participants in the intervention and control groups at baseline (N=212).

Illness and treatment characteristics	Intervention, n (%) (n=52-103)	Control, n (%) (n=64-109)	*P* [a]
Time since diagnosis			.07
<2 years before survey	62 (60.2)	61 (56.0)	
2-3 years before survey	28 (27.2)	42 (38.5)	
≥4 years before survey	13 (12.6)	6 (5.5)	
Stoma			.37
Yes	25 (24.8)	33 (30.3)	
No	76 (75.2)	76 (69.7)	
Metastases			.92
Yes	48 (46.6)	48 (44.0)	
No	52 (50.5)	58 (53.2)	
Do not know	3 (2.9)	3 (2.8)	
Relapse			.72
Yes	12 (11.7)	11 (10.1)	
No	91 (88.3)	98 (89.9)	
Other disease			.33
Yes	40 (38.8)	35 (32.4)	
No	63 (61.2)	73 (67.6)	
Chemotherapy			.91
Completed	53 (58.9)	61 (60.4)	
Ongoing	29 (32.2)	29 (28.7)	
Planned or uncertain	5 (5.6)	6 (5.9)	
Not received	3 (3.3)	5 (5.0)	
Radiotherapy			.88
Completed	33 (63.5)	43 (67.2)	
Ongoing	2 (3.8)	2 (3.1)	
Planned or uncertain	2 (3.8)	1 (1.6)	
Not received	15 (28.8)	18 (28.1)	
Surgery			.60
Completed	88 (89.8)	96 (93.2)	
Ongoing	1 (1.0)	1 (1.0)	
Planned or uncertain	8 (8.2)	4 (3.9)	
Not received	1 (1.0)	2 (1.9)	

[a] *P* values for group comparisons are based on chi-square tests for categorical variables.

Table 4. Health information-seeking characteristics and mean scores for patient competence, social support, and depression of participants in the intervention and control groups at baseline (N=212).

Patient characteristics	Intervention	Control	*P* [a]
Health information-seeking behavior	n=71-103	n=83-109	
Used psycho-oncological support, n (%)			.59
Yes	39 (43.8)	35 (39.8)	
No	50 (56.2)	53 (60.2)	
Participates in self-help-groups			.46
Yes	12 (16.9)	18 (21.7)	
No	59 (83.1)	65 (78.3)	
Sought Internet health information, n (%)			.62
Yes	96 (97.0)	101 (98.1)	
No	3 (3.0)	2 (1.9)	
Had contact with others affected, n (%)			.81
Yes	76 (73.8)	82 (75.2)	
No	27 (26.2)	27 (24.8)	
Participated actively in Internet chats and forums, n (%)			.74
Yes	19 (23.5)	19 (21.3)	
No	62 (76.5)	70 (78.7)	
Read Internet reports of others affected before entering trial, n (%)			.87
Yes	76 (74.5)	80 (75.5)	
No	26 (25.5)	26 (24.5)	
Self-efficacy for coping with cancer, mean (SD)[b]	99.74 (17.20)	96.27 (19.71)	.20
Patient competencies, mean (SD)			
Problem-focused	n=96-103	n=103-108	
Seeking information	4.00 (0.79)	4.04 (0.78)	.73
Self-regulation	3.61 (0.51)	3.48 (0.75)	.18
Patient-physician interaction	4.09 (0.71)	4.00 (0.78)	.40
Autonomous decision	2.92 (0.82)	2.84 (0.89)	.51
Interest in social benefits	3.98 (1.42)	3.92 (1.38)	.76
Emotion-focused	n=58-86	n=61-94	
Coping with distress	3.54 (0.88)	3.32 (0.77)	.14
Dealing with threat	3.78 (0.56)	3.70 (0.72)	.53
Low avoidance	3.39 (0.78)	3.35 (0.80)	.74
Depression, mean (SD)[c]	1.58 (1.55)	1.81 (1.51)	.29
Social support, mean (SD)	n=103-109	n=102-106	
Positive support	4.43 (0.62)	4.22 (0.78)	.04
Distressing interaction	2.00 (0.77)	1.92 (0.70)	.48

[a] *P* values for group comparisons are based on chi-square tests for categorical variables and on one-way ANOVAs for self-efficacy for coping with cancer, patient competence, depression, and social support.

[b] Intervention: n=94; control: n=97.

[c] Intervention: n=101; control: n=105.

Website Use of Intervention Group

On average, participants in the intervention group visited the intervention website for mean 42.21 (SD 45.64, median 26) minutes in total. The mean number of sessions at the site was 3.43 (SD 2.94, median 3). A mean 40.15 (SD 42.14, median 26) clicks across all sessions suggests that the intervention participants accessed a moderately large number of subpages.

Primary and Secondary Outcomes at Weeks 2 and 6

Table 5 shows the results of the regression analyses of the scores of the intervention and control group at 2 weeks. As shown by the unstandardized regression weight for the group factor (b group), there were no significant differences at 2 weeks between the intervention and control groups for self-efficacy for coping with cancer as the primary outcome. Furthermore, no significant group differences were determined for the secondary outcome measures of patient competencies, such as self-regulation, coping effectively with emotional distress, dealing explicitly with the threat posed by cancer, and low avoidance. The b coefficients obtained for the respective baseline scores serving as a covariate were generally significant. The corresponding effect sizes (expressed as beta weights) ranged from 0.49 to 0.72, thus indicating large effects [42]. The mean scores tended to be lower at 2 weeks in comparison to baseline (Table 5). Additional group×time repeated measures ANOVAs of changes from baseline to 2 weeks showed a generally significant decrease in all outcome variables except for coping with distress (unimputed data, *F* values not shown, for mean values see Table 5). With values of eta squared less than .06, effect sizes were judged as small [42].

Table 6 presents the results of the regression analyses of the scores of the intervention and control subjects at time 2. Again, intervention and control did not differ with respect to the primary and secondary outcomes as shown by the nonsignificant b coefficients for the group factor. The size of the significant beta weights of the baseline scores entered as covariates ranged from 0.46 to 0.70, also suggesting a large effect of the baseline measure here [42].

Table 5. Results of regression analyses of group effects on primary and secondary outcomes at 2 weeks including the respective baseline score as additional predictor.

Outcomes	Participants, mean (SE)[a]			Group effect[a]			Baseline predictor[a]		
	Intervention (n=103)	Control (n=109)	Total (N=212)	b	*P*	beta (range)	b	*P*	beta (range)
Primary outcome									
Self-efficacy for coping				–2.25	.21	–0.07, –0.05	0.79	<.001	0.74, 0.76
Baseline	98.35 (1.66)	94.45 (1.94)	96.34 (1.29)						
Week 2	96.06 (1.68)	90.71 (2.09)	93.31 (1.36)						
Secondary outcomes									
Patient competencies									
Self-regulation				–0.03	.60	–0.03, –0.01	0.83	<.001	0.76, 0.80
Baseline	3.58 (0.06)	3.48 (0.07)	3.53 (0.05)						
Week 2	3.49 (0.06)	3.37 (0.08)	3.43 (0.05)						
Coping with distress				–0.13	.07	–0.12, –0.07	0.64	<.001	0.68, 0.72
Baseline	3.62 (0.08)	3.42 (0.07)	3.52 (0.05)						
Week 2	3.53 (0.06)	3.27 (0.07)	3.39 (0.05)						
Dealing with threat				–0.05	.52	–0.07, –0.03	.50	<.001	0.49, 0.54
Baseline	3.74 (0.06)	3.73 (0.07)	3.74 (0.04)						
Week 2	3.72 (0.06)	3.67 (0.06)	3.69 (0.04)						
Low avoidance				0.03	.68	0.01, 0.04	0.66	<.001	0.66, 0.71
Baseline	3.40 (0.08)	3.38 (0.08)	3.39 (0.05)						
Week 2	3.24 (0.07)	3.25 (0.07)	3.25 (0.05)						

[a] Results based on 10 multiple imputations, b coefficient combined (mean), beta coefficients as effect size, minimum and maximum across imputations, group dummy coded with intervention=0, control=1.

Table 6. Results of regression analyses of group effects on primary and secondary outcomes at 6 weeks including respective baseline scores as additional predictor.

Outcomes	Participants, mean (SE)[a]			Group effect[a]			Baseline predictor[a]		
	Intervention (n=103)	Control (n=109)	Total (N=212)	b	*P*	beta (range)	b	*P*	beta (range)
Primary outcome									
Self-efficacy for coping				–0.00	.99	–0.01, 0.01	0.62	<.001	0.61, 0.64
Baseline	98.35 (1.66)	94.45 (1.94)	96.34 (1.29)						
Week 6	93.73 (1.62)	91.29 (2.01)	92.48 (1.30)						
Secondary outcomes									
Patient competencies									
Self-regulation				0.09	.23	0.04, 0.08	0.62	<.001	0.63, 0.70
Baseline	3.58 (0.06)	3.48 (0.07)	3.53 (0.05)						
Week 6	3.46 (0.06)	3.48 (0.07)	3.47 (0.05)						
Coping with distress				–0.01	.86	–0.03, 0.02	.53	<.001	0.59, 0.65
Baseline	3.62 (0.08)	3.42 (0.07)	3.52 (0.05)						
Week 6	3.50 (0.06)	3.38 (0.06)	3.44 (0.04)						
Dealing with threat				–0.02	.75	–0.05, 0.01	0.47	<.001	0.46, 0.54
Baseline	3.74 (0.06)	3.73 (0.07)	3.74 (0.04)						
Week 6	3.73 (0.06)	3.70 (0.06)	3.71 (0.04)						
Low avoidance				–0.04	.62	–0.07, 0.01	0.61	<.001	0.61, 0.67
Baseline	3.40 (0.08)	3.38 (0.08)	3.39 (0.05)						
Week 6	3.24 (0.08)	3.18 (0.07)	3.21 (0.05)						

[a] Results based on 10 multiple imputations, b coefficient combined (mean), beta coefficients as effect size, minimum and maximum across imputations, group dummy coded with intervention=0, control=1.

Discussion

Principal Results

This randomized controlled trial investigated the effects of a website presenting systematically collected and organized patients' experiences of living with colorectal cancer on self-efficacy for coping with the disease and on patient competencies such as coping with emotional distress or dealing with the life threatening nature of cancer [10]. Participants randomized to the intervention were given access to the website for two consecutive weeks. Contrary to expectations, no intervention effects were found at 2 and 6 weeks after baseline. Also contrary to expectations, primary and secondary outcome scores showed a slight but significant decrease from baseline to follow-up measurements.

In what follows, we will briefly discuss possible explanations for each of these observations. Insofar as these explanations involve factors relating to characteristics of the new website module itself or to its use by participants, they will primarily be discussed in the section comparing these results to prior work. In contrast, explanations that involve methodological factors will be discussed in the limitations section. Considering these factors in more detail may help improve the design of future studies that aim at evaluating websites providing patient narratives on living with (colorectal) cancer. This appears especially important if one shares the conviction that such narratives contain elements that are relevant for empowering cancer patients and helping them develop their coping competencies and coping self-efficacy.

Regarding the slight, but significant, decrease of self-efficacy for coping with cancer and three patient competence scales across time observed in this study, a possible explanation may lie in assuming the operation of a response shift [52]. In the course of the study, participants may have undergone a change in their frames of reference for rating coping self-efficacy and patient competencies. One may speculate, for example, that the observed decrease might reflect some sort of disillusionment resulting from participants' encountering narratives that describe coping options, which they perceived as beyond their own repertoire of coping behaviors. Then, however, one would expect this change not to occur in the waiting list control group, which is not the case. Thus, this explanation appears rather unlikely. Finally, one could argue that the observed decrease in coping self-efficacy and competence may indicate a regression toward the mean stemming from the self-selection of participants into the trial who already score high on these measures at baseline. Comparing trial participants to the sample of a previous study [10,41] in fact shows them to score significantly higher on the seeking information scale of the competence measure used here. Their scores on the scales used for measuring the secondary outcome criteria are fairly comparable, rendering regression to the mean an implausible explanation. The foregoing discussion focused on possible explanations of an observed decrease in coping self-efficacy and patient competencies. Therefore, we would like to conclude stressing that identifying factors that help patients' develop their coping self-efficacy and competencies remains an important task for future research.

Limitations

A major limitation of this study may be that its participants were much younger on average (mean 54.1, SD 11.1 years) than patients with colorectal cancer in Germany in general (mean 71 years) [53]. Although access to and use of the Internet is increasing in all age groups, older patients still appear to be active on the Web to a lesser percentage than younger patients in Germany [54]. Therefore, including participants from this segment of the population of colorectal cancer patients in future research is called for to gain more insight into how websites such as the one studied here may affect these patients. A comparable argument would apply to the potential role of gender in this context, which was beyond the scope of this study. Finally, including patients' family or friends in such a study might add another facet to future research in this field because these people often support patients in seeking health information on the Internet [55].

Another important limitation may be the fact that far fewer participants could be recruited for the study than suggested by the initial determination of the necessary sample size. This inevitably reduced the power of the trial to detect a treatment effect, if it in fact existed. It would certainly have been preferable to extend the recruitment phase of the study. Unfortunately, this was not possible because of the timeline of the study and the intention to make the newly constructed website available to the public in due time. Nevertheless, achieving the targeted sample size would by no means have guaranteed to establish the hypothesized effect.

Comparison With Prior Work

Traditional face-to-face psychoeducational interventions in cancer patients have been shown to yield small-to-medium positive effects on distress and quality of life, although problems with study quality and heterogeneity have to be acknowledged [56-59]. Internet-based interventions targeting these domains are gradually appearing and tend to give comparable results [60-62]. This study extended these latter efforts to providing scientifically based narrative information on living with colorectal cancer online and including self-efficacy for coping with cancer and patient competence as outcome criteria in a randomized controlled trial. However, a feature that distinguishes the aforementioned interventions from the website under study is the apparent curricular structure that is typically designed in accordance with the changes desired in the targeted behavioral domain. Also, these interventions appear to require more participant involvement in terms of time investment when progressing through a series of defined tasks for one or more weeks. In contrast, this study allowed participants to explore the site under study according to their immediate personal goals and preferences. As a consequence, they may have utilized the website to a narrower extent than was theoretically possible. The observation that participants in this study spent a limited amount of time using the site is in line with this argument. Therefore, more detailed analyses of patients' website user behaviors as a mediator of online intervention effects are called for in future research. Beyond this, evaluating the effects of online interventions presenting illness narratives by cancer patients may also profit from supplementary measures of more general psycho-oncological constructs such as the ones used here, with measures capturing subjectively perceived effects and changes more directly. Efforts in that direction might profit from Pols' research into patients' knowledge [63,64] that aims at a reconceptualization incorporating patients' day-to-day coping transactions with illness on a more specific level.

Conclusions

Regarding self-efficacy for coping with cancer and patient competence, this study found that having access to a new website presenting illness narratives of colorectal cancer patients that have been systematically collected on a scientific basis has no effect compared to a control condition. Possible explanations of this finding may be seen in specific features of the website itself and in features of patients' on-site usage behavior that might operate as a moderator of online intervention effects on coping self-efficacy and patient competence and other patient-reported outcomes. As a consequence, it may be of importance to analyze patients' usage behavior in more detail in future research. Furthermore, future research should extend the range of outcome criteria and include measures that more directly reflect patients' perceived effects of using such a website.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

CONSORT-EHEALTH (v.1.6.1).

[PDF File (Adobe PDF File), 7MB - jmir_v19i10e334_app1.pdf]

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Abbreviations

CBI: Cancer Behavior Inventory
CONSORT: Consolidated Standards of Reporting Trials
DIPEx: Database of Individual Patients’ Experiences
EORTC: European Organisation for Research and Treatment of Cancer

PHQ: Patient Health Questionnaire
SSUK: Illness-specific Social Support Scale

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Original Paper

Factors Associated With Engagement With a Web-Based Lifestyle Intervention Following Provision of Coronary Heart Disease Risk: Mixed Methods Study

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Abstract

Background: Web-based interventions provide the opportunity to combine the tailored approach of face-to-face interventions with the scalability and cost-effectiveness of public health interventions. This potential is often limited by low engagement. A number of studies have described the characteristics of individuals who engage more in Web-based interventions but few have explored the reasons for these variations.

Objective: We aimed to explore individual-level factors associated with different degrees of engagement with a Web-based behavior change intervention following provision of coronary heart disease (CHD) risk information, and the barriers and facilitators to engagement.

Methods: This study involved the secondary analysis of data from the Information and Risk Modification Trial, a randomized controlled trial of a Web-based lifestyle intervention alone, or alongside information on estimated CHD risk. The intervention consisted of three interactive sessions, each lasting up to 60 minutes, delivered at monthly intervals. Participants were characterized as high engagers if they completed all three sessions. Thematic analysis of qualitative data from interviews with 37 participants was combined with quantitative data on usage of the Web-based intervention using a mixed-methods matrix, and data on the views of the intervention itself were analyzed across all participants.

Results: Thirteen participants were characterized as low engagers and 24 as high engagers. There was no difference in age (P=.75), gender (P=.95), or level of risk (P=.65) between the groups. Low engagement was more often associated with: (1) reporting a negative emotional reaction in response to the risk score (P=.029), (2) perceiving that the intervention did not provide any new lifestyle information (P=.011), and (3) being less likely to have reported feeling an obligation to complete the intervention as part of the study (P=.019). The mixed-methods matrix suggested that there was also an association between low engagement and less success with previous behavior change attempts, but the statistical evidence for this association was weak (P=.16). No associations were seen between engagement and barriers or facilitators to health behavior change, or comments about the design of the intervention itself. The most commonly cited barriers related to issues with access to the intervention itself: either difficulties remembering the link to the site or passwords, a perceived lack of flexibility within the website, or lack of time. Facilitators included the nonjudgmental presentation of lifestyle information, the use of simple language, and the personalized nature of the intervention.

Conclusions: This study shows that the level of engagement with a Web-based intervention following provision of CHD risk information is not influenced by the level of risk but by the individual's response to the risk information, their past experiences of behavior change, the extent to which they consider the lifestyle information helpful, and whether they felt obliged to complete the intervention as part of a research study. A number of facilitators and barriers to Web-based interventions were also identified, which should inform future interventions.

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KEYWORDS

Web-based intervention; cardiovascular disease; engagement; risk; qualitative research

Introduction

Noncommunicable diseases have now overtaken communicable diseases in causing the greatest disease burden worldwide, with coronary heart disease (CHD) being the number one cause of disability-adjusted life years globally [1]. Four modifiable lifestyle risk factors (tobacco use, high alcohol consumption, unhealthy diet, and low levels of physical activity) have been associated with 80% of deaths caused by cardiovascular disease (CVD) [2]. This finding has led to an increasing focus on affordable effective behavior change interventions, including collective approaches that aim to shift the entire population distribution of risk factors, and approaches that focus on individuals.

With the expanse and scope of the Internet, Web-based interventions provide the opportunity to combine the tailored approach of face-to-face interventions with the scalability and cost-effectiveness of public health interventions, and are potentially appealing to the public because they are convenient and easily accessible [3,4]. Systematic reviews have shown that Web-based interventions have the potential to influence behavior [5-7]. However, this potential is often limited by low levels of engagement and high rates of attrition [8,9]. Understanding why some individuals engage in Web-based interventions whilst others do not is important to optimize future interventions.

A number of quantitative studies have described the characteristics of individuals who engage more in Web-based behavior change interventions. The findings have been mixed, with one study finding no association between website use and clinical and sociodemographic variables [10], whilst others have reported higher engagement in younger people and those with higher mental health scores, higher perceptions of general health, higher perceived risk, lower income, and in less than full-time employment [11,12]. To our knowledge, only one qualitative study has explored the reasons for these differing levels of engagement and that study only reported reasons given by women who had not logged onto a Web-based intervention providing information about risks of breast cancer [11]. More research is needed to better understand the factors (at an individual level) that are associated with engagement with Web-based health behavior interventions.

A number of behavior change theories additionally suggest that lifestyle interventions will only be successful if individuals perceive themselves to be at risk of developing the target disease [13,14]. This factor has led to the incorporation of risk communication into many major clinical guidelines for routine practice [15-19] and the English National Health Service (NHS) Health Checks program, which aims to assess CVD risk for individuals aged 40-74 years without preexisting CVD [20]. Whilst the evidence for any impact of risk communication on behavior change is limited [21], very little is known about the impact of risk communication on subsequent engagement with Web-based health behavior interventions.

The Information and Risk Modification (INFORM) Trial [22] was a randomized controlled trial comparing the impact of providing phenotypic and genetic CHD risk scores alongside a Web-based lifestyle intervention. In additional to behavioral outcomes, INFORM included quantitative measurements of engagement with the Web-based lifestyle intervention and a nested qualitative study with face-to-face individual interviews with participants throughout the trial [23]. The aims of this study were to use the data from the face-to-face interviews to explore the factors associated with different levels of engagement with the Web-based intervention, and the barriers and facilitators to engagement in general.

Methods

Participants and Setting

This study is a secondary analysis of data collected as part of the INFORM trial. Details of that trial are reported elsewhere [22]. In brief, INFORM was a parallel group randomized controlled trial that aimed to explore the short-term effects on health-related behaviors of giving people different types of information online about their estimated risk of CHD in the subsequent 10 years, together with Web-based lifestyle advice. A convenience sample of 956 blood donors aged 40-84 years from across England who took part in the INTERVAL study [24] with no previous history of CVD were allocated to either no intervention (control group), or to one of three active intervention groups: Web-based lifestyle advice only; Web-based lifestyle advice plus information on estimated 10-year CHD risk as a percentage, heart age (the chronological age of someone with the same absolute risk of CHD but with healthy risk factors), and comparison with someone of the same age and gender who had a healthy lifestyle based on phenotypic characteristics; and Web-based lifestyle advice plus information on estimated 10-year CHD risk, heart age, and healthy comparison based on phenotypic and genetic characteristics.

The Web-based Intervention

The Web-based lifestyle advice was based on an intervention originally developed for the Heart to Health study, which was shown to be effective in a randomized controlled trial [25]. The advice consisted of a library of over 250 webpages providing advice on physical activity, diet, smoking, and medication tailored to the participants' responses to a prestudy questionnaire and choice of risk-reducing strategies. The intervention was delivered through three interactive sessions at monthly intervals, each lasting up to 60 minutes. Prior to the first session, participants were presented with their 10-year CHD risk information and asked to choose to take part in any or all of the modules related to diet, physical activity, and smoking cessation. The first session then began with education on either diet, physical activity, or smoking cessation alongside tips on how to overcome self-identified barriers to risk reduction and the creation of steps toward self-identified actionable goals. The second and third sessions included similar content, with participants beginning by reviewing their progress toward goals, continuing with education, and tips to overcome barriers, and then finishing with identification of new goals [22].

Qualitative Data

Face-to-face interviews with a purposive sample of 41 participants were conducted as part of the INFORM trial by an experienced qualitative researcher (GS). Full details of the recruitment and methods are reported in detail elsewhere [23]. Briefly, in order to sample participants who could provide the richest data on the primary trial question, participants who received medium to high risk scores (a 10-year CHD risk >10% or heart age at least two years older than their real age) were mainly selected. In this study, we only included the 37 participants who had received either a phenotypic or phenotypic plus genotypic risk score. Each interview lasted between 30-45 minutes and was guided by a schedule covering the participants' understanding of CHD risk, their reaction to receiving a risk score, their intentions to change behavior, their attempts at actually changing behavior, and their experience of the Web-based intervention. All interviews were audio-recorded and professionally transcribed.

Quantitative Data

Quantitative data on usage of the Web-based intervention was collected by tracking which pages participants had accessed during the trial. Participants were considered high engagers with the website if they completed all three sessions for either diet, physical activity, or smoking, and low engagers if they did not. Student's t-tests or Chi-squared tests were used to assess differences between the high and low engagers with significance set at *P*<.05.

Analysis

We first used thematic analysis [26] to analyze the qualitative data from the interviews undertaken within the INFORM study. Using an inductive approach, after repeated reading of the transcripts, three members of the team (LW, GS, and JUS) developed a coding framework from the empirical data focusing on how people reacted to and assigned meaning to risk information, their prior experiences of health behavior change, their engagement with the Web-based intervention, and their views on the intervention itself. This framework was independently piloted on four transcripts by two researchers (LW and GS) to ensure a consistent approach to coding. The coding of the remaining transcripts was then completed by one researcher (LW) using NVivo software.

Once coding was complete, we combined the qualitative data with the quantitative data in a mixed-methods matrix with one row for each of the 37 participants. Data on the level of website engagement was used to divide participants based on whether they were low or high engagers and Chi-square tests were used to test associations. After identifying themes associated with engagement with the website from this matrix, we then returned to the qualitative data to explore those themes in greater depth. Data on the views of the intervention itself were also analyzed separately across all participants using thematic analysis.

Results

Participant Characteristics

The characteristics of the 37 participants are described in Table 1. The majority of individuals were married with university degrees and in the high-income category. The mean phenotypic risk was 12.6% for men (range 4-62%) and 3.8% (range 0.6-11%) for women and the mean genotypic risk was 12.6% (range 5-28%) for men and 4.1% (range 0.5-15%) for women.

Qualitative Themes Associated With Low Engagement

Using the quantitative data from the website, 13 participants were characterized as low engagers and 24 as high engagers. There was no difference in age (*P*=.75), gender (*P*=.95), or the difference between the estimated phenotypic heart age the participants received and their chronological age (*P*=.65) between the groups. Table 2 shows a section of the mixed-methods matrix ordered according to the level of website engagement.

Low engagement with the website was more often associated with: (1) reporting a negative emotional reaction to the risk score (*P*=.029), (2) perceiving that the intervention did not provide any new lifestyle information (*P*=.011), and (3) being less likely to have reported feeling an obligation to complete the intervention as part of the study (*P*=.019). The matrix also suggested an association between low engagement and less success with previous behavior change attempts, although the statistical evidence for this was weak (*P*=.16). No associations were seen between engagement with the website and barriers or facilitators to health behavior change, or comments about the design of the intervention itself. In the latter case, participants in both groups described aspects of the intervention which they thought were helpful or unhelpful, but whether they chose to engage with the intervention or not appeared to be dominated by other factors.

Table 1. Characteristics of participants.

Participant characteristic	n=37
Gender	
Male	23
Female	14
Age at baseline (years)	
40-49	5
50-59	14
60-69	13
70-80	5
Study group	
Phenotypic risk + genetic risk + lifestyle advice	22
Phenotypic risk + lifestyle advice	15
Marital status	
Married	26
Separated or divorced	3
Widowed	3
Single	5
Level of education	
No formal education	1
Secondary education (to age 18)	17
University education	19
Annual income	
Less than £8000	1
Between £8001-40,000	13
More than £40,000	19
Did not know or did not answer	4
Estimated phenotypic 10-year CHD risk	
<5%	11
5-10%	14
10-20%	9
>20%	3

Table 2. Mixed-methods matrix ordered according to the level of website engagement, where dots indicate the presence of that theme within the qualitative interview data.

Level of engagement	Participant characteristics			Response to risk information	Previous behavior change attempts		Views of the intervention	
	ID	Age	Sex	Negative emotional reaction	Unsuccessful	Successful	No new information	Felt obliged to complete
Low engagers	9	73	F				●	
	12	69	M	●	●		●	
	13	64	M				●	
	15	56	M	●	●		●	
	19	75	F				●	
	22	59	M	●			●	
	24	55	M	●	●		●	
	25	67	M			●	●	
	26	44	F	●	●		●	
	27	54	F	●		●	●	
	30	56	M	●			●	
	31	44	F		●		●	
	33	59	M	●			●	
High engagers	1	64	M				●	
	2	70	M					
	3	57	M				●	
	4	59	F		●			
	5	72	M	●		●		●
	6	63	F				●	
	7	57	M	●		●	●	
	8	67	M			●	●	
	10	68	M			●	●	
	14	68	F					
	16	63	M		●			
	17	64	F				●	●
	18	61	M	●	●			
	20	49	M			●	●	●
	21	55	M	●				
	23	76	M			●	●	●
	28	58	M					
	29	64	M			●	●	
	32	66	M				●	●
	34	51	F	●		●	●	●
	35	55	F	●			●	●
	36	56	F		●	●	●	
	37	46	F		●			
	40	45	F		●		●	●

1) A Negative Emotional Reaction to the Risk

A greater proportion of low engagers described a negative emotional reaction to the risk, which was understood as expressing fear, anxiety, worry, shock, concern, or irritation when being asked during the interview to recall their feelings at the time they received the risk information. In many cases this reaction was surprise, disappointment, or worry because the risk did not match how they perceived themselves in relation to their health behavior and comparison with others:

> *It was a bit of a shock to be honest, because as I say, I thought that when I would get the results of that my, say, I'm 59, I know, but I thought my heart would be, or my rating would be say down much lower at 54, 55 or something like that...'cos of the amount of exercise I do and, you know, my weight I think is about right and I'm, I don't get ill at all and fortunately I haven't got any, you know, any long-term health problems.* [I22 – Male, aged 59, low engager]
>
> *Yeah, my heart age was...It was about seventy I think and I'm fifty-five and that was, you know, it was worrying, especially considering I've never smoked or anything like that...I thought, well rather than having twenty-five years maybe, hopefully, I might only have ten or less.* [I24 – Male, aged 55, low engager]

In some cases, particularly amongst those participants who did not fully understand the risk information, this led to confusion, irritation, or annoyance.

> *Yeah, it was [confusing] actually, because it just came, it didn't explain why it would be that way so I mean I did, I haven't angst, I haven't sort of lost sleep over it but I did kind of think why basically, why should it be that way? The percentages were pretty much the same which seemed bizarre given the differential on the age thing.* [I27 – Female, aged 54, low engager]

By comparison, several high engagers had also felt irritated, surprised, or concerned by receiving risk scores higher than they had expected but, unlike the low engagers, described acceptance of the score as a reasonable assessment.

> *Well, pretty irritated really, but since it was based on answers I'd given, and I'd given them fairly honestly, I mean I had no, you know, it, it's an algorithm that you've applied to the information I gave so I could question the, I can't question the information, I could question the algorithm but I wasn't going to. I, I took it as being a reasonable assessment of probabilities or of causal factors.* [I18 – Male, aged 61, high engager]
>
> *Useful and concerned 'cos I think 60, a heart age of 69 is significantly greater than I would like it to be, so that's why I read on all the material about diet and exercise because I wanted to see if I could do something about it.* [I21 – Male, aged 55, high engager]

2) Reporting That the Intervention Did Not Provide Any Helpful Lifestyle Information

Notably all of the low engagers reported that the intervention did not provide any new lifestyle information.

> *I don't think I learnt anything new, it just told me what I could do and, to be fair, what I know I could do, you know, or know what I should do, I don't think I learnt anything more.* [I15 – Male, aged 56, low engager]

Whilst many of the high engagers also felt there was little new lifestyle information, some of those nevertheless considered that the intervention was still helpful as it presented the lifestyle information differently or reinforced their prior knowledge.

> *No [I did not learn anything new], I think I was aware of it, but it's when, you know, you see it linked up, because you, so much information comes out about diet, food, and it does change quite regularly, sometimes it's difficult, it is difficult to try and keep up with everything.* [I20 – Male, aged 49, high engager]
>
> *I think it reinforced what I was aware of, and I think it's always good to keep refreshing, because things might change a little. So, I don't think I thought that there was any "wow" in it, but it was, yeah, yeah, okay that's fine.* [I3 – Male, aged 57, high engager]

3) Not Feeling Obliged to Complete the Intervention

A further theme associated with level of engagement was the finding that many of the high engagers had completed all three sessions partly for the purpose of the study. For these participants, any reactions they had to the risk information or views about the intervention were superseded by a desire to "do what they had been told" or committed to.

> *I thought having been asked to do it you know, I'd religiously go through it and make sure you know, I'd covered all the elements.* [I32 v Male, aged 66, high engager]
>
> *I'm the sort of person who does do, I mean as I say, I tend to do what I'm told, having signed to do this, I will do it and I will do every module.* [I35 – Female, aged 55, high engager]

4) Less Success With Previous Behavior Change Attempts

Although not statistically significant, the final theme found amongst low engagers related to prior experiences of behavior change. Compared to high engagers, low engagers tended to have had more unsuccessful prior behavior change attempts and less successful experiences.

> *...the, the eating habit I've got, that's going to be my biggest problem, I bring a banana into work and then I, five o'clock, oh, it's still there, and I've walked down to the shop and got myself a roll [laughs]. So, changing that is my bigger problem, the eating part, although I have been on a diet in the past and lost*

> *nearly four stone, but then it all came back again.* [I15 – Male, aged 56, low engager]
>
> *Well when I, when I discovered my, I suppose when I was, what 55, I was thirteen stone and hadn't done any exercise much since I'd left school, so I was introduced to a friend to walking and stuff and running and a bit of jogging, so you know, I'm two stone lighter now than I was then.* [I10 – Male, aged 68, high engager]

Perspectives on the Web-Based Intervention

Almost all participants, regardless of their level of engagement with the website, described aspects of the Web-based intervention that acted as either barriers or facilitators to use (Table 3 and Table 4).

The most commonly cited barriers related to issues with access to the intervention itself, either due to difficulties remembering the link to the site or passwords, or a perceived lack of flexibility within the website. Several participants also felt that the lifestyle advice provided was too limited and did not include sufficient options for those already achieving the goals, or with particular likes/dislikes or medical problems. Conversely, most participants commented favorably about the content of the lifestyle information provided. For many participants, the nonpreaching and nonjudgmental presentation of the lifestyle information was an important facilitator, along with the use of simple language and inclusion of up-to-date lifestyle information from a respected source. Several individuals also described how the personalized nature of the risk and lifestyle information made them feel more engaged.

A number of participants also suggested possible additions to the intervention to improve it; these included incorporating a progress chart or tracker that would allow participants to log in and update the website with their progress whilst also providing a reason to return to the website regularly to remind them of the information, and linking it with calendar applications to allow participants to add reminders to their calendars to prompt them between the scheduled sessions.

Table 3. Barriers to engagement.

Barrier	Representative quotations
Difficulty remembering passwords	*The thing I found most difficult was each time having to go back and try and find the password and the name thing, which I'd lost a million times down the thing, and every time I wanted to go into it so it stopped me going there so regularly because it was quite hard to go back and look at it, that might just be me!* (I37 – Female, aged 46, high engager)
Difficulty getting back into the website after clicking on additional information	*The only thing that did annoy me was when you go out… when it says, "If you want to know more about five a day" or whatever, "click here." So, you click there and you go into the other website which sort of tells you all the information you want to know, but I couldn't get back to the original study. So, I had to go right out and then log back in, but then it brought me back to the page I was on, so that was okay.* (I14 – Female, aged 68, high engager)
Difficulty getting back into the website for the later modules	*Well when I got the email I think last week, to do session two of the informed study I was a bit surprised there wasn't a link on it to take me straight into it, so I had to refer back to the original email with my password and login details, I've now set up my own link so that's fine, I was just a bit surprised I just didn't press a button and it was there...but that's a minor point and it's something I could cope with but if I'd deleted all the information from session one I'm not sure how I would have got into it.* (I1 – Male, aged 64, high engager)
Difficulty remembering all the information	*I think the only difficulty I had was because there are quite a few pages on some of them when you go through the study, if you didn't print them off it was difficult to remember with some of the things you might have read before, so there wasn't like, I didn't think there was enough of a summary at the back so when you got to the end you could then pick up all the salient points in one go and just print that off.* (I28 – Male, aged 58, high engager)
Lack of flexibility/too prescriptive	*I mean the whole thing seemed very very linear so that you started at the beginning and there really wasn't any, you know, straight, you know, and I just felt as I say, railroaded.* (I29 – Male, aged 64, high engager)
Limited options for those with particular likes/dislikes, medical problems or already achieving the goals	*The problem is that I felt that I was only going to be able to sign up to more exercise if I honestly felt that I was going to stick to it and I hate exercise and most of the recommendations in the first module are the kind of exercise that frankly I'm not interested in doing.* (I29 – Male, aged 64, high engager) *I found the exercise one quite tricky for that because the exercise site is very much set up for people who aren't exercising enough and it's trying to set goals to exercise more, and it almost didn't have any options to do the same.* (I40 – Female, aged 45, high engager)

Table 4. Facilitators to engagement.

Facilitator	Representative quotations
Nonpreaching nature of lifestyle information	*I found it was at a good level to read, you know, it wasn't preaching. Sometimes you can find it's very preachy information that comes across and, and therefore that makes me react, but when it's just informative, saying, these are the facts, you have to now make a decision, that's much better from my point of view.* (I20 – Male, aged 49, high engager)
Nonjudgmental	*I thought it was pretty good, it was better than I expected. I did wonder if it was going to lecture me or try to frighten me, but I thought it was quite easy to use, it was clear, the information was there and it didn't sort of judge you or anything. So, I thought it was quite good and I did the whole thing and that was fine, yeah...If it had have been sort of condescending or over instructive, I'd have probably switched it off.* (I3 – Male, aged 57, high engager)
Links to further information	*Quite useful. Particularly, actually I'll come back to it again, what constitutes five-a-day because you could be thinking about a large fruit or a small fruit and cooked vegetables versus non-cooked vegetables, so it was quite informative, not just the information on the site but the links it had to other information.* (I21 – Male, aged 55, high engager)
Simple language	*I found it very easy to use, very easy to digest, there was no jargon or technical terms, there was, it was just plain and simple, stating what in some cases was the obvious but put in such a way that you actually digested it.* (I36 – Female, aged 56, high engager)
Easy to navigate	*In terms of usability, it, it was quite easy to use. It was attractively laid out, it was easy to follow, yeah, I think the website was, was quite straightforward.* (I40 – Female, aged 45, high engager)
Up to date information from respected source	*I felt the quality of the advice was, it was high information content but with, with useful interpretation, and seemingly very up to date.* (I18 – Male, aged 61, high engager) *I think the INFORM stuff has helped me to, well it has a bit more authority, you know, than the [national newspapers], choose which end you want to be of the spectrum.* (I2 – Male, aged 70, high engager)
Personalized	*I know it goes to a lot of people but I feel it's on a one-to-one, "We've told you this and you've set yourself a goal" and then however many weeks later they send you an email and it's not hard and fast, it's gentle but you know, "Do you remember you did this? And do you remember we said this?" And you think "Oh yeah, okay".* (I36 – Female, aged 56, high engager)
Reminder emails	*The emails have come at the right time, they're not coming all the time so you don't think, "Oh I'm just going to delete it, I'm not going to read it," it comes and you think, "Oh yeah, I haven't thought about this," so you read it all and you take it all in and it just revives your initial thoughts.* (I36 – Female, aged 56, high engager)

Discussion

Principal Results

Using a mixed-methods approach, this study demonstrates that lower engagement with a Web-based lifestyle intervention following provision of an estimate of 10-year CHD risk was associated with reporting a negative emotional reaction to the risk score, perceiving that the intervention did not provide any helpful lifestyle information, being less likely to have reported feeling an obligation to complete the intervention as part of the study and less success with prior experiences of behavior change attempts. No associations were seen between engagement with the website and the level of CHD risk or reported barriers or facilitators to health behavior change. The most commonly cited barriers to engagement were difficulty accessing the website, a perceived lack of flexibility within the website, and lack of time. Facilitators included the nonjudgmental presentation of lifestyle information, the use of simple language, and the personalized nature of the intervention.

Strengths and Limitations

A key strength of this study is the use of a mixed-methods approach to explore associations between participants' views expressed during the qualitative interviews and their engagement with a Web-based intervention. Unlike previous studies which have focused on differences in the clinical and sociodemographic characteristics of individuals [10-12], this approach provided us with a richer understanding of the data [27] and allowed us to compare within groups and across groups of low and high engagers to identify patterns in the qualitative and quantitative data associated with engagement with the website intervention [28]. The themes identified in the qualitative data were also the result of an inductive process using responses to questions related to the understanding of CHD risk, reactions to receiving a risk score, intentions to change behavior, and attempts at actually changing behavior rather than direct questions about engagement. Using this approach, we were able to identify associations between participants' views and engagement that have not been reported previously.

However, the findings must be interpreted with consideration of the limitations of the study. The main limitation is that the participants were a small purposive sample selected from blood donors already taking part in another trial, so they may have had better knowledge or a more positive attitude towards healthy lifestyles than the general population. Participants were also highly educated and earning more money than the national average; their views may, therefore, not be representative of the general population and our findings may not reflect the reasons for participation among less educated or lower socioeconomic groups. By using an inductive approach guided by the data, the analysis is also limited to the topics raised during the interviews. While we identified no new themes when coding the later interviews and believe we reached data saturation, it is possible that new themes would have been present in a larger, more diverse sample. A second limitation is our measure of website engagement. We measured engagement by tracking which pages participants had accessed during the trial and considered participants high engagers if they completed all three sessions, and low engagers if they did not. While this method is better than self-report [29] as it removes the risk of recall or social desirability bias, it has been suggested that such a summative approach misses additional levels of data [30]. Tracking the time spent on each page and individual participants' routes through the intervention would have provided more data.

Comparison With Prior Work

Although not reported previously, the findings that engagement was lower in those who expressed negative emotions such as fear, anxiety, or worry when being asked during the interview to recall their feelings at the time they received the risk information, and in those who reported less success with prior experiences of behavior change attempts, are consistent with behavioral theory. Two widely used theories of behavior change (Protection Motivation Theory [13] and the Extended Parallel Processing Model [31]) suggest that perceptions of a health risk can cause either adaptive self-protective actions, or maladaptive self-defeating actions depending on perceptions of threat (perceived vulnerability or susceptibility, and perceived severity) and efficacy (response efficacy or the perceived effectiveness of the recommended actions; and self-efficacy, a person's belief about his or her ability and capacity to achieve the recommended changes). These models suggest that if the health threat is believed to be inevitable or unrealistic, or people do not believe in their own ability to change their behavior, instead of engaging in health protective behaviors, people may experience thoughts of fatalism or hopelessness and engage in psychological defense mechanisms such as avoidance and denial. Together with the findings in this study, this suggests that providing individuals with risk information may potentially decrease engagement in prevention activities through maladaptive behaviors, and that different approaches may be needed depending on an individual's prior beliefs and understanding of their own risk. In this study, participants viewed their risk online, but when risk is provided in face-to-face consultations it is easier to address negative emotional reactions at the time, which may reduce maladaptive coping strategies and improve subsequent engagement.

The findings that perception that there was little or no helpful lifestyle information provided by the intervention was associated with not completing the intervention, and a third of those who were high engagers with the Web-based intervention reported feeling an obligation to complete the intervention as part of the study, are also consistent with reports on participation in research. Two of the key motivators for taking part in clinical trials are a willingness to help others and contribute towards furthering medical knowledge, and perceiving some benefit (and/or no significant disadvantage) for themselves [32-34]. A number of participants completed the intervention out of a sense of duty, with their focus less on improving their own health and more about contributing to the improvement of others' health. This is not entirely surprising, but does have implications for the generalizability of the findings of Web-based interventions outside of trial settings.

In addition to these individual-level factors associated with engagement with the intervention, this study also highlights a number of features of Web-based interventions that can act as either barriers or facilitators. The most common barriers that were reported related to difficulties with access to the intervention itself, such as forgetting the link to the website or passwords [35]. Simple amendments, such as including links to the website in every email correspondence and incorporating an automatic password reset option for forgotten passwords, may therefore increase engagement. Similarly, being mindful when developing interventions to include a wide range of options for those with particular needs (where possible) may help to retain the interest of some individuals. While one style is unlikely to suit everyone, the findings of this study also suggest that in the context of behavior change interventions, presenting lifestyle information in a nonjudgmental and nonpreaching style is appreciated. This finding is echoed in studies reporting why people chose not to take up the offer of cardiovascular screening within the NHS Health Check program, in which a number described not wishing to be *told off* as a contributory factor [36-38].

Conclusions

In the context of a growth of interest in scalable interventions, where small effect sizes across large numbers of individuals have the potential to impact health at the population level, this study has a number of implications for clinicians involved in communicating risk of disease and providing lifestyle advice, and those developing Web-based interventions. Our findings suggest that tailoring Web-based health behavior change interventions to take account of participants' prior perceptions of their risk, any earlier attempts at behavior change, and their current knowledge of health behaviors may improve engagement. These approaches could be achieved by presenting risk in different visual or verbal formats, using behavior change techniques targeted at improving self-efficacy for those with previous failed attempts at behavior change, and providing information in a stepwise manner with more complex information available for those with greater baseline knowledge. Seeking to prevent or address negative emotions at the time of delivery of risk information by providing endorsement of the risk information and Web-based intervention at the time of referral or provision of risk, may also reduce subsequent maladaptive coping strategies. Developing or recommending interventions that take account of difficulties with access and perceived lack of flexibility by having simple password reminder systems and clear navigation, whilst continuing to present lifestyle information in a nonjudgmental way using simple language, may also increase engagement and reduce attrition.

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A complete list of investigators and contributors to the INTERVAL trial is provided elsewhere [23]. A complete list of investigators and contributors to the INFORM study is also provided elsewhere [22]. NHS Blood and Transplant, the sponsor of the INTERVAL trial, assisted with the involvement of blood donors in INFORM. The Web-based lifestyle intervention for CHD prevention is based on one that was originally developed for the Heart to Health study [39]. In addition, some materials were originally developed by Leicester Diabetes Centre [40]. Affymetrix (Santa Clara, US) provided genotyping services. The Cambridge Medical Research Council Epidemiology Unit Physical Activity Team provided expertise. UK Biocentre (Stockport, UK) provided laboratory support. Vitas (Oslo, Norway) conducted assays. We would like to thank the Patient and Public Involvement representatives Kathryn Lawrence and Chris Girling for reviewing study documents. Lastly, we would like to thank to all participants who agreed to take part in the qualitative part of the INFORM trial.

Authors' Contributions

JUS contributed to the design of the INFORM study, analyzed the qualitative and quantitative data, and wrote the first draft of the manuscript. LW analyzed the qualitative data and critically revised the manuscript. GS designed the qualitative elements of the INFORM study, contributed to the development of the Web-based intervention, conducted the interviews, analyzed the qualitative data, and critically revised the manuscript. BS designed the INFORM study, developed the content for the Web-based intervention, and critically revised the manuscript. RP developed the Web-based intervention, contributed to the design of the INFORM study, and critically revised the manuscript. SG designed the INFORM study and critically revised the manuscript. All authors were involved in interpretation of the data.

Conflicts of Interest

None declared.

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Abbreviations

CHD: coronary heart disease
CVD: cardiovascular disease
INFORM: Information and Risk Modification
NHS: National Health Service

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Original Paper

Effectiveness of Two Web-Based Interventions for Chronic Cancer-Related Fatigue Compared to an Active Control Condition: Results of the “Fitter na kanker” Randomized Controlled Trial

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Abstract

Background: Approximately one third of all patients who have been successfully treated for cancer suffer from chronic cancer-related fatigue (CCRF). Effective and easily accessible interventions are needed for these patients.

Objective: The current paper reports on the results of a 3-armed randomized controlled trial investigating the clinical effectiveness of two different guided Web-based interventions for reducing CCRF compared to an active control condition.

Methods: Severely fatigued cancer survivors were recruited via online and offline channels, and self-registered on an open-access website. After eligibility checks, 167 participants were randomized via an embedded automated randomization function into: (1) physiotherapist-guided Ambulant Activity Feedback (AAF) therapy encompassing the use of an accelerometer (n=62); (2) psychologist-guided Web-based mindfulness-based cognitive therapy (eMBCT; n=55); or (3) an unguided active control condition receiving psycho-educational emails (n=50). All interventions lasted nine weeks. Fatigue severity was self-assessed using the Checklist Individual Strength - Fatigue Severity subscale (primary outcome) six times from baseline (T0b) to six months (T2). Mental health was self-assessed three times using the Hospital Anxiety and Depression Scale and Positive and Negative Affect Schedule (secondary outcome). Treatment dropout was investigated.

Results: Multiple group latent growth curve analysis, corrected for individual time between assessments, showed that fatigue severity decreased significantly more in the AAF and eMBCT groups compared to the psycho-educational group. The analyses were checked by a researcher who was blind to allocation. Clinically relevant changes in fatigue severity were observed in 66% (41/62) of patients in AAF, 49% (27/55) of patients in eMBCT, and 12% (6/50) of patients in psycho-education. Dropout was 18% (11/62) in AAF, mainly due to technical problems and poor usability of the accelerometer, and 38% (21/55) in eMBCT, mainly due to the perceived high intensity of the program.

Conclusions: Both the AAF and eMBCT interventions are effective for managing fatigue severity compared to receiving psycho-educational emails.

Trial Registration: Trialregister.nl NTR3483; http://www.trialregister.nl/trialreg/admin/rctview.asp?TC=3483 (Archived by WebCite at http://www.webcitation.org/6NWZqon3o)

(J Med Internet Res 2017;19(10):e336) doi:10.2196/jmir.7180

KEYWORDS

fatigue; cancer survivors; Internet interventions; mindfulness-based cognitive therapy; physiotherapy; accelerometry; latent growth analysis; implementation; RCT

Introduction

Cancer-related fatigue (CRF) is, “a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning” [1]. In approximately 30% of the patients who have been successfully treated for cancer, severe fatigue persists for months or even years [2]. This persistent fatigue, termed chronic CRF (CCRF) is often accompanied by distress and poor mental health [1,3].

Physical activity interventions and psychosocial interventions specifically designed to reduce CCRF have been shown to be effective [4-9]. Readily accessible interventions are needed for patients who do not have the energy or time to travel to a specialized health care institute [10,11], and so we have developed two different Web-based interventions aimed at reducing CCRF: (1) a physiotherapist-guided Ambulant Activity Feedback (AAF) [12], and (2) a psychologist-guided Web-based Mindfulness-Based Cognitive Therapy (eMBCT) [13]. Wolvers et al [14] detail an elaboration on the theoretical models underlying these interventions.

The overall aim of the project *More fit after cancer* (in Dutch *Fitter na kanker*, hereafter referred to as the FNK trial) was to study the effectiveness, effect predictors, and mediators of AAF and eMBCT in comparison to a minimal active control condition that consisted of emails with psycho-education about CCRF [14]. This paper reports on the clinical effectiveness of AAF and eMBCT in reducing fatigue severity and improving mental health in severely fatigued cancer survivors, compared to psycho-education. We hypothesized that fatigue severity would be reduced more, and mental health would be increased more in AAF and eMBCT compared to PE, between baseline and six-month follow-up.

Methods

Patients and Setting

In our previous article [14] we provided a detailed description of the methods of this trial. Severely fatigued cancer survivors were recruited via online and offline channels (via patient organizations, walk-in consultation services, social media, newspapers, and health care professionals; see Multimedia Appendix 1), inviting them to follow a Web-based intervention in a research setting for their fatigue, and invited them to register on an open-access website [15,16]. To recruit a group of participants with open expectations, we did not specify the exact content of the interventions in the advertisements. See Multimedia Appendix 2 (advertisement) and Multimedia Appendix 3 (informed consent) for the information given during recruitment.

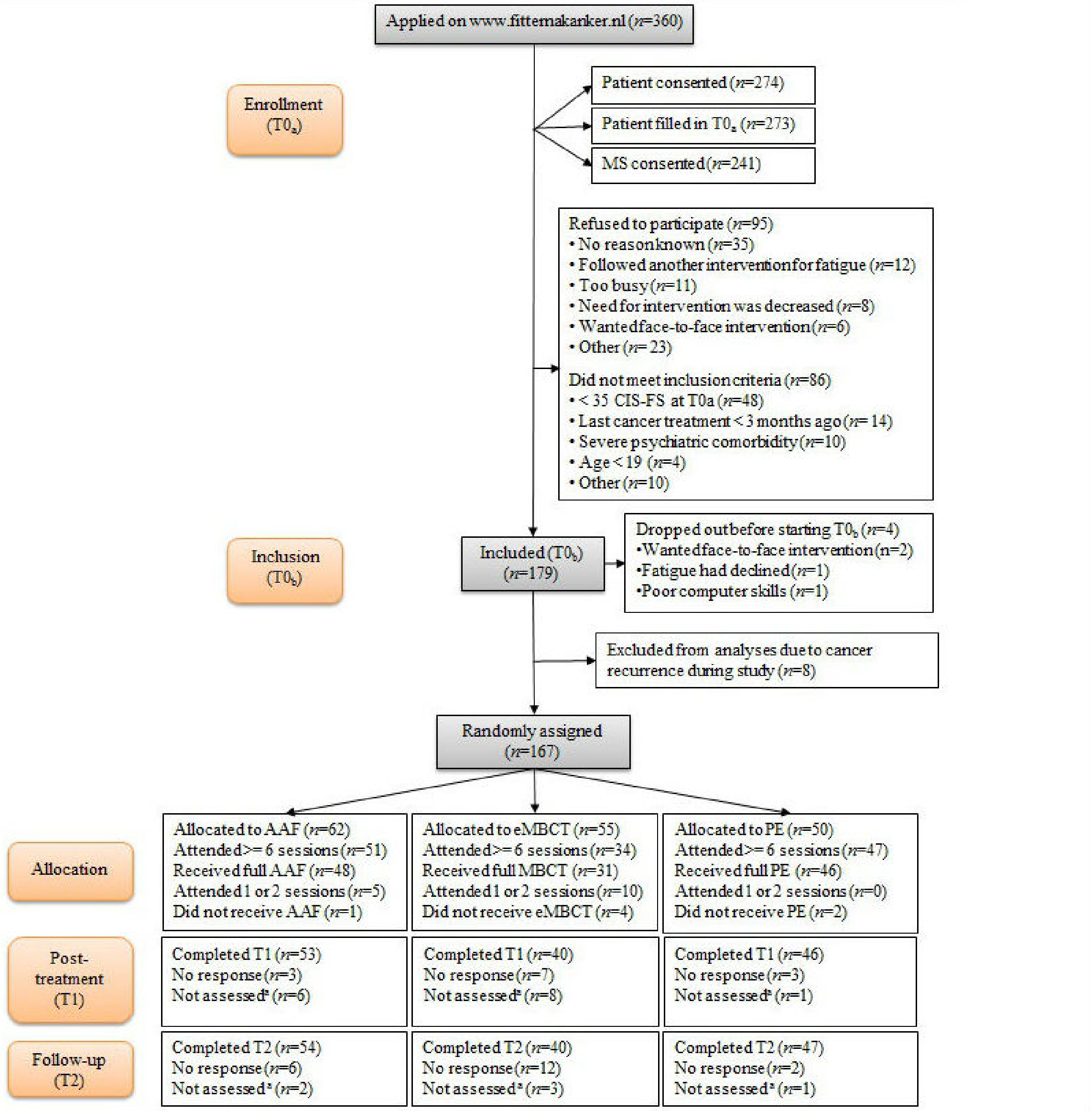
Participants (all cancer types included) had finished curative-intent cancer treatment (with the exception of hormonal treatment, as this is often low intensity and may last up to five years) at least three months previously, and had been suffering from severe fatigue ever since (≥35 on the Checklist Individual Strength - Fatigue Severity [CIS-FS] subscale) [7,17]. Participants had no current or former severe psychiatric morbidity (eg, suicidal ideation, psychosis, or schizophrenia), were >19 years old, and were at least 18 years old at disease onset. For external validity purpose, nontreatable comorbid somatic diseases that were possible causes for fatigue (eg, rheumatoid arthritis, diabetes, myocardial damage) were not excluded, and were registered during the study. We chose not to statistically control for these comorbidities, but to check whether comorbidities were equally divided between the conditions (see Multimedia Appendix 4). We contacted each participant’s medical doctor (general practitioner, oncologist, or other medical specialist) after participant consent was obtained, to check for psychiatric morbidity and whether curative intent cancer treatment had finished at least three months previously.

We aimed to include 330 participants to be able to study working mechanisms, in addition to the effectiveness of the interventions. Despite persistent recruitment efforts and an extension of the recruitment period by three months, this number proved infeasible as we had to exclude more patients than anticipated (see Figure 1). However, we continued recruiting until we had enough participants to study the effectiveness with enough power; namely 55 participants per condition [14].

Trial Design

Participants were randomized to one of three conditions by a computerized tool [14], which included two experimental conditions: (1) AAF and (2) eMBCT; or (3) an active control condition in which participants received psycho-education. The intervention period was nine weeks for all three conditions. The primary outcome was self-perceived fatigue severity measured after the eligibility check ($T0_b$; baseline), three times during the intervention (M3, M6, M9), two weeks after completion of the interventions (T1), and six months after baseline (T2; primary outcome). The secondary outcome was mental health, measured at recruitment ($T0_a$), T1, and T2. All outcomes were self-reported and Web-assessed. Participants were reminded to complete the measurements twice, and at T2 participants were also reminded by telephone. Dropouts from the treatment groups were interviewed by telephone to inquire about their reasons for dropping out.

Figure 1. Flowchart of Fitter na kanker trial. The last five participants were not included in the analysis, as they were still in the trial at time of analysis. AAF: Ambulant Activity Feedback; CIS-FS: Checklist Individual Strength - Fatigue Severity subscale; eMBCT: Web-based Mindfulness-Based Cognitive Therapy; MS: medical specialist; PE: psycho-education.



Randomization, Masking, and Blinding

We have described the randomization process in detail in our trial article [14]. Randomization was carried out blind via a script embedded in the researchers' Web portal and used the random function of *php [rand(1,3)]* [18]. The researchers could neither influence nor predict the outcome of the randomization process. Due to an error in the website's randomization algorithm, allocation was temporarily dependent on the number of participants who were allocated at the same time between January 14, 2014 and July 15, 2014 (see Wolvers et al [14] for more information). This issue resulted in unequal sample sizes for the conditions. We argue that the participants were randomly assigned, as it was not the researchers' decision regarding how many participants were allocated at the same time. Neither researchers, participants, nor therapists were blind to treatment, as the medical ethical committee insisted that we announced the minimal intervention as our control group. An independent statistician (RvdS) was blind to allocation while checking all analyses. We did not specify the exact content of the interventions in the advertisements, in an effort to limit influencing expectations before the trial began.

Interventions

See Multimedia Appendix 5 for additional screen shots of all interventions studied. The eMBCT is a Web-based psychologist-guided intervention, which follows the MBCT protocol specifically designed for CCRF [19,20]. eMBCT aims to change the patient's behavioral and cognitive reactions to cancer-related stressors, including fatigue itself [5,19,21]. Following the original eMBCT protocol, participants who were randomized into eMBCT were diagnosed according to the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR) [22]. The intervention's time-investment involves reading the weekly information, doing mindfulness exercises while listening to the MP3 files, filling out logs with their experiences, reading the weekly feedback of the therapist, and replying to this feedback by email weekly.

The time investment for participating the eMBCT was estimated to be four hours per week (on average) for nine weeks. Participants could not continue with a following session before they had registered their experience with a homework assignment from the previous week. Bruggeman-Everts et al [13] have published a pilot study on the effectiveness of eMBCT and a detailed description of the eMBCT protocol, setting, and development.

The AAF consists of a home-based physiotherapist-guided protocol in which participants use an accelerometer to gain insight into their physical activity patterns, and increase or balance their daily activities in ways that improve their energy levels [5,23]. The time investment for the AAF intervention is estimated to be three hours per week (on average) for nine weeks. The time-investment involves taking notice of the Personal Digital Assistant messages, responding to these messages by changing physical activity, reading the weekly feedback from the physiotherapist, reporting experiences, and replying to the feedback by email. Participants could not continue with a following session before they had registered their experience with a homework assignment from the previous week. See Wolvers and Vollenbroek-Hutten [12] for a detailed description of the development of AAF.

Patients in the psycho-education condition received psycho-educational emails describing possible causes of fatigue, sleep hygiene, balancing energy during the day, and how to cope with worrying thoughts. We estimated that patients dedicated ten minutes per week to the nine-week minimal control intervention. The intervention involves reading the psycho-education information in no-reply emails. Whether participants had indeed read the psycho-education information was not checked, as asking participants was considered unreliable. This psycho-education information was derived from the eMBCT protocol for CCRF [13,19], and was included in the current eMBCT and AAF protocols, so participants in all three conditions were given the same PE.

Outcomes

The primary outcome of fatigue severity was measured using the CIS-FS [7,17], which consists of eight items that are rated on a seven-point Likert scale (range 8-56, Cronbach alpha=0.84). The CIS closely resembles the Multidimensional Fatigue Inventory [24,25]. The secondary outcome was the concept of *mental health* measured using both negatively and positively framed questionnaires [26]: the Positive and Negative Affect Schedule [27,28] was used to measure Positive Affect (PA; range 10-50, Cronbach alpha = 0.90) and Negative Affect (NA; range 10-50, Cronbach alpha = 0.89); and the Hospital Anxiety and Depression Scale (HADS; range 0-42, Cronbach alpha=0.88) [29-31] was used to measure distress.

Baseline characteristics were assessed, including demographics, medical history, and help received in the past. Participants could only continue with the next week's exercises after finishing the previous, so adherence was calculated based on the week number that participants had reached. The proportion of nonadherence was based on the number of participants who dropped out of the intervention before completing 6 weeks of the protocol (ie, intended usage) [14].

Data Analyses

First, analysis of variance (ANOVA) and Chi-square tests were performed to: (1) check for differences in baseline characteristics between all conditions; and (2) check whether baseline variables correlated with missing data patterns, to check if data was randomly missing. The significance level was set at $P<.01$ to correct for multiple testing; this resulted in no auxiliary variables or covariates being included in the model. Outcome measures were checked for normality and outliers, and resulted in no modifications being made. These analyses were performed in SPSS Version 23 for Windows (SPSS Inc, Chicago, IL).

Second, Longitudinal Growth Modeling (LGM) was performed to test which model best fit the longitudinal data of the outcome measures (CIS-FS, HADS, PA, and NA) using Mplus version 7.31 [32]: (1) a linear versus linear and quadratic slope; (2) one slope versus a piece-wise model with two slopes (piece-wise only for CIS-FS); and (3) with versus without individual time scores (the exact time points when a participant filled in the assessment). See Multimedia Appendix 6 for the procedure of selecting the best fitting model for CIS-FS. Next, we studied the effectiveness of AAF and eMBCT compared to PE by testing whether the trajectories of the best fitting model significantly differed between the three conditions by applying Wald testing (for linear slopes) or Chi-square difference testing (for linear and quadratic slopes). This was done on an intention-to-treat basis (thus including adherent and nonadherent participants) and we checked whether the results for CIS-FS changed when only including participants who were adherent to treatment.

Third, to measure the clinical importance in addition to statistical significance, the proportion of participants who were clinically relevantly changed on CIS-FS was calculated for each condition, using the reliable change index (RCI) [33,34]. See Multimedia Appendix 7 for the calculations of the proportion of clinically relevantly changed participants. We used a clinical cut-off score of a normative group (CIS-FS< 28.0 [35]) which consisted of nonfatigued breast cancer survivors [35]. In our trial design paper [14], we suggested the use of a normative group of women without a history of breast cancer [35], however we think it is better to use a normative group that indeed had a history of cancer, as it is such a disruptive illness, and comparing the group to healthy subjects would be less informative. The proportions of participants who had *recovered* (passed both the cut-off score of the normative group and the RCI criteria), *improved* (passed the RCI criteria in the direction of fatigue reduction), were *unchanged* (did not pass the RCI criteria), or *deteriorated* (passed the RCI in the direction of fatigue increase) were all calculated.

Finally, notes and quotations from the telephone interviews with nonadherent participants were analyzed by close reading, followed by clustering of emerging themes concerning reasons for dropping out. ANOVA and Chi-square tests were performed to identify differences between adherent and nonadherent participants. The proportion of nonadherent participants was calculated.

Ethical Approval

All participants gave written informed consent prior to their inclusion in the study. This trial was approved by the Twente Medical Ethical Committee (Enschede, The Netherlands), number P12-26, and was registered in The Netherlands National Trial Register under number NTR3483 [36].

Results

Patients

Between March 2013 and June 2015, 360 people applied on the website to participate (see Figure 1 for flowchart). See Multimedia Appendix 1 for details about recruitment over the course of time. Applicants for the FNK-trial had heard about the project via family or friends (16.1%, 58/360), via patient societies (12.5%, 45/360), through a search on the Internet (11.7%, 42/360), via health professionals (5.8%, 21/360), or otherwise (unknown; 53.8%, 194/360).

We excluded 23.8% (86/360) of the applicants (mean age=56.3 years, standard deviation [SD]=13.3; 59%, 51/86 women) for the reasons given in Figure 1, and another 26.4% (95/360) declined to participate (mean age=58.0 years, SD=12.7; 67%, 64/95 women) before the eligibility criteria were checked. Eventually, 179 participants were included (see Multimedia Appendix 4 for baseline characteristics); of these, four participants dropped out before filling in $T0_b$(mean age=60.5 years, SD=7.7; 75%, 3/4 women), and eight participants were excluded from analyses due to cancer recurrence during the study (mean age=59.8 years, SD=6.5; 50%, 4/8 women), leaving 167 participants for analyses.

Participants were randomized to one of the three conditions: (1) AAF (n=62), (2) eMBCT (n=55), or (3) psycho-education (n=50). All participants in the eMBCT group met the DSM-IV-TR criteria for undifferentiated somatoform disorder, of whom 4 of 55 (7%) were additionally diagnosed with a sleeping disorder, 7 (13%) experienced work-related psychosocial problems, and 6 (11%) suffered from problems in their peer-support group.

Effectiveness

Model selection for CIS-FS showed that a model with both linear and quadratic slopes, individual times cores, freely estimated mean and slope variances, and residual variances fixed to be equal between conditions best fit the data. Figure 2 shows the sample means of CIS-FS between $T0_b$ and T2 per condition.

Chi-square difference testing (see Table 1), with linear and quadratic slopes fixed to be equal between conditions, showed that the CIS-FS trajectories differed between all three conditions ($\chi^2(4)=27.63$, $P<.001$). More specifically, the trajectories of AAF and psycho-education differed ($\chi^2(2)=28.28$, $P<.001$), and eMBCT and psycho-education differed ($\chi^2(2)=10.89$, $P=.004$), while the trajectories of AAF and eMBCT were equal ($\chi^2(2)=2.19$, $P=.34$). When only including adherent participants (n=132), the results were similar: the slopes of AAF and eMBCT were equal ($\chi^2(2)=0.991$, $P=.61$), while the slopes of psycho-education and AAF differed ($\chi^2(2)=28.109$, $P<.001$), and psycho-education and eMBCT differed ($\chi^2(2)=9.735$, $P=.008$). The slope estimates indicated that CIS-FS decreased significantly more in the AAF and eMBCT conditions compared to the psycho-education condition.

The model fits for HADS, PA, and NA were best for linear models with individual time scores and slope variances fixed at zero. As shown in Table 2, the slopes in all three conditions were significantly different from zero: HADS and NA decreased, and PA increased. Table 3 presents the results of Wald testing, and shows that there were no significant differences in slopes between the HADS, PA, and NA between conditions.

Clinically Relevant Change

The proportion of *recovered* participants for AAF was 21% (13/62), for eMBCT was 9% (5/55), and for psycho-education was 2% (1/50). Of the adherent participants, 26% (13/51) recovered in the AAF condition, 6% (2/34) recovered in the eMBCT condition, and 2% (1/47) recovered in the psycho-education condition. Figure 3 shows the proportion of *improved*, *unchanged*, and *deteriorated* participants per condition. In the AAF condition 66% (41/62) improved, in the eMBCT condition 49% (27/55) improved, and in the psycho-education condition 12% (6/50) improved.

Treatment Dropout

Nonadherence, the proportion of participants who dropped out the intervention before completing 6 weeks of the protocol, was 18% (11/62) in the AAF condition, 38% (21/55) in the eMBCT condition, and 6% (3/50) in the psycho-education condition. No differences in baseline characteristics were found between adherent and nonadherent participants.

Reasons for dropping out of AAF were mainly technical problems and poor usability of the accelerometer. Nonadherence of eMBCT was mainly due to the high intensity of the program, the exercises were considered too woolly, poor usability of the eMBCT portal, and difficulty in communicating in writing with the therapist. In both interventions, nonadherent participants said they stopped using the intervention due to a lack of confidence that the intervention would help them reduce fatigue. Other reasons were that fatigue had reduced considerably and treatment was no longer desired, or that participants preferred face-to-face contact instead.

Table 1. Results of the Chi-square testing of fatigue severity change (CIS-FS) between groups.

Hypothesis test	Results of Chi-square test
AAF = eMBCT = psycho-education	$\chi^2(4)=27.63$, *P*<.001
AAF = psycho-education	$\chi^2(2)=28.28$, *P*<.001
eMBCT = psycho-education	$\chi^2(2)=10.89$, *P*=.004
AAF = eMBCT	$\chi^2(2)=2.19$, *P*=.34

Table 2. Model results of all outcome measurements. The mean intercepts and mean slope factors of all outcome measures with standard errors (in brackets) are presented.

Outcome	Condition	Intercept at $T0_b$(I)	Linear slope factor (S)	Two-tailed *P* value of linear slope (*P*)	Quadratic slope factor (Q)	Two-tailed *P*- value of quadratic slope (*P*)
CIS-FS	AAF	42.838 (0.873)	-1.072 (0.162)	<.001	0.026 (0.005)	*P*<.001
	eMBCT	42.752 (1.020)	-0.876 (0.178)	<.001	0.022 (0.006)	*P*<.001
	Psycho-education	39.893 (1.243)	-0.208 (0.170)	.22	0.006 (0.006)	*P*=.31
HADS	AAF	13.237 (0.921)	-0.076 (0.017)	<.001	*N/A*	*N/A*
	eMBCT	13.903 (0.771)	-0.110 (0.022)	<.001	*N/A*	*N/A*
	Psycho-education	14.579 (1.012)	-0.083 (0.024)	<.001	*N/A*	*N/A*
PA	AAF	31.762 (0.939)	0.101 (0.022)	<.001	*N/A*	*N/A*
	eMBCT	28.995 (0.932)	0.156 (0.026)	<.001	*N/A*	*N/A*
	Psycho-education	29.422 (1.091)	0.128 (0.027)	<.001	*N/A*	*N/A*
NA	AAF	20.330 (0.931)	-0.068 (0.023)	.003	*N/A*	*N/A*
	eMBCT	20.718 (0.914)	-0.071 (0.032)	.03	*N/A*	*N/A*
	Psycho-education	20.805 (1.215)	-0.082 (0.029)	.004	*N/A*	*N/A*

Table 3. Results of Wald testing for differences between conditions (HADS, PA, and NA). All Wald tests were nonsignificant, indicating that there was no significant difference between the slopes of the conditions.

	Wald test	Result
HADS	AAF = psycho-education	0.067(1), *P*=.80
	eMBCT = psycho-education	0.665(1), *P*=.41
	AAF = eMBCT	1.491(1), *P*=.22
PA	AAF = psycho-education	0.599(1), *P*=.44
	eMBCT = psycho-education	0.573(1), *P*=.45
	AAF = eMBCT	2.640(1), *P*=.10
NA	AAF = psycho-education	0.148(1), *P*=.70
	eMBCT = psycho-education	0.065(1), *P*=.80
	AAF = eMBCT	0.006(1), *P*=.94

Figure 2. Sample means of fatigue severity (CIS-FS) for all three conditions (n=167). On the x-axis, the mean of timescores between T0b and M3, M6, M9, T1 and T2 are shown. Please note that the model included individual time scores. The average timescores (denoted in weeks, with standard deviations between brackets) between T0b and M3, M6, M9, T1, and T2 were 7.6 (2.4), 11.0 (2.8), 14.0 (2.6), 16.7 (3.2), and 28.1 (1.9), respectively. See Multimedia Appendix 6 for the average distribution of individual timescores between T0b and T2.

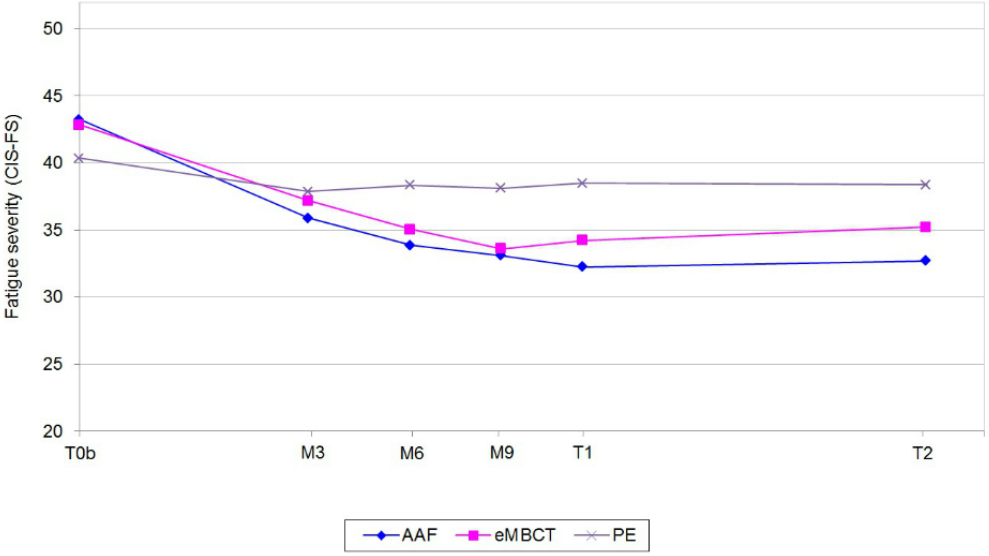
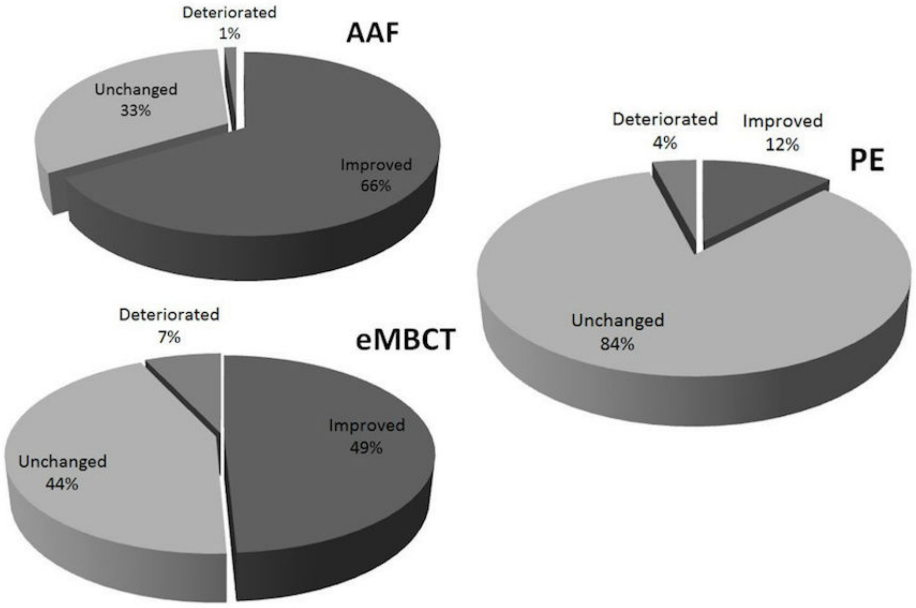


Figure 3. Proportions of clinically relevant changes (improved, unchanged, deteriorated) for each condition (intention-to-treat).



Discussion

Main Results

This is the first study to report on effectiveness of two guided Web-based interventions for CCRF. Using latent growth curve modeling, we found that AAF and eMBCT were significantly more effective in reducing fatigue severity than psycho-education. The proportions of participants that showed clinically relevant improvement were 66% (41/62) in the AAF condition, 49% (27/55) in the eMBCT condition, and 12% (6/50) in the psycho-education condition. Mental health improved in all three conditions. Treatment dropout was 18% (11/62) in the AAF condition and 38% (21/55) in the eMBCT condition. Reasons for dropping out of AAF were technical problems with the accelerometer, and eMBCT was considered to be too intensive. The AAF dropout rate is comparable to other online interventions [37], and in a previous pilot study in clinical practice we also found a dropout rate of 38.1% in eMBCT [13]. Taking these dropout rates into account, we can conclude that both AAF and eMBCT are effective interventions for reducing fatigue severity.

Strengths and Limitations

Our study design has several strengths. First, in contrast to multivariate ANOVA, LGM allows the study of individual longitudinal development instead of average group effects. Furthermore, LGM does not require complete data as it deals with missing data elegantly [38-40], and individual times between assessments can be included in the analysis.

Second, we used an active control condition that consisted of psycho-education. As psycho-education has been found to be effective for cancer-related fatigue [41], comparing AAF and eMBCT to PE is a strict way of evaluating these interventions. Interestingly, fatigue severity did not significantly reduce in the psycho-education condition. We speculate that this lack of effect may be due to the presentation of psycho-education, namely that it was the minimal control intervention. Participants were perhaps disappointed not being randomized to one of the guided interventions. However, mental health did significantly increase in psycho-education.

Third, as we wanted to study the intervention effect alone, we chose $T0_b$ (after the eligibility check) as our baseline measurement instead of $T0_a$ (at recruitment). As fatigue significantly reduced between $T0_a$ and $T0_b$(n=174, t=6.293, df=173, P<.001, r=.548), which was before any experimental intervention took place, choosing $T0_b$ as baseline assessment prevented overestimation of the intervention effect.

Fourth, to make these results relevant for health care practice, we 1) chose not to exclude patients suffering from comorbidities that may also explain fatigue, 2) we included all cancer types and 3) included patients who were using hormone therapy or antidepressants during the study. We did not control for these contributing factors, except from the check that they were equally divided between the three conditions. In this way, the sample better represents the population for which these interventions were developed, and the results of effectiveness are better representative for health care practice. Although cancer type has not been found to be related to the persistence of fatigue [2], comorbidities (eg, thyroid dysfunction, cardiovascular diseases, rheumatism) and the use of hormone therapy or antidepressants are presumably influencing the level of fatigue [42,43]. Therefore, the effectiveness we found would probably be higher if we had chosen to study a population without comorbidities. In contrast, other researchers may choose exclusion criteria to limit confounding factors with the intervention effect to study the proof of concept. Although this decision is valid for research purposes, it consequently extends the gap between research findings and health care practice [44]. Therefore, we and others (eg, Treweek and Zwarenstein [45]) encourage researchers to study interventions that are intended to be applied in health care practice using a pragmatic randomized controlled trial (RCT) study design, with no strict exclusion criteria that extend the gap between research and health care practice.

In previous research it was found that female breast cancer patients with high education are well represented in the population that seeks support in mental health institutes specializing in psycho-oncology [46]. We therefore think the current sample, which has a large proportion of female breast cancer patients and a high level of education, is representative of this population, but less representative of the cancer population in general.

In line with the arguments above, clinicians and researchers should be cautious when comparing the effectivity results reported by different intervention studies (eg, for comparison Gielissen et al [7] and Abrahams et al [44]), because assessment points, normative groups, data analyses methods, and inclusion and exclusion criteria vary.

A limitation of this study was the unequal sample size of the conditions. As was previously reported in our trial design paper [14], the unequal sample size was partially caused by an error in the website’s randomization algorithm.

We noted several disadvantages of the RCT study design when evaluating these Web-based interventions. One limitation is that in an RCT design, the intervention is “frozen” in time, while technical applications evolve rapidly, resulting in the intervention being outdated when the effectiveness has been investigated. For example, the eMBCT webpage (developed in 2010) functioned poorly on a tablet, which led to treatment dropout of participants who used a tablet instead of a computer. Smaller and more elegant accelerometers have also come to the market, which affected the credibility of the devices that were used in this study. Another limitation of our study design is that we had to exclude participants based on scoring too low on CIS-FS at recruitment, despite the fact that they said they indeed suffered from extreme fatigue.

Another limitation was that the norm group that was used to calculate the percentage of clinically relevant improved participants was younger than our sample (norm group: mean age=45.9 years; SD=6.3 [35] versus our sample: mean age=55.1 years; SD=10.1) and only consisted of breast cancer patients. Ideally, we would have used a nonseverely fatigued group of cancer survivors, of approximately the same age as our sample, but this was not available in existing literature.

In conclusion, both the AAF and eMBCT are effective for managing fatigue severity compared to receiving psycho-educational emails. This is the first study that reported on the effectiveness of Web-based interventions for CCRF compared to an active control condition. The analytical methods of this study were new, and thereby added to the scientific knowledge on evaluating the clinical effectiveness of Web-based interventions. We are currently working on the analyses of a one-year follow-up [47]. To improve the interventions, we are also studying working mechanisms [48,49], and which baseline characteristics predict treatment outcomes. Additionally, to better attune interventions to the patients’ needs and reduce dropout, we performed qualitative analyses of semi-structured interviews with participants about their experiences with the interventions.

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Authors' Contributions

FBE drafted of manuscript, and acquired, analyzed, and interpreted the data. FBE and MW acquired the data. MW and RvdS analyzed and interpreted the data. ML and MV designed the trial. All authors critically revised the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Recruitment over the course of time. The cumulative number of persons who applied to participate in the study and the number of included participants are shown over the course of recruitment time. The figure also shows when major recruitment actions were performed, such as when the improved Web page was launched.

[PDF File (Adobe PDF File), 111KB - jmir_v19i10e336_app1.pdf]

Multimedia Appendix 2

Recruitment advertisement.

[PDF File (Adobe PDF File), 35KB - jmir_v19i10e336_app2.pdf]

Multimedia Appendix 3

Informed consent.

[PDF File (Adobe PDF File), 37KB - jmir_v19i10e336_app3.pdf]

Multimedia Appendix 4

Baseline characteristics of included participants (n=167).

[PDF File (Adobe PDF File), 59KB - jmir_v19i10e336_app4.pdf]

Multimedia Appendix 5

Screenshots of the interventions.

[PDF File (Adobe PDF File), 657KB - jmir_v19i10e336_app5.pdf]

Multimedia Appendix 6

Selection procedure and results of best model fit for fatigue severity (CIS-FS).

[PDF File (Adobe PDF File), 144KB - jmir_v19i10e336_app6.pdf]

Multimedia Appendix 7

Calculations of proportion reliably changed participants.

[PDF File (Adobe PDF File), 37KB - jmir_v19i10e336_app7.pdf]

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Abbreviations

AAF: Ambulant Activity Feedback
ANOVA: analysis of variance

CCRF: chronic cancer-related fatigue
CIS-FS: Checklist Individual Strength - Fatigue Severity subscale
CRF: cancer-related fatigue
DSM-IV-TR: Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision
eMBCT: Web-based Mindfulness-Based Cognitive Therapy
FNK: Fitter na kanker
HADS: Hospital Anxiety and Depression Scale
LGM: Longitudinal Growth Modeling
NA: Negative Affect
PA: Positive Affect
RCI: reliable change index
RCT: randomized controlled trial
SD: standard deviation

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Original Paper

Experiences From a Web- and App-Based Workplace Health Promotion Intervention Among Employees in the Social and Health Care Sector Based on Use-Data and Qualitative Interviews

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Abstract

Background: An increasing number of Web- and app-based tools for health promotion are being developed at the moment. The ambition is generally to reach out to a larger part of the population and to help users improve their lifestyle and develop healthier habits, and thereby improve their health status. However, the positive effects are generally modest. To understand why the effects are modest, further investigation into the participants' experiences and the social aspects of using Web- and app-based health promotion tools is needed.

Objective: The objectives of this study were to investigate the motivation behind taking part in and using a Web- and app-based health promotion tool (SoSu-life) at the workplace and to explore the participants' experiences with using the tool.

Methods: Qualitative interviews with 26 participants who participated in a 38-week randomized controlled trial of a workplace Web- and app-based tool for health promotion were conducted. Data were supplemented with tracking the frequency of use. The basic features of the tool investigated in the trial were self-reporting of diet and exercise, personalized feedback, suggestions for activities and programs, practical tips and tricks, and a series of social features designed to support and build interactions among the participants at the workplace.

Results: The respondents reported typically one of the two reasons for signing up to participate in the study: either a personal wish to attain some health benefits or the more social reason that participants did not want to miss out on the social interaction with colleagues. Peer pressure from colleagues had made some participants to sign up even though they did not believe they had an unhealthy behavior. Of the total of 355 participants in the intervention group, 203 (57.2%) left the intervention before it ended. Of the remaining participants, most did not use the tool after the competition at the end of the initial 16-week period. The actual number of active users of the tool throughout the whole intervention period was low; however, the participants reported that lifestyle habits became a topic of conversation.

Conclusions: A tool that addresses group interactions at workplaces appears to initiate peer pressure, which helped recruitment for participation. However, active participation was low. A social change was indicated, allowing for more interaction among colleagues around healthy lifestyle issues. Future and more long-term studies are needed to determine whether such social changes could lead to sustained improvements of health.

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KEYWORDS

eHealth; health promotion; workplace; smartphone; weight reduction programs; Internet; qualitative research

Introduction

Background

The number of Web- and app-based tools for potentially inexpensive health promotion that are being developed at the moment is increasing. Mobile phone apps and websites are being designed to help users keep track of their behavior, develop healthier habits, and improve their lifestyle [1]. At the same time, the workplace is gradually becoming more used in health promotion because many people spend a lot of their waking hours at work, and the World Health Organization has declared the workplace a prioritized arena for health promotion [2]. Lifestyle interventions are needed to combat the increasing prevalence of obesity and diseases related to unhealthy lifestyle. In Denmark, this is especially the case in people with low education attainment.

Social and health care workers in Denmark have comparatively less education and lower health status than the average population [3]. They generally smoke more and are more overweight [4]. Furthermore, they have a higher level of absence from work and a higher risk of leaving the workforce early because of sickness.

Scientific research on apps and websites for weight loss is still evolving, and the results from these studies show that the effects are generally modest, of a limited duration, or inconclusive. In addition, two recent systematic reviews with meta-analysis on the use of mobile devices or apps for weight loss found that the use of these tools induced weight loss [5] but did not have an effect on physical activity [6], and another recent study found promising results using a Web-based app for promoting healthy lifestyles [7]. Studies evaluating Web-based weight loss programs [8,9] and the use of text messaging (short message service, SMS) for weight loss [10] found positive results. Furthermore, in a review, eHealth tools for physical activity and dietary behavioral change were found to have the potential for improving these issues [11]. All these features are included in the SoSu-life tool (see Methods section).

A systematic review on workplace health promotion for healthy eating and physical activity found the evidence for positive effects of the interventions to be limited to modest [12], and another review targeted to increase physical activity found that the interventions can be efficacious, but the overall results were inconclusive [13]. However, a recent meta-analysis found that workplace health promotion interventions resulted in improvements in self-perceived health, decreased absence due to illness, and increased productivity [14].

Workplace interventions in social and health care workers have been addressed in a few studies from Norway, with clinical data as well as subjective measures as outcomes. One study evaluated health promotion of physical exercise at the worksite in nursing homes and unexpectedly found an increase in sickness absence in both intervention and control groups during the study period [15]. Another study including physical activity found no improvements in health-related quality of life and no difference in sickness absence between the two groups [16]. Therefore, the results regarding the effect of workplace interventions in social and health care workers are indecisive.

Although the clinical effects of health interventions have been investigated, insight into *why* interventions work at a practical and social level is less frequently examined. There is very little information about the participants' subjective experiences, their use of the tools, and the social settings of the interventions in the available literature. Examining these parameters might give some insight into why the effects found in these intervention studies are generally modest [17]. In this paper, we explore practical and social experiences of using a Web- and app-based tool for health promotion.

In 2012, a Web- and app-based tool for health promotion at the workplace was developed (called the SoSu-life tool), targeting social and health care workers in Denmark to help them to make lifestyle changes. The health promotion tool included behavior change techniques (BCTs) at both the individual and the social level. The tool's main feature is the individual feedback system, which operates on the individual level in the BCT taxonomy [18,19]. The tool also entails social features such as team competition operating on a social level. All features were designed to encourage health-related changes for the individual participant. It was designed to work both at nursing homes, where colleagues work side by side, and at home care units, where colleagues work individually in elderly citizens' homes and only meet with workmates for lunch breaks or short daily meetings. In the SoSu-life study, the tool was evaluated in a 38-week randomized controlled trial. The results from this study were modest [20].

The Aim of This Study

In this study, we examine the participants' experiences with the tool both by analyzing use-data and by conducting interviews with the participants. We examine how the tool was used during the intervention period and which features were most popular in a simple descriptive manner. In the interviews, we wanted to investigate what kind of motivation the participants had for using the tool and which changes in lifestyle behavior occurred at the individual level as well as in the group interaction.

Methods

Setting: The SoSu-Life Intervention Study

In 2012, a 38-week cluster randomized controlled intervention study (NCT02438059) among 556 employees in the social welfare and health care sector (SoSu's) in Denmark was carried out (overview of the study presented in Figure 1). In total, 6 municipalities agreed to participate, and in each municipality, between 2 and 5 nursing homes or home care units signed up, covering a total of approximately 1203 potential study participants. A total of 12 units were randomized to the intervention group and 8 to the control group with no treatment. The intervention group went through an initial 16-week period with team competition, and a 22-week follow-up period without team competition. The control group had no activities, but both groups went through a health examination at weeks 0, 16, and 38. Both groups were aware of the overall study design and also that the aim of the intervention was to promote individual health of the participants.

Qualitative Data Collection

The qualitative data were collected using personal interviews (n=24) and focus group interviews (2 groups with 7 in each; n=14), among both active users of the SoSu-life tool and nonusers of the tool in the intervention group. Of the health care units in the intervention group, 4 out of 12 were represented in the qualitative data. The participants for the interviews were recruited by phone and selected according to their earned points, which can be seen as an expression of how much the user uses the tool; participants with both low and high number of points were selected for the personal interviews to ensure that both positive and negative experiences were collected. Participants with low, middle, and high number of points were recruited for the focus group interviews. The first round of interviews were conducted approximately 8 weeks after baseline health examination and the second round of interviews approximately 8 weeks after the health examination held after 16 weeks.

An interview guide was developed, making sure the interviews covered all aspects of the intervention. The participants were encouraged to talk freely about their experiences with participating in the project and using the tool. They were asked to describe in detail how they had been introduced to the project, their experience with the health examinations, how they used the tool, which features they found useful, and which features they were particularly critical of. They were prompted to reflect on the changes they had experienced individually and at the workplace during the intervention period.

The interviews were transcribed and coded according to the standard qualitative analysis procedure to themes related to motivation, and use of and experiences with the different features in the tool. In the second round of coding, special attention was paid to whether the participants' experiences were positive or negative and whether the motivation for joining the study was for individual reasons or for social reasons. Then the relevant arguments were considered and substantial quotes were chosen. Finally, the interpretation of the chosen data was done (Figure 2).

Use-Data Collection

In this paper, we further present a simple descriptive analysis of data about the participants' use of the tool. The user statistics were collected centrally from the distributor of the SoSu-life tool during the intervention period. In this analysis, data consist of the pledges among the participants, number of collected points, number of days diet and exercise were registered, and number of accepted weekly assignments and sent *colleague challenges* (all described in the following section). The user data were extracted from the database at the end of the intervention at week 38.

Description of the SoSu-Life Tool

The SoSu-life tool's basic features are self-reporting of diet and exercise, personalized feedback, suggestions for activities and programs, practical tips and tricks, and a series of social features, including weekly assignments and colleague challenges designed to support and build interactions at the workplace. The SoSu-life tool aims at mobilizing whole groups of colleagues not only to encourage each other in achieving personal goals but also to have all group members work on identical small weekly assignments. Points were assigned to all individual and group activities and were collected by both individuals and groups. Individual activities gave points not only to the individual but also to the group, as part of the group competition. In this way, each individual's use of the digital tool benefited the whole group.

Figure 1. Overview of the SoSu-life study.

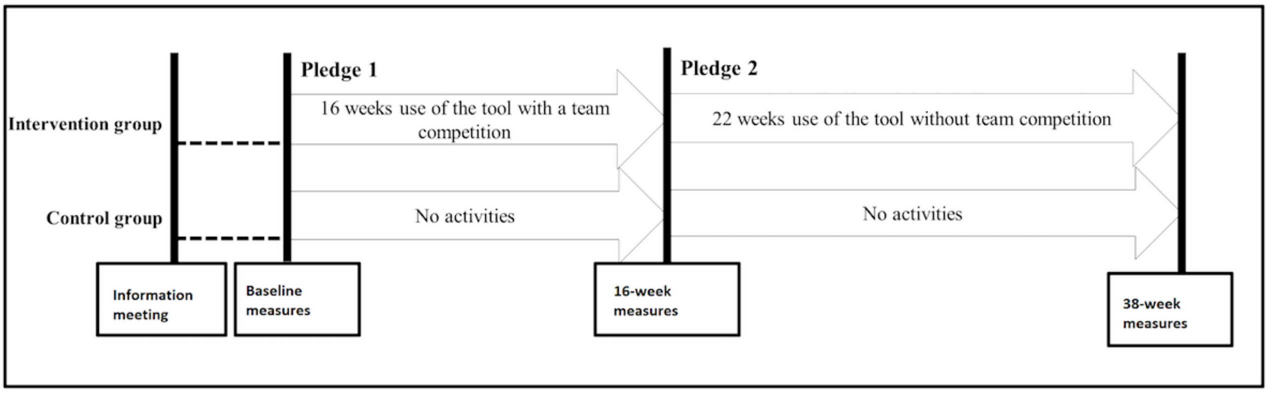
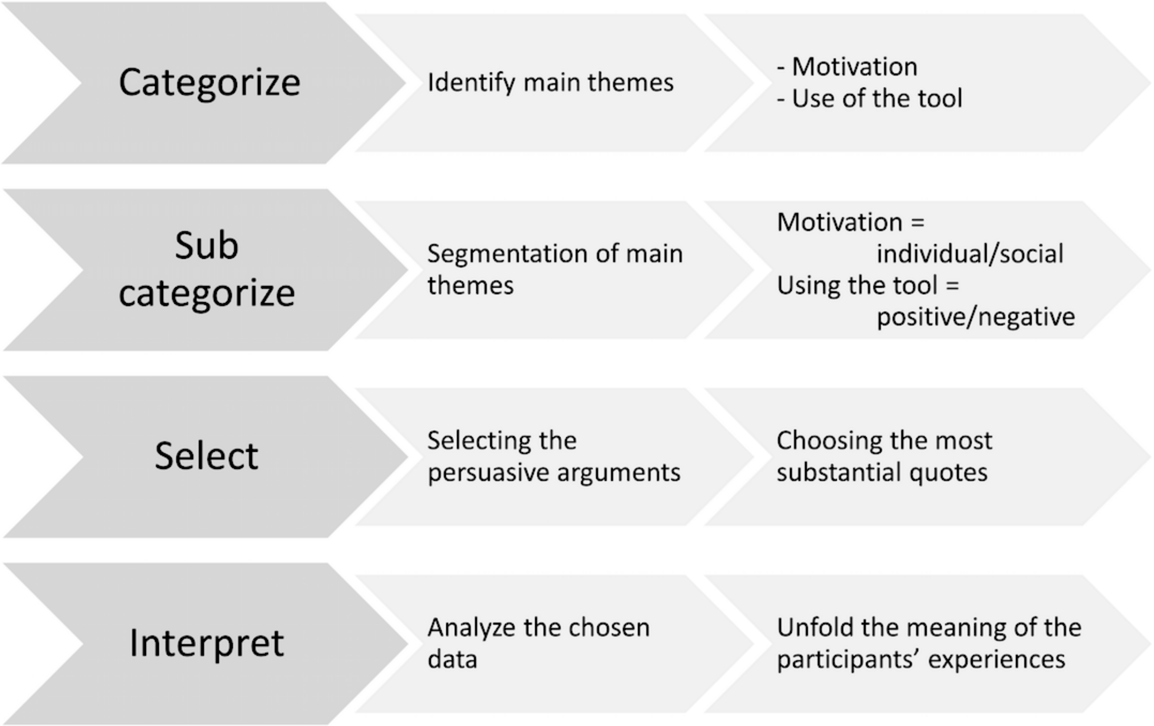


Figure 2. Steps in the analysis coding process.



Each participant was given a 10- to 15-min introduction to the website and the app by a member from the project team and was provided a pamphlet with information on content and functionalities of the tool. When the user signed up to use the tool during the introduction, she or he chose 1 pledge out of 7 to focus on the following: lose weight, eat healthier, improve physical fitness, improve physical strength, quit smoking, decrease the number of cigarettes, or maintain a healthy lifestyle. The program itself would indicate a recommended pledge based on individual information from the health examination. The choice of pledge influenced the features and feedback provided by the SoSu-life program, such as the frequency and content of emails and SMS texts sent to the participant. The messages contained information about specific health issues related to the pledge, general tips, and tricks on health and well-being.

The program had different functional tools to help the user succeed with the pledges. The self-reporting of diet and exercise functioned as a weight loss tool based on a unit system. All foods were assigned a number of units based on the portion size, calories, and macronutrient composition. Daily energy level was calculated based on the user's height and weight, and the number of units that should be consumed per day for losing weight was suggested. The user registered his or her food intake and daily exercise, and the program gave feedback on the energy balance of the day, a green code indicating a proper energy balance and a red code for excessive energy intake. Exercise was registered as bonus units so that the user could compare the number of units earned from food consumption with the number of units earned from exercise (the bonus units). The same system was used for those participants wishing to focus on exercise alone, and feedback was given in the form of the number of bonus units earned. Additionally, the website provided access to a number of suggested video-supported exercise programs to increase fitness level or improve strength. Smokers wishing to either change their smoking habits or quit smoking were advised to begin by registering their habitual use of cigarettes, the time the cigarettes were smoked, and the mood they were in when they were smoking the cigarettes.

The social features included shifting weekly assignments for the whole group of participating colleagues. Such weekly assignments could be *drink at least one liter of water every day all week* or *remember to say Good Morning to your colleagues every morning all week*. The tool also included *colleague challenges*, which were sent from colleague to colleague and were determined by the participants' individual pledge. Challenges might be *do not eat sugar for three days* or *bring some fruit for us to eat together tomorrow during the afternoon break*.

All features could be accessed from both the app and website (Figures 3 and 4)

The SoSu-life tool used a point system where all activities performed using the tool gave points to the individual user. The point system provided the highest reward for taking part in social activities. Performing the weekly challenges and sending and carrying out *colleague challenges* were rewarded with more points than registering diet or exercise or taking tests or quizzes. During the first 16 weeks, each of the participating nursing homes or home care units constituted a team of participants, and each of the user's individual points were added to the team's total points. A ticket was generated for every point collected by the team, and this was put in a lottery. Each month, the teams had a chance to win a prize by a simple lottery. The more points the team had, the bigger the chances were of winning. The prizes could be a shopping bag for each team member, a Zumba class for the team, or a visit from a bartender who served fruit smoothies during lunch hours. The team with the most points after 16 weeks also won a prize. Points were still collected in the second (22-week) intervention period, but no prizes were provided. All prizes were provided by the main sponsor of the project. The social features were designed to create a supporting atmosphere to help generate behavior change for the individual participant.

Figure 3. SoSu-life app main menu.

Figure 4. SoSu-life website frontpage.

Kære Nina.
Dit løfte er at fastholde sunde vaner
Dit hold: SoSu-liv Projektholdet

Din medalje status: Ingen medaljer
Se dine medaljer »

Ugens opgave
Denne uges opgave hedder:
Mmm massage
Gå til ugens opgave »

Mine point
I dag: 1 point
Min uge: 1 point
Min måned: 1 point
Total: 485 point

Mit holds point
Konkurrencen er slut.
Se stilling »

Ugens kollega-udfordringer
Nye: 0

Mine vaner (3)
Udløber denne uge: 0

Results

Registered Use of the SoSu-Life Tool

The use-data gave insight into the engagement with the SoSu-life tool and which features were most popular. Points are an indicator on how much engagement the participants had with the tool, as they earned points according to the activity they performed or the feature they used in the tool. A general overview of the average points earned per day (Figure 5) shows that it was more popular to use the tool during the first 16 weeks where the team competition took place. But the gradual decline of use began around 40 days, indicating an even earlier drop of interest in the tool.

At the baseline health examination, all participants earned between 1 and 40 points when they were introduced to the tool by the SoSu-life project workers. Figure 6 shows that approximately two-thirds of the participants only made a few extra points during the rest of the intervention period, meaning that they did not really use the tool actively after the introduction.

The Diet and Exercise Modules

Registering physical activity worked in the same way as registering diet, with feedback provided in the form of bonus units, depending on the time and type of exercise performed. It required less time and effort from the user to register one or two types of exercises compared with a full day's diet, which made it easier for the participants to use. Furthermore, the exercise feature appealed to both participants with pledges on losing weight and those choosing to improve physical fitness and strength.

It appears that the number of days registering exercise was slightly higher than for those registering diet (Figure 7). More participants tried the diet registration (about 58%) compared with those who tried the exercise module (about 44%) because the diet module was a part of the standard introduction to the tool. However, most of the participants stopped using both parts of the tool after a while.

The Social Features in the Tool

The SoSu-life tool had social features that were meant to improve social interactions and group dynamics at the workplace. These were most popular during the first 16 weeks of the intervention period. These social features seemed to be used slightly more (Figure 8) than diet and activity registration (Figure 7).

Figure 5. Average points earned per day.

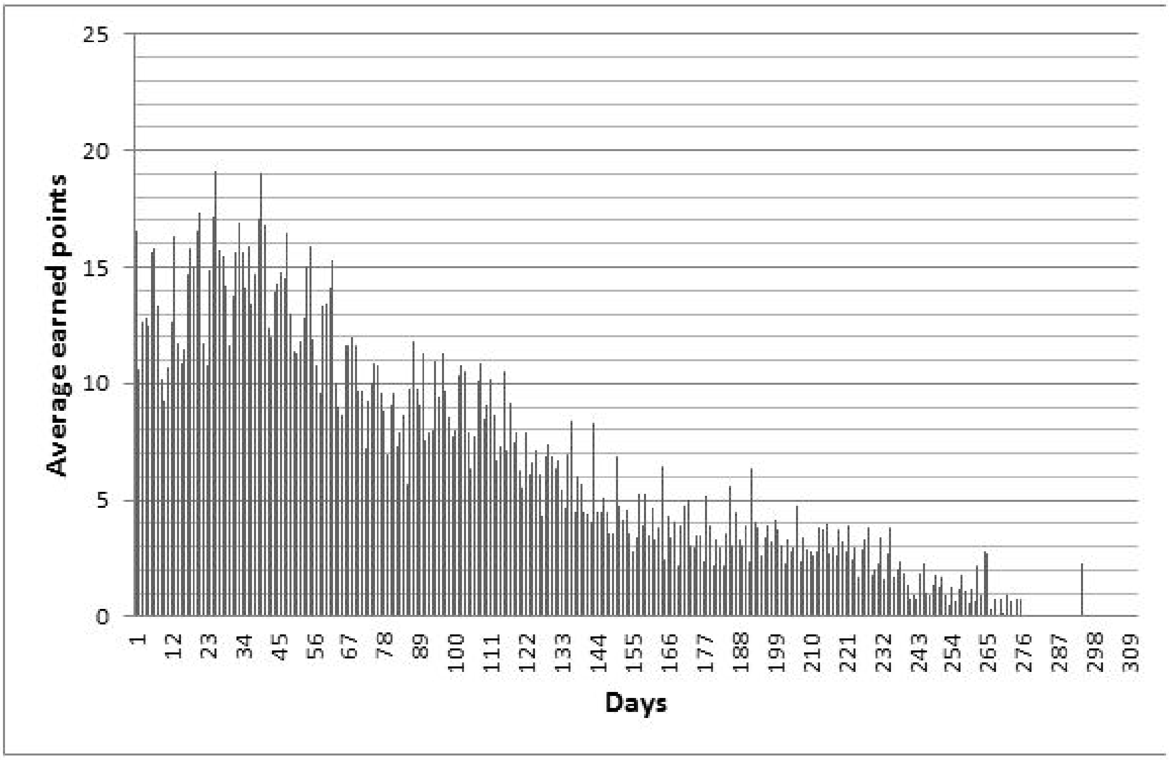


Figure 6. Distribution of total amount of points earned during the 38-week intervention period (n=152).

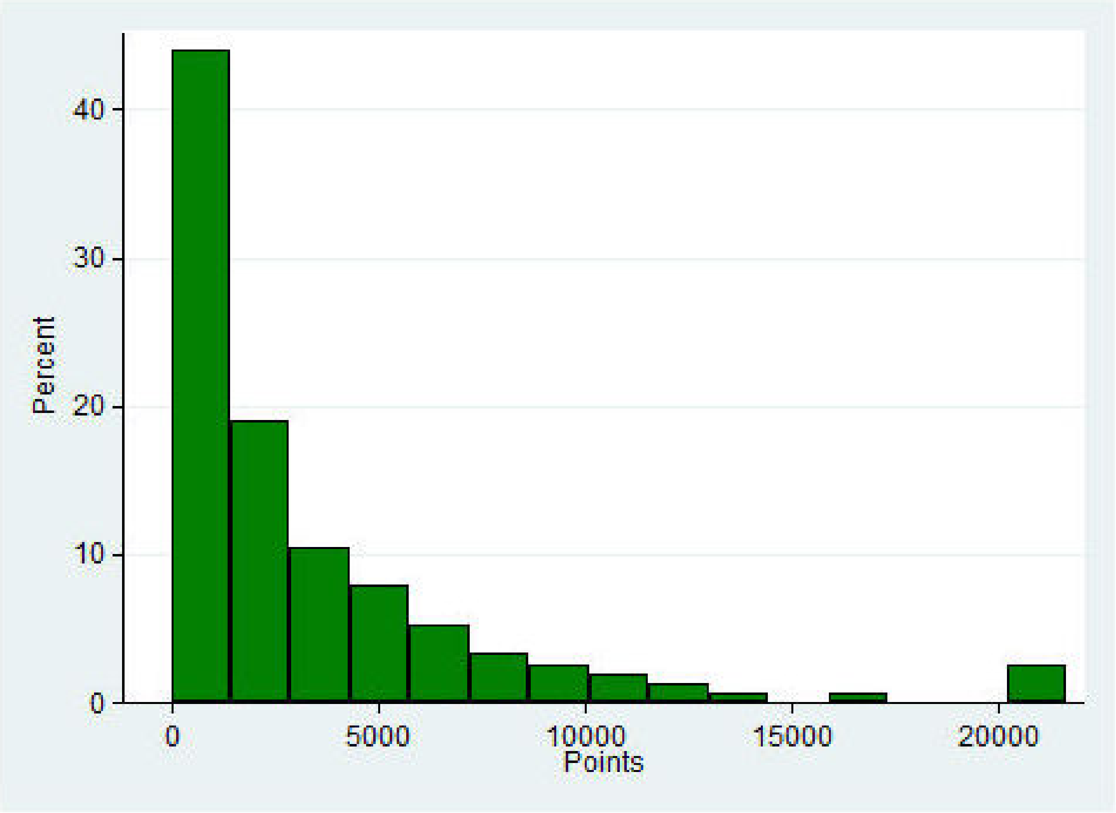


Figure 7. Distribution of days with respective registered diet and exercise during the 38 weeks (n=152).

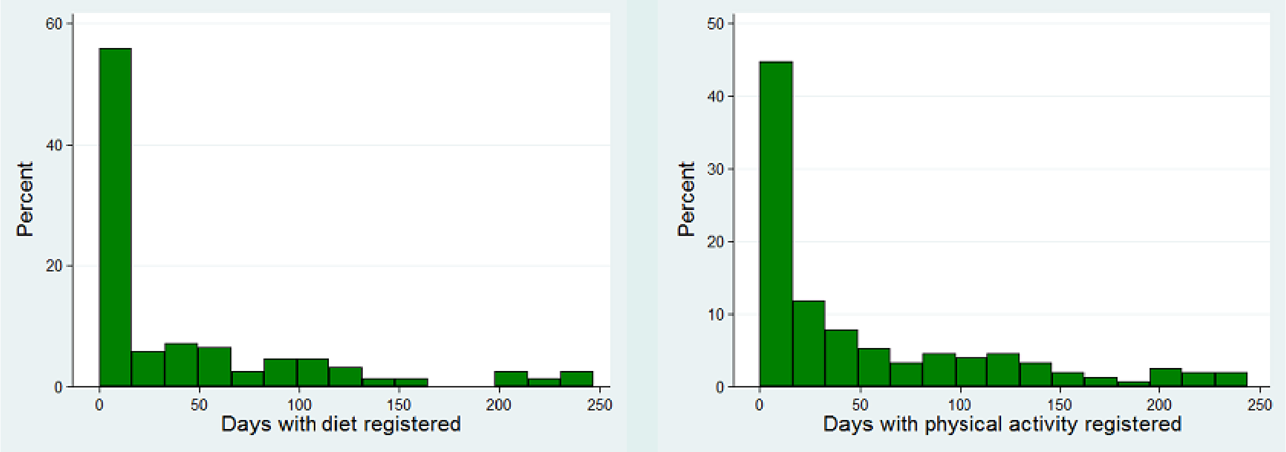
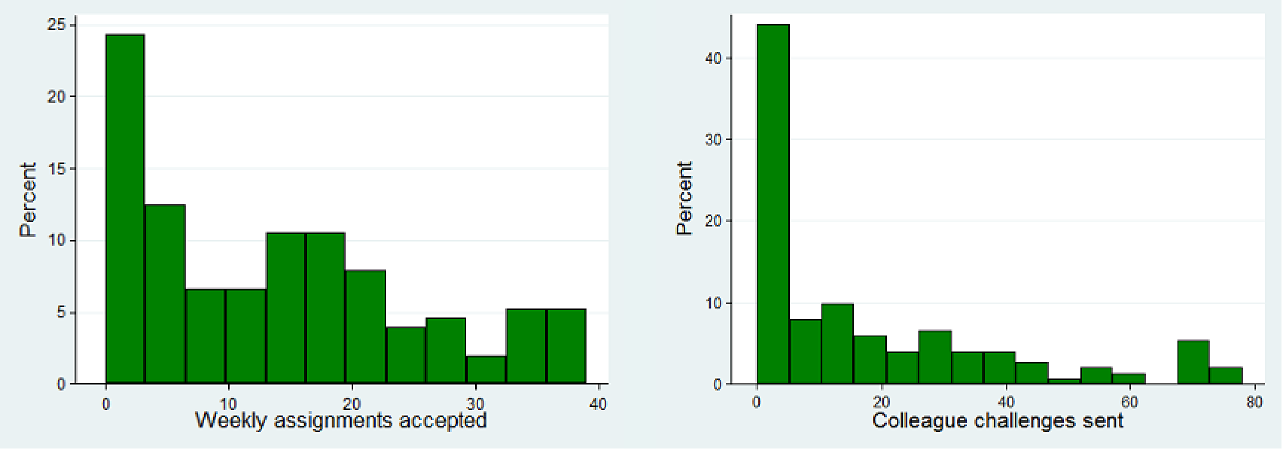


Figure 8. Distribution of number of days for weekly assignments accepted and “colleague challenges” sent out (n=152).



Findings From the Interviews

Motivation

From the interviews conducted, we found that the participants were motivated by different aspects of the intervention. Some were motivated by the prospect of getting help to lose weight, eat more healthily, or exercise more, including the feedback on dietary habits and health behavior. Others were motivated by the anthropometric and clinical examination, where getting the physiological data on their bodily measures worked as an incentive to change their lifestyle. None of the respondents mentioned the chance of winning prizes as a reason for signing up when they were asked an open question on why they signed up for participation, but the social part of being a team in the competition was a reason for continually using the tool during the first 16 weeks. When the project was presented to the participants, the social interactions and community elements were emphasized as important factors, and the participants and daily leaders of the workplaces encouraged each other to take part in the project. This meant that participants with no specific individual motivation for making lifestyle changes or no obvious unhealthy lifestyle also signed up for participation in the intervention.

Experiences With the Diet and Exercise Modules

In the interviews, some of the participants expressed that they found the tool too technically difficult to use or too time-consuming, whereas others did not think the weight loss tool was useful for them.

The participants who used the self-monitoring tool to keep track of their food intake and exercise level said that they had a starting period where they had to learn how to use the features. Only a small number of participants really changed their eating habits using the SoSu-life weight loss tool.

As explained here, by a very active user:

> *Yes, I actually type almost straight after [I have eaten] and sometimes I will make the food ready, and I will type before I eat. Someone tells me, you must not get stressed by it, because people say you tend to sit and type before you eat. (...) My partner says, by now, you must be able to remember what you eat and then type afterwards. Now, concentrate on eating your food.*

Here, another participant is talking about how the unit system is constantly giving her feedback on her diet habits:

> *But really, it ensures an increased focus all the time because one sees the damn units every time one types it in. And then I just need to learn to weigh the food before I eat it.*

Using the unit system has transformed these participants’ relationship to food. The app had become an integrated element in their relationship to food and eating, as it was telling them how much more they could eat or how much more they should exercise. The typing of food intake together with using the field system thus gave those users a more instrumental relationship to food.

Others registering diet for a short period gained new knowledge about the food they ate, which could help them attain a balanced diet. For example, the unit system was still present in a participant’s consciousness when choosing whether to eat a piece of cake:

> *No, I don’t know if I want to use units for this—it’s a little funny. Because, this means, that now I’m more conscious about what I consume, and also how much it costs in units.*

Others viewed the feedback with ambivalence. When they registered the actual food they ate, the tool highlighted them in a red color when they ate too much, which gave them a bad conscience and made them want to drop using the tool.

> *But, I just get cravings to eat a cake when I think it gets damn annoying with all this typing. And then I just eat a cake and type it in, and then that day is just wasted.*

This participant was critical about her colleagues being so focused on food that she felt like deliberately eating unhealthy food as some kind of protest. Furthermore, when the feedback from the unit system was negative, she felt the day was wasted. Instead of regulating her calorie intake, she became really frustrated and acted with resistance toward healthy food and gave up using the tool completely.

On the basis of the findings above, we interpret that the individual feedback mechanisms in the tool are of great importance; however, they work in very different ways for the participants. Some participants learned how to eat a more balanced diet because of the feedback the tool gave them. However, others simply dropped using the technology when the feedback was negative to their habits. Only those participants who were motivated by the control system of registration and feedback were able to overcome the practical and technological challenges and became comfortable and at ease with using the daily registration system.

Experiences With the Social Features of the Tool

Both weekly assignments and colleague challenges were designed to encourage the whole workplace to engage in the project and to support each other. These features were designed to create a *we-are-in-this-together* spirit. At some nursing homes, the SoSu-life project was embraced with enthusiasm. In those places, the participants spoke about a change in how the colleagues engaged with each other and about the norms related to the participants' personal health. At these locations, the norms relating to how the colleagues addressed each other regarding health habits seemed to change, which is illustrated in the following quotes from the respondents. It became legitimate to approach a participating colleague and ask how her weight loss was going or to ask a smoking colleague how her quitting smoking project was coming along.

In a group interview approximately 6 weeks into the intervention period, participants discussed how they now talked more about their habits regarding smoking and food. One participant said:

> *But Susanne asked me the other day—well, have you been blowing on your cigarette [refers to a newly purchased electronic cigarette]. She would not have asked me that, if we weren't participating in this.*

Another participant explained:

> *That we have had this dialogue back-and-forth with each other and that it has been completely legitimate to stop each other in the halls and say "say…how much weight have you lost." We had not done this before, even if there was someone who had lost weight and it was visible.*

Furthermore, new social bonds were formed as colleagues began interacting with other participants, sending messages and talking to colleagues they did not talk to before the project, whereas others formed small groups supporting each other in keeping the healthy habits.

The SoSu-life tool gave the participants a reference within which to engage in each other: to talk about food, talk about weight loss, talk about smoking, and a common reference regarding healthy habits.

Some of the active users of the SoSu-life tool mentioned that they had an agenda of replacing unhealthy elements in their workplace with healthier ones, such as having more fruit instead of cake available at the workplace.

With the introduction of SoSu-life tool, there seemed to be a change in the social interactions at the workplace in terms of what was legitimate to talk with other colleagues about. They now discussed weight loss and smoking cessation with less hesitation—issues that were previously considered private matters. However, the change was not only positive. For some participants, the constant focus on health and food was followed by an aversion to being healthy. Thus, the social features, with the chatting and social interaction tool, also had a tiring effect on some of the participants.

A participant expressed her opinion about the project after the first 16 weeks:

> *It was not like this in the beginning, but now...I think the others are doing really well with the tool, and I don't know why this [demotivated and exhaustion regarding the project] is happening to me. I just think I have too much to deal with at the moment. I'm really tired of it. I'm really tired of all the typing and I'm tired of...because it doesn't matter where ever I turn people are talking about some sort of food. And this is what I'm tired of because this is exactly what I wanted to stop, having to focus on food.*

Discussion

Principal Findings

The study found that only very few participants used the SoSu-life tool throughout the project period. Especially, the individual features of the tool were rarely used, whereas the social features were somewhat more popular. The overall clinical health benefits in this project [20], as in other similar projects, were minor, but the SoSu-life project seems to have initiated some potentially positive changes in the social interaction among colleagues, although the increased focus on healthy eating turned out to be demotivating for some participants. Furthermore, the social features of the tool meant that more social and health care workers signed up to participate in the project, which was positive. On the other hand, the limited use of the individual features of the tool suggests that although participation was prompted by the social features, these were not sufficient to motivate engagement with the individual features of the tool and with individual lifestyle change.

Interpretation

In the literature, incentives were described as important for signing up to participate in workplace health promotion [21]; however, in this study, none of the respondents reported the prizes in the competition as a reason for signing up, but merely the social aspect of being part of a team.

It should also be taken into consideration that the SoSu-life project was the first time some of the social and health care workers tried to use a smartphone. Clearly, participants with no specific motivation or limited technical skills had strong odds against them being active users of the SoSu-life tool. They would probably have benefited from a more thorough introduction to the functionalities of both the smartphone and the website.

In both Web- and app-based health promotion and workplace health promotion, a general problem is the high level of dropout and attrition in the use of the tools [21,22]. This is also the case in this study. In the literature, high dropout rate is considered to be natural and typical, and the fact that participants stop using the digital interventions has even been called one of the fundamental characteristics and methodological challenges in the evaluation of eHealth interventions [22]. A scientific review investigating participation in worksite health promotion programs found that only half of employees are usually reached in workplace-based intervention, and another review found that typically around one-third of participants left worksite health promotion programs early [21,23].

Strategies designed to help participants change their behavior with an aim to adopt a healthy lifestyle may be implicit or explicit. The BCT taxonomy categorizes the specific strategies that are used in interventions to promote behavior change, ranging from techniques that work on the individual to techniques that work on the social level [18,19]. Currently, and most commonly, health interventions are described as using techniques focusing at the individual level. This category is differentiated with several subcategories within the BCT framework. Interventions using techniques on the social level are less often reported. Furthermore, the social level category is only described with the broad term “planning social support or social change” [18]. The SoSu-life tool includes several mechanisms that operate on the social level. The results of this study indicate that the BCT framework should be developed with more refined categories of social techniques. It is relevant to distinguish between mechanisms that ensure that individual activity benefits the social group, mechanisms that initiate joint activities, mechanisms that create team spirit, and mechanisms that initiate team-based competition. Our findings give a more nuanced view on how Web- and app-based health promotion tools work. They suggest that it might be the social interactions and conversations among colleagues at the workplace initiated by the intervention, rather than individual use of the tool, that create actual behavioral changes, thus influencing whether the whole intervention as such is beneficial. The changes at the social level might not result in immediate measureable health benefits, but it is possible that this social change at the workplace could have an effect in the longer term. This would depend on whether the achieved changes can be sustained.

Limitations of the Study

The time limit of this study prevented us from investigating long-term sustainability and effects of the social change, and a follow-up period of 6 months or a year would have allowed for an evaluation of long-term results. Furthermore, the dynamics in the different teams at different locations had a great impact on how the change came about. Further examination into these differences could help determine the factors that influence whether a tool has success or not. We only visited 4 out of 12 locations, and we cannot know whether other changes happened at the other locations. The fact that 90% of the study population was women also has to be considered when generalizing results into other contexts. Another weakness of this study is the lack of data on the individual reasons for dropout.

Conclusions

Although having only a modest impact on individual participants’ lifestyle, a digital tool that encourages employees to participate in social activities at the workplace appears to initiate a social change in social and health care workers’ worksites, stimulating more social interaction around healthy lifestyle issues and habits. Future and more long-term studies are needed to decide whether such a change leads to sustained improvements in health. The potential role of social changes should be taken into consideration when designing and evaluating health promotion interventions. With regard to the BCT taxonomy of health promotion interventions, this study indicates that the category of social level behavior change techniques could be refined and described in more detail in the literature.

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Conflicts of Interest

Mobile Fitness is founded and owned by the University of Copenhagen, CAT Innovation A/S, and private initiators, but it had no further role in the study design, the data collection, the analysis, the interpretation of data, and the decision to submit the paper for publication. The University of Copenhagen takes full responsibility for the study design, the data collection, the analysis, the interpretation of data, and the decision to submit the paper for publication.

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Abbreviations

BCTs: behavior change techniques
SMS: short message service

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Original Paper

Social Media–Promoted Weight Loss Among an Occupational Population: Cohort Study Using a WeChat Mobile Phone App-Based Campaign

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Abstract

Background: Being overweight and obese are major risk factors for noncommunicable diseases such as cardiovascular diseases. The prevalence of overweight and obesity is high throughout the world and these issues are very serious in the Shunyi District in China. As mobile technologies have rapidly developed, mobile apps such as WeChat are well accepted and have the potential to improve health behaviors.

Objective: This study aims to evaluate the effectiveness of a mobile app (WeChat) as an intervention on weight loss behavior.

Methods: This study was conducted among an occupational population from August 2015 to February 2016 in the Shunyi District of Beijing. Before the intervention, the Shunyi District Government released an official document for weight loss to all 134 government agencies and enterprises in Shunyi District. Participants willing to use our official WeChat account were enrolled in a WeChat group and received 6 months of interventions for weight loss; those who were not willing to use the account were in a control group given routine publicity on weight loss.

Results: In total, 15,310 occupational participants including 3467 participants (22.65%) in the control group and 11,843 participants (77.35%) in the WeChat group were enrolled. Participants in the WeChat group lost more weight (mean 2.09, SD 3.43 kg) than people in the control group (mean 1.78, SD 2.96 kg), and the difference in mean weight loss between the two groups for males was significant based on the stratification of age and educational level. To control for confounding factors and to explore the effects of WeChat on weight loss, the propensity score method with a multinominal logistic regression was utilized. For males, this showed that the WeChat group (with both active and inactive subgroups) had a higher probability of maintaining weight, weight loss from 1 to 2 kg, or weight loss more than 2 kg than the control group. However, the control group had higher probability of weight loss from 0 to 1 kg. Being active in WeChat was likely to be associated with weight loss. The more active participants were in the weight loss program via WeChat, the more weight they lost.

Conclusions: The weight loss intervention campaign based on an official WeChat account focused on an occupation-based population in Shunyi District was effective for males. The more active male participants were in using WeChat, the more weight they lost. There might be no effect or there may even be a negative effect on weight loss for females. Future research should focus on how to improve adherence to the WeChat weight loss interventions, to improve and refine the WeChat content such as developing a variety of materials to attract interest, and to protect personal privacy, especially for females.

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KEYWORDS

WeChat; weight loss; social media; health; intervention

Introduction

Being overweight is defined as having a body mass index (BMI) of 25 kg/m^2 or higher; a person with a BMI of 30 kg/m^2 or higher is regarded as obese. Worldwide in 2014, more than 1.9 billion adults were overweight and more than 600 million adults were obese. The percentage of obesity in the world's adult population was 13%. The prevalence of obesity in 2014 was twice that of 1980 [1]. In China in 2013, 30.1% of adults were overweight and 11.9% of adults were obese, an increase of 7.3% and 4.8%, respectively, from 2002 [2]. Shunyi District is located in the northeast part of Beijing City. Its economy has developed rapidly because the Beijing Capital International Airport is located there. In Shunyi District in 2014, 38.3% of adults were overweight and 27.1% of adults were obese [3]. The issues of being overweight and being obese in Shunyi District are very serious.

Obesity is a major risk factor for noncommunicable diseases such as diabetes, cardiovascular diseases, and some cancers [4,5]. Obesity is a multifactorial and complex condition. Environmental factors, endocrine and inflammatory pathways, and endogenous genetic factors have effects on the development of obesity and obesity-related diseases [4]. Additionally, some demographic characteristics, such as age, education level, and social support, are associated with obesity. Older people, with lower education levels, lack of social support, and psychosocial pressures are more likely to be obese. Compared with men, socioeconomic parameters are more strongly associated with obesity in women [6]. Some scholars even argue that obese people suffer from social discrimination in medical care, employment, and education settings [7]. Therefore, how to reduce these determinants has become an important question that has confused public health practitioners because people who are overweight or obese have great difficulty losing weight. Traditionally, calorie restriction, exercising more, and eating less fat are the most common methods for weight loss [8]. Although there were some traditional weight loss interventions, the prevalence of obesity remains high and is increasing. Additionally, a large number of people who are obese do not adhere to weight loss interventions. Thus, new interventions should be developed to help people lose weight.

Various media such as radio, television [9], and Web-based interventions [10] have been utilized for mass outreach health campaigns [11]. Social media can influence health knowledge, beliefs, and attitudes, and also health behaviors, especially for large groups of people [9]. Recently, with the dramatic growth of Web 2.0 technologies, online social networks have also grown and account for approximately 27.18% of all time spent online among Chinese college freshmen [12]. Because online social networks have several advantages, such as a large audiences, higher levels of user engagement [13], and higher retention levels of existing contacts [14], they might have numerous potential effects on changing health behaviors [11].

Social media interventions have measurable impacts on health outcomes compared with non-social media–based interventions [15]. For women, the more time spent on Facebook leads to more comparisons of body and weight, more attention to the physical appearance of others, and more negative body attitudes [16]. An average weight loss of 42.3 pounds has been reported since weight loss bloggers started to blog about their weight loss attempts, and weight loss during blogging can be predicted by blogging duration [17]. A mobile phone app known as With U that allows friends to challenge one another to lose weight by using offline social networks of friends and the online network Facebook was effective regarding both the motivation to lose weight and on the amount of weight lost [18]. For some participants, especially for regular users of social media, a private Twitter weight loss group was found to be feasible and acceptable in losing weight [19]. Compared with offline friends, family members, and Facebook friends, participants who use Twitter to discuss their weight loss are exposed to more sources of positive social influence and fewer sources of negative social influence regarding weight loss [20]. Women of childbearing age actively use Twitter and show great interest in Twitter-based weight loss interventions [21].

WeChat (the Chinese version is *Weixin*), the popular instant-messaging app created by China's largest Internet company, Tencent, has been regarded as the best social networking site in China [22] and is used in more than 200 countries [23]. Throughout the world, its registered users and active users total more than 1.12 billion and 600 million, respectively [24]. WeChat, similar to Facebook, Twitter, and YouTube, is a platform where people of all ages and professions can work with others, find and share information, and so on [25]. As a representative form of modern messaging software, WeChat has been used to change health behaviors and has shown potential impacts. A health education program using an official WeChat account to improve malaria health literacy among Chinese expatriates was proven to be effective, sustainable, feasible, and well accepted [23]. Using the WeChat app for follow-up was time-effective, cost-effective, and convenient [26]. WeChat interventions were effective in improving patient compliance and in reducing the treatment duration of orthodontic treatment [27]. Other social media platforms such as Facebook and Twitter have been used for weight loss; however, little is known about whether WeChat can be just as effective. Therefore, we hypothesize that interventions via WeChat will help people who are overweight or obese to lose weight.

Methods

Design and Setting

This study was conducted on an occupation-based population from August 2015 to February 2016 in the Shunyi District of Beijing to explore the effectiveness of the mobile app WeChat on weight loss behavior. Participants who were willing to use our official WeChat account were enrolled in a WeChat group and received 6 months of interventions for weight loss, and those who were not willing to use the account were in the control group. Before the interventions began, the Shunyi District Government released an official weight loss document to all 134 government agencies and enterprises in Shunyi District. At least 60% of the staff of government agencies were required to participate in this activity. The government agencies included the Shunyi Branch of the Beijing Municipal Public Security Bureau, the Shunyi Court, the Shunyi People's Procuratorate, the Shunyi Branch of the Beijing Administration for Industry and Commerce in the Urban Management Law Enforcement Bureau, the Shunyi State Administration of the Taxation of China, the Beijing Shunyi Local Taxation Bureau, and the Food and Drug Administration of Beijing Shunyi District. At least 30% of the staff of other units were required to participate as well.

Measures

Interventions were given to the WeChat group through the WeChat app and routine publicity, such as the slogan "take the stairs and lose weight," was given to the control group. Participants were asked to report their demographic characteristics such as gender, age, educational level, and telephone number online when they registered with our official WeChat account. Additionally, on average, two weight managers per agency were trained to obtain participants' data on height, weight, and waist circumference before and after the interventions were initiated for both groups. The demographic characteristics of participants in the control group were collected by weight managers.

Sample Selection

Participants were enrolled if they (1) were from one of any of the 134 government agencies and enterprises in Shunyi District, (2) were 18 years of age or older, and (3) wanted to lose weight. Participants willing to lose weight via WeChat were enrolled as members of the WeChat group and those who were willing to lose weight but did not want to use WeChat were in the control group. Pregnant women and those whose health conditions were not suitable for weight loss were excluded from the study.

Ethics Statement

All participants gave verbal consent to participate in the study and they were entitled to withdraw from the study whenever they wished and for whatever reason. The official weight loss document also addressed all the individuals who enrolled or who dropped out of our study voluntarily. People in the WeChat group would scan a QR code, below which was the phrase "enrolled or dropped out voluntarily" and for people in the control group, before they enrolled, weight managers in each agency told them everything about our study and asked them if they were willing to enroll. From the perspective of each participant's private information, an agreement was made between the Shunyi Center for Disease Prevention and Control (SYCDC) and a technology company that provided technological support to protect all private information. Only two people from the technology company and two people from the SYCDC knew all the information. Private information such as a telephone number or identification number was deleted when the data were analyzed.

Official WeChat Account Development and Components

The SYCDC developed an official WeChat account, known as the "Health Education in Shunyi District, Beijing," with the technological support of a specialized information technology company (Figure 1). Before becoming members of the official WeChat account, users were to register and provide information on their age, gender, educational level, and telephone number. Then, they were provided and could log in with a WeChat identification and password. All participants were asked to follow the instructions set forth in the official account after registration. Participants could read new messages and review the message history of all content published in the official account.

The official WeChat account consisted of the following six components: introduction, weight loss process, weight loss unit rankings, weight loss school, activity area, and awards (Figure 1). Each component is described in detail subsequently.

The weight loss process was designed to provide feedback on weight, diet, and exercise during the intervention process to motivate participants to lose weight. The duration of 12 types of activities, including walking, running, cycling, playing, skipping, swimming, sit-ups, push-ups, plank flat support, doing housework, workshops, and climbing stairs, were reported daily (Figure 1). According to a diet pagoda that was based on the Chinese Dietary Guidelines set forth by the Chinese Nutrition Society, each type of food was given a reasonable intake range; therefore, participants could know whether the amount of food they ate was excessive, moderate, or inadequate (Figure 1). Weight data were reported each week. When an individual reported data on diet, exercise, or weight, his or her physical condition would be assessed and the results would be provided immediately.

The weight loss unit rankings component aimed to rank the total score per unit, including the number of participants and the total amount of weight lost, to motivate and encourage participants to compete with one another (Figure 1). The weight loss school component consisted of a variety of materials on weight loss including micro videos and popular science knowledge (Figure 1) in addition to five experts (two from the Peking University Third Hospital, one from Peking University People's Hospital, one from Peking University Health Science Center, and one from the Beijing Center for Disease Prevention and Control) who formed a consulting group to address questions from participants (Figure 1). The activity area component included a microcommunity (Figure 1) and other types of activities, where participants could communicate with one another. Finally, there was a rewards component. Participants received scores during the intervention and, to win a competition, participants had to lose weight and actively participate in various activities.

At the end of the program, winners and losers were determined on the basis of their cumulative scores (Figure 1). The scores could be from interactions, feedback information, reading articles, and so on. Different types of activities resulted in different scores. For example, if an individual registered with our official WeChat account, he or she would earn 10 points; reading articles earned two points per day and feedback information on weight, exercise, and diet were worth five points each. The top 60 WeChat active participants per month and the top 50 at the end of the project could win a prize.

Figure 1. The interface of the WeChat interventions (originally in Chinese). (a) The official WeChat account “Health Education in Shunyi District, Beijing,” (b) introduction of the official account, (c) feedback on exercise, (d) feedback on diet, (e) the weight loss unit rankings, (f) the weight loss school, (g) the experts team, (h) the microcommunity, and (i) cumulative scores.

Content of WeChat Messages

A total of 210 messages were sent (one message every other day, on average) to participants in the intervention group during the period. The messages were read more than 247,000 times and were sent to other WeChat accounts more than 6500 times. In total, 3620 participants communicated with others in “microcommunity discussions” and there were more than 20,000 posts.

Participants in the intervention group could ask weight loss-related questions on our official WeChat account expert consultation page at any time during the 6-month period. Experts were consulted online more than 14,576 times and 28,000 questions were asked, among which 270 representative questions were responded to in detail. In addition, more than 8200 people regularly received feedback on their weight, diet, and exercise data and conducted self-assessments via WeChat. Examples of the content of WeChat messages can be found in Table 1.

Table 1. Examples of the content of WeChat messages.

Content examples[a]	Reading quantity	Number of forwards and favorites
Will beer increase your weight? Eight diet mistakes that will make you fatter!	2871	26
You do not have to go to the gym, seven other ways to burn fat	2945	44
Obesity is not an excuse to keep smoking	2982	24
Excessive weight will shorten your life! Eat less and exercise more to lose weight.	3060	60
Have you been cheated by the eight fallacies of weight loss?	3222	41
Want to have a good body image by spring? Do you know how to exercise now?	3233	24
New ways to lose weight. You do not need to diet.	3411	7
Five bad habits of running that will hurt your body!	3853	8
Do not miss the best season for weight loss! Weight loss is easier in winter!	4248	25
Changing these habits will keep you from regaining weight!	4577	28

[a] Original text was in Chinese.

Statistical Methods

Data was analyzed using SPSS version 18.0. Mean and standard deviation were used to present continuous variables for normal distribution or median and quartile for nonnormal distribution. Frequency and percentages were employed to express categorical variables. The chi-square test for categorical variables was used to compare parameters between the control group and the WeChat group, or *t* test for continuous variables with normal distribution. To control for confounding factors and to explore the effects of WeChat on weight loss, propensity score methods with a multinominal logistic regression was utilized; the propensity score replaced all single covariates to adjust the effectiveness on weight loss. A *P* value less than .05 was considered statistically significant.

Results

Participant Flow and Follow-Up

At the beginning, a total of 15,818 participants were enrolled, including 12,296 participants in the WeChat group and 3522 in the control group. Data were collected on a total of 15,523 participants, including 12,002 in the WeChat group and 3521 in the control group at the baseline. After 6 months of interventions, data were collected on a total of 15,310 participants, including 11,843 in the WeChat group and 3467 in the control group at the baseline and after 6 months of interventions (Figure 2).

Participant Characteristics and WeChat Active

The data that were collected both at baseline and after 6 months of interventions were used. That is, a total of 15,310 participants were enrolled in this study. The mean age of the control group was 39.0 (SD 9.5) years and that of the WeChat group was 35.1 (SD 8.5) years. Participants in the WeChat group were younger than those in the control group, and the difference was significant. Participants in the WeChat group were largely females (66.53%, 7879/11,843) and largely had university/college degrees or above (91.85%, 10,878/11,843). In the control group, nearly half the participants were female (40.47%, 1403/3467) and more participants had university/college degrees or above. Baseline demographics including age, gender, and educational level between the two groups were not balanced (Table 2).

WeChat activeness was represented by WeChat cumulative scores, which were related to actual official WeChat account use. Higher scores indicated that an individual was more active in using WeChat to lose weight. Scores less than or equal to 50 were regarded as inactive, and scores of 50 or more were active. A significant number of participants in the WeChat group were inactive (83.18%, 9852/11,843) and only 16.8% (1991/11,843) were active. The differences between the control group and the WeChat group on demographics were all statistically significant (Table 2).

Changes in Weight Loss Between the Control Group and the WeChat Group

The weight and waist circumference in the control group decreased by mean 1.78 (SD 2.96) kg and mean 2.39 (SD 3.91) cm, respectively, whereas in the WeChat group, weight and waist circumference decreased by mean 2.09 (SD 3.43) kg and mean 2.74 (SD 4.48) cm. A stratified analysis was performed to show the mean weight loss of the two groups. It also showed that for males, a decrease in weight loss was statistically significant, which indicated the 6-month WeChat interventions were effective for weight loss; however, for females, weight loss changes were not statistically significant (Table 3).

Figure 2. The flowchart of participation.

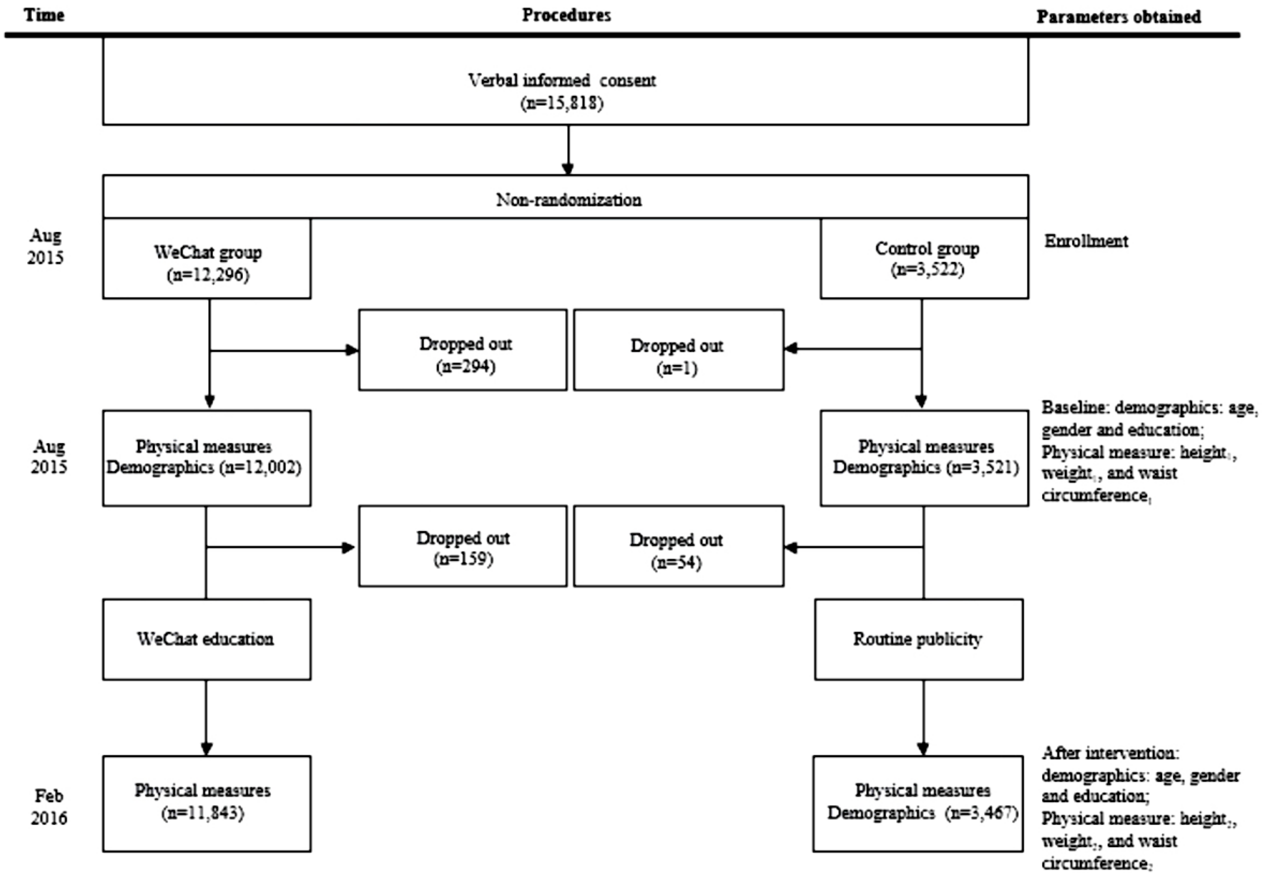

Table 2. Demographic characteristics of the control group and the WeChat group (N=15,310).

Demographics	Control group, n (%) (n=3,467)	WeChat group, n (%) (n=11,843)			χ^{2a}	*P* [a]
		Inactive (n=9852)	Active (n=1991)	Total (n=11,843)		
Gender					798.0	<.001
Male	2064 (59.53)	3415 (34.66)	549 (27.57) 3964 (33.47)			
Female	1403 (40.47)	6437 (65.34)	1442 (72.43)	7879 (66.53)		
Age group (years)					443.1	<.001
<40	1672 (50.61)	6,874 (70.32)	1180 (59.78)	8054 (68.55)		
≥40	1632 (49.39)	2,901 (29.68)	794 (40.22)	3695 (31.45)		
Education[b]					536.9	<.001
Low	772 (22.31)	779 (7.91)	186 (9.34)	965 (8.15)		
High	2689 (77.69)	9073 (91.09)	1805 (90.66)	10,878 (91.85)		

[a] Chi-square and *P* value are difference between the control group, the inactive group, and active group.

[b] Low education level: high school or below; high education level: university/college or above.

Table 3. Mean weight loss in the two groups by gender, educational level, and age (N=11,530).

Gender, educational level,[a] age, and groups		n	Mean (SD)	*t* (df)	*P*
Male					
Low educational level					
<40 years				3.36 (291)	.001
	Control	104	1.18 (4.51)		
	WeChat	189	3.22 (5.20)		
≥ 40 years				3.32 (485)	.001
	Control	274	1.95 (3.88)		a
	WeChat	213	3.27 (4.91)		
High educational level					
<40 years				8.10 (2231)	<.001
	Control	856	1.48 (2.79)		a
	WeChat	2405	2.51 (4.14)		
≥ 40 years				2.25 (1649)	.03
	Control 723	1.7 (2.82)			
	WeChat	1115	2.01 (3.12)		
Female					
Low educational level					
<40 years				1.95 (263)	.05
	Control	46	3.37 (5.26)		
	WeChat	219	2.08 (3.77)		
≥ 40 years				1.45 (540)	.15
	Control	237	2.57 (3.40)		
	WeChat	305 2.17 (2.96)			
High educational level					
<40 years				0.36 (914)	.72
	Control	666	1.98 (2.73)		
	WeChat	5241	1.94 (3.21)		
≥ 40 years				0.43 (622)	.66
	Control	392	1.87 (2.29)		
	WeChat	2062	1.82 (2.73)		

[a] Low education level: high school or below; high education level: university/college or above.

Estimating Adjusted WeChat Effectiveness

Propensity score methods are increasingly used to control for confounding factors in many medical studies. In our study, demographics including age, gender, and educational level between the two groups were not balanced at the baseline; thus, propensity score methods were used to control for them. With a group variable (the WeChat group and the control group) as the dependent variable and two demographic characteristics (age and educational level) as covariates, a binomial logistic regression analysis was used to estimate the propensity score based on gender.

To estimate WeChat effectiveness on weight loss, multinominal logistic regression used to test the parallel lines of the ordinal logistic regression that did not meet the criteria. The weight loss outcome was categorized as follows: weight gain, weight unchanged, weight loss from 0 to1 kilograms, weight loss from 1 to 2 kilograms, and weight loss more than 2 kilograms. The reference category for the dependent variable was the classification of weight gain. The propensity score was used as a continuous covariate replacing all single covariates with the independent variable, WeChat active group, in the multinominal logistic regression to estimate the adjusted WeChat effectiveness on weight loss.

For males, in the control group, 52.37% (1081/2064) of participants lost 0 to 1 kg, 35.72% (1220/3415) in the inactive group, and 41.17% (226/549) in the active group lost more than 2 kg. For females, 38.92% (546/1403) of participants in the control group and 31.30% (2015/6437) in the inactive group lost 0 to 1 kg and 33.36% (481/1442) in the active group lost more than 2 kg (Table 4).

Table 4. The frequency and percentage of weight loss outcomes between two groups based on gender.

Gender and weight	Control, n (%)	Inactivity, n (%)	Activity, n (%)	Total, n (%)
Male				
Weight gain	187 (9.06)	272 (7.96)	45 (8.20)	504 (8.36)
Weight unchanged	61 (2.96)	305 (8.93) 41 (7.47)	407 (6.75)	
Weight loss (0-1 kg)	1081 (52.37)	932 (27.29)	136 (24.77)	2149 (35.65)
Weight loss (1-2 kg)	219 (10.61)	686 (20.09)	101 (18.04)	1006 (16.69)
Weight loss (≥2 kg)	516 (25.00)	1220 (35.72)	226 (41.17)	1962 (32.55)
Female				
Weight gain	81 (5.77)	597 (9.27)	105 (7.28)	783 (8.44)
Weight unchanged	77 (5.49)	732 (11.37)	112 (7.77)	921 (9.92)
Weight loss (0-1 kg)	546 (38.92)	2015 (31.30)	427 (29.61)	2988 (32.19)
Weight loss (1-2 kg)	259 (18.46)	1317 (20.46)	317 (22.00)	1893 (20.39)
Weight loss (≥2 kg)	440 (31.36)	1776 (27.59)	481 (33.36)	2697 (29.06)

For males, the results of the multinominal logistic regression showed that when controlling for confounding factors, compared with the classification of weight gain, the WeChat group (with both active and inactive subgroups) had higher probability of maintaining weight, weight loss from 1 to 2 kg, or weight loss of more than 2 kg than the control group. However, the control group had higher probability of weight loss from 0 to 1 kg. For females, the difference between maintaining weight and weight gain was not statistically significant. As for weight loss of more than 1 kg, the WeChat inactive group had lower probability than the control group. As for weight loss from 0 to 1 kg, the WeChat group (with both active and inactive subgroups) had lower probability than the control group (Table 5).

Table 5. Results of the multinomial logistic regression based on gender.

Gender and weight loss[a]	B	SE	Wald	*P*	OR (95% CI)
Male					
Weight unchanged					
Intercept	–0.08	0.44	0.03	.85	
Propensity score	–1.68	0.67	6.20	.01	0.19 (0.05-0.70)
WeChat active[b]					
Activity (1)	1.10	0.26	17.47	<.001	3.01 (1.80-5.05)
Inactivity (2)	1.34	0.18	58.70	<.001	3.84 (2.72-5.41)
Weight loss 0-1 kg					
Intercept	1.03	0.33	9.61	<.001	
Propensity score	1.01	0.51	4.02	.045	2.75 (1.02-7.41)
WeChat active[b]					
Activity (1)	–0.62	0.19	10.61	<.001	0.54 (0.37-0.78)
Inactivity (2)	–0.50	0.11	20.68	<.001	0.61 (0.49-0.75)
Weight loss 1-2 kg					
Intercept	1.22	0.36	11.62	<.001	
Propensity score	–1.77	0.55	10.34	<.001	0.17 (0.06-0.50)
WeChat active[b]					
Activity (1)	0.75	0.21	13.09	<.001	2.12 (1.41-3.18)
Inactivity (2)	0.90	0.13	49.17	<.001	2.46 (1.91-3.17)
Weight loss >2 kg					
Intercept	1.48	0.33	19.91	<.001	
Propensity score	–0.73	0.51	2.06	.15	0.48 (0.18-1.30)
WeChat active[b]					
Activity (1)	0.61	0.19	10.93	<.001	1.85 (1.28--2.66)
Inactivity (2)	0.53	0.11	21.69	<.001	1.69 (1.36--2.11)
Female					
Weight unchanged					
Intercept	–0.56	0.58	0.94	.33	
Propensity score	0.61	0.68	0.79	.37	1.83 (0.48-6.97)
WeChat active[b]					
Activity (1)	0.10	0.21	0.24	.63	1.11 (0.73-1.68)
Inactivity (2)	0.23	0.17	1.85	.17	1.26 (0.90-1.77)
Weight loss 0-1 kg					
Intercept	1.43	0.45	10.32	<.001	
Propensity score	0.46	0.53	0.76	.38	1.59 (0.56-4.49)
WeChat active[b]					
Activity (1)	–0.41	0.16	6.26	.01	0.66 (0.48-0.91)
Inactivity (2)	–0.62	0.13	21.93	<.001	0.54 (0.42-0.70)
Weight loss 1-2 kg					
Intercept	1.40	0.46	9.30	<.001	
Propensity score	–0.31	0.55	0.32	.57	0.73 (0.25-2.14)

Gender and weight loss[a]	B	SE	Wald	*P*	OR (95% CI)
WeChat active[b]					
Activity (1)	–0.02	0.17	0.02	.89	0.98 (0.70-1.37)
Inactivity (2)	–0.34	0.14	5.96	.02	0.71 (0.54-0.93)
Weight loss >2 kg					
Intercept	2.37	0.43	29.91	<.001	
Propensity score	–0.86	0.52	2.78	.10	0.42 (0.15-1.16)
WeChat active[b]					
Activity (1)	–0.09	0.16	0.32	.57	0.91 (0.66-1.26)
Inactivity (2)	–0.54	0.13	16.25	<.001	0.58 (0.45-0.76)

[a] The reference category for the dependent variable was the classification as weight gain.

[b] WeChat active was a subgroup variable, and the reference group was the control group.

Discussion

This study proved that the weight loss intervention campaign, which was largely promoted by the Shunyi Government and based on an official WeChat account focused on an occupation-based population in Shunyi District, was very effective for males.

A total of 15,310 participants were enrolled in this study, among which 77.35% were willing to use WeChat for weight loss, which was consistent with a study that a WeChat health education program was evaluated with high levels of satisfaction from participants [23]. WeChat, one of the most popular mobile phone apps in China, may have significant potential to improve public health **.**

Participants in the WeChat group lost more weight (2.09 kg) on average than people in the control group (1.78 kg), and the difference in mean weight loss between the two groups for males was significant. For males, the results of the propensity score methods with a multinominal logistic regression showed that the WeChat group (with both active and inactive subgroups) had a higher probability of maintaining weight, weight loss from 1 to 2 kg, or weight loss more than 2 kg than the control group. However, the control group had higher probability of weight loss from 0 to 1 kg. Being active in WeChat is likely to be associated with weight loss. The more active participants were in the weight loss program via WeChat, the more weight they would lose.

Our WeChat intervention campaign provided participants with information on weight loss that could improve their knowledge, attitudes, practices, and so on. The results were in accordance with a previous study showing that participants' knowledge, attitudes, skills, practices, and overall health literacy experienced greater changes via official WeChat accounts [23]. Our WeChat intervention campaign applied regular self-monitoring of physical activities, dietary intake, and weight, which played an important role in weight loss [28]. A study showed that specifically tailored text message reminders had no significant influence on weight loss among obese male employees for the possible reason that this intervention did not apply regular self-monitoring [29]. Moreover, our WeChat intervention campaign had interactive components such as the "microcommunity" component and the expert consultation component where people could get feedback and social support, which also played an important role in weight loss [30]. Social support was associated with weight loss in that the more positive social support, the greater the weight loss [31]. People have found positive social support for weight loss on Twitter [20]. Social support and information might be the two most common benefits of tweeting about weight loss. In addition, the WeChat intervention program might provide psychological benefits, where individuals can record their daily experiences, feelings, opinions, and so on [32], which might be useful for participants to lose weight.

The difference in mean weight loss between the two groups of females was not significant. WeChat might not affect or may even negatively affect weight loss for females. For females, the results of the propensity score methods with a multinominal logistic regression showed that the difference between maintaining weight and weight gain was not statistically significant. For the classification of weight loss more than 1 kg, the WeChat inactive group had lower probability than the control group. As for weight loss from 0 to 1 kg, the WeChat group (with both active and inactive subgroups) had lower probability than the control group. WeChat might have no effect on maintaining weight and might result in a lower chance of weight loss for females.

The WeChat intervention was effective on weight loss only for male employees. Females were more active using WeChat, but they lost less weight during the study. One reason might be that females were more motivated by the rewards than males and the rewards were given to the top 60 WeChat active participants per month, regardless of whether or not they in fact lost weight. Additionally, the fact that females spent more time on WeChat might negatively affect weight loss. One study showed that the more time a person spent on Facebook, the more negative feelings they had about their bodies due to more frequent body and weight comparisons for females [16]. Another explanation was that females might be more willing to lose weight but they did not prefer reporting personal information such as their weight and waist measurements publicly via WeChat. Thus, they were more active in WeChat but received less social support, feedback, and other benefits from WeChat. However, these people accounted for a large proportion of all participants. Thus, the difference between the two groups was not significant. In addition, males might have less offline social support and feedback than females, but males could obtain these benefits via our official WeChat account. Moreover, males were more competitive than females. In the future, interventions on weight loss, especially for females, should be developed with measures to protect personal privacy not with measures that collect private information in public. Additionally, a reward is a two-edged sword; in the future, WeChat activity as well as the amount of actual weight lost should be taken into consideration.

In the WeChat group, most of the participants were inactive in this study. It may be that participants showed greater interest in our WeChat intervention program at the beginning, but few people were able to adhere to our weight loss activities. The effectiveness of a weight loss intervention has been associated with intervention adherence [33]. Supervised attendance programs and interventions that offer social support result in higher adherence to weight loss activities [34]. Therefore, in the future, measures should be taken to improve adherence to our WeChat intervention program such as incorporating a supervisory component. Moreover, improving and refining the WeChat content is also very important. We must develop a variety of materials, not only articles but also more videos and cartoons on weight loss to attract interest. WeChat content should also be more authoritative and more concise. With the widespread use of WeChat and the large number of active users, WeChat may be a convenient, cost-effective medium to improve adherence to weight loss behaviors in China.

Limitations

This study had some limitations. First, this study was a nonrandomized trial and although propensity score methods were used to control for confounding factors, the conclusions were limited. Second, weight loss behavior is a multifactorial phenomenon in that adherence [33], holidays, certain seasons, and important festivals [35], such as New Year’s Eve celebrations, may influence weight loss. Therefore, in the future, there should be greater focus on how to improve adherence to weight loss behaviors, and future studies over a longer period of time are necessary. Additionally, there was selection bias in the study.

Conclusions

This weight loss intervention campaign based on an official WeChat account focused on an occupation-based population in Shunyi District was found to be effective for males. The more active male participants were in using WeChat, the more weight they lost. There might be no effects or even negative effects on weight loss for females. Future research should focus on how to improve adherence to the WeChat weight loss interventions and to protect personal privacy, especially for females.

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Authors' Contributions

HC was responsible for the study design and data collection. SYW performed the statistical analysis, interpreted the results, and wrote the manuscript. YYZa, ZL, and YYZb were responsible for the manuscript translation. JL, LW, SYW, and CQL helped interpret the results. YDL and XYS were responsible for reviewing the study design, the manuscript, and all study results.

Conflicts of Interest

None declared.

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Abbreviations

BMI: body mass index
SYCDC: Shunyi Center for Disease Prevention and Control

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Original Paper

Assessing the National Cancer Institute's SmokefreeMOM Text-Messaging Program for Pregnant Smokers: Pilot Randomized Trial

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Abstract

Background: Automated text messages on mobile phones have been found to be effective for smoking cessation in adult smokers.

Objective: This study aims to test the acceptability and feasibility of SmokefreeMOM, a national smoking cessation text-messaging program for pregnant smokers.

Methods: Participants were recruited from prenatal care and randomized to receive SmokefreeMOM (n=55), an automated smoking cessation text-messaging program, or a control text message quitline referral (n=44). Participants were surveyed by phone at baseline and at 1 month and 3 months after enrollment.

Results: Results indicate that the SmokefreeMOM program was highly rated overall and rated more favorably than the control condition in its helpfulness at 3-month follow-up ($P<.01$) and in its frequency of messaging at both 1-month and 3-month follow-ups ($P<.001$, $P<.01$, respectively). Despite the presence of technical problems, the vast majority of intervention participants read all program messages, and few participants unsubscribed from the program. There were no significant differences between groups on the use of extra treatment resources or on smoking-related outcomes. However, at the 3-month follow-up, some outcomes favored the intervention group.

Conclusions: SmokefreeMOM is acceptable for pregnant smokers. It is recommended that SmokefreeMOM be further refined and evaluated.

Trial Registration: Clinicaltrials.gov NCT02412956; https://clinicaltrials.gov/ct2/show/NCT02412956 (Archived by WebCite at http://www.webcitation.org/6tcmeRnbC)

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KEYWORDS

mHealth; text messaging; SMS; mobile phone; pregnant; smoking; quit

Introduction

Cigarette smoking in pregnancy poses serious health risks to both the pregnant woman and the fetus. It has been shown to cause adverse fetal outcomes including stillbirths, spontaneous abortions, premature births, low birthweight, and sudden infant death syndrome and has been linked to cognitive and behavioral problems in children [1,2]. It is estimated that 20% or more of low birth-weight births could be prevented by eliminating smoking during pregnancy [3].

Approximately 10% of women smoke throughout their pregnancy in the United States [4,5]. Pregnant smokers are typically younger, less educated, and more likely to be white or of Native American ancestry [6]. Barriers to quitting reported by pregnant smokers include a lack of willpower, stressful life events and relationships, and factors associated with smoking among family and friends [7]. The stigma associated with pregnancy smoking has also been reported as a barrier to treatment seeking [7].

Mobile phones and text messaging have become widespread. In the United States, 95% of all American adults own a mobile phone, and among those with a high school education or less, 92% own a mobile phone [8]. Most mobile phone owners (88%) send and receive text messages [9]. Texting is more common in younger adults than older adults, those of African American or Hispanic ethnicity compared with whites [9], and in people with Medicaid health insurance compared with other forms of private insurance [10].

Automated text messages on mobile phones have been found to be effective for smoking cessation in adult smokers [11-13]. These programs, which generally consist of interactive text messages, can mirror many of the elements of in-person counseling including goal setting and feedback, social support, and the provision of a personalized quit plan [14]. The Guide to Community Preventive Services in the United States added mobile programs for smoking cessation to its list of recommended treatments for smoking cessation [15].

Mobile phone based programs may be especially well suited to pregnant smokers for several reasons. Mobile phones have nearly universal penetration among women of childbearing age [9]. In addition, because of the stigma associated with smoking during pregnancy, pregnant smokers may prefer a self-help program where they seek help anonymously [16]. Furthermore, as standard in-person counseling programs fail to reach most pregnant smokers [17,18], new delivery platforms are needed.

A handful of studies have been conducted on smoking cessation in pregnancy with mobile phone based support [19-21]. In a smoking cessation text-messaging program with pregnant smokers enrolled in Text4baby, Abroms et al found that text messages increased self-reported quitting during pregnancy [20]. In addition, a randomized trial by Naughton et al in prenatal clinics found that those randomized to text messages reported favorable outcomes on the psychosocial mediators of quitting [21]. Finally, in a pilot, Pollak et al found support for text messages that were used to prompt a scheduled gradual reduction in smoking among pregnant smokers [19].

The current study is the first to test the acceptability and feasibility of an existing national text-messaging program, SmokefreeMOM, which is aimed at pregnant smokers. SmokefreeMOM was created by researchers at the George Washington University and has been offered as a free service by the National Cancer Institute as part of their Smokefree website since 2014. This study examines SmokefreeMOM in the context of a pilot randomized trial of patients recruited from prenatal care clinics in the greater Washington, DC, area. The results of this study are important because this study is the first formative evaluation of a program that is nationally available, and new treatments are needed aimed at pregnancy cessation.

Methods

Study Procedures

The study was approved by the George Washington University (GWU) Institutional Review Board in 2013. Patients were recruited from 11 obstetrics-gynecology clinics in the Washington, DC, metropolitan area between September 5, 2014, and May 25, 2016. Nine of the clinics were associated with Medstar Health, while one was part of the George Washington University Medical Faculty Associates (GWU MFA) and the other part of Capital Women’s Care. Patients were recruited in two ways. First, at Medstar Health and GWU MFA, patients were identified by searching the electronic health record (EHR) for patients who met the criteria of being pregnant and a current smoker. Once identified, these patients were sent a letter with study-related information and instructions on contacting study staff to join the study or be removed from the list. For patients who did not contact study staff, research clinical staff called patients to assess their interest in participating. In addition to this strategy, clinical providers at all study sites were made aware of the study and asked to refer their pregnant patients who smoked to the study staff. In this case, providers assessed patient interest in participating in the study, and with patient permission, provided contact information to GWU study staff. See Multimedia Appendix 1 for the CONSORT checklist for this study [22].

Research staff called patients over the phone and assessed their eligibility. Patients were eligible if they were currently pregnant, spoke and read English proficiently, had a mobile phone with unlimited text-messaging, and were currently smoking or had smoked in the past 2 weeks at the time of enrollment. If interested and eligible, participants were consented over the phone and enrolled in the study, given a baseline survey and then randomized to a study arm. Participants were followed up with a phone survey at 1 month and 3 months after enrollment. A saliva sample was also collected from participants who reported not smoking in the past 7 days at the 3-month follow-up. For saliva collection, participants were mailed a kit with instructions, a salivette, and a prepaid postage envelope for sample return. Samples that were returned were kept in a refrigerator and mailed in batches to J2 Labs (Tucson, AZ) for cotinine analysis, following methods from our earlier trials [13,20]. Participants received a US $25 gift card for completing each survey and for providing a saliva sample. All survey data were collected with the REDCap data collection tool [23].

At the start of the trial, participants were randomized to one of three groups: the control group, the SmokefreeMOM group, and the SmokefreeMOM + quitline group. Recruitment progressed slower than projected because potential participants, the majority of whom were identified through the EHR as pregnant and smoking, when screened were determined not to be pregnant or smoking. Because of these difficulties associated with recruitment and because on initial review the quitline group did not appear to be receiving quitline services at high rates, a decision was made 2 months after the start of the trial to discontinue recruitment into the SmokefreeMOM + quitline group and randomize future participants to only the

SmokefreeMOM and control groups. At this time, 8 participants had been enrolled in the SmokefreeMOM + quitline group.

Control Group

Control group participants were texted a single text message after enrollment and were mailed self-help printed materials from the Centers for Disease Control and Prevention (CDC) on quitting smoking while pregnant [24]. The single text message provided a referral to the telephone quitline: “BeFree Study. For help quitting smoking, call the quitline and get free advice from a quit counselor. Call 1-800-784-8669 (1-800-QUIT-NOW).”

SmokefreeMOM

Participants randomized to the SmokefreeMOM group were enrolled in the SmokefreeMOM text messaging program by study staff and were mailed self-help materials from the CDC on quitting smoking while pregnant [24]. SmokefreeMOM is an automated, text-messaging program designed to help pregnant smokers quit smoking. It was created at GWU and incorporated into Smokefree.gov service offerings before the start of the trial. It is publicly available at the Smokefree website, but for the purposes of the trial, participants were enrolled using a trial-specific Web portal.

The text-messaging program was developed following a series of indepth interviews with pregnant smokers about their needs and preferences for smoking cessation (N=23) [25]. The program was developed based on Bandura’s social cognitive theory [26]. Messages provided advice and tips about how to quit smoking (ie, behavioral capability), social support, encouragement for quitting (ie, self-efficacy), information about the harms of smoking on a baby’s development (ie, outcome expectations of not quitting), and advice from ex-smokers (ie, self-efficacy). While most messages were one-way messages, some provided opportunities for two-way interaction. These included interactive surveys that assessed readiness to quit and progress in quitting. Interaction also occurred through keywords. Participants were told in messages that they could text keywords to receive additional messages or unsubscribe from the service. Participants could text at any time the keyword SMOKED if they had experienced a lapse, CRAVE if they were craving a cigarette, DATE to reset their quit date, and FACT to get a fact and learn about the harms of smoking. See Table 1 for sample messages.

Following a series of messages timed to enrollment, messages were scheduled around a participant’s quit date and baby’s due date, which were entered in as part of the enrollment process. Depending on dates entered, users received approximately 3-6 messages/day with a higher volume of messages around the quit date and around the baby’s due date. While the study ended 3 months after enrollment, program messages were designed to last 6 months after the quit date and 3 months after the baby’s due date. As the program was publicly available, those randomized to receive SmokefreeMOM could continue to receive program messages after the study’s completion.

SmokefreeMOM + Quitline

Participants randomized to the SmokefreeMOM + Quitline group received the same intervention as the SmokefreeMOM group with the addition of the opportunity to be enrolled in state quitline services at the time of enrollment. With permission from the participant, research staff fax enrolled participants in the SmokefreeMOM + Quitline group in quitline services. Staff faxed the name and phone number of participants to the quitline from their corresponding state (ie, District of Columbia [DC], Maryland [MD], and Virginia [VA]). Once the fax referral was received, quitline staff operated under their usual service protocol and made multiple attempts to reach participants and enroll them in quitline counseling and other services. In MD, during the study period, participants were offered an additional financial incentive for engaging in phone counseling by quitline staff. Besides this, quitline services were comparable across MD, DC, and VA, with 10 proactive counseling calls provided for pregnant smokers.

Measures and Analysis

Measures for this study were collected on the baseline, 1-month, and 3-month follow-up surveys.

The baseline survey captured information on participant demographics, mobile phone and social media use, and smoking behavior. Nicotine dependence was measured on the baseline survey with the Fagerstrom Test for Cigarette Dependence (FTCD). Scores range from 0-10, with a score of 6 or more indicating the highest level of dependence [27,28].

Program Acceptability and Feasibility

Acceptability was measured at 1-month and 3-month follow-up by questions that asked participants to rate their agreement with statements about the text programs (eg, “The text(s) was/were helpful in getting me to try to quit,” “I would recommend the text(s) to a friend who was pregnant and smoking,” and “The texts were a trigger and made me want to smoke”). These statements were rated on a 5-point Likert scale from completely disagree (1) to completely agree (5). Acceptability was also measured by having participants rate their satisfaction with the number of texts received (too many, just the right number, or too few). For the intervention group, participants reported on the proportion of text messages read (100%, 75%, or 50% or less). Intervention group participants were also asked in an open-ended format what they liked and did not like about the program. Likes were grouped into the following categories: the content of texts, social support provided by texts, reminders about quitting, encouragement about quitting, interactive tools, general liking, and other. Dislikes were coded into the following categories: nothing, technical problems experienced, message frequency, the content of texts, texts were a trigger, and other. Participants could indicate more than one like or dislike.

Table 1. Examples of text messages from SmokefreeMOM.

	Message	Sending algorithm
Welcome message	Welcome to Smokefree Moms! Quitting smoking is the best thing for you and your baby! Up to 6 msgs/day. Msg&data rates may apply. Reply STOP to opt-out, HELP for info.	Triggered by enrollment
Pre-quit advice	SFM: Almost the big day! Throw any remaining cigs in the trash before you go to bed tonight. Get plenty of sleep. Wake up feeling fresh and ready!	Quit date -1, 10 a.m.
Message from peer ex-smoker	SFM/Lea: It was really hard for me to give up my morning cig. When is going to be hardest for you? Text 1 for when you wake in the morning, 2 for after you eat, and 3 after the kids go to bed.	Quit date -2, 12 p.m.
Quit day	SFM: Just 20 minutes after you stop smoking your blood circulation beings to improve—quitting will improve blood flow to your developing baby.	Quit date, 5 p.m.
Postquit advice	SFM: Feeling cranky? It will pass. Your body is in nicotine withdrawal. Text CRAVE at any time to help with a craving.	Quit date +2, 12 p.m.
Quit status check-in	How is it going? Have you smoked a cig, even a drag, in the past week? Text YES or NO	Quit date + 7, 2 p.m.
Baby tips	BabyTip: At 26 weeks, your baby has fingernails and may be 14 inches long from head to feet.	Due date - 94
DATE	SFM: Let’s set your new quit date for mm/dd/yy. Reply 1 to accept this date or send us another date in the next 2 weeks in MMDDYY format (051215 for May 12th).	User texts in DATE
GAME	SFM: Adults have 206 bones. When babies are born, how many bones do they have? A) 150 B) 200 C) 300. Reply with letter of your response.	User texts in GAME
FACT	Smoking speeds up heart rate and increases blood pressure. Every puff increases the carbon monoxide in your blood making less oxygen available to baby.	User texts in FACT
CRAVE	To calm self, breathe in through nose and stretch arms up to the sky. Breathe out through mouth and bring arms back down. For more, reply TIP or GAME.	User texts in CRAVE

In addition, for the intervention group, acceptability was measured by a retrospective review of computer records of their engagement with the program. Engagement was assessed by measuring participant responses to a series of quit status check-ins (eg, “SFM: How is it going? Have you smoked a cig, even a drag, in the past week? Text YES or NO”). Over 3 months, there were potentially 20 check-ins, depending on the scheduled quit date. The number of total replies to the check-ins was tabulated and averaged across participants. While other types of engagement would also be of interest (eg, keyword use), the research team did not have access to this data. In addition, dissatisfaction with the program was measured by examining whether participants unsubscribed from the program. The proportion of SmokefreeMOM participants who texted STOP, a keyword for unsubscribing, was calculated at 1 month and 3 months.

Feasibility was assessed by asking all participants about the presence of technical problems related to the text messages. Technical problems were assessed using a combination of two survey items on the 1-month and 3-month surveys to capture the full extent of problems. Participants were asked whether they experienced any technical problems since enrolling in the study. If they answered “yes,” they were coded as having had a technical problem. In addition, participants were coded as having had a technical problem if they answered “no” on this survey item but reported technical problems in a separate open-ended question about what they did not like about the program.

Use of Treatments and Resources for Quitting

Use of treatments and resources for quitting was assessed with a question at 1-month follow-up that asked, “Since enrolling in this study, did you use any of the following to help you quit?” Participants were read the following options: Telephone help/quitline, one-on-one counseling, study-provided self-help materials, other self-help materials, quit smoking website, e-cigarettes, text messages from this study, text from another program, medication, other, and none of the above. Participants could indicate use of more than one treatment or resource.

Smoking-Related Outcomes

Smoking was measured by assessing 7-day biochemically confirmed point prevalence abstinence (PPA) at the 3-month follow-up, defined as a self-report of no smoking in the past 7 days on the 3-month survey and a cotinine level ≤13 ng/mL from the saliva sample [29]. Other outcomes assessed at 1-month and 3-month follow-up consisted of self-report of abstinence (7 days and 30 days), consecutive days quit, and 24-hour quit attempts. In addition, cigarettes smoked per day were measured, and number of cigarettes smoked was compared to baseline numbers by calculating a change score for each participant. Finally, self-efficacy was measured using the item, “How confident are you that you can quit smoking during this pregnancy?” Self-efficacy was measured on a 7-point scale ranging from “not at all” to “extremely.” Self-efficacy levels at 1 month and 3 months were compared to baseline levels by calculating a change score for each participant.

Analysis

Because very few participants in the SmokefreeMOM + Quitline group reported receiving quitline services (n=2) and because the group was small, a decision was made to combine the SmokefreeMOM + Quitline group (n=8) with the SmokefreeMOM group (n=47) and to compare these combined groups (referred to as "the intervention group") to the control group (n=44). Before combining groups, baseline demographic characteristics between the SmokefreeMOM + Quitline group and the SmokefreeMOM group were compared with no major differences observed.

Next, baseline demographic differences between the intervention and control groups were tested with independent *t* tests or chi-square tests. At 1-month and 3-month follow-up, differences between outcomes in the intervention and control groups were tested with independent *t* tests or chi-square tests. For dichotomous smoking outcomes (eg, 7-day and 30-day PPA), missing data were imputed as smoking. Where baseline differences were observed between groups, unadjusted and adjusted regression models were run to control for differences. Results were found to be similar for the unadjusted and adjusted models; therefore, unadjusted models are presented. Analyses were conducted in SPSS v. 22.0.

Figure 1. Participant enrollment and follow-up.

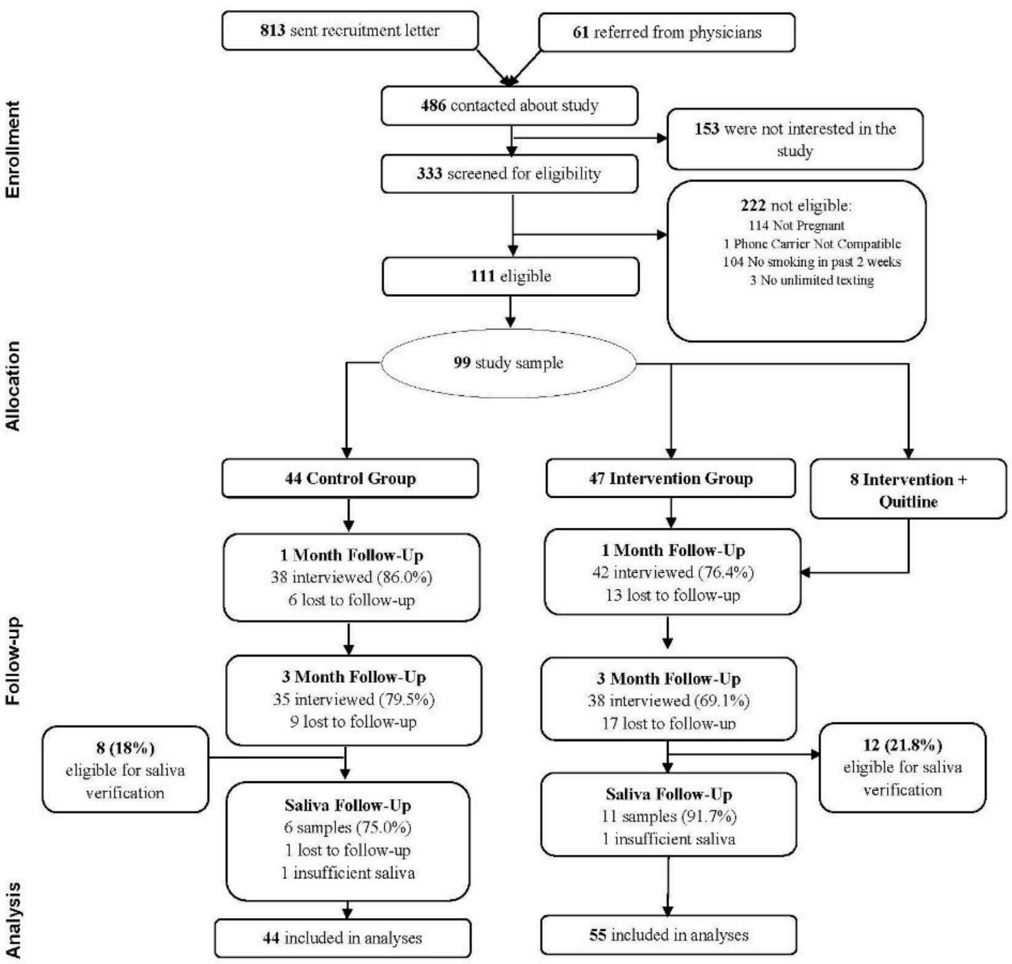

Table 2. Demographic characteristics of participants.

Baseline characteristics	Intervention, n=55	Control, n=44	Total, N=99
Age, mean (SD)	27.18 (4.98)	28.25 (4.78)	27.66 (4.90)
Race/ethnicity, n (%)			
White	32 (58.18)	23 (52.27)	55 (55.56)
African American	22 (40.00)	18 (40.91)	40 (40.40)
Other	1 (1.82)	3 (6.82)	4 (4.04)
Education[a] , n (%)			
12th grade or less with no high school diploma	17 (30.91)	9 (20.45)	26 (26.26)
High school graduate or equivalent	15 (27.27)	11 (25.00)	26 (26.26)
Some college	20 (36.36)	10 (22.73)	30 (30.30)
Associates or higher	3 (5.45)	14 (31.82)	17 (17.17)
Employment status, n (%)			
Part time	6 (10.91)	7 (15.91)	13 (13.13)
Full time	19 (34.55)	15 (34.09)	34 (34.34)
Not at all	30 (54.55)	22 (50.00)	52 (52.52)
Household income in US $, n (%)			
$15,000	22 (40.00)	18 (40.91)	40 (40.40)
$15,001-$30,000	14 (25.45)	13 (29.55)	27 (27.27)
$30,001-$47,099	8 (14.55)	5 (11.36)	13 (13.13)
≥$47,100	10 (18.18)	7 (15.91)	17 (17.17)
Marital status, n (%)			
Single, never married	26 (47.27)	20 (45.45)	46 (46.46)
Living with significant other	16 (29.09)	12 (27.27)	28 (28.28)
Married	11 (20.00)	9 (20.45)	20 (20.20)
Divorced/separated, widowed	2 (3.64)	3 (6.82)	5 (5.05)
Gestational age (in weeks), mean (SD)	22.15 (9.54)	20.51 (10.49)	21.42 (10.17)
Mobile phone ownership, n (%)	49 (89.09)	42 (95.45)	91 (91.92)
Social media: Facebook user, n (%)	49 (89.09)	36 (81.82)	85 (85.86)
Texts per day, n (%)	64.36 (113.61)	115.73 (334.24)	87.19 (238.31)
Cigarettes per day at baseline, mean (SD)	6.89 (4.86)	6.69 (5.38)	6.80 (5.07)
FTCD (0-10), mean (SD)	2.68 (2.15)	2.68 (2.24)	2.68 (2.17)
Baseline self-efficacy (1-7), mean (SD)	4.95 (1.74)	4.59 (1.86)	4.79 (1.79)
Smoked an e-cig in the past 30 days, n (%)	12 (21.82)	6 (13.64)	18 (18.18)
Alcohol consumption in past 30 days (≥1 drink), n (%)	5 (9.09)	3 (6.82)	8 (8.08)

[a]*P*<.01.

Results

As shown in Figure 1, 333 participants were screened for eligibility and 111 were found to be eligible. Reasons for ineligibility were not being pregnant (n=114), not smoking in the past 2 weeks (n=104), not having unlimited texting (n=3), and not having a phone carrier compatible with SmokefreeMOM (n=1). Of those eligible, 99 participants enrolled in the study (89.2%, 99/111). We randomized 44 participants to the control group and 55 participants to the combined intervention group; initially 47 were in the SmokefreeMOM group and 8 in the SmokefreeMOM + Quitline group. Follow-up rates were 80.8% for 1-month follow-up and 73.7% for 3-month follow-up. The majority (85%, 17/20) of eligible participants returned a valid saliva sample to biochemically verify smoking status.

Differences in follow-up rates were not statistically different between groups.

Participant Characteristics

Participant characteristics are presented in Table 2. Participants were on average 27.66 (SD 4.90) years old, predominantly white non-Hispanic (56%, 55/99) and African American (40%, 40/99), and on average, 21.42 weeks pregnant (SD 10.17) at the time of the enrollment. Over half the sample (53%, 52/99) had a high school diploma or less, and over half were not employed (53%, 52/99). The majority of the sample had a household income of US $30,000 a year or less (68%, 67/99). At the time of enrollment, participants smoked an average of 6.80 (SD 5.07) cigarettes per day and had an FTCD score of 2.68 (SD 2.17). About 18% (18/99) of the sample reported smoking an e-cigarette in the past 30 days at baseline. On average, participants sent or received 87.19 (SD 238.31) text messages per day prior to enrolling in the study. Intervention and control group participants were similar across all variables except for education, where more participants in the control group had an associate’s degree or higher and fewer with a high school diploma or less (*P*<.01).

Program Acceptability and Feasibility

As shown in Table 3, while participants in both groups rated the program favorably on a 5-point scale, there was a trend for the intervention group to provide higher ratings. The intervention group gave higher overall ratings to the program for the degree to which they would recommend it to a friend and for its helpfulness compared with the control group. Differences between groups were significantly different at 3-month follow-up for helpfulness (*P*=.003), with intervention group participants agreeing at a higher level (4.00) on average that the program was helpful compared with the control group (3.12). While the question was not asked of the control group, participants in the intervention group agreed at low levels that the program texts were a trigger for smoking: 1.76 (SD 1.22) for 1 month and 1.56 (SD 0.97) for 3 months. The acceptability of message frequency was found to be significantly different between intervention and control at both 1 month (*P*<.001) and 3 months (*P*=.002) with most intervention participants indicating that the number of texts was just the right number. At 1-month follow-up, 78% (31/40) of intervention participants reported that the number of text messages was just right compared with 52% (15/29) of the control participants. Control participants were more likely to say that texts were too few. At both time points, a high proportion of intervention participants reported reading all (100%) of the text messages: at 1-month follow-up, 78% (31/40) of participants reported reading all of the text messages and at 3 months, 82% (22/27) of participants reported reading all of the text messages.

Participants in the intervention group provided a variety of reasons for liking the program. The most common reason volunteered was that they liked the program for the content or information provided in the program (eg, information on the harms of smoking to the baby). This reason was followed by the social support provided (eg, support from the stories about other people’s quitting), the messages served as reminders, the messages provided encouragement, the help provided by the interactive tools such as the keywords GAME and FACT, general liking and finally, for other reasons (eg, the timing of the messages, the confidence for quitting from the messages). Participants also provided a variety of reasons for not liking the program including, in order of prevalence, nothing, the technical problems associated with receiving the program, the message frequency (eg, too many messages), the content of the messages (eg, messages were too congratulatory, information was repetitive), the texts were a trigger for smoking, and other reasons (eg, needed a human element, the timing was not good).

Based on computer records of intervention program use, few participants in the intervention group unsubscribed from the program with 2 participants unsubscribing by the 1-month follow-up and 1 additional participant unsubscribing by the 3-month follow-up. For engagement, intervention participants responded 3.49 times (SD 4.02) on average to the quit-status check-ins over the 3-month period, and 69% (38/55) of participants replied to the status check-in at least once. On average, participant replies lasted 28.96 days (SD 35.09) after enrollment.

Feasibility was measured by the presence of technical programs: 29% (12/42) of participants reported technical problems at 1-month follow-up and 13% (5/38) of participants reported technical problems at 3-month follow-up. Most of these problems involved not receiving the messages, not being able to get responses when they replied back to the program or used a keyword.

Use of Treatment and Resources

The use of treatments and resources for quitting at 1-month follow-up did not vary significantly across groups, with the exception of text messages from the study (*P*<.01), which was by design (see Table 4). Aside from the study-related text messages, over 20% of both groups reported using the study provided self-help materials. The control group did report using at higher rates other self-help materials (18% compared with 7%) (not significant) and “other” treatments and resources (21% compared with 2%) (*P*<.01). Other resources used by the control group included counseling from family members and friends, willpower, and eating sunflower seeds and candy. Both groups used one-on-one counseling (21%, 17/80), called the quitline (9%, 7/80), and used websites at similar rates (10%, 8/80).

Table 3. Program acceptability and feasibility.

Acceptability and feasibility	1-month follow-up			3-month follow-up		
	Intervention, n=42	Control, n=38	*P*	Intervention, n=38	Control, n=35	*P*
I would recommend the text(s) to a friend who was pregnant and smoking, mean (SD)	4.39 (1.09)	3.84 (1.42)	.07	4.32 (1.09)	3.74 (1.56)	.08
The text(s) was/were helpful in getting me to try to quit smoking, mean (SD)	3.70 (1.29)	3.07 (1.51)	.06	4.00 (1.09)	3.12 (1.65)	.003[a]
The texts were a trigger and made me want to smoke, mean (SD)	1.76 (1.22)			1.56 (0.97)		
Number of text messages, n (%)			<.001[a]			.002[a]
Too many	8 (20.00)	1 (3.45)		5 (17.24)	2 (6.06)	
Just the right number	31 (77.50)	15 (51.72)		20 (68.97)	12 (36.36)	
Too few	1 (2.50)	13 (44.83)		4 (13.79)	19 (57.58)	
Proportion of text messages read, n (%)						
100%	31 (77.50)	–	–	22 (81.48)	–	–
75%	9 (22.50)	–	–	3 (11.11)	–	–
≤50%	0 (0.00)	–	–	2 (7.41)	–	–
Liked about the program[b] , n (%)						
Content/information (eg, on harms of smoking)	18 (42.86)			13 (34.21)		
Social support/other’s people’s quitting stories	6 (14.29)			3 (7.89)		
Reminders	6 (14.29)			2 (5.26)		
Encouragement	4 (9.52)			2 (5.26)		
Interactive tools (eg, GAME, FACT)	4 (9.52)	–	–	5 (13.16)	–	–
General liking	4 (9.52)			5 (13.16)		
Other (eg, timing, confidence, made accountable)	4 (9.52)			5 (13.16)		
Disliked about the program[b] , n (%)						
Nothing	23 (54.76)			20 (52.63)		
Technical problems	6 (14.29)			2 (5.26)		
Message frequency (eg, too frequent)	3 (7.14)			2 (5.26)		
Content (eg, too congratulatory, repetitive)	2 (4.76)			1 (2.63)		
Text as trigger	2 (4.76)	–	–	0 (0.00)	–	–
Other (needed human element, timing)	4 (9.52)			0 (0.00)		
Total replies to quit day check-ins, mean (SD)	2.74 (3.29)	–	–	3.49 (4.25)	–	–
Unsubscribed from the program	2 (4.76)	–	–	1 (2.63)	–	–
Experienced any technical problems	12 (28.57)	2 (5.26)	.006[a]	5 (13.15)	2 (5.71)	.28

[a] *P* values are statistically significant.

[b] Participants could select multiple reasons.

Table 4. Use of treatments and resources for quitting at 1 month.

Quit treatment and resources[a]	1 month, n (%)		
	Intervention, n=42	Control, n=38	Total
Telephone help/quitline	4 (9.52)	3 (7.89)	7 (8.75)
One-on-one counseling	9 (21.43)	8 (21.05)	17 (21.25)
Study-provided self-help materials	10 (23.81)	9 (23.68)	19 (23.75)
Other self-help materials	3 (7.14)	7 (18.42)	10 (12.50)
Quit smoking website	4 (9.52)	4 (10.53)	8 (10.00)
E-cigarettes	6 (14.29)	3 (7.89)	9 (11.25)
Text messages from this study[b]	31 (73.81)	4 (10.53)	35 (43.75)[c]
Text from another program	1 (2.38)	1 (2.63)	2 (2.50)
Use of medication	1 (2.38)	0 (0.00)	1 (1.25)
Others[b]	1 (2.38)	8 (21.05)	9 (11.25)[c]
None of the above	5 (11.90)	9 (23.68)	14 (17.50)

[a] Responses are not mutually exclusive.

[b] Statistical significance.

[c] *P*<.01.

Table 5. Smoking-related outcomes by time period.

	1-month follow-up		3-month follow-up	
	Intervention, n=55	Control, n=44	Intervention, n=55	Control, n=44
Biochemically confirmed 7-day PPA[a], n (%)			8 (14.55)	4 (9.09)
Not smoked in past 7 days[a], n (%)	11 (20.00)	7 (15.90)	14 (25.45)	8 (18.18)
Not smoked in past 30 days[a], n (%)	6 (10.91)	1 (2.27)	9 (16.36)	7 (15.91)
Consecutive days quit, mean (SD)	9.58 (11.17)	5.95 (8.21)	27.24 (32.19)	17.85 (23.24)
Quit attempt (≥24 hours), n (%)	32 (58.18)	22 (50.00)	26 (47.3)	30 (68.2)
Cigarettes smoked/day, mean (SD)	3.95 (4.85)	3.46 (3.34)	2.82 (3.83)	4.26 (4.80)
Change in cigarette per day from baseline, mean (SD)	-2.74 (3.70)	-2.86 (4.79)	-3.15 (3.68)	-2.61 (4.96)
Self-efficacy (1-7), mean (SD)	5.44 (1.83)	5.28 (1.71)	5.41 (1.76)	5.03 (1.70)
Change in self-efficacy, mean (SD)	0.39 (1.63)	0.34 (1.80)	0.34 (1.99)	0.39 (2.00)

[a] Missing data were imputed to indicate smoking.

Smoking Outcomes

Table 5 summarizes the unadjusted smoking-related outcomes. Adjusting the dichotomous smoking outcomes for baseline differences in education did not significantly change the results. At both 1-month and 3-month follow-up, there were no significant differences in any of the smoking-related outcomes between groups, including biochemically confirmed 7-day PPA, self-reported 7-day and 30-day abstinence, consecutive days quit, quit attempts, and changes in cigarettes smoked/day. Though not significantly different, results were favorable to the intervention group at 3 months on biochemically confirmed 7-day PPA with 15% (8/55) of the intervention group reporting abstinence compared with 9% (4/44) of the control group and on consecutive days quit with the intervention group reporting 27.24 (SD 32.19) days quit compared with 17.85 (23.24) days quit in the control group. Change in self-efficacy was not significantly different between groups.

Discussion

Principal Findings

This study aimed to assess the acceptability and feasibility of an existing national text-messaging program, SmokefreeMOM, with pregnant smokers recruited from prenatal clinics. Results indicate that SmokefreeMOM was rated highly and more favorably than a control condition that consisted of a single text message in its helpfulness at 3-month follow-up and in its frequency of messaging at both time points. Among the intervention group participants, messages were read at high rates and participants unsubscribed from the program at low rates. Nonetheless, almost 30% of participants experienced some technical problems with the program during the study period, largely related to not being able to get responses from the automated system after replying to queries or sending in keywords. There were no significant differences between groups on use of extra treatment resources or on smoking-related outcomes, though some outcomes favored the intervention group at 3-month follow-up.

Consistent with findings of other studies of text messaging for smoking cessation in pregnant women [19-21], it was encouraging to find that overall the program was rated favorably. SmokefreeMOM participants stated that the number of messages sent was appropriate and messages were read at high rates. They noted that they liked the program for several reasons including the information provided by the messages such as the harms of smoking to the baby, the social support from the program, and the constant reminders about quitting. Participants also noted some negative aspects of the program. A couple of participants noted that program messages were a trigger for smoking. While this had been reported in other text-messaging programs for smoking cessation [16,30], a public health intervention should not have deleterious effects on any of its participants, and the possible triggering caused by messages is worthy of future investigation. In addition, participants noted that they experienced technical problems. Still, despite these technical problems, the majority of participants replied to the status check-in at least once during the study period, and on average, participants replied 3 times. Health promotion programs that stimulate interaction and engagement have generally been found to be more likely to result in behavior change [31]. Given the difficulty associated with engaging pregnant smokers [7,18], the findings for interaction are encouraging for the SmokefreeMOM program.

It should also be noted that while the SmokefreeMOM program was rated favorably on most measures, there were no significant differences between SmokefreeMOM and the control condition on likelihood of recommending the program to a friend. This may imply that one text message with a quitline referral may be helpful compared with currently available services in prenatal care and that a fully developed program like SmokefreeMOM may be unnecessary. As prior studies have not used a lower intensity text-messaging program as their control [19-21], the utility of such an intervention based on a single text remains an open question.

The presence of technical problems in interacting with the system is also a lesson. Almost a third of participants reported technical problems, primarily related to replying to program messages. Though the program was tested prior to the launch of the study, it was not tested continuously during the study, and study staff was not aware of these problems until after study completion. To avoid technical problems, future programs should check the proper functioning of the system not only initially but repeatedly throughout the study period. It remains an open question whether the same program without technical problems would have resulted in higher levels of engagement and more favorable smoking-related outcomes.

The study was not powered to detect differences in smoking-related outcomes, and unlike prior studies [19-20], none were detected. As most indicators of acceptability are promising and the technical problems encountered have been resolved, future studies may wish to investigate the efficacy of SmokefreeMOM with larger samples of pregnant smokers. It remains unclear whether such programs are helpful in the context of prenatal care where other types of assistance may be readily available, though a prior study indicates that it may be promising [21].

One final finding of note was that few participants—9% (7/80) of all participants—reported receiving extra treatment help in the form of help from the quitline. This was in spite of a clear effort to get all participants to call the quitline. For the control group, the only text message they received was a referral to the quitline with the number provided on their phone. For the intervention group, text messages repeatedly referred participants to the quitline, including every time they indicated that they were having difficulty quitting. Additionally, 8 participants who were later included as part of the intervention group were connected (n=8) via fax enrollment to the quitline. Of these, only 2 reported receiving quitline services. This low level of use of quitline services use may indicate that this service is not appealing or not congruent with the lives of pregnant smokers. This may be because for low-income smokers, quitline services may consume almost a third of mobile phone talk minutes [32]. As quitlines remain a dominant public health strategy for pregnant smokers, this finding warrants further exploration and may point to the need to develop novel services that better fit with communication preferences of pregnant smokers [9].

Strengths and Limitations

A main strength of this study is that this study is the first evaluation of a program that is nationally available for pregnant smokers—a group that is high-risk, underserved, and in need of new treatments. Other strengths include the use of a control group, biochemical verification of self-reported smoking status, and overall good follow-up rates.

Limitations include that recruitment was a challenge for this study. The primary mechanism for identifying potential participants was by generating a list of potential participants using the pregnant and smoking fields in the EHR. The majority of potential participants identified and later screened were found to not be pregnant or smokers. This points to the limitations of relying on EHR records for recruitment. In addition, because of difficulties with recruitment, we discontinued enrollment in one of the planned groups of the trial (SmokefreeMOM + Quitline group) 2 months after the start of the trial. Participants from this group were fax enrolled in quitline services (n=8) and may have received additional services that shaped their rating of the program and smoking-related outcomes. However, as only 2 participants from this group received counseling services from the quitline, the effect of the additional quitline service is likely limited. Another limitation is that while the intervention was aimed at pregnancy cessation, by 3-month follow-up some women gave birth during the study period (n=20: 7 in intervention and 13 control). As birth of a baby is a significant risk factor for smoking relapse, it remains unclear what the impact of the birth was on study outcomes. Additionally, as noted earlier, the SmokefreeMOM program experienced technical problems during the study period, which may have minimized the effect of the intervention. Furthermore, the study results may not be generalizable to all pregnant smokers as participants had the following characteristics: they had disclosed their smoking status to their medical provider, were from a mid-Atlantic metropolitan area, and on average were 21.42 weeks pregnant.

Conclusions

The findings of this study show that a text-messaging program that makes use of interactive text messages timed around the quit date and a baby's due date is acceptable to pregnant smokers. Given the evidence for the efficacy of text messaging for smoking cessation in adult smokers [11-13] and emerging evidence in pregnant smokers [19-21], it is recommended that SmokefreeMOM be further refined and a future study be designed to evaluate whether this free and readily available resource can promote cessation in pregnant smokers.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

CONSORT-EHEALTH checklist V1.6.1 [32].

[PDF File (Adobe PDF File), 413KB - jmir_v19i10e333_app1.pdf]

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Abbreviations

CDC: Centers for Disease Control and Prevention
EHR: electronic health record
FTCD: Fagerstrom Test for Cigarette Dependence
GWU MFA: George Washington University Medical Faculty Associates
GWU: George Washington University

NCI: National Cancer Institute
PPA: point prevalence abstinence

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Original Paper

An International Study on the Determinants of Poor Sleep Amongst 15,000 Users of Connected Devices

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Abstract

Background: Sleep is a modifiable lifestyle factor that can be a target for efficient intervention studies to improve the quality of life and decrease the risk or burden of some chronic conditions. Knowing the profiles of individuals with poor sleep patterns is therefore a prerequisite. Wearable devices have recently opened new areas in medical research as potential efficient tools to measure lifestyle factors such as sleep quantity and quality.

Objectives: The goal of our research is to identify the determinants of poor sleep based on data from a large population of users of connected devices.

Methods: We analyzed data from 15,839 individuals (13,658 males and 2181 females) considered highly connected customers having purchased and used at least 3 connected devices from the consumer electronics company Withings (now Nokia). Total and deep sleep durations as well as the ratio of deep/total sleep as a proxy of sleep quality were analyzed in association with available data on age, sex, weight, heart rate, steps, and diastolic and systolic blood pressures.

Results: With respect to the deep/total sleep duration ratio used as a proxy of sleep quality, we have observed that those at risk of having a poor ratio (≤0.40) were more frequently males (odds ratio $[OR]_{\text{female vs male}}$=0.45, 95% CI 0.38-0.54), younger individuals ($OR_{>60 \text{ years vs } 18\text{-}30 \text{ years}}$=0.47, 95% CI 0.35-0.63), and those with elevated heart rate ($OR_{>78 \text{ bpm vs} \leq 61 \text{ bpm}}$=1.18, 95% CI 1.04-1.34) and high systolic blood pressure ($OR_{>133 \text{ mm Hg vs} \leq 116 \text{ mm Hg}}$=1.22, 95% CI 1.04-1.43). A direct association with weight was observed for total sleep duration exclusively.

Conclusions: Wearables can provide useful information to target individuals at risk of poor sleep. Future alert or mobile phone notification systems based on poor sleep determinants measured with wearables could be tested in intervention studies to evaluate the benefits.

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KEYWORDS

connected devices; sleep; Withings; Nokia; determinants; Internet of Things; epidemiology; wearables; lifestyle; blood pressure; steps; heart rate; weight

Introduction

Extreme sleep duration has been increasingly recognized as a behavioral factor of interest, along with diet, physical activity, and being overweight, involved in the pathogenesis of various chronic noncommunicable diseases such as cancer [1,2], type 2 diabetes [3-5], and hypertension [6]. Sleep has been shown to be influenced by age, sex, obesity [7], hypertension [6], physical activity [8], alcohol consumption [9], and anxiety [10,11]. Poor sleep has been shown to have similar effects on health as major sleep disorders but is often neglected in primary and tertiary prevention programs [12].

As a lifestyle-related and modifiable factor, sleep can be a target for efficient intervention studies to improve the quality of life [13] and health of people [14,15]. Therefore, knowing the profiles of individuals with poor sleep quantity or quality is a prerequisite for an optimal identification of key populations of interest. However, in large cohort studies, sleep is often evaluated through self-report as the number of hours that participants typically sleep per night [16]; little is known about the duration of deep sleep or the quality of sleep.

As the information and communication technology market has exploded in recent years, more and more wearable activity trackers provide information about sleep but with limited evidence of their accuracy [17,18]. Information about sleep is estimated thanks to proprietary algorithms from data generated from in-built accelerometers to determine sleep parameters. It has been shown that some fitness trackers overestimate total sleep time when evaluated by polysomnography, in particular on nights with more disrupted sleep [19], and that they tend to underestimate sleep disruptions and overestimate total sleep times and sleep efficiency in normal subjects [20-22]. Nevertheless, previous work has suggested that trackers can be a low-cost and wide-availability alternative to standard activity monitoring of daily sleep-wake rhythms over several days, especially in large population or cohort studies.

Therefore, based on data from an international sample of sleep information from more than 15,000 customers of the consumer electronics company Withings (now Nokia), we have evaluated several determinants of poor total and deep sleep quantity and determined a ratio of deep/total sleep duration that indicates poor sleep.

Methods

Study Sample and Available Data

The population was composed of a sample of 16,441 Withings highly-connected customers—those who had purchased at least 3 Withings devices (a Pulse activity tracker [23,24], a Body weighing scale [25], and a BP-800 blood pressure monitor [26]) and had some data on sleep [27] available between July 1, 2013, and April 1, 2016. Individuals were excluded from the analysis if they did not have 7 consecutive days of complete sleep data. We excluded a few individuals with missing or unlikely information on weight, heart rate, steps [28], and diastolic or systolic blood pressure prior to the selected week of sleep evaluation. After these few exclusions, the final study sample was composed of 15,839 individuals (13,658 males and 2181 females).

Assessment of Sleep

We selected the first 7 consecutive days with complete data on sleep available and computed the average duration of total and deep sleep per night. Sleep duration is defined thanks to a proprietary algorithm using data provided at a minute-level from both the accelerometer and the temperature sensor present inside the wearable (the body temperature drops during sleep). Deep sleep is further defined based on the information provided by the accelerometer in the device and corresponds to a period with a lower motion quantity. The ratio of deep/total sleep duration was also derived from average duration of total and deep sleep durations. Binary variables were then computed to categorize individuals' sleep as short or adequate. We used the common threshold of 6 hours per night to define a short total sleep duration [29]. Short deep sleep duration was defined as lass than 3 hours per night, which is the closest integer to the 1st quartile of the deep sleep duration distribution in our study. Similarly, a ratio of deep/total sleep duration indicating poor sleep was defined as below 0.40, which corresponds to the 1st quartile of the distribution.

In the dataset, information on age (18 to 30 years, 31 to 40 years, 41 to 50 years, 51 to 60 years, and >60 years), sex, weight (kg), heart rate (bpm), steps (n/day), diastolic blood pressure (mm Hg), systolic blood pressure (mm Hg) was available. As our exposure, we used the average value of all the data available in the month prior to the week of sleep considered.

Statistical Analysis

Characteristics of the study population were described according to categories of total sleep, deep sleep, and ratio of deep/total sleep duration and are displayed in Table 1. Logistic regression models were computed and odds ratios (OR) and their 95% confidence intervals (CI) were estimated. Multivariate models were adjusted for age, sex, weight, heart rate, steps, diastolic blood pressure, and systolic blood pressure (Table 2). SAS 9.4 (SAS Institute) software was used. Statistical tests were 2-sided, and *P* values were considered significant if *P*<.05.

Results

Characteristics of the Study Population

As described in Table 1, individuals with a low total sleep duration (≤6 hours) were more frequently males aged between 31 and 60 years with greater weight, heart rate, and number of steps than those with a high sleep duration, whereas average blood pressure was rather similar between the 2 groups. Concerning deep sleep duration, those with a duration ≤3 hours were also more frequently males but more frequently aged 51 years or more. They were also characterized by a greater weight, heart rate, number of steps per day, and blood pressure compared to those with a high deep sleep duration. Finally, individuals with a low deep/total sleep duration ratio were more frequently males aged between 31 and 50 years and had a greater weight, heart rate, and blood pressure and a lower number of steps.

Table 1. Characteristics of the study population (N=15,839).

Factors	Total sleep duration		Deep sleep duration		Deep/total ratio	
	≤6h n=4169	>6h n=11670	≤3h n=5845	>3h n=9994	≤0.40 n=3309	>0.40 n=12530
Age, years (%)						
18-30	1.66	2.22[a]	1.93	2.31[a]	3.08	1.80[a]
31-40	13.60	12.28	11.40	14.73	14.90	12.03
41-50	30.56	29.53	29.12	30.97	31.22	29.43
51-60	32.14	31.25	31.90	30.78	29.65	31.97
>60	22.04	24.72	25.66	21.21	21.15	24.77
Sex (% female), mean (SD)	10.75	14.85[a]	8.96	16.58[a]	7.89	15.32[a]
Weight (kg), mean (SD)	89.26 (19.35)	87.33 (18.19)	89.07 (18.93)	87.12 (18.23)	89.41 (19.01)	87.42 (18.37)
Heart rate (bpm), mean (SD)	71.32 (13.97)	70.26[b] (13.83)	71.27 (14.23)	70.12 (13.66)[b]	71.26 (14.29)	70.34 (13.76)[b]
Steps (n/day), mean (SD)	7237.32 (3333.24)	7159.29 (3193.64)	7245.94 (3231.00)	7141.00 (3230.60)	7146.26 (3143.14)	7188.00 (3253.93)
Diastolic blood pressure (mm Hg), mean (SD)	77.99 (10.16)	77.20 (9.71)	78.14 (10.08)	76.98 (9.67)	78.55 (10.14)	77.11 (9.73)
Systolic blood pressure (mm Hg), mean (SD)	126.03 (14.10)	125.15 (13.30)	126.08 (13.83)	124.98 (13.31)	126.92 (13.65)	124.98 (13.65)

[a] Chi-square and *t* tests were computed to compare percentages and mean values from qualitative and quantitative variables, respectively, between the low and high categories for total sleep duration, deep sleep duration and deep/total ratio.

[b] All the corresponding *P* values were below .001 except for the heart rate variable where they were all above 0.05.

Factors Associated With Poor Sleep

Age is strongly associated with sleep (see Table 2). Indeed, when compared to individuals aged between 18 and 30 years, the risk of poor total sleep was significantly increased up to the age of 60 years (OR 1.5, 95% CI 1.06-2.13) and tended to decrease for people age 60 years or more. Despite this, the linear trend is maintained (*P*=.024). On the other hand, age was not associated with a poor deep sleep duration except for the oldest category, where people aged 60 years or more had a lower risk of having a deep sleep less than 3 hours per night (OR 0.71, 95% CI 0.53-0.94). Finally, the risk of having a low sleep quality, evaluated by a deep/total sleep duration ratio below 0.40, decreased with age (*P*<.001). Individuals aged 60 years or more had a 53% reduction in the risk of having a low deep/total ratio (OR 0.47, 95% CI 0.35-0.63).

Women had a consistently lower risk of poor total sleep duration (OR 0.70, 95% CI 0.61-0.81), poor deep sleep (OR 0.51, 95% CI 0.45-0.58), and deep/total ratio (OR 0.45, 95% CI 0.38-0.54) compared to men. Weight was neither associated with deep sleep nor deep/total ratio. However, individuals with a weight over 98 kg, when compared to those under 75 kg, had a higher risk of having a poor total sleep duration (OR 1.17, 95% CI 1.03-1.33).

Aside from sex, heart rate was the most consistent factor associated with poor sleep. Indeed, high heart rate (>78 bpm) was associated with a poor total sleep quantity (OR 1.14, 95% CI 1.01-1.29), a poor deep sleep duration (OR 1.14, 95% CI 1.02-1.27), and a poor deep/total ratio (OR 1.18, 95% CI 1.04-1.34).

A high number of steps per day (>9028) and a high diastolic blood pressure (>83 mm Hg) were both associated exclusively with an increased risk of poor deep sleep (OR 1.13, 95% CI 1.01-1.27 and OR 1.21, 95% CI 1.06-1.39, respectively) when compared to a low number of steps and a low diastolic blood pressure but was not related to total sleep and deep/total ratio.

Systolic blood pressure was not related to total sleep or deep sleep but was associated positively with a poor deep/total ratio (*P*<.001). Individuals with a high systolic blood pressure (>133 mm Hg) had a 22% increased risk of having a deep/total sleep duration ratio below 0.40 (OR 1.22, 95% CI 1.04-1.43) when compared to those with a low one (≤116 mm Hg).

Table 2. Associations between cofactors and low total and deep sleep durations and deep/total ratio (N=15,839).

Factors	RIsk of low total sleep duration (≤6 hours)			Risk of low deep sleep duration (≤3 hours)			Risk of low deep/total ratio (≤0.40)		
	OR[a]	95% CI[b]	P value	OR	95% CI	P value	OR	95% CI	P value
Age, years			.024			<.001			<.001
18-30	1	Ref		1	Ref		1	Ref	
31-40	1.59	1.10-2.27		0.99	0.74-1.34		0.63	0.46-0.86	
41-50	1.46	1.03-2.07		0.83	0.63-1.11		0.54	0.40-0.73	
51-60	1.50	1.06-2.13		0.79	0.60-1.05		0.50	0.37-0.68	
>60	1.33	0.94-1.89		0.71	0.53-0.94		0.47	0.35-0.63	
Sex									
Male	1	Ref		1	Ref		1	Ref	
Female	0.70	0.61-0.81		0.51	0.45-0.58		0.45	0.38-0.54	
Weight (kg)			.002			.162			.992
≤75	1	Ref		1	Ref		1	Ref	
76-86	0.94	0.84-1.07		0.96	0.86-1.07		0.96	0.84-1.09	
87-98	0.98	0.86-1.11		0.97	0.87-1.09		0.92	0.80-1.05	
>98	1.17	1.03-1.33		1.05	0.94-1.18		0.97	0.85-1.12	
Heart rate (bpm)			.003			.005			.016
≤61	1	Ref		1	Ref		1	Ref	
62-68	1.00	0.89-1.12		1.02	0.91-1.13		1.01	0.89-1.15	
69-78	1.17	1.05-1.32		1.10	0.99-1.22		1.05	0.93-1.19	
>78	1.14	1.01-1.29		1.14	1.02-1.27		1.18	1.04-1.34	
Steps (n/day)			.170			.081			,441
≤4890	1	Ref		1	Ref		1	Ref	
4891-6737	0.95	0.84-1.07		1.00	0.89-1.12		1.00	0.88-1.14	
6738-9028	1.05	0.93-1.18		1.09	0.98-1.22		0.97	0.85-1.10	
>9028	1.07	0.94-1.20		1.13	1.01-1.27		0.99	0.87-1.13	
Diastolic blood pressure (mm Hg)			.083			<.001			.005
≤70	1	Ref		1	Ref		1	Ref	
71-77	1.03	0.91-1.17		0.95	0.85-1.06		0.91	0.79-1.04	
78-83	1.05	0.92-1.20		1.06	0.93-1.19		1.01	0.87-1.17	
>83	1.10	0.95-1.28		1.21	1.06-1.39		1.12	0.95-1.32	
Systolic blood pressure (mm Hg)			.305			.222			<.001
≤116	1	Ref		1	Ref		1	Ref	
117-124	0.93	0.82-1.05		0.98	0.87-1.09		1.08	0.94-1.24	
125-133	0.98	0.86-1.12		0.96	0.85-1.08		1.15	0.99-1.33	
>133	0.99	0.85-1.14		1.00	0.88-1.15		1.22	1.04-1.43	

[a] OR: odds ratio.

[b] CI: confidence interval.

Discussion

Principal Findings

Based on data from more than 15,000 highly connected Withings customers, we were able to study factors associated with poor sleep, evaluated by the total sleep duration, the deep sleep duration, and the deep/total ratio as a proxy of sleep quality.

We approximated sleep quality with the deep/total sleep duration ratio. Those at risk of having a ratio value indicating poor sleep were males, younger individuals, and those with elevated heart rate and systolic blood pressure. It is usually reported that women have a poorer self-reported sleep quality when compared to men, especially when aged older than 50 years [30].

In accordance with our findings, heart rate and its variation, which are modulated by the combined effects of the sympathetic and parasympathetic nervous systems, have been previously associated with poor sleep [31]. In a previous report, blood pressure was not associated with sleep duration [29], which is consistent with our findings with total sleep duration, but we did find an association between diastolic blood pressure and poor deep sleep and another between systolic blood pressure and deep/total sleep duration ratio. It has been previously shown that women tended to report poorer quality of sleep than men [30,32]. Indeed, the poorer self-reported sleep quality in women appears to be partly mediated by their increased risk of depression and anxiety symptoms and in part to social factors such as socioeconomic status [33]. In comparison to self-report, women tend to have better sleep than men across a wide age range when sleep is evaluated with polysomnographic recordings, suggesting that objective and subjective assessments are tapping into different constructs of sleep. We are in agreement with the latest point. The decreased risk of poor sleep observed in women in our work raises the fact that passive information collected from connected devices can actually help to capture a more objective measure of sleep quality than the subjective measure collected by questionnaire. Therefore, these devices could serve as substitutes to polysomnography measurements at a much lower cost in large real-life observational or intervention studies.

Strengths and Limitations

This study has some limitations. First, the study sample was mainly composed of men; a similar study should be reproduced in another population with a larger proportion of women. The analysis was also limited by the number of factors available to identify determinants associated with sleep. Some of these factors such as the sleep duration and number of steps can also be prone to biases in specific situations. Unfortunately, we did not have access to the algorithm for sleep evaluation or other determinants, so we were not able to retrieve information on how these variables were computed. But previous validation studies demonstrated that the correlation between total sleep duration evaluated by Withings devices and polysomnography, considered here as the gold standard in sleep evaluation, was strong (rho=0.94) [27]. Similarly, a high correlation between data on steps from the Withings Pulse activity tracker and an ActiGraph GT3X+ (rho=0.99) has been previously reported [34]. Nevertheless, our results confirm that the connected devices can be a useful tool to track sleep in large populations and identify sleep determinants and associated risk factors [35].

Perspectives and Conclusion

We have been able to highlight several factors associated with either total or deep sleep duration and with the ratio deep/total sleep as a proxy of sleep quality. Because poor sleep is one of the lifestyle factors that is often neglected but in our modern society is associated with many chronic conditions, providing useful services to decrease its prevalence can be easily implemented through wearables devices. Even if these devices are imperfect, this study has shown as a proof of concept for further large population studies that tracking physical activity, anthropometry, and sleep with the help of mainstream connected devices is feasible and rich with information. We recommend other studies replicate our findings to have a consistent set of determinants of poor sleep measured from connected devices in different subpopulations.

Besides, these wearables could serve as prevention tools—for instance, with an alert or mobile phone notification system based on poor sleep risk factors. Such a service could be evaluated in future intervention studies to quantify its benefits in terms of improvement of sleep quality and quantity.

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Authors' Contributions

All persons who meet authorship criteria are listed as authors, and all authors certify that they have participated sufficiently in the work to take public responsibility for the content including participation in the concept, design, analysis, writing, or revision of the manuscript. Furthermore, each author certifies that this material or similar material has not been and will not be submitted to or published in any other publication. The authors have contributed as follows: conception or design of the work (GF), data

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Conflicts of Interest

None declared.

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Abbreviations

CI: confidence interval
OR: odds ratio

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Original Paper

Consumer Health-Related Activities on Social Media: Exploratory Study

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Abstract

Background: Although a number of studies have investigated how consumers use social media for health-related purposes, there is a paucity of studies in the Australian context.

Objective: This study aimed to explore how Australian consumers used social media for health-related purposes, specifically how they identified social media platforms, which were used, and which health-related activities commonly took place.

Methods: A total of 5 focus groups (n=36 participants), each lasting 60 to 90 minutes, were conducted in the Sydney metropolitan area. The group discussions were audiorecorded and transcribed verbatim. The transcripts were coded line-by-line and thematically analyzed.

Results: Participants used general search engines to locate health-related social media platforms. They accessed a wide range of social media on a daily basis, using several electronic devices (in particular, mobile phones). Although privacy was a concern, it did not prevent consumers from fully engaging in social media for health-related purposes. Blogs were used to learn from other people's experiences with the same condition. Facebook allowed consumers to follow health-related pages and to participate in disease-specific group discussions. Wikipedia was used for factual information about diseases and treatments. YouTube was accessed to learn about medical procedures such as surgery. No participant reported editing or contributing to Wikipedia or posting YouTube videos related to health topics. Twitter was rarely used for health-related purposes. Social media allowed consumers to obtain and provide disease and treatment-related information and social and emotional support for those living with the same condition. Most considered their participation as observational, but some also contributed (eg, responded to people's questions).

Conclusions: Participants used a wide range of social media for health-related purposes. Medical information exchange (eg, disease and treatment) and social and emotional support were the cornerstones of their online activities. Social media appears to be used as a key tool to support disease self-management.

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KEYWORDS

social media; social networking sites; Facebook; YouTube; Wikipedia; Twitter; health; consumers; patients; focus groups

Introduction

Since the mid-1990s, the Internet has become widely available enabling consumers (including patients) to freely search for health-related information. This increased access has changed the role of consumers from passive recipients to active consumers of health information [1]. Initially consumers obtained health information from the Web on a noninteractive, unidirectional platform. However, with the advent of social media, consumers not only access but also create and share online content. As a result, it has been claimed that social media has supported a shift from the informed patient to the participative patient [2]. Social media can be defined as Web-based technologies and applications whose content is created by the users [3]. It can be divided into content sharing platforms (eg, blogs, YouTube, Wikipedia) and relationship building platforms (eg, Facebook, LinkedIn) [4]. The latter primarily consist of social networking sites, social media platforms in which users create a profile and establish connections with other users within it, creating a network [5].

The interactive and participatory nature of social media has afforded consumers not only a greater opportunity to access health-related information but also a venue to provide health-related content to others [6]. Although online communities existed before the advent of social media, the appearance of social networking sites fostered its growth, and they have become very popular [7]. Disease symptoms, complications and prognosis, examinations, and treatments are popular topics discussed in these online communities [8]. One very popular social media platform widely used for health-related purposes is Facebook, where a wide array of health topics, pages, and groups is present [9]. Studies have shown that interactions among peers in these online groups have been beneficial for those living with chronic conditions such as diabetes [10,11], epilepsy [12], and breast cancer [13,14]. In these online communities people can provide and receive social support, cultivate companionship, exert social influence, and communicate with one another [15,16]. As chronic conditions are currently the leading cause of morbidity and mortality [17,18], it is important to fully comprehend how social media is being used for health-related purposes in order to optimize its use and implement new ways of supporting its application for health promotion. As long-term use of medications is a key component of chronic disease management, it is also imperative to investigate how online interactions between peers influence medication-related decisions.

Previous research has provided a limited understanding of the different social media platforms consumers use for health-related purposes, particularly in the Australian context. Understanding current online health practices of consumers is important for the development of online health resources and services. This research was designed to investigate consumer self-reported participation in social media and other online forums, with the specific objectives of (1) investigating how consumers identify social media platforms for health-related purposes, (2) exploring the social media platforms used, and (3) examining the health-related activities that commonly take place.

Methods

Focus Groups

A qualitative study was undertaken using semistructured focus groups to explore consumer experiences, opinions, and perceptions about their use of social media for health-related purposes. Specifically, the group discussions investigated how consumers identified and chose social media, what platforms they used, and what kind of information they were looking for and providing to others. A qualitative approach was chosen because it can expose subtleties and complexities about the topic under investigation that are often missed by more positivistic inquiries [19]. Focus groups are more advantageous than surveys because participants do not have to write their answers down, which can be time consuming, and therefore they may provide more information with more explanations and detail. The facilitator can gain further information from them, participants can seek clarification if they do not understand a question (which they cannot do when completing a self-reported survey), the facilitator can ask follow-up questions and seek clarification from participants based on the responses provided, and other participants present in the focus group providing their responses can trigger participants’ memory and therefore aid in obtaining more complete data. The focus groups were semistructured as the discussions were guided by an interview protocol (Multimedia Appendix 1) containing key, broad, open-ended questions allowing participants to elaborate on their responses. Focus groups are also advantageous compared to other qualitative methods. They are an efficient way of gathering the views of several individuals simultaneously [20] and uncovering important constructs that may not be tapped through individual interviews [21]. Focus groups are highly recommended for health services research [22]. In the field of pharmacy, they have been used to explore important areas of research such as consumers behaviors [23]. The literature also recommends further investigation about consumer online communication and participation in forums using qualitative methods such as focus groups and in-depth interviews [24]. Therefore, focus groups were selected as the most appropriate research method. This study received approval from the University of Sydney Human Research Ethics Committee prior to its commencement.

Participants and Recruitment

Inclusion Criteria

Participants in this study consisted of adults aged 18 years and older with chronic conditions (ongoing health problems that have occurred for 3 months or longer) managed by medications [25]. Even though certain chronic conditions can be managed without medication, this study required participants to be on at least 1 chronic condition medication so that it would be possible to explore how they searched for, discussed, and provided information about their medications and medical conditions on social media. Other study inclusion criteria were that participants had used social media to discuss health-related issues in the last 12 months and were able to participate in the study without the assistance of a translator.

Recruitment

A recruitment agency identified participants meeting the inclusion criteria from the metropolitan Sydney area. All participants received detailed information about the study background, aims, and researchers conducting the study. Out of 40 participants recruited, 36 took part in this study. Each participant was reimbursed Aus $80 (US $62) for their time and travel expenses. All participants received verbal and written information about their participation and a consent form.

Data Collection

The focus groups (n=5) were conducted in 3 distinct geographical areas of Sydney to capture consumers from a range of socioeconomic backgrounds. The focus groups were held in venues commonly used for meetings and group discussions. Upon arrival at the focus group venue, participants were provided with a participant information statement and asked to complete a consent form and demographic questionnaire. Discussions lasted between 60 and 90 minutes and were facilitated by PA, a female pharmacist and academic experienced in conducting focus groups. Discussions were audiorecorded with permission from all participants. Notes were taken in order to facilitate data analysis. Focus groups were conducted until data saturation [26] was observed, which was at the conclusion of the fourth focus group. One extra focus group was conducted for validation purposes.

Data Analysis

The analytical process started during and in parallel with data collection [27]. Note-taking during the focus groups and debriefing after each session ensured that important information was not missed and constituted a preliminary analysis [21]. All discussions were audiotaped and transcribed verbatim with tracking of individual speakers, without identifying the individual. The qualitative data from the focus groups were analyzed using the inductive approach of thematic analysis [28] to derive themes and subthemes. Themes are “best used to describe an integrating, relational statement derived from the data that identifies both content and meaning” [29]. Additionally, some of the findings were descriptively analyzed as described by Sandelowski [30], as these findings were best suited to descriptive rather than thematic analysis (eg, what social media platforms were used; where, when, and how frequently social media was accessed). Therefore, a blended approach combining descriptive and thematic analysis was employed to interpret the focus group discussions. This combination allowed for the description of findings that did not lend themselves to being thematically analyzed and for the derivation of themes and subthemes through the iterative process of comparing and contrasting the codes within and between the focus groups. All discussions were coded by AB, and the coding process, including its classification into themes and subthemes, was discussed with PA. Repeated reading of notes and transcriptions was the first analytical step in order to gain familiarity with the data and knowledge of the content in each group. Next, the transcriptions were coded line-by-line with the assistance of NVivo 11 (QSR International) computer software. The coding process was open and not restricted by theoretical framework. It was dynamic and iteratively evolving throughout the analysis. An inductive approach [31] assured a data-driven process. Codes with a repeated pattern across the data (ie, codes with similar or nearly similar meanings) were collated and grouped into subthemes and later assembled into overarching themes. Themes were carefully named according to their overall content.

Results

Participant Characteristics and Major Themes

A total of 36 participants took part in 5 focus groups (Multimedia Appendix 2). Overall, there were slightly more men (19/36, 53%), with the majority of participants having been born in Australia (26/36, 72%). Participants had a range of different chronic disease states including hypertension, depression, anxiety, cancer, arthritis, and Crohn disease.

Thematic analysis of the focus group discussions identified 7 key themes related to the objectives. The emerging themes and their subthemes are presented in this section together with illustrative quotes. Table 1 provides a summary of the themes derived from the data organized according to the respective study objectives.

Table 1. Themes derived from the data.

Study objectives	Themes	Major qualitative analysis employed
Investigate how consumers identify social media platforms for health-related purposes	Search facilitates and precedes access to social media platforms	Descriptive
	Social media has ill-defined boundaries	Thematic
Explore the social media platforms consumers used	Social media platforms used for health-related purposes	Descriptive
	Access to social media platforms	Descriptive
Explore the health-related activities that commonly take place	Health-related activities that take place on social media • Getting more information • Fulfilling a social need	Thematic
	Observing versus posting	Descriptive
	Social media identity and privacy	Thematic

Search Facilitates and Precedes Access to Social Media Platforms

Overall, 2 approaches were adopted for accessing social media for health-related purposes. The most popular method was to use a general search engine such as Google. As consumers were using search engines to search for health information (eg, condition and treatment), they ended up finding online platforms where they could not only learn from peer experiences but also interact with other consumers. The top hits on the first page were generally the most frequently accessed ones. Subsequent pages would be accessed only when nothing of interest could be found in the first one. A shortcut to finding online health forums was to insert the word “forum” along with other key terms, such as disease name.

The second search approach was to use the social media platform itself. For example, in order to find disease-specific groups or related pages within Facebook, participants would use the Facebook search engine feature and type in the disease for which they were searching. Regardless of which strategy was used, most participants resorted to a general search engine for further research on the topic of interest.

Social Media Has Ill-Defined Boundaries

This research did not aim to systematically assess participant understanding of social media. However, it was observed that in some cases, the concept had no clear boundaries with other online platforms. When asked about their use of social media, several participants mentioned websites not technically classified as social media, such as search engines, Internet browsers, and health websites. For example, websites with some sort of user engagement or with a chat room were commonly mentioned: Medscape, Blue Board, Psych Central, WebMD, Mayo Clinic, and Beyondblue. Chat rooms, in particular, were used by several participants as a venue for interacting with peers dealing with the same condition. Participants were free to express and discuss their online behavior. However, when a misunderstanding about social media platforms was noticed or they spoke about nonsocial media platforms (eg, “dot.com” websites), they were refocused back to social media. Importantly, a user-friendly definition of social media with examples (eg, Facebook, YouTube, Wikipedia, blogs) was provided at the beginning of the discussion to ensure clarity in the discussion topic.

Social Media Platforms Used for Health-Related Purposes

Participants used a range of social media platforms for health-related purposes including Facebook, Wikipedia, YouTube, blogs, and Twitter.

Most participants were active on Facebook, and only a few did not have a Facebook profile. Some were members of disease-specific Facebook groups, such as an arthritis group, as their approach to using Facebook for health-related information. Some of these disease-specific groups had an international membership. The use of Facebook for health-related purposes was regarded as very convenient since such use was integrated into the general use of the platform.

> *...the good thing about Facebook is that it’s not just about your health issues. It’s about the whole world and all the groups that you're on. So you don’t have to sort of...you can just flick through it in the morning and cover everything.* [FG1, m4]

Belonging to a Facebook group was very practical as participants did not need to leave it to access health-related content by browsing different websites or platforms. The group activities appeared on their Facebook newsfeed.

Wikipedia was a source of health information frequently accessed by most participants. It also served as a way of reaching other sources of health information through its references and external links. Despite its common use, some participants expressed mistrust in the content found on the Wikipedia.

> *I always trusted it and then, I looked up something I knew the answer to, and it was wrong. And I thought ‘this is not good’...so, yeah, I’ve now taken a more...I’m not as wide-eyed when it comes to Wikipedia.* [FG2, f15]

As a consequence of not fully trusting Wikipedia, some consumers developed double-checking mechanisms for the information retrieved (ie, crosschecking the information found on Wikipedia with another online source.) Participants reported that they had not updated any Wikipedia content.

The majority of participants accessed video-sharing platforms, but very few used them for health-related reasons. YouTube, the only video-sharing platform cited, allows participants to access health information and peer experiences in a video format. The only use of YouTube for health-related reasons reported was to learn about medical procedures and to watch surgeries participants had undergone or were to undergo.

> *I wanted to know how that process was done, the ultrasound...and injecting, cortisone injection. So I wanted to know what the procedure was. So, I went through the whole thing.* [FG3, f17]

While the graphic details of health procedures in video footage were not attractive to some participants, the discussion sparked interest in accessing video footage for health-related purposes among those who had not used YouTube for that purpose to date. No participant had uploaded videos about their own health experiences.

> *I use YouTube but I never thought about [it] for health...but probably there must be something. I’m curious to see.* [FG3, f18]

Blogs were considered good platforms to learn about other people’s health experiences. Most participants would read blogs but not write on them. Only 1 participant was blogging about his own experiences with the disease and therapeutic breakthroughs in the area.

> *I like to blog my own experience so that others can relate and get the benefit. And if I find something which is innovative, then that’s something I would like to share. Because I tend to read a lot of medical journals, the original research findings.* [FG1, m6]

However, blog use was much less common among participants. Blogs were surpassed by newer platforms like social networking sites.

> *...since Facebook came along, blogs went out the window for me.* [FG2, m13]

A few participants reported using Twitter, mostly to access general information or news. Only 1 participant used Twitter to obtain medical information.

> *...talking about drugs and their effects. Legal drugs... Nobody follows me. But I follow them. I don't post anything but I read all that stuff.* [FG1, m1]

Access to Social Media Platforms

This theme describes how long participants had been accessing social media platforms, how often, how they were accessed, and when social media was used. The duration of time consumers had been using social media varied. While the majority reported having using it for a long time, some had started using it later, with a few participants reporting that they had only recently started using social media.

The frequency of social media use among participants ranged from "virtually on it all the time" to "a few times a week" to "daily" to "whenever you've got a pocket of time." The frequency of social media use was related to its availability on several electronic devices, such as computers, laptops, tablets, and mobile phones. The devices used for accessing online platforms varied depending on where participants were at the time of access (eg, traveling, at home, or at work). For example, portable devices, particularly hand-held ones like mobile phones, were commonly used for social media access during commuting time on public transportation, while laptops and tablets were mainly used at home, and desktops were mostly used at work.

For those working in offices, social media was constantly present on their computer screens. Facebook, for example, was accessed multiple times a day by those working in front of a computer. However, not everyone was comfortable using social media at work due to job restrictions or privacy concerns; some preferred to only access social media during their free evening time at home.

Some participants preferred to regularly access social media for health-related activities in the evenings at home, with one participant recognizing that it would be wise to allocate time to conduct online health-related activities.

> *I should be doing it when I'm on an even keel or probably allocating a certain amount of time to do proper research and understand a little bit more about the types and nature of the medications.* [FG, m13]

Most commonly, a new health problem or a disease flare-up were triggers for online engagement.

> *I've got Crohn's disease and it comes and goes. So, I could go for 6 months, I'm fine, I don't need to get any help. But, if I'm going through a bad period, and I'm finding it really hard going then I'll go on to forums, just look up anything that I can find, just to get me through.* [FG5, f34]

Indeed, it was expressed by a few participants that social media for health-related purposes was only used when needed.

> *I only go on it when I'm not well.* [FG5, f34]
>
> *I don't kind of scroll through this all the time, I only use it when I need it.* [FG5, m35]

Health-Related Activities That Take Place on Social Media

Reasons For Social Media Engagement

Several reasons were mentioned by participants for engaging in social media platforms for health-related reasons. Information (ie, accessing user-friendly health information, especially other people's experiences and treatment information) and social support (ie, relating to people with the same problem and providing and gaining encouragement) were the main motives for accessing social media for health-related purposes.

Getting More Information

Obtaining user-friendly health information was one of the major reasons for using social media for health-related purposes. Social media also had the advantage of being interactive, with participants being able to ask questions and provide answers and comments.

Participants were interested to know what other people with the same condition were being treated with and to learn about other people's experiences with the same medication.

> *I'm on medication of course I did some research on medication. And also, I just want to know what other people take and what they eat and what they do.* [FG2, f12]
>
> *I look for a testimonial, the history of using it [medication], the experiences they've had, the side effects, and so forth. Whether it was effective.* [FG2, m11]

Sometimes this represented a double-checking mechanism in order to verify if the medication prescribed for them really was the adequate course of action to be taken.

Side effects were a major trigger for online research, particularly when starting a new medication. Participants stated that the information presented on pharmaceutical company websites did not meet consumer needs since they provided too much general information, particularly for side effects. Therefore consumers preferred to hear what was really happening with people taking the medication.

> *...if it [side effect] really happens to people. So I think it's better to talk to somebody who is really using medication.* [FG3, f18]

Interacting on social media with peers influenced the way most participants perceived their treatment, which could in turn impact medication adherence.

> *...my wife says 'those new tablets the doctor gave me is giving me pains in the chest'...and I'll go 'let's have a look at that'...and all of a sudden there's a forum and 'don't take them.'* [FG2, m13]

Social media was also used to identify and learn about complementary and alternative medicines, especially as participants felt that doctors were reluctant to provide such options.

> *I go in and ask people 'what are you taking?' So it's not chemicals, not prescription drugs. And I've been*

> *suffering from GORD for years. And people start taking apple cider vinegar. So, every day I drink apple cider vinegar and I'm throwing the [medicine name] tablets away...with my wife's medication as well, I look to see if there's alternative medicines for her as well so we can start getting off prescription drugs.* [FG2, m13]

Provision of incomplete health information from health care professionals was another reason for resorting to online sources

> *...there is a forum that I basically sometimes belong to on Facebook, for one condition, my arthritis...so, when I'm considering a medication, when I'm concerned about a contradiction, because I find my doctor, despite his best efforts, is not very thorough. Same with the pharmacist.* [FG2, m11]

Fulfilling a Social Need

An important activity reported was to gain social and emotional support from others with the same problem, particularly after receiving a diagnosis of a chronic condition, to feel that "this is not the end of the world" (FG1, f5).

It was emphasized that getting support from people going through the same health problems was really important because people could easily relate to one another. It was mentioned that although people receive help and support from family and friends, the fact that they were not experiencing that same problem themselves prevented them from completely understanding what the disease bearer was going through or experiencing.

Additionally, consumers were resorting to online support because they could not find the support they needed from their regular health services. This revealed a problem within the way the current health care system: a lack of a holistic approach to address consumer needs. It was revealed that participant needs were not only medical and therapeutic but also social.

> *...you find like-minded people, people you haven't met before but like posting things that are really helpful. And you feel like you can find supports there. And you can go into support groups. And like, actually meet up and stuff like that. So, I think that's really a great part of today's world. Like, I find it very hard to go to a support group within a hospital that a hospital organizes, but you can find...* [FG5, f32]

Observing Versus Posting

The majority of participant engagement in social media was observational (ie, accessing and reading health information rather than providing).

> *I don't usually post. I usually just go in to read other people's, to get experiences and see if I can learn something else about what's out there. If I'm trying out a new pump device, I'll try and get people's feedback about what their experiences with health insurance or with the pump itself have been.* [FG2, f10]

Participants refrained from contributing if they felt that they would not add new or relevant information.

> *I don't tend to give because I find a lot of it is already there. So, like, yeah, I'll just be repeating what other people [say]...* [FG3, m19]

A participant even expressed a feeling of guilt for not being an active contributor on online forums, especially as he gained information from them. Another participant raised the legal responsibility for medical advice on health-related social media groups as a reason for not providing information.

> *...because someone could say, I took his advice and now look at what it's done to me. It's made me so sick I want to sue them. I want to sue him for telling me the information.* [FG2, m9]

Nevertheless there were some participants who were very active in providing information, and in general, participants seemed to be willing to contribute as long as they considered themselves knowledgeable about the topic (disease condition or treatment). Those who were actively contributing were comfortable because most of the time the information shared was related to their own experiences.

> *I'm very comfortable because I'm not really giving out information. I'm just sharing what my experiences are. So I'm not really advising somebody this is what happens. I just say, well, this happened to me and this works for me, those sorts of things.* [FG1, m7]

Some participants expressed their approximate involvement: "80% absorbing, reading and then 20 basically would be contributing" (FG2, m11); "mine is about 70-30. I observe about 70 and post about 30" (FG4, m26); "but yeah probably 95 to 5" (FG4, f28); "I'm 95-5" (FG4, m23). However active contribution could increase if more people were attracted to the discussion.

> *I'm probably about 60-40...absorbing 60, contributing 40. But once I get going, and then all of a sudden, bang someone's asking me a question back. I'm like 'hang on, I'm out here alone, people are reading what I'm typing'...so then I'm back again and then 2 people come back and then all of a sudden it's good conversation—we've got 100 people in the conversation.* [FG2, m13]

A genuine desire to help others going through the same health issues was a driver for being an active contributor on online forums.

> *I feel it is essential as well...because the interested parties can benefit. Even if one person gets some additional benefit due to your experience, it's well worth your time.* [FG1, m6]

Social Media Identity and Privacy

Several approaches dealing with social media identity and privacy were identified. They ranged from total openness, such as consumers using their own names and pictures on social media profiles and online forums, to participants restricting the availability of their private details. A few participants were totally open about their identity while interacting on social media and did not consider it problematic to have friends and contacts seeing their online health-related activities.

> *I'm not concerned about people seeing a perception of my identity just because I've contributed to a discussion forum...and I'm really aware of the fact that if I am discussing something in a public forum, it's something that I'm quite happy for everyone to know.* [FG2, m11]

Some were using their first name only, instead of their full name, to avoid complete disclosure of their personal information. Some preferred to omit certain personal details, such as surname or date of birth.

Another approach was the use of social media privacy settings. Participants felt that this safeguarded their privacy and confidentiality of the health information posted online. In order for this process to be effective, the social media friends or contacts had to be organized into different lists according to their interests (ie, health-related contacts). Then future posts could be seen only by those in selected lists chosen as the audience.

> *...that's why I have groups. I have different subgroups. Like then you can check like I'm sharing this and I want only these people to know, or I'm sharing that and anybody to know it.* [FG1, f8]

The use of privacy settings, however, was not perceived to be a complete guarantee of privacy for 2 reasons: social media platforms were perceived to benefit from providing participant details to third parties for a profit and social media platform privacy policies could change unexpectedly.

Those who were more concerned about online privacy resorted to the use of pseudonyms or avoided using their own pictures in social media profiles. It is noteworthy that anonymity on social media platforms evoked different opinions. On the one hand, it was mentioned that anonymity could have a deleterious effect on the trustworthiness of the information provided online. On the other hand, the use of an alias was regarded as crucial by some participants to not only safeguard their privacy but also to foster the provision and sharing of personal information needed for peer discussions. The supporters of anonymity emphasized that the content of the information and the way it was presented was more important than the source's identity.

The reasons provided for keeping online activities private ranged from personal concerns (ie, not wanting friends to know their health problems) to stigma associated with certain diseases and the risk of impacting their professional life (eg, worried about losing their jobs because of their medical condition).

Discussion

Principal Findings

This study sheds light on how consumers with chronic medical conditions and on medications were accessing social media for health-related purposes, which social media platforms they were accessing, and how they used social media for health-related purposes. Although focused on the Australian context, these findings may be transferable to other similar settings due to the ubiquitous nature of social media and the ability to access social media from any part of the globe with Internet access.

Despite the reported widespread use of social media, it was interesting to note that general search engines remained the key starting point for online health searches. This finding confirms and helps to consolidate the prominent position of general search engines as the initial and most used strategy to locate online health information [32-37]. This study further highlights that even though participants were seeking social media platforms for health-related information and peer interactions, very few knew how to effectively search within social media platforms themselves. This may be due to the limited understanding of search engines and how to effectively and efficiently search in the online environment. However, once certain social media platforms were used for health-related reasons, consumers tended to keep using them and use the search function within social media platforms to locate topics of interest. As more and more health-related services and other daily services are moving to an online interface, it is essential that consumers are better educated on how to efficiently search, access, and effectively use social media platforms as well as other platforms. It is possible that their limited searching abilities narrow the social networking sites and other online sites they can access for information.

One important factor leading consumers to use social media for health-related purposes was the fact that these platforms were already part of their online daily activities, and incorporating a health component was easy and very convenient. The high availability of mobile phones has afforded easy access and therefore, participants do not need to be at home or in the office and can conduct searches and interact online even while in transit. This important finding demonstrates that consumer access and experience with social media platforms for nonhealth-related reasons has been easily extended and applied to health-related purposes and health-specific social media platforms. More and more consumers are therefore online, with the ability to access people online becoming today's norm. This increased access to consumers provides a significant opportunity for health care professionals and the health care system that should be capitalized for better patient health outcomes.

The range of social media platforms used highlights the diversity of consumer health-related needs and the importance of having a range of sources of information that can be accessed and interacted with online. Not surprisingly, Wikipedia was commonly used to access health-related information. Besides being user-friendly, Wikipedia appears on the first page of most searches and is considered a prominent source of online health information [38]. The common use of Wikipedia for health information reported in this study strengthens the call for the medical community to join in editing Wikipedia entries in order to ensure their accuracy and also to use Wikipedia as a tool for global public health promotion [39]. The study findings demonstrated that some consumers do contribute to social media (in particular via social networking sitess, such as Facebook) by providing information, responding to other consumers, and supporting people. Therefore, Wikipedia, as a commonly accessed social media, could provide a novel opportunity for consumers to contribute; for example, health-related entries could have a section about consumer experiences and testimonials where first-hand information about disease and treatment could be provided by people. Additionally, links to other platforms providing experiential knowledge (such as YouTube clips) could be included in this section. As demonstrated in this study, consumers value each other's knowledge and experiences, and entries in Wikipedia are likely to be welcomed by consumers.

This study has shown that consumers were actively searching for health information online and interacting with peers for health-related reasons. Despite having access to health care professionals, consumers felt they were not getting as much information as they felt that they needed. This is in line with previous research that has identified lack of information provided by health care professionals as a reason for consumers resorting to online information [35,40,41]. However, this study has also demonstrated that support is a key reason for consumers going online. This is an important finding and highlights the gap in the current health care and social support patients with chronic medical conditions are receiving. The participants in this study have voiced this gap in their overall health care which they felt they were addressing through engagement with social media. Participation in online groups creates a sense of belonging to a community and being connected to others [42]. This online connection with peers provides an avenue to vent emotional difficulties [43-46] and obtain emotional relief from peers [44,45]. This emotional support could positively impact consumer ability to cope with problems [44,46-48] and increase self-esteem and confidence [49]. Additionally, social and emotional support obtained online from peers can improve disease self-management and control [42,50].

Most of the study participants had a passive role in the social media groups and online communities they belonged to (ie, they were reading much more than they were contributing). However, they appeared satisfied with this level of active engagement, although there were comments that they contribute when they felt that they had something new and valuable to add. This low level of active contribution is in agreement with findings from a US survey that revealed that less than 15% of Internet users were engaged in the creation of online content [51]. Even smaller numbers were reported in a UK study, which found that only 7.5% of users were responsible for posting most of the health-related content [52]. It has been claimed that writing about health problems could have a positive effect on reducing emotional distress [53]. In contrast, another research study concluded that observational participants (also called lurkers) benefited as much as those who actively contributed [45,50]. This is certainly a topic that needs further exploration because if providing information really has a positive impact, social media has a great potential to improve the well-being of consumers as identified in this study.

One explanation for the low contribution found in this study could be the perceived requirement to disclose a great deal of personal information on social media [54]. This study has shown that consumers were concerned about their privacy when using social media for health-related purposes, with some participants concealing their identities to remain anonymous when discussing and sharing health information online and others using pseudonyms. These strategies were adopted by the participants so they could still participate and gain benefits from social media engagement. Consumers could be more active since anonymity afforded them the opportunity to express themselves truly and freely [55,56]. Consumers therefore value social media (the information they can share and the social support they can provide and receive) enough to take extra steps to ensure their privacy and still engage in social media. Moreover, the online anonymity is regarded as an important facilitator for full participation of patients suffering from conditions with high levels of stigma, as they can participate without fear of judgment [57]. It is known that social networking sites have created the privacy paradox, as users disclose personal information on social media and at the same time are concerned about their privacy [54]. This privacy paradox can impact the extent of information shared on social media. Facebook has afforded its users the ability to control their profile and activity visibility through the use of privacy settings, which were used by some of our participants. But as personal information disclosure is the default, users have to be vigilant and make an effort to control what is public or private, and of course they have to first be aware of the privacy settings and how to use them. The use of privacy settings, however, is an issue for all users of social media. A 2012 survey showed that almost 60% of general social media users set profile privacy, despite half of them reporting some difficulty in the task [58].

Limitations

The findings of this study should be considered in light of certain limitations. First, the findings despite providing useful insights are not intended to be generalizable due to the qualitative approach used. Additionally, all participants were recruited from the Sydney metropolitan area, which might restrict the transferability of findings to other populations (ie, it may not be representative of a cross-section of Australian consumer experience and views related to the use of social media for health). Second, it was not possible to completely isolate consumer activities on social media platforms from other online platforms, such as websites. It seems that consumers and regular users of social media do not see a clear and definite separation between dot.com websites and social media platforms and instead see an evolution within the same concept. The facilitator ensured that the focus was always on social media platforms. Third, the focus group approach, despite serving as a way of stimulating participants to express their experiences and opinions, could also have deterred some participants from fully expressing themselves. To minimize this, all focus groups were run by an experienced facilitator who ensured that each participant could report on their experiences and opinions. Last, due to the dynamic nature of social media, the findings represent the situation at the time of the study only and patterns of use might change quickly.

Conclusion

Consumers used a wide range of social media platforms for health-related purposes, accessing social media at home, in transit, and in the workplace. Several electronic devices, in particular mobile phones, were used to access social media. Consumers still relied heavily on search engines for their initial health searches, but explorations within social media platforms were also mentioned. Participants observed far more than they actively posted on social media. They wanted to learn about their disease and treatment (including potential side effects) and to provide and seek social and emotional support. Identity and privacy was a concern but did not prevent consumers from fully engaging with a community of peers dealing with the same health problem. Social media platforms provide important opportunities for health care professional involvement in patient care, from public health initiatives to treatment and monitoring of patients.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Focus group discussion guide.

[PDF File (Adobe PDF File), 39KB - jmir_v19i10e352_app1.pdf]

Multimedia Appendix 2

Participant demographics.

[PDF File (Adobe PDF File), 40KB - jmir_v19i10e352_app2.pdf]

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Original Paper

Raising Awareness About Cervical Cancer Using Twitter: Content Analysis of the 2015 #SmearForSmear Campaign

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Abstract

Background: Cervical cancer is the second most common cancer among women under 45 years of age. To deal with the decrease of smear test coverage in the United Kingdom, a Twitter campaign called #SmearForSmear has launched in 2015 for the European Cervical Cancer Prevention Week. Its aim was to encourage women to take a selfie showing their lipstick going over the edge and post it on Twitter with a raising awareness message promoting cervical cancer screening. The estimated audience was 500 million people. Other public health campaigns have been launched on social media such as Movember to encourage participation and self-engagement. Their result was unsatisfactory as their aim had been diluted to become mainly a social buzz.

Objective: The objectives of this study were to identify the tweets delivering a raising awareness message promoting cervical cancer screening (sensitizing tweets) and to understand the characteristics of Twitter users posting about this campaign.

Methods: We conducted a 3-step content analysis of the English tweets tagged #SmearForSmear posted on Twitter for the 2015 European Cervical Cancer Prevention Week. Data were collected using the Twitter application programming interface. Their extraction was based on an analysis grid generated by 2 independent researchers using a thematic analysis, validated by a strong Cohen kappa coefficient. A total of 7 themes were coded for sensitizing tweets and 14 for Twitter users' status. Verbatims were thematically and then statistically analyzed.

Results: A total of 3019 tweets were collected and 1881 were analyzed. Moreover, 69.96% of tweets had been posted by people living in the United Kingdom. A total of 57.36% of users were women, and sex was unknown in 35.99% of cases. In addition, 54.44% of the users had posted at least one selfie with smeared lipstick. Furthermore, 32.32% of tweets were sensitizing. Independent factors associated with posting sensitizing tweets were women who experienced an abnormal smear test (OR [odds ratio] 13.456, 95% CI 3.101-58.378, *P*<.001), female gender (OR 3.752, 95% CI 2.133-6.598, *P*<.001), and people who live in the United Kingdom (OR 2.097, 95% CI 1.447-3.038, *P*<.001). Nonsensitizing tweets were statistically more posted by a nonhealth or nonmedia company (OR 0.558, 95% CI 0.383-0.814, *P*<.001).

Conclusions: This study demonstrates that the success of a public health campaign using a social media platform depends on its ability to get its targets involved. It also suggests the need to use social marketing to help its dissemination. The clinical impact of this Twitter campaign to increase cervical cancer screening is yet to be evaluated.

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KEYWORDS

uterine cervical neoplasms; Papanicolaou test; social media; early detection of cancer; health promotion; Twitter

Introduction

Background

Cervical cancer is the second most common cancer among women under 45 years of age and leads to significant mortality [1]. Cervical cancer is caused by human papillomavirus [2]. Smear test (Papanicolaou test) detects precancerous changes and early-stage cervical cancers. Its introduction has allowed a dramatic decline of cervical cancer incidence and death rates in many countries, especially the developed countries [3]. In the United Kingdom, an organized national screening program has been established in 1988. Incidence of cervical cancer in women aged 20-79 years in the United Kingdom has almost halved from 1982 to 2006, thanks to this program. However, its incidence is now rising in 20- to 29-year-olds from 1996 onward in most regions in the United Kingdom [4]. From 1999 to 2013, the number of women who did not attend their smear test for a 5-year period has progressively increased from 16% to 22% [5]. It suggests that organized screening is not intrinsically strong enough to keep a high coverage rate.

Social media would have a great potential to improve behavior change as interactive tools, encouraging participation and self-engagement instead of a descending information [6-8]. They are also seen as an opportunity to promote adherence to cancer prevention programs and a new way to screen at-risk population based on their personalized profile [9]. Facebook, Twitter, or Instagram had, respectively, more than 1.86 billion, 317 million, and 500 million monthly active users in December 2016. For Twitter, more than 500 million tweets are traded every day [10]. These social media platforms have become a valuable source of information for health professional and clinicians to effectively discover health-related topics and behaviors [11-14].

Public health campaigns have already tried to take advantage of the ability of social media to make a campaign viral. The amyotrophic lateral sclerosis (ALS) Ice Bucket Challenge's goal was to mediatize and raise funds for the ALS association. The campaign had involved many celebrities worldwide. On September 1, 2014, more than 17 million videos had been shared on Facebook and had been watched more than 10 billion times by more than 440 million people [15]. Thanks to this campaign, more than US $100 million had been raised by the ALS association [16]. Hundreds of thousands of people had tweeted daily about ALS, which is a much higher number of tweets than those emitted about multiple sclerosis, a disease better known to the public [17]. Movember is an annual event organized each November since 2003 whose goal is to raise awareness about and raise funds for diseases affecting men such as prostate or testicle cancer. Participants let their moustache grow and post selfies on social media platforms to raise the awareness of their contacts and show their involvement in this campaign. In Denmark, after the initiation of the 2011 Movember campaign, a significant decline in the prostate-specific antigen level at referral and an increase in the number of patients referred under suspicion of prostate cancer were observed. However, only minor differences in referral patterns and prostate cancer diagnosis were detected [18]. These campaigns may be parasitized by the buzz they sought to create and may vehicle nonhealth-related messages. A content analysis of the 2013 Movember Canada campaign on Twitter showed that it did not meet the stated campaign objective of creating conversations about men's health and, specifically, about prostate and testicular cancers [19].

To deal with the decrease of smear coverage in the United Kingdom, a Twitter campaign called #SmearForSmear has been launched in 2015 by Jo's Cervical Cancer Trust for the European Cervical Cancer Prevention Week. Its goal was to encourage women to take a picture of themselves (selfie) showing their lipstick going over the edge and post it on Twitter with an awareness message promoting cervical cancer screening. The estimated audience was 500 million people [20].

Objectives

The objectives of this study were to identify the tweets delivering raising awareness messages about cervical cancer screening and to understand the characteristics of Twitter users posting about this campaign.

Methods

We conducted a 3-step content analysis of the English tweets posted on Twitter during the 2015 European Cervical Cancer Prevention Week.

Data Collection and Extraction

To collect the tweets, we used the Twitter application programming interface. It allows the user to conduct manual searches for keywords in tweets with specific parameters such as hashtags, language, and date range. The ones used for this research were as follows: #SmearForSmear, English language, and tweets posted between January 25, 2015 and January 31, 2015, both dates inclusive (European Cervical Cancer Prevention Week). All tweets have been manually collected and assessed. Only original tweets, rather than retweets, were analyzed. In the tweets, only the verbatims were transcribed. Hashtags and content preceded by "@" were removed if that action did not make the verbatim unintelligible. We also considered all hypertexts linked to another verbatim on another Web platform (eg, Instagram). The corresponding verbatims were transcribed only if they were informative.

Data Analysis

A total of 3019 tweets that met the search criteria were imported into Excel for data extraction. An analysis grid had been created based on the first 200 original tweets collected and thematically analyzed by 2 independent researchers to extract the themes (topics) of tweets' verbatims and Twitter users' statuses. Then, this grid had been tested on 50 new tweets. No new themes had been identified, confirming that category saturation was achieved [21]. The thematic analysis methodology used consists of transforming qualitative content into a quantitative form by establishing coding categories. The number of data units that fall into each coding category was counted (such as phrases, messages, and responses). Finally, they were categorized based on similar meanings and overt or inferred communication [22,23]. Themes were not restricted to preexisting themes. They emerged through an inductive process whereby open coding of data revealed themes that moved from the specific to the general [24]. The 2 researchers, both general practitioners and trained in qualitative study, elaborated a 7-theme codebook, based on tweets, to identify if the tweets delivered raising awareness messages about cervical cancer screening: incentive to carry out the smear test, evocation of smear test importance without any precision, reminder of the smear test preventive nature, reminder of the low incidence of smear test, allusion to the mortality or morbidity of cervical cancer, reminder of the incidence of cervical cancer, and testimony of an experience related to smear test or cervical cancer. If a tweet had at least one of these awareness-raising messages, it was considered a sensitizing tweet. Reproducibility of the classification of the first 300 original tweets by the 2 independent researchers was tested and calculated with Cohen's kappa coefficient. The agreement was strong and varied between .8842 and 1.

The following information was collected about each tweet: verbatim, posting date, retrieval date, presence of a selfie with lipstick going over the edge, picture or video referring to the campaign, user's sex, user's location, number of followers at the date of retrieval, and user's status. To classify the users, we used their Twitter status. If it did not exist or was incomplete, we extracted this information from links on their Twitter profile, whenever possible. The analysis grid enlisted 14 themes regarding Twitter users' status: health company, media company, nonhealth and nonmedia company, marketing company, fashion company, blogger or YouTuber, health professional, National Health Service (NHS), politician, woman who experienced cervical cancer or who had relatives with cervical cancer, woman with an unspecified cancer or relatives with a similar status, woman who experienced an abnormal smear test, general public, and unknown. The "unknown" status was attributed when no information to categorize the user was available. Only the "unknown," "general public," or "NHS" statuses were exclusive.

An initial global description of the sample has been performed, using the frequencies of the different categories for the qualitative variables. As the distribution of quantitative variables was not always Gaussian (Shapiro–Wilk test), they were expressed by their mean, standard deviation, median, minimum and maximum values, and interquartile. Comparison of means was executed through the Student test when distribution was Gaussian; otherwise, it was based on Mann–Whitney test. Comparison of qualitative variables was executed through the chi-square test for parametric tests, or Fisher exact test when the conditions for applying chi-square test were not observed. A multivariate logistic modeling process was then conducted to identify the independent factors associated with the presence of a sensitizing message in the tweets and associated with each type of sensitizing message. A "step-by-step" selection procedure of the variable was used with an input and output variable set at 0.10 and 0.05, respectively. The significance threshold was set to 5%. Statistical analysis was performed by the Department of Medical Information at Montpellier Teaching Hospital with SAS version 9.4 (SAS Institute Inc).

Results

Study Population

A total of 3019 tweets met the search criteria; 1138 tweets were removed (retweets or copies of tweets); and 1881 tweets were analyzed.

Moreover, 608 tweets (32.32%) were sensitizing. Each of them included from 1 to 5 raising awareness message. The mean number of raising awareness messages among original tweets was 0.54 (standard deviation [SD] 0.93; Table 1). Incentive to carry out the smear test was the most frequent raising awareness message.

Main users were people from English-speaking countries. The United Kingdom accounted for 69.96% of the posted tweets, followed by the United States (8.67%) and Australia (1.06%). Nationality was unknown in 15.20% of cases. Moreover, 57.36% of users were women, and sex was unknown in 35.99% of cases. Twitter users had a mean number of followers of 44,420.8 (SD 420,819.04). A total of 54.44% of the users had posted at least one selfie with smeared lipstick. In addition, 15.63% tweets were associated with a picture or a video referring to the #SmearForSmear campaign.

Univariate and Multivariate Analysis

Statistically significant associations between emitting sensitizing tweets and Twitter users' status are detailed in Table 2.

The "step-by-step" selection procedure has allowed to identify independent factors influencing the sensitizing characteristic of a tweet (Table 3).

Table 1. Description of tweets and Twitter users.

Variable	Total, n (%)
Number of raising awareness messages in a tweet	
0	1273 (67.68)
1	347 (18.45)
2	149 (7.92)
3	83 (4.41)
4	25 (1.33)
5	4 (0.21)
Sensitizing tweet	608 (32.32)
Incentive to carry out the smear test	440 (23.39)
Reminder of smear test preventive nature	217 (11.54)
Allusion to the mortality or morbidity of cervical cancer	134 (7.12)
Testimony of an experience related to smear test or cervical cancer	92 (4.89)
Smear test importance	63 (3.35)
Evidence of the number of cervical cancers	41 (2.18)
Low incidence of smear test	27 (1.44)
Categories of Twitter users	
Unknown	442 (23.5)
Nonhealth and nonmedia company	396 (21.05)
Health company	292 (15.52)
Blogger or YouTuber	262 (13.93)
Media company	240 (12.76)
Fashion activity	240 (12.76)
Marketing activity	220 (11.70)
National Health Service	79 (4.2)
General public	77 (4.09)
Woman who experienced cervical cancer or who had relatives that had experienced cervical cancer	60 (3.19)
Health professional	53 (2.82)
Woman who experienced an abnormal smear test	33 (1.75)
Politician	12 (0.64)
Woman who experienced an unspecified cancer or had relatives with a similar status	6 (0.32)

Table 2. Twitter users' known characteristics.

Characteristics	Total, n (%)	*P* value
Characteristics linked to a higher probability of emitting sensitizing tweets		
United Kingdom	1316 (82.51)	<.001
Female gender	1079 (89.62)	<.001
National Health Service	79 (4.2)	<.001
Woman who experienced an abnormal smear test	33 (1.75)	<.001
Characteristics linked to a higher probability of emitting nonsensitizing tweets		
Nonhealth or nonmedia company	396 (21.05)	<.001
Media	240 (12.76)	.045
Marketing activity	220 (11.70)	<.001
Male gender	125 (10.38)	<.001

Table 3. Independent factors influencing the emission of sensitizing tweets.

Message of tweet, variables	Adjusted OR (95% CI)	*P* value
Sensitizing tweet		
Woman who experienced an abnormal smear test	13.456 (3.101-58.378)	<.001
Female gender	3.752 (2.133-6.598)	<.001
United Kingdom	2.097 (1.447-3.038)	<.001
Nonhealth or nonmedia company[a]	0.558 (0.383-0.814)	.002
Directly encouraging people to go for a smear test		
Female gender	5.967 (2.606-13.659)	<.001
Health company	2.203 (1.042-4.656)	.04
United Kingdom	1.997 (1.320-3.021)	.001
Selfie	1.673 (1.228-2.280)	.001
Nonhealth or nonmass media company[a]	0.481 (0.310-0.746)	.001
Evocation of the importance of smear test without any precision		
Woman who experienced an abnormal smear test	7.365 (2.314-23.436)	<.001
National Health Service	4.266 (1.778-10.238)	.001
United Kingdom	2.888 (1.015-8.212)	.047
Fashion	2.724 (1.430-5.188)	.002
Selfie	2.158 (1.163-4.002)	.001
Reminder of the preventive aspect of smear test		
Woman who experienced an abnormal smear test	4.216 (1.734-10.254)	.001
Politician	3.545 (1.028-12.221)	.045
Female gender	2.555 (1.156-5.646)	.002
Marketing activity[a]	0.414 (0.211-0.812)	.001
Evocation of the mortal or morbid aspect of cervical cancer		
Woman who experienced an unspecified cancer or had relatives with a similar status	6.359 (1.043-38.776)	<.001
Woman who experienced an abnormal smear test	5.591 (2.227-14.035)	<.001
Female gender	3.396 (1.050-10.982)	.04
Woman who experienced cervical cancer or had relatives with a similar status	2.598 (1.228-5.495)	.001
United Kingdom	2.268 (1.069-4.808)	.03
Reminder of the low incidence of smear test		
Politician	14.754 (3.074-70.816)	<.001
Reminder of the incidence of cervical cancer		
General public	2.913 (1.002-8.474)	.049
Picture or a video linked to the #SmearForSmear campaign	2.701 (1.372-5.318)	.004
Statement from people who experienced abnormal smear test or cervical cancer		
Woman who experienced an abnormal smear test	65.364 (22.709-188.140	<.001
Woman who experienced an unspecified cancer or had relatives with a similar status	14.371 (2.335-88.417)	.004
Woman who experienced cervical cancer or had relatives with a similar status	7.641 (3.690-15.822)	<.001

[a] Statistically significant influence on the emission of nonsensitizing tweets).

Discussion

Principal Findings

A total of 32.32% of the tweets of the #SmearforSmear campaign were sensitizing. This result was promising as it goes well beyond the results of the 2013 Movember campaign where only 0.85% of the posted tweets may raise awareness about men's health risks [18]. Many factors may explain this gap. On one hand, this campaign had been created using social marketing in a holistic approach. Its objective was clear, and its title referred to its objective. Jo's Cervical Cancer Trust posted key messages reflecting the need to adhere to the screening of cervical cancer, and these messages have been reused by the participants of this campaign to fill the content of their tweets. A slogan had also been created "Attend your smear, reduce your risk," widely retweeted in this campaign. On the other hand, this campaign created to detect an exclusive feminine cancer was based on elements of 2 women's social construct: lipstick and selfies [25,26]. This approach was possible because this campaign had been designed for the United Kingdom, where the cervical cancer screening is organized. Targeted women automatically received a letter explaining them what to do to get screened and where. Receiving an invitation letter is an independent sensitizing factor associated with greater likelihood of cervical cancer screening [27].

As for the Twitter users, our expectations were broadly confirmed. From a general point of view, Twitter users posting sensitizing tweets were people personally involved in cervical cancer screening: women; women concerned by a feminine cancer, either for themselves or for their relatives; people living in the United Kingdom (where this English-speaking campaign took place); the NHS as a partner of this campaign; and women who experienced an abnormal smear test. As peers, women raised awareness by insisting on the preventive aspect of smear test and directly encouraged other women to attend their smear test. Peer influence is known as an important social lever for health-related behavior change [28]. Likewise, women or their relatives who experienced a pathological state (abnormal smear test, cervical cancer, or an unspecified cancer) had the greatest potential among categories of Twitter users to post a sensitizing tweet. Hashtags, such as #SmearForSmear, tend to create communities behaving as support group [29]. Unveiling elements of private life is conducive to trust and emotional bond [30]. Fashion company was a user status that has a significant potential to post tweets about the importance of smear test without any precision. Actively participating in the campaign by posting selfies and pictures or videos linked to the #SmearForSmear campaign helped in encouraging people to attend their smear test and disseminate the importance of smear test. Women's magazines also acted as a guidebook and reinforced women's individual responsibility to create and maintain good health for themselves and their families [31]. As for the other user categories, the raising awareness message in their tweets was in line with expectations. Politicians broadcasted information about the low incidence of smear test and how it helped preventing cervical cancer, in relation with their use of social media to communicate with the press and the public [32]. Health companies' raising awareness message was more direct, encouraging people to attend their smear test. The general public was cautioned about the incidence of cervical cancer. The NHS insisted on the importance of smear test without giving more information. It was probably in relation to the fact that NHS was only a partner of this campaign and that it only helped disseminating it. Finally, there was a scotoma of health professionals. This status did not emerge as a relevant category. Their participation in a health campaign on social media platforms is interesting as it has been shown that the information contained in their posts are more likely to be true compared with those of other groups [33]. This underrepresentation was probably due to the shortness of the studied campaign period.

Conversely, "nonsensitizing" tweets had a much greater probability to be sent either by users not directly concerned with cervical cancer such as men (exclusively feminine cancer) or by users who participated but only broadcasted information, without getting involved: media, marketing companies, and nonhealth and nonmedia companies. It questions their participation in this campaign. Was it about an opportunistic appropriation of a viral campaign? It is probably one of the main limitations of the virality of health campaigns on social media. Most tweets posted for the 2013 Movember campaign and the breast cancer prevention month did not spark conversations about prostate and testicular cancer nor promote any specific preventive behavior about breast cancer [19,34]. They may also be an interesting lever for social stimulation.

Strengths and Limitations

To our knowledge, no study analyzing the content of the #SmearForSmear campaign on Twitter has been published yet. Our findings are corroborated by the content analysis of others health campaigns on Twitter. We used a content analysis method based on a double analysis of the sensitizing capacity of each tweet, in an exploratory process. We also mined Twitter to gather information about users' characteristics and complete the tweets' content.

This highly demanding method made us decide early to restrict our study to one week. This choice was also relevant, in our opinion, as this campaign had been created for the European Cervical Cancer Prevention Week. Compared with other Twitter campaigns, our relatively high results must question its ability to keep a high proportion of sensitizing tweets in other countries (particularly where the cervical cancer screening is not organized) and if it remains high over time.

The choice to collect the tweets based on the hashtag #SmearForSmear may have limited their number, by omitting those not using it. As for the content analysis, 2 safeguards have been used: analyzing the content of tweets to create the categories before the study and evaluating the reproducibility of the classification by 2 independent researchers with Cohen's kappa coefficient, which was strong in this study. The shortness of Twitter posts, limited to 140 characters, may have created a loss of information as users often used hyperlinks to be exempt from this limit. We then chose to manually mine Twitter to complete the tweets' content and gather information about users' characteristics.

Perspectives

The #SmearForSmear campaign has allowed to disseminate sensitizing messages about cervical cancer screening and to become viral. It was based on a well-designed campaign, on a facilitating audience, and a facilitating health system using an organized screening.

Choosing a social media platform adapted to the target is a major concern for a successful campaign. Twitter is interesting as it is well suited for appointment campaigns such as #SmearForSmear or the ALS Ice Bucket Challenge. It also is a social media platform used by young adults to keep up in real time with news [35]. But its audience is mainly men, living in urban areas. Although diverse, its percentage of users with college educations and incomes over US $50,000 is much higher than those of Facebook or Instagram. Users of Instagram are mainly female, but 72% of online American adults use Facebook, and its audience is the most engaged with 70% logging on daily [35]. Health campaigns on social media platforms should be a way to reduce social inequities in health. In the United Kingdom, the main decline in screening was about 25- to 49-year-old women and black and Asiatic ethnic minorities [5]. Targeted audience must be on the social media platform chosen and then adapt to the shift of the evolution of their audiences.

The impact of facilitators is to be studied. As previously shown, many Twitter users of this campaign did not engage in this campaign as they did not post sensitizing tweets. But they participated and helped broadcasting to their audience. Models such as Cara Delevingne also posted a selfie to support the campaign and to raise awareness among her millions of followers (8.5 million in May 2017) [36]. They may boost a campaign as influencers and a role model.

Our findings show a clear need for studies that are capable of automatically analyzing the data and extracting useful insights from the #SmearForSmear Twitter campaign. We propose the use of machine learning to tackle these challenges, and we suggest 3 perspectives for future directions. First, we plan to undertake a large-scale analysis using a collection of tweets that we are currently collecting since February 2017. This analysis will include the application of the Latent Dirichlet Allocation to extract the topics emerging from the discussions about the campaign, as well as the exploration of the linguistic style of the Twitter' users [11,37-39]. Second, we could benefit from statistical learning techniques to predict automatically the categories of all tweets about the campaign [40]. This study may allow us to assess our findings and generalize our results. We will learn a model with the one-vs-the-rest multiclass classifier based on an annotated dataset, and we will apply it on all tweets about the campaign. We will compare the results with the manual processing and annotation done so far. Moreover, within a sufficiently large dataset, we can take advantage of machine learning models to use features that are more complex to characterize the users tweeting about the campaign. We suggest focusing on user groups including health professionals, celebrities, general public, and politicians. This will lead us to understand which group of users is prominent, so that it could influence others, making them to retweet the messages relevant to the campaign, to like and reply to tweets, or more importantly donate money. Third, we plan to investigate the temporal distribution of messages to focus on the campaign dynamics over time. We may study the temporal correlations between the reactions of twitter users and real-world events such as media coverage of the campaign. This analysis is exploratory, and it could help in identifying the factors contributing to raising the awareness. For example, a televised promotion of the campaign or a promotion published by a celebrity may stimulate a huge volume of tweets and reactions online. Beyond this, we can also analyze the geographical distribution of tweets during the campaign.

Health campaigns on social networks may raise awareness of public health issues. Becoming viral is not an end in itself. Long-term effect of social media campaigns to raise people's awareness of health conditions is to be evaluated. The ALS Ice Bucket Challenge has proven to be disappointing as after 2 years, the level of Web-related activities about ALS has remained practically the same as it was before the campaign [41]. The campaigns' clinical impact is also yet to be evaluated. It will be a difficult task in an hyperconnected world to be able to individualize the effect. This scientific step is important to convince stakeholders, health professionals, and general public to get involved and use Web 3.0 as a collective intelligence to drive back chronic diseases, particularly for the most fragile ones.

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Conflicts of Interest

None declared.

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Abbreviations

ALS: amyotrophic lateral sclerosis
NHS: National Health Service
OR: odds ratio

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Original Paper

Scaling Up Research on Drug Abuse and Addiction Through Social Media Big Data

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Abstract

Background: Substance use–related communication for drug use promotion and its prevention is widely prevalent on social media. Social media big data involve naturally occurring communication phenomena that are observable through social media platforms, which can be used in computational or scalable solutions to generate data-driven inferences. Despite the promising potential to utilize social media big data to monitor and treat substance use problems, the characteristics, mechanisms, and outcomes of substance use–related communications on social media are largely unknown. Understanding these aspects can help researchers effectively leverage social media big data and platforms for observation and health communication outreach for people with substance use problems.

Objective: The objective of this critical review was to determine how social media big data can be used to understand communication and behavioral patterns of problematic use of prescription drugs. We elaborate on theoretical applications, ethical challenges and methodological considerations when using social media big data for research on drug abuse and addiction. Based on a critical review process, we propose a typology with key initiatives to address the knowledge gap in the use of social media for research on prescription drug abuse and addiction.

Methods: First, we provided a narrative summary of the literature on drug use–related communication on social media. We also examined ethical considerations in the research processes of (1) social media big data mining, (2) subgroup or follow-up investigation, and (3) dissemination of social media data-driven findings. To develop a critical review-based typology, we searched the PubMed database and the entire e-collection theme of “infodemiology and infoveillance” in the Journal of Medical Internet Research / JMIR Publications. Studies that met our inclusion criteria (eg, use of social media data concerning non-medical use of prescription drugs, data informatics-driven findings) were reviewed for knowledge synthesis. User characteristics, communication characteristics, mechanisms and predictors of such communications, and the psychological and behavioral outcomes of social media use for problematic drug use–related communications are the dimensions of our typology. In addition to ethical practices and considerations, we also reviewed the methodological and computational approaches used in each study to develop our typology.

Results: We developed a typology to better understand non-medical, problematic use of prescription drugs through the lens of social media big data. Highly relevant studies that met our inclusion criteria were reviewed for knowledge synthesis. The characteristics of users who shared problematic substance use–related communications on social media were reported by general group terms, such as adolescents, Twitter users, and Instagram users. All reviewed studies examined the communication characteristics, such as linguistic properties, and social networks of problematic drug use–related communications on social media. The mechanisms and predictors of such social media communications were not directly examined or empirically identified in the reviewed studies. The psychological or behavioral consequence (eg, increased behavioral intention for mimicking risky health behaviors) of engaging with and being exposed to social media communications regarding problematic drug use was another area of research that has been understudied.

Conclusions: We offer theoretical applications, ethical considerations, and empirical evidence within the scope of social media communication and prescription drug abuse and addiction. Our critical review suggests that social media big data can be a tremendous resource to understand, monitor and intervene on drug abuse and addiction problems.

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KEYWORDS

opioid epidemic; opioid crisis; opioid-related disorders; substance use; substance-related disorders; prescription drug misuse; addiction; Facebook; Twitter; Instagram; big data; ethics

Introduction

User-generated content and user interactions related to drug use (eg, opioid misuse) are prevalent and are rapidly emerging forms of communication across social media platforms [1,2]. Social media big data on this topic offer an avenue for observing and understanding the temporal trends of problematic drug use and relevant risk factors in real time [3], as well as the ability to measure the collective human behavior of an extremely large population of interest [4]. Social media big data involve large, digitized data resources that contain naturally occurring communication phenomena observable through social media platforms and that can be used in computational or scalable solutions to generate data-driven inferences. Not only do some people communicate and share personal experiences, questions, and thoughts about substance use problems on social media, but also persons with addiction problems seek out social support from others with similar addiction problems through networks and communications available on social media [5]. Davey and colleagues argued that online communities and forums are well suited for people to communicate about problematic drug use activities because of their presumed anonymity and relative freedom from geographic constraints and perceived stigma [6]. Shutler and colleagues noted that social media, such as Twitter, can be an observatory platform that can reveal patterns of the current opioid epidemic, as users tweet about illicit, nonmedical use of prescription opioids in part due to users' perceived protection of their real identity [7].

Although well-established resources in the United States such as the Drug Abuse Warning Network and the National Survey on Drug Use and Health offer critical information about substance abuse practices, these traditional platforms are known to lag in time in terms of data availability to the public for possible use in research [3]. On the other hand, online communications regarding drug use problems (eg, opioid use disorders) are surprisingly prevalent on social media [8]. These unsolicited communication datasets provide researchers a novel opportunity to unobtrusively assess and track various health risks, human factors, and emerging trends surrounding drug use [3,9]. Daniulaityte and colleagues stated that online technologies have become one of the leading-edge sources for detecting patterns and trends in illicit drug use [3]. Miller and Sonderlund suggested that online communication technologies can be an effective means for communicating with hard-to-reach populations that have illicit drug use problems [10].

Along with advances in information and communication technologies, seeking health information, disclosing personal health concerns, and exchanging social support are pervasive forms of human communications on social media [2,11-20]. It is critical to develop a conceptual framework to enhance our scientific understanding of these naturally occurring communications on social media related to drug use problems. The use of social media data-driven knowledge may help researchers better identify the utility of these technologies for public health research beyond the knowledge gained from domain experts. Furthermore, computational findings that emerge from self-disclosed social media data may ameliorate concerns about research validity in self-reported data, namely in terms of social desirability, response bias, and memory recall biases.

Due to the analogous and reflective nature of one's social media world to one's own real world, user-generated social media big data are increasingly being embraced and analyzed to observe and predict psychological states and collective human behavior [21,22]. For example, researchers found that social media communications and profiles correlate with real-world reflection of the self [23,24]. Communication patterns and interactions on social media also predict narcissistic personal traits [25], psychological functioning and well-being [26], and personality traits [27,28]. In recent years, studies have demonstrated the utility of social media big data in understanding public health problems, ranging from mental health conditions [29], population-level influenza monitoring [30,31], pronounced use of cannabis concentrates in the marijuana-legalized states in the United States [32], and the prescription stimulant Adderall [2] to perceived risks and sentiment around marijuana use [17].

With a growing line of empirical evidence demonstrating social media's usefulness for observing and predicting health behaviors, social media data on drug use–related communications are being analyzed to address various research inquiries, including temporal trends of problematic substance use [33,34], market changes, social norms and cultural aspects of drug use [35], public perceptions, and relevant psychological factors (eg, sentiments [7]). Systematically assessed results of these social media communication data at scale for drug use problems can further inform key outreach methods, future intervention components, harm-reduction methods, and control and prevention strategies, which, in turn, can be delivered via vital social media channels for public health promotion. To maximize the utility of social media big data in addressing the urgent public health problems (eg, substance use problems, the opioid crisis) in the Untied States, we present a conceptual framework designed to guide investigation on problematic drug use–related communications that are observable via social media and to advance their potential impact for public health outreach efforts.

A Multidimensional Framework to Analyze Social Media Communications for Problematic Use of Prescription Drugs

Our conceptualization classifies the communication on drug use problems that is evident on social media into 4 key dimensions: (1) user characteristics, (2) communication characteristics, (3) mechanisms and predictors of problematic substance use–related communications on social media, and (4) psychological and behavioral consequences of these social media communications at an individual and a societal level.

First, understanding user characteristics (eg, who are the users that share drug abusive, risky behaviors and addiction-related psychological states on social media?) permits in-depth subgroup or moderator analyses of the drug-related communications and related risks [36]. More specifically, understanding the demographic characteristics of these communications can advance targeted monitoring of drug abuse trends, as well as enhance the development of moderation modeling for a specific subgroup categorization of interest [37,38].

Second, identifying the communication features of target social media big data can offer insights into temporal, linguistic, and psychological patterns associated with self-disclosed social media communications about problematic use of prescription drugs [35]. For example, Paul and Dredze led a promising study to develop data crawling and surveillance systems to capture contextual factors associated with recreational drug uses through data mining of online communication data [35]. They modified and used a factorial latent Dirichlet allocation, a multidimensional text modeling approach, to incorporate prior knowledge about contextual factors such as drug type (eg, cocaine), delivery method (eg, smoking), and outcome aspects (eg, effects, health). Their approach has demonstrated successful application of data informatics to capture and discover an arbitrary number of contextual factors that are clinically important to understand new recreational drugs and trends.

As emphasized in a recent study incorporating machine learning techniques on Twitter feeds for a mental health diagnosis, analyzing linguistic properties of self-disclosed communication on social media regarding substance use problems provides a novel opportunity to identify communication themes and unmet needs among people with substance use problems [39]. Understanding communication characteristics of these unsolicited social media data will facilitate timely treatment initiation and health communication outreach strategies. Furthermore, the communication properties can be examined in conjunction with analyzing the user characteristics of those communications to identify interacting subgroups of users who share specific topics or valence (eg, anger, fear) regarding problematic substance use.

Third, investigating why and in which contexts people use social media to communicate about substance use–related problems reveals the mechanisms of various unsolicited behaviors (eg, self-disclosing personal stories about the nonmedical use of prescription drugs; using social media to receive social support during the addiction recovery process). Identifying this mechanism of communication behavior through analyzing social media big data, along with user interviews and self-reported surveys, can inform a strategic mediating construct for investigators when developing social media-based prevention or intervention programs (eg, [2]).

Fourth, understanding the psychological effects (eg, self-disclosure) and behavioral outcomes (eg, social influence) that such unsolicited uses of social media communications have on the self and others has received increased public attention [40]. However, this area of research has not been fully explored with a focus on the practical and clinical potential of social media technologies to promote health outcomes [41-43]. Social media big data analytics, in conjunction with mixed methodologies involving longitudinal follow-up and cross-sectional surveys or qualitative interviews, may help researchers identify these potential outcomes (eg, the effects of using recovery support groups on Facebook). Examining the outcomes of naturally occurring social media communications can offer intervention models that target critical moments to deliver a just-in-time intervention via social media at scale.

Integrating these 4 themes into a multidimensional framework enables systematic observation of factors and conditions explaining pervasive uses of social media for drug use–related communications. Development of this multiconceptual framework can also help researchers and clinicians explore the predictive and mechanistic values of social media-based communications in delivering state-of-the-art drug abuse recovery support and engagement systems. Furthermore, learning outcomes relevant to this multidimensional framework will offer data-driven strategies for leveraging social media data, features, and platforms for health promotion (eg, campaigns), as well as for understanding the nature of human communications concerning time-sensitive health issues.

In this work, we begin by reviewing the current use of social media for problematic drug use–related communications. Then, we highlight ethical challenges and methodological considerations when using social media big data for research on drug abuse and addiction. Lastly, based on these 4 conceptual dimensions and ethical considerations, we provide a narrative summary of the literature on social media-based drug communications and propose a typology with key initiatives aimed at addressing knowledge gaps in the use of social media for research on problematic and nonmedical use of prescription drugs.

Prevalence of Drug Use–Related Communication on Social Media and Its Social Impact

Substance Use–Promoting Communication and Its Impact

User-generated content that promotes substance use (eg, positively commenting on pictures of illicit drugs [44]) is prevalent across market-leading social media platforms, such as Instagram and Twitter [45]. Such content can diffuse rapidly and widely through easily accessible network ties within and across media platforms [44,46]. Capurro and colleagues conducted a systematic review of 73 studies that used social networking sites to understand various public health issues, including sexual risks and mental health [47]. The review reported that 86% of the reviewed studies described user-generated content and served as passive observational investigations for surveillance on target health events among hard-to-reach populations. Their review also implied that researchers are increasingly leveraging social media platforms and data within the domain of various public health issues, thus directly benefitting from the prevalence of user-centered data that indicate risky health behaviors and psychological states. This systematic review, however, did not report research that focused on social media big data–based findings for prescription drug addiction.

Moreno and colleagues [48,49] found that 41% of young adult participants had pictures or messages referencing alcohol, tobacco, or other drug use in their publicly accessible social media profiles. When social media users are frequently and repeatedly exposed to or engage in such substance-promoting communications, they may become more accepting of or immune to these risky behaviors. As noted in media and social influence frameworks, drug-use promotional communications on social media that are shared across social network ties can influence the exposed users to normalize the frequency of these behaviors and, as a result, may change their attitudes toward or risk perceptions of these substances (eg, [50,51]). A national survey of US adolescents found that 40% of all teens in a nationally representative sample had seen pictures on social media depicting other teens getting drunk or using tobacco or illicit drugs [46]. According to the National Survey of American Attitudes on Substance Abuse , adolescents who reported seeing pictures of peers using substances on social media were more likely to use substances than were those who had never seen this peer-generated content on social media [46].

Social psychology and media communication theories explain this link between content exposure and an increased willingness to engage in the behavior being promoted. For example, cultivation theory [52,53] posits that frequent media exposure to risky behavior influences the belief that the mediated version of reality is real, leading to overestimation of the frequency and prevalence of those risky behaviors in the real world. This distorted perception of reality leads people to accept risky or detrimental behaviors portrayed in the media, such as substance use, as relatively normal [46,54]. Social learning theory [55] further buttresses the claim that observing risky behaviors via social media can influence people to mimic behaviors or adopt specific values and thoughts. Bandura’s social learning theory [56] posits that media communication can considerably promote changes in human beliefs and behaviors by “informing, enabling, motivating, and guiding” the audience (pg 76).

Social media communication platforms allow substance users to connect with a wide array of social networks and readily accessible substance use–related content. A news feed on a social media site can become a platform that constantly provides both personalized and socially infused content for social modeling and mimicry. These socially mediated learning processes on social media underscore the importance of considering the consequences (eg, mimicry) of routine exposure to content that is positively framed for and, indirectly or directly, promotes problematic drug use.

Substance Recovery Support and Prevention Communication and Its Clinical Implications

While content that promotes substance use is prevalent on social media, use of social media networks and online communities to explore recovery support for drug addiction problems is an increasingly popular form of communication [42]. Social media-based platforms (eg, Facebook Groups and Pages) are generated and led by self-motivated users with a goal of sharing and providing social support for users who have substance use problems or are in addiction recovery processes. Recently published work led by Rubya and Yarosh examined the characteristics of video-mediated, peer-led synchronous online support communities for addiction recovery [42]. Although the platform they examined in their work is not one of the social media platforms in the current market (eg, Facebook, Twitter), it did offer social media components, such as user interaction features, social networking functions, and engagement tools, that are important for peer-based online social support [57]. Through data crawling, self-selected online surveys, and in-depth interviews, Rubya and Yarosh examined the role of video-based online forums for people in addiction recovery and reported that these forums were viewed as critical in helping people with opioid use disorders overcome any perceived barriers (eg, access, anonymity) to seeking recovery support for drug addiction.

Compared with their application in the drug addiction context, the values of peer support and user engagement on social media platforms have been leveraged in health interventions for other health contexts, such as smoking cessation [58] and weight loss among vulnerable populations [59]. For example, Kim and colleagues [57] used various Facebook Group features for a 6-week smoking cessation and reduction intervention. Their findings support a successful rate of smoking reduction predicted by user engagement (eg, the number of comments posted) and the amount of social support received (eg, the number of “likes” participants received). These mechanisms were facilitated within their Facebook Group intervention that was designed to assist regular smokers to quit cigarette smoking. As discussed in 2 recent systematic reviews on social media-based studies within the public health interest, social media technologies and features have not been fully applied or used for long-term, scalable investigations that can generate successful social network-based health diffusion phenomena for health promotions [47,58]. We further argue that, despite the potential value of unique technology features in social media platforms, most of these platforms have not been systematically leveraged to offer evidence-based content or scientifically guided support for people in opioid addiction recovery processes. Accordingly, the public health and clinical benefits of leveraging social media platforms for substance prevention and recovery support remain underexplored.

A national report released by the US Centers for Disease Control and Prevention stated that almost 48,000 deaths in the United States in 2014 were induced by potent substance poisoning, surpassing the number of deaths caused by motor vehicle accidents [60]. The US National Institute on Drug Abuse reported that the total number of substance use–related deaths in the United States increased since 2001, with as much as a 6.2-fold increase in the number of overdose deaths from heroin from 2002 to 2015 [61]. The substance use epidemic in the United States has caused detrimental consequences on both individual and societal levels that call for urgent research on understanding this phenomenon in a scalable, systematic fashion.

The proliferation of substance use prevention and addiction recovery support communications among social media users provides empirical resources to systematically analyze naturalistic, real-time communications data and to gain time-sensitive insights into substance use risk factors, behavioral patterns, and prevention and recovery processes. Applying big data informatics—the process of examining large unstructured data to discover hidden patterns and useful information [62]—to substance use prevention and recovery support-related social media data will help us gain important and novel knowledge regarding the characteristics of substance use–linked users and their health behaviors [63-65]. Given the prevalence of social media use among people with drug use problems, in addition to the potential opportunities for learning about relevant risk behaviors and factors via user-solicited communication data on social media, we posit that this novel approach will be of importance to the development of evidence-based frameworks that promote addiction prevention and recovery support.

With these clinical implications and opportunities for understanding and enhancing a sensitive health problem, the social media data that contain various levels of user information (eg, age, gender) and users' expectations and nuances embedded in social media contexts require cautionary attention to ethical boundaries and practices. In the following section, we discuss key ethical principles, challenges, and considerations applicable in this novel research setting when incorporating user-centered social media communication data for behavioral health research.

Researchers' Responsibilities and Big Data Ethics in Studying Social Media Users With Substance Use Problems

The use of social media big data for informatics can provide population-level inferences, such as pattern or trend recognition [66] and natural language processing [67], for drug use–related behaviors and psychological states. When using publicly available and personally relevant communication data to understand human health behaviors and risks, special attention should be given to research ethics, especially for data concerning sensitive topics like drug addiction. A balance between ethical principles and scientific discoveries gleaned from novel technology tools should be actively sought and put into practice prior to designing and performing data mining and informatics. Mittelstadt and Floridi [68] explored research ethics-related themes that emerged from meta-analyses of big data–based studies. From those themes, we synthesize relevant principles applicable to each stage of research using social media big data to understand the drug epidemic. Those stages are identified as follows: (1) determining the scope of search for data mining or retrieval, (2) conducting subgroup analysis or follow-up investigation, and (3) disseminating and presenting social media data-driven findings.

Social Media Big Data Mining and Retrieval

Throughout the process of mining and retrieving social media big data, it is important to balance an understanding of data privacy from the user's perspective beyond the needs of researchers who are interested in the data to provide broader public health benefits. Taking a user's perspective (eg, on beliefs and priorities from a user's mental state) can be a useful practice for ethical considerations. Perspective taking is an other-centered social cognitive process that involves simulation of and making inference about the target counterpart's mind and cognitive state [69]. Accurately understanding a user's mind and expectations requires taking their perspective, perceiving the situation through the lens of the users who generated these social media communications [70]. In the context of social media data mining, it is necessary to take the perspectives of users who self-disclose personal content on social media, as users' expectations of the privacy of their social media posts can differ from researchers' own perceptions regarding the privacy of the posts. For example, one possible scenario might be that Facebook users post personal stories about their addiction problems on "closed" Facebook Groups, expecting that the self-disclosed content will be kept within the groups. Researchers may perceive the content as part of the aggregated piece of information that is technically available to others who join the groups. In this specific scenario, there is a perceptual discrepancy between social media users and researchers regarding how much access researchers should have to the social media data for data mining and analysis. Given this perceptual discrepancy, failure to communicate research purposes and data protection plans up front is likely to leave users feeling deceived, uninformed, or manipulated [71]. Prior to data mining and retrieval, we encourage investigators to understand ethical expectations and the notion of moral harm, which is assessed by the risk level versus the values of scientific discovery from the research activities, from the perspectives of users in a context-specific manner. One method of building mutual understanding between users and investigators might be contacting the groups' administrators to gain insight on in-group norms and user expectations. Researchers might ask for an introduction to the group members or coordinate an announcement within the groups to inform members of the group that researchers may use anonymous data (without disclosing personally identifying user information) in an aggregated manner for research purposes (eg, [72]).

To protect users' privacy and understand their expectations on the use of their potentially sensitive social media content, such as drug use–related communications, we also encourage researchers to construct guidelines for case-specific scenarios concerning potential ethical issues. For example, a research program at Harvard University published a guideline booklet that reviews ethical norms, case reports, and concrete guidance to help researchers who use social media sites for patient recruitment and contact [72]. The guideline booklet provides a series of dilemma-type scenarios that can occur between researchers, participants, and different stakeholders when social media sites are used for patient recruitment. The guideline booklet also provides multiple case analysis results for each scenario. In line with the guideline booklet, we argue that the same ethical and regulatory practices used in traditional recruitment settings (eg, respect for privacy) can be applied to social media contexts. However, different operational implications should be considered, such as prospectively understanding sensitive values of the social media communities and their users, and the impacts of social media-based research methods on public trust [73]. Given the increasing research attention focus on use of social media for observatory resources and for health communication outreach and delivery platforms, there is a need for developing a concrete guideline on ethical research practices for use of naturally occurring social media communication data and social media-based networks and users for observational purposes and health outreach studies.

As demonstrated in Harvard's guideline for social media use for recruitment research, scenario-specific solutions for ethical challenges on social media-based observational studies can be implemented through "cognitive rehearsals" (or scenario planning) prospectively, rather than retrospectively. Cognitive rehearsal is a cognitive behavioral technique that allows individuals to develop an effective set of responses to a critical event. A cognitive rehearsal approach [74,75] is based on the assumption that a person's reaction to a critical event can be learned and enhanced through reading instructions and building a knowledge base of responses specific to the event. Through cognitive rehearsal techniques, individuals can subsequently adapt learned skills from scripted responses when they face the previously rehearsed event. Cognitive rehearsal approaches have been used as an intervention component to improve responses to impulse control issues and lateral violence [74]. These cognitive rehearsal techniques can be applied during challenging events specific to ethical dilemmas concerning big data use. By "rehearsing" situations and events in advance and generating instructive guidelines, investigators can be better prepared for such situations if they arise, thus establishing a healthy academic culture and mutual trust between the researcher and the community of interest. This scenario-specific, empathetic approach to examine social media big data can be applied to various data mining and retrieval activities, including developing protocols for data anonymization, implementing confidentiality and data protection plans applicable to data mining, and mobilizing plans for strategic communications with social media users for the informed consent process.

Subgroup Analysis and Follow-Up Investigation

Researchers' responsibilities extend to maintaining data confidentiality and protection, and ensuring the transparency of research activities. These activities include not only data mining and analysis, but also subgroup analysis or follow-up investigation (eg, distributing surveys among subgroups, or invitations for interventions). Investigators may need to conduct follow-up surveys or interventions to address questions raised by big data–driven findings. Electronic data are track-(back)-able and technological advances can allow deidentified social media data to be reidentified. Therefore, failures in confidentiality or lack of transparency during the follow-up processes can cause great concern among users if their data were aggregated from social media without their prior consent. The ethical implications and social consequences of contacting individuals who were attributes of the big data–driven findings should be recognized by researchers and policy makers in relation to data protection and human autonomy issues in big data research, even as the attributes of individuals were imperceptible to the aggregate level of big data–driven knowledge [68,76]. Before pursuing follow-up investigation, researchers should consider the rights of subjects and weigh context-specific risk levels in comparison with the value of scientific discovery from the research activities. Additional caution should be used with respect to not only the confidentiality and privacy of reidentified subjects and data security and protection, but also to the compliance between research activities conducted for follow-up purposes and the policies and terms of use of relevant websites [72].

Dissemination of Social Media Big Data–Driven Findings

Emerging technologies and big data have ethical implications beyond those identified in accomplishing research aims. Researchers are also responsible for ethically disseminating the findings extracted from social media big data [77]. Even if the anonymization of individual-level data is successful, findings that describe participants by specific geographical characteristics, socioeconomic status, health condition, risky behavior, or a combination of these characteristics can cause discrimination and stigmatization of those groups, which in turn can raise group-level harm and risk [78]. The consequences of ignoring group-level harm (eg, increased stigmatization of patients in addiction recovery as a result of big data–driven findings reported in an academic article) are nontrivial and can affect broad members of the identified groups or community [79], including those who have opted out of the study. Group-level effects of reidentifiable anonymized data require further research exploration in terms of their social implications for the groups' users (eg, group-level stigma and group-level privacy) and potential unintended discrimination against subgroups with particular demographic characteristics or health-related problems [80].

Ethical principles, including the fundamental rights of "autonomy, protection, safety, maximization of benefits and minimization of harm, and respect for beneficence" ([81], pg 4), are not difficult concepts to understand. However, applying these principles to a sensitive social media big data context (eg, substance use) can raise ethical challenges. Ethics protocols and guidelines for social media big data–driven health research are evolving relatively slowly, compared with the pace of research outcomes using social media big data. These challenges require special sensitivity to the dynamics of social network-based communities and can only be addressed by carefully engaging in iterative ethical decision-making processes, both prospectively in designing studies and retrospectively by learning from ethical practices conducted in the relevant literature.

Methods

We developed a typology based on a critical review process [82]. The strength of a critical review is not only that the review process evaluates the previous body of work, but also that it results in models of thought that can offer a new phase of conceptual framework development [82]. The typology is focused on delivering a set of relevant previous studies in terms of 4 conceptual attributes: (1) the characteristics of users who engage in substance use–related communications for promotional or preventive and control purposes; (2) the nature of substance use–related communications, such as their valence, expressed sentiment properties, and patterns of interactions; (3) the social and psychological predictors and mechanisms of those social media communication behaviors; and (4) the effects of problematic substance use–related social media communications on users. This knowledge development method is designed to elaborate on and identify the utility of social media as a means of communication delivery and observational platforms for users with substance use problems. Developing a multidimensional framework can further help theorize and synthesize underlying factors and conditions that influence social media use behaviors among online communities for problematic substance use–related reasons [43].

In our critical review, 1 researcher (SJK) independently searched for relevant literature within the PubMed database and the entire e-collection theme of “infodemiology and infoveillance” of JMIR Publications which includes the *Journal of Medical Internet Research* and articles in other JMIR journals indexed with this topic (http://www.jmir.org/themes/69). The search keywords were “prescription drug abuse,” “nonmedical drug use,” “social media,” “social network sites,” “big data,” “data mining,” “social media data,” “informatics,” “machine learning,” “Twitter,” “Instagram,” and “Facebook.” The same researcher (SJK) then evaluated the titles and abstracts of published studies based on their topical relevance (ie, problematic or nonmedical use of prescription drugs) and included studies that used social media communication data and computational analytic methods (eg, data mining, social network analysis, and supervised or unsupervised natural language processing).

Given the scope of the review—that is, focusing on how social media big data can be used to understand communication and behavioral patterns of nonmedical or problematic use of prescription drugs— in our typology, we did not include studies that reported data from nonsocial media platforms (eg, online forums), problematic use of other substances (eg, alcohol, cigarettes, and cannabis), or noncomputational analytic methods (eg, survey only) (eg, [1,3,5,6,35]). Note that demonstrating the systematic nature of the article search and conducting quality assessment are not components of critical review, and, thus, a Consolidated Standards of Reporting Trials (CONSORT) diagram is not required. After screening a large number of searched articles within the PubMed database and the entire e-collection theme of “infodemiology and infoveillance” within the *Journal of Medical Internet Research*, we reviewed findings from 8 highly relevant studies that met all the inclusion criteria. We report empirical evidence from the studies in relation to the 4 research inquiries, the methodological and computational approaches, and ethical practices and considerations discussed in each study (Multimedia Appendix 1 [2,4,7,33,36,83-85]).

Results

Multimedia Appendix 1 lists studies that met eligibility criteria and were closely related to the topic of interest, along with the 4 conceptual dimensions, as well as methodological and ethical domains.

User Characteristics

The characteristics of users who shared substance use–related communications on social media were reported by general group characteristics, such as college students, youth and adolescents, Twitter users, and Instagram users. Different types and levels of substance uses tended to be associated with different demographic characteristics, including sex, age, and socioeconomic status [38]. The demographic and social-psychological characteristics of users can be classification markers for certain types and patterns of substance use–related communications on social media (eg, polydrug use tweets with positive action verbs). Understanding social media communication data with specific user characteristics can inform the division of subgroups when targeting just-in-time interventions, addiction recovery support systems, or antidrug recovery campaigns through social media. However, relatively less research attention was given to analyzing or incorporating user characteristics along with the analyzed communication characteristics.

Communication Characteristics

All the reviewed studies examined various communication characteristics, ranging from geographic and temporal trends associated with nonmedical use of prescription stimulants to sentimental (eg, positive vs negative connotation, emotions), contextual (abusive vs therapeutic), and thematic (eg, feeling high) aspects of social media communications regarding problematic use of prescription drugs (eg, [33]). In a prominent work, Hanson and colleagues analyzed alternative motives and potential side effects of drug intake for nonmedical purposes (eg, as a study aid) through tweets matching [33]. Hanson and colleagues also examined how social network factors explained the nonmedical use of prescription drugs and relevant risk behavior [2]. The empirical evidence in the reviewed articles demonstrated that aggregated, time-stamped social media big data can reveal linguistic characteristics, interaction activities (eg, posting text or image content portraying substance use), needs of and thoughts on drug intake, social relations, and risk behaviors concerning problematic prescription drug and polydrug use.

Mechanisms and Predictors

There was limited work on directly examining moderating or mechanistic factors of drug abuse–related social media communications. The predictors and mechanisms of social media communications for nonmedical use of prescription drugs (eg, attitudes, risk perceptions) were not directly investigated in the studies we reviewed, and thus remain largely underexplored. Applying use and gratification theory of media can shed light on what motivates individuals to share or engage with such content on social media and what kinds of media use gratification (eg, entertainment, sharing problems for moral support) these media activities provide for people with substance use problems [86,87]. Understanding these mechanisms of social media use for drug-related communications (eg, drug use–related activities and seeking recovery support) can produce clinical insights into how these features can be used in a clinically meaningful manner to fulfill the realistic needs of people with substance use problems. For example, people with substance use problems disclose and share information, and interact with others for substance promotional and prevention- and recovery-related purposes. These self-initiated communication activities might be associated with psychological deficits or the need for social support among substance users, or might coincide with the finding that substance users find self-disclosure activities therapeutically rewarding [57,88]. Mechanistic investigation is likely to help researchers and clinicians identify key factors when considering the designs and development of an intervention to effectively treat substance use problems.

Outcomes

The psychological and behavioral consequences (eg, increased behavioral intention for mimicking risky health behaviors) of engaging with and being exposed to social media communications regarding problematic drug use is another area of research that has been understudied. This dimension was not directly examined or empirically identified in the reviewed studies. However, the importance of understanding the varied aspects of these outcomes was discussed in some studies [7,33]. For example, Shutler and colleagues discussed the potential presumed effects of normalizing illicit drug use behavior on social media [7]. Hanson and colleagues discussed how the prevalence of tweets about nonmedical use of Adderall (eg, as a study aid) may produce a misperception that risky drug use behavior is acceptable among peer groups, and that, in turn, may lead to socially normalizing abusive drug behavior and increasing the levels of abuse [33].

Understanding short-term and long-term effects of media exposure and engagement for problematic drug use–related communications may require population-level-based surveys or longitudinal follow-up investigation in addition to social media big data analytics. By examining the psychological and behavioral effects of using social media for drug promotional or prevention- and control-related purposes, investigators can be well positioned to improve their ability to develop theoretical and methodological models when harnessing social media platforms for health promotion targeting public health problems, such as nonmedical and problematic use of prescription drugs. Investigating the outcome dimension will also help researchers understand the clinical implications and the utility of social media as behavioral intervention platforms.

Methodological Domain

For the data mining process, some studies developed and tested their own social media data monitoring and crawling systems. For example, Cameron and colleagues developed the Prescription Drug Abuse Online Surveillance and Epidemiology (PREDOSE) infrastructure to extract and analyze entities and sentiments of unstructured social media text data regarding prescription drug abuse [83,89]. Data collection periods varies across studies, ranging from 2 weeks to more than 1 year (eg, [7,36]).

With the exception of 2 studies conducted by Correia and colleagues [4], who used Instagram data, and Cameron and colleagues [83], who did not disclose the name of the analyzed social media platform, all other reviewed studies analyzed Twitter data. Also, with the exception of the Hanson et al study [2] that explored social networks, most of the reviewed studies examined the linguistic properties of Twitter communication data. In doing so, they applied different machine learning (supervised or unsupervised learning) models to a random subset of filtered Twitter text data to identify common latent themes, patterns, and sentiments associated with nonmedical prescription drug or polydrug use (eg, [84]). A study led by Hanson and colleagues examined social networks of nonmedical or abusive use of prescription drugs and polydrug use among college students by selecting 25 subsets of tweet networks that comprised 2227 unique Twitter users. They explored social circles and interaction patterns within each network [2]. They used mixed methods involving human coding, qualitative content analysis, and manual annotation tasks, along with filtered keyword searches, as part of an iterative process to precisely understand a large volume of Twitter content promoting nonmedical use of prescription drugs, such as opioid analgesic drugs [7,33,36,84,85].

Ethical Domain

Among the reviewed studies, 4 reported that an institutional review board (IRB) approved their study [2,33,83]. Two studies reported that the IRB review was waived or was not applicable [7,36]. The status of IRB review and approval was not explicitly reported or discussed in some studies [4,84,85]. The reviewed studies used either Twitter text data or Instagram data, and these datasets were considered publicly open sources, although the topic of interest was problematic use of prescription drugs, which can be personal and risk sensitive. Some researchers reported ethical practices they applied in compliance with their IRB guidelines. For example, Cameron and colleagues [83] did not disclose the name of the social media platform they analyzed, and Kalyanam and colleagues [84] discussed the data anonymization process (eg, removing user name and profile information before analysis). In most studies, potential ethical issues and practices were not discussed in detail. This might be, in part, because the social media data in their studies was considered publicly open or because discussing ethical aspects was not directly within the scope of their study.

Discussion

The detrimental consequences of substance use highlight the urgent need for research to understand the drug epidemic in a scalable, systematic manner. Performing big data analytics on social media content allows researchers to generate data-informed insights into the phenomena of interest, such as the promotional communication of problematic substance use shared on social media platforms. The use of social media data to monitor and observe problematic use of prescription drugs, such as nonmedical use of analgesic opioid drugs, is as yet an unexplored area of biomedical research. In our reviewed studies reported in a typology, the communication properties were used to identify high-risk events [90], indicating the potential utility of social media data as a resource in scaling up surveillance systems for substance use problems. More specifically, social media communication data aggregated by drug use–related search keywords can indicate the level and stage of drug dependence, the actions of patients engaging in addiction recovery support groups, former users with or without relapse episodes, or current users with or without dependence. Given the large scale of social media communications posted by people who have engaged or are engaging in nonmedical use of prescription drugs such as opioids, harnessing social media platforms and data will provide insight into important novel discoveries of collective public health risk behavior.

In this paper, we propose a multilevel framework and ethical considerations that are applicable to social media communication data to understand problematic drug use phenomena. Based on the 4 dimensions in the framework, along with methodological and ethical domains, we conducted a critical, narrative review of empirical findings that were based on social media communication data involving problematic use of prescription drugs. The 4 primary conceptual dimensions are (1) understanding characteristics of users who share their data (eg, texts, pictures) about nonmedical substance use on social media; (2) the communication characteristics of such self-disclosed data; (3) predictors and underlying mechanisms of social media communications on problematic use of prescription drugs; and (4) the psychological and behavioral consequences that social media use for problematic drug use–related communications may have for users themselves (eg, active users) or others (eg, observers, lurkers). The state of social media uses among people with substance use problems is receiving increased attention. We designed an evidence-based, multiconceptual framework in our typology to inform potential future research directions, which may also offer insights into public health outreach strategies, as well as the development of social media-based substance use prevention and recovery intervention programs.

Advances in communication technology and informatics offer novel opportunities for understanding substance use problems through naturally occurring, self-disclosed communications on social media. This research requires multidisciplinary collaborative efforts between data scientists, social scientists, and clinicians to systematically structure and identify the ongoing substance abuse problems observable through problematic drug use–related communications on social media. Various social media features and characteristics (eg, easy access, perceived anonymity), automated analytic approaches at scale, and the prevalence of sharing and engaging user activities for such communications underscore the benefits of harnessing social media platforms and data to study drug use trends, patterns, and the underlying psychology and subsequent outcomes. Social media big data on the nationwide public health problem of nonmedical use of prescription drugs in the United States can also have a practical impact at the individual level (eg, seeking social support for addiction recovery support), as well as at the societal level (eg, public health campaign efforts on this topic). Although a different and extended set of ethical challenges exists in the realm of social media big data research, we expect that principle-guided, multidisciplinary, and iterative processes will soon start to converge for this topic. We also raise the importance of the precision and sensitivity of social media big data that can be prone to type I error (ie, falsely identifying and overgenerating inferences from data [3,91]). For future research, mixed methods incorporating survey research and recruitment strategies for longitudinal follow-up investigation can be used to improve the validity of social media data-driven findings.

We acknowledged a lack of theoretical frameworks that are applicable to social media big data for substance use monitoring and observational systems [91]. To bridge this gap in the research, we proposed a typology of the substance use epidemic that was traceable and observed through social media data. This knowledge synthesis is designed to analyze the state of the research on this topic and to guide future research directions. In this typology, we focused on previous work that used automated data analytics such as computational linguistic analysis and social network analysis, rather than using research outcomes purely based on manual coding of content analysis or noncomputational methods. The reviewed articles incorporated findings from supervised or unsupervised machine learning and various computational approaches. The reviewed findings demonstrated that surveillance systems incorporating social media data can produce comparable and valid findings in an epidemiological and scalable manner, in comparison with conventional survey and manual coding content analysis methods (eg, [33,84]).

In this paper, we aimed to offer key conceptual applications, ethical considerations, social media data-based empirical evidence, and a typology framework within the scope of dominant public health issues centered on nonmedical and problematic prescription drug use. As proposed in the novel typology, integrating the 4 conceptual dimensions and multidisciplinary research efforts may advance our knowledge on this nationwide crisis of prescription drug use problems in the United States. Future research may use the proposed conceptual framework and the perspectives delivered in this paper as a leverage in advancing scientific scholarship on this important topic.

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Authors' Contributions

SJK conceived of this project, conceptualized the study, undertook the literature review and critical review processes, and drafted the first and the last versions of the manuscript. LAM, JTH, and AKD provided recommendations and edits. All authors read drafts and approved the final manuscript to be published.

Conflicts of Interest

None declared.

Multimedia Appendix 1

A typology of social media big data analysis for prescription drug abuse and addiction research.

[PDF File (Adobe PDF File), 28KB - jmir_v19i10e353_app1.pdf]

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Abbreviations

CONSORT: Consolidated Standards of Reporting Trials
IRB: institutional review board
PREDOSE: Prescription Drug Abuse Online Surveillance and Epidemiology

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Original Paper

Views of Community Managers on Knowledge Co-creation in Online Communities for People With Disabilities: Qualitative Study

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Abstract

Background: The use of online communities to promote end user involvement and co-creation in the product and service innovation process is well documented in the marketing and management literature. Whereas online communities are widely used for health care service provision and peer-to-peer support, only little is known about how they could be integrated into the health care innovation process.

Objective: The overall objective of this qualitative study was to explore community managers' views on and experiences with knowledge co-creation in online communities for people with disabilities.

Methods: A descriptive qualitative research design was used. Data were collected through semi-structured interviews with nine community managers. To complement the interview data, additional information was retrieved from the communities in the form of structural information (number of registered users, number and names of topic areas covered by the forum) and administrative information (terms and conditions and privacy statements, forum rules). Data were analyzed using thematic analysis.

Results: Our results highlight two main aspects: peer-to-peer knowledge co-creation and types of collaboration with external actors. Although community managers strongly encouraged peer-to-peer knowledge co-creation, our findings indicated that these activities were not common practice in the communities under investigation. In fact, much of what related to co-creation, prototyping, and product development was still perceived to be directed by professionals and experts. Community managers described the role of their respective communities as informing this process rather than a driving force. The role of community members as advisors to researchers, health care professionals, and businesses was discussed in the context of types of collaboration with external actors. According to the community managers, most of the external inquiries related to research projects of students or health care professionals in training, who often joined a community for the sole purpose of recruiting participants for their research. Despite this unilateral form of knowledge co-creation, community managers acknowledged the mere interest of these user groups as beneficial, as long as their interest was not purely financially motivated. Being able to contribute to advancing research, improving products, and informing the planning and design of health care services were described as some of the key motivations to engage with external stakeholders.

Conclusions: This paper draws attention to the currently under-investigated role of online communities as platforms for collaboration and co-creation between patients, health care professionals, researchers, and businesses. It describes community managers' views on and experiences with knowledge co-creation and provides recommendations on how these activities can be leveraged to foster knowledge co-creation in health care. Engaging in knowledge co-creation with online health communities may ultimately help to inform the planning and design of products, services, and research activities that better meet the actual needs of those living with a disability.

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KEYWORDS
community networks; internet; patient-centered care; telemedicine; community participation; co-creation

Introduction

Online Health Communities

Online health communities (OHCs) are an increasingly popular source of health information and peer-to-peer support, particularly for patients with chronic health conditions [1-4]. They enable individuals to connect and exchange their experiences with symptoms, treatments, side effects, and strategies for self-management [5]. By publicly sharing their experiential expertise and health advice, individuals can provide important support to others in need [6-8]. Building on the findings of earlier work [9-13], this study proposes that in addition to the several purposes of OHCs, including their role as peer-support networks, these communities can also be used as platforms to promote patient participation in health care. By enabling patients to actively participate in the health care discourse online, OHCs can, in turn, also foster collaboration and knowledge co-creation between patients, researchers, health care professionals, and businesses, allowing for a multilateral exchange of knowledge and ideas to create new knowledge [14,15]. The main objective of this paper was to explore community managers' views on knowledge co-creation taking place in existing online communities for people with disabilities.

Patient Participation

Traditionally, patient participation (also commonly referred to as *patient involvement* or *patient engagement*) refers to the active role that patients can play in their own care process by engaging in activities such as shared decision making and self-management of their health condition [14,16]. As such, it emphasizes patients' rights to choose and control medical decisions concerning their own health and has been recognized as a promising strategy to enhance individual care and health outcomes [17].

More recently, the role of peer-to-peer support has gained increasing attention from health care research and practice. Increasingly, patients are recognized as an important resource for other patients and as allies for health care professionals [18]. They can complement existing health care services by sharing their experiential knowledge to provide emotional and practical support to individuals facing similar health issues [19]. In this context, patients can become health coaches who guide and motivate those facing similar struggles to adopt or modify certain health behaviors, for example, to engage in effective self-management practices [20,21].

Being deeply rooted in the traditional view on patient participation, we propose an extension of the concept of patient participation to account for patients' contributions to the planning and design of health care services, products, and research by co-creating knowledge with other patients, health care professionals, researchers, or businesses. Our conceptualization of patient participation draws on the literature on user-driven innovation in general [22] and patient-driven innovation in particular [10,23], which recognizes the patient as an active collaborator in the health care innovation process. Informed by earlier work [24], we consider the health care innovation process to be concerned with the identification and introduction of new concepts and ideas related to services, processes or products that seek to improve treatment, diagnosis, education, outreach, prevention, and research with the ultimate goal of improving health outcomes, quality, safety, efficiency, and cost-effectiveness [9]. As such, our conceptualization of patient participation also relates to work in the field of codesign and co-creation in health care quality improvement, which actively involves patients, family members, and health care professionals in the planning and design of health services [25-27]. In the context of this paper, the term patient participation thus refers to a patient's active role in the health care process that is not limited to his or her own health but also accounts for patients' contributions to the planning design of health care services, products, and research through knowledge co-creation.

Knowledge Co-creation

Knowledge constitutes a key element to foster product and service innovation and has thus created much scholarly interest, particularly in the marketing and management literature. Whereas there is no universally accepted definition of co-creation, it has been described as an act of collective creativity, with applications ranging from product and service design to more abstract spheres of value creation taking place between two or more individuals who may or may not belong to the same actor group (eg, patients, researchers, and health care professionals) [28]. It builds on but extends beyond knowledge collaboration, which involves providing and receiving information or support (eg, peer-to-peer support), in that it constitutes an exchange that leads to the creation of new knowledge and ideas. As such, co-creation can, for example, involve a group of patients who by sharing their know-how and lived experience develop new strategies for managing a specific health problem, but it can also refer to the exchange taking place between patients and health care professionals who work together to develop a new health service or information brochure. Following Bagayogo and colleagues [29], we thus consider knowledge co-creation in health care to be a voluntary collaborative process that involves individuals, including patients, researchers, and health care professionals, sharing and creating new knowledge about health care services, products, and research. The creation of new knowledge, in turn, constitutes a key driver for product and service innovation [30], which is of key interest to health care institutions.

One of the main challenges health care organizations face in this context is the transfer of tacit knowledge (*know-how*, lived experience) that is stored in the minds of different actors, including patients, health care professionals, and researchers into explicit organizational knowledge [31,32]. To overcome this challenge, Kohlbacher [33] suggests that whereas knowledge creation is usually conducted in a unilateral way, where firms generate, collect, and analyze information about customers, the focus should be on knowledge co-creation. Here, he refers to Prahalad and Ramaswamy [34] who describe how "co-creation converts the market into a forum where dialogue among the consumer, the firm, consumer communities, and networks of firms can take place" to create value for the stakeholders involved in the co-creation process. Similarly, Sawhney and Prandelli [35] argue that there is a need for a shift from the perspective of the firm as sole knowledge creator to a perspective where firms are co-creators of knowledge and learn to co-create value with their consumers.

In health care, however, knowledge co-creation is still in its infancy. Although the value of patient participation is widely acknowledged in the domains of self-management and peer-to-peer support (knowledge collaboration), the patient's role as an active participant in the health care innovation process remains contested. Similar to traditional market research, health care organizations and researchers are currently more focused on gaining information about patients rather than co-creating knowledge with patients.. Health care organizations, for example, rely on patient satisfaction indicators as a basis for improvement of their offers, rather than directly involving patients in the planning and design of health care services [36].

However, there are some noteworthy advances, particularly in the field of health care quality improvement, that draw on design-thinking principles to enable knowledge co-creation between service users and health care providers [27,37-40]. Co-creation projects have been carried out in different settings, including emergency departments, intensive care units, cancer services, and mental health services, resulting in ideas for modification of processes, practices, and clinical environments, as well as tangible service changes and impacts on patient experiences [39]. Research in the field of patient-driven innovation further shows that patients can also innovate and co-create among themselves without requiring a health care organization to initiate or mediate these activities. The Nightscout initiative constitutes an example of such a collaborative patient-driven effort. The Nightscout community has created an open-source do-it-yourself mobile technology system for individuals living with type 1 diabetes, which can be accessed, used, and modified by anyone. In doing so, it allows patients, their caregivers, and health professionals to better monitor, predict, and manage diabetes using personalized tools [41].

So while there is more and more evidence on the innovative potential of patients' contributions to the health care innovation process, methods and ideas on how to involve them as active partners are less established [14,42]. Moreover, time and resource constraints constitute an additional challenge to co-creation in health care [38].

Online Health Communities as Platforms for Co-creation

With their increasing interactivity, social media technologies provide an ideal platform to foster co-creation between the different stakeholders in health care [14,43]. Here, social media technologies refer to Web-based technologies that enable individuals around the globe to connect with each other to share and exchange information via virtual platforms, often also referred to as online communities or networks [44]. Technologies for these Web-based communities include, among others, online message boards (forums), chat rooms, as well as an ever-expanding landscape of social networks such as Twitter, Facebook, YouTube, or Instagram [45].

There is an extensive body of literature investigating the role of OHCs in the context of peer-to-peer support [5,46,47], with findings suggesting there is indeed an ongoing exchange taking place in OHCs, leading to the development of rich databases of experiential knowledge that individuals can draw on [21]. Particularly, people with rare and chronic health conditions are likely to seek and benefit from emotional and practical online peer-to-peer support [48,49]. Rains and colleagues [46] found that informational and emotional support messages were, in fact, the most prevalent forms of exchange in more general health–related online contexts, whereas action-facilitating forms of knowledge were more characteristic in the context of chronic health conditions. However, few attempts have been made to better understand the process of social media-enabled knowledge co-creation, where the exchange of information between individuals results in the creation of new knowledge and ideas. Here, the work of Bagayogo and colleagues [29] constitutes a noteworthy exception. The authors propose a three-stage model that explains the process of knowledge co-creation through social media. The first phase, initiation, refers to users sharing or requesting knowledge related to aspects such as diagnosis, treatment, or self-management. In the transition phase, an increasing number of users then collaboratively engage in a discussion, supplementing information that other community members may have shared, or responding to questions posed by others. In the normalization phase, the main focus is on reaching consensus on a specific idea, such as, for example, a self-management strategy [29].

More and more health care organizations are realizing the significance of OHCs as an important form of complementary service to enhance the overall quality of health care services delivery. The key focus of most of these OHCs is to provide a platform for patient support, where patients can interact with others to obtain and provide emotional support in disease management and care [50]. However, whereas many other industries have started to harness the innovative potential of these communities by using them as a venue for customer co-innovation and value co-creation, health care organizations are lagging behind [9,51]. One of the key issues health care organizations face related to deploying the so-called online patient innovation communities is the fact that they are resource-intensive endeavors that require a clear strategy and organizational support [9].

Given that building and maintaining an entirely new community from scratch requires an essential investment without guaranteed success [52], an alternative option would be to engage existing OHCs in a co-creation process. An example of this form of co-creation from the consumer goods industry is the NikeTalk community [53]. NikeTalk is an independent basketball-enthusiast community with no official affiliation with the same-named shoe manufacturer, Nike. The community is occasionally approached by Nike to gain users' insights and ideas for new designs and features. There are even examples showing that sometimes users actively initiate contact with sporting goods companies on their own [53].

Objectives of This Study

With this study, we seek to contribute to the literature on patient participation in health care, focusing particularly on the role that OHCs can play in fostering knowledge co-creation among the different stakeholders in health care. Here, the term patient participation, as outlined earlier, refers to a patient's active role in the health care process that is not limited to his or her own health but also accounts for patients' contributions to the planning design of health care services, products, and research through knowledge co-creation. More specifically, we aim to further explore the phenomenon of knowledge co-creation in existing message boards for persons with disabilities by investigating community managers' views on and experiences with knowledge co-creation.

In this study, we focus on pan-disability online communities and online communities for people with spinal cord injury in particular. Given the overarching consequences a spinal cord injury entails for those affected [54], we chose to explicitly include online communities for spinal cord injury in addition to pan-disability online communities, as they present a particularly interesting case in this context. Prior research suggests that people with disabilities increasingly use online and social media technologies such as message boards or mailing lists to find like-minded individuals to exchange their health-related experiences [55,56]. Under the biopsychosocial model of disability, these experiences are recognized as a valid form of expertise, originating from the person's *lived experience* with a disability [57].

Our study differs from prior research with respect to two points. First, in addition to peer-to-peer knowledge co-creation, we also explore knowledge co-creation between community members and external actors, such as health care professionals, researchers, and businesses. Second, by focusing on the community managers' perspective, we aim to gain a more in-depth understanding of the process of knowledge co-creation taking place in OHCs that is deeply rooted in the experiences of those users most familiar with the community and its members. Due to their role in the community, community managers possess insider-knowledge that extends beyond what is visible to regular community members and external observers. This study thus provides important insights on community managers' views on knowledge co-creation in OHCs taking place between different actors, offering a new perspective on the interactions taking place in OHCs.

Methods

Study Design

As this study is explorative in nature, our aim was not to explain or proof but rather to provide a rich description of the phenomenon under investigation. We thus adopted a descriptive qualitative research design, following the consolidated criteria for reporting qualitative research guidelines (see Multimedia Appendix 1) [58]. According to Braun and Clarke, descriptive qualitative work aims to "'give a voice' to a topic or a group of people, particularly those we know little about" [59]. In line with this aim, the focus of our study was to give a voice to the community managers of existing online communities for people with disabilities to explore their views and experiences related to knowledge co-creation in their respective communities. Data were collected through semi-structured interviews with community managers. To complement the interview data, additional structural and administrative information was collected from the respective communities. To document and reflect upon the research process, a study journal was used, capturing the researchers' underlying values and assumptions. The project was conducted in accordance with ethical guidelines for Web-based research proposed by Eysenbach [60].

Participant Recruitment

A purposeful sampling approach was adopted. To identify English-language disability OHCs, we conducted a Google search with a combination of the terms "online community," "disability," and "spinal cord injury." One author (JA) screened the first 100 search results, applying the following inclusion criteria: interactive, health condition-specific (disability), targeted at patients, and English as the main language. Both organization-initiated and individual-initiated OHCs were included. The search led to the identification of 22 OHCs that met the inclusion criteria: 12 spinal cord injury specific and ten for disability in general. A total of three OHCs were closed at the time they were identified. Personalized messages were sent to the indicated contact persons of all 22 platforms to inform them about the study and its purpose and to invite them to participate in a Web-based interview. Individuals were given the choice of an oral (video-calling) or written (email or chat) interview. Out of the 22 platform managers contacted, ten did not reply, two declined with no reason, and two confirmed interest but did not react to follow-up messages that were sent out three weeks after the initial invitation to participate.

Data Collection

Data collection was carried out from October 2015 to June 2016. A total of nine semi-structured interviews (three email, five video-calling, and one face-to-face) were conducted with community managers of the remaining eight online communities (five spinal cord injury specific and three pan-disability). In one of the included OHCs, two moderators agreed to participate in the interview. All interviews were conducted by one author (JA), a female PhD student in health communication, trained in qualitative research methods with a particular research interest in patient participation. Informed consent was obtained from all participants. The semistructured interview guide was developed by the two authors and was not guided by a preexisting framework to allow for a certain degree of flexibility, enabling us to identify and follow up on participants' individual experiences. The interview guide consisted of four subsections exploring participants' perceptions and experiences with (1) the platform and its challenges, (2) open and user innovation, (3) external inquiries to interact with the community (eg, requests to participate in marketing research), and (4) members' reactions to external inquiries (see Multimedia Appendix 2). Oral interviews lasted between 30 min and 1.5 h and were audio-recorded and transcribed verbatim. To complement the interview data, we retrieved additional information from the communities where available, including structural information (member lists, number and names of topic areas covered by the forum) and administrative information (terms and conditions and privacy statements, forum rules). Member lists were not available for some of the communities (C5, C7, and C8). Observations were documented in form of field notes by one researcher (JA). Once data collection was completed, informal exchange related to the study took place between one researcher (JA) and three community managers (M3, M4, and M5) via the private messaging function of the respective communities.

Data Analysis

Data were analyzed using inductive thematic analysis following the six stages of coding and analysis proposed by Braun and Clarke [59], where the analysis is generated from the data (bottom-up) rather than shaped by existing theory. Here, however, Braun and Clarke note that the analysis is always to a certain degree shaped by the researcher's standpoint and knowledge [59]. Two researchers, both health communication scholars, were involved in the analysis. The first researcher (JA) coded the majority of the material in an iterative process. A second researcher (SR) read and reflected on the material, providing an independent view on the data. We started by familiarizing ourselves with the data material. In the next step, the interview transcripts, terms and conditions and privacy statements, forum rules, and field notes were manually highlighted, coded, and collated. Upon this initial coding phase, recurring themes were identified in the material, and codes were collated into tentative themes. Our conceptualization of knowledge co-creation was primarily based on the coding of those examples drawn from the data, where interaction between members of the community was addressed that extended beyond emotional support and involved the creation of new ideas or knowledge. Data saturation was reached as indicated by the repetition in themes after the seventh interview. Regular meetings were held throughout the entire analysis process to reduce a potential bias. In case of a disagreement, we drew on the original data material and coding to reach a consensus.

Results

Reporting

To warrant the anonymity of the OHCs under investigation and in compliance with guidelines for conducting Web-based research proposed by Eysenbach [60], any information that would allow readers to draw inferences about the respective OHCs was omitted. In the text, interview quotes are attributed to the respective participant by using a participant identifier. In cases where forum content is quoted, compound quotes were used. The Results section is structured as follows. First, we provide some contextual findings in form of general information about the included communities. In the next step, we then present our findings related to community managers' views on and experiences with knowledge co-creation in online communities for people with disabilities.

Table 1. Community characteristics.

Community	Community manager (role)	Focus	Size
Individual-initiated			
Community 1 (C1)	M1 (founder and moderator)	Spinal cord injury	Large
Community 2 (C2)	M2 (founder and moderator)	Spinal cord injury	Medium
Community 3 (C3)	M3 (founder and moderator)	Spinal cord injury	Small
Community 4 (C4)	M4 (founder and moderator)	Spinal cord injury	Medium
Community 5 (C5)	M5 (moderator)	Pan-disability	N/A[a]
Community 6 (C6)	M6a (moderator) M6b (moderator)	Pan-disability	Small
Organization-initiated			
Community 7 (C7)	M7 (moderator)	Spinal cord injury	N/A[a]
Community 8 (C8)	M8 (moderator)	Pan-disability	N/A[a]

[a] N/A: not applicable.

Characteristics of the Studied OHCs

Out of the eight communities investigated, five were initiated by individuals directly affected (C1, C2, C3, C4, and C5), one by an individual whose health status is unknown (C6), and two by organizations that involve volunteers who initiate and moderate forum discussions (C7 and C9). Out of the eight communities, three were classified as pan-disability (C5, C6, and C8), and five were focused on spinal cord injury (C1, C2, C3, C4, and C7). Communities were classified as large, medium, and small according to the number of registered members: small ones having less than 1000 members, medium-sized ones having between 1000 and 2500 members, and large ones having more than 2500 registered members. The study included both content moderators as well as community founders (Table 1). All of them indicated to have administrative rights to perform activities such as editing or removing content and blocking users, which is why from now on we refer to them as community managers. Table 1 presents an overview of the characteristics of the communities included in this study.

Similar to most message boards, each of the communities was divided into different sections and subsections, covering a wide array of topics related to disability such as *adaptive sports and recreation*, *assistive devices and technology*, *work life*, and *health issues*. With respect to access and openness of the respective communities, we found that most communities did not require users to register to view forum content, whereas some did have members-only sections for more personal topics such as relationships and sexuality. Only one of the communities was entirely members-only (C4). In all the communities, registration was required to actively share content on the forum, for example, posting a new thread or answering to an existing one. In addition to using the message board, registered users could also send private messages. Four of the communities entertained a chat room (C2, C3, C4, and C5), allowing for synchronous communication between users. Registration was not required to access and interact with other users in the chat rooms provided by two of these communities (C2 and C5).

The Role of Community Managers

As founders or as assigned moderators, community managers have more power than regular community members. In their function as the community's authority, they ensure that all members adhere to the community's guidelines and rules. Not only can community managers edit, move, or pin content, but they can also permanently remove content from the community. The decision whether a contribution is in violation of the rules is entirely up to the community manager as reflected in the forum rules and terms and conditions statements of the communities investigated in this study (C1-C8). Community managers are the ones who make and enforce the rules, as clearly stated in the forum rules of the respective communities (C1-C8). Forum rules further state that community managers reserve the right to, at their sole discretion, modify or remove content. In addition, they also reserve the right to revoke membership to the forum and ban members from the community, temporarily or permanently, without prior notice or warning by blocking their Internet protocol address.

Community managers reported sometimes spending several hours a day taking care of the community, as one participant explained:

> *Whether I'm active on the site or not, I'm usually investing my time into finding information and stuff like that. (M6a)*

Another participant mentioned he tries to "respond to every topic" (M3) he can, speaking of:

> *...hundreds of hours building [the community] and then thousands of hours managing it. (M3)*

Two of the community managers (C1 and C8) reported being predominately involved in technical, strategic, and safeguarding issues, as one of them explained:

> *I do not tend to initiate discussions too much, as forum members start their own discussions. (M1)*

Being in control of both the content and access to the community, community managers play an essential role in the knowledge co-creation process taking place in the respective communities. They act as the community's boundary managers and gatekeepers who monitor all interaction and determine the interpretation of the rules and policies. In their role as the community's authority, community managers can, therefore, facilitate or inhibit knowledge co-creation between members by removing or editing content, banning users, or by restricting access to certain areas of the community (eg, members-only areas).

Knowledge Co-creation

After having provided some contextual information about the communities, we now present our findings related to community managers' views on and experiences with knowledge co-creation in the communities under investigation. The analysis of the structural information extracted from the communities revealed that the number of registered users varied greatly between the communities, with some having less than 1000 registered users and others having several thousand users (see Table 1). Despite these discrepancies, all of the community managers reported having a small number of highly active users who are the main source of content, as summarized by one of the participants:

> *Active forums are usually maintained by moderators and a core membership who usually regularly post. (M6b)*

These findings are supported by evidence gained from the structural information extracted from the communities. When comparing the number of replies to a post with the number of times it had been viewed, we found strong discrepancies, with much higher numbers in views than replies, indicating that users were much more likely to consume information than to actively post information (C1-C8). The comparatively small number of active users also became apparent when analyzing the communities' member lists, which in addition to the username, usually also displayed information related to the users' contribution behavior such as the number of posts and the number of likes.

Despite relatively small numbers of active contributors, community managers reported that knowledge co-creation did occur in their respective communities. These knowledge co-creation activities and community managers' views on them constituted the main focus of our analysis. Our analysis revealed that there are different forms of knowledge co-creation in online communities for people with disabilities. More precisely, we identified two main themes: *peer-to-peer knowledge co-creation* and *types of collaboration with external actors*, including several subthemes (see Multimedia Appendix 3). In the context of this research, the terms *professional* or *external stakeholder* refer to health care professionals, researchers, students, and businesses alike, as we found that community managers rarely distinguished between the different types of external inquiries in their narrations. In the following subsections, we present a narrative account of our findings.

Peer-to-Peer Knowledge Co-creation

In the peer-to-peer context, co-creation captures users' joint efforts to develop new or modify existing products and services by actively building on each other's ideas and insights. Our findings indicate that the idea of jointly creating new products that are more tailored to the actual needs of the disabled community appealed to the community managers. It was in fact an activity they strongly encouraged by asking members to share and exchange their experiences with products and services to develop new ideas, as outlined by one of the participants:

> *I mean that's why we tell people to leave comments and ideas on the comments section below. To see if maybe, I don't know, if they could come up with either a similar product that does a better job doing it, and they could share that with people, that would be cool. [...] I mean that's what we want, its people to come up with ideas that generate innovation and new products and—to make our lives easier so we can regain some of the independence that we lost when we got injured. (M4)*

In this context, one of the participants referred to his experiences outside the community, acknowledging the power and revolutionary nature of online communities in combination with advancing three-dimensional (3D) printing technologies. He particularly emphasized the driving force that online communities constitute in promoting the sharing of ideas and co-creation:

> *I've seen this very much in the 3D printing world recently—it has joined with the disabled world. [...] People are printing and making what's the word, prosthesis orthosis, you know like splints, leg braces, and wrist braces—and they'll be using 3D printers to do this. And it is revolutionary because usually these kind of things are crafted very meticulously by people in that line of industry. [...] And you know, this has been revolutionary and the sharing of information—nobody is trying to sell these blueprints or these 3D models, they're all sharing the information openly. (M5)*

The quote above illustrates how advancing technologies such as 3D printing, can empower and more importantly equip individuals with the tools they need to increase their independence and autonomy, reducing their dependence on professionals and experts who were traditionally the ones in charge of their health. It further highlights the altruistic aspects underlying co-creation in the peer-to-peer context and the idea of a "free flow of information" (M1) that allows individuals to use and build upon each other's work to create new devices, tools, and ideas, as something beneficial within itself.

Despite community managers' positive attitudes toward knowledge co-creation, we found that these activities were not yet common practice in the respective communities, where exchange involved users providing and receiving support rather than building on each other's knowledge to create new knowledge and ideas, as illustrated by the quote below:

> *If someone would say, "I have got a problem putting a pair of trousers on," then someone else would say "Well, I use, you know, this to do it." or they got other techniques for doing it. And they help each other out. (M2)*

So while participants recalled instances of users sharing ideas and making suggestions, there was a lack of concrete examples of knowledge co-creation efforts. When speaking of a section that was created to promote the exchange of users' ideas and co-creation activities in a peer-to-peer format, the community manager of the respective community shared his experience, attributing the lack of interaction mainly to usability issues:

> *Unfortunately, so far there is not so much happening in this section [the one created to promote the exchange of users' ideas]. I hoped that there would be much more but I think it's also a problem of the usability of the website. (M7)*

In addition, much of what related to co-creation, prototyping, and product development was still perceived to be controlled by professionals and experts. In this sense, most of the community managers mentioned how sharing ideas could inform product development, positioning themselves as informants to this process rather than claiming a more active role and decision power in the development and production phase:

> *We do get in ideas, disability aids mostly, good wheelchairs, what people want from them. But really it's mostly all suggestions at the moment and not many people are coming together to make new ideas. [...] It's just a case of how to implement it, to make people feel like they can have an input [...] I think if we'd have companies post on the site, say "We are interested in what you think" then more people would look into it. (M6a)*

The quote above shows the perceived dependence on manufacturers, suggesting that community members' ideas were regarded as input that could only realize its value once it was taken up by professionals (eg, manufacturers). It suggested that community members do not see a purpose in sharing their ideas if there is no business interested in producing them.

Types of Collaboration With External Actors

All of the communities allowed members of different groups, including researchers, health care professionals, and students to join and were open to collaborating with them, as long as their involvement was not purely commercially motivated. Any form of pure advertisement was strictly forbidden, as outlined in the forum rules and terms and condition statements of the respective communities (C1-C8). One of the participants summarized:

> *We allow members with different disabilities, service providers, and charities to join discussions if it's not simply for commercial gain. [...]. We are in favor of assisting with research participation where able. [...] We also allow requests on the forum regarding product research and development, however research for the sole purpose of profiting from members opinions is discouraged. (M1)*

Despite low numbers of businesses actively seeking the communities' insights, community managers were also open to them joining their respective communities as long as they "are transparent as to who they are" (M6b) and "willing to get involved in the conversations and do not just use the forum to promote their products or services" (M6b). Community managers, in fact, underlined the benefits and importance of businesses looking at the ideas and insights users are sharing online and "to listen to disabled consumers" (M8). In these statements, participants expressed hope that this may help to improve the life of those living with a disability by creating a better understanding of what their needs are.

According to the participants, most of the external inquiries related to research projects of students or health care professionals in training. In this context, it was noted that collaboration did usually not take place in an interactive manner or over longer periods. Most of the time, there was a set of questions that community members were asked to answer, for example, in the form of a poll or a survey. According to the community managers, researchers and students often joined the community for the sole purpose of recruiting participants for scientific studies and usually did not have the intention of getting involved with the community or to follow up, for example, by sharing or discussing their research findings with the community members. In other words, they recognized that these forms of exchange were unilateral, limited in time, and in pursuit of a clear goal set by the person seeking the community's insights. As one participant explained:

> *Usually, it's just you know "I'm studying something would you mind if I asked a few questions?" And nobody would ask to see the results or to read the paper—and that's usually it, that's the extent of our interaction. [...] You know they come, they ask the questions, they leave. You know, they just use us. Well, because they need to continue their own path, you know their education. They were always very clear that they were doing a study and were looking for volunteers [...] it was always clear what the purpose was. (M5)*

The notion of "they use us" in this context reflects frustration regarding the unilateral nature of the collaboration and the lack of true involvement with the community and its needs. Comments as the one above, however, also show that community managers understand and accept the reasons for this form of interaction from the perspective of nondisabled researchers, health care professionals, and students. For them, the mere interest of these user groups in their community was already perceived as beneficial within itself, recognizing it as an important first step. In this sense, most of the community managers underlined the importance of welcoming students, researchers, health care professionals, and businesses to spread important information and help to inform health care research and practice. As one of the community managers commented:

> *Educating people on this matter is good, can't really harm us at all—it's a good thing, you know, it's good to raise awareness. (M3)*

Another participant described it as a win-win situation, turning the traditional patient education approach around, highlighting the community's role in educating professionals, helping them to gain a better understanding of persons with disabilities and their needs. He explained:

> *We're educating tomorrow's doctors, we're educating tomorrow's nurses, tomorrow's engineers in some cases. [...] We've all had bad experiences with doctors or nurses, physiotherapist or occupational therapists—so the general idea is: The more we can help them, the better they will be. (M5)*

As illustrated by the quote above, being able to contribute to advancing research and improving practice was an essential aspect voiced by the part(icipants. The underlying hope expressed by participants in this context is not only to help oneself but rather to also "improve stuff for everyone else [living with a disability]" (M2), including not only products but also treatment. In this context, participants emphasized the importance of knowledge dissemination, describing it as a "ripple effect" by which good ideas are spread (M2). One participant particularly emphasized the community's readiness to take on a more active role in the health care process:

> *I just want the information to be out there. That I'm not just another sick person sitting in my room 24 hours a day, you know. I just want to let the world know that we are people—we are not just disabled. At the back of the community we have brains and we want to use them. (M6a)*

Besides the generally positive attitudes of community managers, some of them recalled instances where community members expressed skepticism toward external inquiries, as one of them explained:

> *Feedback from users is that they felt like they were just being used for free research, so we aim to keep these [external inquiries] separate for other conversations. (M8)*

Comments as this one reflect the frustration experienced by certain users who felt exploited by external requests, which were often time-consuming and did not offer any immediate benefit to users. These users feel disturbed, perceiving external inquiries as an intrusion to their privacy and personal space. Unlike community managers, they are focused on their own situation and do not always see the big picture. In this context, one of the community managers recalled the need to introduce a new policy that clearly stated that students and researchers were welcome in the community to counterbalance users' expression of "negative attitudes like 'Oh no, I'm not nobody's Guinea pig, I don't want to be, I get enough questions asked from doctors!'" (M5)

In this context, community managers underlined how the adoption of a give-and-take approach by researchers could make a difference in users' perceptions and how this would in turn help to establish trust and encourage co-creation. Even though some researchers offered vouchers or gift certificates as compensation for members' time and effort to participate in a study, we found that actions such as "making research fun" (M4), avoiding lengthy questionnaires, and sharing research findings with the community were perceived as equally important by community managers:

> *When people agree to [sharing their research findings], I guess you feel a little less used because*

> *you've seen the result. You've seen how it has helped somebody and you see the light in which their information has been used. (M5)*

In the context of an increasing number of external inquiries, some community managers have emphasized the need to shield the community and its members from too many external inquiries, as they may disrupt the communication taking place between regular users. So to protect the community members' interests, they established clear rules such as "dedicated areas for research requests" (M1) and other external inquiries, separating these requests from the general discussion taking place in the community. This separation serves a similar purpose as the separation of editorial and advertising content in mass media—protecting consumers by ensuring transparency and editorial integrity. An additional precaution taken by community managers was to review external inquiries to ensure that they adhere to the rules and regulations of the respective communities. In this context, community managers reported checking whether requests originated from a legitimate source and whether they complied with "professional standards." (M6b)

There was only one community (C7) that did not allow any external inquiries to be posted to the community, acknowledging that measures taken against these inquiries, such as removing posts by students seeking to recruit study participants, were not only in the best interest of the community members but also motivated by the organization's own agenda:

> *We also want to do studies in the future with users so if they get one call every day, the motivation to participate might decrease a lot. So we also want to check that they don't get too many offers for study participation. (M7)*

Discussion

By adopting the community managers' perspective, our results reflect the experiences, views, and in-depth knowledge of those members who play a key role in governing their respective communities. Thus, our results offer a unique insider perspective on what is happening *behind the scenes* of the included OHCs beyond what is publicly visible. In the following paragraphs, we critically discuss our findings and provide recommendations on how these findings can be leveraged to foster knowledge co-creation in online communities.

Principal Findings

Our findings contribute to existing research in that they highlight the currently under-investigated role of OHCs as platforms for collaboration and co-creation between patients, health care professionals, businesses, and researchers. By taking online communities for people with disabilities as a case in point, we aimed to highlight the potential of existing OHCs to contribute to the improvement of products, services, and research.

In this paper, we explored community managers' views and experiences in relation to knowledge co-creation in online communities for people with disabilities. Here, we identified two main themes: *peer-to-peer knowledge co-creation* and *types of collaboration with external actors*. On the one hand, our findings showed that most community managers had positive attitudes toward knowledge co-creation. Here, they highlighted the potential of knowledge co-creation to improve health care service delivery as well as its positive impact on individual care situations. They also advocated for openness and a free flow of information to promote co-creation among patients and between patients and professionals. On the other hand, community managers also stressed the need to establish and enforce certain ground rules for collaboration to protect the community's interests, particularly with respect to the involvement of external stakeholders. Although we identified positive attitudes toward knowledge co-creation and examples of collaborative efforts involving the exchange of information, concrete examples of knowledge co-creation were scarce, indicating a lack of concrete experiences community managers could refer to. This, in turn, suggests that whereas community managers are not only open but supportive of knowledge co-creation, it is not yet taking place to the extent they would hope for. As a result, much of the knowledge that resides within the OHCs under investigation lies idle.

Whereas prior research has shown that patients can come up with innovative ideas and solutions [23,61,62], less is known about whether and how these ideas can be captured and further developed in collaboration with other patients or health care organizations. In line with previous research in the marketing and management literature [53], we found that existing OHCs constitute a promising way of fostering knowledge co-creation and innovation. Indeed, our findings suggest that community managers have positive attitudes toward knowledge co-creation, providing a fruitful and supportive environment for these activities to take place. Here, participants indicated an interest to contribute not only as participants but as collaborators, taking on tasks such as assisting in the formulation of relevant research questions, assisting with data collection, prototype testing, or product reviewing, acknowledging that in this way a much wider patient population could benefit. In fact, community managers promoted and encouraged their communities to be active in sharing their experiences not only to help others but also to create new knowledge to educate health care professionals and to help advance research. This active role described and promoted by community managers is also a key issue addressed by a paradigm shift in disability studies, most well known for its mantra "Nothing About Us Without Us" [63]. Here, many patient advocates, as well as scholars, have argued that research should embrace the experiential knowledge of persons with disabilities. It has further been highlighted that participatory research, which builds from socially informed models of disability, constitutes an approach benefiting both individuals as well as the quality of the research [64]. Even though participatory research is gaining increasing attention, particularly in the field of disability studies, it is not clear how persons with disabilities should be identified as collaborators in these projects [65]. Findings of our study indicate that whereas online communities for people with disabilities are interested in collaborating with researchers and practitioners, they are currently not involved in this process. In the following paragraphs, we outline why we believe OHCs constitute a promising way of fostering knowledge co-creation between different stakeholders in the disability context.

Whereas in health care we usually aim for representativeness, we here draw on lead user theory to make a case for focusing on knowledge co-creation with those individuals who we refer to as lead users. Lead user theory [66] describes lead users as those users of a certain product or service who are (1) early adopters of the product or service, (2) ahead of an important market trend, and (3) experiencing high benefits from innovating. Lead users usually experience needs before the general market does, and in the absence of adequate solutions, they innovate to fulfill their needs. According to lead user theory, this makes them a promising source of innovative ideas to generate new products and services. Indeed, there is a growing body of literature on open and user innovation, providing strong empirical evidence that lead users are likely to come up with commercially lucrative innovations [66-68]. To harness these innovations, it has been suggested to integrate lead users into the corporate innovation process using the lead user method [66,67,69]. The lead user method, as proposed by von Hippel [66], enables companies to identify and capture both lead users' needs as well as their ideas and solutions, allowing them to derive promising ideas for new products and services.

Applying the concept of lead users to the health care context, it was suggested that disabled persons adhere to two key attributes of lead users originally defined by von Hippel [65]. Rather than considering persons with a disability as lead users merely as a result of their disability, we propose that in the case of persons with disability, it is also individuals' high product or service use experience that can be a driver for innovative ideas and motivation to engage in knowledge co-creation [70]. Moreover, we build on prior lead user research conducted in online communities of practice, which suggests that lead users are highly likely to be able to provide knowledge to the community and also do so, given the low cost of providing knowledge they have readily available. Indeed findings show that lead user characteristics relate positively to making contributions to the community [71].

Interpreting our findings in light of these considerations, we argue that community managers, as well as other active core members who actively contribute to OHCs, are likely to possess lead user attributes, making them an important resource of innovative ideas for health care organizations and researchers. Hence, we propose that existing OHCs can help researchers and practitioners to identify and get in touch with lead users who, as our study has shown, usually constitute a small core community, with community managers acting as gatekeepers. We further suggest that existing OHCs can also serve as a platform for knowledge co-creation. Here one of the key benefits is that knowledge co-creation can take place independent of time and geographical restrictions, as it does not require individuals to meet face-to-face. In this way, it may also help to include individuals who may not be able to participate in traditional face-to-face focus groups or interviews because of reduced mobility.

Practical Implications

Previous research has shown that OHCs can not only be an important resource for patients and their families but also for health care professionals and researchers [11,21]. However, as outlined earlier, building and maintaining such platforms constitutes a resource-intensive endeavor without guaranteed success [9,52]. In this study, we found that there are several active online communities for people with disabilities that are very much interested in and open to collaborating with different stakeholders such as health care professionals, researchers, students, and businesses to create ideas and new knowledge. These findings are in line with previous research [15] and emphasize the need to harness existing resources to realize the potential of fostering relationships between researchers and patients via OHCs.

We thus propose that collaborating with existing OHCs may, in fact, be a promising alternative to setting up entirely new communities, as it reduces efforts related to attracting and maintaining community members. This, in turn, allows also those institutions or individual professionals who may lack the needed resources to build and maintain an active community themselves to engage with well-established OHCs. However, gaining access to these communities can be challenging [72-74]. On the basis of our findings and in line with ethical recommendations for conducting health research online [60], we propose that the most efficient way of gaining access to a community is through the community manager. In their role as gatekeepers, community managers are in control of content and access to their respective OHCs and thus play an essential role in the knowledge co-creation process [75]. In this context, particular attention should be paid to the considerable impact that involving gatekeepers may have not only on the quantity and quality of data collected [76] but also on the research project as a whole [74,77]. Community managers may, for example, influence how a particular research project is presented to the community. This framing of a project may in turn influence not only how the project is understood by community members but may also influence their response and participation behavior.

However, even though existing OHCs provide a promising platform to promote knowledge co-creation between patients, health care professionals, researchers, and businesses, there are some important aspects to be considered. First, there are considerable challenges related to the adoption of eHealth initiatives on the part of professionals who are concerned about the additional benefits of Web-based tools, the effort needed to implement and sustain them, as well as issues relating to workload, role clarity, and accountability [17,78,79]. It will thus be essential to provide clear evidence and guidelines on how OHCs can be used to facilitate knowledge co-creation in health care and how these activities can ultimately benefit each stakeholder group. Moreover, it is important to acknowledge that there are parts of the population lacking access, skills, confidence, or interest in using online communities [80-83]. Stakeholders should thus be attentive and, if possible, mitigate negative effects, for example, by combining co-creation activities taking place in OHCs with more conventional face-to-face approaches such as focus groups [13].

Limitations and Directions for Future Research

Our study has some limitations, which are inherent to the qualitative research design we adopted. Recognizing that as researchers we cannot completely separate our beliefs and expectations from the subject of research [84], we tried to mitigate this potential bias through regular meetings throughout the course of the study. These meetings helped us to discern our own perceptions, allowing us to better understand and interpret our data to represent our participants' experiences [84]. Given its exploratory nature and its focus on OHCs for people with disabilities, our findings are not generalizable. Furthermore, our results might be biased in that the included communities and community managers might be more open to collaboration and co-creation than those communities who declined to participate in the study or did not respond to our inquiry. Also, in our study, we did not include OHCs that were moderated by health professionals.

In light of the findings and limitations of this study, future research should further investigate knowledge co-creation taking place in different health condition–specific OHCs to gain a better understanding of the factors favoring and hindering knowledge co-creation and to identify best practice approaches. This may in turn also help to determine promising and less promising areas for investigation. In addition, it will be essential to demonstrate how OHCs can not only help to identify unmet patient needs but can also uncover ideas, tips, and tricks developed by patients themselves. These may be in the form of homemade assistive devices, innovative self-management techniques, or out-of-the-box thinking when it comes to interpreting research findings. In this context, it will be particularly important to compare and contrast online co-creation activities with traditional approaches to patient participation, such as face-to-face focus groups, to determine the true added value online communities have to offer.

In light of community managers' essential role in the community, we recommend involving them not only at the stage of data collection, as it is currently common practice, but rather to collaborate throughout the entire research process to benefit from their in-depth knowledge of the community and its members. In addition to traditional dissemination strategies, we strongly recommend disseminating and discussing research findings with the communities involved in the project. A closer involvement of online communities in health care may indeed contribute to fostering knowledge dissemination, thus favoring knowledge translation [85,86]. As such, it may be beneficial for patients and health care professionals alike [87]. In this context, it could be particularly interesting to also further investigate online interactions related to co-creation taking place between patients and health professionals who act as moderators of OHCs [87].

Conclusions

This paper enriches our understanding of OHCs by providing a rich description of community managers' views on knowledge co-creation in online communities for people with disabilities. Findings of our study indicate that whereas online communities for people with disabilities are interested in collaborating with researchers and practitioners to create new ideas and knowledge, they are currently not involved in this process. By building on lead user research, we draw attention to the currently under-investigated role of online communities in fostering knowledge co-creation between different stakeholders in the disability context. In doing so, we suggest that innovative ideas may not necessarily emerge from traditionally used forms of health care research focused on covering a representative sample of individuals. Rather we propose that they may result from engaging lead users, who possess the required skill, knowledge, and motivation to engage in knowledge co-creation and are likely to come up with innovative ideas on how to modify and improve existing health care services, products, and research.

Here, we argue that community managers, as well as other core members who actively contribute to online communities, are likely to possess lead user attributes, making them an important resource of innovative ideas for health care organizations and researchers. We thus believe that existing online communities can help researcher and practitioners not only to identify lead users but that they can also serve as a platform to foster knowledge co-creation between patients, health care professionals, researchers, and businesses. Ultimately, knowledge co-creation will help to inform the development of products, services, and research activities that better meet the needs of those living with a disability. This study provides some initial insights into knowledge co-creation in online communities for people with disabilities; however, more research is needed to better understand and harness this new role of OHCs.

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Authors' Contributions

Authors JA and SR jointly designed the study. JA developed the interview guide, recruited the participants, collected and analyzed the data, and wrote the initial draft of the manuscript. SR contributed to the development of the interview guide and data analysis. SR also provided substantial feedback on the manuscript. Both authors read and approved the final manuscript.

Conflicts of Interest

At the time this study was planned and carried out, authors JA and SR were actively involved in one of the communities investigated in this paper. This community was initiated and supported by the funding institution, Swiss Paraplegic Research, on behalf of the Swiss Paraplegic Foundation.

Multimedia Appendix 1

Consolidated criteria for reporting qualitative research checklist.

[PDF File (Adobe PDF File), 209KB - jmir_v19i10e320_app1.pdf]

Multimedia Appendix 2

Interview guide.

[PDF File (Adobe PDF File), 365KB - jmir_v19i10e320_app2.pdf]

Multimedia Appendix 3

Overview of themes and subthemes generated from the analysis.

[JPG File, 148KB - jmir_v19i10e320_app3.JPG]

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Abbreviations

OHC: online health communities
3D: three-dimensional

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Original Paper

Comparison of Health Information Technology Use Between American Adults With and Without Chronic Health Conditions: Findings From The National Health Interview Survey 2012

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Abstract

Background: Health information technology (HIT) is utilized by people with different chronic conditions such as diabetes and hypertension. However, there has been no comparison of HIT use between persons without a chronic condition, with one chronic condition, and multiple (≥2) chronic conditions (MCCs).

Objective: The aim of the study was to assess the difference in HIT use between persons without a chronic condition, with one chronic condition, and with MCCs, to describe the characteristics of HIT use among those with chronic conditions and to identify the predictors of HIT use of the persons with one chronic condition and MCCs.

Methods: A secondary data analysis was conducted in spring 2017 using the National Health Interview Survey (NHIS) 2012 Family Core and Sample Adult Core datasets that yielded 34,525 respondents aged 18 years and older. Measures included overall HIT use (ie, any use of the following five HIT on the Internet: seeking health information, ordering prescription, making appointment, emailing health provider, and using health chat groups), as well as sociodemographic and health-related characteristics. Sociodemographic and health characteristics were compared between HIT users and nonusers among those who reported having at least one chronic condition using chi-square tests. Independent predictors of HIT use were identified using multiple logistic regression analyses for those with one chronic condition, with MCCs, and without a chronic condition. Analyses were weighted and performed at significance level of .005.

Results: In 2012, adults with one health chronic condition (raw count 4147/8551, weighted percentage 48.54%) was significantly higher than among those with MCCs (3816/9637, 39.55%) and those with none of chronic condition (7254/16,337, 44.40%, *P*<.001). Seeking health information was the most prevalent HIT use. Chi-square tests revealed that among adults with chronic conditions, those who used HIT were significantly different from their counterpart peers who did not use HIT in terms of sociodemographic and health characteristics (*P*<.001). Overall, the significant factors related to HIT use were similar among the adults with one chronic condition, with MCCs, or without a chronic condition: younger age, female sex, non-Hispanic white, higher education level, and higher income level were shown to be positively related to the HIT use.

Conclusions: This study provides a snapshot of HIT use among those with chronic conditions and potential factors related to such use. Clinical care and public health communication efforts attempting to leverage more HIT use should acknowledge differential HIT usage as identified in this study to better address communication inequalities and persistent disparities in socioeconomic status.

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KEYWORDS

health information technology; chronic illness

Introduction

According to the 2012 update of National Health Interview Survey (NHIS) data [1], among the noninstitutionalized, civilian US adult population, approximately half (117 million) of US adults have at least one of 10 chronic conditions (eg, hypertension, coronary heart disease, stroke, diabetes, and cancer). More specifically, 24.3% report 1 chronic condition, 13.8% report 2 chronic conditions, and 11.7% report 3 or more chronic conditions, which indicates that around 1 in 4 American adults have multiple (≥2) chronic conditions (MCCs).

The use of health information technology (HIT) can include a wide range of activities, from searching general health information to using individual computerized modules or Web portals. HIT has been utilized by people with different specific chronic conditions such as diabetes [2,3] and hypertension [4]. Five HIT uses measured in NHIS include seeking Web-based health information, ordering a Web-based prescription, scheduling a Web-based appointment, communicating with a health care provider over email, or using Web-based chat groups to learn about health topics. On the basis of NHIS 2009 and 2011 data, of all the five HIT uses, seeking health information was 7 to 14 times more likely to occur than the other HIT activities among American adults [5]. Other national surveys reported increasing trend of those other HIT activities when compared with their use in the past two decades [6-8]. Literature revealed that the general HIT users tend to be young, women, white, with a relatively higher education level, and a higher income level [9-11]. However, there has been no comparison of HIT use between persons without a chronic condition, with one chronic condition, and with MCCs.

To address this research gap, we analyzed NHIS 2012 data to (1) assess whether patterns of HIT use differ for persons without a chronic condition, with one chronic condition, and with MCCs; (2) describe the characteristics of HIT use among those with chronic conditions; and (3) identify predictors of HIT use among individuals with one chronic condition and MCCs. The aim of this study was to provide health professionals with a better understanding of HIT use among patients with one or more chronic conditions to facilitate better clinical care and patient education.

Methods

Study Design

This paper reports a secondary analysis of data from the NHIS, a cross-sectional household interview survey targeting the noninstitutionalized civilian population of the United States conducted by the Centers for Disease Control and Prevention's (CDC) National Center for Health Statistics (NCHS) periodically. This study utilized the 2012 NHIS Family Core and Sample Adult Core. The NHIS Family Core questionnaire contained information on the participant's sociodemographic characteristics and health status. Data on chronic conditions and computer use were collected via the Sample Adult Core questionnaire. Details of the NHIS sampling are reported elsewhere [12]. In brief, the interviewed sample consisted of 42,366 eligible households, which yielded 34,525 respondents aged 18 years and older with a final response rate of 79.7%. We retrieved the dataset and performed the analyses in spring 2017.

Measures

Use of Health Information Technology (HIT)

Participants were asked whether they have ever used computers in the past 12 months for any of the following tasks: (1) to look up health information on the Internet (referred as seeking Web-based health information in the text below), (2) to fill a prescription (referred as ordering a Web-based prescription in the text below), (3) to schedule a Web-based appointment with a health care provider, (4) to communicate with a health care provider by email, or (5) to use online chat groups to learn about health topics (referred as using Web-based chat group in the text below). If an individual indicated use for any of these five purposes, they were considered to have used HIT in the past 12 months.

Chronic Conditions

The chronic conditions included in this study were 10 most frequently reported physical health conditions from a list of 20 conditions identified by the US Department of Health and Human Services (DHHS) to foster a more consistent and standardized approach to measuring the occurrence of chronic conditions in the United States [13]. Participants were identified as having 1 of the 10 conditions if they have ever been told by a doctor or health care provider that they had hypertension, coronary heart disease, stroke, diabetes, cancer, arthritis, hepatitis, experienced weak or failing kidneys during the past 12 months, asthma, or chronic obstructive pulmonary disease (COPD). COPD was assessed by using responses from 2 survey questions asking adults whether they had ever had emphysema or chronic bronchitis in the past 12 months; adults answering yes to either question were identified as having COPD. Adults who reported having 2 or more chronic conditions were defined as having MCCs.

Sociodemographic Characteristics

HIT use has been found to vary by age [12,14], sex [6,15], race or ethnicity [10,16], education level [6,16], employment, marital relationship, and income level [11]. To account for the variations, we included the following sociodemographic data in the analysis: sex (male or female), age (18-29, 30-39, 40-49, 50-64, 65-74, and 75+ years), race or ethnicity (Hispanic, non-Hispanic white, non-Hispanic black, non-Hispanic Asian, and non-Hispanic other), educational attainment (less than high school, high school graduate or some college, Bachelor's degree, Master's degree or higher), employment status (not employed in the past 12 months or employed in the past 12 months), annual household income (less than US $15,000, US $15,000-34,999, US $35,000-54,999, US $55,000-74,999, and US $75,000 or more), and marital status (not in relationship or in relationship).

Health-Related Characteristics

Previous research suggests that after controlling for sociodemographic characteristics, self-rated health status may not be significantly associated with HIT use [17]. To examine whether this is also true in the population with chronic conditions, we included factors such as general health status (poor or fair, good, and very good or excellent) and body mass index (BMI; <18.5, 18.5-24.9, 25-29.9, or 30 or above) in our analysis.

Statistical Analyses

Analyses were performed using the Statistical Package for Social Sciences (SPSS) software (IBM SPSS Statistics for Windows, release 24.0. Armonk, NY: IBM Corp). Because NHIS is a complex survey using a multistage probability complex sampling design that incorporates stratification, clustering, and oversampling of some subpopulations (eg, black, Hispanic, and Asian), sampling weights must be used to produce representative estimates and standard errors. We utilized SPSS Complex Samples to compute statistics and standard errors from complex sample designs by incorporating sample designs into survey analysis. HIT use by respondents with and without chronic conditions as well as characteristics of HIT users and nonusers were compared among those who reported having at least one chronic condition, using chi-square tests. Independent predictors of HIT use were identified using multiple logistic regression analyses for those with one chronic condition, with MCCs, and without a chronic condition. All variables were included in the logistic regression analyses without forward or backward procedures. Due to the large sample size, a statistical significance level of .005 was chosen, and the 99.5% CI were calculated.

Results

Prevalence of Health Information Technology Use and Chronic Condition Status

In 2012, an estimated 98.5 million US adults (42%) sought Web-based health information, 15.8 million (6.7%) ordered a Web-based prescription, 10.8 million (4.6%) made Web-based appointments with their health care provider, 13.5 million (5.7%) emailed their health care provider, and 6.8 million (2.9%) used Web-based health chat groups. Approximately half (116.7 million, 49.7%) of US adults reported having at least one chronic condition, and 57.3 million (24.4%), 32.7 million (13.9%), and 26.9 million (11.4%) reported having one, two, and three or more chronic conditions, respectively. The prevalence of each condition varies from the most frequently reported hypertension (50.5 million, 21.5%) to the least reported weak or failing kidneys (3.9 million, 1.7%).

Chronic Conditions and HIT Use

A comparison of HIT use by respondents with and without chronic conditions is shown in Table 1. Prevalence of HIT use among adults with one chronic condition (raw count 4147/8551, weighted percentage 48.54%) was significantly higher than among those with MCCs (3816/9637, 39.55%) and those with none of chronic condition (7254/16,337, 44.40%). Adults with one chronic condition were significantly more likely than those in the other two groups to use HIT to look up health information, make an appointment, and use health chat group, whereas adults with MCCs reported highest prevalence of HIT use for ordering prescription and emailing health providers. The HIT use among adults varied by health conditions, ranging from 24.8% of respondents with stroke to 48.7% with asthma (data not provided in this paper).

Table 1. Weighted percentage of persons who had used health information technology by chronic condition groups.

Health information technology use variables	All, % (N[b]=34,525)	No chronic condition, % (N[b]=16,337)	One condition, % (N[b]=8551)	MCCs[a], % (N[b]=9637)	Chi-square	*P* value
Any health information technology use	44.2	44.4	48.5	39.6	141.3	<.001
Looked up health information	42.0	42.4	45.9	37.2	133.5	<.001
Ordered prescription	6.7	4.7	8.4	9.0	218.8	<.001
Made appointment	4.6	4.4	5.4	4.3	15.5	.02
Emailed health provider	5.7	5.3	6.3	6.4	15.0	.02
Used health chat groups	2.9	3.0	3.2	2.5	8.5	.07

[a] MCCs: multiple chronic conditions.

[b] N: raw count.

Table 2. Comparison of characteristic between health information technology (HIT) users and nonusers among those who had at least one chronic condition in the past 12 months: weighted percentage and 99.5% CI.

Sociodemographic and health characteristics	All, % (N=34,525)	Did not use health information technology, % (99.5% CI) (N=20,178)	Used health information technology, % (99.5% CI) (N=14,347)
Age (in years)			
18 to 29	8.6	7.4 (6.6-8.2)	10.2 (9.2-11.3)
30 to 39	9.9	7.4 (6.8-8.2)	13.1 (12.2-14.0)
40 to 49	16.0	13.6 (12.8-14.5)	19.1 (18.0-20.2)
50 to 64	34.8	32.1 (30.9-33.4)	38.2 (36.7-39.7)
65 to 74	16.9	19.2 (18.3-20.2)	14.0 (13.1-14.9)
75+	13.7	20.2 (19.2-21.3)	5.4 (4.8-6.0)
Gender			
Male	46.2	49.0 (47.8-50.2)	42.6 (41.1-44.1)
Female	53.8	51.0 (59.8-52.2)	57.4 (55.9-58.9)
Ethnicity			
Hispanic	10.5	13.1 (12.3-14.0)	7.1 (6.3-7.9)
Non-Hispanic white	72.2	66.6 (65.3-67.9)	79.3 (78.1-80.5)
Non-Hispanic black	12.6	15.4 (14.5-16.4)	9.1 (8.3-10.0)
Non-Hispanic Asian	3.8	3.9 (3.4-4.4)	3.7 (3.2-4.3)
Non-Hispanic all other race	0.9	1.0 (0.7-1.4)	0.8 (0.6-1.1)
Education			
Less than high school	15.2	23.7 (22.6-24.8)	4.4 (3.8-5.0)
High school graduate and some college	59.4	61.8 (60.6-63.0)	56.4 (54.8-57.9)
Bachelor’s degree	15.6	9.3 (8.5-10.1)	23.6 (22.4-24.9)
Master’s degree or higher	9.8	5.2 (4.6-5.8)	15.7 (14.6-16.8)
Employment			
Not employed	44.9	54.5 (53.1-55.8)	31.5 (30.1-33.0)
Employed	55.1	45.5 (44.2-46.9)	68.5 (67.0-69.9)
Income (in US$)			
Up to 14,999	22.8	26.8 (24.8-28.9)	19.7 (18.3-21.1)
15,000 to 34,999	24.2	32.3 (30.4-34.3)	24.2 (22.6-25.8)
35,000 to 54,999	21.8	21.4 (19.7-23.2)	21.8 (20.2-23.4)
55,000 to 74,999	14.0	9.3 (8.2-10.6)	14.0 (12.8-15.3)
75,000 and higher	20.4	10.1 (8.7-11.7)	20.4 (18.7-22.1)
Marital status			
Not in relationship	38.3	43.0 (41.7-44.4)	32.3 (31.0-33.7)
In relationship	61.7	57.0 (55.6-58.3)	67.7 (66.3-69.0)
Body mass index			
Up to 18.49	1.2	1.6 (1.3-2.0)	0.7 (0.5-1.0)
18.5 to 24.9	25.6	25.0 (23.9-26.1)	26.3 (25.0-27.7)
25-29.9	34.4	33.7 (32.5-34.9)	35.3 (34.0-36.6)
30 and more	38.8	39.6 (38.5-40.8)	37.7 (36.3-39.0)
Health status			

Sociodemographic and health characteristics	All, % (N=34,525)	Did not use health information technology, % (99.5% CI) (N=20,178)	Used health information technology, % (99.5% CI) (N=14,347)
Very good to excellent	44.8	38.2 (37.1-39.3)	53.2 (51.7-54.7)
good	33.4	34.6 (33.4-35.8)	31.8 (30.5-33.2)
poor to fair	21.8	27.2 (26.1-28.4)	15.0 (14.0-16.1)

Characteristics Associated With HIT Use Among Adults With Chronic Conditions

The characteristics related to HIT use among adults with at least one chronic condition are presented in Table 2. We found that HIT users significantly differed from nonusers with regard to sociodemographic and health characteristics. Compared with HIT nonusers, HIT users were significantly more likely to be under the age of 65 years, female, non-Hispanic white, with education level of bachelor’s degree or higher, having annual income of US $55,000 or higher, currently employed, and in a relationship. HIT users were significantly less likely than nonusers to report higher BMI level (≥30) and poorer self-rated health status (≤good).

Potential Predictors of HIT Use

When adding the chronic condition status as an independent variable in the logistic regression model, the finding shows that higher prevalent HIT use is more likely to be reported by adults with one chronic condition (odds ratio, OR 1.55, 99.5% CI 1.44-1.68, *P*<.001) or with MCCs (OR 1.81, 99.5% CI 1.64-2.01, *P*<.001) than those with none of the 10 chronic condition. Table 3 presents results of the logistic regression analyses examining factors associated with HIT use by persons with none of the chronic conditions, one chronic condition, and MCCs. Overall, the significant predictors of HIT use were similar across all the three chronic condition groups. Specifically, after adjusting for all of the sociodemographic and health factors, those who were relatively younger, female, non-Hispanic white, with comparatively higher education level, and higher income level were significantly more likely to be HIT users. The OR differences varied in ±1 range for most of the predictors between those with chronic conditions and MCCs.

Table 3. Factors associated to health information technology (HIT) use among respondents with none, one chronic condition, and multiple chronic conditions (MCCs): weighted logistic regression model results.

Independent variable	With one chronic condition, adjusted OR[b] (99.5% CI) N=8551	With MCCs[a], adjusted OR (99.5% CI) N=9637	With no chronic conditions, adjusted OR (99.5% CI) N=16,337
Age (in years)			
18 to 29	1.00	1.00	1.00
30 to 39	0.95 (0.61-1.49)	0.61 (0.27-1.34)	0.77 (0.62-0.95)
40 to 49	0.66 (0.42-1.04)	0.46 (0.22-0.98)	0.68 (0.55-0.85)
50 to 64	0.51 (0.33-0.80)	0.40 (0.19-0.85)	0.54 (0.42-0.69)
65 to 74	0.37 (0.21-0.65)	0.25 (0.12-0.55)	0.44 (0.26-0.76)
75+	0.12 (0.03-0.45)	0.11 (0.04-0.32)	0.19 (0.04-0.91)
Gender			
Male	1.00	1.00	1.00
Female	1.92 (1.49-2.46)	2.21 (1.63-3.00)	2.25 (1.62-2.63)
Ethnicity			
Hispanic	1.00	1.00	1.00
Non-Hispanic white	1.93 (1.36-2.73)	1.95 (1.24-3.06)	1.58 (1.28-1.96)
Non-Hispanic black	1.18 (0.76-1.83)	1.09 (0.62-1.91)	0.90 (0.68-1.20)
Non-Hispanic Asian	0.93 (0.52-1.66)	1.04 (0.47-2.30)	1.20 (0.84-1.71)
Non-Hispanic all other	1.39 (0.37-5.18)	2.00 (0.57-6.98)	1.01 (0.44-2.33)
Education			
Less than high school	1.00	1.00	1.00
High school graduate and some college	3.02 (1.71-5.35)	4.28 (2.38-7.68)	2.79 (2.07-3.787)
Bachelor’s degree	6.88 (3.73-12.72)	12.66 (6.56-24.44)	5.89 (4.21-8.25)
Master’s degree or higher	9.89 (5.00-19.57)	13.18 (6.55-26.51)	7.57 (5.11-11.20)
Employment			
Not employed	1.00	1.00	1.00
Employed	0.88 (0.47-1.64)	1.00 (0.56-1.78)	1.02 (0.65-1.61)
Income (in US$)			
Up to 14,999	1.00	1.00	1.00
15,000 to 34,999	1.05 (0.73-1.50)	0.88 (0.59-1.31)	1.05 (0.85-1.29)
35,000 to 54,999	1.30 (0.90-1.87)	1.08 (0.71-1.64)	1.28 (1.01-1.61)
55,000 to 74,999	1.46 (0.89-2.40)	2.02 (1.24-3.31)	1.35 (1.01-1.82)
75,000 and higher	2.13 (1.34-3.37)	1.86 (1.09-3.18)	1.89 (1.39-2.56)
Marital status			
Not in relationship	1.00	1.00	1.00
In relationship	1.21 (0.94-1.55)	1.28 (0.95-1.73)	1.07 (0.91-1.25)
Body mass index			
Up to 18.49	0.90 (0.29-2.79)	0.34 (0.07-1.74)	0.87 (0.45-1.70)
18.5 to 24.9	1.00	1.00	1.00
25-29.9	1.10 (0.80-1.52)	1.12 (0.73-1.73)	0.87 (0.73-1.03)
30 and more	1.01 (0.76-1.35)	0.94 (0.62-1.41)	0.90 (0.74-1.11)
Health status			

Independent variable	With one chronic condition, adjusted OR[b] (99.5% CI) N=8551	With MCCs[a], adjusted OR (99.5% CI) N=9637	With no chronic conditions, adjusted OR (99.5% CI) N=16,337
Very good to excellent	1.00	1.00	1.00
Good	0.95 (0.72-1.25)	0.99 (0.72-1.36)	1.06 (0.86-1.31)
Poor to fair	1.11 (0.73-1.70)	0.93 (0.61-1.4)	1.31 (0.87-1.98)

[a] MCCs: multiple chronic conditions.

[b] OR: odds ratio.

Discussion

Principal Findings

Our findings show that HIT use is relatively common among people with chronic conditions, ranging from about 40% of those with MCCs, to 49% of those with one chronic condition. The number of HIT users is expected be even higher nowadays with the increasing adoption of electronic health record (EHR) systems since the passage of the Health Information Technology for Economic and Clinical Health (HITECH) provisions of the American Recovery and Reinvestment Act (ARRA) of 2009 [18-20]. Of the five types of HIT use that were assessed, seeking Web-based health information was the most frequently reported use among all adults. This finding resonates with other reports that show health consumers are increasingly relying on the Internet for health information [9,10]. Among adults with one or more chronic condition, ordering Web-based prescriptions is the second most prevalent type of HIT use, with nearly 1 in 10 adults using the Internet to order prescriptions via a patient portal or pharmacy website. Recent research suggests that Web-based patient portal use may arguably be associated with better medication adherence, improved health care quality, and favorable patient outcomes [21,22]. Given that medication adherence is critical for chronic disease management, interventions including Internet-based approach that promote medication adherence are worth exploring [23]. Use of HIT to make appointments, email health care providers, and participate in chat groups for health topics was less prevalent. Although there has been little research to explain why the use of HIT for those other purposes is much lower, usability, availability, and accessibility of HIT functions, as well as health literacy could be some reasons [24,25]. Additionally, some adults with chronic conditions may face different difficulties accessing health care services, resulting in lower use of different kinds of HIT [26]. How the nature of a disease, severity and prevalence of the chronic conditions, and health care access affect HIT use warrants further examination.

We found that overall HIT use significantly differed among adults with or without chronic conditions, those with one chronic condition being the most active HIT users, those with MCCs the least, and those with none of the 10 chronic conditions falling in between. Our findings based on the multivariate regression models suggest that socioeconomic factors may have more influence on HIT use than health-related characteristics because the same sociodemographic factors were predictive of HIT use across all three of our study groups (adults with no chronic conditions, one chronic condition, and with MCCs). Specifically, consistent with the findings of previous studies on digital divide [8,27-29], we found that that across all three groups, HIT users were more likely than nonusers to be younger, female, non-Hispanic white, with comparatively higher education level, and with higher income level.

The lower use of HIT among adults with MCCs than those with one or no chronic condition may be explained by differences in the sociodemographic profile of each group. Whereas prevalence of MCCs varies by age, gender, and race or ethnicity, older age might be the key factor related to the lower use of HIT by adults with MCCs. First of all, for both genders, adults with MCCs are more likely to be older (aged ≥65 years) than those with only one or no chronic conditions [30,31]. Considering the rates of HIT use reportedly being significantly lower among the age groups 65 or older compared with the younger age groups [32], it is not surprising to find less prevalent HIT use among our MCCs respondents. The variation of gender and race or ethnicity might be outweighed by the impact of older age among those with MCCs [33]. This may further explain why HIT use is less among people with MCCs. In addition, adults with chronic conditions are reported more likely to have lower educational attainment and income [34,35]. Education and income factors are also related to health literacy [36], which in turn can have an impact on HIT use [24]. Aforementioned observations suggest that adults with MCCs are more likely than those with one or no conditions to be racial minorities, older, less educated, and with lower income; it is reasonable to expect lower HIT use in the MCCs group based on previous research. Regardless of which socioeconomic factors have more influence on HIT use, the above finding implies that educational materials or interventions to promote HIT use among those with chronic conditions must take into account socioeconomic factors that influence use. For instance, efforts should be made to help older adults and ethnic or racial minorities improve their abilities to navigate and utilize the Internet and recognize dependable Web-based sources so that they may increase their trust in its use, thereby increasing satisfaction with their own ability to seek and use sources of health information [37].

Limitations

This study has a number of strengths, including using a dataset with a good response rate and a large sample drawn from a representative nationwide survey. Nonetheless, this study was subject to a few limitations. First, NHIS information was collected via self-report and the questions relating to health conditions and HIT use examined the participant's experience in the previous 12 months; hence, the study findings are potentially subject to recall bias and social desirability bias. Second, because of the nature of the cross-sectional study design, it is not possible to draw conclusions about probable causal pathways between the two explored variables (eg, chronic conditions and computer use), and therefore, the study findings should be interpreted with caution. These limitations should be balanced against the strengths of the study, including the large sample size and representativeness of the US population.

Conclusions

Our study provides a snapshot of HIT use among those with chronic conditions and potential factors related to such use. Our study suggests that HIT may serve as an alternative to more traditional methods of obtaining health information or communicating directly with health care providers, which in turn may help those with chronic conditions to better manage their illness over the long term. However, clinical care and public health communication efforts attempting to leverage more HIT use should acknowledge differential HIT usage as identified in this study to better address communication inequalities and persistent disparities in socioeconomic status.

Authors' Contributions

Conception of the work was done by YZ, DS, and JA. Data analysis was done by RL, YZ, and DS. Introduction was written by YZ, BO, and JA. Methods and Results were written by RL, YZ, and DS. Discussion was written by YZ, BO, RC, and JA.

Conflicts of Interest

None declared.

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Abbreviations

BMI: body mass index
CDC: Centers for Disease Control and Prevention
COPD: chronic obstructive pulmonary disease
DHHS: Department of Health and Human Services
EHR: electronic health record
HIT: health information technology
HITECH: health information technology for economic and clinical health
MCCs: multiple chronic conditions
NHIS: National Health Interview Survey
NCHS: National Center for Health Statistics
OR: odds ratio
SPSS: Statistical Package for Social Sciences

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Original Paper

Examining Internet and eHealth Practices and Preferences: Survey Study of Australian Older Adults With Subjective Memory Complaints, Mild Cognitive Impairment, or Dementia

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Abstract

Background: Interest in electronic health (eHealth) technologies to screen for and treat a variety of medical and mental health problems is growing exponentially. However, no studies to date have investigated the feasibility of using such e-tools for older adults with mild cognitive impairment (MCI) or dementia.

Objective: The objective of this study was to describe patterns of Internet use, as well as interest in and preferences for eHealth technologies among older adults with varying degrees of cognitive impairment.

Methods: A total of 221 participants (mean age=67.6 years) attending the Healthy Brain Ageing Clinic at the University of Sydney, a specialist mood and memory clinic for adults ≥50 years of age, underwent comprehensive clinical and neuropsychological assessment and completed a 20-item self-report survey investigating current technology use and interest in eHealth technologies. Descriptive statistics and Fisher exact tests were used to characterize the findings, including variability in the results based on demographic and diagnostic factors, with diagnoses including subjective cognitive impairment (SCI), MCI, and dementia.

Results: The sample comprised 27.6% (61/221) SCI, 62.0% (137/221) MCI, and 10.4% (23/221) dementia (mean Mini-Mental State Examination=28.2). The majority of participants reported using mobile phones (201/220, 91.4%) and computers (167/194, 86.1%) routinely, with most respondents having access to the Internet at home (204/220, 92.6%). Variability was evident in the use of computers, mobile phones, and health-related websites in relation to sociodemographic factors, with younger, employed respondents with higher levels of education being more likely to utilize these technologies. Whereas most respondents used email (196/217, 90.3%), the use of social media websites was relatively uncommon. The eHealth intervention of most interest to the broader sample was memory strategy training, with 82.7% (172/208) of participants reporting they would utilize this form of intervention. Preferences for other eHealth interventions varied in relation to educational level, with university-educated participants expressing greater interest in interventions related to mood (*P*=.01), socialization (*P*=.02), memory (*P*=.01), and computer-based exercises (*P*=.046). eHealth preferences also varied in association, with diagnosis for interventions targeting sleep (*P*=.01), nutrition (*P*=.004), vascular risk factors (*P*=.03), and memory (*P*=.02).

Conclusions: Technology use is pervasive among older adults with cognitive impairment, though variability was noted in relation to age, education, vocational status, and diagnosis. There is also significant interest in Web-based interventions targeting cognition and memory, as well as other risk factors for cognitive decline, highlighting the urgent need for the development, implementation, and study of eHealth technologies tailored specifically to older adults, including those with MCI and early dementia. Strategies to promote eHealth use among older adults who are retired or have lower levels of education will also need to be considered.

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KEYWORDS

eHealth; dementia; mild cognitive impairment; Internet; Alzheimer disease

Introduction

It is estimated that by 2050 there will be over 115 million people living with dementia worldwide [1]. As there are currently no cures for dementia, efforts are increasingly focused on targeting potentially modifiable risk factors for cognitive decline [2-4], with particular emphasis on intervention early in the disease course [5]. Recent meta-analytic data highlight that approximately one-third of the burden of Alzheimer’s disease can be attributed to seven key modifiable risk factors, including depression, diabetes, midlife hypertension, midlife obesity, smoking status, low physical activity, and low educational attainment [6]. In turn, it is estimated that a mere 10% reduction per decade for each of these modifiable risk factors could reduce the prevalence of Alzheimer’s disease by 8.3% in 2050 [6]. Although prevention is the ultimate goal, supportive programs for individuals experiencing cognitive decline or dementia and their carers are also essential to reduce the risk of further cognitive decline, medical comorbidities, mental health problems, and functional decline, as well as to promote quality of life, healthy brain aging, and general well-being. Given the scale of the dementia health care crisis globally, low-cost, effective, and easily accessible strategies addressing these modifiable risk factors and providing support for people with dementia are required. In this regard, there is increasing interest in the use of Internet technologies, particularly electronic health (eHealth).

Increasingly, the Internet is becoming a critical medium for the delivery of medical and mental health information and services, referred to as *eHealth*. eHealth is broadly defined by the World Health Organization as the use of information and communication technologies for health-related purposes such as service delivery [7]. eHealth tools such as mobile and Internet-based apps can be used to screen “at risk” individuals, offer self-help through Web-based interventions, or deliver proactive and guided interventions. eHealth interventions have been shown to be effective for the management and/or treatment of symptoms in a range of mental health and medical conditions, including depression [8-10], diabetes [11], weight loss [12], problematic alcohol use [13], sleep [14], and exercise [15]. Various models of eHealth services have been shown to be successful, including stand-alone systems for symptom prevention and self-help, consumer-assisted care such as peer support, virtual clinics offering professional care, and stepped care systems for integrated care [16]. There is also an emerging literature regarding important methodological considerations affecting adherence (eg, interface design and feasibility testing) and treatment outcomes (eg, time spent in activities) [17-20].

The growing interest in the utility of mobile and Internet-based apps and e-tools for health-related purposes has been facilitated by a dramatic increase over the last two decades in Internet access worldwide. As of 2016, 40% of the global population had an Internet connection compared with only 1% in 1995 [21]. In relation to specific regions, there has been a 500% growth in Internet usage in Europe from 2000 to 2017, with 77% of the population now having access [22]. Similarly, 88% of the population in North America had Internet access in 2017, reflecting an almost 200% increase since 2000 [22]. Importantly, older adults represent the fastest growing group of Internet users [23]. This increase in Internet use among this population has spurred a growing interest in the development and implementation of eHealth technologies for improved health and well-being for older adults [24-26].

However, to date, there has been limited research evaluating the utility of eHealth technologies for the prevention or slowing of cognitive decline in older adults. Additionally, there are no published studies specifically targeting people with existing cognitive impairment, such as mild cognitive impairment (MCI). This represents a significant gap, given that approximately 45% of people with MCI convert to dementia within 5 years [27] and that secondary prevention strategies for cognitive decline are likely to be optimal during this critical period [5,28-32]. Such technologies could be employed for information provision, for interventions encouraging social engagement, physical or cognitive exercise, for treating depression and sleep, and for provision of adaptive or compensatory strategies to improve memory or daily functioning [29]. Importantly, one small study of 37 people with MCI demonstrated that participants utilized the Internet to the same extent as cognitively intact older people, with 73% of those with MCI using such technologies to search for health care–related information and 81% reporting technology use for communication [33]. Despite these promising figures, older people do have more difficulty engaging with the Internet for health care [34], which has been attributed, at least in part, to poor website design, complex navigation requirements, and a lack of Internet training—factors that are secondary to cognitive decline and can be addressed with further research [35].

Whereas mobile and Internet-based apps and e-tools hold great promise in relation to the promotion of healthy aging and the self-management of health-related conditions and modifiable risk factors of cognitive decline, it is first necessary to better understand the feasibility and likely acceptability of such e-tools for older adults. Therefore, this study was designed to characterize the current patterns of Internet use, as well as interest in eHealth technologies (ie, mobile- and Internet-based apps and e-tools) among older adults with varying degrees of cognitive impairment ranging from subjective cognitive complaints to MCI and dementia. We also aimed to generate prevalence data essential to determining the feasibility of future eHealth efforts in an aging population.

Methods

Participants

From February 2015 to October 2016, data were collected from the Healthy Brain Ageing (HBA) Clinic cohort at the Brain and Mind Centre, University of Sydney, Sydney, Australia. Participants attending the HBA Clinic, an early intervention clinic for people aged 50 years or older, represent an inner-city cross section of the population. They were all asked to complete a self-report survey regarding patterns of Internet use, as well as interest in and preferences for eHealth technologies, including mobile and Web-based interventions targeting individual risk factors for cognitive decline and dementia. This patient population was specifically chosen to evaluate the potential to use eHealth technologies with older adults with cognitive impairment or early dementia.

Consecutive referrals of adults were invited to participate. Exclusion criteria included limited English proficiency, intellectual disability, Mini-Mental State Examination <20 (MMSE; [36]), history of stroke, traumatic brain injury (with loss of consciousness >30 min), neurological or other medical conditions known to affect cognition, and current substance misuse or major psychiatric disorder (eg, psychosis). All participants were referred to the HBA Clinic by their general practitioner or specialist clinician for evaluation because of concerns regarding their cognition or mood. Inclusion and exclusion criteria were verified with participants over the phone by a member of the research team before completing the face-to-face medical, neuropsychological, and mood assessments.

Assessments

Diagnosis and Clinical Characteristics

As described previously (Jayaweera et al [37]), all eligible participants underwent a comprehensive clinical assessment. A specialist physician (geriatrician or neurologist) carried out a structured review of medical and psychiatric history, and a clinical neuropsychologist administered a standardized neuropsychological evaluation. Participants with no evidence of objective cognitive impairment were classified as having subjective cognitive impairment (SCI). Diagnoses of MCI and early dementia were determined by consensus rating of 3 raters, including a neurologist or geriatrician and 2 clinical neuropsychologists. Background and medical history, clinical presentation, neuropsychological performance, and neuroimaging findings (if available) were all taken into account in the diagnostic process. Using established criteria [38], MCI was defined as at least a 1.5 standard deviation decline on one or more neuropsychological tests relative to the participant's estimated baseline level of performance, alongside subjective complaints and in the absence of significant functional decline. Established diagnostic criteria were also utilized in the differential diagnosis of dementia [39-41].

HBA eHealth Questionnaire

Each participant completed the HBA E-Health Questionnaire (see Multimedia Appendix 1), a 20-item self-report survey designed by members of the HBA team at the University of Sydney, to identify patterns of technology and Internet use in older people, with an emphasis on the current use of or interest in health-related e-tools. For example, questions included "Do you have access to the Internet at home?" and "Would you use the Internet to receive programs or interventions for any of the following: mood, sleep, exercise, nutrition, socialization, management of vascular risk factors, practical strategies for memory, or online computer exercise for cognition?" The survey was created to inform the development, feasibility, acceptability, and delivery of future eHealth trials with older adults. This is a newly developed measure that has not been used in previous research studies.

Importantly, during data collection, we identified several additional issues related to technology use that we believed were relevant in relation to eHealth practices of older adults. As such, the HBA E-health Questionnaire was revised, accounting for the variability in the number of respondents for some questions. The second version of the questionnaire included more specific questions about how individuals connect to the Internet, website preferences, confidence in the information available on health-related websites, and barriers to accessing information on health-related websites.

Data Collection

After being scheduled to attend the HBA Clinic, printed questionnaires were sent by mail to verbally consenting participants, along with detailed study information and a consent form. Some participants may have received documents by email at their request. Participants had the option to return completed questionnaires by mail (postage paid) or to bring questionnaires with them to their HBA Clinic appointment for collection by research staff. All questionnaires were handled by members of the HBA Clinic and were briefly reviewed for missing items by the clinic coordinator on participant arrival to their clinic appointment. Missing responses were subsequently collected from the participant in person or via telephone.

Data Analysis

Descriptive statistics were used to analyze all aspects of the survey data. Given that the overall sample size was <300 and that the subset of participants with early dementia was relatively small (n=23), bivariate analyses using Fisher exact tests were used to evaluate group differences. To determine the association between sociodemographic factors, including age, years of education, gender, vocational status, and diagnosis on eHealth preferences, binary logistic regression models were constructed with all variables entered into the model in block 1 (method: enter). All of the assumptions of binary logistic regression were examined and met. The alpha level was <.05. The Statistical Package for the Social Sciences (SPSS) version 24 (IBM Corp) was used for all analyses.

Ethics Approval and Registration

Participation was voluntary, and written informed consent was obtained from all participants. Ethical approval was obtained from the University of Sydney Human Research Ethics Committee (Project number: 2012/1873).

Results

Participants

A total of 221 participants (mean age=67.6 years, range=51-88 years; 57.5% [127/221] female; and mean MMSE=28.2, range=20-30) from the HBA Clinic completed the survey. Three participants who provided written consent to the undergo medical, neuropsychological, and mood assessments at the HBA Clinic failed to complete the self-report questionnaire. Demographic characteristics of the participants are presented in Table 1. Notably, participants had above average levels of education, and the majority were retired (142/218, 65.1%).

Computer Use

The majority of participants (167/194, 86.1%) reported using a computer routinely, defined as more than 4 times a week. Most respondents had access to an electronic device at home, primarily in the form of a computer (205/221, 92.8%), though more than one-third of respondents also had access to a tablet (87/221, 39.4%). Only 5 participants had no access to a computer or tablet (5/221, 2.3%). There was no notable difference in the prevalence of computer use across gender (*P*=.57). Whereas, as noted above, the overwhelming majority of participants used computers, responses indicated that older participants (≥65 years) were significantly less likely to use a computer relative to middle-aged respondents (50-64 years) (*P*<.001; Table 2). Similarly, markedly, fewer respondents with lower levels of education (less than a bachelor's degree) reported using a computer relative to those with at least a university degree (*P*<.001; Table 2).

Table 1. Demographic characteristics of study participants.

Characteristic	Descriptive statistic
Continuous variables	
Age, in years **,** mean (SD)	67.6 (8.5)
Years of education, mean (SD)	14.0 (3.1)
MMSE[a], mean (SD)	28.2 (2.0)
Categorical variables	
Gender	
Female, n (%)	127 (57.5)
Male, n (%)	94 (42.5)
Vocational status	
Retired, n (%)	142 (65.1)
Full-time employment, n (%)	31 (14.2)
Part-time employment, n (%)	31 (14.2)
Other[b], n (%)	14 (6.5)
Diagnosis	
Mild cognitive impairment, n (%)	137 (62.0)
Dementia[c], n (%)	23 (10.4)
Subjective cognitive complaints only, n (%)	61 (27.6)

[a] MMSE: Mini-Mental State Examination.

[b] Includes individuals who are homemakers (3/14, 20%), full-time students (2/14, 13%), on medical or psychiatric leave of absence (1/14, 6%), discontinued work or study because of illness (1/14, 6%), currently unemployed (5/14, 36%), or other (2/14, 13%).

[c] Dementia diagnoses include Alzheimer's disease (20/23, 87%), fronto-temporal dementia (1/23, 3%), and mixed dementia or unknown etiology (2/23, 9%).

Table 2. Frequency of use of computers, mobile phones, and health-related websites. Discrepancies in the number of respondents for some questions relate to an update to the questionnaire during the data collection process (refer to Methods).

Sociodemographic variable	Computer use: yes		Smartphone: yes		Texting: yes		Use health-related websites: yes	
	n (%)	*P* value	n (%)	*P* value	n (%)	*P* value	n (%)	*P* value
Age group, in years		<.001		.001		<.001		.01
50-64	77 (95)		52 (65)		75 (96)		59 (77)	
≥65	115 (81.6)		65 (46.4)		99 (76.7)		88 (59.9)	
Level of education		<.001		.002		.10		.004
<Bachelor's degree	87 (79.1)		47 (43.1)		83 (81.4)		65 (56.9)	
≥Bachelor's degree	103 (94.5)		69 (63.3)		90 (88.2)		81 (75.6)	
Vocational status		.009		.007		<.001		.01
Working[a]	59 (94)		40 (65)		58 (97)		48 (80)	
Retired	119 (83.8)		66 (46.5)		101 (77.7)		88 (60.3)	
Other[b]	11 (79)		9 (68)		13 (93)		10 (63)	
Diagnosis		<.001		.001		<.001		.001
SCI[c]	57 (92)		35 (57)		55 (95)		40 (68)	
MCI[d]	120 (87.6)		76 (55.5)		106 (83.5)		96 (70.6)	
Dementia	15 (64)		6 (25)		13 (62)		9 (31)	

[a] Part- or full-time gainful employment.

[b] Includes individuals who are homemakers (3/14, 20%), full-time students (2/14, 13%), on medical or psychiatric leave of absence (1/14, 6%), discontinued work or study because of illness (1/14, 6%), currently unemployed (5/14, 36%), or other (2/14, 13%).

[c] SCI: subjective cognitive impairment.

[d] MCI: mild cognitive impairment.

Also shown in Table 2, working participants were more likely to use a computer as opposed to those who were retired or otherwise not formally employed (*P*=.009) Computer use also varied by degree of cognitive impairment (*P*<.001), and the means suggest that participants who met the criteria for early dementia were less likely to use a computer than both individuals with SCI and those with MCI (Table 2).

Mobile Phone Use

The vast majority of participants reported having a mobile phone (201/220, 91.4%), with approximately half using a smartphone (117/220, 53.2%). Most respondents already used texting (174/206, 84.5%), and a small group preferred to access the Internet via their mobile phone (18/183, 9.8%). Mobile phone use did not differ by gender (*P*=.83); however, as shown in Table 2, the middle-aged participants were significantly more likely to have a smartphone (*P*=.001) and to use texting relative to older respondents (*P*<.001). Although more university-educated participants reported having smartphones (*P*=.002), there was no difference in the use of texting compared with respondents with fewer years of education (*P*=.10; Table 2). Retired adults were also less likely to have a smartphone (*P*=.007) or to use texting (*P*<.001). Again, the proportion of participants who had a smartphone (*P*=.001) and who used texting (*P*<.001) varied with diagnosis, with respondents with early dementia appearing to be less likely to use either compared with those with SCI or MCI (Table 2).

Internet Practice

Access

The overwhelming majority of participants had access to the Internet at home (204/220, 92.6%), primarily via a computer. Approximately three-quarters of respondents reported using the Internet without difficulty (164/220, 74.5%), whereas a very small portion of the sample indicated that they lacked the skills to use the Internet proficiently (14/220, 6.4%). Internet use did not differ markedly across gender (*P*=.31); however, respondents over 65 years of age (23/140, 16.3%) or with lower levels of education (19/109, 17.4%) were more likely to experience difficulties, need assistance, or lack the skills required to use the Internet reliably relative to middle-aged participants (2/80, 3%; *P*<.001) or those who were more educated (6/109, 5.5%; *P*=.006). Importantly, participants who were retired (98/141, 69.5%) or otherwise not engaged in gainful employment (10/14, 70%) were equally able (*P*=.07) to use the Internet without complications relative to employed participants (53/62, 86%). Similarly, respondents with early dementia were not more likely (*P*=.08) to experience difficulties using the Internet (4/23, 16%) relative to those with SCI (4/61, 7%) or MCI (17/136, 12.5%). The majority of participants used a broadband or digital subscriber line connection at home to access the Internet (115/183, 62.8%), and most respondents were satisfied with the speed of their Internet connection (151/176, 85.8%).

Internet Activities

Most participants used email (196/217, 90.3%); however, the use of social media websites was less common (Facebook: 93/216, 43.1%; Twitter: 12/216, 5.6%; Instagram: 15/216, 6.9%; Pinterest: 20/216, 9.3%; and LinkedIn: 40/216, 18.5% or 30/122, 24.6% of working respondents). Furthermore, the majority of respondents indicated that they used the Internet most frequently for email relative to other common Web-based activities, including social connectedness, searching for information, and reading the news. Of note, older respondents were significantly less likely to use Facebook relative to middle-aged respondents (P=.002). Additionally, diagnosis (P=.02) was associated with the use of Facebook, with the percentages suggesting that individuals with early dementia (6/27, 21%) are less likely to use Facebook relative to those with SCI (32/62, 52%) or MCI (58/141, 41%).

eHealth Engagement

As shown in Table 2, the reported use of health-related websites varied considerably. A small proportion of the participants reported regular use of health-related websites, and approximately half of the respondents visited health-related websites occasionally. However, one-fifth of the sample (42/207, 20.3%) indicated they would never use health-related websites, primarily because of a lack of interest (42/112, 37.5%). Strikingly, the vast majority of participants who access health information via the Internet are at least reasonably confident in the reliability of information (reasonably confident: 62/114, 54.4%; quite confident: 18/114, 15.8%; and very confident: 5/114, 4.4%). As mentioned in the Methods section, discrepancies in the number of respondents for the latter questions relates to an update to the questionnaire during the data collection process. As shown in Table 2, the use of health-related websites did not differ by gender (P=.78) but varied with age (P=.01), education (P=.004), vocational status (P=.01), and diagnosis (P=.001).

Interest In and Preferences for eHealth Technologies

The majority of participants (198/209, 94.7%) reported that they would find it useful to be able to access a website designed to support healthy aging, including physical health and cognition, self-manage existing conditions, and track changes in cognition over time. Similarly, most respondents also reported interest in a website designed to specifically measure mood-related concerns and changes (172/206, 83.5%). When asked about Web-based interventions targeting individual risk factors for cognitive decline and dementia, there was an overwhelming interest in programs offering practical memory strategies and computer exercises to improve cognition (see Figure 1). Although not as pronounced, there was also considerable interest in Web-based interventions for a range of health concerns and lifestyle factors, including mood, sleep, physical activity, diet and nutrition, social engagement, and the management of vascular risk factors. Notably, preferences for eHealth technologies did not differ on the basis of employment status. Similarly, interest in eHealth interventions generally did not differ in relation to age and gender. However, middle-aged participants were more interested in interventions for sleep (P=.005) relative to the older respondents, and women were more interested in social programs (P=.004) compared with men. In relation to education, university-educated participants expressed greater interest in interventions relating to mood (P=.01), socialization (P=.02), memory (P=.014), and computer-based exercises (P=.046) compared with those with fewer years of education. Finally, variability in the preference for eHealth technologies varied in association with diagnosis for interventions targeting to sleep (P=.01), nutrition (P=.004), vascular risk factors (P=.03), and memory (P=.02). As presented in Figure 1, it appears that individuals with SCI and MCI were more likely to indicate interest in the aforementioned interventions relative to those with early dementia. In general, participants with MCI were most likely to indicate that they would use Web-based interventions.

After confirming that all assumptions had been met, age, years of education, gender, vocational status, and diagnosis were entered into a binary logistic regression to determine their association with interest in eHealth interventions for memory. As shown in Table 3, the model was statistically significant (χ^2_7=19.1, P=.008), explaining 13.8% of the variance in the preference for interventions targeting memory. Younger age (P=.02), more years of education (P=.03), and being retired (P=.03) were associated with a greater likelihood of being interested in eHealth interventions for memory, whereas those participants with a diagnosis of dementia were significantly less likely to be interested in such interventions relative to those with SC1 or MCI (P=.02).

As shown in Table 4, a similar model was generated to evaluate the relationship between sociodemographic factors and a preference for eHealth interventions targeting sleep. Again, the model was statistically significant (χ^2_7=22.7, P=.002). The model explained 13.3% of the variance in the preference for sleep-related interventions, with younger age (P=.001) and a diagnosis of dementia being the significant predictors (P=.008).

Figure 1. Interest in electronic health (eHealth) technologies varies with diagnosis. Abbreviations: SCI: subjective cognitive impairment, MCI: mild cognitive impairment, ^eg, outings, public talks and seminars, groups, etc, and *eg, high blood pressure, cholesterol, etc.

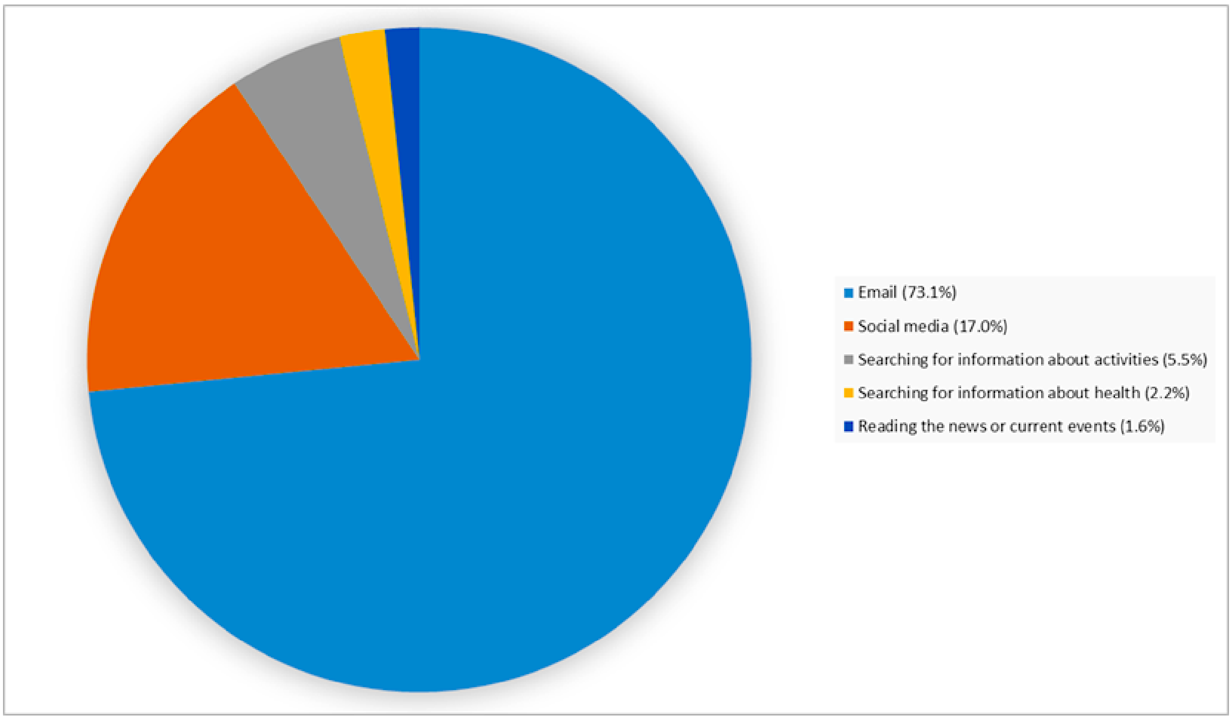

Table 3. Predictors of interest in electronic health (eHealth) interventions for memory.

Variables	Beta	SE[a]	Wald test	*P* value	Odds ratio (95% CI)
Age	−.06	0.03	4.72	.02	0.93 (0.88-0.98)
Gender (female)	−.03	0.40	0.01	.91	0.95 (0.43-2.10)
Years of education	.13	0.05	4.87	.03	1.14 (1.02-1.31)
Vocational group					
Working[b]			4.55	.09	
Retired	−1.32	0.92	1.98	.16	0.27 (0.03-1.67)
Other[c]	−.18	0.87	0.04	.81	0.81 (0.14-4.50)
Diagnosis					
SCI[d]			6.94	.02	
MCI[e]	.20	0.46	0.20	.64	1.24 (0.49-3.12)
Dementia	−1.19	0.48	5.83	.02	0.31 (0.12-0.79)

[a] SE: standard error.

[b] Part- or full-time gainful employment.

[c] Includes individuals who are homemakers (3/14, 20%), full-time students (2/14, 13%), on medical or psychiatric leave of absence (1/14, 6%), discontinued work or study because of illness (1/14, 6%), currently unemployed (5/14, 36%), or other (2/14, 13%).

[d] SCI: subjective cognitive impairment.

[e] MCI: mild cognitive impairment.

Table 4. Predictors of interest in electronic health (eHealth) interventions for sleep.

Variables	Beta	SE[a]	Wald test	*P* value	Odds ratio (95% CI)
Age	−.06	0.01	10.87	.001	0.92 (0.88-0.98)
Gender (female)	.08	0.29	0.10	.76	1.10 (0.61-1.97)
Years of education	−.003	0.05	0.004	.95	1.00 (0.91-1.10)
Vocational group					
Working[b]			2.45	.28	
Retired	−.73	0.67	1.17	.28	0.47 (0.12-1.78)
Other[c]	−.13	0.63	0.03	.83	0.87 (0.24-3.07)
Diagnosis					
SCI[d]			7.17	.03	
MCI[e]	−.29	0.33	0.80	.36	0.74 (0.38-1.44)
Dementia	−1.26	0.48	7.03	.008	0.27 (0.10-0.72)

[a] SE: standard error.

[b] Part- or full-time gainful employment.

[c] Includes individuals who are homemakers (3/14, 20%), full-time students (2/14, 13%), on medical or psychiatric leave of absence (1/14, 6%), discontinued work or study because of illness (1/14, 6%), currently unemployed (5/14, 36%), or other (2/14, 13%).

[d] SCI: subjective cognitive impairment.

[e] MCI: mild cognitive impairment.

Another statistically significant model (χ^2_7=19.9, *P*=.005) explained 11.8% of the variance in the interest in social eHealth programs, indicating that being female (*P*=.001) and having more years of education (*P*=.01) were both significantly associated with a preference for this type of intervention (Table 5).

As displayed in Table 6, the same sociodemographic factors were entered into a logistic regression model to examine their relationship with interest in eHealth interventions targeting mood. The model was statistically significant (χ^2_7=14.1, *P*=.047). The model explained 8.5% of the variance in the preference for interventions for mood, with younger age (*P*=.011) being the only significant predictor.

Interest in eHealth interventions for nutrition was also significantly associated with sociodemographic factors (χ^2_7=21.0, *P*=.004). As shown in Table 7, the model explained 12.5% of the variance in preference for nutrition interventions. Younger participants were significantly more likely to be interested (*P*=.01), whereas participants with dementia were significantly less likely to endorse this preference (*P*=.001).

On the basis of binary logistic regression models, no significant associations were found between the aforementioned sociodemographic variables and a preference for eHealth interventions targeting exercise (*P*=.08), vascular risk factors (*P*=.08), and computer-based exercises (*P*=.12).

Table 5. Predictors of interest in electronic health (eHealth) interventions for socialization.

Variables	Beta	SE[a]	Wald test	*P* value	Odds ratio (95% CI)
Age	−.02	0.01	2.51	.10	0.97 (0.93-1.01)
Gender (female)	1.00	0.29	11.10	.001	2.72 (1.50-4.94)
Years of education	.11	0.05	6.01	.01	1.13 (1.03-1.23)
Vocational group					
Working[b]			3.00	.21	
Retired	−.61	0.60	1.03	.30	0.54 (0.15-1.79)
Other[c]	.08	0.57	0.02	.88	1.07 (0.33-3.37)
Diagnosis					
SCI[d]			2.26	.31	
MCI[e]	.48	0.33	2.03	.14	1.64 (0.82-3.20)
Dementia	−.06	0.44	0.03	.87	0.93 (0.38-2.18)

[a] SE: standard error.

[b] Part- or full-time gainful employment.

[c] Includes individuals who are homemakers (3/14, 20%), full-time students (2/14, 13%), on medical or psychiatric leave of absence (1/14, 6%), discontinued work or study because of illness (1/14, 6%), currently unemployed (5/14, 36%), or other (2/14, 13%).

[d] SCI: subjective cognitive impairment.

[e] MCI: mild cognitive impairment.

Table 6. Predictors of interest in electronic health (eHealth) interventions for mood.

Variables	Beta	SE[a]	Wald test	*P* value	Odds ratio (95% CI)
Age	−.04	0.01	6.40	.01	0.95 (0.90-0.99)
Gender (female)	.29	0.28	0.96	.31	1.32 (0.74-2.36)
Years of education	.03	0.05	0.35	.54	1.03 (0.94-1.13)
Vocational group					
Working[b]			0.69	.69	
Retired	−.48	0.61	0.57	.45	0.61 (0.17-2.10)
Other[c]	.22	0.60	0.14	.70	0.78 (0.25-2.54)
Diagnosis					
SCI[d]			4.64	.10	
MCI[e]	−.57	0.32	3.05	.79	0.56 (0.29-1.06)
Dementia	−.70	0.44	2.51	.10	0.48 (0.19-1.17)

[a] SE: standard error.

[b] Part- or full-time gainful employment.

[c] Includes individuals who are homemakers (3/14, 20%), full-time students (2/14, 13%), on medical or psychiatric leave of absence (1/14, 6%), discontinued work or study because of illness (1/14, 6%), currently unemployed (5/14, 36%), or other (2/14, 13%).

[d] SCI: subjective cognitive impairment.

[e] MCI: mild cognitive impairment.

Table 7. Predictors of interest in electronic health (eHealth) interventions for nutrition.

Variables	Beta	SE[a]	Wald test	*P* value	Odds ratio (95% CI)
Age	−.06	0.01	6.81	.01	0.93 (0.89-0.97)
Gender (female)	.40	0.29	1.83	.18	1.50 (0.82-2.74)
Years of education	−.011	0.04	0.04	.81	0.99 (0.90-1.08)
Vocational group					
Working[b]			4.64	.10	
Retired	−.68	0.65	1.10	.30	0.49 (0.14-1.83)
Other[c]	.19	0.64	0.09	.74	1.23 (0.34-4.27)
Diagnosis					
SCI[d]			10.52	.01	
MCI[e]	−.23	0.35	0.48	.49	0.79 (0.40-1.54)
Dementia	−1.50	0.47	10.52	.001	0.21 (0.09-0.55)

[a] SE: standard error.

[b] Part- or full-time gainful employment.

[c] Includes individuals who are homemakers (3/14, 20%), full-time students (2/14, 13%), on medical or psychiatric leave of absence (1/14, 6%), discontinued work or study because of illness (1/14, 6%), currently unemployed (5/14, 36%), or other (2/14, 13%).

[d] SCI: subjective cognitive impairment.

[e] MCI: mild cognitive impairment.

Discussion

Principal Findings

Our results demonstrate that technology use is pervasive among older adults presenting to a specialized metropolitan early intervention clinic for cognition and mood in an Australian context. Specifically, the data show that 91.4% (201/220) of participants used a mobile phone, with 53.2% (117/220) using a smartphone, and 92.8% (205/221) had access to a computer in the home, with 39.4% (87/221) of participants also using a tablet. Whereas computer use varied somewhat based on age, education, vocational status, and diagnosis, the vast majority of participants used computers routinely irrespective of these factors. Importantly, this is the first study to highlight that older adults with cognitive impairments that may affect Internet and mobile phone use are still actively engaging with technology.

In accordance with global data showing growing computer use and Internet access among older adults, a striking 92.7% (204/220) of our respondents have access to the Internet at home. Adults ≥65 years and with fewer years of schooling were more likely to require assistance, experience difficulties, or lack the necessary skills to use the Internet relative to participants aged 50 to 64 years and those with higher levels of education. Importantly, however, diagnosis did not impact upon proficiency in Internet use. Of significance, the prevalence of Internet access and use within this study sample exceeds the 2015 estimates reported by the Australian Bureau of Statistics [42]. This may relate to sociodemographic factors specific to the study sample, including having above average levels of education and residing in a metropolitan area. Indeed, it is likely that in rural and remote regions, Internet access may not be as readily available [43]. Similarly, older age and lower socioeconomic status are also associated with lower rates of Internet access [44]. Of note, residents of Greater Sydney, which would mostly comprise our study participants, report higher wages and total annual income relative to other regions in the state [45].

The finding that older people with MCI or early dementia have access to technology and the Internet indicates that targeted eHealth interventions could be developed to address modifiable risk factors. A recent study reported that 63.1% of 1014 community-dwelling older adults aged 57 to 77 years would use eHealth if given the opportunity [46]. This is consistent with our finding of 67.6% (140/207) of respondents visiting health-related websites either regularly or occasionally (see Table 2). Our results further highlight that individuals with MCI and early dementia are also interested in using eHealth interventions for cognition, lifestyle factors, and health concerns, suggesting the potential for the targeted use of eHealth technology in these groups. However, this study is the first to show that preferences for eHealth differ depending on the severity of cognitive impairment. Whereas interest in computer-based cognitive exercises was roughly equivalent across diagnostic groups, those with SCI and MCI expressed greater interest (>80% of those groups) in Web-based strategies specifically targeting memory relative to respondents with early dementia. Additionally, younger age and higher levels of education were also associated with an increased preference for memory-related eHealth interventions. These group differences may reflect the health-seeking status of participants with SCI and MCI, as well as the concomitant desire to delay or prevent cognitive decline among middle-aged educated adults. Notably, however, 63.6% (14/22) of individuals with early dementia were also interested in Web-based memory activities.

In relation to other eHealth interventions, participants with early dementia appeared most interested in those designed to facilitate exercise, as well as to improve social engagement and participation; however, given the small sample size of this subgroup, these data are interpreted cautiously. With this caveat in mind, the relative interest in social programs may reflect the isolation that often occurs with aging and in particular, when an individual is diagnosed with dementia [47]. A longitudinal cohort study of >4000 older adults reported that the combination of Internet use and social engagement (eg, attending art exhibits, movies, and theatre) appeared to help older adults maintain the health literacy skills necessary to manage their health, including the ability to understand basic health information and services [48]. Similarly, it has been shown that Internet use for communication and social support is associated with enhanced life satisfaction, psychological well-being, and sense of community [49,50].

Social media networks also have the potential to promote socialization among older adults, regardless of geographic location and mobility issues. Of commonly used social networks, our results demonstrate that older adults are most likely to use Facebook, which has specifically been shown to be associated with social connectedness and well-being in older adults [51] and may have the potential to improve executive functions and processing speed [52]. That being said, in our sample, the older participants (aged 65 years) were significantly less likely to use Facebook relative to the middle-aged respondents. Additionally, our results show that men are less interested in social eHealth programs. Despite potential benefits, adults in later life may have negative attitudes toward social media for varying reasons, including concerns regarding data privacy, a lack of familiarity with Web-based social norms, and discomfort with self-disclosure [53]. Therefore, it is recommended that novice users, which may include more men than woman, are supported by a moderator to help them overcome potential barriers. In addition, the rates of social media use among this well-educated sample were relatively low. Thus, given the potential benefits of engaging with social media networks, future efforts to promote the use and uptake of social media would be vital for programs or interventions that target older adults with concerns about their cognition.

With regard to exercise, recent meta-analytic data showed that exercise is beneficial for cognition in people with dementia [54], more so than other nonpharmacological interventions such as music therapy and cognitive training [55]. Web-based interventions have already proved effective as a method to promote exercise in older adults [15], particularly when they take into account environmental factors such as local neighborhood offerings for physical activity and are tailored to older adults, with the potential to be personalized and adapted to each individual [25]. In light of the existing literature and the relative interest in exercise programs reported in our sample, feasibility and efficacy studies of Web-based exercise interventions for people with dementia are now essential.

Interestingly, a relatively higher percentage of respondents with SCI and MCI generally reported an interest in interventions addressing sleep, nutrition, and vascular risk factors, relative to those with early dementia. Importantly, there is an extensive literature highlighting the benefits of early intervention for cognitive decline [5,28-32]. Indeed, our prior trials of healthy brain-aging cognitive training have been successful and have been shown to improve knowledge, memory, mood, and sleep, as well as reduce disability in people with neurodegenerative diseases and depression [31,56-58].

Studies investigating the potential for targeted interventions of this sort to be delivered via the Internet are now required. In this regard, there is a growing literature regarding the use of eHealth interventions for a range of medical and mental health conditions, including modifiable risk factors for cognitive decline [8-13,15]. However, at present, there are no known eHealth interventions specifically for people with MCI or dementia. There are, however, several large-scale clinical trials in various stages of completion seeking to evaluate the utility of Web-based lifestyle interventions for older adults. For example, Glozier et al [10] showed that an Internet-based cognitive behavioral therapy (CBT) intervention resulted in a significant decrease in depressive symptoms in people with mild-to-moderate depression and high levels of cardiovascular risk factors. There is also evidence to support the use of a Web-based CBT insomnia program (ie, SHUT-I) for the treatment of depression in adults over the age of 50 years [14], including forthcoming data from the Sleep or Mood Novel Adjunctive Therapy trial (ANZCTR12612000985886) [59]. The Body, Brain, Life program (ANZCTR12612000147886), a 12-week dementia risk reduction intervention, was shown to result in a significant decrease in dementia risk among cognitively intact adults (n=58) aged 50 to 60 years at 26 weeks, largely because of an increase in positive protective factors such as fish consumption and cognitive engagement [60]. Similarly, the Maintain Your Brain trial aims to recruit 18,000 people to evaluate the benefits of Internet coaching on dementia risk [61].

As eHealth interventions and clinical registries are being developed and tailored specifically for individuals with MCI and early dementia, it will be essential to investigate potential predictors of use such as level of education, vocational status, degree of cognitive impairment, and medical burden. The optimal timing, frequency, and intensity, as well as the method of delivery (eg, via mobile phone, computer, or tablet) of the intervention may also impact on the acceptability and feasibility of eHealth tools. Given the common use of texting in our sample (174/206, 84.5%), texts may be an easy and cost-effective way in which to provide reminders and key tips and suggestions. Responsive websites that are mobile-friendly and can adapt to any sized device will offer broad accessibility; however, apps allow for personalization of the features and are preferred for interactive games. Our data suggest that adults aged 65 years and older would be more likely to utilize computer-based interventions; however, given that 65% (80/220) of younger (50-64 years) respondents had a smartphone, they may be more apt to use mobile apps, allowing for push notifications, data tracking, and social sharing of content. Importantly, apps also allow content to be downloaded so that it can be accessed without an Internet connection, which may be particularly important in areas with limited and/or unreliable Internet service.

The efficacy of eHealth interventions may vary in relation to the provision of supervision by a coach or clinician [62], as well as severity of the impairment in the target population [29]. In relation to the latter, future eHealth interventions should offer hierarchical support, adapting to the ability level of the patient and guiding them in the selection of the most appropriate intervention given their level of impairment, as well as personal preferences. Factors relating to adherence, including clinician support and coordination of clinical care with eHealth [17], will also need to be further explored. Additionally, researchers will also need to carefully consider recruitment methods when evaluating such interventions to avoid selection bias. Whereas social media networks such as Facebook are optimal for recruiting participants for eHealth studies, the use of such sites differs notably by age [63]. Additionally, although Facebook is the most used site irrespective of age [63], as it was with our participants, a recent study showed that recruitment rates and participant engagement varied based on the content of Facebook advertisements, impacting upon the generalizability of the results [64]. Therefore, recruitment methods will need to be carefully tailored to the target audience.

Limitations

Ultimately, eHealth technologies offer a unique opportunity for scalable and cost-effective screening of cognition and modifiable risk factors of cognitive decline linked with evidence-based, multidisciplinary interventions in a systematic and stepwise fashion, with the primary aim of improving the accessibility of individualized care for older adults. This study is the first to examine computer, Internet, mobile phone, and eHealth technology use with regard to cognitive status in older adults. However, it is important to interpret our findings in the context of study limitations. The reliability of information gathered via self-report questionnaire may be reduced in people with dementia, depending on their degree of cognitive impairment. We must also acknowledge that the study sample may not be representative of the broader population because of socioeconomic factors, including years of education (mean=14.0 years), residency in a metropolitan area, and annual income. It will be important in the future to gather the same type of prevalence data in regional and remote settings, particularly as it is in these settings where eHealth technologies may have a greater impact by increasing access to care. In the future, we propose to update the HBA E-health Questionnaire to broaden the definition of texting to include other communication methods such as Messenger and WhatsApp developed by Facebook, and Viber developed by Rakuten Inc. We will also include additional questions about the use of tablets (ie, iPad, Apple Inc) to determine the appropriateness of eHealth interventions delivered in this format. This is of particular interest as many existing Web-based cognitive tests (ie, Cambridge Neuropsychological Test Automated Battery [65]) are being developed for tablets and, therefore, would provide an opportunity to assess and track cognitive performance in older adults over time and in conjunction with specific eHealth interventions. It is also important to consider that the phrasing of some questions in the survey (eg, “Would you use...”) may have prompted positive responses from respondents, potentially biasing the results. However, approximately 40% to 50% of participants indicated that they were, in fact, *not* interested in several of the interventions, arguing against this concern.

Conclusions

This study presents key data showing the use of and interest in eHealth technologies in older Australian adults with cognitive impairment. Overall, our data demonstrate an overwhelming interest within this demographic for targeted interventions to address modifiable risk factors for cognitive decline, particularly in relation to memory and computer-based exercises for cognition. These findings support future research efforts into the development, implementation, feasibility, and acceptability of eHealth interventions to support the health and well-being of individuals with cognitive impairment and their carers. As part of this process, it will be important to develop strategies to promote the use of eHealth technologies, including social media websites and apps among older adults with lower levels of education.

Conflicts of Interest

Professor Ian Hickie has been a Commissioner in Australia’s National Mental Health Commission since 2012. He is the Co-Director, Health and Policy at the Brain and Mind Centre (BMC) University of Sydney. The BMC operates early-intervention youth services at Camperdown under contract to headspace. Professor Hickie has previously led community-based and pharmaceutical industry-supported (Wyeth, Eli Lily, Servier, Pfizer, and AstraZeneca) projects focused on the identification and better management of anxiety and depression. He is a member of the Medical Advisory Panel for Medibank Private, a Board Member of Psychosis Australia Trust, and a member of Veterans Mental Health Clinical Reference group. He is the Chief Scientific Advisor to, and an equity shareholder in, Innowell. Innowell has been formed by the University of Sydney and PwC to deliver the $30 million Australian Government–funded *Project Synergy*. Project Synergy is a 3-year program for the transformation of mental health services through the use of innovative technologies. No other disclosures to declare.

Multimedia Appendix 1

The Healthy Brain Ageing E-Health Questionnaire.

[PDF File (Adobe PDF File), 583KB - jmir_v19i10e358_app1.pdf]

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Abbreviations

eHealth: electronic health

HBA: Healthy Brain Ageing
MCI: mild cognitive impairment
MMSE: Mini-Mental State Examination
SE: standard error
SCI: subjective cognitive impairment
SPSS: Statistical Package for the Social Sciences

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Original Paper

Exploring the Potential of a Wearable Camera to Examine the Early Obesogenic Home Environment: Comparison of SenseCam Images to the Home Environment Interview

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Abstract

Background: The obesogenic home environment is usually examined via self-report, and objective measures are required.

Objective: This study explored whether the wearable camera SenseCam can be used to examine the early obesogenic home environment and whether it is useful for validation of self-report measures.

Methods: A total of 15 primary caregivers of young children (mean age of child 4 years) completed the Home Environment Interview (HEI). Around 12 days after the HEI, participants wore the SenseCam at home for 4 days. A semistructured interview assessed participants' experience of wearing the SenseCam. Intraclass correlation coefficients (ICCs), percent agreement, and kappa statistics were used as validity estimates for 54 home environment features.

Results: Wearing the SenseCam was generally acceptable to those who participated. The SenseCam captured all 54 HEI features but with varying detail; 36 features (67%) had satisfactory validity (ICC or kappa ≥0.40; percent agreement ≥80 where kappa could not be calculated). Validity was good or excellent (ICC or kappa ≥0.60) for fresh fruit and vegetable availability, fresh vegetable variety, display of food and drink (except sweet snacks), family meals, child eating lunch or dinner while watching TV, garden and play equipment, the number of TVs and DVD players, and media equipment in the child's bedroom. Validity was poor (ICC or kappa <0.40) for tinned and frozen vegetable availability and variety, and sweet snack availability.

Conclusions: The SenseCam has the potential to objectively examine and validate multiple aspects of the obesogenic home environment. Further research should aim to replicate the findings in a larger, representative sample.

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KEYWORDS

environment and public health; obesity; parents

Introduction

The home environment is thought to play an important role in early obesity prevention and weight management [1-3]. Researchers have identified food, physical activity, and media-related influences as core domains that define the obesogenic home environment [4]. Multiple self-report measures have been used to examine aspects within home environment domains, but few are comprehensive, and few have been assessed in terms of criterion validity (the extent to which they relate to concrete criteria in the real world) [5]. The Home Environment Interview (HEI) is one of few comprehensive home environment measures and has recently been associated with diet, physical activity, and TV viewing in a large sample of preschool children [6].

Demonstrating the criterion validity of parent- or self-reported measures (which are prone to social desirability and recall biases) is important to ensure that the results of studies using them are largely unattributable to measurement error. In the case of the home environment, identifying accurate associations with health behaviors and/or weight is important for ensuring the design of effective weight-related interventions. Studies that have assessed criterion validity have tended to use one-off home visits that cannot capture behavioral or social aspects of the home environment, such as mealtime interactions and parental modeling [7]. Multiple home visits can provide further insight [8], but they are costly and labor intensive.

Technologic advances have provided opportunities to objectively examine the obesogenic home environment. Video recording has long been used by developmental researchers to assess child-parent interactions, including those at mealtimes [9-11]. Disposable cameras have been used to capture the food environment from the child's perspective [12]. Although insightful, standard picture cameras do not permit continuous recording and video cameras do not capture events from the first-person perspective, which would provide a more detailed and naturalistic account of an individual's environment.

Visual lifelogging refers to the passive digital capture of everyday activities from the first-person perspective. Numerous devices have been developed for visual lifelogging [13]. The most popular wearable camera in a research setting is the SenseCam (Microsoft Corp) [14], designed to take pictures automatically (approximately every 20 seconds) when triggered by sensors that log temperature, light, acceleration, and passive infrared data [15]. The SenseCam is straightforward to use, has a long battery life (up to 16 hours), a large storage capacity (over one week's worth of images), a wide-angle lens to capture everything within the wearer's view, and does not record sound [16]. Each image is time-stamped so duration of specific events or activities can be deduced.

The SenseCam has predominantly been used in memory and cognitive impairment research [17,18]. More recent research has explored how the SenseCam can be used to assess diet and activity behaviors. SenseCam images have been compared with travel diaries in volunteer adults [19] and teenagers [20], food diaries [21], 24-hour dietary recall [22], and accelerometers in university employees to improve the classification of sedentary behavior [23], highlighting the utility of a wearable camera to validate traditional assessment tools. The SenseCam has also been used to examine the context of eating behavior in adult [24] and teenage [25] participants. No studies have used a wearable camera to examine the early obesogenic home environment.

This study will therefore examine whether the wearable camera SenseCam can be used to examine the early obesogenic home environment and whether it is useful for validation of self-report measures. Specifically, this study will examine whether the Sensecam is acceptable to participants, which aspects of the obesogenic home environment can be captured by the SenseCam, and how this information compares to that captured by the HEI [6].

Methods

Study Sample

The study sample was obtained using convenience sampling. Participants were 15 parents of children aged 2 to 8 years who had taken part in previous research at University College London and agreed to be contacted for future studies. A total of 94 parents were sent an invitation letter. Parents who did not respond to the letter were followed up with a telephone call. Participants gave written consent before taking part. Any other adults living in the home also consented to participation, since they would be photographed. Ethical approval for the study was granted by the University College London Ethics Committee for Research Involving Human Subjects (project approval number 3792/001). The study protocol adhered to the ethical framework outlined by Kelly and colleagues [26].

Measuring and Validating the Home Environment

Participants completed the HEI by telephone while at home. The HEI is one of few comprehensive measures of the home environment, capturing multiple aspects of the food, physical activity, and media domains. Items assess food availability and accessibility, physical activity opportunities, and media equipment availability, as well as social aspects such as parental modeling of eating and activity behaviors. The HEI was adapted from the Healthy Home Survey [7], the most comprehensive home environment measure available at the time, and with evidence for criterion validity [7]. Consistent with the Healthy Home Survey, the test-retest reliability of the HEI (assessed in a sample of 44 parents) was generally moderate to high. The intraclass correlation coefficients (ICCs) and 95% confidence intervals for the total scores were as follows: food environment (0.71, 0.52-0.83), activity environment (0.83, 0.72-0.91), media environment (0.92, 0.85-0.95), and overall (0.92, 0.86-0.96). Additional details of the HEI are provided in a previous publication [6].

Participants were visited at home on average 12 (SD 5.82) days after completing the HEI. The time frame between completing the HEI and wearing the camera was chosen to be largely consistent with the validation study of the Healthy Home Survey, where the home visit took place 7 to 14 days after the initial telephone interview. Participants were asked to wear the camera during waking hours while at home for 4 consecutive days (including at least one weekend day). A 4-day wearing period was chosen to strike a balance between capturing sufficient information about the home environment for the purposes of the study and minimizing participant burden. Participants wore the SenseCam on a lanyard around their neck with adhesive fashion tape attached to the back to reduce movement. Participants were told that they were free to turn off or remove the camera whenever they did not feel comfortable wearing it. The following statement was provided for participants to use if they encountered other people while wearing the camera: "I am volunteering for a research project looking at my home environment. The device is called SenseCam and it takes pictures of my daily activities." Previous research has found that this approach is sufficient to satisfy any queries from other members of the public [19].

Semistructured Interview

After the wearing period, the camera was collected and participants completed a semistructured interview. Participants were asked about ease of use, awareness of the camera, reactions from other people, instances where they did not feel comfortable wearing the camera, and whether they felt that wearing the SenseCam could influence families to change aspects of their household routine. Participants had the opportunity to view and delete their images if they did not wish to have them stored for analysis.

Statistical Analysis

The SenseCam images were manually coded using the Oxford CLARITY-DCU SenseCam browser [27]. Each image was visually inspected and coded for the presence or absence of features assessed in the HEI. Home environment features that could not be captured by the SenseCam were identified before coding and included whether the child was allowed to help him or herself to food and drink; the frequency the child was allowed to play inside and outside the home; parks and indoor recreation centers close to the home; and rules around media use. A total of 54 features were coded (42 food-, 2 activity-, and 10 media-related). These are shown in Tables 2 and 3 and in Multimedia Appendix 1 alongside the corresponding HEI questions.

Images were classified as uncodeable if there were low light levels, something was covering the lens, or in cases of extreme blurring. Home environment features were coded as missing if they were not identifiable in the images.

A total of 60 days of data (75,818 images) were coded. It took 100 hours to code the data. One randomly selected day’s worth of images was recoded by the original coder after study completion to assess intrarater reliability. For interrater reliability, an independent coder analyzed another randomly selected day’s worth of images. There was almost 100% agreement across coding sessions.

ICCs (for continuous variables), percent agreement, and kappa statistics (for categorical variables) were used as validity estimates. As recommended, kappas and ICCs were defined as: <0.40=poor, 0.40-0.59=fair, 0.60-0.74=good, and 0.75-1.00= excellent [28]. In cases where percent agreement was high (≥80) but kappa was poor, the proportion of positive (ppos) and negative (pneg) agreement were presented. This is recommended for better understanding of results [29].

Results

Study Sample

Of the 94 parents contacted, 34 (36%) did not respond to the initial letter and could not be contacted by telephone or email. Among those who responded and did not wish to participate in the study, 62% (28/45) cited discomfort with wearing the camera as the reason and 38% (17/45) cited other reasons such as lack of time. Participants included 13 mothers and 2 fathers. All were main caregivers of their children. Parent and child characteristics are shown in Table 1.

Table 1. Characteristics of families who took part in the study.

Characteristics	Mean (SD) or n (%)
Parent characteristics	
Age (years), mean (SD)	38.6 (6.4)[a]
Education level[b] , n (%)	
Low	1 (7)
Medium	2 (13)
High	12 (80)
Ethnicity, n (%)	
White	13 (87)
Other	2 (13)
Number of children in the home, n (%)	
One	5 (33)
More than one	10 (67)
Child characteristics	
Age (years), mean (SD)	4.8 (1.7)
Sex, n (%)	
Male	10 (67)
Female	5 (33)
Ethnicity, n (%)	
White	9 (60)
Other	6 (40)

[a] Data were missing for 1 participant on this variable (n=14).

[b] Education level categorized as low (no qualifications or basic high school education), medium (vocational or advanced high school education), and high (university-level education).

Table 2. Descriptive statistics for the home environment features (N=15; n [%] who responded yes or mean [SD]).

Home environment feature	HEI[a]	SenseCam
Food availability, n (%)		
Fresh fruit	15 (100)	15 (100)
Tinned fruit	6 (40)	0 (0)
Dried fruit	9 (60)	4 (27)
Frozen fruit	3 (20)	0 (0)
Fresh vegetables	14 (93)	15 (100)
Tinned vegetables	14 (93)	7 (47)
Frozen vegetables	13 (87)	4 (27)
Savory snacks	10 (67)	8 (53)
Sweet snacks	12 (80)	6 (40)
Confectionery	10 (67)	4 (27)
Fruit juice	8 (53)	11 (73)
Squash	5 (33)	4 (27)
Fizzy drinks	2 (13)	4 (27)
Smoothies	3 (20)	1 (7)
Skimmed/semiskimmed milk	10 (67)	13 (87)
Full-fat milk	5 (33)	6 (40)
Food variety, mean (SD)		
Fresh fruit	3.5 (1.4)	4.5 (2.3)
Tinned fruit	0.6 (0.9)	0 (0)
Dried fruit	1.9 (1.9)	0.3 (0.6)
Frozen fruit	0.2 (0.4)	0 (0)
Fresh vegetables	6.3 (3.0)	6.7 (3.1)
Tinned vegetables	3.9 (1.7)	0.8 (1.0)
Frozen vegetables	1.7 (1.4)	0.3 (0.5)
Savory snacks	1.1 (1.1)	0.7 (0.7)
Sweet snacks	1.5 (1.1)	0.7 (1.1)
Confectionery	0.9 (0.8)	0.3 (0.5)
Food displayed, n (%)		
Any fruit	15 (100)	14 (93)
Ready-to-eat vegetables	2 (13)	0 (0)
Savory snacks	0 (0)	0 (0)
Sweet snacks	3 (20)	2 (13)
Confectionery	1 (7)	1 (7)
Fruit juice	0 (0)	0 (0)
Squash	2 (13)	3 (20)
Fizzy drinks	1 (7)	0 (0)
Smoothies	0 (0)	0 (0)
Family meals, n (%)		
Breakfast	11 (73)	11 (73)[b]
Lunch	12 (80)	10 (67)[c]

Home environment feature	HEI[a]	SenseCam
Dinner	11 (73)	12 (80)[b]
Child eating while watching TV, n (%)		
Breakfast	0 (0)	2 (13)[d]
Lunch	0 (0)	0 (0)[e]
Dinner	1 (7)	1 (7)[d]
Snacks	5 (33)	2 (13)[f]
Activity facilities, n (%)		
Garden	12 (80)	10 (67)
Garden equipment	2 (17)	1 (8)[g]
Household media equipment, mean (SD)		
Number of TVs	1.5 (1.1)	1.6 (1.1)
Number of VCR/DVD players	1.5 (1.0)	1.3 (0.9)
Number of computers	2.4 (1.0)	1.6 (0.9)
Number of games consoles	0.7 (1.0)	0.2 (0.6)
Presence of cable or satellite, n (%)	9 (60)	3 (20)[h]
Child's bedroom media equipment, n (%)		
TV	2 (13)	3 (20)[i]
Computer	1 (7)	1 (7)[i]
Console	2 (13)	1 (7)[i]
Caregiver TV viewing (hours), mean (SD)		
Weekday	1.7 (1.3)	1.2 (0.7)[j]
Weekend	2.4 (1.67)	1.5 (0.81)[k]

[a] HEI: Home Environment Interview.

[b] Two cases were coded as missing: 1 participant did not wear the SenseCam during breakfast time and 1 participant said during the semistructured interview that they had modified their mealtime routine.

[c] Three cases were coded as missing: 2 participants did not wear the SenseCam during lunchtime and 1 participant had modified their mealtime routine.

[d] Data were missing in 3 cases: 1 did not wear the SenseCam at breakfast/dinner time, 1 said in the semistructured interview that they had modified their mealtime routine, and the third did not have breakfast/dinner with their children during the wearing period.

[e] Data were missing in 5 cases: 2 did not wear the SenseCam at lunchtime, 1 said that they had modified their mealtime routine, and the last 2 did not have lunch with their children during the wearing period.

[f] Data were missing in 1 case where the caregiver did not wear the SenseCam around their child.

[g] Three cases were coded as missing as the garden wasn't fully visible during the wearing period.

[h] It was only possible to determine the presence or absence of cable or satellite in 4 cases; the remaining cases were coded as missing.

[i] Two cases were coded as missing because the child's bedroom was not visible during the wearing period.

[j] Data were missing in 6 cases where the caregiver did not wear the SenseCam for all of the weekday periods (morning/afternoon/evening).

[k] Data were missing in 7 cases where the caregiver did not wear the SenseCam for all of the weekend periods (morning/afternoon/evening).

Measuring and Validating the Home Environment

Participants wore the SenseCam for 4 (SD 1.1) days on average. The average wearing time per day was 5.9 (SD 2.6) hours . All 54 home environment features were captured to some extent. What was captured by the SenseCam depended on the duration of the wearing period and participant behavior during this period. As shown in Table 2, fresh fruit and vegetables were captured in all cases, tinned and frozen foods were rarely captured, and energy-dense snacks were captured to a slightly less extent than reported in the HEI. In almost all cases, it was not possible to determine the sugar content of drinks. It was possible to identify milk type using the color of the bottle tops. The presence of satellite TV was rarely captured, and child snacking while watching TV was captured less frequently than reported in the HEI. In total, 4470 images (6%) were classified as uncodeable. Figure 1 shows some sample images of home environment features.

Figure 1. Sample SenseCam images showing the presence of confectionery (left), a family dinner (center), and eating breakfast while watching TV (right). Faces are colored for anonymity.

Validity estimates for the 42 home food environment variables are shown in Table 3. Of the 42 variables, 25 (60%) had satisfactory validity (ICC or kappa ≥0.40; percent agreement ≥80 where kappa could not be calculated). Validity estimates were good for fresh fruit, fresh vegetable, and full-fat milk availability, the variety of fresh vegetables, the display of food and drink (except sweet snacks), eating meals as a family, and child eating lunch/dinner while watching TV. Particularly low validity estimates were reported for tinned and frozen vegetable availability and variety, and sweet snack availability. For the display of confectionery, percent agreement was high (87%), but kappa was –0.07 because there was just one yes response at the time of the HEI and one yes response captured by SenseCam (ppos was 0.00, but pneg was 0.93).

Validity estimates for the home activity and media environment variables are also shown in Table 3. The presence of a garden and play equipment had good validity (kappa >0.60). Of the 10 home media environment variables, 9 (90%) had satisfactory validity and 5 (50%) had good or excellent validity. Validity was lower for the number of household computers (ICC 0.3).

Semistructured Interview

All but 1 participant completed the semistructured interview. All completing participants said that the SenseCam was straightforward to use. Initially, 1 participant had trouble charging the camera, and 2 forgot to charge it. Two participants said that the camera sometimes got in the way when they carried their children. Another suggested using a smaller, more discreet camera.

A total of 7 participants said that they forgot to wear the camera on some occasions: when they were returning from an outing, rushing in the morning to get ready for work, or when their children were not around. Situations where participants said they chose not to wear the SenseCam included trips to the bathroom, getting their children ready for bed, and when they had a visitor.

Almost all participants said that wearing the SenseCam made them think about aspects of their behavior and household routines. For example, one of the participants felt that their children were not eating healthily, watched too much TV, and needed to do more constructive activities. Although participants reported that they were aware of their behavior, most said that wearing the camera did not modify it. Two participants said that wearing the camera did affect their behavior: 1 said that they made more of an effort to eat with their child, and the other said that they tried to have meals at the table instead of while watching TV.

Participants generally reported that they were less aware of the camera as time went on. All participants reported that their children were interested in the camera, although this lessened with time. One participant said that their child was initially shy around the camera, and 1 thought that their children behaved better than usual.

Overall, participants were generally positive about the camera. A third of the participants said that they would be happy to wear the camera for a longer period of 1 to 2 weeks; the remaining participants felt that 4 days was sufficient. All participants felt that the SenseCam may be helpful to families that need to change aspects of their behavior or household routine.

Table 3. Validity estimates for the home environment features (N=15).

Home environment feature	Intraclass correlations (95% CI)	Kappa (95% CI)	% Agreement
Food availability			
Fresh fruit[a]	—	__[b]	100
Tinned fruit	—	__[b]	60
Dried fruit	—	0.39 (0.06 to 0.72)	67
Frozen fruit[a]	—	__[b]	80
Fresh vegetables[a]	—	__[b]	93
Tinned vegetables	—	0.12 (–0.11 to 0.35)	53
Frozen vegetables	—	0.11 (–0.09 to 0.30)	40
Savory snacks[a]	—	0.45 (0.04 to 0.87)	73
Sweet snacks	—	0.13 (–0.07 to 0.32)	33
Confectionery	—	0.31 (–0.07 to 0.69)	60
Fruit juice[a]	—	0.59 (0.16 to 1.01)	80
Squash[a]	—	0.51 (0.06 to 0.97)	80
Fizzy drinks	—	0.19 (–0.35 to 0.72)	73
Smoothies[a]	—	0.44 (–0.17 to 1.06)	87
Skimmed/semi-skimmed milk[a]	—	0.47 (0.07 to 0.88)	80
Full-fat milk[a]	—	0.73 (0.41 to 1.04)	87
Food variety			
Fresh fruit[a]	0.43 (–0.09 to 0.76)	—	—
Tinned fruit	__[b]	—	—
Dried fruit	0.19 (–0.34 to 0.63)	—	—
Frozen fruit	__[b]	—	—
Fresh vegetables[a]	0.72 (0.35 – 0.90)	—	—
Tinned vegetables	0.28 (–0.25 to 0.68)	—	—
Frozen vegetables	0.00 (–0.49 to 0.50)	—	—
Savory snacks	0.37 (–0.15 to 0.73)	—	—
Sweet snacks[a]	0.46 (–0.04 to 0.78)	—	—
Confectionery	0.38 (–0.14 to 0.74)	—	—
Food displayed			
Any fruit[a]	—	__[b]	93
Ready-to-eat vegetables[a]	—	__[b]	87
Savory snacks[a]	—	__[b]	100
Sweet snacks	—	–0.19 (–0.40 to 0.02)	67
Confectionery[a]	—	–0.07 (–0.19 to 0.05)[c]	87
Fruit juice[a]	—	__[b]	100
Squash[a]	—	0.76 (0.26 to 1.26)	93
Fizzy drinks[a]	—	__[b]	93
Smoothies[a]	—	__[b]	100

Home environment feature	Intraclass correlations (95% CI)	Kappa (95% CI)	% Agreement
Family meals			
Breakfast[a]	—	—[b]	100
Lunch[a]	—	—[b]	83
Dinner[a]	—	0.63 (–0.09 to 1.35)	92
Child eating while watching TV			
Breakfast	—	—[b]	77
Lunch[a]	—	—[b]	92
Dinner[a]	—	0.63 (–0.16 to 1.41)	92
Snacks	—	0.10 (–0.36 to 0.57)	64
Activity facilities			
Garden[a]	—	0.67 (0.26 to 1.07)	87
Garden equipment[a]	—	0.63 (–0.03 to 1.28)	92
Household media equipment			
Number of TVs	0.97 (0.92 to 0.99)	—	—
Number of VCR/DVD players[a]	0.82 (0.55 to 0.94)	—	—
Number of computers	0.30 (–0.23 to 0.69)	—	—
Number of games consoles[a]	0.55 (0.08 to 0.82)	—	—
Presence of cable or satellite[a]	—	—[b]	100
Child's bedroom media equipment			
TV[a]	—	0.76 (0.27 to 1.25)	93
Computer[a]	—	—[b]	100
Console[a]	—	0.63 (–0.06 to 1.33)	93
Caregiver TV viewing (hours)			
Weekday[a]	0.55 (–0.13 to 0.88)	—	—
Weekend[a]	0.57 (–0.15 to 0.90)	—	—

[a] Feature has satisfactory validity.

[b] ICC was not calculated due to zero variance items or kappa could not be calculated due to cell counts equalling zero.

[c] There was just one yes response at the time of the HEI and one yes response captured by SenseCam (ppos was 0.00, but pneg was high [0.93]).

Discussion

Principal Findings

This study investigated whether a wearable camera can be used to examine the early obesogenic home environment and whether it is useful for validation purposes. The SenseCam captured all 54 home environment features but with varying detail. Features that were captured less frequently included tinned and frozen foods, sweet snacks, and satellite TV. It was not possible to fully capture mealtime and TV viewing behaviors due to there being a single wearer and a limited wearing period. Validity estimates were at least satisfactory for two-thirds of the home environment features. Lower agreement was reported for food variety (except for fresh vegetables) and the number of computers in the home. The SenseCam was generally acceptable to participants, although there were reservations.

While the findings indicate that the SenseCam can be used to examine the obesogenic home environment, a primary issue is that what is captured depends on the actions of the wearer. Although this highlights the utility of the SenseCam as a behavioral measure, it also meant that it was often not possible to determine whether the SenseCam missed a particular feature or whether the feature truly was absent. For most cases of disagreement, a feature was reported at the time of the HEI but not captured by the SenseCam. This was particularly the case for tinned and frozen foods, sweet snacks, and media equipment (excluding TVs). It is possible that certain foods and media equipment were available in the home during the wearing period even though they were not captured.

Comparison With Prior Work

Bryant and colleagues [7] reported generally moderate to high agreement when using home visits to validate their Healthy Home Survey. Overall agreement was high for the presence of all food types, suggesting that the low agreement for some food types in our study may indeed have been due to the SenseCam missing this information. Agreement for food variety was also higher than reported in our study. However, lower values (ICCs) were reported for sweet (0.30) and savory (0.48) snack variety in their study, suggesting that some discrepancies in our study may be due to other reasons than the SenseCam missing information, such as natural changes in food availability. As in our study, agreement for the presence of a garden and play equipment was high. For the number of computers and game consoles, agreement was higher than in our study (65% and 73%, respectively). However, in our study, it was possible to capture eating and TV viewing behavior, with acceptable agreement given the limited wearing period.

There were some cases of disagreement where a feature was not reported in the HEI but was captured by the SenseCam. For example, 2 participants did not report fizzy drinks, but these were present during the wearing period. It is feasible that these differences were due to natural changes in food availability; however, it could also reflect some bias in responding during the HEI. Previous research comparing self-reports to SenseCam images have found that individuals may overestimate their activity levels [19] and underestimate their dietary intake [21]. To determine whether differences really were due to changes in food availability, it would have been useful to ask participants about their shopping habits during the wearing period.

It is noteworthy that the SenseCam captured fewer sweet snacks than were reported in the HEI while slightly more fresh fruit and vegetables were captured. Although this could be a chance finding, participants may have modified their access to certain foods in the home. However, it is not clear if any behavioral effect would result from wearing the camera, completing the interview, or both. A larger scale validation study could use counter-balancing to control for any potential order effects. Nevertheless, most participants said that although wearing the camera made them reflect about their home environment, they did not think that it affected their behavior. When behavior is habitual, behavioral responses are activated automatically [30].

Limitations

The large amount of data accumulated by the SenseCam is important to consider. Manual coding is time-consuming and errors can occur, although interrater reliability in this study was high. Automatic coding procedures for the home environment are needed, particularly if research uses longer wearing periods and involves multiple family members.

Another factor to consider is participant recruitment, as many families contacted in this study were not comfortable with the idea of wearing the camera. The families contacted had previously taken part in a survey-based study; therefore, although they agreed to be contacted for future studies, they may have been happy to take part only in other survey-based research. The sample size was small and comprised mainly white and university-educated participants, which limits our ability to generalize the findings.

Implications and Recommendations

Taken together, the findings suggest that the SenseCam may be particularly useful for assessing behavioral aspects of the home environment and understanding how individuals interact with their home environment more generally, while home visits may be needed to more rigorously assess the availability of food and media equipment. A future study could directly compare SenseCam images with the results of home visits.

Having a longer wearing period or having multiple family members wear a SenseCam might provide a more comprehensive picture of the home environment. Most participants felt that 4 days was sufficient, so some form of incentive might be needed for a longer wearing period. Offering an incentive may also encourage less motivated, harder-to-reach families to take part in future studies, and it may minimize data loss if participants are motivated to keep the camera on for longer. In this study, participants were asked to remove the camera whenever they went outside of the home environment to minimize the chance of certain ethical issues arising and because it wasn't necessary for participants to wear the camera outside. However, future research could have participants wear the camera outside of the home environment, as previous research has done [19,20], provided that certain ethical issues are taken into consideration. The SenseCam was considered unsuitable for young children to wear, although older children could wear one.

Using a device that can capture higher quality images would also benefit future research. Since the start of this study, the SenseCam has been superseded with newer models that can capture indoor images to a higher standard. Asking participants to clarify certain images may also help to minimize data loss.

Conclusions

This study found that a wearable camera can be used to examine and validate aspects of the obesogenic home environment. While the SenseCam can capture physical aspects of the home environment such as food availability, its added strength is in capturing behavior. An optimal validation procedure could use a combination of home visits and wearable cameras.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Home environment features as assessed in the Home Environment Interview.

[PDF File (Adobe PDF File), 54KB - jmir_v19i10e332_app1.pdf]

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Abbreviations

HEI: Home Environment Interview
ICC: intraclass correlation coefficient
pneg: proportion of negative agreement
ppos: proportion of positive agreement

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Original Paper

Reduction in Fall Rate in Dementia Managed Care Through Video Incident Review: Pilot Study

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Abstract

Background: Falls of individuals with dementia are frequent, dangerous, and costly. Early detection and access to the history of a fall is crucial for efficient care and secondary prevention in cognitively impaired individuals. However, most falls remain unwitnessed events. Furthermore, understanding why and how a fall occurred is a challenge. Video capture and secure transmission of real-world falls thus stands as a promising assistive tool.

Objective: The objective of this study was to analyze how continuous video monitoring and review of falls of individuals with dementia can support better quality of care.

Methods: A pilot observational study (July-September 2016) was carried out in a Californian memory care facility. Falls were video-captured (24×7), thanks to 43 wall-mounted cameras (deployed in all common areas and in 10 out of 40 private bedrooms of consenting residents and families). Video review was provided to facility staff, thanks to a customized mobile device app. The outcome measures were the count of residents' falls happening in the video-covered areas, the acceptability of video recording, the analysis of video review, and video replay possibilities for care practice.

Results: Over 3 months, 16 falls were video-captured. A drop in fall rate was observed in the last month of the study. Acceptability was good. Video review enabled screening for the severity of falls and fall-related injuries. Video replay enabled identifying cognitive-behavioral deficiencies and environmental circumstances contributing to the fall. This allowed for secondary prevention in high-risk multi-faller individuals and for updated facility care policies regarding a safer living environment for all residents.

Conclusions: Video monitoring offers high potential to support conventional care in memory care facilities.

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KEYWORDS

video monitoring; video review; mobile app; deep learning; fall; Alzheimer disease; dementia

Introduction

A fall is defined as an “unexpected event in which the participant comes to rest on the ground, floor, or lower level” [1]. Falls are the leading cause of both fatal and nonfatal injuries among people aged 65 and older, with estimated yearly direct medical costs of US $637.2 million for fatal falls and US $31.3 billion for nonfatal falls in the United States alone [2]. Incidence of falls in people with cognitive impairment is estimated to be twice that of cognitively intact older adults [3]. In nursing facilities, individuals with dementia fall 4.05 times per year on average versus 2.33 times per year for other residents [4]. Fall accidents represent the primary cause of Alzheimer disease–related hospitalizations, contributing to 26% of all hospitalizations in the United States [5].

Detecting a fall early and in an ongoing manner provides significant potential for reduced morbidity and mortality in patients and system-wide savings [6]. As 50% to 75% of elderly fallers experience recurrent falls [7-11], detecting the first fall and taking preventative action provides significant potential for reducing fall risk, fall-related injuries, and fall consequences at large [12]. A rapid detection of fall limits the long-lie (ie, the amount of time fallers spend lying on the ground), which has been shown to be a predictor of worse independent walking capacity and autonomy and longer length of hospitalization [10,13]. Real-time diagnosis of falls might result in a more accurate identification and care of direct fall-related injuries (eg, traumatic brain injury and orthopedic fractures) and in lowering short-term indirect consequences (eg, pressure sore, hypothermia, and phlebitis) as well as long-term fall-related consequences (eg, fear of falling again, loss of autonomy as a result of postfall restrictions, and social isolation) [14,15]. As a consequence, considerable research about fall prevention [16] has been conducted with a higher level of evidence for environmental modifications in the homes [17], management of symptomatic hypotension and depression [18], exercise programs in mobile seniors, and combined supplementation of vitamin D and calcium [19,20]. Over the past years, fall management has also become a key criterion of quality of care worldwide and in care facilities in particular [12,15,21-23].

A significant portion of recent health technology innovation regarding fall management has been driven by industry and has taken place in the commercial space. To date, the most well-known commercial solutions include wearable alert systems [24], which demonstrate limited success in dementia care because individuals forget or refuse to wear a device; nonwearable fall detection systems, which are based on radar and optical sensors, are under development but not commercially available in the United States yet [25] and have not demonstrated robustness through evidence-based medical studies [26]; fall mats and bed alarms, which are prevalent solutions in memory care [27] but suffer from high false alarm rates and are mainly targeting those residents who should never be walking independently; and accelerometer-based fall detection [28], which provides meaningful information about the biomechanical features of fall but fails to give a holistic and clinically useful picture of falls (including assessment of environmental hazards). Overall, none of these strategies allow care providers to identify globally how and why a fall occurs and thus leverage this information to enhance safety in residents and improve quality of care practice in the facility staff.

In this study, the video technology was used to review real-world falls in a single memory care facility, thus avoiding artificiality of simulated or acted falls carried out in a contained laboratory environment, as well as biased information about falls gathered from individuals’ recalling the fall or from administrative hospital record [29]. The extent to which video monitoring and fall review can impact quality of care practice and health outcomes is in fact a relatively new and unexplored field. The most relevant work on video monitoring of falls has been conducted by Robinovitch et al [30-33]. In part of that work, video recording was collected from cameras installed in common spaces of two Canadian long-term care facilities in charge of elderly residents over a period of 3 years. In a dataset of 227 falls captured for 130 individuals, the authors confirmed an increased fall incidence among residents with Alzheimer disease and identified the most frequent fall mechanisms in managed care facilities, including incorrect weight shifting (41%), trip or stumble (21%), hit or bump (11%), loss of support (11%), and collapse (11%) [30]. However, the video review process was not carried out with facility staff with the specific intention of identifying and removing any possible causes or providing obvious changes to the environment that staff could address. Another study conducting video monitoring recorded 25 falls in 17 elderly subjects in the lobby of a geriatric complex over 15 months. This group identified predominant causes of falls, including intrinsic factors (60%), environmental factors (36%), and behavioral factors (4%) but did not report any interaction with medical and paramedical staff either [34]. Thus, previous work in the field offers little insight into the effect of introducing cameras and how video review can impact fall rate and care practice.

A holistic approach of the fall management was used in this paper. The objective of the study was to analyze how continuous video monitoring and video review of falls occurring in common spaces and private rooms of residents living in a memory care facility can support best quality of care.

Methods

Design of the Study and Population

This study reports on an ancillary study that is part of a larger project called SafelyYou. SafelyYou aims at developing deep learning (a subfield of machine learning) algorithms for automated real-life real-time fall detection in nursing and memory care facilities (http://www.safely-you.com). This pilot observational study was carried out between July and September 2016. Falls were video-captured in residents 24 hours a day, 7 days a week, and the video recordings were provided to the facility staff for video review. The study took place in a memory care facility that is part of the Memory Care Community in California and of the Integral Senior Living network, in which residents reside in a supportive ecosystem. The facility offers 40 individual bedrooms with individual bathrooms and common indoor areas (2 living rooms, 2 eating areas, and kitchens and hallways) where residents are allowed to walk and spend time freely. Residents of this memory care facility have all been diagnosed with dementia (Alzheimer disease and related dementias), had a mean age of 79.4 years (standard deviation [SD] 3.2), and were predominantly female (71.4%) at the time of the study inclusion.

Outcome Measures

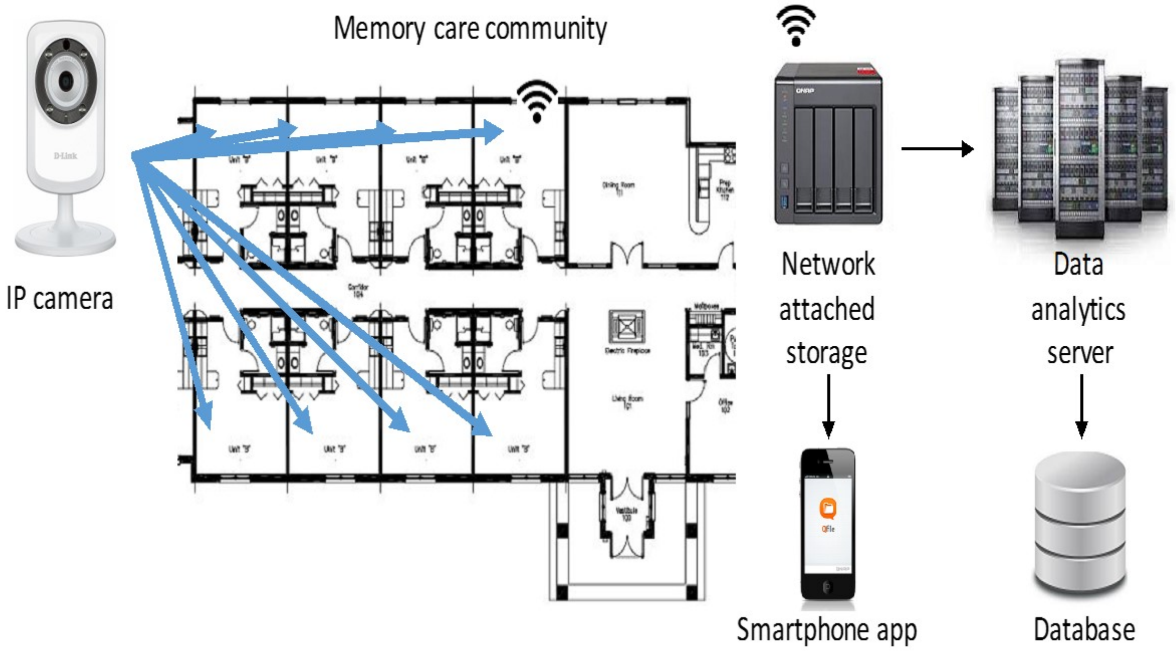
The primary outcome measure is the count of the total number of residents’ falls occurring in the video-covered areas of the facility over the 3-month period of video recording (allowing us to compute a fall rate per month). This count is further compared with the cases of falls that the facility health board independently reported in its daily routine care for each known occurrence of fall (ie, administrative report regardless of the video recording) 2 months before video deployment (baseline occurrence, May-June 2016) and during the 3 months of study (July-September 2016).

The secondary outcome measures qualitatively assess the use of video recording and replay possibilities for care practice. This entails (1) acceptability of video monitoring by residents and facility staff and use of fall review by facility staff to support care practice and quality of care; and (2) the analysis of falls and of fall-related injuries, leveraging video replay to depict intrinsic and extrinsic factors, and environmental circumstances contributing to the falls Acceptability and impact of video review on care practice were assessed through semidirected interviews carried out during bimonthly meetings with the care facility staff over the 3 months of study. An adapted version of the 4-point Hopkins Falls Grading Scale [35] was used to stratify fall severity in near-fall (Grade 1), fall with no need for medical examination (Grade 2), fall requiring medical attention (Grade 3), and fall requiring hospital admission (Grade 4). The fall events were also classified using the International Classification of Disease, Tenth Edition (ICD-10) published by the World Health Organization [36]. A description of what could be identified as cognitive-behavioral dysfunction by itself and as a response to the social-contextual stimuli of the living environment around the individual leveraging to video recording just before and during the fall was provided.

Equipment and Process

A total of 43 wall-mounted cameras were deployed in all common areas and private rooms of consenting residents and families in accordance with the following privacy and ethical guidelines. Figure 1 shows the off-the-shelf video-recording equipment used. Video data were transmitted using Wi-Fi to local network attached storage (NAS) devices. Facility Wi-Fi coverage was upgraded using off-the-shelf routers and range extenders to remove Wi-Fi dead zones. Video was maintained on the local NAS for 72 hours before transmitting to a university server where the complete video dataset was maintained encrypted on a password-protected server. A customized mobile device app was provided for viewing video from the previous 72 hours, developed by the makers of the NAS. The mobile device app for accessing the live video from each camera was provided as developed by the camera manufacturers. Cameras were configured to only record motion and to filter unneeded video. Software was developed to support video transcoding and uploading from the NAS to work around bandwidth limitations defined by the upload speed granted to the memory care facility through their Internet service provider. The specific equipment provided to the facility included the following: 43 DLink 932L IP camera, 2 QNAP 451 including network attached storage, 2 Netgear AC5300 Nighthawk X8 WiFi Router, and 2 Netgear Nighthawk AC1900 WiFi Range Extender. Data were securely stored. The research team had access to the data through a password-protected computer in locked laboratories that are part of virtual private networks.

Figure 1. Loop equipment, including Internet Protocol (IP) cameras, network attached storage, Wi-Fi, secured storage on the university server, and phone apps.



The videos of fall events that had been depicted by the research team were made available to be viewed by the executive director of the facility who would decide to discuss them with her staff. The meetings between the facility staff and research team were carried out twice a month during the 3 months of the study in a rather flexible way and using semidirected interviews. The main purposes of these meetings were as follows: (1) to be sure that no unanticipated issues or concerns with residents, surrogates, and/or staff arose and (2) to observe the use (or no use) of the videos and what were the changes in care practice that were reported. During these meetings, the research team asked about the use of the videos in a neutral way (ie, observing the potential uptake of the recording without pushing attitude). The main focus of the first meeting concerned the confirmation of the resident-surrogate dyads who had agreed to participate, as well as the questions from the executive director. The final meeting focused on the removal of all the cameras of the facility and discussed the practice changes that the video recording had potentially triggered.

Ethical Procedures and Privacy Concerns

Privacy and consent procedures were developed with support from the institutional review board (IRB) of the University of California, Berkeley (http://cphs.berkeley.edu/), and following guidelines from California Department of Social Services Community Care Licensing Division (CDSS-CCLD). Approval of the study protocol was obtained from the Committee for Protection of Human Subjects of University of California, Berkeley, before starting the study (CPHS protocol number 2015-11-8119). Residents living within the care facility showed severe cognitive impairment related to Alzheimer disease and related dementias. Their capacity to consent to research according to the legal standards of informed consent was altered. As a consequence, surrogate consent was required for this pilot study. The legally authorized representatives of the facility residents were informed at a town hall meeting that a study on fall prevention would occur at the facility and were invited to participate in its presentation with their relative. The legally authorized representatives of the facility residents were given oral and written information about the purpose of the study, procedures, risks, and benefits as listed in the consent form. Those who would like to participate signed the self-certification document to confirm they were the legally authorized representatives and were provided the informed consent document provided by the research team. The study was explained to the affected individuals living in the facility. If affected individuals provided assent, they would be included in the study. If they provided any verbal or nonverbal indication that they do not wish to have the camera in their room or object to any other part of the study, they would not be included. The legally authorized representative was the one who could say yes to the study, thus providing informed consent, but the resident retained the right to say no to the study at any time, thus providing assent. If at any time, individuals expressed verbal or nonverbal indication that they would like the camera removed, personnel would remove the cameras. Participants or legally authorized representatives who originally assented or consented to the study and would later revoke consent would also have cameras removed and video data destroyed.

In private bedrooms, cameras were located high-up in a corner in the bedroom but not in the bathroom and remained visible to the participants. When cameras were not unplugged, they would show a small red light when motion is detected in a room. A sticker was positioned on the participants' doors as a reminder to the residents, families, and facility staff that participants were being filmed in their private rooms. This physical sign on the door stating that video recording was in progress ensured that everyone entering the room was aware of the camera. Flyers that explained the goals of the research study, the length of the study, the use of wall-mounted cameras, and the generic email address and centralized phone number were positioned in several locations of the facility. The generic study email address and the centralized phone number were provided to respond to any withdrawal wish, expression of interest, or questions. Cameras were also equipped with an explanatory tag that described the goals of the research, the use of wall-mounted cameras, and the possibility to unplug the camera at any time and the way to do so, as well as the name of the principal investigator, the generic study email address, and the centralized phone number to be used in case of concerns. The guidelines from CDSS-CCLD were followed for the study protocol. Whereas the federal law requires that all residents have the right to privacy, the CDSS guidelines for use of the video surveillance state that recording in a common area does not require a waiver because there is no expectation of privacy in common areas (such as eating areas) [37]. Cameras were finally removed shortly after the end of the study.

A registered nurse was hired specifically for the study and was available to answer concerns from the participants, the families, and the facility staff, which could emerge before and during the study, including potential withdrawal from the study. If the participant or his/her legally authorized representative expressed willingness to withdraw from the study, they were to inform either the facility staff who would transmit this information to the nurse or the research team by directly using the generic study email address and/or the centralized phone number generated for the study. The possibility of participants' withdrawal from the study at any point was mentioned at both oral and written levels during information and inclusion sessions. As mentioned on the camera laminated tag, the equipment could also be turned off at any time by simply unplugging it from the wall outlet. If the camera had been unplugged for over 24 hours, the team would figure out whether the participant or surrogate forgot to plug the camera back in or whether he/she would like to have the camera removed for the rest of the study. If a participant or his/her surrogate wished to withdraw the study at any time, all his/her video data would be destroyed. Video segments found improper by the review board were referred to the dementia care nurse of the team in case of content of potential physical or sexual abuse, neglect, sexual activity, or other actions that could imply abuse if taken out of context and other incriminating behaviors. Before deleting data, the dementia care nurse was responsible for determining whether the matter should be taken to facility management or to adult protective services. In accordance with Californian legislation [37], facility management granted permission to place cameras in common areas. Following California state guidelines [37], audio recording was disabled and signs were posted visibly on the door of each private room in which video recording occurred. Before publishing video or pictures in any way, signatures of individuals contained in the videos or their surrogate decision makers were obtained on media release written forms, allowing for public release of the specific videos in question. Faces were blurred on the video images to minimize identifiers in some cases.

Results

Participation and Acceptability of Video Monitoring

A total of 15 out of 38 resident-family dyads (40%) were able to attend the information meeting about the research study, out of which 10 gave oral and written consent and volunteered for the research, and 5 did not wish to participate. Accordingly, the video recording in private rooms included 10 residents, and video recording in common spaces included the total of 38 residents in July and August, followed by 36 residents in September (because of a slight dip in facility occupancy rate).

No impact of the video deployment, recording, and review on the daily routine of the residents and professional caregivers was reported over the 3-month period. At the end of the study period and based on the preliminary results and care experience, the project partner of memory care facilities of Integral Senior Living network agreed to expand the protocol to 14 facilities.

Fall Review Utilization by Facility Staff

Bimonthly follow-up interviews showed that, in the first 7 weeks of the study, no formal video review was carried out by facility staff despite the fact that video recordings from the previous 72 hours were easily available through secured mobile devices to facility management. Facility management reported hardly ever using the video feeds during this time because of the numerous other challenges faced with operating a memory care facility and the little obvious value granted to the video so far. After 7 weeks, a particularly severe fall incident was recorded during daytime in which the resident was lying on the ground for almost 3 hours without receiving assistance. In accordance with procedures approved by the IRB of the university, this incident was reported to facility management. After reviewing this fall, facility management showed increased interest in reviewing other falls, and the mobile device app provided to review videos proved to be accessible and easy to use to facility staff, who subsequently gained familiarity with it. Further interviews revealed that facility management found video replay useful to grade the severity of the injury and eventually screen patients in the future for external referral to the emergency unit in case of severe injury. In addition, interviews revealed that facility management carried out preventative care interventions, which they believed would address some of the causes of future falls. These preventive actions first included moving furniture and changing room layout based on potential tripping hazards and falls (noticed from videos). Second, changes to care policy that included additional checking on high-risk residents every hour instead of every 2 hours at night were instated following the review of the data.

Falls Count Over Facility Space and Study Period

During the 3-month intervention period, a total of 26 falls were reported in routine conventional care by facility staff for the whole facility (in both video-covered and video-uncovered areas; Figure 2). A total of 16 falls were video-captured and recorded in video-covered areas including 3 falls that were neither witnessed nor recorded by facility staff (Figure 2). In these 3 falls, the resident stood up alone after the fall (as shown in the pictures), and neither care nor administrative report was provided for these cases that would have remained silent falls if not video-witnessed. In other words, without the system, the falls and potential injuries would have gone unnoticed. Among these 16 video-captured falls, 10 happened in common spaces (in a single multi-faller woman) and 6 in private bedrooms (in 4 men fallers) (Table 1). The 13 video-uncaptured falls that were reported in conventional care happened in private rooms of individuals who had not volunteered for the research.

In the 2 months before the video deployment, a total of 18 falls were administratively reported (11 in May and 7 in June), providing a prevideo intervention facility baseline fall rate of a mean of 9 falls per month. An expected facility fall rate adjusted for the number of residents of 12.7 and 12 falls per month was reported for comparison purpose in Figure 3. The fall rate was shown to decrease over the 3-month period from a mean 12 falls per month (average in July and August) to 2 falls during the last month of the study, that is, September 2016. Figure 3 shows that the overall fall rate in this community was 79% of the national average for the 4 months before review and 17% of the national average in the month following review.

Fall Review for Screening Fall Risk Patterns in Residents

As summarized in Table 1,10 out of 16 (62%) falls happened in a multi-faller woman (subject 1), showing quite similar repetitive patterns of falls in common spaces during daytime. Conversely, 6 out of 16 falls (38%) occurred in the residents' bedrooms and half occurred at nighttime. One resident had a moderate head injury (subject 4; Figures 4-7) but stood up alone, and the fall remained unnoticed by the facility. For the 3 other bedroom fallers (subjects 2, 3, 5), a routine diagnosis and report of falls were carried out, as all 3 residents were found lying on the ground. However, the circumstances and natural history of these falls remained unwitnessed and unknown to the staff until they retrospectively video-witnessed why and how the residents fell. Among these 16 falls, biomechanical causes related to preexisting conditions were identified in terms of incorrect shift of body weight, gait disturbances, loss of external support, or motor deficit in legs. According to the Hopkins scale, falls were, on average, moderately severe (mean 2.5; min 2, max 4), but 83% of bedroom falls would have required medical attention (Table 1). Falls occurred predominantly during transfer activities (63%; Table 1). As shown in Table 1 and Figures 4-7, understanding the interaction of the resident with his or her living environment just before, during, and after the fall revealed that extrinsic factors were contributing to the fall in all bedrooms. In addition, dysfunction of cognitive-behavioral processing could be assessed in terms of lack of judgment on self-deficits, poor awareness of dangerous transfer situations and of dual-tasking activities, over-reactivity to external distractors or inattention, and impulsivity (Table 1).

Figure 2. Fall count display over video-covered and video-uncovered areas.

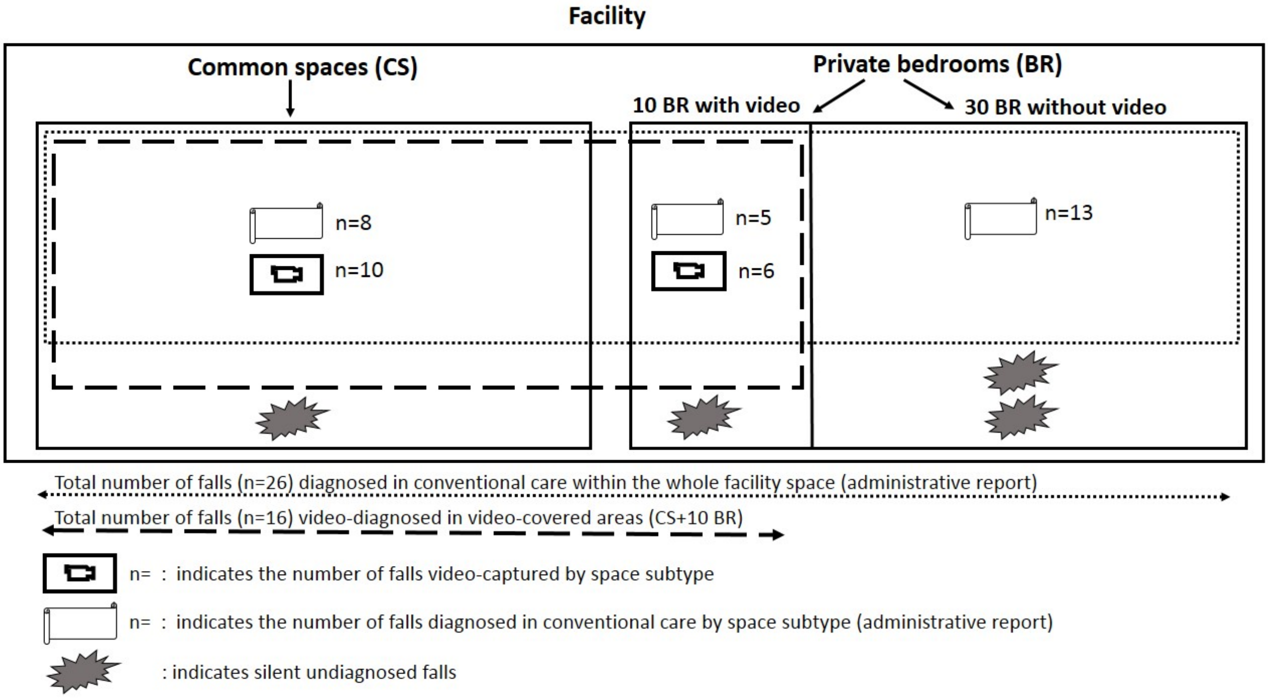


Figure 3. Fall rate per month displayed over the 3-month study period.

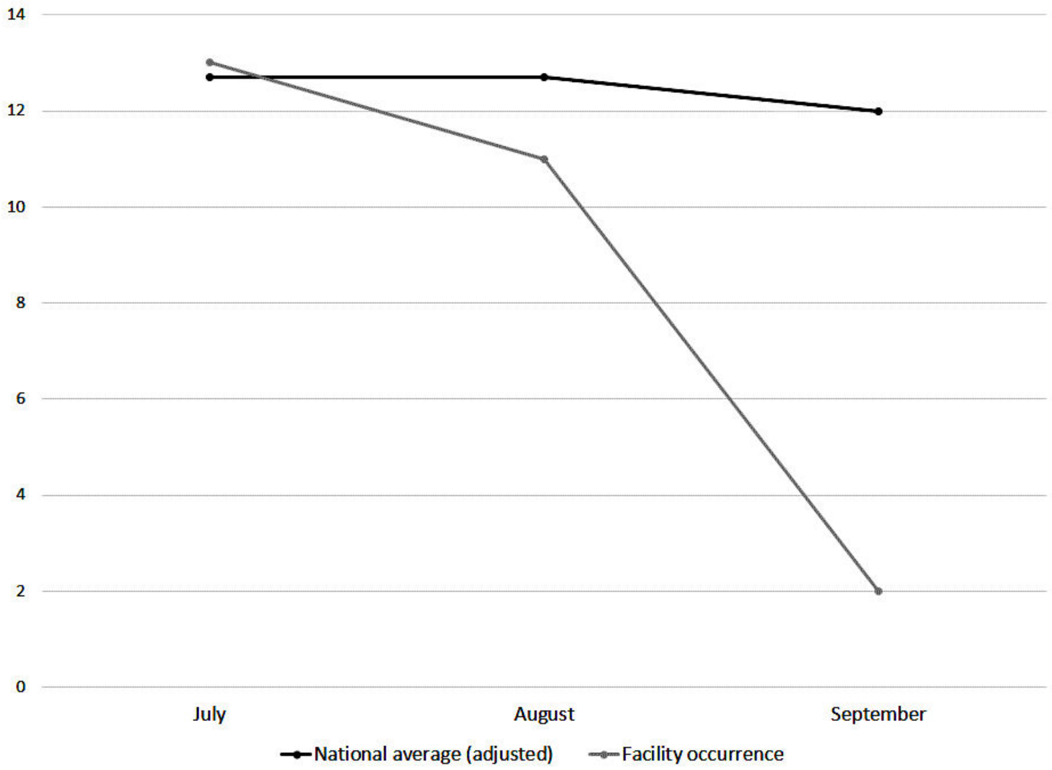


Table 1. Characteristics of falls in a sample of 16 falls collected in 5 individuals over a 3-month period.

Distribution			Severity			Fall circumstances		
Subject (S#)[a]and fall	Location	Time[b]	Body impact	Head injury	Severity grading	Activity performed (corresponding to ICD-10 code)[c]	Interaction with the living environment as a contributor to the fall: 1. extrinsic factor 2. cognitive-behavioral processing	Got up alone
S1 F								
#1	CS[d]	D	0	0	2	Transfer sit-to-stand while talking (W07[e])	No extrinsic factor identified Distraction/inattention in dual tasking (talking to caregiver when transferring)	0
#2	CS	D	0	0	2	Slipping from chair (W07[e])	No extrinsic factor identified	0
#3	CS	D	1	0	2	Walking with caregiver (W03[f], W04[g])	Extrinsic obstacle (other resident in wheelchair in the pathway) Impulsivity and aberrant behavior	0
#4	CS	D	0	0	2	Transfer sit-to-stand (W07[e])	No extrinsic factor identified	0
#5	CS	N	0	0	2	Transfer sit-to-stand (W07[e])	No extrinsic factor identified No anticipation/awareness of her purse blocking her leg	1
#6	CS	D	0	0	2	Slipping from chair (W07[e])	No extrinsic factor identified	0
#7	CS	D	0	0	3	Walking (W01[h])	No extrinsic factor identified Distraction	0
#8	CS	D	0	0	2	Transfer sit-to-stand (W07[e])	No extrinsic factor identified No anticipation/awareness of her purse blocking her valid hand	0
#9	CS	D	0	0	2	Transfer sit-to-stand (W07[e])	No extrinsic factor identified No anticipation/awareness of her purse blocking her valid hand	1
#10	CS	D	1	0	3	Moving with wheelchair (W05[i])	No extrinsic factor identified Impulsivity	0
S2 M								
#1	BR[j]	D	1	0	3	Transfer stand-to-sit while dressing (W06[k])	Environmental hazard (messy bed) Environmental distractor (door open-closed) Poor judgment of the dangerous situation (dual tasking, no appraisal of distance, inappropriate sitting)	0
S3 M								
#1	BR	N	0	0	3	Walking/loss of support (W03[f], W06[k])	Environmental stressor (subject pushed from other resident's bed) Inappropriate use of mobility aid (rollator) Aberrant behavior/confusion	0
#2	BR	D	0	0	3	Transfer stand-to-sit (W08[l], W06[k])	Environmental hazard (grabbing clothes on the floor) Poor awareness of his deficits and of the dangerous situation	0

Distribution			Severity			Fall circumstances		
Subject (S#)[a]and fall	Location	Time[b]	Body impact	Head injury	Severity grading	Activity performed (corresponding to ICD-10 code)[c]	Interaction with the living environment as a contributor to the fall: 1. extrinsic factor 2. cognitive-behavioral processing	Got up alone
#3	BR	D	1	0	4	Transfer sit-to-stand (W06[k])	Environmental hazard (slippery bed blanket/messy bed) No anticipation of the dangerous situation No call for assistance (3 hours—time spent lying on the ground) Confusion	0
S4 M								
#1	BR	N	1	1	3	Transfer stand-to-sit (W06[k])	Environmental hazard (slippery bed sheet/messy bed and poor lighting) Lack of judgment Inappropriate transfer strategy and use of rollator Poor appraisal of distance	1
S5 M								
#1	BR	N	0	0	2	Transfer lay-to-sit (W06[k])	Environmental hazard (slippery bed sheet/messy bed) Poor awareness of deficits Impulsivity	0

[a] F indicates female and M indicates male.

[b] D indicates day and N indicates night.

[c] International Classification of Diseases, Tenth Edition (ICD-10).

[d] CS: common space.

[e] W07: fall involving chair.

[f] W03: other fall on same level due to collision with, or pushing by, another person.

[g] W04: fall while being carried or supported by other persons.

[h] W01: fall on same level from slipping, tripping, and stumbling.

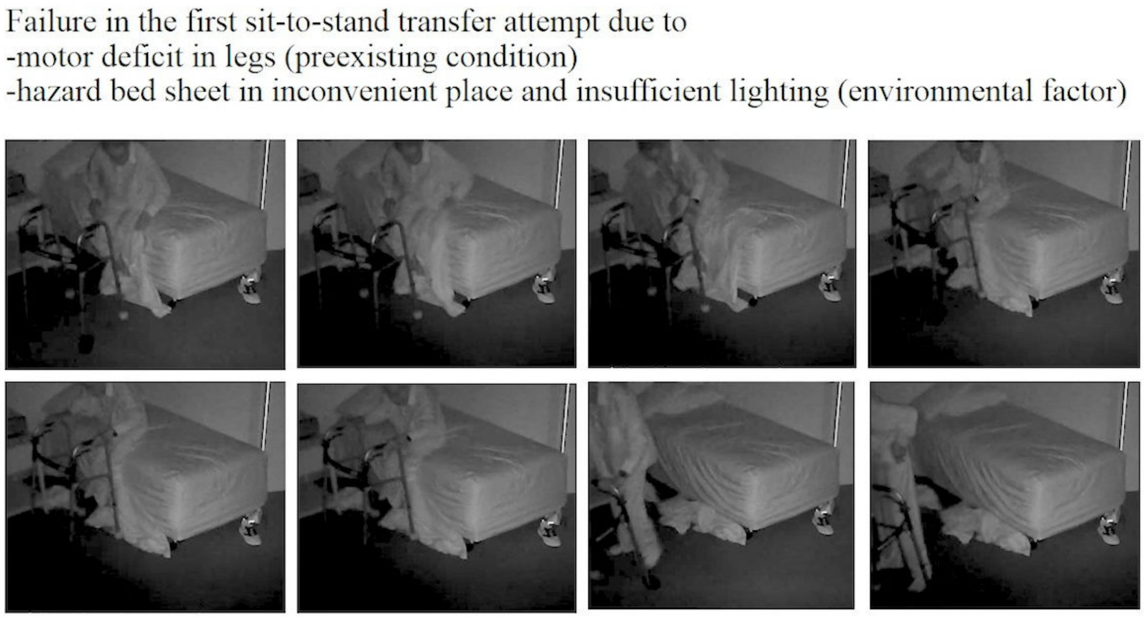
[i] W05: fall involving wheelchair.

[j] BR: bedroom.

[k] W06: fall involving bed.

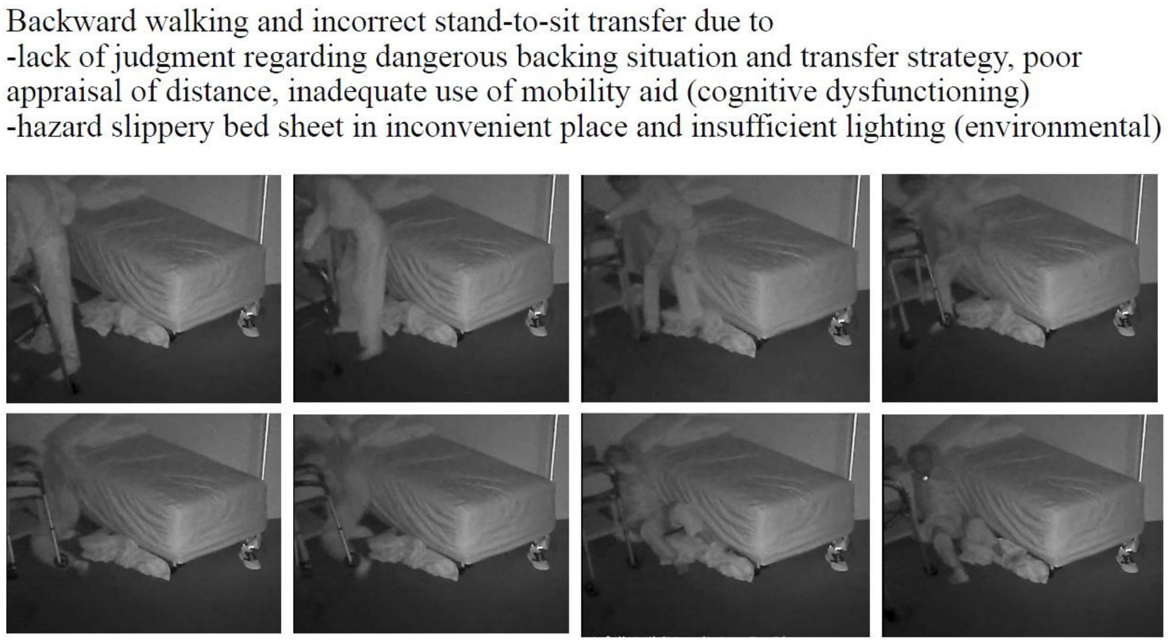
[l] W08: fall involving other furniture.

Figure 4. A video-witnessed pre-fall activity (subject 4, in his private bedroom). Reproduced with permission of the individual and his family.



Failure in the first sit-to-stand transfer attempt due to
-motor deficit in legs (preexisting condition)
-hazard bed sheet in inconvenient place and insufficient lighting (environmental factor)

Figure 5. A video-witnessed backward fall event (subject 4, in his private bedroom). Reproduced with permission of the individual and his family.



Backward walking and incorrect stand-to-sit transfer due to
-lack of judgment regarding dangerous backing situation and transfer strategy, poor appraisal of distance, inadequate use of mobility aid (cognitive dysfunctioning)
-hazard slippery bed sheet in inconvenient place and insufficient lighting (environmental)

Discussion

Principal Findings

This observational study brings evidence that continuous video monitoring and video review of falls of residents in a memory care facility can support best quality of care. It was found in this pilot study that continuous video monitoring in common spaces and private bedrooms of such care facility and fall review were both feasible and acceptable by facility staff after a certain adoption period. Although these preliminary results need to be confirmed with a larger number of facilities and a larger sample of participants and fall cases in future studies, fall review appears as a valuable health care procedure that might contribute to improved safety in residents and yield better quality of care in facility practice. Fall review provides a unique access to the unpredictable unwitnessed history of a fall, thus supporting screening for the severity of the fall and fall-related injury at the acute phase. Video replay might also allow for secondary prevention in high-risk multi-faller residents with cognitive disorders and, more broadly, for updated facility care policies and preventative actions regarding the living environment of all residents.

Although the fall rate is quite high in long-term care facilities [30], the difficulty to capture real-world fall data is now widely acknowledged and the research in the field is scarce [28]. To the best of our knowledge, this study is the first to report on video recording and review in both common and private spaces (ie private bedrooms) of a health care facility. Although another group in Canada has been evaluating a larger sample of 227 falls in two care facilities in common spaces only [30], a recent study investigating administrative records about 70,000 falls in 528 German long-term care facilities reported that 75% of falls occur in residents' rooms [38]. Bearing in mind the major issue of privacy and intrusiveness of health technology in private spaces [39], the results of this study point out the advantages of investigating falling patterns in private bedrooms where most of silent and severe falls were captured (if the multi-faller woman [subject 1] would be excluded). Although the Hawthorne effect has been described (ie, individuals modifying their behavior in response to their awareness of being observed) [40], facility staff did not report orally any such secondary effects in residents or in professional caregivers. However, it must be noted that only falls were of interest in this study, and other behaviors and behavior changes related to the presence of video recording were not studied here. The interviews showed that after an adoption period, facility staff began to incorporate the video review in their traditional care practice during regular staff care meetings of the final month. Implementation of video review triggered off policy changes and practice improvement (additional safety rounds for high at-risk residents and environmental changes when situational factors had been identified as key contributors of falls), which might account for the drop in fall rate during the final month of the study. In that perspective, these preliminary results contrast with other health technologies, such as bed alarms, that did not show a decrease in the incidence of falls in hospitalized patients [27]. Interestingly, two-thirds of falls occurred during transfers of any type that confirms [30] that professional caregivers should pay more attention to dangerous transition activity periods. This also raises the question of the correct benefit-risk trade-off, whether to let at-risk residents stay active independently (but then lowering safety) or be overly protective by restricting their activities (but then precipitating their loss of autonomy) [41]. Regarding repeated falls of subject S1, a wheelchair was introduced by facility staff at some time point during the study, probably because of her repeated falls. Whether the introduction of the wheelchair was related to the video monitoring remained unknown. However, this preventative strategy was not fully successful as it appeared that she fell from her wheelchair also (fall #10), most probably in relation to her neurological disorders. Finally, although not observed in this study, environmental modifications such as compliant flooring [42] or usage of video to train caregivers about at-risk situations [23] have also been reported to manage and prevent falls and ultimately enhance quality of care in care facilities.

The video footage gave access to unrivaled data that were explored from a multidisciplinary perspective, thanks to the combination of the information gathered during the meetings with the facility staff and the analyses of the videos carried out by the researchers. A first finding is that rapid postfall review provides a unique access to the ever-unpredictable "unwitnessed" hidden and silent event of the fall. Access to the natural history of the fall is all the more challenging because individuals suffering from cognitive impairment including memory loss are usually unable to recall the fall [43]. Video capture provides an exclusive support to diagnose the fall (in case of autonomous lift from the floor; Figure 7), to investigate fall-related injuries (given fall direction and body impact), and for grading the severity of the injury requiring further paramedical and/or medical examinations (high-speed falls with traumatic injury for instance; Figures 5 and 6). Traumatic brain injury in particular is one of the most severe and frequent related injury (with an estimated frequency of 33% to 37% in falls [44]). Although the video review was not used in real time in this pilot study, the use of the 4-point Hopkins Falls Grading Scale [35] suggests that video could be a rapid and efficient screening tool to categorize residents requiring either direct emergency referral or in-facility nursing checking or even just regular routine supervision. Furthermore, severity screening and fall anamnesis could be used both in-place and remotely to support decision making of health professionals. Although prior studies have investigated in detail the benefits of video capture for understanding the biomechanical features of falls [30-33], this study suggests that such an assistive health technology tool could efficiently complement (not replace) existing routine care [45] in some care settings. If integrated into a tele-care loop, video reviews of falls clearly offer benefits for patients in terms of better diagnoses of fall-related injuries [45]. Although not documented yet in terms of cost-effectiveness analysis, such a technology-assisted care raises major public health and economics issues in terms of cost savings and better care organization in nursing facilities: more efficient allocation of human resources within facilities could be further discussed, and unnecessary external referral to the emergency unit could be spared, or, reverse, more fall-related comorbidities could be cared for early [2,16]. Given the aging population, the high cost of Alzheimer disease (the single most expensive disease in the United States with an estimated yearly US $236 billion direct costs and US $221 billion indirect costs [5]), and the growing number of care needs in memory care facilities, video-enabled technology avoiding time-consuming and costly black-sighted exploration such as total body scan in case of postfall confusion, as well as hospitalizations and unanticipated comorbidities, could be of great interest for health regulators [46].

This study makes it also challenging to analyze the complex multifactorial falling patterns through video in the particular perspective of cognitively impaired older adults. Factors that contribute to the risk of falls in patients have traditionally been classified as intrinsic (individual predisposition), extrinsic (environmental hazard), and situational (related to the activity being done) [47-51]. These factors have to be addressed to maximize primary and secondary prevention of falls, a major public health and clinical issue (PubMed identifies 5048 papers published on [fall] in 2016), despite a substantial lack of standardization in fall management [16]. Although the impact of environmental modifications on falls and fall-related injuries has been difficult to measure [17] , the findings of this study reinforce recent major studies that showed that home-safety assessment and modifications impacting extrinsic factors reduce falls by 19% to 26% [20,52]. The personalized room-safety modifications (ie, tailored interventions aiming at modifying extrinsic risk factors in the bedrooms of residents) that the facility board reported after video review could account for the drop in fall rate observed in the last month of the study.

However, it must be acknowledged that the persistence of the low fall rate over time was not measured (as the study was over after 3 months) and that residents' turnover might affect fall rate differently in the future. Nevertheless, environmental modifications, one of the four prevention pillars identified by the World Health Organization to prevent falls aside from preventative actions targeting behavioral, biological, and socioeconomic risk factors [21], should be now systematically addressed in health care settings [22,15].

As previously stated, a fall is usually multifactorial and happens as a result of a complex interaction between the individual and his or her living environment [34]. An additional interesting question raised by this research is to find out whether part of cognitive processing and cognitive-behavioral dysfunction before, during, and after the fall can be observed through video review and thus be potentially addressed in the perspective of secondary prevention. Although studies about falls in dementia are numerous, only few authors approached the cognitive component during the falling process and rather recently [50-57]. The St Louis OASIS study classification allocated three out the 24 items to cognition (global cognitive impairment, visual-perceptual impairment [ie, misperceiving the environment], and distraction) and categorized them into the intrinsic factor class. The main research group in the field of video monitoring of falls [17] investigated the falling process in various population, including elderly with and without dementia, and put its focus mainly on the level of functional and biomechanical features; this group studied in detail fall stages (initiation, descent, and impact) and landing configuration and fall direction and addressed causes in terms of cause of imbalance, activity at time of the fall, gait, balance, and motor and functional dysfunction. This group briefly discussed in one of its papers the fact that the cognitive status and psychological state could be a contributing factor to falls [51]. Although no audio was recorded (that could give us more data on behavioral-cognitive disorders), the existing data suggest that part of cognitive-behavioral dysfunction as a particular risk factor can be observed on video footage. The video review might suggest that cognitive-behavioral dysfunction (and executive dysfunction in particular), a major contributor of fall in dementia [4,53,54], can also be partially observed in some cases, where lack of judgment and poor awareness of the danger, poor appraisal of self-deficits and of distances, impulsivity, inattention, and over-reactivity to external distractors in the environment are observable. However, these assumptions about neurocognitive observations need to be confirmed over a larger number of video recordings of falls and should include multiple raters' assessment in the future. Also, other extrinsic and intrinsic factors such as the lighting variation or the fatigue of the individuals should be taken into account as part of the multiple factors that might account for the fall. This proposed holistic framework that includes video observation of cognitive-behavioral dysfunction within its interaction with the living and social environment of individuals might reinforce recent findings documenting that executive dysfunction is strongly associated with multiple falls [53,55] and that cognitive training (apart from motor and gait training) is an underexplored but resourceful approach in reducing falls [56,57]. More attention when reviewing videos of falls should be paid in the future to the complex interaction between cognitive-behavioral responses and the social-contextual stimuli of the living environment just before the fall.

Figure 6. A video-witnessed post-fall recuperation (subject 4, in his private bedroom). Reproduced with permission of the individual and his family.

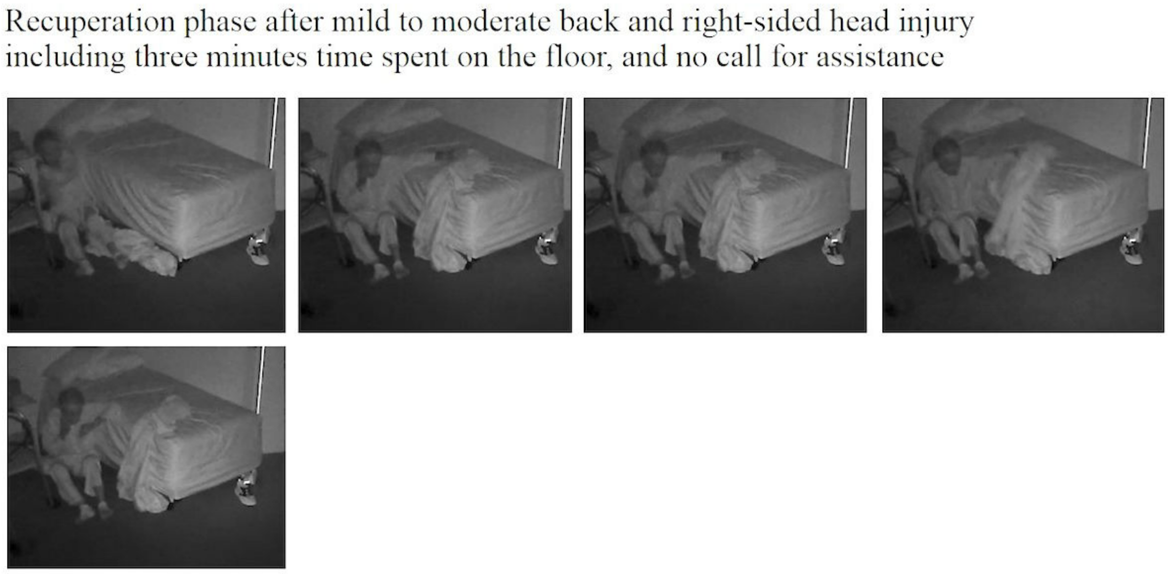


Figure 7. A video-witnessed post-fall activity (subject 4, in his private bedroom). Reproduced with permission of the individual and his family.

Limitations and Recommendations

This study needs to be replicated and results confirmed over a larger sample size of individuals and memory care facilities and over a longer period of time to control for size effect, to measure long-lasting effects, and to allow for meaningful examination of the relation between decrease in fall rate and the proposed intervention. Recommendation for future research include (1) upgrading computational deep-learning algorithms to provide an automated diagnosis (or assumption) of real-time fall, as well as an at-risk screening scale estimating the fall risk in every resident, thanks to an automatized set of video-based biomarkers; (2) measuring time spent lying on the floor (time-to-event between the fall and caregiver intervention); (3) conduction of further studies (if possible randomized) comparing conventional care with real-time utilization of an interactive assistive video diagnostic of falls; (4) proposing a cost-effectiveness analysis of using such technology in memory care facilities; (5) conducting interviews within focus groups using medical anthropology approaches to get a deeper understanding about professional caregivers' perspective on the video monitoring; (6) increasing knowledge about fall epidemiology and falling patterns regarding cognitive functioning of the individuals in particular (including distinct pathologies such as Alzheimer disease, Parkinson disease, Lewy body disease, and frontotemporal dementia); and (7) deploying and testing the device in other settings such as individual homes.

Conclusions

Falls and fall-related injuries are frequent and potentially preventable causes of morbidity, functional decline, and increased health care use and mortality among individuals suffering from Alzheimer disease and related disorders. The findings of this study highlight the potential of video-monitoring deployment to support fall diagnostic and fall-related injuries and suggest that video review can have a positive impact on quality of care in memory care facilities. Given the growing demand for assisted living in elderly and persons with dementia, video monitoring appears as a promising assistive tool to support health care organizations and possibly complement existing conventional care for both detection and prevention of falls. But more data are needed to validate that the fall rate in managed care facilities can be reduced and safer care provided through interactive video review of falls.

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Conflicts of Interest

None declared.

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Abbreviations

CDSS-CCLD: California Department of Social Services Community Care Licensing Division
ICD-10: International Classification of Disease, Tenth Edition
NAS: network attached storage
SD: standard deviation

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Review

Understanding Monitoring Technologies for Adults With Pain: Systematic Literature Review

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Abstract

Background: Monitoring of patients may decrease treatment costs and improve quality of care. Pain is the most common health problem that people seek help for in hospitals. Therefore, monitoring patients with pain may have significant impact in improving treatment. Several studies have studied factors affecting pain; however, no previous study has reviewed the contextual information that a monitoring system may capture to characterize a patient's situation.

Objective: The objective of this study was to conduct a systematic review to (1) determine what types of technologies have been used to monitor adults with pain, and (2) construct a model of the context information that may be used to implement apps and devices aimed at monitoring adults with pain.

Methods: A literature search (2005-2015) was conducted in electronic databases pertaining to medical and computer science literature (PubMed, Science Direct, ACM Digital Library, and IEEE Xplore) using a defined search string. Article selection was done through a process of removing duplicates, analyzing title and abstract, and then reviewing the full text of the article.

Results: In the final analysis, 87 articles were included and 53 of them (61%) used technologies to collect contextual information. A total of 49 types of context information were found and a five-dimension (activity, identity, wellness, environment, physiological) model of context information to monitor adults with pain was proposed, expanding on a previous model. Most technological interfaces for pain monitoring were wearable, possibly because they can be used in more realistic contexts. Few studies focused on older adults, creating a relevant avenue of research on how to create devices for users that may have impaired cognitive skills or low digital literacy.

Conclusions: The design of monitoring devices and interfaces for adults with pain must deal with the challenge of selecting relevant contextual information to understand the user's situation, and not overburdening or inconveniencing users with information requests. A model of contextual information may be used by researchers to choose possible contextual information that may be monitored during studies on adults with pain.

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KEYWORDS

systematic review; pain; technology; patient monitoring; ubiquitous and mobile computing

Introduction

Monitoring involves repeated study of a question that requires collecting data [1] in real time [2]. Patient monitoring technology aims to manage, control, and treat patients while collecting information from their environment [3]. The number of health monitoring apps has increased in recent years because they may reduce health care costs [4]. Since monitoring is done in the patient's environment, it is necessary to understand information about their situation or context. Context may be defined as "any information that can be used to characterize the situation of entities (ie, whether a person, place, or object) that are considered relevant to the interaction between a user and an application, including the user and the application themselves" [5]. The aim of context-aware computing is "to acquire and use data about the context of a device to provide services that are appropriate for the particular setting" [6]. For example, sensors may be used to gather contextual information, such as trunk posture [7,8], and provide feedback so users can improve their posture [9,10].

Pain is an "unpleasant sensory and emotional experience associated with actual or potential tissue damage" [11]. Pain is the most common diagnosis and problem that patients seek help for in hospitals [12]. Pain assessment is done primarily through subjective reports of patients, caregivers, and medical staff, but these reports have several limitations (eg, inconsistent metrics, reactivity to suggestions, and that they cannot be used with children or patients with certain neurological impairments) [13,14]. Additionally, pain is usually evaluated during a medical appointment [15], which means the physician does not have information about how the patient feels during his/her daily routine or how other factors may affect pain intensity. Therefore, patients may benefit from being monitored, since physicians may acquire a more complete and realistic assessment of the patient's situation. There is a large amount of possible contextual information that may be captured, so which data are relevant will depend on the particular situation being studied.

The aim of this work is to determine what types of technologies have been used to monitor adults with pain and propose a model of context information relevant to patients with pain. For this, a systematic literature review (SLR) was conducted, which is a means to identify, evaluate, and interpret all relevant research available for a research question or topic [16].

Methods

A SLR was conducted following Kitchenham and Charter's guidelines for performing SLRs [16]. The review protocol describes all steps performed during the review, reduces risk of bias, and increases its rigor, transparency, and repeatability [17].

Search Strategy

A systematic search of published literature was conducted to analyze recent research about context information related to pain and technologies used to monitor adults with pain. The search was conducted electronically during October 2015 in the following digital libraries: ACM Digital Library, IEEE Xplore Digital Library, ScienceDirect, and PubMed. These libraries were chosen to cover medical and technological aspects. This review was limited to articles published between 2005 and 2015, and duplicate citations across databases were identified and excluded using the Papers software.

The keywords were identified by consulting with medical specialists on appropriate words, manually selecting publications related to the subject, and analyzing frequently used words. The set of keywords was (context-sensitive, context-aware, physiological, environment*) AND (monitor*, sens*, measure*) AND (pain). The asterisk operator (*) indicates that there may be more letters after the root word. With these keywords, the search string was built using Boolean AND and OR operators. The search string was input into each database and the keywords were restricted to be found in the abstract and/or document title and published on or after January 1, 2005. In total, 1758 articles were retrieved, with the following distribution according to the consulted database: ACM (n=113), IEEE (n=55), ScienceDirect (n=548), and PubMed (n=1042).

It is relevant to note that other keywords were tested in the search engines, most notably the word "context." However, a large number of articles use "context" as the context of the study itself, so the words "context sensitive" and "context aware" were used instead.

Selection Criteria

A study was included in this review if it met the following inclusion criteria: (1) it presented a study of context information and pain; (2) the study was carried out on adults; (3) the article was peer reviewed and it was obtained from a journal, conference, or workshop; (4) it was published between January 1, 2005 and October 1, 2015; and (5) the study was published in English. Articles were excluded if they presented studies pertaining to animals, plants, robots, or children, or if the study was a literature review, mapping study, SLR, only presented as an abstract, or if it was not possible for any of the authors to download the full text of the article (no access through university subscriptions).

Selection Process

The included articles were selected through two steps. In the first step, title, publication venue, year of publication, and abstract for each article were collected in an Excel spreadsheet. Two reviewers assessed each publication (IR reviewed all articles; MM and PR each reviewed half) and applied the inclusion/exclusion criteria. Publications with two votes to include or exclude were automatically included or excluded. Publications with differing votes were sent to a third reviewer (VH), who analyzed it and determined whether the publication should be included or not.

In the second step, the primary and secondary reviewers (IR, CG) read the full text of a random sample of 10 publications. Each reviewer independently assessed whether the article should be accepted or rejected. Then, Cohen kappa was calculated, with a result of 1, which suggested that the inclusion/exclusion criteria were clear enough to be applied consistently [18]. Each reviewer also filled out a table of questions in Excel composed of 29 criteria, which were then discussed to clarify the questions and rewrite them if necessary.

Finally, an accelerated liberal approach was applied [19], in which the first reviewer (IR) read the full text of all the publications and rejected those that did not meet the inclusion/exclusion criteria (corresponding to 27 articles). CG validated the rejected publications. There were eight disagreements, which were solved by a third reviewer (CF), who analyzed them and determined whether the publication should be accepted.

Data Extraction and Quality Assessment

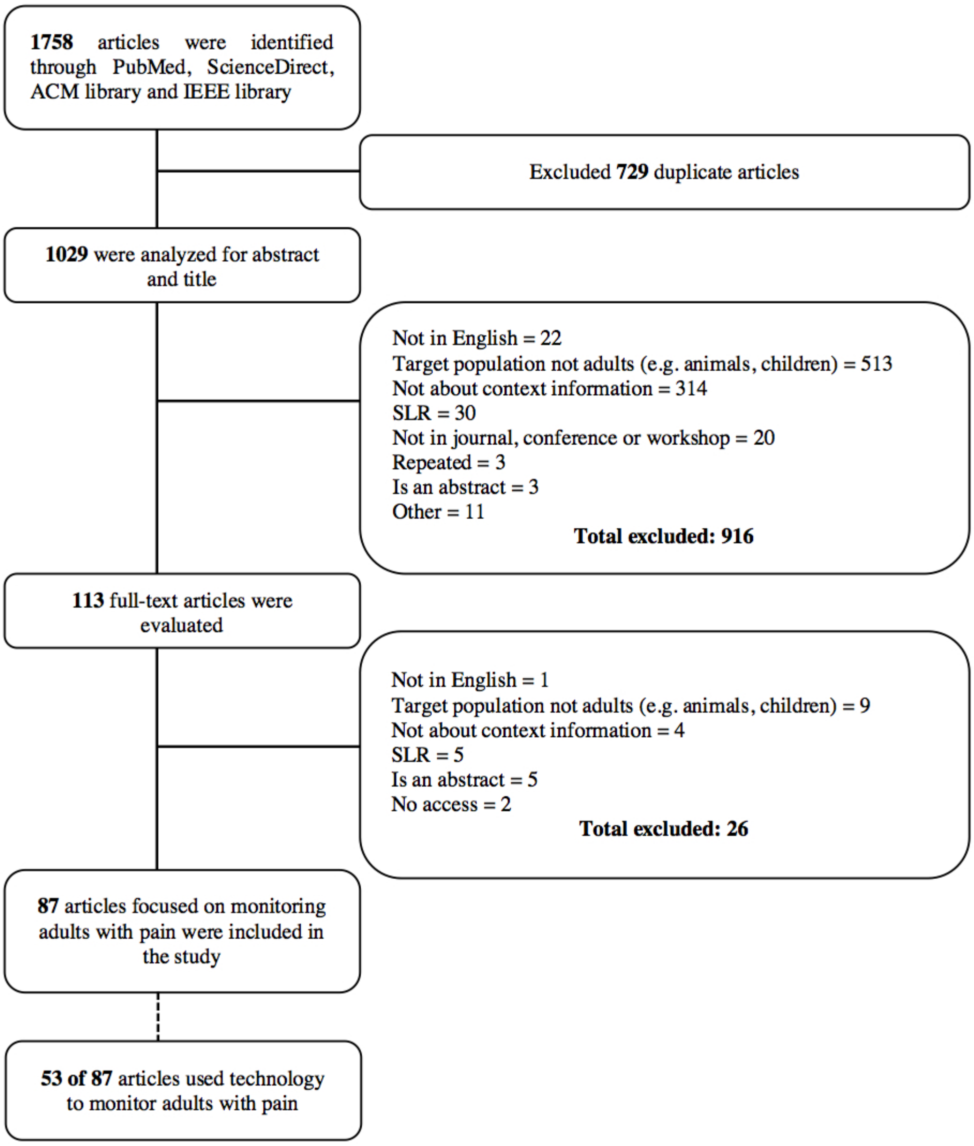
One reviewer (IR) extracted information from each publication using a predesigned Excel spreadsheet with 29 columns (eg, authors; study date; study purpose; country; contextual information; activity being monitored; main user; number of participants; study methodology, such as methods used, number and type of participants, activity; type of monitoring technology used). Quality of studies was not considered in this analysis.

Results

Selection and Inclusion of Studies

In total, 1758 references were identified from the databases. After removal of duplicates, 1029 publications remained. These were analyzed for abstract and title, and 911 publications were excluded because they did not meet the inclusion criteria. A total of 113 publications were evaluated for full text and 87 publications satisfied the aforementioned eligibility criteria and were included in the final review. Out of these, 53 used technology to monitor pain. The selection flow diagram for this study is presented in Figure 1.

Figure 1. Selection flow diagram.



Characteristics of Included Studies

Most of the reviewed articles were published in journals (81/87, 93%) and only 6 of 87 (7%) in conference proceedings. The distribution of studies over the years is presented in Figure 2.

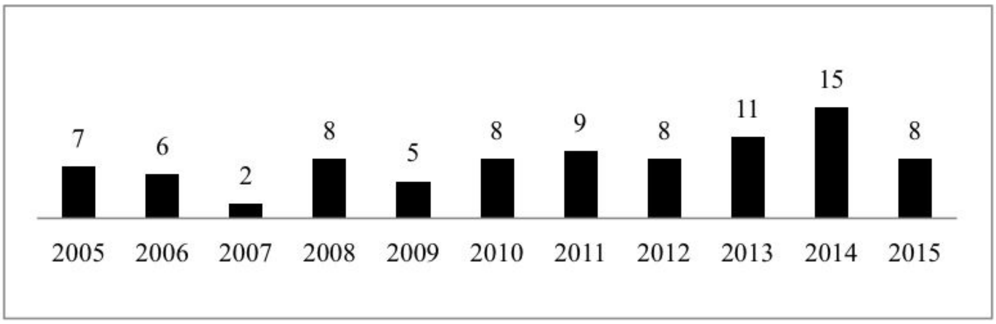
Of all reviewed articles, 53 of 87 (61%) presented technologies (systems, devices, apps) used to monitor adults with pain. The focus of 80% (70/87) of the research was on a specific condition, such as back pain (16/87, 18%), fibromyalgia (5/87, 6%), and neck pain (5/87, 6%). The interventions were tested on patients

(57/87, 66%), on healthy volunteers (27/87, 31%), on students (2/87, 2%), or unspecified (1/87, 1%). Regarding the countries where the research was carried out, the three countries with highest representation were the United States (34/87, 39%), England (11/87, 13%), and Canada (9/87, 10%). Only 6 of 87 (7%) studies were carried out in Africa and Asia, and none in Latin America.

The selected studies collected information for several objectives. Several focused on pain relating to postures and movement in a work environment [20-29]; others studied the impact of therapy and/or exercise [30-35] and a large group saught to describe pain and the experience of pain [36-54] and pain-related pathologies [55-68]. Other studies were aimed at understanding the relationship of pain to other factors: emotional state [69-85], social context [86-88], sleep [89,90], disability [91], quality of life [92-95], and fear or catastrophism [96-98]. Some investigations proposed or evaluated technological apps for pain recognition [99], pain control [100], healthy behavior support [101], sleep monitoring [102], remote health services [103], estimating pain during therapy [104], or measuring changes after surgery [105,106].

Regarding pain measurement, 53 of 87 investigations used pain scales. From these articles, the most frequently used scale was the Numeric Pain Rating Scale (27/53, 51%), followed by the Visual Analog Scale (24/53, 45%) and Verbal Numerical Scale (2/53, 4%). Validated questionnaires were also used: McGill Pain Questionnaire (7 articles), Brief Pain Inventory (5 articles), and Multidimensional Pain Inventory (1 article); 5 articles used their own questionnaires. Six articles used two or more methods to assess pain. Only 14 articles had a control group.

Figure 2. Number of publications per year.



Methodology and Evaluation of the Reviewed Studies

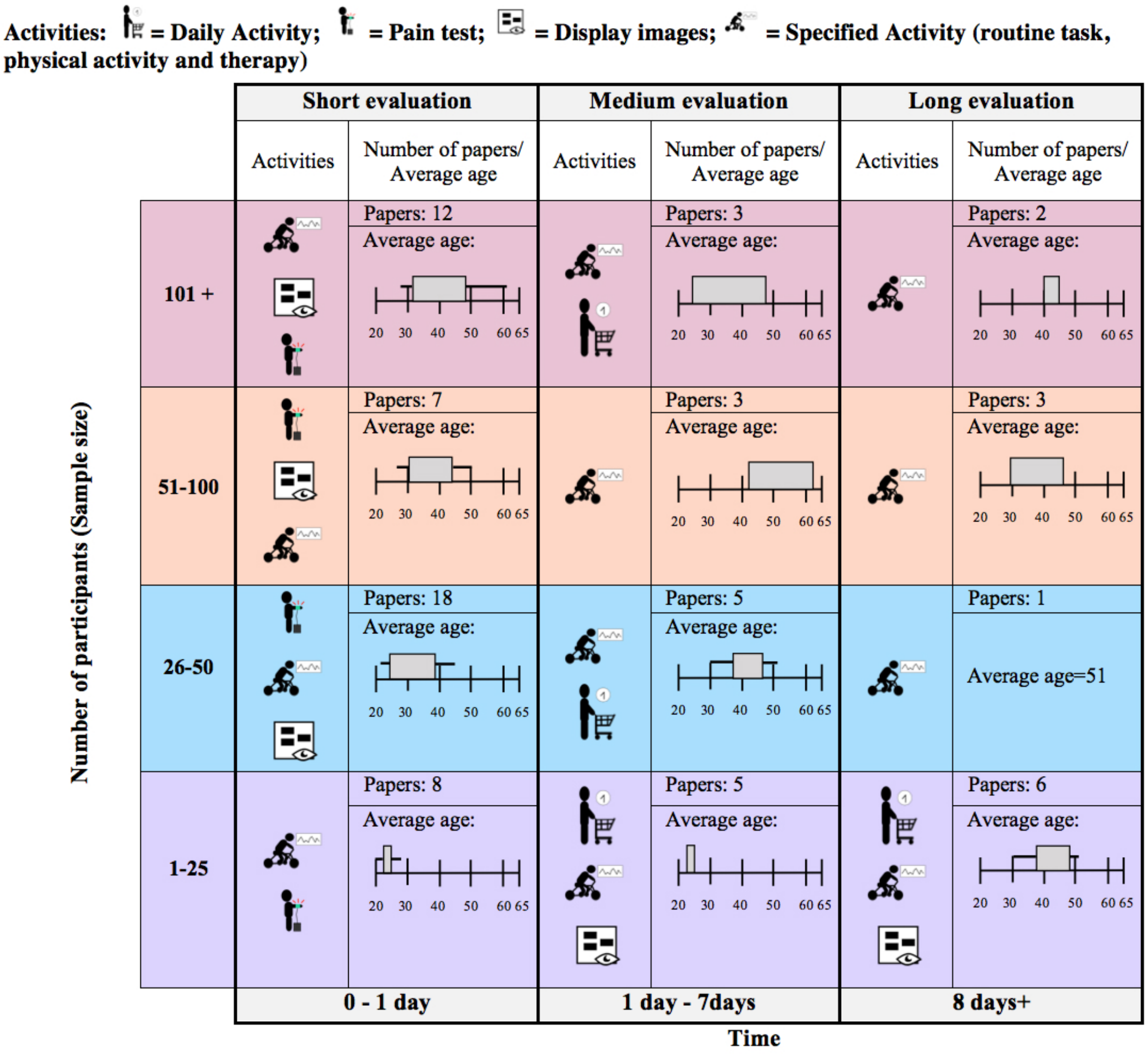
The methodology used in each publication was analyzed. A quantitative methodology was applied in 79 of 87 studies (91%), none used only qualitative methodology, and 6 of 87 (7%) applied mixed methods. The following techniques for data collection were used: questionnaire, sensors (eg, heart rate monitor), diaries, interviews, and analysis of medical records.

The participants were asked to participate in experiments to collect data while they were monitored. The activities that participants underwent were classified into the following five categories:

1. Daily activity: monitoring the activities of a person in his/her daily life [23,27,28,60,89,90,101-103,105,106].
2. Specified activity: monitoring the activities of a person during an activity specified by the researchers, which were classified further into the following categories:
    a. routine task: participants must perform a specified task (eg, reading, writing) [21,22,71,86,87];
    b. physical activity: participants must engage in activities that require physical exertion (eg, lifting, cycling, walking) [20,26,29,38,51,55,59,61,64,66,91,96,97]; and
    c. therapy: participants were evaluated while doing some type of therapy (eg, leg curls, music, behavioral therapy) [30-35,44,46,49,52,58,93,104].
3. Pain test: tests in which the participant feels pain (eg, hand dip tests in cold water and/or heat, or electrical stimuli) [37,39-43,45,50,53,54,70,73,81,98].
4. Display images: participants are shown images (eg, erotic, pleasant, gory images) [47,48,69,75,77-79].
5. Other: other activities [36,57,62,64,72,85,99].

The most frequent activities were pain test (14/87, 16%), therapy (13/87, 15%), physical activity (13/87, 15%), and daily activity (11/87, 13%). A summary of the methodology used in the included studies is presented in Figure 3. The studies were classified by sample size (number of participants) and duration of the evaluation. The mean age of participants in each study (when/as reported by the original research) and the activities that were included in the study (daily activity, pain test, display images, specified activity) are shown in Figure 3. Generally, studies with a longer duration used specific activities, such as therapy or physical activity, and used daily activities only when the sample size was small, possibly because daily activities are more complex to evaluate when the period of time or sample size is larger. Most of the surveyed articles had a short evaluation period, and most studies involved young people or adults, but not seniors.

Figure 3. Summary of study methodologies.



New Context Model for Pain Monitoring

Classification of the existing knowledge in a domain can provide a better understanding of the relationships between the objects, identify gaps, and ease the sharing of knowledge [1]. The 87 selected publications were reviewed and the researchers listed context information that was presented, either to study its relation to pain or to characterize pain. Then, similar context information was merged, resulting in the identification of 49 different types of contextual information.

Lienhard and Legner's recent context model [107] included the categories activity, identity, location, and time. However, during this review, contextual information was found pertaining to new categories, and additional subcategories were found, creating 40 additional subcategories. To create the model, the context information was first categorized into one of the existing categories. Information that did not correspond to a category was placed in a separate set. The time category was eliminated because it was not collected by any of the included studies. Then, the unclassified information was grouped into sets with similar characteristics. From this analysis, three new categories were created: wellness, environment, and physiological. Finally, the location category, which did not have subcategories, was determined to be a subcategory of environment.

The 49 types of context information identified in this study are presented in Table 1, classified according to our proposed five-dimension context model. The following is a brief explanation of the categories of the model:

1. Activity: information collected from activities that require physical or mental effort by the user.
2. Identity: the user's identifying characteristics (eg, roles, behaviors, and personality).
3. Wellness: information about a patient's state of well-being (eg, quality of life, disability, comorbidity, and among others).
4. Environment: the patient's surroundings (eg, noise, food, and music).
5. Physiological: data collected from the patient's body (eg, heart rate, blood pressure, and skin conductance).

Table 1. New context information model for pain monitoring.

Context category and subcategory	Instruments			Articles, n	Correlation with pain, n	No correlation with pain, n
	Questions/ interview	Medical equipment	Technical device			
Activity						
Physical activity		Y	Y	7	3	1
Mental tasks	Y		Y	1		
Positions			Y	3	2	
Movements			Y	4	1	
Walk (gait)			Y	2	1	
Identity						
Behavior	Y			2		1
Personality	Y			1	1	
Role	Y		Y	2	2	
Ethnicity	Y			2	2	
Coping	Y			1	1	
Wellness						
Quality of life	Y			5	3	1
Emotional state	Y			15	7	1
Comorbidity	Y			3	1	
Anxiety	Y			10	3	2
Depression	Y			9	3	
Stress	Y			12	6	
Fatigue	Y			8	1	1
Fear	Y			8	1	1
Muscle injury	Y	Y		1		
Sleep	Y		Y	7		3
Disability	Y	Y	Y	14	1	
Catastrophism	Y			6	2	
Environment						
Vibration			Y	1	1	
Music			Y	1	1	
Workload	Y		Y	5	4	
Food	Y		Y	1	1	
Setting			Y	1		
Voice			Y	1		
Social support	Y			4	1	
Noise			Y	1		
Location			Y	3		
Physiological						
Blood		Y	Y	5	1	1
Saliva		Y	Y	3		
Heart rate		Y	Y	15	3	2

Context category and subcategory	Instruments			Articles, n	Correlation with pain, n	No correlation with pain, n
	Questions/ interview	Medical equipment	Technical device			
Blood pressure		Y	Y	8	1	
Skin conductance		Y	Y	8	2	
Facial expressions			Y	2	1	
Flicker			Y	2	1	
Pupil		Y	Y	1	1	
Muscular strength		Y	Y	2		
Muscle activity		Y	Y	11	2	
Temperature		Y	Y	2		
Column compression		Y	Y	2	1	
Cerebral activity		Y	Y	4	2	
Asymmetry		Y	Y	2	2	
Musculoskeletal symptoms	Y	Y		1		
Breathing		Y	Y	5		
Sensitivity	Y			3	1	
Pain tolerance	Y			4		

The context information that was collected more frequently was heart rate, disability, emotions, and depression. Most publications used physiological information (54/87, 62%) and wellness data (52/87, 60%) because these categories included heart rate, emotions, disability, and depression, which are frequently collected parameters. Next was environment information with 22% (19/87). Activity data were used in 18 of 87 publications (21%), corresponding to physical activities, mental tasks, and walking, among others. Finally was identity data with 9% (8/87).

Table 1 also presents the results of the reviewed studies, displayed next to each subcategory are the number of studies that found that the information was (or was not) correlated to pain. For example, the correlation between sleep and pain was studied three times finding no correlation, whereas stress was found by six studies to correlate to pain and other categories (eg, heart rate, fear, have conflicting results).

The instruments used to collect each type of context information are also listed in Table 1. Questionnaires or interviews were mainly used to gather subjective patient information, such as behavior, emotional state, personality, and quality of life. Medical equipment refers to specialized medical devices to collect patient information. These devices usually were handled by health professionals (eg, devices to get blood, saliva, blood pressure, and brain activity). Finally, technological devices (eg, mobile phones, mobile apps, sensors, and websites) were used to collect data through such things as online surveys and facial expression recognition.

The proposed model may be used by researchers as a base taxonomy of possible information that may be monitored in adult patients with pain; however, it is not expected that any single device should monitor all this information. Rather, researchers may select information that is relevant to their specific study, choosing to focus on information that has been found to correlate with pain or otherwise choosing to fill gaps in the literature (eg, by studying whether some of the information that is frequently monitored has a relation to pain).

Technology to Monitor Adults with Pain

The technologies used to monitor adults with pain were studied to learn about current trends and challenges regarding pain monitoring.

Types of User Interfaces

A technological device includes a user interface (ie, the representation of a system with which a user can interact) [108]. There is not one agreed-on taxonomy to define every possible type of user interface, thus well-known categories of interfaces were used to classify the technologies.

Graphical User Interface

Graphical user interfaces represent information through an image-based representation in a display [108] and provide users with visual controls, such as menus, buttons, lists, and windows [109]. Examples of this type of interface are an electronic diary to input mood, intensity of pain, and sleep [89], electronic questionnaires [26,77,79,86,96], a mobile app [101], and laptops for sleep monitoring [102].

Tangible User Interface

A tangible user interface is a user interface in which a person uses a physical object to interact with digital information [110] (eg, hardware for magnetic resonance imaging) [39,70], apparatus for measuring skin conductance [39,70], joystick [87], and a motion analysis system [22].

Wearable User Interfaces

A wearable user interface is a device that is worn on the body (eg, embedded in clothing or accessories) [111]. This implies the use of the human body as a support environment for the devices [108]. Examples of devices that were used as wearable user interfaces in this study are mobile phones [105,106], a garment for tracking electromyography signals [101], and sensors such as accelerometers [23,60,103] and gyroscopes [66].

Analysis of Technologies for Monitor Adults with Pain

For each of the reviewed articles that presented monitoring technologies, the type of user interface (graphical user, tangible user, or wearable user as previously defined), the target user (either the patient him/herself or the health care worker), what type of information was monitored (according to the categories defined by our model), and the type (whether available commercially or as a research prototype) are listed in Table 2. Tangible user and wearable user interfaces were naturally used more often to collect physiological data and activity information. Physiological data were the most typically collected contextual information (27/53, 50%), whereas identity was not used, possibly because this category did not change dynamically. The devices used were overwhelmingly commercially available devices, with only four research-based devices.

The most common type of interface used to monitor adults with pain was a wearable user interface (37/53, 70%), followed by tangible user interface (22/53, 42%) and graphical user interface (9/53, 17%). Regarding wearable user interfaces, the body part where most devices were placed was the trunk (17/37, 46%) and arms (including hands; 15/37, 41%). Naturally, this was related to the type of condition that was being studied (eg, back pain was more frequently monitored through devices placed on the trunk).

The target users of these technologies were most often the patients themselves (47/53, 89%) and/or health care professionals (22/53, 42%). The devices were worn on the patients' bodies (eg, electrodes, sensors). Most studies used these technologies not to monitor users, but rather to conduct measurements in controlled or supervised environments. Tangible user interfaces in these articles were mostly oriented toward health care professionals and not patients because they used medical equipment such as scanners or blood tests, which require special training to operate.

Using the previous classification of activities used for evaluation, the three activities that were most frequently done to evaluate technological devices to monitor adults with pain were daily activity and physical activity with 19% each (10/53), followed by pain test with 17% (9/53). Using technology allows researchers to monitor patients during their daily activities, which provides more realism and a richer context for evaluation.

Challenges and Trends in Monitoring Adults with Pain

Five challenges in terms of monitoring adults with pain were found:

1. When monitoring is in real contexts, the user of the device must be the patient. This may generate usability challenges when users have low digital skills, as well as other technical challenges such as battery life.
2. Many contextual factors may influence pain and, as previously stated, current sensors allow measuring a large amount of information, but it is not yet clear which types of information to monitor for a particular evaluation.
3. Monitoring technology usually sends reports to health care professionals, whereas almost no feedback is given to the patients to help them understand their pain patterns, triggers, and how to adjust their activities accordingly, for example. A possible explanation for this is that medical-grade health monitors that can provide feedback to patients are rigorously tested and highly regulated [112], which results in slower adoption of new features and may lead researchers to use instead commercially available, consumer-grade monitors that do not provide feedback.
4. Most studies do not collect environmental information from the patient, although there are already sensors on the market to capture this type of information (eg, noise, humidity, temperature).
5. Increasingly, researchers have been taking advantage of available sensor technology and implementing tangible and wearable devices to monitor adults with pain in a mobile way. However, most studies did not collect data in real contexts, rather focusing on laboratory or controlled experiments.

The results were analyzed to see whether trends could be found (ie, whether changes could be detected over the time period of the review), especially regarding study methods, evaluation activities, technologies, and collected context information. No significant differences were found in the contextual data that were collected over the years nor in the types of technology used or evaluation methods.

Table 2. Technology used to collect context information.

Body part and user[a]	Interface[b]			Context data[c]				Type
	WUI	TUI	GUI	Wellness	Environment	Physiological data	Activity info	
Trunk								
Patient								
[105]	Y						Y	Commercial
[20]	Y					Y		Commercial
[106]	Y						Y	Commercial
[38]	Y				Y		Y	Commercial
[72]	Y					Y		Commercial
[58]	Y						Y	Commercial
[59]	Y					Y		Commercial
[60]	Y						Y	Commercial
Patient and HCW								
[33]	Y	Y				Y		Commercial
[23]	Y	Y			Y			Commercial/research
[81]	Y	Y				Y		Commercial
[103]	Y	Y					Y	Commercial
[67]	Y	Y					Y	Commercial
[104]	Y	Y				Y		Commercial
[102]	Y		Y	Y				Commercial/research
Arms								
Patient								
[37]	Y					Y		Commercial
[40]	Y					Y		Commercial
[90]	Y						Y	Commercial
[32]	Y					Y		Commercial
[42]	Y					Y		Commercial
[49]	Y					Y		Commercial
[78]	Y			Y				Commercial
[61]	Y						Y	Commercial
[54]	Y					Y		Commercial
Patient and HCW								
[43]	Y					Y		Commercial
[70]	Y	Y		Y				—
[39]	Y	Y				Y		Commercial
Legs								
Patient								
[55]	Y						Y	Commercial
[69]	Y						Y	Commercial
[66]	Y						Y	Commercial
Head and neck								
Patient								

Body part and user[a]	Interface[b]			Context data[c]				Type
	WUI	TUI	GUI	Wellness	Environment	Physiological data	Activity info	
[36]	Y					Y		Commercial
Patient and HCW								
[21]	Y	Y				Y		Commercial
[47]	Y	Y				Y		Commercial
Head, neck, and legs						Y		
Patient and HCW								
[48]	Y					Y		Commercial
Arms and trunk								
Patient								
[51]	Y					Y		Commercial
[101]	Y		Y				Y	Commercial
Arms and legs								
Patient and HCW								
[77]	Y		Y	Y				Commercial
Not stated								
Patient								
[96]			Y	Y				Commercial
[86]			Y	Y				Commercial
[89]			Y	Y				Commercial
[87]		Y					Y	Commercial
[75]		Y				Y		Commercial
[62]		Y				Y		Commercial
[26]			Y			Y		Commercial
[27]		Y		Y				—
HCW								
[22]		Y					Y	Commercial
[73]		Y		Y		Y		Commercial
[31]		Y					Y	Commercial
[99]		Y					Y	Commercial
[52]		Y				Y		Commercial
[63]		Y				Y		Commercial
Patient and HCW								
[79]		Y	Y	Y				Commercial
[100]		Y	Y		Y	Y		Commercial/research

[a] HCW: health care worker.

[b] GUI: graphical user interface; TUI: tangible user interface; WUI: wearable user interface.

[c] No article monitoring identity data.

Discussion

Principal Results

This SLR found 49 different types of context information used to monitor adults with pain and categorized them into a new five-dimensional model of context information that includes activity, identity, wellness, environmental, and physiological data. Several types of context information have been studied to see whether they correlate to pain; although publication bias tends to skew data toward positive results, we found that some contextual information has not been found to correlate to pain (eg, sleep), whereas other (eg, emotional state) has an increasing amount of evidence of its correlation to pain. This review did not find trends in the contextual information that has been presented in previous research (ie, it has not changed substantially in the 10 years of the review). Therefore, although there is potential for new sensors to allow monitoring new contextual information, there is a degree of independence between the contextual information that is of interest in the monitoring of patients with pain and sensor availability.

A total of 53 studies presented technological devices to collect context information, using wearable, tangible, and graphical user interfaces. Even though several approaches aim to capture context automatically (eg, through sensors), the proposed model makes evident that contextual information also requires manual input because patient-supplied information is relevant (eg, in the identity category of the model). Although sophisticated technologies exist for inferring emotions through facial expressions captured by video [113,114], they also need to be partly input by the patient (eg, information concerning depression, mood, anxiety), which may represent a challenge from a system usability perspective.

Recent advances in the miniaturization of biosensors, wearable technology, and microelectronics have enabled continuous ambulatory monitoring of physiological signals [115]. In this review, adults with pain were found to be more frequently monitored through wearable devices, which allow researchers to place them on the relevant body part being studied, and physiological information was the type of information most frequently captured. Wearable health monitoring technology has been found to be especially appropriate for people suffering from chronic disease, providing continuous monitoring and adequate privacy [115], and it may become pervasive for all populations due to the ubiquitousness of mobile phones and the quantified-self movement [116].

The selected articles were found to have diverse types of evaluations, spanning hours, days, or weeks, and with diverse sample sizes. The most frequent activities that participants underwent were a pain test, therapy, physical activity, and daily activity. Generally, studies with a longer duration use specific activities, whereas daily activities are used when the sample size is small, possibly because daily activities are more complex to evaluate when the period of time or sample size is larger. Usually, evaluation periods are short (less than one day), and most studies involve young people or adults, but not seniors. Only seven studies (8%) had patients older than 50 years; however, it has been found that prevalence of chronic pain does vary with age, increasing as patients age [91].

Researchers have mostly studied patient-supplied context information, and infrequently contextual information from environmental factors or patient activities. For example, studies have suggested that environmental problems may greatly affect health [117] (eg, air pollution may produce nausea [118]), but no information was found about whether this type of factor (or others such as temperature, humidity) affects pain.

Comparison With Prior Work

Several systematic reviews related to pain have been undertaken, but they have focused on pain management (eg, therapy effectiveness [119,120] and alternative therapies [121]). This is the first work to review a large number of studies with the goal of building a model of contextual information that may be related to pain. Studies about context information and pain generally present studies in specific reduced situations (eg, a context model based on data from three interviews and for a specific solution using mobile phones [107], an ontology-based context model for patient home care for chronic diseases [122]). Likewise, research on technologies for chronic pain management only present some examples of types of technologies [123] without undertaking a structured systematic review of existing research.

Challenges and Considerations

This study aims to provide information about contextual data that may be monitored through technological devices. Nevertheless, this area is fraught with interesting challenges. One is preserving the privacy of patients [124], especially when considering monitoring a large amount of sensitive information that may be correlated in many ways. Another is the challenge of providing adequate usability, not only in regard to interaction, but also battery life and portability. Adoption is another challenge. This requires, for example, a device to be esthetically adequate for social activities [125], and requires low amounts of interaction [126]. Designers and computer scientists will have to deal with these challenges and considerations to avoid overburdening patients and therefore negatively impacting use and adoption of monitoring devices.

Limitations

This study only used four specific databases and only in English; therefore, more regional contributions may have been missed, which may explain our low rate of studies in Africa, Asia, and Latin America. This search was restricted to 10 years, partly to uncover recent technological proposals; however, important contextual information may have been discussed in older research articles. Also, only the word “pain” was included in the search string, omitting related words (eg, “misery” or “spasm”), which may have uncovered additional literature on this topic.

Conclusion

A SLR was conducted with the goal of studying technologies to monitor adults with pain and relevant contextual information. Eighty-seven articles were reviewed in depth and 49 types of context information were found and organized into a five-dimension model of contextual information. Most contextual information was related to patient-supplied data and few were collected from the environment or patient's activities. Regarding technology, wearable user interfaces are used most often to collect data and monitor patients. Nevertheless, not all information may be monitored through sensors automatically—some data must be user-supplied because some information from the patient is subjective (eg, pain intensity, fear, and emotional state).

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Authors' Contributions

IR and VH together developed the concept of this systematic literature review. POR provided guidance about the systematic literature review protocol, and MC provided guidance about medical aspects of this work. MM conducted the literature search, and IR, VH, POR, and Maíra Marques reviewed abstracts. IR, CG, and CF worked in the accelerated liberal approach. IR and VH conducted the analyses and contributed to the interpretation of the findings. IR wrote the first draft of the manuscript and Valeria Herskovic contributed to changes in the manuscript. All authors reviewed the final document.

Conflicts of Interest

None declared.

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Abbreviations

SLR: systematic literature review

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Original Paper

Recommending Education Materials for Diabetic Questions Using Information Retrieval Approaches

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Abstract

Background: Self-management is crucial to diabetes care and providing expert-vetted content for answering patients’ questions is crucial in facilitating patient self-management.

Objective: The aim is to investigate the use of information retrieval techniques in recommending patient education materials for diabetic questions of patients.

Methods: We compared two retrieval algorithms, one based on Latent Dirichlet Allocation topic modeling (topic modeling-based model) and one based on semantic group (semantic group-based model), with the baseline retrieval models, vector space model (VSM), in recommending diabetic patient education materials to diabetic questions posted on the TuDiabetes forum. The evaluation was based on a gold standard dataset consisting of 50 randomly selected diabetic questions where the relevancy of diabetic education materials to the questions was manually assigned by two experts. The performance was assessed using precision of top-ranked documents.

Results: We retrieved 7510 diabetic questions on the forum and 144 diabetic patient educational materials from the patient education database at Mayo Clinic. The mapping rate of words in each corpus mapped to the Unified Medical Language System (UMLS) was significantly different ($P<.001$). The topic modeling-based model outperformed the other retrieval algorithms. For example, for the top-retrieved document, the precision of the topic modeling-based, semantic group-based, and VSM models was 67.0%, 62.8%, and 54.3%, respectively.

Conclusions: This study demonstrated that topic modeling can mitigate the vocabulary difference and it achieved the best performance in recommending education materials for answering patients’ questions. One direction for future work is to assess the generalizability of our findings and to extend our study to other disease areas, other patient education material resources, and online forums.

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KEYWORDS

education materials; patients; questions; recommendation; information retrieval

Introduction

Diabetes is a chronic metabolic disease currently affecting almost 415 million patients worldwide with an estimation of this reaching 642 million by the year 2040 [1]. Having diabetes is associated with substantially higher lifetime medical expenditures despite being associated with reduced life expectancy [2]. Optimal control of diabetes requires a high degree of self-management where individuals have the necessary knowledge, skill, and ability for diabetes self-care [3]. Self-management consists of a complex and dynamic set of processes and is deeply embedded in each patient's unique situation [4]. Meeting the information needs of each patient is crucial in facilitating self-management.

Patients' self-learning is an important component of self-management. For example, through self-learning modules, patients can gain more knowledge and be more knowledgeable about practice interventions regarding foot care, which is a widely neglected part of diabetes management [5]. Meanwhile, the Internet has become an important source of self-learning for patients. Many online health communities and forums have emerged as popular platforms for patients to ask questions and share information. However, the quality of health information on the Internet is highly variable [6]. It is crucial to provide expert-vetted information to patients. At the same time, there is an abundant supply of expert-vetted patient education resources that aim to help diabetic patients improve their diabetes self-management [7-9]; however, it is quite challenging for patients without a medical background to find relevant educational materials. A system that can automatically recommend such resources to patients based on their questions in an online forum would be one way to provide relevant expert-vetted education materials.

Retrieving relevant education materials for given questions can be regarded as an information retrieval task. Information retrieval refers to the task of retrieving information of any type from a collection of documents related to search queries. One classic information retrieval approach is based on keyword matching (ie, Boolean model) [10], where documents are represented as a set of terms and queries are represented as Boolean expressions. Another popular information retrieval approach is the ranking model. Unlike the Boolean model where terms are equally weighted, the ranking model ranks the result list in terms of relevance of documents with respect to an information need expressed in the query [10]. Ranking is usually to compute numeric scores of query/document pairs where numerous scoring algorithms have been used. For example, the vector space model (VSM) computes the similarity between a query vector and a document vector, where terms can be weighted using a term frequency-inverse document frequency (TF-IDF) model [11,12]. One common idea of information seeking is to come up with good queries by thinking of words that would likely appear in a relevant document. The language models directly model such ideas where a document is a good match to a query if the document is likely to generate such a query. For a query, the probabilistic language model approach computes a probabilistic language model and ranks documents based on the probability of the model generating the query. Semantic searching intends to improve searches by understanding the semantics in queries and document collections. Concept mapping is popularly used in semantic searches where keywords are mapped to concepts captured in terminological resources. In general English, WordNet is a popular terminology resource where terms are grouped into sets of synonyms according to their meanings and organized into hierarchies based on their semantic relations [13].

Recently, topic modeling, which discovers abstract topics in document collections, has become a frequently used technique in text mining. The most common topic modeling approach is Latent Dirichlet Allocation (LDA), which allows documents to have a mixture of topics. For example, Wang and Blei [14] used topic modeling to generate an interpretable latent structure for users and items, which can provide recommendations about both existing and newly published scientific articles. In information retrieval, topic modeling can be effective in enabling the incorporation of hidden semantics [15].

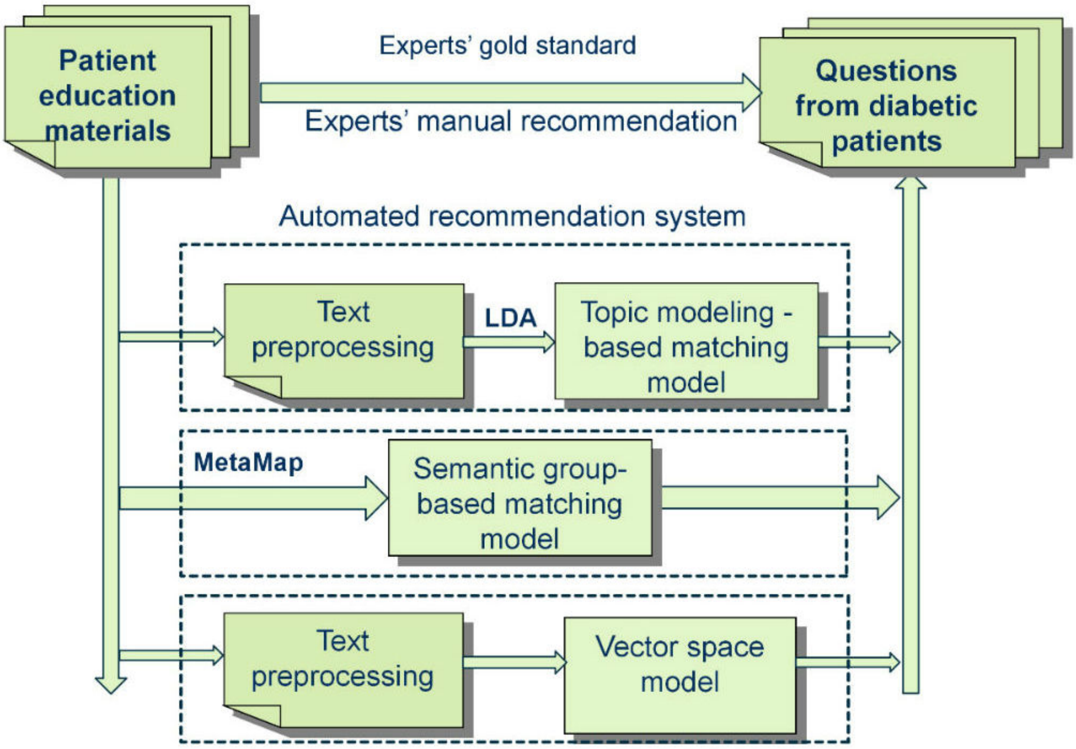
In the clinical domain, there are many information retrieval applications [16], including clinical decision support. For example, InfoRetriever was designed for family medicine providers to practice evidence-based medicine [17]. Information retrieval technology is also popularly used in patient education applications, such as the PERSIVAL system, which is based on individual patient records and provides personalized access to a distributed patient care digital library by retrieving and summarizing relevant education materials.

Here, we propose a system that leverages the latest information retrieval techniques, which recommends patient education materials for questions asked by patients online. The system aims to provide expert-vetted, patient-faced information to patients. A similar system has been proposed by Kandula et al [18] where, instead of patients questions, their system recommended relevant education materials based on medical records. In this study, we investigated the use of state-of-the-art information retrieval approaches to recommend diabetes education materials for questions available in an online diabetes forum.

Methods

An overview of our workflow of this study is presented in Figure 1. We designed a recommendation system using three retrieval models, including a topic modeling-based model, a semantic group-based model, and a VSM. To evaluate the performance of each model in the system, we assembled a gold standard dataset created manually for a randomly sampled subset of questions.

Figure 1. The workflow of this study.



Materials

The materials used for our study included a corpus of patient educational materials for diabetic patients retrieved from Mayo Clinic's patient education database and a corpus of questions retrieved from a diabetic forum. There were more than 7400 high-quality, expert-reviewed, and outcome-based patient education materials available in the Mayo Clinic's Database of Approved Patient Education Materials, which are indexed using disease concepts. We retrieved all diabetes-related education materials, a total of 144 documents, in PDF format and used Apache Tika, a content analysis toolkit [19], to transform the PDF format to plain text and form the patient educational materials corpus. We chose a popular diabetic online forum, the TuDiabetes forum [20], to retrieve questions asked by diabetic patients. There are more than 43,000 forum users who post questions, provide answers or comments, participate in discussions, and share experiences. Questions in the forum have been categorized into 12 categories. We gathered a total of 7510 diabetic questions from the website; for each question, the corresponding title, content, and category were extracted and formed into the corpus of questions from diabetic patients.

Tools

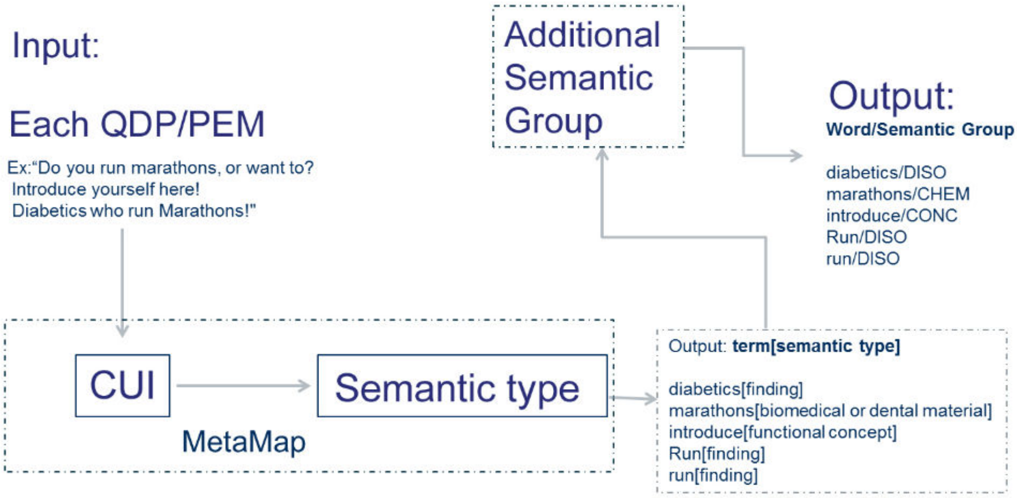
We used the Unified Medical Language System (UMLS) from the US National Library of Medicine (NLM) and the associated concept-mapping tool, MetaMap, to represent and extract clinical concepts from the corpora. The UMLS is a comprehensive resource for clinical concepts, which integrates more than 2 million names for some 900,000 concepts from more than 60 families of biomedical vocabularies, as well as 12 million relations among these concepts [21]. Each clinical concept is assigned a concept unique identifier. The UMLS arranges clinical concepts into 134 semantic types. These semantic types are further grouped into 15 semantic groups. The MetaMap tool is a configurable app developed by NLM to map biomedical text to the UMLS Metathesaurus.

We used the LDA topic model with JGibbLDA software [22] to classify the patient education materials. LDA topic modeling is a common method that generates a high underlying set of topic probabilities with an infinite mixture based on a three-level hierarchical Bayesian model [23]. The statistical analysis was performed using R [24]. The attribute proportion data were analyzed using chi-square tests. We also used Cytoscape software version 3.4 to visualize the networks generated in different models [25].

Information Retrieval Algorithms

We compared three algorithms for recommending patient education materials for matching questions: (1) a VSM model as the baseline model using scikit-learn 0.18.0 package [26], (2) a topic modeling-based matching model motivated by Kandula et al [18] using topic modeling for matching patient educational material to patient's clinic notes, and (3) a semantic group-based matching model that considered each semantic group as a topic in the patient educational materials corpus, the detail processing in Figure 2. See Multimedia Appendix 1 for the weight calculations for the topic modeling-based and semantic group-based models.

Figure 2. The workflow of the semantic group-based model. CHEM: chemicals and drugs; CONC: concepts and ideas; CUI: concept unique identifier; DISO: disease; QDP: questions from diabetic patients; PEM: patient educational materials.



Gold Standard and Evaluation

To compare the performance, we randomly selected 50 questions and assembled a gold standard dataset based on manual review with the agreement of two experts. Specifically, for the pairing of question *q* and education material document *d*, we manually assigned a score in the range of 0 to 2 to indicate if d was relevant to q, where 0 indicated no relevance, 1 partial relevance, and 2 most relevance. Two medical experts performed the task. The weighted Cohen kappa value was calculated to determine interannotator agreement. A gold standard was then created based on the consensus of the two experts. The precision of the top *k* retrieved documents was used to evaluate the performance of the models, defined in the following:

Precision (k)=(number of relevant documents)/k

where a partial relevance document was counted as 0.5.

Results

Overall Statistics

As shown in Table 1, the mean document length (word count) was 968 (SD 115) and 110 (SD 36) for patient educational materials and questions from diabetic patients, respectively. The UMLS mapping rate (the ratio of words that can be mapped to UMLS concepts) for patient educational materials was significantly higher than questions from diabetic patients (*P*<.001) with more unique concepts in questions from diabetic patients than in patient educational materials. The unique word count in questions from diabetic patients was 41,820 with 8952 in patient educational materials. The majority of the words in patient educational materials were present in questions from diabetic patients with 25.06% (2244/8952) of the words not in questions from diabetic patients (Figure 3).

Table 1. An overview of the two corpora.

Corpus	Number	Total word count (mapping rate)[a]	Word count, mean (SD)	Unique word count	Unique UMLS concepts, n
Questions from diabetic patients	7510	829,893 (91.18%)	110 (36)	41,820	19,616
Patient educational materials	144	139,463 (93.31%)	968 (115)	8952	7924

[a] Mapping rate was presented the probability of words mapped to the UMLS from the total word count. Difference in mapping rate between the two corpa was statistically significant (*P*<.001).

Table 2 shows the top 20 words for each corpus. The diabetes technology, community, and type 1 and latent autoimmune diabetes of adulthood (LADA) were the most common topics posted by questions from diabetic patient users, and topic 5, topic 3, and topic 8 were the main topics by topic modeling in patient educational materials documents as shown in Table 3. Table 4 shows some examples of topics obtained using topic modeling, which lists the top 20 words and their corresponding weights for each of the topics. The results of the topic vocabulary similarity analysis calculating the cosine similarity between each two topics of the two corpora are presented by a heat map graphic (Figure 4). There was no vocabulary similarity between the questions from diabetic patients categories and the patient educational materials topics, but one topic to one another topic in interior questions from diabetic patients corpus had high linguistic similarity. The semantic group distribution of the two corpora was significantly different (Figure 5) where procedures, phenomena, objects, living beings, disorders, and anatomy were more prevalent in patient educational materials, whereas physiology, genes and molecular sequences, devices, and chemicals and drugs were more prevalent in patient educational materials.

Figure 3. The Venn diagram of the words in the two corpora. There were 35,112 (83.96%) unique words in the questions from diabetic patients (QDP) corpus and 2244 (25.06%) unique words in the patient educational materials (PEM) corpus.

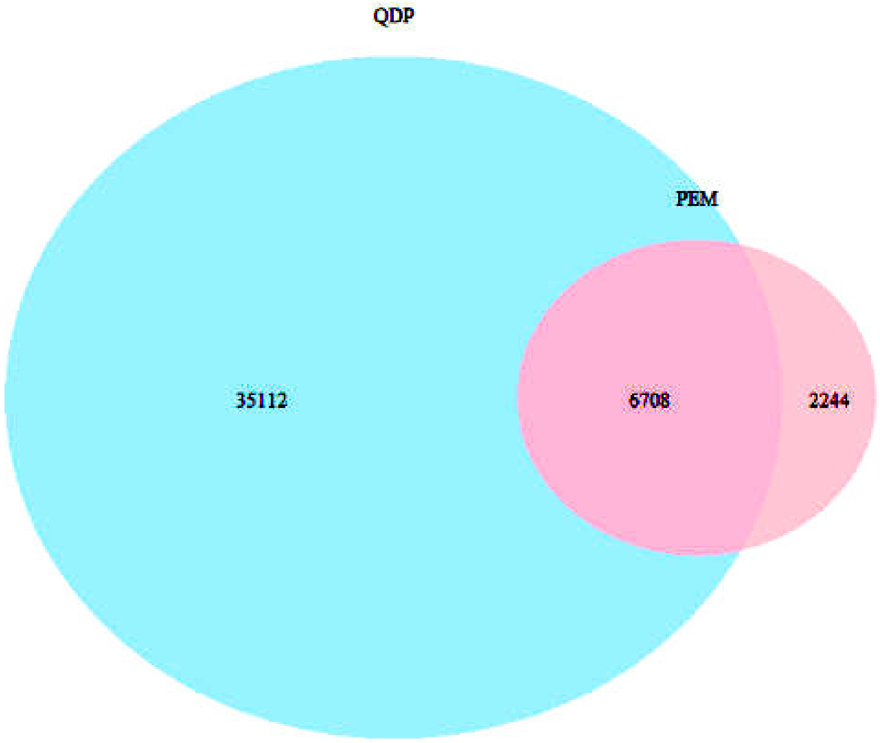


Table 2. The top 20 words in the two corpora.

Rank	Questions from diabetic patients		Patient educational materials	
	Word	Frequency	Word	Frequency
1	Diabetes	9062	Blood	3081
2	Insulin	5369	Insulin	2504
3	Type	4657	Glucose	2074
4	Like	4620	Diabetes	1385
5	Get	4457	Child	1166
6	Time	4107	Meal	1047
7	Know	3875	Childs	815
8	Pump	3428	Care	801
9	Now	3421	Health	797
10	Blood	3388	Dose	782
11	Day	3317	Test	738
12	People	2789	Sugar	728
13	First	2395	Help	671
14	Sugar	2383	Provider	638
15	Go	2309	Day	635
16	Back	2290	High	627
17	See	2219	Evening	583
18	Think	2148	Take	583
19	High	2088	Time	571
20	Use	2036	Eat	547

Table 3. Category and topic distribution of the two corpora.

Category/topic[a]	n (%)
Questions from diabetic patients	
Type 2	454 (6.0)
Type 1 and LADA	1609 (21.4)
TuDiabetes website	97 (1.3)
Treatment	507 (6.8)
Mental and emotional wellness	92 (1.2)
Healthy living	187 (2.5)
Food	321 (4.3)
Diabetes technology	1903 (25.4)
Diabetes complications and other conditions	211 (2.8)
Diabetes and pregnancy	117 (1.6)
Diabetes advocacy	253 (3.4)
Community	1759 (23.4)
Patient educational materials (PEM)	
PEM1	6 (4.2)
PEM2	5 (3.5)
PEM3	13 (9.0)
PEM4	6 (4.2)
PEM5	15 (10.4)
PEM6	10 (6.9)
PEM7	3 (2.1)
PEM8	11 (7.6)
PEM9	5 (3.5)
PEM10	7 (4.9)
PEM11	9 (6.3)
PEM12	9 (6.3)
PEM13	6 (4.2)
PEM14	8 (5.6)
PEM15	3(2.1)
PEM16	3(2.1)
PEM17	6(4.2)
PEM18	7(4.9)
PEM19	5(3.5)
PEM20	7(4.9)

[a] The categories of the questions from diabetic patients corpus were labeled as the website provided, and the topics of the patient educational material (PEM) corpus were generated using LDA topic modeling. The topic proportion was calculated with the maximum distribution of document.

Table 4. Sample topics in the patient educational materials (PEM) corpus.

PEM group	Top 20 most prominent words (corresponding weight)	Topic
PEM2	Disease (0.071), kidney (0.043), risk (0.037), heart (0.031), health (0.023), pressure (0.021), care (0.018), provider (0.017), factors (0.017), people (0.017), kidneys (0.015), cholesterol (0.012), high (0.011), lifestyle (0.010), levels (0.010), protein (0.010), control (0.009), body (0.008), urine (0.008), medications (0.008)	Complication-kidney
PEM8	Food (0.039), fruit (0.024), cup (0.022), foods (0.022), eat (0.020), sugar (0.020), fat (0.019), carbohydrate (0.017), meal (0.016), plan (0.015), milk (0.015), protein (0.014), carbohydrates(0.013), snack (0.013), vegetables (0.013), grams(0.011), meals (0.011), make (0.011), calories (0.010), serving (0.010)	Food
PEM13	Care (0.024), feet (0.023), problems (0.022), provider (0.020), pain (0.020), health (0.017), term (0.017), symptoms (0.015), peripheral (0.015), website (0.014)nerves (0.013), legs (0.012), system (0.012), neuropathy (0.012), stroke (0.012), walking (0.011), figure (0.011), shoes (0.011), infections (0.009), brain (0.009)	Complication-foot

Figure 4. Heat map of questions from diabetic patients categories and patient educational materials topics based on cosine similarity of word vectors weighted using TF-IDF or topic word distribution. The clustering is based on Euclidean distance.

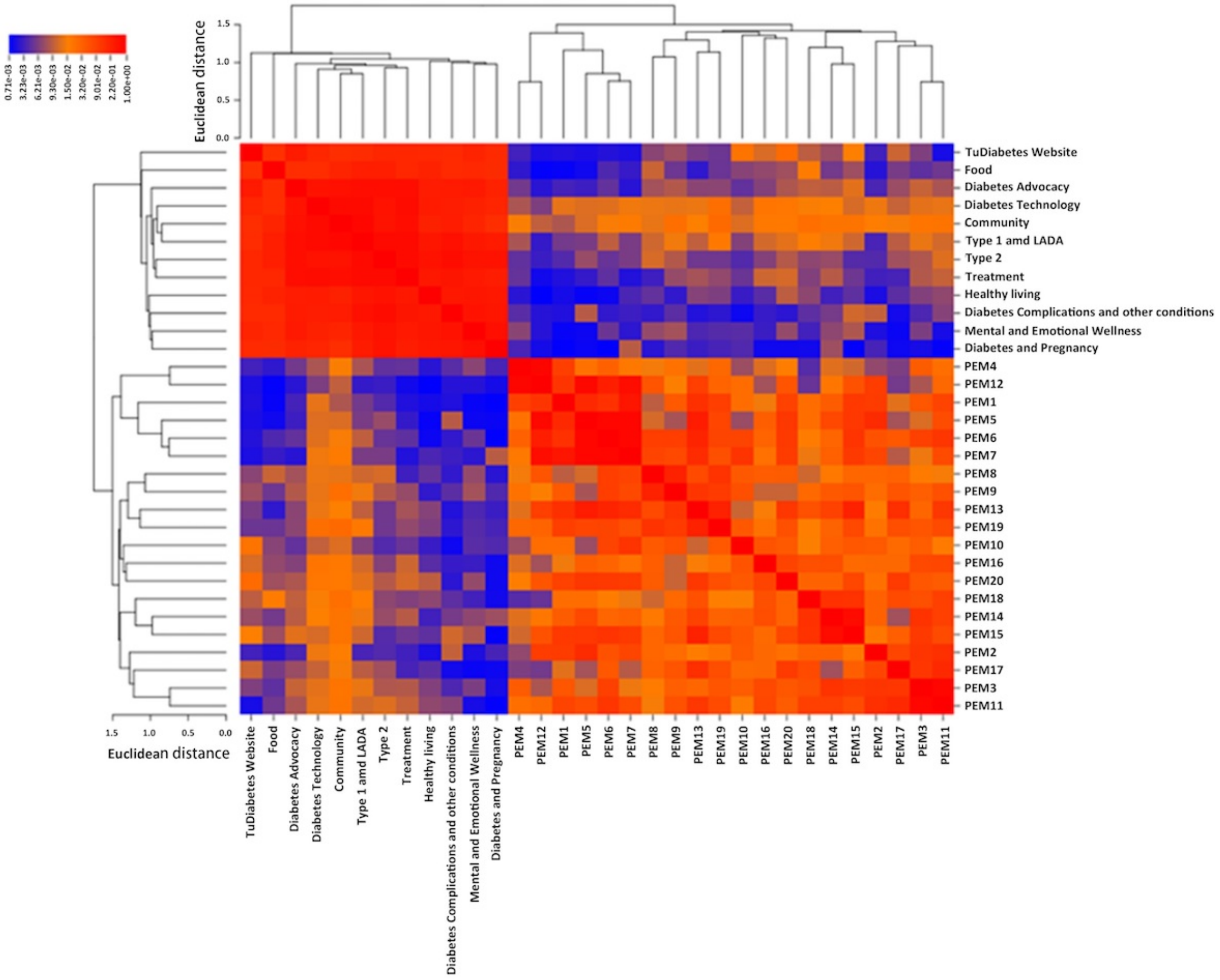
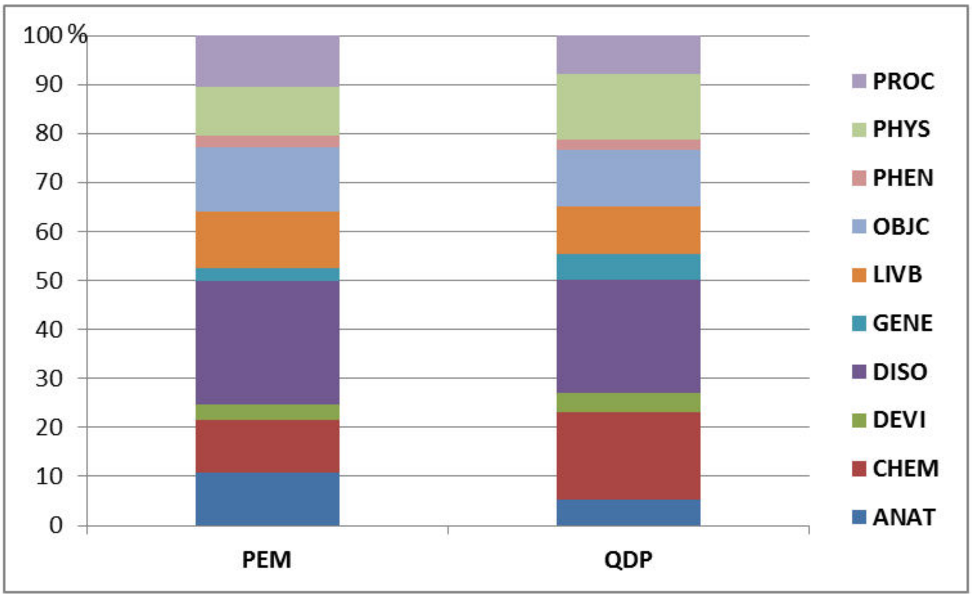


Figure 5. Distribution of 10 clinical semantic groups in the two corpora: questions from diabetic patients (QDP) and patient educational materials (PEM). ANAT: anatomy; CHEM: chemicals and drugs; DEVI: devices; DISO: disorders; GENE: genes and molecular sequences; LIVB: living beings; OBJC: objects; PHEN: phenomena; PHYS: physiology; PROC: procedures.



Network Analysis

Figure 6 shows the networks of topics or semantic groups with questions for those with the topic/semantic group frequency larger than one (ie, question 5220 matched to topic 8 with a topic frequency of 2.22, and question 4124 matched to the physiology semantic group with semantic group frequency of 4.02). In the network of topic modeling-based model (Figure 6), all patient educational materials topics were presented, there were more questions matched to topic 4, topic 8, and topic 9, whereas some topics (eg, topic 1, topic 2, topic 3, or topic 10) were relevant to a small number of questions. Some questions were associated with very specific topics. For example, question 6722 from the diabetes complication and other condition topic in questions from diabetic patients corpus, the content of the question was: “Do you have neuropathy? Introduce yourself here! Foot pain, numbness, nerve pain, does anyone else know what I’m going through? Yes, we do!” It had the unique matching to the PEM13 topic (ie, complication-foot topic). In the network of semantic group-based model (Figure 6), the objects, physiology, and live beings groups had more questions. Similarly, some questions were associated with very specific semantic groups. For example, question 7113 from the diabetes technology topic in the questions from diabetic patients corpus, the content of the question was: “Are you an Accu-Chek user? Jump in here For users of ACCU-CHEK glucose meters.” It was mapped to the devices semantic group. The combination of the two networks (Figure 6) showed that for some questions the two models, topic modeling-based and semantic group-based, were complementary to each other. For example, question 2760 belonged to the diabetes complication and other condition topic in the questions from diabetic patients corpus, the content of the question was: “Balance neuropathy I don’t have the tingling, numbness, painful neuropathy, but the feelings I have in my feet somehow aren’t being delivered to my balance center. I am having a nerve conduction test an electromyography. Any advice?” It is relevant to the complication-foot topic (ie, PEM13) and also to the disorders semantic group.

Performance Comparison

The two experts had a high level of agreement in relevance judgment (κ=0.90). The performance of the three models is presented in Figure 7 and Table 5. The topic modeling-based model outperformed the other two models at each rank, and the semantic group-based model had a better performance than the baseline VSM model. For example, for the top-retrieved document, the precision of the topic modeling-based, semantic group-based, and VSM models were 0.670 (67.0%), 0.628 (62.8%), and 0.543 (54.3%), respectively.

Figure 6. (A) Network formed using the topic modeling-based model (TMB) with topic frequency cutoff 1, (B) network formed based on the semantic group-based model (SGB) with semantic group frequency cutoff 1, and (C) a combined network by linking the two networks (TMB+SGB) based on questions.

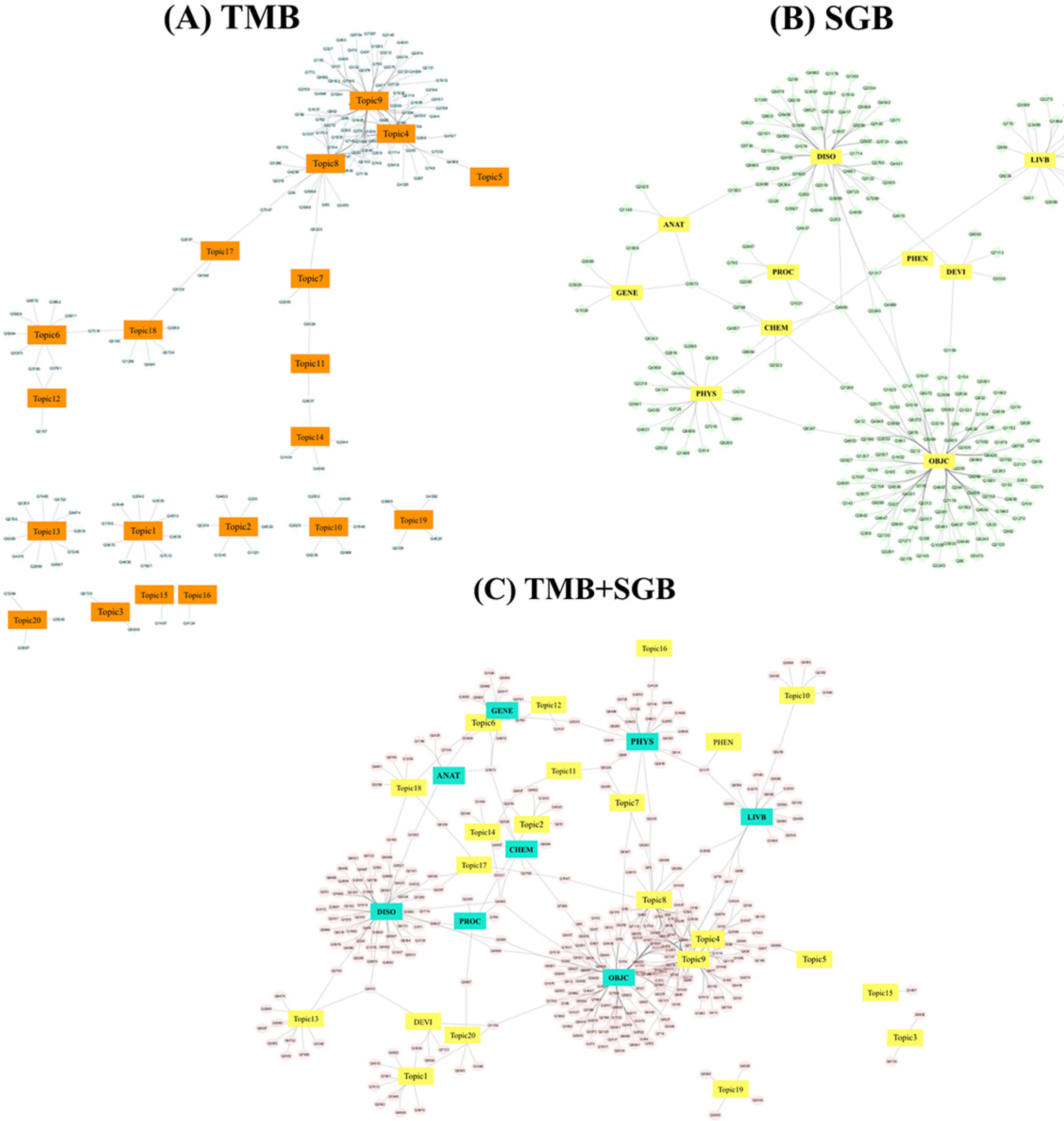
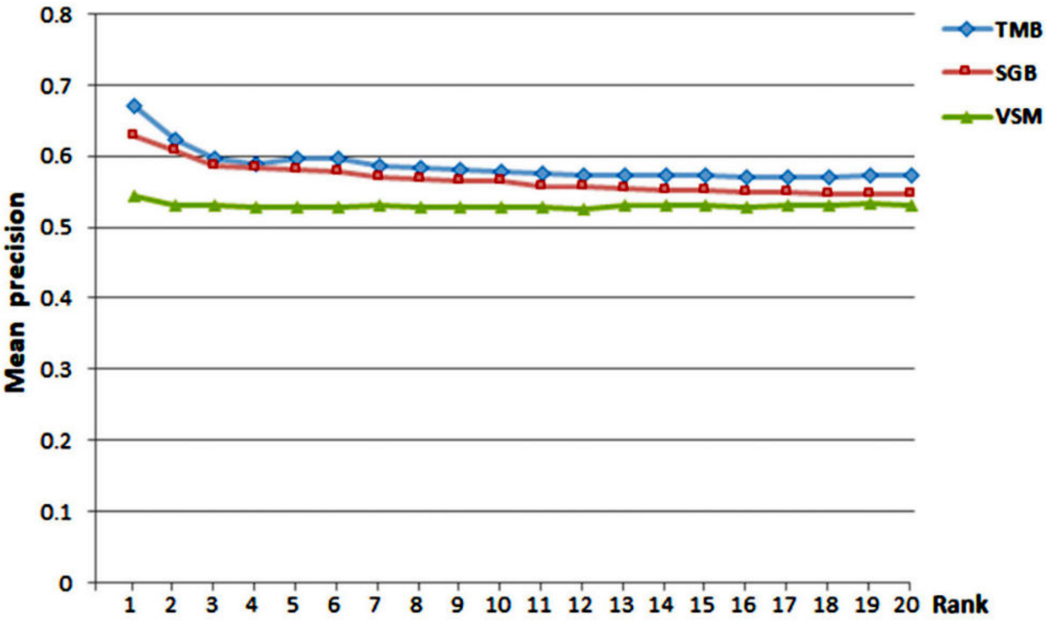


Table 5. Performance comparison of topic modeling-based, semantic group-based, and vector space model (VSM) models.

Model	Mean precision						
	P 1	P 2	P 3	P 4	P 5	P 10	P 20
Topic modeling-based	0.670	0.622	0.596	0.588	0.596	0.579	0.572
Semantic group-based	0.628	0.606	0.585	0.582	0.581	0.564	0.547
VSM	0.543	0.532	0.532	0.529	0.528	0.528	0.531

Figure 7. Precision at rank 1 to 20 for topic modeling-based (TMB), semantic group-based (SGB), and vector space model (VSM) models.



Discussion

In summary, we investigated the use of the state-of-the-art information retrieval approaches to recommend diabetes education materials for questions available in an online forum for diabetes by leveraging a corpus assembled from diabetes education materials and a corpus assembled from an online forum. Our study shows that the language used in patient education materials is different from the language used in questions from an online forum. A topic modeling-based model has the potential to accurately recommend patient education material to a given question. Both topic modeling-based and semantic group-based models outperform the baseline VSM model. Network analysis illustrates that the network formed by topic modeling and the network formed by semantic groups are different and the combination of them may yield a better strategy.

Literature has shown that the language used by patients is different from the one used by clinicians [27]. Our study demonstrated that there is a language difference between patient education materials and questions in an online forum even though the target audiences of patient education materials are the patients. Patient educational materials are often produced internally by hospital staff without sufficient consideration of the patients intended to use them [28]. In our study, patient education materials tend to cover clinical and patient life topics, whereas patients tend to ask about disease-specific technology and treatment from the top words in Table 2. In addition, the semantic group of questions from diabetic patients corpus included mainly chemical drugs, physiology, devices, and gene aspects more than patient educational materials corpus, and these semantic groups also related to complication, treatment, and technology categories. There was consistency between the primary category distribution of questions from diabetic patients and their semantic groups. Therefore, analyzing online forums can identify information needs of patients and provide an opportunity to create patient-centric education materials.

The study demonstrated that topic modeling can mitigate the vocabulary difference between two corpora and achieve the best performance in recommending education materials to questions. In Figure 7, we found that the topic modeling-based model outperformed the other two models. Through topic modeling, topics and their probability distribution can be calculated for analyzing document similarity, which has been explored for document classification and personalized recommendation. For example, the iDoctor used LDA topic modeling for personalized and professionalized medical recommendation based on data available at crowd-sourced review websites [29] and Kandula et al's [18] study also showed that the LDA topic modeling can better recommend patient education material to diabetic patients based on clinical notes. Our network analysis demonstrates that the topic modeling-based and semantic group-based models form two independent networks, which may imply that combining the two automated models has the potential to improve the recommendation.

Here, we only studied one disease and used our institutional patient education materials. More research is needed to see if our findings can be generalized. One direction for future work is to extend our study to other disease areas, other patient education material resources, and online forums.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Information retrieval algorithms.

[PDF File (Adobe PDF File), 128KB - jmir_v19i10e342_app1.pdf]

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Abbreviations

LADA: latent autoimmune diabetes of adulthood
LDA: Latent Dirichlet Allocation
UMLS: Unified Medical Language System
VSM: vector space model

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Original Paper

The Association of Patient Factors, Digital Access, and Online Behavior on Sustained Patient Portal Use: A Prospective Cohort of Enrolled Users

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Abstract

Background: As electronic health records and computerized workflows expand, there are unprecedented opportunities to digitally connect with patients using secure portals. To realize the value of patient portals, initial reach across populations will need to be demonstrated, as well as sustained usage over time.

Objective: The study aim was to identify patient factors associated with short-term and long-term portal usage after patients registered to access all portal functions.

Methods: We prospectively followed a cohort of patients at a large Department of Veterans Affairs (VA) health care facility who recently completed identity proofing to use the VA patient portal. Information collected at baseline encompassed patient factors potentially associated with portal usage, including: demographics, Internet access and use, health literacy, patient activation, and self-reported health conditions. The primary outcome was the frequency of portal log-ins during 6-month and 18-month time intervals after study enrollment.

Results: A total of 270 study participants were followed prospectively. Almost all participants (260/268, 97.0%) reported going online, typically at home (248/268, 92.5%). At 6 months, 84.1% (227/270) of participants had visited the portal, with some variation in usage across demographic and health-related subgroups. There were no significant differences in portal log-ins by age, gender, education, marital status, race/ethnicity, distance to a VA facility, or patient activation measure. Significantly higher portal usage was seen among participants using high-speed broadband at home, greater self-reported ability using the Internet, and routinely going online. By 18 months, 91% participants had logged in to the portal, and no significant associations were found between usage and demographics, health status, or patient activation. When examining portal activity between 6 and 18 months, patients who were infrequent or high portal users remained in those categories, respectively.

Conclusions: Short-term and long-term portal usage was associated with having broadband at home, high self-rated ability when using the Internet, and overall online behavior. Digital inclusion, or ready access to the Internet and digital skills, appears to be a social determinant in patient exposure to portal services.

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KEYWORDS

patient portal; personal health record; Internet; broadband; digital inclusion; social determinants

Introduction

Hopes for personal health records (PHRs) and patient portals run high. The spread of these technologies has been propelled by the US Electronic Health Record Incentive Program and Meaningful Use [1], and consumers' desire to access their health information, email their providers, and request appointments online [2]. As a result, patients and health systems alike increasingly view digital health services as important means to enhance patient access, drive self-care, and improve the care experience [3,4].

As access to broadband Internet grows and citizens increasingly connect to the Internet using mobile devices, there are unprecedented opportunities to expand remote patient services. While the digital divide in the United States narrows, some gaps are likely to persist. Internet use among US adults rose from 64% in 2005 to 84% in 2015, with 74% of adults with low incomes and 78% of rural residents currently online [5]. However, lower use continues among adults with less than a high school education (66%), and those aged 65 years and older (58%) [5]. Disparities have also been seen when comparing patients who do and do not register for a patient portal. Older patients, those with lower levels of education or income, and African-Americans and Hispanics appear less likely to register for portals [6-9]. As health information technology gains sophistication and health systems offer more virtual services, these demographic differences can impact health equity and outcomes.

Evidence on the impact of patient portal use is mixed, depending upon which functions are available and the measures that are examined. Most studies show that portals offer convenience and enhanced patient satisfaction, with users feeling more in control of their care [10,11]. Patients who use secure emails, refill medications, and access their clinical notes and test results may improve self-care and increase adherence to treatments [12-16]. In one study of portal use by patients with diabetes and hypertension, using a secure email and refilling medications online were associated with improved outcomes [17]. Overall, portals show great promise as a key adjunct to, or at times a substitute for, traditional care and communication.

Studying the use of patient portals has been challenging. Measures of portal use vary across studies, and differing patient populations tend to be examined. Patients need to be aware of portal availability, register or enroll, initially sign in online, and ultimately have the capacity to use the portal as their needs arise. Portal registrants, a group frequently presented in studies, may not accurately reflect those using a portal. Additionally, the value of portals to patients and health systems is more complex than measuring usage. However, the repeated and sustained use of portals may serve as a proxy for benefit. Understanding the value of portals, therefore, must at least demonstrate initial reach across a patient population and show sustained usage over time.

Although a digital divide with broadband Internet does exist, adults who are online and have a chronic condition are more likely than other online adults to search for health information, read online reviews about medications and treatments, or use online peer support [18,19]. What is less clear is the degree to which disparities exist among patients registered for a portal who log in more often compared to those with less frequent portal use. In one study, patients refilling medications online were found to have fewer prescription interruptions, and this finding persisted across all racial and ethnic subgroups [20]. Conversely, racial disparities in portal use were found among patients with human immunodeficiency virus, with non-white participants having lower portal use to monitor their treatment outcomes [21].

Studies examining portal usage have largely been cross-sectional or evaluated matched cohorts. We conducted an exploratory study, prospectively following patients newly enrolled to use a portal, and explored factors associated with portal usage over time. The aim of the study was to identify patient factors associated with portal usage at 6 months and 18 months after initial enrollment (among those completing verification in person). We sought to describe short-term and long-term portal usage, and to examine Internet-related or digital divide issues among patients who visited the portal less frequently compared to those who did so more often.

Methods

Design and Setting

Our study was conducted at a large Department of Veterans Affairs (VA) health care facility, where there is a requirement for a patient to complete in-person identity proofing in order to access all portal functions. While this step could prove cumbersome for some, it offered a natural opportunity to examine patients who presumably had some Internet access and were motivated to register for full portal access. We prospectively followed a cohort of VA patients who completed the in-person identity proofing process to fully access the VA's secure portal, My Health *e* Vet (MHV). At the time of the study, patients who verified their identity could use MHV to refill medications, securely email their providers, receive tailored wellness reminders, view appointments, access laboratory test results through the *Blue Button* feature, and search the VA health education library [22].

Patients eligible for the study received care at the VA Portland Health Care System (VAPHCS) and completed identity proofing for MHV. Each VA facility supports staff that assist Veterans in completing the process. At the study site, the MHV office was adjacent to the Outpatient Pharmacy located in the main lobby of the medical center. MHV staff informed patients about the study by handing them an informational flyer. When a patient was interested in the study, a “warm hand-off” was completed: MHV staff contacted research staff by phone or instant messaging, who immediately met with the patient. The study coordinator (ES) consented and enrolled all subjects and conducted a health literacy assessment. All baseline survey questions were completed on paper at the time of enrollment or within 30 days, and returned by mail in a prestamped envelope. Follow-up surveys were conducted at 6 months to collect patient-reported portal usage. Participants were emailed a link to the survey, with two reminders sent. Due to the MHV staff's busy workday, we were unable to collect data on all patients who were informed about the study. Participants received US $20 for the baseline and US $30 for follow-up surveys. The study received approval from the VAPHCS Institutional Review Board.

Measures

The primary outcome measure was the frequency of portal log-ins during 6-month and 18-month time intervals after study enrollment. Log-in data were obtained on all study subjects from the VA's national Connected Health Office, using MHV Activity Reports. These data were an objective measure of portal use, and listed the total number of successful and unsuccessful (incomplete) MHV log-ins for each study subject.

The study collected information on factors potentially associated with portal usage. Baseline patient measures included: demographics; distance to a VA facility; and technology access and use, including type and location of Internet connection, comfort with computers, and regular online activity (eg, emailing, shopping, social networking, and searching for health information). To assess patients' overall use of the Internet, a composite *Internet Use Behavior* measure was created that included 11 online activities: accessing the Internet; email; general search; health search; shopping; banking; geolocation; visiting any social network site; registration on any site; posting on any site; and using Facebook, MySpace, or LinkedIn. High Internet use represented going online for at least 7 activities. Health literacy was approximated using the Short Form Functional Health Literacy Assessment (S-TOFHLA) [23]. Level of patient engagement in their health and health care was measured using the Patient Activation Measure (PAM), which is a validated, 13-item instrument [24]. Subjects were asked to self-report their health status and presence of diabetes, hypertension, heart disease, arthritis, depression, tobacco use, asthma, or chronic pulmonary disease. Questions also solicited beliefs about PHRs, how subjects learned about MHV, and prior training on the use of MHV. Subjects were asked about their expectations for using MHV and its available functions.

Analysis

Baseline characteristics and outcomes were described using frequencies and percentages for the categorical outcomes. Due to the nonnormal distribution of log-ins over time, portal usage was categorized into 4 distinct categories at each time interval. For 6 months, categories included: 0 or 1 log-in, 2 to 5 log-ins, 6 to 11 log-ins, and 12 or more log-ins. Similarly, at 18 months the categories included: 0 to 2 log-ins, 3 to 17 log-ins, 18 to 35 log-ins, and 36 or more log-ins. These 4 categories of log-ins approximately corresponded to portal use frequencies of never/rare use, less than monthly, once or twice per month, and more than twice per month, respectively. To examine the association between frequency of patient portal use and individual patient characteristics, perceptions, and self-reported behavior, we used univariate Chi-square tests. The associations examined frequency of log-ins during the 6-month period after enrollment, the 18-month period after enrollment, between 6 and 18 months, and all patient factors, including demographics (eg, education, income), self-reported health status, PAM score, and S-TOFHLA score. Statistical significance was set at the alpha=0.05 level. All analyses were completed using Stata 14.0 [25].

Results

A total of 270 participants were enrolled from December 13, 2010 to January 24, 2012 and completed baseline surveys. Portal usage was followed for 18 months after the date of consent, from mid-June 2013 through the end of July 2013. A total of 230 participants (230/270, 85.2%) completed follow-up surveys. VA enterprise-level MHV log-in data on all participants for the full 18-month time frame became available to the investigators in 2015.

The study cohort was comprised mostly of men (228/269, 84.8%) who were white (223/270, 82.6%) and over the age of 50 years (184/270, 68.1%; Multimedia Appendix 1). Representation from women (41/269, 15.2%) was somewhat greater than the VA population of approximately 12% [26]. Fewer than 1 in 5 (46/258, 17.8%) participants had a high school education or less, approximately half completed some college (127/256, 49.2%), and one-third were college graduates (85/258, 32.9%). Health literacy screening found 98.1% (261/266) of participants in the adequate category. A total of 48.7% (128/263) of participants stated their health status as fair or poor, with only 15.0% (40/266) reporting not having a chronic condition or disability; 38.7% (103/266) resided more than a one-hour drive from the nearest VA facility.

Almost all study participants (260/268, 97.0%) reported going online at least occasionally, most commonly at home (248/268, 92.5%). A total of 32.3% (86/266) rated their computer ability as intermediate and 57.5% (153/266) rated it as advanced. Just over half (144/266, 54.1%) of the respondents indicated that they had used public Wi-Fi at an airport, coffee shop, or restaurant, while 41.9% (111/265) went online using a mobile device such as an iPhone or other mobile phone or tablet. Most respondents indicated that they had searched online to find information (256/269, 95.2%), to map a specific location (254/268, 94.8%), to shop or purchase a product (219/269, 81.4%), and for banking to pay bills (203/267, 76.0%).

Short-term use of the portal was examined by analyzing the number of successful log-ins for each study participant in the 6 months following study enrollment. Long-term usage examined the total portal log-ins over 18 months. Log-ins were also measured during the time interval between 6 and 18 months following study enrollment. The distribution of log-ins for each time period is shown in Figure 1 and Figure 2, respectively (total log-ins are capped at 78 for 6-months, and at 234 for 18-months). At 6 months, the mean number of log-ins was 14.1 (standard deviation [SD] 22.7), with a median of 7, a minimum of 0, and a maximum of 169 log-ins; 75.9% (205/270) of participants had 17 or fewer log-ins. At 18 months, the mean number of log-ins was 34.8 (SD 48.7), with a median of 17, a minimum of 0, and a maximum of 407 log-ins; 75.2% (203/270) of participants had 49 or fewer log-ins.

Portal usage at 6 months, as measured by successful log-ins, is shown in Table 1. Log-in count is shown in four categories: 0 or 1 log-ins; 2 to 5 log-ins, or approximately less than once per month; 6 to 11 log-ins, or once/twice per month; and 12 or more log-ins, or over twice per month. Six months after having full access to all portal functions, approximately one-third of patients logged in less than once per month, and half logged in approximately monthly or more. Just under 16% (43/270) of patients had never logged in over 6 months.

Six-month portal usage demonstrated some variation across demographic and health-related subgroups; however, there were no statistically significant differences in log-in behavior by age, gender, education level, marital status, race/ethnicity, or distance to a VA facility. Likewise, self-reported health status, having a specific chronic condition, smoking status, or previously obtaining copies of health records were not significantly associated with variation in usage. The baseline PAM was not predictive of future short-term patient portal usage.

Table 2 shows the relationship between portal usage and participants' reports of their technology access and Internet-related factors. Expected differences were found in the use of the portal, with significantly greater usage among those having Internet at home, having a high-speed broadband connection, and greater self-reported ability to use the Internet. The 42.5% (113/266) of participants who reported novice or intermediate abilities using the Internet used the portal less often compared to subjects reporting advanced Internet skills. More frequent log-ins were observed for regular email users, and those who were online more often, or who more frequently searched for health information. Our composite *Internet Use* measure found that while 80.3% (217/270) of the cohort fell into the *high use* category, 43.4% (23/53) of participants in the low use category never logged in or did so only once.

Patient concerns about online privacy showed no significant relationship to portal usage. Higher numbers of portal log-ins were associated with learning about MHV by reading promotional materials or from recommendations by a clinician. Portal use was also higher in participants who had visited MHV prior to completing the in-person verification step for a full access account. Participants' views of anticipated use of specific portal functions appeared to play little role in future portal usage.

Portal usage during the 18-month period is shown in Table 3. By 18 months, never-users decreased to 9%, showing a delay in first use for some patients. Similar to the 6-month results, no significant associations were found between usage and demographics, self-reported health status, or PAM score. When assessing participant self-reports of comorbid conditions, there was a trend showing higher usage associated with having more chronic conditions, although this trend was not statistically significant. Overall use of the Internet was strongly associated with long-term portal use, similar to short-term use (data not shown).

When examining portal log-in frequency during the time interval between 6 and 18 months, as shown in Table 4, the trend between chronic conditions and log-ins was no longer observed.

Log-ins during the first 6 months after enrollment were compared to portal activity during the time interval between 6 and 18 months. Shown in Table 5, patients who rarely used the portal most commonly remained in that category. Similarly, greater usage during the first 6 months led to similar log-in behavior during the later time interval.

Many participants experienced an unsuccessful log-in during the study period; this occurred when a user entered an invalid username or password. At 6 months, a total of 169 subjects (169/270, 62.6%) had at least one unsuccessful log-in with a mean of 3.5 unsuccessful log-in attempts (SD 5.9). At 18 months, 214 subjects (217/270, 79.3%) experienced at least one unsuccessful log-in with a mean of 7.6 (SD 11.2) unsuccessful attempts.

Figure 1. Distribution of the number of patient logins 6 months following full portal access. Total logins are capped, with participants having 78 or more logins shown at the highest count.

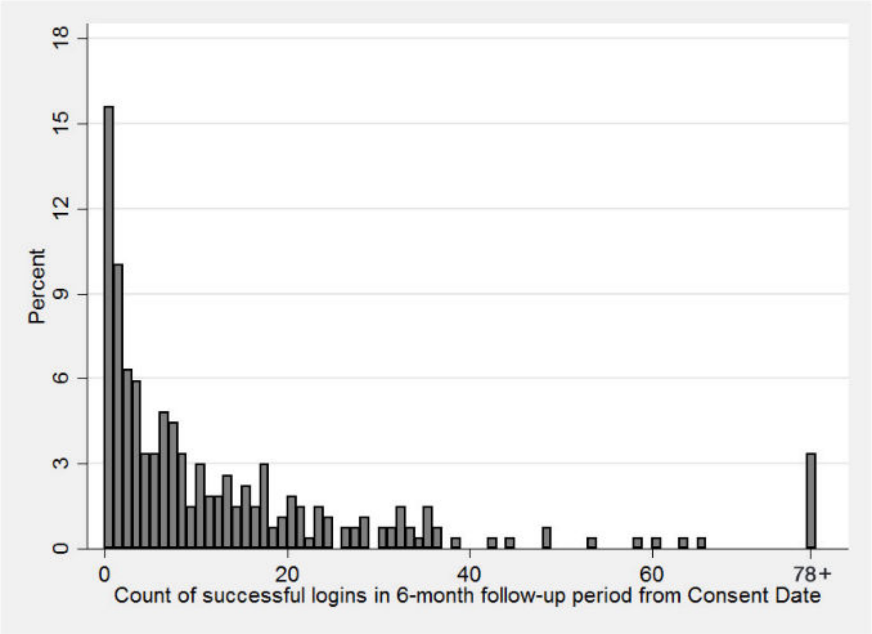

Table 1. Association of demographics and health factors with portal usage 6 months after full access.

Parameter	0 or 1 log-ins, n=69 (25.5%)	2-5 log-ins, n=51 (18.9%)	6-11 log-ins, n=51 (18.9%)	12+ log-ins, n=99 (36.7%)	*P*-value
Gender (%)					.63
Male	60 (88.2)	41 (80.4)	42 (82.4)	85 (85.9)	
Female	8 (11.8)	10 (19.6)	9 (17.7)	14 (14.1)	
Age (%)					.19
18-40	14 (20.6)	10 (19.6)	6 (11.8)	12 (12.1)	
41-50	14 (20.6)	9 (17.7)	6 (11.8)	14 (14.1)	
51-60	11 (16.2)	13 (25.5)	17 (33.3)	23 (23.2)	
61-70	24 (35.3)	16 (31.4)	16 (31.4)	47 (47.5)	
71+	5 (7.4)	3 (5.9)	6 (11.8)	3 (3.0)	
Race/Ethnicity (%)					.10
White	52 (75.4)	40 (78.4)	47 (92.2)	84 (84.9)	
Black	6 (8.7)	0 (0.0)	2 (3.9)	3 (3.0)	
Hispanic	2 (2.9)	3 (5.9)	0 (0.0)	4 (4.0)	
Other/unknown	9 (13)	8 (15.7)	2 (3.9)	8 (8.1)	
Education (%)					.12
HS or less	12 (19.1)	2 (4.1)	8 (16.3)	24 (24.7)	
Some college	30 (47.6)	29 (59.2)	23 (46.9)	45 (46.4)	
College+	21 (33.3)	18 (36.7)	18 (36.7)	28 (28.9)	
Marital Status (%)					.68
Single/widowed	17 (25.0)	11 (22.5)	10 (20.0)	16 (16.7)	
Married	31 (45.6)	27 (55.1)	25 (50.0)	57 (59.4)	
Divorced	20 (29.4)	11 (22.5)	15 (30.0)	23 (24.0)	
Self-Rated Health Status (%)					.47
Excellent	5 (7.5)	4 (8.2)	4 (8.2)	5 (5.1)	
Good	32 (47.8)	18 (36.7)	19 (38.8)	48 (49.0)	
Fair	25 (37.3)	24 (49)	22 (44.9)	31 (31.6)	
Poor	5 (7.5)	3 (6.1)	4 (8.2)	14 (14.3)	
Patient Activation Level (%)					.14
Level 1	9 (13.9)	1 (2.0)	8 (15.7)	23 (23.2)	
Level 2	14 (21.5)	11 (21.6)	10 (19.6)	14 (14.1)	
Level 3	16 (24.6)	18 (35.3)	15 (29.4)	25 (25.3)	
Level 4	26 (40)	21 (41.2)	18 (35.3)	37 (37.4)	
Sought Medical Records (%)					.37
No	28 (41.8)	21 (41.2)	19 (37.3)	29 (29.9)	
Yes	39 (58.2)	30 (58.8)	32 (62.8)	68 (70.1)	
Medical Comorbidities (%)					
Hypertension	43 (69.4)	29 (58.0)	33 (64.7)	61 (64.2)	.67
Heart Disease/Failure	13 (23.2)	8 (18.6)	8 (18.2)	24 (27.6)	.55
Asthma	10 (18.5)	9 (20.5)	9 (20.9)	14 (17.5)	.96
Diabetes	13 (22.8)	13 (30.2)	10 (23.8)	30 (32.6)	.53
Chronic Lung Disease	6 (11.1)	7 (15.9)	8 (17.8)	15 (18.1)	.72

Parameter	0 or 1 log-ins, n=69 (25.5%)	2-5 log-ins, n=51 (18.9%)	6-11 log-ins, n=51 (18.9%)	12+ log-ins, n=99 (36.7%)	*P*-value
Long term disability	38 (61.3)	32 (65.3)	24 (54.6)	50 (58.8)	.75
Number of Medical Comorbidities (%)					.18
None	13 (19.7)	10 (19.6)	5 (9.8)	12 (12.2)	
1 or 2	34 (51.5)	22 (43.1)	35 (68.6)	52 (53.1)	
3+	19 (28.8)	19 (37.3)	11 (21.6)	34 (34.7)	
Smoking Status (%)					.88
Never	17 (25.0)	13 (25.5)	12 (25.0)	21 (21.2)	
Former	31 (45.6)	22 (43.1)	26 (54.2)	49 (49.5)	
Current	20 (29.4)	16 (31.4)	10 (20.8)	29 (29.3)	
Time to nearest VA (%)					.59
0-30 minutes	15 (22.7)	12 (24.0)	15 (29.4)	31 (31.3)	
31-60 minutes	21 (31.8)	22 (44.0)	16 (31.4)	31 (31.3)	
60+ minutes	30 (45.5)	16 (32.0)	20 (39.2)	37 (37.4)	

Figure 2. Distribution of the number of patient logins 18 months following full portal access. Total logins are capped, with participants having 234 or more logins shown at the highest count.

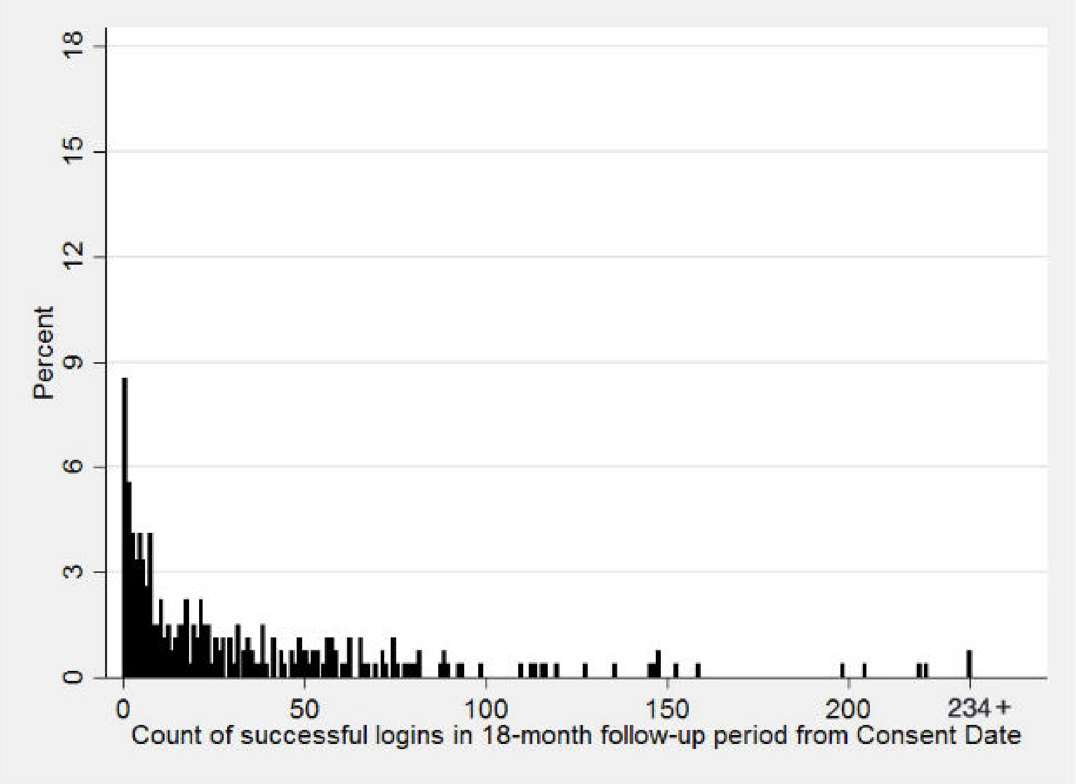

Table 2. Association of Internet access and online activity with portal usage 6 months after full access.

Parameter	0 or 1 Log-ins, n=69 (25.5%)	2-5 Log-ins, n=51 (18.9%)	6-11 Log-ins, n=51 (18.9%)	12+ Log-ins, n=99 (36.7%)	*P*-value
Where do you access the Internet (choose all; %)					
Home	57 (85.1)	47 (92.2)	49 (96.1)	95 (96.0)	.046
Friend/relative’s	20 (29.9)	21 (41.2)	11 (21.6)	18 (18.2)	.017
Work	18 (26.9)	11 (21.6)	13 (25.5)	20 (20.2)	.75
School	8 (11.9)	11 (21.6)	5 (9.8)	9 (9.1)	.151
Where do you access the Internet most frequently (%)					.025
Home	51 (76.1)	44 (86.3)	46 (90.2)	91 (91.9)	
Other	16 (23.9)	7 (13.7)	5 (9.8)	8 (8.1)	
Connection Speed at Home (%)					.012
Not sure/none	10 (14.9)	2 (3.9)	2 (3.9)	3 (3.0)	
Dial-up	6 (9.0)	3 (5.9)	2 (3.9)	2 (2.0)	
High-speed	51 (76.1)	46 (90.2)	47 (92.2)	94 (95.0)	
Ability in Using Internet (%)					.005
Beginner	14 (20.9)	5 (10.0)	3 (5.9)	5 (5.1)	
Intermediate	25 (37.3)	10 (20.0)	17 (33.3)	34 (34.7)	
Advanced	28 (41.8)	35 (70.0)	31 (60.8)	59 (60.2)	
Do/Did you use the Internet to… (%)					
Email yesterday	45 (70.3)	38 (79.2)	46 (92.0)	84 (89.4)	.004
Use search yesterday	42 (62.7)	35 (70.0)	46 (90.2)	81 (81.8)	.002
Shop online	50 (73.5)	42 (82.4)	40 (78.4)	87 (87.9)	.12
Bank or bill pay online	46 (67.7)	39 (76.5)	41 (82.0)	77 (78.6)	.27
Find location of place	60 (89.6)	46 (90.2)	49 (98.0)	98 (99.0)	.015
Look for health Information	56 (82.4)	46 (90.2)	46 (90.2)	96 (97.0)	.016
Sign-up for health alerts	12 (17.7)	19 (37.3)	15 (29.4)	36 (36.4)	.045
Internet Use Behavior[a] (%)					.007
High	46 (66.7)	43 (84.3)	41 (80.4)	87 (87.9)	
Low	23 (33.3)	8 (15.7)	10 (19.6)	12 (12.1)	
Concern about privacy of health information online (%)					.28
Very	35 (51.5)	22 (43.1)	16 (31.4)	38 (38.4)	
Somewhat	20 (29.4)	17 (33.3)	17 (33.3)	29 (29.3)	
Not concerned	13 (19.1)	12 (23.5)	18 (35.3)	32 (32.3)	
How did you learn about MHV (%)					.011
Poster/flyer	13 (18.8)	9 (17.7)	13 (25.5)	29 (29.3)	
Doctor/nurse	11 (15.9)	22 (43.1)	12 (23.5)	27 (27.3)	
Other[b]	45 (65.2)	20 (39.2)	26 (51.0)	43 (43.4)	
Very interested in using MHV to… (choose all; %)					
Look at lab/test results	55 (80.9)	44 (86.3)	43 (86.0)	86 (87.8)	.66
Check for mistakes	36 (52.9)	26 (52.0)	25 (49.0)	57 (57.6)	.77

Parameter	0 or 1 Log-ins, n=69 (25.5%)	2-5 Log-ins, n=51 (18.9%)	6-11 Log-ins, n=51 (18.9%)	12+ Log-ins, n=99 (36.7%)	*P*-value
Track weight, blood pressure, etc.	41 (60.3)	39 (76.5)	29 (56.9)	73 (74.5)	.04
Schedule appointments	49 (72.1)	40 (78.4)	37 (75.5)	79 (79.8)	.69
Refill medication	53 (77.9)	46 (90.2)	45 (88.2)	90 (90.9)	.08
View care reminder	53 (77.9)	41 (80.4)	38 (76.0)	82 (83.7)	.69
Email doctor or nurse	37 (54.4)	37 (72.6)	33 (66.0)	70 (70.7)	.11
Learn about health condition	54 (79.4)	45 (88.2)	36 (70.6)	83 (83.8)	.11
Visited MHV website before Premium Account (%)					.003
No, never	42 (62.7)	22 (44.9)	21 (42.9)	30 (30.6)	
Yes, <once/ week	12 (17.9)	16 (32.7)	14 (28.6)	28 (28.6)	
Yes, once/week or more	13 (19.4)	11 (22.5)	14 (28.6)	40 (40.8)	

[a] High Internet Use Behavior represents doing 7 of 11 online activities, including: accessing the Internet; email; general search; health search; shopping; banking; geolocation; visiting any social network site; registration on any site; posting on any site; and using Facebook, MySpace, or LinkedIn

[b] Category of *Other* includes Friend, Other Patient, VA Website, MHV Booth, and individual write-in.

Table 3. Association of demographics and health factors with portal usage 18 months after full access.

Parameter	0-2 Log-ins, n=49 (18.1%)	3-17 Log-ins, n=87 (32.2%)	18-35 Log-ins, n=46 (17.1%)	36+ Log-ins, n=88 (32.6%)	*P*-value
Age, years (%)					0.14
18-40	10 (20.8)	15 (17.2)	7 (15.2)	10 (11.4)	
41-50	9 (18.8)	19 (21.8)	5 (10.9)	10 (11.4)	
51-60	8 (16.7)	22 (25.3)	10 (21.7)	24 (27.3)	
61-70	17 (35.4)	26 (29.9)	18 (39.1)	42 (47.7)	
71+	4 (8.3)	5 (5.8)	6 (13.0)	2 (2.3)	
Self-Rated Health (%)					0.24
Excellent	6 (12.8)	4 (4.7)	5 (11.4)	3 (3.5)	
Good	21 (44.7)	33 (38.4)	20 (45.5)	43 (50.0)	
Fair	16 (34.0)	42 (48.8)	15 (34.1)	29 (33.7)	
Poor	4 (8.5)	7 (8.1)	4 (9.1)	11 (12.8)	
Medical Comorbidities (%)					
Hypertension	36 (73.5)	43 (49.4)	27 (58.7)	60 (68.2)	0.017
Heart disease	11 (22.5)	10 (11.5)	13 (28.3)	19 (21.6)	0.10
Asthma	6 (12.2)	18 (20.7)	4 (8.7)	14 (15.9)	0.28
Diabetes	11 (22.5)	18 (20.7)	9 (19.6)	28 (31.8)	0.27
Lung disease	5 (10.2)	8 (9.2)	9 (19.6)	14 (15.9)	0.29
Long term disability	30 (61.2)	49 (56.3)	23 (50.0)	42 (47.7)	0.41
Number of Health Conditions (%)					0.07
None	4 (8.5)	21 (24.7)	5 (10.9)	10 (11.4)	
1 or 2	29 (61.7)	39 (45.9)	29 (63.0)	46 (52.3)	
3+	14 (29.8)	25 (29.4)	12 (26.1)	32 (36.4)	
Patient Activation Level (%)					0.15
Level 1	4 (8.7)	9 (10.5)	8 (17.4)	20 (22.7)	
Level 2	8 (17.4)	17 (19.8)	10 (21.7)	14 (15.9)	
Level 3	15 (32.6)	29 (33.7)	6 (13.0)	24 (27.3)	
Level 4	19 (41.3)	31 (36.1)	22 (47.8)	30 (34.1)	

Table 4. Association of demographics and health factors with portal between 6 months and 18 months after full access.

Parameter	0-2 log-ins, n=88 (32.6%)	3-11 Log-ins, n=56 (20.7%)	12-23 Log-ins, n=44 (16.3%)	24+ Log-ins, n=82 (30.4%)	*P*-value
Age, years (%)					0.24
18-40	15 (17.2)	13 (23.2)	4 (9.1)	10 (12.2)	
41-50	18 (20.7)	12 (21.4)	5 (11.4)	8 (9.8)	
51-60	21 (24.1)	10 (17.9)	12 (27.3)	21 (25.6)	
61-70	26 (29.9)	19 (33.9)	20 (45.5)	38 (46.3)	
71+	7 (8.1)	2 (3.6)	3 (6.8)	5 (6.1)	
Self-Rated Health (%)					0.34
Excellent	8 (9.3)	2 (3.6)	5 (11.9)	3 (3.8)	
Good	32 (37.2)	25 (45.5)	19 (45.2)	41 (51.3)	
Fair	40 (46.5)	20 (36.4)	14 (33.3)	28 (35.0)	
Poor	6 (7.0)	8 (14.6)	4 (9.5)	8 (10.0)	
	8 (9.3)	2 (3.6)	5 (11.9)	3 (3.8)	
Medical Comorbidities (%)					
Hypertension	52 (59.1)	29 (51.8)	30 (68.2)	55 (67.1)	0.23
Heart disease	15 (17.1)	10 (17.9)	11 (25.0)	17 (20.7)	0.72
Asthma	16 (18.2)	9 (16.1)	3 (6.8)	14 (17.1)	0.37
Diabetes	20 (22.7)	9 (16.1)	10 (22.7)	27 (32.9)	0.14
Lung disease	9 (10.2)	5 (8.9)	7 (15.9)	15 (18.3)	0.30
Long term disability	50 (56.8)	32 (57.1)	23 (52.3)	39 (47.6)	0.60
Number of Medical Comorbidities (%)					0.56
None	14 (16.5)	11 (20.0)	7 (15.9)	8 (9.8)	
1 or 2	45 (52.9)	31 (56.4)	24 (54.6)	43 (52.4)	
3+	26 (30.6)	13 (23.6)	13 (29.6)	31 (37.8)	

Table 5. Relationship of portal usage in the 6 months after enrollment and from 6 to 18 months.

		Successful log-ins group at 6 months			
		Rarely/never (0-1), n (%)	Less than once a month (2-5), n (%)	Monthly to bimonthly (6-11), n (%)	Bimonthly or more (12+), n (%)
Successful log-ins group from (6 month to 18 months)	Rarely/never (0-2)	46 (66.7)	25 (49.0)	13 (25.5)	4 (4.0)
	Less than once a month (3-11)	15 (21.7)	15 (29.4)	14 (27.5)	12 (12.1)
	Monthly to bimonthly (12-23)	6 (8.7)	8 (15.7)	12 (23.5)	18 (18.2)
	Bimonthly or more (24+)	2 (2.9)	3 (5.9)	12 (23.5)	65 (65.7)

Discussion

Among this VA cohort who took active steps to enroll in, and gain access to, patient portal functions, short-term and long-term portal usage were significantly associated with having broadband Internet at home, high self-rated ability to use the Internet, and overall online behavior. Access to broadband Internet has emerged as a social determinant of health [27], defined as, "a condition in which people are born, grow, live, work, and age, and which shapes their health status" [28]. As virtual health care becomes more commonplace, affordable broadband Internet and devices, and digital know-how, will be needed to ensure equity in care services [29].

In 2009, Kahn et al [30] identified Internet access and digital skills as being vital for the success of PHRs, stating, "if these are not made policy priorities, PHRs risk becoming a tool that is limited to groups of people who are already linked to the Internet with high health literacy and computer skills." Our study findings indicate that ready access to the Internet and digital skills, often referred to as *digital inclusion* [31] and broader in scope than Internet access, appears to be a social determinant for exposure to patient portal services. These results expand upon prior research showing that portal adoption is associated with digital competency and Internet access [32], with usage dependent upon user skills and user-centered design of digital tools [33,34].

We expected to find that patient activation was related to more frequent portal use, but this was not the case. Limited studies examining this relationship have produced varied findings. One study found modest increases in PAM scores in portal users compared to a control group [35]. Others found no significant change in PAM scores among patients with chronic illness who were given access to a portal [36], and no association between PAM and portal log-in frequency [37]. Given our findings correlating portal use and digital access and skills, a more complex relationship likely exists between patient activation and online behavior. Larger prospective studies capturing patients' digital environments and behaviors could offer greater insights into a patient's context and clinical trajectory that are certain to play a role in portal usage (eg, a new diagnosis or worsening of a health condition). It is also important to characterize *stops along the way* to sustained use of digital tools [38]. Each step on the journey of patient portal engagement presents barriers and drivers to continued use [39]. Researchers should specify their targets, as there are several, including: patients routinely given a code to establish an account (which can occur with or without Internet access); patients who activate their accounts or log in at least once to test it; and ultimately, patients with sustained portal usage.

Expanding health care to virtual channels may create greater care disparities among those without affordable and reliable access to the Internet or digital devices. A focus on mutable factors that can positively impact the reach and meaningful use of portals is essential. Marketing and promotion is important, since patients may not be aware of portals, or do not perceive their value [40]. Kaiser Permanente has made a digital strategy an operational goal, and has achieved a high rate of portal engagement and use, by routinely enrolling all members and making benefits clear [41]. Clinicians also play a key role in promoting portals and elevating their significance (eg, by offering the option of secure email and explaining its appropriate use) [42].

Once online, patients will need to easily navigate portals and be able to intuitively use the tools to meet their needs, which is a necessity for sustained usage [43-45]. As consumer trends show shifts in digital devices toward mobile options, patient-facing tools need to be device agnostic. In the United States, low-income adults in particular are increasingly accessing the Internet only via mobile devices [46]. Studies in safety net and senior populations show that many people in these groups have mobile phones, and smartphones are increasingly substituting for computers [47].

Finally, user-centered designs that optimize portal usability will amplify their use [48]. Ease of entry is critical to patient satisfaction. Even the presumably simple task of securely logging-in can challenge users. Indeed, we found that many participants experienced unsuccessful log-ins. Usability challenges have been found in the VA portal, including complex password requirements for log-in [49]. Balancing security with usability is critical; users facing difficulty logging into a portal may abandon efforts altogether.

The capability to effectively use the Internet is vital for health care, as well as for education and employment. Society's digital revolution is evolving faster than our ability to accurately measure and demonstrate digital competence across all populations [50,51]. At a minimum, health care and public health stakeholders should align across industry sectors, partnering for economic development and investment to improve community broadband and digital literacy, in an effort to achieve digital inclusion.

Limitations

There are limitations to our study. Patients were recruited at a single VA facility, and may not represent a general population of patients or those enrolling for the portal. Participants may be more computer-savvy than the general portal user population. Many participants visited the MHV website before the study (VA patients who register but do not complete identify proofing can refill medications using a prescription number). The study setting in a busy MHV office precluded capturing data on all patients informed about the study. However, such issues could potentially underestimate challenges that users faced using the portal. Second, measuring the portal served as a proxy for usage and benefit. While standardized metrics for capturing patient usage of digital tools have not been established, common measures include initial enrollment, log-in frequency, and using specific functions [34]. Measuring total log-ins during 6-month and 18-month intervals is not ideal; however, repeated log-ins over time signals user value. Third, our health literacy assessment found virtually all patients at the highest level of the S-TOFHLA; the acceptability of this instrument has since been questioned [52]. Finally, study subjects may have experienced inconsistent connections to the Internet over the study, complicating the measurements of associations between digital inclusion and portal use.

Conclusion

The ultimate impact of patient portals will rest on their ability to reach across populations and have real-world effects on self-care and outcomes. Realizing potential benefits will require not just initial adoption but also sustained portal usage. Strategies and novel methods to enhance comfort with digital devices and increase Internet skills, along with affordable access to broadband and wireless connections, are required ingredients as the health care community offers an increasing array of online tools and services. There are important relationships between digital inclusion and the use and benefits of virtual care tools.

Conflicts of Interest

Judith Hibbard is a consultant to, and equity stakeholder in, Insignia Health. All other authors declare no conflicts of interest.

Multimedia Appendix 1

Study cohort self-reported demographics, conditions, patient activation, and Internet access.

[PDF File (Adobe PDF File), 24KB - jmir_v19i10e345_app1.pdf]

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Abbreviations

MHV: My HealtheVet
PAM: Patient Activation Measure
SD: standard deviation
S-TOFHLA: Short Form Functional Health Literacy Assessment
VA: Veterans Affairs

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Original Paper

Veterans' Preferences for Exchanging Information Using Veterans Affairs Health Information Technologies: Focus Group Results and Modeling Simulations

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Abstract

Background: The Department of Veterans Affairs (VA) has multiple health information technology (HIT) resources for veterans to support their health care management. These include a patient portal, VetLink Kiosks, mobile apps, and telehealth services. The veteran patient population has a variety of needs and preferences that can inform current VA HIT redesign efforts to meet consumer needs.

Objective: This study aimed to describe veterans' experiences using the current VA HIT and identify their vision for the future of an integrated VA HIT system.

Methods: Two rounds of focus group interviews were conducted with a single cohort of 47 veterans and one female caregiver recruited from Bedford, Massachusetts, and Tampa, Florida. Focus group interviews included simulation modeling activities and a self-administered survey. This study also used an expert panel group to provide data and input throughout the study process. High-fidelity, interactive simulations were created and used to facilitate collection of qualitative data. The simulations were developed based on system requirements, data collected through operational efforts, and participants' reported preferences for using VA HIT. Pairwise comparison activities of HIT resources were conducted with both focus groups and the expert panel. Rapid iterative content analysis was used to analyze qualitative data. Descriptive statistics summarized quantitative data.

Results: Data themes included (1) current use of VA HIT, (2) non-VA HIT use, and (3) preferences for future use of VA HIT. Data indicated that, although the Secure Messaging feature was often preferred, a full range of HIT options are needed. These data were then used to develop veteran-driven simulations that illustrate user needs and expectations when using a HIT system and services to access VA health care services.

Conclusions: Patient participant redesign processes present critical opportunities for creating a human-centered design. Veterans value virtual health care options and prefer standardized, integrated, and synchronized user-friendly interface designs.

(J Med Internet Res 2017;19(10):e359) doi:10.2196/jmir.8614

KEYWORDS

communication; patient participation; quality improvement; health information technology; medical informatics; patient portal; personal health record; telehealth; kiosk; mhealth

Introduction

Patients often have busy schedules and competing priorities and want to control how and when they receive health services to meet their personal needs [1]. They often prefer to complete health-related tasks quickly and efficiently. In recognizing the needs of patients and their demand for convenient, continuous care, the Department of Veterans Affairs (VA) provides health information technology (HIT) resources that put veterans at the helm of their care. VA HIT complements traditional means of service delivery (eg, face-to-face, telephone, mail) and gives veterans the power to maximize the efficiency and convenience of their health care experience [2].

VA's remotely accessible HIT systems and apps include the My HealtheVet (MHV) patient portal, VetLink Kiosks, mobile apps, and telehealth services [3]. VA HIT supports veterans and their informal caregivers as active and informed proactive partners in their health care [4]. These tools help users manage appointments, keep track of medications, log personal health journals, record personal health care information and health measurements (eg, diet, physical activity, vital signs), communicate with their health care team, and access their electronic health record (EHR) [5].

The VA has embraced the era of virtual health care delivery and initiated national efforts to redesign and reorganize HIT services. To ensure that HIT reflects veterans' needs and supports their sustained use [5,6], the VA has leveraged human-centered design strategies [7]. The aim of this study was to provide a deeper understanding of veterans' preferences for using HIT for managing chronic health conditions [8] and to inform VA HIT system design efforts. For the purposes of this paper, we focus on results from methods (ie, focus groups and pairwise comparison activities) that contributed to redesigning VA's HIT systems and apps.

Methods

This participatory study used mixed methods and included an expert panel and veteran participant focus groups. The study protocol has been previously published [8]. Expert panel members (EPMs) and veteran focus group participants provided descriptive information about VA and non-VA electronic health resources that veteran participants use for health care management. Pairwise comparison activities of HIT resources were conducted with both groups. Rapid iterative content analysis was used to analyze qualitative data. Descriptive statistics summarized quantitative data.

Sample and Sampling

Expert Panel

Snowball sampling was used to identify VA providers, key operational representatives, and VA subject matter experts who could serve as EPMs. This study focused on VA HIT, so non-VA technologists were not included in the expert panel. Initial invitations were emailed to operational partners who were asked to represent their departments or technology-focused workgroups and to nominate other experts as needed to address gaps. EPMs participated in monthly meetings for 6 months. Their input, along with veteran participant data, led to the development of the VA HIT Systems Matrix. This novel tool describes the existing VA HIT system and identifies veteran participants' vision for the future of an integrated VA HIT system. The VA HIT Systems Matrix was ultimately used to conduct a pairwise comparison activity [6].

Veteran Participant Sample

Purposive sampling yielded a sample pool for veteran participant recruitment efforts from two sites. We used administrative data to identify veterans who were registered for MHV, had completed the in-person process of authenticating their identity, and had opted to use Secure Messaging: 16,399 veterans in Tampa, Florida, and 1205 veterans in Bedford, Massachusetts. A greater number of veterans had registered for MHV and telehealth in Tampa than in Bedford, accounting for the difference in number of potential participants from each site. Next, we reviewed the list of potential veteran participants and identified 260 Tampa and 198 Bedford veterans who also used VA telehealth services. This ensured study participants had access to at least two forms of VA HIT resources.

All 458 potential veteran participants were contacted and screened using a structured questionnaire. The structured screening questionnaire included items to determine whether potential participants met study criteria, including age (≥35 years of age), the presence of at least two chronic comorbid conditions (eg, diabetes, high blood pressure, chronic obstructive pulmonary disease) and use of specific VA HIT resources (including MHV, kiosks, mobile apps, telehealth). This tool also helped researchers determine if potential participants were high- or low-volume users of VA HIT. High-volume VA HIT users were defined as those using two or more types of VA HIT at least once a month. Low-volume VA HIT users were defined as those using fewer than two VA HIT platforms less than once a month, and using two or more other electronic resources at least once a month.

We recruited approximately 10% of the sample pool. Ultimately, 47 veteran participants (44 male veterans and 3 female veterans) and one caregiver were grouped based on chronic health conditions and frequency of technology use (high, low). One female caregiver participated in a high-volume focus group. One female group (n=3) was convened to address woman's health issues in addition to health conditions. This single group of females represented high-volume HIT users. Two other types of groups were formed: chronic conditions groups (n=7 groups) (eg, chronic obstructive pulmonary disease, diabetes mellitus, high blood pressure) and mental health groups (n=6 groups). These condition groups were then divided into high- and low-volume HIT use groups. See Table 1 for further details.

Table 1. Focus group composition.

Gender	User level	Group condition	Focus groups n	Total participants n
Women	High volume	Chronic condition	1	3
Men	High volume	Chronic condition	3	15[a]
Men	Low volume	Chronic condition	3	8
Men	High volume	PTSD and mental health	4	13
Men	Low volume	PTSD and mental health	2	9
Total			13	48

[a] Female caregiver participated in one high-volume chronic condition focus group.

Data Collection and Asset Development

Data were collected in two phases. In Phase 1, 48 focus group participants described their current use of VA and non-VA HIT and modeled their preferences for using these technologies in the future. A 16-item focus group guide incorporated free-listing (listing items based on their knowledge) and simulation modeling activities [8]. During the first set of focus groups, veteran participants discussed VA HIT system access, design, and functionality preferences in relation to their specific health care management tasks (eg, refilling prescriptions) and identified their vision for the future of an integrated VA HIT system. These data informed development of the aforementioned VA HIT Systems Matrix. This Matrix is a large detailed inventory of virtual platforms, their features, and contexts for use. It has been previously published and is omitted from this publication [9]. The Matrix provides information on the patient-facing platforms that are available to veterans (eg, MHV, mobile health, kiosks, telehealth), key system features (eg, Secure Messaging, Blue Button), access/availability, user groups, and context of use. The Matrix was used as an informational tool that helped veteran participants and EPMs complete the analytical hierarchy pairwise comparison process activity in Phase 2 of the study, further described below.

Focus group data from Phase 1 also informed development of user personas, user scenarios, and low-fidelity representations (schemas, drawings, and process models) of participants' system design and functionality preferences. User personas were "characters" developed to represent a veteran user in the scenarios. Process models provided a mapping strategy for developing interactive modeling simulations. A process model example is illustrated in Figure 1. The VA Human Factors Engineering (HFE) team used these assets, veteran comments provided through the MHV site, changes requested by VA clinicians, other veteran feedback provided by the VA Office of Connected Health, and an independent HFE study to create high fidelity, interactive, visual simulation models using iRise software [10]. HFE created the simulation with Structured Query Language (SQL) databases that enabled functionality similar to a live website. These functions included form submission, registration and credentialed sign-in with user recognition, live-updated data (dates or data previously submitted through forms), and validation error prompting. The simulation allowed a user to realistically use the prototype to support several representative veteran workflows such as refilling a prescription or canceling an appointment.

The interactive simulations of redesigned VA HIT functioned on a variety of platforms (eg, mobile phone or tablet, desktop, kiosk) in test scenarios. These simulated models included mock app screens and webpages for platforms of interest (ie, Web, mobile, telehealth, kiosks). Participants provided feedback to refine modeled content in Phase 2 focus groups. This dynamic process of creating simulated models from participant data is illustrated in Figure 2.

In Phase 2, participants from Phase 1 focus groups were divided into six Phase 2 focus groups based on participant availability. They reviewed the simulations of VA HIT and provided feedback on (1) accuracy of visual simulation models in capturing focus group input, (2) relevance of test scenarios, and (3) simulations' design and functionality. Focus group facilitators gave a semi-scripted presentation that integrated veteran participant personas and user scenarios, multiple health management scenarios, and simulated prototypes of VA HIT on a variety of patient-facing platforms. Respondents' reactions and experiences as they interacted with the simulations were audio recorded. Veteran participants also completed a similar pairwise comparison activity together at the end of each focus group. The data collection flow chart is illustrated in Figure 3. Participants then completed an analytical hierarchy pairwise comparison process activity [7]. This activity was conducted using a structured hierarchy of options for completing specific health care management tasks with VA HIT. The goal of the activity was for participants to select the best tool for completing a given task, by ranking alternatives. See the pairwise comparison worksheet in Figure 4.

Figure 1. Process model example for tracking vitals.

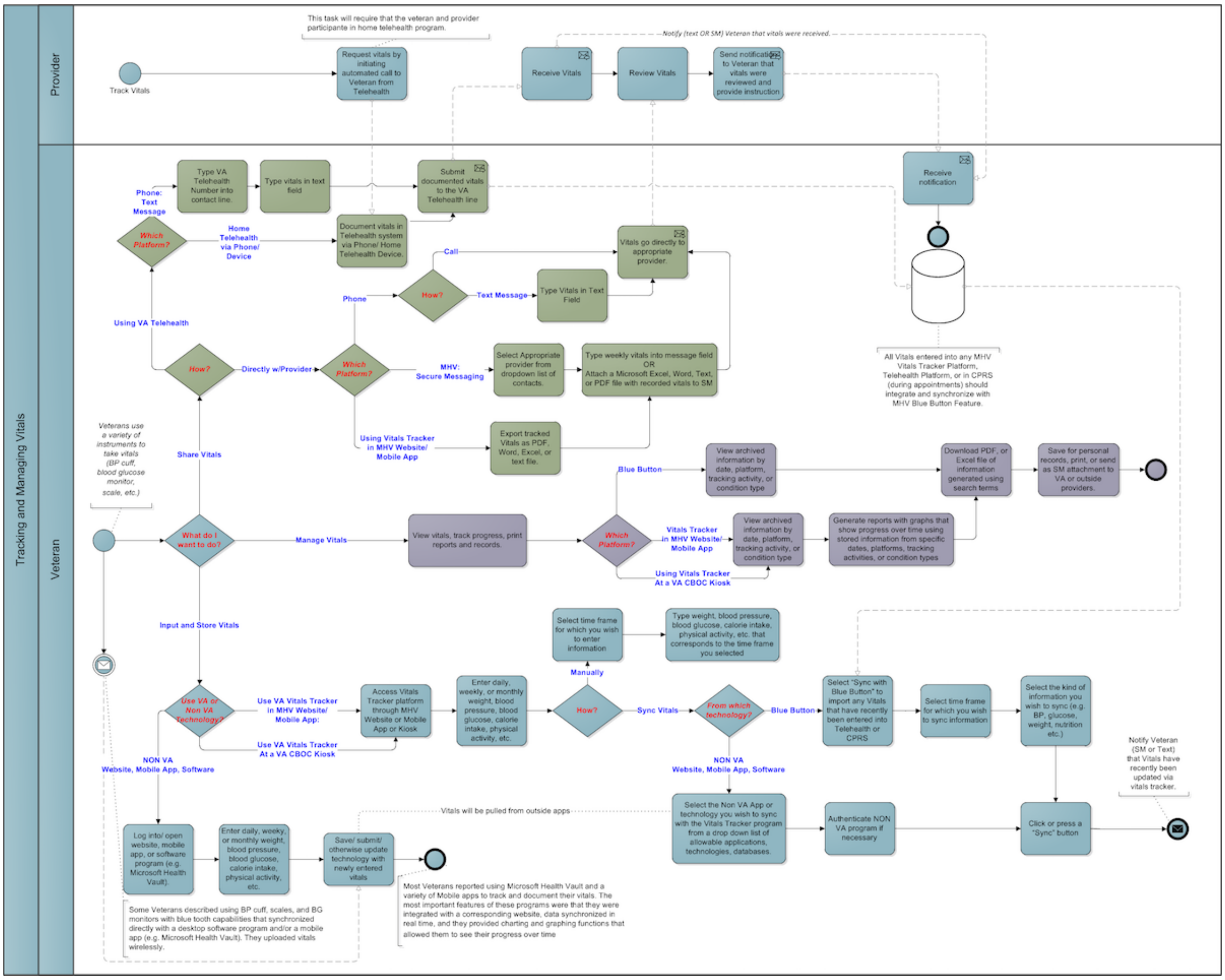


Figure 2. Process of creating simulated models.

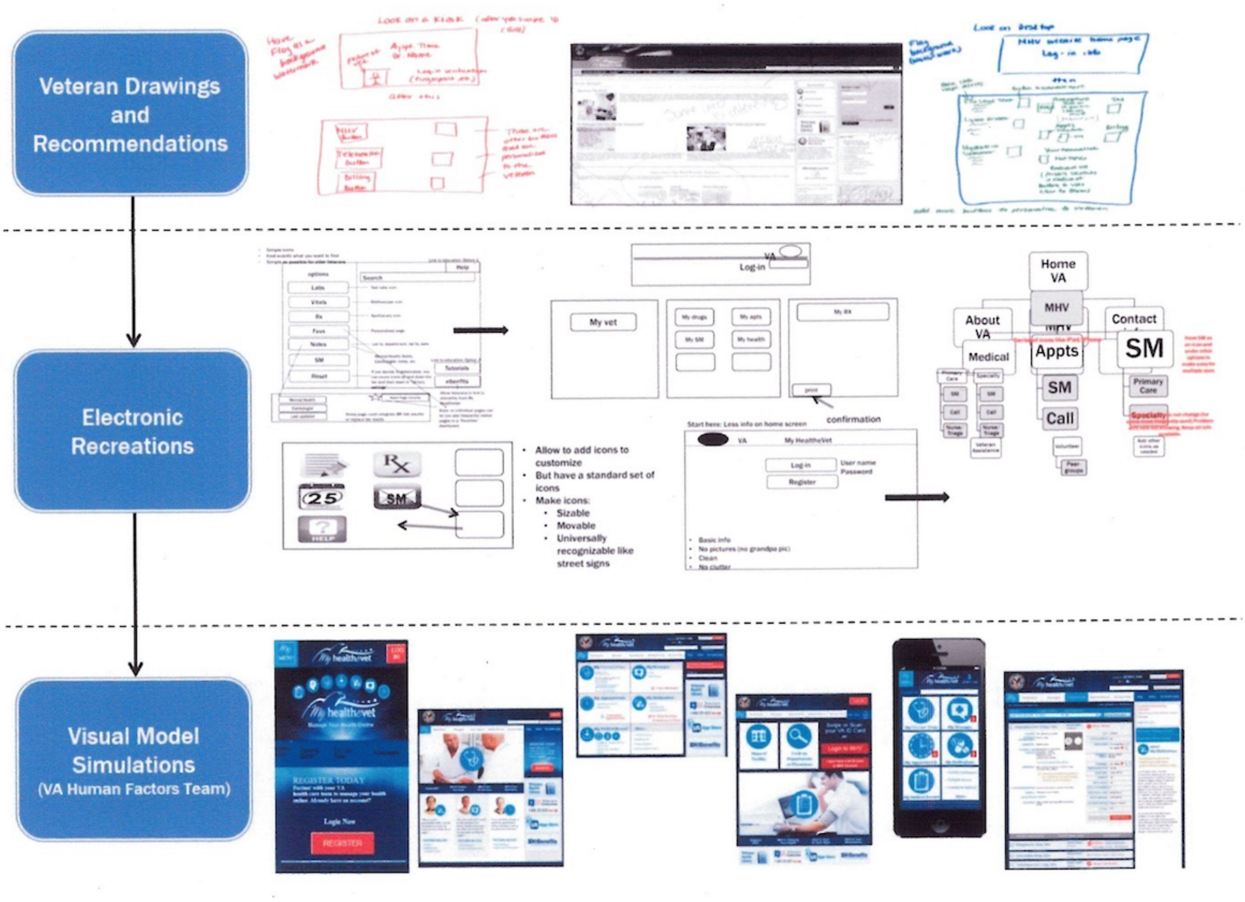


Figure 3. Data collection flow chart.

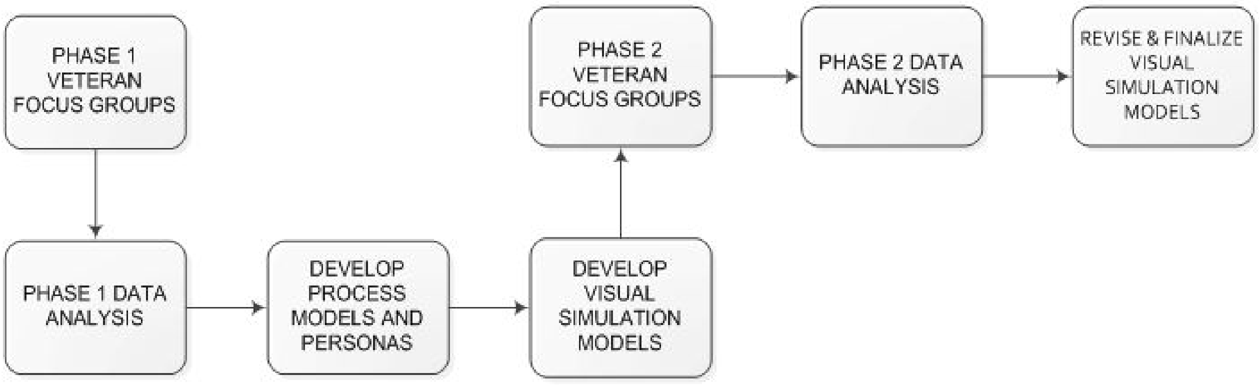
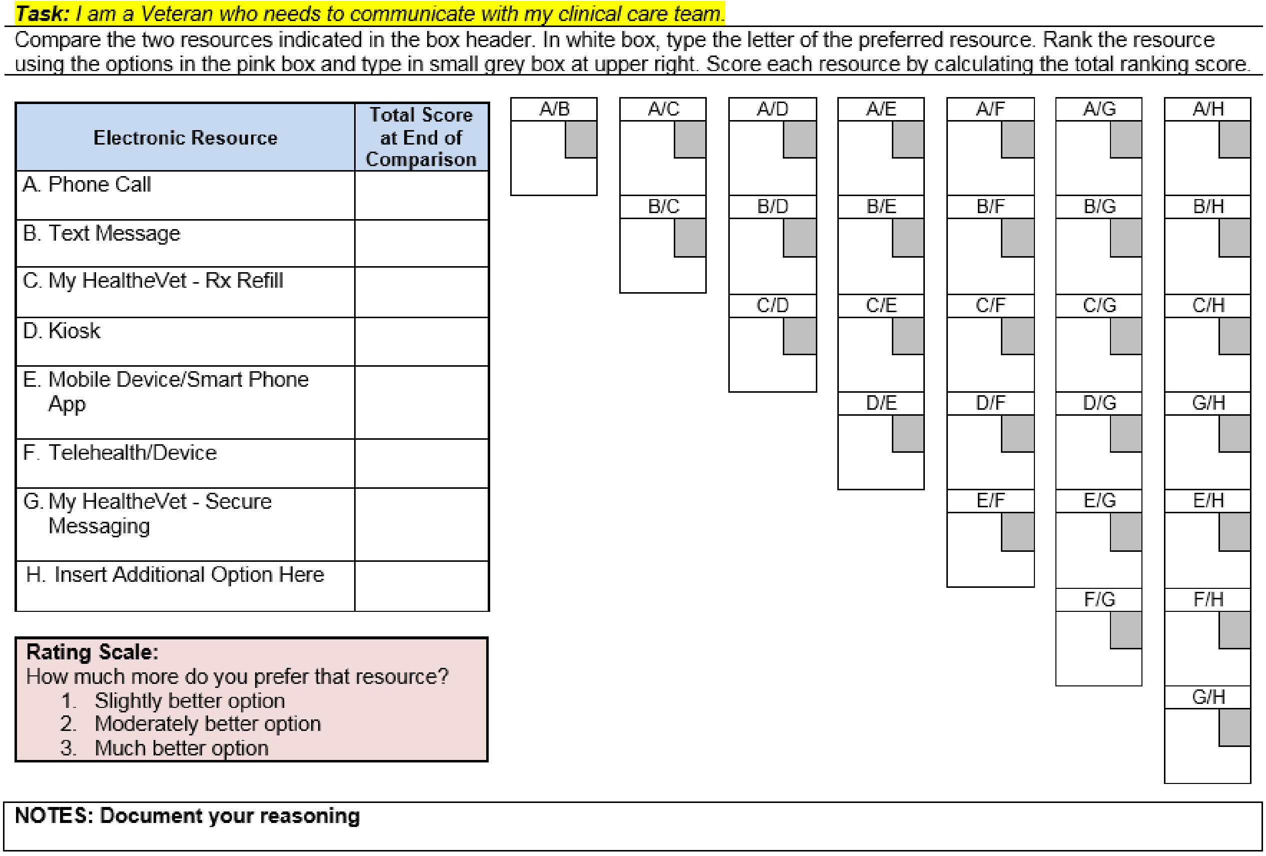


Figure 4. Sample page from pairwise comparison worksheet.



***Task:** I am a Veteran who needs to communicate with my clinical care team.*

Compare the two resources indicated in the box header. In white box, type the letter of the preferred resource. Rank the resource using the options in the pink box and type in small grey box at upper right. Score each resource by calculating the total ranking score.

Electronic Resource	Total Score at End of Comparison
A. Phone Call	
B. Text Message	
C. My HealtheVet - Rx Refill	
D. Kiosk	
E. Mobile Device/Smart Phone App	
F. Telehealth/Device	
G. My HealtheVet - Secure Messaging	
H. Insert Additional Option Here	

Rating Scale:
How much more do you prefer that resource?
1. Slightly better option
2. Moderately better option
3. Much better option

A/B	A/C	A/D	A/E	A/F	A/G	A/H
	B/C	B/D	B/E	B/F	B/G	B/H
		C/D	C/E	C/F	C/G	C/H
			D/E	D/F	D/G	G/H
				E/F	E/G	E/H
					F/G	F/H
						G/H

NOTES: Document your reasoning

Data Management and Analysis

Focus group data were transcribed and managed using the qualitative data analysis software program ATLAS.ti version 7.1 (ATLAS.ti Scientific Software Development). Data were analyzed in two stages [11]. The first round of coding included summarizing and data reduction from notes and transcripts into preliminary metadomains. Methods included deductive, structural coding with codes derived from the interview guide, and inductive, descriptive coding with codes that emerged from the data. A second round of coding allowed researchers to reduce coded data into meaningful domains and themes. The research team established an interrater reliability rate of 80%.

Results

Focus group participants represented a diverse veteran cohort and one caregiver who represented a veteran as a delegate. Participants were primarily male veterans with some college education, living with an average of six comorbid health conditions. Demographic data are presented in Table 2 and participant health conditions data in Table 3.

Table 2. Participant demographics (N=48).

Characteristics	n (%)
Gender	
Female	4 (8)
Male	44 (92)
Status	
Veteran	47 (98)
Caregiver	1 (2)
Education	
High school	7 (15)
Some college/vocational	20 (42)
Associates degree	7 (15)
College degree	7 (15)
Graduate degree	7 (15)
Race	
Caucasian/white	40 (83)
African American/black	5 (10)
Native Hawaiian/other Pacific Islander	1 (2)
American Indian/Alaskan Native	1 (2)
Other-American	1 (2)
Ethnicity	
Hispanic or Latino	2 (4)
Not Hispanic or Latino	45 (94)
Declined to respond	1(2)
Marital status	
Married	28 (58)
Divorced	17 (35)
Single/never married	3 (6)
Annual income (USD)	
≤ $4,999	3 (6)
$5,000-$10,000	1 (2)
$10,001-$15,000	2 (4)
$15,001-$25,000	7 (15)
$25,001-$35,000	7 (15)
$35,001-$45,000	6 (13)
> $45,001	17 (35)
Declined to respond	5 (10)

Table 3. Participants' self-reported health conditions (N=48).

Health condition	n (%)
High blood pressure	35 (73)
Diabetes	27 (56)
PTSD/ Mental health	22 (46)
COPD/ Heart	22 (46)
Pain	11 (23)
Sleep disorder	9 (19)
High cholesterol	9 (19)
Any arthritis	7 (15)
Neuropathy	7 (15)
Cancer	6 (13)
Hearing problem	5 (10)
Hyperthyroidism	4 (8)
Kidney Issues	3 (6)
Acid reflux	3 (6)
Human immunodeficiency virus	2 (4)
Hernia	2 (4)
Gastroesophageal reflux disease	2 (4)
Headaches	2 (4)

Focus Groups

Current Use of VA Health Information Technologies

All participants reported that electronic health tools and portals such as MHV and its component features are useful for managing health. Both types of user groups reported using (1) Secure Messaging (SM), a secure communication tool (like email) with VA health care providers, (2) Prescription Refills (Rx Refill), a secure online prescription refill program, and (3) MHV Appointments, an online resource that allows users to view past and future VA appointments as a list or on a customizable "Health Calendar" and to set up email reminders for upcoming appointments. High-volume HIT users were more likely to use telehealth, VA Mobile Apps, and additional MHV features, including the Blue Button, which allows veterans to view and download a copy of data from their EHRs, and the Veterans Health Library, an online veteran-focused library of reviewed health education resources. Sample quotes of current use of VA and non-VA HIT are included in Table 4.

Table 4. Sample quotes of current use of VA and non-VA HIT.

Domain	Theme	Sample quotes
Current use of VA HIT		
	General	I use My HealtheVet to manage appointments, to check on appointments, to look at lab results. I look at it to order prescriptions and check on my prescription refills to see what is available and what is left. When I get low on refills, I can contact [my care team] through [SM] to let the pharmacy and doctor know that I need to have something renewed.
	Use of the Secure Messaging	Secure Messaging is very helpful. I like the fact that if you have a question and you can't get in [to the office] to see your primary care provider, at least you will get a nurse or whoever is on the other end giving you some information.
	Capabilities of Rx Refill for managing many prescriptions	I manage a lot of prescriptions, about 30 or 40 of them. Sometimes I get a new one and I use it for a month and then I don't need it anymore. I can go on my [RX Refill] page and see what I'm taking… but [the page] still has drugs on there from 2 years ago that I'm no longer using. It's hard to get the system to wipe them out and it can be really confusing.
	Function of MHV Appointments	[Those Appointments] are never up to date. Sometimes I get a call saying that I have an appointment scheduled for such and such a day at this time, but that will be the first I've heard of having an appointment. Those calls don't say what appointments you have that day, they just say you have one. So, I go online to my calendar and, sure enough, there is nothing [indicating I have an appointment]. So, I don't go. Turns out I did have an appointment that day and I get dinged on my record.
	Function of Blue Button	They have an item called Blue Button and on the Blue Button you can determine what information you want from your records. For example, lab results. You can [enter] a date range and say, "I want these items." It has got a full checklist. You check those items and [Blue Button] will give you a full report. You can download the report as a PDF and review.
	Availability and utility of VetLink Kiosks	Kiosks? We don't have those here, but I used one in New York to check in [to an appointment] at the hospital. I didn't have to wait at the desk and someone was showing us how to use it. I'd like it if I could print my prescription list before my appointment, but maybe that would bring up [privacy] issues because the kiosk is right in the lobby.
	Utility of telehealth as a tool for attending therapy	I go for therapy through telehealth. The therapist is [at the hospital], I'm in [my location], and it's incredible. It is so realistic that when I'm done and I get up and just walk out, [I feel] like I should shake his hand. [Using telehealth], I have a [therapy] group, and I have [one-on-one therapy] and then I have a third [therapy] with my psychiatrist for the medication.
	Creating VA Mobile Apps for health care management	I use my [tablet] for everything, but I can't [access] the My HealtheVet [website] there. You can only access it on an actual computer or laptop so that's why I was saying maybe they can come up with an app where you can access [My HealtheVet] from other places other than just the home computer because sometimes you're out and you don't have a way of getting any information until you get back to your house.
	Telephone	I'll call the nurse when I need a prescription renewed. I like SM for questions and prescriptions too, but sometimes you just want to make that call.
Non-VA HIT Use		
	General	With Google, you don't have to really look hard to find something, it's pretty much right there in front of you. If you put [a topic] in your search bar, you are going get the [results] you are looking for. [My HealtheVet] is very difficult to manipulate because you have to figure out how to just get [to the search bar].
	Chronic health conditions	My daughter got me [a Fitbit] for Christmas because I needed to lose a lot of weight. I've lost 70 lbs since my operation…and that Fitbit has done it. I just got my 500 mile award the other day.
	Personal health information management	I've got high blood pressure and diabetes, so I have to check blood sugar levels and monitor my pressure every day. My BP cuff and my glucose monitor both have bluetooth so I just link them up with my [fitness] app and the information goes right in. It's great for me because I can just pull out my phone when I see the doc and show him all the graphs and charts with my data.

My HealtheVet

The most commonly used resource by participants was MHV, particularly the SM and Rx Refill tools. Participants valued SM to communicate with their health care teams. Frequent communication included lab management, appointments, medications, general health concerns, and specialty care requests. Many participants preferred SM because it maintains a record of their communication. High- and low-volume HIT user groups agreed SM was easy to use because it mimicked familiar email formats. They appreciated SM's convenience, stating that providers responded quickly, and veterans could better manage their care while avoiding telephone waits or travel to their local VA facility. Barriers to using SM included providers who were not active SM users, perception of usability issues (ie, too many steps required to log in), and being less convenient than using personal email.

Most participants liked the convenience of ordering prescription medications through Rx Refill. They requested refills in advance and could print Rx Refill pages for their personal records and community (non-VA) providers. High- and low-volume HIT users felt Rx Refill was complicated and did not adequately support management of several prescriptions. For example, users wanted notification when a prescription was going to expire, rather than scrolling through multiple online pages searching for refills or renewals. Many participants felt their Rx Refill page was cluttered with out-of-date prescriptions that impaired their ability to easily review current medications.

Most participants used MHV Appointments, including reminders and a health calendar to check for future appointments and look up appointment instructions. They indicated this tool was not always current, and appointment notifications were often updated late or not at all. They suggested adding details about appointment location (eg, unit, room, floor) and accessible details about past appointments. Veteran participants were concerned that information they provided through the MHV Appointments platform was rarely relayed in a timely fashion to their care teams.

Participants, particularly high-volume HIT users, reported using the Blue Button feature to print labs for community providers and personal records. Some participants reported difficulty using Blue Button, especially when accessing and interpreting lab results, and many felt that there were often too many pages to print out. Last, the Veterans Health Library was used by only one veteran participant in this study. Most veteran participants preferred easy to use non-VA sites for medical information (eg, WebMD).

In general participants reported a desire for clean dashboard designs that were user friendly and easy to navigate. Modeling simulations that were prepared based on veteran participant reported preferences for the MHV home page and dashboard are illustrated in Figure 5.

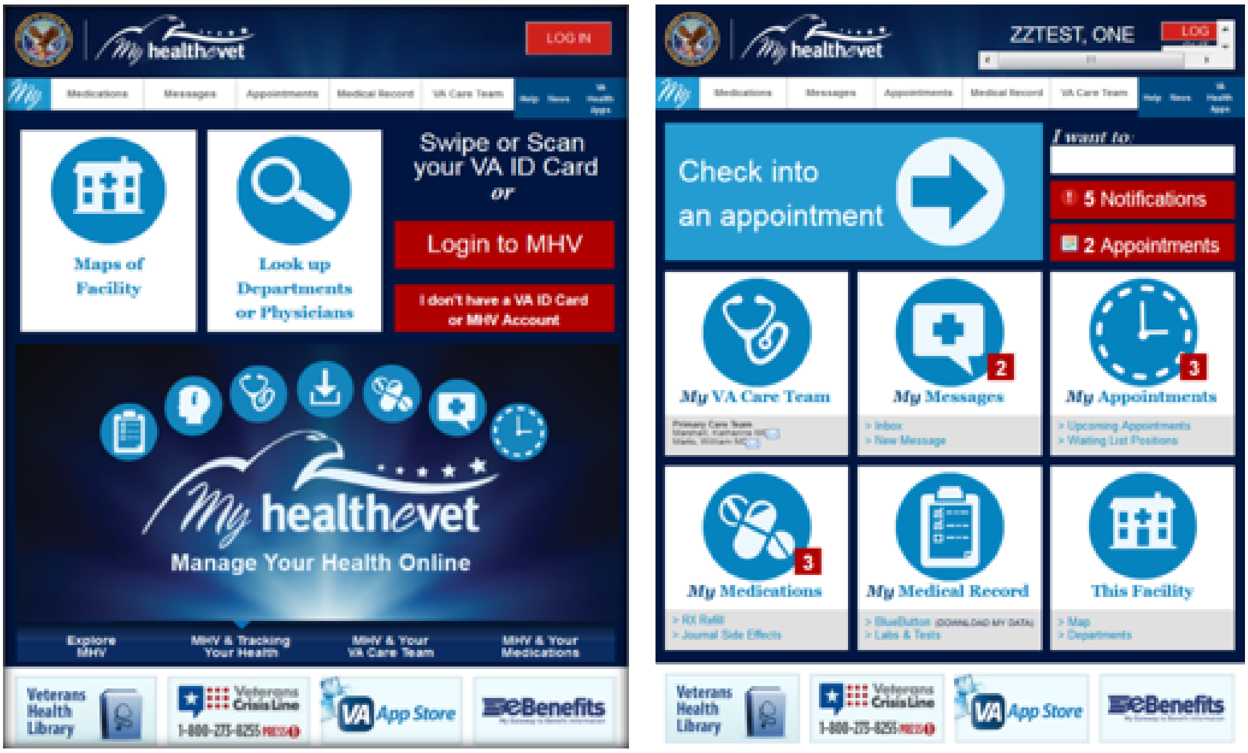
Figure 5. MHV home page and dashboard simulations.

VetLink Kiosks

At the time of the study, VetLink Kiosks were not widely available at the study sites. A kiosk is a veteran-facing touch screen device, found in VA clinics, that allows veterans to perform basic tasks such as checking into an appointment. Some participants used kiosks at appointment check-in, but believed kiosks had additional potential. Participants envisioned using kiosks to view their entire integrated EHR, search their medical records, and print information. They wanted the ability to print facility maps. They conceded privacy risks associated with accessing this information in view of the waiting room and suggested building a cubicle around kiosks to provide privacy.

Veteran participants reported a desire for kiosks to be standardized, synchronized, and integrated with other VA HIT, particularly MHV. They reiterated their desire for a clean, user-friendly design. Modeling simulations that were prepared based on veteran participant reported preferences for the VetLink Kiosks are illustrated in Figure 6.

Figure 6. VetLink Kiosk simulations.



Telehealth

Veteran participants reported that telehealth services improved access to care. Veteran participants who used telehealth frequently used home telehealth to send vital signs to providers; however, they did not have access to previous submissions, making the tool ineffective for personal health monitoring. Participants reported preferring older telehealth equipment to the newer models of the phone telehealth system because the phone was too time consuming, though they did not provide specific details. A minority of veteran participants used video telehealth to communicate with providers for speech pathology and therapy appointments.

The primary theme that emerged was veteran participants' preference for synchronization, integration, and access to their data, particularly through MHV and Blue Button. Modeling simulations prepared using veteran participant reported preferences for access to their vital sign data are illustrated in Figure 7.

Figure 7. Simulations of “Medical Record” containing Blue Button and Vitals/Readings features within My HealtheVet.

Mobile Apps

Few veteran participants used VA Mobile Apps, often due to reports of limited awareness of the available apps. It is also important to note a limited number of apps were available during this study, though many were in development and of interest to this study effort. There was a desire for convenient and easy-to-use apps. For those reporting use of the apps, Post-Traumatic Stress Disorder (PTSD) Coach, was most often cited, albeit infrequently. Veteran participants reported wanting mobile SM, appointment reminders, and Rx Refill apps or a single MHV app that integrated and synchronized all these features. Mobile apps preferences stemmed from a desire to have all health care management platforms conveniently located in a single place. Many veteran participants, particularly those with mental health issues, stressed the importance of creating secure mobile technologies.

Telephone and Mobile Phone

Participants used the telephone and mobile phones to supplement online activities. They communicate with providers, request prescription refills, and manage appointments. Phone use depended on status, urgency, and the level of accountability they wanted for a given issue. Participants reported a strong preference for using mobile phone technology to access MHV, mobile apps, and text alerts. Participants felt that although text messaging is not secure, there are appropriate uses for this technology such as appointment reminders and medication notifications. Modeling simulations for mobile phone designs and text features based on veteran participant preferences are illustrated in Figure 8.

Figure 8. Modeling simulations of mobile phone designs and text features.

Partner with your VA health care team to manage your health online. Already have an account?

This is My HealtheVet reminding Zztest of your appt 09/08/2014 @ 9:00 Am @ DC VAMC Clinic PT ASST-V11-D208. 800-555-1212. Please sign into MHV and view "My Medications" for more details.

Current Use of Non-VA Health Information Technologies

High- and low-volume HIT users used Web browsers and search engines. Both groups preferred "clean," "intuitive," "simple to use" search engines that provided quick results. Participants with chronic health conditions used non-VA health technologies (eg, wearable heart, sleep monitors, pedometers) to better manage their condition. They used non-VA mobile apps to accomplish personal tasks such as tracking health parameters (eg, vital signs, weight, sleep patterns). These programs were described as "purposeful" and "tailored" to specific conditions and needs. High- and low-volume HIT users used multiple devices (eg, desktop, tablet, phone) noting the importance of quickly connecting to, and synchronizing information, across devices.

Preferences for Future Use of VA Health Information Technologies

Electronic Communications

Veteran participants preferred exchanging information with providers electronically. Participants placed value on the use of SM to generate a record of communication that is accessible and accountable. They conceded that physician response time and adoption of this communication tool varied, and that the VA needs to implement mechanisms to overcome these barriers and improve SM effectiveness. Text messaging was thought to be the next logical platform for communicating with care teams. These tools would maintain the immediacy of a phone call and provide accountability by establishing a record of interaction. Sample quotes for future use of VA HIT are included in Table 5.

Table 5. Sample quotes of preferences for future use of VA HITs.

Theme	Sample quotes
On using electronic communications with providers	I've noticed that SM can be hit or miss. I've got some doctors who really use the thing. They get back to you right away and it's great, but if your doctor doesn't use SM then you are relying on the phone or going in to the hospital. [SM] is a great service as long as your doctor is using it.
Notifications or alerts	I have reminders coming in via emails, via text and all I have to do is hit accept and it goes on the calendar in my iPad. If it was that simple with the VA, I would be reminded of every appointment and they'd never have to send out another piece of mail again, the VA could save all this money on sending me these [appointment reminder] cards.
	They could communicate a lot of stuff to the vets through My HealtheVet. Every time you log on [the Vet could] have a [notification] message. It could be anything. It could be "we're having a special on blood tests this week" or "your next appointment is [pause]." Could be tons of things they could put in there.
System integration and synchronization	I would like to have all [VA technologies] linked together in one place and that's why I've been using the [Microsoft] Health Vault. If [the VA] could combine telehealth with My HealtheVet that would be the best website you could go to but also make the information available.
	I travel and [prefer] not having to be tied to a home computer. Anywhere we are with a tablet or phone, we could find out our information, our appointments, our medications, lab work, all the things we need would be available where ever we are whether I'm in an RV driving to the Grand Canyon or whether I'm at home or even in Europe where I could still do it with a mobile app.
Standardization	I think they should all be very similar, same similar appearance anyway. They don't have to be the same but give me the same appearance where if it says Blue Button on one, it says Blue Button on another. If it was set up like Microsoft in your windows where I don't care if you use your phone, your laptop or your home computer when you turn it on, you're going to see the same thing every time. Like you said different items in different locations, but they're all the same items and all the same design and the same look.
Design	I'm saying it should be something simple that if I went and opened the program up, whether it be a button, a little logo, whatever it's going to have, something that would say, be in the shape of a needle I need immunizations…click, something simple that I could identify each thing that I'm going to look for. Use the "KISS" method…"keep it simple…"
	I normally now go to my Windows 8.1; it has a completely different look to it. It's simple, it's pictures and letters, and it tells you. for example, I look at this and I go this is my email, this is my contact list, this is my…and we can do the same for the VA…this is my medication, this is my appointments. I want little boxes, windows to tell me where to go.
Authentication	And whether you get it on the identification card, the microchip which will keep track of that or however, but one time you do need a face to face with somebody to verify who you are who you say you are.
	Why not online like the bank, banking online. You just sign up, you put in your security questions, whatever they ask you and then they send you back a confirmation email.
Delegation and sharing information with community providers	I want to be able to send my outside and VA provider an email with my records of my meds or labs or surgeries, but securely. I don't want to have to go here and there requesting my records. It'd be great to give outside providers limited or one-time access to your records so they could see your [medical] history.
	My brother picks up my laptop and gets on My HealtheVet and he starts ordering stuff for me; technically that should not be allowed because I didn't authenticate him. But if at the same time, I say to my brother I'm in bed, I can't do it, can you go to my computer; there should be a method where I should be able to let him do that for me.
	You would have to be able to give your permission and once you give your permission they should have access. If I'm going to be an invalid and I can't make decisions for myself like turning the power of attorney over to someone, they should have access to everything I have access to.
Single sign-on for federated credentialing	I think if you're a vet, there's difficulty in maintaining what your passwords are sometimes, guys lose them and they don't remember, I think there's merit in having just one login. The downside on the fact that I work with websites and that is that you do expose security cause if somebody gets the one they're going get everything.
	Now the VA is using all the other federal agencies to get information on a veteran–they have access to my social security, they have access to my IRS information, my 1010 that I got for benefits so I don't have a problem with one password being utilized after I [have] vetted with the VA to make sure I am who I [say] am. I don't want to have to do a separate [password] for eBenefits or social security…or whatever other government agency I deal with…it should be all one.
Accessing information and education about VA HIT	I think if the VA really wanted to, there should be opportunity or classes, hey we'll sit in a conference room with a big screen and I'm not trying to create a job for me or anybody else, but get a guy that's a novice like myself and say okay, "hey guys let me show you this website, this is how you get to it, this is how you use"…And I think it should be another veteran, I think it needs to be somebody who is just a layman who says we're going to go through My HealtheVet and just make that person comfortable.

System Design Preferences

Participants drew inspiration from their personal use of technology and each other to model system design, functionality, and features. Models were created using large notepads, paper, and markers to demonstrate their preferences for system integration and synchronization. These data findings are described in the following sections.

Access, Presentation, and Navigation

A salient theme from the focus groups was participants' desire for notifications and alerts. They reported preferences for notifications when secure messages are sent/received; appointments are made/changed; prescriptions are refilled, adjusted, added, or expired; labs are ordered or results are available; and progress notes are available. Participants felt strongly that incorporating text message, phone-based, or SM notifications into the appointment reminders platform was important to facilitate patient appointment adherence. For example, text messaging was the most desirable platform for receiving notifications. Participants also felt notifications via SM, phone, mail, and personal email accounts would be acceptable and beneficial. Figure 9 illustrates a modeled simulation of an MHV appointment manager based on participant-reported preferences.

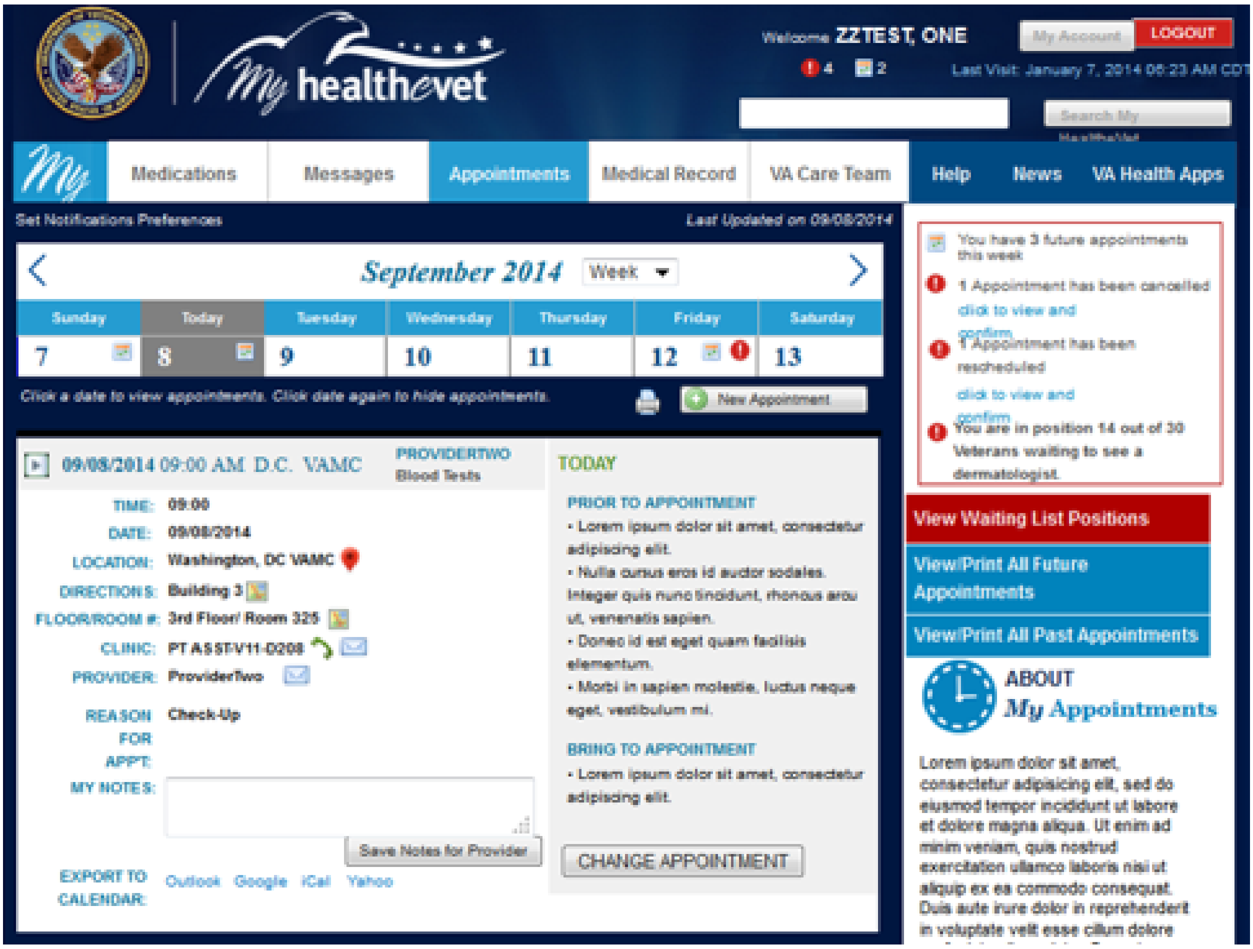
Medication management was also a top priority for participants. They had clear expectations for a user-friendly system that allowed management of many medications. Participants voiced a strong preference for medication lists that could be easily collapsed and expanded for managing information quickly and efficiently. Modeling simulations of this collapsing and expanding medication management system are illustrated in Figure 10.

Last, participants wanted notifications and increased ease of access to lab results. Participants also reported problems interpreting lab results, voicing a strong preference for results to be illustrated in a user-friendly format with graphs and imagery. An example of a simulation based on their preference is presented in Figure 11.

System Integration and Synchronization

Participants reported a strong preference for all of their health information to be synchronized, integrated into their EHR, and accessible to them online. They desired changes to their electronic medical record to update within hours and be rapidly accessible. For example, a participant drew an image indicating a need for all HIT to be integrated, to exchange information provided by and to the patient across systems. Participant renderings were re-created to illustrate their preferences for system functionality (see Figure 12).

Figure 9. Modeled simulation of My HealtheVet appointment manager.



Click a date to view appointments. Click date again to hide appointments.

09/08/2014 09:00 AM D.C. VAMC PROVIDERTWO Blood Tests

TIME: 09:00
DATE: 09/08/2014
LOCATION: Washington, DC VAMC
DIRECTIONS: Building 3
FLOOR/ROOM #: 3rd Floor/ Room 325
CLINIC: PT ASST-V11-D208
PROVIDER: ProviderTwo
REASON FOR APPT: Check-Up
MY NOTES:
EXPORT TO CALENDAR: Outlook Google iCal Yahoo

PRIOR TO APPOINTMENT

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BRING TO APPOINTMENT

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You have 3 future appointments this week

1 Appointment has been cancelled click to view and confirm

1 Appointment has been rescheduled click to view and confirm

You are in position 14 out of 30 Veterans waiting to see a dermatologist.

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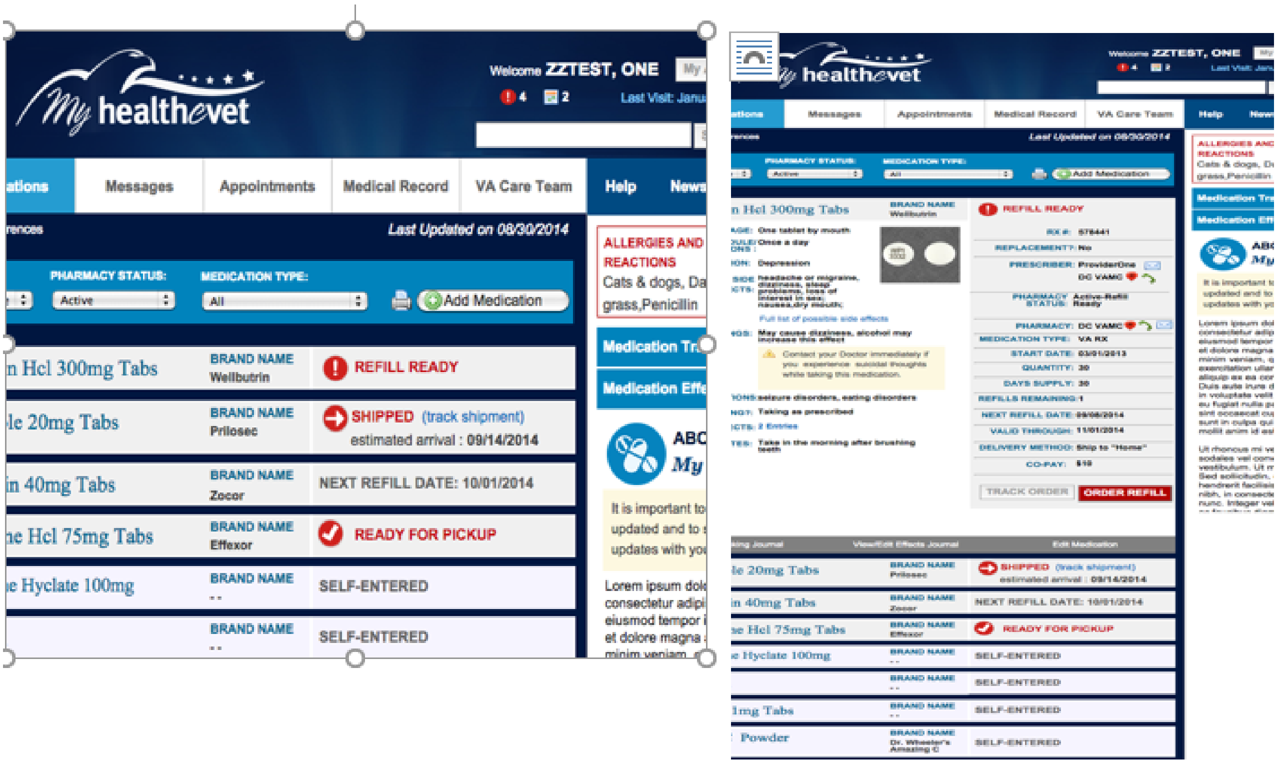
Figure 10. My HealtheVet Medication Manager in collapsed and expanded view.



Cats & dogs, Da grass,Penicillin

n Hcl 300mg Tabs	BRAND NAME Wellbutrin	REFILL READY
le 20mg Tabs	BRAND NAME Prilosec	SHIPPED (track shipment) estimated arrival : 09/14/2014
in 40mg Tabs	BRAND NAME Zocor	NEXT REFILL DATE: 10/01/2014
ne Hcl 75mg Tabs	BRAND NAME Effexor	READY FOR PICKUP
e Hyclate 100mg	BRAND NAME --	SELF-ENTERED
	BRAND NAME --	SELF-ENTERED

It is important to updated and to updates with yo

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Some participants felt kiosks should also provide access to MHV records. In general, they felt synchronization and integration would significantly improve their health care management experience, particularly when managing appointments, medications, and vital signs. Figure 13 provides a conceptualization of their reported preference for providing vital sign information to their VA provider while also being able to immediately access and store that data on their personal software programs for self-care management.

Standardization

Veteran participants felt that standardizing the look, feel, layout, and navigation of all VA tools and platforms would make learning to use different technologies easier for diverse audiences. Participants also voiced preferences for universally recognized imagery, such as icons (eg, prescription, emergency, secure messaging), to be used to standardize the look of imagery across platforms.

Design

Veteran participants preferred a dashboard design for all VA HIT interfaces. The dashboard would be uncluttered, easy to use, and contain universally recognizable icons with large text. Many veteran participants said the look and feel should be based on commonly used software apps. One participant declared the dashboard should look like a car's dashboard with "everything in one place." When discussing MHV, participants also preferred to navigate from the homepage to features in one or two mouse clicks. They preferred that important information be centrally located, while news, updates, and other information be located at the bottom of the dashboard or omitted entirely. Standardization and design features captured across HIT platforms were simulated based on participants' voiced preferences. Figure 14 presents how standardization of esthetics and design features across HIT platforms were simulated based on the group modeling activity.

Figure 11. My HealtheVet Labs & Tests feature.

Lipids-09/07/2014

Blood Specimen

ORDERED BY ProviderOne

TEST	RESULTS	PREVIOUS RESULT	RISK RANGE		
			OPTIMAL	INTERMEDIATE	HIGH RISK
Total Cholesterol (mg/dL)	181	180 All Previous	<200	200-239	≥240
LDC-C Direct (mg/dL)	105	98 All Previous	<100 CHD & CHD risk eq. <70	100-129 CHD & CHD risk eq. <70	≥100 CHD & CHD risk eq. <70
HDL-C(mg/dL)	74	70 All Previous	≥50		<50
Triglycerides (mg/dL)	130	125 All Previous	<150	150-199	>199
Non-HDL-C (mg/dL) (calculated)	107	100 All Previous	<130	130-159	≥160

COMMENTS: LDL cholesterol is above optimal. Please refer to guidelines from the National Cholesterol Education Program Adult Treatment Panel (NCEP-ATPIII) for treatment guidelines related to elevated LDL cholesterol. Also see: Implications of recent clinical trials for the National Cholesterol Education Program Adult Treatment Panel III Guidelines; Coordination Committee of the National Cholesterol Education Program.

Although the LDL cholesteraol is near optimal, LDL particle concentration is bordeline high. Studies have shown that elevated LDL particle concentration is associated with increased risk for coronary heart disease, even in the presesnce of optimal LDL cholesteroal values. Small LDL particles may be observed in assocation with metabloic syndrome and prediates. Statines effectives reduce the number of LDL particles, but do not generally influence the size distrution of the LDL particles. Omega-3 fatty acids, a low carbohydrate diet, niacin, fibrates and combination therapy (statin + niacin) have been shown to increase LDL particle size. Exercies and weight loss also increase LDL particle size.

Metabolic-09/07/2014

Blood Specimen

ORDERED BY ProviderOne

ABOUT

My Labs & Tests

It is important to keep this list updated and to share those updates with your healthcare team.

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Figure 12. Veterans’ drawing of system design preferences.

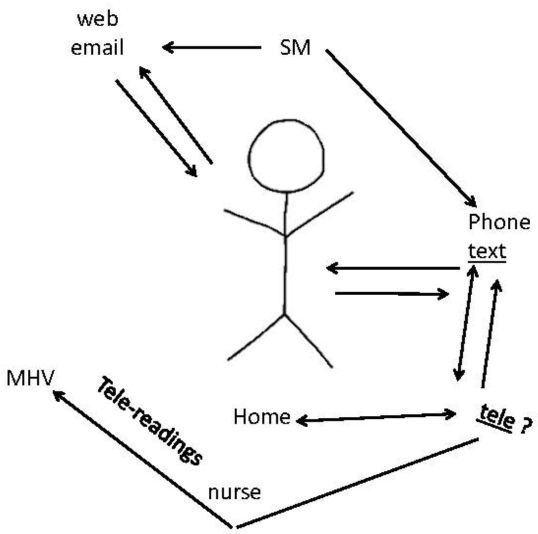

Figure 13. Participant conceptualization of synchronized vitals between VA and personal software programs using telehealth technology.

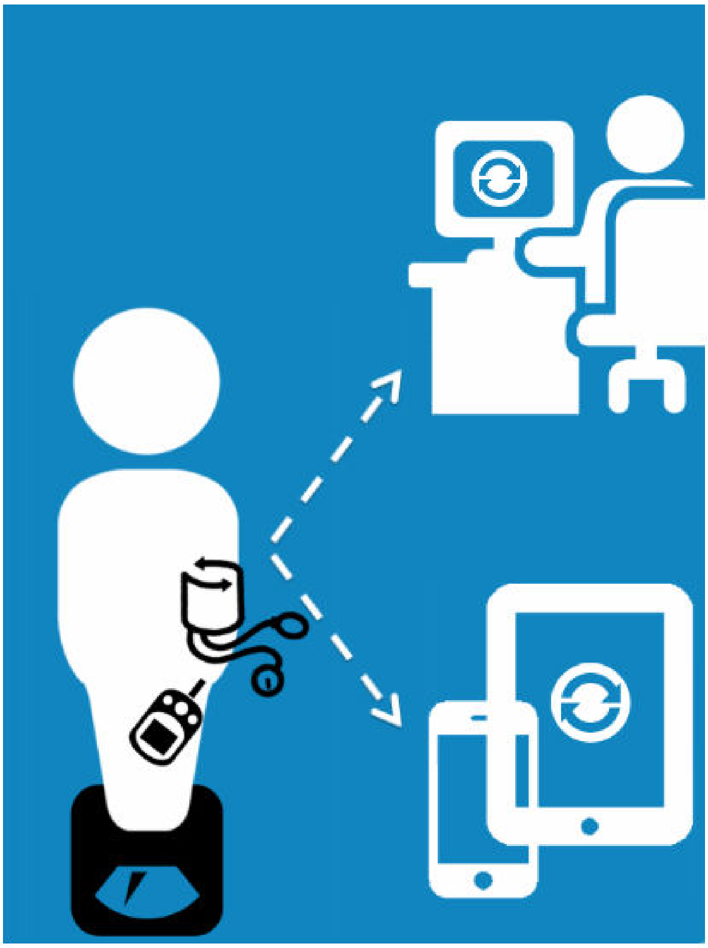

Figure 14. Visual model simulations of VA HIT standardization across various platforms (webpage, VetLink Kiosk, and mobile) based on data from group modeling activity.

Authentication

Participants preferred the secure nature of the initial in-person authentication currently required to allow veterans to access MHV advanced services such as SM and Blue Button. Those veteran participants that preferred online authentication wanted to provide their social security number and answer security questions to allow a remote but secure process for authenticating access.

Delegation and Sharing Information With Community Providers

Participants wanted to securely and electronically share their health care information with community providers and informal caregivers such as their spouses/partners, siblings, parents, or adult children. They appreciated the convenience of delegation. Many veteran participants reported that they already allowed family members to use their secure credentials to access their MHV accounts to help manage their health. Participants felt that they should be able to personalize levels of access to their EHRs and control who has access to different types of health information.

Single Sign-On/Federated Credentialing

Participants' preferences regarding federated credentialing "single sign-on" varied depending on their knowledge of and proficiency in using technology. Commonly, those veteran participants who supported single sign-on explained that they had "password fatigue," with general difficulty remembering usernames and passwords. While nearly all veteran participants acknowledged the expediency of a single-sign on or third-party credentialing mechanism, high-volume users were less likely to prefer this process, citing concerns about security. Low-volume users were less likely to understand federated credentialing but more likely to prefer it after it had been explained. Participants with security concerns were especially wary of credentialing via social media or private email accounts; however, they generally supported the idea of federated credentialing between government websites due to perceptions of high government Internet security standards.

Accessing Information and Education About VA HIT

When asked how the VA could improve awareness and use of VA HIT, most participants believed educating veterans about the availability and use of VA technologies is critical. Suggested education methods included peer-to-peer mentoring programs, instructional text in the form of a website or user guide, and instructional videos.

Pairwise Comparisons

Veteran participants preferred to access MHV resources such as SM, Appointment Reminders, Blue Button, etc, through a mobile app. However, there was uncertainty about the security, accessibility, and usefulness of mobile apps when managing health care. A slim majority of focus group participants preferred to access a VA electronic health resource using an Internet browser. Contrary to veteran participant preferences, EPMs overwhelmingly believed that veterans would prefer to use a mobile app to complete health care management tasks. In general, it was apparent that EPMs had a precise knowledge of which tool was designed for a given task. Differences between EPMs and veteran participant responses appeared to be largely based on EPM expert knowledge of resources, logistics, cost, and workflow issues.

Veteran participants and EPMs agreed that SM is the preferred resource for completing a wide variety of health care management tasks. Veteran participants included SM in their lists of useful comparison resources more often than any other resource, and EPMs frequently ranked SM higher than most other available resources, suggesting that both groups considered it a useful tool for completing a range of health care management tasks even when it was not the most preferred option. Findings indicate that no single HIT solution is acceptable for the full range of health-related tasks, and a full range of options is needed. Preferences can change based on the individual or situation. Preferences among veteran participants and EPMs, and the resources they agreed on are presented in Table 6.

Table 6. Pairwise comparison agreement between participant groups.

Task	Veteran participant only	EPM only	Veteran participant and EPM
Communicate with care team		Mobile App	Secure Messaging
Review lab results	Labs and tests	Mobile App Blue Button	Secure Messaging
Research medical information	Blue Button Non-VA websites	Mobile App	Veterans Health Library (general information)
Track vital signs	Non-VA Vitals Tracker Telehealth	Mobile App	MHV Vitals Tracker
Request appointment	Secure Messaging	Mobile App Text messaging	MHV Appointment Reminders
Cancel/ reschedule appointment	MHV Appointment Reminders	Mobile App Secure Messaging	Telephone
Order Rx refill	Secure Messaging MHV Appointment Reminders	Mobile App	MHV Rx Refill
Rx refill notification		Mobile App	Secure Messaging

Discussion

Principal Results

The goal of this study was to inform the VA’s vision of an integrated HIT system from the veteran perspective [8,9]. Veteran participants value virtual health care delivery and are invested in having access to care anytime, anywhere [12]. Many of the current systems were designed to address a perceived need or fulfill a policy directive. Thus, the greatest value of this work is the development of veteran-driven high-fidelity modeling simulations and assets that illustrate user needs and expectations when using a HIT system and services to access VA health care services. These are critical contributions to the VA, a “patient-centered” organization that seeks to incorporate “the veteran voice” into all service areas, including HIT.

Focus group findings illustrate the role of VA HIT in self-management of health care and chronic illness. It is logical that veterans with multiple chronic illnesses would rely heavily on technologies that support regular communication with providers (Secure Messaging), facilitate appointments (Appointment Reminders), and help with prescription management (RX Refill). For example, we now understand that tools like Rx Refill are vital to veterans with multiple chronic illnesses because they often manage many medications. Similarly, these findings provide important insights about barriers to use, along with suggestions for improvement. Veteran participants highlighted some of the functional improvements that could be made to help them manage a large volume of prescriptions, such as providing prescription expiration and refill notifications to help them maintain medication compliance.

One major finding of this study reaches beyond the needs of veterans with multiple chronic illnesses. Our participants expressed a strong preference for standardized, integrated, and synchronized user-friendly interface designs. Although standardization has long been an issue of importance to usability and design efforts [13], improvements in standardization across VA HIT resources are needed to optimize effective usage. The participants in this study recognized VA HIT’s lack of visual standardization across platforms as a departure from many of the health management technologies available in the private sector and emphasized that improving the “look” of VA HIT was a critical step toward system modernization and promoting use. In addition, current system navigation and usability issues and concerns about security, back-up systems, and delegation can be successfully enhanced with a human-centered design approach. For example, veteran participants’ preferences suggest that navigation and security issues and issues of standardization may influence the potential for adoption and sustained use. When VA HITs appear and function consistently across platforms, it creates a level of recognition that promotes comfort. This could also impact the uptake of newly released VA HIT. It is likely that if new HITs have the same look, feel, and general functionality as other HIT, veterans will have fewer problems learning to use new systems and apps. There was evidence to suggest education on features such as federated credentialing, single sign-on, and associated security issues is needed to promote the acceptance of these features. To ensure veterans are aware of and know how to use VA HIT, the veterans in our study suggested just-in-time marketing and education about how to access and use VA HIT resources.

The pairwise comparison focus group activity provided a unique way of discovering user preferences for use of VA technology platforms. Veteran participants expressed specific preferences for the platforms they wanted to use to accomplish specific tasks, its sense of urgency, and other situational contexts. Veteran participants and expert panel members agreed that a full range of options is needed, noting preferences can change based on the individual, the specific task, or the situation. In general, both veteran participants and expert panel members considered SM the most preferred resource. A slim majority of veteran participants preferred to access electronic health resources such as SM, Appointment Reminders, or Blue Button, using an Internet browser rather than a mobile app, in contrast to the belief of expert panel members who overwhelmingly believed that patients would prefer to use a mobile app. Veteran participants who did want to access resources through mobile apps expressed uncertainty about security, accessibility, and usefulness. Differences between veteran participant and expert panel member perspectives may be the result of panel member's knowledge of logistics, cost, and workflow issues, as well as insights about future technology (mobile apps).

Future research should inform VA's vision for an integrated HIT system to include front-end veteran user experiences and outcomes. Specifically, research should evaluate best practices for supporting patients' proactive and integrated use of VA HIT systems. In addition to assessing front-end veteran user experiences, veteran data also indicate that organization level research is needed to identify large-scale infrastructural consequences relevant to the supply and demand of the growing VA patient population. This research should assess the dynamic interaction of patient-provider electronic communication, and provider and team experiences, including workload and workflow, in order to ensure that the back-end systems and processes supporting the front-end veteran experience are operating effectively. Finally, system preferences such as single sign-on and delegation merit further investigation to better understand the feasibility, acceptability, and usefulness of these features within the current and evolving VA HIT system across traditional (eg, personal computers) and emerging (eg, mobile) technologies. Delegation has become increasingly important as the VA places more emphasis on engaging with community care providers and family care givers. Provision of comprehensive and consistent veteran health care rests on the veteran's ability to securely and easily delegate access to medical records and virtual health services.

Comparison With Prior Work

This work builds on previous work exploring user experiences on individual HIT platforms and tools within and beyond the VA. However, to our knowledge this is the first study to look at user experience across an enterprise-wide system of VA HIT platforms and tools. The unique contribution of this work is its comprehensive approach to looking at currently available VA HIT capacity and emerging functionality. As such, the modeling simulations produced in this work are veteran driven and can inform ongoing VA HIT redesign initiatives.

Limitations

Although this study underscored veteran preferences for using HIT and offered their recommendations for system improvements, it had some limitations. First, the study reports findings from two specific VA facilities. While participants were a representative purposively sampled group [14], additional insights may be gained by expanding this assessment to other VA facilities and veteran populations. Second, findings are primarily relevant to VA HIT systems and technologies but may be useful for the development and redesign of other tethered HIT systems. Third, current technological infrastructure capacity was not a primary focus and thus some desired changes may not yet be technically possible. Fourth, we purposively recruited participants who were invested users of two or more platforms; we may have missed valuable data that may have represented non-invested users. Finally, we included veterans with chronic conditions because they are more likely to leverage electronic resources to manage their health care, as such, we may have missed valuable data that may represent healthier participants [15,16].

Conclusions

This is one of the few published studies to aid in the development of an integrated system of patient-facing HIT resources within a large health care system. The findings from this study have already had a direct impact on the incremental redesign of the My HealtheVet patient portal and the prioritization of approaches that provide integration between VA HIT platforms. Future research can inform the ongoing development of VA's integrated HIT system, to include front-end patient user experiences and back-end workload and workflow. Future work should evaluate best practices for supporting consumers' proactive and integrated use of VA HIT systems. Though this research lends itself to recommendations for future research, our aim in completing this work was to inform a user-centric perspective to assist ongoing development, redesign, and research efforts. These assets were developed from a veteran-centric perspective to support the use of VA's dedicated resources to materialize the findings in ongoing VA HIT redesign efforts. Organizations beyond the VA can benefit from using a similar approach and may discover the findings useful in designing human-centered HIT systems.

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Conflicts of Interest

None declared.

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Abbreviations

EHR: electronic health record
EPM: expert panel members
HIT: health information technology
MHV: My HealtheVet
SM: Secure Messaging
VA: Department of Veterans Affairs

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Original Paper

Psychometric Properties of Patient-Facing eHealth Evaluation Measures: Systematic Review and Analysis

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Abstract

Background: Significant resources are being invested into eHealth technology to improve health care. Few resources have focused on evaluating the impact of use on patient outcomes A standardized set of metrics used across health systems and research will enable aggregation of data to inform improved implementation, clinical practice, and ultimately health outcomes associated with use of patient-facing eHealth technologies.

Objective: The objective of this project was to conduct a systematic review to (1) identify existing instruments for eHealth research and implementation evaluation from the patient's point of view, (2) characterize measurement components, and (3) assess psychometrics.

Methods: Concepts from existing models and published studies of technology use and adoption were identified and used to inform a search strategy. Search terms were broadly categorized as platforms (eg, email), measurement (eg, survey), function/information use (eg, self-management), health care occupations (eg, nurse), and eHealth/telemedicine (eg, mHealth). A computerized database search was conducted through June 2014. Included articles (1) described development of an instrument, or (2) used an instrument that could be traced back to its original publication, or (3) modified an instrument, and (4) with full text in English language, and (5) focused on the patient perspective on technology, including patient preferences and satisfaction, engagement with technology, usability, competency and fluency with technology, computer literacy, and trust in and acceptance of technology. The review was limited to instruments that reported at least one psychometric property. Excluded were investigator-developed measures, disease-specific assessments delivered via technology or telephone (eg, a cancer-coping measure delivered via computer survey), and measures focused primarily on clinician use (eg, the electronic health record).

Results: The search strategy yielded 47,320 articles. Following elimination of duplicates and non-English language publications (n=14,550) and books (n=27), another 31,647 articles were excluded through review of titles. Following a review of the abstracts of the remaining 1096 articles, 68 were retained for full-text review. Of these, 16 described an instrument and six used an instrument; one instrument was drawn from the GEM database, resulting in 23 articles for inclusion. None included a complete psychometric evaluation. The most frequently assessed property was internal consistency (21/23, 91%). Testing for aspects of validity ranged from 48% (11/23) to 78% (18/23). Approximately half (13/23, 57%) reported how to score the instrument. Only six (26%) assessed the readability of the instrument for end users, although all the measures rely on self-report.

Conclusions: Although most measures identified in this review were published after the year 2000, rapidly changing technology makes instrument development challenging. Platform-agnostic measures need to be developed that focus on concepts important for use of any type of eHealth innovation. At present, there are important gaps in the availability of psychometrically sound measures to evaluate eHealth technologies.

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KEYWORDS

telemedicine; computers; evaluation; use-effectiveness; technology; psychometrics

Introduction

Patient-facing eHealth is a multidisciplinary field focused on the delivery or enhancement of health information and health services through information and communication technologies [1]. eHealth helps consumers engage and collaborate more fully in their health care [2,3], independent of geographic location and also enhances access to health care services by offering novel channels for communication and information flow that complement existing systems [4]. There are many terms related to eHealth, including consumer health informatics, digital health, virtual care, connected care, and telehealth, to list only a few. For purposes of consistency, we use the term “eHealth.”

This paper focuses on patient use of eHealth, which includes personal health records and patient portals accessed via computers or mobile devices, and other telehealth devices designed for use primarily by patients and caregivers, even though some patient-facing technologies (eg, secure patient-provider messaging, mobile apps) are also used by clinicians [5]. Several constructs are important to measure to evaluate patient-facing eHealth technologies. Patient-facing eHealth technologies are used to deliver interventions intended to promote healthy behaviors or effective self-management among consumers. When assessing the efficacy of a behavior-change eHealth intervention, evaluations must address both the intervention and the technology platforms and functions used to deliver the intervention in terms of usability, functionality, and availability of the technology to target users [3]. eHealth may improve the efficiency of and accessibility to clinical and health promotion services for patients. For example, it is anticipated that eHealth may reduce the distance between services and the target user, improving accessibility, or reducing physician or patient workload for a specific task, enhancing efficiency [6-9]. Finally, almost all behavior-change eHealth interventions aim to improve communication in one form or another [10,11].

Although studies using eHealth technologies may include measures that attempt to quantify the characteristics or effect of eHealth interventions, to date, there are no uniform, widely agreed-on measures. More rigorous measurement is needed to determine the full benefit(s) of an eHealth-delivered intervention to both patients and the health care system [12]. Scientific inquiry in other domains has benefited from the development of such standardized measures. At present, various measure compendiums are available that categorize measures of patient-reported outcomes. The Grid-Enabled Measures (GEM) database, for example, was developed starting in 2010 with the purpose of moving social and behavioral science forward by promoting the use of standardized measures tied to theoretically based constructs and facilitating sharing of data from use of standardized measures [13]. Sponsored by the National Cancer Institute, GEM is an open-source measure compendium that solicits scientific community participation in contributing and selecting measures. Users can add information about constructs, find measures related to constructs, upload new measures, provide feedback on existing measures, and search for and share harmonized data for meta-analyses. In addition to providing useful information such as associated references and information on validity and reliability, the GEM allows researchers to see how often other researchers have used a measure and the feedback and ratings they have provided.

Similarly, the Patient-Reported Outcomes Measurement System (PROMIS) was developed by the National Institutes of Health in an effort to develop, validate, and standardize items that may be used to measure patient-reported outcomes common across medical conditions [14]. PROMIS is collecting and testing items focused on patient-reported outcomes of interest, as opposed to validated instruments. For example, the item banks for physical function, fatigue, and sleep disturbance contain 124, 95, and 27 items, respectively [15]. These item banks are being tested in large populations [16-18].

Both PROMIS and GEM promote use of standardized measures and data analysis across multiple studies and conditions. Although these measures can be an important component of studies focused on use of eHealth technologies, the items and instruments contained in these compendiums do not specifically focus on issues surrounding use of eHealth technology with and by patients. For example, although GEM or PROMIS may include instruments or items that measure patient satisfaction with communication with a physician, they do not include items specific to physician-patient communication when using telehealth or secure messaging, nor do they specifically address technology usability issues. Recent efforts to summarize measures related specifically to technology use include a compendium of health information technology-related survey tools developed by the Agency for Healthcare Research and Quality (AHRQ). The AHRQ compendium includes a wide variety of measures, but the website does not provide detailed information on psychometric properties. Thus, although work is in progress to develop and identify measures that may address eHealth evaluation needs, more work is needed.

Implementation research focuses on structural and organizational characteristics of the environment where an innovation is being or will be used. Within this environment are individuals (patients, providers, administrators) with various characteristics that may hinder or facilitate adoption of the innovation within the particular environment. In this review, we focus on the innovation (ie, the eHealth intervention) and how features of this innovation will impact implementation. Consistent and well-validated measures will contribute to determining the true benefit of eHealth interventions across studies and over time. Consistently used measures will enable the health care system to collect uniform data on (1) the likelihood of adoption of an eHealth technology; (2) patient, organizational, or health care system barriers and facilitators to adoption; (3) user attitudes toward and/or satisfaction with a technology; (4) the degree to which meaningful user characteristics (eg, health literacy) mediate the relationship between technology use and improved health outcomes (ie, improved self-management of chronic illness, reduced health care utilization), and (5) the return on investment of eHealth technology to assess value.

The objective of this project was to conduct a systematic review to (1) identify existing instruments for eHealth research and implementation evaluation, (2) characterize measurement components, and (3) assess psychometrics. Additionally, this study seeks to highlight current limitations of this body of research.

Methods

Identification of Search Terms

Through a series of investigator meetings, we identified key concepts from existing models, published studies of technology use and adoption, and sociotechnical perspectives on health information technology implementation and evaluation [19-23]. Using these models and studies, our knowledge of the field, and detailed input from an experienced health sciences librarian, we developed a working list of key concepts to focus our search. These were then categorized into five areas: platforms (eg, email), measurement (eg, survey), function/information use (eg, self-management), health care occupations (eg, nurse), and eHealth/telemedicine (eg, mHealth) (Multimedia Appendix 1). Our focus was to identify instruments that could be used for any of these concepts as well as those that may be relevant to only one or two concepts.

Search Strategy

We conducted a systematic search of the literature using the selected search terms. Based on guidance from our health sciences librarian, databases used included MEDLINE, Scopus, PsychInfo, CINAHL, Health and Psychosocial Instruments (HAPI) for articles published through June 2014. Each database was searched using terms included in Multimedia Appendix 1. The search logic followed this format: (A and D and B and C) OR (E and B and C). All terms listed in sets A, B, D, and C were entered and combined using the Boolean operator “and.” Likewise, terms in sets B, C, and E were entered and combined using “and.” The results from these two searches were then combined using the operator “OR.” This logic was used to ensure all possible terms were included and ensured studies included some sort of measurement or evaluations.

Our search strategy also included review of currently funded research projects within the health services research arm of the Veterans Health Administration (VA) system focused on eHealth (n=56), and existing instrument/measure compendiums (GEM, PROMIS, AHRQ). All search results were transferred to a reference management software database (EndNote); duplicates, articles where the text was not in English, and books were eliminated.

Inclusion Criteria

Our article inclusion criteria were broad to identify the full extent of instruments designed for eHealth research and implementation evaluation. We focused explicitly on instruments that assessed an eHealth-specific construct from the patient’s point of view. Articles were selected if they (1) described development of an instrument, or (2) used an instrument in an evaluation of an eHealth technology that could be traced back to an original publication describing its development, or (3) modified an instrument, and (4) with full text in English language. The review was limited to instruments that reported at least one psychometric property. Excluded were investigator-developed measures or sets of questions without psychometric evaluation, disease-specific assessments delivered via technology or telephone (eg, a cancer-coping measure delivered via computer survey), and measures focused primarily on clinician use (eg, the electronic health record). We limited our review to articles that reported at least one established psychometric property (see Table 1 for psychometric evaluation components).

Data Extraction

Two investigators and a research assistant (BW, JH, AM) independently reviewed 100 article titles followed by an in-depth discussion to establish agreement on inclusion of articles. Next, the review was repeated two times using an additional 100 article titles each time, until agreement was reached on articles to include for further review. All article titles were then reviewed to exclude ineligible articles. The abstracts of the remaining articles were reviewed by a pair of investigators (BW, CT) following an independent review of 20 articles to establish interrater consistency. The remaining abstracts were then independently reviewed and discrepancies between reviewers were resolved by discussion and consensus. Articles that did not meet criteria were excluded (no instrument, use of an instrument, or instrument modification), and remaining articles were retained for full-text review. Articles were then classified as describing the development and testing of an instrument or as using an instrument. For articles using an instrument, reference lists were reviewed to identify citations for the original instrument development.

A data extraction form with definitions for each item was developed by the study team (Table 1) [24]. To establish interrater reliability in data extraction, coauthors were divided into pairs, and were assigned to independently review two articles using the data extraction tool. These reviews were discussed in depth by the whole study team to reach consensus on the definitions used in Table 1. Following minor revisions of the data extraction form, articles from the search were then distributed among the six study investigators for final review and data extraction. The first author then reviewed each article and data extraction information to ensure accuracy.

Table 1. Data extraction elements.

Element	Definition
Construct	Constructs are not directly observable, but may be applied and defined based on observable behavior; many health measures are designed to capture some aspect of an underlying construct. In the authors' own words, what the authors of the scale say they are measuring.
Theoretical foundation	Conception of how attributes exist and relate to one another; theoretical framework; can indicate that a conceptual framework (concepts identified in the framework) was used.
Modification of another instrument by others (alternate forms) abbreviated, short forms, different forms targeting the same construct, translations	State if this article is a modification of the format or administration of an instrument already evaluated for psychometric properties.
# items	Number of items included in the measure.
Item types	Structure of the items: such as Likert-type, categorical (multiple options), open ended, yes/no, visual analog scale, other.
Administration time	Estimated amount of time for completion of the measure.
Administration mode	Assessment completed by self-report vs interviewer/researcher administered.
Active vs passive assessment/obtrusiveness	Data collection which does not involve direct solicitation from the research subject or other participant; indirect ways to obtain the necessary data often relying on technology captured information such as response time, number of navigation errors, etc.
Item development	Briefly overview how items were developed for the original form of the measure (ie, expert generation of items, compilation of items from prior measures).
Scoring	Describe how the measure is scored, include a range of possible scores and other descriptive statistics such as significant threshold scores if available.
Readability	Did the developers test the readability of the measure? Were any readability formulas used (eg, Flesch-Kincaid).
Sensitivity to change	Ability to detect change over time, particularly in response to some intervention; known as responsiveness; floor and ceiling effects.
Reliability: test-retest	Consistency in scores between 2 administrations of the measure separated by time (ie, same subject completes the measure twice).
Reliability: interrater	Consistency between 2 independent observers using the measure (for measures that involve observing subjects)% agreement, kappa.
Reliability: internal consistency	Degree to which all items in the scale correlate with each other taking length of measure into account, indicating the items measure the same underlying construct. Based on a single administration of the measure; Cronbach alpha, Kuder-Richardson, split-half reliability.
Validity: content	Typically, from a review of the literature or review by experts.
Validity: criterion, convergent, concurrent, discriminant	Correlation of the scale with other measures to determine independence from other constructs yet some positive correlation to similar constructs and negative correlation to dissimilar constructs.
Validity: construct	Linking the measure to another known attribute. Factor analysis to identify proposed underlying constructs consistent with proposed theoretic content of the measure.
Sample	Patient population used to develop, validate, or test the measure.
Sample studies using the metric/strength of evidence	Studies using the measure including those that did not present psychometric properties of the measure.
Measure website address	If the measure has an associated website, list the website address here and note the date of last update, if available.
Copyright or fees associated with use of the measure	Requires purchase of the measure or the scoring algorithm?

Results

The search strategy yielded 47,320 articles (PubMed: n=16,968; Scopus: n=24,106; PsychInfo: n=3590; CINAHL: n=2187; HAPI: n=468; GEM: n=1). Following elimination of duplicates and full text not in English language publications (n=14,550) and books (n=27), most articles were excluded through review of titles (n=31,647). Following a review of the abstracts of the remaining 1096 articles, 68 were retained for full-text review. Of these, 16 described an instrument and six used an instrument; one instrument was drawn from the GEM database, resulting in 23 articles for inclusion in the review (Figure 1). Of these 23 articles, seven were modifications of existing instruments. No additional measures were identified through our VA, PROMIS, or AHRQ search. Each article was then reviewed by team members, using the data extraction form (Table 1).

We identified common conceptual threads across the 23 instruments. We reviewed the literature to identify salient concepts and constructs from existing technology use models [19-22,25]. Multiple constructs were identified and terminology varied across models. For example, the Technology Acceptance Model includes 16 constructs in four categories (behavioral intention, perceived usefulness, perceived ease of use, and use behavior). Although terminology varied by author and model, categorizations were inferred and grouped. Twelve concepts emerged from this categorization: clinical content, communication, effectiveness, efficiency, frequency/consistency of use, hardware and software, perceived ease of use, policies and procedures, risk and benefits, user preferences, social influence, and usability. Author definitions guided this categorization. The definition of several of these terms are intuitive (eg, effectiveness), but some are not and are briefly defined here. Efficiency includes the concepts of accuracy, costs, learnability, performance expectations, productivity, quality of use, and workflow. Learnability is an aspect of usability and refers to the ease of learning how to use software. Closely related to learnability is performance expectation, where the end user knows what is expected from them to use the software. Hardware and software aspects include availability, human-computer interface (ie, efficient and desirable interaction between a person and the computer), information display, system maintenance and monitoring, and technical quality. Perceived ease of use incorporates anxiety about and attitude toward using a computer, behavioral intention (the likelihood that an individual will use the computer), computer self-efficacy, engagement, enjoyment, and usefulness.

Figure 1. Flow diagram of search.

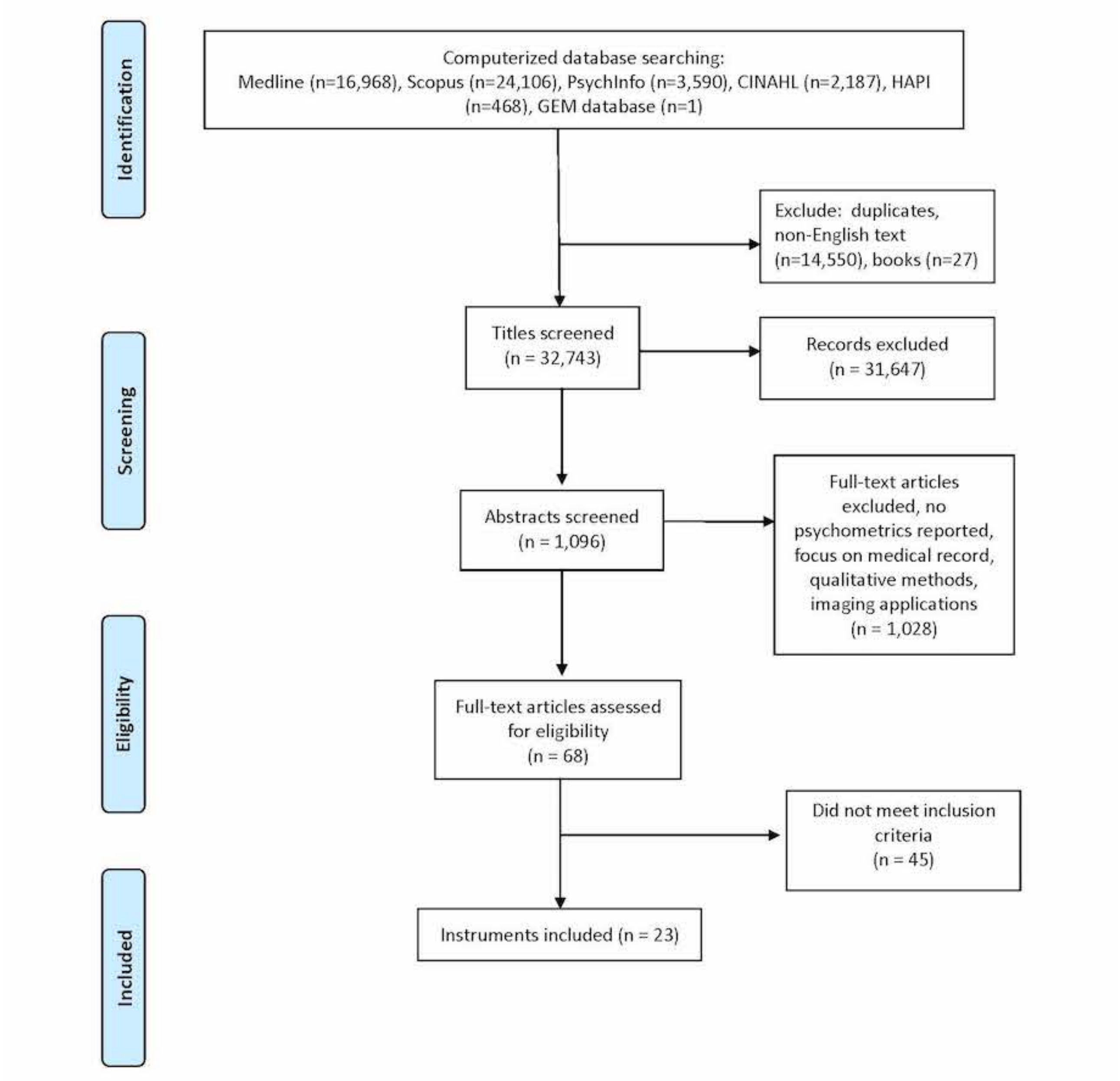

Table 2. Concepts 1 to 6 identified in reviewed instruments (N=23).

Article	Concept and model authors					
	Clinical content [20]	Communication [20,21]	Effectiveness [22]	Efficiency [20-22]	Frequency/consistency of use [21,23]	Hardware and software [19-23]
Atkison, 2007 [29]			X	X		
Bakken, 2006 [30]			X	X		X
Brockmeyer, 2013 [31]						X
Brooke, 1996 [32]			X	X		
Bunz, 2004 [33]			X	X	X	X
Demiris, 2000 [34]			X	X		X
Finkelstein, 2012 [35]	X		X	X	X	
Henkemans, 2013 [36]	X					X
Hudiberg, 1991-1996 [37-40]			X	X		X
Jay & Willis, 1992 [41]			X			
Lewis, 1993 [42]			X	X		X
Lin, 2011 [43]				X		X
Martinez-Caro, 2013 [44]	X				X	X
Montague, 2012 [45]	X		X	X		X
Norman, 2006 [46]	X		X	X	X	X
Pluye, 2014 [47]	X	X		X	X	X
Schnall, 2011 [48]	X	X	X	X		
Tariman, 2011 [49]	X		X	X		X
Wang, 2008 [50]	X		X	X		X
Wehmeyer, 2008 [27]						X
Wolfradt, 2001 [51]		X				X
Xie, 2013 [28]	X		X	X		X
Yip, 2003 [52]	X					X

The 23 articles included in this review were mapped to the 12 identified concepts based on whether the instrument encompassed the concept. The most common constructs addressed by this set of measures were effectiveness, efficiency, hardware and software, perceived ease of use, satisfaction, and usability [19-23] (Tables 2 and 3). Interestingly, although eHealth is a communication technology, only three studies specifically address this aspect. Additionally, to identify potential gaps for future consideration, concepts included in the measures, but not identified in the 12 model concepts, were documented in the crosswalk (last column in Table 3). For example, stress, eHealth literacy, perceived necessity, and others emerged as concepts not identified in the review of existing technology use models. eHealth literacy is defined by Norman and Skinner [26] as "the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem." Wehmeyer [27] introduced three concepts: symbolism, esthetics, and perceived necessity. Symbolism reflects the meaning or status associated with the device (eg, having a mobile device may signify group membership or a certain social status). Esthetics refers to the appearance of the device (eg, the perceived beauty of the device may affect the attachment to the device). Finally, the perceived necessity of the device may affect attachment to the device, creating anxiety when the device is not accessible. Xie et al [28] addressed decision-making autonomy, defined as the level of decision making desired when information about health conditions is electronically available.

No instrument included a complete psychometric evaluation (Multimedia Appendix 2). The most frequently assessed property was internal consistency (21/23, 91%). None of the measures were assessed for sensitivity to change, but several authors indicated the instrument was not designed to assess change. Few measures were assessed for test-retest reliability (4/23, 17%) and only one instrument had been tested for interrater reliability. Testing for aspects of validity ranged from 48% (11/23) of measures tested for criterion, convergent, concurrent, or discriminant validity to 78% (18/23) reporting establishing content validity. Approximately half (13/23, 57%) reported how to score the instrument. Only six (26%) assessed the readability of the instrument for end users, although all measures rely on patient self-report.

Table 3. Concepts 7 to 12 identified in reviewed instruments (N=23).

Article	Concepts and model authors						Concepts not included in models
	Perceived ease of use [19,21-23]	Policies & procedures [20]	Risk & benefits [23]	Satisfaction/ acceptability/ preferences [23]	Social influence [21]	Usability [23]	
Atkison, 2007 [29]	X					X	
Bakken, 2006 [30]	X			X		X	
Brockmeyer, 2013 [31]	X		X	X			
Brooke, 1996 [32]				X		X	
Bunz, 2004 [33]	X			X		X	
Demiris, 2000 [34]	X		X	X		X	
Finkelstein, 2012 [35]	X			X			
Henkemans, 2013 [36]	X		X	X		X	
Hudiberg, 1991-1996 [37-40]	X		X	X	X		Stress
Jay & Willis, 1992 [41]	X				X	X	
Lewis, 1993 [42]	X		X	X		X	
Lin, 2011 [43]	X			X		X	
Martinez-Caro, 2013 [44]	X		X	X			
Montague, 2012 [45]	X		X	X		X	
Norman, 2006 [46]	X			X			eHealth literacy
Pluye, 2014 [47]	X			X			
Schnall, 2011 [48]	X		X				
Tariman, 2011 [49]	X			X			
Wang, 2008 [50]	X			X		X	
Wehmeyer, 2008 [27]	X			X			Symbolism; esthetics; perceived necessity
Wolfradt, 2001 [51]				X			
Xie, 2013 [28]	X			X		X	Decision-making autonomy
Yip, 2003 [52]				X			

Early instruments (prior to the year 2000) [32,37-42] focused on using a computer, reflecting early consumer adoption of personal computers. These measures are not specifically focused on “health” use. During the decade from 2000 to 2009, measures that focused on use of information technology related to health began to emerge, focusing primarily on telehealth [30,34,52]; other measures focused on eHealth literacy [46] and use of eHealth education [29]. Other concepts for which measures were developed included using the Internet [51], use of computers [33], use of mobile devices [27,50], and the effect of video games on engagement [31], although these measures did not specifically focus on “health.” Since 2010, the frequency of “health” themes increased including communication between patients and providers [47,49], patient trust [45], preferences [28], satisfaction [35], and use of technology for care provision [48] or patient self-management [36,48]. One instrument also focused more generally on use of computers [43], and one focused on patient loyalty to online services [44].

Discussion

Principal Findings

Of the 23 articles reviewed, no instrument included a complete psychometric evaluation. The most frequently assessed property was internal consistency. Testing for aspects of validity ranged from 48% (11/23) to 78% (18/23). Approximately half (13/23, 57%) reported how to score the instrument. Only six (26%) assessed the readability of the instrument for end users, although all the measures rely on self-report.

Common theoretical concepts addressed in the instruments were effectiveness, efficiency, hardware/software, perceived ease of use, and satisfaction. A notable exception is that only three instruments focused on communication. Conversely, we identified some concepts addressed in the instruments that have not been included in current theoretical models, including stress, esthetics, eHealth literacy, comfort, and decision-making autonomy. Current instruments require fuller evaluation of psychometric properties.

Measures that can be applied consistently across technologies and platforms are needed so that distinct platforms that serve the same purpose can be compared. For example, evaluation of an intervention to treat depression could utilize a standard measure of usability, regardless of whether it was a mobile app or Web-based (eg, "It took many tries before I knew how to use the key features of this technology" and "I found the layout of the features very intuitive"), regardless of the platform used to deliver the intervention (eg, mobile app or online program). Using these types of measures, investigators and others implementing eHealth technologies can compare technologies and use this information when selecting a technology.

Our review expands on the AHRQ compendium, which lists available measures but provides less detail about their other attributes. We also investigated whether the psychometric properties of the measures had been established, which is a critical information need when selecting a measure for research or evaluation. However, although most would agree that instruments with psychometric properties are very helpful, there may also be a role for using self-developed questions that may more clearly and directly get at the target construct or a specific patient behavior. The AHRQ compendium is populated with many such instruments and future researchers should carefully consider the trade-offs of using investigator-developed question sets that may specifically address their question of interest versus a more validated instrument that may also need to be modified to fit an eHealth evaluation. Furthermore, investigators may want to consider instruments listed in the AHRQ compendium for further development and psychometric evaluation.

Implementation of eHealth technologies can involve substantial investment in terms of costs and effort. Research on eHealth has also increased dramatically over the past several years, yet studies rarely utilize common methods and/or instruments. The results of this project provide critical insights regarding existing eHealth instruments and identify gaps for which new instruments are needed. Use of common and psychometrically sound instruments can inform future studies so that the results from multiple studies can be compared and synthesized.

Although most the instruments identified in this review were published after the year 2000, rapidly changing technology makes instrument development challenging. Platform-agnostic measures need to be developed that focus on concepts important for use of any type of eHealth innovation. Instrument development as a research enterprise is typically undervalued, relative to more direct practice-relevant research. Instrument development can also be a complex and lengthy process. Thus, funding agencies should consider addressing this gap, given the persistent and expected growth in the deployment of technology to improve care processes and patient outcomes.

Limitations

We did not conduct a comprehensive search for all published uses of the identified instruments as it was beyond the scope of this study. The grey literature (eg, conference abstracts, dissertations, and unpublished studies) were not included in our review. Furthermore, the review potentially missed some published as well as unpublished measures based on keyword choice and/or elimination of articles through review of title or abstract. Finally, our choice of theoretical models used to analyze the selected articles may impose limitations on our findings.

Conclusions

Based on our review, we highlight some of the more useful measures that we believe could be useful in most technology studies. These include the eHealth literacy scale (eHEALS) [46], the Computer-Email-Web Fluency Scale [33], and the System Usability Scale [32]. Additional research is needed to build and further refine measures of literacy such as the eHEALS or Computer-Email-Web Fluency Scale so that researchers have access to a validated measure of user's comfort with a target technology.

Development of a standard measure of the intuitiveness of the user interface would allow platform-agnostic comparisons between user interfaces (eg, two mobile apps for depression, or comparison of differences between a Web-based and mobile app). Finally, given the explosion of new technologies in the market focused on health behaviors, a standard measure of the relative advantage of a new technology feature when compared to prior methods and/or a standard measure of the degree to which new technology facilitates a target behavior (eg, weight loss, exercise, self-management techniques, or receipt of care) could provide important insights to inform technology adoption strategies.

Advances in eHealth offer tremendous potential to improve access to care, efficiency of care delivery processes, and overall quality. Significant resources are being invested in eHealth technologies, driven in part by meaningful use requirements. Consumer behavioral health interventions are increasingly being made available via multiple platforms (eg, computer vs mobile versions of interventions proven effective for in-person delivery). Identification of useful and valid measures to evaluate these interventions has important potential to contribute to improved implementation, clinical practice, and ultimately population health since insights gleaned from standardized measurement can directly inform system improvements and optimal implementation strategies. In addition, having better measures to evaluate implementation of eHealth technologies will help improve consumers' experiences with technologies and assess whether use of these technologies is making a measurable difference in quality of care or the patient experience. More longitudinal research will be needed to develop measures that more comprehensively address the wider frame of concepts important for the meaningful implementation of eHealth technologies.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Search Terms.

[PDF File (Adobe PDF File), 41KB - jmir_v19i10e346_app1.pdf]

Multimedia Appendix 2

Detailed Psychometric Properties of Reviewed Instruments.

[PDF File (Adobe PDF File), 113KB - jmir_v19i10e346_app2.pdf]

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Abbreviations

AHRQ: Agency for Healthcare Research and Quality
CINAHL: Cumulative Index to Nursing and Allied Health Literature
GEM: Grid-Enabled Measures
HAPI: Health and Psychosocial Instruments
PROMIS: Patient-Reported Outcomes Measurement System
VA: Veterans Health Administration

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Original Paper

Using the Internet to Train Therapists: Randomized Comparison of Two Scalable Methods

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Abstract

Background: One of the major barriers to the dissemination and implementation of psychological treatments is the scarcity of suitably trained therapists. The currently accepted method of training is not scalable. Recently, a scalable form of training, Web-centered training, has been shown to have promise.

Objective: The goal of our research was to conduct a randomized comparison of the relative effects of independent and supported Web-centered training on therapist competence and investigate the persistence of the effects.

Methods: Eligible therapists were recruited from across the United States and Canada. They were randomly assigned to 1 of 2 forms of training in enhanced cognitive behavior therapy (CBT-E), a multicomponent evidence-based psychological treatment for any form of eating disorder. Independent training was undertaken autonomously, while supported training was accompanied by support from a nonspecialist worker. Therapist competence was assessed using a validated competence measure before training, after 20 weeks of training, and 6 months after the completion of training.

Results: A total of 160 therapists expressed interest in the study, and 156 (97.5%) were randomized to the 2 forms of training (81 to supported training and 75 to independent training). Mixed effects analysis showed an increase in competence scores in both groups. There was no difference between the 2 forms of training, with mean difference for the supported versus independent group being –0.06 (95% Cl –1.29 to 1.16, *P*=.92). A total of 58 participants (58/114, 50.9%) scored above the competence threshold; three-quarters (43/58, 74%) had not met this threshold before training. There was no difference between the 2 groups in the odds of scoring over the competence threshold (odds ratio [OR] 1.02, 95% CI 0.52 to 1.99; *P*=.96). At follow-up, there was no significant difference between the 2 training groups (mean difference 0.19, 95% Cl –1.27 to 1.66, *P*=.80). Overall, change in competence score from end of training to follow-up was not significant (mean difference –0.70, 95% CI –1.52 to 0.11, *P*=.09). There was also no difference at follow-up between the training groups in the odds of scoring over the competence threshold (OR 0.95, 95% Cl 0.34 to 2.62; *P*=.92).

Conclusions: Web-centered training was equally effective whether undertaken independently or accompanied by support, and its effects were sustained. The independent form of Web-centered training is particularly attractive as it provides a means of training large numbers of geographically dispersed therapists at low cost, thereby overcoming several obstacles to the widespread dissemination of psychological treatments.

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KEYWORDS

psychotherapy; training; Internet; eating disorders; cognitive therapy

Introduction

Psychological treatments are difficult to disseminate [1,2]. One of the major barriers to their dissemination and implementation is the scarcity of suitably trained therapists [3]. The currently accepted method of training typically involves attending a specialist workshop, reading relevant texts, and receiving subsequent supervision from someone expert in the treatment [4]. A fundamental flaw with this method is that it is not scalable, as it is both labor-intensive and costly [5,6].

One solution to the problem of scalability is the “train the trainer” model in which an expert provides training to an individual who subsequently trains other providers, thereby increasing the reach of the training [7,8]. While this method has advantages in comparison to the conventional method [3], it is still relatively resource-intensive and potentially slow to have an impact [9].

Recently there has been growing interest in training therapists using the Internet [10]. This has a number of potential advantages. Training can be offered simultaneously to large numbers of geographically dispersed trainees with Web resources that can be accessed at any time and from any place. Furthermore, trainees can review and revisit material in a way that potentially reinforces learning and prevents subsequent therapist drift [9,11]. In addition, clinical illustrations and formative assessments such as knowledge tests can be integrated into the training program. The program can also be updated regularly to incorporate new information. Last, data collection on website usage can provide information to inform and improve the training process.

We have developed a form of therapist training called Web-centered training [12,13]. It differs from conventional training in that the training is fully automated with the expertise residing within the program rather than provided by an outside expert. Thus, Web-centered training can be undertaken completely autonomously (independent training). Alternatively, it can be accompanied by support from a nonspecialist worker (supported training), an approach that closely resembles supported or guided self-help [14-16], with the aim of the support being to increase adherence to the training program. As the role of the support worker is solely to encourage the trainee to follow the training program rather than to provide clinical supervision, it can be undertaken by people with limited training. Thus, the supported form of Web-centered training is also scalable. A recent proof-of-concept study of this supported form of Web-centered training found that the method was feasible and acceptable to therapists and was effective in improving therapist competence [13]. This finding requires replication. In addition, whether supported training is more beneficial than undertaking training independently needs to be investigated. A further question concerns the persistence of the benefits of training, as transitory effects would be of limited value.

Our study had 2 aims. The first was to determine the relative effects of independent and supported Web-centered training on therapist competence, and the second was to investigate the persistence of these effects.

Methods

Design

The study was a randomized comparison of 2 educational interventions, independent and supported Web-centered training. Eligible therapists were randomly assigned to 1 of these 2 forms of training. Therapist competence was assessed before the training, after 20 weeks of training, and at 6 months after the completion of training.

The research protocol was submitted to the Oxford University Central Research Ethics Committee. As the intervention was judged to be educational rather than clinical, the committee decided that formal ethical approval was not required.

Recruitment

Participants were recruited from across the United States and Canada by advertisements offering free training in enhanced cognitive behavior therapy (CBT-E), a multicomponent evidence-based psychological treatment for any form of eating disorder [17,18]. Potential participants had to be licensed mental health professionals who were prepared to take part in research evaluating Web-centered training. Advertisements were placed in the publications of the following professional bodies: American Psychological Society, National Association of Social Workers, American Psychiatric Nurses Association, American Psychiatric Association, and Academy for Eating Disorders. These advertisements included a link to an online description of the training and study.

Participants had to meet the following eligibility criteria: have been previously trained in delivering short-term psychological treatments, work with individuals with eating disorders, be willing to be randomized to independent or supported Web-centered training, be willing to devote at least 9 hours to the training program, be able to treat 1 or more patients using CBT-E during the 20-week period of training, and provide informed digital consent. In the information provided to participants, it was stressed that clinical responsibility for their patients would remain with their local clinical team and not be shared with the researchers or support workers.

Eligible participants were asked to complete a brief online survey about their professional background, age, gender, and clinical experience. They also completed an online therapist competence assessment. They were subsequently sent a link to the training website together with instructions about how to use the training program, tailored to whether they were to receive independent or supported training. In addition, they were sent brief details about the minimum technical specifications for accessing the website.

Training Program

The CBT-E Web-centered training program has 2 main parts: the Course and the Library. A summary of the content of the training is provided in Multimedia Appendix 1; the CBT-E training program and complete details are provided elsewhere [13]. Briefly, the Course is linear in nature and takes between 8 and 9 hours to complete. It is a detailed practical description of how to implement the main focused form of CBT-E given by an expert on the treatment (CGF). This description is delivered in the form of multiple brief video presentations accompanied by handouts and interspersed with formative learning exercises, video recordings of acted illustrations of the treatment, and tests of knowledge together with feedback. While working through the Course, trainees are encouraged to read relevant sections from the treatment manual [19] and treat 1 or 2 patients.

The second part of the training website, the Library, contains all the material in the Course including the handouts, learning exercises, and clinical illustrations in indexed form as well as further longer clinical illustrations. In addition, there is a large amount of supplementary material on how to use CBT-E with specific subgroups of patients including those who are severely underweight and those with clinical perfectionism, core low self-esteem, and marked interpersonal difficulties. There is also a detailed account of how to use CBT-E to treat younger patients.

The participants were granted access to the Course and the core Library material from the start of training, and they continued to have access during the follow-up. They only had access to the supplementary Library material focusing on specific subgroups of patients once they had completed the study.

Information about participants' use of the training program, in particular the number of Course modules viewed and completed, was obtained from the website.

Participants randomized to independent training were given access to the Course and the Library. There was no external support, but they did receive reminder emails at 6, 10, 14, and 18 weeks informing them of the number of weeks of training that had elapsed and the number of weeks remaining.

Participants randomized to supported training were offered up to 12 telephone calls over the 20-week period of training, each lasting no longer than 30 minutes. These were weekly for the first 4 weeks and then every other week. The calls were designed to be purely supportive in nature. Their goal was to encourage participants to work through the training material and implement CBT-E with their training cases [13]. A protocol defined the nature and limits of the supportive role. The support was provided by research assistants who were not clinicians and had no experience delivering CBT-E. They were supervised by 2 senior clinicians (ZC and SBS).

Assessment

Participants' competence at delivering CBT-E was assessed before training, immediately following training, and 6 months later. It was measured using a scalable online measure with sound psychometric properties that had previously been developed independently of the creation of the training website. Its development and validation are described in detail in a separate publication [20]. Measure development included detailed blueprinting, state-of-the-art item writing, independent item review, and initial field-testing, followed by formal Rasch analysis to test for good model fit. Strict criteria of unidimensionality were met by stepwise exclusion of misfitting items until there was no individual item misfitting at $P<.01$. The resulting measure consists of 22 items addressing trainee knowledge and understanding of CBT-E and its implementation (ie, applied knowledge). The instrument generates a total score (out of a possible 22), and trainees can be classified as scoring at or above the previously established cut-point. This was established using receiver operator characteristic analyses to determine the best cut-point from the values of sensitivity and specificity calculated at increasing test score cut-points. This analysis yielded a score of 12 or more as indicative of competence at delivering CBT-E (area under the curve 0.964, sensitivity 0.909, specificity 0.881). Three equivalent versions of the measure are available so that different versions can be used on different assessment occasions.

Randomization

An independent statistician, not otherwise involved in the study, randomized participants to independent and supported training. To ensure that therapists who worked in the same organization did not receive different forms of training, the trainees were randomized by zip code. The first therapist from each zip code was randomized to a training group thereby determining the assignment of the cluster, with further participants from that zip code being allocated to the same group. Minimization on size of cluster was used to balance the number of participants in each training arm.

Data Analysis

To investigate the immediate and longer term effects of training, a mixed effects model was fitted to the scores from the competence measure. The use of a mixed effects model allowed all time points to be modeled simultaneously and all randomized therapists to be included in the model in an intent-to-train analysis. The model assumes that the data are missing at random conditional on the covariates included in the model and scores at the other time points. The model included separate fixed effects for the mean score and time by training group interactions at the posttraining and 6-month time points. This allowed the means in the independent and supported groups to vary both at posttraining and 6 months. The model also included a normally distributed random effect for person to account for repeated measures nested within a normally distributed random effect for zip code.

A second mixed effects model without training group effects was used to look at the change in scores over time in both the independent and supported groups combined.

Logistic regression, with adjustment for pretraining score, was used to assess scoring over the competence cut-point with a binary variable created to indicate a score above the previously determined competence cut-point. A clustered sandwich estimator to account for clustering within zip code was used.

Missing competence data were tabulated and a sensitivity analysis was carried out to assess their impact on the findings. This analysis examined what difference would be required between the means in those missing and those observed for there to be a statistically significant difference between the training groups and compared these to the differences in expected scores between the 2 groups. All analyses were conducted in Stata 14 (StataCorp LLC) .

Results

Recruitment

A total of 160 therapists expressed an interest in participating in the study, 156 (97.5%) of whom were randomized to the 2 forms of training (81 to supported training and 75 to independent training). These therapists were located in 30 different US states and 5 Canadian provinces. Figure 1 shows their progress through the study.

The median age of the participants was 36 years (interquartile range [IQR] 31 to 47; range 23 to 70 years) and 93.3% were female (140/150). They belonged to 2 main professional groups: 64 (41.0%) were clinical psychologists, while 45 (28.9%) were social workers. The remainder came from a variety of other backgrounds including counseling, family therapy, psychiatry, and psychiatric nursing. Median years of full-time equivalent clinical experience was 5.9 years (IQR 3 to 13.3; range 0 to 36 years). Participants reported seeing patients with eating disorders for face-to face treatment for a median of 14 hours per week (IQR 6 to 20; range 0 to 50 hours). Participant details by randomization group at baseline are shown in Table 1.

Training Completion

The median number of modules of the training program completed was 14 out of a possible 18 (IQR 4 to 18). There was no strong evidence of a difference between the 2 training conditions in this regard (independent training 14 [IQR 1 to 18], supported training 16 [IQR 7 to 18], *P*=.10 [Somers D, adjusting for clustering by zip code]). The median number of support sessions received by those in the supported group was 10 (IQR 5 to 11).

Immediate Effects of Training

Mean scores for the participants in the 2 training groups at the 3 assessment points are given in Table 2. The mixed effects analysis showed that there was an increase in competence scores in both training groups. Mean change score in the independent training group was 4.57 (95% CI 3.61 to 5.53; *P*<.001) while mean change in the supported training group was 4.51 (95% Cl 3.62 to 5.40; *P*<.001). As can be seen in Figure 2 there was no difference between the 2 forms of training in their effects on competence scores, with the mean difference for the supported versus independent group being –0.06 (95% Cl –1.29 to 1.16, *P*=.92).

After training, half of the participants (58/114, 50.9%) scored above the competence threshold. Of the 96 participants who had not met this threshold before training, 43 (43/96, 45%) met the threshold after training. Only 3 participants who had scored above the competence threshold before training failed to do so after training. The supported trainees were just as likely to score above the competence threshold as the independent trainees (odds ratio [OR] 1.02, 95% CI 0.52 to 1.99; *P*=.96).

Effects of Training at Follow-Up

There was little change in participant competence scores from the end of training to the 6-month follow-up assessment (see Table 2). At follow-up assessment (see Figure 2), mean change in competence scores from pretraining baseline was 3.72 (95% Cl 2.56 to 4.88; *P*<.001) in the independent training group and 3.91 (95% Cl 2.90 to 4.93; *P*<.001) in the supported group. Again, the difference between the 2 forms of training was very small, with the mean difference for supported versus independent group being 0.19 (95% Cl –1.27 to 1.66, *P*=.80).

Table 2 Competence scores for the 2 training groups before and after training and at follow-up.

Table 1. Baseline characteristics of randomized therapists by training group.

Characteristics	Supported training (n=81)	Independent training (n=75)
Age, years, median (IQR[a])	36 (29-45)	36 (32-47)
Female[b], n (%)	75 (94)	65 (93)
Professional background, n (%)		
Clinical psychologist	35 (43)	29 (39)
Social worker	23 (28)	22 (29)
Weekly contact hours with patients with eating disorders[c], median (IQR)	12.5 (6.0-18.5)	15.0 (7.0-21.0)
Clinical experience, full-time equivalent years[d], median (IQR)	4.7 (2.6-13.0)	6.0 (3.5-14.0)

[a] IQR: interquartile range.

[b] Data missing for 1 participant in the supported training group and 5 in the independent group.

[c] Data missing for 1 participant in the independent group.

[d] Data missing for 3 participants in the supported group and 1 participant in the independent group.

Figure 1. Flow of the participants in the study.

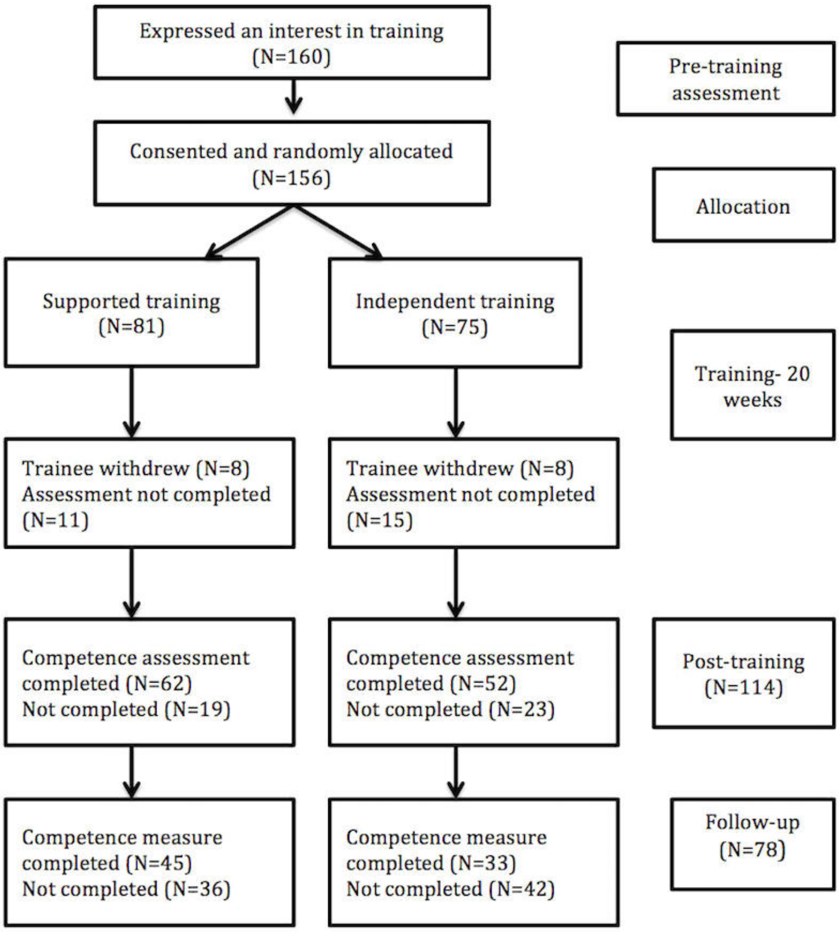

Figure 2. Mean scores and confidence intervals estimated by the mixed effects model for the 2 training groups.

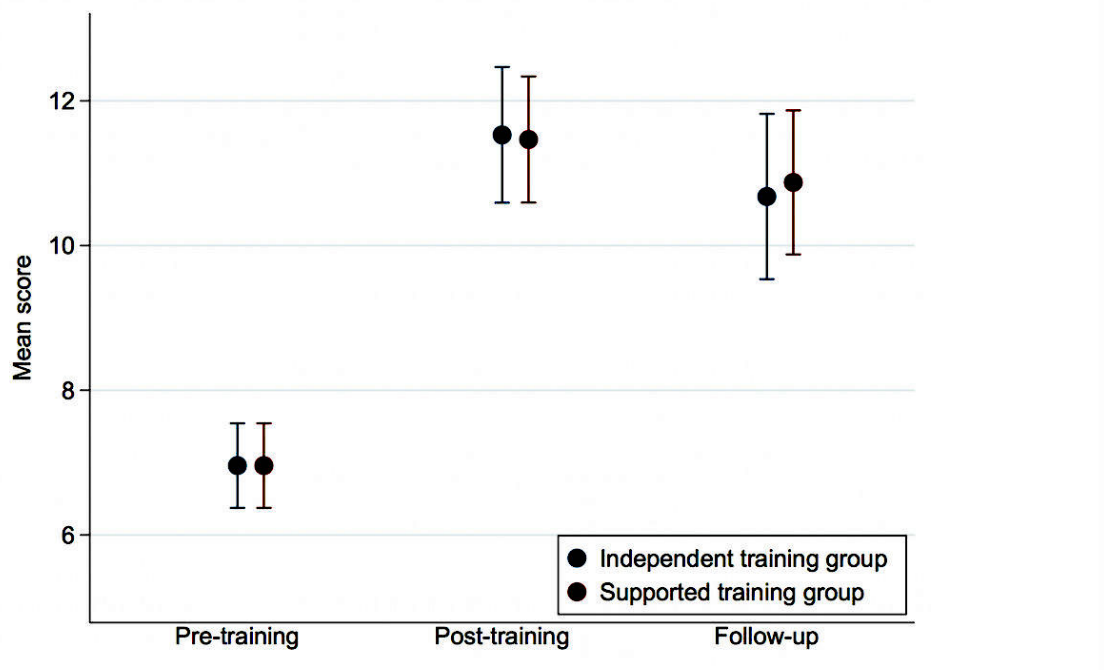

Table 2. Competence scores for the 2 training groups before and after training and at follow-up.

Time point	Independent training	Supported training	All participants
Pretraining			
Number of participants	75	81	156
Mean competence score (range)	6.6 (1-19)	7.3 (2-16)	7.0 (1-19)
Number competent, n (%)	9 (12)	11 (14)	20 (13)
Posttraining			
Number of participants (% completing competence assessment)	52 (69)	62 (77)	114 (73)
Mean competence score (range)	11.6 (0-18)	11.7 (4-19)	11.7 (0-19)
Number competent, n (%)	26 (50)	32 (52)	58 (51)
Follow-up			
Number of participants (% completing competence assessment)	33 (44)	45 (56)	78 (50)
Mean competence score (range)	11.0 (3-18)	11.2 (2-17)	11.1 (2-18)
Number competent, n (%)	16 (48)	21 (47)	37 (47)

Results from the second mixed effects model without the effects for training group indicated that although scores decreased over time, the change from end of training to follow-up was not statistically significant (mean difference –0.70, 95% CI –1.52 to 0.11; *P*=.09). There was no difference between the 2 training groups in the odds of scoring over the competence threshold (OR 0.95, 95% Cl 0.34 to 2.62; *P*=.92).

Sensitivity Analysis

The sensitivity analysis suggested that unless fairly extreme assumptions were adopted about the differences between the mean scores of those whose scores are missing as compared to those observed, the present findings are relatively robust. (see Multimedia Appendix 2).

Discussion

Principal Findings

The findings of this study comparing 2 forms of Web-centered therapist training replicate and extend those of the earlier proof-of-concept study [13]. They show that Web-centered training is acceptable to therapists and that it is effective. The great majority of the training modules were completed, and scores on the competence measure increased significantly. As in the proof-of-concept study of the supported form of training, almost half the participants obtained competence scores indicative of a good level of competence, and this was true of both the supported and independent forms of training. Furthermore, the changes obtained with both forms of training appeared to be well maintained.

Comparisons With Other Studies

There has been limited research on the outcome of training against which to compare the present findings [6,11,21]. Therapist training in general has been relatively neglected as a research topic until recently [22,23], and few studies have used validated competence measures [24]. Competence figures that have been reported following training in psychological treatment for depression range from 21% after attending a training workshop to 96% after extensive consultation with an expert including session review and feedback [25]. A study of community clinicians receiving training in transdiagnostic cognitive behavior therapy reported 59.5% of clinicians competent after training [26]. However, the latter training also involved extensive expert consultation and session review of a kind that is not scalable; thus, the findings are not directly comparable. Last, as part of our ongoing training program we have collected data employing the same competence measure as used in this study with therapists undergoing conventional training. Training involved an expert-led face-to-face workshop and 20 sessions of expert supervision while treating patients. Of 20 therapists studied to date, 19 were not competent at the start of training, and at completion of training 10 were competent (53%). As these trainees received extensive expert supervision, the findings are not directly comparable to those obtained in this study.

Study Strengths

The study has a number of strengths. First, a relatively large number of trainees, dispersed across an extensive geographical area, was recruited and trained. Second, the trainees were randomized to 2 scalable forms of training thereby adding to the limited literature on scalable therapist training. Third, it used a validated measure of therapist competence that had an empirically established competence threshold that distinguished between therapists independently judged to be competent and those who were not. Fourth, the study included a follow-up assessment to investigate the durability of training effects.

Study Limitations

The study also has limitations. First, it did not include a no-training control condition or a delayed training group. Thus, we cannot discount the possibility that competence scores would have increased over time without training, but this seems unlikely. Second, there was a significant amount of missing data, especially at the follow-up assessment 6 months after training. While this is clearly regrettable, the results of the sensitivity analyses indicate that this was unlikely to distort the overall findings. Attrition, both in the form of participants ceasing to use an intervention and not completing study assessments, has been noted as a particular problem in Internet interventions [27]. Third, the sample was not sufficiently large to investigate the characteristics of those who do and do not benefit from this form of training—for example, whether there are gender differences in the uptake and outcome of training.

Conclusions

This study confirms that Web-centered training can successfully train a large number of therapists dispersed across a wide geographical area. Training on this scale cannot be provided with current methods of training. Another striking finding is that the training was equally effective whether undertaken independently or accompanied by support. Given the high degree of scalability of independent training, this finding is of great practical importance.

Independent Web-centered training therefore provides a means of training large numbers of geographically dispersed therapists at low cost, overcoming several obstacles to the dissemination of psychological treatments.

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Conflicts of Interest

CGF receives royalties from the treatment guide.

Multimedia Appendix 1

Enhanced cognitive behavioral therapy training program.

[PDF File (Adobe PDF File), 24KB - jmir_v19i10e355_app1.pdf]

Multimedia Appendix 2

Sensitivity analysis.

[PDF File (Adobe PDF File), 25KB - jmir_v19i10e355_app2.pdf]

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Abbreviations

CBT-E: enhanced cognitive behavioral therapy
IQR: interquartile range
OR: odds ratio

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Original Paper

Web-Based Information on the Treatment of Tobacco Dependence for Oral Health Professionals: Analysis of English-Written Websites

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Abstract

Background: Studies have been conducted on the content and quality of Web-based information for patients who are interested in smoking cessation advice and for health care practitioners regarding the content of e-learning programs about tobacco cessation. However, to the best of our knowledge, there is no such information about the quality of Web-based learning resources regarding smoking cessation dedicated to oral health professionals.

Objective: The aim of this study was to identify and evaluate the quality of the content of webpages providing information about smoking cessation for oral health care professionals.

Methods: Websites were identified using Google and Health on Net (HON) search engines using the terms: smoking cessation OR quit smoking OR stop smoking OR 3As OR 5As OR tobacco counselling AND dentistry OR dental clinic OR dentist OR dental hygienist OR oral health professionals. The first 100 consecutive results of the 2 search engines were considered for the study. Quality assessment was rated using the DISCERN questionnaire, the Journal of the American Medical Association (JAMA) benchmarks, and the HON seal. In addition, smoking cessation content on each site was assessed using an abbreviated version of the Smoke Treatment Scale (STS-C) and the Smoking Treatment Scale-Rating (STS-R). To assess legibility of the selected websites, the Flesch Reading Ease (FRES) and the Flesch-Kinkaid Reading Grade Level (FKRGL) were used. Websites were also classified into multimedia and nonmultimedia and friendly and nonfriendly usability.

Results: Of the first 200 sites selected (100 of Google and 100 of HON), only 11 met the inclusion criteria and mainly belonged to governmental institutions (n=8), with the others being prepared by Professional Associations (n=2) and nonprofit organizations (n=1). Only 3 were exclusively dedicated to smoking cessation. The average score obtained with the DISCERN was 3.0, and the average score in the FKRGL and FRES was 13.31 (standard deviation, SD 3.34) and 40.73 (SD 15.46), respectively. Of the 11 websites evaluated, none achieved all the four JAMA benchmarks. The mean score of STS-R among all the websites was 2.81 (SD 0.95) out of 5. A significant strong positive correlation was obtained between the DISCERN mean values and the STS-R (*R*=.89, *P*=.01).

Conclusions: The mean quality of webpages with information for oral health care professionals about smoking cessation is low and displayed a high heterogeneity. These webpages are also difficult to read and often lack multimedia resources, which further limits their usefulness.

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KEYWORDS

tobacco use cessation; Internet; general practice; dentistry; education, continuing

Introduction

Oral health care professionals are well placed to motivate and dispense smoking cessation advice to their patients [1]. Tobacco plays a major role in the development and poor treatment outcomes of many oral diseases. The most serious consequence of tobacco use in the oral cavity is the increased risk of oral squamous cell carcinoma. There is a strong dose-response relationship between tobacco smoking and the development of potentially malignant disorders and oral cancer [2,3].

Tobacco use is also a risk factor for periodontal disease (including increased periodontal pockets depth; increased insertion loss, and as a consequence, dental mobility; increased tooth loss; gingival recessions; increased risk of failure of dental implants; increased risk of perimplantitis; and worse response to surgical and nonsurgical periodontal therapy) [4]. Tobacco has also been associated with delayed healing following oral surgery and an increased risk of alveolar osteitis following tooth extraction [5]. In addition, tobacco use has also been associated with halitosis, tooth and dental restorations staining, gingival pigmentation, and reduced taste sensation [6].

There is strong evidence that smoking cessation results in oral health benefits [7]. Smoking cessation is associated with the potential for reversal of premalignant oral disorders, enhanced outcomes following periodontal treatment, and better periodontal status compared with individuals who continue to smoke. The risk for oral cancer and periodontal disease progression of former smokers approximates to that of never smokers after 10 years of complete tobacco cessation [8].

To encourage oral health professionals to become more involved in smoking cessation, a care pathway based on recognized national and international guidelines has been produced by the European Workshop on Tobacco Use Prevention and Cessation for Oral Health Professionals. This is recommended as guidance for tobacco use cessation activity in dental practice. This guideline recommends an evidence-based technique called the “5As” approach: *A* sk about tobacco use, *A* dvise them to quit, *A* ssess willingness to quit, *A* ssist with quitting attempts, and *A* rrange for follow-up [9].

Research has confirmed that members of the dental team can be effective in assessing and advising tobacco users to quit [10]. Despite this, members of the dental team often cite issues such as lack of time or education as a reason to not offer smoking cessation advice to all smoking patients [11,12]. Support and training for oral health professionals can be provided through face-to-face contact but also via the Internet [13]. It has been shown that Web-based training for health care professionals, including dentists, can increase number of referrals to stop smoking services, and importantly, the rate of referrals converted to quit-line registrations. There is also evidence to suggest that training could improve provider knowledge, alongside improving attitudes toward tobacco cessation services, resulting in increased self-efficacy for providing appropriate interventions [14]. Studies have been conducted regarding the content and quality of Web-based information among patients searching for smoking cessation advice [15-17]. However, there is no information regarding the quality of Web-based smoking cessation information for oral health care professionals.

The aim of this study was to identify and evaluate the quality of the content of webpages that provide information about smoking cessation for oral health care professionals.

Methods

Website Identification

Websites were identified on February 18, 2017 using Google and Health on Net (HON) medical professional search engines using the terms “smoking cessation OR quit smoking OR stop smoking OR 3As OR 5As OR tobacco counselling AND dentistry OR dental clinic OR dentist OR dental hygienist OR oral health professionals” written in English, without predetermined location or filters. The websites were displayed (10 sites per page), accessed, and saved for subsequent analysis.

The first 100 consecutive results from both search engines were considered for the study. Exclusion criteria were non-English language; irrelevant content; links to PubMed scientific articles; exclusively commercial information; patient-targeted sites; duplicated websites, forums, and discussion groups; non-operative sites; and password-protected webpages.

The review process was independently undertaken by 2 observers (AI and MD); in case of disagreement, a third reviewer (coordinator) was involved.

Evaluation Procedures

The websites were grouped based on their affiliation (commercial, nonprofit, medical or university centers, government, professional societies) and level of specialization (exclusively dedicated to smoking cessation or partially dedicated to smoking cessation).

Quality Assessment

Quality assessment was rated using the DISCERN questionnaire, the Journal of the American Medical Association (JAMA) benchmarks and the HON seal.

DISCERN is a validated questionnaire of 16 points, consisting of 8 questions examining reliability (questions 1-8) and specific details of information on treatment options (question 9-15) plus an overall quality score (question 16). Each question is classified in a numerical scale of 1 to 5 (1=very poor, 2=poor, 3=moderate, 4=good, 5=excellent). DISCERN has been designed to help users of consumer health information judge the quality of written information about treatment choices. Additionally, DISCERN has demonstrated interobserver reliability and construct validity when used by both medical and nonmedical professionals [18].

The JAMA benchmarks propose four basic standards of quality that include authorship of medical content (authors and contributors, relevant affiliations and credentials), attribution (list of references and sources of information), disclosure (website, sponsorship, advertising, commercial financing arrangements, conflicts of interest), and currency (content of the published and updated dates) [19].

Selected websites were also categorized by the presence of the HON seal. The HON seal is awarded to websites that meet with eight basic quality criteria: (1) authorship, (2) complementarity, (3) privacy, (4) attribution of references and currency, (5) justification, (6) transparency of the author, (7) sponsor transparency (financial disclosure), and (8) honesty in advertising policy [20].

Smoking Cessation Content Assessment

The smoking cessation content on each site was assessed using an abbreviated version of the Smoke Treatment Scale (STS-C) and the Smoking Treatment Scale-Rating (STS-R) [17]. The STS-C is a 12-item checklist on which website reviewers documented the extent to which each website covered material related to key components of treatment as described in the US Public Health Service guidelines for the treatment of tobacco dependence. The resulting 12 items on the STS-C are as follows: (1-2) advise every smoker to quit smoking (subdivided into two categories: clear or strong and personalized), (3) assess readiness to quit, (4-5) assist with a quit plan (subdivided into three actions related to setting a quit date and seven topics for providing practical counseling), (6) provide intratreatment social support, (7) recommend use of approved pharmacotherapy, (8) arrange follow-up and four areas aimed at enhancing motivation to quit by discussing the (9) relevance of quitting smoking, (10) the risks of continued smoking, (11) the rewards of quitting, and (12) the potential roadblocks or barriers to quitting smoking [17].

STS-R was developed to provide numeric ratings of quality of coverage for each of the key components of treatment documented in the STS-C. Each website received ratings for (1) coverage, (2) accuracy, and (3) interactivity. Coverage ratings were used to indicate the relative depth and breadth of the information provided in each topic area. The ratings used a 5-point scale. If the treatment component was not mentioned, it received a rating of 1. If the topic was mentioned very briefly, it received a rating of 2. Key components covered briefly but with sufficient detail to be adequately helpful to smokers seeking to quit were given a rating of 3. Sites that provided more detail and more extensive information were given ratings of either 4 or 5 depending on the extent of the information provided [17].

Readability Assessment

The Flesch Reading Ease (FRES) and the Flesch-Kinkaid Reading Grade Level (FKRGL) were used to assess legibility of the selected websites. A Web-based tool to calculate readability (Readability Formulas) was employed for this purpose. We used the following readability formulas:

FRES=206.835−(1.015×Average number of words per sentence)−(84.6×Average number of syllables per word); FKRGL=(0.39×Average number of words per sentence)+(11.8×Average number of syllables per word)−15.59 [21].

The FRES score was categorized as very difficult (college graduate level) (scores 0-29); difficult (30-49); fairly difficult (50-59); standard (easily understood by 13- to 15-year-old students) (60-69); fairly easy (70-79); easy (80-89); and very easy (90-100) [22]. Websites were also graded according to the FKRGL scale as easy (≤6th-grade level) or difficult (≥10th-grade level) to read [23]. Additionally, websites were also classified as multimedia and nonmultimedia and friendly or nonfriendly.

Statistical Analysis

Statistical analysis was expressed using mean, minimum, and maximum values. Spearman correlation coefficients were calculated to examine the relationship between the DISCERN and STS-R mean values of each website. The significance level chosen for all statistical tests was $P \leq .05$. The analyses were performed using SPSS Statistics version 23 software package (IBM Corp, Armonk, NY, USA).

Results

The search identified 1,680,000 sites on Google and 889,000 sites on the HON search engines. Of the first 200 sites selected (100 of Google and 100 of HON), only 11 met the inclusion criteria (Figure 1). The most common reasons for exclusion were scientific articles (92 out of 200), patient-specific sites (66 out of 200), and books (7 out of 200). Of the 11 websites analyzed, the majority belonged to governmental institutions (73%, 8/11), the others being prepared by Professional Associations (18%, 2/11) and commercial organizations (9%, 1/11). Only 27% (3/11) were exclusively dedicated to smoking cessation.

Figure 1. Schematic representation of the websites screening and the inclusion and exclusion process.

Quality Assessment

The average score obtained with the DISCERN was 3.04 (standard deviation, SD 0.89). Mean quality ratings across the 11 included sites are shown in Figure 2. Mean score for the questions (1-8) that address reliability was 3.82 (SD 0.69) and for questions (9-15) that focus on specific details of the information about treatment choice was 2.26 (SD 0.69). The questions with the higher response score were as follows: “Does it provide details of additional sources of support or information?” and “Are the aims clear?” On the other hand, the question with the lowest score was “Does it describe how the treatment choices affect overall quality of life?

The results in relation to the JAMA benchmarks are shown in Table 1. None of the 11 evaluated websites achieved all four benchmarks, while 6 (54%), 2 (18%), 2 (18%), and 1 (9%) achieved 3, 2, 1, and 0 benchmarks, respectively. The highest scoring JAMA benchmark was authorship; over 80% identified the author. On the other hand, the lowest scoring benchmark was disclosure (9%) and this was usually because of the omission of financial details and conflicts of interest. None of the websites included in this study presented the HON seal.

Table 1. Website quality content based on Journal of the American Medical Association (JAMA) benchmarks.

JAMA benchmarks		n (%)
Number of websites containing each benchmark		
	4 benchmarks	0
	3 benchmarks	6 (54)
	2 benchmarks	2 (18)
	1 benchmarks	2 (18)
	0 benchmarks	1 (9)
Percentage of included websites containing each benchmark		
	Authorship	9 (82)
	Attribution	7 (64)
	Disclosure	1 (9)
	Currency	7 (64)

Figure 2. Median quality ratings scores of the 11 included websites using the DISCERN instrument.

Smoking Cessation Content

The results in relation to STS-C and STS-R evaluation tool are shown in Table 2 and Figure 3, respectively. All the sites contained a quit tobacco advice and a quit plan assistance. Three out of 11 (27%) provided intratreatment social support, and 72% (8/11) included the use of pharmacotherapy.

The mean of all parameters of STS-R was 2.81 (SD 0.95). The highest scores (3.45 [SD 0.82]) were obtained in clarity and strength advice and planning the quit. On the contrary, the lowest values were obtained in the rewards and roadblocks parameters (2.18 [SD 1.33]).

A significant strong positive correlation was obtained between the DISCERN mean values and the STS-R (*R*=.89, *P*=.01; Figure 4).

Table 2. Content analysis: Smoking Treatment Content Scale.

Smoking Treatment Content Scale (STS-C)	n (%)
Advise every tobacco user to quit	11 (100)
Assess readiness to quit	10 (91)
Assist with a quit plan	11 (100)
Provide practical counseling	6 (54)
Provide intratreatment social support	3 (28)
Recommend use of approved pharmacotherapy	8 (73)
Arrange follow-up contact	7 (64)
Enhance motivation: relevance	9 (82)
Enhance motivation: risks	6 (55)
Enhance motivation: rewards	5 (45)
Enhance motivation: roadblocks	4 (36)

Figure 3. Median quality ratings scores of the 11 included websites using the Smoking Treatment Rating Scale (STS-R).

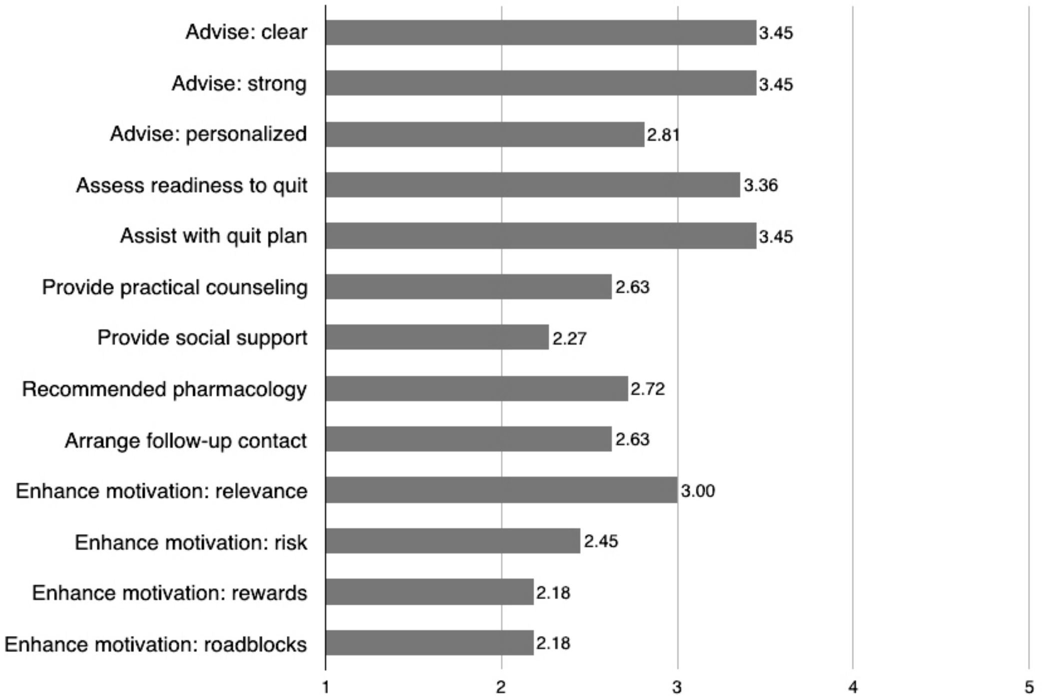


Figure 4. Correlation between DISCERN and Smoking Treatment Rating Scale (STS-R) grading scores. A significant positive correlation was obtained between the DISCERN mean values and the STS-R (R=.895, P=.01).

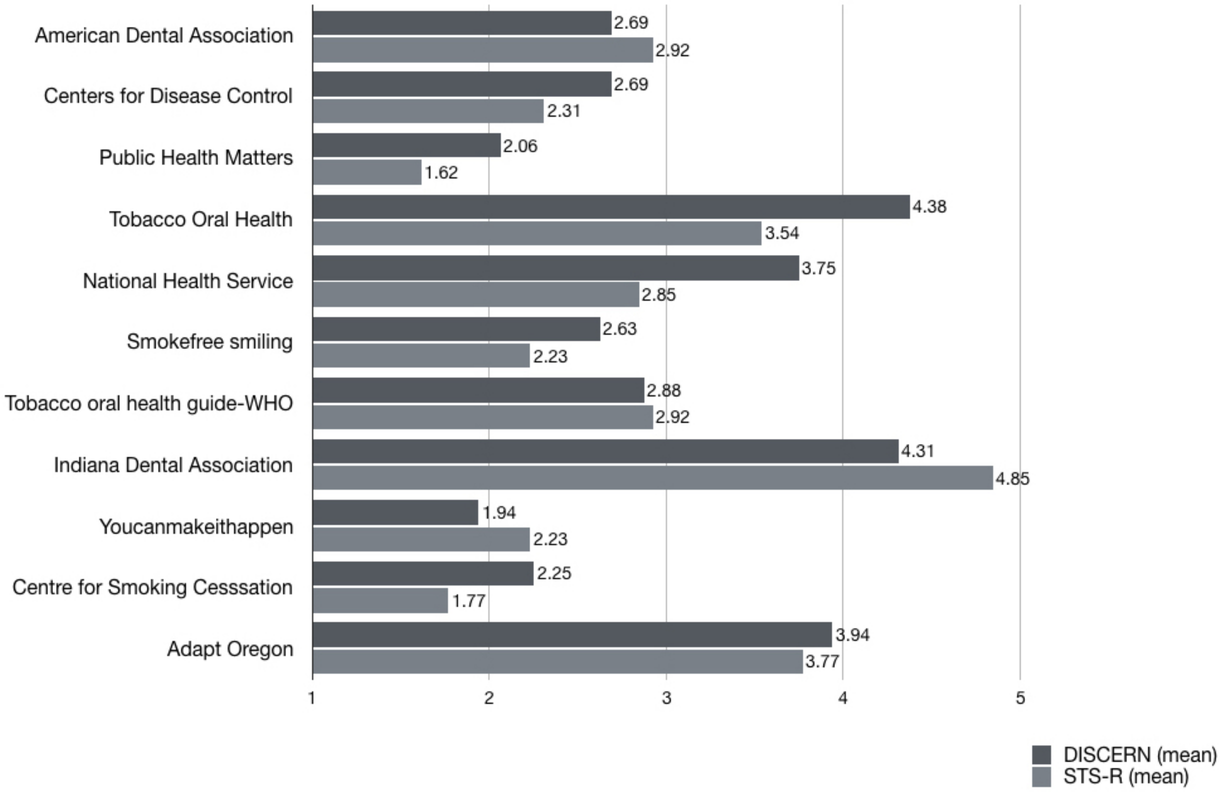


Table 3. Features of the selected websites by content and quality rating.

Website name	Country	Affiliation	Site type	Flesch reading	Flesch-Kinkaid	JAMA[a] benchmark	DISCERN mean	Smoking treatment rating scale (STS-R)
Indiana Dental Association	United States of America	Indiana Dental Association	Dental society	25.6	16	3	4.31	4.85
Adapt Oregon	United States of America	Private page	Commercial	46.7	10.2	2	3.94	3.77
Tobacco Oral Health	Switzerland	Oral Health Network on Tobacco Use Prevention and Cessation[b]	Governmental	40	13	3	4.38	3.54
American Dental Association	United States of America	American Dental Association	Dental society	17.3	16.4	1	2.69	2.92
Tobacco oral health guide	United States of America	World Health Organization	Governmental	32	13.9	3	2.88	2.92
National Health Service	United Kingdom	National Institute for Health Research	Governmental	43.7	11	3	3.75	2.85
Centers for Disease Control	United States of America	Centers for Disease Control and Prevention	Governmental	75.2	7	3	2.69	2.31
Smokefree smiling	United Kingdom	Government of the United Kingdom	Governmental	48.6	12.1	3	2.63	2.23
Youcanmakeithappen	Canada	Public Health Units of Canada	Governmental	35.2	17.7	0	1.94	2.23
Centre for Smoking Cessation	United Kingdom	The National Centre for Smoking Cessation and Training	Governmental	31.7	17.4	1	2.25	1.77
Publichealthmatters	United Kingdom	Government of the United Kingdom	Governmental	52.1	11.8	2	2.06	1.62

[a] JAMA: Journal of the American Medical Association.

[b] The Oral Health Network on Tobacco Use Prevention and Cessation (OHNTPC) is a subsidiary of the Swiss Task Force Tobacco-Interventions in dental practices.

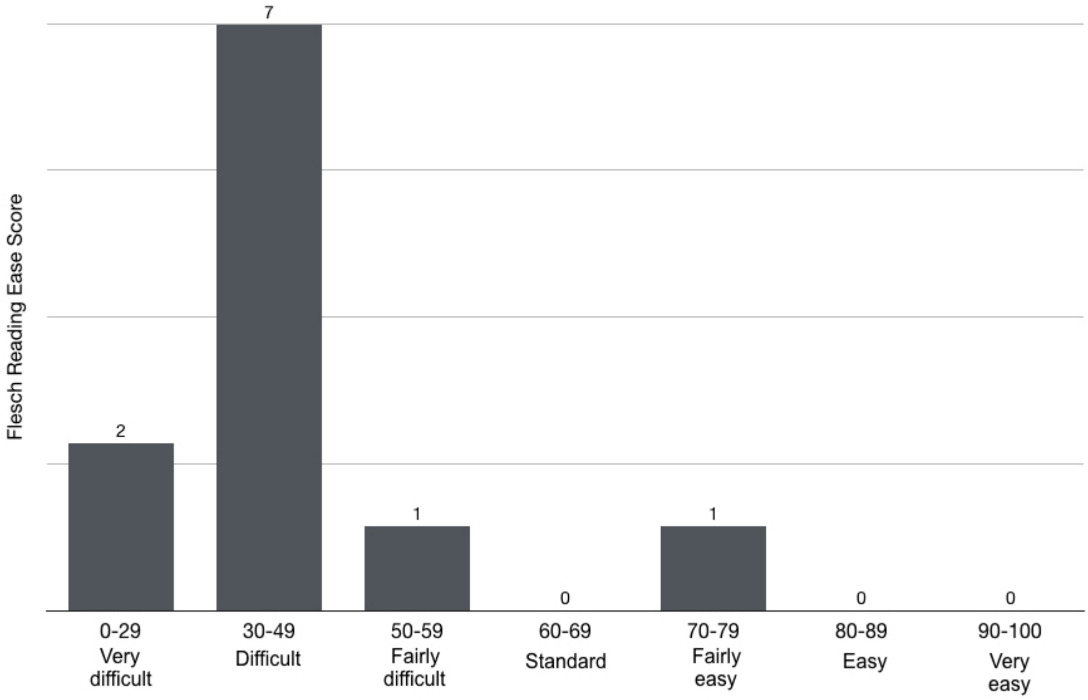
Readability Assessment

Most of the assessed webpages 64% (7/11) showed a FRES of 30 to 49, and 82% (9/11) were scored between 0 and 49 points. One webpage obtained a score of 50 to 59 and another one 70 to 79 (Figure 5). The mean FRES was 40.73 (SD 15.46) and the mean FKRGL was 13.31 (SD 3.34).

Moreover, 45% (5/11) webpages showed their content in a PDF file. Just one of the webpages (9%) contained multimedia files and 45% (5/11) were considered as having a friendly usability.

Features of the 11 selected websites by content and quality rating are shown in Table 3.

Figure 5. Frequency distribution of Flesch Reading Ease score of included websites.



Discussion

Principal Findings

The goal of this study was to assess and examine the content of webpages with information for oral health care professionals about smoking cessation. After applying the inclusion and exclusion criteria described, just 11 webpages with information on smoking cessation for oral health professionals were analyzed. Unfortunately, the main finding of our review was the small number of websites found in the search. In addition to the scarce number and low quality of content, the order of appearance might also affect the effectiveness of the search. In fact, the best 3 websites ranked by STS-R (Table 3) were found in the position 18th, 96th, and 47th, respectively. The results of a study by SISTRIX GmbH reported by AOL (America OnLine) in 2006 indicated that the chance of a site being accessed by a user, if ranked as the first result on an Internet search engine, was 59.6%. This reduced to 0.73% for the 10th place. The other combined 90 places (until reaching the 100th position) had a chance of 0.9%. On the basis of these data, a routine search might not be effective because of the browser algorithm, even if the website shows an adequate content.

As health professionals, dentists, dental hygienists, and dental assistants can play an important role in primary and secondary prevention of tobacco addiction. Brief tobacco dependence treatment provided by health care professionals, including dentists, is an effective way to prevent and reduce tobacco use [24].

Oral health professionals are in a unique position to motivate and assist their patients to quit smoking [1]. According to the latest meta-analysis performed by Carr and Ebbert in 2012, interventions for tobacco users delivered by oral health professionals can increase the odds of quitting tobacco (OR 2.38, 95% CI 1.70-3.35) [10,25]. Smoking cessation programs conducted through dental practices report cessation rates comparable with studies in other primary care settings [26]; however, we did not find studies comparing interventions conducted by oral health professionals and other health professionals.

Brief advice lasting less than 3 min given by a health professional will help an additional 2% of smokers to successfully stop smoking. With more intensive support lasting up to 10 min, plus nicotine replacement therapy, an additional 6% of the smokers will quit. By referring to stop smoking services, this increases by 15% to 20% [27,28].

Studies in private practice and dental schools ascertaining the knowledge and attitudes of dental health care professionals and students reveal that oral health professionals are aware of their responsibility to advise their patients to quit smoking. However, they do not feel sufficiently educated to help or advise their patients in a smoking cessation attempt. Therefore, smoking patients who seek help for smoking cessation are often assisted poorly from professionals within dentistry. It could be assumed that an improvement in the education of dentists and dental hygienists regarding interventions for smoking cessation could result in an increase in self-confidence and the frequency of their provision [29].

Although theoretical education about smoking is addressed in most European dental schools, more practical training in prevention and skills of implementing smoking cessation techniques are needed [30]. A recent survey reveals that although most dental schools in the United States and Canada provide tobacco dependence education, this is not a curricular component in all dental schools in the United States and Canada.

The survey responses revealed that faculty members were most confident in teaching tobacco-related pathology but may lack the interest and skills needed to integrate tobacco dependence education as part of patient care [31].

These findings may partly explain the low level of adherence to tobacco use cessation guidelines among oral health professionals [32-35]. Effective tobacco cessation training should include skills and strategies that address student perceptions to foster the belief that tobacco cessation efforts are a part of quality clinical practice [36]. There is evidence that the training of health professionals in interventions for smoking cessation is associated with an increase in the smoking cessation rate [37].

Web-based education about the treatment of tobacco dependence could be an important way to build the understanding necessary to provide evidence-based treatment for tobacco dependence [38] and complement tobacco education received during undergraduate or postgraduate training. Houston et al demonstrated that a training program for oral health professionals, through a website designed to promote and support tobacco control in dental practice, can be effective. The intervention provided by a structured dynamic webpage increased the rates of detection of tobacco use and cessation advice for tobacco users. This result supports the potential of the Internet for oral health professional training in tobacco use cessation [39].

However, the Internet seems to be a relevant but underused tool to seek health information by health professionals, and one of the barriers described for its use by health professionals is that Web-based information is heterogeneous in quality [40].

The content and quality of health care information available on the Internet for patients searching for smoking cessation advice [15-17] and e-learning training programs about tobacco cessation for health care practitioners [38] have been reviewed in the literature. Selby et al reviewed and evaluated e-learning training programs about tobacco cessation for health care practitioners and found an overall poor quality of Web-based courses. Their results indicated that there is a widespread lack of well-designed Web-based continuing education courses in tobacco dependence treatment based on an analysis of instructional design quality [38].

However, no information about the quality of available Web-based smoking cessation (training/learning) for oral health professionals was reported.

The results of this study suggest that very few websites display high standards according to the DISCERN tool. DISCERN has been designed to help users of consumer health information judge the quality of written information about treatment choices. However, despite its potential interest, DISCERN is rarely used by patients and consumers in general [41]. Despite the lack of mainstream usage, it has been proven to be a reliable instrument when used by professionals with good interexaminer reliability [42]. Moreover, in this study, a significant strong positive correlation was obtained between the DISCERN mean values and the STS-R.

The JAMA benchmark is a condensed and relatively easy-to-apply tool to assess the reliability of health webpages and has been shown to correlate with high levels of accuracy [43,44].

In this study, of the websites that met the inclusion criteria, none displayed the HON seal. Although the HON seal indicates the reliability of a website, it does not imply that the reviewed websites lack reliability. As receipt of the HON seal must be requested, websites that do not display the HON seal may simply have not applied for, or are unaware of, the scheme. This does not mean that they do not adhere to the criteria proposed by the HON Foundation [45,46].

When applying the FRES tool to assess the readability of the selected webpages, it was found that most (81.8%) content was classified as “difficult” or very “difficult to read”. In the same way, the mean FKRGL (above 13th grade) showed that the assessed webpages were difficult to read. As the webpages were specific to dental practitioners, this is not as relevant as it would be in patient-centered websites. Regardless, clearer content should be advocated. Similarly, almost half of the websites presented their content in a PDF file, resulting in a more difficult way to access the text and read it. Just one of the sites included multimedia content with videos showing examples to the practitioners, advice, and tips to better explain the patients on how to quit tobacco use. Lack of multimedia content and a friendly graphic interface might limit the use of these sites.

With regard to the presence of contents using the STS-C, most of the websites (90-100%) included the advice on quitting tobacco, the readiness of the patient to quit, and the assistance of creating a plan to quit along the time. Recommendation of supplemental pharmacotherapy was included in 73% of the sites but just the 28% presented with information about the relevance of the social support or difficulties (roadblocks 36%) during the process. The quality of the Web content was higher in the Advise, Assess, and Assist phases (mean 3.45 [SD 0.82], 3.36 [SD 1.03], and 3.45 [SD 1.04], respectively). On the contrary, the websites failed in the personalization of the message (mean 2.81 [SD 1.17]), highlighting to the dentist the need to understand the specific situation of each patient and modulate the message to them. As stated before, the social support was ranked inferiorly (mean 2.27 [SD 1.10]) and so were the presence of practical counseling (mean 2.63 [SD 0.92]) and the presence of rewards and roadblocks (mean 2.18 [SD 1.33]).

Limitations

Some limitations of this study should be highlighted. This study cannot be considered an exhaustive analysis since only webpages written in English were revised. In addition, only webpages addressed to oral health professionals were considered. For this reason, it is possible that webpages that were not directly addressed to oral health professionals but which may contain useful information and could be equally applied in the dental setting could have been excluded. Therefore, generalization of the overall context of results is limited, and similar reviews should be considered on websites not written in English and addressed to other health professionals.

Future Work

After assessing the quality of the content available on webpages with information for oral health care professionals about smoking cessation, shortcomings in the available educational resources were identified. Developing of e-learning materials on the topic to improve the skills, self-confidence, and frequency of provision of interventions for smoking cessation in the dental setting by members of the dental team is encouraged.

There have been recommendations for the development of dental “continuing professional development” e-learning resources. Such resources must be learner-friendly, interactive, and allow the user to gain knowledge at a rate that is appropriate to the individual. There should also be flexibility, alongside the opportunity to critically analyze data either individually or as part of a team. Content should be relevant, accurate, easy to access, and regularly evaluated and updated when necessary. The visual design of the module’s webpage should be attractive, appropriate, and uncomplicated, with content presented in a manner to facilitate easy reading and to guide the learner appropriately through the content. Feedback should be available for those who use the resource. Colors, graphics, animations, and different media should be used to complement or provide information in an educationally useful manner [47].

On the basis of a European Union (EU) initiative for lifelong learning, our group has been commissioned to deliver a Web-based learning program designed to be used by health care professionals, including dentists and dental hygienists, to increase their professional skills in providing smoking cessation advice for tobacco users. This can be accessed online [48].

To assess the utility of this resource, we aim to (1) carry out an evaluation of the webpage by external experts; (2) subsequently extend the evaluation to health care professionals, including dentists and oral hygienists from different countries, translating the text, and adapting content to incorporate local policy; and (3) finally investigate whether the resource has caused a change in the user’s routine clinical practice via feedback questionnaires.

Conclusions

In conclusion, the number of smoking cessation webpages for oral health care professionals is scarce and displayed a low quality and high heterogeneity in their content. We found it difficult to find good quality information, an absence of multimedia resources and readability levels, which further limited the usefulness of most websites.

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Conflicts of Interest

None declared.

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Abbreviations

EU: European Union
FKRGL: Flesch-Kinkaid Reading Grade Level
FRES: Flesch Reading Ease
HON: Health on Net
JAMA: Journal of the American Medical Association
SD: standard deviation
STS-C: Smoke Treatment Scale
STS-R: Smoking Treatment Scale-Rating

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Original Paper

Using a UK Virtual Supermarket to Examine Purchasing Behavior Across Different Income Groups in the United Kingdom: Development and Feasibility Study

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Abstract

Background: The majority of food in the United Kingdom is purchased in supermarkets, and therefore, supermarket interventions provide an opportunity to improve diets. Randomized controlled trials are costly, time-consuming, and difficult to conduct in real stores. Alternative approaches of assessing the impact of supermarket interventions on food purchases are needed, especially with respect to assessing differential impacts on population subgroups.

Objective: The aim of this study was to assess the feasibility of using the United Kingdom Virtual Supermarket (UKVS), a three-dimensional (3D) computer simulation of a supermarket, to measure food purchasing behavior across income groups.

Methods: Participants (primary household shoppers in the United Kingdom with computer access) were asked to conduct two shopping tasks using the UKVS and complete questionnaires on demographics, food purchasing habits, and feedback on the UKVS software. Data on recruitment method and rate, completion of study procedure, purchases, and feedback on usability were collected to inform future trial protocols.

Results: A total of 98 participants were recruited, and 46 (47%) fully completed the study procedure. Low-income participants were less likely to complete the study (P=.02). Most participants found the UKVS easy to use (38/46, 83%) and reported that UKVS purchases resembled their usual purchases (41/46, 89%).

Conclusions: The UKVS is likely to be a useful tool to examine the effects of nutrition interventions using randomized controlled designs. Feedback was positive from participants who completed the study and did not differ by income group. However, retention was low and needs to be addressed in future studies. This study provides purchasing data to establish sample size requirements for full trials using the UKVS.

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KEYWORDS

food; diet; public health; United Kingdom; socioeconomic status

Introduction

Background

Unhealthy diets pose a substantial threat to public health. Globally, dietary risk factors account for 11.3 million deaths and 241.4 disability-adjusted life years per year [1]. In the United Kingdom, dietary risk factors account for nearly one-fifth of deaths and one-tenth of disability-adjusted life years [2]. Improvements in diet could be achieved by tackling key determinants of food choice.

Price is a key determinant of food choice: 36% of shoppers consider price to be the most important, and 90% of shoppers list price in the top five most important influences on food purchases in the United Kingdom [3]. Health-related food taxes and subsidies (HRFTS) are interventions that raise the price of unhealthy foods or lower the price of healthy foods to encourage healthier diets. Several HRFTS have been implemented. Sugar-sweetened beverage taxes have been introduced in Mexico, France, and Chile [4-6] and recently announced in the United Kingdom [7]. Dominica applies an excise tax to foods and drinks with high sugar content; Hungary has a public health tax that is applied to selected foods, including those with high salt or sugar content; and Finland levies taxes on confectionery and ice-cream [6]. Other HRFTS that have been suggested include subsidies on healthy foods and taxes based on nutrient profiling models [8]. HRFTS are one of the several population interventions recommended by the World Health Organization [9].

In the United Kingdom, the majority of food is purchased in supermarket chains [10]. This makes supermarkets an important environment to consider when examining the impact of specific price changes on food purchasing. However, testing the impact of HRFTS and other interventions in real supermarkets is difficult. Supermarkets may not wish to participate in trials where there is a risk of reduced sales, loss of customers, or negative media coverage (eg, taxes on unhealthy foods). Nationwide promotional and pricing strategies by retailers may limit what interventions can be implemented at individual sites, and there may be reluctance to implement interventions that depend on the input of supermarket staff time (eg, changing product placement). The resources required to run full trials in real supermarkets (eg, the cost of subsidies) also prohibit the number of interventions that can be tested in real supermarkets. Evidence on the effects of interventions on supermarket purchases may therefore need to be gathered by other means—virtual supermarkets are one prospect.

A virtual supermarket is a three-dimensional (3D) graphical representation of a real supermarket in which participants can complete shopping tasks. Virtual supermarkets have been previously used to examine price interventions and have been validated against real supermarket purchases [11-13]. In these virtual supermarkets, participants are asked to complete a shopping task specified by researchers and do not pay real money or receive real versions of the foods purchased in the virtual environment. The New Zealand Virtual Supermarket (NZVS) was validated by comparing participants' real-life purchases with those made in the NZVS over a 3-week period [13]. The validation study found that shopping patterns in the NZVS were comparable with those in real life: the four food groups with the highest relative expenditure were the same, and there was no trend of overspending in the NZVS.

Objectives

This paper introduces a United Kingdom Virtual Supermarket (UKVS) that resembles a small supermarket store and presents the results of a feasibility study assessing recruitment, retention, purchasing variability, and participant responses to the newly developed software. In this study, we recruited participants to complete two shopping tasks and sociodemographic questionnaires at a single time point. The shopping tasks asked participants to purchase all foods for their household for at least the next day, which was in line with previous studies [14-16] and likely to be comparable with smaller top-up shops that comprise around 60% of household food spending in the United Kingdom [17]. We also examined differences in the above across different income groups. Lack of evidence on the differential impacts of HRFTS among population subgroups has been identified in a number of reviews [18-20]. In addition, previous experimental studies of food pricing strategies have observed differential recruitment and retention rates by participant group, possibly linked to differences in ease of participation [21]. Finally, as no previous UKVS studies have been done, we needed to collect data on purchases and variability in purchases to assess likely sample sizes for randomized controlled trials (RCTs) in the UKVS.

This study aimed to address the following research questions:

- How effective are online methods, plus snowballing, for the recruitment of participants for a UKVS study?
- What are the dropout rates for a UKVS study?
- How much variability is there in next-day shopping behavior in the UKVS?
- How do participants report ease of participation and appreciation of the UKVS?
- Do recruitment and dropout rates, variability in next-day shopping behavior, and ease of participation vary by income group?

Methods

Development of the UK Virtual Supermarket

The use of the existing Dutch Virtual Supermarket [22] as the template for a new UKVS was agreed with researchers at VU University Amsterdam and SURFsara, a not-for-profit software development company that was responsible for the development of both the Dutch and New Zealand versions of the virtual supermarket.

The creation of the UKVS from the Dutch Virtual Supermarket template comprised the replacement of Dutch products with UK products, changes to the software to make it fit within the UK context (eg, English aisle signs), and changes to the study procedure format. The UKVS most closely represents a smaller supermarket in the United Kingdom and not a large superstore. Screenshots from the completed UKVS are displayed in Figure 1.

Figure 1. Screenshots from the United Kingdom Virtual Supermarket.

Shelf spaces were allocated to food categories based on the distribution of shelf spaces in surveys of three actual small supermarket stores in the United Kingdom. This set the number of product spaces that were available in each food category. Data from the Living Costs and Food Survey [23] were used to check that popular food categories were represented in the shelf space allocation. Nonfood items were excluded from the UKVS, and the virtual supermarket did not contain end-of-aisle displays or products at the checkout.

An online supermarket [24] was used to review the full range of products available in each food category allocated spaces in the UKVS. We recorded information on the number of products, price range, sizes available, brands, top sellers, and types of product. Specific products were selected to reflect popularity (from the *top sellers* list) and to reflect diversity within each category. For example, there were three spaces allocated to fresh pizza in the UKVS. The available products ranged in price from £0.55 to £4.50, varieties included thin base and deep base, and most pizzas had meat-based toppings. The final products selected were a supermarket value-brand cheese and tomato 7-inch pizza (top seller), Pizza Express American pepperoni pizza (one of the top-selling thin base options), and a supermarket own-brand deep pan ham and pineapple pizza (one of the top-selling deep pan options). *Meal Deal* products that were not available online were selected from actual products available in a real small store. A total of 530 real products were selected, which is similar to the original Dutch version of the virtual supermarket, containing 512 products [22]. Full details on the selected products are available from the authors on request.

Moreover, 3D models of the selected UK products were created in Blender (Blender Foundation, Amsterdam, Netherlands), an open source product modeling software [25], using images provided by Brandbank (one of the largest providers of digital product information [26]). The 3D models were designed to replicate the real products (eg, branding, size, color, and style of packaging). Where the real products were supermarket own-brand varieties, the supermarket name was blurred in the 3D model, but all other aspects of the packing were retained. Brand names (eg, Heinz) were retained in the 3D models. Nutritional information was provided by Brandbank and supplemented by matching products with online equivalents. Usual prices (ie, excluding offers) for the selected products were collected from the same supermarket website in January 2016.

Software Testing

Following the development of the UKVS, software testing was conducted with a convenience sample of 20 adults to ensure the software was working appropriately. Software testers completed the same study procedure that was used in this study and were then interviewed in person or over the phone. The protocol and detailed results from software testing are available from the authors on request. Minor changes were made to the content and layout of participant information screens (eg, information on expected time commitment and additions to the frequently asked questions section) based on software testing participants' comments.

Participants

For the actual study, potential participants had to be older than 18 years, able to speak and read English, be the primary household shopper, have access to a computer with a working Internet connection, have an email address, and be confident in using basic computer skills. As data collection in the UKVS is conducted at the household level, only one person from any household was eligible to take part.

Setting

Participants could complete the study remotely from any location with access to a computer and Internet connection. Participants were recruited, consented, and completed the study online, and data were transferred securely to a university-hosted server via the Internet.

Sample Size

As this was a feasibility study, no formal sample size calculations were conducted. This feasibility study aimed to recruit 30 participants in each UK equivalized income tertile. The cut-offs for equivalized income tertiles were derived from the Living Costs and Food Survey [23]: low income was defined as equivalized income <£12,844 per year, middle income was £12,844 to £21,372 per year, and high income was >£21,372 per year. On the basis of dropout rates of around 25% in previous virtual supermarket studies [11-13], it was anticipated that recruiting 30 participants in each income tertile would result in approximately 23 study completers per income tertile.

Recruitment

Participants were recruited via a combination of a free Web-based participant recruitment website [27], Facebook adverts, and snowballing. Recruitment took place over 8 weeks beginning March 2016. The Call for Participants advert was displayed for the entirety of the recruitment period. Facebook adverts were planned for the first 30 days, with a maximum lifetime budget of £250. On the basis of recruitment from previous studies using Facebook adverts [2-5], we estimated that the adverts would generate an average of 58 clicks per day and lead to daily recruitment of 3.6 participants. Additional strategies were in place to recruit through community groups if the estimated sample size was not met in the first 30 days of recruitment.

Procedure

Participants read the participant information sheet and completed a Web-based consent form on the UKVS website. Upon submission of the consent form, the participant received an automated email with a unique participant identifier or password combination and a link to download the UKVS software. Participants were sent email reminders 1 and 2 weeks after consent if they had not completed the study procedure. Email reminders have previously been shown to increase response rates, but it has been suggested that more than two reminders increase the number of people who view the email as spam [28].

The UKVS study procedure consisted of a preshop questionnaire that gathered sociodemographic details and shopping habits of the household, two *next-day* shopping tasks, and a postshop questionnaire that gathered participant responses to the UKVS software. The participants completed the entire study procedure in one sitting. For the shopping tasks, participants were provided with the following instructions: “Imagine that you have no food or drink in the house (apart from herbs and spices). It is the evening and you are going to the supermarket to buy all the food and drinks for your household for tomorrow. You only need to buy the foods that you would normally purchase in the shop. For example, if you have lunch in the canteen at work, you don’t need to buy lunch in the UK Virtual Supermarket.” We refer to this shopping task as a next-day shopping task throughout the paper, as it requires participants to choose enough food for at least the next day. No restrictions were placed on the total amount that participants could purchase; we expected purchases to be in excess of food requirements for the next day owing to package size restriction (eg, breakfast cereal box is likely to last more than 1 day). Participants were told to imagine that the second shopping task took place a week after the first shopping task. This procedure is similar to instructions that have been provided to participants in other studies examining responses to food price changes [14-16]. All purchases were virtual—participants did not use their own money, and they did not receive actual food products purchased in the UKVS.

Outcome Measures and Analysis

Outcome measures were collected in relation to four domains: recruitment, participant characteristics, participant purchases, and participant feedback on the UKVS. Participant characteristics collected included age, gender, household income, occupation, and typical shopping habits (eg, usual spend, usual supermarket, and proportion of food purchased in supermarkets). Expenditure and quantity data for participant purchases in the UKVS were collected. UKVS purchase data were combined with each products’ nutritional information to determine the total nutrient content of the basket for energy, protein, carbohydrates, sugars, total fat, saturated fat, salt, and fiber. We also calculated the percentage of the sample that made purchases in each food category. Participants’ feedback was gathered in relation to ease and understanding of the shopping tasks, UKVS product choice, and whether UKVS purchases were representative of typical food shopping behavior.

Using the purchase data, we estimated the number of participants that would be required to detect 5%, 10%, and 20% changes in nutrient purchases using analysis of covariance (ANCOVA) methods in a full trial in the UKVS. We used the power twomeans command for estimating sample size in STATA [29], assuming power=0.8 and Cronbach alpha=.05. These values were then adjusted to the sample size that would be required for ANCOVA using the Borm and colleagues’ method that incorporated estimates of the correlation between the two shops for the nutritional variables [30].

Ethical Approval

The feasibility study received ethical approval from the University of Oxford Medical Sciences Inter-Divisional Research Ethics Committee (reference no. MSD-IDREC-C1-2013-149).

Results

Recruitment

A total of 96 participants consented to take part in the feasibility study. Figure 2 shows the number of participants recruited in each week of the study by recruitment method. No participants were recruited in week 3 because the Facebook adverts were temporarily suspended to review the study website.

Differences in Recruitment by Equivalized Income

A total of 30% (29/96) of participants were classified as belonging to the lowest (national) income tertile, 16% (16/96) to the middle income tertile, and 26% (25/96) to the highest income tertile. Furthermore, 27% (26/96) of the participants did not provide sufficient details for their equivalized household income to be calculated. Further details of recruitment method by income tertile are provided in the Multimedia Appendix 1.

Facebook Adverts

Facebook estimated that there were 5.4 million users daily that met the advert target audience. Demographic characteristics for those who saw and clicked on the adverts are shown in the Multimedia Appendix 1. In total, the Facebook adverts were shown on 374,996 occasions to 183,399 Facebook users. The adverts generated 690 clicks through to the UKVS study website.

Completion and Participant Characteristics

Out of the 96 participants, 46 fully completed the study procedure, and 2 participants partially completed it (only one shopping task completed). There were significant differences in completion by household size, income, and equivalized income tertile, with lower completion rates in smaller and poorer households. Demographic characteristics for completers and noncompleters are shown in Table 1, with further demographic details for completers presented in the Multimedia Appendix 1.

Participant Feedback

Table 2 displays participant responses to statements relating to the ease of use, product choice, and similarity of UKVS purchases to real purchases. The majority of participants appeared to have adhered to the instructions for the shopping tasks. Typical weekly budget correlated with the amount spent in shopping tasks (*r*=.56). The concept of a next-day shopping task appeared familiar to most participants. Furthermore, 24 (50%, 24/48) participants reported that they do next-day shopping tasks monthly or more often, and 10 (22%, 10/48) participants reported doing next-day shopping tasks at least a few times per year. However, 7 (15%, 7/48) participants reported that they never did next-day shopping tasks.

Figure 2. Recruitment over time, by recruitment method.

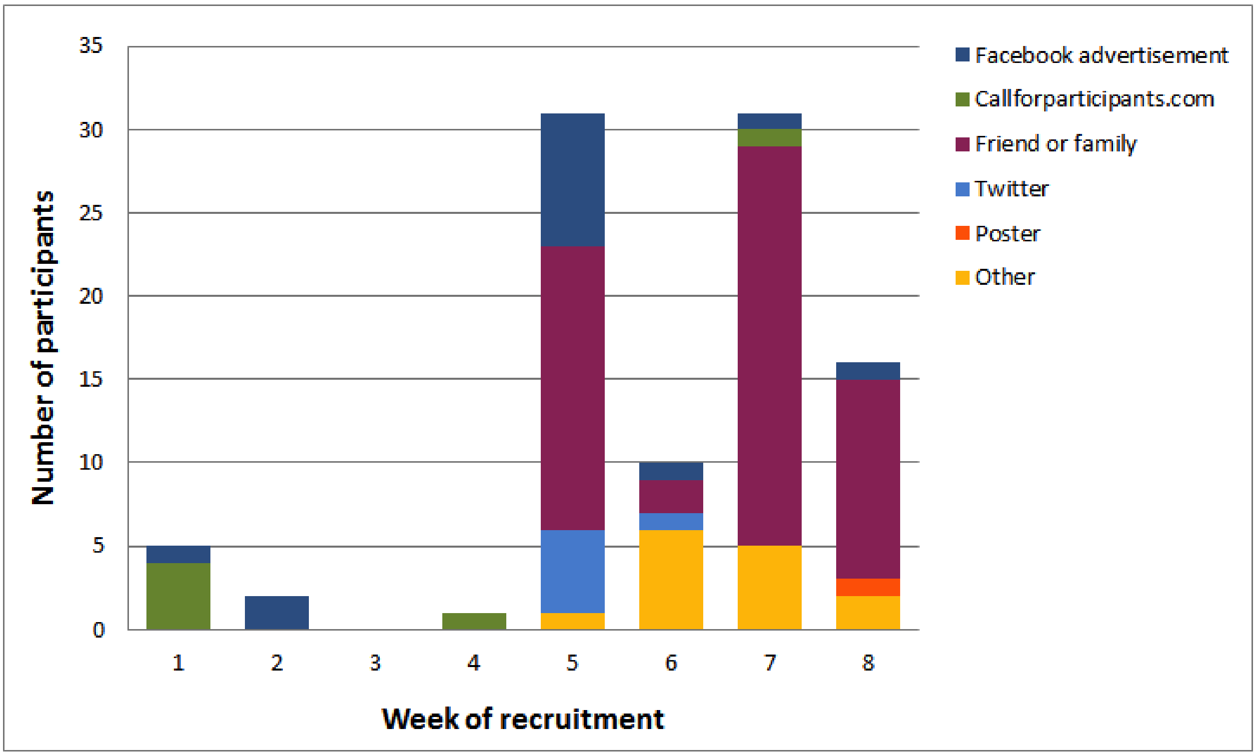

Table 1. Characteristics of completers and noncompleters.

Characteristics	Completers (n=48)	Noncompleters (n=48)	Total (n=96)	*P* value[a]
Age in years, mean (standard deviation)	38.5 (2.3)	37.3 (2.3)	37.9 (1.6)	.69
Household size, n (%)				.03[b]
1	16 (33)	12 (25)	28 (29)	
2	23 (48)	17 (35)	40 (42)	
3	6 (13)	5 (10)	11 (12)	
≥4	3 (6)	14 (29)	17 (18)	
Responsibility for food shopping, n (%)				.42
All	26 (54)	28 (58)	54 (56)	
Most	13 (27)	7 (15)	20 (21)	
Half	8 (17)	9 (19)	17 (18)	
Little	1 (2)	3 (6)	4 (4)	
None	0 (0)	1 (2)	1 (1)	
Computer type, n (%)				.68
Windows 8	8 (17)	7 (15)	15 (16)	
Windows 7	17 (35)	12 (25)	29 (30)	
Windows Vista	0 (0)	2 (4)	2 (2)	
Mac OS	13 (27)	12 (25)	25 (26)	
Other or unknown	11 (23)	14 (29)	25 (26)	
Computer age in years, n (%)				.91
<1	7 (15)	7 (15)	14 (15)	
1-5	33 (69)	33 (69)	66 (69)	
>5	6 (13)	7 (15)	13 (14)	
Unknown	1 (2)	1 (2)	2 (2)	
Recruitment method, n (%)				.14
Call for participants	3 (6)	3 (6)	6 (6)	
Facebook advert	4 (8)	10 (21)	14 (15)	
Friend or family	32 (67)	23 (48)	55 (57)	
Other	9 (19)	12 (25)	21 (22)	
Income, n (%)				.02[b]
£0-£15,000	9 (19)	11 (23)	20 (21)	
£15,000-£25,000	14 (29)	4 (8)	18 (19)	
£25,000-£50,000	13 (27)	9 (19)	22 (23)	
More than £50,000	7 (15)	9 (19)	16 (17)	
Unknown	5 (10)	15 (31)	20 (21)	
Equivalized income tertile, n (%)				<.01[b]
Low	8 (17)	21 (44)	29 (30)	
Middle	16 (33)	0 (0)	16 (16)	
High	21 (44)	4 (8)	25 (26)	
Unknown	3 (6)	23 (48)	26 (27)	

[a] Values represent *P* values for Fisher exact test, apart from for age where a *t* test was conducted to test for differences between completers and noncompleters.

[b] Statistically significant difference between completers and noncompleters at *P*<.05.

Table 2. Participant perceptions of the United Kingdom Virtual Supermarket (UKVS); n=46.

Statement	Strongly agree or agree, n (%)	Neither agree nor disagree, n (%)	Disagree or strongly disagree, n (%)
The virtual supermarket program was easy to understand	38 (83)	6 (13)	2 (4)
The products I purchased in the virtual supermarket resemble my usual food purchases	41 (89)	5 (11)	0 (0)
I could find my way around the virtual supermarket easily	42 (91)	3 (7)	1 (2)
The virtual supermarket contained sufficient product variety	17 (37)	13 (28)	16 (35)
I felt I had sufficient product choice options in the virtual supermarket	18 (39)	10 (22)	18 (39)
Stock in the virtual supermarket is representative of stock in an actual supermarket	31 (67)	6 (13)	9 (20)
I could find the products I wanted to find in the virtual supermarket relatively easily	36 (78)	8 (17)	2 (4)
I could imagine doing my real-life shopping in the virtual supermarket	21 (46)	8 (17)	17 (37)
Prices in the virtual supermarket are similar to prices in an actual supermarket	26 (57)	14 (30)	6 (13)
In the shopping tasks, I think I spent around the same amount of money in the virtual supermarket as I would have in the same task in real life	27 (59)	12 (26)	7 (15)
In the shopping tasks, I bought the same sorts of food and drink as I would have in the same task in real life	41 (89)	4 (9)	1 (2)

Table 3. Food category purchases in the United Kingdom Virtual Supermarket (UKVS).

Food category	Participants that were purchasers, %		Amount spent (£)		Grams purchased	
	Shop 1 (n=48)	Shop 2 (n=46)	Mean[a] (SD[b])	Mean difference (SD)[c]	Mean[a] (SD)	Mean difference (SD)[c]
Bread and cereal products	96	93	4.88 (3.31)	1.22 (3.30)	2056 (1190)	457 (1507)
Fruits and vegetables	96	96	5.24 (3.31)	0.72 (3.02)	2696 (1790)	217 (1626)
Meat and fish	75	83	5.28 (3.30)	−0.11 (4.58)	765 (485)	−47 (777)
Milk and dairy	90	83	4.71 (3.33)	1.12 (2.61)	2061 (1444)	390 (911)
Sugar products	33	37	1.54 (1.18)	−0.14 (0.92)	370 (432)	−67 (336)
Beverages	85	67	7.66 (13.61)	2.47 (9.56)	2418 (5217)	345 (1150)
Composite foods or miscellaneous	83	76	3.83 (2.79)	0.51 (3.03)	746 (503)	129 (655)
Total			29.53 (19.55)	5.80 (13.90)	10,123 (6743)	1424 (4091)

[a] Values represent means for the participants that made purchases in the category.

[b] SD: standard deviation.

[c] First shop minus second shop.

Variability in Purchases

Details of food category level purchases in the UKVS are shown in Table 3. Participants spent an average of £29.53 per shop (standard deviation [SD] 19.55). On average, participants spent £5.80 (SD 13.90) less in the second shop than the first shop. Average spend was highest for *beverages* and lowest for *sugar products*. Nearly all participants purchased products in *fruits and vegetables* and *bread and cereal products*. Table 4 displays overall nutrient content of purchases in the UKVS; differences between the two shopping tasks are provided to give an indication of within-participant variability. There was considerable variation in the mean nutrients purchased in the UKVS, and this was apparent in all three income groups. The high variability indicates that large sample sizes would be required to detect changes in nutrient purchases in a full trial in the UKVS. The total sample sizes that would be required to detect 5%, 10%, and 20% changes in nutrient purchases are given in the Multimedia Appendix 1.

Table 4. Nutrient quantities purchased in the United Kingdom Virtual Supermarket (UKVS) across all completers.

Nutrients	All (n=46)	Lowest income (n=8)	Middle income (n=15)	High income (n=20)
Mean amounts purchased[a] (SD[b])				
Energy (kcal)	14,479 (8742)	10,247 (5489)	16,354 (8859)	14,282 (9878)
Protein (g)	836 (969)	1087 (1996)	941 (792)	632 (442)
Fat (g)	541 (353)	334 (240)	643 (335)	533 (403)
Saturated fat (g)	194 (125)	117 (91)	235 (130)	183 (129)
Carbohydrate (g)	1706 (1140)	1155 (547)	1830 (1195)	1764 (1275)
Sugar (g)	665 (549)	592 (714)	684 (491)	645 (545)
Fiber (g)	214 (153)	203 (208)	238 (174)	195 (128)
Sodium (mg)	13,750 (8290)	9634 (4545)	15,452 (9594)	13,829 (8607)
Mean percentage energy from selected macronutrients[c] (SD)				
Protein	22.4 (17.6)	32.5 (39.8)	20.5 (7.5)	19.6 (8.2)
Fat	33.0 (9.9)	29.2 (11.9)	36.8 (10.5)	31.6 (8.6)
Saturated fat	11.8 (4.3)	10.8 (5.61)	12.9 (4.7)	11.1 (3.6)
Carbohydrate	47.2 (9.4)	47.0 (14.1)	43.4 (7.8)	49.9 (8.1)
Sugar	18.7 (9.1)	22.0 (16.1)	15.7 (5.0)	19.7 (8.1)
Fiber	3.0 (1.1)	3.7 (2.02)	2.8 (0.9)	2.9 (0.5)
Mean difference between the two shops[b] (SD)				
Kcal	1825 (6732)	−238 (2728)	2437 (6927)	1894 (7884)
Protein (g)	53 (855)	−497 (1322)	220 (1006)	141 (401)
Fat (g)	62 (279)	−51 (126)	36 (271)	86 (289)
Saturated fat (g)	15 (123)	−19 (44)	−10 (113)	25 (119)
Carbohydrate (g)	259 (1192)	242 (569)	469 (1434)	133 (1286)
Sugar (g)	63 (409)	101 (272)	163 (421)	−26 (466)
Fiber (g)	27 (113)	−46 (144)	43 (126)	45 (89)
Sodium (mg)	2314 (7475)	−299 (3742)	3973 (10,185)	1560 (5712)

[a] First shop minus second shop.

[b] SD: standard deviation.

[c] Average of the average of two shops across participants.

Discussion

Summary

This feasibility study set out to assess recruitment, retention, purchasing variability, and participant responses to the newly developed UKVS and to examine differences in the above by household income. We found that completion rates in the UKVS were lower than anticipated but that feedback from participants was positive and similar across all income groups. The results from this study suggest the UKVS would be a feasible tool for examining purchasing behavior in different income groups.

Comparison With Other Literature

To our best knowledge, the UKVS is the first 3D simulation of a supermarket that has been developed exclusively for research purposes in the United Kingdom. Recent comparisons have shown that virtual reality better represents purchasing behavior in actual brick-and-mortar stores than picture-based approaches [31]. This suggests that the UKVS may elicit more realistic purchasing behavior than other experimental settings, though future direct comparisons between purchases in experimental environments (including the UKVS) and the real-life environments they are designed to replicate (in this case brick-and-mortar stores) are warranted to examine this explicitly.

We are aware that other, non-3D online shopping platforms that allow participants to select from a list of possible food items have been developed in the United Kingdom [30]. Forwood and colleagues' online shopping platform differs from the UKVS, as it was designed to mimic an online supermarket website rather than a brick-and-mortar store. Online shopping is growing in popularity in the United Kingdom, though the market share remains low at 6% [32]. Given the variability in real food shopping environments, complementary evidence examining different types of purchases (eg, online vs brick-and-mortar stores) is needed to build a complete picture of the likely impacts of specific interventions on purchases.

The product selection in the UKVS is representative for what can be found in a real supermarket, and the tool contains over 500 different products. Other studies using supermarket models to study the impact of HRFTS on food purchases have offered a selection of as few as 60 products [33], though more recent studies have had a selection of as many as 708 products [14,34]. The stores surveyed as part of the UKVS product selection process contained between 2600 and 3300 food products, and online supermarkets contain around 11,000 food products [30]. Smaller product selections in experimental environments may still elicit typical purchasing decisions given the large numbers of similar products in real stores, provided that the most commonly consumed products are represented. For example, there were more than 110 varieties of baked beans available in the online store used for this study.

The UKVS is similar to other virtual supermarkets developed by the same company. The New Zealand version has been validated against real purchases [13], and the Dutch Virtual Supermarket has been used for a number of trials of pricing interventions [11,12,35,36]. Across all the virtual supermarket studies, feedback from participants has been positive. The validation and use of previous virtual supermarkets and positive participant experiences suggest that the UKVS is a good experimental environment for testing the effects of pricing interventions.

This is the first study to examine how suitable the virtual supermarket environment is for examining purchases across different income groups. Positive feedback from study completers suggests that the UKVS is suitable for examining differences in purchases across different income groups. In real supermarkets, different availability of certain foods may influence observed differences in purchasing behavior across different groups. For example, an Australian study found that there are more energy-dense snack foods and soft drinks available in supermarkets in more disadvantaged neighborhoods than in less disadvantaged neighborhoods [37]. As all participants are exposed to the same environment, the UKVS has the potential to examine the contribution of income and other socioeconomic factors to differences in purchasing behavior independent of differences in access and availability.

Strengths and Limitations of the UK Virtual Supermarket

The use of the existing Dutch Virtual Supermarket as a template for the UKVS considerably reduced the resources required for development. The similarity of the Dutch layout with the layout of surveyed UK stores suggests that using a template from a different country is unlikely to have detracted from the realism of the UKVS.

Although the UKVS was developed primarily to assess the impact of HRFTS, the tool can also be used to assess other supermarket-based interventions. The UKVS software incorporates the ability to provide traffic light labels when participants hover over products, and shelf tags can be added to indicate promotions on a particular product. The UKVS is not designed to test the impact of changing product placement, but this feature could be added in future versions.

The next-day shopping task used in this feasibility study was selected to represent an important aspect of household food purchasing—smaller or top-up purchasing. UK data suggest that an increasing proportion of grocery spend is because of top-up shops compared with main shopping trips. Currently, top-up shops represent 61% of spending [17]. In this study, 50% of participants stated that they would conduct a similar shop to the UKVS task on at least a monthly basis. This suggests that although not comparable to participants’ usual supermarket routines, the task was nevertheless familiar to participants. Similar shopping tasks have been used in previous studies looking at the impact of price on purchases [14-16]. The size and type of shopping task that can be conducted in the UKVS is limited by the experimental environment—nonsupermarket and occasional impulse purchases are not captured. This means that results from trials in the UKVS will need to be combined with trials in other settings to build a full picture of the impact of changing prices on household purchases.

The external validity of UKVS and similar experimental studies is limited by participants not making real purchases [13,15]. Self-report data from this feasibility study suggest that participant purchases were similar to their usual purchases. These responses, coupled with results from the NZVS validation study [13], provide an initial indication that results from trials of pricing interventions in the UKVS would be externally valid. However, continued validation of experimental purchases compared with actual purchases and consumption patterns should be built into future studies of this kind.

Strengths and Limitations of the Feasibility Study

Completion rate of the study procedure was lower than we had anticipated. In addition, many of the reasons for noncompletion were not known. Completion in previous virtual supermarket studies was around 80% [11,12,35,38], with 60% completion observed in the NZVS validation study where participants had to complete a series of shopping tasks over a 3-week period [13]. Difficulties downloading the software and incorrect entry of email address appeared to contribute to noncompletion in this study. In the future, this could be minimized with additional methods to ensure participants receive user details (eg, text message [short service message, SMS] with user identifier or password, in addition to email and multiple email address entry).

There were several aspects of the feasibility study process that could be improved for future studies. Unfortunately, we were not able to collect data on the number of noncompleters who attempted to download the software. In addition, the registration process could be improved to better screen participants; one person who registered did not meet the criterion of being a primary household shopper, and it may have been possible for multiple people from the same household to enroll without our knowledge.

The relationship of completion with household income and participant feedback on problems with the download procedure indicate that some participants may need more support to take part in the study. In Great Britain, 82% of adults use the Internet every day or almost every day, and 89% of households have an Internet connection [39]. Of the 11% of households in Great Britain with no Internet access, 59% report that this was because they did not need Internet access, 21% reported that this was because of lack of skills, and 18% reported cost barriers [39]. These data suggest that some selection bias may have been created because of computer availability, but the magnitude of this bias is likely to be small. The sample in this study had high levels of education; 85.4% of participants had degree level or above education compared with 27.2% of adults in England and Wales [40]. To improve recruitment and completion across all socioeconomic groups, future studies could adopt mixed recruitment approaches where participants have the option of remote participation or completing the study procedure at set locations where both computers and assistance from researchers are available to overcome barriers related to skill and computer cost. Completers across all three income tertiles appeared to have similar responses to the UKVS; this suggests that if completion rates were improved, the UKVS would be suitable for examining the impacts of interventions across different income groups.

We found that Facebook was less successful as a recruitment strategy than anticipated from previous literature [2-5]. In this study, we have provided details on views and clicks generated via Facebook to enable future comparisons of recruitment rates across different study types. In the PriceExaM study that was recruiting in the same time period using the NZVS [41], Facebook adverts were more successful than observed in this study, but full analysis is still underway (Wilma Waterlander and Rita George, personal communication). The content of the UKVS adverts was similar to that in PriceExaM; features that differed were that PriceExaM adverts contained a video, and incentives and duration differed across the two studies (NZ $40 payment for completing 5 shopping tasks over 5 weeks vs prize draw for completing two immediate shopping tasks). Future UKVS studies could consider testing a guaranteed incentive structure and incorporating videos into adverts to see whether these improve recruitment and retention in the United Kingdom.

This feasibility study collected purchasing data across a broad range of outcome measures to establish sample sizes required to detect changes across multiple outcome measures. Patterns of purchasing behavior in the UKVS reveal the types of intervention that are more or less suited to being examined in the UKVS environment. The UKVS would be an appropriate environment to examine the impacts of interventions that target a broad spectrum of foods, as the majority of completers made purchases across the majority of categories. However, the UKVS is less suited to trials targeting more specific food categories. For example, only one-third of participants made purchases in the *sugar products* category, which included chocolates and confectionery. This means that the impact of price changes on chocolates and confectionery would be estimated with poor precision in UKVS studies.

Suggestions for Future Research

RCTs in the UKVS could provide valuable evidence of the potential effectiveness of HRFTS in the United Kingdom. However, as the UKVS represents a single purchasing environment, it is important that data from the UKVS are combined with information from other settings (eg, canteens, vending machines, fast food vendors, and restaurants). Schroeter et al [42] note that a tax on away-from-home foods could result in overall increases in food consumption because of substitution behavior. Ideally, we need studies that can assess overall changes in purchases across multiple settings to establish the overall impacts of HRFTS on purchases.

Resource constraints are likely to continue to be an important barrier to testing pricing interventions in real life; artificial environments such as the UKVS can help fill this gap. Continued research is required to improve the external validity of experimental studies by identifying features of trial design that prompt realistic purchasing behavior in experimental environments. For example, Epstein et al [43] charged participants for purchases made in an experimental setting from the (large) monetary incentive that was provided. They found that participants still spent more than they would in real life, possibly because of the additional income afforded by the incentive. An alternative approach may be to offer decoupled incentives. Households allocate budgets to particular categories of expenditure, and people are reluctant to spend money in one budget on items that fall under another budget [44,45]. By providing incentives in a different form (eg, vouchers for clothing or payment of energy bills), experiments may prompt more realistic food purchasing behavior and provide adequate financial compensation to participants.

Conclusions

Participant feedback on the UKVS was positive, and self-report data suggest that the UKVS did reflect participants' real purchasing decisions. However, this study revealed important limitations with recruitment and retention in the UKVS that need to be addressed before the software can be used for a full trial. The results of this study suggest that the UKVS would be a feasible tool for examining purchasing behavior in different income groups if these issues surrounding recruitment were resolved (eg, by providing participants the option to participate at study centers in addition to online).

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Supplementary information.

[PDF File (Adobe PDF File), 41KB - jmir_v19i10e343_app1.pdf]

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Abbreviations

3D: three-dimensional
ANCOVA: analysis of covariance
HRFTS: health-related food taxes and subsidies
NZVS: New Zealand Virtual Supermarket
RCT: randomized controlled trial
SD: standard deviation
UKVS: United Kingdom Virtual Supermarket

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Original Paper

Ill Literates or Illiterates? Investigating the eHealth Literacy of Users of Online Health Communities

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Abstract

Background: Electronic health (eHealth) literacy is an important skill that allows patients to navigate intelligibly through the vast, often misleading Web-based world. Although eHealth literacy has been investigated in general and specific demographic populations, it has not yet been analyzed on users of online health communities (OHCs). Evidence shows that OHCs are important Web 2.0 applications for patients for managing their health, but at the same time, warnings have been expressed regarding the quality and relevance of shared information. No studies exist that investigate levels of eHealth literacy among users of OHCs and differences in eHealth literacy between different types of users.

Objective: The study aimed to investigate eHealth literacy across different types of users of OHCs based on a revised and extended eHealth literacy scale (eHEALS).

Methods: The study was based on a cross-sectional Web survey on a simple random sample of 15,000 registered users of the most popular general OHC in Slovenia. The final sample comprised 644 users of the studied OHC. An extended eHEALS (eHEALS-E) was tested with factor analytical procedures, whereas user types were identified with a hierarchical clustering algorithm. The research question was analyzed with analysis of variance (ANOVA) procedure and pairwise comparison tests.

Results: Factor analysis of the revised and extended eHEALS revealed six dimensions: awareness of sources, recognizing quality and meaning, understanding information, perceived efficiency, validating information, and being smart on the Net. The factor solution demonstrates a good fit to the data (root mean square error of approximation [RMSEA]=.059). The most developed dimension of eHEALS-E is awareness of different Internet sources (mean=3.98, standard deviation [SD]=0.61), whereas the least developed is understanding information (mean=3.11, SD=0.75). Clustering resulted in four user types: active help-seekers (48.3%, 311/644), lurkers (31.8%, 205/644), core relational users (16.9%, 109/644), and low-engaged users (3%, 19/644). Analysis of the research question showed statistically significant differences among user types across all six dimensions of eHEALS-E. Most notably, core relational users performed worse than lurkers on the validating information dimension (*P*=.01) and worse than active help-seekers on the being smart on the Net dimension (*P*=.05). Active help-seekers have the highest scores in all dimensions of the eHEALS-E, whereas low-engaged users have statistically significantly lower scores on all dimensions of the eHEALS-E in comparison with the other groups.

Conclusions: Those who are looking for advice and support in OHCs by making queries are well equipped with eHealth literacy skills to filter potential misinformation and detect bad advice. However, core relational users (who produce the most content in OHCs) have less-developed skills for cross-validating the information obtained and navigating successfully through the perils of the online world. Site managers should monitor their activity to avoid the spread of misinformation that might lead to unhealthy practices.

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KEYWORDS

health literacy; online health community; user types; weights and measures; survey methods

Introduction

eHealth Literacy and Online Health Communities

With the undeniable prevalence of self-managing patients who are building expertise and making health decisions based on experiences in the online world, the recent upsurge of research on electronic health (eHealth) literacy is not surprising [1-6]. eHealth literacy originates from the multidimensional, dynamic concept of health literacy [7], which pertains to the cognitive and social skills for obtaining, processing, understanding, communicating, and using health-related information to function in the contemporary health care environment and to engage in appropriate self-care [7-10]. In addition to the dimension of health literacy, eHealth literacy embraces the human ability to meaningfully and efficiently navigate vast online spaces and is vital for the contemporary Internet patient to be able to make informed decisions that lead to successful health self-management, more effective contact with physicians, and positive health outcomes [2,6,11-13]. This literacy has been investigated mostly on general or specific demographic segments of populations in different national contexts, and it has not yet emerged as a topic researched among users of online health communities (OHCs). We believe that this is a critical gap that research needs to address for at least two reasons.

First, OHCs as a specific subset of online communities are commonly used Web-based applications, integrating discussion board communicative spaces that are dedicated but not limited to health-related issues, where users (patients, caregivers, or other individuals interested in health-related issues) participate, interact with other users and health professional moderators (usually health care providers), or just observe others' interactions. OHCs can range from small-knit groups dedicated to specific health conditions or they may encompass hundreds of thousands of users, covering a wide variety of health conditions, from general and acute issues to specific (chronic) conditions such as heart disease, diabetes, cancer, mental health issues, and so on [14]. In OHCs, users can obtain information before or after visiting a physician [15]; can receive social support, advice, and hints for coping with a health issue from other users; can face various perspectives of the health issue; and receive health consultations and clinical expertise from health professional moderators [16-20]. Moreover, OHCs are often hailed for the availability of rich information and psychosocial resources that enable patients and users in general to achieve psychological empowerment [16,19-23]. However, warnings and concerns [24-27] have been issued, backed by research evidence [28-30], indicating that OHCs can be places where users can be misguided and exposed to information of low relevance and questionable validity. Although OHCs are implementing mechanisms to minimize risks regarding misinformation by integrating health professional moderators [31-33] or artificial intelligence tools for filtering information [34-36], they are not immune to deceptions and exaggerations, which are characteristic of online phenomena in general [37]. Experiences with OHCs and consequent benefits or damages for health outcomes are thus largely dependent on the degree to which a user's eHealth literacy is developed [1,38]. Users with low eHealth literacy can fall a prey to advertising misguidance [39] and might also be unable to detect irrelevant or invalid information [40] or practices that can lead to very problematic health outcomes, for example, in the case of OHCs in which users have been stimulated to practice unhealthy lifestyles [41,42].

Second, another important aspect of eHealth literacy in OHCs is that they are typical Web 2.0 applications, where users are not only consumers of health-related information but also its producers. Users thus are involved not only in information-receiving communication processes but also in knowledge creation and sharing practices [36]. By posting messages in discussion threads, users in OHCs share experiences with health issues, offer advice and support to others, answer questions, chit-chat with other users, and share links to other websites [18,20,34,43]. In other words, by conducting such activities, users provide examples of health practices and educational material in general for other users [26].

Types of OHC Users and Their eHealth Literacy

As participation in online environments demands certain levels of computer and media literacy, which are components of eHealth literacy [12,13], we might expect that those who create content (ie, posters) have higher eHealth literacy than those who do not create content (ie, lurkers). However, a recent study [44] showed that there is no correlation between eHealth literacy and participatory behavior in online environments. In other words, users who cocreate knowledge in OHCs are not necessarily more eHealth literate than lurkers. Current research does not provide insights into levels of eHealth literacy among posters. We believe this issue is immensely important, as posters' eHealth literacy presents an important background against which knowledge in OHCs is produced.

In addressing the differences between those who consume and those who produce content in OHCs, we must consider recent reviews of the different types of participation in such online venues [27,34], which clearly show that the typologies of users in OHCs should go beyond the poster–lurker dichotomy [19,20]. Especially, the nomenclature for the types of posters varies greatly and is dependent on different metrics and approaches (see [34]). At a minimum, there exist at least three different, but not mutually exclusive, types of posters that are relevant while investigating eHealth literacy. One type, often called crisis-oriented users [45] or help-seekers [34], are users who typically produce query-based posts when searching for tailored answers to their specific needs. The second user type, which are often termed relational users [46], are more versatile, engaged in giving advice and support to others, and also involved in trivial conversation with other users, which is important for the sustainability of an online community [47]. The third type, commonly called superusers [48] or core users [49], are a small minority of those who create the majority of content and, most importantly, determine the tenor and the core knowledge base of the community.

As all these user types can have an important direct or indirect influence on other users [48,50], the question of their eHealth literacy in connection with their role in cocreating the social and informational terrain of OHCs is very relevant. Thus, the main aim of this paper was to investigate differences in eHealth literacy among various types of users of OHCs. In other words, the research question is—what is the level of eHealth literacy among various types of users of OHCs? First, we revised the common scale for measuring eHealth literacy (eHealth literacy scale or eHEALS) and proposed an extended version (eHEALS-E). Then empirical types of users were identified and compared regarding their degrees of eHealth literacy.

Methods

Procedure and Participants

The cross-sectional survey study was limited to users of Med.Over.Net (MON), the largest OHC in Slovenia that was established in 2000 and offers around 200 online discussion forums, of which the majority are moderated. In general, this OHC covers three types of online interactional spaces: (1) online counseling forums in which health professional moderators answer users' queries; (2) social support group forums focused on specific symptoms or health conditions; and (3) general social forums dedicated to topics that are indirectly associated with health issues (parenting, food, relationships, etc). MON has, on average, more than 400,000 monthly visits and more than 70,000 registered users. This study was conducted in collaboration with the community managers of MON as part of their annual survey of user experiences and satisfaction with the OHC. The survey, in which respondents participated voluntarily and anonymously, was administered during June 2016 by the OHC provider, which followed ethical standards for administering scientific surveys. After clicking the link for the Web survey in the email, potential respondents were taken to an informed consent Web page with information about the purpose of the research and the length of the survey, an assurance that the data would be dealt with in accordance with national and European Union (EU) laws, information about the investigator, contact information, and a statement that the potential respondents were under no obligation to participate and that the aggregated results might be published. After giving their informed consent and clicking the Next button, respondents could start to fill out the survey. The survey was conducted on the platform english.1ka.si, open source online survey application that was developed at Centre for Social Informatics, Faculty of Social Sciences, University of Ljubljana. 1ka has mechanisms that disallow multiple entries by the same users. MON is a reputable Web service that treats all personal information (emails) in accordance with national and EU laws and protects data with standard security procedures, which include the deidentification of locally held data files, physical protection of hardware, and strong password protection. The authors of this study did not have access to the respondents' emails and received an anonymized dataset that contained no identifiable personal information. Per the Code of Ethics for researchers at the University of Ljubljana [51], no institutional ethics approval was needed for this retrospective type of study. All research was conducted in line with the World Medical Association (WMA) Declaration of Helsinki on ethical principles for medical research involving human subjects.

The provider first designed a random sample of 40,000 registered users from the list of all registered users who visited MON at least once within the last 6 years. Approximately 15,000 of these registered users were randomly assigned to the Web survey used for this study, whereas approximately 25,000 users were randomly assigned to a second survey that mostly focused on users' experiences with physicians and did not provide data for this study. Of approximately 15,000 potential respondents, 2147 clicked on a link on the Web survey, and 29.99% (644/2147) provided answers to items for the analysis of the research question. To present the sociodemographic characteristics of the sample, we performed missing values imputation on these variables, as they appeared at the end of the lengthy questionnaire and consequently contained a larger number of item nonresponse. More information about the Web survey can be found in the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) in Multimedia Appendix 1.

The sample comprised 17.0% (109/644) men and 83.0% (535/644) women (Table 1). Respondents ranged in age from 15 to 90 years (mean=40.0, SD=10.3). More than half (67.7%, 436/644) of the respondents had at least a college degree, a large majority (77.1%, 497/644) were married or de facto married, 71.1% (458/644) were employed or self-employed, and 37.3% (240/644) claimed that they have a chronic or acute disease. The majority (58.5%, 377/644) of respondents use the OHC because of their own health issues, 23.0% (148/644) as caregivers, and 18.5% (119/644) for other purposes.

Measures

Extended eHealth Literacy Scale (eHEALS-E)

The definition of eHealth literacy as "the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem" ([13]:1) underpins eHEALS, one of the most frequently used measurement instruments for eHealth literacy [2,6,52]. The eHEALS was originally developed for practical use in clinical settings [13] and thus comprises only 8 to 10 items. This number of items might be too small to grasp the complex essence of eHealth literacy, which integrates various literacies and comprises four components, which are as follows: accessing, understanding, appraising, and applying online information that is relevant to health [13]. In this light, it is unsurprising that studies show conflicting results regarding the unidimensionality of the scale [53] and that the scale, in general, lacks evidence of psychometric quality [6,54]. One author of the original scale [55] has called for improvement of the eHEALS. Therefore, we decided to revise the existing scale and offer an improved and extended version based on the original theoretical premises, addressing documented critical issues. In doing so, we followed a strict methodology for developing valid and reliable scales [56] and without any a priori limitations on a small number of items. In the initial item set, we retained all the items of the original eHEALS and introduced a small change by reverse coding two items with the intention of minimizing social desirability bias [57]. We developed an additional set of items by leaning on the essential elements of eHealth literacy as deduced from the definition of the concept [12]. These items thus pertain to the components of accessing, understanding, appraising, and applying relevant online health information, which are not well represented in the eHEALS and includes the following: knowing about or being aware of professional online resources, performing the search process, cross-validating health-related information obtained from the Internet, grasping meaning from the information obtained from the Internet, verifying the credibility of the online information, and maintaining a critical awareness of biases in Internet-based information. This last dimension is especially important in the context of recent warnings about filter bubbles [58,59] and the echo chamber effect [60], which point out that an individual user can unintentionally get locked in an information space that is seemingly open and objective but in reality is closed and biased, which in turn can have a problematic impact on health outcomes [49,61].

Table 1. Sample characteristics (N=644).

Variable	n (%)
Gender	
Male	109 (17.0)
Female	535 (83.0)
Education	
Lower	47 (7.3)
Middle	161 (25.0)
Higher	436 (67.7)
Labor market status	
School-age youth	25 (3.9)
Worker, farmer	458 (71.1)
Retired, unemployed, disabled	146 (22.7)
Other	15 (2.3)
Marital status	
Married or de facto married	497 (77.1)
Single, divorced, widowed	147 (22.9)
Chronic or acute disease	
Yes	240 (37.3)
No	404 (62.7)
Purpose for visiting the OHC [a]	
User’s own health issues	377 (58.5)
As a caregiver	148 (23.0)
Other purposes	119 (18.5)
Total	644 (100)

[a] OHC: online health community.

Table 2. Confirmatory factor analysis of the extended eHealth literacy scale (eHEALS-E). All items are on a scale of 1=completely disagree to 5=completely agree. Only factor weights of absolute value equal or larger than .40 are reported.

Scale items	Fac1[a]	Fac2[a]	Fac3[a]	Fac4[a]	Fac5[a]	Fac6[a]
I know what health resources are available on the Internet.	.61					
I know where to find helpful health resources on the Internet.	.61					
I know how to use the Internet to answer my health questions.	.57					
I have the skills I need to evaluate the health resources I find on the Internet.		.78				
I can tell high-quality from low-quality health resources on the Internet.		.75				
I can easily extract the essential meaning of some health information on the Internet.		.50				
Considering all health information on the Internet, I sometimes find it difficult to select the most relevant for my health.			−.73			
The huge quantity of health information available on the Internet usually confuses me.			−.78			
I do not have any difficulties understanding the terminology used by some online health resources.			.71			
Sometimes, when I am confronted with a health issue, I am not sure where to start searching for information on the Internet.			−.56			
I feel confident using information from the Internet to make successful health decisions.				.66		
Usually, I do not find helpful health information on the Internet.				−.43		
The Internet helps me to make decisions about my health more easily.				.56		
It is important for me to be able to access health-related online information.				.63		
If I do not fully understand health information on the Internet, I try to make sense of it.					−41	
If I do not understand health information on the Internet, I would rather ask somebody for an explanation than to form my own conclusions.					.52	
It is important to me to check health information that I find on the Internet with other resources (such as doctors, books, friends, or relatives).					.46	
I think that most of the health information we find on the Internet can be trusted (R).						.77
I am satisfied with the first health resource on the Internet that can deliver answers to my questions (R).						.64
On the Internet, I prefer reading short and simple health explanations instead of complicated expert clarifications (R).						.63
Cronbach alpha	.75	.81	.80	.75	.52	.70

[a] Fac1 corresponds to the factor *awareness of sources*, Fac2 to *recognizing quality and meaning*, Fac3 to *understanding information*, Fac4 to *perceived efficiency*, Fac5 to *validating information*, and Fac6 to *being smart on the Net*.

An initial item set of 31 items was evaluated for content validity by 3 experts (one in social science methodology, one in health communication, and one in Internet studies), and on this basis, a refined set of 26 items was selected. Exploratory factor analysis did not reveal factors that would fit the four components of eHealth literacy as proposed by Norman and Skinner [13] but unveiled six factors, which, nevertheless, are meaningful and can be coined as awareness of sources, recognizing quality and meaning, understanding information, perceived efficiency, validating information, and being smart on the Net. The name of the last dimension comes from a resemblance to skills that Rheingold [62] identified as crucial in using the Internet in his book *Net Smarts*. This solution was tested with confirmatory factor analysis, which demonstrated an acceptable fit of the proposed model (root mean square error of approximation [RMSEA]=.059, standardized root mean residual [SRMR]=.058, comparative fit index [CFI]=.94). In Table 2, all items per dimension, their factor loadings, and Cronbach alphas per each dimension are listed. Correlations between dimensions (see Table 3) and analysis of average variance extracted (AVE) values (not reported but available from the authors) demonstrated satisfactory discriminant validity, noting somewhat lower discrimination between dimensions of awareness of sources and perceived efficiency. The final scale comprises 20 items, as the communalities of some items were too low on the existing factor solution and had to be excluded from the analysis (including two reverse-coded items from the original eHEALS).

Table 3. Correlations between dimensions of the extended eHealth literacy scale (eHEALS-E).

eHEALS-E dimensions	Validating information	Being smart on the Net	Understanding information	Awareness of sources	Perceived efficiency	Recognizing quality
Validating information	1	.34[a]	.07	.16[a]	.10[b]	.11[a]
Being smart on the Net		1	.31[a]	.08	.09[b]	.16[a]
Understanding information			1	.39[a]	.39[a]	.45[a]
Awareness of sources				1	.59[a]	.64[a]
Perceived efficiency					1	.47[a]
Recognizing quality						1

[a] $P<.01$.

[b] $.01< P<.05$.

Table 4. Nominal items that measure users' activities.

Set of nominal items that measure users' activities	Yes (%)
Did you post any questions for other users on discussion boards within the last 12 months?	23.0
Did you post any questions for health professional moderators on discussion boards within the last 12 months?	37.1
Did you start a new thread on discussion boards within the last 12 months?	24.8
Have you ever posted a message on the discussion boards on MON[a]?	71.0
Did you post answers to other users' questions within the last 12 months?	23.4
Did you visit social support discussion boards within the last 12 months?	42.3
Did you visit general social discussion boards within the last 12 months?	57.3
Did you visit professional counseling discussion boards within the last 12 months?	82.2

[a] MON: Med.Over.Net.

Users' Activities

As there is little evidence for consistent user typology across different OHCs [34], the typology was empirically established based on clustering units by similarities across various participation variables. An extensive set of metrics for participation in OHCs exists [34], of which some are overdetailed or unsuitable for our type of research design. Consequently, we included some of the most common survey-based measures of user activity in an OHC. The first was a set of dichotomous questions that pertain to the participation styles and the type of discussion boards visited (see Table 4 for the wording of the items and the frequencies). The second was a set of ordinal measures that pertain to the length of membership and the frequency of activities in the OHC (see Table 5 for the wording of the items and the frequencies).

Analyses

In line with previous studies [34], we did not a priori assume the user typology but obtained it empirically with a hierarchical agglomerative clustering algorithm, which iteratively joins the most similar users according to the users' activity metrics based on Ward's minimum variance method [63]. More precisely, users were assigned to clusters according to similarities across the 11 users' activities items above. Cluster membership was stored in a new variable that was used to analyze the research question.

Exploratory factor analysis was conducted to explore the factor structure of the scale to measure eHealth literacy and to determine which items of the scale should be retained. Factors were extracted using principal axis factoring with oblimin rotation, as we did not expect an orthogonal factor solution. The number of factors was selected based on eigenvalues higher than 1. This decision was also supported by inspection of the scree plot. The obtained factor solution was put in a confirmatory factor procedure (using package lavaan in R [64]), which resulted in several statistics that estimate the goodness of fit of the factor model to the study data. As the statistics showed a good fit of the model, no modifications were needed.

To analyze the research question, a one-way analysis of variance (ANOVA) method was used with post hoc pairwise comparison tests to investigate the statistical significance of differences among pairs of user types.

Table 5. Ordinal items that measure users' activities.

Set of ordinal items that measure users' activities	Values	%
When did you last visit discussion boards on MON[a]?	1-last 7 days	33.4
	2-a week to 1 month ago	28.4
	3-a month to half a year ago	27.8
	4-half a year to a year ago	10.4
How long have you been a user of discussion boards on MON?	1-more than 3 years	56.7
	2-from 1 to 3 years	32.4
	3-less than a year	9.4
	4-less than a month	1.5
How often have you posted messages on message boards on MON within the last 6 months?	1-every day or almost every day	1.2
	2-at least once a week	2.0
	3-at least once a month	4.0
	4-less frequent than once a month or never	92.8

[a]MON: Med.Over.Net.

Results

User Typology

Clustering resulted in four meaningful groups of users, who have high within-group similarity and high between-group variance regarding the user activity variables. The emergent typology of the studied OHC overlaps to a great extent with that of the existing studies [34]. If we try not to depart from the nomenclatures of existing studies, then we can name and describe the following four clusters of users with distinct characteristics of their activities in the OHC: active help-seekers, lurkers, core relational users, and low-engaged users (see Table 6).

The largest group of users—active help-seekers—comprises 48.3% (311/644) of the whole sample. This group is characterized by users who regularly visit the OHC, the majority of whom have been members of the OHC for more than 3 years. They mostly participate in help- and advice-seeking behavior by posting messages for health professional moderators, while occasionally also lurking in the online support and socializing sections of the community. The second group comprises typical lurkers and represents 31.8% (205/644) of the sample. They are moderately frequent users of all types of forums on the OHC but never post messages—not for other members and not for health professional moderators. The third group represents 16.9% of the sample (109/644) and includes very active members—core relational members—who are experienced users, with a high frequency of participation in support and social groups and who occasionally also interact with health professional moderators. We can safely claim that these users probably produce most of the user-generated content in the social and support forums. The fourth group, low-engaged users, is the smallest and represents only 3% of the sample (19/644). These are very infrequent, short-term users of the OHC, who have not been in the community for a long time, post questions only in the medical consultation forums, and are not interested in others' experiences.

The sociodemographic profiles of the clusters of users and their health-related characteristics are presented in Table 7. In this table, row percentages are presented to describe the characteristics of the obtained clusters.

The sociodemographic profiles show several differences among the clusters of users. In the group of active help-seekers, there is the highest percentage of women (72.3%, 225/311) and highly educated (52.4%, 163/311) in comparison with the other three clusters. Conversely, the mean age of the users in this cluster is smaller (mean=38.9 years) in comparison with the other three clusters. In the cluster of low-engaged users, the percentage of men (58%, 11/19) is the highest, and this is the oldest cluster among the four clusters (mean=41.8 years).

Table 6. User types on Med.Over.Net (MON).

Cluster	n (%)	Description in terms of typical activities
Active help-seekers	311 (48.3)	Moderately frequent users, long-term members, occasionally post questions, and mostly for health professional moderators; less involved in support and social forums
Lurkers	205 (31.8)	Moderately frequent users, experienced, do not post any sort of messages, and visit all types of forums
Core relational users	109 (16.9)	Frequent users, very frequent posters, experienced members, ask and answer questions, and engaged in discussions in all types of forums
Low-engaged users	19 (3.0)	Infrequent users, rarely open new threads, and post questions only for health professional moderators

Table 7. Sociodemographic and health-related characteristics of the user clusters.

Cluster	% of females	% with high education	Mean age in years	% with a long-term chronic or acute disease	% visiting because of own health issues	% visiting as caregivers
Active help-seekers	72.3	52.4	38.9	36.0	60.5	25.2
Lurkers	64.4	36.1	41.4	30.7	53.7	35.1
Core relational users	67.0	45.0	40.4	43.5	62.4	11.0
Low-engaged users	57.9	36.8	41.8	52.6	58.8	17.6

There are also observable differences in the users' health-related characteristics. Interestingly, the highest percentage of users with a long-term chronic or acute disease is in the low-engaged cluster (53%, 10/19), whereas the smallest percentage is in the lurkers cluster (31%, 63/205). The group with the highest percentage of caregivers is the lurkers cluster (35%, 72/205). In the core-relational group, the percentage of caregivers is the lowest (11%, 12/109), whereas the percentage (62%, 68/109) of those who visit the OHC because of their own health issues is the highest. The remaining 27% (30/109) are using the OHC because of other non-health-related reasons. The design of the research and the limited space in the questionnaire did not allow more detailed analysis of the types of health issues.

Presence of the eHEALS-E Dimensions

To investigate the levels of eHealth literacy, we first computed the scores for all six eHEALS-E dimensions as obtained with the factor analytical procedures. A series of paired sample *t* tests revealed that awareness of different sources (mean=3.98, SD=0.67) and perceived efficiency (mean=3.94, SD=0.65) are the most developed dimensions of the eHEALS-E, as users score statistically significantly higher in these two dimensions in comparison with all others (*P*<.001). The dimensions of recognizing quality and meaning (mean=3.84, SD=0.80) and validating information (mean=3.80, SD=0.61) are statistically significantly more common (*P*<.001) than being smart on the Net (mean=3.74, SD=0.81) and understanding information (mean=3.11, SD=0.75). Being smart on the Net and understanding information are the least developed dimensions and are statistically significantly less developed (*P*<.001) than all other dimensions. Table 8 reports differences among all dimensions.

Analysis of Research Question

To analyze the research question, we compared the scores of the eHEALS-E dimensions across the four user groups. We first conducted ANOVA to test differences in the eHEALS-E across groups and then conducted pairwise post hoc tests to determine among which groups the differences are statistically significant (see Table 9).

The user typology is weakly associated with the eHEALS-E dimensions, as the effect sizes are small according to the established guidelines [65]. However, the analysis nevertheless reveals that there are statistically significant differences among the groups of users regarding all six dimensions of eHealth literacy. Post hoc tests reveal that active help-seekers have statistically significantly higher levels of eHealth literacy in comparison with lurkers in four dimensions: understanding information (*P*=.002), awareness of resources (*P*=.002), perceived efficacy (*P*<.001), and being smart on the Net (*P*=.006). Active help-seekers also perform better in all these dimensions in comparison with low-engaged users.

Table 8. Means of the extended eHealth literacy scale (eHEALS-E) dimensions and the statistical significance of the mean differences.

Dimension of eHEALS-E[a] or group	Mean (SD[b])	Row-VI[c]	Row-UI[d]	Row-AS[e]	Row-PE[f]	Row-RQ[g]
Validating information	3.80 (0.61)					
Understanding information	3.11 (0.75)	0.69[g]				
Awareness of sources	3.98 (0.67)	−0.18[h]	−0.87[h]			
Perceived efficiency	3.94 (0.65)	−0.14[h]	−0.83[h]	0.04		
Recognizing quality	3.84 (0.80)	−0.04	−0.73[h]	0.14	0. 10[i]	
Being smart on the Net	3.74 (0.78)	−0.06	0.63[h]	−0.24[h]	−0. 20[h]	−0. 10[i]

[a] eHEALS-E: extended eHealth literacy scale.

[b] SD: standard deviation.

[c] VI: validating information.

[d] UI: understanding information.

[e] AS: awareness of sources.

[f] PE: perceived efficiency.

[g] RQ: recognizing quality.

[h] *P*<.01.

[i] .01< *P*<.05.

Table 9. Comparison of user types across dimensions of the extended eHealth literacy scale (eHEALS-E).

Dimension of extended eHealth literacy scale or group	Active help-seekers (N=311)	Lurker (N=205)	Core relational users (N=109)	Low-engaged (N=19)	Whole sample (N=644)	Significance of *F*-statistics	Effect size (eta-squared)
Validating information	3.84[a,b]	3.83[c]	3.64[a,c]	3.57[b]	3.80	.01	0.02
Understanding information	3.20[a,b]	2.97[a,c]	3.16[c,d]	2.75[b,d]	3.11	<.001	0.02
Awareness of sources	4.06[a,b]	3.87[a,c]	4.02[c,d]	3.69[b,d]	3.98	<.001	0.03
Perceived efficiency	4.02[a,b]	3.81[a,c]	3.98[c,d]	3.58[b,d]	3.94	<.001	0.03
Recognizing quality	3.88[a]	3.72[a,b]	3.98[b]	3.78	3.84	.05	0.01
Being smart on the Net	3.84[a,b]	3.64[a]	3.67[b]	3.59	3.74	.02	0.02

[a] Group has statistically different mean value (*P*<.05) of the corresponding row dimension of eHEALS-E in comparison to the mean value of the other group with the same superscript.

[b] Group has statistically different mean value (*P*<.05) of the corresponding row dimension of eHEALS-E in comparison to the mean value of the other group with the same superscript.

[c] Group has statistically different mean value (*P*<.05) of the corresponding row dimension of eHEALS-E in comparison to the mean value of the other group with the same superscript.

[d] Group has statistically different mean value (*P*<.05) of the corresponding row dimension of eHEALS-E in comparison to the mean value of the other group with the same superscript.

In comparison with lurkers, core relational users have higher levels of eHealth literacy in the dimensions of understanding information (*P*=.04), perceived efficiency (*P*=.03), and recognizing quality (*P*=.01). In contrast, core relational users perform worse than lurkers in the dimension of validating information (*P*=.01). Core relational users also score worse in this dimension of eHealth literacy in comparison with active help-seekers (*P*=.005). More importantly, core relational users have significantly lower scores for the being smart on the Net dimension in comparison with active help-seekers (*P*=.05).

Low-engaged users perform the worst in terms of eHealth literacy, as they score significantly lower in the dimension of understanding information in comparison with the other three groups. Low-engaged users also score significantly lower than active help-seekers in the dimensions of awareness of sources (*P*=.02) and perceived efficacy (*P*=.004). Other differences are also notable, but they are not statistically significant because of the small size of this group.

Discussion

Variable Presence of Different Dimensions of eHealth Literacy

The main aim of this research was to investigate the levels of eHealth literacy that various types of users of OHCs possess. To investigate this question, we first revised and extended the existing measurement instrument for eHealth literacy in light of numerous criticisms of the eHEALS [5,54]. With the inclusion of additional items that tap into various essential components of the eHealth literacy concept, the data surprisingly unveiled a set of six distinct yet meaningful dimensions of the eHEALS-E. These dimensions are developed to different extents in the sample of OHC users. Awareness of different health-related sources on the Internet and self-assessed efficiency in search and use of health-related information are the most common dimensions of eHealth literacy across all groups of OHC users, whereas the other dimensions are less common. Interestingly, skills for using the Web smartly and skills for understanding the information are the least developed. The latter is quite expected, as understanding medical information demands a high level of health literacy coupled with professional knowledge [12].

Whereas previous research demonstrated one or at the most two dimensions of eHealth literacy, the eHEALS-E reveals six dimensions. Although we added items to more thoroughly represent components of accessing, understanding, appraising, and applying health-related online information, these items combine in a different manner than was theoretically assumed [12]. For example, the original access dimension seems to resonate in the dimension awareness of Internet sources, whereas perceived efficiency seems to integrate elements of efficiency in the accessing and applying the information dimension. The dimension understanding is supplemented with that of validating information. The dimension that we coined, being smart on the Net, seems to be an important and distinct part of eHealth literacy, which has not been satisfactorily considered by the existing measures.

This point is also emphasized, at least indirectly, by the authors of the electronic health literacy scale (e-HLS; [5]), a recently introduced eHealth literacy scale, which unfortunately could not be considered in this study, as we had already collected the data. Whereas the eHEALS-E builds on the theoretical underpinnings of the eHEALS, the e-HLS builds on a somewhat broader set of studies and is represented by items that measure different activities that users undertake when browsing online resources (checking credentials, last update, etc), trust in online information, and communicating about information obtained with health providers [5]. Although the items in the e-HLS are rather different, the eHEALS-E similarly tries to incorporate skills assumed by the e-HLS by considering the perspectives of cross-validating information with colleagues and health providers, the ability to discern reliable sources from unreliable ones, and critical appraisal of online information. The main difference is that items in the eHEALS-E measure not only activities but also self-assessed skills (similar to the eHEALS) and attitudes. The latter, in our opinion, are more subtle at revealing skills and practices (or the lack of them) that pertain to the most critical issues of appraising online information. In this way, we managed to discern the presence of the so-called *bad literacy* phenomenon [39], which is the phrase we coined and computed in our study in its reverse meaning (being smart on the Net) for methodological reasons to compare the dimensions. High correlations between the items that compose this dimension (between "I'm happy with the first search result that I get, when I search for health information" and "I think that most of the health information that we can find on the Internet can be trusted," and "When I get useful information on the Net, I'm not interested who is its author") clearly demonstrate practices that show the absence of an important dimension of eHealth literacy—the one that deals with the awareness of misinformation and biases in search engines and popular social media [58-60]. Moreover, this dimension of eHealth literacy combines a lack of interest in verifying authorship, coupled with a naïve trust in the objective gatekeeping function of Internet search engines. In comparison with the e-HLS, trust in this study appears here as a component that diminishes the critical appraisal of online health information and thus, diminishes eHealth literacy. In any case, we believe that complementing the theoretical and operational perspectives of the eHEALS-E and the e-HLS would lead to higher quality of eHealth literacy measurements.

The Users Who Participate the Most Are Not the Most Literate

The analysis of the newly introduced eHEALS-E among users of OHCs reveals several noteworthy findings. First, we demonstrated, theoretically and empirically, that it is important to distinguish between different types of users in investigating eHealth literacy. Active help-seekers, a common user type in other studies of OHCs [34], are, interestingly, the most literate users in almost all dimensions of eHealth literacy in comparison with other user types. These users have the skills to navigate smartly around the Internet, recognize information biases, and validate the information obtained through their colleagues and professional sources. However, these users scored a bit lower on the dimension of recognizing quality, revealing limited medical knowledge for directly recognizing the quality and essence of health-related information and its implications for their own decision making and actions. The likely consequence of this is that the group's use of OHCs is characterized by tailor-made queries in professional consultation forums, where they can find clarifications and illustrations of professional knowledge [31]. As the group of active help- seekers is the most literate in all other dimensions of the eHEALS-E, this group likely has an important positive cumulative effect on the whole OHC. The many questions that these users post to health professional moderators enable lurkers, who are less literate, to browse intelligibly through the questions and answers. Moreover, results show that the group of active help-seekers is (comparably) female dominant and highly educated. The majority of users within this cluster use the OHC because of their own health issues, yet more than a quarter of the cluster is composed of caregivers. It is important to notice that active help-seeker have relatively high eHEALS-E scores, which likely helps them to provide adequate care to their close ones.

As a group of users, lurkers (who never participate by asking questions or sharing their knowledge but only browse discussions) in general have lower eHEALS-E scores in comparison with the other groups of active participants. As posters and lurkers can reach similar levels of psychological empowerment [19,20], it becomes important that OHCs enjoy high enough levels of valid information. If users were able to build awareness that they can cope with the given health issue and have control over it [18,20] based on low eHealth literacy and the questionable validity of information in OHCs, this would lead to conflicts in relationships with physicians [39] and worse health outcomes in general [66]. Moreover, we found that the highest percentage of caregivers was among the lurkers. Thus, although lurkers do not have a direct impact on the OHC, they have an impact on people to whom they offer health care. Since lurkers score relatively low in the majority of the eHEALS-E dimensions, there is a danger that this group's interpretation of the information they obtain might not result in the most efficient care for their family members or friends.

On the basis of user activity metrics, we identified another very small group of users that seems to be the most problematic in terms of eHealth literacy. This group, which we, similarly as in some other studies [67], identified as low-engaged users, has the lowest percentage of highly educated users, lowest percentage of females, is the oldest in comparison with other groups, and has the highest percentage of users with long-term chronic or acute illness. On the one hand, members of this group figure the lowest in terms of validating, understanding, and being smart users of the Internet for health-related information, but on the other hand, they are self-confident and trust in their abilities to recognize quality information and grasp the essence from Internet-obtained health information. As items of the latter dimension mostly rely on a self-reported belief in one's own competence, we can note here a divergence between how people assess their skills and the true nature of their skills. Low-engaged users might be convinced that they get from the Internet the essential health information that they need, but they don't care much about the validity of that information. This issue becomes more crucial with the most active group of users.

Core relational users represent users who are the most active in the OHC, and their contributions likely have the largest impact on the OHC. This user type probably confounds the more detailed subtypes found in other studies [34]. In comparison with other groups, this group is female dominant and has the smallest percentage of caregivers. The level of eHealth literacy of core relational users is similar to that of active help-seekers, but core relational users perform significantly worse in the dimensions validating information and being smart on the Net. Even in comparison with lurkers, core relational users' *bad literacy* is significantly higher. In other words, whereas core relational users are very confident about their ability to grasp essential health information efficiently by browsing the Internet, they are mostly unaware of the dangers of biases and misguiding websites, which unarguably exist [58,60]. This finding should be a cause for some concern. Participation by core relational users is strongly motivated by identification with the community. Interestingly, this identification is based mostly on benevolence trust, not on integrity trust [36]. In other words, for a user of an OHC to belong to a community, it is not as important that other users are truthful, consistent, and honest in their messages but that they show concern for them. Consequently, participating users with a strong sense of belonging are not concerned as much about the credibility of their messages but that their behaviors are aligned with the group norms and beliefs. In the context of the finding that users perceive peer advice in OHCs as very credible [30], this opens up affordances of OHCs for the spread and domination of misinformation, especially when group norms and beliefs support unprofessional or unhealthy practices.

Current research does not provide much empirical evidence for the suggestion that such affordances are abused by a minority of motivated individuals to control the discourse in the community [46,61], but it is worrying that discussions in OHCs are very rarely equipped with references to external professional websites [46] and that users reject advice from credible websites when they are not in accordance with their beliefs and lifestyles [68]. Thus, there is a great concern that core relational users could be misguided by pseudoscientific research, as they do not have the expertise to judge the reliability and credibility of the information [46]. In turn, this can have real consequences, as the information these users publish becomes available to other OHC users who can use it to build knowledge about a particular issue and even apply the information to manage their own condition. This study does not provide evidence for existence of such process in the studied OHC. However, we claim that core relational users might present a certain risk for the production of credible OHC knowledge because of their relatively lower developed eHealth literacy in the dimension being smart on the Net. Patients can develop feelings of empowerment and control over their health decisions through social support in OHCs [16,18], but as ideological similarity might be more important than the credibility of the information in judging the quality of peer support [32], such empowerment does not necessarily lead to better health outcomes. On the contrary, when information published by people with low eHealth literacy is validated by other people with low eHealth literacy, users of OHCs can get empowered on invalid bases, which could lead to serious negative consequences [69]. Moreover, as such knowledge becomes prevalent, it provides a template for other members to follow [31], thus resulting in problematic collective behaviors such as in the case of the antivaccination movement [56] or pro-anorexia forums [41].

Practical Implications

The discussion above provokes practical considerations for OHC managers. Existing research on misinformation in OHCs suggests interventions either at the level of procedures of artificial intelligence in selecting and detecting problematic information and/or regarding the importance of the role of health professional moderators in OHCs. This research adds another practical implication for OHC managers. Occasional assessments of eHealth literacy among core relational users could help identify potential risks for the quality of published information, especially if critical elements of eHealth literacy start decreasing. This way, site managers could intervene before actual misinformation or noncredible information gets published and spreads among the community. The core relational users' lower values for the dimension being smart on the Net clearly indicate that the site managers of the studied OHC should be more attentive toward this segment and plan suitable interventions. These should be created with great care, as core relational users and their everyday conversations that satisfy different motives are important for successful sustainable online communities [47]. If such conversations are intermeshed with the sharing of health information of questionable validity, this becomes a problem for the community. One mechanism could be to engage health professional moderators, who mostly participate in consultation forums, to enter discussions where core relational users with low eHEALS-E scores dominate the discussion. Another preventive measure might be to provide mechanisms that discourage the closure of conversational space. In other words, users should be stimulated to build bridging social capital, encounter different perspectives on an issue, and not be limited to relatively isolated islands of known and similar persons. This, for example, could be stimulated by awarding participation in different areas of the community.

Furthermore, users should be encouraged by positive awards to support their statements in the form of links to credible websites, as this increases the quality of conversation, which further affects the nature of the impact on health outcomes [70].

In light of the findings above, we find the mechanisms that bring together users on the basis of matchmaking and similar beliefs problematic [26,28], as they might attenuate the bubble effect. It is true that OHCs and online communities in general (most notably Wikipedia) have a sort of self-correcting mechanism by which inaccurate and invalid information is corrected by peers. However, the success of such a mechanism is based on the assumption that contributors have high eHealth literacy. When this assumption is not justified, a community could quickly build on false knowledge and nurture problematic ideas or practices.

In addition, although the awareness of the need for the strong presence of health professional moderators is growing as they filter information, provide links to external websites, and so on [31,43], their role could be further expanded. As suggested above, they should be encouraged to participate or at least lurk in more socializing-oriented parts of the forum. In this way, health professionals could not only discover problematic contents but also inform their professional practice and that of their colleagues about the misinformation and ambiguous discourses regarding symptoms, treatments, or remedies.

Limitations

The research design used in this study faces several methodological issues that limit the generalizability of the results. For one, this study focused on a single OHC in a specific national context. On the positive side, this OHC is large and encompasses different types of forums, thus resembling OHCs that are more internationally known (such as PatientsLikeMe, WebMD, and MedHelp). We should add that Slovenia is one of the most typical EU countries regarding usage of information and communication technologies. According to many of Eurostat's information society indicators, the country is close to the median position among all EU countries [71]. In addition, although we used simple random sampling on the basis of a list of all OHC users, there are certain limitations. The total response rate (4.2%) is not uncommon with this type of research designs [72] but nevertheless is small. We can assume from other studies [73,74] that users who more frequently use and post in the OHC are also more likely to provide responses on the survey. Consequently, the proportions of user types are not representative of the whole OHC. It is likely that the sizes of the lurkers and low-engaged users groups are underestimated, whereas the sizes of the core relational users and active help-seekers groups are probably overestimated. One implication of this limitation is that under a different data collection procedure, which would allow better representation of low-engaged users, the clustering algorithm might reveal a higher variability in user types among low- and nonactive users. For instance, we might get a so-called butterfly user type, which was identified in several other studies [34] as a group of users who visit OHCs frequently but spend short amounts of time per session and jump from one discussion board to another. In addition, among lurkers we might be able to distinguish between short-term users, searching for usable information and long-term users who eventually become active users. Another methodological implication of this limitation is that future studies should focus on the use of various methods for recruiting less- or nonactive users. However, we should be aware that though such methods (eg, log analysis or automated data analysis) might be useful for detecting more complex types of users, they need to be combined with methods that are more informative about the cognitive, emotional, and other psychosocial process in OHCs to be able to measure such tacit phenomena as eHealth literacy.

Furthermore, the data refer only to a specific population of OHC users and do not allow any comparison with the general population. Consequently, we do not know whether the average eHealth literacy level of OHC users is similar to the eHealth literacy of the general population. We can compare only the scores of individual items that are the same as those used in studies in other national contexts [1-3,6] and realize that the scores are fairly similar. It does not seem that the OHC users, on average, would be very different from the general population. However, this is more of a speculation than a scientifically validated statement. This issue is connected to the testing of the eHEALS-E scale. Although tests on the specific sample proved that the revised and extended scale has a meaningful structure, the eHEALS-E scale needs to be retested on a different population and in different national contexts. Moreover, to get a stronger confirmation of validity, criterion validity should be assessed by associating the scale with the outcome measures.

Conclusions

In this study, we identified different types of OHC users who perform differently regarding eHealth literacy and affect the production of knowledge in this OHC. The proposed extended version of the eHEALS scale, which in our opinion more validly taps various dimensions of this complex construct, allowed us to gain a more nuanced insight into the differences among various types of users. We specifically exposed the core relational users who represent a group of users that produce the most content in OHCs and at the same time show less-developed skills for cross-validating the information obtained and navigating successfully through the perils of the online world. OHC site managers should better monitor these users' activities to avoid the spread of misinformation and unhealthy practices. However, the value of OHCs should not be rejected despite some rather worrisome findings of this research about the credibility of the information shared in OHCs. Existing research demonstrates many benefits of participation in the OHCs for users and patients in dealing with health issues. However, further research is needed to focus on the early discovery of potential problems in OHCs to eliminate them and to prevent a loss of credibility of the information shared in OHCs. We believe that investigating different dimensions of the eHEALS-E across different types of users can provide important help in this process by discovering segments of users who publish information based on low eHealth literacy, and as such present a risk of growing into a dominant social force that could change the nature of the OHC in an unexpected and harmful way.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Checklist for Reporting Results of Internet E-Surveys.

[PDF File (Adobe PDF File), 40KB - jmir_v19i10e331_app1.pdf]

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Abbreviations

ANOVA: analysis of variance
AVE: average variance extracted
CFI: comparative fit index
CHERRIES: Checklist for Reporting Results of Internet E-Surveys

eHealth: electronic health
e-HLS: electronic health literacy scale
eHEALS: eHealth literacy scale
eHEALS-E: extended eHealth literacy scale
EU: European Union
OHC: online health community
MON: Med.Over.Net
RMSEA: root-mean-square error of approximation
SD: standard deviation
SRMR: standardized root-mean-square residual
WMA: World Medical Association

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Original Paper

Reliability and Validity of the Telephone-Based eHealth Literacy Scale Among Older Adults: Cross-Sectional Survey

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Abstract

Background: Only a handful of studies have examined reliability and validity evidence of scores produced by the 8-item eHealth literacy Scale (eHEALS) among older adults. Older adults are generally more comfortable responding to survey items when asked by a real person rather than by completing self-administered paper-and-pencil or online questionnaires. However, no studies have explored the psychometrics of this scale when administered to older adults over the telephone.

Objective: The objective of our study was to examine the reliability and internal structure of eHEALS data collected from older adults aged 50 years or older responding to items over the telephone.

Methods: Respondents (N=283) completed eHEALS as part of a cross-sectional landline telephone survey. Exploratory structural equation modeling (E-SEM) analyses examined model fit of eHEALS scores with 1-, 2-, and 3-factor structures. Subsequent analyses based on the partial credit model explored the internal structure of eHEALS data.

Results: Compared with 1- and 2-factor models, the 3-factor eHEALS structure showed the best global E-SEM model fit indices (root mean square error of approximation=.07; comparative fit index=1.0; Tucker-Lewis index=1.0). Nonetheless, the 3 factors were highly correlated (r range .36 to .65). Item analyses revealed that eHEALS items 2 through 5 were overfit to a minor degree (mean square infit/outfit values <1.0; t statistics less than –2.0), but the internal structure of Likert scale response options functioned as expected. Overfitting eHEALS items (2-5) displayed a similar degree of information for respondents at similar points on the latent continuum. Test information curves suggested that eHEALS may capture more information about older adults at the higher end of the latent continuum (ie, those with high eHealth literacy) than at the lower end of the continuum (ie, those with low eHealth literacy). Item reliability (value=.92) and item separation (value=11.31) estimates indicated that eHEALS responses were reliable and stable.

Conclusions: Results support administering eHEALS over the telephone when surveying older adults regarding their use of the Internet for health information. eHEALS scores best captured 3 factors (or subscales) to measure eHealth literacy in older adults; however, statistically significant correlations between these 3 factors suggest an overarching unidimensional structure with 3 underlying dimensions. As older adults continue to use the Internet more frequently to find and evaluate health information, it will be important to consider modifying the original eHEALS to adequately measure societal shifts in online health information seeking among aging populations.

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KEYWORDS

social media; aging; health literacy; Web 2.0; Internet

Introduction

The increasing amount of online health information available to the public [1,2], coupled with the popularity of health-related Internet searches [3,4], has greatly increased Internet use for health-related purposes. With this increased use come both benefits and challenges. Greater Internet adoption has increased the availability of health information for consumers, yet disparities in access to relevant online health information persist, especially among users with insufficient skills to discriminate between credible and fraudulent online health information. The broad reach of the Internet has potential to increase health knowledge and to build self-efficacy to carry out protective health behaviors, yet the large volume of health information on the Internet often lacks quality, relevance, and veracity [5,6]. Online health information seeking is also generally an independent, goal-driven activity that puts the user in control of sifting through an abundant amount of health information. To do this effectively, users must possess skills to identify reliable sources, appraise the relevance of online health information, and translate knowledge gained into meaningful action that addresses a health-related concern.

Older Adults and Online Health Information Seeking

Proficiency in carrying out online health information-seeking behaviors varies by sociodemographic factors, including age [7]. For example, greater adoption of the Internet by older adults has increased the accessibility of health information to this subset of the population [8,9]. One recent study in the United States showed that Web adoption among older adults is climbing, with 67% of people over 65 years of age using the Internet and more than 40% using smartphones [10]. Over 50% of US adults aged 35 to 60 years reported searching for online health information, while only 31% over the age of 60 years reported doing so [11]. Older adults need high-quality, relevant, and accurate health information regarding age-related physical conditions and ailments that require regular and consistent medical attention [12,13]. However, research suggests that most older adults do not access high-quality health information that addresses their health concerns [14].

There are several reasons why older adults may be unable to benefit from increased access to online health information. Older adult populations report high computer anxiety, which compromises their ability to carry out functional tasks using Internet-based technologies [15]. Only 26% of older adult Internet users reported feeling confident when using the Internet to complete daily tasks [10]. This lack of confidence using digital devices often leads to lack of Internet use for health information among older adult populations [10,16-18]. Nevertheless, older adults who overcome anxiety toward using health information technology demonstrate greater patient activation (ie, enhanced knowledge, skills, and confidence a person has in managing their own health and health care) and are more satisfied after talking with their provider about their own medical questions [19,20].

Moreover, routine online health information seeking has the potential to motivate older adults living with chronic disease to become more proactive in their health care decision making [21,22]. Because it is very likely that older adults will increasingly use the Internet to access health information to improve their health, it is important to measure the extent to which they have the capacity to search for, retrieve, and evaluate health-related resources that they come across online (ie, eHealth literacy).

Measurement of eHealth Literacy

eHealth literacy was originally defined by Norman and Skinner [23] as “the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem.” To conceptualize eHealth literacy, Norman and Skinner [23] used the metaphor of a lily flower with 6 discrete petals (literacies) feeding into a core pistil. They categorized the core literacies proposed to contribute to eHealth literacy as being either context specific (ie, health, computer, and science literacies) or analytic specific (ie, traditional and numeracy, information, and media literacies). The concept of eHealth literacy is dynamic and evolving, meaning it varies per a variety of individual and contextual factors, including an individual’s health status, their purpose(s) for seeking health information, and the technology they select to access health information. Recent research suggests that people with greater eHealth literacy are more informed health decision makers [24], which ultimately increases their capacity to engage in health protective behaviors [25] and improve their quality of life [26]. While several studies have examined eHealth literacy, rigorous measurement of the 6 constituent eHealth literacies is underdeveloped and presents an ongoing challenge for health promotion researchers.

In 2006, Norman and Skinner [27] developed the eHealth Literacy Scale (eHEALS), an 8-item rating scale that measures consumers’ knowledge of and perceived confidence in their ability to seek, understand, and evaluate health information obtained from the Internet to address health-related concerns. Scores from eHEALS have supported its reliability as a unidimensional scale in diverse populations, including adolescents [27], college students [28], adults in the general US population [28], older adults recruited on the Internet [29], and people living with chronic disease [30,31]. eHEALS has been translated into many different languages and administered in countries around the world (eg, Germany, Italy, the Netherlands, Israel, and China).

Several studies have explored the dimensionality of data produced by eHEALS, reporting varied results. This literature describes some potential problems related to the internal structure of the eHEALS. Specifically, the number of factors (and factor loadings) derived in measurement studies of the eHEALS have shown some variability. Two recent studies reported that up to 3 unique, yet highly correlated, factors may be present when the scale is administered to older adults [30,32]. However, studies reporting the presence of multiple subscales have yet to explicate which eHEALS items load onto distinct factors (or constructs) when eHEALS is completed by older adults [29,30,32]. This variability has caused some difficulty when attempting to define what these unique factors, or subscales, are actually measuring.

Soellner and colleagues [33] translated the eHEALS into German and found that, despite poor global model fit, data from 18-year-old university students may best fit a 2-factor model, where eHEALS items measure online health information seeking (items 1-5, and 8) and online health resource appraisal (items 7 and 8). Neter and colleagues [7] also found adequate global model fit with a 2-factor model of eHEALS data when collected among adults over 21 years of age. This 2-factor structure consisted of 1 factor measuring online health information seeking (items 1-3) and another measuring online health resource appraisal (items 4-8). It should be noted, however, that 1 study [33] primarily consisted of adolescents. Younger people are more likely to report higher eHealth literacy than their older counterparts [7,31]. The factor structure and variance of eHEALS scores may differ as a function of age, which could influence results from eHEALS studies including younger versus older samples. Diviani et al [34] conducted a validation study of the Italian version of eHEALS administered among young to middle-aged adults (mean age 37.37 years, SD 13.78). Confirmatory factor analysis results showed suboptimal model fit among 2 rival models (1-factor structure vs 2-factor structure), yet parametric and nonparametric item response theory (IRT) analyses confirmed that the single-factor model best fit the data in the study sample. However, studies reporting the presence of multiple subscales have yet to explicate which eHEALS items load onto distinct factors (or constructs) when eHEALS is completed by older adults [29,30,32].

It is also important to note that the mode of survey administration can affect the reliability and validity evidence of survey data [35]. Many studies examining the internal structure of eHEALS data collected from older adults have only used Web-based survey methods [29,30,32]. Web-based surveys have several advantages, including time and cost efficiencies, but they are prone to response bias, especially when respondents demonstrate concerns about the privacy of disclosing information through Web-based survey portals [36]. Also, analyzing eHEALS data collected from only active Internet users may reduce the quality of reliability and validity assessments due to sampling bias. Older adults who use the Internet to complete the eHEALS are more likely to be more confident in their online health information-seeking skills; thus, solely relying on Web-based survey methods to establish evidence for the validity of eHEALS scores may introduce measurement bias. Administering Web-based versions of eHEALS to older Internet users may skew data toward respondents with high overall eHealth literacy, which may partly explain why existing studies report moderate to high eHealth literacy in older adult populations.

Dillman [37] recommended use of telephone-based surveys for collecting data among older populations, who often feel more comfortable answering questions asked by an actual person rather than via online or paper-and-pencil questionnaires. In a recent study, Neter and Brainin [38] conducted a nationally representative random digital dial telephone household survey of Israeli adults aged 50 years and older to determine their perceived eHealth literacy as measured by eHEALS. In this older population, perceived eHealth literacy was judged to be moderate (mean 3.17, SD 0.93), with a moderate correlation established between perceived and actual eHealth literacy (r=.34, P=.01). However, no psychometric data on eHEALS responses was reported in this age-restricted (50 years of age and older) sample. Therefore, much variability has been documented in the literature and has led to difficulty defining what the unique factors, or eHEALS subscales, may be measuring. These discrepancies in confirmatory factor analysis and IRT analysis results highlight the importance of conducting additional psychometric research that considers differences in eHEALS item measurement, factor structure, and item difficulty among older adults. The purpose of this study was to examine the reliability and explore the internal structure of eHEALS data, when the scale is administered to older adults using telephone-based survey methods.

Methods

Recruitment

We conducted a cross-sectional landline telephone survey as part of the Florida Consumer Confidence Index (F-CCI) Survey [39]. At least 500 households in the US state of Florida were contacted over 1 month. A minimum of 10 call attempts per household were made every Monday through Friday (between 9:00 AM and 9:00 PM), Saturday (between 12:00 PM and 6:00 PM), and Sunday (between 3:00 PM and 9:00 PM) using the random digit dialing method. The Institutional Review Board at the University of Florida approved the conduct of this study. Overall, 6695 calls were placed, and 493 individuals (response rate 7%) agreed to participate in the telephone survey. Participants were not provided incentives as part of participating in the F-CCI. We included data from these individuals in the main analyses if respondents reported being (1) at least 50 years old, and (2) Internet or email users. We selected the age cutoff based on Watkins and Xie’s [40] systematic review of eHealth literacy interventions for older adults, citing that chronological age for the older population “can range from 50 to over 100” years, and the age range of 50 years and older “is consistent with growing appreciation of the role that health behavior interventions play in healthy aging for those under age 65” years (pg e255). While screening participants for this study, we found that 393 F-CCI Survey respondents reported being at least 50 years old, yet 110 responded “no” when asked if they used the Internet or email. Therefore, the final sample size for this study was N=283.

Measures

Sociodemographics and Health Status

We asked respondents to provide the following personal information: (1) age (in years); (2) sex (male, female); (3) race (white, African American, Asian or Pacific Islander, American Indian or Alaskan Native, multiracial or mixed race nonwhite); (4) ethnicity (Spanish or Hispanic, non-Spanish or non-Hispanic); (5) education (less than high school, high school or general equivalency diploma, some college, college graduate, postgraduate); (6) income (less than US $20,000, $20,000-49,999, $50,000-$99,999, $100,000 or more); and (7) perceived health status (poor, fair, good, very good, excellent). Additionally, respondents reported whether they had any experience (yes/no) using social media platforms (ie, online support group, popular social media websites such as Facebook or Twitter, or online blogs) to access or share health information.

eHealth Literacy

Norman and Skinner's [27] eHEALS was included as part of the FCC-I Survey. eHEALS comprises 8 items that measure consumers' perceived knowledge about how to find, use, and evaluate Internet-based health information to make informed health decisions. Response options are based on a 5-point Likert-type scale that ranges from 1 (strongly disagree) to 5 (strongly agree), with total summed eHealth literacy scores ranging from 8 (lowest possible eHealth literacy) to 40 (highest possible eHealth literacy).

Data Analysis

An exploratory structural equation modeling (E-SEM) approach [41] using the weighted least squares and adjusted means and variances (WLSMV) estimator examined the model fit of eHEALS scores with 1-, 2-, and 3-factor structures. This model uses an exploratory factor analysis measurement model and applies a structural equation model to describe (1) which items significantly load onto the extracted factor(s); (2) the dimensionality or number of factors (or subscales) produced; and (3) the relationships between factors (if more than 1 factor is extracted). The following global model fit indices provided evidence of good model fit [42]: (1) root mean square error of approximation (RMSEA) value close to .06; (2) comparative fit index (CFI) value >.95; (3) Tucker-Lewis index (TLI) value >.95; and (4) nonstatistically significant chi-square test. We evaluated factor loadings of each item for statistical significance ($P<.05$) and computed fit indices for all 3 factor structures to determine the best overall model fit. We used Mplus v7.3 (Muthén & Muthén; [43]) to conduct all E-SEM analyses.

Following E-SEM analyses, we used the partial credit model (PCM), an IRT analysis [44,45], to explore the internal structure of the self-reported polytomous (ie, more than 2 possible response options) eHEALS data. This analysis was appropriate given that the final sample size (N=283) was over 200 cases and greater than 10 times the number of eHEALS items (ie, 8) [46,47]. PCM constrains item discrimination, or the strength (slope) of the relationship between responses and a latent trait. This provides important information on which response options have the greatest probability of being answered at a particular theta (ie, a person's latent trait score) level on the latent continuum. Information from PCM analyses helps to evaluate stability across items, which reduces the potential for item bias [48,49]. Allowing step variability to vary across items provides useful information about the range of difficulties measured in a scale, including whether differences in step difficulties exist across items. RStudio's eRm software package version 0.15-7 (R Foundation; [50]) computed all PCM estimates.

Finally, Linacre's guidelines [46] for optimizing rating scales under IRT assumptions informed item fit analyses that calculated step difficulties of each response option. Optimized rating scales have threshold values (ie, relative difficulties to advance from one response option to the other) that increase across the theta continuum, which helps confirm that higher response options coincide with greater ability levels. Relative difficulties across response options helped to determine how precisely each eHEALS item was measured on the latent continuum. Values for each item that advanced less than 1.4 logits indicated a lack of variability across response categories, whereas values advancing more than 5.0 logits indicated extremely high variability, or low precision, between response categories.

Infit and outfit mean square (MSQ) and *t* statistics determined the level of noise or randomness in item response options. For outfit MSQ values, any value greater than 1.5 indicates unpredictable random error, whereas a value less than 1.0 indicates a degree of overpredictability and nonrandom error. Values less than 0.5 are interpreted as troublesome for overfit. For outfit *t* statistics, a value greater than 2.0 indicates underfit and less than –2.0 indicates overfit [50]. Measurement stability, which describes adequate item placement across the latent continuum, is determined based on adequate item reliability (>.80) and satisfactory item separability (>2.0) [51].

Results

Participant Characteristics

As reported by Tennant and colleagues [14], the mean age of respondents was 67.46 years (SD 9.98 years). Most respondents were white (n=252, 89.1%) and non-Hispanic (n=264, 93.3%). A little over half identified as being male (n=155, 54.8%). Over three-quarters of the sample (n=215, 75.9%) reported at least some college-level education, and over half (n=138, 60.4%) reported earning more than US $50,000 per year. Additionally, nearly three-quarters of respondents reported their health as being "good" (n=72, 25.1%), "very good" (n=103, 36.4%), or "excellent" (n=62, 21.9%). A little more than one-third of respondents reported accessing social media (n=101, 35.7%) to locate or share health information.

Descriptive eHEALS Scores

Total eHEALS scores ranged from 11 to 40 (mean 29.05, SD 5.75). Table 1 presents the mean (SD) score for the response to each item. Internal consistency estimates of eHEALS data collected in this study were relatively high (Cronbach alpha=.91).

Exploratory Structural Equation Modeling Analyses

Table 2 lists global model fit statistics and factor loadings for models fitting 1, 2, and 3 factors.

E-SEM Model 1 (1 Factor)

Only the 1-factor eHEALS structure had an eigenvalue greater than 1 (eigenvalue = 5.55). Despite high CFI and TLI values (.96 and .94, respectively), the RMSEA value, .24, exceeded the recommended value around .06 (Table 3). This high RMSEA value suggested poor structural fit of eHEALS in a unidimensional model.

Table 1. Mean (SD) eHealth Literacy Scale (eHEALS) scores rated on a 5-point Likert-type scale[a].

eHEALS items		Mean	SD
E1.	I know what health resources are available on the Internet.	3.61	0.91
E2.	I know where to find helpful health resources on the Internet.	3.76	0.86
E3.	I know how to use the health information I find on the Internet to help me.	3.81	0.85
E4.	I know how to find helpful health resources on the Internet.	3.80	0.86
E5.	I have the skills I need to evaluate the health resources I find on the Internet.	3.72	0.93
E6.	I know how to use the Internet to answer my questions about health.	3.82	0.88
E7.	I can tell high quality health resources from low quality health resources on the Internet.	3.35	1.06
E8.	I feel confident in using information from the Internet to make health decisions.	3.19	1.09

[a] Scored from 1=strongly disagree to 5=strongly agree, where 1 indicates low confidence and 5 indicates high confidence.

Table 2. Factor loadings of the eHealth Literacy Scale (eHEALS) by dimension among adults 50 years of age and older surveyed by telephone (N=283).

eHEALS items		1 Factor		2 Factors				3 Factors					
		1	*P* value	1	*P* value	2	*P* value	1	*P* value	2	*P* value	3	*P* value
E1.	I know what health resources are available on the Internet.	0.71	<.05	0.73	<.05	0.05	NS[a]	0.71	<.05	–0.00	NS	0.21	<.05
E2.	I know where to find helpful health resources on the Internet.	0.89	<.05	1.01	<.05	–0.01	NS	0.82	<.05	0.24	<.05	0.00	NS
E3.	I know how to find helpful health resources on the Internet.	0.94	<.05	0.58	<.05	0.41	<.05	0.51	<.05	0.55	<.05	–0.02	NS
E4.	I know how to use the Internet to answer my questions about health.	0.85	<.05	0.01	NS	0.88	<.05	0.02	NS	0.8	<.05	0.03	NS
E5.	I know how to use the health information I find on the Internet to help me.	0.89	<.05	0.03	NS	0.89	<.05	0.01	NS	0.93	<.05	0.00	NS
E6.	I have the skills I need to evaluate the health resources I find on the Internet.	0.82	<.05	–0.15	<.05	0.97	<.05	–0.03	NS	0.59	<.05	0.37	<.05
E7.	I can tell high quality health resources from low quality health resources on the Internet.	0.75	<.05	–0.03	NS	0.79	<.05	0.15	NS	0.00	NS	0.88	<.05
E8.	I feel confident in using information from the Internet to make health decisions.	0.72	<.05	0.03	NS	0.72	<.05	0.10	NS	0.45	<.05	0.30	<.05

[a] NS: not statistically significant at *P*<.05 alpha level.

Table 3. Global model fit indices.

Indices	1 Factor	2 Factors	3 Factors
RMSEA[a] (90% CI)	.24 (.21-.26)	.15 (.13-.18)	.07 (.02-.11)
Comparative fit index	.96	.99	1.0
Tucker-Lewis index	.94	.98	1.0
Chi-square test, *P* value	<.001	<.001	<.001
Eigenvalue	5.55	0.83	0.53

[a] RMSEA: root mean square error of approximation.

E-SEM Model 2 (2 Factors)

Global model fit indices improved in the 2-factor model (Table 3). CFI and TLI fit statistics improved to .99 and .98 respectively, while the RMSEA value decreased to .15. Even though RMSEA decreased in the 2-factor model, it remained over .07, which suggests poor global model fit. In the 2-factor model, eHEALS items 1 to 3 loaded onto factor 1, while items 4 to 8 loaded onto factor 2. Interestingly, item 3 appeared to have 2 relatively high (and statistically significant) factor loadings on both factors (factor 1=0.58; factor 2=0.41).

However, it should be noted that these 2 factors were both highly correlated (r=.71, P<.01).

E-SEM Model 3 (3 Factors)

For the 3-factor model, global model fit indices were near the acceptable range (Table 3). CFI and TLI both improved to 1.0 and RMSEA decreased to .07. While the chi-square test of model fit remained nonsignificant, this statistic is sensitive to sample size and thus should be interpreted with caution [52]. Items 1 and 2 loaded onto factor 1, while item 3 (“I know how to use the health information I find on the Internet to help me”) significantly loaded onto both factors 1 (λ=.51) and 2 (λ=.55), making its assignment to 1 unique factor unclear. Similarly, we found that item 6 (“I know how to use the Internet to answer my questions about health”) loaded onto factors 2 (λ=.59) and 3 (λ=.37), as did item 8 (“I feel confident in using information from the Internet to make health decisions”; factor 2: λ=.45; factor 3: λ=.30). In the 3-factor model, we also found statistically significant correlations between factors 1 and 2 (r=.58), and between factors 2 and 3 (r=.65). Factors 1 and 3 were also significantly correlated, albeit to a lesser degree (r=.36).

Partial Credit Model Analyses

The item reliability of eHEALS scores in this sample was estimated at .92 (observed variance=4.58), while the item separation index was 11.31. Both values were indicative of high reliability and stability across the latent continuum.

Table 4 shows that Linacre’s assumption of monotonicity was satisfied, with thresholds (ie, relative difficulty advancing from response options) increasing across the theta continuum, as demonstrated in the item characteristic curves and reported threshold values, confirming that greater eHealth literacy coincided with higher response options. However, not all step difficulties advanced from 1.4 to 5 logits. Relative difficulty moving from “strongly disagree” to “disagree” for almost all items was less than 1.4 logits, except for eHEALS item 8 (“I feel confident in using information from the Internet to make health decisions”), where it was 1.96. Relative difficulty moving from “agree” to “strongly agree” was within the acceptable range for all items (ie, all below 5.0 logits), but they were quite large as compared with advances in the relative difficulty for thresholds 1 (“strongly disagree” to “disagree”), 2 (“disagree” to “neutral”), and 3 (“neutral” to “agree”) [46].

Table 5 shows that all outfit MSQ values were <2.0 yet closer to 1.0, which suggested an optimal degree of randomness in responses to eHEALS items. However, the outfit MSQ values for items 2 to 5 fell well below 1.0, suggesting some level of overpredictability (ie, respondents with a particular eHealth literacy level were responding to items 2 to 5 using similar response options). Subsequently, we noted that infit t statistics for items 2 to 5 were all below –2.0, which is outside of the acceptable range of –2 to 2.

Table 4. Threshold[a] values of response options for 8-item eHealth Literacy Scale (eHEALS).

eHEALS items	Item difficulty	Threshold 1	Threshold 2	Threshold 3	Threshold 4
E1	0.85	–1.63	–0.77	1.19	4.63
E2	0.69	–1.45	–0.84	0.36	4.68
E3	0.68	–1.35	–0.49	–0.09	4.65
E4	0.66	–1.15	–0.47	–0.19	4.47
E5	0.61	–1.53	–0.53	–0.07	4.58
E6	0.86	–1.28	–0.09	0.10	4.70
E7	1.55	–0.86	0.34	1.38	5.36
E8	1.76	–1.12	0.84	1.83	5.49

[a] Thresholds for response options on the 5-point Likert-type scale: 1 (from “strongly disagree” to “disagree”), 2 (from “disagree” to “neutral”), and 3 (from “neutral” to “agree”).

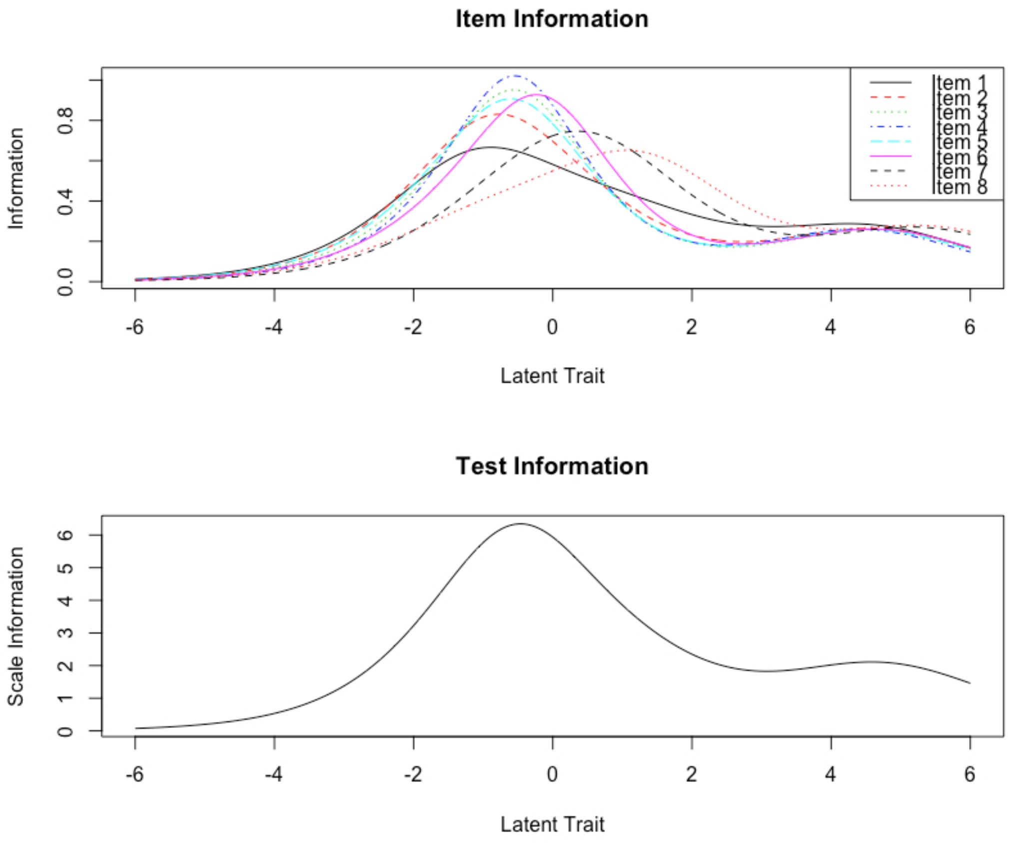
Table 5. Infit and outfit mean square (MSQ), and infit and outfit t statistics for eHealth Literacy Scale (eHEALS) items.

eHEALS items	P value	Infit MSQ	Outfit MSQ	Infit t statistic	Outfit t statistic
E1	.04	1.16	1.16	1.65	1.16
E2	>.99	0.70	0.70	–2.09	0.80
E3	>.99	0.54	0.54	–3.74	0.64
E4	>.99	0.61	0.61	–2.56	0.74
E5	>.99	0.60	0.60	–3.55	0.66
E6	.95	0.86	0.86	–1.30	0.87
E7	.32	1.03	1.03	0.47	1.04
E8	.22	1.06	1.06	0.55	1.05

Figure 1 depicts item and test information functions. The test information curve shows a high degree of information with minimal standard measurement error around theta levels –2 to 2 on the latent continuum. The test information curve shows that eHEALS provides some degree of information for participants at the higher end of the latent continuum, but reliability and validity evidence for this level of information is likely unstable. Moreover, the test information function is positively skewed, rather than bell shaped. This result indicates that eHEALS items may capture more information about eHealth literacy among participants who place higher on the latent continuum (ie, those with high eHealth literacy) than among those at the lower end of the continuum (ie, those with low eHealth literacy).

Item information curves showed that all eHEALS items followed a similar curvature pattern, yet the peak of most item curves (greatest amount of information) were plotted at different points on the latent continuum. Despite test information functions that were positively skewed, item information curves suggested that each eHEALS item made important contributions to the complete measure of eHealth literacy. Interestingly, information obtained from items 2 to 5 did not vary across different points on the latent continuum. Therefore, items 2 to 5 may produce a similar amount of information at each point on the latent continuum.

Figure 1. Item and test information function curves for eHealth Literacy Scale (eHEALS).



Discussion

This measurement study was the first, to our knowledge, to provide evidence for the factor structure and dimensionality of eHEALS when administered to older adults over the telephone. Overall, results from E-SEM and PCM analyses support that use of eHEALS as a reliable measure of eHealth literacy produces a sufficient degree of internal structure reliability evidence when administered to older adults using telephone-based survey methods. Despite several poor-fitting items in this brief 8-item instrument, global model fit indices produced by E-SEM analyses suggest the eHEALS has the potential for 3 factors (or subscales) when measuring the latent construct of eHealth Literacy among older adults. However, 2 of these 3 factors were highly correlated with one another, providing additional evidence to support an overarching unidimensional structure of eHEALS data when collected in an older adult population.

Similar to this study, whose findings suggesting that a 3-factor solution is promising in the older adult population, the study of Sudbury-Riley et al [32] found 3 underlying factors in eHEALS data collected from baby boomers located in 3 different countries (United States, United Kingdom, and New Zealand). The 3 factors identified by those authors were awareness and learning about what online resources are available and where they are located (items 1-2), skills and behaviors needed to access Internet-based health resources (items 3-5), and the self-belief in one’s ability to evaluate online health content once accessed (items 6-8). Further, Sudbury-Riley and colleagues suggested that these 3 factors reflected social cognitive theory’s explanation of a triadic reciprocal causation among 3 dimensions (personal factors, behavioral factors, and environmental factors) that influence behavior change [53]. Data from our study produced acceptable fit indices for assigning eHEALS items to these 3 factors; however, item 3 (“I know how to use the health information I find on the Internet to help me”), item 6 (“I know how to use the Internet to answer my questions about health”), and item 8 (“I feel confident in using information from the Internet to make health decisions”) loaded onto multiple factors, which made it difficult to assign these particular items to the 3 unique eHEALS subscales. Moreover, these 3 factors showed moderate to high correlations with one another, which supports the reciprocity described in social cognitive theory. The relationship between personal motivations for health information seeking and an individual’s perceived capability to use digital technologies can be affected by online environments with socially persuasive forms of media. Since social cognitive theory was the theoretical foundation used during the original development of eHEALS [27], future research should investigate how eHEALS items map to the main theoretical constructs of social cognitive theory.

Linacre’s [46] guidelines for optimizing rating scales were satisfied regarding item fit of eHEALS data in this study. Even with constrained item discrimination, item characteristic curves showed that each response option had the highest probability of selection at a particular point on the latent continuum. This suggests that the rating scale is functioning as intended, where older adults higher on the eHealth literacy continuum demonstrate the greatest probability of selecting response option “agree” or “strongly agree,” and individuals scoring lower on the eHealth literacy continuum have the greatest probability of selection response option “disagree” or “strongly disagree.” This finding is similar to results reported in previous research exploring the internal structure of eHEALS [28,30], which noted that data produced by eHEALS among older adults showed evidence of monotonicity.

Step difficulties also advanced within acceptable standards [46] across the latent continuum for each eHEALS item. Tests of the internal structure of each item showed that step difficulties advancing across response options 1 to 3 were located close to one another on the latent continuum. In contrast, the relative difficulty of advancing from “agree” to “strongly agree” was located further away from the threshold, suggesting relative difficulty of advancing from “neutral” to “agree” response options. To capture this “dead zone” between these 2 response option thresholds, future research should consider analyzing the effects of adding more response options to each eHEALS item.

Given that the 3 factors identified in this study showed moderately strong correlations with one another and the 1-factor model showed adequate fit, we conducted item fit analyses using PCM analyses. Like in the work of Diviani et al [34], who administered the Italian version of eHEALS in young to middle-aged adults, in this study the level of random error in eHEALS responses from older adults was within the acceptable range. However, parametric IRT analyses did reveal that items 2 to 5, which assessed knowledge of using the Internet to access and use health information, showed a minor degree of overpredictability and random error. This minor level of overpredictability on eHEALS items 2 to 5 was less evident in the Diviani et al [34] study’s younger sample, although eHEALS items 1 through 5 in their study did show outfit MSQ values of less than 1. While data that are potentially overfit do not present a substantial threat to measurement validity [46], eHEALS items asking about finding knowledge and using Internet-based health information may be redundant, with the potential to (1) violate the assumption of local independence, (2) overestimate the reliability of eHEALS, and (3) underestimate the standard error of eHEALS measurements [54]. It is important to note that the negative impact of overfit in both studies is likely minimal, given relatively minor deviations from acceptable values [46]. However, in both Diviani et al [34] and our study of older adults, eHEALS items 2 and 4 had standardized infit *t* statistics less than the lower end of the acceptable range (less than –2.0). Conducting think-aloud cognitive interviews with respondents while they complete the eHEALS should provide much-needed information regarding whether older adults perceive different eHEALS items to be asking the same questions.

Limitations

There are several limitations to note in this study. First, this was a cross-sectional study and, therefore, we were unable to compute test-retest reliability or predictive validity estimates. Second, our analyses used telephone survey data with a very low overall response rate (7.4%), resulting in the possibility of nonresponse bias. Third, comparative measures of model fit did not inform decisions regarding the optimal internal structure of eHEALS data collected in this study. Comparative fit measures such as the Akaike information criterion can only be estimated with maximum likelihood data extraction methods, which Mplus v7.3 does not allow for under the WLSMV estimator. We selected the WLSMV estimator to examine model fit in this study for several reasons: (1) WLSMV estimation compensates more effectively than the maximum likelihood estimation for bias due to ordinal response options in the eHEALS, and (2) WLSMV estimation is less likely to produce unrealistic indices of overall model fit [55,56]. Therefore, we based conclusions regarding the internal structure of eHEALS data on noncriterion-based judgments made through interpretation of E-SEM and IRT analyses results.

Fourth, this study contacted participants through a landline sampling technique, which may have selectively excluded individuals who may only own a mobile phone. Although this telephone sampling method targeted older adults living in the state of Florida, this state is home to the greatest proportion (19.1%) of older adults in the United States [57].

Fifth, this study examined eHEALS responses derived from telephone administration of the survey, despite all participants reporting use of the Internet or email. Widespread adoption of the Internet and mobile phone technology has contributed to nonuse of landline telephones. We did not account for mobile devices and cellular telephones, which are increasingly being used by middle- to older-aged adults [58], in this sample. Partnering with community-engaged research programs or local community organizations to reach older adults via telephone may enhance recruitment efforts in this population traditionally underrepresented in health-related survey research.

Conclusions

Assessing consumer comfort and self-efficacy in using technology to access online health resources can help identify skill gaps and gauge the likelihood that users will be successful when using the Internet to access relevant health information [23]. Results from this study suggest that administering eHEALS to older adults via telephone produces a reliable measure with scores that possess sufficient construct validity evidence. Specifically, results from this study support the previously reported unidimensionality of eHEALS scores. Among older adults, however, there is potential for additional underlying subscales to measure older adults' confidence to locate, use, and evaluate online health information. As older Internet users continue to visit online support groups and discussion forums to find new information about health care perspectives and experiences, it will be important to consider modifying the original eHEALS to adequately measure online health information-seeking behaviors in older populations.

Conflicts of Interest

None declared.

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Abbreviations

CFI: comparative fit index
eHEALS: eHealth Literacy Scale
E-SEM: exploratory structural equation modeling
F-CCI: Florida Consumer Confidence Index
IRT: item response theory
MSQ: mean square
PCM: partial credit model
RMSEA: root mean square error of approximation
TLI: Tucker-Lewis index
WLSMV: weighted least squares and adjusted means and variances

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Original Paper

What Clinical Information Is Valuable to Doctors Using Mobile Electronic Medical Records and When?

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Abstract

Background: There has been a lack of understanding on what types of specific clinical information are most valuable for doctors to access through mobile-based electronic medical records (m-EMRs) and when they access such information. Furthermore, it has not been clearly discussed why the value of such information is high.

Objective: The goal of this study was to investigate the types of clinical information that are most valuable to doctors to access through an m-EMR and when such information is accessed.

Methods: Since 2010, an m-EMR has been used in a tertiary hospital in Seoul, South Korea. The usage logs of the m-EMR by doctors were gathered from March to December 2015. Descriptive analyses were conducted to explore the overall usage patterns of the m-EMR. To assess the value of the clinical information provided, the usage patterns of both the m-EMR and a hospital information system (HIS) were compared on an hourly basis. The peak usage times of the m-EMR were defined as continuous intervals having normalized usage values that are greater than 0.5. The usage logs were processed as an indicator representing specific clinical information using factor analysis. Random intercept logistic regression was used to explore the type of clinical information that is frequently accessed during the peak usage times.

Results: A total of 524,929 usage logs from 653 doctors (229 professors, 161 fellows, and 263 residents; mean age: 37.55 years; males: 415 [63.6%]) were analyzed. The highest average number of m-EMR usage logs (897) was by medical residents, whereas the lowest (292) was by surgical residents. The usage amount for three menus, namely inpatient list (47,096), lab results (38,508), and investigation list (25,336), accounted for 60.1% of the peak time usage. The HIS was used most frequently during regular hours (9:00 AM to 5:00 PM). The peak usage time of the m-EMR was early in the morning (6:00 AM to 10:00 AM), and the use of the m-EMR from early evening (5:00 PM) to midnight was higher than during regular business hours. Four factors representing the types of clinical information were extracted through factor analysis. Factors related to patient investigation status and patient conditions were associated with the peak usage times of the m-EMR ($P<.01$).

Conclusions: Access to information regarding patient investigation status and patient conditions is crucial for decision making during morning activities, including ward rounds. The m-EMRs allow doctors to maintain the continuity of their clinical information regardless of the time and location constraints. Thus, m-EMRs will best evolve in a manner that enhances the accessibility of clinical information helpful to the decision-making process under such constraints.

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KEYWORDS

mobile health; electronic medical records; clinical information; rounding; timeliness; accessibility; smartphone

Introduction

Clinical work that takes place in various locations (ie, wards or clinics) and involves various treatment tasks (ie, diagnosis or operation) requires doctors to move a lot [1,2]. Mobility is a particularly important feature of clinical practice in large medical institutions with complex treatment procedures [1]. Therefore, mobile-based electronic medical records (m-EMRs) have been expected to help doctors efficiently access patient data [1,2], and many tertiary hospitals have increasingly moved toward the use of m-EMRs in recent years [3-5]. However, because the overall rates of m-EMR utilization and adoption have been low [3,6], several studies have been conducted to improve the usability of m-EMRs in hospitals [3-8].

One research stream examined the behavioral patterns related to the adoption and use of m-EMRs, including personality traits and social norms [3,6]. Another research stream studied the design of m-EMR systems and their integration with existing hospital systems [4,7,8], whereas another focused on demonstrating the utility of m-EMRs with regard to information flow efficiency [9-11]. Such studies have certain implications in that they examined the theoretical and technical factors associated with the adoption and utilization of m-EMRs and demonstrated that m-EMRs increase the work efficiency. However, to the best of the authors' knowledge, none of these previous studies have evaluated the value of each type of clinical information accessed through m-EMRs based on actual usage log data. Because an m-EMR is a method of information delivery, an evaluation is crucial for designing m-EMRs in a manner that allows doctors to access valuable information in a convenient manner.

Typically, clinical work is carried out through a daily process, which is organized based on hospital conditions [12,13]. Because each process unit requires different tasks from the doctors, the demand for information access may vary according to the daily process unit [1,12]. In addition, the need for specific clinical information related to the treatment context may vary within the daily process. So, it is important to assess the value of clinical information accessed through m-EMRs from the perspective of the daily treatment process. Despite the importance of m-EMRs, there have been no attempts at exploring when the value of m-EMR usage increases during the day and what clinical information is associated with its increased value.

These attempts may provide fundamental solutions for increasing the use of m-EMRs in large hospitals by identifying the most valuable clinical information accessed through such records. Additionally, these discussions may provide knowledge in research areas investigating the value of m-EMR usage in terms of information flow efficiency. Therefore, as a first attempt to shed light on the issues mentioned above, this study aimed to explore an empirical resolution on what type of clinical information is most valuable for doctors to access through an m-EMR based on their actual usage logs and when such information is accessed. In addition, this study aimed to discuss the importance of such information.

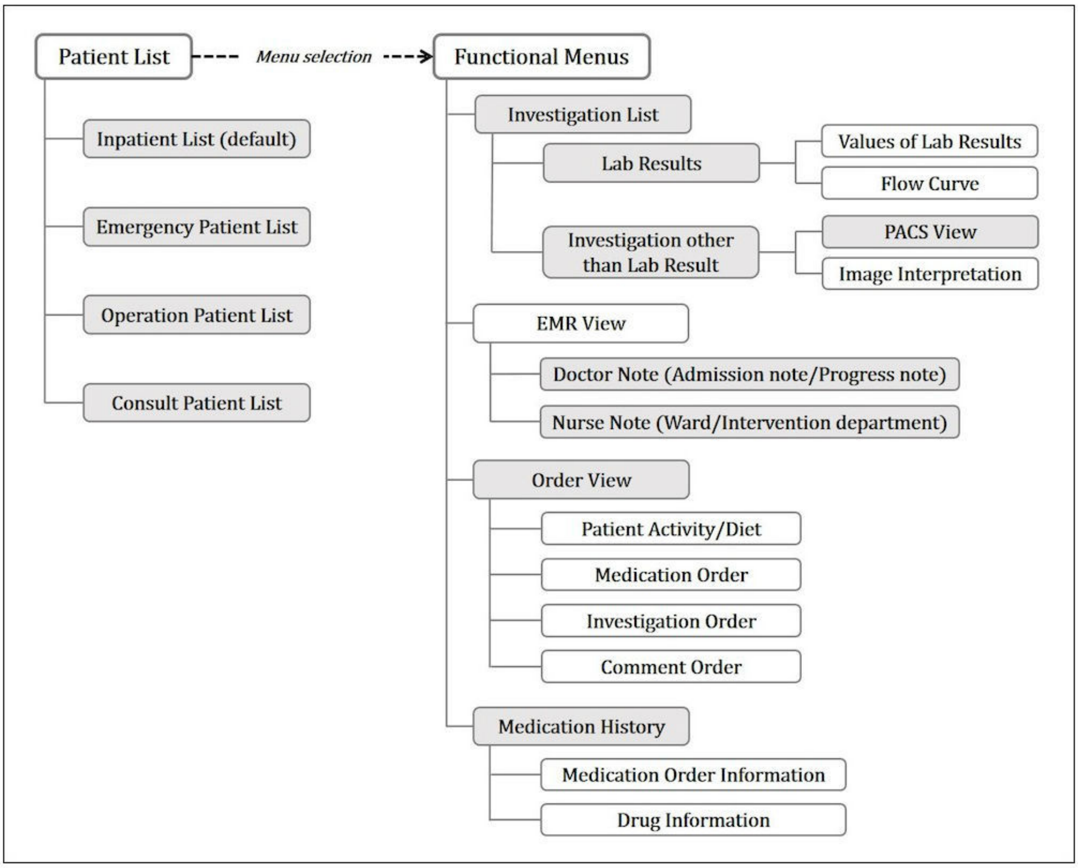
Methods

Introduction to m-EMR App

A tertiary hospital in Seoul, South Korea, with more than 2700 beds and approximately 912,300 admissions each year developed an m-EMR app in 2010. The main purpose of this m-EMR app is to allow medical personnel to read patient information without issuing treatment orders [14]. The second version of the upgraded m-EMR app, based on user feedback in 2012, was used in this study. An add-on security system temporarily displays clinical information without storing the information on a smartphone device.

The app comprises four default menus and several submenus. The default menus provide patient lists, and doctors can choose one of the following menus: inpatient list, operation patient list, consult patient list, and emergency patient list. The submenus allow doctors to access patient details such as laboratory test results, medical records, and medication orders. The structure of information accessed through the m-EMR app is shown in Figure 1 (see the details on the m-EMR app in Multimedia Appendix 1).

Figure 1. Structure of information accessed through the hospital's mobile-based electronic medical records app. Usage logs from 12 menus (gray-shaded menus) providing 22 types of information were used in this study. PACS means picture archiving and communication system.



Empirical Analysis Design

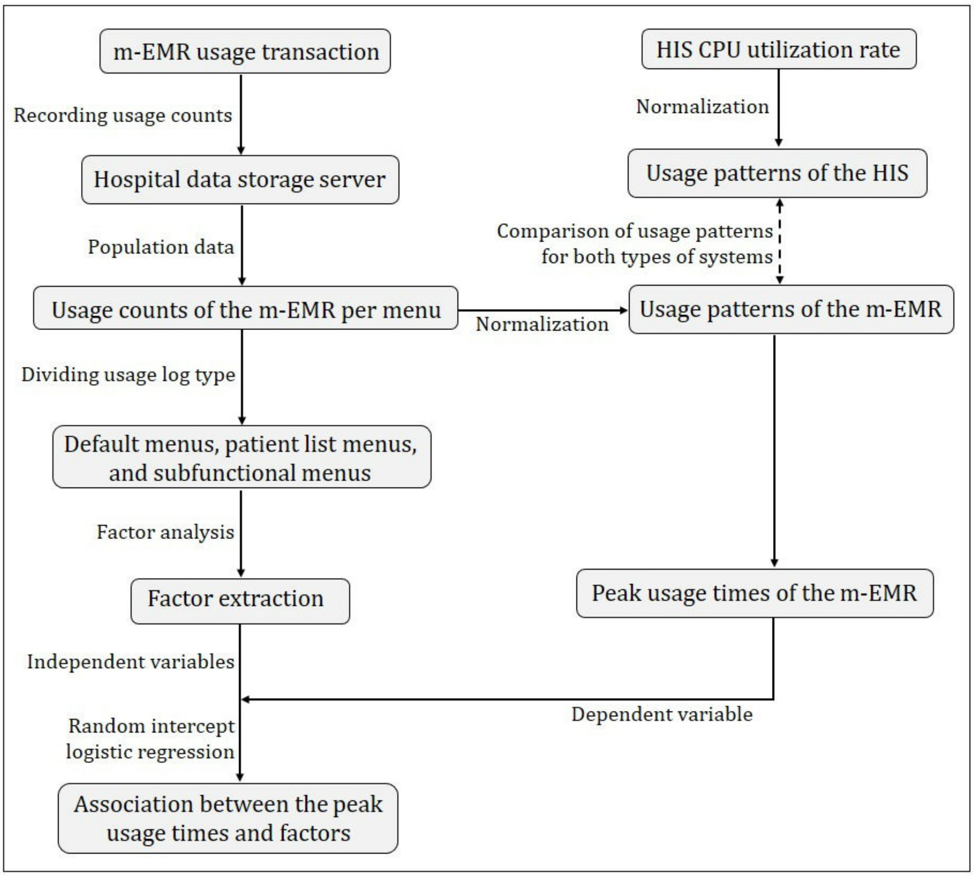
This research was approved by the institutional review board (IRB No. 2016-0287). To determine what type of clinical information is most valuable for doctors to access through an m-EMR and when such information is accessed, a two-step empirical analysis was conducted. First, the usage patterns of both the m-EMR and the hospital information system (HIS) on an hourly basis were explored. Comparing the usage patterns for both types of systems can provide an explanation on when access to clinical information through m-EMRs is valuable. Furthermore, it can provide a basis to explain why certain clinical information read through an m-EMR is more valuable than when read using the HIS.

Second, the types of clinical information accessed most frequently during m-EMR peak usage times were investigated. The usage concentration of a particular type of information within a specific time interval indicated that its value was high at that time [15]. Therefore, associating the peak intervals of usage with specific clinical information can explain what types of clinical information are most valuable to access through m-EMRs.

When evaluating clinical information, it might be inappropriate to analyze the m-EMR usage logs at a very raw level (ie, usage count of each menu). Although some menus are used frequently, they may serve as intermediary channels to reach submenus that access detailed information. Thus, it is important to mine the raw usage logs so that usage patterns become representational clinical information. Data preprocessing and factor analysis were applied to extract representational clinical information. Finally, a random intercept logistic regression was employed to determine the association between usage peak intervals and representational clinical information.

For the study data, usage counts (population data) of the m-EMR and the utilization rate of the HIS central processing unit (CPU) were used. The CPU usage rate represents the amount of time that the CPU processes tasks in a specific time interval [16]. The HIS CPU processes tasks when requests are made to read patient information from a local personal computer (PC). Thus, the HIS CPU usage rate indicates how often doctors read clinical information through a desktop computer during specific time intervals. Figure 2 provides a flowchart illustrating the data preprocessing and analysis.

Figure 2. Flowchart of data preprocessing and analysis; m-EMR: mobile-based electronic medical records, HIS: hospital information system, CPU: central processing unit.



Data Preprocessing for Mining m-EMR Usage Patterns

The structure of the m-EMR was designed to display some lower-level information (ie, lab result values) simultaneously using upper-level information (ie, lab results) (Figure 1). The hospital data storage server records the usage transactions for each of the m-EMR menus when the app menu is used.

Owing to their default status, the four patient list menus are likely to be used regardless of intent. Thus, the usage amount of these menus should be treated differently from that of the other submenus, even though these menus provide the function of a patient list check. To address this issue, logs used primarily to check patient lists (the four patient list menus) were separated from logs used to access detailed patient information. Specifically, if the log remained in the four default menus (ie, there were no usage traces after these default menus had been used) during one usage session, it was considered that the doctor simply identified the patient lists during that session. However, if there were traces indicating that the submenus were used after the four default menus had been used, it was considered that the doctor accessed detailed information. Thus, the four patient list menus could each have had two purposes (four menus × two purposes). Therefore, 16 variables representing the usage logs of the menus were included in this study (four patient list menus assumed to be default menus used to access submenus, designated by the subscript “default”; four patient list menus assumed to be used to check patient lists; and eight submenus). R version 3.3.2 (The R Project for Statistical Computing) was used for data preprocessing.

Descriptive Analysis of Usage Patterns of m-EMR

First, the general usage statistics of the medical and surgical departments were reviewed to determine whether m-EMR use differed according to the user characteristics and tasks. Second, the usages of the m-EMR and the HIS CPU over time were compared. The units of the two usage logs are different because the m-EMR usage level is based on the usage counts, whereas the HIS CPU usage level is based on the CPU utilization rate. Thus, the normalized values of the HIS and m-EMR usage over time were compared. Third, the peak usage intervals of the m-EMR were defined. The usage counts (number of times the m-EMR was accessed) per hour were normalized, and a continuous interval with normalized values that are greater than 0.5 (ie, the median of the normalized values) was defined as a peak interval. Details of the usage per menu during the peak usage interval were then examined at the raw-data level.

Factor Analysis: Identification of Representational Clinical Information

In a hierarchical app design, higher-level menus serve as links to the submenus while providing particular information [3,8]. Therefore, usage logs for some upper- and middle-level menus might not adequately represent a doctor accessing particular information from the m-EMR menu. Thus, the usage logs were partitioned into usage session units, and indicators representing how closely a usage session is associated with specific clinical information were parameterized. A usage session for a smartphone app represents the interval between the time an app is launched and the time it is closed [17-19]. To identify a usage session, usage logs are separated into 30-min intervals set in the hospital system to force an automatic m-EMR app log-off.

To generate indicators of how relevant a usage session is to specific clinical information (ie, representational clinical information), a factor analysis was applied [20-22]. There were 16 variables applied to this analysis to indicate the usage level of the menus during a usage session. A principal component analysis was used to extract the factors [20,21]. The promax rotation method was used to rotate the factors because this method is recommended when factors might have certain correlations [22]. The factors were extracted until the communality of all variables was greater than 0.4, and variables with the lowest communality values were excluded [23]. In addition, only factors with eigenvalues greater than 1 were extracted [24]. To assess the validity of the factor analysis, a Keiser–Meyer–Olkin test and a Bartlett test were applied [25-27]. SPSS version 23 (IBM Corp) was used for the factor analysis. A detailed description of this factor analysis has been provided in previous studies [20-27].

Analysis of Frequently Accessed Clinical Information During Peak Usage Intervals

To analyze what type of clinical information is accessed frequently during peak m-EMR usage intervals, a random intercept logistic regression was applied. The random intercept model is often used to address individual heterogeneity when data are observed repeatedly [28]. The random intercept logistic model in this study is designed as shown in Figure 3.

The dependent variable (1=peak usage time, 0=outside the peak usage time) indicates whether a usage session belonged to the usage peak interval of the m-EMR. For the independent variables, the scores from the results of the factor analysis were used. In addition, the model controlled whether the m-EMR was used on a weekday or holiday, and for the demographics, that is, age, gender, and six positions (residents, fellows, and professors from medical departments and residents, fellows, and professors from surgical departments). The model was implemented using STATA version 14 (StataCorp LLC).

Figure 3. Equation for random intercept logistic regression.

$$Peak\ interval_{is} = \alpha + \sum_f \beta_f \times factor_{isf} + \delta_1 \times weekday_{is} + \sum_d \vartheta_d \times demographics_{id} + \varepsilon,$$

where i indicates the doctor, s is the usage session, f is a factor indicator, and d is a demographics indicator

Results

Descriptive Analysis

A total of 524,929 usage logs for 12 menus, which provide 22 types of information, were stored during the study period (March to December 2015). The overall user characteristics and usage statistics are listed in Multimedia Appendix 2. When simultaneously considering the medical and surgical departments, the mean usage counts for professors, fellows, and residents were 732, 754, and 897, respectively. For the medical departments, the mean usage counts for doctor positions were 789, 865, and 1216, respectively, and 656, 594, and 292 for the surgical departments, respectively. Therefore, the m-EMR was used the most by medical residents, whereas the individual average usage of the m-EMR by the surgical residents was the least.

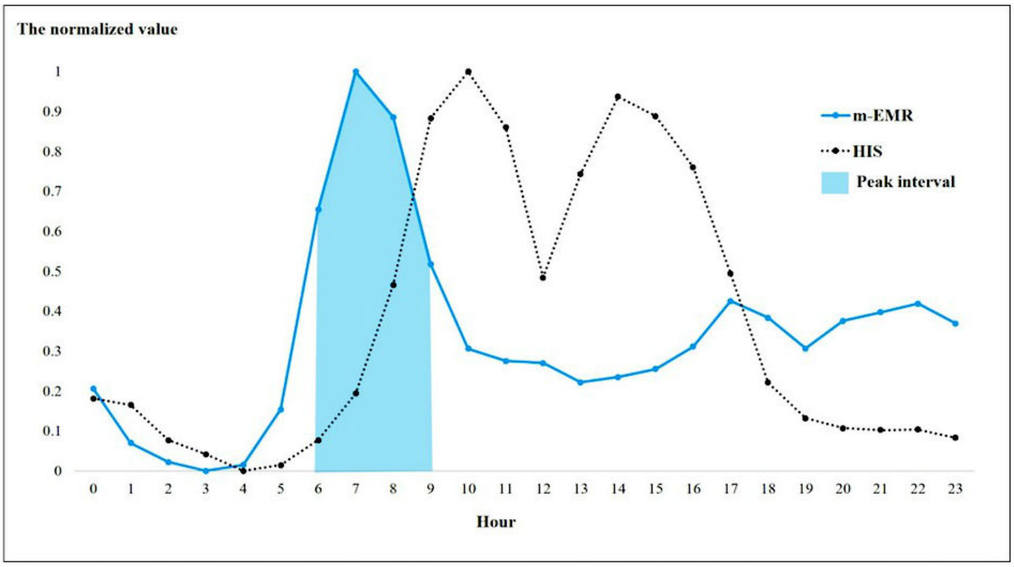
The HIS CPU usage rate for one week of November 2016 was used in this study. The usage patterns of both the HIS and the m-EMR based on the time of day were significantly different (Figure 4). The use of the HIS was highly concentrated during regular business hours. The HIS was used most frequently at two different periods: the first from approximately 9:00 am to 12:00 pm and the second from approximately 1:00 pm to 5:00 pm. In contrast to the usage patterns for the HIS, the m-EMR was heavily used during the early morning hours (6:00 am to 10:00 am). Moreover, the usage rate of the m-EMR from early evening (5:00 pm) to midnight (0:00 am) was higher than that during regular business hours.

The peak usage interval for the m-EMR was defined as 6:00 am to 10:00 am. Table 1 lists the details of the per-menu usage statistics during the usage peak interval in descending order. The most commonly used menus include the inpatient list (47,096), lab results (38,508), and investigation list (25,336). The usage amounts of these three menus accounted for approximately 60.1% of the peak time usage.

Table 1. Usage statistics of the m-EMR menus at peak usage intervals.

Usage count	Time				Total
	6-7 am (n=357)	7-8 am (n=460)	8-9 am (n=474)	9-10 am (n=429)	(6-10 am)
Inpatient list	10,059	15,207	13,681	8149	47,096
Lab results	5810	10,051	12,818	9829	38,508
Investigation list	3668	7156	8636	5876	25,336
Doctor note	6083	5587	4193	2088	17,951
Nurse note	7654	5655	2581	1196	17,086
Investigation other than lab results	2169	5285	5134	2339	14927
PACS (picture archiving and communication system) view	1639	2661	2586	1324	8210
Order view	1073	2352	1430	724	5579
Consult patient list	1379	1718	1168	506	4771
Emergency patient list	816	1042	937	538	3333
Operation patient list	219	856	323	257	1655
Medication history	15	54	54	28	151

Figure 4. Difference in peak times between the m-EMR (mobile-based electronic medical records) and HIS (hospital information system). The graph of the m-EMR shows the normalized values over time, based on the m-EMR usage log. The graph of the HIS indicates the normalized values over time, based on the HIS CPU utilization rate. Each unit on the x-axis represents the hour (ie, 9 indicates the hour between 9:00 AM and 10:00 AM.).



Results of Factor Analysis: Identification of Representational Clinical Information

A total of five factors with 13 variables were extracted under the conditions that the eigenvalues were greater than 1 and that the communality value for all variables was greater than 0.4 (Table 2) [23,24]. The results of the two tests, Keiser–Meyer–Olkin test (0.663) and Bartlett test (*P*<.01), indicated the validity of the factor analysis [25-27].

Factor 1 (F1): investigation status. This indicates a session in which a doctor accesses the investigation status and is defined based on a positive association with the variables of investigations (Table 2).

Factor 2 (F2): emergency patient information. This indicates a session in which a doctor accesses emergency patient information and is defined based on a positive association with the Emergency patient list$_{\text{default}}$ and Doctor note variables.

Factor 3 (F3): patient conditions. This indicates a session in which a doctor accesses previous patient conditions and is defined based on a positive association with the Nurse note and Order view variables.

Factor 4 (F4): identification of patients in the emergency room (ER) or ward. This indicates a session in which a doctor identifies a patient in the ER or ward and is defined based on a positive association with the Emergency patient list and Inpatient list variables.

Factor 5 (F5): miscellaneous. This indicates a session in which the information access does not show a clear pattern. These sessions are associated with default menus and are indications that the doctor is accessing patient details through the submenus. However, because no usage patterns of the submenus can be determined, sessions associated with this factor are considered as miscellaneous.

None of the factors have a strong relationship (ie, factor loading with an absolute value greater than 0.4) with the Inpatient list$_{\text{default}}$ variable. This indicates a lack of correlation between Inpatient list$_{\text{default}}$ and other menu uses during a single usage session. Figure 5 shows the association between these five factors, and Table 3 provides brief descriptions of them.

Table 2. Results of factor analysis.

Variables	Factor					Communality[e]
	F1	F2	F3	F4	F5	
Investigation other than lab results	*.809* [a]	.050	−.022	.204	.096	.603
PACS (picture archiving and communication system) view	*.793*	−.017	−.120	.126	.060	.549
Investigation list	*.750*	.016	.078	−.119	−.087	.693
Lab results	*.465*	−.173	.120	−.281	−.199	.460
Emergency patient list$_{\text{default}}$[b]	−.003	*.944*	−.220	.021	.011	.808
Doctor note	−.041	*.730*	.376	.044	−.079	.800
Nurse note	−.140	.075	*.815*	.044	−.030	.649
Order view	.109	−.147	*.753*	.100	.107	.544
Emergency patient list	.200	.064	.099	*.793*	−.027	.529
Inpatient list	−.023	−.030	.067	*.742*	−.053	.552
Inpatient list$_{\text{default}}$	.227	.347	.066	−.375	.103	.516
Operation patient list$_{\text{default}}$	.070	.053	−.136	−.004	*.714*	.541
Consult patient list$_{\text{default}}$	−.049	−.099	.264	−.100	*.700*	.544
Result of adequacy tests for factor analysis	Bartlett test[c]: *P*<.01 Keiser–Meyer–Olkin test[d]: 0.663					

[a] Factor loadings with absolute values greater than 0.4 are in italics.

[b] The “default” subscript indicates a menu likely used as the default screen.

[c] Bartlett test evaluates the presence of a common component.

[d] The Keiser–Meyer–Olkin test evaluates the appropriateness of the size of observations and number of variables used in the factor analysis.

[e] Communality indicates how much the extracted factors account for each variable.

Analysis of Frequently Accessed Clinical Information During Peak Usage Interval

The results of a random intercept logistic regression indicate that F1 (investigation status) and F3 (patient conditions) are positively associated with peak usage intervals (*P*<.01) (Table 3). By contrast, F2 (emergency patient information), F4 (identification of patients in the ER or ward), and F5 (miscellaneous) are positively associated with periods outside the peak usage intervals (*P*<.01).

The control variable, Weekday, is statistically significant (*P*<.01), indicating that usage sessions on weekdays are positively associated with the peak intervals. In addition, the usage sessions of doctors other than surgical residents are more positively associated with the usage peak than those of surgical residents (*P*<.05). Age and gender are not statistically associated with the usage sessions at the peak usage intervals (*P*>.05).

Figure 5. Diagram of associations between factors (only factors with loading values greater than 0.4 are listed); PACS: picture archiving and communication system.

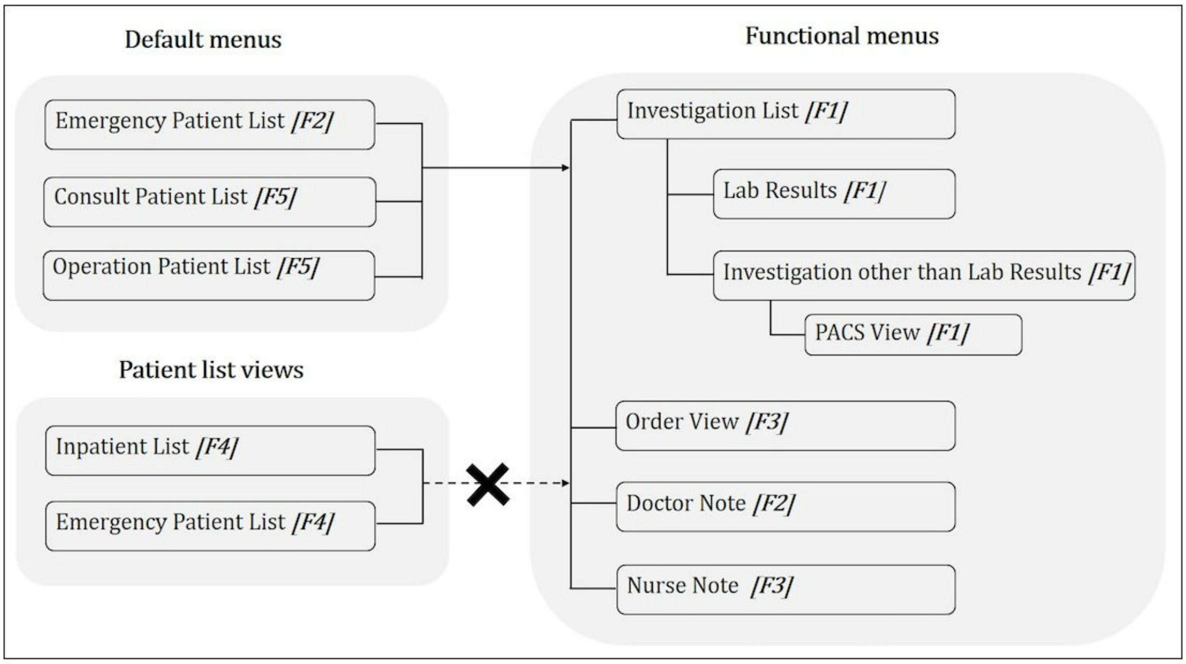


Table 3.

Variable	Coefficient	Standard error	*P* value
Main variables			
F1 (investigation status)	.038	0.011	.001
F2 (emergency patient information)	−.226	0.017	<.001
F3 (patient conditions)	.210	0.013	<.001
F4 (identification of patients in the emergency room or ward)	−.109	0.013	<.001
F5 (miscellaneous)	−.126	0.014	<.001
Control variables			
Weekday	.566	0.023	<.001
Position[a]			
Fellows (general medical departments)	.667	0.126	<.001
Fellows (surgical departments)	.417	0.146	.01
Professors (general medical departments)	.503	0.153	<.001
Professors (surgical departments)	.440	0.166	.01
Residents (general medical departments)	.302	0.111	.01
Age	−.008	0.006	.22
Gender	.0240	0.073	.75
Cons	−1.445	0.216	<.001

[a] The rank of residents from surgical departments was used as the baseline position to control the doctor position characteristics. The dependent variable indicates whether the usage session belongs to the peak interval or lies outside the usage peak interval (1=peak usage, 0=outside the peak usage). The number of observations is 56,756 (usage sessions), and the number of doctors is 653.

Discussion

This study aimed to explore what types of clinical information accessed through an m-EMR are most valuable for doctors and when they access such information and to discuss how valuable such clinical information actually is. In large hospitals with complex treatment processes, patient care necessarily entails significant doctor movement. In such an environment, continuous awareness of the patient information through a desktop PC may not be efficient for doctors. Thus, several previous studies have demonstrated the utility of using mobile devices in relation to information flow efficiency during the treatment process [9-11]. However, there has been no empirical assessment on the value of clinical information from the viewpoint of routine treatment, which provides a fundamental explanation as to what type of valuable clinical information is accessed through m-EMRs and when. Therefore, this study is distinct from previous studies in that, to the best of the authors' knowledge, it is the first attempt to evaluate clinical information accessed through an m-EMR from large real-usage data. Ultimately, this study may contribute to promoting the adoption and usability of m-EMRs in large hospitals by providing some important insights.

Location Independence in Accessing Information Through m-EMRs

The analysis conducted in this study demonstrates the unique value of an m-EMR system, which is distinct from a PC-based system in terms of information transaction. Interestingly, the m-EMR appears to be used frequently at times when the HIS is rarely used. Specifically, the HIS is heavily used during regular business hours (9:00 am to 6:00 pm), whereas the use of the m-EMR peaks early in the morning (6:00 am to 10:00 am). The m-EMR usage peak corresponds to morning rounds or the time just before routine work begins [29,30]. During this time, access to patient information is necessary, but information accessed through a desktop PC can be limited because the doctors should move around a great deal (ie, commuting and conducting ward rounds) [11,31]. Earlier studies have shown that the use of mobile devices during ward rounds is effective with regard to information acquisition because mobile devices provide doctors with location-independent access to information [11,32]. Consistent with this evidence, the results of this study may indicate that doctors use m-EMRs intensively to identify patient information during their ward rounds. Moreover, this result suggests that doctors use m-EMRs to read patient information even before and during their morning rounds.

Furthermore, the use of the m-EMR is higher from early evening (5:00 pm) to midnight than during regular business hours. The high usage rate of the m-EMR during this time may indicate that doctors outside the hospital access patient information through the system. Owing to the continuity of patient care, doctors should check their patient information after work or share their opinions with colleagues who are on the night shift [33]. However, it is very troublesome for doctors to return to the hospital to check their patient information. In this regard, m-EMR can be a valuable tool that allows them to access such information regardless of location and time constraints. Therefore, the results of this analysis further strengthen the evidence that m-EMRs are valuable to doctors in terms of location-independence when accessing clinical information.

High Demand for Data Science Skills to Explore m-EMR Usage Patterns

The results of this study indicate that an analysis of raw-level usage logs might lead to distorted results when exploring m-EMR usage patterns. Owing to the nature of the m-EMR structure, some menus can often be used regardless of intent. For instance, the inpatient list as one of the default menus is most frequently used during the peak usage interval at the raw-data level. There are two purposes for using this menu. First, the menu can be used as a simple patient checklist to review a list of patients under the doctor's responsibility or a list of newly admitted patients. Second, the menu can be unintentionally used owing to the default state of the menu. Considering the entire analysis, most doctors in this study might have set the inpatient list as their default screen. Specifically, the results of a descriptive analysis show that the use of the inpatient list was overwhelming, in contrast to the low use of other candidate default menus (ie, consult, emergency, and operation patient lists). Given that doctors have to use the default menu before using other submenus of the m-EMR app, its high utilization may indicate that the inpatient list menu is used most frequently as the default menu. Moreover, the results of a factor analysis indicate that there is no clear usage pattern after the Inpatient $\text{list}_{\text{default}}$ has been used. These results suggest that the inpatient list is used frequently as the default screen regardless of the doctor's intention. In addition, the investigation list is a gate menu located at the middle level for grouping the investigation results of patients rather than providing specific clinical information. Although the usage of these menus is high (ie, the first and third most frequently used menus), their usage amount may not be crucial in assessing the value of specific clinical information accessed through an m-EMR. These facts emphasize the importance of data science skills when examining the usage features of m-EMRs. Several advanced data mining techniques can be useful to investigate the usage characteristics of m-EMRs in more detail. For instance, process and sequential mining techniques may provide a better explanation on how doctors use m-EMRs by identifying and visualizing the sequence of usage patterns [34,35].

Information on Patient Investigation Status and Conditions That Help With Decision Making During Ward Rounds

This study found four patterns of representational clinical information access (ie, investigation status, patient conditions, emergency patient information, and identification of patients in the ER or ward) when using an m-EMR. These differentiated usage patterns might indicate that specific information was accessed in an m-EMR usage session according to the treatment context. In other words, it might indicate that the m-EMR was used for unique purposes during each usage session. According to a regression analysis, the investigation status and patient conditions are positively associated with the times of peak usage, which correspond to the morning rounds or the time just before the rounds begin. Previous studies showed that important decisions in a treatment environment are made during the ward rounds [31,36,37]. To make a correct decision, it is important to have discussions based on the specific clinical information according to the treatment context. Information on the investigation results and patient progress records is known to be crucial to the decision-making process [31,36,37]. The information is associated with the investigation status (investigation other than lab results, PACS [picture archiving and communication system] view, investigation list, and lab results) and patient conditions (nurse note and order view) based on a factor analysis conducted in this study. Information access through a desktop PC is likely limited during the early hours at approximately the time of morning rounds. Thus, using a desktop PC to keep track of an investigation status and the conditions of the patients may not be convenient for doctors. Under such circumstances, m-EMRs can help doctors to communicate with their colleagues for information sharing or discussions by providing immediate access to the investigation status and patient conditions. Hence, the results of this study suggest that access to the investigation status and patient conditions through m-EMRs is highly valuable to doctors in terms of decision making during the time ward rounds are conducted.

Different Needs for Accessing Information Through m-EMR Depending on Department

The results of this study suggest that information obtained by a doctor through an m-EMR varies depending on the doctor's department or task. A descriptive analysis shows that the overall usage of the m-EMR by doctors in general medical departments is higher than that of doctors in surgical departments. These results can be explained in terms of the intrinsic differences between the medical and surgical departments. Although both groups of doctors have the common goal of treating their patients, their tasks and working environments are different [38]. Specifically, because the doctors in surgical departments often have important tasks in an operating room [38], they may have already experientially shared important information when they were there. Additionally, they often obtain information through direct patient contact such as physical investigations or wound dressing. By contrast, doctors in medical departments often work by examining the patient's condition or interpreting the patient's diagnosis based on various types of information [31]. These differences between the two groups may constitute different needs for information and different preferences for the way the information is acquired. Therefore, doctors in surgical departments may use an m-EMR only to acquire key patient information. On the other hand, doctors in medical departments have a high demand for reviewing and sharing patient information with other colleagues. In this regard, information access through m-EMRs can be more valuable to doctors in medical departments than doctors in surgical departments.

Limitations

This research has several limitations. First, the research was conducted using log data from an m-EMR app used in only a single hospital. It is likely that each hospital has a unique m-EMR system and different schedules for its ward rounds. Therefore, other research environments might yield different results from those of this study. However, the value of an m-EMR in terms of information access is expected to also be demonstrable in other research environments. Second, it is acknowledged that more data are required to enable much better research. The data collection period for the m-EMR usage in this study differed from that for the HIS CPU usage rate. However, considering that the medical staff do not significantly change the way they use the HIS during their work processes, an analysis using log data from the m-EMR app and the HIS during the same period is expected to yield results similar to those of this study. In addition, information on personal and organizational tendencies regarding the use of m-EMRs was not included in this study. Previous studies have shown that personal and organizational characteristics have significant impacts on information technology usage in hospitals [3,39-42]. Therefore, using this information for analysis is expected to improve the robustness of this research stream. Third, this study focused only on information read through an m-EMR and did not consider information entries. It would be valuable to examine whether the investigation status or patient conditions are not frequently recorded through m-EMRs during morning ward rounds.

Conclusions

The most prominent feature of an m-EMR is location-independence in terms of information accessibility. Thus, m-EMRs can be best designed to facilitate access to information when doctors are under time and location constraints. Particularly during the early morning when access to clinical information through a desktop PC is highly limited, doctors can read information regarding a patient's status using an m-EMR. In this regard, m-EMRs will best evolve in such a way that patient information essential for decision making during ward rounds is easily accessed and effectively presented.

Further research is required to gain a deeper understanding of m-EMR usage. The requirements for information acquisition through an m-EMR may vary according to the characteristics of different medical tasks. In addition, clinical information can be presented in various ways, depending on the design of particular m-EMRs. Thus, there may be research opportunities in exploring representational clinical information in other medical environments or using other m-EMR designs. Additionally, further research may aim to investigate the association between specific doctor groups and preferences for the types of information accessed through an m-EMR.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Service Structure and Contents of the mobile electronic medical record.

[PDF File (Adobe PDF File), 351KB - jmir_v19i10e340_app1.pdf]

Multimedia Appendix 2

Overall usage statistics of the m-EMR based on doctor position.

[PDF File (Adobe PDF File), 670KB - jmir_v19i10e340_app2.pdf]

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Abbreviations

CPU: central processing unit
ER: emergency room
HIS: hospital information system
m-EMR: mobile electronic medical records
PACS: picture archiving and communication system
PC: personal computer

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Original Paper

What is eHealth (6)? Development of a Conceptual Model for eHealth: Qualitative Study with Key Informants

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Abstract

Background: Despite rapid growth in eHealth research, there remains a lack of consistency in defining and using terms related to eHealth. More widely cited definitions provide broad understanding of eHealth but lack sufficient conceptual clarity to operationalize eHealth and enable its implementation in health care practice, research, education, and policy. Definitions that are more detailed are often context or discipline specific, limiting ease of translation of these definitions across the breadth of eHealth perspectives and situations. A conceptual model of eHealth that adequately captures its complexity and potential overlaps is required. This model must also be sufficiently detailed to enable eHealth operationalization and hypothesis testing.

Objective: This study aimed to develop a conceptual practice-based model of eHealth to support health professionals in applying eHealth to their particular professional or discipline contexts.

Methods: We conducted semistructured interviews with key informants (N=25) from organizations involved in health care delivery, research, education, practice, governance, and policy to explore their perspectives on and experiences with eHealth. We used purposeful sampling for maximum diversity. Interviews were coded and thematically analyzed for emergent domains.

Results: Thematic analyses revealed 3 prominent but overlapping domains of eHealth: (1) health in our hands (using eHealth technologies to monitor, track, and inform health), (2) interacting for health (using digital technologies to enable health communication among practitioners and between health professionals and clients or patients), and (3) data enabling health (collecting, managing, and using health data). These domains formed a model of eHealth that addresses the need for clear definitions and a taxonomy of eHealth while acknowledging the fluidity of this area and the strengths of initiatives that span multiple eHealth domains.

Conclusions: This model extends current understanding of eHealth by providing clearly defined domains of eHealth while highlighting the benefits of using digital technologies in ways that cross several domains. It provides the depth of perspectives and examples of eHealth use that are lacking in previous research. On the basis of this model, we suggest that eHealth initiatives that are most impactful would include elements from all 3 domains.

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KEYWORDS

qualitative research; interview; health care; eHealth; models, theoretical

Introduction

Despite the growth in eHealth research, there remains a lack of consistency in the use of the term and little consensus on a taxonomy of eHealth technologies [1]. The term *eHealth* has been used to describe a broad range of digital technologies and interventions used by a variety of stakeholders across diverse settings [2-6]. As far back as 2005, a total of 51 unique definitions for eHealth were identified in a systematic review of published definitions of this term [7]. At that time (and to date), the most cited definition was Eysenbach's [3]:

> *e-health is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology.*

Although helpful for understanding the broader context of eHealth, definitions can provide limited guidance on the functions and tools captured by the term. Subsequent to publication of this definition (which remains the most cited) [3], Boogerd et al [8] highlighted the evolution of eHealth in clinical practice and queried the need for a literature review to determine an updated definition and creation of a taxonomy for the field. Noted were the increasingly common language but inconsistent use of terms, such as mHealth, telehealth, and telecare, as well as emergent labels, such as medicine 2.0 [9]. In the absence of clarity, terms will continue to be used inconsistently and interchangeably, to the detriment of opportunities for shared discourse and eHealth implementation.

To understand the landscape of eHealth, literature reviews have been used to identify commonly used definitions [7,10] and key components of these definitions [6]. Consistently, these studies have shown that eHealth definitions are varied and have little or no operational clarity. In an attempt to address these limitations, Reed [11] conducted a concept analysis of eHealth in nursing and developed case examples of eHealth, explicitly demonstrating how eHealth is applied and the attributes of eHealth users. Focusing on telemedicine, researchers have developed taxonomies that outlined the elements of telemedicine and the relationships between them [12,13]. These studies provided some clarity around eHealth in particular contexts, and their specificity enables eHealth to be operationalized. On the other hand, this focus reduces the applicability of the case examples and taxonomies to other health contexts (including different clinical disciplines and nonacute care) or applications of eHealth. Building on these studies, further work is required to identify a model of eHealth that is operational and applicable at each step along the health process (from prevention to acute care and long-term management).

Methodologically, literature reviews provide a summary of published definitions, often with a time delay due to publication processes for the original articles and review papers. They capture frequencies and common elements or themes [7] while potentially losing the depth of definitions that are integral for understanding how concepts might be operationalized. Qualitative research methods, on the other hand, are well suited to the discovery of emergent concepts or determining the meaning of a phenomenon [14]. Multiple informant perspectives can generate a valuable snapshot that captures a realistic and current representation of the studied landscape. The diversity of participant perspectives, understandings, and implementation examples are represented in this approach. A snapshot such as this can be extremely valuable in a rapidly evolving environment such as eHealth.

This study aimed to construct a conceptual practice-based model for eHealth by interviewing eHealth practitioners and scholars. This model would enable health professionals in a range of contexts to apply the different components of eHealth to their own practice through shared understanding of eHealth. With an emphasis on operationalizing eHealth, this practical model will serve as a foundation for eHealth innovation, practice, research, education, and policy.

Methods

Design

We undertook an exploratory thematic analysis of participant interviews [15,16] to capture a multitude of individual and contextually distinct perspectives across an extended time frame. Since group dynamics and interactions were not the focus of this study, we conducted interviews instead of focus groups. We conducted semistructured interviews for the primary purpose of producing a massive open online course (MOOC) on the topic of eHealth, with timing of interviews dependent on participant availability. A MOOC is an open access Web-based learning resource aimed at large-scale global participation. This study reports on the interview data and analysis using the consolidated criteria for reporting qualitative research [17]. We used the results to inform the development of an interdisciplinary conceptual model upon which the framework of the final eHealth MOOC curriculum was based.

Setting and Participants

The study was conducted at The University of Sydney. We used purposeful sampling to recruit key informants (N=25) from diverse professional contexts. Inclusion criteria were that they have significant expertise or vested interests in eHealth research, education, practice, or policy. This included potential participants with key strategic or influential positions. A list of potential participants was generated by investigators (TS, DM, MB, and SB), identified via known eHealth networks and identified by the research team from recent eHealth-related conference proceedings. A research officer invited participants via email. Participation was completely voluntary, and we obtained informed consent from all participants.

Textbox 1. Semistructured interview guide.

1. What does eHealth mean to you?
2. What impact do you think it's having on health care currently, both personally and professionally?
3. What impact do you see it might have over the next 5 years?
4. How do you feel it might contribute to the quality or safety of your own health care or your work as a health professional?
5. What eHealth technologies are being used in your field?

Data Collection

We conducted face-to-face, semistructured interviews, in a location negotiated with each participant, using a semistructured interview guide (Textbox 1). Interviews were audio- and videorecorded by the University's audiovisual staff. Interview questions were designed to encourage open exploration of conceptual understandings and definitions of eHealth, as well as to capture current practice applications of eHealth technologies. The interview guide was developed by the research investigators, informed by previous research [8,18,19], and ratified by members of the Interdisciplinary eHealth Advancement and Research Team (IeHART) at The University of Sydney.

Data Analysis

Interviews were transcribed verbatim and thematically analyzed [20]. Analysis was conducted by 2 authors (DM and MB), and all transcripts were continuously read to obtain a good overall sense of the material prior to open coding, where code words were assigned to specific segments of text. Line-by-line coding ensured full inclusion of all possible data. We grouped codes by related themes and subthemes, which we systematically refined to reduce redundancy and emphasize prominent groupings. We conducted constant comparative analysis with iterative discussion of emerging and final domains and subcategories. The coding process continued until saturation; that is, until no new themes emerged. During analysis, we highlighted illustrative quotes and grouped them by domains. We used the Delphi method [21,22] to refine the model over multiple iterations, allowing for systematic consideration of the breadth, complexity, and overlapping nature of eHealth technologies and applications, with consensus reached when all investigators came to a majority agreement.

Ethics

We obtained ethics approval from The University of Sydney Human Research Ethics Committee prior to study commencement (Protocol No. 2014/1017).

Results

We conducted interviews between August 2015 and April 2016. Interviews ranged from 9 minutes to 95 minutes (mean 28 minutes, median 19.07 minutes). Variations in interview length were predominantly due to the availability or unique contributions of the participants, with some participants contributing detailed examples of eHealth in research or clinical practice.

Participant Demographics

A total of 25 key informants participated in the interviews. Participants' professional specialties and work contexts were specified by their primary place of employment, appointment, and key duties at the time of the study (Table 1). Some participants held senior roles in their organizations, such as faculty deans, academic directors, senior administrators, or chief executive officers. Other participants were health care clinicians, researchers, academics, and PhD candidates. All participants were primarily located in Australia, except for 1 participant who was located in the United States. Despite the large representation of the Australian health context, several participants were involved in international collaborations and offered examples of international eHealth implementation and contexts.

Views on the Definition and Scope of eHealth

The breadth of participants' definitions of eHealth varied widely. The range of definitions and examples they provided emphasize the need for a framework that encapsulates both the current eHealth landscape and eHealth practice into the future. Responses to "What does eHealth mean to you?" ranged from the traditional (representative of current literature):

> *eHealth is a way to incorporate technology into health care to promote health and well-being. It can be as simple as using some form of technology to self-monitor your activity, communicate with different people about health and health conditions, coordinating care within the health system, and actively using technology to provide intervention.*

to those that could be considered progressive:

> *eHealth is so pervasive now[a]days in health research and the implementation of and practice of health that it's almost like the oxygen [of health]...It involves the collection, the management, the analysis, and the communication of all health-related data. That spans individuals, individual patients, all the way through to entire health care systems.*

or possibly contentious:

> *You know eHealth is really old fashioned? Nobody talks about eHealth anymore. Electronic health—everything's electronic! The devices, everything! We're talking about digital health, digitizing health, not eHealth.*

and thought provoking:

> *eHealth means the ability to dial a doctor from home and the interconnectedness of all of our medical details—it's the future we were promised from sci-fi!*

Table 1. Demographic characteristics of participants (N=25).

Characteristics	n (%)
Male	13 (52)
Female	12 (48)
Professional specialties	
Senior health administration/executive management	4 (16)
Psychology	3 (12)
Exercise and movement science/coaching	2 (8)
Information technology	2 (8)
Physiotherapy	2 (8)
Speech pathology	2 (8)
Clinical health informatics	1 (4)
Data science	1 (4)
Digital gaming	1 (4)
Engineering	1 (4)
Genetics/genomics	1 (4)
Medical radiation science	1 (4)
Metabolic health and chronic disease	1 (4)
Neurology	1 (4)
Patient-based care	1 (4)
Patient-reported outcomes	1 (4)
Professional contexts [a]	
University (education and research)	20 (80)
Health care delivery (hospital, community, private practice, Web based)	9 (36)
Governing department of health (state or federal)	3 (12)

[a] Includes participants with multiple professional contexts.

With a global focus on the implementation of electronic records, responses suggested that eHealth has, at times, been considered synonymous with electronic health records and electronic medical records. However, as exemplified by participant descriptions, the scope of eHealth is much broader. Participant examples of digital technologies in health included mobile devices, software apps, wearables, social media, the Internet, Web-based portals and programs, specific software, information management systems, data warehouses, digital gaming, and virtual reality. Practical examples of eHealth technologies encompassed remote service provision, health monitoring, care planning and coordination, communication, information storage and exchange, precision and predictive health care, professional support and development, and consumer empowerment.

Several participants spoke of the intended aims of eHealth, including enabling best care, ensuring safety and quality, enhancing existing services, improving access, connecting points of care, and supporting human health in general. One participant expressed that:

> *To me, eHealth is about the use of new technologies to create new models of care. “E” to me is enabling, how technologies are enabling new delivery, health services, health efficiencies, and overall improvement to health quality.*

Participants emphasized that the focus should not be placed on the technologies but on the potential benefits and improvements that they afford; for example:

> *It’s not about the technology, it’s about using tools to do what we do, better, faster, safer, more patient-centric, broadening horizons...that’s eHealth.*

Participants also highlighted that eHealth implementations need not be overt, as exemplified in the following quote:

> *The patient probably won’t even notice eHealth because that just means that we have the right tools in the right place being able to be used by the patients and the clinicians, and really that just supports the delivery of the best possible care.*

Analysis of stakeholder groups confirmed that eHealth stakeholders are multidisciplinary, spanning medical and allied health professionals, and inclusive of professionals in the social sciences and humanities. Also included are professional groups perhaps not typically thought to be associated with health care, such as professionals in engineering, information technology, business, and economics. Health consumers were an emphasized stakeholder group, encompassing broad demographics. Multiple examples were provided of implementations involving young adolescents, in particular associated with access to mental health services. eHealth interventions were thought to be particularly relevant to the younger population due to their digital competence and their motivation for engagement with digital platforms, including social networking sites. Examples also highlighted the engagement of the older population with eHealth to improve lifestyle behaviors and manage chronic health issues. Caregivers were another noted stakeholder group. Examples of consumer engagement with eHealth were provided right across the health and wellness spectrum, from monitoring and maintaining wellness on an independent basis, through to their engagement with health services and health care providers spanning primary, secondary, and tertiary care.

Domains

Analysis of the interview data revealed 3 dominant eHealth domains: (1) health in our hands, (2) interacting for health, and (3) data enabling health, with each encompassing several subcategories (Table 2).

Domain 1: Health in Our Hands

Analysis revealed repeated reference to mobile devices (eg, smartphones, tablets, and clinical devices), mobile sensors and wearables, apps, social media, and online information. Referring to the personal, accessible, and mobile nature of eHealth technologies that enable access to health information as and when needed, this domain is named “Health in our hands.” One participant, a university researcher, summarized several aspects of this domain as follows:

> *I put my pedometer or my fitness app and it tells me how many steps I’ve taken, how many hours I slept. I have a sore throat when I go to Google and gives me information from a huge variety of sources, or I go onto an online support program and I again get access to the stories and the experiences and the recommendations and advice of all sorts of people who have gone through what I’m going through.*

Participants emphasized how this area is fueled by consumer enthusiasm for gadgets and personal health informatics. The “quantified self” movement and exponential growth in the mobile health technology market has led to increased recording and monitoring of personal health data [23]. Participants noted, coupled with increased consumer health literacy, the growth of a population invested in their own health and well-being. Within this domain, participants listed multiple benefits in terms of improving access, empowering consumers, and facilitating behavior change.

Health, Not Just Health Care—Solutions for Health and Well-Being

Within this subcategory, the relevance of and potential for eHealth supporting health and wellness, as distinct from health care, was emphasized. Participants highlighted that managing one’s health and participating in health care transcend interactions with health care professionals or health services. It was emphasized that health and well-being happens on a day-to-day basis and that most people spend very little time with a health care provider or service each year. Rather, they spend much more time and effort self-monitoring and self-caring to maintain health and wellness. One participant, a university researcher, asserted that a shift in mentality is required to:

> *...stop thinking about health and health care as synonymous things and eHealth will encourage that. It’s not about fixing people when they’re unwell; it’s about making sure people are well for as long as they can be.*

Participants acknowledged increases in age-related illnesses and chronic conditions, and the positive role eHealth technologies can play in managing the impact. Multiple examples were provided of eHealth tools being integrated into everyday life, assisting individuals to remain well, out of the health care system, and to participate in life to their full potential. Participants spoke of how increasing consideration is being given to how digital health technologies can be integrated into everyday settings, such as homes, schools, workplaces, and the community.

Table 2. eHealth domains and subcategories.

Domain		Subcategories
1	Health in our hands: the use of eHealth technologies to monitor, track, and inform health	Health, not just health care
		Consumer-driven and -controlled health
		Health via social media and the Internet
2	Interacting for health: the use of technologies to communicate between stakeholders in health	Connecting for real-time health
		Social discourses and storytelling
		New ways of interacting to personalize care
		Supporting health professionals
3	Data enabling health: the collection, management, and use of health data sources	Data management systems and data repositories
		Data for precision health
		Data enabling quality

One participant, a university researcher, referred to “positive computing,” how technologies are being designed to specifically support psychological well-being and human flourishing [24]. Examples were provided outlining how apps are being used to provide users with positive reinforcement through a meaningful text message, a personal image, or quantification of a self-generated goal for compliance with a healthy behavior, such as drinking water or using a preventive inhaler. Within mental health contexts, examples included supporting individuals at risk of substance abuse or self-harm. These included the use of mobile devices, apps, and global positioning system coordinates to monitor for specified trigger events. If a trigger event occurs, the user is provided with an immediate response on the device, and a nominated person (such as a partner or professional counsellor or psychologist) is alerted via short message service (SMS). A health executive expressed that:

> *In the prevention end, it’s going to be about consumers owning their own health, and the devices that are available will be there to support them to do that.*

Consumer-Driven and -Controlled Health

A recurring theme was that this is the “dawn of consumer-driven health care.” Patient centeredness is a well-recognized factor for high-quality health care [25], and participants acknowledged that consumers are increasingly taking control of or playing a more active role in their health. There was a strong sense that innovations in eHealth are being driven by demand for consumer-oriented solutions. However, it was acknowledged that health care remains slower than other customer-focused industries, such as banking and finance, in integrating technology with service users.

Commonly cited examples of consumer-driven and -controlled health included access to and control of their personal electronic health records, such as the My Health Record in Australia [26]. OpenNotes in the United States [27] was another cited example, which gives consumers access to the clinical notes captured in their medical record. Consumer access and control is thought to empower the consumer to take greater control of their health, foster involvement in decision making [28], and promote a more equal relationship with their health care [29]. This was reinforced by a health executive who asserted that:

> *Patients are really the experts here, they’re the people who know themselves best, and they have a great opportunity to be able to contribute information and to really manage that information.*

Another health executive reinforced the value of patient access to health records in terms of quality and safety:

> *I don’t think anybody cares more about the information about a patient than the patient themselves. So if we can show them that information and they can be part of the discussions about that information, that is inherently a very powerful safety and quality measure.*

Participants noted that health consumers increasingly have access to information that affects their choices about the care they receive. This includes not only access to evidence-based online health information, but also ratings of health professionals and experiences of care [30-32].

Health Via Social Media and the Internet

There was particular emphasis on the role of social media in health and well-being within this domain. Participants identified a range of social media platforms that were driving online health communities, including blogs, such as WordPress; collaborative projects, such as Wikipedia; social networking sites, such as Facebook and Twitter; content communities, such as YouTube; virtual social worlds, such as Second Life; and social online games [33]. There was particular focus on consumer use of social media to obtain information and connect with other people with similar experiences or a common diagnosis. Similarly, health professionals noted their use of social networking platforms, like Twitter, to access professional information and networks.

Participants discussed how health consumers are using social media and the Internet to check symptoms, gather and clarify information, compare options, and potentially to self-treat, as captured in the following quote:

> *I think we will go to our [general practitioner] much more knowledgeable, knowing what our problem is, and we will be expecting to have choices offered to us so that we can make reasonable decisions about where we should be going next.*

One participant described the development of a patient portal that tracks their activity to capture what information they are searching for online and displays this on a dashboard for the care provider. The participant, a researcher and clinician, explained how the portal aims to enrich the encounter between the patient and the provider and encourage collaborative decision making:

> *So it’s another window into what that patient’s state is...What are questions that’s important to that patient? So rather than spending that time procuring that information in the clinical encounter, they have that available to them.*

With increased access to computers at the bedside, mobile devices, and the Internet, clinicians noted how point-of-care tools provide just-in-time access to evidence-based information to support clinical decision making. A clinician expressed that:

> *...you have so much access to information in your pocket, when you’re doing things like recharting medications for a patient or explaining something, to be able to pull out your phone and look it up and get the answer right there on the spot.*

Domain 2: Interacting for Health

Participants discussed the impact of eHealth on health communication. They emphasized that, although this domain may have been traditionally dominated by teleconferencing and videoconferencing, the field increasingly includes a wide range of synchronous and asynchronous communication tools, such as SMS and push notifications from apps, patient storytelling through dedicated portals and social media platforms, and via virtual or simulated therapy tools. Transcript analysis revealed that eHealth plays a role in multiple communicative interactions, including provider to consumer, provider to provider, and consumer to consumer. Participants acknowledged that eHealth is providing new ways of interacting and, as such, enabling new models of care.

Connecting for Real-Time Health

One participant argued that, despite advances in technology, we have not yet replaced, nor perhaps should we ever replace, the need for health professionals and consumers to communicate with one another. Participants referred to multiple examples of digital health services, including virtual consultations, telehealth clinics, and Web-based group forums, using a variety of telecommunications and Web-based conferencing software to connect for real-time interactions. Examples included a physiotherapist whose Web-based business is delivering interventions for musculoskeletal injuries to clients worldwide and an exercise physiologist who provides remote consultations for cancer rehabilitation and supportive care services. The following quote from a clinician captured how such digital health services give the consumer an advantage:

> *The Skype or videoconferencing service was really convenient. He could book in via his Outlook or email system that he would use for work, and treat this like he would a normal appointment, and reduce the time from 2-3 hours with driving to half an hour of purposeful engagement with that health professional.*

A neurologist provided the following example of how they are connecting health professionals and patients between satellite and specialist centers to deliver an acute care telestroke service:

> *The ceiling camera allows us to communicate with the patient, with the relatives of the patient, and with the nurses, and with the help of the nurses or the emergency department physicians, we are capable to perform an assessment of the patient that just came into the [satellite] department.*

In another example, an emergency department physician explained how connecting in these ways increased opportunities to accurately triage a critically ill patient at a distance, limit unnecessary transfer to a central facility, and start advanced treatments early. In terms of outcomes, he noted that these interventions often meant that the patient could be transferred with lower levels of support and arrive at the central facility in a more stable condition.

In each of the provided examples, improved access by bridging temporal and geographical limits was cited as a distinct advantage of eHealth, as exemplified in the following quote:

> *eHealth, to me, means delivering appropriate care to patients that would have otherwise missed out because of location.*

Social Discourses and Storytelling

Participants discussed the opportunities afforded by social media for discourses about health that may not be possible in face-to-face conversations. They noted how it allows for professional and peer interactions that can be either overt or anonymous. One participant described how a moderated, anonymous, and secure online mental health platform for young adolescents provides a community of support that empowers participants to maintain healthy behaviors.

Social media was considered highly amenable to consumer storytelling. As highlighted by a psychology researcher:

> *Social media reminds us that our stories are important and our voices need to be heard.*

It was acknowledged that, while perhaps not medically trained, consumers have experiential knowledge that is very powerful in recovery and motivating others.

New Ways of Interacting to Personalize Care

One physiotherapist asserted that, for health care services to be successful, now and into the future, they have to “effectively harness that intersection between automation and personalization.” Clinicians acknowledged the increasing integration of digital tools into practice to customize services, including the prescription of tailored therapy and rehabilitation programs. For example, participants from physiotherapy and exercise physiology outlined the use of apps to tailor therapy programs with personalized advice, education materials, and high-quality video demonstrations. They explained how digital tools are providing key interventions benefits and new service choices for clients, such as in-home therapy involving remote consultation, monitoring, and program adjustment. In other examples, participants highlighted how apps are helping consumers to alert health care professionals to changes in their condition, including for in-home renal patients who log their own health data and self-evaluations of their current wellness status to be monitored by service-based clinicians.

A speech pathologist described how Twitter and other social media platforms are being used in communication rehabilitation for clients who have a traumatic brain injury. She described how communicating via social media reduces literacy demands, allows time for message composition and message processing, and provides options for photos or hyperlinks, which may be of significant advantage for someone with a communication impairment. These individuals may then “use social media so that they can communicate in what is considered a normal everyday activity.”

Supporting Health Professionals

Participants acknowledged that eHealth technologies have a significant role in supporting health professional interactions for interprofessional collaboration, remote mentoring, and professional support of new, generalist, or isolated providers. In particular, participants emphasized the advantage of eHealth-enabled information exchange and conferencing for collaborative case reviews and discussions that support diagnostic and therapeutic decision making. Examples included models of distributed professional collaboration, such as multidisciplinary cancer care team case reviews.

Participants highlighted how digital technologies are increasingly embedding relevant information and just-in-time learning episodes into routine workflows. Examples included alerts within electronic record systems and information delivered via clinical decision support tools at the point of care. One participant discussed a targeted professional development program that provides learners with short case-based learning scenarios via email or app. They outlined how the use of routinely collected clinical data is starting to inform more adaptive or tailored professional development activities directly related to their actual clinical encounters. The university researcher and clinician explained:

> *So you have to contrast that to what we've done traditionally, which is just sort of "one size fits all;" not customized to the patient, to the clinical encounter; not in the workflow...This is all an effort to now have it embedded in the clinical environment.*

Domain 3: Data Enabling Health

Participants reported being in the middle of a health care reformation, whereby access to and use of vast amounts of health-related data are being realized. This domain encompasses the collection, management, analysis, and application of health data, including the design and implementation of technologies that provide new and expanded forms of knowledge about ourselves as individuals, our community, and the population as a whole.

Data Management Systems and Data Repositories

A prominent theme under this domain was the emphasis on the role of electronic medical records and electronic health records in the collection, storage, and communication of health data, and in particular, routine clinical data. One health executive described the function of electronic records as both the central repository of health information and a communication tool that enables the sharing of information across a network of providers. Yet, despite the intense implementation efforts worldwide, participants acknowledged that electronic records are, as yet, not as seamless as perhaps expected by both providers and consumers. Participants spoke at length about implementation efforts dedicated to overcoming challenges of privacy and security, connectivity and integration of data across silos of information and various provider systems, completeness and quality of data, and development of commonly agreed-upon information standards.

While conventional electronic record systems dominated discussions, a unique example of a consumer-owned and -controlled data management system provided insight into future possibilities. The university researcher referred to the concept of the "unpatient," where people are the custodians of their data and their personal health records, not the government or health providers. In this example, personal health data, including familial history, specialist reports, pathology records, lifestyle data, and even genomic sequencing, were recorded and maintained on a personal mobile device. In the future, the participant would like to see electronic health data from personal data management systems shared securely with nominated people, including medical professionals and researchers.

Data for Precision Health

Participants acknowledged the opportunities and challenges associated with the growing swathes of data, including the abundance of routine clinical data and emergence of new forms of consumer-generated data, such as the data generated from personal devices and monitors and patient-reported outcome measures. They acknowledged that, while data from personal trackers, such as steps taken and calories eaten, provide useful information about lifestyle, as yet, the data don't capture the detail necessary to predict and personalize how we deliver health care. One university researcher described how making sense of data will further our understanding of the complex relationship between biology and environment to better inform how health care can be delivered in a personalized or "precise" way.

Participants also noted the exponential growth in research activities involving large omics datasets. They agreed that there is tremendous potential for the abundance of health-related data to have significant impact on health and wellness of an individual, cohorts of individuals, and the population as a whole. They expressed enthusiasm for the linkage and integration of various data sources contained within electronic health records and other data repositories, as captured in the following quote:

> *Working in genetics, I think the idea of having a full set of data is where things become important. You can have lots and lots of data and you can have these huge troves within the genome, but if it's not connected to the clinical side or the phenotype, it really becomes quite useless.*

Participants frequently referred to the role of big data analytics and the need for sophisticated procedures to manage data into a form that is tractable for designing personalized interventions, maintaining health, and predicting and preventing disease. They suggested that one of the most exciting things about eHealth is the potential to enable data-driven care. Participants spoke of the increasing potential of data analytics to determine an individual's likely health trajectory and inform diagnostics and clinical decision making. Clinician participants reinforced the desire to have linked datasets and real-time clinical decision support tools that interrogate data sources. Ultimately, they look forward to the day when complex data analytics provide them with the most appropriate information and relevant options to guide best practice and personalize care for their clients.

Data Enabling Quality

Participants emphasized that eHealth is contributing to safer and higher-quality health care. One health executive noted the potential for eHealth technologies to reduce harm, especially in situations that are subject to human error. Electronic medication systems, for example, were noted to reduce some of the risks associated with dispensing pharmaceuticals. Other examples included the emergence of expert guided computer intelligence systems that integrate expert knowledge and reasoning with best evidence, such as Dr Watson by IBM.

Participants discussed how data analytics can provide information about the quality of the health care experience and enable more informed decisions about quality improvement priorities. They discussed how electronic record systems have facilitated access to routine data for the purposes of quality indicator implementation, performance feedback, and quality improvement. Discussions included the potential for data visualization tools to inform performance and behavior change for individual clinicians, clinical teams, and whole organizations.

Discussion

Principal Findings

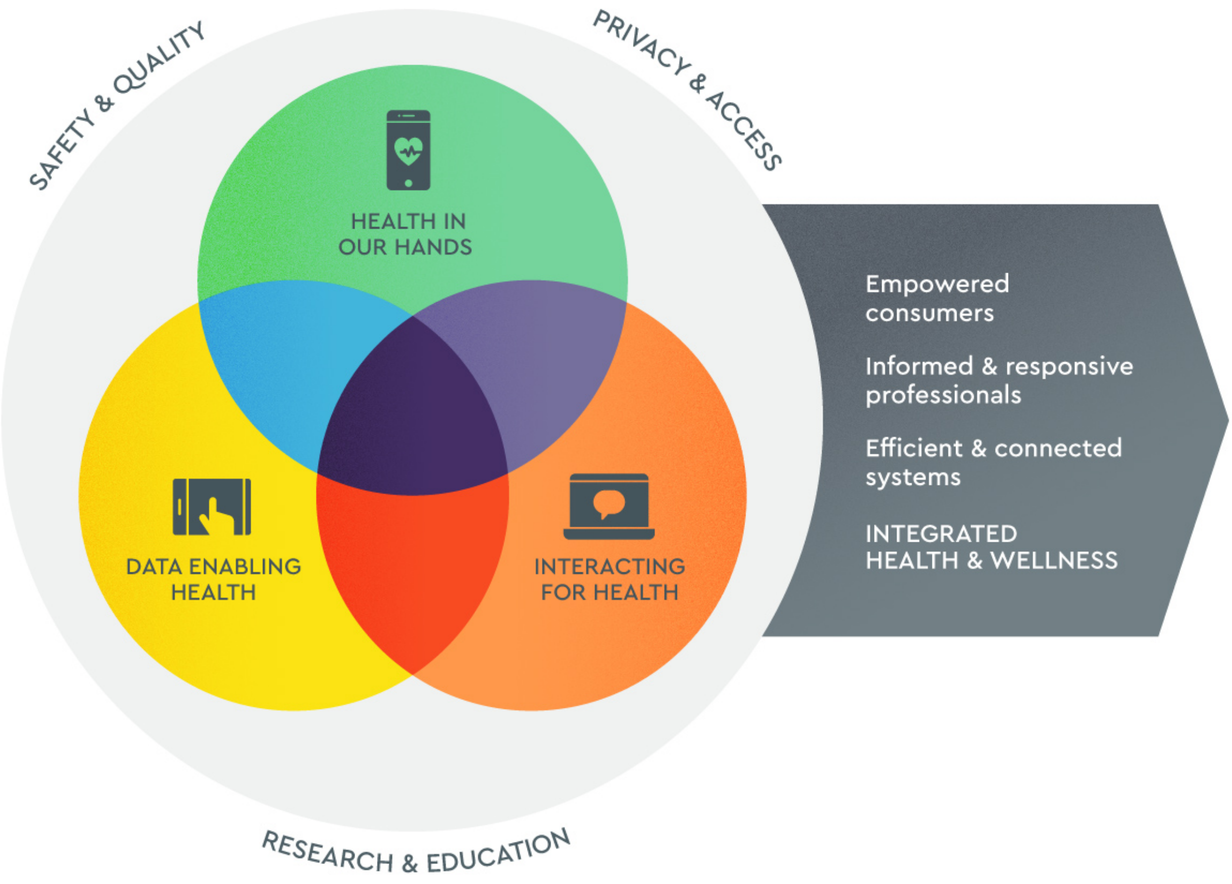
We interviewed eHealth practitioners, scholars, and policy influencers to develop a model for conceptualizing eHealth (Figure 1). This model responds to calls in the recent literature for an updated, operationalizable definition of eHealth and a taxonomy of eHealth technologies [8]. Informed by the dominant themes emerging from the qualitative interviews, the model consists of 3 overlapping domains: (1) health in our hands, (2) interacting for health, and (3) data enabling health. Separately, these domains describe, respectively, the use of digital technologies to monitor, track, and inform; the use of digital technologies to facilitate communicative encounters between health stakeholders; and the use of data to improve health and health services.

The Overlapping Nature of eHealth

A distinctive feature of eHealth, however, is its fluid boundaries. Previous research has identified numerous overlapping definitions for eHealth. This is, in part, a key limitation of studying eHealth, but also a distinctive feature of the field. Classifying telemedicine along 3 dimensions (type of technology; perspective of the individual, such as client or practitioner; and context in which eHealth is applied), Tulu et al [13] demonstrated the necessity of overlap between different domains of eHealth. For example, a social networking site used to provide social support for consumers sharing a diagnosis can be categorized under domain 1, health in our hands, and domain 2, interacting for health. The overlapping nature of our model acknowledges the complexity of eHealth while providing a practical way of understanding how eHealth is perceived and implemented.

Of particular importance is the role of overlap among these domains for guiding the development of highly impactful innovations. In particular, where all 3 domains overlap is the optimum point that integrates health data for enhancing interactions and communications so as to empower consumers to be active in their health and health care. The model provides a conceptual framework that can assist individuals and organizations in developing and integrating eHealth initiatives and transforming current models of care. We propose that interventions incorporating multiple domains have the greatest potential impact. For example, the developer of an app targeting self-management of a chronic health condition will consider how the user interacts with the technology to monitor or manage their condition (health in our hands); how it provides opportunities for communication and interactions with caregivers, peers, or professionals for monitoring, coaching, or support (interacting for health); and how gathered data are stored, managed, and analyzed for immediate decision support and, increasingly, personalized and precision health care (data enabling health).

Figure 1. A conceptual model for eHealth.



One participant exemplified this in a mental health program they described that provides an online assessment of a program participant's mental health status using validated tools, automatically recommends reviewed and evidence-based apps, makes an appointment for the participant with a virtual or face-to-face consultation if required, and stores all data in a format that can be included in a health record for future review. Similarly, in the case of an individual health professional, the model provides a framework for evaluation and decision making regarding digital technologies being considered for implementation or prescription. The health practitioner can use the model to guide how they effectively implement eHealth into their practice. For instance, when looking at recommending apps such as those designed to monitor blood sugars, the health professional needs to understand how the app will be used collaboratively with their patient, how this may affect their collaboration, and how any data may usefully be stored and used in consultations. We assert that the future of eHealth lies with technologies that incorporate all 3 of the highlighted domains.

At The University of Sydney, this model has been used to underpin research and education in eHealth and has formed the basis for curriculum development in allied health education.

To the best of our knowledge, no other model or conceptual framework exists that provides a practical guide for both the development of eHealth resources and the application of these resources into an individual's practice. The model aligns with Black et al [1], who described eHealth technologies as having 3 main overlapping functions: (1) to enable the storage, retrieval, and transmission of data; (2) to support clinical decision making; and (3) to facilitate remote care.

Limitations and Future Research

Strengths of the study include the breadth of experience and clinical disciplines possessed by the stakeholders and experts whom we interviewed. The interview methodology also allowed for greater depth of understanding about how eHealth is conceptualized and implemented, and included examples that previous literature reviews did not capture. Limitations of this study include that the key informant interviews did not include health consumers. Future research could test the assumption that multidomain eHealth initiatives would be more impactful. Further validation through interviews with health consumers would also strengthen the model.

The development of this model provides a framework to guide discussion and development of eHealth in practice in a rapidly evolving market. For health professionals, educators, researchers, and consumers, this model may help to inform how eHealth can facilitate coordinated care and wellness into the future. For funders of health care, such as governments and health insurers, it provides a framework that can be used to maximize the return of investment on the development of tools to support health and wellness. This includes the development of mobile ecosystems that integrate the 3 domains of this model into easy-to-access and integrated "one-stop shops" for supporting health and wellness and positive behaviors. This model extends current understanding of eHealth by providing clearly defined domains of eHealth while highlighting the benefits of using digital technologies in ways that cross several domains. It is clear from this model that there is significant overlap between aspects of these eHealth domains, and it is important not to draw boundaries around each of them too tightly. Perhaps the greatest strength of this model is identifying the "sweet spot" where the domains coalesce to provide the ideal integration of informed consumers, proactive health professionals, and a responsive health system. The model may enable awareness of how eHealth can empower professionals and health consumers alike to be more active participants in ongoing health and well-being management. It may also facilitate greater clinical and organizational understanding of the application of eHealth resources into practice for better outcomes for all. At this point in time, the model ultimately provides a rich snapshot description of the overlapping nature and broad scope of eHealth in a health care landscape that continues to transform the way in which we view health and well-being.

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Conflicts of Interest

None declared.

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Abbreviations

IeHART: Interdisciplinary eHealth Advancement and Research Team
MOOC: massive open online course
SMS: short message service

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Original Paper

The Promise and Pitfalls of Using Crowdsourcing in Research Prioritization for Back Pain: Cross-Sectional Surveys

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Abstract

Background: The involvement of patients in research better aligns evidence generation to the gaps that patients themselves face when making decisions about health care. However, obtaining patients’ perspectives is challenging. Amazon’s Mechanical Turk (MTurk) has gained popularity over the past decade as a crowdsourcing platform to reach large numbers of individuals to perform tasks for a small reward for the respondent, at small cost to the investigator. The appropriateness of such crowdsourcing methods in medical research has yet to be clarified.

Objective: The goals of this study were to (1) understand how those on MTurk who screen positive for back pain prioritize research topics compared with those who screen negative for back pain, and (2) determine the qualitative differences in open-ended comments between groups.

Methods: We conducted cross-sectional surveys on MTurk to assess participants’ back pain and allow them to prioritize research topics. We paid respondents US $0.10 to complete the 24-point Roland Morris Disability Questionnaire (RMDQ) to categorize participants as those “with back pain” and those “without back pain,” then offered both those with (RMDQ score ≥7) and those without back pain (RMDQ <7) an opportunity to rank their top 5 (of 18) research topics for an additional US $0.75. We compared demographic information and research priorities between the 2 groups and performed qualitative analyses on free-text commentary that participants provided.

Results: We conducted 2 screening waves. We first screened 2189 individuals for back pain over 33 days and invited 480 (21.93%) who screened positive to complete the prioritization, of whom 350 (72.9% of eligible) did. We later screened 664 individuals over 7 days and invited 474 (71.4%) without back pain to complete the prioritization, of whom 397 (83.7% of eligible) did. Those with back pain who prioritized were comparable with those without in terms of age, education, marital status, and employment. The group with back pain had a higher proportion of women (234, 67.2% vs 229, 57.8%, *P*=.02). The groups’ rank lists of research priorities were highly correlated: Spearman correlation coefficient was .88 when considering topics ranked in the top 5. The 2 groups agreed on 4 of the top 5 and 9 of the top 10 research priorities.

Conclusions: Crowdsourcing platforms such as MTurk support efforts to efficiently reach large groups of individuals to obtain input on research activities. In the context of back pain, a prevalent and easily understood condition, the rank list of those with back pain was highly correlated with that of those without back pain. However, subtle differences in the content and quality of free-text comments suggest supplemental efforts may be needed to augment the reach of crowdsourcing in obtaining perspectives from patients, especially from specific populations.

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KEYWORDS

research prioritization; crowdsourcing; MTurk; Amazon Mechanical Turk; patient engagement; stakeholder engagement; back pain; comparative effectiveness research; patient participation; low back pain

Introduction

Modern health care decision making incorporates expert opinion, practice standards, and the individual preferences and values of patients themselves [1,2]. The patient's voice is essential to ensuring that treatment plans address what is most important to them. In support of patient-centered care, patient-centered outcomes research equally seeks to engage patients and the public in designing and implementing research studies. Efforts to involve patients in research can take various forms ranging from consultative (eg, researchers can seek patient opinion about the design of a study) to more collaborative approaches (eg, patients can be involved as members of the study team itself). Engagement throughout the research process is an important step in developing evidence that will support patients and providers as they make health care decisions. Identifying and prioritizing research topics—the first phases of patient-centered outcomes research—direct researchers to address the relevant and important problems facing those who may benefit most from study findings; thus, patient involvement is imperative [3].

Patient-centered outcomes research teams have begun to use novel technology-driven engagement strategies—including social media and crowdsourcing platforms—to augment traditional engagement activities. Emerging evidence has suggested that online engagement methods such as crowdsourcing may provide an efficient alternative to in-person meetings [4,5]. Crowdsourcing as a whole is appealing in its ability to rapidly obtain responses from a broad and potentially diverse population. For prevalent conditions, such platforms may provide an efficient and effective method for obtaining input on research activities, including research prioritization.

One example is Amazon Mechanical Turk (MTurk; Amazon.com, Inc), a crowdsourcing platform where users are paid a small fee for performing designated tasks [6]. Originally designed to allow the rapid completion of complex but repetitive work, MTurk has been adopted by behavioral scientists and market researchers to serve as a virtual laboratory to quickly and inexpensively administer thought experiments via online surveys, perform market research for organizations, and give insight into the thought processes underlying decision making [4,7-9]. Furthermore, some have begun to use MTurk to obtain public opinion on health care-related topics [10].

Our group has worked to understand the relative strengths and weakness of various patient engagement activities for research prioritization in the context of low back pain. Low back pain occurs in 80% of the population at some point in their life [11], accounting for about 8% of all disability from all disease in the United States; 25% of the population reports having had back pain in the past 3 months and 55% report back pain in the past year [12,13]. Despite its prevalence and health burden, there is no clear mechanism for patient engagement in the decision making around back pain research [5]. In a prior study, we compared the research priorities established by patients with back pain who participated in a patient registry with those established by MTurk participants who self-reported having back pain. The 2 groups ranked research topics similarly, despite large differences in age (the MTurk cohort being younger) and in selection into the cohorts: those in the patient registry had a formal diagnosis of back pain, whereas the MTurk group was selected on the basis of their Roland Morris Disability Questionnaire (RMDQ) score. The RMDQ is a validated tool that is used to score back-related disability and was used as a proxy to distinguish those with back pain from those without back pain. The conclusion of the study was that these two methods of identifying patients for engagement—patient registries and crowdsourcing—complement one another [14].

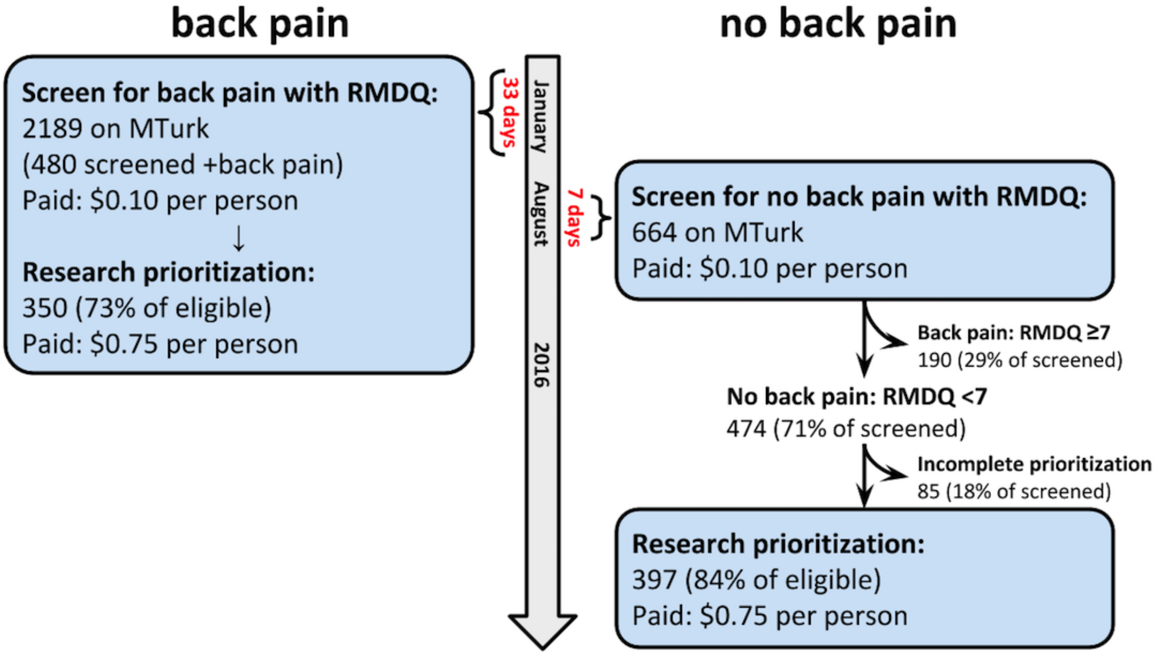
Our prior study exposed difficulties in participant selection from a crowdsourced sample for research prioritization. We had used the RMDQ to find those with back pain but had no understanding of whether this selection process changed the ranking of research topics or improved the information gathered from our cohort. This study, therefore, expands our prior work to a broader population on MTurk, comparing those who screen positive for back pain against those who screen negative for back pain, with categorization based on the RMDQ score. We sought to understand how these 2 groups differed with respect to their research topic rank lists and additional commentary in order to guide the use of MTurk as a platform to support research prioritization for low back pain. We hypothesized that this comparison would also give insight into the use of MTurk for research prioritization, generally.

Methods

Overview

This study is part of a series of investigations to understand methods of patient engagement, and specifically research topic prioritization for back pain [14-16]. We conducted 2 cross-sectional surveys via MTurk: the first in January 2016 targeting those with back pain, and the second in August 2016 targeting those without back pain (Figure 1), limiting the MTurk sample to only those residing in the United States. The University of Washington Human Subjects Division provided ethical approval for this study prior to administration of the surveys.

Figure 1. Mechanical Turk (MTurk) enrollment. Schematic flow diagram of enrollment of both cohorts, including screening and response rates. Compensation is in US $. See also Figure 1 in Truitt et al [15]. RMDQ: Roland Morris Disability Questionnaire.



We used the RMDQ as a screen to categorize individuals as those with back pain (RMDQ ≥ 7) and without back pain (RMDQ < 7) [17]. The RMDQ screens for current back-related disability but does not offer clear insight into a possible history of back pain. Therefore, the group without back pain could have contained individuals with a history of back-related disability that had since improved. We paid MTurk users US $0.10 for completing the RMDQ. We invited a subset of those who took the screening survey to complete a prioritization activity, based on the above categorization. The prioritization survey was extended to those with back pain during the first survey administration and to those without back pain during the second administration. This separate prioritization survey elicited participants' top 5 of 18 back pain research topics adapted from a list previously generated by primary care providers and researchers (see Multimedia Appendix 1) [18]. We paid MTurk users an additional US $0.75 for completing the prioritization survey [18]. In addition, participants could add up to 5 additional topics in open-ended comment fields beyond the topics in the list provided. Users provided demographic information at the conclusion of the prioritization survey. Both the screening RMDQ and the prioritization surveys were administered using Research Electronic Data Capture (REDCap), a software platform specifically designed for electronic data capture in research studies [19]. Both surveys were developed by our team prior to administration as an open survey on MTurk. We used neither randomization nor adaptive questioning methods. We added an internal validation question to the screen such that, if none of the 24 items on the RMDQ applied, participants were instructed to check a box noting this. Those who did not pass this internal check were removed from analysis. Participants were not able to review their answers prior to submitting, but they were able to change answers as they proceeded through screening and prioritization.

Demographic and Ranking Analysis

We tabulated age, sex, highest level of education attained, current level of employment, and ethnicity and race, reporting frequencies for categorical variables and means for continuous variables to compare participant demographic characteristics. To understand the geographic distribution of our MTurk sample, we tabulated the US states of residences within each group. We created a ranked list of research topics within each group by determining the frequency that each topic was selected as the top 1-5 priorities and ordered them accordingly. A Spearman rank-order coefficient was used to compare the rank lists of research topics generated by each group. A Spearman coefficient close to 1 would signify a high level of agreement in the order of the ranked research topic lists between groups; a value close to 0 would signify little agreement in the rank lists; a value approaching –1 would signify that the rank lists are opposite one another. We performed a Wilcoxon rank sum test, without continuity correction, to understand whether the distribution of rankings—that is, the relative importance of the top- versus bottom-ranked research topic—was the same or different between groups. A significant result ($P<.05$) would indicate that the distributions of rankings are different.

Administering 2 separate surveys at 2 different time points opened the possibility for MTurk users to repeat the exercise. We selected those individuals who took the RMDQ both in January and in August to compare how their RMDQ score changed over the time period and, for those who were eligible to take the prioritization survey twice, how their research prioritizations changed.

Content and Quality Analysis

We performed a directed content analysis on the additional comments provided by participants in both groups using an iterative process. After reviewing all comments, we generated a list of codes that reflected the content. Two members of our team, blinded to the work of one another, applied the codes and, where there were disagreements, a third member reconciled the code applied. To assess the quality of the content provided through open-ended comments, we created a coding scheme to indicate how helpful comments were for designing future research topics. Those coded as “no information” were comments that were off-topic from back pain and back pain research (eg, “Thanks”). Those coded as “some information” identified a broad topic area, but neither specified further nor gave insight about the study population (eg, “posture” or “cortisone shots”). Finally, those coded as “rich information” identified a broad research topic area and either included a specific research question within that broad topic or gave insight about the study population, or both (eg, “Can the spread of pain be calculated when the first indicators become evident? My pain has spread from the lower lumbar region into the hips and down the legs over the last 25 years.”). We applied all codes using Dedoose version 7.5.9 (SocioCultural Research Consultants, LLC).

Results

Overview

We screened a total of 2812 individuals over 40 days. Of those, 718 (25.53%) were grouped as having back pain (RMDQ score ≥7). The prioritization activity was completed by 350 of those with back pain (72.9% of 480 eligible) during the first administration of the screen and by 397 of those without back pain (84% of eligible) during the second administration of the screen.

Demographic and Ranking Analysis

Table 1 presents the demographic information for the 2 groups.

The groups were similar with respect to age, ethnicity, and race. The 2 groups differed in the proportion of men versus woman, current employment status, highest level of education completed, and marital status (see Table 1). Compared with the US population as a whole, the study cohort from MTurk was younger (US population: 38 years; MTurk cohort: 33 years), had proportionally more women (US population: 51% female; MTurk cohort: 62% female), was more highly educated (US population: 30%; MTurk cohort: 47%), and was less racially diverse (US population: 77% white; MTurk cohort: 81% white) [20]. The study sample represented 48 states and the District of Columbia, with representation from Wyoming and South Dakota missing in the prioritization results.

The rank lists of research topics for the 2 groups were highly correlated (Spearman correlation coefficient, ρ=.88). The 2 groups agreed on 4 of the top 5 and 9 of the top 10 research topics ranked as most important (see Table 2). Those with back pain ranked “treatment—self-care” as their top research topic, whereas those without back pain ranked “diagnosis—causes of back pain” as their top research topic. Both groups ranked topics related to treatment and diagnosis most highly overall, accounting for all of the top 5 most highly ranked topics in the back pain group, and 4 of the top 5 in the no back pain group. The rank lists differed in how the groups ranked the importance of topics such as prevention, clinical definition, and treatment. The Wilcoxon rank sum test was not statistically significant (*P*=.87), indicating a similar distribution of votes for the research topics.

A total of 41 participants (1.45%) took the RMDQ screen twice. Of those, 2 (5%) were eligible to prioritize twice, 33 (81%) maintained the same back pain classification based on the RMDQ cutoff score of 7 to distinguish back pain from no back pain, and 6 (15%) changed from the no back pain group in the first screen to the back pain group in the second screen and were never eligible to participate in the prioritization activity. The mean change in RMDQ score of those who screened twice was 0.7 points (SD 3.5, range –9 to 9). Of the 2 participants eligible to prioritize twice, 1 completed the prioritization activity twice and ranked the same research topic as their top priority both times.

Content and Quality Analysis

Additional comments were provided by 53 (15.1%) of the group with back pain (n=350) and 44 (11.3%) of the group without back pain (n=397). The comments from the group with back pain were nearly twice as long as comments from the group without back pain as measured by word and character counts (word count average of 17.3 words vs 8.3 words, respectively; see Table 3). The comments from the group with back pain were marginally more informative toward directing future research based on our application of a quality code: only 5% of the comments from the group with back pain were coded as “no information” compared with 17% of the comments from the group without back pain.

Table 1. Demographic data, by back pain group.

Characteristics	Back pain (RMDQ[a] ≥7) (n=350)	No back pain (RMDQ <7) (n=397)	*P* value[b]
Age (years), mean (SD)	36.6 (11.9)	36.1 (12.3)	.36
Total RMDQ score, median (interquartile range)	10 (8-14)	2 (1-4)	N/A[c]
Sex, n (%)			.009
Male	114 (32.8)	166 (42.1)	
Female	234 (67.2)	229 (57.8)	
Highest education level, n (%)			<.001
Less than high school	6 (1.7)	2 (0.5)	
High school diploma or equivalent	42 (12.0)	40 (10.1)	
Some college, no degree	112 (32.1)	97 (24.5)	
Associate degree	56 (16.0)	38 (9.6)	
Bachelor’s degree	104 (29.8)	150 (37.9)	
Professional or graduate degree	29 (8.3)	69 (17.4)	
Employment status, n (%)			<.001
Employed full-time	153 (43.7)	209 (52.9)	
Employed part-time	74 (21.1)	72 (18.2)	
Not employed, looking for work	47 (13.4)	48 (12.2)	
Not employed, not looking for work	23 (6.6)	42 (10.6)	
Retired	14 (4.0)	19 (4.8)	
Unable to work	39 (11.1)	5 (1.3)	
Marital status, n (%)			.005
Married	133 (38.0)	179 (45.1)	
Widowed	8 (2.3)	4 (1.0)	
Divorced or separated	43 (12.3)	25 (6.3)	
Single, never married	129 (36.9)	161 (40.6)	
Living with a partner	37 (10.6)	28 (7.1)	
Ethnicity, n (%)			.63
Hispanic	26 (7.5)	33 (8.5)	
Non-Hispanic	324 (92.5)	364 (91.5)	
Race, n (%)			.31
American Indian or Alaska Native	2 (0.6)	2 (0.5)	
Asian	18 (5.1)	30 (7.6)	
Native Hawaiian or other Pacific Islander	0 (0.0)	1 (0.3)	
Black or African American	25 (7.1)	25 (6.3)	
White	286 (81.7)	309 (77.8)	
Other	4 (1.1)	10 (2.5)	
Mixed	15 (4.3)	20 (5.0)	

[a] RMDQ: Roland Morris Disability Questionnaire.

[b] Tests of significance were Wilcoxon rank sum test for nonnormally distributed continuous variables (age), and Pearson chi-square test for categorical variables (education, employment, marital status, ethnicity, and race). Race was recategorized into Asian, black or African American, white, and other to perform the test of significance, but the original categories are displayed here. *P*<.05 was considered significant.

[c] N/A: not applicable (no *P* value is reported for RMDQ score, since this was used to divide the groups).

Table 2. Ranked (by number of votes) research priorities[a].

Research topics	Back pain rank (frequency)	No back pain rank (frequency)
Treatment—self-care	1 (176)	2 (213)
Treatment—cost effective	2 (165)	3 (183)
Diagnosis—causes	3 (149)	1 (219)
Diagnosis—effective tests	4 (145)	5 (143)
Treatment—physical health programs	5 (128)	6 (132)
Prevention—disability reduction	6 (120)	4 (163)
Treatment—patient factors predicting good response	7 (115)	7 (130)
Treatment—primary care services	8 (111)	9 (95)
Outcome measures—treatments	9 (105)	10 (91)
Communication—provider education	10 (80)	12 (78)
Communication—patient education	11 (64)	10 (91)
Work and disability—benefits and compensation	11 (64)	15 (54)
Prevention—reduced disability	11 (64)	8 (101)
Treatment—mental health	14 (61)	17 (52)
Communication—evidence dissemination	15 (53)	15 (54)
Work and disability—return to work	16 (49)	14 (60)
Clinical definition—definition of low back pain	17 (47)	13 (62)
Outcome measures—expectations	18 (46)	17 (52)

[a] Research topics were ranked by frequency of being most important (#1 to #5). Rank lists are divided by group (back pain vs no back pain) and ordered by rank of the back pain group.

Table 3. Qualitative and quantitative differences in the additional comments between groups (back pain vs no back pain)[a].

Comparative factors	Back pain (n=350)	No back pain (n=397)	*P* value
Individual people who commented, n (%)	53 (15.1)	44 (11.1)	.10
Total comments, n	95	95	
Average word count	17.3	8.3	<.001
Average character count	99.8	49.9	<.001
Quality label [b]			
“No information:” off-topic, no reference to back pain, n (%)	5 (5)	16 (17)	.02
“Some information:” identifies a general topic area, but neither specifies a question within a broad topic nor gives context of their comment, n (%)	48 (51)	36 (38)	
“Rich information:” identifies a general topic and either specifies an area or question within a broad topic or gives insight about the study population, n (%)	42 (44)	43 (45)	

[a] Tests of significance were Wilcoxon rank sum test (word count, character count), chi-square test.

[b] Percentages, noted in parentheses, were calculated as a proportion of the total comments in each group, back pain and no back pain, both of which had 95 comments.

Table 4. Topic areas identified by additional comments, by back pain group, subdivided by quality of the comment.

Topic areas	Back pain (RMDQ[a] ≥7)		No back pain (RMDQ <7)	
	All (n=95)	Topics labeled “rich information” (n=42)	All (n=95)	Topics labeled “rich information” (n=43)
Treatment, n (%)	44 (46)	21 (50)	58 (61)	29 (67)
Communication, n (%)	13 (14)	2 (5)	6 (6)	3 (7)
Prevention, n (%)	11 (12)	6 (14)	3 (3)	1 (2)
No codes applied, n (%)	10 (11)	3 (7)	15 (16)	4 (9)
Epidemiology, n (%)	9 (9)	6 (14)	10 (11)	6 (14)
Diagnosis, n (%)	8 (8)	4 (10)	1 (1)	0 (0)
Work and disability, n (%)	4 (4)	0 (0)	2 (2)	1 (2)
Outcome measures, n (%)	3 (3)	1 (2)	1 (1)	0 (0)

[a] RMDQ: Roland Morris Disability Questionnaire.

We grouped the topic areas of additional comments into 13 overarching categories, some of which are shown in Table 4. Of note, research topics related to treatment were suggested most commonly by both groups, followed by prevention-related topics in the back pain group and epidemiology-related topics in the group without back pain. Considering only the additional comments that were coded as “rich information” (44% from the group with back pain; 45% from the group with no back pain; Table 3), the distribution of topics was largely unchanged (see Table 4).

Discussion

Overview

To our knowledge, our work is novel in its use of the MTurk platform for obtaining input on research prioritization and its application of a patient-reported outcome measurement tool to select a cohort from a crowdsourced sample [14]. In fact, only recently has crowdsourcing been used outside of the realm of behavioral and psychological investigations for patient engagement research, and specifically for research prioritization determination [21-23]. The implications of this work are potentially far-reaching: understanding the strengths and limitations of crowdsourcing techniques is important given both the need to engage the public in research activities and the ease of use of platforms such as MTurk.

Obtaining patient and public input and including a diversity of perspectives has posed and remains a challenge. While crowdsourcing platforms can provide a large and often captive audience, finding the right individuals to engage—whether by using a screening survey or by some other method—adds a layer of difficulty. We therefore sought to understand how those with a condition would rank research topics compared with those without a condition. In the context of low back pain, a prevalent condition, the research topic rank lists of those on MTurk with back pain and those without were very similar, with agreement on 4 of the top 5 and 9 of the top 10 topics. However, we found nuanced differences in the ranked lists of research topics and the additional commentary. The groups differed in that those with back pain ranked topics related to treatment as #1 and #2, whereas those with no back pain ranked topics related to diagnosis as their top priority. While the rate at which participants provided additional commentary was similar between groups (15% in the back pain group and 11% in the no back pain group), the level of detail and length of free-text answers differed: those with back pain who provided comments wrote more than twice as much as those without back pain (see Table 3).

In addition, those with back pain provided comments that were longer and of marginally higher quality than those without back pain, and this difference in quality was statistically significant. As compared with traditional methods, MTurk can be used as one method to prioritize research topics in a short time frame. However, given that those without the experience of back pain provided shorter and less content-rich additional comments, a central challenge of using a crowdsourcing method like MTurk will be adequately selecting those participants whose opinions are most representative of the population in question.

Comparison With Other Approaches for Obtaining Input on Research Priorities

Patient engagement aims to involve those affected by research findings in the research design and implementation process. This study sought to understand the priorities of a broad population through MTurk. Crowdsourcing as an engagement tool could expand the research community’s ability to obtain input throughout the research process, delivering a broad reach to individuals and timely feedback. This study furthers prior work to determine how crowdsourcing could be used for research prioritization, and specifically whom to study [23].

There are no formal criteria by which to evaluate the various types of patient engagement activities [3,24]. How, then, can a team of researchers determine appropriate patient engagement activities for the purpose of research prioritization among the various options available? Those seeking to engage with and learn the opinions of a targeted patient population must weigh several factors in designing outreach and engagement activities, including the ease of implementation, and time and cost requirements; the ability to obtain a representative sampling of opinions from the target population; and the likelihood of those opinions being informative toward answering the overall question. Traditional methods have included focus groups, one-time questionnaires, Delphi technique, voting, and structured group discussion [3]. These methods may be prohibitive due to resource constraints or potentially being nonrepresentative of a target population [25].

In the context of back pain, a prevalent and easily understood condition, we found the rank list of research priorities among those with back pain to be very similar to the rank list among those without back pain. The wide reach of MTurk coupled with its ease of use adds to its appeal. MTurk provides a platform to connect with a broad audience quickly as compared with other traditional survey- or interview-based methods of engagement. While concern exists that MTurk participants can "game the system," providing false answers in order to earn more and therefore undermining the validity of the data [4], participants provided thoughtful comments about their experiences in our analysis. It seems, then, that for back pain research, crowdsourcing and MTurk are viable patient engagement activities. Future research is needed to explore the relationships between the prevalence of the condition in question and the degree of correlation in research prioritization among those with the condition versus those without.

It must be noted that a core principle of engagement is relationship building [3,26]. The use of MTurk is limited in that the policies of the platform prohibit follow-up communication. Thus, it is limited to more consultative and cross-sectional approaches for obtaining input on research activities. The importance of this point will depend on the purpose of the engagement activity, although as others have advocated, it may be best to view crowdsourcing as a complement rather than a replacement for interviews, in-person meetings, and other conversational techniques [21].

Limitations

Our study has several key limitations necessary to contextualize our results and conclusions.

First, dividing our study groups using a threshold cutoff of the RMDQ may have yielded a less-specific determination of back pain versus no back pain, meaning that some with a high RMDQ score, and thus a designation of back pain, may not truly have had a medical diagnosis of low back pain. Moreover, the RMDQ identifies those with current back-related disability and, given the prevalence of the disease itself, many of those categorized as having no back pain may have had it in the past, granting insight into the condition. In addition, we performed 2 separate screening surveys during different times of the year, and this could have biased our groupings.

Second, we did not specifically ask individuals about whether they had sought health care for their back pain. Health care utilization and knowledge about health care seeking may be important for some engagement activities and disease topic areas. For this work on back pain, we decided that the opinions and perspectives of people with back pain—regardless of their health care access or utilization—would give valuable and potentially different insights from a sample derived using noncrowdsourced approaches.

Third, there are limitations to generalizing the results derived from an MTurk sampling. Recruitment with MTurk becomes subject to various selection filters that can introduce bias: the MTurk population can vary by time of day and day of the year [7]. Our MTurk study population was younger, more highly educated, less representative of minority races, and with proportionately more females than the US population as a whole [20,27]. Prior studies on how the MTurk population compares with the general population have noted that MTurk participants are younger and more educated, with an overrepresentation of white and Asian races [7]. This makes sense, given the barriers to entering the MTurk market: access to a computer and reliable Internet connection, having a baseline technological literacy, and establishing an online method to receive payment for tasks.

Conclusion

This work contributes to an understanding of the strengths and weaknesses of using MTurk in patient engagement activities, and specifically research prioritization. MTurk provides a rapid, easy-to-use, and relatively inexpensive method of obtaining public opinion. We found that, while the groups ranked research topics similarly, there were subtle differences in the content and quality of free-text comments. Given these differences, we suggest that supplemental efforts may be needed to augment the reach of crowdsourcing in obtaining the patient's voice, especially from specific populations.

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Conflicts of Interest

BAC is a cofounder of C-SATS, Inc., a start-up company that uses crowdsourcing to evaluate intraoperative technical skills performance. The work presented in this paper was not conducted by nor has any relationship with C-SATS. JGJ is a Section Editor for UpToDate for which he receives personal fees; is a cofounder, stockholder, and intellectual property holder for PhsyioSonics, a high-intensity focused ultrasound company; has received royalties from Spring Publishing; holds grants from NIH, Agency for Healthcare Research and Quality (AHRQ), and PCORI, during the conduct of the study; and receives personal fees from HealthHelp, radiology benefits management company.

Multimedia Appendix 1

Mechanical Turk survey including the Roland Morris Disability Questionnaire and prioritization survey.

[PDF File (Adobe PDF File), 603KB - jmir_v19i10e341_app1.pdf]

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Abbreviations

MTurk: Mechanical Turk
RMDQ: Roland Morris Disability Questionnaire
REDCap: Research Electronic Data Capture

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Original Paper

eHealth System for Collecting and Utilizing Patient Reported Outcome Measures for Personalized Treatment and Care (PROMPT-Care) Among Cancer Patients: Mixed Methods Approach to Evaluate Feasibility and Acceptability

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Abstract

Background: Despite accumulating evidence indicating that collecting patient-reported outcomes (PROs) and transferring results to the treating health professional in real time has the potential to improve patient well-being and cancer outcomes, this practice is not widespread.

Objective: The aim of this study was to test the feasibility and acceptability of PROMPT-Care (Patient Reported Outcome Measures for Personalized Treatment and Care), a newly developed electronic health (eHealth) system that facilitates PRO data capture from cancer patients, data linkage and retrieval to support clinical decisions and patient self-management, and data retrieval to support ongoing evaluation and innovative research.

Methods: We developed an eHealth system in consultation with content-specific expert advisory groups and tested it with patients receiving treatment or follow-up care in two hospitals in New South Wales, Australia, over a 3-month period. Participants were recruited in clinic and completed self-report Web-based assessments either just before their upcoming clinical consultation or every 4 weeks if in follow-up care. A mixed methods approach was used to evaluate feasibility and acceptability of PROMPT-Care; data collected throughout the study informed the accuracy and completeness of data transfer procedures, and extent of missing data was determined from participants' assessments. Patients participated in cognitive interviews while completing their first assessment and completed evaluation surveys and interviews at study-end to assess system acceptability and usefulness of patient self-management resources, and oncology staff were interviewed at study-end to determine the acceptability and perceived usefulness of real-time PRO reporting.

Results: A total of 42 patients consented to the study; 7 patients were withdrawn before starting the intervention primarily because of changes in eligibility. Overall, 35 patients (13 on treatment and 22 in follow-up) completed 67 assessments during the study period. Mean completeness of patient-reported data was 93%, with 100% accuracy of data transfer. Ten patients completed cognitive interviews, 28 completed evaluation surveys, and 14 completed evaluation interviews at study-end. PROMPT-Care patient acceptability was high—100% (28/28) reported the time to complete the Web-based assessments (average

15 min) as *about right*, most willing to answer more questions (79%, 22/28 yes), 96% (27/28) found the Web-based assessment *easier or same as* completing a paper copy, and they valued the self-management resources . Oncology staff (n=5) also reported high acceptability and potential feasibility of the system.

Conclusions: Patients and oncology staff found the PROMPT-Care system to be highly acceptable, and the results suggest that it would be feasible to implement it into an oncology setting. Suggested modifications to the patient assessment survey, clinician access to the reports, and system requirements will be made as part of the next stage of large-scale testing and future implementation of the system as part of routine care.

Trial registration: Australian New Zealand Clinical Trials Registry ACTRN1261500135294; https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=369299&isReview=true (Archived by WebCite at http://www.webcitation.org/6lzylG5A0).

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KEYWORDS

patient reported outcome measures; eHealth; self-management; medical oncology; patient-centered care; electronic health records

Introduction

Routinely collecting and utilizing patient-reported outcome (PRO) measures enables better patient-centered care [1-4]. Recently published research demonstrates improvements in clinical and health service outcomes, including reduced emergency room visits, longer tolerability of chemotherapy, and improved short- and long-term survival [5,6].

Our published protocol [7] details the proposed methodology for developing and testing the acceptability and feasibility of PROMPT-Care (Patient Reported Outcome Measures for Personalized Treatment and Care), an electronic health (eHealth) system that supports routine collection and analysis of cancer patients' PROs, real-time feedback of PRO results to their cancer care team to inform patient-centered care, and delivery of evidence-based self-management information to address patient-reported problems. As reported in the protocol, the key feature distinguishing PROMPT-Care from previous oncology-based eHealth systems is its integration into the hospital's point-of-care oncology information system (OIS).

The objectives of our feasibility study were as follows:

1. To develop an eHealth system that is integrated into the OIS (MOSAIQ, Elekta) to support the assessment of cancer patients' PROs through the use of electronically administered standardized assessment tools, provision of *real-time* feedback of the results to their treating clinicians, and generation of links to self-management resources for patients, which are tailored to their PROs. This includes developing a production version of the PROsaiq prototype system [8].
2. To implement the pilot version of PROMPT-Care at two hospitals and test the feasibility and functionality of the system.
3. To test the acceptability of the pilot version of PROMPT-Care in a sample of cancer patients and clinicians at the two participating hospitals.

The term *patient* used throughout this document encompasses all people diagnosed with cancer who are currently on treatment and in follow-up.

Methods

The detailed study methods have been previously outlined in the study protocol [7]. The following is a summary of these methods.

Study Design and Objectives

Setting

The feasibility study was undertaken in the cancer centers of two public hospitals, Liverpool and Wollongong, in New South Wales, Australia. Ethics approval was obtained from the Human Research Ethics Committee of South Western Sydney Local Health District (Reference Number HREC/14/LPOOL/405), with Site Specific ethics approvals obtained for Liverpool Hospital and Wollongong Hospital.

Development of the PROMPT-Care eHealth System

To facilitate the development of key clinical and technical aspects of the PROMPT-Care system, a clinical advisory group and a technical advisory group were established, as detailed in the protocol [7].

Selection of PRO Measures and Assessment Frequency

The clinical advisory group identified distress, symptoms, and unmet needs as the PRO domains to include in this initial feasibility study, with these domains being the most important for informing patient care and most amenable to evidence-based intervention. Following a comprehensive review of measures, the Distress Thermometer [9] with the problem checklist [10], the Edmonton Symptom Assessment Scale (ESAS) [11], and the Supportive Care Needs Survey-Screening Tool 9 (SCNS-ST9) [12] were selected for inclusion in the PROMPT-Care assessment. For each of the selected PRO measures, item or scale cut-off scores differentiating between *normal* (below threshold—no intervention required) and *clinical* (above threshold and therefore flagged for review or intervention) responses were determined. For each measure, *clinical* thresholds were as follows: a score ≥5 for DT [9], any item checked *yes* for the Distress Thermometer checklist items, a score of ≥4 for ESAS items [11], and a rating of 4 or 5 (ie, moderate or high unmet need) on the SCNS-ST9 [12].

The clinical advisory group also determined the frequency of patients completing the PRO assessments as approximately every 2 weeks for patients who were currently receiving treatment and approximately monthly for those who were in follow-up. It was agreed that the feasibility and acceptability testing would inform future assessment frequency.

Development of Algorithms to Guide Response to PROs

A multidisciplinary clinical algorithms working group (n=8; medical and radiation oncologists, social worker, clinical psychologist, and care coordinators) developed actionable recommendations for each item that breaches the clinical threshold, with a total of 15 recommendations developed across the main categories of (1) *No action required*, (2) *Consider reasons for concern and, if required, refer to (types of specialties indicated here, depending on issue) for further assessment and care*, (3) *Clinically address as appropriate OR refer to (types of specialties indicated here, depending on issue) for further assessment and care*, and (4) *Address (type of) needs and identify appropriate sources of support and information.*

Development of PRO Clinical Feedback Reports

Two report formats were developed in consultation with the clinical advisory group members: (1) a summary report of the patient's most recent PROMPT-Care assessment, which included the relevant actionable recommendations (from the 15 developed by the clinical algorithms working group) and (2) a longitudinal report summarizing the PROs over time. The reports utilized graphics and colors to readily highlight issues of patient concern—samples of these reports are included in the protocol publication [7].

Collation and Review of Patient Self-Management Resources

A self-management working group (subgroup of the clinical advisory group) identified and reviewed readily available self-management resources in each of the PROMPT-Care assessment domains with those meeting the selection criteria [7] then included on the five domain-specific pages (physical well-being, emotional well-being, social and family well-being, practical support, and maintaining health and well-being) hosted on the Cancer Institute NSW (CINSW) eviQ website [13]. Patients received links only to the pages that were relevant to them, that is, where their scores on any item in that domain breached threshold. Additionally, all resource pages included national cancer support services such as the Cancer Council and Lifeline hotlines and the emergency services.

Participants

Patients

At the two participating sites, patients who were currently receiving cancer care (including follow-up care) or had recently been diagnosed with cancer and were scheduled to commence cancer treatment were eligible to participate. Eligibility criteria included (1) having a confirmed diagnosis of cancer, (2) aged 18 years or older, (3) cognitively able to provide informed consent and understand the assessments, and (4) having sufficient English skills to complete the survey in English. Exclusion criteria were (1) having a diagnosis of a blood cancer and (2) not having access to the Internet outside the clinic.

Staff

All staff who provided care in the oncology departments at the participating hospitals during the study period were eligible to participate, with the exception of those who were directly involved in the development of key aspects of the PROMPT-Care system (GPD and AM).

Procedure

The following is a summary of the feasibility study procedures. More detailed procedures are included in the protocol [7].

Oncology Team Training

During the setup phase, oncologists and other staff (including nurse care coordinators and allied health staff) from the two participating cancer centers were introduced to the PROMPT-Care program through presentations and training resources to explain the purpose of PROMPT-Care and how to access and interpret the reports.

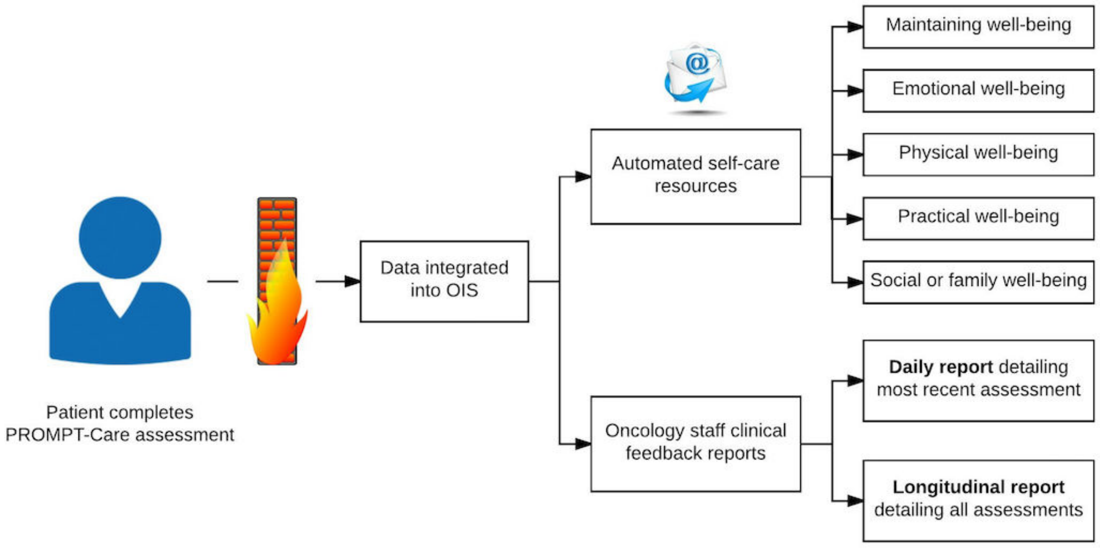
Patient Recruitment

Participating clinicians reviewed their patient lists for the upcoming 4 to 6 weeks and identified eligible patients who were then mailed an information and consent pack and telephoned by the research staff to confirm eligibility and to obtain verbal consent. Participants were then assigned a unique study identifier to ensure anonymity during analysis. Consenting patients attended a PROMPT-Care appointment 20 min before their upcoming scheduled appointment at the cancer center to complete study paperwork and their first PROMPT-Care assessment, with research staff available to assist patients who needed help completing the assessments.

PROMPT-Care Assessments

Patients who were on treatment completed the PROMPT-Care assessment every 2 to 4 weeks, depending on the schedule of their review appointments, and those on follow-up completed assessments approximately monthly. Patients attending the clinic for an appointment completed the PROMPT-Care assessment in the waiting area using an electronic tablet device provided by the research team, and follow-up patients either completed their PROMPT-Care assessment from home via a link sent by email or in the clinic if they were attending for a review appointment. Patients who were due to complete their PROMPT-Care assessments from home were sent one reminder email if they had not completed it within the requested time frame (48 hours). Submitted data were stored on a secure server hosted by the hospital OIS (MOSAIQ). To ensure successful transfer of assessment data to the OIS, two patient identifiers, surname and unique medical record number, were used at survey log-in. Patients were able to review and change responses by navigating back and forward buttons and were able to save a draft copy before submission. An overview of the PROMPT-Care pilot eHealth system is described in Figure 1.

Figure 1. Simplified representation of the PROMPT-Care pilot eHealth system.



Access and Review of Reports

All patients participating in this PROMPT-Care feasibility study were flagged as *PROMPT-Care Trial* participants on the OIS used by the participating sites, with clinicians instructed to access the report during the consultation, review any issues flagged as problematic by the patient (ie, scores above threshold), discuss these with the patient, and take any appropriate actions to address the issues.

Patient Self-Management

Upon completion of the PROMPT-Care assessment, patients received an email with links only to the website pages of the domains in which they breached threshold scores on any of the items in that domain. Patients who scored below threshold on all items received the link to a *maintaining health and well-being* page.

Evaluation of Acceptability of PROMPT-Care

The functionality and acceptability of the PROMPT-Care eHealth system was tested at the two participating hospitals with a focus on the assessment of the accuracy and completeness of data transfer procedures (from the point of the patient completing an assessment to a report appearing via MOSAIQ), the extent of missing data from participants' assessments, the acceptability of the eHealth system and usefulness of the self-management resources, and the acceptability and perceived usefulness of the real-time PRO reporting.

Cognitive Interviews

A subset of participants volunteered to take part in cognitive interviews [14], including a combined think-aloud and verbal probing technique [15], the first time they completed the PROMPT-Care assessment. The cognitive interviews were used to identify issues with participant item comprehension, recall, and judgment and ability to use the Web-based PROMPT-Care assessment tool.

Patient Surveys and Interviews

Participants completed a Web-based evaluation survey at the end of the trial period. The evaluation survey explored several elements of user acceptability and feasibility such as device usage, attitude toward electronic PRO collection (eg, privacy, ease of completion, and time to complete), willingness to answer more questions, and preferred frequency of assessment completion. They also rated the perceived usefulness of the self-management resources and review of clinical feedback reports during consultations. A subset of participants were invited (based on their evaluation survey responses) to participate in a brief semistructured telephone interview to further explore their experience with the eHealth system and the usefulness of the self-management resources.

Oncology Staff Interviews

Participating oncology staff were invited to participate in a brief semistructured telephone interview at study completion to provide feedback on the feasibility and acceptability of the PROMPT-Care system. Specifically, the interviews explored the ease of access, relevance of content, and usefulness of the feedback reports.

Data Transfer and Completeness

Patient data regarding clinical details, response counts, PROMPT-Care assessments, and time taken to complete each assessment were extracted from the OIS system and provided to the research team. Additionally, user and technical errors observed were monitored and recorded by research staff.

Analysis

Descriptive statistical analysis was conducted using OIS system data and patient evaluation surveys. User and technical errors recorded in error logs were analyzed using content analysis. All patient and health care provider interviews were digitally recorded and transcribed verbatim. Evaluation interviews were analyzed using thematic content analysis. Four experienced psycho-oncology or health services researchers (JL, ID, TS, and MG) reviewed the transcripts independently and developed preliminary coding schedules, with discrepancies resolved through discussion and consensus. Cognitive interviews were analyzed using content analysis. Transcripts were reviewed by 2 researchers (TS and HC) using a coding framework adapted from Willis [15], with differences resolved by a third reviewer (ID) and consensus reached.

Results

User Characteristics

During the 3-month recruitment period, 205 patients were approached, and 42 (20.5%) patients consented to participate in the program. Seven patients were withdrawn before starting the program: one because of health issues, 2 patients because of changes in personal circumstances, and 4 participants were no longer contactable by email. Overall, 35 patients were involved in testing the usability of the PROMPT-Care system, of whom 28 completed evaluation surveys, 14 participated in evaluation interviews, and 10 participated in cognitive interviews. Table 1 lists participants' clinical and demographic information. Mean age of participants was 62 years (range: 39-85 years; standard deviation=11.2), and 69% (24/35) of the participants were female. Participants had been diagnosed with a range of cancers; 13 participants were currently receiving active treatment and 22 were receiving follow-up care. Patients reported diverse views on their preferred frequency of assessment completion, with 36% (10/28) preferring specific milestones in treatment (eg, start or end of treatment and first follow-up visit), 33% (9/28) at specific time points (eg, monthly, quarterly, and biannually), and 21% (6/28) preferred completing assessments before every clinic appointment.

The 5 oncology staff involved in the pilot study included 1 medical oncologist, 2 radiation oncologists, 1 nurse, and 1 health services manager.

Feasibility Evaluation

Assessment of Data Completeness

Overall, participants completed 67 (77%, 67/87) assessments, each comprising 67 items (including demographics), totalling 4489 data items. Most (63%, 22/35) participants had completed at least two assessments, with 9 participants completing three assessments and 1 participant completing four assessments. Completeness of PROMPT-Care assessment survey data was high, with only 6.48% (291/4489) missing items. The items that were most commonly skipped by participants were assessment start and completion times and some demographic variables, which together represented 29.2% (85/291) of all missing data. No other pattern of missing data was observed among the remainder of items.

Data Transfer

Eight (12%, 8/67) instances of failed survey submissions from the point of a patient completing an assessment to initial data transfer into the OIS were observed. Each problem was investigated and resolved by study staff and assessment data subsequently transferred into the OIS. Errors experienced were due to either technical issues (n=5) such as rejection of data parameters by the OIS and Wi-Fi or browser problems within the clinics or were a result of patient end user errors (n=3) where participants entered incorrect patient identifiers such as surname or personal medical record numbers. However, once the errors were addressed and data were successfully received in the OIS, the accuracy of data transfer from the OIS to presentation in clinical feedback reports was 100.00% (4489/4489) across all data items submitted, with no errors in patient data noted in the reports.

Acceptability Evaluation

Patient Feedback

Usability of PROMPT-Care Tool to Complete Assessments

Overall, cognitive interviews (mean time: 30 min and range: 17-42 min) demonstrated that patients completed the PROMPT-Care assessments with ease and indicated that the items were not confronting or upsetting and that they captured all of their concerns. Most participants demonstrated a high understanding of the questions and were able to follow instructions appropriately. Additionally, no patients reported having difficulty changing response options for the different question sets and were easily able to adapt to the scales of the instrument. One participant felt that the variety of response formats (Distress problem checklist, *yes or no*, ESAS numeric *0-10* scale, and SCNS TS-9 5-point Likert scale *no need-high need*) should be retained, as a single response type such as yes or no held potential for automated thoughtless assessment completion and could lead to error.

Of the 10 participants who completed a cognitive interview, 2 demonstrated difficulty with recall strategies and appeared to answer items outside the instrument time frames. They were also observed to answer questions generally and not specifically in relation to their cancer experience and/or care.

The Distress Thermometer was presented as a graphic in the Web-based assessment, in line with its original display [16], with patients required to slide a bar up to the score signifying their level of distress (0-10). However, half of the cognitive interview participants experienced difficulty completing this item, particularly with reading the font and selecting their desired response option because of the widget layout. They often required assistance from the interviewer to input their score.

Additionally, minor issues in comprehension and judgment errors were observed among a variety of items, for example, insurance, family health issues, housing, feeling swollen, and fear of cancer spreading. However, they were deemed unproblematic as participants self-resolved queries and provided reasonable insight into their thought process and how they arrived at their responses.

Table 1. Participant characteristics (N=35).

Participant characteristic	n (%)
Age in years	
Range	39-85
Mean (standard deviation)	62.23 (11.2)
Sex	
Male	11 (31)
Female	24 (69)
Site of cancer	
Breast	20 (57)
Gastrointestinal	7 (21)
Gynecological	1 (3)
Prostate	7 (20)
Treatment	
Surgery	14 (25)
Chemotherapy	17 (31)
Radiotherapy	24 (44)
Patient type	
Active treatment	13 (37)
Follow-up	22 (63)
Relationship status[a]	
Single	7 (20)
Married or partnered	26 (74)
Education status[a]	
Secondary school	13 (37)
Postsecondary education	20 (57)
Employment[a]	
Employed	12 (34)
Retired	19 (54)
Other	1 (3)

[a] Some level of missing data.

Use and Satisfaction With PROMPT-Care Assessments

Overall, patients reported high acceptability and valued completing the assessments, as expressed below:

> *It actually gave me a handle to express something that I hadn't—couldn't figure out how to express to the person [doctor] I was speaking to, and it prompted them to ask me...it allowed me to have a clear avenue of what I wanted to say* [PT01, patient interview]
>
> *I do really think it is an excellent idea and it's a valuable tool.* [PT02, patient interview]
>
> *It [PROMPT-Care assessment] makes you think about yourself when you're completing the questionnaires, which is something we tend to overlook sometimes.* [PT03, patient interview]

Patients (n=28) who actively used PROMPT-Care were surveyed about their acceptance of the eHealth system, satisfaction with the self-care resources, and use of clinical feedback reports during consultations. All patients reported the time to complete assessments (mean time: 15 min) was *about right*, and most were willing to answer more questions (79%, 22/28 yes).

All participants reported they had enough privacy to complete their assessments, and 96% (27/28) had no concerns about which oncology staff member was going to review their responses. The only participant who expressed some concern about staff reviewing their assessments did not have any issues requiring additional support and, as a result, did not realize that his or her clinical feedback report would be reviewed:

> *Not looking for call to action based on my results. I found that invasive. I assumed you were using data*

> *to improve ongoing care and support for general public.* [PT04, evaluation survey]

Additionally, most patients (75%, 21/28) found electronic patient-reported assessments to be easier than completing assessments by pen-and-paper; 21% (6/28) found it to be similar, whereas only one (4%) participant found it to be more difficult.

Satisfaction With Self-Management Resources

Almost half (43%, 12/28) of the patients spent between 11 to 20 min reviewing the self-management resources at any one time, and 39% (11/28) reported they were very satisfied with the resources provided. Whereas most patients felt the self-management resources were easy to understand and navigate (61%, 17/28) and were easy to access from the link sent via email (61%, 17/28), only half (54%, 15/28) reported they were relevant to their concerns (see Table 2).

Furthermore, qualitative interviews showed that most patients valued the self-management resources, noting that they provided relevant information and came from reliable approved sources. Patients felt that the information prompted them to be more engaged in their own health:

> *I changed my diet quite a lot...all the information encouraged me...you realize you got to do these things if you want to get better.* [PT05, patient interview]
>
> *...I found them [self-management resources] very interesting. Being able to go over to different sites and suggestions...I found them useful.* [PT03, patient interview]
>
> *It's [self-management resources] probably the ones I have referred to when I was first diagnosed and researching for what was going on, and also amplifies or complements all the booklets. They're very well-designed and easy to navigate.* [PT05, patient interview]
>
> *It's pretty good. I've been having treatment for 4.5 years now and the self-management resources—I knew quite a bit of it but there were still a few ideas that were new to me. But I think as a new patient, they're excellent.* [PT06, patient interview]

However, some patients expressed a desire for more targeted resources specific to their needs and suggested that the level of tailoring needs to be improved. They considered the advice listed on the pages as general, with resources addressing a variety of issues on the Web page. All self-management resource links relating to each corresponding domain of well-being were presented on a single page, whereas patients indicated they would have preferred an email with resources only related to the specific items they had issues with. The participants stated:

> *The email links for the self-management resources were just a link to the main website and should have been a direct specific link to the issue.* [PT09, patient interview]
>
> *...when I looked at it, it was a lot of other things in there. I really had to hunt for anything that was directly related to me.* [PT07, patient interview]

Impact on Clinical Care

Due to the short study period, only 11 of the patients who took part in evaluation interviews had seen their treating doctor. These participants had mixed opinions about the value of discussing their PROMPT-Care assessment results during consultations. Only 3 patients recalled discussing their assessment report during consultations but felt that it facilitated communication and increased recognition and acknowledgment of their concerns:

> *Yes it did. It [PROMPT-Care] really did [help], because you were more than just the cancer. Your life is more than just cancer...And as a result, she [clinician] said did I want to be referred to a psychologist.* [PT08, patient interview]
>
> *It [PROMPT-Care] actually came up [in consultation] straight away and it actually gave me a handle to express something that I hadn't—couldn't figure out how to express to the person I was speaking too. And it prompted them to ask me questions.* [PT01, patient interview]

Additionally, another 3 patients indicated they would have liked to have discussed their responses with their specialist but were not given the opportunity. The remaining patients felt they had no need or did not see any benefit of discussions with their specialist, with one patient noting that the self-management resources adequately dealt with their concerns:

> *No, 'cause I think I'm quite an upbeat person and—yeah. I don't think I would've gotten anything from that other than maybe what I've got from the website.* [PT05, patient interview]

Furthermore, the vast majority of interviewed patients indicated they saw great benefit in their general practitioner (GP) receiving a copy of their clinical feedback reports in the future. They felt that it would be a good approach for their GP to keep up to date on their cancer care. Patients also commented that it held potential to reduce unnecessary repetition of information and ensure that key information regarding their treatment and clinical care was not forgotten or overlooked. One patient noted:

> *Definitely. Definitely. I have no problems with them receiving anything and I think it saves me then having to go and then try to explain everything and I will forget things. It is the ideal for him to have as much information as they had about whatever is going on with me.* [PT05, patient interview]

Table 2. Summary of self-management resource evaluation (N=28).

Self-management resource evaluation		n (%)
Overall satisfaction with resources[a]		
	Satisfied or very satisfied	11 (39)
	Neutral	7 (25)
	Unsatisfied or very unsatisfied	2 (7)
Time spent accessing resources, in minutes[a]		
	0-10	9 (32)
	11-20	12 (43)
	21-30	0 (0)
	Greater than 30	1 (4)
Place where resources were accessed[a]		
	At home	17 (55)
	At work	2 (6)
	In a public place	2 (6)
	At a family or friend’s house	1 (3)
Shared resources with others[a]		
	Yes	5 (18)
	No	17 (61)
Easy to access via email sent[a]		
	Strongly agree or agree	17 (61)
	Neutral	4 (14)
	Strongly disagree or disagree	1 (4)
Relevant to concerns[a]		
	Strongly agree or agree	15 (54)
	Neutral	6 (21)
	Strongly disagree or disagree	1 (4)
Easy to understand and navigate[a]		
	Strongly agree or agree	17 (61)
	Neutral	4 (14)
	Strongly disagree or disagree	1 (4)
Helped to personally deal with some concerns[a]		
	Strongly agree or agree	7 (25)
	Neutral	8 (29)
	Strongly disagree or disagree	3 (11)

[a] Some level of missing data.

Oncology Staff Feedback

Overall, all staff reported high acceptability of the eHealth system. Oncology staff indicated that the PROMPT-Care system was a useful screening tool that allowed them to identify specific issues to raise with the patient during consultations, and the clinical feedback reports allowed them to adequately prepare for the upcoming consultation:

> *[PROMPT-Care] would sort of give a greater value to the time they spent because it would be troubleshooting in a very sort of quick way. So it’s a tool for troubleshooting. It gives better value for patients in terms of what they get out of the consultation.* [HCP04, staff interview]
>
> *Well, I quite liked the physical problems [checklist] because patients sometimes forget to tell us things,*

> *and/or they don't think things are important...So, from that point of view, it sort of gave me a quick look and targets the consultation a bit more.* [HCP01, staff interview]

They also felt the clinical feedback reports enabled them to get to know their patients better, provided them with an in-depth understanding of their patients' issues and needs, and created an opportunity to discuss sensitive topics:

> *I would have an impression about a patient that things weren't going fantastically, but it [clinical feedback reports] gave greater granularity and specificity about where the needs were.* [HCP04, staff interview]

Oncology staff also suggested that PROMPT-Care brought patients back into the system when issues remained unresolved and enabled them to better support patients through referral to appropriate supportive care options and health care professionals:

> *A lady who I know has a very high level of anxiety. So, I contacted her because I was surprised that she had still identified these factors as I thought she had turned a corner. So, it was good from that point to catch up with her...So, I sent a letter to her GP notifying about that.* [HCP02, staff interview]

However, some oncology staff mentioned concern that some patient responses were not directly related to their cancer care and could lead to difficulty interpreting patient responses and problems. Additionally, some felt that certain emotional issues, such as anxiety and fear of cancer recurrence, could not be resolved regardless of information and support provided. They felt that these elements of care could possibly be better followed up by appropriate nursing teams who could either address these ongoing concerns or refer the patient onto the appropriate services:

> *Part [of the clinical feedback report] was sort of more about family problems that often have things in there that there were stressors with their partner or whatever. But when I'd explore that a bit further with them, it would actually have nothing to do with the oncology situation...But when you go back and take the history, it hasn't been so good for the last 10 years. So, it's picking up a lot of things that are not specifically related to malignancy.* [HCP01, staff interview]

> *Looking at a report, if there were flags beyond the biological component of the cancer...did make their consultations probably double in time. So, if that was followed up by the care coordinator or the CNC [clinical nurse consultant] along those lines, that they had the time for it.* [HCP03, staff interview]

Some oncology staff commented that the assessments collected a large and diverse amount of information and felt that they were unable to adequately review all items and address the issues in a single short clinical consult. They felt that this had the potential to increase clinical workloads and extend consultation times, raising new issues in service delivery and patient care:

> *It's quite likely that the [PROMPT-Care] report has much deeper value or—significant value than my 3-minute or 5-minute time to explore these.* [HCP04, staff interview]

Additionally, one oncologist suggested that the assessments picked up issues that were already known to the clinical team, leading to information being communicated repetitively:

> *I...it's just putting the nuance context of it on each patient because for some of these patients everything is red...and many of the areas were [already] being addressed, and so anybody coming to it [the consultation] cold wouldn't really have that information and couldn't really sort of graduate their questioning or directly questioning.* [HCP05, staff interview]

Throughout training and pilot testing, all staff demonstrated relatively high competency with technology and overall ability to use the OIS. However, all 5 staff reported difficulty identifying which patients were on the PROMPT-Care trial and also initially locating the clinical feedback reports within the OIS because of a lack of familiarity with navigating the sections of the OIS in which the PROMPT-Care reports were located. They felt that these issues needed to be resolved and included in ongoing staff training in how to use the hospital OIS generally to avoid decreased usage of the PROMPT-Care system over time.

Discussion

The objectives of our feasibility study were to (1) develop a fully integrated eHealth system to support electronic assessment of cancer patients' PROs, feedback of PRO results in real time to their treating clinicians, and support of patients' self-management through generation of links to resources, which are tailored to their PROs; (2) implement the pilot version of PROMPT-Care at two hospitals and test the feasibility and functionality of the system and receive feedback to fine-tune any future system; and (3) test the acceptability of PROMPT-Care in a sample of cancer patients and clinicians at the two participating hospitals.

Overall, the results suggest that the PROMPT-Care eHealth system is both feasible and acceptable to the users, that is, the patients and cancer care team. This feasibility study also identified important modifications, particularly relating to patient assessment completion and clinician access to the reports, which should be undertaken to increase PROMPT-Care's acceptability and feasibility before its large-scale implementation during the next trial phase and for future implementation as part of routine care.

Patient Experience Completing Assessments

Data capture is a critical first step in any ePRO-based system. Study participants found the Web-based survey completion to be easy, consistent with published evidence of patients' preference for this mode compared with paper versions of surveys [17]. The length of time taken to complete the assessments (mean: 15 min) was also highly acceptable. Importantly, the results indicate very low levels of missing data, which were predominantly the assessment start and completion times and some demographic variables. This may reflect a perception by patients that these items were not important for informing either their clinical care or self-management. In the context of implementing this system as routine care, these fields are in fact the least important, with assessment start or finish times only collected in this pilot study to determine assessment completion time, and patient demographic characteristics can be accessed by the care team via patients' medical records through the OIS, when required. It is important to note that there were no other patterns of missing data observed.

The cognitive interviews highlighted areas where patients experienced some difficulties completing the PROMPT-Care assessment. First, the Distress Thermometer widget, which required patients to slide the cursor vertically to the number between 0 and 10 that best reflected their level of distress, was observed to be non-responsive for some patients or was not sliding to the exact number that patients were verbally reporting their distress score to be. As a result, modification for the next phase of this program will be made, with the thermometer widget abandoned in preference for a standard 11-point (0-10) scale item. Second, the differing time frames for each of the measures (ESAS *today*; Distress Thermometer and problem checklist *in the past week, including today*; and SCNS-ST9 *in the last month*) was unclear to some patients. As the PRO instruments used are validated, it is important to retain the time frames as per the originals. Therefore, the amendments for phase 2 will include provision of much clearer instructions that draw more attention to the time frame to consider when answering each item. Third, the cognitive interviews suggested that some of the patients' responses were not specifically in the context of their cancer experience (eg, childcare and dealing with partner or family). This was confirmed by some oncology staff, who expressed concern that some patients' responses were not directly related to their cancer care and could lead to difficulty interpreting patient responses and problems. Review of the PROMPT-Care assessment highlighted the need for greater specificity in the instructions for phase 2, which will ask patients to answer all questions only in relation to their cancer and cancer care experience. Finally, patient feedback suggested a need to simplify item response options to reduce response burden in the next phase of research (eg, only requiring patient to select *yes* if they were experiencing a particular Distress Thermometer Checklist issue—total of 39 issues—instead of having to select either *yes* or *no* for each of those issues).

Informing Clinical Care

Integration of the PRO measures into the existing hospitals' OISs was hypothesized to enhance their relevance and usefulness in informing routine cancer care [18,19]. However, it is worth noting that during this pilot phase, only 3 out of 11 patients who had appointments during the study period reported that their clinician discussed the PROMPT-Care report with them during their consultation. Whereas this suggests low clinician engagement, when the clinical feedback reports were reviewed, the clinicians felt that they enabled them to get to know their patients better, provided them with an in-depth understanding of their patients' issues and needs, and created an opportunity to discuss sensitive topics. They also believed that the report facilitated them concentrating on the issues highlighted as important by the patients. Furthermore, the 3 patients who recalled discussing their assessment report during consultations felt that it facilitated communication and increased recognition and acknowledgment of their concerns. It is therefore perhaps not the usefulness of the reports that limited their use but potentially other reasons. Identifying the PROMPT-Care trial patients and accessing the clinical feedback reports proved to be problematic for the 5 clinicians involved in the pilot phase. Hence, the opportunity to review the PROMPT-Care report may have been missed for the remaining 8 patients who had a consultation during the pilot phase. The clinicians interviewed in this study expressed the need for these issues to be resolved and included the importance of ongoing staff training, particularly with regard to accessing the reports within the OIS once assessment data had been imported. They also indicated that others from the cancer care team, such as the nurses, are well placed to review the PROMPT-Care reports and to act on their recommendations. It is also important to note that patients also saw great benefit in their GPs receiving reports detailing their treatment and clinical care, as a useful tool to enhance communication and reduce information repetition. These results underscore important modifications for the next phase of research, in particular, streamlining accessibility to the PROMPT-Care report and training all members of the cancer care team to access and respond to report content.

In the pilot configuration of the PROMPT-Care system (version 1), clinicians received an alert via the OIS when a PROMPT-Care patient was attending an appointment, which served as a trigger to review their report. However, the pilot study highlighted a need for alerting the cancer care team when PROMPT-Care patients who did not have a scheduled appointment (eg, follow-up patients) reported unresolved issues. As a result, version 2 of the PROMPT-Care system will incorporate a clinical email alert to inform the cancer care team of patients with ongoing issues to trigger appropriate action as per that cancer center's care agreed pathway.

Supporting Patient Self-Management

In addition to informing clinical care, the other key feature of the PROMPT-Care program was to support patient self-management, with patients receiving links to pages of information and resources based on their PROs. Patient feedback suggests that they valued the resources, appreciated having access to reliable information, and felt that the information prompted them to be more engaged in their own health. However, in version 1 of PROMPT-Care, patients received the domain page relevant to their concern even if they only reported one item above threshold. For example, if a patient only reported above-threshold pain, she or he would be sent the physical well-being page, which contains access to 29 resources. This resulted in only approximately half of the participants reporting the self-management resources to be directly relevant to their concerns. These results highlight the need for review and improvement of the self-management resources and consideration of a tiered approach in PROMPT-Care version 2, with generic information resources available for patients initially reporting an issue above threshold but more dynamic and interactive resources (eg, videos, podcasts, or interactive self-help programs such as *Coping-Together* [20] or the Cancer Council ENRICH [Exercise and Nutrition Routine Improving *Cancer* Health] survivorship program [21]) available when issues remain unresolved on a subsequent PROMPT-Care assessment.

Conclusions

An issue that remains unresolved from this pilot is the recommended frequency of PROMPT-Care assessments, with a diversity of responses from patients regarding this issue. This suggests that further evaluation of this aspect is required in the next phase of our research, particularly exploring whether different assessment frequency is required for patients on treatment versus in follow-up.

To our knowledge, this is the first study piloting an integrated PRO eHealth system in the Australian health care context. Although the patient participant numbers were small, our sample aligns with feasibility and usability testing recommendations, which suggest that a sample of 30 to 40 will allow for 97% to 98% of usability problems to be identified [22]. Additionally, Nielsen and Landauer's model suggests that most usability problems can be detected by 10 users and 50% by 5 users [23]. Therefore, although some of our evaluation numbers are low, they are consistent with other similar feasibility and acceptability studies [24-27] and sufficient to evaluate the acceptability and feasibility of version 1 of PROMPT-Care and to identify modifications required for version 2 to utilize in the next stage of large-scale testing.

The nature of this study also meant that we neither evaluate the frequency of patients' accessing of self-management resources nor the oncology staff's use of clinical feedback reports. These utility elements of the PROMPT-Care system will be evaluated within a larger future study.

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Authors' Contributions

All authors contributed to aspects of the development and content of the PROMPT-Care system and its implementation in participating centers. AG, JL, ID, MG, and TS led the evaluation of the system; all authors reviewed this manuscript.

Conflicts of Interest

None declared.

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Abbreviations

CINSW: Cancer Institute NSW
eHealth: electronic health
ePRO: electronic patient-reported outcome
ESAS: Edmonton Symptom Assessment Scale
GP: general practitioner
OIS: oncology information system
PRO: patient-reported outcome
PROMPT-Care: Patient-Reported Outcome Measures for Personalized Treatment and Care
SCNS-ST9: Supportive Care Needs Survey–Screening Tool 9

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Original Paper

Web-Based Tools for Text-Based Patient-Provider Communication in Chronic Conditions: Scoping Review

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Abstract

Background: Patients with chronic conditions require ongoing care which not only necessitates support from health care providers outside appointments but also self-management. Web-based tools for text-based patient-provider communication, such as secure messaging, allow for sharing of contextual information and personal narrative in a simple accessible medium, empowering patients and enabling their providers to address emerging care needs.

Objective: The objectives of this study were to (1) conduct a systematic search of the published literature and the Internet for Web-based tools for text-based communication between patients and providers; (2) map tool characteristics, their intended use, contexts in which they were used, and by whom; (3) describe the nature of their evaluation; and (4) understand the terminology used to describe the tools.

Methods: We conducted a scoping review using the MEDLINE (Medical Literature Analysis and Retrieval System Online) and EMBASE (Excerpta Medica Database) databases. We summarized information on the characteristics of the tools (structure, functions, and communication paradigm), intended use, context and users, evaluation (study design and outcomes), and terminology. We performed a parallel search of the Internet to compare with tools identified in the published literature.

Results: We identified 54 papers describing 47 unique tools from 13 countries studied in the context of 68 chronic health conditions. The majority of tools (77%, 36/47) had functions in addition to communication (eg, viewable care plan, symptom diary, or tracker). Eight tools (17%, 8/47) were described as allowing patients to communicate with the team or multiple health care providers. Most of the tools were intended to support communication regarding symptom reporting (49%, 23/47), and lifestyle or behavior modification (36%, 17/47). The type of health care providers who used tools to communicate with patients were predominantly allied health professionals of various disciplines (30%, 14/47), nurses (23%, 11/47), and physicians (19%, 9/47), among others. Over half (52%, 25/48) of the tools were evaluated in randomized controlled trials, and 23 tools (48%, 23/48) were evaluated in nonrandomized studies. Terminology of tools varied by intervention type and functionality and did not consistently reflect a theme of communication. The majority of tools found in the Internet search were patient portals from 6 developers; none were found among published articles.

Conclusions: Web-based tools for text-based patient-provider communication were identified from a wide variety of clinical contexts and with varied functionality. Tools were most prevalent in contexts where intended use was self-management. Few tools for team-based communication were found, but this may become increasingly important as chronic disease care becomes more interdisciplinary.

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KEYWORDS

Internet; telemedicine and telecommunication; chronic diseases; physician-patient relations; communication; electronic mail; text messaging; patient portal; patient care team; interdisciplinary communication

Introduction

As the number of individuals living with chronic conditions increases [1], the needs of patients are shifting the delivery of health care services based solely on appointments to a patient-driven model that addresses care management and supportive needs on an ongoing basis [2]. This is because the management of chronic diseases often entails a greater degree of patient self-management, supported by a relationship with several providers [3-5].

Numerous organizations such as the Agency for Healthcare Research and Quality and the Institute of Medicine have advocated for the use of electronic health (eHealth) technologies to improve the quality of care, pointing to their value in care coordination and in enabling patients to have greater access to health care providers [6-9]. Especially in the context of chronic or complex conditions, such tools can give patients the opportunity to ask questions, refine understanding, provide updates, and receive test results between appointments. As such, disease self-management may be improved because of timely support from health care providers involved in their care [10,11]. Research has shown that with provider guidance, treatment adherence and motivation to be involved in decision making are improved [12]. Furthermore, although much of the care delivery by health care providers is disease specific or based on medical specialty [9], patients often do not view care in the form of health encounters but rather as continuous between their life and the health care system [13].

Whereas much attention has been paid to tools for telemedicine that allow for patients to upload clinical data (such as glycated hemoglobin [HbA1c] levels or blood pressure values) for the purpose of remote monitoring [14,15], less is known about tools that facilitate dialogue with health care providers. These allow patients to share contextual information, personal narrative, and perspective, which are crucial to the therapeutic function of the patient-provider relationship [16]. Text-based electronic communication, specifically, has grown in popularity because of its simplicity and accessibility [17-19]. This includes formats such as email, phone-based texting, and secure messaging. Furthermore, because communication may be asynchronous (users do not have to be on the Web concurrently), tools for text-based communication have the potential to allow patients to coordinate care across multiple health care providers, in addition to supplementing care provided through appointments [20,21].

As the field of eHealth has rapidly expanded with information and communication technologies (ICTs) taking on a variety of configurations, there is a need for a more focused study on specific forms of eHealth. Recent reviews have broadly examined ICTs in the health care setting for communication between health care providers [22,23] in the pediatric context [24] and the effect on health-related outcomes [10,25-29]. However, such reviews often limited their inclusion to randomized controlled trials (RCTs; which may be inappropriate for eHealth evaluation [30]) and synthesized the effects across several chronic diseases, which may be misleading because such measures are often too heterogeneous to be objectively compared. Furthermore, granularity at the level of features, functions, and implementation of these interventions is often lacking, with studies instead compromising on the depth of description to focus on outcomes [31].

Given the potential value of ICT tools for text-based communication in the health care setting, there is a need to identify and document how common such tools are, what form they take, how they have been used, in what contexts, and for what purpose. Therefore, we undertook a scoping review, as described by Arksey and O'Malley [32], of the published literature and the Internet on Web-based tools for text-based patient-provider communication. The scoping review approach is suitable for reviews that aim to examine the extent, range, and nature of a topic; to identify key concepts in the field; and to identify gaps in the existing literature [33]. Scoping reviews are especially useful when little is known or a field is broad and where a formal systematic review (with narrow selection criteria and focus on study design) may limit what is retrieved. Our specific objectives were to (1) conduct a systematic search of the published literature and the Internet for Web-based tools for text-based communication between patients and physicians; (2) map tool characteristics, their intended use, contexts in which they were used and by whom; (3) describe the nature of their evaluation; and (4) understand the terminology used to describe tools and index articles.

Methods

Review Type and Process

We conducted a scoping review using the Arksey and O'Malley framework to identify Web-based tools for text-based patient-provider communication in the published literature and on the Internet [32,34]. We followed the following five steps articulated in this framework: (1) identify the study aim, (2) identify relevant studies, (3) study selection, (4) chart the data, and (5) collate, summarize, and report results [32,33].

Search of the Published Literature

Search Strategy

The search protocols are presented in Multimedia Appendices 1 and ; the Internet search protocol is presented in Multimedia Appendix 3. Given that our target was Internet-connected electronic (Web-based) tools used in health care, we focused our search on MEDLINE (Medical Literature Analysis and Retrieval System Online) and EMBASE (Excerpta Medica Database) for articles in the published literature. The search strategy was developed in consultation with an academic librarian with expertise in eHealth using key concepts, keywords, and controlled vocabulary. We confirmed the completeness of the search strategy by testing it with seed articles that represent expected articles for inclusion [35-38]. We included original studies and captured tools described in editorials and commentaries published up to March 2016. Findings were restricted to those in English because of limited resources for translation services.

Selection Criteria

Following the scoping review methodology [32], screening articles for inclusion was done in two stages: title and abstract review and full article review (see Textboxes 1 and 2 for inclusion and exclusion criteria).

Textbox 1. Inclusion criteria.

Studies were considered for inclusion if they described a tool that:

- Supports Web-based communication between patients and health professionals for within-tool communication (ie, messages sent within the tool are responded to using the tool rather than via phone call outside the tool environment)
- Uses a text-based form of dialogue (including text messages via cell phone)
- Involves communication with patients with one or more chronic conditions, defined as a condition that is ongoing or persistent or requiring complex care, defined as requiring nearly continuous care or otherwise high health care resource utilization and multiple health care providers
- Is used in the health care context
- Is intended for patients and health care providers (physician, nurse, pharmacist, social worker, etc) to communicate regarding direct patient care (defined as private communication about care specific to the patient between health care provider and the patient or surrogate (such as a caregiver), rather than general health advice findable on the open Web. Communication may be guided but not restricted (ie, patient should have the opportunity to ask any question)
- Involves communication between a minimum of one patient and one health care professional (ie, at least two end users)

Textbox 2. Exclusion criteria.

From the published literature, we excluded:

- Tools that function for information transfer but not communication (eg, lab results, telepathology, telemonitoring of vitals or symptoms [heart rate], and algorithm-based automated feedback)
- Audio or video-based forms of communication that do not include text-based communication
- Electronic medical records, patient health data repositories, and portals that do not have a communication component
- Online support forums, even if they support communication between many patients and many health professionals
- Tools for communication exclusively between patients
- Theoretical or conceptual papers, frameworks, and descriptions
- Offline native apps for mobile devices (ie, those which are not connected to the Internet)
- Tools to support behavior change interventions in otherwise healthy patients (ie, without a chronic condition; eg, smoking cessation, diet, and alcoholism)

Study Identification, Selection, and Data Extraction

In the first step of study identification, 2 reviewers (TV and TM) independently reviewed retrieved titles and abstracts from MEDLINE and EMBASE. The reviewers tested agreement on a sample of 100 citations before reviewing all retrieved citations. Where there was uncertainty, citations were included for full article review. We hand-searched the reference lists of identified reviews for potentially relevant articles. We reviewed the full texts of articles designated for inclusion or those labeled as *maybe*. From included articles, 2 authors (TV and TM) independently extracted relevant information. The data extraction form was pilot-tested and revised. It is presented in Multimedia Appendix 4. We extracted data on (1) article characteristics (ie, study setting and disease context); (2) tool characteristics—structure (such as medium of communication), functions (ie, additional components such as viewable care plan), and communication paradigm (ie, one-many, one-one communication flow); (3) intended use, context, and users; (4) evaluation (ie, study design, stage of evaluation, and outcomes); and (5) terminology (ie, tool label or description and medical subject headings [MeSH] terms used to index studies on MEDLINE or keywords on EMBASE). At each step, where there were disagreements, the senior author (JB) was involved to achieve consensus.

Internet Search

Internet Search Strategy

The search of the published literature was supplemented with an Internet search using Google search engine on September 16, 2016 to identify tools that are used but may not have been evaluated or published. Five search queries composed of keywords and Boolean operators were created with the help of the same academic librarian who guided the search of published articles. The first 100 retrieved search results for each query were examined. The same inclusion or exclusion criteria that was used for the published literature was applied to the Google search results, except that findings were not exclusive to tools for chronic diseases because such detail was lacking on most websites.

Selection Criteria, Selection Process, and Data Extraction

In the first step, the initial page accessed from the search result was examined (see Multimedia Appendix 3). If it appeared relevant to ICTs or mentioned a tool, it was included. At this stage, search results that led to published primary research articles from an academic database were excluded, as were theoretical or conceptual papers, or those not from the health care context. In the second step, if a search result linked to a specific tool, the website was explored for further information about communication tools that could be used for a patient or caregiver to communicate with a health care provider. Data extraction involved exploring the search result and directly-linked (one-step away) websites for additional information. We modified the data extraction form used for the published literature search to reflect the lack of detail typically available on websites (presented in Multimedia Appendix 5). Two authors (TV and TM) reviewed 20% of search results to establish consistency in extraction, and then the first author (TV) extracted the remaining data.

Synthesis

Data extracted from published articles and the Internet search were summarized separately. A coding framework was iteratively developed by the reviewing authors (TV and TM) to categorize extracted data according to prespecified definitions based on the published literature or white papers (eg, the Cochrane Collaboration definitions of various study designs [39]), common patterns observed in the data, and expert consultation (JB). The coding framework is presented in Multimedia Appendix 6.

Results

The search of published literature retrieved 6443 results from MEDLINE (n=4296) and EMBASE (n=2147). After removal of duplicates (n=1756), 4687 titles and abstracts were screened, 121 full-text articles were reviewed, and 40 articles met the selection criteria. At the screening stage, chance-corrected agreement between the 2 reviewers was 0.51 (95% CI 0.44-0.57), calculated with Cohen's kappa, and raw agreement was 0.97. Additionally, 40 review articles were identified, of which 16 were hand-searched for articles meeting the selection criteria. Fourteen studies from the review articles met our selection criteria, bringing the total number of studies included to 54 (see Figures 1 and 2).

Figure 1. Flow diagram for published literature search.

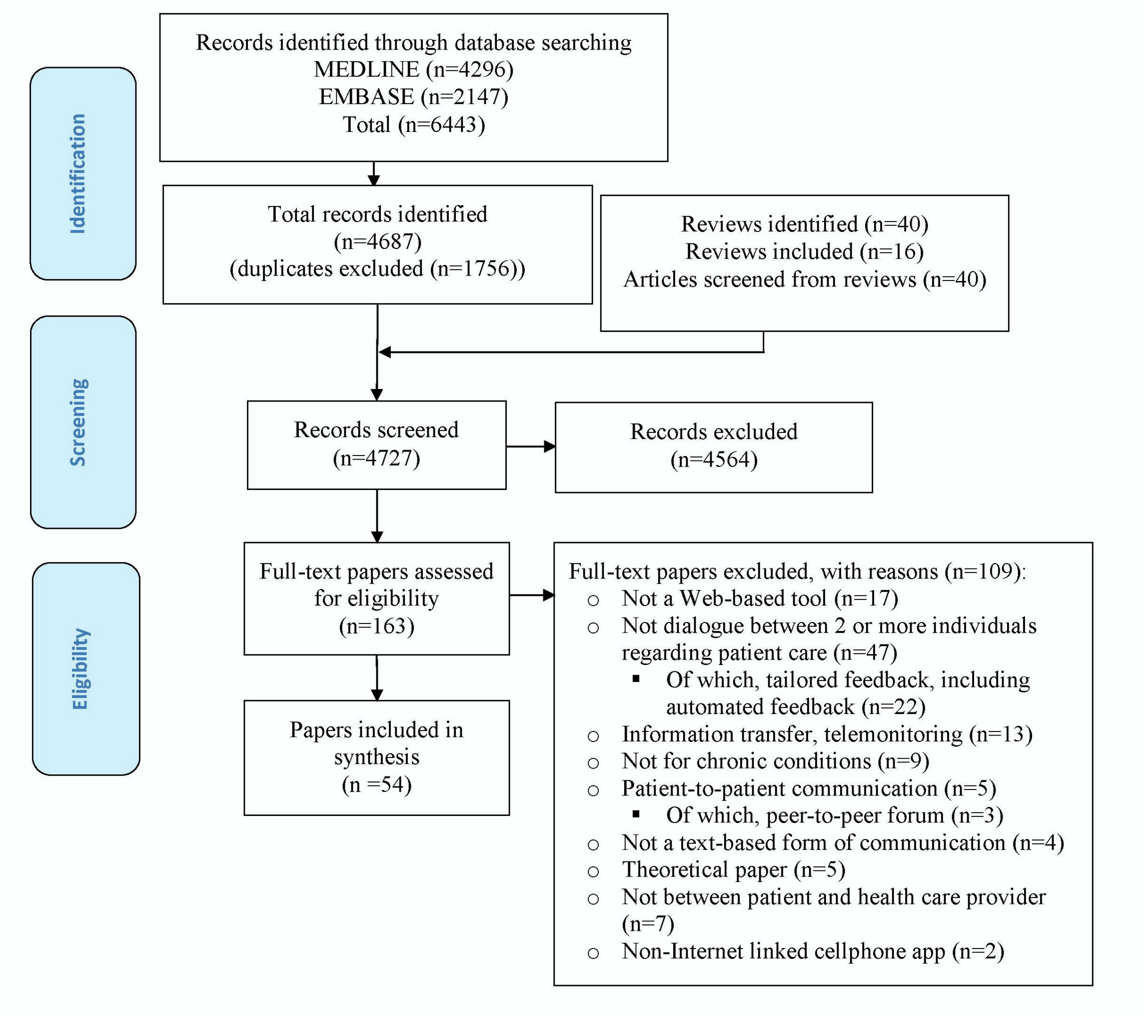
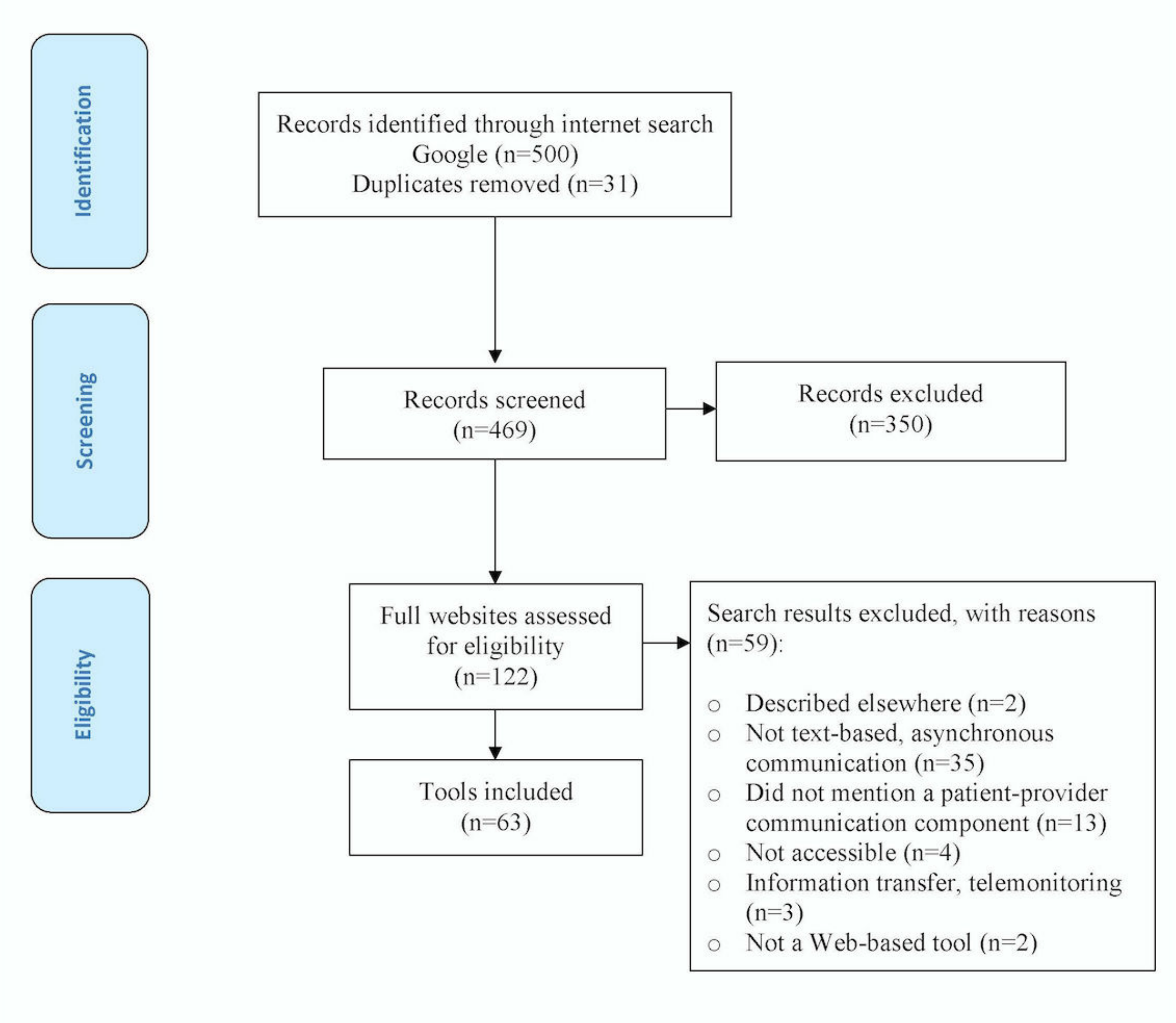


Figure 2. Flow diagram for Internet-based search.



Article Characteristics

Of the 54 articles, there were 53 unique studies describing 47 unique tools (after accounting for multiple articles from one study). The earliest article identified was published in 2002. As shown in Figure 3, the number of published articles on this topic has been increasing annually. The majority of articles were from the United States (48%, 26/54; see Table 1). Most studies were conducted at tertiary care outpatient clinics specializing in a particular condition (51%, 27/53), though a large number were from the primary care setting (36%, 19/53). Only four studies (7.5%, 4/53) were conducted in exclusively pediatric populations (<18 years old).

Tool Characteristics

Characteristics of tools from published articles were organized according to tool structures, functions, and communication paradigm and are presented in full in Table 2 (by characteristic) and Multimedia Appendix 7.

Structures

Of the 47 tools identified, the majority (74.5%, 35/47) were Internet-enabled applications accessible from a Web browser, whereas 9 (19%, 9/47) were native applications developed as computer software or for use on a mobile phone. Most (77%, 36/47) were multidimensional tools with multiple features and functions, of which 30% (14/47) were part of an informational or educational website, and 40% (19/47) were patient portals; 30% (14/47) were stand-alone communication tools.

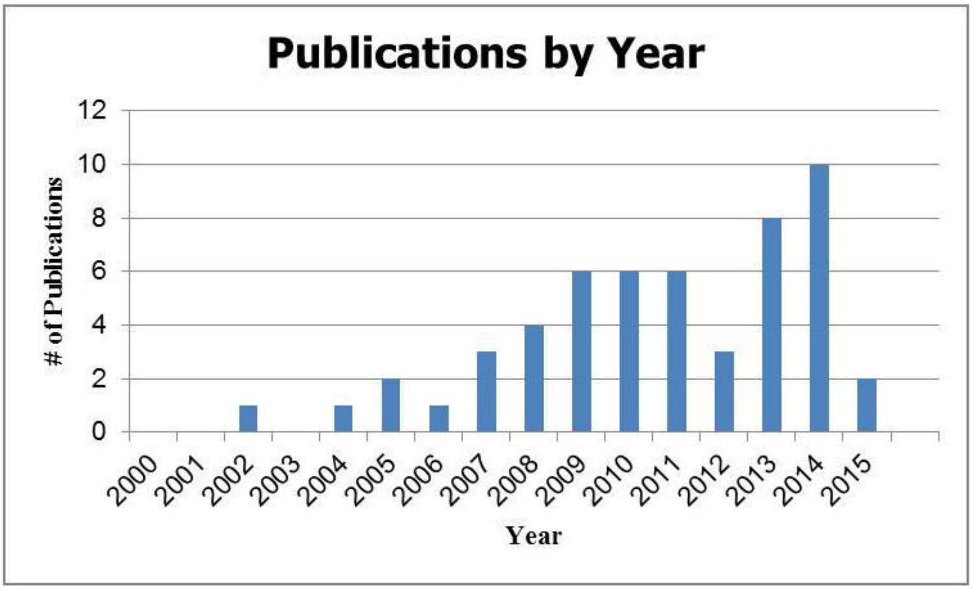
Table 1. Published article characteristics (n=54).

Characteristic	n (%)
Publication country of origin (n=54)	
Australia	1 (2)
Canada	5 (9)
China	1 (2)
Finland	2 (4)
Germany	1 (2)
Netherlands	4 (7)
Norway	7 (13)
Portugal	1 (2)
Slovenia	1 (2)
Spain	2 (4)
Sweden	2 (4)
Switzerland	1 (2)
United States	26 (48)
Unique studies (n=53)	
Original study	48 (91)
Protocol	4 (7.5)
Editorial or commentary	1 (2)
Study context or setting of use (n=53)	
Academic (ie, Department of behavioral sciences)	4 (7.5)
Business (ie, CVS and Walmart)	1 (2)
Integrated health care organization (ie, Kaiser Permanente)	2 (4)
Primary care	19 (36)
Tertiary care outpatient clinics	27 (51)
Population (n=53)	
Adults or all	49 (92)
Pediatrics (<18 years)	4 (7.5)
Disease or clinical area of interest (n=68)[a]	
Cardiovascular disease or stroke	6 (9)
Chronic respiratory condition	10 (15)
Diabetes	20 (29)
Mental health	8 (12)
Chronic pain	5 (7)
Other	
Dermatology	2 (3)
Irritable bowel disease or syndrome	2 (3)
Cerebral palsy	1 (1.5)
Human immunodeficiency virus (HIV) or acquired immunodeficiency syndrome (AIDS)	1 (1.5)
Rheumatic disease	1 (1.5)
Obesity	1 (1.5)
Hypertension	2 (3)
Fibromyalgia	2 (3)

Characteristic	n (%)
Cystic fibrosis	1 (1.5)
Impaired mobility	1 (1.5)
Nonspecific (*Chronically ill*)	5 (7)

[a] Some studies evaluated the tool in multiple contexts, for example, in diabetes and mental health.

Figure 3. Published articles by year (n=54).



Functions

Two categories of communication functions were identified: unstructured and structured text-based communication. The majority of tools (79%, 37/47) involved unstructured text-based communication that allowed a patient to enter open-ended free text. Conversely, 10 tools involved structured communication whereby a patient would submit an inquiry into a form with structured fields that returned a response to questions (tools with automated responses were excluded). The majority of tools (77%, 36/47) had other functions in addition to the communication component, including disease information or education (53%, 25/47), symptom diary or tracker (45%, 21/47), and viewable care or treatment plans (25.5%, 12/47).

Communication Paradigm

The majority of tools (94%, 44/47) used asynchronous communication of which two specified that health care providers were to respond in a specified amount of time (ie, within 3 days). With most tools (83%, 39/47), patients could communicate with one specific health care provider (ie, one-to-one communication). Only 17% (8/47) of tools were described as allowing the patient to communicate with their health care team or multiple health care providers (ie, one-to-many communication). These were evaluated in the diabetes (3/8), respiratory conditions (1/8), human immunodeficiency virus (1/8), depression (1/8), and general outpatient (1/8) contexts. One tool described having patient-professional and interprofessional communication paradigms in patients with cerebral palsy. Eighteen tools (38%, 18/47) described allowing the patient to communicate with their *own provider* (presumably, someone involved in their direct care).

Intended Use, Context, and Users

The intended use of tools described in articles were grouped into four categories: symptom reporting (49%, 23/47), lifestyle or behavior modification (36%, 17/47), care planning (4%, 2/47), and medication adherence (2%, 1/47). No intended use was stated in the articles for 4 tools though these were in nonrandomized studies where the tool was not evaluated as an intervention.

Studies were conducted in several different chronic disease populations, with many studies evaluating tools in multiple disease contexts. In total, the studies covered 68 health conditions. Notably, 29% (20/68) were evaluated for diabetes, 15% (10/68) for chronic respiratory conditions, and 12% (8/68) for mental health. Few studies were evaluated in cardiovascular disease (CVD; 9%, 6/68).

The type of health care provider who used the tool varied greatly: 23% (11/47) were used by nurses, 19% (9/47) by physicians, and 30% (14/47) involved allied health professionals of various disciplines (see Table 2 and Multimedia Appendix 7 for details). Only two studies mentioned that providers were given monetary compensation for tool use.

Table 2. Tool characteristics, intended use, and users (n=47). The table classifies variables according to unique tools rather than individual studies as the unit of analysis.

Characteristic	n (%)
Structures	
Medium of communication or format	
Web-based tool	35 (4.5)
Hybrid Web and software application	6 (13)
Mobile phone–based native app (ie, short message service)	3 (6)
Email-based application	3 (6)
Component of another platform	
Patient portal	19 (40)
Informational or educational website	14 (30)
Stand-alone	14 (30)
Functions	
Type of communication	
Unstructured communication (patient-provider free form dialogue)	37 (79)
Structured communication (tailored feedback)	10 (21)
Number of tools with functions beyond patient-provider communication component	36 (77)
With 3 or more additional functions	19 (40)
Linked to a health record	9 (19)
Linked to laboratory or test results	12 (25.5)
Linked to appointment or scheduling	7 (15)
Linked to viewable care or treatment plan	12 (25.5)
Linked to new prescription requests	3 (6)
Linked to prescription renewal	8 (17)
Linked to symptom diary or tracker	21 (45)
Linked to disease information or education	25 (53)
Communication paradigm	
Asynchronous tools	
Asynchronous	44 (94)
Of asynchronous tools, time-limited (response from provider within a specified time window)	2 (4)
Synchronous	2 (4)
Both	1 (2)
Patient-provider communication flow	
One-many	8 (17)
Communication with own provider	4 (50)
One-one health care provider	39 (83)
Communication with own provider	18 (46)
Of patient-multiple provider tools (n=8), direct communication with each member of health care team (providers receive information at the same time)	
Yes	1 (12.5)
No	3 (37.5)
Unclear	4 (50)

Characteristic			n (%)
Intended use and users			
	Intended use of communication intervention[a]		
		Lifestyle or behavior modification	17 (36)
		Symptom reporting	23 (49)
		Care planning	2 (4)
		Medication adherence	1 (2)
		Not specified	4 (8.5)
	Type of health care provider intended to use tool with patients or caregivers		
		Nurse	11 (23)
		Physician	9 (19)
		One of several professions (ie, physician or nurse or social worker)	7 (15)
		Case manager or social worker	5 (11)
		Psychologist	4 (8.5)
		Therapist or counselor	4 (8.5)
		Pharmacist	1 (2)
		Research assistant	1 (2)
		Not specified	5 (11)
Other			
	Compensation to health care providers		
		Did not provide compensation	45 (96)
		Did provide compensation	2 (4)
	Tool access		
		Free through research participation	29 (62)
		Organizational license	10 (21)
		Prior registration required via website or service	8 (17)
	URL available in article		
		Yes	17 (36)
		No	30 (64)

[a] Purposes are grouped based on descriptions from each paper.

Evaluation Characteristics

Study Design and Study Stage

The evaluation characteristics of completed studies (ie, excluding protocols) are reported in Table 3. Twenty-five studies were RCTs. Twenty-three were nonrandomized studies, of which nine were prospective cohort studies, four were retrospective cohort studies, four were quasi-experimental or non-RCTs, two were cross-sectional studies, one was a cost-effectiveness study, and three were qualitative studies. All were real-world evaluations and not in a laboratory setting. Regarding the stage of study according to the 2008 MRC Framework for the Evaluation of Complex Interventions [40], 96% (24/25) of RCTs were at the evaluation stage compared with 26% (6/23) of nonrandomized studies, of which 43.5% (10/23) were at the feasibility and piloting stage. The only studies at the implementation stage were nonrandomized studies (30%, 7/23).

The sample size of RCTs ranged from 15 to 415 patients and spanned 1 to 20 months of follow-up. By comparison, the sample size of nonrandomized studies ranged from 2 in a stand-alone qualitative study to 14,102 in a retrospective analysis of administrative cohort data.

Study Outcomes

See Table 3 for outcomes captured: RCTs (n=37 outcomes measured) tended to focus mostly on clinical outcomes (70%, 26/37; eg, cholesterol reduction, depression symptoms, and patient activation), whereas nonrandomized studies (n=35 outcomes measured) examined outcomes related to acceptability (11%, 4/35), feasibility (9%, 3/35), and usability (14%, 5/35) more often. Experience-related outcomes (eg, perceptions and open-ended feedback) were not captured in RCTs; however, they were captured in nonrandomized studies either as stand-alone qualitative studies (9%, 3/35) or as part of a study capturing quantitative and qualitative outcomes (9%, 3/35).

Table 3. Evaluation characteristics of unique completed studies (n=48). It refers to unique studies, counting studies resulting in multiple publications and excludes protocols, editorials, or commentaries.

Study design and evaluation characteristics	Outcome
Randomized controlled trials (n=25)	
Is the communication component the primary feature or a supplemental feature? (n)	Primary feature=17
	Supplemental feature=8
Stage of study[a], n	Development=0
	Feasibility and piloting=1
	Evaluation=24
	Implementation=0
Type of results captured in each study[b], n	Acceptability=1
	Clinical=26
	Usability=2
	Feasibility=1
	Usage=7
Sample size, median (IQR; range)	104 (75.5-140; 15-415)
Study length of follow-up in months, median (IQR; range)	8 (3-12; 1-20)
Nonrandomized studies (n=23)	
Prospective cohort studies (n=9)	
Is the communication component the primary feature or a supplemental feature? (n)	Primary feature=7
	Supplemental feature=2
Stage of study[a], n	Development=0
	Feasibility and piloting=7
	Evaluation=2
	Implementation=0
Type of results captured in each study[b], n	Acceptability=2
	Clinical=6
	Experience[d]=3
	Feasibility=2
	Usability=4
	Usage=1
Sample size, median (IQR; range)	21 (15-30; 6-222)
Study length of follow-up in months, median (IQR; range)	6 (3-6.5; 1-13)
Retrospective cohort studies (n=4)	
Is the communication component the primary feature or a supplemental feature? (n)	Primary feature=1
	Supplemental feature=3
Stage of study[a], n	Development=0
	Feasibility and piloting=0
	Evaluation=1
	Implementation=3
Type of results captured in each study[b], n	Clinical=2
	Usage=3
Sample size, median (IQR; range)	2603 (1750.75-5718.5; 157-14102)

Study design and evaluation characteristics	Outcome
Study length of follow-up in months, median (IQR; range)	13.5 (10.5-17.25; 6-24)
Quasi-experimental/nonrandomized controlled trials (n=4)	
Is the communication component the primary feature or a supplemental feature? (n)	Primary feature=4 Supplemental feature=0
Stage of study[a], n	Development=0 Feasibility and piloting=1 Evaluation=3 Implementation=0
Type of results captured in each study[b], n	Acceptability=1 Clinical=3 Usage=1
Sample size, median (IQR;range)	141 (93.25-348.75;46-876)
Study length of follow-up in months, median (IQR; range)	9 (6-14.5; 6-22)
Cross-sectional surveys (n=2)	
Is the communication component the primary feature or a supplemental feature? (n)	Primary feature=2 Supplemental feature=0
Stage of study[a], n	Development=0 Feasibility and piloting=0 Evaluation=0 Implementation=2
Type of results captured in each study[b], n	Acceptability=1 Feasibility=1 Usability=1
Sample size, median (IQR; range)	2327.5 (1236.25-3418.75; 145-4510)
Study length of follow-up in months, median (IQR;range)	N/A[e]
Cost-effectiveness analyses (n=1)	
Is the communication component the primary feature or a supplemental feature? (n)	Primary feature=1 Supplemental feature=0
Stage of study[a], n	Feasibility and piloting=0 Evaluation=0 Implementation=1 Development=0
Type of results captured in each study[b], n	Costs or clinical=1
Sample size, median (IQR; range)	778
Study length of follow-up in months, median (IQR; range)	12 months
Qualitative studies (n=3)	
Is the communication component the primary feature or a supplemental feature? (n)	Primary feature=2 Supplemental feature=1
Stage of study[a], n	Development=0 Feasibility and piloting=2 Evaluation=0

Study design and evaluation characteristics	Outcome
	Implementation=1
Type of results captured in each study[b], n	Experience[c]=3
Sample size–median (IQR; range)	7 (4.5-23; 2-39)
Follow-up (yes), n	2
Study length of follow-up in months, median (IQR; range)	3 (2-4; 1-5)

[a] Definitions according to 2008 MRC Framework for Evaluation of Complex Interventions. See coding framework for elaboration.

[b] All types of results (outcomes) in a study are counted so that multiple outcomes may be counted from individual studies.

[c] Three studies captured qualitative results as secondary outcomes. Three studies were stand-alone qualitative studies.

[d] N/A: not applicable.

Terminology

The terminology used to describe the tools was explored in published articles by examining author descriptions of the tool and the terms used to index the articles by academic librarians. “Portal” was often used to describe tools with more than three additional functions (42%, 8/19). Of studies where the communication component was the primary feature, “Web-based” (29%, 7/24) and “Internet-based” (21%, 5/24) were frequently used as adjectives in intervention descriptions. However, the actual intervention descriptor varied considerably (ie, diaries, self-management intervention). Regarding the indexing terminology of articles, the MeSH terms Internet (n=40), telemedicine and telecommunication (n=11), physician-patient relations (n=12), cell phones (n=9), communication (n=7), electronic health records (n=7), and electronic mail (n=7) and therapy, and computer-assisted (n=5) appeared 5 or more times.

Internet Search Results

An Internet search identified websites for 63 unique tools, 82.5% (52/63) of which were identified from health care institution websites (hospitals and care networks) and 17.5% from businesses (including tool developer companies; see Table 4). None of the tools identified on the Internet were found in the published literature. The majority of health care institution–based tools came from 6 developers or companies: FollowMyHealth (19%, 10/52), Athena Health (15%, 8/52), MyChart Epic Systems (15%, 8/52), eClinicalWorks (11.5%, 6/52), NextGen Healthcare Information Systems LLC (10%, 5/52), and Cerner IQ Health (8%, 4/52). Most (94%, 59/63) of the websites described their tool as having a communication component integrated with an electronic health record (EHR). Most websites (84%, 53/63) also reported that their tool allowed the patient to communicate with one health care provider, 11 (17.5%, 11/63) of which stated in the description that patients could talk with their *own provider* directly. Two websites described tools that allowed patients to talk with multiple health care providers. Of 60 tools (95%, 60/63) that used asynchronous text-based communication, only 8 (13%, 8/63) of the websites stated that a response from a provider could be expected within a specified time frame (ie, 3-5 days).

Table 4. Tools identified from the Internet search (n=63).

Characteristic	n (%)
Organization type	
Health care institution (ie, hospitals and care networks)	52 (82.5)
Business (ie, tool developers)	11 (17.5)
Health record integration	
Yes	59 (94)
No	3 (5)
Unclear	1 (2)
Target population	
Outpatients	47 (75)
Both	8 (13)
Not specified or unclear	6 (9.5)
Health care provider intended to use tool with patients or caregivers as described (excluding business tools)	
“Members of the health care team”	11 (17.5)
“Doctor's office”	18 (29)
“Physician”	5 (8)
“Nurse”	2 (3)
“Provider”	11 (17.5)
Unclear	4 (6)
Asynchronous tools	
Asynchronous	60 (95)
Of asynchronous tools, time-limited (response from provider within a specified time window)	8 (13)
Unclear	3 (5)
Synchronous	0 (0)
Patient-provider communication flow	
One-many	2 (3)
Communication with own provider	0 (0)
One-one	53 (84)
Communication with own provider	11 (17.5)
Unclear	8 (13)
Product names of health care institution tools (n=52)	
Athena Health	8 (15)
Beth Israel Deaconess Medical Center	1 (2)
Carolinas Healthcare	1 (2)
Cerner IQ Health	4 (8)
eClinicalWorks	6 (11.5)
FollowMyHealth	10 (19)
IASIS Healthcare	1 (2)
Intermountain Healthcare	1 (2)
MedFusion-Greenway Health	1 (2)
MyChart Epic Systems	8 (15)
NextGen Healthcare Information Systems LLC	5 (10)
Partners HealthCare	1 (2)

Characteristic	n (%)
RelayHealth	2 (4)
University of Wisconsin-Madison	1 (2)

Discussion

Principal Findings

In this scoping review, we found 54 published articles that described text-based patient-provider communication tools for chronic diseases. These tools were predominantly accessed from websites as opposed to Internet-linked native apps and mainly functioned as part of a multifunction platform such as patient-facing portals. Few tools enabled patients to communicate with multiple health care providers at the same time (ie, one-to-many communication). Tools were used for lifestyle or behavior modification, symptom reporting, care planning, and medication adherence purposes. We found that the majority of tools were studied in the diabetes and chronic respiratory condition contexts. Around half of the studies were RCTs that focused on clinical outcome evaluations, whereas nonrandomized studies examined impact on outcomes such as acceptability and usability. Terminology used to describe the tools varied greatly by intervention type and functionality and did not consistently include the theme of communication. The Internet search results did not show overlap with tools found in the search of published articles, and tools found on the Internet were primarily produced by a small number of developers.

We found many tools that facilitated both communication and sharing of data. Most studies (77%, 36/47) described tools with capabilities additional to communication such as access to EHRs (25% 9/36), lab or test results (33%, 12/36), and care or treatment plans (33%, 12/36), among others. Due to the shared infrastructure, platforms for communication can easily accommodate components for information sharing (eg, lab test results) to allow for more productive interaction. Building on Wagner’s Chronic Care Model [41] which delineates organizational domains needed to support patient self-management and interaction with the health care team, the eHealth Enhanced Chronic Care Model (eCCM) by Gee et al [42] reenvisions chronic care management as reinforced by the breadth of eHealth technologies. The eCCM postulates that the sharing of data and information in different ways, which is facilitated by technologies, can enhance patient and provider knowledge and wisdom, making communication between patients and health care teams more productive. Therefore, multifunction platforms may make communication more informed through added access to medical data.

The growing recognition that care of chronic conditions is rooted in self-management has also been met with a parallel shift in the role of health care providers from experts to collaborators with patients [11]. We identified 8 tools that allowed patients to communicate with multiple health care providers or their *team* as a group (ie, one-to-many communication). Only one tool [43] clearly described that it facilitated patient-professional and interprofessional communication. Intervention descriptions of other studies were vague as to whether patient messages were simultaneously delivered to all team members or to a moderator who triaged messages to health care providers. Here, we found that nurses were most often the provider who used the communication tool with patients (23%, 11/47). Also, 15% (7/47) of tools were described as involving patient communication with individuals of one of several different professions (ie, a nurse, physician, or social worker) suggesting that patients are not necessarily in direct contact with their own physician. The importance of patient-multiple provider tools may be magnified in contexts where multiple providers are responsible for different aspects of care and where provider decisions can benefit from the insight of other providers. Tools for collaboration are not novel [44]; in business, collaborative platforms such as Microsoft’s Yammer, Slack, and Hipchat, which facilitate synchronous (such as live video), asynchronous individual and group-based communication, and data exchange with multiple users are prevalent [45]. Traditionally, responsibility for patient care transfers from physician to physician according to disease or treatment modality, and therefore tools for asynchronous collaborative communication may be better suited in health care [46]. However, lack of financial compensation for physician consults (including group-based interactions) and concerns about security of data are significant barriers to the use of ICTs for physicians to communicate with each other about a case and with the patient directly [47] and may partly explain the dearth of tools for teams. Only two articles [48,49] identified here from the literature and none from the Internet-based search mentioned compensation for health care provider tool use.

Our findings indicate that the number of studies of patient-physician text-based communication tools has increased in the last decade for purposes related to self-management and for many conditions, pointing to the broadening appeal of this communication medium. We found that tools for certain chronic conditions with high prevalence were most common (diabetes=20 and chronic respiratory conditions=10) but found few tools for several less common conditions (eg, cerebral palsy and cystic fibrosis). Notably, we found very few tools for other common chronic conditions such as CVD (n=6) and none for cancer. This pattern could be reflective of the type of care associated with these conditions: for typical cases of diabetes [50] and respiratory conditions such as asthma [51], care protocols usually emphasize supported self-management. Furthermore, conditions such as diabetes and respiratory diseases are particularly costly, with progression to advanced stage or complications, such that prevention and management at early stages is viewed as an effective approach [52-54]. Though CVD also entails a degree of self-management, our findings could suggest that dialogue with a provider is less necessary. Instead, it can be substituted with telemonitoring (eg, cardiac telemetry and blood pressure monitoring), which are part of usual CVD care [52,53]. These conditions also make use of specialized diagnostic and treatment protocols that involve different professions. As such, these conditions may benefit from tools allowing for patient-multiple provider communication to address complex needs. However, none of the patient-multiple provider communication tools found here were from the CVD and cancer contexts and could suggest a potential gap.

Evaluations of effect of the identified tools tended to adopt RCT designs (n=25) where outcomes were clinical, whereas non-RCTs were more inclusive in capturing implementation outcomes. We found, however, that usage data were poorly reported across studies of all designs. Usage data, as a measure of process, are critical to understanding why an intervention has functioned in a particular context, as the data provide insight into which components of an intervention were used and may be responsible for the observed effect [27]. It is therefore important for appreciating the generalizability of findings in other contexts. Traditional study designs, such as RCTs, may not adequately address the dual goals of unbiasedly ascertaining effect and sufficiently capturing the practical realities of implementation [54]. Furthermore, we encountered few qualitative studies (6%, 3/53) and mixed-methods studies (11%, 6/53), which are better suited to understanding how the users, setting, and cointerventions in the existing environment have affected the intervention [55]. Novel designs, for example, hybrid trials [56] for evaluating complex interventions such as eHealth tools, incorporate clinical and process evaluations to better contextualize findings and shed light on the mechanisms of action.

The terminology used to describe eHealth tools presented a challenge for conducting a review on this topic because of the diversity of terms and the lack of standardized vocabulary to label them. We found that the theme of communication was not always reflected in descriptions or indexing terminology. Multifunction tools were often described as portals, whereas other tools made use of technology-related adjectives added onto standard intervention terms (eg, Web-based self-help and e-coaching). Articles were sometimes indexed with MeSH terms that denoted specific functions such as “Patient-physician relations” and “Therapy, Computer-assisted” or with recognized communication modalities such as “Electronic Mail” and “Cell Phones.” MeSH terms for narrower descriptions such as “Secure Messaging” are lacking, although “Patient Portal” was newly introduced in July 2016. These patterns reflect the inchoate and rapidly evolving nature of this field, may indicate that structured taxonomies in eHealth are yet premature, and suggest that ontologies relating to the terminology of similar interventions may be needed to facilitate article retrieval. These findings are also suggestive of the trade-off in performing searches between the need for sensitivity to accurately detect articles on interventions of common functionality but varied design, and specificity of labeling articles with descriptions that are transparent and replicable. As noted elsewhere about reviewing complex interventions, overall, keywords should attempt to reflect both breadth and depth to maximize capture [57].

In performing a parallel search of the Internet, we found that most tools were developed by six health care software companies. This may speak to the greater Internet visibility of those tools produced by companies with the biggest market share. None of the tools found on the Internet were found in the published literature search (or vice versa). This could suggest that many commercially available tools bypass rigorous, research-driven evaluation (or research findings are not shared) in the process of creating a product whose goal is to meet demand rather than understand improvement in health outcomes [58]. However, the compromise is that without research to bolster the theoretical or evidentiary rationale of such products, they may not meet effectiveness goals. Conversely, tools evaluated and published in articles were not found publically on the Internet, suggesting that research-driven tools often lack the support needed for iterative development and long-term sustainability if they do not have a commercial or business-driven foundation.

Limitations

The scoping review methodology appropriately pursues breadth in identifying articles with a trade-off to performing an in-depth study of specific literature. Although we aimed to conduct a comprehensive search with an extensive search strategy (using 159 technology-related terms), it is possible that we may have missed some relevant articles, given the lack of standardized terminology in this field. We limited our search to MEDLINE and EMBASE because our objectives were related to health and also because we found few articles of relevance in other databases (eg, Cumulative Index to Nursing and Allied Health Literature or CINAHL) while developing the search strategy. Through screening and selection, we did not find tools implemented in the cancer context. Whereas cancer is considered a chronic disease by organizations such as the World Health Organization, it is possible that medical databases have only recently begun to index cancer-related articles within terms such as chronic diseases (we did not base our search protocol on named chronic diseases, as that would have limited the contexts in which tools are found.). Regarding the Internet search, we acknowledge that, as the Google search engine algorithms are continuously updated, it is unlikely that the Internet search is replicable. However, the purpose of the Internet search in this study was to complement and compare with findings from the published literature rather than report stand-alone results. We limited our review to English-language publications. However, given the large number of findings from countries with a primary language other than English (eg, Norway and The Netherlands), we may have missed publications that have not been translated or are not accessible from databases.

Conclusions

We conducted a scoping review of Web-based tools for text-based patient-physician communication. In this review, we identified tools for a variety of chronic conditions, the majority of which targeted diabetes and chronic respiratory conditions for the purposes of updating providers about symptoms or for providers to facilitate lifestyle or behavior change. Our findings seem to suggest that asynchronous text-based patient-provider communication is increasingly being used to support patient self-management functions for conditions such as diabetes, which, when properly controlled, are amenable to routine online check-ins. On the other hand, we identified few tools for CVD, which could suggest a gap in the literature. We found that there were few tools for patient-multiple provider communication, which will become a growing area of interest to patients, providers, developers, and organizers of care as care for chronic conditions becomes more interdisciplinary. The terminology used to describe tools and index articles is widely varied, suggesting that to optimize findability, researchers need to label articles by both tool characteristics and communication functionality. Reviewers may still need to cast a wide net to capture potentially relevant tools, and our findings suggest a need for ontologies that associate similar terms of related interventions to improve article retrieval without diluting the specificity with which authors describe tools. The difference in findings between the search of the published literature and the Internet could reflect the competing need for rigorous evaluation and for real-world implementation to both generate revenue for sustainability and upgrades of tools over time. In an era of health care where patients expect information on demand, the provision of information supplemented by communication with their providers can enable care when and where a patient needs it, contributing to the betterment of chronic disease management.

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Authors' Contributions

TV, EG, and JB were involved in study conception and study design. TV and TM screened and reviewed identified studies. TV and JB were involved in synthesizing results. TV drafted the manuscript, and all authors contributed to revisions.

Conflicts of Interest

None declared.

Multimedia Appendix 1

MEDLINE(R) (Ovid Interface) 1946- Week 1 March 2016.

[PDF File (Adobe PDF File), 29KB - jmir_v19i10e366_app1.pdf]

Multimedia Appendix 2

EMBASE (Ovid Interface) 1946- Week 1 March 2016.

[PDF File (Adobe PDF File), 30KB - jmir_v19i10e366_app2.pdf]

Multimedia Appendix 3

Google search strategy.

[PDF File (Adobe PDF File), 20KB - jmir_v19i10e366_app3.pdf]

Multimedia Appendix 4

Data extraction form for published literature search.

[PDF File (Adobe PDF File), 43KB - jmir_v19i10e366_app4.pdf]

Multimedia Appendix 5

Internet data extraction form.

[PDF File (Adobe PDF File), 34KB - jmir_v19i10e366_app5.pdf]

Multimedia Appendix 6

Coding framework.

[PDF File (Adobe PDF File), 55KB - jmir_v19i10e366_app6.pdf]

Multimedia Appendix 7

References by selected tool design and function.

[PDF File (Adobe PDF File), 83KB - jmir_v19i10e366_app7.pdf]

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Abbreviations

CVD: cardiovascular disease
eCCM: eHealth Enhanced Chronic Care Model
eHealth: electronic health
EHR: electronic health record
EMBASE: Excerpta Medica Database
ICT: information and communication technology
MEDLINE: Medical Literature Analysis and Retrieval System OnlineMeSH: medical subject heading
RCT: randomized controlled trial

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Original Paper

Discovering Cohorts of Pregnant Women From Social Media for Safety Surveillance and Analysis

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Abstract

Background: Pregnancy exposure registries are the primary sources of information about the safety of maternal usage of medications during pregnancy. Such registries enroll pregnant women in a voluntary fashion early on in pregnancy and follow them until the end of pregnancy or longer to systematically collect information regarding specific pregnancy outcomes. Although the model of pregnancy registries has distinct advantages over other study designs, they are faced with numerous challenges and limitations such as low enrollment rate, high cost, and selection bias.

Objective: The primary objectives of this study were to systematically assess whether social media (Twitter) can be used to discover cohorts of pregnant women and to develop and deploy a natural language processing and machine learning pipeline for the automatic collection of cohort information. In addition, we also attempted to ascertain, in a preliminary fashion, what types of longitudinal information may potentially be mined from the collected cohort information.

Methods: Our discovery of pregnant women relies on detecting pregnancy-indicating tweets (PITs), which are statements posted by pregnant women regarding their pregnancies. We used a set of 14 patterns to first detect potential PITs. We manually annotated a sample of 14,156 of the retrieved user posts to distinguish real PITs from false positives and trained a supervised classification system to detect real PITs. We optimized the classification system via cross validation, with features and settings targeted toward optimizing precision for the positive class. For users identified to be posting real PITs via automatic classification, our pipeline collected all their available past and future posts from which other information (eg, medication usage and fetal outcomes) may be mined.

Results: Our rule-based PIT detection approach retrieved over 200,000 posts over a period of 18 months. Manual annotation agreement for three annotators was very high at kappa (κ)=.79. On a blind test set, the implemented classifier obtained an overall F_1 score of 0.84 (0.88 for the pregnancy class and 0.68 for the nonpregnancy class). Precision for the pregnancy class was 0.93, and recall was 0.84. Feature analysis showed that the combination of dense and sparse vectors for classification achieved optimal performance. Employing the trained classifier resulted in the identification of 71,954 users from the collected posts. Over 250 million posts were retrieved for these users, which provided a multitude of longitudinal information about them.

Conclusions: Social media sources such as Twitter can be used to identify large cohorts of pregnant women and to gather longitudinal information via automated processing of their postings. Considering the many drawbacks and limitations of pregnancy registries, social media mining may provide beneficial complementary information. Although the cohort sizes identified over social media are large, future research will have to assess the completeness of the information available through them.

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KEYWORDS

natural language processing; machine learning; text mining; social media; pregnancy; cohort studies; data analysis

Introduction

Pregnancy Exposure Registries

Premarket clinical trials assess the safety of medications in limited settings, and so, the effects of those medications on particular cohorts (eg, pregnant women, children, or people suffering from specific conditions) cannot be assessed. Pregnant women are actively excluded from clinical trials during the development of new medications because of fetal safety concerns [1]. Therefore, once a medication is released into the market, there is typically no data available to assess the fetal effects of in utero exposure other than from animal reproductive toxicology studies [2]. However, conclusions derived from animal studies may not generalize to humans [3]. Spontaneous reporting systems, such as the Food and Drug Administration Adverse Event Reporting System, are used for postmarketing drug safety surveillance, and they provide a mechanism for reporting adverse events associated with medication consumption. Although these sources may accumulate medication safety knowledge about specific population groups, studies have shown that they suffer from various problems such as underreporting, lack of denominator data, and absence of controls [2,4]. In addition, postmarketing surveillance techniques such as spontaneous reporting systems are retrospective in nature, with cases enrolled based on adverse outcome reporting from an unknown number of exposed pregnancies, making the samples biased toward adverse outcomes.

To address these issues, pregnancy exposure registries are developed for new medications. These registries enroll women prospectively (eg, after exposure but before childbirth) in a voluntary fashion and follow them for the entire duration of the pregnancy or longer. This design of pregnancy exposure registries enables researchers to conduct prospective observational studies, which are superior to retrospective studies because of the biases associated with the latter (eg, the outcome, such as birth defect, is already known in retrospective studies) [2]. Thus, the model followed by pregnancy exposure registries has distinct advantages over other study designs, because these registries can produce human data regarding medication safety in pregnancy while avoiding the ethical and logistical pitfalls of randomized controlled trials [5].

Despite the advantages over other study designs, pregnancy exposure registries face a number of challenges. Enrollment or recruitment is perhaps the most crucial issue, with most registries only capable of enrolling a small fraction of the exposed pregnancies, resulting in lack of power to assess specific malformations or health outcomes [6]. There may also be bias in the voluntary enrollment process [7], as women who agree to sign up to registries may already be aware of certain health conditions. Additional challenges include large dropout or lost-to follow-up rates [7], which result in the loss of information from many exposed pregnancies, the lack of availability of information before the discovery of the pregnancy, and incomplete reporting [8]. These challenges associated with pregnancy registries necessitate the exploration of additional sources of information for assessing drug safety during pregnancy.

Motivation, Goals, and Contributions

Social networks have seen an unprecedented growth in terms of users worldwide. According to the Pew Research Report [9], nearly half of all adults worldwide and two-thirds of all American adults (65%) use social media, including 35% of those aged 65 years and older and over 90% of those aged between 18 and 29 years. Public health monitoring and surveillance research studies are therefore rapidly embracing the data made available through social media and developing tools that can effectively mine social media data [10]. Due to the limited amount of information that is available about pregnant women during premarket clinical trials and the challenges and disadvantages of existing prospective and retrospective surveillance approaches, there is a need to explore additional resources of information. Social media has the potential for serving as a crucial complementary resource for obtaining critical medication safety information following the release of medications into the market. The usability of generic social media for this task, however, depends on the successful development of systems that can actively identify pregnant women and collect relevant pregnancy-related data about them. This need is the primary motivation for the study reported in this paper. The specific goals of this paper were as follows:

- Design and validate a set of query patterns that can be used to retrieve posts that are highly indicative of pregnancy from Twitter users.
- Develop and evaluate a supervised machine learning approach that can accurately distinguish between real pregnancy-indicating tweets (PITs) and false positives.
- Design an end-to-end pipeline for collecting longitudinal data from the identified pregnancy cohort.
- Perform preliminary analyses of the extracted health timelines to assess their usefulness, identify limitations, and establish future research goals.

The main contributions of the paper are as follows:

- We present a mechanism and a set of queries by which large numbers of potentially pregnant women may be identified over social media.
- We present a supervised text classification approach for accurately detecting and enrolling a pregnancy cohort for data collection.
- We discuss a pipeline that incorporates the two aforementioned techniques to actively collect information posted by the detected pregnancy cohort.
- We discuss potential uses of the data collected from the cohort.

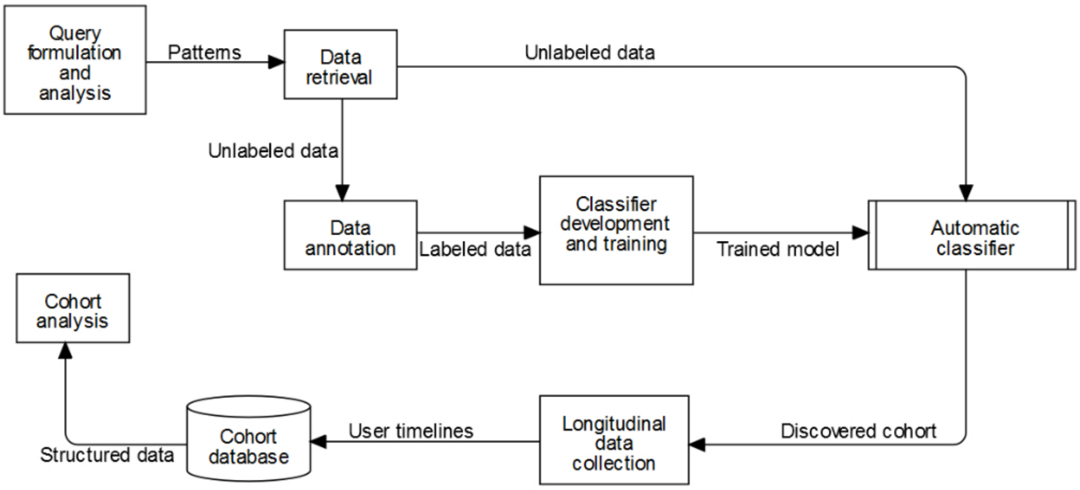
Methods

Preliminary Analysis

To assess whether social media can be utilized to identify cohorts of pregnant women, we performed a preliminary analysis using Twitter [11]. For the analysis, we employed one manually created query pattern of the form— "I.*(m|am|'m).*(weeks|months).*pregnant." Tweets retrieved by the query were manually analyzed and grouped into two categories: PIT and not PIT. In total, 1200 retrieved tweets were labeled in this way, and 753 (62.75%) tweets were tagged as true PITs, whereas 447 (37.25%) were classified as false positives. This early analysis was very promising as it showed that tweets retrieved by such queries were quite likely to be real indications of pregnancy posted by the women themselves. In addition, the pattern collected over 1500 announcements per month, which suggested that in the long run, large cohorts could potentially be detected, particularly with the addition of new queries.

In the same analysis, we also assessed the possibility of employing an automated supervised classifier to further filter the collected tweets so that pregnancy cohorts could be identified with greater precision. We experimented with several supervised classification approaches including Naïve Bayes and support vector machines (SVMs), and found the latter to produce acceptable performance with an F_1 score of 0.80 (precision approximately 0.83) for the PIT class. These outcomes from our feasibility analysis study provided strong encouragement for us to further explore the problem and develop a more robust solution for cohort collection. We discuss the expansion of this preliminary study in the following subsections. Figure 1 presents a flowchart illustrating the overall workflow, beginning from the query formulation part until cohort analysis using structured data.

Figure 1. Flowchart for the pregnancy cohort discovery pipeline from social media.



Query Formulation

We manually studied the tweets identified by the preliminary study, and using the Twitter graphical interface (ie, the actual website), we identified additional high-frequency word n-gram patterns and rules by which PITs could be detected with high precision. For each potential pattern, we assessed its usefulness by manually using it as a query on the Twitter graphical interface. For each query, approximately 50 tweets were manually assessed. Patterns capable of retrieving approximately more than 60% true pregnancy posts were selected for large-scale retrieval. Patterns that retrieved large numbers of true positives, but with too many noisy false positives, were discarded, as we were primarily focused in ensuring high precision.

In this fashion, we identified 13 query patterns in addition to the pattern employed in the preliminary analysis. Once each query was identified, it was used to collect tweets from the Twitter Streaming application programming interface (API). This API exposes a sample of all the public tweets at real time and enables collection. However, the API does not allow the direct use of regular expressions. Therefore, we used the seed terms "pregnancy," "pregnant," "baby," "family," and "mom" to retrieve tweets from the API and then matched them with the specific regular expressions. The data collection module was run over a period of 18 months, with minor variations for each of the 14 queries. Table 1 presents the queries used along with estimates of the relative frequencies of tweets retrieved by them within a defined period.

Annotation

A sample of the data gathered early on during the collection period was prepared for annotation. We observed early during the collection phase that there was a large variation in the number of tweets that were retrieved by each of the queries (as the third column in Table 1 indicates). To ensure that the distribution of the tweets in the annotation set represented the full set of retrieved data, we selected a stratified random sample of 14,300 tweets. An annotation guideline was prepared to ensure consistency in the annotation process. The annotation guideline is available in Multimedia Appendix 1.

Three annotators annotated all the tweets in a binary fashion, with overlapping annotations for 1000 tweets. Majority voting was used to resolve disagreement for the overlapping tweets. The interannotator agreement for the sample was κ=.79 (Fleiss kappa), which represents significant agreement. In total, 9819 tweets were tagged as true PITs, and 4338 tweets were annotated as false positives. These annotated tweets were then passed on to the next phase for training and optimizing an automated supervised classifier. Table 2 shows a sample of annotated tweets, with usernames deidentified.

Classification

Out of the 14,300 completed annotations, 14,156 tweets were suitable for use in classification. The rest were removed for various reasons such as encoding issues and presence of another language. We explored a number of feature sets for effectively performing the classification task, including those that we had determined to be useful for social media text classification via our extensive past work in the domain [12-14]. In addition, we experimented with several popular supervised classification approaches to identify the best performing one on the problem, along with a baseline classification system. The classifiers we explored were SVMs, random forest (RF), and convolutional deep neural networks (DNN) with 3 hidden layers, and the baseline was Naïve Bayes. We divided the annotated dataset into an approximately 80-20 split (80% for training and system development and 20% for evaluation). We used the larger split for optimizing the classifiers and for identifying useful features. In line with our past research, we have made samples of the training data and additional resources publicly available for the research community [15]. To maintain a balance between privacy and reproducibility and to comply with Twitter’s data sharing policy, we will only share the tweets using their IDs, rather than the verbatim text. Therefore, all tweets deleted by the original posters will not be available to the public. The following is a description of the features we chose for our final classification system.

Table 1. Query patterns used for retrieving the pregnancy-indicating tweets and some notes specifying additional details. “.*” represents sequences of characters of any length, “|” represents “or” and “&” represents “and” in any order. Queries are shown in simplified forms. Frequency and relative frequency of tweets for each pattern is also shown (N=14,156).

Query pattern	Notes	Relative frequency, n (%)
(im|i am|i’m).*[*time*].* pregnant	Time can be week, weeks, month or months	4374 (30.90)
baby & arriving	N/A[a]	375 (2.65)
baby coming soon	Exact sequence with whitespace or punctuations in between	297 (2.10)
been.*[*time*] & since & i & pregnant	Time can be day, days, week, weeks, month or months; exact sequence for “been time” with whitespace or punctuations in between	22 (<1.00)
growing & baby & belly	N/A	150 (1.06)
(im|i am|i’m) expecting.*baby	Exact sequence for “(im|i am|i'm) expecting” with whitespace or punctuations. “baby” must appear anywhere after	74 (<1.00)
(im|i am|i’m) going to (b|be) a mom	Exact sequence with punctuations or whitespace in between	179 (1.26)
(im|i am|i’m) having a baby	N/A	1396 (9.86)
i (hav|have) been pregnant	N/A	88 (<1.00)
(ive|i’ve) been pregnant	N/A	735 (5.19)
adding & one & “our family”	Exact sequence for “our family” with punctuations or whitespace in between	13 (<1.00)
my pregnancy	Exact sequence with whitespace or punctuations in between	6211 (43.88)
(im|i am|i’m) going to have a baby	N/A	234 (1.65)
our family.*growing.*(2|two) feet	N/A	8 (<1.00)

[a] N/A: not applicable.

Word n-Grams

In text classification, word n-grams are typically the most informative features. These n-grams are preprocessed sequences of words, and they are excellent in capturing the meanings of text segments. We preprocessed the tweets by lowercasing them and performing stemming using the Porter stemming algorithm [16]. We used 1-, 2-, and 3-grams as features without the removal of stopwords, and during training, each tweet was represented as a vector of the counts of all the n-grams in the training vocabulary. In our preliminary study, we had also experimented with synonyms of certain terms, but we removed them from the final system as they did not appear to improve performance.

Dense Word Embeddings

A potential problem with n-grams, particularly with Twitter data, is that there may be a lot of variation within the set of n-grams, giving rise to very sparse vectors. Recently, the use of dense word vectors, or embeddings, has become popular in natural language processing (NLP) research [17]. These embeddings are learned from large volumes of unlabeled data, and they are capable of capturing semantic information about each word in the form of dense vectors. For this classification task, we obtained dense vector representations of each tweet simply by adding dense representations of all individual tokens. To obtain dense vector representations of the terms, we used publicly available pretrained vectors [18]. The vectors were learned from 400 million tweets, and each word was represented using a dense vector of size 400.

Word Clusters

One strategy to address the problem of sparse vectors in classification is to use generalized representations of terms that are created based on some predefined grouping criteria. In past work, we discovered that using cluster representations of words improves classification performance [19]. In our work, we used the Twitter word clusters provided by Owoputi et al [20]. These clusters are generated by first learning word embeddings from over 56 million tweets and then employing a hidden Markov model to partition the words into a hierarchical set of 1000 base clusters.

When generating features, we used the cluster number for each token in a tweet (if available) and represented the clusters as binary vectors. Therefore, the cluster vector for each tweet represented the general categories of words present in the tweets.

Table 2. Sample tweets retrieved by the 14 queries and their binary annotations. "True" indicates real pregnancy indications and "False" indicates false positives. For the true category, we have included at least one sample from each of the 14 queries.

Tweet	Category
one month today (give or take) I am going to be a mom...I can not wait to see what my baby girl looks like :-)	True
So I thought I would let Twitter know that I am expecting a baby in eight months!!!	True
this belly and the sweet baby growing inside is the best christmas gift I could ever ask for!!! Merry Christmas e...	True
been 3 weeks since I've heard bebes heart or seen it. So sometimes I don't feel pregnant but this new stretch mark is proving otherwise	True
Just s few short months from adding another one to our family!	True
Ready for Christmas and pumped to announce that baby boy **** will be arriving May 2017! #MC3	True
Pregnancy announcement Our family is growing by 2 feet and 1 heart	True
Hoping & praying for a solution to income issues. Baby coming soon! Need better #job & better #pay	True
i literally cannot wrap my head around the fact that I am going to have a baby in 16 days or less..	True
so I am having a baby and super excited	True
swear since I have been pregnant everyone's forgot about me and doesn't involve me in anything	True
well... im currently 39 weeks and 6 days pregnant... you can come any time now sweetie	True
i just took my pregnancy cravings to a whole new level: I put ranch on my macaroni and cheese. #Yummmmmmmm	True
i'm so crafty since I've been pregnant before I couldn't even color a rainbow.	True
forever amazed at the number of women that ask me when I am going to have a baby instead of asking me about my career goals.	False
i swear I've been pregnant for 2 years now. #theobesityneedstostop #ineedwine	False
I'm having a baby JB day and it's killing me. I love him so much @justinbieber	False
my sister is five weeks and three days pregnant. I’m going to be an auntie oh my god	False
girls will be two days pregnant already posting pictures talking bout “I’m getting big.”	False
Cant believe im having a baby brother!	False

Sentiment Features

Our inspections of the collected tweets during the preliminary analysis suggested that users might express strong sentiments when announcing their pregnancies, as can be seen in some of the examples from Table 1. Sentiment analysis itself is an active research area, and there has been a flurry of work in this domain, particularly for social media texts [21]. To capture the sentiments in the posts as features, we added features that represent sentiments in chosen scales. To each tweet, we assigned three sets of scores representing three different measures of sentiment based on the following: (1) lists of positive and negative terms [22], (2) prior polarities of terms [23], and (3) the subjectivity of the terms, which present both polarity and subjectivity [24].

Structural Features

These include features that present structural information about each tweet. The features include tweet length (in words and characters), number of sentences within the tweet, average lengths of sentences, and so on.

Experiments

For each of the four classifiers mentioned previously, we used the training set to explore features and identify near-optimal settings for specific hyperparameters, when appropriate, via 10-fold cross validation. The training set consisted of 11,325 tweets, and the test set consisted of 2832 tweets. These optimal settings for the classifiers were used to classify the tweets in the test set. In addition, we also combined the three classifiers to form an ensemble and predicted the test set labels via majority voting. The best performing classifier was then used to classify all the pregnancy-related tweets collected by our patterns. The entire annotated dataset was used for training before classification of the collected unlabeled data.

We also assessed the performance of the best classifier for each type of query pattern to understand whether tweets retrieved by specific queries require more attention. In addition, we performed an analysis of the learning rate of the classifier by performing classifications on the same test set with different proportions of the training set for training—starting at 1133/11,325 (10.0%) tweets and increasing by 10% at each step. We analyzed the receiver operating characteristic (ROC) curve at each training set size and also the overall performance to assess whether further annotation is likely to improve performance. We present the results in the next section, along with details about the contribution of each feature set. We used the python scikit-learn library for the SVMs and RF implementations and TensorFlow for the DNN implementation.

Cohort Information Retrieval and Storage

All the user handles associated with the tweets classified to be positive by our chosen classifier were collected and stored. For each user, the Twitter Search API was used to collect all available past posts by the user, as per the restrictions of the API. In addition, new tweets posted by each of these users were collected on a weekly basis, resulting in the formation of a *timeline* for each user that encapsulates longitudinal information. All the information was stored in a Mongo database for future analysis.

A wide range of longitudinal information became available about each user's pregnancy from the timeline. These included, but were not limited to, information about their medication usage, health habits (eg, smoking or drinking), and birth outcomes. Our detection and collection approach was targeted toward the large-scale analysis of this information. We present some of the possibilities in the Discussion section and leave the specific analyses for future work, as that is beyond the scope of this study.

Health Information Analysis

We performed several preliminary level analyses using the collected data to assess the utilities of the timelines, their potential use in future studies, and the NLP-oriented future work required to increase their usefulness. These analyses included the following: (1) assessing the possibility of detecting trimester information from the collected cohort, (2) determining the presence of medication-related information for the cohort members, and (3) determining the presence of information regarding miscellaneous health conditions in the timelines. We now briefly discuss these analytical methods.

Trimester Detection

The duration of a pregnancy may be divided into three trimesters: first—week 1 to week 12, second—week 13 to week 27, and third—week 28 to birth. Trimester information is crucial for the future analysis of the pregnancy cohort as health events (eg, medication intake) may affect the fetal outcome uniquely, depending on the trimester. To successfully identify the trimester associated with a posted health-related event, information about the pregnancy start date is required. Our analysis of a sample of timelines suggested that the key NLP challenge in this problem is to detect the statements regarding the progress of the pregnancies, which are often available in the pregnancy tweets retrieved by our queries. We employed a simple, rule-based approach to assess the portion of the pregnancy cohort from which trimester information could be derived. In our rule-based algorithm, we first attempted to identify all tweets within a timeline that mentioned the terms “pregnant” and “pregnancy” (seed word). Next, terms occurring within a symmetric context window of size 6 of the seed term were collected. Within the context window, the algorithm then searched for key temporal terms such as “week“ and “month,” along with the presence of a number mention (eg, “6,” “12,” “18,” and so on). If all these rules were satisfied, the number mention and the temporal term mention were used to determine the progress of the pregnancy (eg, “6,” “week,” and “pregnancy” in "6 weeks into the pregnancy"). The number and the other mentioned terms were extracted and compared with the time stamp of the associated tweet to identify the approximate start date and trimester of the pregnancy.

Medication Mention Analysis

Medication intakes during pregnancy and their potential links to fetal outcomes is an important research topic, as discussed earlier in the paper. Pregnancy registries are currently the only source of information regarding this. In the future, if social media is to be used as a complementary source for studying medication safety during pregnancy, there must be intake-related information available within the collected pregnancy timelines. Although a full study is outside the scope of this paper, we performed a preliminary assessment by automatically computing the frequencies of mentions of a set of medications on a sample of our data (the same sample for which potential trimester information was detected). The goal was to ascertain whether medication usage information is available, rather than to perform a thorough analysis, which we leave as future work.

Assessment of Availability of Health Conditions

We manually analyzed a small sample of 30 user timelines to identify the types of health information that were present and also to ascertain what future tasks are necessary to improve the utility of the collected information. We present a sample timeline in the Results section and provide further details in the Discussion section.

Results

Classification Results

The final training set consists of 7830 instances of the pregnancy class and 3494 instances of the nonpregnancy class. The test set consists of 1989 instances of the pregnancy class and 843 instances of the nonpregnancy class. Table 3 presents the performance of the classifier on the test set. From the table, it can be seen that the three nonbaseline classifiers and the ensemble perform similarly in terms of pregnancy class F_1 score. The performances of the SVMs and DNN are better than that of the RF classifier, although these performances are not statistically significant. The ensemble of the three classifiers performs marginally better than the others on the test set, but the improvement is not significant and comes at a very high price in terms of time (eg, it is approximately 5 times slower to run than the stand-alone SVMs). All these classifiers significantly outperform the Naïve Bayes baseline.

On the basis of these results on the annotated set, we chose to use the SVMs in our system. Compared with the DNN, the SVMs appear to have marginally higher precision, which is preferred in our overall pipeline. Note that there is a possibility that using deeper DNNs would result in better performance, as typically is the case. However, deeper networks would also be computationally much more expensive, and so we did not include them in our exploration. SVMs performed much faster than both the DNN and the ensemble. Thus, consideration of all these factors favored the use of the SVMs.

Figure 2 presents the performance of the chosen classifier on posts retrieved by each of the query patterns. These performance results were obtained via 10-fold cross validation over the entire annotated set. The figure shows that for the two queries with the largest retrieval rates ("(im|i am|i'm).*[time].*pregnant" and "my pregnancy"), the performance scores were better than the overall averages. This is likely because of the fact that the annotations were carried out on a stratified random set, and therefore, the total number of annotated tweets for these sets was much higher than that for others, leading to the better training of the algorithms for these patterns. The pattern "(im|i am|i'm) having a baby" has the third highest retrieval rate, but the performance of the classifier is much lower for this set, which drives the overall performance down. In general, the patterns with low retrieval rates appear to perform poorly from the figure. We provide a brief analysis of the causes of errors in the Discussion section.

Figure 3 provides further insight into the performance of the system. The ROC curves in the figure (top) show that once over 50% of the training data are used, the prediction performances remain fairly stable. This suggests that further annotations of the same type of data are not likely to improve performance of the classifier. The learning rate chart (bottom) shows the performance metrics over the two classes and the full dataset at different sizes of the training data. This chart also shows that for each set, the performances remain stable after about 60% of the training set size. Unsurprisingly, as the training set size is increased, the biggest improvements are seen in the performance metrics of the smaller nonpregnancy class. As the performance over this class improves, so does the overall performance, albeit marginally.

Table 4 presents the performances obtained by the classifier during leave-one-out and single feature experiments. Recall, precision, and F_1 score for each class and the full set are shown. In none of the leave-one-out experiments, the performance of the combination of features drops significantly when a single feature is removed. The removal of n-grams results in the largest drop, but it is only marginal. This suggests that the performance of the classifier is not dependent on any of the single features but on the combination of all the features. This is desirable in a classifier for Twitter data because the low number of words in each tweet means that one type of feature may often not be able to capture enough information to perform classification correctly. Incorporating a number of features increases the chances of correct classification. The single feature scores in the table give a clearer idea of which features are most informative when employed in a stand-alone manner. Unsurprisingly, n-grams appear to be the strongest set of features and result in performances that are very close to the best performance of the classifier. Dense vectors and word clusters also produce good performances on their own, verifying the usefulness of these two feature sets. Structural features and sentiment features, although proved to be useful in our preliminary study using a much smaller training data, do not contribute significantly once the training set size is sufficiently increased. For these two features, large drops in performances are observed when they are used stand-alone. In all cases, we see a greater drop in the nonpregnancy class compared with the pregnancy class once a feature or a combination of features is removed. Although our focus is the pregnancy class, it is crucial to improve performance over the nonpregnancy class as changes in performance in one class directly affect the performance in the other.

Cohort Collection Statistics

Over a period of 18 months, the data collection component of our system (retrieval and classification) collected a total of 71,954 potentially pregnant users. Past data collection of the users resulted in the collection of over 250 million tweets, at about 3500 tweets per user on average. New pregnant users were detected at a rate of approximately 9000 to 10,000 per month, and 25 to 35 million new tweets were detected on average during the same period. At this rate, we expect the collection of an additional 100,000 to 120,000 timelines in the next 12 months.

Table 3. Classifier performances for the three strong classifiers, the Naïve Bayes baseline, and the ensemble classifier. Precision, recall, and F_1 score for the pregnancy class for each classifier are shown along with overall accuracy and 95% CI for the accuracy.

Classifier	Pregnancy class			Both classes
	Precision	Recall	F_1 score	Accuracy (95% CI)
Naïve Bayes	0.44	0.90	0.59	0.57 (0.56-0.58)
Random forest	0.95	0.79	0.86	0.81 (0.80-0.82)
Deep neural network	0.90	0.87	0.88	0.84 (0.83-0.85)
Support vector machines	0.92	0.85	0.88	0.84 (0.83-0.85)
Ensemble	0.93	0.85	0.89	0.84 (0.83-0.85)

Table 4. Leave-one-out and single feature scores for the features used in classification. "-" indicates that the feature was removed.

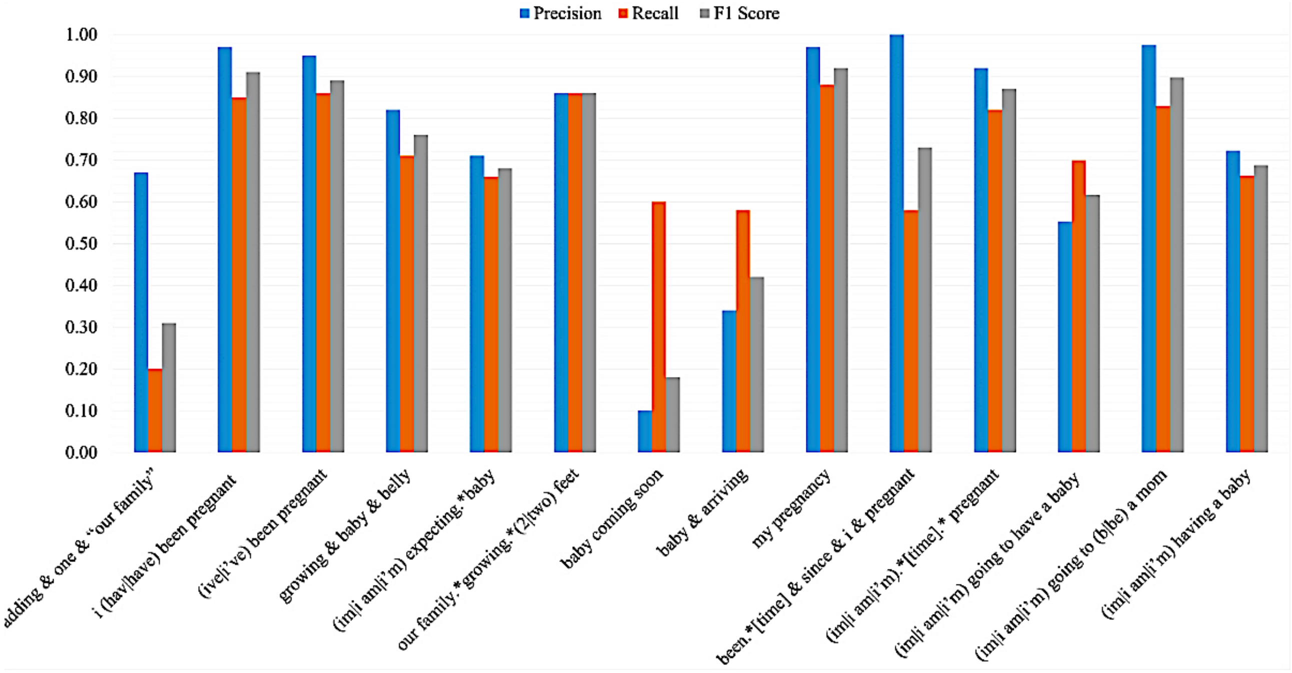
Feature set	Pregnancy class			Nonpregnancy class			Full set		
	P[a]	R[b]	F[c]	P	R	F	P	R	F
All	0.92	0.85	0.88	0.62	0.76	0.69	0.85	0.83	0.84
-N-grams	0.90	0.85	0.87	0.61	0.73	0.67	0.83	0.82	0.82
-Dense vectors	0.92	0.85	0.88	0.61	0.76	0.68	0.84	0.83	0.83
-Word clusters	0.92	0.84	0.88	0.58	0.76	0.66	0.84	0.82	0.83
-Sentiment features	0.92	0.85	0.88	0.62	0.76	0.68	0.85	0.83	0.84
-Structural features	0.92	0.85	0.88	0.62	0.76	0.68	0.85	0.83	0.84
N-grams	0.92	0.83	0.86	0.55	0.76	0.63	0.84	0.81	0.82
Dense vectors	0.89	0.82	0.85	0.54	0.68	0.61	0.81	0.79	0.80
Word clusters	0.90	0.83	0.86	0.56	0.70	0.82	0.82	0.80	0.81
Sentiment features	0.70	0.64	0.67	0.28	0.20	0.24	0.55	0.49	0.52
Structural features	0.67	0.69	0.68	0.30	0.28	0.29	0.55	0.56	0.56

[a] P: precision.

[b] R: recall.

[c] F: F_1 score.

Figure 2. The performance of the supervised classifier on the pregnancy class for each query pattern.



Health Information Analysis Results

We applied our pregnancy trimester extraction algorithm on 34,895 user timelines who were classified to be pregnant by our classifier in the early part of the study. Our algorithm detected pregnancy trimester information for 15,523 (approximately 44%) users. The algorithm further categorized each tweet belonging to these timelines into one of the three trimesters. Although detection of the availability of trimester information was highly accurate, manual analysis of a small sample of the timelines suggested that the algorithm was accurate in only about 50% of the cases in terms of categorizing the timelines into trimesters. This verified that trimester information is available in a large sample of our cohort, but a more robust algorithm is required for automatic categorization of information into trimesters.

Computation of medication mention frequencies on the same sample for which trimester information was detected verified that there is some medication-related chatter available in the timelines. Figure 4 shows the distribution of popular drug mentions across the pregnancy trimesters for Twitter users. Manual analysis of the previously mentioned timelines, however, showed that only a sample of the medication mentions are real examples of intake. In addition to medication mentions, the analysis revealed that a variety of other health-related information could potentially be mined from the timelines. This information, however, is intertwined with a large amount of noise. Table 5 shows sample posts in chronological order from one of the timelines that we manually analyzed, illustrating some of the types of information that are available. From Table 5 it can be seen that tweets 8, 11, and 15 present information regarding the progress of the pregnancy, and paired with the time stamps on the tweets, this information can be used to identify the trimester of a post.

Figure 3. Receiver operating characteristic (ROC) curves for the pregnancy tweet classifier at different sizes of the training data (top). Values for the area under the ROC curve (AUC) are also shown for each training set proportion. Classification precision, recall and F1 score over each class and the full dataset at each training set proportion (bottom).

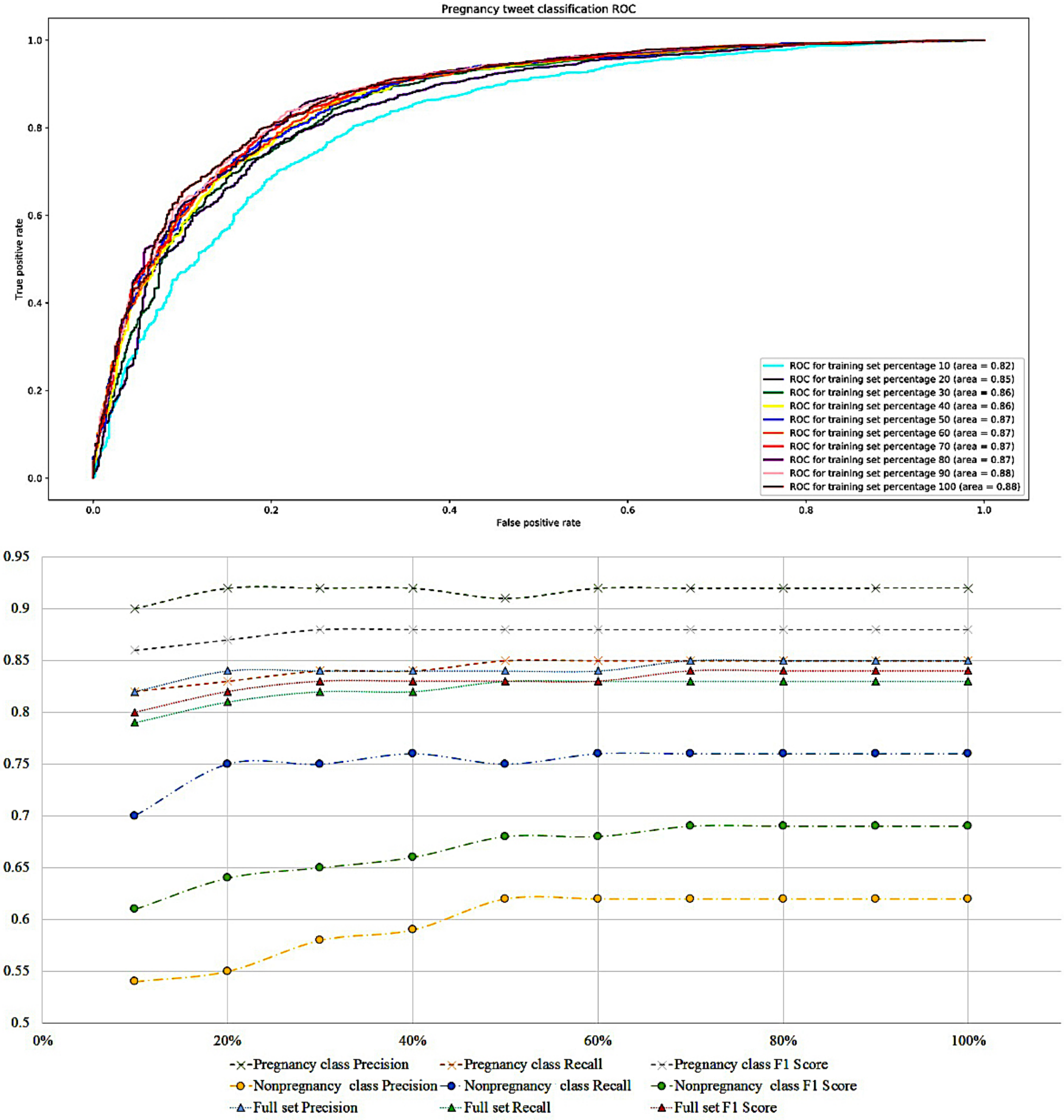
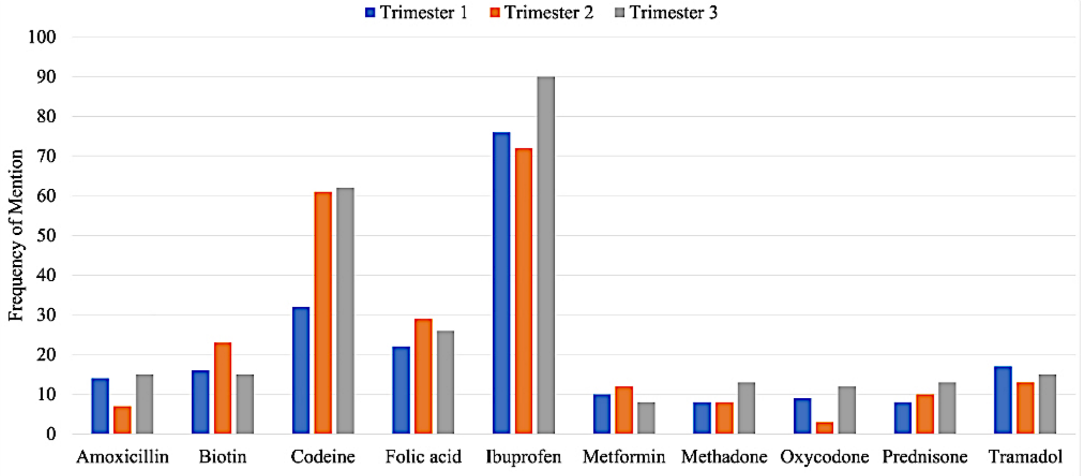


Table 5. Sample of 20 relevant posts from the timeline of a user classified as pregnant by our system. The posts were manually curated and categorized. Usernames have been anonymized.

Number#	Tweet	Trimester	Information type or comment
1	The tonsils are being evicted...1st October they will be no more!	First	Health condition
2	God...I'm 30...The right thing to do is probably to eat lots of cake to make it better #happybirthdaytome #30s	First	Age of user
3	@username yep I'm all done, not feeling too bad at the moment, got a pharmacy full on painkillers to see me through! Thanks xx	First	Medication
4	@username thanks, had some toast before I came home, just made a second batch to take painkillers with!	First	Medication
5	@username hazel on dw worked out the adult dose of calpol the other day so I saved that for emergencies, we always have calpol in! Xx	First	Medication
6	@username @username I've had tramadol this week post tonsils and can confirm that it definitely leaves you feeling pissed and sleepy!	First	Medication
7	poor you doesn't sound fun. I'm ok, throat is much better, off all the painkillers now which is good!	First	Stopping medication
8	20 week scan today! So pleased its first thing and I don't have to wait all day. Big question is, pink or blue??	Second	Progress information
9	So baby conn number 2 is a girl! Alex was right all along, now I need some nice girl names! #baby	Second	Gender of baby or health condition
10	Looking forward to #oneborneveryminute, love baby shows even if I am 25 weeks pregnant	Second	Pregnancy post detected by our query
11	Nothing like seeing a tiny baby to make me realise I'm getting one of those soon #10weekstogo #realitycheck	Third	Progress of pregnancy
12	Looks suspiciously like we are joining the pox bench, anyone else? #chickenpox	Third	Health condition
13	Think we may over the worst for the pox, day 5 no new spots but lots crusted over. #poxwatch	Third	Health condition
14	me! 36 weeks pregnant and travelling from sunny weston super mare to see you!	Third	Pregnancy indicating post
15	@username i am not burnt as I am mainly inside or in the air conditioned car where I am cooler #37weekspregnant	Third	Progress of pregnancy
16	This is Charlotte Amelia Conn born today at 11:22 weighing in at 7lb 10ozs	Birth	Birth announcement
17	@username Charlotte was 7lb 10ozs and dropped to 6lb 12ozs today. Apparently anything over a 10% drop triggers a whole load of stuff	Post birth	Weight loss in newborn
18	@username thought you'd think so! Yeah apparently 10% is the cut off, hers was an 11.2% drop. Hoping to avoid readmission tomorrow	Post birth	Weight loss in newborn
19	@username yup. She needed to gain and she lost another 10g. :-(	Post birth	Continuing weight loss
20	@username does indeed suck to be a grown up. We are good now thanks, Lottie's gaining weight well too. Need a bit more sleep though!	Post birth	Newborn regaining weight

Figure 4. Distribution of mentions of a set of medications in the data collected for a sample of our collected pregnancy cohort. Mentions are also categorized by our preliminary trimester detection approach.



Discussion

Principal Findings

The goal of our study was to determine whether cohorts of pregnant women could be detected using publicly posted social media data and natural language processing. We designed queries for retrieval of user posts that strongly indicate that the user is pregnant. Following the collection of such posts, supervised classification was used to further filter out false positives and collect a set of users that were highly likely to be pregnant. The results obtained show that such an approach was capable of detecting pregnant women and creating a social media–based pregnancy cohort that can be used for further analysis. Our overarching goal is to complement existing sources of pregnancy safety information with data mined from social media data. To be able to do that, the first, and most crucial, step is to be able to detect pregnant women with high accuracy or precision. Our study confirmed that by using carefully constructed queries and a well-designed supervised classification strategy, this can be achieved. Although the queries were able to collect PITs with varying accuracies for each query, the supervised classification approach had an overall F_1 score of 0.88 for the pregnancy class, which was almost equal to human agreement on these data. This suggests that our model was indeed effective in accurately detecting pregnancy cohorts from noisy social media data.

In addition to the performance of our classifier, the large volumes of user posts collected from the cohort and the health-related information detected via our small-scale analysis strongly support our initial motivation for such a system. The data collected from the cohorts appear to encapsulate, based on our small postclassification analyses, crucial knowledge regarding a variety of health-related information, albeit within an abundance of noisy, irrelevant information. The data may therefore be used for studying potential associations between medication intake and pregnancy outcomes, maternal health patterns, behavioral patterns and their associations with pregnancy outcomes, health of newborn children, and many more.

Our supervised classification approach also has the potential of being applied to other similar problems. Our approach combines sparse and dense vectors that independently perform well in the classification task. Such a combined representation is likely to benefit other social media text classification tasks that use short text nuggets, with limited contextual information, as input.

Applications of Automated Cohort Detection

As mentioned in the first section of the manuscript, certain cohorts such as pregnant women are not included in clinical trials. Thus, drug safety information for pregnant populations is typically not known when medications are released into the market, and discovering new associations to adverse effects may take years. The development of successful monitoring techniques utilizing social media data may expedite the process of discovery of unknown associations. Such techniques will have to be developed on top of our detection mechanism in the future. In addition, social media may provide information about the mothers' behavioral patterns, which they may not reveal to their doctors. Such patterns may include smoking, drinking, depressive behavior, and prescription medication abuse. Such information may help derive causal associations with adverse fetal outcomes and postpregnancy maternal health.

Our framework may be used to detect and monitor other cohorts as well. The key is to be able to identify queries that can retrieve posts where users *subscribe* to a cohort and an automated classification strategy that can filter out noise. The strategy can be used, for example, to detect users suffering from particular health conditions, users of a particular medication or medical intervention, and users addicted to prescription or illicit drugs.

Error Analysis and Linguistic Analysis

Error Analysis

We performed a limited error analysis to determine what factors commonly caused errors. The results of the analysis were in strong agreement with the per query result break down shown in Figure 2. To summarize, we found large proportions of errors for three specific query patterns—"baby & arriving," "baby coming soon," and "adding.*one 'our family'." In the first two cases, the term "baby" was found to be often used to refer to a loved one rather than to refer to a to-be born child. Both these queries had decent representation in the total annotated data (>2%), but the many variations meant that it was not possible for an automated algorithm to distinguish real announcements from false positives. For the third query, we found that although some tweets genuinely indicated the birth of an upcoming child from the mother, others referred to unrelated life events such as getting a new pet or getting married. Some were also posted by other family members and not the pregnant woman and thus were considered to be false positives according to our guideline.

On the basis of these common error cases, we envision several possible solutions that can be attempted in the future to further improve classification accuracies. As we selected a stratified random sample for annotation, some of the tweets retrieved by the patterns with low retrieval rates only received a small number of annotations. Therefore, it is likely that performance over those tweets will improve if more of them are annotated. However, considering their low retrieval rates, it may be prudent to simply remove such error-prone patterns from our future retrieval effort. As for tweets from the male counterparts of pregnant women that are detected by our queries (eg, the query patterns that include *our*), a module can be added to our pipeline that attempts to automatically detect gender from user timelines. We will consider the development of such a module or component in the future.

Linguistic Analysis

Gaining insight into the linguistic features that characterize and differentiate the "pregnancy" and "nonpregnancy" tweets could inform modifications to the queries for future data retrieval. To gain such insight, we drew upon a tool for corpus analysis called *DocuScope* [25]. On the basis of DocuScope's classification and frequency counts of linguistic patterns in 3000 of the "pregnancy" tweets and 3000 of the "nonpregnancy" tweets, we conducted a *factor analysis* [26] to explore the features that frequently co-occur in the tweets. Finally, we used the results of the factor analysis—in particular, the factor scores—as input for analysis of variance (ANOVA) to assess whether any of the factors (ie, groups of highly correlated linguistic features) explain significant linguistic variation [27] between the two groups of tweets.

One of the factors in the analysis reveals that the words *pregnancy* and *pregnant* frequently occur with first-person references (eg, *I* and *my*) in "pregnancy" tweets, whereas references to other people (eg, *she*, *he*, *brother*, and *sister*) and goal-oriented actions (eg, *having a baby*) are frequently absent in "pregnancy" tweets and vice versa for "nonpregnancy" tweets. The salient features in many of the "nonpregnancy" tweets aggregate to announce that a sibling is having a baby (eg, *my sister is having a baby*) or that the author of the tweet is going to be a sibling (eg, *I'm having a baby brother*), whereas the salient features in many of the "pregnancy" tweets combine to announce the author's own pregnancy. According to ANOVA, this factor explains statistically significant linguistic variation between the two groups of tweets.

Factor analysis can shed light on the micro-level linguistic cues that latently contributed to the annotators' high-level decisions to classify the tweets as "true" or "false" indications of pregnancy; consequently, it may also provide insight into the linguistic features that are playing an influential role in the automatic classification of the tweets. For instance, knowing that first-person references are a salient feature of "pregnancy" tweets might explain the relatively weaker performance of the classifier on the "having a baby" query pattern; in tweets such as "I'm having a baby brother," the *I'm* might be confusing the classifier into thinking that this is a "true" pregnancy announcement. Such insight could inform modifications to the queries for future data retrieval.

Limitations

This study has several methodological limitations that warrant further research. First, the cohort members for this study were chosen from a single social network, Twitter. Twitter is unique as a social media resource as posts can have a maximum length of 140 characters. This presents numerous problems to NLP tools because of lack of context, alternate spellings, and so on [28], but this property also limits the number of patterns that can be used to describe pregnancy-related information. Extending our framework beyond Twitter will require customizing queries to the social network chosen and the training of supervised learning algorithms with additional data.

The population reached through Twitter is also limited, and the sample is biased to social network users only. However, such biases exist in all samples for similar tasks, and social media is perhaps the most efficient way to reach, communicate, and collaborate with a large, diverse population [29,30]. A more important limitation of using social media is that complete information about individual cases may be harder to obtain, unlike traditional epidemiological studies. Although large numbers of cohorts can be detected, not all their health-related activities and health conditions may be available from their posts. The benefits of large cohort size may be diminished because of this. There is also the problem of discovering demographic information—only limited or no information regarding individual user demographics may be available. In some cases, the geographic locations of the users are available. Other demographic information such as age and race need to be determined via automated techniques. Reliable techniques for discovering demographic information for the pregnancy cohorts must be developed in the future. At this point, however, the use of social media in a manner that we have described appears to be very promising to complement traditional sources in the future.

Comparison With Prior Work

To the best of our knowledge, there is currently no existing work that attempts to identify cohorts of pregnant women over social media for large-scale drug safety analysis. Social media–based research has primarily focused on more generic surveillance tasks such as influenza spread forecasting [31,32], pharmacovigilance [33], medication abuse monitoring [13,34], and drug-drug interaction [35] to name a few. Most of the social media–based studies attempt to derive conclusions from information at the post level, rather than attempting to derive associations from longitudinal data. Some studies have utilized simple detection methods to identify users with specific characteristics and then analyzed the posted information. Correia et al [35], for example, used hashtags on Instagram to collect user timelines and detect drug-drug interactions, and De Choudhury et al [36] utilized Twitter data to predict postpartum depression. Hoang et al [37] assessed the feasibility of detecting detrimental prescribing cascades from Twitter user timelines. However, as discussed by the authors, such detection is challenging because of uncertainty and rarity of social media data. The work presented in this paper goes beyond these prior works by establishing a thorough and accurate approach for detecting a specialized cohort and also provides a novel opportunity to perform safety surveillance for pregnant women using publicly available data.

Conclusions

In this paper, we presented an approach for automatically identifying large cohorts of pregnant women over social media. Our proposed two-step approach for this detection first identifies potential pregnant women using targeted queries and then employs supervised classification to filter out most false positives. We thoroughly evaluated our cohort identification and classification approaches to validate that this is a viable approach for pregnancy cohort detection. We also showed potential uses of the information collected and future tasks.

On the basis of the findings of our study, social media promises to be a useful resource for performing drug safety research on pregnancy cohorts, particularly given the drawbacks associated with other sources including pregnancy registries. It must be noted, however, that social media is not expected to replace these traditional sources but rather serve as a complementary resource. An identical pipeline may also be used for automatic detection of other types of cohorts. Future research, with specific targeted applications of the data collected, will provide further insight regarding its usefulness.

Acknowledgments

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Authors' Contributions

AS performed the training and evaluation of the classification algorithms and the development of the classification strategies. He was also responsible for preparing most of the manuscript. PC designed and analyzed some of the query patterns and performed the initial data collection and the preliminary study. AM designed and analyzed some of the query patterns and performed some initial data collection. He was also one of the annotators and prepared the annotation guideline. AK performed the factor analysis and helped prepare the final manuscript. HC was in charge of implementing the end-to-end collection and storage pipeline and the implementation of the technical aspects of the study (eg, database integration and querying). GG was responsible for providing high-level guidance to the project and the preparation of the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Pregnancy tweet annotation guideline.

[PDF File (Adobe PDF File), 17KB - jmir_v19i10e361_app1.pdf]

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Abbreviations

ANOVA: analysis of variance
API: application programming interface
DNN: deep neural network
NLP: natural language processing
PIT: pregnancy-indicating tweet
RF: random forest
ROC: receiver operating characteristic
SVM: support vector machine

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Corrigenda and Addenda

Correction of: Using New and Emerging Technologies to Identify and Respond to Suicidality Among Help-Seeking Young People: A Cross-Sectional Study

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Related Article:

Correction of: http://www.jmir.org/2017/7/e247/

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In the paper by Frank Iorfino et al, “Using New and Emerging Technologies to Identify and Respond to Suicidality Among Help-Seeking Young People: A Cross-Sectional Study” (J Med Internet Res 2017;19(7):e247), a mistake was made in the final stage of copy editing. In the Introduction, the first sentence of the second paragraph should have appeared as follows: “This is a particularly pertinent issue given that almost half of those who have died by suicide had contact with a primary care provider within one month of the suicide [12], and one-quarter of those with depression who die by suicide are likely to have been in active engagement with mental health services at the time of death [13-16].”

Instead of the above, the first part of the sentence was incorrectly worded as: “This is a particularly pertinent issue given that almost half of those who have died by suicide had contact with a primary care provider within one month before *committing suicide* [12]...” (emphasis added). The phrase “committing suicide” was chosen by the proofreader without realizing that it can be perceived as stigmatizing and at times offensive in the mental health field. We regret this error and have updated our copyediting guidelines to reflect the recommended terminology [1].

Another minor error was introduced in the section, “Suicidality Escalation in Primary Care—A Proof of Concept.” In the first paragraph, where factors reported by clinicians as influencing the decision to escalate an individual are given, the “(4)” was repeated. The list should have appeared as follows: (1) concerns over specific suicidal ideation attributes such as little of control over suicidal thoughts (5/7 participants) and closeness to making an attempt (5/7 participants), (2) concerns over the presence of hypomania or psychosis-like symptoms (1/7 participants), (3) recent plans to make an attempt that were identified upon follow-up (1/7 participants), (4) few protective factors identified upon follow-up (1/7 participants), (5) few protective factors identified at follow-up (1/7 participants), and (6) recent self-harm (1/7 participants).

The corrected article will appear in the online version of the paper on the JMIR website on October 30, 2017, together with the publication of this correction notice. Because this was made after submission to PubMed Central, the corrected article will also be re-submitted to PubMed Central.

Reference

1. Mindframe. Mindframe National Media Initiative. Canberra: Australian Government, Department of Health; 2014. Reporting and portrayal of suicide URL: http://www.mindframe-media.info/for-media/reporting-suicide

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