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Original Paper

Drinker Prototype Alteration and Cue Reminders as Strategies in a Tailored Web-Based Intervention Reducing Adults’ Alcohol Consumption: Randomized Controlled Trial

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Abstract

Background: Excessive alcohol use is a prevalent and worldwide problem. Excessive drinking causes a significant burden of disease and is associated with both morbidity and excess mortality. Prototype alteration and provision of a cue reminder could be useful strategies to enhance the effectiveness of online tailored interventions for excessive drinking.

Objective: Through a Web-based randomized controlled trial, 2 strategies (ie, prototype alteration and cue reminders) within an existing online personalized feedback intervention (Drinktest) aimed to reduce adults’ excessive drinking. It was expected that both strategies would add to Drinktest and would result in reductions in alcohol consumption by intrinsic motivation and the seizure of opportunities to act.

Methods: Participants were recruited online and through printed materials. Excessive drinking adults (N=2634) were randomly assigned to 4 conditions: original Drinktest, Drinktest plus prototype alteration, Drinktest plus cue reminder, and Drinktest plus prototype alteration and cue reminder. Evaluation took place at 1-month posttest and 6-month follow-up. Differences in drinking behavior, intentions, and behavioral willingness (ie, primary outcomes) were assessed by means of longitudinal multilevel analyses using a last observation carried forward method. Measures were based on self-reports.

Results: All conditions showed reductions in drinking behavior and willingness to drink, and increased intentions to reduce drinking. Prototype alteration (B=–0.15, $P<.05$) and cue reminder usage (B=–0.15, $P<.05$) were both more effective in reducing alcohol consumption than when these strategies were not provided. Combining the strategies did not produce a synergistic effect. No differences across conditions were found regarding intentions or willingness.

Conclusions: Although individuals’ awareness of their cue was reasonable, their reported alcohol consumption was nevertheless reduced. Individuals appeared to distance their self-image from heavier drinking prototypes. Thus, prototype alteration and cue reminder usage may be feasible and simple intervention strategies to promote reductions in alcohol consumption among adults, with an effect up to 6 months.

Trial Registration: Nederlands Trial Register (NTR): 4169; http://www.trialregister.nl/trialreg/admin/rctview.asp?TC=4169 (Archived by WebCite at http://www.webcitation.org/6VD2jnxmB).

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KEYWORDS

Internet; intervention studies; prototypes; drinking; intention; willingness; adults; randomized controlled trial

Introduction

Background

Excessive alcohol use is a prevalent and worldwide problem [1]. In the Netherlands, 12.9% of the general population engages in weekly binge drinking, defined as ≥4 and ≥6 glasses of alcohol (10 gram each) per occasion for women and men, respectively. Also, 8.3% drink excessively, defined as drinking 14 or 21 glasses per week for women and men, respectively [2]. The percentage of drinkers and amount of alcohol consumed is generally higher among men than women [2]. Excessive drinking causes a significant burden of disease [3]. It is associated with both morbidity and excess mortality [4]. Also, it is an underlying cause, in part or entirely, of more than 30 health conditions and a contributing factor to many more problems, such as social harm, costs, etc [5].

It is important to further our understanding of how to reduce excessive drinking. A large number of interventions have targeted drinking behavior assuming that behavior is intentional. However, medium-to-large changes in intentions only lead to small-to-medium changes in behavior [6]. Effect sizes are found to vary for different behavior types and specific populations (eg, age-specific) with lower effect sizes for risk behavior than for health behavior [7]. A meta-analysis showed that, among the interventions that were based on Theory of Planned Behavior (TPB) components [8], only half were found to guide changes in intentions and two-thirds guided changes in behavior, and only small effect sizes were produced [9]. In addition, a meta-analysis based on 7 studies found a medium effect size (Hedges' g=0.39) regarding the effectiveness of online self-help interventions in reducing adults' drinking behavior in the general population, with an effect up to 6 or 9 months [10]. These types of interventions have several advantages, such as reach and cost-effectiveness (eg, [11-14]). However, single-session interventions, such as Drinktest.nl (described subsequently), have been found to produce small effect sizes only [10]. Drinktest has been shown to be more effective at reducing alcohol consumption among adult males in the experimental group than in the control group up to 1-month follow-up, but not up to 6-month follow-up [15]. In sum, the results of previous research and interventions often focused on explaining or changing intentional behavior; these suggest that a significant proportion of intentions and behavior remains unexplained and that the effectiveness of interventions can be improved.

Two main reasons may account for the small-to-medium (or lack of long-term) effects. First, individuals may not be fully aware of the opportunities of how to act on their intentions. For example, in the case of drinking behavior, the individual may intend to limit his alcohol consumption. The person needs to be aware of, for example, opportunities and resources to accomplish this limitation, such as responses to others to resist drinks when offered. As a result, many studies and interventions have focused on helping people act on their intentions (eg, [16]), acknowledging the well-known intention-behavior gap. However, the second reason is that behaviors may occur without intentions or even when having intentions not to do so [17,18]. Risk behaviors may also be guided by socially induced situations and factors, such as impulsivity, sensation seeking, and heat of the moment [19], following implicit and social reactive processes [20]. Importantly, people do not always comply with their intentions, and intentions are less likely to predict impulsive behaviors (eg, excessive drinking). Therefore, some researchers have suggested that targeting this social reactive process may be more fruitful than addressing the explicit goal-directed route to overcome these issues [21-23].

Additional Strategies

This study addresses these issues by examining the effect of 2 intervention strategies that could potentially help enhance the effect of an existing online (ie, Web-based) tailored intervention, Drinktest.nl: prototype alteration and cue reminders. Drinktest is based on the TPB [8], I-Change [24], and Stages of Change Model [25], providing normative and personalized feedback regarding self-help guidelines to reduce alcohol consumption. As described previously [15]:

> *Drinktest was developed by the Netherlands Institute for Health Promotion and Disease Prevention (NIGZ). Drinktest offers brief personalized feedback regarding an individual's personal alcohol consumption patterns. The intervention consists of various components: overview of mean weekly alcohol intake, associated health risks, self-help guidelines to reduce alcohol intake, and normative feedback to compare one's own alcohol consumption to the level of one's own cohort.*

The first strategy that could potentially enhance the effect of Drinktest is prototype alteration. Prototypes refer to the mental image of a typical person engaging in a certain behavior [17,18], such as a typical drinker or smoker. Prototypes are described in the Prototype Willingness Model (PWM), a dual-process model [17,20,23] assuming that behavior is guided by (1) reasoned intentions and (2) unintentional implicit social reactions. These "routes" may coexist in guiding behavior. For unintentional implicit social reactions, behavior is the result of behavioral willingness (further referred to as willingness). Willingness is defined as an "openness" to risk situations [18,20], such as the willingness to drink more than was planned. Specifically, many risky behaviors are facilitated or prompted by external stimuli or (social) situations [18]. Thus, the PWM recognizes factors such as impulsivity.

Prototypes have been shown to explain behavior through their effect on willingness and intentions and have also been shown to directly explain drinking behavior [26-31]. The assumption is that the more similar to the self and the more favorably the prototype is perceived, the more the individual will be willing or intending to engage in certain behavior [17,20]. Prototypes can incorporate core values (ie, goal states) that individuals desire (or avoid) (eg, [18,32]). Altering the perception of prototypes can be used as a strategy to cultivate behavior change by, for instance, contemplation of or accentuating the negative or positive characteristics attributed to the prototypes [33,34] and by encouraging social comparison and distancing from health-risk prototypes [35,36]. Experiments and intervention studies revealed that prototype alteration was effective in (1) postponing the onset of drinking among children aged 10-12 years with an effect up to 2 years [37], (2) quitting success for an adult smoking cessation group [36,38], and (3) changing (health-risk and health-protective) behavior among adolescents and undergraduates [28,33,34,37,39]. Although prototype alteration has been applied to alcohol use, few interventions aimed at reducing excessive drinking by using dual-process models (PWM) have been applied to young adults (usually incorporating only university students) and results have been mixed [40-42]. To our knowledge, there are no such interventions for the general adult population.

A second strategy is the use of cue reminders. The limited number of studies focusing on cue reminders has shown that cue reminders can help in changing (and maintaining) behavior [43-45] because cue reminders can help people remember the content of interventions or their personal goals. Cue reminders can support enactment of intentions as they can unconsciously prompt self-enhancing or self-protecting opportunities. That is, experimental research suggests that cue reminders could function through their salience and through an inhibiting mechanism. This would result in the inhibition of other cues (ie, to engage in health-risk behavior) that are present in a situation and, as a result, impulsive behaviors can be hampered [43,44]. Cue reminders are found to be effective even when people lack the cognitive capacity to reason, such as when being under time pressure or when already having consumed alcohol. This suggests an effect through the implicit route [43,44]. Finally, a cue reminder strategy has the advantage that it can be a simple means, such as a bracelet (one's own or provided), that can remind people of an intervention or of their intentions.

This study examined whether prototype alteration and provision of a cue reminder can be useful strategies to enhance the effectiveness of an existing online (ie, Web-based) tailored intervention, Drinktest. Drinking behavior, intentions to reduce drinking, and willingness to drink were targeted as primary outcomes. It was expected that (1) prototype alteration may intrinsically motivate people to drink less, (2) cue reminders may strengthen the salience of alcohol reduction goals, and (3) the combination of prototype alteration and a cue reminder may produce a synergistic effect and thus increase the salience and intrinsic motivation to drink less. As such, we tested whether the strategies of prototype alteration and a cue reminder in addition to the Drinktest intervention would be more effective in addressing excessive drinking behavior than the original Drinktest without those additional strategies. Other outcomes are also addressed, as will be described subsequently.

Methods

Design and Participants

A randomized controlled trial was conducted in the Netherlands in which participants were randomly assigned by computer to 1 of 4 conditions: (1) original Drinktest, (2) Drinktest plus prototype alteration, (3) Drinktest plus cue reminder, and (4) Drinktest plus prototype alteration and cue reminder (further referred to as the "combined condition"). The online tailored intervention consisted of baseline measurements and tailored feedback. Follow-up measurements were conducted at 1 and 6 months (postintervention: T2 and T3). Eligible participants were individuals aged 18 or older engaging in excessive drinking: exceeding ≥14 and ≥21 glasses of alcohol per week or drinking ≥4 and ≥6 glasses per occasion for women and men, respectively [46]. This norm was set by the original Drinktest and left unchanged.

Recruitment and Procedure

Participants were recruited online and by printed materials (posters and newspaper advertisements) from September 2012 to June 2013. The website of Drinktest was also easily accessible by online search engines. Before entering the intervention (T1), participants read the study information and were told that the existing Drinktest website was being evaluated. It was explicitly stated that participants did not have to commit themselves to reducing their alcohol consumption. Participants were then asked to sign the online informed consent form. In case participants declined to participate, they could close the browser or receive the original Drinktest without taking part in the study. After the informed consent form had been signed, participants were randomized into the conditions. Nonexcessive drinkers (of which the status was known only after drinking behavior was measured) were excluded from the study sample and routed to the original Drinktest.

All questions were self-administered and data were collected online. Participants were invited by email to participate in the 2 follow-up measurements and received reminders if necessary (maximum of 3). Participants were invited for the 6-month follow-up irrespective of their participation in the 1-month follow-up. A total of 50 vouchers worth €50 were distributed (by means of a raffle) as incentive. Ethical approval was granted by the independent ethics committee of the Erasmus MC, Rotterdam, the Netherlands (ref no: MEC-2010-112).

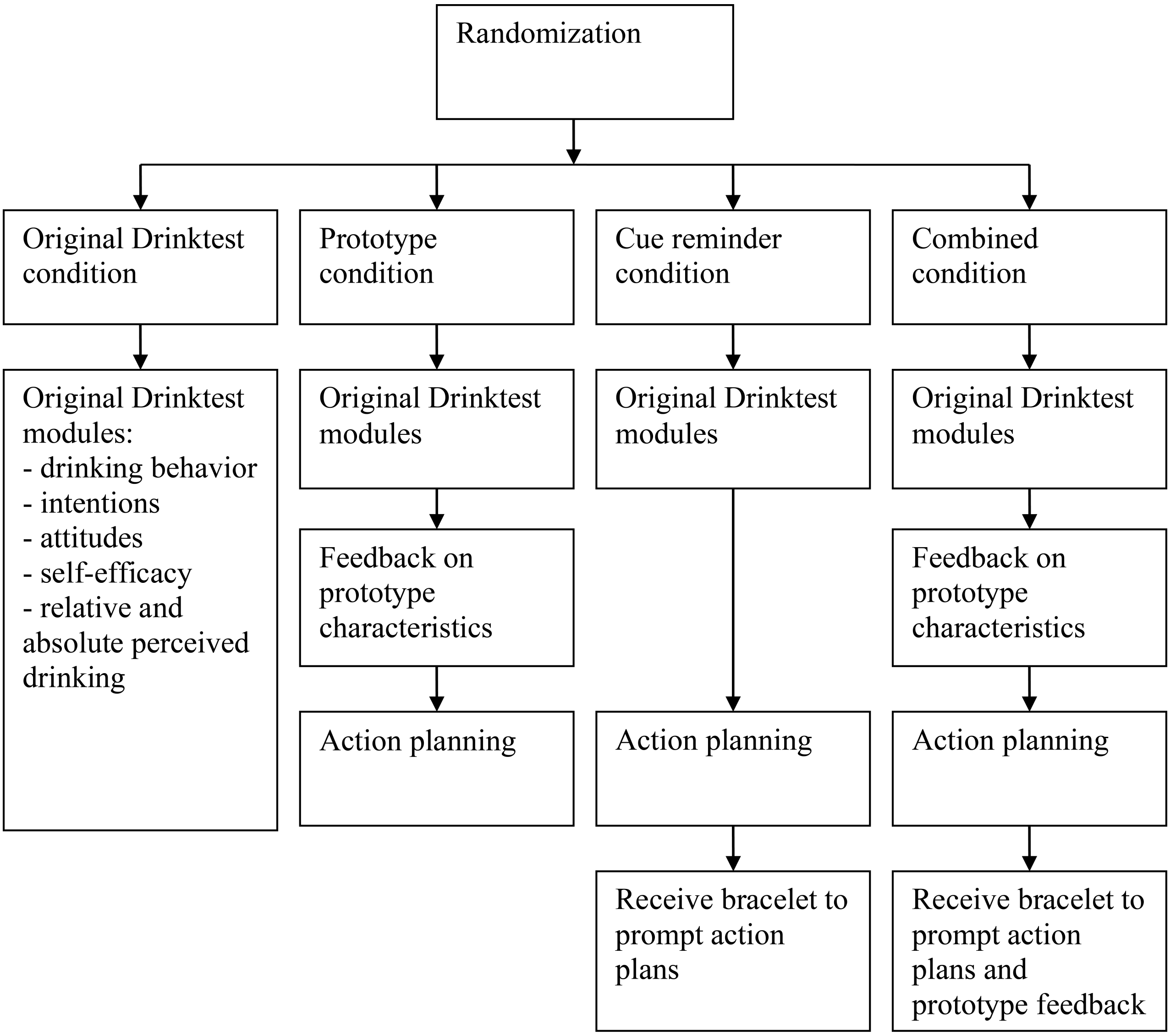
Power analyses using G*Power3 (eg, [47]) were performed. We expected to need a total sample size of 368 (4 groups × 3 time repetitions ANOVA_rm (repeated measures); ES(f)=.10, alpha=.05, power=.80, nonsphericity correction=.50, rho=.5), excluding dropout. Compensating for dropout (25% was expected), approximately 480 (120 participants per subgroup) would be needed. Given the larger dropout than expected, a larger inclusion at baseline was needed and achieved. As a result, the minimal required criterion of 480 participants to be included in all 3 measurements was met.

Intervention

Overview

Figure 1 represents the flow of the intervention. All tailored feedback was based on participant's responses and gender and was delivered online. All participants, irrespective of condition, received questions and feedback according to the original Drinktest. Feedback was derived from a computer program linking each possible combination of responses with an appropriate message. Feedback was not provided during the second and third measurement.

Figure 1. Flowchart illustrating the flow of the intervention per condition.



Original Drinktest Condition

Participants in the original Drinktest condition only received the standard version, in which they received feedback tailored to demographic background (gender), alcohol consumption, and intentions to reduce drinking. These messages reflected on personal drinking levels in comparison to the Dutch norm and peers' drinking behavior, the correctness of their absolute and relative perceived drinking risks regarding health risks due to their alcohol consumption, intentions, temptations (eg, coping with fights), correctness of positive effects of alcohol (eg, whether alcohol helps to sleep better), and correctness of negative effects of alcohol (eg, consequences for the liver and heart). To improve self-efficacy participants were encouraged to make a plan (without guidance) or to balance the advantages and disadvantages of reducing alcohol consumption. This part took approximately 10 minutes [15]. Multimedia Appendix 1 provides examples.

Prototype Condition

After completing the original Drinktest, participants in the prototype condition received feedback regarding prototype alteration (see Measures and Figure 1, and see Multimedia Appendix 1 for examples) tailored to gender, drinking behavior (also including normative feedback), intentions, and prototypical self-characterization. This addition to the Drinktest took approximately 5 minutes. The prototype message reflected on characteristics that the participants evaluated as personally desirable or undesirable by evaluating oneself on 11 characteristics (see Measures). Negative characteristics were accentuated as being negatively valued by peers and were linked to excessive drinking (ie, implicitly referring to heavier drinking prototypes) and positive characteristics were linked to moderate drinking and being positive valued by peers (ie, moderate drinker prototype). Participants were encouraged to reduce their drinking to achieve their desired characteristics and, in turn, to be positively valued by peers. Thus, this feedback implicitly aimed to distance participants from the heavier drinking prototypes, such as the drunk and heavy drinker, and to encourage similarity to and favorability of the moderate drinker prototype (see [35,36,38]).

Then, participants were guided in their goal setting by selecting action plans (adapted from [48,49]) to achieve the desired characteristics. First, they selected how they felt about reducing their alcohol consumption after having received tailored feedback ranging from 1="I do not wish to reduce my alcohol consumption" to 4="I want to quit drinking." If they were in doubt or were certain about reducing or quitting, participants were guided in their action plans by selecting a date to quit or start reducing. If they chose to reduce their consumption, they could set a limit of number of glasses per day and per week and the number of days on which the participant will not drink alcohol. Participants could also refuse to make plans (ie, "I do not wish to make a plan") or could set their own goals. (Participants in the original Drinktest condition did not form action plans.)

Participants selected action plans rather than forming their own because (1) forming plans of good quality has proven to be difficult for participants [50] and (2) plans formed by individuals are subject to additional variables compared to plans provided by the researcher [51].

Cue Reminder Condition

After finishing the original Drinktest modules, cue condition participants followed the same procedure in forming action plans as in the prototype condition (adapted from [48,49]). Feedback was provided that reflected on their action plans explaining that a cue reminder may help remember their plans (if made) and they were offered a free silicone bracelet (see [43]) by mail. If participants did not want to receive the bracelet, they were encouraged to select a piece of their own jewelry or another object of frequent use. After the cue selection, participants were instructed to think of their plans when they were aware of their cue so that the cue was linked to the action plans. If no plans were formed, participants were requested to use a cue for the duration of 1 month for the sake of the study and they were told to think of the content of Drinktest when they were aware of the cue. All participants were asked to wear their cue at least 1 month (ie, until T2). See Multimedia Appendix 1 for examples. This addition to the Drinktest took less than 5 minutes.

Combined Condition

Participants in the combined condition completed the original Drinktest modules, the prototype alteration module, and the cue module (see Figure 1). These participants were offered a cue reminder and were instructed to remember their plans (if made) and the desired characteristics they could achieve by reducing their alcohol consumption when they were aware of the cue reminder. See Multimedia Appendix 1 for examples.

Measures

Overview

All measurements included the same questions and followed the same guidelines for drinking norms unless otherwise specified. Measures from the original Drinktest were left unchanged and items regarding demography, willingness, prototypes, cue reminder, and process evaluation were added.

Process Evaluation (Measured at T2)

Participants reported on their appreciation of the intervention at the 1-month posttest by answering the statement: "The information and advice of Drinktest.nl were..." Answers ranged from 1=I disagree to 7=I agree regarding reliability, novelty, being informative, ease of understanding, personal relevance, persuasiveness, enjoyability, and usefulness (α=.86).

At 1-month posttest, all participants were asked, regarding the past 4 weeks (1) how aware they had been of their alcohol use, (2) how often they had contemplated on the intervention's feedback, and (3) their perception of having tried to reduce their alcohol consumption. Finally, we checked whether participants had correctly remembered their choice of cue, how aware they were of their cue, and how often they had worn or used the cue reminder. Answers to the Likert scales ranged from 1=not at all to 7=a lot.

Self-Characterization (Measured at T1, T2, and T3)

These items were assessed only at baseline among the prototype and combined conditions because it was part of their manipulation and feedback. Participants were asked to characterize themselves by prototypical characteristics. That is, prototypes are usually assessed by a list of characteristics describing them (eg, [18,52]). In this case, participants were instructed to rate themselves (ie, self-image) on 11 semantic pairs of prototype adjectives to reflect which adjectives they generally desired to be described with (7-point scale). The adjectives (ie, characteristics) were derived from a previous study on drinker prototypes [53]: unsociable-sociable, insecure-self-confident, loud-quiet, volatile-nonvolatile, reserved-spontaneous, annoying-funny, boring-amiable, sad-cheery, uncontrolled-controlled, irresponsible-responsible, and unordered-determined. A higher mean indicated a more positive desired self-image (T1-T3: α=.79-.86).

Primary Outcome Measures (Measured at T1, T2, and T3)

Drinking Behavior

Drinking behavior was assessed by the Dutch version of the Quantity-Frequency-Variability (QFV) index of alcohol intake [54], which asked participants to report the number of glasses they had consumed for each day of the past week. The mean number of drinks per day was calculated and used for analyses. A standard unit of alcohol contains 10 gram of ethanol, generally irrespective of the type of drink.

Intentions

To assess intentions, the item was framed by Drinktest in behavioral stages in which participants chose from the following options: (1) I do not plan to reduce my alcohol consumption, (2) I plan to reduce my alcohol consumption within half a year, (3) I plan to reduce my alcohol consumption within a month, (4) I already started reducing my alcohol consumption, and (5) I have reduced my alcohol consumption more than half a year ago. This single item was treated as a continuous variable.

Behavioral Willingness

Willingness was assessed by describing a scenario with 2 possible actions (adapted from [22,42]): "Imagine that it is Saturday night. You're going out with friends and you already had several alcoholic drinks. You feel you've had enough. One of your friends offers you a drink." This scenario was followed by the question "How willing would you be to..." with the statements "I take it and drink it" and "I refuse" rated from 1=certainly not to 7=very certain (T1-T3: *r*=.76-.85). Answers to the second statement were reversed.

Secondary Outcome Measures (Measured at T1, T2, and T3)

Absolute and Relative Perceived Drinking

Absolute perceived drinking risks was assessed with the item "With regard to my health, I consume too much alcohol" rated from 1=I disagree to 3=I agree. Relative perceived drinking was assessed with the item "Compared to [women/men] of my age, I drink..." rated from 1=a little to 3=a lot.

Attitude

Attitude was examined by the original Drinktest using 12 items measuring advantages and disadvantages of drinking alcohol regarding health, sociability, and coping. For instance, "My alcohol use is healthy for my heart and veins" rated from 1=yes, healthy to 3=no, unhealthy and "My alcohol use is a bad example to others" and "My alcohol use is bad for my liver" both rated from 1=yes, bad to 3=no, good. If needed, items were reversed so that a higher score represented a more positive attitude toward drinking. Because reliability over the 12 items was low, principle component analysis was performed revealing 2 factors. Only the first factor (5 items regarding relaxation, sleep, group conformation, sociability, and coping) was used in analyses (T1-T3: α=.73-.78) because the second factor still had low reliability (T1-T3: α=.35-.43).

Self-Efficacy

A single item assessed self-efficacy: "I find reducing my alcohol use" rated from 1=very hard to 5=very easy.

Temptations

Twelve items examined temptations, which regarded emotions, coping, habit, and social situations, such as "How tempting do you find it to drink alcohol when you are at a party or in a restaurant?" with answers ranging from 1=not tempting at all to 5=very tempting (T1-T3: α=.86-.87).

Statistical Analyses

All analyses were performed in SPSS 21.0 (IBM Corp, Armonk, NY, USA). First, we determined whether dropout between baseline and follow-up measurements was different for condition, gender, age, ethnicity, level of education, intentions, willingness, and drinking behavior. Second, potential differences between conditions at baseline were assessed regarding these measures. Third, the process evaluations were assessed. Fourth, longitudinal multilevel analyses (mixed models) were performed using the last observation carried forward (LOCF) method (1) to account for dropout and (2) because of the nested design (measurements such as time were nested in individuals). Using the LOFC method implies that if data for a follow-up measurement were missing, then data from the previous known data were used for analyses. For example, if data were available for the first and third measurements and the second was missing, then the data from the first measurement were also used as the second measurement instead of treating this data as missing. It should be noted that reported descriptives are based on LOCF.

Following previous research [55], a multilevel regression model for longitudinal data was used including a random slope and intercept to analyze differences between conditions in the changes in the dependent variables from baseline to both follow-up measurements. The most important reason for using this method is that it provides a solution to the problem of missing data and thereby increases the power of the study [56].

The following independent variables were included in the multilevel longitudinal analyses: having received prototype alteration feedback (yes/no), having received a cue reminder (yes/no), and the interaction of prototype alteration (yes/no) and cue reminder (yes/no) to assess the added value of their combination (following previous research [57]; between-group variable), and including time (measurements, coded as 0, 1, 2 following Blom et al [55]; within-participant variable). For instance, the analysis group that received the prototype alteration strategy (prototype=yes) was compared to the group that did not receive a prototype alteration strategy in addition to the Drinktest (prototype=no). Analyses were corrected for potential significant differences between conditions at baseline. The means are given per analysis group instead of per condition for clarity and continuity with the effects presented in the tables and figures. For sensitivity purposes, the analyses were repeated for complete cases only. We used the median absolute deviation (MAD) to detect outliers for the behavioral measures (at all time measurements). MAD was applied because it is more robust to outliers than standard deviation [58]. After applying MAD, the variables were normally distributed.

Results

Participants' Characteristics

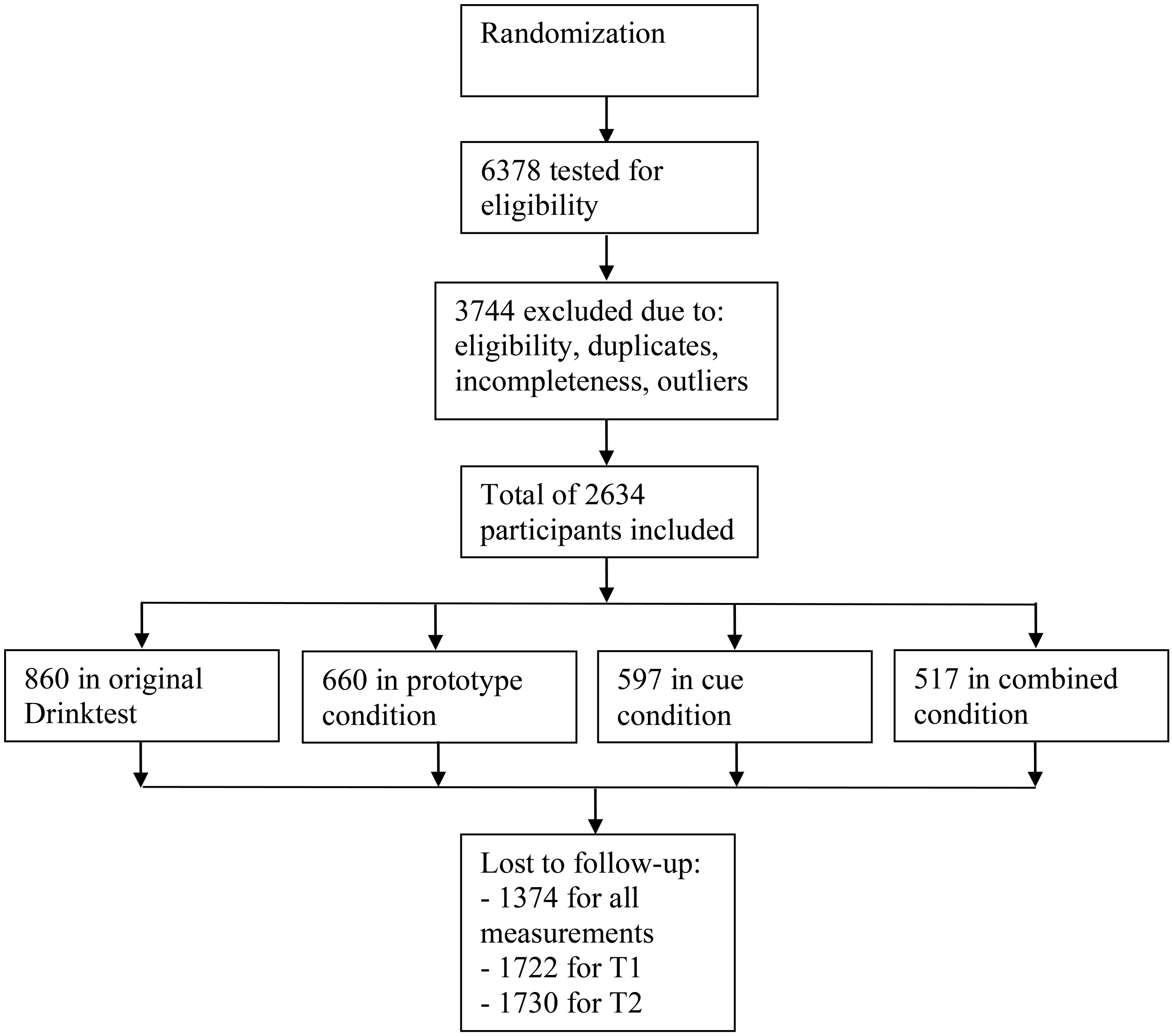
Figure 2 presents the flowchart of participants showing that a total of 6378 persons started the program. After data collection was completed, 9 same email addresses were used by different persons and were removed (n=19). Then, duplicates (n=99), nonexcessive drinkers (n=2506), incomplete (n=892), and outliers based on MAD (n=228) at baseline were removed. The resulting final sample consisted of 2634 eligible participants (male: 1351/2634, 51.29%; age: mean 37.03, SD 15.19). LOCF was applied. Most (94.46%, 2488/2634) of the sample was of Western origin, as defined by Statistics Netherlands [59], most originating from the Netherlands, followed by Belgium and Germany. *Western origin* includes all countries in Europe (except for Turkey), North America, Oceania, Japan, and Indonesia (including former Netherlands East Indies). *Non-Western* includes Turkey and all countries of Africa, Latin America, and Asia, except Japan and Indonesia [59]. Also, most were either pursuing or had completed a middle or higher educational level (64.58%, 1701/2634).

Intervention analyses were corrected for age and educational level because these were significantly different between conditions at baseline. Table 1 presents the baseline characteristics of participants overall and per condition.

Table 1. Participant characteristics and primary outcome measures at baseline (T1) presenting differences between study conditions.

Variables	Condition				Overall (N=2634)	$F_{3,2633}$	χ^2_3	P
	Original Drink-test (n=860)	Prototype (n=660)	Cue reminder (n=597)	Combined (n=517)				
Age (years), mean (SD)	35.24 (15.30)	37.43 (15.03)	37.43 (15.03)	39.03 (15.18)	37.03 (15.19)	7.33		<.001
Gender, n (%)							4.6	.20
Male	467 (54.3)	330 (50.0)	297 (49.7)	257 (49.7)	1351 (51.29)			
Female	393 (45.7)	330 (50.0)	300 (50.3)	260 (50.3)	1283 (48.71)			
Educational level							15.4	.002
Low	346 (40.4)	224 (34.0)	197 (33.1)	161 (31.1)	928 (35.23)			
High	511 (59.6)	435 (66.0)	399 (66.9)	356 (68.9)	1701 (64.58)			
Origin, n (%)							0.4	.94
Non-Western	49 (5.7)	33 (5.0)	31 (5.2)	28 (5.4)	141 (5.35)			
Western	809 (94.3)	626 (95.0)	564 (94.8)	489 (94.6)	2488 (94.46)			
Drinking behavior, mean (SD)	3.51 (1.82)	3.65 (1.79)	3.64 (1.83)	3.64 (1.83)	3.60 (1.82)	1.08		
Intentions, mean (SD)	2.58 (1.40)	2.71 (1.34)	2.69 (1.36)	2.71 (1.33)	2.66 (1.36)	1.58		
Willingness, mean (SD)	4.60 (1.98)	4.65 (1.95)	4.57 (2.04)	4.41 (2.08)	4.57 (2.01)	1.57		

Figure 2. Flowchart illustrating the flow of participants through the study.



Dropout

A total of 1260 participants completed 1 or both of the follow-up measurements (attrition 47.84%, 1260/2634). A total of 599 participants participated in all 3 measurements (attrition 77.26%, 599/2634). Dropout analyses were performed for those who did not participate in either of the 2 follow-up measurements. Dropout was highest among the original Drinktest condition (57.4%, 494/860) and was significantly higher than the prototype condition (OR 1.48, 95% CI 1.20-1.81, *P*<.001), cue condition (OR 1.26, 95% CI 1.02-1.55, *P*=.03), and combined condition (OR 1.38, 95% CI 1.10-1.71, *P*=.004); the 3 added conditions did not differ from one another. Dropout was also higher among men (OR 1.34, 95% CI 1.15-1.57, *P*<.001), lower educated participants (OR 2.21, 95% CI 1.87-2.60, *P*<.001), and non-Western participants (OR 1.46, 95% CI 1.03-2.07, *P*=.03). Additionally, those who dropped out were also slightly younger ($F_{1,2633}$=48.83, *P*<.001) and reported a slightly higher alcohol consumption ($F_{1,2633}$=17.66, *P*<.001). We used LOCF in the longitudinal multilevel analyses to account for dropout and corrected the analyses for age and education.

Process Evaluation

Second, the appreciation of the intervention was assessed. The original (mean 4.85, SD 0.96) and extended Drinktest (combining the 3 added conditions; mean 4.88, SD 1.12) did not differ in their intervention evaluations ($F_{1,802}$=0.06, *P*=.81). Both Drinktest versions were rated as equally interesting, new, informative, understandable, personally relevant, persuasive, enjoyable, and useful. The results were similar across all 4 conditions.

Furthermore, among the participants in the cue and combination conditions, 34.2% (193/564) received a bracelet and 43.1% (243/564) chose to use their own cue, whereas only 22.7% (128/564) did not wish to be reminded. At follow-up, the vast majority were found to remember their chosen cue reminder correctly (94.1%, 365/388) and reported using or wearing their cue reminder frequently (61.4%, 127/207). The awareness of the cue was reasonable (mean 3.27, SD 2.11).

Based on the means, participants that received a prototype alteration and/or cue reminder strategy generally had higher awareness of their alcohol consumption, contemplation of the intervention, and perception of having reduced alcohol consumption than those who only received the original Drinktest (Table 2). For those in the combination condition, a significant higher contemplation of the intervention was found compared to those in the original Drinktest condition. Also, participants in either the prototype or combination condition reported higher perceptions of having tried to reduce their drinking than participants in the Drinktest condition. Furthermore, an increase of self-characterization was found for those participants that received the prototype alteration strategy.

Table 2. Means and standard deviation of process evaluation for 1-month posttest (T2) and 6-month (T3) follow-up measurements overall and per condition.

Variable	Condition, mean (SD)[a]				Overall, mean (SD) (N=2634)
	Original Drinktest (n=860)	Prototype (n=660)	Cue reminder (n=597)	Combined (n=517)	
Process evaluation					
Awareness of drinking					
T2 posttest	5.33 (1.56)	5.64 (1.44)	5.51 (1.51)	5.65 (1.43)	5.53 (1.49)
Contemplation of intervention					
T2 posttest[b]	2.83 (1.91)	3.23 (2.05)	3.28 (1.96)	3.70 (2.18)	3.23 (2.04)
Tried to reduce drinking					
T2 posttest[c]	4.49 (2.09)	5.00 (2.09)	4.95 (2.13)	5.22 (2.11)	4.89 (2.12)
Self-characterization					
T1 baseline		5.42 (0.92)		5.46 (0.87)	
T2 posttest		5.57 (0.86)		5.66 (0.83)	
T3 follow-up		5.63 (0.84)		5.73 (0.82)	

[a] There were only means for self-characterization at baseline for the prototype and combination condition. Differences for contemplation and trying to reduce drinking are significant at *P*<.05. Analyses were corrected for age and level of education.

[b] Original Drinktest and Combined differ.

[c] Original Drinktest and Prototype differ, and Original Drinktest and Combined differ.

Primary Outcomes

Table 3 shows that the reported mean number of drinks per day was 3.60 glasses at baseline (SD 1.82), 3.19 glasses at 1-month posttest (SD 1.82), and 3.06 at 6-month follow-up (SD 1.81). Table 4 presents effects over time and for short-term (baseline and 1-month posttest) and long-term effects (baseline and 6-month follow-up). Alcohol consumption was reduced overall and participants who received the separate strategies of prototypes alteration (B=–0.15, *P*=.03) and a cue reminder (B=–0.15, *P*=.03) had larger reductions than those who did not receive these strategies in addition to the original Drinktest (Figure 3). The short-term effect was strongest and the long-term effect was only significant for the overall analysis (Table 4). Small effect sizes were found (Table 3).

Table 3. Means and standard deviations (based on last observation carried forward) and effect size (Cohen's *d*)[a] for primary and secondary outcomes for baseline (T1), 1-month posttest (T2), and 6-month follow-up (T3) measurements, overall and per analysis group.

Variable	No prototype or cue, mean (SD) (n=857)	Received prototype, mean (SD) (n=1176)	*d*	Received cue, mean (SD) (n=1113)	*d*	Received cue and prototype, mean (SD) (n=517)	*d*	Overall, mean (SD) (N=2634)
Primary outcomes								
Drinking behavior								
T1 baseline	3.51 (1.82)	3.65 (1.81)		3.64 (1.83)		3.64 (1.83)		3.60 (1.82)
T2 posttest	3.20 (1.79)	3.17 (1.85)	0.09	3.21 (1.85)	0.07	3.18 (1.88)	0.08	3.19 (1.82)
T3 follow-up	3.10 (1.81)	3.03 (1.82)	0.12	3.04 (1.84)	0.10	3.03 (1.88)	0.11	3.06 (1.81)
Intentions								
T1 baseline	2.58 (1.40)	2.71 (1.34)		2.70 (1.35)		2.71 (1.33)		2.66 (1.36)
T2 posttest	2.67 (1.42)	2.86 (1.35)	0.04	2.83 (1.35)	0.03	2.85 (1.35)	0.04	2.79 (1.38)
T3 follow-up	2.74 (1.45)	2.88 (1.41)	0.01	2.88 (1.43)	0.01	2.88 (1.43)	0.01	2.84 (1.43)
Behavioral willingness								
T1 baseline	4.60 (1.98)	4.55 (2.01)		4.50 (2.06)		4.41 (2.08)		4.57 (2.01)
T2 posttest	4.45 (2.02)	4.25 (2.08)	0.08	4.24 (2.11)	0.06	4.11 (2.15)	0.08	4.34 (2.06)
T3 follow-up	4.39 (2.04)	4.16 (2.06)	0.09	4.11 (2.11)	0.09	4.02 (2.10)	0.09	4.24 (2.07)
Secondary outcomes								
Attitude								
T1 baseline	1.48 (0.35)	1.47 (0.32)		1.46 (0.32)		1.46 (0.31)		1.47 (0.33)
T2 posttest	1.47 (0.34)	1.45 (0.32)	0.03	1.46 (0.33)	–0.03	1.45 (0.31)	0.00	1.46 (0.33)
T3 follow-up	1.46 (0.34)	1.46 (0.33)	–0.03	1.47 (0.34)	–0.09	1.47 (0.32)	–0.09	1.47 (0.34)
Self-efficacy								
T1 baseline	2.38 (0.96)	2.31 (0.93)		2.29 (0.92)		2.35 (0.94)		2.31 (0.93)
T2 posttest	2.48 (0.94)	2.47 (0.98)	0.06	2.44 (0.95)	0.05	2.50 (0.96)	0.05	2.45 (0.96)
T3 follow-up	2.58 (1.00)	2.54 (1.00)	0.03	2.48 (0.98)	–0.01	2.53 (0.97)	–0.02	2.53 (1.00)
Temptations								
T1 baseline	2.27 (0.43)	2.28 (0.42)		2.29 (0.42)		2.25 (0.42)		2.29 (0.42)
T2 posttest	2.22 (0.43)	2.22 (0.42)	0.02	2.24 (0.42)	0.00	2.20 (0.43)	0.00	2.23 (0.42)
T3 follow-up	2.48 (0.66)	2.44 (0.66)	–0.12	2.43 (0.66)	–0.16	2.42 (0.65)	–0.09	2.45 (0.66)
Absolute perceived drinking risks								
T1 baseline	2.38 (0.75)	2.47 (0.73)		2.49 (0.71)		2.48 (0.72)		2.45 (0.73)
T2 posttest	2.37 (0.76)	2.81 (1.26)	0.47	3.27 (1.54)	1.05	3.27 (1.57)	10.07	2.77 (1.23)
T3 follow-up	2.34 (0.77)	2.54 (1.06)	0.15	2.74 (1.28)	0.39	2.71 (1.30)	0.36	2.53 (1.03)
Relative perceived drinking								
T1 baseline	4.80 (1.25)	5.03 (1.15)		5.03 (1.18)		5.00 (1.16)		4.96 (1.20)
T2 posttest	3.55 (1.53)	3.52 (1.61)	0.21	3.66 (1.66)	0.10	3.54 (1.62)	0.17	3.59 (1.61)
T3 follow-up	3.21 (1.49)	3.13 (1.55)	0.25	3.23 (1.61)	0.17	3.16 (1.57)	0.20	3.19 (1.55)

[a] Effect sizes (Cohen's *d*) are based on changes between T1 and T2, and T1 and T3 for the analysis groups that received an additional strategy compared to the analysis group that did not receive an additional strategy added to Drinktest.

Table 4. Longitudinal multilevel analyses (mixed models) including analyses over all measurements (baseline, T1; 1-month posttest, T2; and 6-month follow-up, T3) and separately for short term (T1 to T2) and long-term measurements (T1 to T3), corrected for education and age. Regression coefficient (B) and 95% confidence intervals are presented regarding change over time for the strategy-added group versus no strategy added to the original Drinktest analyses group.

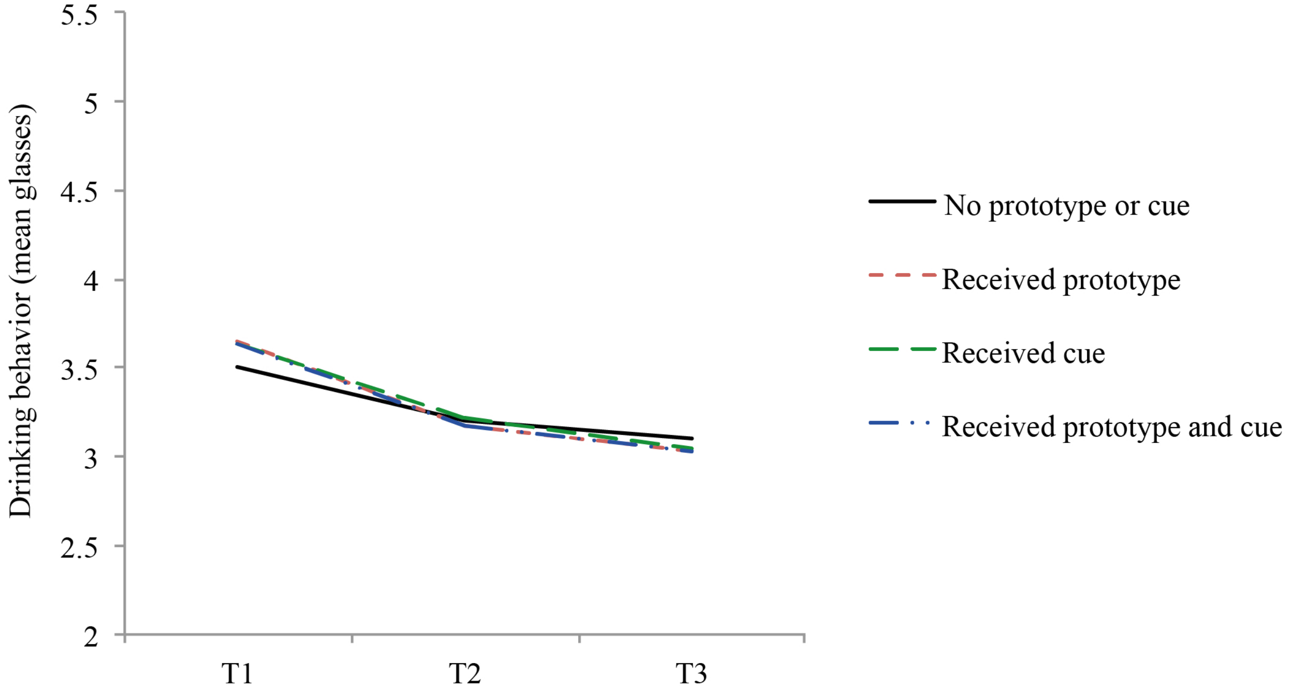
Variables and time[a]	Prototype received vs no prototype received		Cue reminder received vs no cue received		Interaction cue and prototype vs no additional strategy received		Effect over 4 conditions	
	B	95% CI	B	95% CI	B	95% CI	B	95% CI
Primary outcomes								
Drinking behavior								
T1,T2,T3	–0.15*	–0.28,–0.01	–0.15*	–0.29,–0.01	0.08	–0.11, 0.27	–0.07**	–0.11,–0.02
T1,T2	–0.32*	–0.59,–0.05	–0.30*	–0.58,–0.02	0.27	–0.13, 0.66	–0.11*	–0.20,–0.02
T1,T3	–0.22	–0.48, 0.05	–0.23	–0.50, 05	0.08	–0.31, 0.47	–0.11*	–0.20,–0.02
Intentions								
T1,T2,T3	–0.01	–0.10, 0.09	0.09	–0.01, 0.20	–0.08	–0.22, 0.06	0.01	–0.02, 0.05
T1,T2	0.15	–0.05, 0.36	0.20	–0.01, 0.41	–0.18	–0.47, 0.12	0.06	–0.01, 0.13
T1,T3	–0.06	–0.26, 0.14	0.15	–0.06, 0.36	–0.12	–0.41, 0.18	0.01	–0.06, 0.08
Willingness								
T1,T2,T3	–0.05	–0.18, 0.08	–0.10	–0.24, 0.05	0.01	–0.19, 0.21	–0.05	–0.09, 0.00
T1,T2	–0.23	–0.51, 0.05	–0.12	–0.42, 0.17	–0.01	–0.42, 0.40	–0.10*	–0.19,–0.00
T1,T3	–0.05	–0.32, 0.23	–0.17	–0.46, 0.12	0.02	–0.39, 0.43	–0.07	–0.16, 0.02
Secondary outcomes								
Attitude								
T1,T2,T3	0.00	–0.03, 0.03	0.01	–0.02, 0.04	0.00	–0.03, 0.04	0.00	–0.00, 0.01
T1,T2	–0.03	–0.08, 0.03	0.01	–0.05, 0.07	0.01	–0.06, 0.08	0.00	–0.02, 0.02
T1,T3	0.00	–0.05, 0.05	0.02	–0.04, 0.07	0.01	–0.07, 0.08	0.01	–0.01, 0.02
Self-efficacy								
T1,T2,T3	0.01	–0.06, 0.09	–0.02	–0.10, 0.06	0.01	–0.10, 0.11	–0.00	–0.03, 0.03
T1,T2	0.00	–0.15, 0.16	0.04	–0.13, 0.20	0.03	–0.19, 0.24	0.02	–0.03, 0.08
T1,T3	0.02	–0.13, 0.17	–0.05	–0.21, 0.11	0.02	–0.20, 0.23	–0.01	–0.06, 0.05
Temptations								
T1,T2,T3	–0.00	–0.06, 05	–0.01	–0.07, 0.04	–0.00	–0.07, 0.07	–0.01	–0.03, 0.01
T1,T2	0.01	–0.10, 0.13	0.05	–0.06, 0.17	–0.08	–0.23, 0.06	0.00	–0.04, 0.04
T1,T3	–0.00	–0.11, 0.11	–0.03	–0.15, 0.08	0.03	–0.11, 0.18	–0.01	–0.05, 0.04
Absolute perceived drinking risks								
T1,T2,T3	–0.01	–0.10, 0.09	0.27***	0.17, 0.37	–0.05	–0.17, 0.08	0.09***	0.06, 0.13
T1,T2	0.00	–0.14, 0.15	2.46***	2.31, 2.61	–0.27***	0.48,–0.07	0.90***	0.85, 0.95
T1,T3	–0.01	–0.15, 0.13	–0.10	–0.24, 0.05	–0.04	–0.24, 0.17	–0.05	–0.10, 0.00
Relative perceived drinking								
T1,T2,T3	–0.11*	–0.22,–0.01	–0.13*	–0.24,–0.02	0.04	–0.09, 0.18	–0.07**	–0.10,–0.02
T1,T2	–0.17*	–0.33,–0.01	–0.12	–0.29, 0.04	0.04	–0.18, 0.26	–0.07*	–0.13,–0.01
T1,T3	–0.23**	–0.39,–0.07	–0.21*	–0.38,–0.05	0.16	–0.07, 0.38	–0.09**	–0.15,–0.03

[a] T1,T2,T3 refers to analyses showing whether there is an effect over time during all 3 measurements for the added strategy vs no added strategy; T1,T2 represents short-term effects from T1 baseline to T2 posttest; T1,T3 represents long-term effects from baseline T1 to T3 follow-up.

**P*<.05, ***P*<.01, ****P*<.001.

On average, intentions to reduce alcohol consumption increased and behavioral willingness to drink more decreased over time (Table 3), but no differences were found across groups (Table 4). An exception was a significant short-term overall effect on willingness. The interaction of prototype alteration × cue reminder was not significant; thus, it did not produce an extra effect beyond the effect of the separate strategies.

Figure 3. Effects on drinking behavior (mean glasses per day) per analysis group at baseline (T1), 1-month posttest (T2), and 6-month follow-up (T3).



Secondary Outcomes

Although a change in attitude, temptation, and self-efficacy was found (see means in Table 3 and effects in Table 4), prototype alteration or a cue reminder did not produce a larger change than when those strategies were not received.

Additionally, absolute perceived drinking risk was higher for those who used a cue reminder in addition to the original Drinktest (B=0.27, *P*<.001) than for those who did not (see Figure 4). However, both the cue reminder (B=–0.13, *P*=.04) and prototype feedback (B=–0.11, *P*=.04) resulted in a lower relative drinking perception than when these strategies were not received in addition to Drinktest (see Figure 5). Medium-to-large effect sizes were found. The nonsignificant prototype alteration × cue reminder interaction for the secondary outcomes showed that combining the strategies did not produce an extra effect beyond the separate strategies.

Figure 4. Effects on absolute perceived drinking risks per analysis group (means) at baseline (T1), 1-month posttest (T2), and 6-month follow-up (T3).

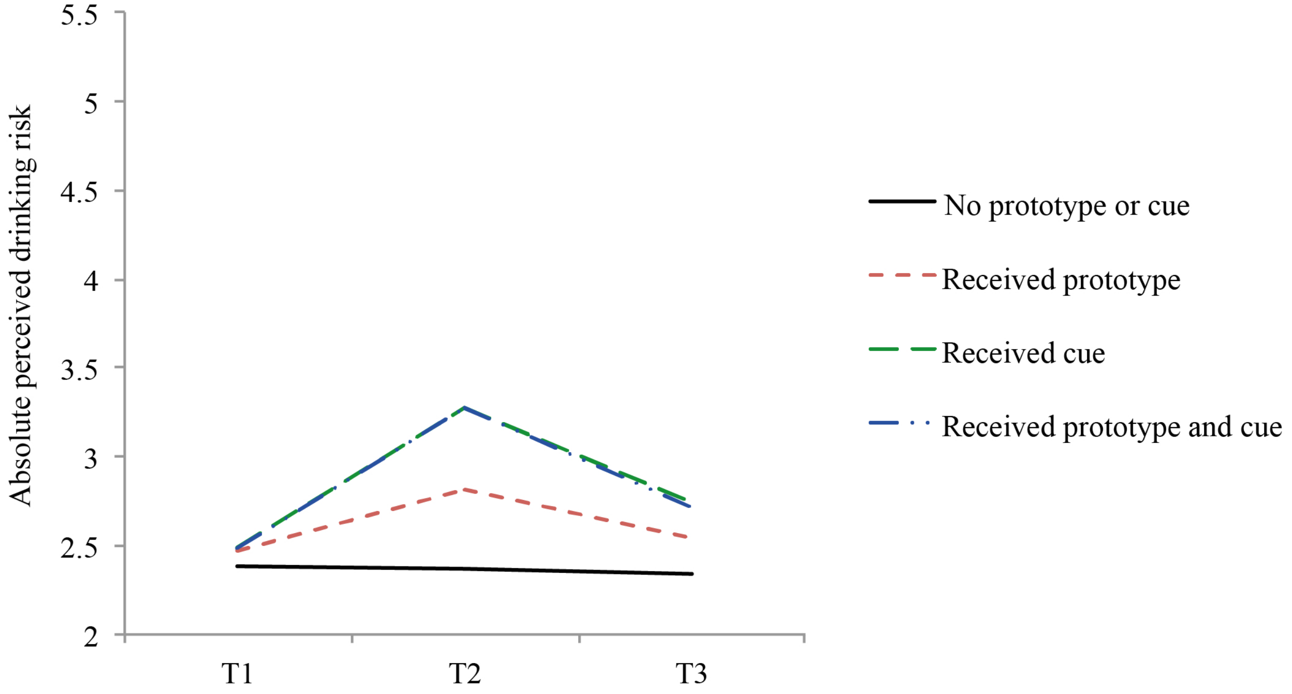
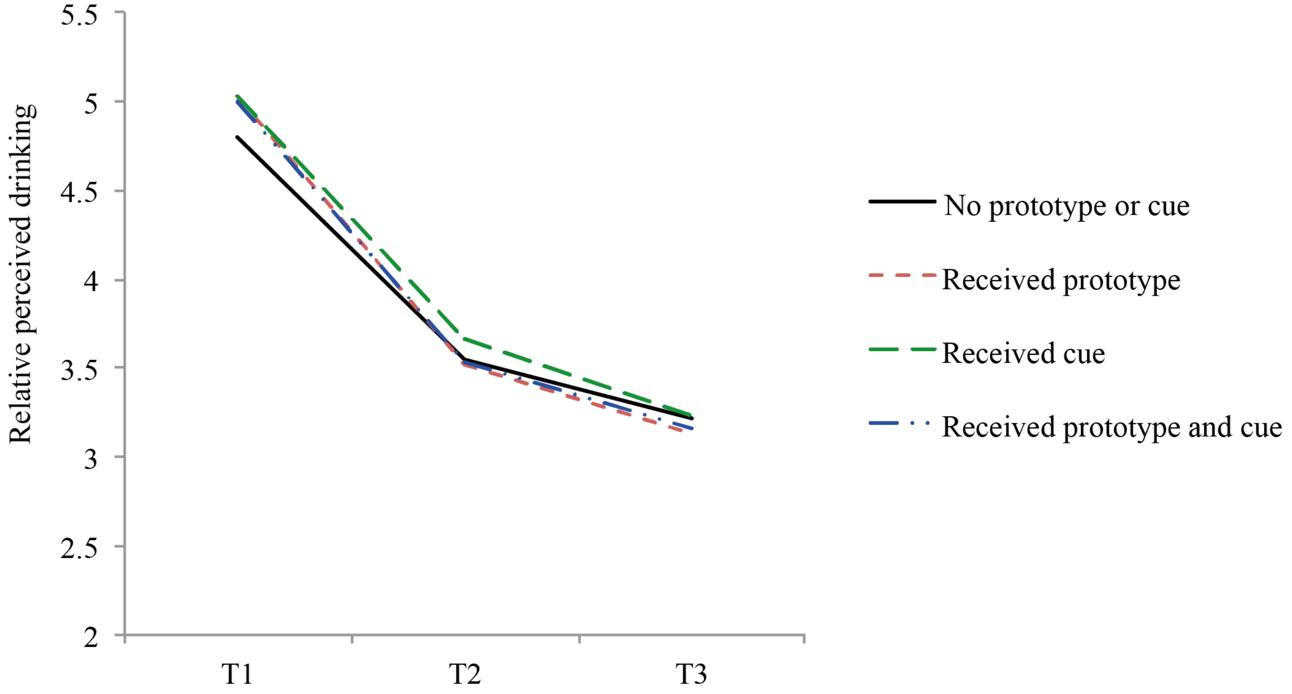


Figure 5. Effects on relative perceived drinking per analysis group (means) at baseline (T1), 1-month posttest (T2), and 6-month follow-up (T3).



Analyses With Complete Cases Only

Finally, the analyses were repeated including full cases only (ie, without LOCF). Similar patterns of results were found as when the LOCF method was applied, albeit the effect of the cue reminder on relative perceived drinking became nonsignificant (*P*=.08). The effect of prototype alteration (in addition to Drinktest) on drinking behavior became nonsignificant.

Discussion

Overview

An online randomized controlled trial showed that prototype alteration and a cue reminder usage can be useful strategies to complement an existing tailored intervention (Drinktest) in reducing alcohol consumption. Although all conditions showed reductions in alcohol consumption and willingness, and increased intention to reduce drinking over a period of 6 months, reductions in alcohol consumption were higher among people who had received the prototype alteration or a cue reminder in addition to the original Drinktest compared to those who did not. The combination of the cue reminder and prototype alteration did not enhance the effect of either of the independent strategies. Importantly, participants in all conditions equally appreciated the intervention, but dropout was lower for participants who received the prototype alteration and/or cue reminder in addition to Drinktest than for participants who received the original Drinktest only.

Regarding the effect of the prototype alteration strategy, the reduced drinking levels that were found were expected. It is plausible that distancing from heavier drinking prototypes (eg, drunk and heavy drinker prototypes) [52,53] was at play, so that corresponding negative characteristics of excessive drinking were avoided (see also [33]), which may have led individuals to perceive their personal risk as lower than for others (which corresponds with this significant effect). This explanation seems to be supported by the finding that participants' positive self-characterization increased over time (based on prototypical characteristics). It may also be that individuals changed their unhealthy behavior to feel good and positive about themselves (eg, [60]) and may be motivated to engage in self-consistent behavior and, thus, may feel less at risk than others.

The results show that cue reminders may be an effective strategy in addition to an existing intervention such as Drinktest, and that the type of cue that we provided is feasible (ie, silicone bracelet). Our study adds to the knowledge of testing the effect of cue reminders on drinking behavior [43-45] by applying it in a real-life setting (ie, participants used the cue in their own environment and aimed at self-regulation). The cue was directly linked to reducing drinking behavior and may have inhibited the urge to drink. However, although participants generally wore or used their cue frequently, they were only reasonably aware of it. Conditions did not differ in perceived attempts to reduce their drinking, but participants that received both the cue and prototype strategies (combination) contemplated more on the intervention than those who received the original Drinktest only. This may imply that rather than functioning through their salience as previously proposed, the cue reminder may have functioned through its presence in the context instead [44]. Finally, usage of the cue in addition to Drinktest was associated with changes in drinking behavior and absolute drinking risks rather than intentions. It could be that, as would be expected, the cue has reminded the participant to seize opportunities to act rather than that it changed intentions or willingness.

The interaction of prototype alteration and cue reminders did not produce an extra effect beyond the separate effects of the 2 strategies. It suggests that both strategies have an independent effect on drinking behavior, but that there is no synergistic effect by combining them. Thus, for those effects that were significant for both strategies, both may be effective but by separate means. Perhaps the link between the characteristics to be achieved and the cue reminder should have been stronger. It could be that the characteristics were already salient in the prototype alteration and hence no additional benefit of cue reminders may have occurred. Or it may be that a cue reminder does not support remembering an abstract construct such as "achievable personal characteristics" but does support the remembrance of concrete implementation intentions and action plans. To our knowledge, a bracelet as a cue reminder has not been used as a means to help decrease drinking behavior. It is conceivable that another type of cue (eg, text messages) may have a different but additional effect on the prototype alteration. Future research could shed light on this possibility.

Limitations

The following study limitations must be addressed before discussing the implications. First, dropout was large and the sample largely consisted of Western participants. However, it is unlikely that selection based on ethnicity would have changed the results because non-Western and Western samples have been found to show similar drinking behavior in the Netherlands [2] and the analyses were corrected for ethnicity. In addition, comparison of analyses in which LOCF was applied and analyses including the full cases sample produced the same pattern of results, which may indicate that a selection bias is likely to have been limited. Moreover, it is unclear whether demand effects may have played a role, which may have caused the skewed distribution across the conditions. Also, results often only remained significant in the short term. Altogether, the results should be interpreted with caution and generalizability may be decreased due to the larger dropout among specific groups. Furthermore, the results were based on self-report. However, we do not think that underreporting was a problem because of the removal of outliers based on the MAD method in the measurements. In addition, the prototype alteration and cue effects that were found in addition to Drinktest can be partly explained by the addition of action plans, although they both had unique contributions to the outcomes. The effects are meaningful and are generally consistent with expectations. Finally, tailored feedback was provided at baseline only. Although the results span a period of 6 months, future studies could determine whether feedback at several measurement points would improve these findings.

Implications and Future Research

The findings suggest the following implications and future directions. First, our findings support earlier suggestions that future interventions may benefit from providing relevant prototypes to be achieved and avoided [29] and to tailor prototypical characteristics according to the individuals' relevance [53]. Heavier drinking prototypes (eg, heavy drinker, drunk) [52] could be relevant prototypes to be distanced from by accentuating the attributed negative characteristics [33], and the moderate drinker prototype could be encouraged to assimilate with [29] by accentuating the achievability of its positive characteristics if alcohol consumption were reduced. Thus, in the case of experienced drinkers, modifying the valence of prototypes could prove worthwhile and the effect of prototypes on drinking behavior could be overcome by implementation intentions or action plans (see also [41]).

Second, the bracelet had the advantage of being self-regulated by participants and that it can be effective even when alcohol is already consumed [43,44]. However, only limited knowledge is available on the effectiveness of different types of cue reminders. Future research should determine which type of cue reminder is most effective and how to make individuals more aware of the cue. Future research also needs to be aware of the different mechanisms influencing the effect of cue reminders.

Third, it may be important for future interventions to complement the strategies with messages that make people aware of their drinking behavior and that especially informs excessive drinkers about the consequences of their behavior as was done by the original Drinktest [15]. However, future research is necessary to further our understanding of how to optimize prototype alteration and cue reminders as strategies.

Acknowledgments

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Conflicts of Interest

The second author is scientific director of Vision2Health, a company that licenses evidence-based, innovative, computer-tailored health communication tools. All other authors declare that they have no conflicts of interest.

Multimedia Appendix 1

Examples of tailored feedback.

[PDF File (Adobe PDF File), 31KB - jmir_v17i2e35_app1.pdf]

Multimedia Appendix 2

CONSORT-EHEALTH checklist V1.6.2 [61].

[PDF File (Adobe PDF File), 990KB - jmir_v17i2e35_app2.pdf]

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Abbreviations

ES(f): effect size f
LOCF: last observation carried forward
MAD: median absolute deviation
PWM: Prototype Willingness Model
QFV: Quantity-Frequency-Variability
TPB: Theory of Planned Behavior

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Original Paper

Effectiveness of a Web-Based, Computer-Tailored, Pedometer-Based Physical Activity Intervention for Adults: A Cluster Randomized Controlled Trial

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Abstract

Background: Computer-tailored physical activity (PA) interventions delivered through the Internet represent a promising and appealing method to promote PA at a population level. However, personalized advice is mostly provided based on subjectively measured PA, which is not very accurate and might result in the delivery of advice that is not credible or effective. Therefore, an innovative computer-tailored PA advice was developed, based on objectively pedometer-measured PA.

Objective: The study aim was to evaluate the effectiveness of a computer-tailored, pedometer-based PA intervention in working adults.

Methods: Participants (≥18 years) were recruited between May and December 2012 from eight Flemish workplaces. These workplaces were allocated randomly to an intervention or control group. Intervention group participants (n=137) received (1) a booklet with information on how to increase their steps, (2) a non-blinded pedometer, and (3) an Internet link to request computer-tailored step advice. Control group participants (n=137) did not receive any of the intervention components. Self-reported and pedometer-based PA were assessed at baseline (T0), and 1 month (T1) and 3 months (T2) months post baseline. Repeated measures analyses of covariance were used to examine intervention effects for both the total sample and the at-risk sample (ie, adults not reaching 10,000 steps a day at baseline).

Results: The recruitment process resulted in 274 respondents (response rate of 15.1%) who agreed to participate, of whom 190 (69.3%) belonged to the at-risk sample. Between T0 and T1 (1-month post baseline), significant intervention effects were found for participants' daily step counts in both the total sample (*P*=.004) and the at-risk sample (*P*=.001). In the at-risk sample, the intervention effects showed a daily step count increase of 1056 steps in the intervention group, compared to a decrease of 258 steps in the control group. Comparison of participants' self-reported PA revealed a significant intervention effect for time spent walking in the at-risk sample (*P*=.02). Intervention effects were still significant 3 months post baseline for participants' daily step counts in both the total sample (*P*=.03) and the at-risk sample (*P*=.02); however, self-reported PA differences were no longer significant.

Conclusions: A computer-tailored, pedometer-based PA intervention was effective in increasing both pedometer-based and self-reported PA levels, mainly in the at-risk participants. However, more effort should be devoted to recruit and retain participants in order to improve the public health impact of the intervention.

Trial Registration: ClinicalTrials.gov: NCT02080585; https://clinicaltrials.gov/ct2/show/NCT02080585 (Archived by WebCite at http://www.webcitation.org/6VvQnRQSy).

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KEYWORDS

physical activity; computer tailoring; Web-based intervention; cluster randomized controlled trial

Introduction

Regular physical activity (PA) leads to multiple health benefits and reduces the risk of many chronic diseases [1-3]. Although these benefits are well established, most adults do not meet current PA recommendations [4,5]. International guidelines recommend at least 20 minutes of continuous, aerobic vigorous-intensity PA at least three times a week or at least 30 minutes of moderate-intensity PA five times a week [6]. An alternative guideline, proposed by Hatano [7] and frequently used in physical activity research, recommends at least 10,000 steps a day [8,9]. To stimulate adults in reaching these guidelines, different types of PA interventions have been developed in the past, such as pedometer-based interventions and computer-tailored interventions [10-12].

A recent meta-analysis, examining the effect of pedometer-based physical activity interventions, suggested that pedometer use has a moderate and positive effect on the increase of PA. Moreover, the effect was more pronounced when integrating 10,000 steps a day as the step goal [13]. Computer-tailored interventions have also been shown to be effective in supporting PA [14-18] and are offering several advantages. First, most computer-tailored interventions are Web-based interventions, which means that the advice can be requested online. Online interventions are shown to be appealing and feasible and have the ability to reach many people in a cost-effective manner at any time and location [19-21]. Second, computer-tailored interventions provide individualized advice, which is automatically generated based on participants' answers to a predefined diagnostic questionnaire. Previous studies have shown that participants are more likely to increase their PA level when receiving tailored feedback, compared to generic feedback [12,22-24].

However, existing computer-tailored interventions also have limitations. Completing questionnaires is time-consuming, and self-reported PA data may have been influenced by response and recall biases [25]. Therefore, we developed Web-based, computer-tailored PA advice, based on participants' objectively measured daily step counts [26]. Consequently, the assessment of baseline PA will be more accurate and participants will no longer need to complete an extensive questionnaire to assess their baseline PA level. This PA advice is relatively innovative, given that to date, only a few computer-tailored physical activity interventions were coupled with a personal activity monitor [14,27].

Feasibility of this Web-based, computer-tailored step advice was examined by De Cocker et al [26] in a pilot study. They conducted a randomized controlled trial among participants recruited through general practitioners (GPs) [26]. This demonstrated that the majority of the participants accepted the step advice well and that it was perceived as useful. While PA increased, no superior intervention effects on PA levels were found in the tailored condition, compared with the standard condition. This could be explained by three factors. First, the statistical power was limited, since the study sample at posttest was rather small (N=69). Only 20 participants provided objective pedometer data on both baseline and post-intervention measurements. Second, participants of the control condition also received a pedometer and step information during the study period; however, pedometers as a stand-alone intervention have shown to be effective in increasing step counts in adults as well [28]. Third, the pilot study assessed only pedometer-based and self-reported PA at two time points (baseline and 3 months post baseline), so it is not possible to examine the effect of the intervention immediately after requesting the advice.

To overcome these shortcomings, a new cluster randomized controlled trial was conducted to assess the effectiveness of Web-based tailored step advice in adults with (1) a larger sample, (2) a control group that did not receive any intervention component, and (3) three assessment points.

Methods

Participants and Study Design

This study used a cluster randomized controlled trial to evaluate the effects of a computer-tailored, pedometer-based PA intervention delivered through the Internet. Potential participants were recruited from "white-collar" workplaces, given that the majority of the employees in these workplaces were not physically active during the day. Managers of 18 workplaces were invited by email in three waves at different times of the year (to overcome seasonal effects). The first wave started in May 2012, the second wave in September 2012, and the third wave in December 2012. Eight workplaces, of which three schools (ie, secondary schools), three commercial organizations (ie, two software companies and one consulting company), and two non-profit organizations (ie, health insurance organizations), consented to participate. All employees of a single workplace were allocated at random to either the intervention or a waiting list control group by the first author using a computer-generated random list, in order to avoid contamination between employees receiving the intervention and those not receiving the intervention. Every wave contained at least one intervention and one control workplace, and both the intervention group and the control group contained at least one school, one commercial organization, and one non-profit organization. Subsequently, employees of the participating workplaces were recruited by email. Only Dutch-speaking employees between 18 and 65 years old and who had access to the Internet at work or at home were eligible. Interested employees could sign up by returning a confirmation email to the researchers. On receiving this information, a meeting was organized in each of the eight worksites to deliver all documents for baseline measurement (T0) to the participants, including an informed consent form, a blinded pedometer, an activity log, and a self-administered questionnaire. During this meeting, information was provided on how to use the pedometer, how to log PA activities, and how to answer the questionnaire. To reduce expectancy effects, researchers concealed information on the study's focus, and asked participants to adhere to their usual PA pattern throughout the measurements. After 1 week, all measurement tools were collected, and average daily step counts were calculated. At this point, participants in the intervention condition received (1) a booklet with information on how to increase steps, (2) a non-blinded pedometer, which they could use for 3 months, and (3) a username, password, and the number of average daily steps, calculated by the researchers, so that participants could use this number when requesting the Web-based, computer-tailored step advice. Participants in the control condition did not receive any of the above mentioned intervention components. At 1 month and 3 months, all participants again received a blinded pedometer, which was worn for 1 week. When wearing the blinded-pedometer 1 month (T1) and 3 months (T2) post baseline, wearing the non-blinded pedometer was also allowed. Furthermore, the same self-reported questionnaire was used to measure PA level at T1 and T2. This study protocol was approved by the Ghent University Ethics Committee, and an informed consent was obtained from each participant before the study started.

See Multimedia Appendix 1 for the CONSORT-EHEALTH checklist [29].

Computer-Tailored Intervention Website

The intervention website was developed based on previous computer-tailored interventions to increase PA in Flanders [16,30-32] and consists of two main parts, a Web-based questionnaire and computer-tailored step advice. The questionnaire assesses demographic variables, average daily steps, and psychosocial determinants towards 10,000 steps/day (Figure A in Multimedia Appendix 2; Table 1). The computer-tailored step advice includes feedback to help people reaching the PA recommendation of 10,000 steps/day. Three parts can be distinguished in the computer-tailored step advice. The first part consisted of a general introduction. The second part, included personalized feedback on the participants' current number of steps. In this part, a schedule was provided on how they could reach the goal of 10,000 steps/day, based on participants' preference of increasing their current step level with 500 or 1000 steps per week. The third part contained recommendations and suggestions to increase daily step counts (see Figures B-D in Multimedia Appendix 2). All three parts are based on the Theory of Planned Behavior [33] and the Transtheoretical Model [34]. The Theory of Planned Behavior is reflected by providing feedback on participants' intentions, attitudes, self-efficacy, social support, knowledge, benefits, and barriers towards physical activity (see Table 1).

The Transtheoretical Model was used to adapt the content of the advice and the way of providing feedback to the stages of change. Precontemplators were mainly informed in an impersonal way about the idea of 10,000 steps, and its associated health benefits. Contemplators received the same information in a more personal way and were carefully informed that taking more steps might be beneficial for them. In the preparation stage, participants received less general information but were decisively asked to increase their daily steps. In the action stage, participants were encouraged in a supportive way to sustain their average daily steps. Some tips and tricks were provided to prevent relapse. In the maintenance stage, the feedback was limited to the message that they were doing well and should continue this way. If participants requested the computer-tailored step advice for a second time or more, progress feedback was provided by comparing their previous step level with their current step level. A more detailed description of the step advice can be found in De Cocker et al [26].

Table 1. Overview of the included psychosocial determinants.

Psychosocial determinant	Question	Answer possibilities	Example of the step advice
Intentions	Are you planning to step more within the upcoming 6 months? Are you planning to step more within the upcoming month?	Yes/no	You are planning to increase your daily step counts within 1 month. This is a good idea, as your current number of daily step counts is less than 10,000.
Attitudes	I find it healthy to increase my daily step counts I find it enjoyable to increase my daily step counts I find it good to increase my daily step counts I find it relaxing to increase my daily step counts	Not agree/ sometimes agree, sometimes not agree/ Agree	You indicated that you did not find it healthy to increase your daily step counts. However, previous research has indicated that people who are physically active are less likely to develop cardiovascular diseases, obesity, hypertension, diabetes, osteoporosis, depression, cancer, etc
Self-efficacy	Do you think you are able to increase your daily step counts on (1) most of the days in a usual week? (2) on days that you feel bad, tired, nervous, or depressed? (3) on days that you have a busy schedule?	I'm sure I can/ I think I can/ I'm sure I can't	You are sure that you are not able to increase your daily step counts when you feel tired or depressed. However, it has been shown that being physically active reduces feelings of depression and exhaustion.
Social support	To what extent do you receive support from the following people to increase your daily step counts? Partner? Children (>12 years)? Friends? Are the following people regularly physically active? Partner? Children (>12 years)? Friends?	Never/ Sometimes/ Often/ I do not have a partner, children, or friends Yes/ No/ I do not have a partner, children, or friends	Studies have shown that people who have a partner to be physically active with, are more likely to sustain their physically active lifestyle. As you indicated that your partner is regularly physically active, it may be good idea to be physically active together.
Knowledge	Are you familiar with the use of a pedometer?	Yes/ No	You indicated that you are not familiar with the use of a pedometer. Therefore, you will find some general information about the use of a pedometer below.
Benefits	What is the most important benefit for you to increase your daily step counts?	To lose weight/ To feel less depressed/ To feel more attractive/ To get a better physical condition/ To meet new people/ To have fun/ To feel the kick of competition	Feeling less depressed as a consequence of an active lifestyle is important for you. This could be a good reason, as previous research has indicated that being physically active results in feeling less depressed.
Barriers	What are the two most important barriers for you to increase your daily step counts?	Lack of interest/ Lack of time/ Lack of self-discipline/ Lack of social support/ Lack of pleasure/ External factors, such as bad weather conditions, lack of money, lack of facilities/ Lack of a walking partner/ Lack of good health/ Being active makes me feel tired/ Having an injury	External factors hinder you from increasing your daily step counts. Nevertheless, being physically active does not have to be expensive, eg, walking, running and swimming are very cheap. Moreover, some sports do not require specific sport facilities.

Measurements

Self-Reported Measurements

Demographic variables, PA, sitting time of the participants, and acceptability of the step advice were measured by means of a paper-based questionnaire. Demographic variables were assessed at baseline and included sex, age, height, weight, highest degree of education (primary or secondary education, college, university), health (very good, good, fair, bad, very bad), and place of residence (town, outskirts of town, village, or countryside). PA and sitting time were measured with the validated International Physical Activity Questionnaire (IPAQ), short version, at all time points [35]. In the questionnaire, both the frequency and duration of walking, moderate PA, vigorous PA, and time spent sitting during the past week were measured. Acceptability of step advice was examined by asking participants about the understandability, the logic, the practical use, and the length of the questionnaire. Furthermore, questions were asked about the relevance, the credibility, the understandability, the instructiveness, and the length of the step advice.

Objective Measurements

A blinded Omron HJ-203-ED pedometer, which showed good validity and reliability, and an activity log were used in the study [36]. The pedometer was equipped with a 7-day memory, allowing for daily steps to be automatically reset to zero at midnight. Participants were instructed to wear the pedometer around the neck, given that the least amount of error was observed for this wearing position [36]. Furthermore, the pedometer had to be worn for at least 5 days, including at least one weekend day, at all time points. Removal of the pedometer was permitted only during sleeping or water-based activities, such as bathing or swimming. The activity log was used to record the time and duration of non-walking activities (eg, swimming or cycling) and to document information about non-wearing of the pedometer (date and hours).

Data Reduction

Participants' baseline characteristics were described using means and standard deviations for quantitative variables and percentages for qualitative variables. Body mass index (BMI) was computed as self-reported weight in kilograms divided by self-reported square height in meters. Pedometer-based PA was expressed in steps/day and calculated for all participants with valid pedometer data (ie, if the total counts were >100, and the pedometer had been worn for at least 8 hours [37,38]) for at least 5 consecutive days [39]. Pedometer-data exceeding 20,000 steps/day were truncated as 20,000 to avoid unrealistically high data [40]. Self-reported total PA was computed by summing the time spent walking and doing moderate and vigorous PA in the last week. All self-reported physical activities were expressed in minutes/day. Data were cleaned as outlined in the IPAQ guidelines [41]. Both pedometer-based and self-reported PA data were log-transformed to correct for positive skewness (indicated by a significant Kolmogorov-Smirnov test) prior to further analyses.

Statistical Analyses

Descriptive statistics were used to summarize participants' baseline characteristics and to describe the acceptability of the step advice. Participants' characteristics at baseline were compared by independent sample *t* tests for quantitative variables and by chi-square tests for qualitative variables to detect baseline differences between the control and the intervention group and to perform a drop-out analysis. Baseline characteristics that differed significantly between intervention and control group were used as covariates in further analyses. To determine what analyses should best be used to examine intervention effects, a three-level regression analysis was conducted (because of the hierarchical structure of the data) with assessment point at the first level, individual at the second level, and company at the third level. As the random part of the null model showed that the variance at the company level was not significantly different from zero (χ^2_1=3.06, *P*=.08), it is possible to examine intervention effects on PA behavior by conducting three 2x2 repeated measures analyses of covariance (ANCOVA) with time (two measurement moments) as within factor and condition (intervention group, control group) as between factor. Using these analyses also increases the interpretability of the outcomes. All repeated measures ANCOVAs were conducted separately for the total sample, as well as for the at-risk sample only (ie, adults not reaching 10,000 steps a day at baseline). Analyses were performed using MLwiN version 2.29 and IBM SPSS Statistics 21.0. The level of statistical significance was set at *P*≤.05; *P* values between .05 and .10 were considered borderline significant.

Results

Participant Characteristics, Response, and Attrition Rate

Figure 1 shows the flow of participants through the study. Invitation letters were sent to 1817 people, spread over eight workplaces. This recruitment process resulted in 274 respondents (response rate of 15%) who agreed to participate, of which 137 (50%) were allocated to the intervention group and 137 (50%) to the control group. Of the 137 intervention participants, 6 (4.4%) were in the precontemplation phase, 12 (8.8%) in the contemplation phase, 64 (47%) in the preparation stage, 35 (26%) in the action phase, and 20 (15%) did not provide information on their intentions. A total of 101 (74%) intervention participants and 112 (82%) control participants completed 1-month post baseline measurements, and 91 (66%) intervention participants and 107 (78%) control participants completed 3-month post baseline measurements. Finally, 91 intervention group participants and 107 control group participants had complete data. Drop-out analyses indicated that participants from the intervention group (χ^2_1=4.661, *P*=.03, two-tailed) and commercial companies (χ^2_2=27.087, *P*<.001, two-tailed) were more likely to drop out. No significant differences were found for demographic variables, pedometer-based PA, and self-reported PA between completers and dropouts (see Multimedia Appendix 3).

Baseline characteristics of the intervention and control group are presented in Table 2. The groups differed significantly at baseline in time spent sitting, with participants in the intervention group having a higher sitting time than participants in the control group (*P*=.01) (see Table 2). A trend of significance was observed for place of residence, with more participants living in a village or in the countryside in the intervention group (*P*=.06). No significant differences were found for the other demographic variables, pedometer-based and self-reported PA between intervention and control participants (see Multimedia Appendix 3).

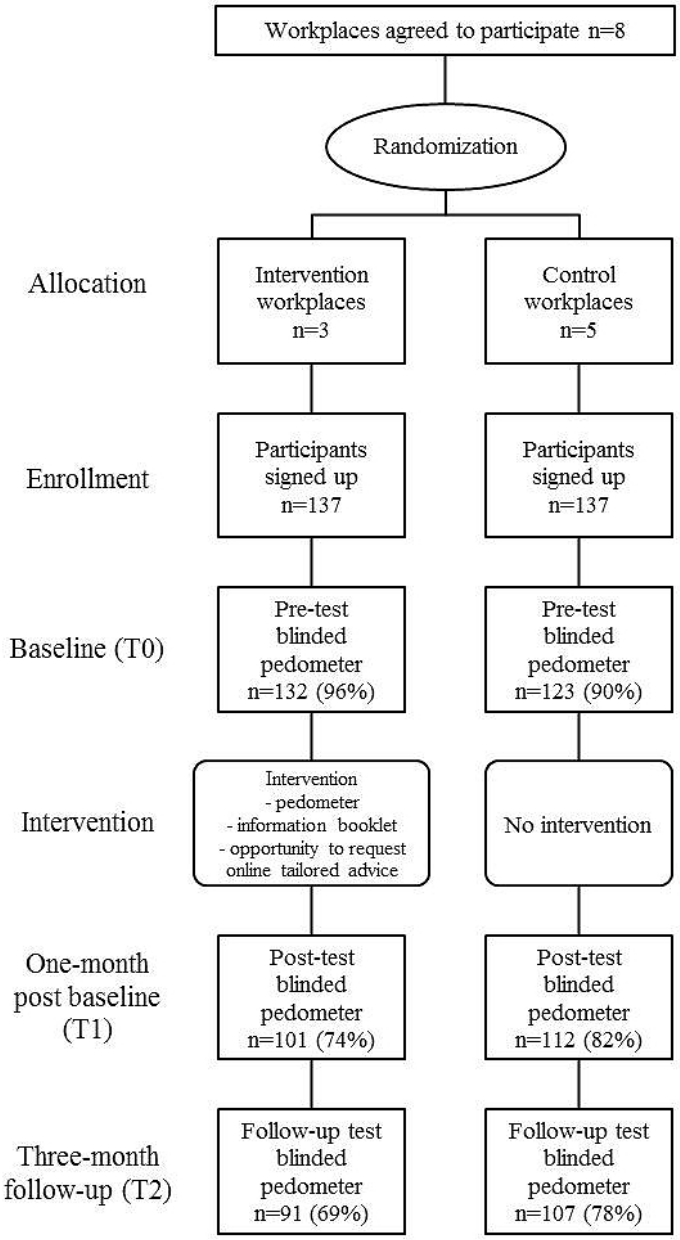
Table 2. Comparison of baseline characteristics.

Characteristic	Intervention group	Control group	Group comparison	*P* value
Demographic variable				
Gender, n (%)			$\chi^2_1=0.10$	.76
Male	50 (38.5)	45 (36.6)		
Female	80 (61.5)	78 (63.4)		
Age, mean (SD)	42.1 (11.4)	41.9 (10.7)	$t_{253}=0.20$	.84
BMI, mean (SD)	25.5 (4.9)	24.7 (3.8)	$t_{253}=1.37$	.17
Education, n (%)			$\chi^2_2=2.06$	.36
Primary/secondary	40 (31.2)	28 (23.1)		
College	56 (43.8)	59 (48.8)		
University	32 (25.0)	34 (28.1)		
Self-rated health, n (%)			$\chi^2_2=0.09$	.95
Very good/good	101 (78.9)	96 (78.7)		
Fair	22 (17.2)	22 (18.0)		
Very bad/bad	5 (3.9)	4 (3.3)		
Place of residence, n (%)			$\chi^2_2=5.79$	.06[a]
Town	25 (19.4)	30 (24.8)		
Outskirts of town	47 (36.4)	56 (46.3)		
Village/countryside	57 (44.2)	36 (29.8)		
Pedometer-based PA (steps/day), mean (SD)	8329 (3869)	8324 (3926)	$t_{253}=0.14$	.89
Self-reported PA and sedentary time (minutes/day)				
Sitting time	526.7 (163.7)	465.2 (186.1)	$t_{253}=2.82$	.01[b]
Walking	22.2 (65.2)	24.7 (77.9)	$t_{253}=0.04$	.97
Moderate PA	22.2 (26.2)	26.9 (39.6)	$t_{253}=0.82$	.41
Vigorous PA	9.9 (18.0)	9.0 (21.3)	$t_{253}=1.18$	.24
Total PA	53.6 (85.2)	55.7 (75.9)	$t_{253}=0.19$	.85

[a] $P<.10$.

[b] $P<.05$.

Figure 1. Participant flow through the study.



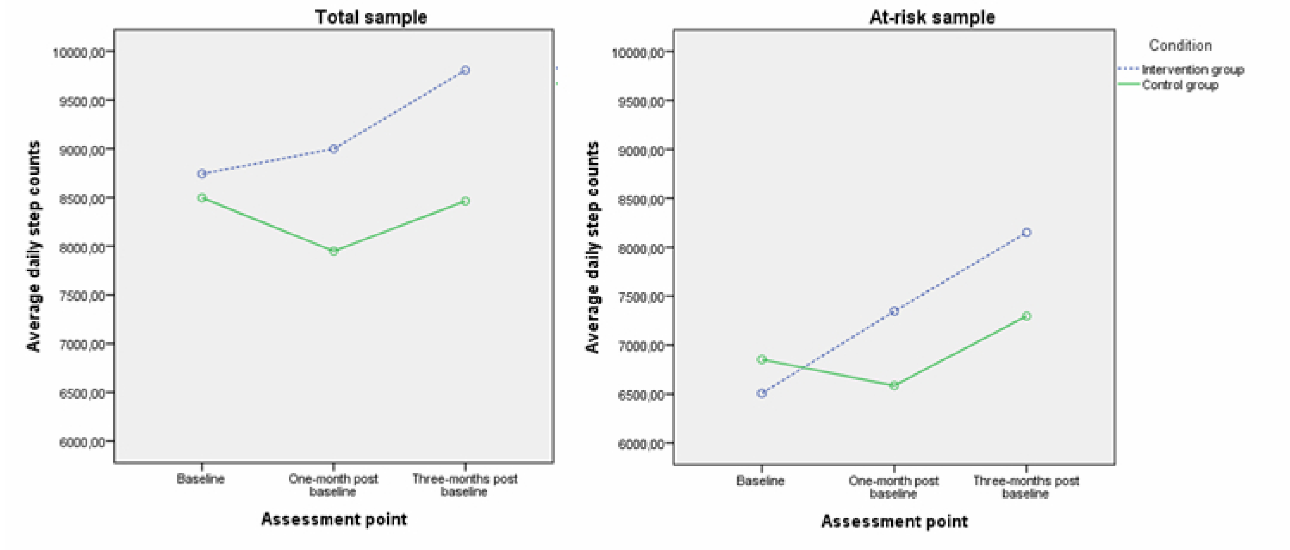
Acceptability of the Step Advice

The majority of the intervention group participants (118/137, 86%) did request the computer-tailored step advice. Most participants found the questions easily understandable (91/93, 98%) and that they progressed logically (88/90, 98%). Almost half of the participants considered the length of the questionnaire to be adequate (41/89, 46%), and 94% (84/89) of the participants had no problems answering the questions. The step advice itself was rated as interesting by 94% (82/87), as credible by 95% (84/88), as understandable by 96% (85/89) and as instructive by 80% (71/89). The only downside that was addressed was the length of the advice. More than half of the participants (80%, 71/89) found the advice too long.

Changes in Physical Activity for the Total Sample

Tables 3 to 5 present intervention effects for participants' daily step counts, sitting time, walking time, moderate PA time, vigorous PA time, and total PA time. For the total group, comparison of participants' pedometer-based PA revealed a significant intervention effect between T0 and T1 ($F_{1,192}$=8.70, P=.004) and between T0 and T2 ($F_{1,176}$=4.59, P=.03). Daily step counts in the intervention group increased from 8760 steps at T0 to 9235 at T1 (1 month later) and to 9484 at T2 (3 months later), while daily step counts of the control group decreased from 8628 at T0 to 8102 at T1, and to 8589 at T2. The percentage of individuals meeting the recommended guideline of 10,000 steps a day evolves from 36% (35/97) at T0 to 55% (36/65) at T1 and 65% (36/55) at T2 in the intervention group, and from 32% (30/93) at T0 to 35% (29/83) at T1 and 53% (37/70) at T2 in the control group. Figure 2 shows the change of average daily step counts of participants completing all three measurements. Comparison of participants' self-reported PA indicated a trend of significance for moderate PA between T0 and T1 ($F_{1,161}$=3.13, P=.08). Intervention group participants increased their moderate PA by 2.29 min/day, while control group participants decreased their moderate PA by 9.06 min/day. No significant intervention effects were found for time spent sitting, walking, being vigorously active, and for total PA.

Figure 2. Change of average daily step counts of participants completing all three measurements from the total sample (N=168) and the at-risk sample (n=119).



Changes in Physical Activity for the At-Risk Sample

For the at-risk sample, which included only the participants not reaching 10,000 steps at baseline (n=190, 69%), significant intervention effects on step counts were found between T0 and T1 ($F_{1,136}$=11.98, P=.001) and between T0 and T2 ($F_{1,124}$=5.54, P=.02). Daily step counts in the intervention group increased from 6697 steps at T0 to 7753 at T1 (1 month later) and to 8019 at T2 (3 months later), while daily step counts of the control group first decreased from 6898 at T0 to 6640 at T1 and subsequently increased to 7308 at T2. The percentage of individuals meeting the recommended guideline of 10,000 steps a day increased from 0% at T0 to 30% (16/53) at T1 and 34% (16/47) at T2 in the intervention group, and from 0% at T0 to 11% (8/76) at T1 and 28% (17/61) at T2 in the control group. No significant intervention effects were found between T1 and T2 ($F_{1,161}$=.04, P=.84). Figure 2 represents the change of average daily step counts of at-risk participants completing all three measurements. Comparison of participants' self-reported PA demonstrated a significant intervention effect for time spent walking between T0 and T1 ($F_{1,101}$=3.06, P=.02). Both intervention and control group participants increased their walking time, though the increase in walking time was much higher in the intervention group (26.96 min/day) than in the control group (6.99 min/day). A trend for significance was found between T0 and T1 for moderate PA ($F_{1,107}$=5.80, P=.08) and for total PA ($F_{1,96}$=3.58, P=.06). From T0 to T1, intervention group participants increased their moderate PA by 4.68 min/day and their total PA by 33.93 min/day, while control group participants decreased their moderate PA by 9.89 min/day and their total PA by 3.48 min/day. Between T0 and T2, a trend was also found for vigorous PA ($F_{1,94}$=3.05, P=.08). Vigorous PA increased by 5.47 min/day in the intervention group and decreased by 0.68 min/day in the control group. No intervention effects were found for time spent sitting.

Table 3. Effects on pedometer-based and self-reported PA in both conditions for the total sample and the at-risk sample (<10,000 steps at baseline) from T0 to T1[a].

	Total sample					Risk sample				
		T0	T1	Time x Group			T0	T1	Time x Group	
	n	Mean (SD)	Mean (SD)	*F (df)*	*P*	n	Mean (SD)	Mean (SD)	*F (df)*	*P*
Pedometer-based PA (steps/day)										
IG	96	8759.98 (3771.32)	9235.48 (4281.05)	8.698 (1,192)	.004[b]	65	6697.34 (1864.33)	7753.18 (3196.10)	11.977 (1,136)	.001[b]
CG	99	8627.69 (3786.73)	8101.77 (3882.31)			74	6898.16 (1979.35)	6640.43 (2751.43)		
Self-reported PA and sitting time (min/day)										
Sitting time										
IG	83	512.11 (164.33)	511.20 (155.56)	0.003 (1,171)	.95	54	534.07 (163.11)	541.67 (142.90)	0.362 (1,116)	.55
CG	91	460.91 (184.68)	464.73 (194.56)			65	497.46 (193.33)	498.46 (193.72)		
Walking										
IG	71	14.49 (22.86)	37.05 (92.52)	2.246 (1,153)	.14	45	12.49 (24.17)	39.48 (113.45)	5.801 (1,101)	.02[c]
CG	85	26.17 (51.93)	42.37 (86.66)			59	12.56 (16.60)	19.55 (22.35)		
Moderate PA										
IG	81	23.30 (28.11)	25.59 (36.85)	3.133 (1,161)	.08[d]	52	16.94 (24.05)	21.62 (34.70)	3.057 (1,107)	.08[d]
CG	83	24.94 (36.21)	15.43 (20.08)			58	19.45 (37.70)	9.56 (11.27)		
Vigorous PA										
IG	84	10.64 (17.80)	9.13 (15.20)	0.422 (1,169)	.52	54	6.88 (13.57)	6.67 (12.70)	0.534 (1,114)	.47
CG	88	9.76 (23.10)	6.78 (13.48)			63	5.87 (18.68)	3.68 (8.13)		
Total PA										
IG	70	49.00 (52.11)	73.68 (106.35)	1.989 (1,145)	.16	44	36.87 (52.74)	70.80 (124.19)	3.575 (1,96)	.06[d]
CG	78	56.11 (72.67)	55.47 (64.56)			55	35.72 (49.60)	32.24 (27.81)		

[a] IC=intervention group, CG=control group.

[b] *P*<.01.

[c] *P*<.05.

[d] .05<*P*<.10.

Table 4. Effects on pedometer-based and self-reported PA in both conditions for the total sample and the at-risk sample (<10,000 steps at baseline) from T1 to T2[a].

		Total sample					Risk sample				
			T1	T2	Time x Group			T1	T2	Time x Group	
		n	Mean (SD)	Mean (SD)	*F (df)*	*P*	n	Mean (SD)	Mean (SD)	*F (df)*	*P*
Pedometer-based PA (steps/day)											
	IG	78	8823.67 (3956.87)	9629.90 (4971.40)	0.003 (1,167)	.96	52	7298.08 (2654.68)	8092.41 (4068.30)	0.041 (1,116)	.84
	CG	92	8184.75 (3972.33)	8679.54 (4420.83)			67	6622.99 (2857.11)	7342.06 (3822.00)		
Self-reported PA and sitting time (min/day)											
Sitting time											
	IG	60	514.31 (156.97)	463.10 (156.01)	0.062 (1,140)	.80	37	554.44 (131.22)	488.47 (135.07)	0.299 (1,91)	.59
	CG	83	461.23 (196.16)	413.95 (197.17)			57	499.45 (196.35)	462.09 (202.54)		
Walking											
	IG	51	35.42 (50.86)	37.87 (55.20)	0.039 (1,127)	.84	33	29.07 (52.89)	30.97 (56.82)	<0.001 (1,82)	1.00
	CG	79	43.42 (89.54)	47.74 (71.75)			52	18.88 (21.59)	39.52 (50.35)		
Moderate PA											
	IG	56	27.28 (32.17)	32.61 (38.16)	1.089 (1,131)	.30	35	22.33 (23.71)	32.24 (38.52)	1.709 (1,85)	.20
	CG	78	16.62 (20.24)	37.67 (60.26)			53	10.75 (11.33)	32.83 (55.47)		
Vigorous PA											
	IG	54	7.94 (12.50)	12.29 (19.36)	0.779 (1,130)	.38	34	5.55 (10.20)	10.21 (18.43)	1.433 (1,84)	.23
	CG	79	8.83 (17.68)	10.84 (18.82)			53	4.03 (8.66)	6.02 (14.28)		
Total PA											
	IG	43	68.84 (81.74)	82.48 (80.06)	0.714 (1,114)	.40	28	55.51 (80.35)	79.54 (86.90)	0.943 (1,74)	.34
	CG	74	63.08 (80.74)	92.52 (100.54)			49	33.71 (28.30)	80.55 (96.10)		

[a] IC=intervention group, CG=control group.

Table 5. Effects on pedometer-based and self-reported PA in both conditions for the total sample and the at-risk sample (<10,000 steps at baseline) from T0 to T2[a].

		Total sample					Risk sample				
			T0	T2	Time x Group			T0	T2	Time x Group	
		n	Mean (SD)	Mean (SD)	*F*	*P*	n	Mean (SD)	Mean (SD)	*F*	*P*
Pedometer-based PA (steps/day)											
	IG	86	8418.95 (3843.53)	9483.86 (4875.34)	4.587 (1,176)	.03[b]	59	6443.42 (1917.63)	8019.24 (3997.34)	5.536 (1,124)	.02[b]
	CG	93	8613.87 (3774.78)	8589.15 (4379.61)			68	6805.71 (2074.47)	7308.22 (3803.62)		
Self-reported PA and sitting time (min/day)											
Sitting time											
	IG	69	525.58 (153.76)	467.76 (168.87)	0.010 (1,153)	.92	45	559.56 (134.90)	501.78 (152.09)	0.005 (1,101)	.95
	CG	87	463.02 (185.45)	411.26 (197.00)			59	507.71 (183.27)	460.25 (201.61)		
Walking											
	IG	51	28.05 (88.35)	35.16 (52.49)	1.091 (1,127)	.30	38	12.50 (23.27)	31.45 (56.88)	0.847 (1,86)	.36
	CG	79	27.37 (54.01)	47.37 (72.60)			51	12.24 (15.65)	37.87 (50.84)		
Moderate PA											
	IG	62	25.38 (26.76)	32.37 (37.68)	1.233 (1,138)	.27	40	18.50 (23.94)	30.38 (36.23)	1.850 (1,90)	.17
	CG	79	30.88 (42.50)	38.44 (60.04)			53	26.13 (44.55)	33.95 (55.84)		
Vigorous PA											
	IG	63	10.00 (17.20)	13.73 (21.58)	1.893 (1,141)	.17	41	5.51 (11.31)	10.98 (20.89)	3.053 (1,94)	.08[c]
	CG	81	11.31 (24.30)	10.69 (18.44)			56	6.71 (19.73)	6.03 (14.02)		
Total PA											
	IG	52	62.72 (113.96)	81.62 (78.03)	0.139 (1,120)	.71	35	34.18 (47.64)	76.02 (80.73)	0.329 (1,80)	.17
	CG	71	60.55 (74.29)	90.59 (100.21)			48	39.32 (51.21)	79.63 (95.13)		

[a] IC=intervention group, CG=control group.

[b] *P*<.05.

[c] .05<*P*<.10.

Discussion

Principal Findings

The aim of this study was to evaluate the effectiveness of a Web-based, tailored, pedometer-based PA intervention in adults. The results revealed that the combination of the pedometer, the information booklet, and the computer-tailored step advice has the potential to enhance objectively measured daily step counts in both the total sample and the at-risk sample. Although, the intervention effects were noticeable in both samples, differences were much more pronounced in the at-risk sample. Effects on subjectively measured physical activity were rather limited, with only one significant intervention effect found for self-reported time spent walking in the at-risk sample. This highlights the need for objective measurement.

The findings of this study add new evidence for the effectiveness of computer-tailored PA interventions. Previous reviews [12,42] showed that computer-tailored PA interventions demonstrated mixed effects. Whereas some studies reported significant increases in PA [14-18], others did not yield significant improvements [43-45]. However, it should be noted that all these interventions formulated feedback based on self-reported PA data. Self-reported PA is prone to reporting biases, most often in the direction of overestimating physical activity [46]. Consequently, people might receive feedback indicating that they are doing enough PA, whereas in reality, they are not meeting the PA guidelines. Therefore, integrating objectively measured PA in a computer-tailored intervention is of added value, as it will result in more accurate feedback with a higher personal relevance. As such, the advice will have a higher credibility and consequently be more effective in changing behavior. To our knowledge, only one other study also used objective PA measures [27]. In this study, participants received a personal activity monitor (PAM) combined with tailored PA advice. However, no significant improvements in PA levels were found, which is in contrast with our results. A possible explanation could be that because the attractiveness of the activity advice in that study was rather low (only 39% of the users found the advice appealing), it was not encouraging enough for participants to become more active; whereas, the acceptability of the step advice was rated more positively in our study, with more than 90% of the participants rated the advice as interesting, understandable, and credible.

Strengths and Limitations

In the pilot study of De Cocker et al [26], participants were recruited through general practitioners (GP). This was considered as a favorable dissemination channel, since GPs have personal face-to-face contact with their patients, and GPs are a credible health information source [47]. Unfortunately, this recruitment strategy was not as successful as expected, since only 6.2% of those approached consented to participate. Therefore, we used another recruitment strategy, in which employers and employees of a convenience sample of white-collar workplaces were invited. This recruitment strategy appeared to be more effective, given that more than twice as many people (15%) agreed to participate. This could possibly be explained by the fact that employers and employees experienced more social support than people invited by their GP, since all employers and employees within a company were invited to participate. Nonetheless, although the response rate was higher than in the study by De Cocker et al [26], it should be noted that still relatively few people enrolled for the intervention, in comparison with previous computer-tailored intervention studies [20]. Moreover, the recruitment through white-collar workplaces resulted in a selection bias with more highly educated people being involved in the study, which is in line with the outcomes of previous reviews that indicated that mainly higher educated people participate in online interventions [20,48]. This hampers the generalizability of the study results for those who are not as well educated.

An unexpectedly high attrition rate was observed in the intervention group as well as in the control group. Almost half of the intervention group participants (43%) and over one third (34%) of the control group participants dropped out at T2, which is relatively high in comparison with the attrition rates reported in recent reviews. In the review of Joseph et al assessing Internet-based PA interventions, an average attrition rate of 22% was reported [10]. In the meta-analysis of Davies et al [49], in which the overall effect size of PA interventions delivered through the Internet was calculated, an average attrition rate of 20% was found. Nevertheless, when considering only intervention groups, the average attrition rate reported by Davies et al was higher, more specifically 23% [49]. This higher percentage of dropouts in the intervention group is in line with our results and may be due to the fact that many intervention websites are not designed for people to be visited more than once. The main reason to revisit the step advice website is to see how one’s PA level has been changed, but it is unlikely that participants will do this without specific prompts to return to the website.

Additionally, beyond the computer-tailored module, the website did not have many interactive features, although many studies indicated that a high level of interactivity is needed to keep people interested and engaged with online interventions [31,50]. Due to the higher than expected attrition rate, the absolute sample size at 3 months post baseline is rather low, especially concerning the self-reported PA data. This results in a restricted statistical power, which could probably explain the lack of intervention effects at 3 months post baseline on the self-reported PA data. Moreover, it should be noted that the intervention group received different components (ie, pedometer, information booklet, and computer-tailored step advice). However, our study design does not allow us to determine whether all components are effective and whether their combination is necessary. Future studies should separate the different intervention components, in order to assess their individual impact. Finally, the relatively short study duration must be taken into account when interpreting the results. It may be that the intervention effects will disappear over time. As stated in the socio-ecological model, PA is the result of a complex interaction between individual level factors, and sociocultural, political, physical, and economic environmental factors [51]. Therefore, it is plausible that an individual initially changes their behavior as a result of an intervention but then relapses to previous unhealthy behavior as a consequence of the unchanged, obesogenic environment. Hence, multilevel interventions, where individual components are supported by environmental intervention components, have gained importance and should be evaluated.

Conclusions

In conclusion, this is the first study to examine the effectiveness of integrating Web-based, computer-tailored, pedometer-based step advice in a physical activity intervention. The use of objective measures in providing tailored advice seems promising, given that this Web-based, computer-tailored, pedometer-based PA intervention showed significant effects on both pedometer-based PA and self-reported PA. However, more efforts should be devoted to recruit and retain participants in order to improve the public health impact of the intervention. Furthermore, we would like to encourage future research to include the assessment of other objective health risk factors (eg, blood pressure, BMI) in order to evaluate the intervention’s impact on health.

Acknowledgments

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Conflicts of Interest

The authors are the developers of the intervention.

Multimedia Appendix 1

CONSORT-EHEALTH checklist V1.6.2 [51].

[PDF File (Adobe PDF File), 992KB - jmir_v17i2e38_app1.pdf]

Multimedia Appendix 2

Screenshots of the Web-based, computer-tailored, pedometer-based physical activity advice.

[PDF File (Adobe PDF File), 921KB - jmir_v17i2e38_app2.pdf]

Multimedia Appendix 3

Comparison of completers and noncompleters.

[PDF File (Adobe PDF File), 181KB - jmir_v17i2e38_app3.pdf]

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Abbreviations

ANCOVA: analysis of covariance
BMI: Body Mass Index
GP: general practitioner
IPAQ: International Physical Activity Questionnaire
PA: physical activity

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Original Paper

Utilization of a Web-Based vs Integrated Phone/Web Cessation Program Among 140,000 Tobacco Users: An Evaluation Across 10 Free State Quitlines

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Abstract

Background: Phone-based tobacco cessation program effectiveness has been established and randomized controlled trials have provided some support for Web-based services. Relatively little is known about who selects different treatment modalities and how they engage with treatments in a real-world setting.

Objective: This paper describes the characteristics, Web utilization patterns, and return rates of tobacco users who self-selected into a Web-based (Web-Only) versus integrated phone/Web (Phone/Web) cessation program.

Methods: We examined the demographics, baseline tobacco use, Web utilization patterns, and return rates of 141,429 adult tobacco users who self-selected into a Web-Only or integrated Phone/Web cessation program through 1 of 10 state quitlines from August 2012 through July 2013. For each state, registrants were only included from the timeframe in which both programs were offered to all enrollees. Utilization data were limited to site interactions occurring within 6 months after registration.

Results: Most participants selected the Phone/Web program (113,019/141,429, 79.91%). After enrollment in Web services, Web-Only were more likely to log in compared to Phone/Web (21,832/28,410, 76.85% vs 23,920/56,892, 42.04%; *P*<.001), but less likely to return after their initial log-in (8766/21,832, 40.15% vs 13,966/23,920, 58.39%; *P*<.001). In bivariate and multivariable analyses, those who chose Web-Only were younger, healthier, more highly educated, more likely to be uninsured or commercially insured, more likely to be white non-Hispanic and less likely to be black non-Hispanic, less likely to be highly nicotine-addicted, and more likely to have started their program enrollment online (all *P*<.001). Among both program populations, participants were more likely to return to Web services if they were women, older, more highly educated, or were sent nicotine replacement therapy (NRT) through their quitline (all *P*<.001). Phone/Web were also more likely to return if they had completed a coaching call, identified as white non-Hispanic or “other” race, or were commercially insured (all *P*<.001). Web-Only were less likely to return if they started their enrollment online versus via phone. The interactive Tobacco Tracker, Cost Savings Calculator, and Quitting Plan were the most widely used features overall. Web-Only were more likely than Phone/Web to use most key features (all *P*<.001), most notably the 5 Quitting Plan behaviors. Among quitlines that offered NRT to both Phone/Web and Web-Only, Web-Only were less likely to have received quitline NRT.

Conclusions: This paper adds to our understanding of who selects different cessation treatment modalities and how they engage with the program in a real-world setting. Web-Only were younger, healthier smokers of higher socioeconomic status who interacted more intensely with services in a single session, but were less likely to re-engage or access NRT benefits. Further research should examine the efficacy of different engagement techniques and services with different subpopulations of tobacco users.

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KEYWORDS

Internet-based intervention; tobacco cessation; smoking cessation; Internet; telephone; behavior; evaluation studies; online support

Introduction

Fifty years after the release of the first Surgeon General's Report on Smoking and Health, tobacco use is still the leading preventable cause of death in the United States [1]. Although cigarette use in particular has declined among American adults in the past 20 years, this shift is driven by a small proportion of relatively higher-income counties [2], indicating a widespread need for accessible and affordable cessation services. Over the past 2 decades, state governments throughout the United States have provided phone-based tobacco cessation services, called quitlines, to help tobacco users quit by providing evidence-based counseling. These services are offered statewide at no charge and often include nicotine replacement therapy (NRT). More recently, quitlines have responded to the aforementioned need for more easily accessible services by offering Web programs for use not only alongside traditional phone-based programs, but also as a stand-alone service without phone-based counseling. According to North American Quitline Consortium (NAQC) data [3], 44 state quitlines offered a self-directed Web-based intervention in 2012 [4], representing a notable increase from 27 in 2010 [5]. NAQC does not specify whether these Web services are stand-alone or integrated with standard quitline phone services, highlighting the need for more research into the structure of these services.

Tobacco users want to access cessation help via the Internet for a number of reasons, including convenience and a desire to remain anonymous [6]. Users also have reported a desire to access personalized, interactive websites, which are less common than sites simply containing educational content related to tobacco cessation [7]. State health departments have an interest in implementing Web-based services because they have been associated with the lowest cost per quit when compared to treatment delivered via phone or in person at a health care clinic or workplace [7]. Web-based services also have the potential to combine the wide reach of Internet-based health promotion with aspects of face-to-face counseling; those Web-based interventions that mirror other counseling modalities with a tailored, interactive approach have been shown to be more effective [8,9].

Despite the proliferation of Web-based services and the study of reasons for use, relatively little is known about who uses Web-only services, especially when users are given the choice between different programs. Randomized controlled trials have provided support for the efficacy of some Web-based cessation services [10], but more research is needed to understand how tobacco users select a treatment modality, their demographics, and how they engage with treatments in a real-world setting of tobacco users seeking help with quitting. The purpose of this paper is to examine the characteristics, utilization patterns, and return rates of tobacco users self-selecting into 1 of 2 free state tobacco cessation programs: stand-alone Web services versus Web services offered in combination with phone-based counseling. This information could inform outreach strategies, content tailoring, and future research evaluating outcomes for different program types.

Methods

Study Design

In this real-world observational study, participants selected 1 of 2 tobacco cessation programs offered through their state quitlines: (1) an integrated phone/Web program (Phone/Web) or (2) a stand-alone Web program (Web-Only). The Western Institutional Review Board reviewed the study and determined that it met the requirements for a waiver of consent under 45 CFR 46.116(d) on March 20, 2014.

Participants and Sample Selection

Ten state quitlines that offered both (1) a phone-based 1-call or multiple-call cessation program integrated with the Web Coach website (Phone/Web) and (2) a stand-alone Web Coach website program (without coaching calls; Web-Only) for the majority of the study timeframe were invited and agreed to participate in the study: Connecticut, Delaware, Florida, Idaho, Indiana, Kansas, New Mexico, North Carolina, Oklahoma, and Oregon. English-speaking participants aged 18 years and older who enrolled in a Phone/Web or Web-Only program through 1 of the 10 state quitlines from August 2012 through July 2013 were included in this analysis; for each state, registrants were only included from the timeframe in which both programs were offered to all enrollees.

Based on these inclusion criteria, 149,362 registration records were identified, of which 6698 individuals (4.48%) had 2 or more program enrollments during the study timeframe. To represent individuals only once in the analysis groups, the following steps were taken to remove duplicate registrations:

1. For participants with multiple Phone/Web program enrollments (4620/149,362, 3.09%), the first enrollment was retained to include the less biased case.
2. Because each individual who enrolled in Web-Only was intended to have only 1 Web Coach website account for life, those participants with multiple Web-Only program enrollments (623/149,362, 0.42%) were duplicated in error. In light of this, the enrollment with the greatest number of log-in days was retained to include the most accurate and complete data.
3. For participants who enrolled in the Web-Only program and switched to a Phone/Web program soon after (1394/149,362, 0.93%), the phone program enrollment was retained.
4. The most appropriate record could not be determined for the remaining participants (380/149,362, 0.25%) who had enrolled in both the Phone/Web and Web-Only programs. Because this group amounted to a very small percentage of the final sample, these participants were excluded from all analyses.

Analyses focused on the 141,429 unique adult English-speaking participants who enrolled in an integrated Phone/Web (113,019/141,429, 79.91%) or Web-Only (28,410/141,429, 20.09%) program offered by 1 of the 10 participating state quitlines. All participating states had contracted with Alere Wellbeing for the services offered through the quitline (including phone counseling, mailed materials, and Web-based services).

Phone/Web and Web-Only Program Descriptions

Enrollment

Quitline participants started their enrollment ("method of entry") in the cessation program online, over the phone by calling the quitline, or via fax referral, a process in which health care providers fax-referred their patients who were then proactively called by the quitline. Participants who started enrollment online could also request a callback to complete their enrollment with a registration specialist by phone. During both phone and Web enrollment procedures, participants were presented with the program options available to them and then selected their preferred program.

Participants in both the Phone/Web and Web-Only programs enrolled in the Web Coach website by providing their email address and consenting to be contacted via email. Participants then had to authenticate their account by using the log-in information provided in the initial email sent to them by the program.

Phone Program

The phone-based coaching program (Phone/Web) operated by Alere Wellbeing was offered as a 1-call or multiple-call program. The 1-call program included an initial assessment and planning call with Quit Coach staff to identify the participant's strengths and challenges, and to develop a quit plan. The multiple-call program included all aspects of the 1-call program plus either 3 or 4 outbound calls from the quitline. Participants in both phone programs were encouraged to call their quitline for support as needed. Both phone programs also included written educational materials for the participant (Quit Guide), referrals to community resources (when requested), health plan information (when appropriate), and access to the Web Coach website.

Web Coach Website

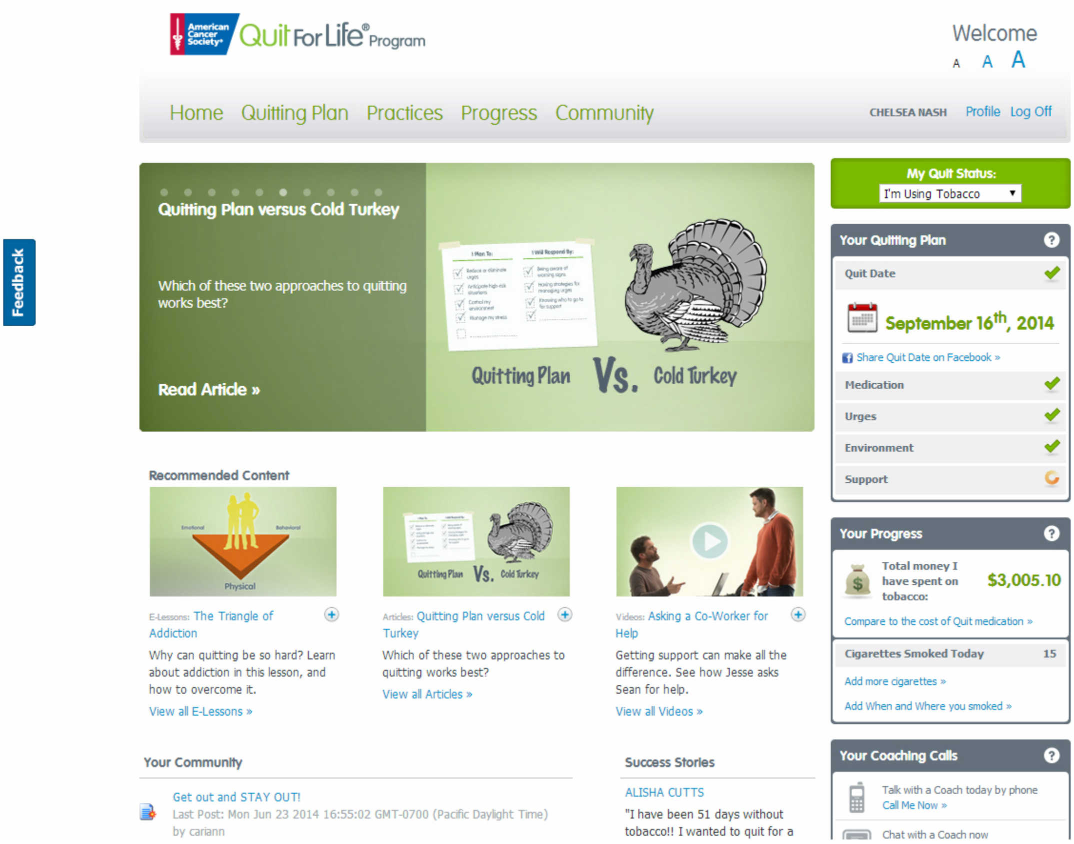
The Web Coach 2.0 website is the second version of the online participant application for the tobacco cessation coaching program operated by Alere Wellbeing (1.0 launched in 2006; 2.0 launched July 2011). It is grounded in social cognitive theory and designed to guide tobacco users through an evidence-based process of quitting tobacco. The website was offered as a stand-alone program (Web-Only) or integrated with the phone-based coaching program described previously (Phone/Web) and was tailored to each participant's tobacco status and needs (ie, different content was recommended and enabled based on the participant's quit status and activities completed). The Web Coach website also allowed participants to reach out to Quit Coach staff through phone call requests (for those in the Phone/Web program) and through chat and email in both Phone/Web and Web-Only; Quit Coach staff also moderated and participated in community forum discussions on the site. However, the focus of this paper is on the utilization of Web-based features and not the counseling options with a coach.

The Web Coach website home page (Figure 1) included links to recommended site content for each participant. The 4 key groups of features included:

1. The Quitting Plan (Figure 2): an interactive tool that enabled participants to build a personalized plan to quit using tobacco. The Quitting Plan guided participants through choosing a quit medication, setting a quit date, conquering urges and cravings to use tobacco, controlling their environment, and getting social support.
2. Progress Trackers: tools that helped participants who had not quit record and track their smoking patterns (Tobacco Tracker) and the potential financial savings of quitting (Cost Savings Calculator) (Figure 3). Participants who quit could use the Urge Tracker to record the strength of their urges or cravings to use tobacco (Figure 4), and could use the Cost Savings Calculator to review time quit, money saved, smoke-free breaths taken, and free time gained by quitting (Figure 5).
3. Interactive Practice Content (Figure 6): the Practices page introduced the 4 Essential Practices of Quitting, where participants could access e-lessons, articles, videos, and worksheets based on the Practices.
4. Community (Figure 7): the Community area was a place for participants to connect with one another to discuss their successes and challenges with quitting and staying quit; Quit Coach staff moderated the forums and actively participated in the discussions.

Web Coach website participants in both programs were sent the same tailored emails (up to approximately 25 messages) to remind and encourage them to log in to the site. First-time participants were sent a reminder email to visit if they had not logged in to the site within several days of enrolling in the program; additional reminder emails were sent if the participant still had not logged in at later time points. Participants who logged in but did not return within a certain time period received a reminder email to visit the site. Participants also received reminders to set a quit date, complete their quit plan, or update their tobacco status after their quit date if they had not done so. When a participant ordered NRT through the Web Coach website, summary information and links to use instructions were emailed. Emails also provided motivation through encouraging messages around the quit date, and through congratulatory emails when the participant reduced their tobacco use. The email schedule was designed to anticipate typical withdrawal symptoms and send encouragement to track urges and work on coping skills after the participant quit. Finally, regular check-in emails were sent to encourage participants to stay quit and follow their stay-quit plan.

Figure 1. Screenshot of Web Coach website home page.



Quitting Plan versus Cold Turkey

Which of these two approaches to quitting works best?

September 16th, 2014

Total money I have spent on tobacco: $3,005.10

Cigarettes Smoked Today 15

Talk with a Coach today by phone

Recommended Content

E-Lessons: The Triangle of Addiction

Why can quitting be so hard? Learn about addiction in this lesson, and how to overcome it.

Articles: Quitting Plan versus Cold Turkey

Which of these two approaches to quitting works best?

Videos: Asking a Co-Worker for Help

Getting support can make all the difference. See how Jesse asks Sean for help.

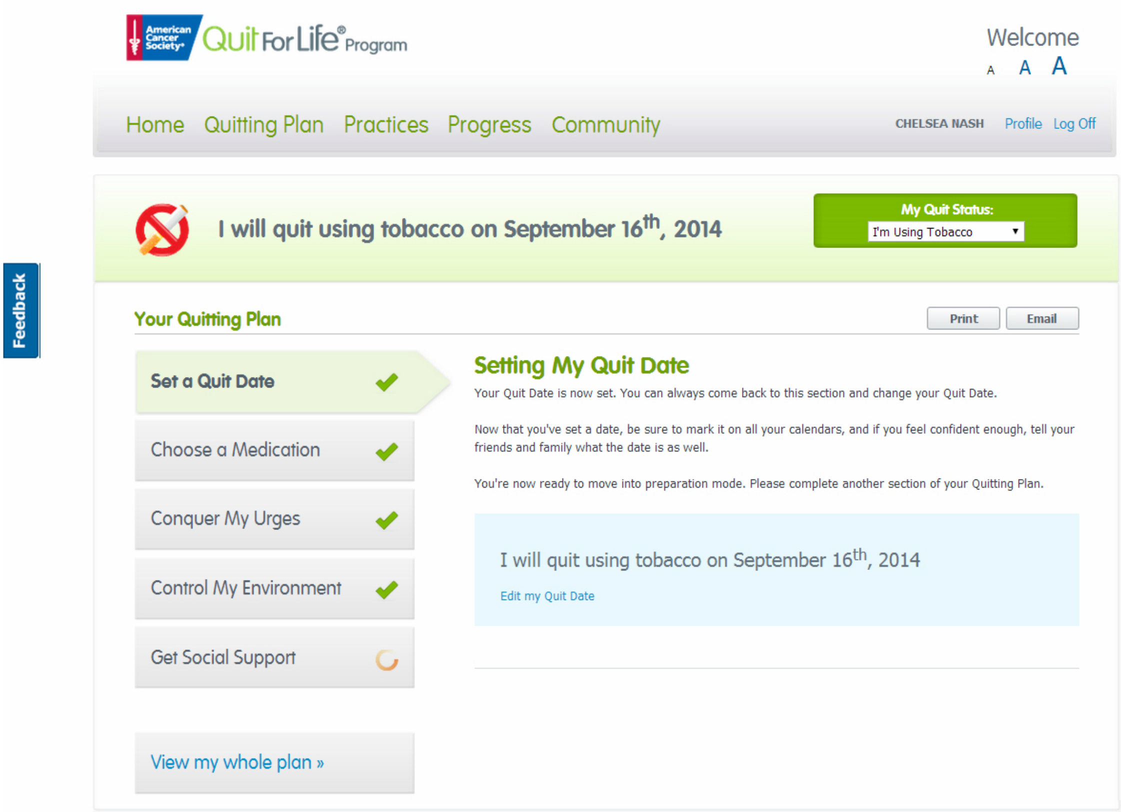
Your Community

Get out and STAY OUT!
Last Post: Mon Jun 23 2014 16:55:02 GMT-0700 (Pacific Daylight Time)
by cariann

Success Stories

ALISHA CUTTS
"I have been 51 days without tobacco!! I wanted to quit for a

Figure 2. Screenshot of Quitting Plan webpage: setting a quit date.



I will quit using tobacco on September 16th, 2014

Your Quitting Plan

Setting My Quit Date

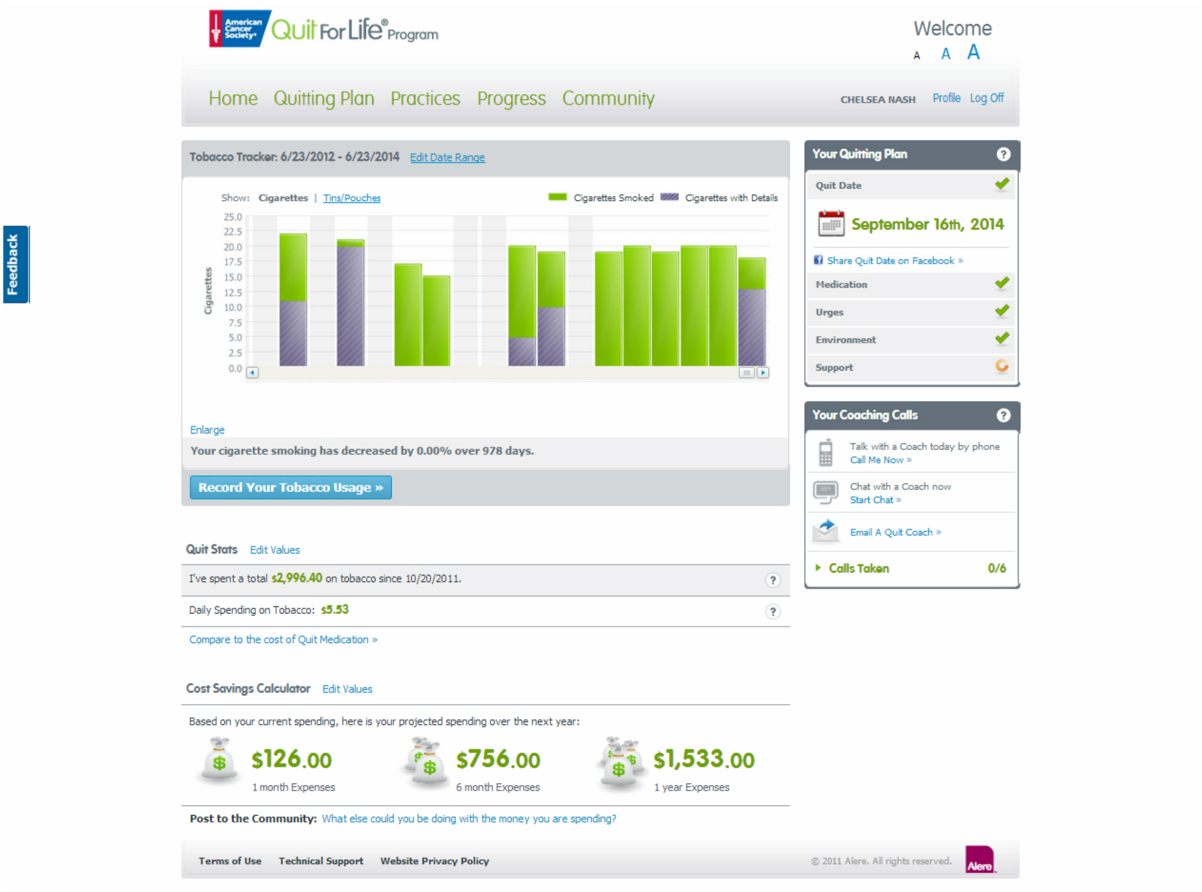
Your Quit Date is now set. You can always come back to this section and change your Quit Date.

Now that you've set a date, be sure to mark it on all your calendars, and if you feel confident enough, tell your friends and family what the date is as well.

You're now ready to move into preparation mode. Please complete another section of your Quitting Plan.

I will quit using tobacco on September 16th, 2014

Figure 3. Screenshot of Progress webpage with Tobacco Tracker and Cost Savings Calculator for participants who reported that they were still using tobacco.



Tobacco Tracker: 6/23/2012 - 6/23/2014

Your cigarette smoking has decreased by 0.00% over 978 days.

Quit Date ✓

September 16th, 2014

Medication ✓

Urges ✓

Environment ✓

Support

Talk with a Coach today by phone

Chat with a Coach now

Calls Taken 0/6

Quit Stats

I've spent a total $2,996.40 on tobacco since 10/20/2011.

Daily Spending on Tobacco: $5.53

Cost Savings Calculator

Based on your current spending, here is your projected spending over the next year:

$126.00	$756.00	$1,533.00
1 month Expenses	6 month Expenses	1 year Expenses

Post to the Community: What else could you be doing with the money you are spending?

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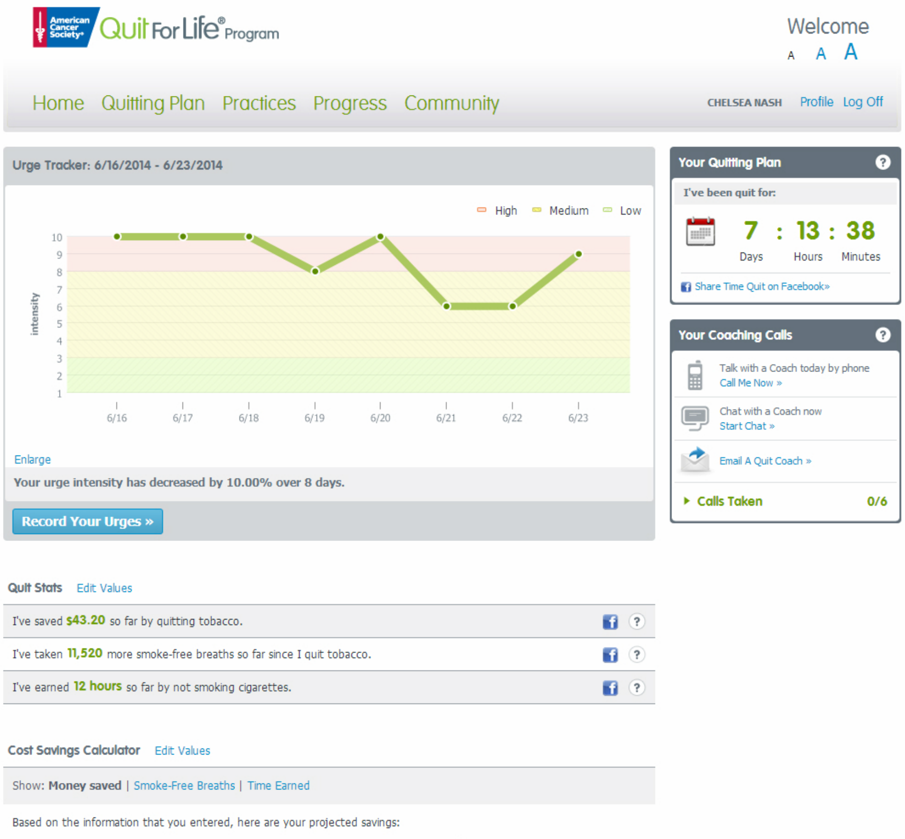
Figure 4. Screenshot of Progress webpage with Urge Tracker for participants who reported that they had quit using tobacco.



Urge Tracker: 6/16/2014 - 6/23/2014

Your urge intensity has decreased by 10.00% over 8 days.

I've been quit for:

7	13	38
Days	Hours	Minutes

Talk with a Coach today by phone

Chat with a Coach now

Calls Taken 0/6

Quit Stats

I've saved $43.20 so far by quitting tobacco.

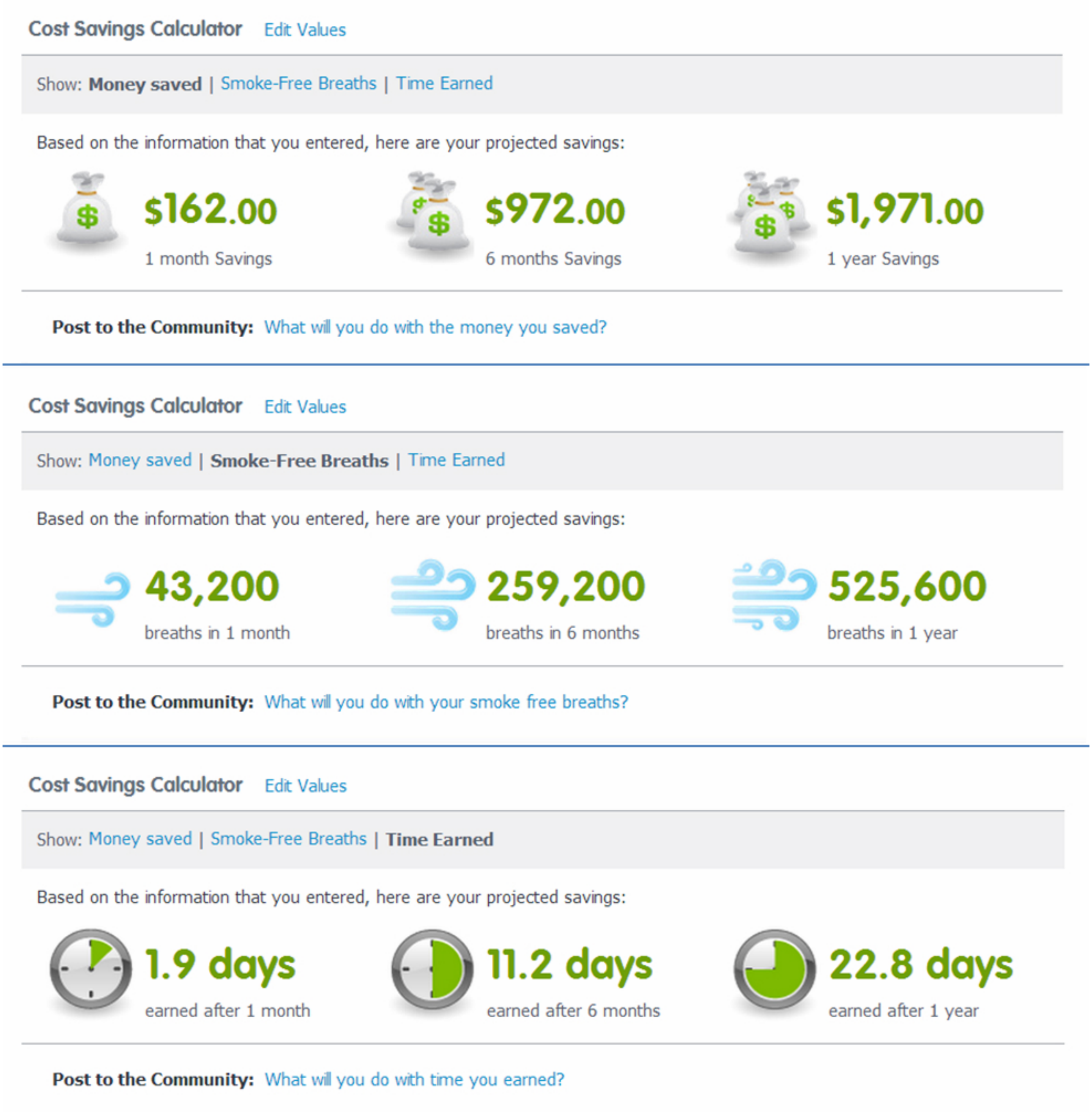
I've taken 11,520 more smoke-free breaths so far since I quit tobacco.

I've earned 12 hours so far by not smoking cigarettes.

Cost Savings Calculator

Based on the information that you entered, here are your projected savings:

Figure 5. Screenshot of Progress webpage with Cost Savings Calculator for participants who reported that they had quit using tobacco. Participants could select money saved, smoke-free breaths, or time earned.



Cost Savings Calculator Edit Values

Show: **Money saved** | Smoke-Free Breaths | Time Earned

Based on the information that you entered, here are your projected savings:

$162.00 1 month Savings

$972.00 6 months Savings

$1,971.00 1 year Savings

Post to the Community: What will you do with the money you saved?

Cost Savings Calculator Edit Values

Show: Money saved | **Smoke-Free Breaths** | Time Earned

Based on the information that you entered, here are your projected savings:

43,200 breaths in 1 month

259,200 breaths in 6 months

525,600 breaths in 1 year

Post to the Community: What will you do with your smoke free breaths?

Cost Savings Calculator Edit Values

Show: Money saved | Smoke-Free Breaths | **Time Earned**

Based on the information that you entered, here are your projected savings:

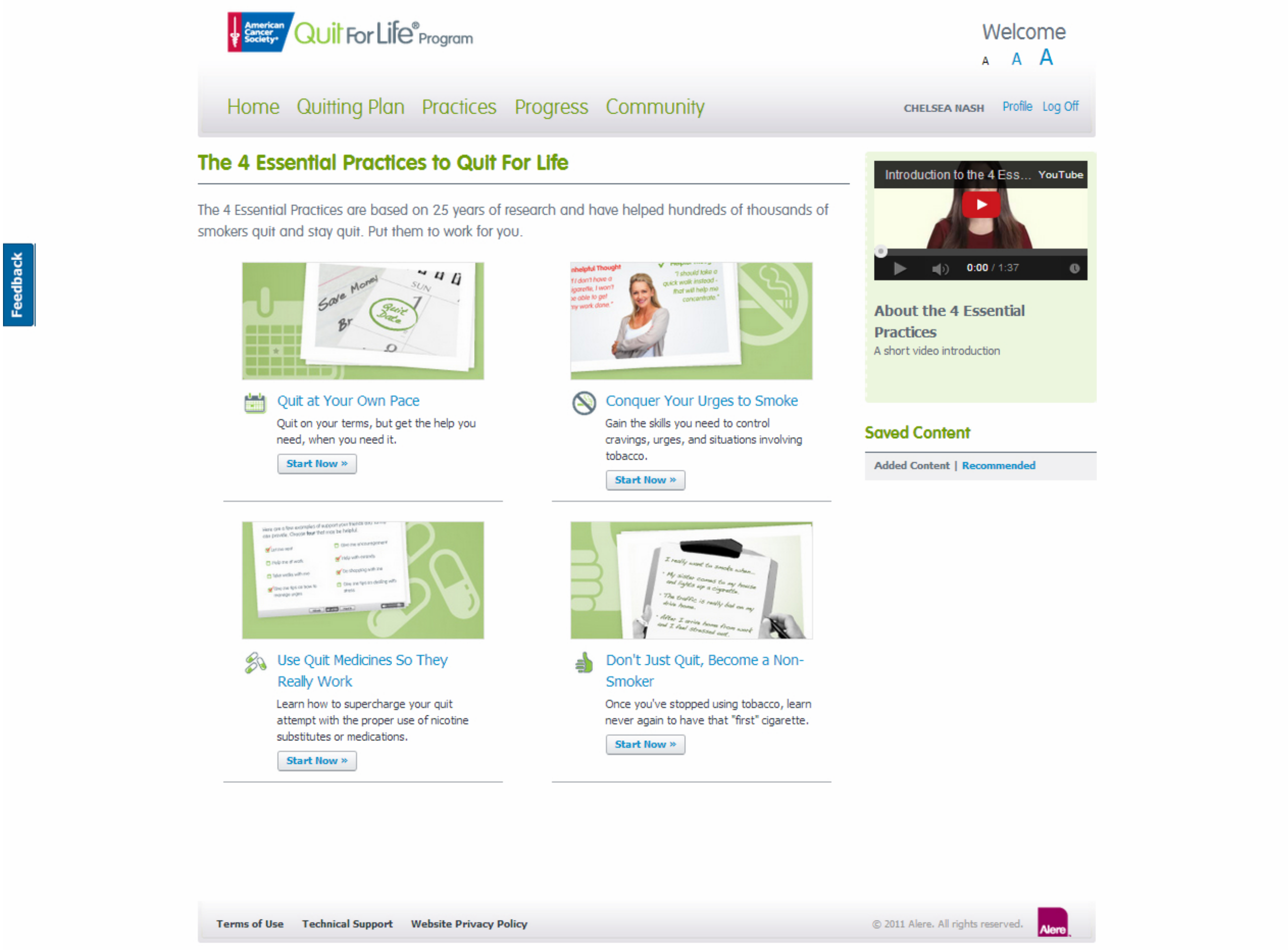
1.9 days earned after 1 month

11.2 days earned after 6 months

22.8 days earned after 1 year

Post to the Community: What will you do with time you earned?

Figure 6. Screenshot of Practices webpage.



The 4 Essential Practices to Quit For Life

The 4 Essential Practices are based on 25 years of research and have helped hundreds of thousands of smokers quit and stay quit. Put them to work for you.

Quit at Your Own Pace

Quit on your terms, but get the help you need, when you need it.

Conquer Your Urges to Smoke

Gain the skills you need to control cravings, urges, and situations involving tobacco.

Use Quit Medicines So They Really Work

Learn how to supercharge your quit attempt with the proper use of nicotine substitutes or medications.

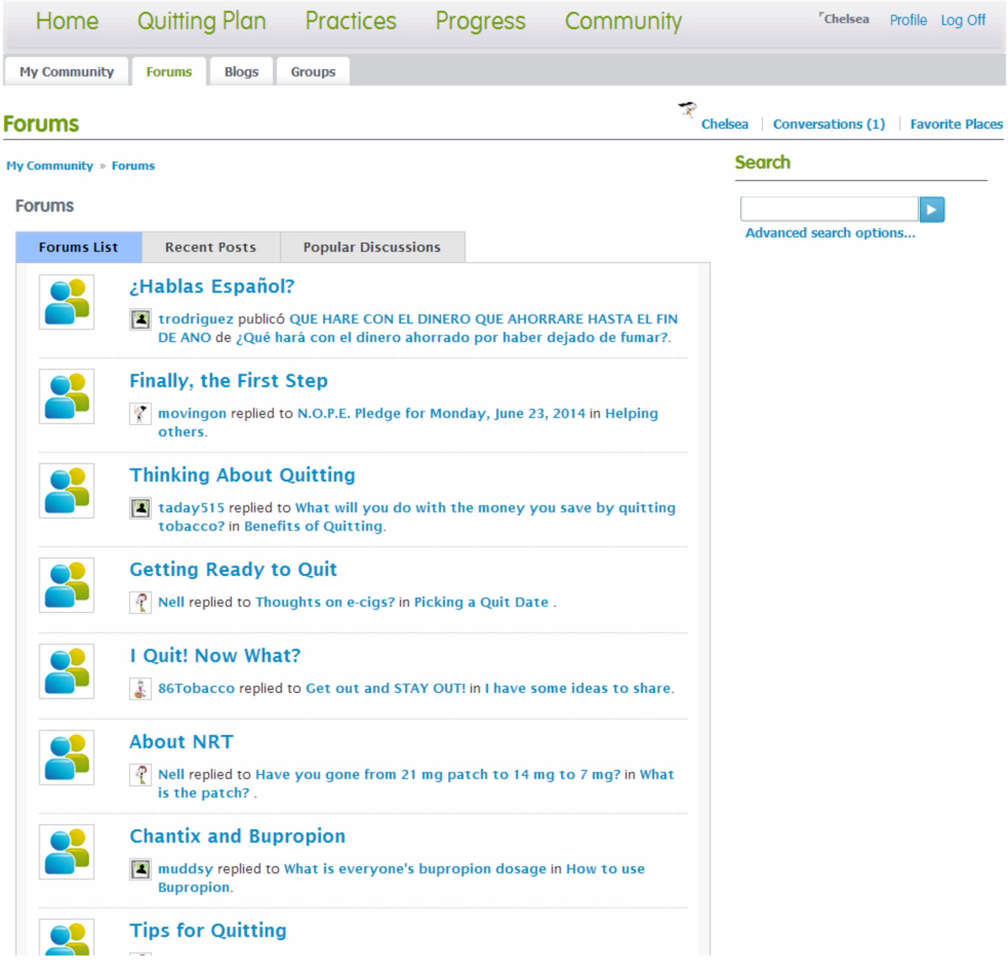
Don't Just Quit, Become a Non-Smoker

Once you've stopped using tobacco, learn never again to have that "first" cigarette.

About the 4 Essential Practices

A short video introduction

Figure 7. Screenshot of Community area.



¿Hablas Español?

trodriguez publicó QUE HARE CON EL DINERO QUE AHORRARE HASTA EL FIN DE ANO de ¿Qué hará con el dinero ahorrado por haber dejado de fumar?.

Finally, the First Step

movingon replied to N.O.P.E. Pledge for Monday, June 23, 2014 in Helping others.

Thinking About Quitting

taday515 replied to What will you do with the money you save by quitting tobacco? in Benefits of Quitting.

Getting Ready to Quit

Nell replied to Thoughts on e-cigs? in Picking a Quit Date .

I Quit! Now What?

86Tobacco replied to Get out and STAY OUT! in I have some ideas to share.

About NRT

Nell replied to Have you gone from 21 mg patch to 14 mg to 7 mg? in What is the patch? .

Chantix and Bupropion

muddsy replied to What is everyone's bupropion dosage in How to use Bupropion.

Tips for Quitting

State Offerings

All 10 states included in the study offered both a Web-Only program and an integrated Phone/Web program to all participants. Eight of 10 states offered the multiple-call program described previously to all adults (dependent on readiness to quit for some states). In 2 state quitlines, the multiple-call program was only available to select groups of registrants (eg, uninsured, Medicaid); other registrants in these quitlines were eligible for the 1-call program. Eight states also offered a 10-call program to pregnant tobacco users. During the study timeframe, 6 states offered NRT through both their Phone/Web and Web-Only programs, 2 states offered NRT to Phone/Web enrollees only, and 2 states did not offer NRT through either program.

Measures

Demographic characteristics (gender, age, race/ethnicity, education, health insurance, chronic condition status) and tobacco use (type, frequency, amount, years of tobacco use, time to first use after waking, other users at home and/or work) data were collected during standard program registration that is compliant with the NAQC Minimal Data Set [11]. Participants who enrolled online were asked the same questions in a participant-facing Web enrollment process. Several state quitlines also collected custom demographic data during registration (marital status, income, sexual orientation, mental health condition status). Data that were not collected for all states are identified in the table notes.

Every unique participant who enrolls in the Web Coach website is intended to have access to the same account for life, regardless of the number of times the participant re-enrolls in a quitline program. To avoid a time-lapse bias, website utilization data for this study were limited to site interactions occurring in the 6 months (up to 185 days) after registration.

Web Coach website activity (interactions and feature use) was recorded and linked to unique participants automatically through Google Analytics and the website. Efforts were also made to record log-ins and the duration of each log-in session; however, Google Analytics was often blocked by individual users or employer networks, resulting in missing data in the log-in and session minutes fields. To circumvent this issue, engagement was determined by creating a log-in days variable, which counted 1 log-in day for every distinct date on which the participant completed a site interaction.

To classify study participants by engagement level, *users* were defined as participants who logged in to the Web Coach website at any time in the 6 months following registration. *Return users* were defined as anyone who logged in at any time in the 6 months following registration and then returned at a later date during the same 6-month time period (ie, logged in to the Web Coach website on at least 2 different days in the 6 months following registration).

Statistical Analysis

Chi-square and *t* test analyses were used to examine differences in characteristics and Web utilization between Phone/Web and Web-Only enrollees, as well as differences in return rates between subpopulations within each program. Bivariate post hoc analyses were completed as necessary. Multivariable logistic regression analyses were used to examine predictors of program choice and return rates within each program. Models included predictor variables that were collected by all 10 states, had limited amounts of missing data, and measured participant characteristics (age, gender, race/ethnicity, education, insurance status, chronic condition status), tobacco dependence (time to first use, cigarettes per day), and method of program entry. A secondary model for program choice also included mental health condition status, which was only asked by 6 states; this secondary model was examined because mental health condition status was a significant predictor of program choice in bivariate analyses and data were available from the majority of states. Both return user models (within Phone/Web and Web-Only) also included receipt of quitline NRT as a predictor variable; analyses examining return users within Phone/Web additionally included phone treatment intensity (1-call vs multiple-call program) and call completion (0 calls vs ≥1 calls) as predictors. Because these behaviors (eg, call completion, NRT selection, selection of the multiple-call program) occurred after tobacco users selected the Phone/Web or Web-Only program in some or all cases, these variables were not included in the program choice model. State quitline was included as a fixed effect in every model to account for pre-existing differences in services and tobacco control policies within each state. All analyses were conducted in SAS v9.3 (SAS Institute, Inc, Cary, NC, USA).

Because of the large sample size, a number of findings were statistically, but not meaningfully, significant. We used a Bonferroni adjustment to account for the large number of statistical comparisons. Results are reported as significant where *P*<.0001 and the absolute difference in percentage points between comparison groups rounded to 5 or greater; this significance threshold was determined post hoc after initial review of analysis findings.

Results

Participant Characteristics

Overall, the majority of registrants were female (59.29%), mean age 44.4 (SD 13.8) years, white non-Hispanic (72.90%), heterosexual (93.86%), had a high school degree (27.40%) or higher (47.27%), but an annual household income of less than US$15,000 (51.45%), were uninsured (42.62%) or commercially insured (25.47%), and were daily cigarette smokers (94.02%) at a mean rate of 19 cigarettes per day (SD 11.3) (Table 1). Nearly one-half (48.32%) used tobacco within 5 minutes of waking at the time of enrollment, indicating high nicotine dependence. Approximately one-third (32.62%) reported at least 1 of 4 chronic health conditions (asthma, chronic obstructive pulmonary disease, coronary artery disease, and/or diabetes) and nearly one-half (46.59%) reported a mental health condition diagnosis.

Table 1. Characteristics of total sample and the Phone/Web and Web-Only programs (N=141,429[a]).

Baseline characteristic or program component	Total N=141,429	Phone/Web n=113,019	Web-Only n=28,410	*P*
Gender, % (n/N)				<.001
Female	59.29 (83,833/141,386)	59.03 (66,695/112,981)	60.33 (17,138/28,405)	
Male	40.71 (57,553/141,386)	40.97 (46,286/112,981)	39.67 (11,267/28,405)	
Pregnancy status (among females <50 years of age), % (n/N)				<.001
Yes, currently pregnant, planning pregnancy, or breastfeeding	5.64 (2782/49,344)	5.92 (2192/37,003)	4.78 (590/12,341)	
Not pregnant	94.36 (46,562/49,344)	94.08 (34,811/37,003)	95.22 (11,751/12,341)	
Age (years)				<.001[b]
Mean (SD)	44.4 (13.8)	45.3 (14.0)	40.8 (12.8)	
Range	18-98	18-98	18-93	
Age group, % (n/N)				
18-24	8.95 (12,663/141,427)	8.57 (9682/113,017)	10.49 (2981/28,410)	
25-34	19.42 (27,465/141,427)	17.72 (20,028/113,017)	26.18 (7437/28,410)	
35-44	19.34 (27,352/141,427)	18.22 (20,589/113,017)	23.80 (6763/28,410)	
45-54	27.11 (38,336/141,427)	27.99 (31,630/113,017)	23.60 (6706/28,410)	
55-64	18.19 (25,722/141,427)	19.60 (22,151/113,017)	12.57 (3571/28,410)	
≥65	6.99 (9889/141,427)	7.91 (8937/113,017)	3.35 (952/28,410)	
Race/ethnicity, % (n/N)				<.001[b]
White, non-Hispanic	72.90 (101,492/139,220)	71.10 (79,160/111,340)	80.10 (22,332/27,880)	
Black or African American, non-Hispanic	13.20 (18,382/139,220)	14.80 (16,476/111,340)	6.84 (1906/27,880)	
Hispanic or Latino	7.47 (10,405/139,220)	7.39 (8226/111,340)	7.82 (2179/27,880)	
Other	6.42 (8941/139,220)	6.72 (7478/111,340)	5.25 (1463/27,880)	
Education, % (n/N)				<.001[b]
< High school degree	17.90 (24,807/138,620)	19.96 (22,087/110,681)	9.74 (2720/27,939)	
General education development (GED)	7.43 (10,298/138,620)	7.21 (7979/110,681)	8.30 (2319/27,939)	
High school degree	27.40 (37,983/138,620)	28.69 (31,749/110,681)	22.31 (6234/27,939)	
> High school	47.27 (65,532/138,620)	44.15 (48,866/110,681)	59.65 (16,666/27,939)	
Health insurance status, % (n/N)				<.001[b]
Uninsured	42.62 (59,432/139,461)	41.00 (45,688/111,422)	49.02 (13,744/28,039)	
Commercial	25.47 (35,525/139,461)	22.14 (24,668/111,422)	38.72 (10,857/28,039)	
Medicaid	19.25 (26,853/139,461)	22.12 (24,647/111,422)	7.87 (2206/28,039)	
Medicare	12.66 (17,651/139,461)	14.74 (16,419/111,422)	4.39 (1232/28,039)	
Marital status, [c] % (n/N)				<.001[b]
Single	36.13 (17,867/49,455)	36.64 (15,823/43,183)	32.59 (2044/6272)	
Married or domestic partner	36.04 (17,826/49,455)	34.63 (14,954/43,183)	45.79 (2872/6272)	
Divorced, separated, or widowed	27.83 (13,762/49,455)	28.73 (12,406/43,183)	21.62 (1356/6272)	
Annual household income (US$), [d] % (n/N)				<.001[b]
<$15,000	51.45 (21,073/40,961)	54.39 (18,614/34,224)	36.50 (2459/6737)	
$15,000 to $35,000	31.30 (12,819/40,961)	30.11 (10,304/34,224)	37.33 (2515/6737)	
>$35,000	17.26 (7069/40,961)	15.50 (5306/34,224)	26.17 (1763/6737)	

Baseline characteristic or program component	Total N=141,429	Phone/Web n=113,019	Web-Only n=28,410	*P*
Sexual orientation,[e] % (n/N)				.13
Heterosexual	93.86 (99,315/105,814)	93.92 (78,244/83,312)	93.64 (21,071/22,502)	
Lesbian, gay, bisexual, transgender, or other	6.14 (6499/105,814)	6.08 (5068/83,312)	6.36 (1431/22,502)	
Chronic health conditions, % (n/N)				<.001[b]
None	67.38 (94,919/140,862)	65.26 (73,611/112,798)	75.93 (21,308/28,064)	
≥1[f]	32.62 (45,943/140,862)	34.74 (39,187/112,798)	24.07 (6756/28,064)	
Mental health conditions,[g] % (n/N)				<.001[b]
None	53.41 (65,466/122,579)	50.58 (49,269/97,404)	64.34 (16,197/25,175)	
≥1[h]	46.59 (57,113/122,579)	49.42 (48,135/97,404)	35.66 (8978/25,175)	
Tobacco environment (other tobacco users present),[e] % (n/N)				<.001[b]
Home and/or work	56.99 (67,022/117,612)	56.24 (58,666/104,308)	62.81 (8356/13,304)	
Neither home nor work	43.01 (50,590/117,612)	43.76 (45,642/104,308)	37.19 (4948/13,304)	
Years used tobacco, % (n/N)				<.001[b]
<20 years	33.14 (44,268/133,589)	30.66 (32,590/106,284)	42.77 (11,678/27,305)	
≥20 years	66.86 (89,321/133,589)	69.34 (73,694/106,284)	57.23 (15,627/27,305)	
Dependence (time to first tobacco use after waking), % (n/N)				<.001[b]
Within 5 minutes	48.32 (65,575/135,716)	49.86 (53,927/108,154)	42.26 (11,648/27,562)	
≥6 minutes	51.68 (70,141/135,716)	50.14 (54,227/108,154)	57.74 (15,914/27,562)	
Tobacco type,[i] % (n/N)				
Cigarette	96.05 (135,593/141,174)	95.97 (108,237/112,783)	96.35 (27,356/28,391)	<.01
Smokeless tobacco	4.02 (5679/141,174)	3.74 (4215/112,783)	5.16 (1464/28,391)	<.001
Cigar	4.57 (6448/141,174)	4.55 (5136/112,783)	4.62 (1312/28,391)	.63
Pipe	0.44 (628/141,174)	0.39 (445/112,783)	0.64 (183/28,391)	<.001
Other	0.97 (1365/141,174)	0.79 (893/112,783)	1.66 (472/28,391)	<.001
Cigarettes per day				<.001
Mean (SD)	19.0 (11.3)	19.1 (11.6)	18.4 (10.0)	
Range	0-100	0-100	0-100	
Cigarette frequency,[e] % (n/N)				<.001
Every day	94.02 (121,360/129,083)	93.68 (96,225/102,720)	95.34 (25,135/26,363)	
Some days	2.36 (3044/129,083)	2.27 (2329/102,720)	2.71 (715/26,363)	
Not at all	3.62 (4679/129,083)	4.06 (4166/102,720)	1.95 (513/26,363)	
Method of entry into program, % (n/N)				<.001[b]
Fax referral	4.61 (6515/141,429)	5.17 (5842/113,019)	2.37 (673/28,410)	
Phone call	82.59 (116,801/141,429)	91.93 (103,893/113,019)	45.43 (12,908/28,410)	
Web enroll	12.81 (18,113/141,429)	2.91 (3284/113,019)	52.20 (14,829/28,410)	
Treatment intensity, % (n/N)				n/a
Multiple-call	10.67 (15,087/141,429)	13.35 (15,087/113,019)	0.00 (0/28,410)	
1-call	67.69 (95,728/141,429)	84.70 (95,728/113,019)	0.00 (0/28,410)	
Switch from Web to multiple-call phone	1.56 (2204/141,429)	1.95 (2204/113,019)	0.00 (0/28,410)	
Web-Only	20.09 (28,410/141,429)	0.00 (0/113,019)	100.00 (28,410/28,410)	

Baseline characteristic or program component	Total N=141,429	Phone/Web n=113,019	Web-Only n=28,410	*P*
Calls completed	n/a[j]		n/a[j]	n/a[j]
Mean (SD)		1.6 (1.1)		
Range		0-10		
Number of calls completed, % (n/N)				
0 calls		10.13 (11,445/113,019)		
1 call		53.87 (60,878/113,019)		
2 calls		19.03 (21,512/113,019)		
3 calls		9.41 (10,638/113,019)		
4 calls		5.82 (6575/113,019)		
≥5 calls		1.74 (1971/113,019)		

[a] Responses of “refused,” “don’t know,” and “not collected” were excluded from analyses and resulted in different N’s for each analysis.

[b] Met meaningful significance threshold requirements of *P*<.0001 and absolute difference in percentage points between comparison groups rounded to 5 or greater.

[c] Marital status was assessed at enrollment by 3 states; analysis focused on a limited sample.

[d] Annual household income was assessed at enrollment by 5 states; analysis focused on a limited sample.

[e] Sexual orientation, tobacco environment, and cigarette frequency were assessed at enrollment by 9 states; analyses focused on a limited sample.

[f] Endorsed 1 or more of the following chronic health conditions: asthma, diabetes, coronary artery disease, chronic obstructive pulmonary disease.

[g] Six states (87.4% of study sample) assessed mental health condition status at enrollment by asking the question, “Do you currently have any mental health conditions, such as attention deficit hyperactivity disorder (ADHD), bipolar disorder, depression, drug or alcohol use disorder (substance use disorder; SUD), generalized anxiety disorder, posttraumatic stress disorder (PTSD), schizophrenia?” Analysis focused on a limited sample.

[h] Endorsed 1 or more of the mental health conditions assessed.

[i] Multiple reporting; total may not add up to 100%.

[j] Coaching calls were not included in the Web-Only program.

Characteristics of Web-Only Versus Phone/Web Enrollees

Quitline registrants were more likely to select Phone/Web over a Web-Only program (113,019/141,429, 79.91% vs 28,410/141,429, 20.09%). Participant characteristics and differences between those who opted for the Web-Only versus Phone/Web program are shown in Table 1.

Compared to Phone/Web enrollees, participants who enrolled in a Web-Only program were younger (mean 40.8, SD 12.8 vs mean 45.3, SD 14.0 years; *P*<.001), more likely to be white non-Hispanic (80.10% vs 71.10%; *P*<.001) and less likely to be black or African American non-Hispanic (6.84% vs 14.80%; *P*<.001). Web-Only enrollees were more highly educated (59.65% vs 44.15% had greater than a high school degree; *P*<.001) and reported higher household incomes (36.50% vs 54.39% reported an annual household income of less than US$15,000; 37.33% vs 30.11% reported US$15,000 to US$35,000; 26.17% vs 15.50% reported greater than US$35,000; all *P*<.001). Participants who opted for the Web-Only program were more likely to be uninsured (49.02% vs 41.00%; *P*<.001) or commercially insured (38.72% vs 22.14%; *P*<.001), and less likely to have Medicaid (7.87% vs 22.12%; *P*<.001) or Medicare coverage (4.39% vs 14.74%; *P*<.001). Web-Only were also more likely to be married or in a domestic partnership (45.79% vs 34.63%; *P*<.001), and more likely to live and/or work with other tobacco users (62.81% vs 56.24%; *P*<.001). Smaller proportions of Web-Only enrollees reported having a chronic health condition (24.07% vs 34.74%; *P*<.001) or a mental health condition (35.66% vs 49.42%; *P*<.001) at enrollment. Web-Only were also less likely to be highly nicotine-addicted (42.26% vs 49.86% reported using tobacco within 5 minutes of waking; *P*<.001) or long-term tobacco users (57.23% vs 69.34% had used tobacco for ≥20 years; *P*<.001). Web-Only were less likely to have started their enrollment for quitline services over the phone (45.43% vs 91.93%; *P*<.001) and more likely to have started their enrollment online (52.20% vs 2.91%; *P*<.001). There were no meaningful differences in program selection as a function of gender, pregnancy status, sexual orientation, cigarettes smoked per day, or frequency of cigarette use at enrollment.

As shown in Table 2, multivariable logistic regression analyses confirmed that participants who opted to enroll in Web-Only were younger, more highly educated, more likely to be white non-Hispanic and less likely to be black non-Hispanic, more likely to be uninsured or commercially insured, less likely to be highly nicotine dependent or have a chronic health condition, and more likely to have started their enrollment online.

Table 2. Multivariable model of the relationship of participant characteristics and program choice between Phone/Web versus Web-Only programs.

Baseline characteristic	Chose Web-Only program	
	AOR (99.99% CI)	*P*
Age	0.983 (0.981-0.986)	<.001[a]
Gender		
Male	Ref	<.001[a]
Female	1.106 (1.028-1.189)	
Race/ethnicity		
Black or African American, non-Hispanic	Ref	
White, non-Hispanic	1.681 (1.482-1.907)	<.001[a]
Hispanic or Latino	1.308 (1.094-1.564)	
Other	1.462 (1.216-1.758)	
Education		
< High school degree	Ref	
General education development (GED)	1.411 (1.202-1.656)	<.001[a]
High school degree	1.481 (1.314-1.669)	
> High school	1.792 (1.604-2.003)	
Health insurance status		
Medicaid	Ref	
Commercial	1.594 (1.415-1.794)	<.001[a]
Uninsured	1.380 (1.237-1.541)	
Medicare	0.945 (0.803-1.112)	
Chronic health conditions		
≥1[b]	Ref	<.001[a]
None	1.234 (1.137-1.340)	
Cigarettes per day	0.998 (0.995-1.002)	.06
Dependence level		
Within 5 minutes	Ref	<.001[a]
≥6 minutes	1.127 (1.046-1.213)	
Method of entry		
Phone call	Ref	
Web enroll	26.710 (24.270-29.396)	<.001[a]
Fax referral	1.323 (1.102-1.589)	

[a] Met meaningful significance threshold of *P*<.0001.

[b] Endorsed 1 or more of the following chronic health conditions: asthma, diabetes, coronary artery disease, chronic obstructive pulmonary disease.

Multivariable analyses also indicated that Web-Only enrollees were more likely to be female, which was significant in bivariate analyses but did not meet our meaningful significance threshold requirement of an absolute difference in percentage points rounding to 5 or greater. A secondary model (not shown) limited to the 6 states that assessed mental health condition status at registration confirmed that Web-Only were also more likely to report not having any mental health condition diagnoses (AOR 1.49, 99.99% CI 1.38-1.61; *P*<.001).

Utilization of Web Services and Nicotine Replacement Therapy Benefit

Table 3 summarizes Web utilization overall and between program types. Half (50.34%) of Phone/Web and all (100.00%) Web-Only registrants “enrolled” in Web services by providing their email address and consenting to be contacted via email. Among those who consented to this enrollment step, Web-Only registrants were significantly more likely than Phone/Web to log in to the Web Coach website (*users*) in the 6 months following their registration (76.85% vs 42.04%; *P*<.001). Although Web-Only were more likely to log in at least once, this group was less likely to return to the site on a later day (*return users*) compared to Phone/Web (40.15% vs 58.39%; *P*<.001). Among program participants who used the Web Coach website at least once, Phone/Web participants logged in on more days than Web-Only participants (median 2.0, IQR 1-4 vs median 1.0, IQR 1-2; *P*<.001).

Table 3. Web Coach website enrollment rates, log-in days, return rates, and receipt of nicotine replacement therapy (NRT) benefit among total sample and between Phone/Web versus Web-Only programs.

Utilization metric	Total	Phone/Web	Web-Only	*P*
	N=141,429	n=113,019	n=28,410	
Enrolled in Web Coach website by providing email address and consenting to contact via email (among all participants), % (n/N)	60.31 (85,302/141,429)	50.34 (56,892/113,019)	100.00 (28,410/28,410)	<.001[a]
Logged in to Web Coach website (among enrolled), % (n/N)	53.64 (45,752/85,302)	42.04 (23,920/56,892)	76.85 (21,832/28,410)	<.001[a]
Web Coach website log-in days (among enrolled), % (n/N)				<.001[a]
0 days	46.36 (39,550/85,302)	57.96 (32,972/56,892)	23.15 (6578/28,410)	
1 day	26.99 (23,020/85,302)	17.50 (9954/56,892)	45.99 (13,066/28,410)	
2 days	9.22 (7866/85,302)	7.42 (4220/56,892)	12.83 (3646/28,410)	
3 days	4.55 (3877/85,302)	4.12 (2346/56,892)	5.39 (1531/28,410)	
4 days	2.68 (2287/85,302)	2.56 (1455/56,892)	2.93 (832/28,410)	
≥5 days	10.20 (8702/85,302)	10.45 (5945/56,892)	9.70 (2757/28,410)	
Returned to Web Coach website after initial log-in day (among logged in), % (n/N)	49.69 (22,732/45,752)	58.39 (13,966/23,920)	40.15 (8766/21,832)	<.001[a]
Web Coach website log-in days (among logged in), Median (IQR)	1.0 (1-3)	2.0 (1-4)	1.0 (1-2)	<.001[a]
NRT benefit shipped, [b] **% (n/N)**				<.001[a]
Sent NRT	68.04 (96,229/141,429)	73.58 (83,159/113,019)	46.00 (13,070/28,410)	
Not sent NRT	31.96 (45,200/141,429)	26.42 (29,860/113,019)	54.00 (15,340/28,410)	
NRT benefit shipped [c] **(among states offering NRT through Phone/Web and Web-Only), % (n/N)**				<.001[a]
Sent NRT	75.56 (84,530/111,875)	83.11 (71,460/85,987)	50.49 (13,070/25,888)	
Not sent NRT	24.44 (27,345/111,875)	16.89 (14,527/85,987)	49.51 (12,818/25,888)	

[a] Met meaningful significance threshold requirements of *P*<.0001 and absolute difference in percentage points between comparison groups rounded to 5 or greater.

[b] Analysis included total sample, regardless of whether or not states offered an NRT benefit through their Phone/Web and/or Web-Only programs.

[c] Analysis focused on the 6 states that offered an NRT benefit through both their Phone/Web and Web-Only programs.

Six states offered an NRT benefit through both their Phone/Web and Web-Only programs. In these states, Web-Only enrollees were significantly less likely to have received NRT from their quitline (50.49% vs 83.11%; *P*<.001). Among all 10 states (regardless of whether NRT was offered through either program), 46.00% of Web-Only versus 73.58% of Phone/Web were sent quitline NRT.

Return Users: Subpopulations More Likely to Return to Web Services

Table 4 shows the percentages of different subpopulations within Phone/Web and Web-Only logging in to the Web Coach website on 2 or more days (ie, *return users*). Among both Phone/Web and Web-Only, participants who were female, more highly educated, had used tobacco for 20 years or longer, were sent NRT through their quitline, or had Medicare coverage were more likely to return to the site after their initial log-in day (Table 4). Older participants were also more likely to return among both Phone/Web (age of return users: mean 43.0, SD 13.0 vs age of nonreturn users: mean 40.5, SD 12.8; *P*<.001) and Web-Only (mean 41.9, SD 12.7 vs mean 39.8, SD 12.5; *P*<.001). Phone/Web participants were also more likely to return if they had reported a higher household income or identified as white non-Hispanic or “other” race at registration; these differences in return users as a function of income and race/ethnicity were not observed in the Web-Only population. Trends in return users also differed between program groups as a function of smoking frequency reported at enrollment. Phone/Web enrollees who smoked cigarettes every day or some days at enrollment were more likely to return than those who reported smoking not at all. The opposite was found for the Web-Only population: enrollees who initially reported not smoking at all were more likely to return than Web-Only enrollees who smoked daily or only some days. For Phone/Web, participants who completed more coaching calls were also more likely to return to the Web Coach website. There were no meaningful differences in return rates that met our threshold for significance for either program group as a function of pregnancy status, marital status, chronic health or mental health condition status, tobacco environment, or nicotine dependence at enrollment.

Multivariable analyses confirmed that Phone/Web and Web-Only participants who were older, female, more highly educated, and received NRT from their quitline were more likely to return to the Web Coach website (Table 5). Patterns of return as a function of race/ethnicity were also confirmed: Phone/Web participants were more likely to return if they identified as white non-Hispanic or “other” race, whereas no difference was observed among Web-Only. Phone/Web were also significantly more likely to return if they were commercially insured and had completed at least 1 call with Quit Coach staff. Among Web-Only, differences in return rates between insurance groups did not meet our significance threshold. Web-Only were less likely to return if they started their enrollment online rather than over the phone; there were no differences in return rates by method of program entry for Phone/Web. As in bivariate analyses, there were no differences in return rates within either program as a function of chronic condition status or nicotine dependence.

Table 4. Subpopulations in the Phone/Web and Web-Only programs more likely to return to the Web Coach website after an initial log-in day.[a]

Baseline characteristic or program component	Phone/Web			Web-Only		
	%	(# Returned/subgroup n)	*P*	%	(# Returned/subgroup n)	*P*
Overall	58.39	(13,966/23,920)		40.15	(8766/21,832)	
Gender			<.001[b]			<.001[b]
Female	60.26	(8760/14,537)		42.30	(5591/13,216)	
Male	55.48	(5202/9376)		36.86	(3174/8612)	
Pregnancy status (among females <50 years of age)			<.001			.81
Yes, currently pregnant, planning pregnancy, or breastfeeding	51.03	(273/535)		40.09	(170/424)	
Not pregnant	58.39	(5391/9232)		40.68	(3755/9230)	
Race/ethnicity			<.001[b]			.26
White, non-Hispanic	60.59	(10,369/17,114)		40.54	(7010/17,290)	
Black or African American, non-Hispanic	51.86	(1435/2767)		39.33	(542/1378)	
Hispanic or Latino	50.74	(1307/2576)		40.10	(719/1793)	
Other	59.87	(719/1201)		37.61	(378/1005)	
Education			<.001[b]			<.001[b]
< High school degree	52.78	(1217/2306)		31.94	(611/1913)	
General education development (GED)	56.09	(810/1444)		33.08	(573/1732)	
High school degree	56.14	(3188/5679)		37.98	(1767/4653)	
> High school	60.61	(8566/14,132)		43.20	(5709/13,215)	
Health insurance status			<.001[b]			<.001[b]
Uninsured	57.09	(5767/10,102)		37.74	(3999/10,597)	
Commercial	60.24	(4377/7266)		42.52	(3630/8538)	
Medicaid	54.85	(2165/3947)		38.36	(600/1564)	
Medicare	64.86	(1460/2251)		48.54	(417/859)	
Marital status [c]			.04			<.01
Single	69.17	(821/1187)		32.08	(385/1200)	
Married or domestic partner	72.45	(1270/1753)		36.92	(687/1861)	
Divorced, separated, or widowed	73.76	(711/964)		32.48	(266/819)	
Annual household income (US$) [d]			<.001[b]			.22
<$15,000	60.03	(952/1586)		36.76	(569/1548)	
$15,000 to $35,000	65.62	(1002/1527)		39.52	(677/1713)	
>$35,000	68.40	(844/1234)		39.20	(490/1250)	
Sexual orientation [e]			<.01			.41
Heterosexual	56.96	(11,129/19,537)		40.89	(6885/16,836)	
Lesbian, gay, bisexual, transexual, or other	61.15	(1012/1655)		42.12	(497/1180)	
Chronic health conditions			<.001			.09
None	57.69	(9999/17,333)		39.91	(6596/16,526)	
≥1[f]	60.41	(3942/6525)		41.25	(2078/5037)	
Mental health conditions [g]			.08			.21
None	57.57	(6340/11,013)		39.57	(5024/12,698)	

Baseline characteristic or program component	Phone/Web			Web-Only		
	%	(# Returned/subgroup n)	*P*	%	(# Returned/subgroup n)	*P*
≥1[h]	58.78	(5420/9221)		40.50	(2731/6744)	
Tobacco environment (other tobacco users present) [e]			<.001			<.01
Home and/or work	58.41	(7074/12,111)		40.25	(2425/6025)	
Neither home nor work	60.86	(5240/8610)		43.54	(1558/3578)	
Years used tobacco			<.001[b]			<.001[b]
<20 years	53.92	(4637/8600)		36.44	(3280/9002)	
≥20 years	61.40	(8433/13,735)		42.41	(5063/11,938)	
Dependence (time to first tobacco use after waking)			<.001			<.001
Within 5 minutes	57.57	(5972/10,373)		38.58	(3406/8828)	
≥6 minutes	59.87	(7611/12,712)		40.86	(5053/12,367)	
Cigarette frequency [e]			<.001[b]			<.001[b]
Every day	58.95	(12,071/20,478)		39.69	(7662/19,307)	
Some days	58.31	(256/439)		37.96	(205/540)	
Not at all	45.36	(308/679)		50.14	(184/367)	
Method of entry into program			<.001[b]			<.001
Fax referral	55.09	(379/688)		37.98	(109/287)	
Phone call	59.45	(12,685/21,337)		41.80	(3989/9543)	
Web enroll	47.60	(902/1895)		38.89	(4668/12,002)	
Phone program intensity			<.001[b]	n/a[i]	n/a[i]	n/a[i]
1-call	48.34	(842/1742)				
Multiple-call	59.18	(13,124/22,178)				
Call completion			<.001[b]	n/a[i]	n/a[i]	n/a[i]
0 calls	16.39	(362/2208)				
1 call	55.99	(6989/12,482)				
2 calls	66.91	(3171/4739)				
3 calls	74.51	(1815/2436)				
4 calls	78.68	(1336/1698)				
≥5 calls	82.07	(293/357)				
NRT benefit shipped [j]			<.001[b]			<.001[b]
Sent NRT	63.24	(11,988/18,957)		48.63	(6325/13,006)	
Not sent NRT	39.85	(1978/4963)		27.66	(2441/8826)	
NRT benefit shipped [k] **(among states offering NRT through Phone/Web and Web-Only)**			<.001[b]			<.001[b]
Sent NRT	62.20	(10,523/16,917)		48.63	(6325/13,006)	

Baseline characteristic or program component	Phone/Web			Web-Only		
	%	(# Returned/subgroup n)	*P*	%	(# Returned/subgroup n)	*P*
Not sent NRT	27.76	(855/3080)		26.16	(1907/7289)	

[a] Analyses focused on those who logged in to the Web Coach website at least once. Responses of “refused,” “don’t know,” and “not collected” were excluded from analyses and resulted in different N’s for each analysis.

[b] Met meaningful significance threshold requirements of $P<.0001$ and absolute difference in percentage points between comparison groups rounded to 5 or greater.

[c] Marital status was assessed at enrollment by 3 states; analysis focused on a limited sample.

[d] Annual household income was assessed at enrollment by 5 states; analysis focused on a limited sample.

[e] Sexual orientation, tobacco environment, and cigarette frequency were assessed at enrollment by 9 states; analyses focused on a limited sample.

[f] Endorsed ≥1 of the following chronic health conditions: asthma, diabetes, coronary artery disease, chronic obstructive pulmonary disease.

[g] Six states (87.4% of study sample) assessed mental health condition status at registration by asking the question, “Do you currently have any mental health conditions, such as attention deficit hyperactivity disorder (ADHD), bipolar disorder, depression, drug or alcohol use disorder (substance use disorder; SUD), generalized anxiety disorder, PTSD, schizophrenia?” Analysis focused on a limited sample.

[h] Endorsed ≥1 of the mental health conditions assessed.

[i] Coaching calls were not included in the Web-Only program.

[j] Analysis included total sample, regardless of whether or not states offered an NRT benefit through their Phone/Web and/or Web-Only programs.

[k] Analysis focused on the 6 states that offered an NRT benefit through both their Phone/Web and Web-Only programs.

Table 5. Multivariable models of the relationship of participant characteristics and likelihood of returning to the Web Coach website within Phone/Web and Web-Only programs.[a]

Baseline characteristic or program component	Phone/Web return users		Web-Only return users	
	AOR (99.99% CI)	*P*	AOR (99.99% CI)	*P*
Age	1.011 (1.006-1.016)	<.001[b]	1.013 (1.008-1.018)	<.001[b]
Gender				
Male	Ref	<.001[b]	Ref	<.001[b]
Female	1.216 (1.078-1.373)		1.252 (1.105-1.419)	
Race/ethnicity				
Black or African American, non-Hispanic	Ref		Ref	
White, non-Hispanic	1.410 (1.176-1.690)	<.001[b]	0.947 (0.738-1.216)	.50
Hispanic or Latino	1.151 (0.902-1.469)		1.001 (0.728-1.377)	
Other	1.464 (1.071-2.002)		0.891 (0.616-1.289)	
Education				
< High school degree	Ref		Ref	
General education development (GED)	1.132 (0.847-1.513)	<.001[b]	1.055 (0.783-1.422)	<.001[b]
High school degree	1.063 (0.857-1.318)		1.206 (0.945-1.539)	
> High school	1.277 (1.046-1.557)		1.501 (1.202-1.874)	
Health insurance status				
Medicaid	Ref		Ref	
Commercial	1.245 (1.034-1.499)	<.001[b]	1.183 (0.914-1.531)	<.001[b]
Uninsured	1.109 (0.936-1.314)		1.009 (0.785-1.296)	
Medicare	1.167 (0.910-1.496)		1.192 (0.814-1.746)	
Chronic health conditions				
≥1[c]	Ref	.50	Ref	.67
None	1.024 (0.896-1.170)		0.985 (0.854-1.136)	
Cigarettes per day	0.999 (0.993-1.005)	.36	0.995 (0.988-1.001)	.002
Dependence level				
Within 5 minutes	Ref	.001	Ref	.33
≥6 minutes	1.106 (0.979-1.249)		1.033 (0.909-1.173)	
Method of entry into program				
Phone call	Ref		Ref	
Web enroll	0.919 (0.734-1.151)	.33	0.804 (0.702-0.920)	<.001[b]
Fax referral	0.959 (0.664-1.386)		0.862 (0.496-1.499)	
NRT benefit shipped [d]				
Not sent NRT	Ref	<.001[b]	Ref	<.001[b]
Sent NRT	1.828 (1.490-2.242)		3.091 (2.692-3.550)	
Phone program intensity				
1-call	Ref	<.001	n/a[e]	n/a[e]
Multiple-call	1.375 (1.000-1.893)			
Call completion				
0 calls	Ref	<.001[b]	n/a[e]	n/a[e]

Baseline characteristic or program component	Phone/Web return users AOR (99.99% CI)	P	Web-Only return users AOR (99.99% CI)	P
≥1 call	4.599 (3.360-6.296)			

[a] Analyses focused on those who logged in to the Web Coach website at least once.

[b] Met meaningful significance threshold of $P<.0001$.

[c] Endorsed ≥1 of the following chronic health conditions: asthma, diabetes, coronary artery disease, chronic obstructive pulmonary disease.

[d] Analysis included total sample, regardless of whether or not states offered an NRT benefit through their Phone/Web and/or Web-Only programs.

[e] Coaching calls were not included in the Web-Only program.

Web Coach Website Feature Use

Figure 8 and Table 6 show the percentages of Web Coach website users (logged in on 1 or more days) who used key site features at least once in the 6 months following their enrollment in a program. Table 6 shows all percentages and *P* values, whereas Figure 8 is included to facilitate synthesis of findings. Features used by the largest percentages of participants overall included the Tobacco Tracker (65.33% of all Web Coach website users) and the Cost Savings Calculator (60.64%). Participants also completed Quitting Plan behaviors at relatively high rates; 41.91% of all users completed at least 1 behavior: Choose a Medication (38.68%), Set a Quit Date (28.93%), Conquer My Urges (28.54%), Control My Environment (25.75%), and Get Social Support (19.22%). Although 27.92% of users visited the page introducing the 4 Essential Practices of Quitting, less than half of those individuals viewed any of the Practices content in an e-lesson (13.31%), article (9.13%), or video (4.03%). Use of the Community features was also low, with 10.87% of all Web Coach website users visiting the Community area, 10.44% creating a Community account, 6.48% reading a discussion thread, and 1.99% posting in a Community discussion. Small proportions of users reached out to Quit Coach staff: 5.02% of all Phone/Web and Web-Only participants clicked to chat with a coach, and 4.85% clicked to send an email. Phone/Web participants could also request a call from a coach; 4.04% of Phone/Web used this feature.

With regard to differences in feature use between Phone/Web and Web-Only, Web-Only participants were less likely than Phone/Web to use both the Tobacco Tracker (56.87% vs 73.06%; $P<.001$) and Cost Savings Calculator (58.37% vs 62.72%; $P<.001$; only approached threshold for meaningful significance), but they were more likely to use all other key features, including completing the 5 Quitting Plan behaviors: Choose a Medication (68.05% vs 11.87%; $P<.001$), Set a Quit Date (56.17% vs 4.06%; $P<.001$), Conquer My Urges (48.22% vs 10.58%; $P<.001$), Control My Environment (43.75% vs 9.33%; $P<.001$), and Get Social Support (32.47% vs 7.12%; $P<.001$) (Figure 8 and Table 6). Web-Only participants were also slightly more likely to use the Urge Tracker (10.72% vs 6.42%; $P<.001$; only approached threshold for meaningful significance), which was available only when a participant had a self-reported status of “I’m Quit.”

Table 6. Participants using key Web Coach website features among total users and between Phone/Web versus Web-Only users.[a]

Website feature	Total users, n (%) (N=45,752 [b])	Phone/Web users, n (%) (n=23,920 [b])	Web-Only users, n (%) (n=21,832 [b])	*P*
Quitting plan behaviors				
Completed any Quit Plan behavior	19,176 (41.91)	3475 (14.53)	15,701 (71.92)	<.001[c]
Choose a Medication[d]	17,696 (38.68)	2840 (11.87)	14,856 (68.05)	<.001[c]
Set a Quit Date	13,236 (28.93)	972 (4.06)	12,264 (56.17)	<.001[c]
Conquer My Urges	13,058 (28.54)	2531 (10.58)	10,527 (48.22)	<.001[c]
Control My Environment	11,782 (25.75)	2231 (9.33)	9551 (43.75)	<.001[c]
Get Social Support	8793 (19.22)	1704 (7.12)	7089 (32.47)	<.001[c]
Progress trackers				
Tobacco Tracker (not quit)	29,892 (65.33)	17,477 (73.06)	12,415 (56.87)	<.001[c]
Cost Savings Calculator	27,745 (60.64)	15,002 (62.72)	12,743 (58.37)	<.001
Urge Tracker (quit)	3877 (8.47)	1536 (6.42)	2341 (10.72)	<.001
Interactive practice content				
Viewed Practices page	12,775 (27.92)	3984 (16.66)	8791 (40.27)	<.001[c]
Viewed an e-lesson	6090 (13.31)	1715 (7.17)	4375 (20.04)	<.001[c]
Viewed an article	4176 (9.13)	1266 (5.29)	2910 (13.33)	<.001[c]
Viewed a video	1845 (4.03)	691 (2.89)	1154 (5.29)	<.001
Community				
Visited Community area	4975 (10.87)	2074 (8.67)	2901 (13.29)	<.001[c]
Created Community account	4776 (10.44)	1904 (7.96)	2872 (13.16)	<.001[c]
Read a discussion thread	2966 (6.48)	1277 (5.34)	1689 (7.74)	<.001
Posted in Community	912 (1.99)	407 (1.70)	505 (2.31)	<.001
Reaching out to Quit Coach staff				
Clicked to chat with a Coach	2297 (5.02)	586 (2.45)	1711 (7.84)	<.001[c]
Clicked to email with a Coach	2220 (4.85)	375 (1.57)	1845 (8.45)	<.001[c]
Clicked to call a Coach (Phone/Web only)	n/a[e]	967 (4.04)	n/a[e]	n/a[e]

[a] Analyses limited to those who logged in to the Web Coach website at least once.

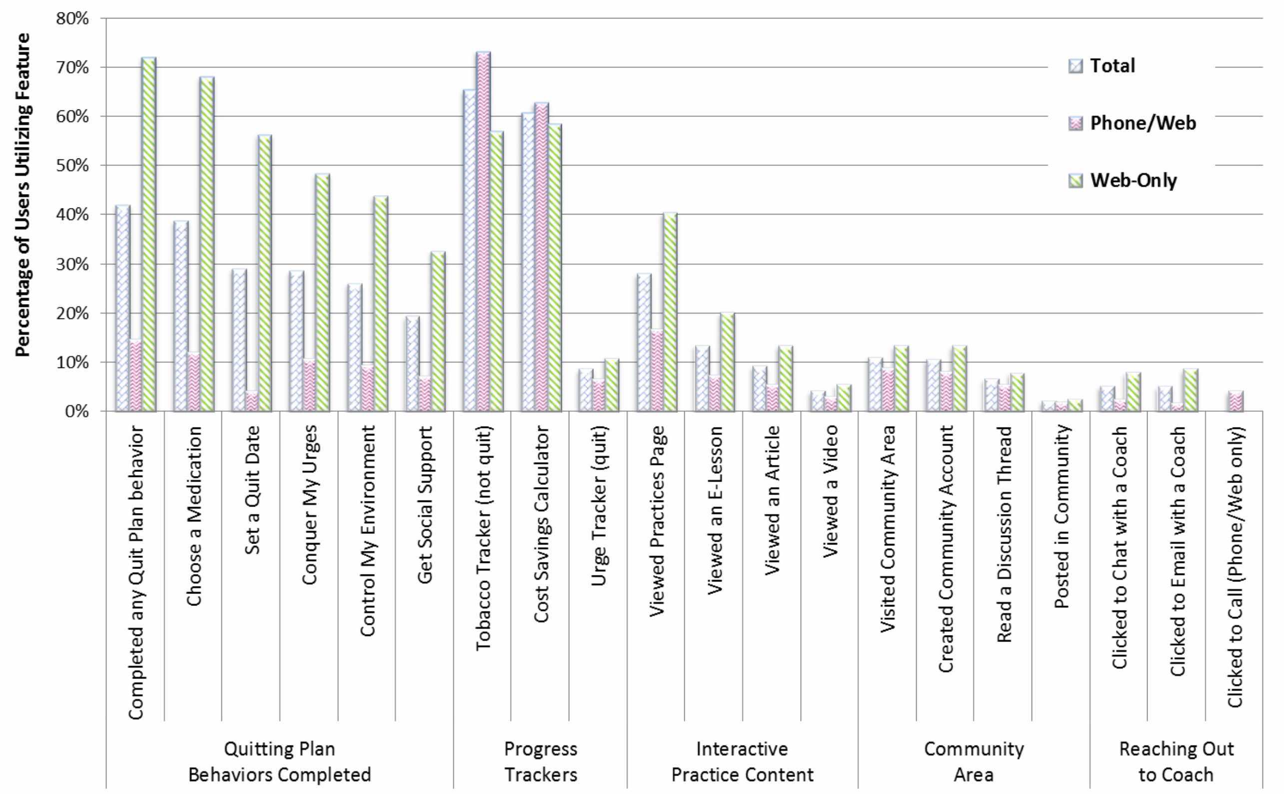
[b] Denominator applies to entire column.

[c] Met meaningful significance threshold requirements of *P*<.0001 and absolute difference in percentage points between comparison groups rounded to 5 or greater.

[d] The Choose a Medication behavior was available to all Web Coach website users to guide their medication selection and dosing, regardless of whether the participant's state quitline offered cessation medication. In addition, Web-Only participants who completed the activity but had a medical use exclusion contraindicating NRT use were not sent NRT; Phone/Web participants with a use exclusion could receive NRT from the quitline with physician approval.

[e] Coaching calls were not included in the Web-Only program.

Figure 8. Participants using key Web Coach website features among total users and between Phone/Web versus Web-Only users.



Discussion

Principal Results and Comparison With Prior Work

This examination of tobacco users' enrollment in and use of Phone/Web and Web-Only tobacco cessation programs through 1 of 10 state quitlines describes program selection in a large, real-world sample, and is also the first examination of return users from Web-based versus integrated Phone/Web programs and among subpopulations within these programs. Four-fifths of the 141,429 tobacco users in the study selected cessation support through the integrated Phone/Web program. Method of entry was the strongest predictor of program selection (92% of those who started their enrollment by phone selected Phone/Web; 52% of those who started enrollment online selected Web-Only), which may indicate that the phone program is highlighted more during phone registration, in quitline advertisements, and/or through word of mouth. It is also possible that participants tend to contact the program using the modality in which they would prefer to receive services.

Those who chose to enroll in the Web-Only program were younger, healthier (in terms of chronic health condition and mental health condition status), more highly educated, less likely to have insurance through Medicaid or Medicare, more likely to be white non-Hispanic and less likely to be black non-Hispanic, and less likely to be highly nicotine-addicted. This profile of smokers may be more tech savvy and not as interested in the more intensive support available via phone. These findings and previous research indicate that Web-Only is an attractive option for the harder-to-reach population of younger smokers [7,9] and those without symptoms of depression [9]. In addition to differences in education and insurance status, among 4 states that assessed income, Web-Only enrollees had higher annual household incomes, which may relate to socioeconomic disparities in Internet access or experience using computers. If Web-based services prove to be effective for tobacco users of higher socioeconomic status, this may present an avenue for conserving tobacco control funds to provide the higher-cost phone programs [7,12] for smokers who are more highly addicted and socioeconomically disadvantaged.

Phone/Web and Web-Only enrollees engaged with Web services differently. After initial enrollment in the Web Coach website, more Web-Only participants actually logged in to the program, as would be expected by their program selection. However, Phone/Web participants who used the site were more likely to return after their initial log-in. Despite being less likely to return to the site, Web-Only participants were more likely than Phone/Web to use most key features, most notably completing the 5 Quitting Plan behaviors. These findings suggest that Web-Only participants tended to use the site for a single, intense session of quit plan development and site exploration, but typically did not return. Phone/Web participants, on the other hand, who already demonstrated their desire for support and program contact by choosing a program with phone interaction, used the Web Coach website planning features at much lower rates (likely because they had already completed planning with Quit Coach staff over the phone), but were more likely to return to the site for additional program contact. Phone/Web participants may have returned to the site because they were encouraged to do so during their ongoing coaching calls (call completion was correlated with return visits to the site), although participants may have completed more calls and returned to the site simply because they were more engaged overall. These motivations and usage profiles should be considered as program designers decide how to present and highlight Web-based cessation content to ensure participants find the most important and relevant content during their visit.

Within both the Phone/Web and Web-Only populations, participants were more likely to return to the Web Coach website after their initial log-in day if they were women, older, or more highly educated, which is in-line with the previous research [13]. Those who were sent NRT through their quitline (for both programs) and those who had commercial health insurance (among the Phone/Web program) were also more likely to return. Given findings that services are most successful [14,15] and cost-effective when utilized at higher rates [12], effective strategies for re-engaging participants across the board, or particularly for less engaged groups, are needed.

The interactive Tobacco Tracker, Cost Savings Calculator, and Quitting Plan behaviors were the most widely used features among all registrants; previous research has suggested that use of interactive Web components is associated with higher quit rates, particularly in nondepressed populations [9,14]. Program designers should continue to focus on interactive features as opposed to static informational sites. Designers should also consider how best to encourage use of key features. Among quitlines that offered NRT to both Phone/Web and Web-Only participants, Web-Only were less likely to have received NRT from their quitline program. It is unclear why Web-Only participants were less likely to take advantage of the NRT benefit through their quitline, but it may be the result of different program processes. Although a Phone/Web participant is typically guided through the process of creating a quit plan (including selection and dosing for a cessation medication) by Quit Coach staff, the Web-Only program is designed to be more self-guided; participants are required to authenticate their account, log in, and then complete the Choose a Medication behavior on their own to access NRT. In addition, Phone/Web participants with a medical use exclusion contraindicating NRT use are mailed an override letter that their physician can fax to the quitline to approve NRT for the participant; this override process has not been an option for Web-Only participants with a use exclusion. Because use of Food and Drug Administration-approved cessation medications is associated with greater odds of achieving abstinence [16], Web programs should employ strategies to promote awareness of medication options and prioritize access to cessation medication benefits.

Limitations and Future Directions

A strength of this study is that analyses were conducted with a large census sample of tobacco users from different regions of the country who registered in 10 state tobacco quitlines. However, the large sample size resulted in numerous statistically significant results that may not reflect meaningful differences; the authors used a Bonferroni adjustment to account for the large number of statistical comparisons and selected a criterion level to provide a consistent benchmark for identifying meaningful differences. We believe a 5 percentage point difference is a reasonable threshold; however, others may view smaller or larger differences to be meaningful.

Several other limitations should be noted. First, all participants self-selected their program of choice, but we do not know what factors influenced participants' selections nor how aware tobacco users were of the services available to them in each program. In particular, we cannot know how carefully those who enrolled online read the program option descriptions. Second, not all 10 states offered identical services to all tobacco users (eg, the multiple-call program was not available to subgroups of registrants in 2 states); future work should examine the impact of different service offerings on program choice. Third, data were not available from Web-Only participants on motivation, confidence, readiness to quit, or previous quit attempts. These data would better inform whether individuals less ready or who might feel they needed less support with quitting selected the Web-Only service. It is important to note that the demographic differences found between participants who chose Web-Only versus Phone/Web may be due in part or entirely to differences in 1 or more of these variables for which data were not available. Fourth, we focused on the number of distinct log-in days as our metric of engagement and were not able to examine the specific number of log-ins or minutes on the site. Log-in days provides a more consistent estimate of use given potential variations in time before automatic logouts; however, log-ins and minutes could have provided additional context regarding typical program use. Fifth, we did not examine utilization of other resources; Web-Only users or other subgroups less likely to return to the Web Coach website may also be more likely to use other additional sources of support (eg, multiple online programs). Future research could examine this hypothesis and determine whether encouraging sustained engagement in a single evidence-based program produces the best outcomes. Sixth, there was not a mobile accessible/compatible version of the Web Coach website at the time of this study. Future research should examine whether mobile accessible websites change how participants engage with Web-based programs, especially in terms of differences in use between various levels of socioeconomic status. Moreover, because Web features can change, feature use could be impacted by changes in site design, which can affect the replicability of these findings and comparisons across Web-based programs.

This paper was not about outcomes; although the effectiveness of phone-based cessation programs has been established [17] and randomized controlled trials have provided support for Web-based cessation services [10], data were not available to evaluate the effectiveness of the Phone/Web and Web-Only programs for participants in this study, and the Centers for Disease Control and Prevention has not yet deemed Web-based services as having a sufficient evidence base in their 2014 Best Practice Guidelines [18]. More research is needed to better understand the effectiveness of Web-Only cessation services for populations who select into that service, and reasons tobacco users select Web-Only over integrated Phone/Web.

Conclusions

Understanding who is selecting different tobacco cessation program modalities and how they engage with the program in a real-world setting will help the scientific and treatment community to better understand program outcomes and can inform engagement and re-engagement strategies. Our findings suggest that a Web-based program attracts younger, healthier smokers of higher socioeconomic status who interact more intensely with services in a single session, but are also less likely to re-engage or access the important NRT benefits available to them. Further research is needed to examine the efficacy of different engagement techniques and services with different subpopulations of tobacco users.

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Authors' Contributions

CN was the principal investigator of the project; she analyzed the data and wrote the first draft of the manuscript Methods, Results, and Discussion. SZ was responsible for the initial project concept and provided feedback on project planning. CN and KV conducted project planning and reviewed and interpreted the data. LK conducted the initial literature review and wrote the first draft of the Introduction. All authors contributed to manuscript revisions and interpretation of results.

Conflicts of Interest

All authors are employed by Alere Wellbeing, Inc, which is the service provider for the state quitlines included in this study.

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Abbreviations

GED: general education development
NAQC: North American Quitline Consortium
NRT: nicotine replacement therapy

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Original Paper

A Web-Based Program to Increase Knowledge and Reduce Cigarette and Nargila Smoking Among Arab University Students in Israel: Mixed-Methods Study to Test Acceptability

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Abstract

Background: Among Arab citizens in Israel, cigarette and nargila (hookah, waterpipe) smoking is a serious public health problem, particularly among the young adult population. With the dramatic increase of Internet and computer use among Arab college and university students, a Web-based program may provide an easy, accessible tool to reduce smoking rates without heavy resource demands required by traditional methods.

Objective: The purpose of this research was to examine the acceptability and feasibility of a pilot Web-based program that provides tailored feedback to increase smoking knowledge and reduce cigarette and nargila smoking behaviors among Arab college/university students in Israel.

Methods: A pilot Web-based program was developed, consisting of a self-administered questionnaire and feedback system on cigarette and nargila smoking. Arab university students were recruited to participate in a mixed-methods study, using both quantitative (pre-/posttest study design) and qualitative tools. A posttest was implemented at 1 month following participation in the intervention to assess any changes in smoking knowledge and behaviors. Focus group sessions were implemented to assess acceptability and preferences related to the Web-based program.

Results: A total of 225 participants—response rate of 63.2% (225/356)—completed the intervention at baseline and at 1-month poststudy, and were used for the comparative analysis. Statistically significant reductions in nargila smoking among participants (*P*=.001) were found. The intervention did not result in reductions in cigarette smoking. However, the tailored Web intervention resulted in statistically significant increases in the intention to quit smoking (*P*=.021). No statistically significant increases in knowledge were seen at 1-month poststudy. Participants expressed high satisfaction with the intervention and 93.8% (211/225) of those who completed the intervention at both time intervals reported that they would recommend the program to their friends, indicating excellent acceptability and feasibility of the intervention. This was further emphasized in the focus group sessions.

Conclusions: A tailored Web-based program may be a promising tool to reduce nargila smoking among Arab university students in Israel. The tailored Web intervention was not successful at significantly reducing cigarette smoking or increasing knowledge. However, the intervention did increase participants' intention to quit smoking. Participants considered the Web-based tool to be an interesting, feasible, and highly acceptable strategy.

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KEYWORDS

Web-based intervention; smoking cessation; nargila smoking; Arabs in Israel; university students; tailored feedback

Introduction

It is widely known that smoking is the most preventable cause of morbidity and mortality worldwide [1]. Cigarette smoking is a serious public health problem in Israel, particularly among the male Arab population. Data from the Israeli Ministry of Health (2012) indicates that over 52% of Arab males smoke cigarettes [2]. In addition to cigarette smoking, nargila smoking is a phenomenon that has increased significantly over the years among the Arab population in Israel. A survey conducted by the Rikaz Database (2010) using a representative sample revealed that 60.5% of Arabs in Israel have tried using nargila at least once, and about 20% use nargila regularly, daily, or once a week [3]. When examining nargila smoking with respect to age, it is evident that the largest percentage (60.5%) of smokers are 18 to 34 year olds, the age of most college/university students. Females make up a sizable percentage (about 19.6%) of nargila smokers, in comparison to their low representation among cigarette smokers [3]. Multiple studies have shown nargila smoking to be equally dangerous to one's health as cigarette smoking, linking it with lung disease, cancer of the lung, mouth, and cheek, cardiovascular disease, hypertension, and chronic respiratory disease [4-6].

Well-designed smoking prevention and cessation programs can substantially contribute to global public health. Interventions that can reduce tobacco use, offer global reach, and do so in a cost-effective manner have a tremendous opportunity to reduce the future burden of disease. Several studies have evaluated the effectiveness, feasibility, and acceptability of using computer- and Web-based health interventions to reduce smoking behavior [7-12]. A recent Cochrane review of 28 randomized and quasi-randomized trials on Internet-based interventions for smoking cessation concluded that Internet-based interventions were promising and effective at assisting smoking cessation [13]. The most promising interventions were ones that were tailored to the individuals. Computer-tailored health interventions can be defined as the adaptation of health education materials to one specific person through a largely computerized process [12]. Computer-tailored health programs provide respondents with personalized feedback about their present health behavior and/or behavioral determinants, based on responses reported in a questionnaire. Computer-tailored health interventions may offer a mix of highly professional expertise, typical of individual professional attention (tailored messages), while maintaining the cost-effectiveness of mass communication [14]. Compared with nontailored messages, tailored health messages are more likely to be read and remembered, saved and discussed with others, perceived as interesting and personally relevant, and designed especially for the recipient [15,16].

To date, there are no studies in the literature that have developed, or examined the acceptability and feasibility of, computer-based programs providing tailored health educational feedback among Arabs in Israel. Particularly among the Arab minority in Israel, cigarette and nargila smoking are a serious public health problem. With the dramatic increase of computer and Internet access and use among Arab university students, specifically, and educated Arabs in general, a Web-based program could provide an easy, accessible tool to collect data, increase smoking knowledge, and reduce smoking behavior without the heavy demands of time, manpower, and resources required by traditional methods of data collection and health education.

The aim of this study was to pilot-test the feasibility and acceptability of a Web-based health education program that provides tailored feedback on improving knowledge about cigarette and nargila smoking and changing smoking behaviors of Arab college/university students in Israel. This study aimed to determine if a tailored Web-based program was perceived as an acceptable, preferable, and useful tool among Arab university students.

Methods

Study Design and Procedure

We conducted a mixed-methods study utilizing quantitative and qualitative tools to evaluate the feasibility and acceptability of a Web-based smoking cessation program to improve cigarette and nargila smoking knowledge and behaviors among Arab university students in Israel. Quantitative analysis involved a pre-/poststudy design with follow-up measurements after 1 month. Students were recruited to the study using flyers and announcements placed in academic departments, through student message boards, during classes, and through Facebook. Participants were sent an introductory email in Arabic with basic information regarding the questionnaire, the link to the program, and their assigned username and password to allow access to the program. Participants could access the program online from any computer with Internet access.

Participants' responses were automatically saved into the computer database system. This allowed participants to log on multiple times at different sittings, if needed, to complete the questionnaire and receive educational feedback. Following completion of the questionnaire by the participants, responses were saved into the system and could be downloaded into a Microsoft Excel file by the researcher for analysis. Website analytics were used to assess participants' engagement in the program and length of time that participants used the website.

Email messages were used to remind individuals about follow-up dates for completing the questionnaires after 1 month. Reminders were sent out by email and/or via Facebook messages 2 weeks, 1 week, and 1 day before students were expected to participate in the follow-up session. Participants were given 1 week to complete the online questionnaire. If after 1 week they had not logged on to complete the program, another email reminder was sent to them every other day for a period of 2 weeks. Those participants who did not respond were removed from the follow-up analysis.

Following the online intervention, focus group methodology was utilized to further examine participants' personal perceptions and opinions regarding the acceptability, appeal, and effectiveness of such a Web-based health program. A focus group guide was developed in a semistructured way to ensure that key questions were addressed and to permit comparisons across groups, while at the same time providing the facilitator with the freedom to follow up on unanticipated topics. During the focus group sessions, participants were also asked to report on how thoroughly they read the educational materials and how interesting and helpful they found the material to be. Five focus group sessions were conducted based on procedures suggested by Krueger [17]. Due to sensitive issues that were expected to arise in the discussion, males and females were separated in the focus group sessions to allow them to discuss issues more comfortably. Participants who completed both the pre- and poststudy questionnaires were randomly recruited to participate in the sessions. To select participants, the researcher used an online random number generator and contacted those chosen via email or phone requesting their participation until the needed number of participants were recruited. All five focus group sessions lasted approximately one and a half hours each. The sessions were moderated by an Arab professional group facilitator, familiar with the health field.

This trial was registered with the ISRCTN registry (ISRCTN59207794).

Intervention

A Web-based program was developed using the already existing Questions Sharing and Interactive Assignments (QSIA) system, an online assessment system that enables users, teachers, and students to generate, share, and manage knowledge items for learning, teaching, and assessment [18]. The validity and reliability of QSIA has been evaluated by previous research studies [19].

The program, which was in the Arabic language, consisted of two parts: (1) a self-administered online questionnaire, and (2) dissemination of tailored health education material via text and videos. The self-administered online questionnaire consisted of a total of 13 questions on cigarette and nargila smoking behavior and knowledge. The program consisted of a second module with seven questions on demographic information about the participant (ie, age, gender, year of study, subject of study, religion, religiosity, and hometown). The smoking module was only one of four health behaviors of the complete program, the rest of which is not discussed in this paper. All participants gave informed consent before beginning the online program. They were asked to participate in the intervention at baseline, with follow-up after 1 month. The questionnaires that they completed at the follow-up session were identical to the questionnaires at baseline. The module on demographic information was completed only once, at baseline.

After completion of the module, the program was designed to immediately analyze responses and to automatically display on the screen the health educational material in Arabic for the participant to read and watch. The educational material consisted of the following components: (1) introduction, including specific feedback on the respondent's cigarette and nargila smoking behavior and his or her intention to quit smoking or to maintain nonsmoking, (2) educational feedback on the adverse health impact of smoking and a list of potential health risks of smokers (or protective factors for nonsmokers), (3) recommendations with specific actions to help participants quit smoking (based on their intention to quit), and (4) suggestions and tips to cope with difficult social situations, including peer pressure. Various educational YouTube videos showing the adverse health impacts of cigarette and nargila smoking were integrated into the text feedback. The feedback that was given to the tailored-feedback group was done so according to the individual's perceived intention to change certain behaviors, according to the Transtheoretical Stages of Change Model [20]. The feedback was also tailored according to the demographic variables indicated, particularly gender, marital status, and family status. Females received information regarding how smoking can have hazardous implications for future pregnancies, and participants with families received feedback regarding adverse impacts on the health of their children. For example, if an individual in the tailored-feedback intervention group reported that they did not smoke cigarettes or nargila, the feedback given was the following:

> *Congratulations! You are not a smoker. You are protecting your health and have less chance of developing certain diseases like cancer and heart disease in the future! Keep up the good work!*

On the other hand, if the participant reported that they smoked only nargila, for example, they would receive the following recommendation:

> *It is good that you do not smoke cigarettes. However, by smoking nargila you are putting your health at risk. As a nargila smoker, you are greatly increasing your risk of getting certain diseases like cancer and heart disease in the future. Nargila smoking is just as dangerous as cigarette smoking. It is very important that you quit smoking now to protect your health. It seems that you are ready to quit smoking! You can quit smoking by...(continue with recommendations).*

Feedback for cigarette smoking and nargila smoking was given independently. Thus, a participant who did not smoke cigarettes, but smoked nargila would receive positive feedback that they were not a cigarette smoker, and educational feedback regarding nargila smoking.

This feedback was also sent via email message to the address provided by the participant and was given at the baseline session, as well as after the 1-month follow-up session. As part of the feedback and recommendations, there were also links to the educational YouTube videos that the participants could watch.

The intervention was developed with an embedded tracking system—all user activities were logged in a tracking area by username. These database files were accessible through the program website, allowing participants to save answers and complete the program in more than one sitting. The log files contained dates of each individual’s participation in the intervention sessions, and time spent logged into the program.

Pilot-Testing of the Program

Before the program was administered to the participants, it was pilot-tested for appropriateness to (1) familiarize data collection personnel with the computer program (QSIA), (2) examine online interactions between the participants and the researcher, (3) identify potential problems in the computer process, and (4) modify the questions appropriately to assure cultural appropriateness, user friendliness, and clarity. The program was sent to 25 individuals, including teachers of the Arabic language. These people were then asked to provide feedback regarding clarity of the questions and health educational materials, grammar and spelling, and other administrative issues, such as the correct ordering of questions, and whether appropriate health education was received in the tailored-feedback intervention. After receiving the feedback from the pilot participants, either through email, phone conversation, or face-to-face meeting, changes were made to the program before administering it to the participants. The data from the pilot study was not used in the analysis.

Target Population and Sampling Procedure

Male and female Arab students attending colleges and universities in Israel from 2007 to 2010 were recruited to participate in this study. The study sample chosen was not meant to be representative of the entire Arab population in Israel—the study was not aimed at describing the whole Arab population, but rather to study an influential group that can affect the future. This research will assess whether this type of program is applicable to this particular group. Data are lacking on the health knowledge, attitudes, and practices of young, educated Arab adults. In general, this group is often overlooked because its members are regarded as a healthy, invulnerable population. However, university students are likely to engage in risky health behaviors, including smoking, which can significantly impact their future health. University students are a very influential group who are likely to become the future leaders of their communities. Knowledge obtained from studying this group may have an impact on the whole Arab population. Increasing health knowledge and awareness by this target population is likely to have a significant impact on others. For example, many of these students will become the future educators and leaders of the next generation. It is likely that these students either have young children or will soon become parents and raise families. Increasing their awareness and knowledge regarding health issues and health-related behaviors empowers them to promote healthy behaviors among their future students, spouses, children, and families.

Potential participants received email messages in Arabic prior to the study, explaining its purpose and general procedure. All individuals who agreed to participate provided online consent prior to completing the online questionnaire. Once informed consent was given, participants were sent an email message containing their assigned username and password, and a link to enter the online program.

Participant Recruitment

Students were recruited to the study using flyers and announcements placed in academic departments and student Internet message boards in various colleges and universities throughout Israel. Social media was also utilized as a means of recruiting participants. An event page on Facebook was created—individuals that “liked” the page were asked by the researcher to spread the word regarding the need for students by sending messages to their friends. Finally, the researcher requested permission from lecturers to enter during certain classes to recruit participants. Interested participants were asked to provide their contact details, including mobile phone number and email address.

The eligibility criteria included the following: (1) an Arab studying at a college or university in Israel, (2) 18 years of age or older, (3) has access to the Internet either at home or at their corresponding college or university, and (4) agrees to provide informed consent for participation.

Measures

Outcome Measures

Our primary outcome measure was self-reporting of cigarette and nargila smoking behavior. Smoking behavior was assessed by asking the questions, “In the past 7 days, have you smoked a cigarette?” and ;“ In the past month, have you smoked nargila at least once a week?” The answer options were *Yes* or *No, not even a puff*.

Increases in cigarette and nargila smoking knowledge was also an outcome measure. To measure participants’ knowledge regarding cigarette and nargila smoking at baseline, we administered two questions on the health consequences of smoking. Increase in knowledge was assessed through completion of the self-administered questionnaire.

Acceptability and preference of the program were additional outcome measures that were assessed both from the online questionnaire and through the focus group sessions. Participants were asked to assess their satisfaction with the Web-based intervention as *very satisfied*, *satisfied*, *neutral*, *dissatisfied*, and *very dissatisfied*. In addition, they were asked if they would recommend the intervention to a friend.

Secondary outcome measures included intention to quit smoking, reason for wanting to quit, and seeking of professional help to quit smoking. Intention to quit smoking was assessed by *Yes* or *No* answers to the question, “Do you intend to quit smoking cigarettes/nargila in the next 6 months?” Participants were also asked about the reasons they had for wanting to quit smoking, as well as how they have tried to quit in the past (eg, seeking professional help, support from family/friends).

Baseline Measures

Sociodemographic characteristics, including age, gender, year of study, subject of study, religion, religiosity, and hometown, were collected from all the participants during the baseline questionnaire.

Statistical Analysis

Descriptive statistics were first calculated to identify the characteristics of the participants and frequencies of behavior and knowledge change. Pearson's chi-square test was used to determine statistical differences between the pre- and poststudy questionnaires for categorical variables. Only participants who completed both pre- and poststudy questionnaires were used in the comparative analysis. Measures of acceptability and satisfaction were summarized using counts and sample proportions. Given the preliminary nature of the study and small sample size of smokers, multivariate analyses were not conducted.

In order to analyze the focus group sessions, all sessions were audiotaped and then transcribed. Notes were kept during the sessions to capture the nonverbal “mood of the moment” that could not be documented through the recordings. Following each focus group session, members of the research team conducted a debriefing to identify issues that could affect analysis, such as domineering or quiet members [21]. The completed transcripts were compared with handwritten notes, and any inaudible phrases or gaps in the tapes were noted. Verification of the accuracy of the transcripts was achieved by randomly cross-checking the transcripts against the tapes.

The results from the focus groups were analyzed using thematic analysis of the transcripts. This was done by organizing the statements from the focus group sessions into categories on the basis of themes (or concepts) for each of the focus group questions that were asked. Concepts were then linked together as opposites or as sets of similar categories, which were then made into theoretical statements. A selective coding template was developed based on major data themes—each theme was given a different coding letter.

Results

Participation and Demographics

At baseline, 356 participants completed the intervention. The completion rate was 63.2% (225/356) at the 1-month follow-up session. Only participants who completed both the pre- and poststudy questionnaires were used in the analysis.

The mean age of respondents was 25 years (SD 5). More than two-thirds of all respondents were female (155/225, 68.9%). There were slightly more Muslim students that Christians—47.1% (106/225) versus 43.1% (97/225), respectively. The majority (164/225, 72.9%) of students reported that they were religious. Most students were undergraduate-level students (165/225, 73.3%). About 70.2% (158/225) of students were single. These sociodemographic factors may have an important impact on how the participants use and perceive computers, which could directly impact the results of the intervention. Thus, it is important that these factors were controlled for and considered throughout the results and discussion. Demographic characteristics of the participants are presented in Table 1.

Cigarette and Nargila Smoking Behavior and Knowledge

At baseline, 22.2% (50/225) of participants reported that they smoked at least one cigarette in the past week. Participation in the tailored-feedback intervention did not have a significant impact on cigarette smoking behavior—the percentage of smokers remained approximately the same at the 1-month poststudy session (see Table 2).

More than 58.2% (131/225) of participants reported that they smoked nargila at baseline. At the 1-month follow-up session after the intervention, this decreased significantly to 22.2% (50/225) of participants reporting they smoked nargila on a regular basis (χ^2_1=60.6, *P*=.001).

More than half of participants who smoked cigarettes (29/50, 58%), indicated that they had recently tried to quit smoking. The percentage of participants in the tailored-feedback intervention who tried to quit smoking increased to 73% (33/45) at the 1-month poststudy session. At 1-month poststudy, there was a statistically significant increase in intention to quit smoking from 58% (29/50) to 80% (36/45) (χ^2_1=5.3, *P*=.021). At this time, the number of smokers who sought professional help to quit smoking increased from 68% (34/50) to 76% (34/45), however, this increase was not statistically significant.

The primary reason given for trying to quit smoking was to improve health status. There was no significant change over time related to this. The majority of participants (156/225, 69.3%) were knowledgeable that smoking, even for a short period of time (1 to 2 years), had an adverse impact on health. There was a slight increase in this knowledge to 73.3% (165/225) at 1-month poststudy, but this increase in knowledge was not found to be statistically significant.

Table 1. Demographic characteristics of participants in the intervention group (n=225).

Demographic characteristic		n (%)
Sex		
	Male	70 (31.1)
	Female	155 (68.9)
Religion		
	Muslim	106 (47.1)
	Christian	97 (43.1)
	Druze	5 (2.2)
	Other	17 (7.6)
Religiosity		
	Very religious	23 (10.2)
	Religious	141 (62.7)
	Nonreligious	50 (22.2)
	No answer	11 (4.9)
Year of study		
	First	49 (21.8)
	Second	69 (30.7)
	Third	36 (16.0)
	Fourth, or higher	11 (4.9)
	Graduate level (master's or doctoral level)	60 (26.7)
Marital status		
	Single	158 (70.2)
	Married	67 (29.8)

Table 2. Pre-/poststudy smoking knowledge and behavior of participants.

Question about smoking knowledge and behavior		Prestudy, n (%)	Poststudy, n (%)	χ^2_1	*P* value
Did you smoke at least one cigarette during the last week? (n=225)					
	Yes	50 (22.2)	45 (20.0)	0.1	.732
	No	175 (77.8)	180 (80.0)		
In the past month, did you smoke nargila at least once a week? (n=225)					
	Yes	131 (58.2)	50 (22.2)	60.6	.001
	No	94 (41.8)	175 (77.8)		
Do you think it is safe to smoke cigarettes for only a year or two, as long as you quit after that? (n=225)					
	Yes	156 (69.3)	165 (73.3)	0.9	.348
	No	69 (30.7)	60 (26.7)		
Only smokers: In the past year, did you try to quit smoking? (prestudy n=50, poststudy n=45)					
	Yes	29 (58)	33 (73)	2.5	.117
	No	21 (42)	12 (27)		
Only smokers: Do you intend to quit smoking cigarettes in the next 6 months? (prestudy n=50, poststudy n=45)					
	Yes	29 (58)	36 (80)	5.3	.021
	No	21 (42)	9 (20)		
Only smokers: Have you received any support in trying to quit smoking? (prestudy n=50, poststudy n=45)					
	Yes	34 (68)	34 (76)	0.7	.415
	No	16 (32)	11 (24)		

Program Acceptability and Satisfaction

Participants expressed high satisfaction with the intervention (see Table 3). Of all the participants, 53.8% (121/225) reported that they were satisfied with the intervention, and 44.0% (99/225) were very satisfied with the program. Of all the participants, 94% (211/225) expressed that they would recommend the program to a friend.

Table 3. Acceptability and satisfaction of the Web-based tailored intervention (n=225).

Question about the tailored intervention	n (%)
What is your satisfaction level regarding the Web-based tailored intervention?	
Very satisfied	99 (44.0)
Satisfied	121 (53.8)
Neutral	5 (2.2)
Dissatisfied	0 (0)
Very dissatisfied	0 (0)
Would you recommend the Web-based smoking intervention to a friend?	
Yes	211 (93.8)
No	14 (6.2)

Focus Group Session Results

Five focus group sessions were held with a total of 56 individuals—35 (63%) females and 21 (38%) males—who completed the pre- and poststudy questionnaire. A focus group interview guide consisting of semistructured topics (shown in Textbox 1) was developed. However, since the goal of the focus group sessions was to give participants as much freedom as possible to express their opinions and views regarding the Web-based program, these semistructured questions were used only as a guide by the facilitator. The facilitator intervened with further exploratory questions only when the discussion reached a dead end. The facilitator diverged many times from the question pool to explore emergent themes and opinions that came up through the discussion.

Textbox 1. Focus group topics from the interview guide.

Focus group topics:

1: Smoking information

2: Acceptability, feasibility, and availability of the program

3: Suggestions for improvement

4: Topics of interest

5: Educational health feedback received

6: Other health topics

7: Learning preferences

8: Satisfaction

The Internet was a predominant theme that arose when participants expressed how they usually received health information. To gain insight into whether participants felt the computer program was an acceptable, preferable, and useful tool, several questions were posed. The majority (50/56, 89%) of participants—males and females, as well as control and intervention group members—reported preference of the computer program over other traditional means of health education. However, more females (32/35, 91%) than males (17/21, 81%) indicated that they would likely use an online health intervention in the future. The following seven themes emerged when asked what they liked or preferred about the computer program: (1) interesting and easy to complete and understand, (2) educational videos, (3) easily accessible, (4) private and comfortable, (5) comparable to real life, (6) feedback, and (7) in Arabic. Similarly, the participants—intervention and control, alike—reported the feedback to be relevant, effective, clear and to the point, and interesting. The following statements demonstrate the predominant themes that resulted during the discussion regarding positive aspects of the Web program and feedback:

> *I usually get bored quickly when I participate in programs like this. Usually, the health education material is boring and irrelevant to my lifestyle. But this was different. The feedback, especially the videos, was very interesting and I actually learned something. I felt like the education given was specifically directed to me, telling ME exactly what I need to change and what I need to do to improve my health.* [Participant, female]

> *What I liked most was that I could access the program anytime and from anywhere. The first time, I completed it at a coffee shop. The second time, I did it while waiting for the bus at the bus station, and the last time I did it on campus. It was nice that in my spare time, and when I was ready and free, I could complete it.* [Participant, male]

> *I am a pretty shy person. I prefer to search the Internet. I am not always comfortable to talk about some things, such as what I eat or that I smoke, in front of my family doctor or nurse, so I never ask them questions. I always feel like they will look negatively upon me. With this, it was just me and the computer, and there was no one to judge me on how I choose to live my life.* [Participant, female]

All participants agreed that they would recommend the computer program to their friends and family, since it provides important information in a concise interesting way, is easily accessible, easy to understand, and does not require a lot of time. This strengthened the quantitative data regarding the program's acceptability. The majority (46/56, 82%) of participants agreed that even friends or family members who were not very familiar with using the computer could easily use and understand such a program. Most participants in the tailored-feedback intervention stated that they read at least 90% of the material presented.

The majority (49/56, 88%) of participants reported that the feedback regarding nargila smoking was most useful and interesting. During all sessions, participants agreed that there is a real lack of awareness and knowledge regarding nargila smoking. Furthermore, the majority (40/56, 71%) agreed that nargila smoking was socially and culturally acceptable. The following statements were made by participants:

> *Before reading the feedback on nargila smoking, I had no idea how dangerous it was. Everyone knows cigarettes are not healthy, but I didn’t realize that nargila was just as bad as (cigarettes) or even worse. No one has ever talked to me about health hazards associated with nargila smoking. To me, this is really scary since everyone today is smoking nargila. I know kids as young as 10 years who smoke nargila and their parents think it is ok. It’s socially acceptable, not like cigarettes. As a girl, I am not ashamed to smoke nargila in public but I would never smoke cigarettes in public or in front of my parents and family.* [Participant, female]

> *Nargila smoking just seems better for you than cigarette smoking. The tobacco is fruit flavored, the smell and taste of the smoke is very fruity. Also, it seems that with the water pipe, the water would clean out, or purify, the tobacco before you inhale it.* [Participant, male]

Discussion

Principal Findings

This study used mixed methodology to investigate the feasibility and acceptability of a Web-based intervention as a tool to increase knowledge and reduce cigarette and nargila smoking behavior among Arab college and university students in Israel. There were 225 participants who completed the prestudy questionnaire and the poststudy questionnaire after participating in the online tailored-feedback intervention. The findings from the study suggest that a tailored Web intervention was found interesting and acceptable among Arab university students and seems promising in reducing nargila smoking and increasing intention to quit smoking.

Based on previous findings in the literature, we originally hypothesized that a Web-based intervention would be an effective tool to decrease smoking behavior among the target population. However, this was only true for nargila smoking. The tailored intervention reduced nargila smoking from 58.2% at baseline to 22.2% at the 1-month follow-up.

The tailored intervention did not have a significant impact on reducing cigarette smoking. However, the cigarette smokers who participated in the tailored-feedback intervention reported a statistically significant increase in the intention to quit smoking (P=.021).

The program had a greater impact regarding changing nargila smoking. Unlike cigarette smoking, which is widely known by the general public to be dangerous to health, there is very little awareness among the target population regarding the heath impact of nargila smoking. From the focus group sessions, we learned more in-depth reasons as to why the Web-based intervention was so effective at reducing nargila smoking, but did not have any impact on cigarette smoking. It was evident that the harmful effects of cigarette smoking were recognized by all participants. However, this was not the case with nargila smoking, which is socially acceptable in Arab culture. The fruity smell and taste of the nargila smoke misled participants to believe it was not very harmful to health. Furthermore, it was clear that there was a lack of knowledge and awareness regarding nargila smoking. All participants reported that no one had previously talked to them about the harmful health hazards associated with nargila smoking, unlike cigarette smoking, which was thoroughly discussed in schools, through media campaigns, and advertisements.

Participants reported in the questionnaires, and emphasized during the focus group sessions, that they found the program to be acceptable, relevant, and interesting. Participants reported preference of the Web as an educational and data collection tool to more traditional strategies, such as printed materials. Almost all of the participants reported that they would recommend a similar program to a friend. Participants appreciated that the feedback they received was tailored to their responses. Similar findings throughout the literature have shown that participants preferred tailored feedback over general feedback because it is more relevant, interesting, and personal [22-30].

At the time the intervention was implemented (2007-2010), Web-based health programs were increasing in popularity around the world and nonexistent among our specific target population, Arab university students in Israel. Although the type of Web-based intervention presented is out of date in many technologically advanced countries, we believe it is still very important to present the findings of this basic technology. This is particularly true since there is a significant proportion of the general Arab population in Israel who lack access to more advanced technologies. Furthermore, such basic technologies remain unique and new to the specific target population at hand. However, with the increased use of mobile phone and other mobile technologies today, there is a need to develop and examine the effectiveness of more advanced technologies.

Comparison With Prior Work

The results of our study are partially consistent with some studies in the literature. Our study found no significant changes in cigarette smoking among the target population at the 1-month poststudy session. This is consistent with findings from a randomized controlled trial (RCT) implemented by McKay et al that tested two Web-based smoking cessation interventions and failed to find any differences in smoking behavior at 3- and 6-month follow-up [31]. However, following participation in the tailored Web intervention, there were significant increases in the intention to quit smoking cigarettes, indicating that the tailored intervention may have had a positive impact. One systematic review concluded the evidence supporting the use of Web-based interventions for smoking cessation is insufficient in showing moderation of smoking behavior in adults, as well as insufficient in college students and adolescents [32]. On the other hand, another systematic review conducted by Civljak et al concluded that some Internet-based interventions can assist cigarette smoking cessation if programs last 6 months or longer, particularly those which are tailored to individuals [13,30]. The review found few trials that reported success rates for smoking cessation after 6 months or more, and other trials provided only limited evidence of long-term benefits of Web-based smoking cessation programs. However, it was found that the Internet-based programs may have an additional benefit when used alongside other interventions, such as nicotine replacement therapy or other pharmacotherapy [30]. A meta-analysis of 22 studies evaluating the effectiveness of Web- or computer-based smoking cessation programs indicated that there is sufficient clinical evidence to support the use of these programs for adult smokers [28].

In our study, the tailored-feedback Web intervention resulted in statistically significant reductions in nargila smoking (P=.001). To the best of our knowledge, this is the first Web-based program that has been developed to specifically change nargila smoking behavior, thus, we could not compare this study to others in the literature. However, if we consider nargila smoking to be smoking behavior in general, then our results are consistent with those found by other researchers indicating that Web-based programs are successful at effecting smoking cessation. [13,28,30].

Study Limitations

There were several limitations in the study that must be considered. A major limitation was the small sample size of smokers, both at baseline and throughout the follow-up sessions, thus, a lack of statistical power. Despite recruiting an adequate sample size, there were a large number of participants that did not smoke from the outset. Since smoking was only one of four lifestyle behaviors examined in the program, it was not feasible for us to recruit only smokers. Of the 225 participants who completed the pre- and poststudy questionnaire, only 50 were cigarette smokers. With this small sample size, the statistical power of the study was low. In future studies, it would be more appropriate to recruit only cigarette and nargila smokers from the outset to guarantee that a larger sample of smokers remain at follow-up. Further research is needed to validate the effectiveness of the Web intervention with a larger sample of Arab-Israeli university students, using a rigorous research design, such as a randomized controlled trial. Since we do not have a control group, conclusions regarding the effect of the intervention cannot be made. Despite positive behavior changes regarding nargila smoking and intention to quit, we cannot directly state that these improvements were a result of the program.

Another limitation was that our findings were based on self-reports, which may have led to recall bias. However, because we used the same questions at all measurement sessions, this may not have influenced our data showing changes in behavior, and thus the effectiveness of the intervention. Despite sound theoretical underpinning and knowledge learned from previous work, there will always be limitations involved in using self-administered questionnaires. In future studies, self-reported changes should be compared with objective measures. It must be noted that outcomes of self-reported behavior and objective measures of the same type of behavior do not always match [33]. Consequently, additional research that utilizes measures of directly observed smoking behavior would strengthen the findings of this study and should be incorporated as part of future studies. Another aspect of the study that must be considered is the validation of the participants’ engagement and reading of the educational materials. During the focus group sessions, participants were also asked to report on how thoroughly they read the educational materials and if they found them to be interesting. Website analytics were used to assess when, and for how long, participants used the website. However, this does not provide enough accurate information regarding the validation of whether participants actually read the educational material.

The results obtained in this study are only applicable and generalizable to educated Arabs in Israel. It was assumed that if this program was not effective among the educated Arab population, then it would not be effective among the general population who may have less access to, and less experience using, the Internet. However, the distribution of education among participants is important. The participants included had various levels of education, including undergraduate students at college and university, as well as graduate students at the master's and doctoral levels. Since it was found that computer-based health interventions are a promising tool among educated Arabs, it could be an important strategy for change among the whole Arab population. Future research is necessary to test for applicability in other groups within the general Arab population, who may have lower education levels.

Conclusions

Our findings revealed that a tailored Web-based program may be a promising tool to reduce nargila smoking among Arab university students in Israel. The tailored Web intervention was reported to be feasible, acceptable, relevant, and interesting. Future research is necessary to test for applicability in other groups within the general Arab population of Israel, who may have lower education levels. With the increased use of mobile phone and other mobile technologies today, there is also the need to develop and examine the effectiveness of more advanced technologies.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

CONSORT-EHEALTH checklist V1.6.2 [34].

[PDF File (Adobe PDF File), 995KB - jmir_v17i2e39_app1.pdf]

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Abbreviations

QSIA: Questions Sharing and Interactive Assignments
RCT: randomized controlled trial

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Original Paper

Development of a Twitter-Based Intervention for Smoking Cessation that Encourages High-Quality Social Media Interactions via Automessages

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Abstract

Background: The medical field seeks to use social media to deliver health interventions, for example, to provide low-cost, self-directed, online self-help groups. However, engagement in online groups is often low and the informational content may be poor.

Objective: The specific study aims were to explore if sending automessages to online self-help groups encouraged engagement and to see if overall or specific types of engagement related to abstinence.

Methods: We conducted a Stage I Early Therapy Development Trial of a novel social media intervention for smoking cessation called Tweet2Quit that was delivered online over closed, 20-person quit-smoking groups on Twitter in 100 days. Social media such as Twitter traditionally involves non-directed peer-to-peer exchanges, but our hybrid social media intervention sought to increase and direct such exchanges by sending out two types of autocommunications daily: (1) an “automessage” that encouraged group discussion on an evidence-based cessation-related or community-building topic, and (2) individualized “autofeedback” to each participant on their past 24-hour tweeting. The intervention was purposefully designed without an expert group facilitator and with full automation to ensure low cost, easy implementation, and broad scalability. This purely Web-based trial examined two online quit-smoking groups with 20 members each. Participants were adult smokers who were interested in quitting and were recruited using Google AdWords. Participants’ tweets were counted and content coded, distinguishing between responses to the intervention’s automessages and spontaneous tweets. In addition, smoking abstinence was assessed at 7 days, 30 days, and 60 days post quit date. Statistical models assessed how tweeting related to abstinence.

Results: Combining the two groups, 78% (31/40) of the members sent at least one tweet; and on average, each member sent 72 tweets during the 100-day period. The automessage-suggested discussion topics and participants’ responses to those daily automessages were related in terms of their content (r=.75, P=.012). Responses to automessages contributed 22.78% (653/2867) of the total tweets; 77.22% (2214/2867) were spontaneous. Overall tweeting related only marginally to abstinence (OR 1.03, P=.086). However, specific tweet content related to abstinence including tweets about setting of a quit date or use of nicotine patches (OR 1.52, P=.024), countering of roadblocks to quitting (OR 1.76, P=.008) and expressions of confidence about quitting (OR 1.71, SE 0.42, P=.032). Questionable, that is, non-evidence-based, information about quitting did not relate to abstinence (OR 1.12, P=.278).

Conclusions: A hybrid social media intervention that combines traditional online social support with daily automessages appears to hold promise for smoking cessation. This hybrid approach capitalizes on social media's spontaneous real-time peer-to-peer exchanges but supplements this with daily automessages that group members respond to, bolstering and sustaining the social network and directing the information content. Highly engaging, this approach should be studied further.

Trial Registration: Clinicaltrials.gov NCT01602536; https://clinicaltrials.gov/ct2/show/NCT01602536 (Archived by WebCite at http://www.webcitation.org/6WGbt0o1K)

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KEYWORDS

smoking cessation; social media; text messaging

Introduction

The medical field is increasingly interested in using social media such as Facebook and Twitter for delivering health interventions, including interventions that involve peer-to-peer social support and information exchange such as online self-help groups [1]. Social media holds promise for delivering health interventions because it is popular; 73% of online adults reportedly use social media with 42% using multiple sites and often daily [2]. Also, social media is virtually free to users, interactive, and accessible 24-7 to anyone with a mobile phone, tablet, or computer connected to the Internet.

Twitter seems especially promising for facilitating online self-help groups because it allows users to send short messages or "tweets" of up to 140 characters instantly to multiple others and to receive immediate feedback from one or many. Moreover, private Twitter groups can be set up in which all members, and only members, can simultaneously see and reply to the posts. Group members can post photographs further encouraging intimate relationships and online communities to form [3,4].

In addition, Twitter's user-friendly application programming interface (API) facilitates health care and research applications. Software programs written for Twitter can send out "autocommunications" or pre-scheduled automatically delivered communications as Twitter posts, or alternatively as mobile texts or emails. Other programs written for Twitter can download past tweets into searchable databases, and all of this has substantial utility for supporting and understanding health behavior change. As a result, there is an abundance of health and medical applications of Twitter [1].

Nevertheless, there are concerns about using social media-based health interventions on Twitter or elsewhere. An overriding concern is that engagement or interactivity may be low [5-8]. For example, though millions of people use health forums to obtain health information, most users do not post frequently or continually and so effects on health outcomes have been modest [6]. However, people who actively engage online often do benefit [9,10]. Thus the underlying problem seems to be low engagement [11], which is potentially correctable by finding mechanisms to increase engagement [4,11]. For instance, sending daily automessages to online self-help groups that suggest group discussion topics might possibly trigger engagement.

Another concern about using social media for health interventions and especially for online self-help groups is that peer-to-peer postings may be of poor quality, for example, inconsistent with clinical practice guidelines [12,13]. In fact, many studies have documented questionable postings [14,15]. For instance, a study of Twitter accounts identified using the search criteria of "quit or stop smoking" found a preponderance of use by bloggers to promote non-evidence-based cessation products such as e-cigarettes, herbs, and lasers [14]. Sending daily automessages to online self-help groups might also possibly help with the problem of non-evidence-based content, by directing the information content toward evidence-based topics.

The current research builds on past studies of one-way automessage-based health interventions, that is, interventions involving text or email messages created by health experts that are automatically sent out to individual recipients via computers on fixed schedules to encourage health behaviors. Several initial studies indicated that automessage interventions were effective for smoking cessation [16-20], but a recent review found that just three of 15 randomized trials of automessage-based smoking cessation interventions demonstrated a significant improvement over control [21]. Sending daily automessages to online quit-smoking groups that encourage evidence-based information exchange and social support might possibly increase intervention efficacy, and so our study takes a first look at this.

The current research involved a Stage I Early Therapy Developmental Trial [22] of a novel social media-based intervention for smoking cessation called Tweet2Quit. This was a hybrid social media intervention because traditional social media like Twitter is characterized by non-directed peer-to-peer exchanges, and we sought to encourage and direct such exchanges with our daily autocommunications. Using automated software programs that ran off our study website, we sent out daily automessages to bolster and sustain the peer-to-peer exchanges and to encourage evidence-based discussion topics, and we sent out daily individualized autofeedback on prior-day tweeting.

Consistent with the call for N-of-1 or small-scale trials that target discrete but significant questions for advancing mHealth interventions [23,24], this initial trial tested the Tweet2Quit intervention in two pilot groups of 20 members each. To assess the possible social media-based behavior change mechanisms, we coded participants' tweets on two dimensions: (1) whether or not the tweet was an automessage-generated response, that is, a response to an intervention automessage, and (2) the specific content of the tweet. To examine the potential merits of our hybrid approach of combining peer support with automessages, we formulated two specific research aims: (1) to explore whether the automessages encouraged engagement, that is, tweeting, and (2) to assess if overall engagement or specific types of engagement were related to abstinence. Due to the nonrandomized treatment-only research design, statistical models were used that included three participant-level covariates that have been found to relate to abstinence success in the literature: education [25-28], gender [26,29], and baseline cigarettes per day [27,30,31].

Methods

Overview

We conducted a developmental trial of the Tweet2Quit intervention by setting up two consecutive online quit-smoking groups with 20 adult smokers per group (total N=40). Recruitment, screening, informed consent, assessments (baseline, 7, 30, and 60 days), and intervention delivery all occurred online. The research took place in 2012 with approval and oversight from the Institutional Review Boards of the three sponsoring US universities. As a main function of the developmental trial, in Group 1 we identified improvements in participant screening, intervention delivery, and assessment methods that we implemented in Group 2.

Twitter-Based Intervention

Tweet2Quit was delivered using closed, 20-person, 100-day peer-to-peer Twitter support groups. The decision to include 20 smokers in each group was based on research indicating that a typical virtual social network has about 17-20 active participants [32-34]. The intervention combined (1) a daily “automessage” that appeared as a Twitter post and posed a question to encourage a group-level discussion on an evidence-based cessation-related topic [12,13] or community-building topic [3,4], and (2) daily individualized “autofeedback” that either praised engagement or encouraged more engagement based on past 24-hour tweeting.

The intervention was purposefully developed without an expert group moderator in order to be low cost, fully automated, completely scalable, real-time, and peer-to-peer. We selected Twitter as the social media platform over Facebook because it was easier to keep posts private, that is, within the group, relative to Facebook and also because the Twitter programming language is superior. We set up the groups to be private to ensure confidentiality. That is, we set up each group member to follow and be followed exclusively by the other members, and we instructed members not to let others join.

Twitter Set-Up

We created new email and Twitter accounts for the study participants because this allowed us to access the accounts if a participant’s tweeting behavior became problematic, although this never occurred. Participants provided their own preferred usernames and passwords. We sent participants simple instructions to set up their mobile phones to send and receive texts from Twitter because this required physical access to their phones. We encouraged participants to post a photo or image for personalization of their Twitter account. Most importantly, we encouraged participants to tweet their group daily, reiterating this multiple times during recruitment, screening, and group assignment, and in the daily autocommunications. Participants often directed their tweets to one or more specific group members using the @ sign, and over time numerous social dyads and triplets formed (CM Lakon et al, unpublished data, 2015), but Twitter automatically sent every tweet simultaneously to all group members ensuring their full access to all posts at all times.

Intervention Autocommunications

A novel part of the intervention was the development of daily automessages suggesting discussion topics that were posed as questions to prompt tweeting. The automessages were sent out mechanically from the study website using a Twitter-based software program. The messages came from an account labeled “smokingcessat” and were posted as tweets, that is, they appeared on the group’s Twitter feed. Most of the automessages encouraged discussions that were consistent with clinical practice guidelines for smoking cessation [12,13] and referred to the functional, emotional, and/or self-identity benefits of quitting smoking [35,36]. Additional automessages promoted group bonding, that is, online community formation [3,4]. As a main function of our developmental trial, based on our initial learnings, we increased the number and improved the timing of the automessages from Group 1 to Group 2.

Table 1 summarizes the complete set of 100 automessages that were used in Group 2. A similar or representative subset of these automessages, totaling 58, was used in Group 1. The automessages encouraged participants to share their smoking histories or other personal information (23%), identify rewards for quitting (19%), counter roadblocks to quitting (13%), identify roadblocks to quitting (9%), express emotional support for quitting (9%), set a quit date or use nicotine patches (6%), or express confidence about quitting (5%). Some of the automessages asked about the intervention (16%) at the intervention end.

Table 1. Automessage topics versus automessage-generated tweets[a].

Automessage topics	Verbatim examples	Main benefit to participants	Percent of automessages (N=100), % (n)	Percent of automessage-generated tweets (N=653), % (n)
Sharing of smoking histories or other personal information	How many years did you smoke?	Self-identity	23.0 (23)	38.0 (248)
Identification of rewards for quitting	How do you reward yourself for being a nonsmoker each day?	Emotional	19.0 (19)	18.1 (118)
Countering of roadblocks to quitting	What will you do when you feel the urge to smoke?	Functional	13.0 (13)	3.1 (20)
Identification of roadblocks to quitting	What activities, responsibilities, tasks, or people were or are the biggest triggers for you to smoke?	Functional	9.0 (9)	8.0 (52)
Expressions of emotional support for quitting	Many of you have quit smoking for an entire month! Congratulations! How does it feel?	Emotional	9.0 (9)	3.0 (19)
Setting of a quit date or use of nicotine patches	How do you remind yourself to put on a new patch each day?	Functional	6.0 (6)	2.0 (13)
Expressions of confidence about quitting	Do you feel confident that you are now a nonsmoker?	Self-identity	5.0 (5)	6.0 (39)

[a] 16.0% (16/100) of automessages asked about the intervention, eliciting 11.0% (72/653) of automessage-generated tweets. No automessages asked for questionable information about quitting or assertions of abstinence but, of the tweets coded as automessage-generated due to their timing, 6.0% (39/653) and 5.1% (33/653) were coded as containing such content, respectively.

Group 1 received daily automessages for the first 30 days followed by automessages 3x/week for 70 days, and these automessages were sent out at nighttime (12 a.m. Pacific, 3 a.m. Eastern) to stimulate a response the next morning. Analyses, however, indicated that the nighttime automessage timing was suboptimal because there were no spikes in tweeting the next morning (details below), and so the timing was changed. Furthermore, when Group 1's automessages were reduced to 3x/week, their tweeting declined markedly. Thus Group 2 received one automessage per day for the full 100 days, and these automessages were sent out in the evening (5 p.m. Pacific, 8 p.m. Eastern) to stimulate an immediate response.

Intervention Autofeedback Sent via Twitter

To further encourage engagement, each morning for 100 days (9 a.m. Pacific, 12 p.m. Eastern), participants received daily autofeedback on their prior 24-hour tweeting behavior from the study website. A Twitter-based software program automatically downloaded the tweets every night, identified tweeters and non-tweeters, and sent prewritten autofeedback praising tweeters for engaging and encouraging non-tweeters to engage using varied wording. In Group 1, the autofeedback was posted on the group's Twitter feed, but we learned that many participants were not logging onto Twitter and so they were not receiving the autofeedback. Hence in Group 2, the autofeedback was sent out as texts to each participant's mobile phone to reach those not logged onto Twitter. We had initially planned to cease all autocommunications at 60 days when the free nicotine patches and abstinence surveys ended. However, many of the Group 1 participants kept tweeting past 60 days, and so we continued the autocommunications through day 100 in both groups.

Nicotine Patches and Quit Date

Each participant was mailed an 8-week supply of nicotine patches that was dosed per the baseline smoking level (starting with 14 mg patches if <10 cigarettes/day and 21 mg patches if >10 cigarettes/day). Participants were instructed to initiate patch use on their quit date. Clinical practice guidelines recommend combined pharmacological and behavioral treatment to address the physiological and psychological components of nicotine addiction in regular daily smokers [13].

In addition, participants were referred to the National Institutes of Health online quit-smoking guide to develop a quit plan and were instructed to set a quit date and initiate patch use on their quit date. Group 1 participants were instructed to set a quit date that was within 14 days of intervention start based on clinical practice guidelines [13]. We found, however, that those who delayed setting a quit date until the second week also delayed engaging with the group and were marginalized by the group. Thus for Group 2, the quit window was reduced to within 7 days of intervention start.

Sample Recruitment and Screening

Smokers were recruited using Google AdWords and a US $2,000/month pro bono ad budget provided by the Bonnie J. Addario Lung Cancer Foundation. When a person typed a cessation keyword into a Google search (eg, nicotine patches, quit smoking), a study ad appeared if our automated ad bid (maximum of $2/keyword) exceeded competing bids. The Google ads linked to the Tweet2Quit website that provided study information and a brief application form. Recruitment took about 4 months per group.

Applicants were contacted by email about 1 month prior to study start and given a link to the screening survey that also included the informed consent form. Exclusion criteria included contraindications to nicotine patch use; active prescription medicine for depression, anxiety, or quitting smoking; use of an illicit hard drug in the past 4 weeks; or residency with another participant. The inclusion criteria were smoked 100+ cigarettes in one's lifetime, currently smoking 5+ cigarettes per day, intending to quit in the next month, aged 18-59, English speaking, and continental US resident with an active email account, mobile phone with Internet access and unlimited texting, and weekly texting. For Group 2, daily Facebook use was added as an inclusion criterion because this related significantly to Group 1 participants' tweeting volume. Also for Group 2, daily marijuana use was added as an exclusion criterion because a Group 1 member reported using marijuana daily to avoid tobacco and recommended this to others.

Survey Measures

The baseline survey assessed participants' age, gender, ethnicity, marital status, education, and smoking history, and it included the Fagerstrom Test of Nicotine Dependence [37]. The primary outcome, smoking abstinence, was assessed at 7, 30, and 60 days after the quit date that participants had recorded on the study website. In both groups, 25% (10/40) of participants chose day 1 as their quit date while 75% (30/40) chose a later date. Three participants, all from Group 1, failed to enter a quit date and were given the last possible date.

At each assessment point, abstinence was measured using two standard self-report questions about 7-day point prevalence smoking: "How many cigarettes have you smoked in the past 7 days?" and "Have you puffed on a cigarette within the past 7 days?" Any smoking or puffing was recorded as non-abstinent. Non-responses were recorded as missing. As a secondary outcome and an indicator of treatment adherence, we also measured participants' nicotine patch use (yes/no). We measured this for the past week at the 7-day follow-up, and for the past month at the 30-day and 60-day follow-ups. Non-responses were recorded as missing.

In Group 1, the follow-up assessments were conducted via emailed links to online surveys, but response rates were lower than expected: 60%, 65%, and 60% at 7, 30, and 60 days post quit date, respectively. So for Group 2, we also sent texts and called by phone to obtain the survey responses, and response rates improved to 95%, 90% and 80%, respectively.

Tweeting Measures

The groups' tweets for each day were automatically downloaded to an Excel database using another Twitter software program, and we assessed tweeting volume, content, and timing as secondary outcomes. The database contained a separate record for each tweet that showed the verbatim message sent, the sender's username, each recipient's username if designated (eg, by @), and the date and time. We then summed the tweets by group, participant, week of study, and time of day. We also recorded whether each participant tweeted at least once and continued tweeting past day 30.

Furthermore, the tweets were content coded based on the discussion topics that were posed in the automessages and based on other common discussion topics as reflected in the tweets. A codebook was created with 15 mutually exclusive and collectively exhaustive content codes, and each tweet received a single code (see Table 2). Furthermore, the tweets were coded to indicate whether they were in response to an automessage or spontaneous. Automessage-generated responses or tweets were identified based on whether the tweet was addressed to the account "smokingcessat" that sent the automessage and/or occurred shortly after the automessage was sent and was associated with the question posed. All other tweets were coded as spontaneous.

Two trained research assistants independently coded the tweets. For the tweet content coding, the kappa or intercoder reliability was .94 for Group 1 (95% CI 0.93-0.96) and .80 for Group 2 (95% CI 0.78-0.82). For the coding of automessage-generated versus spontaneous tweets, the kappa was .86 for Group 1 (95% CI 0.79-0.94) and .91 for Group 2 (95% CI 0.88-0.93).

Table 2. Total tweets and spontaneous tweets by topic and abstinence[a].

Overall tweet topics	Verbatim examples	Main benefit	Total tweets (N=2867), % (n)	Spontaneous tweets (N=2214, 77%), % (n)	Relationship between total tweets and abstinence	
					OR (SE)	*P* value
Sharing of smoking histories or other personal information	I'm a mom of 4, just got married a month ago	Self-identity	24.00 (688)	20.01 (443)	1.08 (0.07)	.237
Expressions of emotional support for quitting	Day 2 for you? Hang in there...it gets easier!!	Emotional	22.01 (631)	28.00 (620)	1.04 (0.03)	.156
Assertions of abstinence	@jenjencan I have been 32 hours without it after the last 18years!!!!	Self-identity	12.00 (344)	14.00 (310)	1.17 (0.09)	.031
Identification of roadblocks to quitting	Anyone else smoke when they drive alone? I have a 30-55 min commute each way to work, usually smoke 2x b4 arrival. Ideas to fight the urge?	Functional	10.01 (287)	10.00 (221)	1.02 (0.08)	.754
Identification of rewards for quitting	My goal after quitting in playing in local tennis tournament and hope i make it past first round.	Emotional	8.00 (229)	5.01 (111)	1.26 (0.16)	.065
Sharing of questionable information about quitting	each time i want to grab for a smoke i eat a single piece of candy	Emotional	6.00 (172)	6.01 (133)	1.12 (0.11)	.278
Setting of a quit date or use of nicotine patches	Set my date for 1/21	Functional	4.01 (115)	5.01 (111)	1.52 (0.28)	.024
Countering of roadblocks to quitting	I'm doing yoga and chewing straws to cope, what is everyone else doing?	Functional	3.00 (86)	2.98 (66)	1.76 (0.37)	.008
Expressions of confidence about quitting	I quit once before so I'm counting on doing it again	Self-identity	3.00 (86)	2.98 (66)	1.71 (0.42)	.032

[a] Miscellaneous topics comprised 8.00% (229/2867) of total tweets and 6.01% (133/2214) of spontaneous tweets and included positive evaluations of the intervention (3.00% (86/2867), eg, It's good to know there is a group of people going thru it w/me); reporting of stressful life events (eg, Have a cold. Chest hurts a lot); mentions of another's support of the quit (eg, Oh and my hubby is still smoke free too! We're both on day 10); negative evaluations of the intervention (eg, I dunno how this Twitter stuff works); reporting of non-abstinence (eg, I'm still not all the way a non smoker. I've had a few this week); and other, each at about 1.01% (29/2867).

Analyses

Models using generalized estimating equations (GEE; Proc Genmod, SAS v9.3) were run to assess the group effects (Group 1 versus 2) on abstinence status and nicotine patch use over time, after accounting for the clustering of participants within group, the time period (7, 30, or 60 days post quit date), and three participant-level covariates that the literature has identified as relating to abstinence success: education [25-28], gender [26,29], and baseline cigarettes per day [27,30,31]. We used similar models to assess the group effects on tweeting.

Additional models using GEE were run to assess how tweet volume, tweet content, and nicotine patch use related to abstinence status over time, after accounting for the effects of group, participants clustered within group, time period, and the three participant-level covariates. Separate models were estimated for total tweets, automessage-generated tweets, spontaneous tweets, each of the nine most common tweet types based on total tweets, and nicotine patch use. Abstinence at 7, 30, and 60 days post quit date was modeled as a function of the number of tweets of each type during the applicable time period (0-7 days, 8-30 days, and 31-60 days, respectively); thus, we used only the 2460 total tweets sent through day 60, which included 2023 spontaneous tweets (82.24%) and 437 automessage-generated tweets (17.76%).

Results

Participant Screening

Of the 813 smokers who completed the brief application form in response to our Google ads, 106 (13.0%) went on to complete the screening survey, and 45 of those (42.5%) met the eligibility criteria. The first 40 were chosen, and the other 5 were waitlisted. Ineligibility mostly occurred due to failure to complete the screening survey (21%), less than daily Facebook use (21%, Group 2), a phone that lacked Internet access (19%), lack of an unlimited texting plan (12%), smoking fewer than 5 cigarettes per day (12%), or texting less than weekly (10%). The eligibility rate was unrelated to gender or age but was higher for Caucasians (47%) than African Americans and Asian Americans (28%) and no Hispanics took the screener in this developmental trial.

Participant Demographics and Smoking Histories

Participants averaged 36.5 years of age (SD 9.5, range 20-57), were 60% female, 95% Caucasian, 58% married or partnered, and 43% with a college degree. On average at baseline, participants smoked 15.5 cigarettes per day, had smoked for 18 years, and had a Fagerstrom nicotine dependency score of 4.9 indicating medium dependency [37]. The groups did not differ on any of these baseline variables (*P*=.187 to *P*=.667) except that Group 1 smoked marginally more cigarettes per day at baseline than Group 2 (mean 18.0 versus 13.0, *P*=.086), and thus cigarettes per day was included as a participant-level covariate in all models.

Abstinence by Group

At 7, 30, and 60 days post quit date, Group 1's abstinence rates were 50%, 57%, and 42% respectively; while Group 2's abstinence rates were 21%, 61%, and 75% (*P*=.813). At the same time points, Group 1's nicotine patch use rates were 67%, 50%, and 50% respectively, while Group 2's use rates were significantly higher at 82%, 100%, and 42% (*P*=.019). In sum, the groups did not differ significantly on abstinence; however, Group 2 participants were more likely to use the study-provided nicotine patches.

Tweeting by Group

Across the two groups, the total tweet volume was 2867 or an average of 72 tweets per group member; also 78% of the group members tweeted at least once. Automessages generated 22.78% (653) of the tweets, while the remaining 77.22% (2214) of the tweets were spontaneous. Figures 1 and 2 show tweeting volume and duration by group and participant. Group 1 sent 1125 total tweets or an average of 56 tweets per member, while Group 2 sent 1742 total tweets or an average of 87 tweets per member (*P*=.355). Also 70% of Group 1 members and 85% of Group 2 members tweeted at last once (*P*=.121), and 45% of Group 1 members and 75% of Group 2 members continued tweeting past 30 days (*P*=.144). The groups differed significantly only in terms of their responses to the intervention automessages. Group 1 sent 51 automessage-generated responses or an average of 2.6 per member, while Group 2 sent 602 automessage-generated responses or an average of 30.1 per member (*P*<.001). This indicates that the developmental improvements made to the automessaging for Group 2 may have helped to increase responding to the automessaging.

The groups were also compared on whether they showed spikes in tweeting that corresponded to the times when they were sent automessages and/or autofeedback (Figures 3 and 4). Group 1 members were sent automessages at 12 a.m. (midnight) Pacific, and autofeedback at 9 a.m. Pacific via Twitter, and they showed no time-related tweet spikes. In contrast, Group 2 members were sent automessages at 5 p.m. Pacific so that they could immediately respond, and they were sent autofeedback at 9 a.m. Pacific via text with no Twitter login required. Correspondingly, Group 2 showed tweet spikes after they were sent autofeedback and more markedly after they were sent automessages suggesting discussion topics.

Figure 1. Tweeting volume and duration in Group 1.

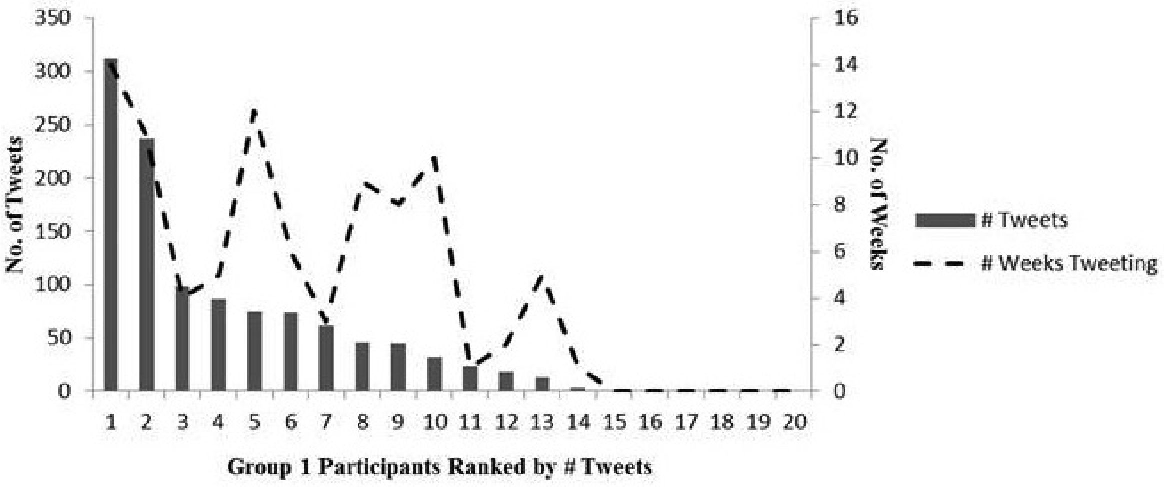


Figure 2. Tweeting volume and duration in Group 2.

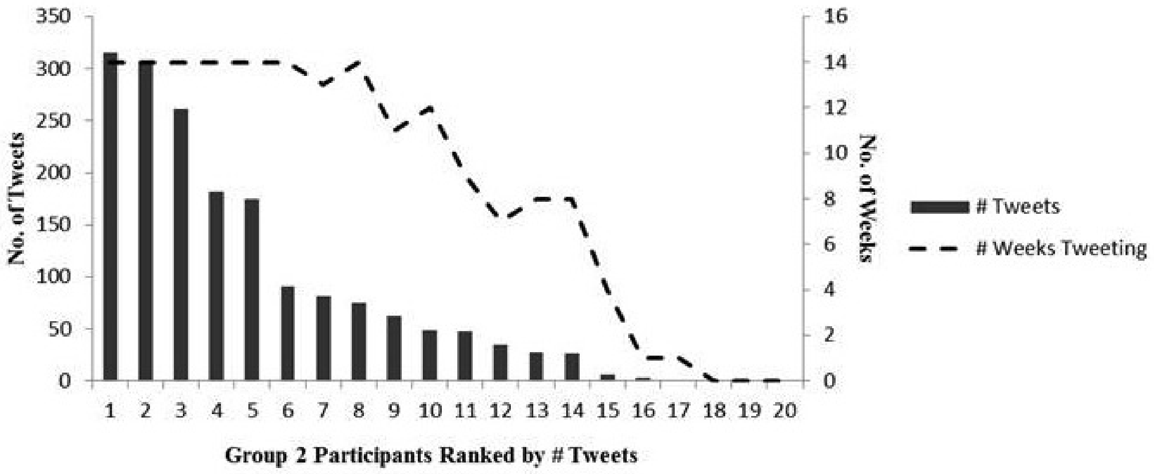


Figure 3. Tweeting by time of day in Group 1.

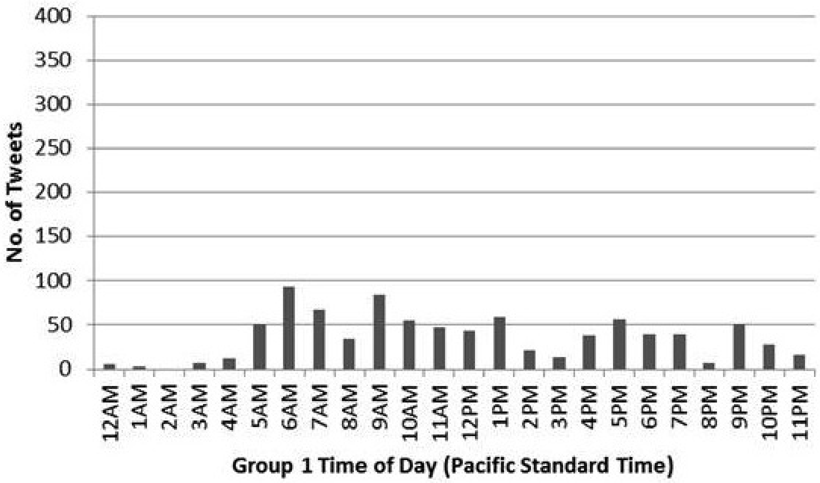
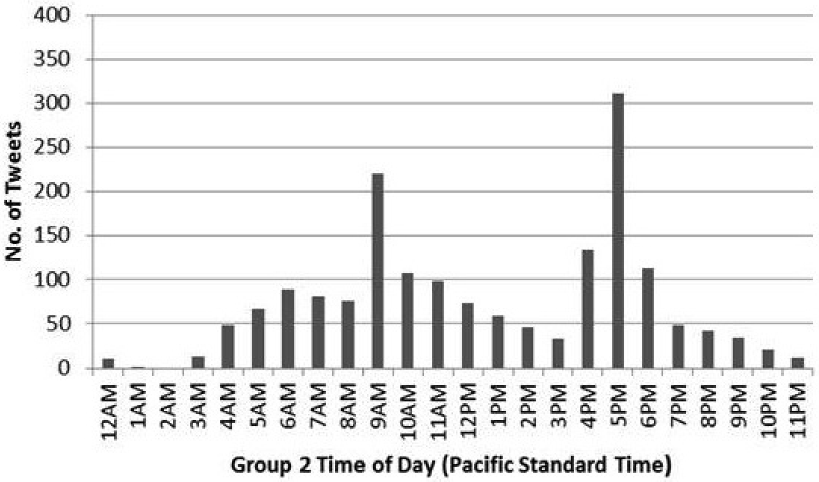


Figure 4. Tweeting by time of day in Group 2.



Content of Automessages and Automessage-Generated Responses

The automessages and automessage-generated responses were significantly correlated in terms of their content (*r*=.75, *P*=.012; Table 1). Looking at the automessage-generated responses, participants primarily shared smoking histories or other personal information (38%), identified rewards for quitting (18%), identified roadblocks to quitting (8%), or expressed confidence about quitting (6%). Also 11% of the automessage-generated responses discussed the intervention because so prompted.

Of the tweets that were coded as automessage-generated due to their timing, 6% provided questionable information about quitting (ie, non–evidence-based) and 5% asserted abstinence. This content was not prompted. Most of the questionable information about quitting mentioned using marijuana, e-cigarettes, candy, or food as a substitute for smoking rather than evidence-based substitutes such as exercise or relaxation.

Content of Total Tweets

Total tweets and spontaneous tweets were highly correlated in terms of their content (*r*=.94, *P*<.001), that is, in terms of the number of tweets corresponding to each content code. Total tweets and automessage-generated tweets were less correlated (*r*=.57, *P*=.083), and spontaneous tweets and automessage-generated tweets were least correlated (*r*=.27, *P*=.444). Also, total tweets in Group 1 and Group 2 were highly correlated (*r*=.96, *P*<.001).

Prevalent content in the total tweets (Table 2) included sharing smoking histories or other personal information (24%), expressing emotional support for quitting (22%), asserting abstinence (12%), identifying roadblocks to quitting (10%), identifying rewards for quitting (8%), sharing questionable information about quitting (6%), or setting a quit date or using nicotine patches (4%). In effect, about 172 of the 2867 tweets contained questionable information about quitting (6.00%).

Relationships Between Tweeting and Abstinence

In the models relating tweeting to abstinence, there were no group effects (*P*s>.420), but on the participant-level covariates, men were more likely to be abstinent (*P*s<.014). However, tests of treatment engagement by gender were all nonsignificant: men were not more likely than women to tweet, to tweet more, or to use the nicotine patch (*P*s>.500).

Abstinence related only marginally to overall tweet volume (OR 1.03, *P*=.086). Associations between abstinence and spontaneous tweet volume (OR 1.03, SE 0.02, *P*=.108) and automessage-generated tweet volume (OR 1.09, SE 0.08, *P*=.230) were not significant. Abstinence, however, was significantly related to sending tweets with this specific content (Table 2): assertions of abstinence (OR 1.17, SE 0.09, *P*=.031), setting of a quit date or use of nicotine patches (OR 1.52, SE 0.28, *P*=.024), countering of roadblocks to quitting (OR 1.76, SE 0.37, *P*=.008), and expressions of confidence about quitting (OR 1.71, SE 0.42, *P*=.032). Sending tweets about identifying rewards for quitting related only marginally to abstinence (OR 1.26, SE 0.16, *P*=.065).

Sending tweets with the following content did not relate to abstinence: sharing of smoking histories or other personal information (OR 1.08, SE 0.07, *P*=.237), expressions of emotional support for quitting (OR 1.04, SE 0.03, *P*=.156), identification of roadblocks to quitting (OR 1.02, SE 0.08, *P*=.754), or sharing of questionable information about quitting that was non–evidence-based (OR 1.12, SE 0.11, *P*=.278). Finally, nicotine patch use was unrelated to abstinence (OR 1.33, SE 0.66, *P*=.560).

Discussion

Principal Findings

In this developmental trial, we studied a novel, low-cost, fully automated social media-based smoking cessation intervention called Tweet2Quit. The intervention contained these components: smokers who were ready to quit were recruited online; they were placed in 100-day, 20-person, peer-to-peer Twitter support groups that were autonomous with no expert monitor; they were given free nicotine patches; and they were sent daily automessages suggesting discussion topics for tweeting and daily autofeedback on their prior day tweeting. This hybrid intervention combined the traditional social media approach of spontaneous, real-time, peer-to-peer social support with daily automessages that encouraged discussions consistent with guidelines for smoking cessation [12,13] and online community building [3,4].

Our first specific study aim was to explore if the automessages encouraged engagement and the findings look promising. Overall engagement in the intervention was high with 78% of the group members sending at least one tweet and each member sending an average of 72 tweets. Also 23% of the tweets were in response to the intervention's automessages. Furthermore, when we improved the automessaging for Group 2 participants by increasing its frequency and improving its timing, automessage-generated responses rose significantly and we observed tweeting spikes corresponding to when the automessages were delivered. Moreover, the content of the automessages correlated with the content of the automessage-generated responses, indicating that the automessages largely produced the desired content. However, a randomized controlled trial is needed to study intervention efficacy.

Our second specific study aim was to assess whether overall engagement with the intervention or specific types of engagement were associated with abstinence. We found that the volume of overall tweets was only marginally related to the tweeter's abstinence. However, the following specific types of tweets related significantly to the tweeter's abstinence: countering of roadblocks to quitting, setting of a quit date or use of nicotine patches, expressions of confidence about quitting, and assertions of abstinence. Also identification of rewards for quitting was marginally related to abstinence.

Due to the correlational nature of our research, we cannot ascertain if specific types of tweets promoted abstinence; instead, perhaps abstinence elicited the tweeting. Nevertheless, it appears that automessages sent to online quit-smoking groups should try to encourage thinking and discussions on setting quit dates, using nicotine patches, countering roadblocks to quitting, building confidence about quitting, and identifying rewards for quitting. In our study, tweets that merely identified roadblocks to quitting were unrelated to abstinence, so it seems automessages should encourage participants to identify and counter roadblocks simultaneously.

In our study, expressions of emotional support for quitting (eg, “we can do this”) and the sharing of smoking histories or other personal information were unrelated to the tweeter’s abstinence; yet, these tweets may have promoted online community building [3,4]. Finally, we found that tweets conveying questionable or non-evidence-based information about quitting, for example, use of marijuana, e-cigarettes, or candy as substitutes for cigarettes, were in the minority (6%). Furthermore, these tweets were unrelated to the tweeter’s abstinence. Consistent with prior tobacco treatment studies [26,29], men were found to have higher rates of abstinence than women, and this appeared unrelated to treatment engagement. More research is needed to better understand gender differences in success with quitting smoking.

Strengths and Limitations

This development trial was an important first step in exploring the utility of Twitter-based social support groups combined with automessages to promote smoking cessation. Limited by the nonrandomized treatment-only design, a randomized controlled trial is now needed. Also, our sample was small and primarily Caucasian. Although recruitment via Google was broad-based, offering nicotine patches as an incentive may have been more attractive to non-Hispanic Caucasian smokers given research that minorities are less likely to use patches [38,39]. Future research should test other approaches for engaging a more diverse group of smokers. Another study limitation was the reliance on self-reported abstinence, and so future research should test for bioconfirmation of abstinence, although the demand characteristics for false reporting of abstinence were likely low in our study due to the anonymity in the groups. Last, there were correlations among tweets addressing different content, making it difficult to fully assess the unique relationship between each content and abstinence.

Conclusions

We have developed a hybrid social media–based smoking cessation intervention called Tweet2Quit that combines traditional real-time, peer-to-peer social support and nicotine patch with daily automessages and autofeedback. Engagement was high and the automessages helped ensure that the peer-to-peer discussions were consistent with guidelines for smoking cessation and building online communities. Hence, this novel intervention should be studied further.

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Conflicts of Interest

None declared.

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Original Paper

Short-Term Trajectories of Use of a Caloric-Monitoring Mobile Phone App Among Patients With Type 2 Diabetes Mellitus in a Primary Care Setting

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Abstract

Background: Self-management plays an important role in maintaining good control of diabetes mellitus, and mobile phone interventions have been shown to improve such self-management. The Health Promotion Board of Singapore has created a caloric-monitoring mobile health app, the “interactive Diet and Activity Tracker” (iDAT).

Objective: The objective was to identify and describe short-term (8-week) trajectories of use of the iDAT app among patients with type 2 diabetes mellitus in a primary care setting in Singapore, and identify patient characteristics associated with each trajectory.

Methods: A total of 84 patients with type 2 diabetes mellitus from a public primary care clinic in Singapore who had not previously used the iDAT app were enrolled. The app was demonstrated and patients’ weekly use of the app was monitored over 8 weeks. Weekly use was defined as any record in terms of food entry or exercise workout entry in that week. Information on demographics, diet and exercise motivation, diabetes self-efficacy (Diabetes Empowerment Scale-Short Form), and clinical variables (body mass index, blood pressure, and glycosylated hemoglobin/HbA1c) were collected at baseline. iDAT app use trajectories were delineated using latent-class growth modeling (LCGM). Association of patient characteristics with the trajectories was ascertained using logistic regression analysis.

Results: Three iDAT app use trajectories were observed: Minimal Users (66 out of 84 patients, 78.6%, with either no iDAT use at all or use only in the first 2 weeks), Intermittent-Waning Users (10 out of 84 patients, 11.9%, with occasional weekly use mainly in the first 4 weeks), and Consistent Users (8 out of 84 patients, 9.5%, with weekly use throughout all or most of the 8 weeks). The adjusted odds ratio of being a Consistent User, relative to a Minimal User, was significantly higher for females (OR 19.55, 95% CI 1.78-215.42) and for those with higher exercise motivation scores at baseline (OR 4.89, 95% CI 1.80-13.28). The adjusted odds ratio of being an Intermittent-Waning User relative to a Minimal User was also significantly higher for those with higher exercise motivation scores at baseline (OR 1.82, 95% CI 1.00-3.32).

Conclusions: This study provides insight into the nature and extent of usage of a caloric-monitoring app among patients with type 2 diabetes and managed in primary care. The application of LCGM provides a useful framework for evaluating future app use in other patient populations.

(J Med Internet Res 2015;17(2):e33) doi:10.2196/jmir.3938

KEYWORDS

type 2 diabetes mellitus; self-management; mobile phone; mobile apps; longitudinal studies

Introduction

The prevalence of type 2 diabetes mellitus is expected to rise globally with an increasingly urbanized and aging population [1]. In Singapore, prevalence among adults aged 18-69 years increased from 8.2% in 2004 to 11.3% in 2010 and is expected to continue to rise as the population gets older and more obese [2,3]. Diabetes is a chronic condition that requires patient self-management as well as continual medical care by health care providers. Patients with better self-care behaviors such as adherence to meal recommendations and glucose monitoring have been shown to develop better control of their condition than patients who were given more medications [4].

A meta-analysis of 22 trials attested to the possibility of significant reductions in glycosylated hemoglobin (Hb_{A1c}) levels (mean 0.5%; 95% CI 0.3-0.7) through the self-management of diabetes using mobile phone interaction [5]. In 2012, at 74%, Singapore was the world’s leading country in smartphone penetration and by 2013, smartphone penetration had increased to 78% [6]. In terms of app usage, Singapore is presently 5th in the world at 75% [7]. To leverage the increasing ownership and use of smartphones and apps, the Singapore Health Promotion Board (HPB) created a mobile app called the “interactive Diet and Activity Tracker” (iDAT), which enables users to track daily calories consumed and burned using a database of locally available foods. Although the app is intended for use by anyone whether they have diabetes or not, a healthy diet, exercise, and weight loss or healthy weight maintenance are still the mainstay of first-line therapies for managing diabetes [8]. The iDAT app can function in a supportive role to aid diabetes patients in lifestyle self-management by allowing them to monitor diet and exercise.

Several studies have been conducted on the use of technology and mobile phones in diabetes management, including studies using interventional approaches—as opposed to control—whereby intervention groups received mobile phone reminders or feedback on self-monitoring of glucose levels [9,10]. However, research attempting to understand usage patterns of mobile phone-based interventions has been challenging. A few studies have attempted to assess usage patterns, but in a simplistic manner that provided minimal useful information—descriptions, averages, or tabulation of usage data [9,11]. Comparing predictors and clinical outcomes among diverse usage patterns becomes problematic owing to the difficulty in defining and distinguishing meaningful usage patterns over time.

“Latent-class growth modeling” (LCGM) is a statistical technique that exploits the existence of latent groups of individuals who share similar time trajectories of a particular trait, the characterization of which allows better understanding of the pattern of change in that variable [12,13]. LCGM has been used for some time in criminological and behavioral research, and only more recently in medicine and public health research studies of body mass trajectories in children and adults [14,15]. To our knowledge, LCGM has not been used to analyze app usage patterns in a patient population. In applying this data analysis technique, we aimed to better understand and characterize the nature and extent of technological engagement with a caloric-monitoring mobile health app (iDAT) by type 2 diabetes patients in Singapore’s primary care setting—an app that could be helpful for self-management of their chronic condition.

The primary aim of our study was to assess iDAT app usage in patients with type 2 diabetes. More specifically, our goal was to identify and characterize short-term (8-week) trajectories of use of the iDAT app among patients with type 2 diabetes mellitus in a primary care setting in Singapore and to identify patient characteristics associated with different trajectories.

Methods

Study Design, Site, and Population

The study was conducted at one of the 18 public primary care clinics (polyclinics) located in the northeastern part of Singapore. It is a typical polyclinic, which managed almost 5000 patients with type 2 diabetes in 2013. Patients enrolled for the study had to meet all of the following inclusion criteria: (1) above 21 years of age, (2) type 2 diabetes mellitus diagnosed based on World Health Organization criteria [16], (3) ownership of smartphone that is able to download the iDAT app (ie, Apple iOS or Android platform only), and (4) able to understand and use the iDAT app. Exclusion criteria were patients with (1) significant physical and/or cognitive impairment, (2) type 1 diabetes mellitus, (3) pregnant, or (4) prior use of the iDAT app.

Participants were enrolled over a 5-month period from November 2013 to March 2014. Patients attending the diabetes counselling and screening services for eye and foot complications at the polyclinic were approached. Patients who declined participation, did not feel comfortable using apps, or could not understand English were not recruited (Figure 1). Recruited participants were introduced to the iDAT app and taught how to use it to monitor food intake and physical activity. Personal email addresses were used for app registration, and monitoring of app usage was based on the email address provided. A questionnaire was administered that included demographic questions, scale-based questions evaluating iDAT app usefulness, current diet and exercise, motivation to improve diet, and motivation to exercise (Figure 2). The questionnaire also included an 8-question instrument, the Diabetes Empowerment Scale-Short Form (DES-SF), developed and validated in a group of 239 African American subjects by the Michigan Diabetes Research and Training Center (Figure 3) [17]. This instrument is graded on a score of 1 (low self-efficacy) to 5 (high self-efficacy) and allows for an assessment of patients’ diabetes-related self-efficacy [17]. Patients’ clinical data including height, weight, blood pressure, and Hb_{A1c} were also collected. The questionnaire was primarily self-administered, with assistance from the researcher as needed.

Initially, the plan was to recruit only newly diagnosed patients. But due to slow recruitment and to reach our preliminary target of 80 patients, recruitment was expanded, 3 months into the study, to all patients who otherwise satisfied the inclusion criteria.

Patient use of the iDAT app was monitored weekly over a period of 2 months post-enrollment. There were no financial reimbursements to the patients for study participation. This study was approved by the SingHealth Centralized Institutional Review Board E (CIRB) (Ref: 2013/743/E), in accordance with all applicable regulations, and informed consent was obtained after the nature and possible consequences of the study were explained. Participants were informed when consent was taken and in the Participant Information Sheet that the email addresses used for iDAT registration would be collected and used to track app usage. This personal information, together with the other data collected, were to be kept confidential and only used on a need-to-know basis as approved by the CIRB.

Figure 1. Recruitment and study flowchart.

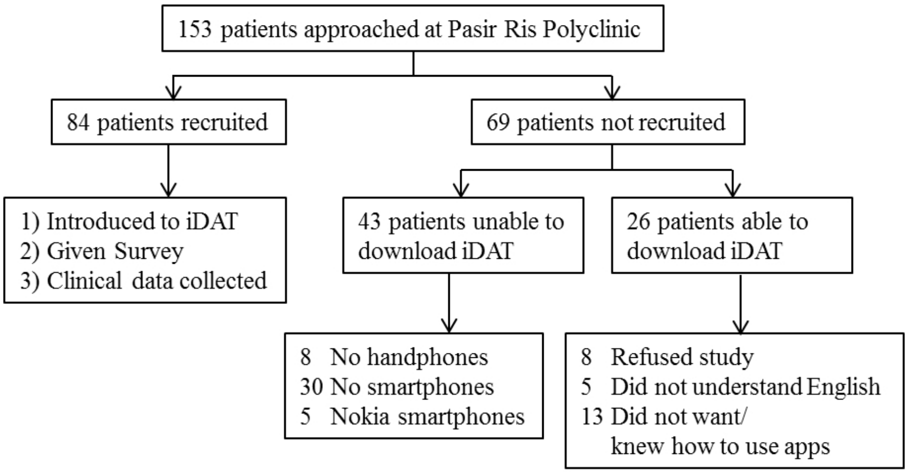
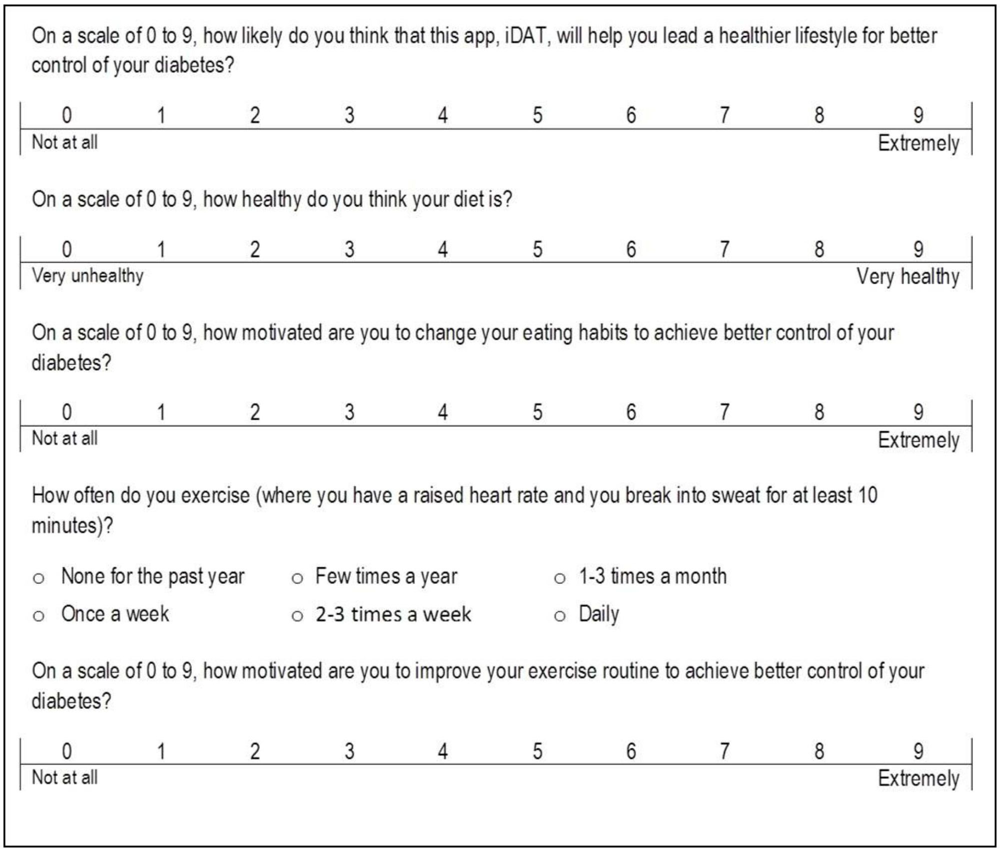


Figure 2. Questions evaluating "interactive Diet and Activity Tracker" (iDAT) app usefulness, current diet and exercise, motivation to improve diet, and motivation to exercise.



On a scale of 0 to 9, how likely do you think that this app, iDAT, will help you lead a healthier lifestyle for better control of your diabetes?

0 1 2 3 4 5 6 7 8 9

Not at all Extremely

On a scale of 0 to 9, how healthy do you think your diet is?

0 1 2 3 4 5 6 7 8 9

Very unhealthy Very healthy

On a scale of 0 to 9, how motivated are you to change your eating habits to achieve better control of your diabetes?

0 1 2 3 4 5 6 7 8 9

Not at all Extremely

How often do you exercise (where you have a raised heart rate and you break into sweat for at least 10 minutes)?

○ None for the past year ○ Few times a year ○ 1-3 times a month

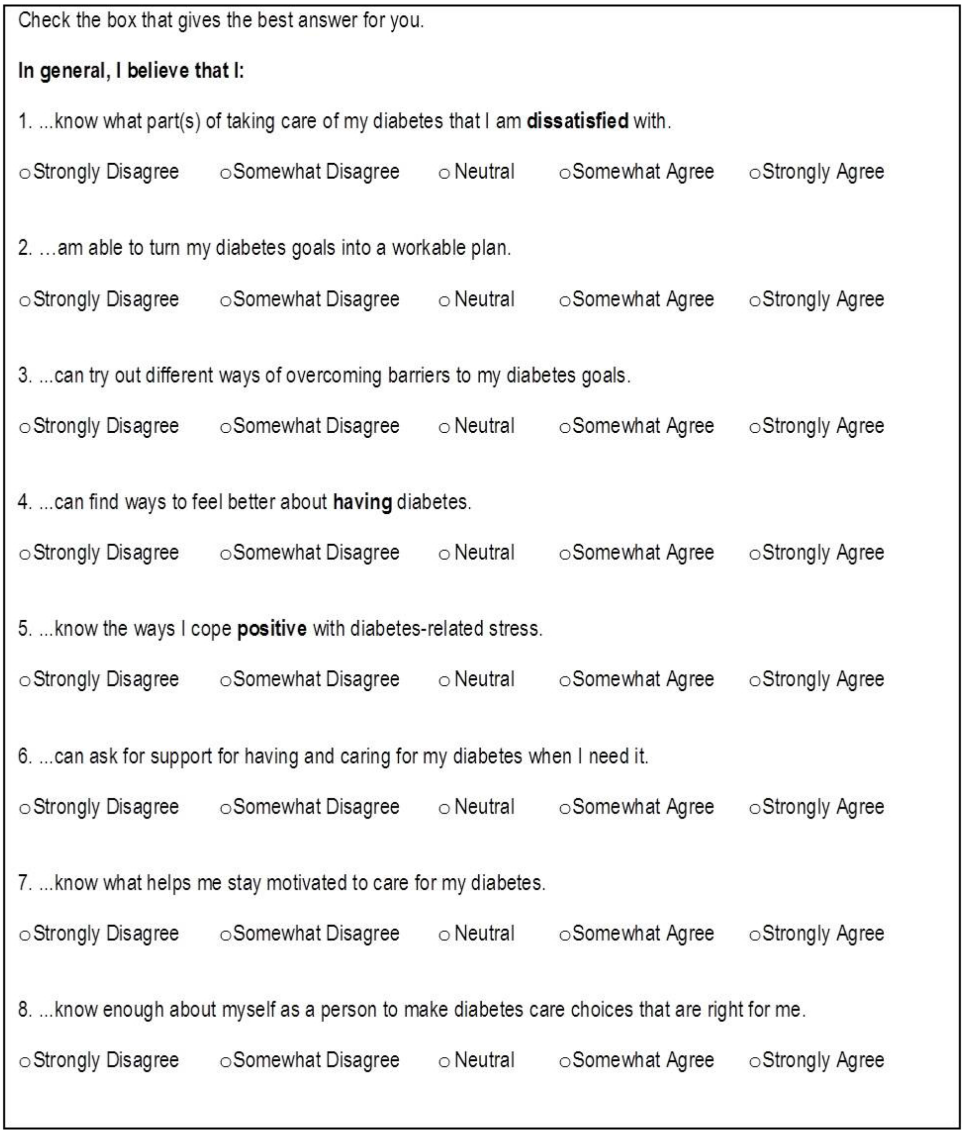
○ Once a week ○ 2-3 times a week ○ Daily

On a scale of 0 to 9, how motivated are you to improve your exercise routine to achieve better control of your diabetes?

0 1 2 3 4 5 6 7 8 9

Not at all Extremely

Figure 3. Diabetes Empowerment Scale-Short Form (DES-SF) questions developed and validated by the Michigan Diabetes Research and Training Center.



Check the box that gives the best answer for you.

In general, I believe that I:

1. ...know what part(s) of taking care of my diabetes that I am **dissatisfied** with.

○Strongly Disagree ○Somewhat Disagree ○ Neutral ○Somewhat Agree ○Strongly Agree

2. …am able to turn my diabetes goals into a workable plan.

○Strongly Disagree ○Somewhat Disagree ○ Neutral ○Somewhat Agree ○Strongly Agree

3. ...can try out different ways of overcoming barriers to my diabetes goals.

○Strongly Disagree ○Somewhat Disagree ○ Neutral ○Somewhat Agree ○Strongly Agree

4. ...can find ways to feel better about **having** diabetes.

○Strongly Disagree ○Somewhat Disagree ○ Neutral ○Somewhat Agree ○Strongly Agree

5. ...know the ways I cope **positive** with diabetes-related stress.

○Strongly Disagree ○Somewhat Disagree ○ Neutral ○Somewhat Agree ○Strongly Agree

6. ...can ask for support for having and caring for my diabetes when I need it.

○Strongly Disagree ○Somewhat Disagree ○ Neutral ○Somewhat Agree ○Strongly Agree

7. ...know what helps me stay motivated to care for my diabetes.

○Strongly Disagree ○Somewhat Disagree ○ Neutral ○Somewhat Agree ○Strongly Agree

8. ...know enough about myself as a person to make diabetes care choices that are right for me.

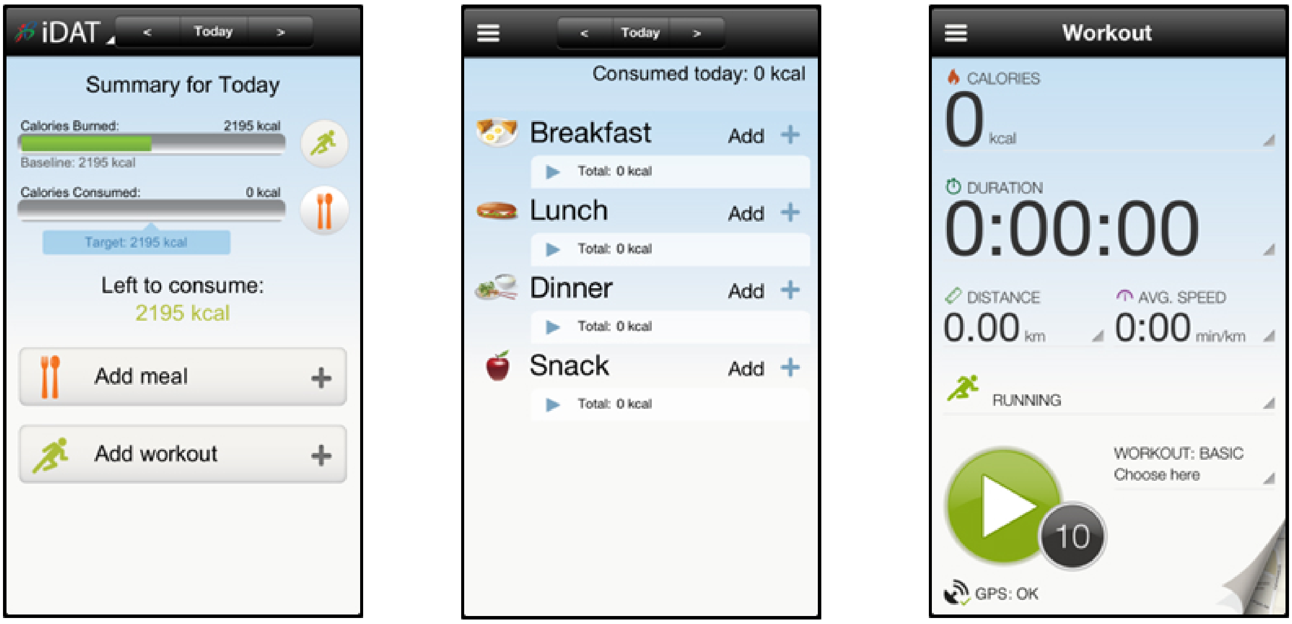
○Strongly Disagree ○Somewhat Disagree ○ Neutral ○Somewhat Agree ○Strongly Agree

iDAT Smartphone App

The iDAT app (Figure 4) was developed by the HPB, a statutory board under the Ministry of Health, Singapore, established to drive national health promotion and disease prevention programs. The iDAT app, though not diabetes-specific, was chosen because it was created for the local Singapore population, is freely and easily available on the two most common smartphone platforms (iOS and Android), targets first-line diabetes management of diet and exercise, and does not require any additional devices like glucometers for patients to fully utilize the app.

The app is free to download through Apple's iTunes/App Store and Android's Google Play. It functions as a calorie counter, helping users to balance calories consumed with calories burned on a daily basis. The "Meal" section allows the user to input food consumed via a food database with their estimated calories, including local ethnic foods. The "Workout" section enables the user to tap on their smartphones' Global Positioning System (GPS) to monitor fitness workouts and calculate estimated calories burned. Workouts can be added manually or by using the app's "Step Counter". Other functions include social features such as Facebook-sharing and a "Weight and Goal" feature that allows users to set a weight loss goal and track weight loss over time.

Figure 4. "interactive Diet and Activity Tracker" (iDAT) screen captures.



Statistical Analysis

Demographic variables and clinical characteristics at baseline were summarized as mean with standard deviation for continuous variables and counts and percentages for categorical variables. HPB provided the iDAT app backend information in the form of weekly use. To summarize this data, any record in terms of food entry or exercise workout entry in a week was considered as usage for that week.

A statistical analysis software (SAS) macro, PROC TRAJ, was used to apply LCGM to analyze weekly iDAT app usage data and to identify the latent groups characterizing the iDAT app use trajectories for the cohort. LCGM uses maximum likelihood to estimate model parameters [18,19]. To determine number of latent trajectory groups and trajectory shapes, multiple factors were considered: model fit statistics (Bayesian Information Criterion/BIC), significance of polynomial terms, and value of average posterior probability with an eye to parsimony in the number of trajectory groups [13,20]. The best-fit-model was chosen based on the magnitude of difference in BIC and the linear/polynomial specification that best defined the trajectory in each group, given the number of groups [18,20]. Each patient was assigned to the trajectory group for which he/she had the highest posterior probability of membership [20]. Subsequently, univariate and multivariate (stepwise) polytomous logistic regression were used to identify demographic features or clinical characteristics predictive of trajectory group membership.

Results

Baseline Characteristics of Recruited Patients

Of 153 patients approached, 84 who consented and satisfied the inclusion/exclusion criteria were enrolled (Figure 1). Demographics, clinical and diabetes-related variables, social lifestyle factors, smartphone characteristics, scores for motivation, and DES-SF at baseline are presented in Table 1. The mean age of the study participants was 48.2 (SD 8.5) years, with a nearly equal gender distribution. In terms of ethnic composition, 54% (45/84) were Chinese, 27% (23/84) Malays, 12% (10/84) Indians, and Other ethnicities make up the remaining 7% (6/84). Most were married (83%, 70/84) and employed (83%, 70/84). The largest group (46%, 39/84) had educational qualification of secondary school or below, followed by diploma (21%, 18/84), degree (20%, 17/84), and post-secondary school education (12%, 10/84). Their mean Body Mass Index (BMI) was 29.1 (SD 6.1) kg/m^2, mean systolic blood pressure was 130.5 (SD 18.5) mmHg, mean diastolic blood pressure was 77.6 (SD 10.9) mmHg, and mean Hb$_{A1c}$level was 8.7 (SD 2.5) %. A minority smoked (15%, 13/84) while 31% (26/84) were regular or social drinkers.

As we prioritized the enrollment of newly diagnosed patients, only 21% (18/84) of the enrolled participants had been diagnosed with diabetes more than a year prior to enrollment. Therefore, most of the participants had “diet only” treatment without medications (31%, 26/84) or were using one diabetes medication but not insulin (42%, 35/84).

When asked to rate how healthy their diet was on a scale of 0-9 (0-very unhealthy and 9-very healthy), the participants reported a mean score of 4.8 (SD 1.9). Their reported exercise frequency ranged from 25% (21/84) who stated they have “not exercised for the past year” to 7% (6/84) who indicated that they exercise “between 1 to 3 times per month”. They were generally quite motivated to improve their diet and exercise, giving similar mean scores of 7.3 (SD 1.5) and 6.7 (SD 1.5) respectively when asked to rate their motivation on a 0-9 scale.

Most owned Android-based smartphones (70%, 59/84). Most used their smartphones and apps frequently, with 87% (73/84) indicating that they used their smartphones more than 5 times a day and 76% (64/84) used apps more than 5 times a day. After being shown how to use iDAT, they gave a positive baseline rating for its usefulness with mean score of 6.7 (SD 1.5) on a 0-9 scale.

Table 1. Characteristics of enrolled patients at baseline.

Characteristic			Total recruited (n=84)
Demographics			
	Age (years), mean (SD)		48.2 (8.5)
	Gender, n (%)		
		Male	43 (51)
		Female	41 (49)
	Ethnicity, n (%)		
		Chinese	45 (54)
		Malay	23 (27)
		Indian	10 (12)
		Others	6 (7)
	Marital status, n (%)		
		Single	10 (12)
		Married	70 (83)
		Divorced / Separated	4 (5)
	Occupational status, n (%)		
		Retired	6 (7)
		Homemaker	7 (8)
		Unemployed	1 (1)
		Employed	70 (83)
	Educational level, n (%)		
		Secondary and below	39 (46)
		Post-secondary (‘A’ levels, technical)	10 (12)
		Diploma	18 (21)
		Degree and above	17 (20)
Clinical variables, mean (SD)			
	BMI (kg/m^2)		29.1 (6.1)
	Height (cm)		163.7 (8.7)
	Weight (kg)		78.3 (18.9)
	Blood pressure (mmHg), mean (SD)		
		Systolic	130.5 (18.5)
		Diastolic	77.6 (10.9)
Diabetes-related variables, n (%)			
	Time of diagnosis		
		New (less than 1 year)	66 (79)
		Long-term (more than 1 year)	18 (21)
	Diabetes treatment		
		Diet only	26 (31)
		On 1 diabetes medicine (without insulin)	35 (42)
		On 2 diabetes medicines (without insulin)	16 (19)
		On insulin	7 (8)
Social lifestyle			

Characteristic		Total recruited (n=84)
Healthy diet score (0-9), mean (SD)		4.8 (1.9)
Smoking status, n (%)		
	No	63 (75)
	Ex-smoker	8 (10)
	Yes	13 (15)
Drinking status, n (%)		
	Non-drinkers	53 (63)
	Used to drink	5 (6)
	Regular/social drinkers	26 (31)
Exercise frequency, n (%)		
	None in the past year	21 (25)
	Few times per year	13 (15)
	1-3 times per month	6 (7)
	Once per week	18 (21)
	2-3 times per week	18 (21)
	Daily	8 (10)
Smartphone characteristics, n (%)		
Smartphone operating system		
	Apple	25 (30)
	Android	59 (70)
Smartphone usage		
	More than 5 times /day	73 (87)
	Less than 5 times /day	11 (13)
Apps usage		
	More than 5 times /day	64 (76)
	Less than 5 times /day	20 (24)
	iDAT[a]usefulness score (0-9), mean (SD)	6.7 (1.5)
Motivation and self-efficacy scales, mean (SD)		
Diet motivation score (0-9)		7.3 (1.5)
Exercise motivation score (0-9)		6.7 (1.5)
DES-SF[b](1-5)		4.1 (0.5)

[a] iDAT: interactive Diet and Activity Tracker

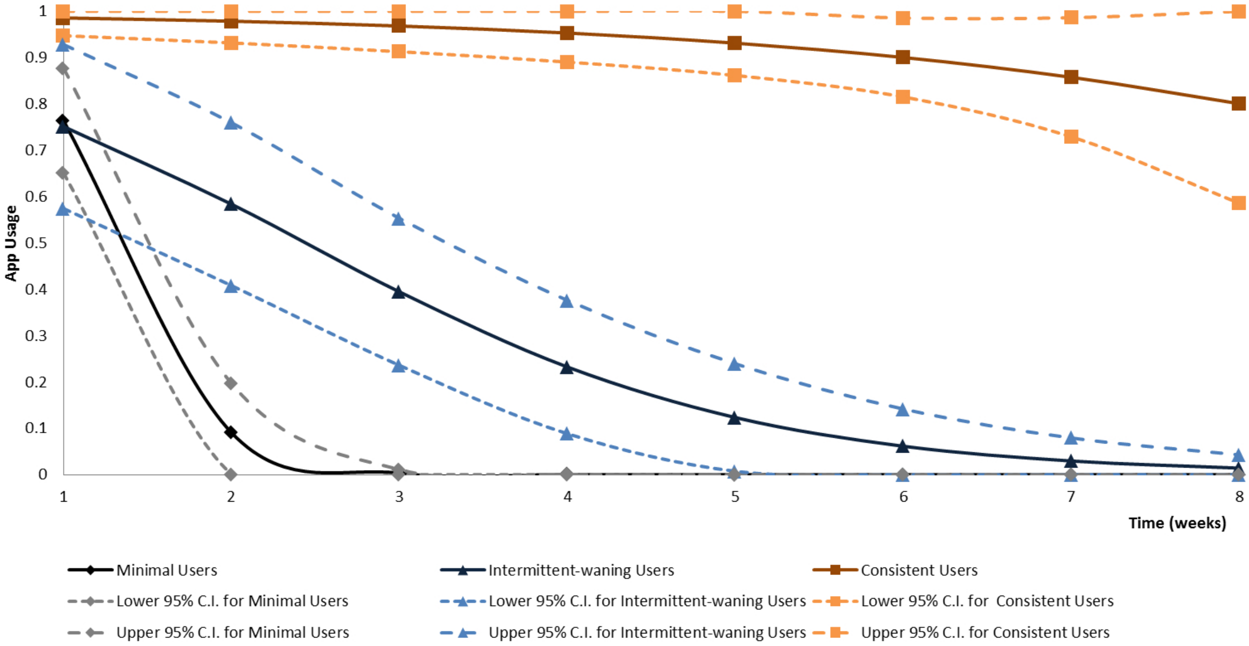
[b] DES-SF: Diabetes Empowerment Scale-Short Form

Weekly iDAT App Use Latent Trajectory Groups

Using the LCGM approach and applying goodness-of-fit criteria, weekly iDAT app use was best characterized as three latent trajectory groups (Figure 5). The model specifying four trajectory groups failed to converge and the model postulating two underlying trajectory groups had a higher BIC value indicating a poorer fit. Based upon the shape of the iDAT app use trajectory for each group, the three latent trajectory groups were labelled “Minimal Users”, “Intermittent-Waning Users”, and “Consistent Users”.

A total of 78.6% (66/84) of study participants were Minimal Users with a typical usage pattern of no iDAT input or iDAT input only during the first 2 weeks post-recruitment; 11.9% (10/84) were Intermittent-Waning Users with a typical input pattern of an occasional weekly input, mainly in the first 4 weeks post-recruitment. The remaining 9.5% (8/84) were Consistent Users with a typical input pattern of weekly input throughout all or most of the 8-week post-recruitment period.

Figure 5. Weekly "interactive Diet and Activity Tracker" (iDAT) app use trajectory groups identified using latent class growth modeling.



Predictors of Trajectory Group Membership

Univariate (Table 2) and multivariate (Table 3) polytomous logistic regression (Minimal Users as the reference category) was used to assess the baseline characteristics deemed most plausible as predictors of trajectory group membership. Univariate analysis showed that healthy diet (OR 1.6, 95% CI 1.0-2.5) and exercise motivation (OR 3.9, 95% CI 1.6-9.6) were associated with Consistent Users, and that exercise motivation (OR 1.8, 95% CI 1.0-3.1) and DES-SF scores (OR 6.6, 95% CI 1.4-29.8) were associated with Intermittent-Waning Users. The multivariate analysis resulted in two significant predictors: females had higher odds of being Consistent Users (OR 19.55, 95% CI 1.78-215.42) than males, and subjects with higher exercise motivation scores at baseline had higher odds of being Intermittent-Waning Users (OR 1.82, 95% CI 1.00-3.32) and Consistent Users (OR 4.89, 95% CI 1.80-13.28).

Table 2. Univariate polytomous logistic regression for baseline predictors of iDAT app use trajectory group membership (odds ratios are calculated with Minimal Users as the reference group).

	Minimal Users (n=66)	Intermittent-Waning Users (n=10)			Consistent Users (n=8)			Overall *P* value
	n (%) or mean (SD)	n (%) or mean (SD)	OR (95% CI)	*P*	n (%) or mean (SD)	OR (95% CI)	*P*	
Gender (female)	30 (45%)	4 (40%)	0.8 (0.2-3.1)	.75	7 (88%)	8.4 (1.0-72.1)	.052	.14
Age, years	47.8 (8.7)	47.2 (7.7)	1.0 (0.9-1.1)	.82	52.0 (7.7)	1.1 (1.0-1.2)	.20	.41
Body Mass Index (BMI)	29.1 (6.3)	31.0 (5.7)	1.0 (0.9-1.2)	.38	26.3 (4.2)	0.9 (0.8-1.1)	.20	.27
Glycosylated hemoglobin (HbA_{1c})	8.9 (2.5)[a]	7.2 (1.6)	0.7 (0.4-1.0)	.07	8.5 (3.0)[b]	0.9 (0.7-1.3)	.71	.19
iDAT[c] usefulness score (0-9)	6.6 (1.6)	7.2 (1.1)	1.4 (0.8-2.3)	.21	7.4 (1.2)	1.5 (0.9-2.7)	.15	.20
Healthy diet score (0-9)	4.6 (1.9)	5.2 (1.5)	1.2 (0.8-1.7)	.39	6.1 (2.1)	1.6 (1.0-2.5)	.045	.11
Diet motivation score (0-9)	7.1 (1.6)	7.7 (0.9)	1.4 (0.8-2.3)	.25	8.3 (1.0)	2.1 (1.0-4.5)	.055	.10
Exercise frequency								.32
Few times or none per year	29 (44%)	4 (40%)	0.6 (0.1-2.7)	.49	1 (13%)	0.1 (0.1-1.1)	.06	
1-4 times per month	20 (30%)	2 (20%)	0.4 (0.1-2.6)	.36	2 (25%)	0.3 (0.1-2.0)	.23	
More than once a week	17 (26%)	4 (40%)	Ref		5 (62%)	Ref		
Exercise motivation score (0-9)	6.4 (1.5)	7.4 (1.3)	1.8 (1.0-3.1)	.049	8.3 (0.9)	3.9 (1.6-9.6)	.003	.004
DES-SF[d] (1-5)	4.0 (0.5)	4.4 (0.3)	6.6 (1.4-29.8)	.02	4.3 (0.5)	4.0 (0.8-19.4)	.09	.02

[a] n=56, not all patients had HbA_{1c} levels at baseline. [b] n=7, not all patients had HbA_{1c} levels at baseline.

[c] iDAT: interactive Diet and Activity Tracker

[d] DES-SF: Diabetes Empowerment Scale-Short Form

Table 3. Multivariate polytomous logistic stepwise regression[a] for baseline predictors of iDAT[b] app use trajectory group membership with Minimal Users group as reference category.

	Intermittent-Waning Users (n=10)		Consistent Users (n=8)		Overall *P* value
	OR (95% CI)	*P*	OR (95% CI)	*P*	
Gender (female)	1.21 (0.28-5.20)	.80	19.55 (1.78-215.42)	.02	.052
Exercise Motivation Score (0-9)	1.82 (1.00-3.32)	.05	4.89 (1.80-13.28)	.002	.003

[a] SLE (Significance Level to Enter)=SLR (Significance Level to Remove)=0.20.

[b] iDAT: interactive Diet and Activity Tracker

Discussion

Principal Results

To our knowledge, this is the first study to apply LCGM to delineate trajectories of app usage. We were able to distinguish usage patterns of a caloric-monitoring mobile health app into three latent trajectory groups: Minimal (76.8%), Intermittent-Waning (11.9%), and Consistent Users (9.5%). While a majority of patients did not use or rarely used the app, about 20% used the app, with close to 10% using the app on a regular basis during the 8-week post-enrollment period. The adjusted odds of being a Consistent User, as opposed to a Minimal User, were significantly higher for females and for subjects with higher exercise motivation scores at baseline. The adjusted odds of being an Intermittent-Waning User were also significantly higher for those with higher exercise motivation scores at baseline. The application of LCGM allowed us to delineate distinct trajectories of iDAT app usage and then identify predictors of specific patterns of app use.

Comparison With Prior Work

There is strong evidence that good self-management in the chronic care of diabetes leads to better outcomes of the condition [4,21,22]. To further support patients in their effort toward better diabetes control, recent studies have tried to investigate the usage and effectiveness of incorporating technologies like the Internet and mobile phones to facilitate and support self-efficacy of diabetes patients [9,11,23]. While results have generally been positive, usage rates of the technological systems vary substantially with some as low as 13% and others as high as 92% [9,23]. To some extent, this is likely due to different study designs, conditions, and device types, which leads to difficulty in comparing results and making generalizations. Furthermore, some earlier interventions required additional resources such as dedicated health care personnel to operate a personalized messaging system or gadgets for the subjects' use that may not have been readily available outside the study. Generalizing usage patterns in a broad context is difficult as usage varies widely among individuals and over time and, in this regard, statistical methodologies such as LCGM are of great value in identifying, segregating, and characterizing underlying latent behavioral trajectories.

Our study protocol initially aimed at enrolling newly diagnosed diabetes patients, defined as patients in their first year following a diagnosis of diabetes. We felt these patients would benefit most from using the iDAT app, since they would likely be learning new diets and making lifestyle changes. In addition, there have been few studies focused on patient self-motivation in newly diagnosed diabetes [24]. As the study progressed, we found ourselves unable to recruit sufficient numbers of patients in their first year following diagnosis and so we expanded the inclusion criteria to include patients diagnosed with diabetes longer than one year prior to enrollment. Hence, our study cohort includes a disproportionate number of newly diagnosed diabetes patients. Most participants were on no diabetes medication or only a single medication, and the average participant age was younger than that of the overall population of individuals with diabetes in Singapore [25]. However, we found no association between duration of disease and iDAT app trajectory group membership.

The younger relative age of our study cohort could also be attributed in part to the larger proportion of the younger generation owning mobile phones or being familiar with app usage. The larger representation of Indians and Malays among our study participants was consistent with the demographic profile of patients with diabetes in Singapore's multi-ethnic population [25].

In appraising patient clinical characteristics, it was not surprising that average BMI in our study was in the "high risk category". Obesity is a well-known risk factor for diabetes and urbanized Singapore has a rising obesity trend [2]. Average Hb_{A1c}level was relatively high at 8.7% (SD 2.5), indicating that some of the patients had not been meeting their Hb_{A1c}targets or due to late diagnosis of diabetes.

While the medical literature has not been clear in reflecting the differences in app usage between genders, this topic has been thoroughly analyzed in marketing research studies so that app development could be directed toward a targeted audience. Their results have shown that, while well-known and popular apps like Facebook and Twitter have equal gender usage, there are differences in the type of apps that males and females download or use [26-29]. For example, Flurry Analytics, a provider of mobile business data, found that males were more likely to download sports and automotive-related content while females downloaded more shopping catalogue apps [26]. AppAware, an app company that specializes in recommending apps for Android users, published an infographic in 2012 showing that males used more system tools while females preferred word, brain, and bubble shooting games [27]. However, in the category of health and fitness apps, results are not so definitive. According to data from Apsalar, a mobile analytics and advertising company, males used health and fitness apps 10% more than females, but information from Flurry Analytics showed that women were more likely to download health and fitness apps [26,28]. Nevertheless, this demonstrates that gender can play a role in determining app usage and a caloric-monitoring app like iDAT may appeal more to females. Further in-depth, gender-specific research may be required to determine why females have a greater preference towards iDAT or a particular type of app.

Our findings also showed that patients with higher exercise motivation scores had greater app usage. There are many barriers to initiating or increasing an exercise routine, so patients who indicate higher exercise motivation may be more determined to take active steps toward improving their diabetes, including more diligent use of the app.

Strengths and Limitations

Implementation of this study in a primary care environment void of external pressure or add-on facilitation such as regular reminders, reimbursements, or financial incentives for participants to use the iDAT app, underpins its strength. The study provides insight into the potential of a typical mobile phone app to reach out to a target group of users in a patient population. We believe our results provide a good indication of the extent and pattern of use of this caloric-measuring app based largely on self-motivation, in a naturalistic "real-world" setting.

The analysis was limited by the fact that the app database could only provide information on app usage on a weekly basis. This limitation was considered during the study design process and was accepted on the basis of what we felt were realistic expectations for participant compliance and diligence in entering data. A database with daily app input would likely have enabled a more detailed picture of usage patterns, assuming adequate participant compliance for daily data entry.

The study has practical implications and applications. Health care providers who recommend health-related apps alongside diet and exercise instructions should be aware that only 2 in 10 are likely to use the apps and only 1 in 10 is likely to be a consistent user. Males and those with lower motivation for exercise are less likely to be frequent users of such apps. Further research is needed to understand the user's psychological construct in the three trajectory groups, which will influence their app adoption. The design, features, and functionalities of the respective app are other potential factors that can facilitate or hinder the user's engagement with the app and this requires further investigation.

This inaugural study using LCGM as the modality of analysis is limited by the relatively small study sample and short length of observation. However, the information gathered, especially the variations in uptake of the app across the three trajectory groups will inform the design and sample size estimation of a future study to determine the effectiveness of a caloric-measuring mobile phone app on clinical outcomes among users with diabetes.

Conclusions

Our successful, novel application of the statistical method, LCGM, provides insightful analysis of longitudinal data to determine app utility among a target population. For selected patients with diabetes, the iDAT app can serve as an adjunct tool to facilitate lifestyle changes in conjunction with the usual modality of counselling.

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Conflicts of Interest

None declared.

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Abbreviations

BIC: Bayesian information criterion
BMI: body mass index
CIRB: Centralized Institutional Review Board
DES-SF: Diabetes Empowerment Scale-Short Form
GPS: Global Positioning System
HbA1c: glycosylated hemoglobin
HPB: Health Promotion Board
iDAT: interactive Diet and Activity Tracker
iOS: Apple operating system
LCGM: latent-class growth modeling
SLE: significance level to enter
SLR: significance level to remove

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Original Paper

The Role of Mobile Technologies in Health Care Processes: The Case of Cancer Supportive Care

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Abstract

Background: Health care systems are gradually moving toward new models of care based on integrated care processes shared by different care givers and on an empowered role of the patient. Mobile technologies are assuming an emerging role in this scenario. This is particularly true in care processes where the patient has a particularly enhanced role, as is the case of cancer supportive care.

Objective: This paper aims to review existing studies on the actual role and use of mobile technology during the different stages of care processes, with particular reference to cancer supportive care.

Methods: We carried out a review of literature with the aim of identifying studies related to the use of mHealth in cancer care and cancer supportive care. The final sample size consists of 106 records.

Results: There is scant literature concerning the use of mHealth in cancer supportive care. Looking more generally at cancer care, we found that mHealth is mainly used for self-management activities carried out by patients. The main tools used are mobile devices like mobile phones and tablets, but remote monitoring devices also play an important role. Text messaging technologies (short message service, SMS) have a minor role, with the exception of middle income countries where text messaging plays a major role. Telehealth technologies are still rarely used in cancer care processes. If we look at the different stages of health care processes, we can see that mHealth is mainly used during the treatment of patients, especially for self-management activities. It is also used for prevention and diagnosis, although to a lesser extent, whereas it appears rarely used for decision-making and follow-up activities.

Conclusions: Since mHealth seems to be employed only for limited uses and during limited phases of the care process, it is unlikely that it can really contribute to the creation of new care models. This under-utilization may depend on many issues, including the need for it to be embedded into broader information systems. If the purpose of introducing mHealth is to promote the adoption of integrated care models, using mHealth should not be limited to some activities or to some phases of the health care process. Instead, there should be a higher degree of pervasiveness at all stages and in all health care delivery activities.

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KEYWORDS

mhealth; cancer supportive care; cancer care; new models of care; integrated care; health care process; care delivery value chain

Introduction

Nowadays, health care systems are facing multiple challenges that are gradually leading to the adoption of new care models. The majority of these new care models are based on a shift away from mostly large general hospitals with fewer hospital beds dedicated to acute care and toward the delivery of more health care services in primary care settings, day care facilities, and health centers [1].

This is also true for cancer care, especially for the treatment of its side effects, known as cancer supportive care whose intention is to give patients relief from side effects such as nausea, pain, and fatigue. More precisely, the main purpose of cancer supportive care is not to cure cancer, but to manage the symptoms of cancer. To this extent, cancer supportive care is part of the treatment phase of the health care process, as it is usually given alongside the actual cancer treatment [2].

New care models put greater emphasis on the role of the patient [3] and are moving toward activities carried out by the patient on a self-management basis. More specifically, patients are required to self-manage the side effects of the care processes they are receiving. On the other hand, there is great emphasis on the effectiveness of care and on the quality of life. However, the combination of these two trends points to a tradeoff between rising costs and enhancing quality [4] and technology can play a major role in the management of this tradeoff [5].

In light of these challenges, it is important to identify the promise held by mHealth for achieving new care models, as outlined by decision makers, communications media, and literature.

According to literature, mHealth has a crucial role to play since it can improve communication and enhance the integration of care processes [6,7]. Looking at the internal processes in use at health care organizations, mHealth can increase the productivity of health care providers, and consequently may even improve the productivity of health care systems [8-11]. Focusing on the external relations of health care organizations, mHealth can enhance transparency [12,13] and so increase the accountability of health care providers and systems, but it can also empower patients [14-16]. Finally, the greatest promise of mHealth is to enhance the quality of life and the appropriateness of care [17-19].

Therefore, mHealth can help in the pursuit of new health care models, requiring a shift from inpatient to outpatient care, also enabling the delivery of care in rural settings and other places where there is no ready access to medical personnel [20]. More precisely, mobile phone-based initiatives can solve several of the major problems encountered in low-income countries: distance, limited computer access, and a lack of health care workers, thus enabling improvements in terms of efficiency and lower health care delivery costs [21].

mHealth appears to complement current transitions within health care models, shifting care from the acute hospital setting to the home, with technology being used to rationalize and integrate services, where appropriate, based on the patient's needs. Moreover, mHealth can play a significant role in empowering patients, giving them the tools to manage their condition and any associated side effects themselves, in their own home and without the need for direct supervision by health care personnel [22].

This paper aims to review existing studies on the actual role of mobile technology during the different stages of care processes and how and why it is used, with particular reference to cancer supportive care. This will enable us to determine whether using mHealth actually supports the introduction of new models of care.

The systematic use of technology in health care can be traced back to the more comprehensive evolution of information systems with the gradual automation of structured, semi-structured, and unstructured processes and activities [23,24]. As a result, it is important to determine the types of data and activities that need to be designed and performed, because identifying them helps to determine the best technologies to be implemented.

We should note that mHealth is a broad concept including various types of mobile technologies. It often refers to consumer health care technologies, such as Web-based information resources, telephone messaging (short message service/SMS, multimedia messaging service/MMS), remote monitoring of patients, remote interpretation of medical reports, videoconferencing, and telehealth, including the remote services of a surgeon operating at a distance, and telerobotics [25].

More specifically, the World Health Organization [26] has stated that mHealth includes technologies like mobile phones, personal digital assistants (PDAs), and smartphones, patient monitoring devices, mobile telemedicine/telecare devices, MP3 players for mLearning, and mobile computing. Based on this classification, the category of "SMS" (or text messaging) should be kept separate from the broader description of "mobile devices", which will be used to classify smartphones, tablets, and apps. The difference is based on the distinctive features of the two categories: SMS is a tool to remind patients of an appointment whereas a "mobile device" is an instrument that is useful for collecting and processing data. This consideration is also valid when referring to the differences between "mobile devices" and "mobile telemedicine/telecare devices". Even if integrated with a mobile phone, telemedicine devices are standalone technologies [26] taking advantage of wireless telecommunications infrastructures and are defined as "the use of telecommunications and computer technologies, including patient remote sensing and monitoring, and the use of telemetry devices, with medical expertise to facilitate health care delivery" [8].

Mobile technology should be introduced in line with the activities it aims to support. It first supports automation [27], data collection [10,28], and then operations. However, it can also support clinical decision making [29], especially monitoring (eg, pain monitoring) [30], and the planning of activities. However, most strategic documents on mHealth issued by international organizations and leading organizations in the field, and adopted by decision makers, suggest that mHealth should assist human-executed processes and should play a fundamental role in new models of care [31,32].

If we focus on health care processes, we can examine the potential role of mHealth in the value chain of care delivery [5]. mHealth can play a role in all phases of the care delivery process, supporting prevention, diagnosis, decision, treatment, and follow-up. Since it can support data collection, monitoring, and new care models, it can contribute to the creation of value if it is embedded into the entire care process, making a difference in the way care is delivered and shifting its focus onto homecare and mobile care.

mHealth can be introduced at each phase of the health care delivery process in order to support structured activities, such as data collection, semi-structured activities like monitoring, and unstructured activities, like assisting human-executed processes.

The prevention phase uses mobile apps for promoting healthy habits by scheduling reminders, as well as more unstructured campaigns that use mobile technologies for mLearning activities aimed at teaching people about diseases.

In the diagnosis phase, mobile technology can facilitate remote access to patient information, but it can also help to carry out more complex and human-executed processes like telediagnosis. Once the diagnosis has been carried out, the clinician has to make decisions and mHealth can be helpful in several ways for decision making—from automated mobile libraries with clinical descriptions of diseases to the use of mobile technologies for shared decision making by health care professionals.

During treatment, mobile technology can be used to manage a patient's symptoms and condition or to enable the patient to do this himself (self-management), but it can also be helpful for treating patients at remote locations by means of telehealth and telesurgery equipment.

Finally, after a patient has been treated, fundamental follow-up activities have to be put in place and these can be supported by mobile technology, for example, the real-time measuring of a patient's vital signs or for achieving better and ongoing quality communication between patients and health care professionals. Some authors consider the follow-up and "survivorship phase" as being strictly connected. The survivorship phase includes several components, ranging from the prevention of recurrence or new cancer to the treatment of the consequences of cancer, including deferred psychological effects [33]. As the US Institute of Medicine recommends, survivorship care plans should be provided to patients at the end of their treatment in order to improve health-related outcomes such as distress, self-efficacy, and quality of life [34].

mHealth has the potential to make a difference in terms of better quality of life, more appropriate care, and less burden on health care processes, if it is used in its multiple roles, as shown in Figure 1, throughout the care process, as shown in Figure 2, if it is embedded in the organization or in the environment where the health care process takes place, and if it is pervasive in human executed activities.

Figure 1. The role of mHealth.

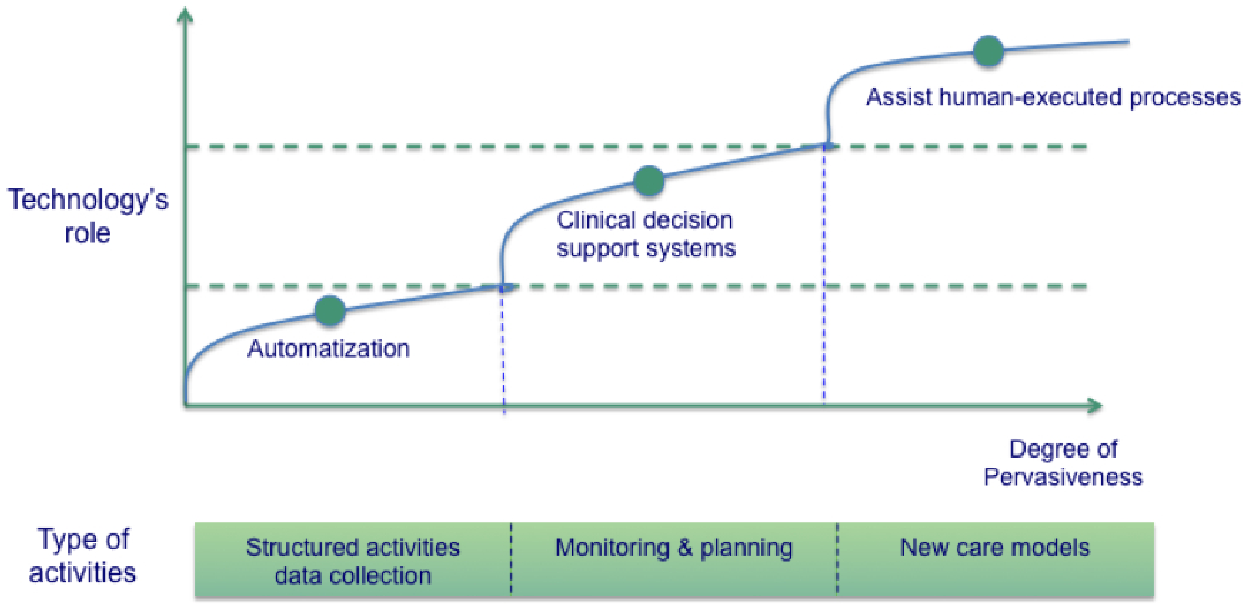


Figure 2. Mobile technologies in the health care process.

Methods

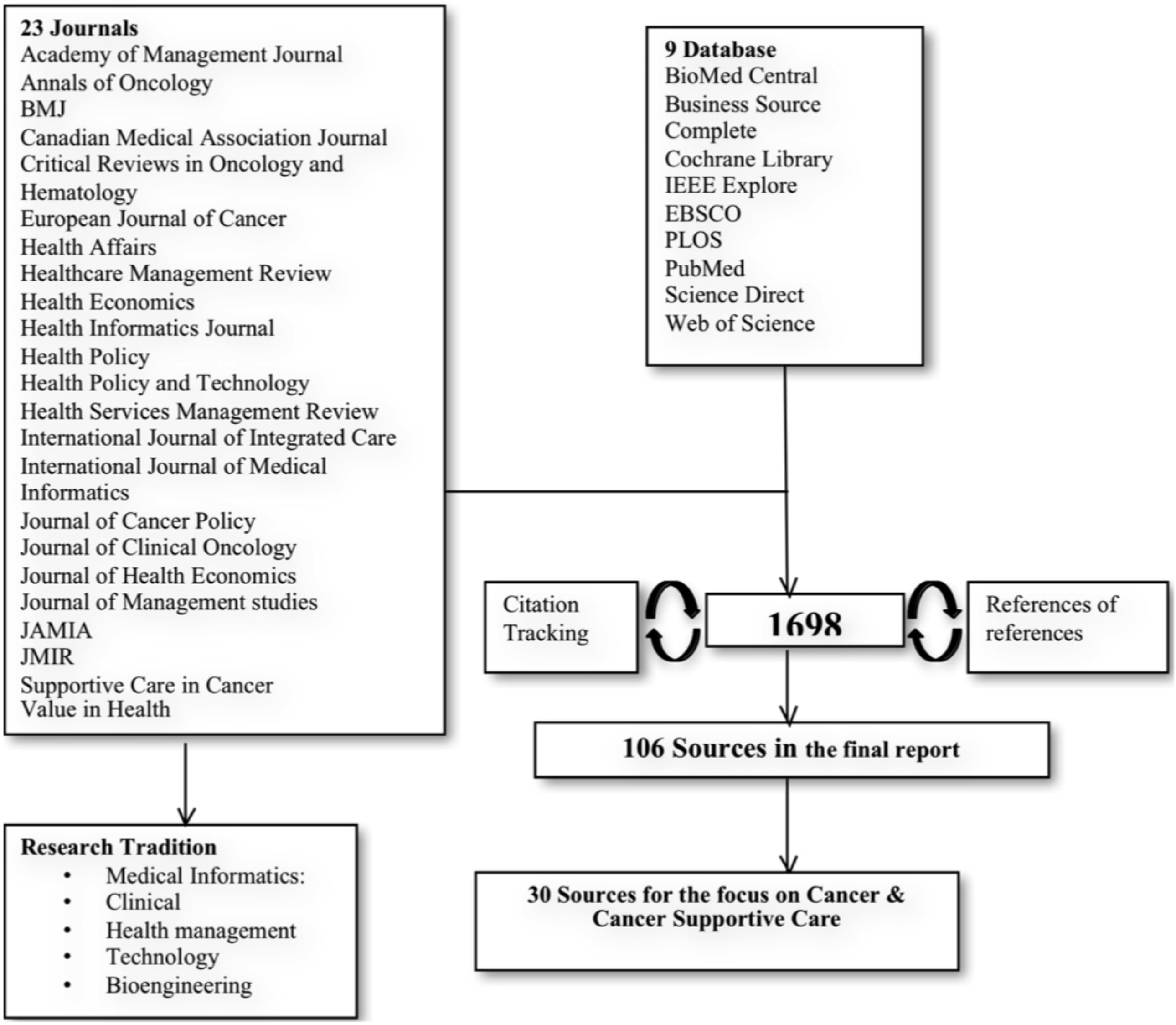
We undertook a review of literature in order to understand the evidence relating to the actual use and role of mHealth, particularly with regard to cancer supportive care. We reviewed papers from three bodies of literature: Medical Informatics, Healthcare Management, and Medicine, with particular reference to oncology journals. The first step of our research strategy (Table 1, Figure 3) was aimed at identifying and collecting all existing studies of mHealth and integrated care focusing on cancer and cancer supportive care.

We then applied a “snowball” method and tracked the articles whose list of references included the works we considered fundamental for our research. We retrieved papers and studies that were published after 1999 in scholarly reviews and journals that were not listed in the database at the time of the analysis, but that were familiar to scholars. We also examined papers published in *JAMIA*, *JMIR*, *BMJ*, *Health Affairs*, *HealthCare Management Review*, *Health Policy*, and *Health Policy and Technology*.

Table 1. Research strategy.

Keywords	Generic search using the concept words: “mHealth”, “cancer”, “quality of life” Specific searches: “mHealth” (“mHealth” OR “mHealth” OR “mobile health” OR “mobile healthcare”) + “cancer” (cancer OR “cancer care” OR “cancer supportive care” OR “supportive care in cancer” OR “chemotherapy” OR “side effects” OR “adverse effects” OR “integrated care” OR “cancer integrated care”) “Quality of life” (“quality of life” OR “quality of service” OR “quality of care” OR “healthcare delivery” OR “healthcare management” OR “care management” OR “health policy” OR “promises” OR “continuity of care” OR “lean healthcare” OR “lean health care” OR “lean thinking” OR “patient-centered”) + “performance” (“performance” OR “evaluation” OR “impact” OR “assessment” OR “return” OR “promises” OR “adoption”)
Databases	BioMed Central, Business Source Complete, IEEE Xplore, PLOS (One, Medicine and Clinical Trials), PubMed, Science Direct, Web of Science (which embeds Elsevier, Wiley, JMIR, JAMIA), Cochrane Library
Specific Journals	JAMIA, JMIR, BMJ, Health affairs, HealthCare management review, Health Policy, Health Policy and Technology, Value in Health (ISPOR), Journal of Cancer Policy, Academy of Management Journal, Journal of Management studies, Journal of Health Economics, Health economics, Canadian Medical Association Journal, Health Informatics Journal, Journal of Clinical Oncology (ASCO), Annals of Oncology (ESMO), Supportive Care in Cancer (MASCC), European Journal of Cancer (published by Elsevier, official journal of EORTC, ECCO, EACR and EUSOMA), Critical Reviews in Oncology and Hematology (ESO), Health Services Management Review (EHMA), IEEE Antennas and Propagation Magazine, Current Oncology
Inclusion criteria	Peer reviewed published articles Published since 1999
Exclusion criteria	Grey literature (blogs, newsletters, videos) Provisional or structured abstracts Poster sessions, presentations, comments, opinions, discussions, editorials, prefaces, summaries, interviews, correspondence, tutorials Studies on psychology, ie, behavioral models and theory of psychology Studies where mobile health means mobile clinics or mobility of professionals or mobile screening units Studies or articles with no author Studies or articles with no abstract

Figure 3. Research strategy: results.



Results

Overview of Findings

This section describes the results of our review of existing studies on the actual role of mobile technology at the different stages of the care process.

The first finding to be highlighted is that studies mainly refer to high income countries (50.9%, 54/106) [35,36] and focus less on low income (8.5%, 9/106) [37] and middle income countries (3.8%, 4/106) [38]. We should mention that 6.6% (7/106) of papers refer to different types of countries. A total of 30.2% (32/106) [14,29] of the selected studies do not refer to any specific country or region (Figure 4), as they review literature or describe a specific mobile technology.

Looking at the analysis in greater detail, we examined the role of mobile technology in health care delivery. As mentioned above, mHealth can be used for supporting structured, semi-structured, and unstructured activities, and different technologies can be introduced as a result. In particular, with regard to the type of technologies analyzed, our research found that mobile devices (like smartphones and tablets) and apps are analyzed by 75.5% (80/106) [14,17,35,36,39,40] of papers, remote monitoring technologies by 28.3% (30/106) [37] of papers, and text messaging technologies by 17.9% (19/106) [36,41] of papers (Figure 5). It should be noted that some papers refer to several types of mobile technologies. We found that mHealth is mainly used for supporting data collection, monitoring, and pain management [35,42-44], especially in cancer supportive care.

These various technologies are not spread evenly across all areas of the world: more complex processes and human-executed activities seem to be more common in high income countries. This difference can be observed in the technologies adopted; telehealth technologies are only found in high income countries for instance [45], whereas text messaging prevails in middle income countries [38] (Figure 6).

If we look specifically at individual health care processes, we found that mHealth can play a role in all stages of the care process, namely prevention, diagnosis, decision, treatment, and follow-up. However, evidence focuses only on specific phases and most papers suggest a use for treatment purposes

[14,35,36,39]. This is because the treatment phase includes all self-management activities carried out by patients [38,46]. Some papers also suggest a role for diagnosis [21,30,47] and a few papers look at prevention [37,41]. A minority of papers look at follow-up [8,48] and there is limited evidence on using mHealth for decision making [49,50] (Figure 7). Consequently, there is scant evidence about using mHealth for integrated care processes or to support new models of care.

Analyzing the health care process in more detail, we observed the different types of technology used in the phases of the care delivery process (Figure 8). The distribution of mobile technologies used in the different phases of the care process reflects the distribution shown in Figure 4. In particular, we noted the predominant use of smartphones and apps [29,36,37,50] in all phases followed by remote monitoring devices [20,43], even if fewer papers reported this (Figure 5).

On the contrary, less marked differences were observed for the decision [49] and follow-up [8] phases. Since mobile devices like smartphones are used predominantly for self-management activities, the treatment phase features a high use of this type of technology [35,46]. Remote monitoring was the second-most prevailing technology we observed, even if there is a remarkable difference compared to the use of mobile devices. Remote monitoring devices also seem to be used mainly for treatment [46]. Looking at the decision [49] and prevention [16] phases, we observed fewer differences in use, probably because a limited number of papers looked at these stages of the care process.

Finally, looking at how the implementation of mobile health systems is paid for and who pays for it, we noted the whole range of solutions, even if literature does not currently examine this aspect adequately. There are projects [7,37] built entirely in-house, others that are funded by the European Community [16,45], and others requiring both public and private institutions [25] to contribute.

Based on our analysis we found interesting results concerning other types of chronic diseases, such as diabetes, which is mentioned in 18 of our 106 papers. Together with cancer, stroke, and chronic obstructive pulmonary disease (COPD), diabetes is on the list of the major chronic diseases responsible for more than 60% of deaths in the world [51]. The mobile device is the main technology adopted but text messaging and remote monitoring devices are also used. Larsen [39] showed how a mobile phone with a pre-configured app and a Bluetooth-enabled blood glucose meter supported the optimization of insulin dosage, improving control of blood sugar levels.

Figure 4. Type of country.

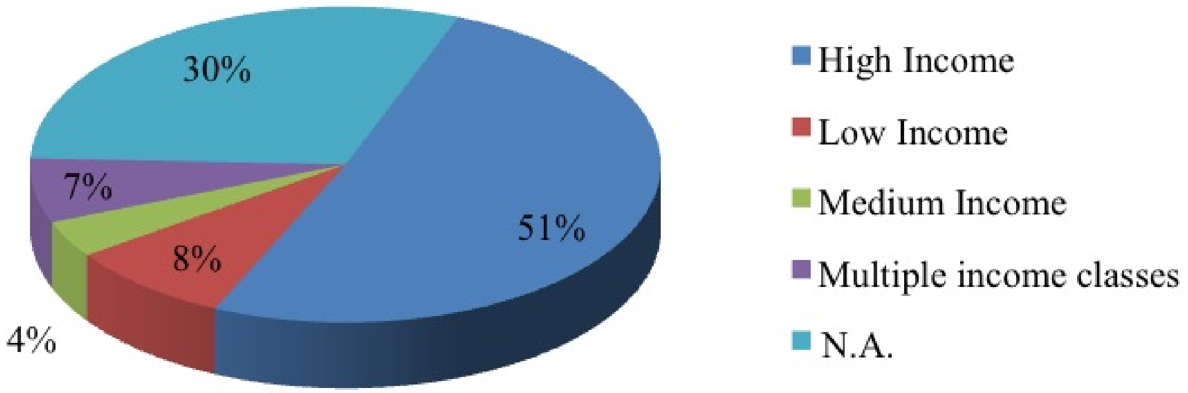


Figure 5. Mobile technologies.

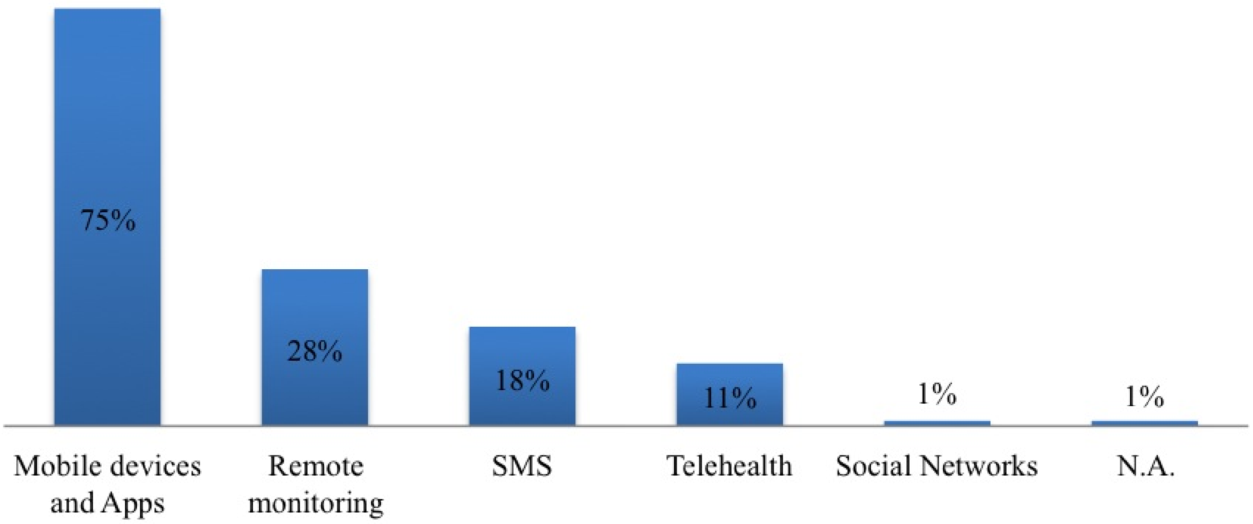


Figure 6. The role of mHealth in high, middle, and low income countries.

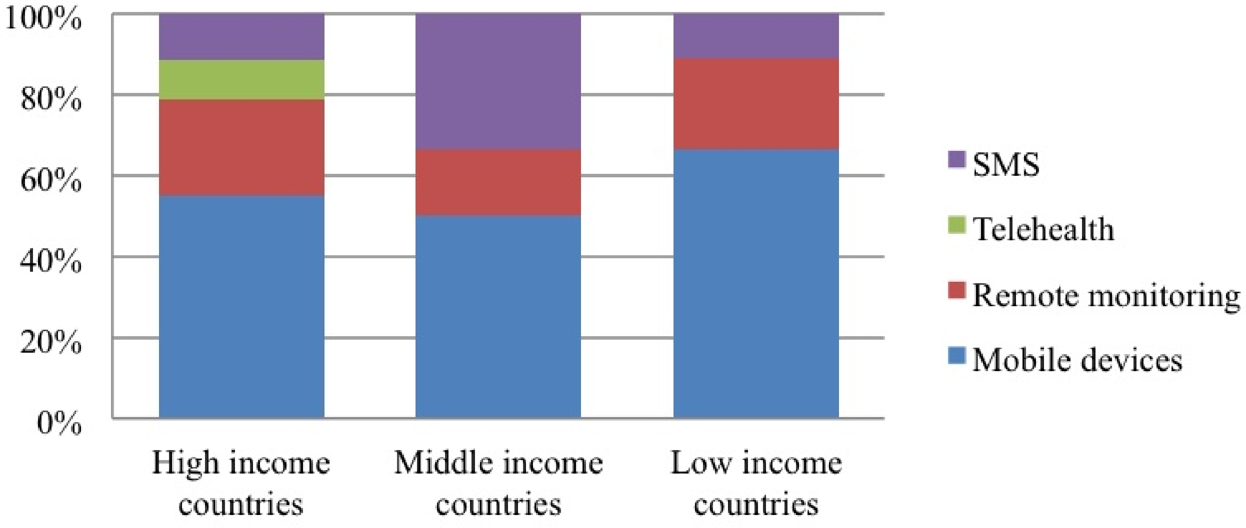


Figure 7. Papers on the different phases of the health care process.

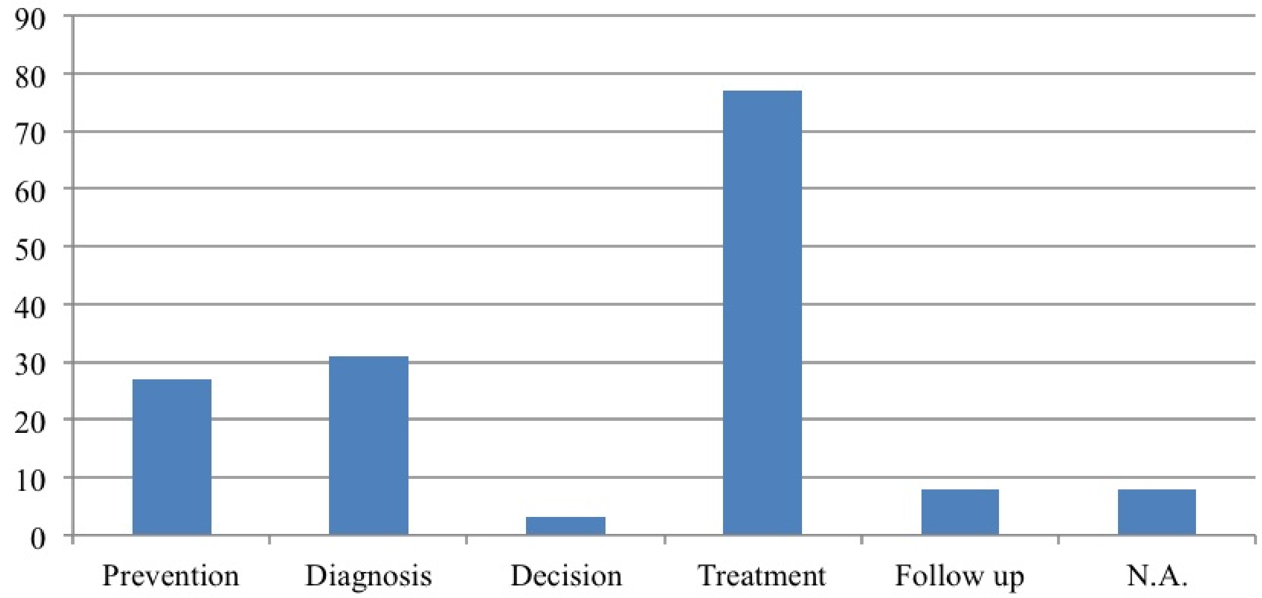
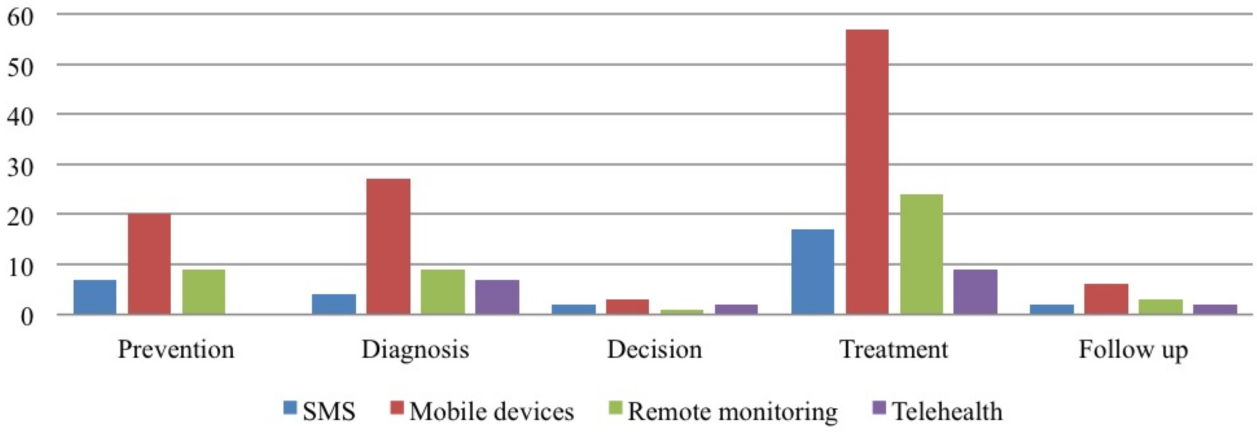


Figure 8. Mobile technologies in health care process phases.

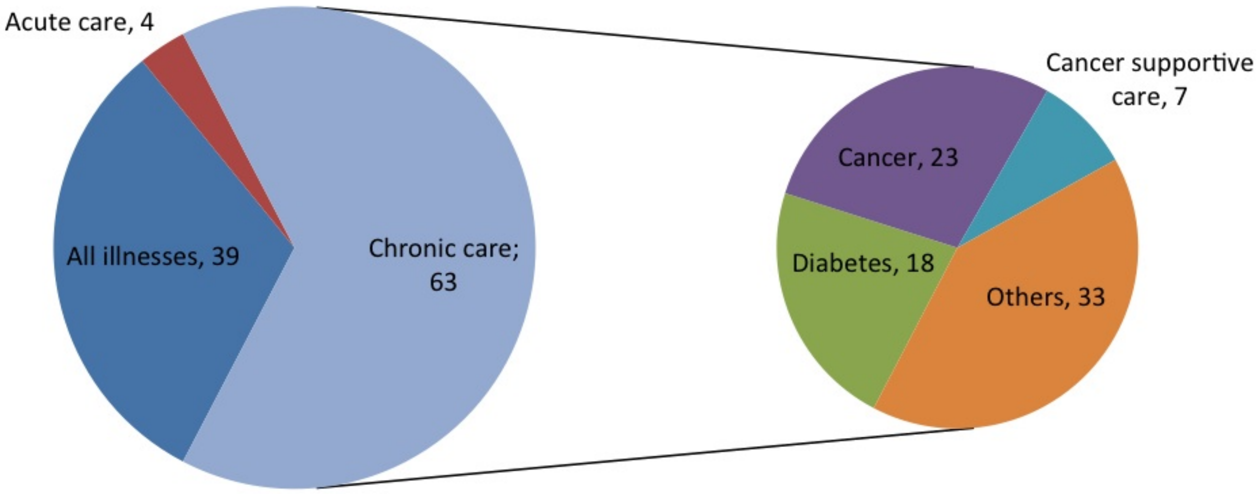


Focus on Cancer Supportive Care

Nevertheless, cancer supportive care remains the main focus of our research. We found that the role of mHealth in cancer supportive care does not seem to be sufficiently or adequately investigated in literature. Even if our search strategy aimed to look at papers related to mHealth in cancer supportive care, our actual results show that only 59.4% (63/106) of the papers focused specifically on chronic diseases, a category including cancer and cancer supportive care (Figure 9).

Two researchers subsequently screened the records fulfilling our eligibility criteria (n=63) and excluded those that were not pertinent. With regard to the exclusion criteria, the researchers considered certain records as not pertinent after reading the articles themselves; those that did not match the definitions of our streams of research were excluded. This section therefore concentrates on 30 references regarding cancer and cancer supportive care.

Figure 9. Analyzed diseases.



Focusing on cancer supportive care, mobile devices and apps are the main technology adopted, but text messaging is also used. This may be related to the fact that cancer supportive care revolves mainly around the management of symptoms, and mobile devices and apps are the type of technology used for the most part in this type of activity (Figure 10).

Jaatun [40] analyzed the case of an iPad-based pain assessment tool, developed with a user-centered design, compared to paper-based and conventional laptop-based tools.

We also investigated the Advanced Symptom Management System (ASyMSA) proposed by Kearney [52]. This system requires patients to fill in an electronic symptoms questionnaire and then immediately sends them written feedback via the mobile phone interface, including tailored self-care advice related directly to their symptoms. Patients use a handheld computer to record and send in daily symptom reports to the cancer care center and receive instant, tailored symptoms management advice based on a two-treatment cycle [52]. Finally, Mooney [53] analyzed a daily telephone-linked care (TLC) system for a single cycle of chemotherapy and reporting on seven common chemotherapy-related symptoms. Using selected symptom data, symptoms that met a preset severity threshold generated a fax notification of the patient’s symptom pattern sent to their physician.

Since few papers examined cancer supportive care and focused mainly on self-management, we looked at cancer care in more general terms. Again, smartphones and mobile apps are the most commonly used technology (Figure 10) [54].

When we looked at the health care process in detail, we observed the different types of technology used in the phases of the cancer care delivery process (Figure 11) and failed to find any specific differences from the results presented in Figure 8. We again noted a prevailing focus on treatment activities based on mobile devices, with the decision and follow-up phases being rarely analyzed.

Finally, looking at the location where the pilot and case studies were conducted, we noticed a sharp prevalence of studies conducted in cancer centers [35,39,52], although there is limited evidence.

Figure 10. Mobile technologies and diseases.

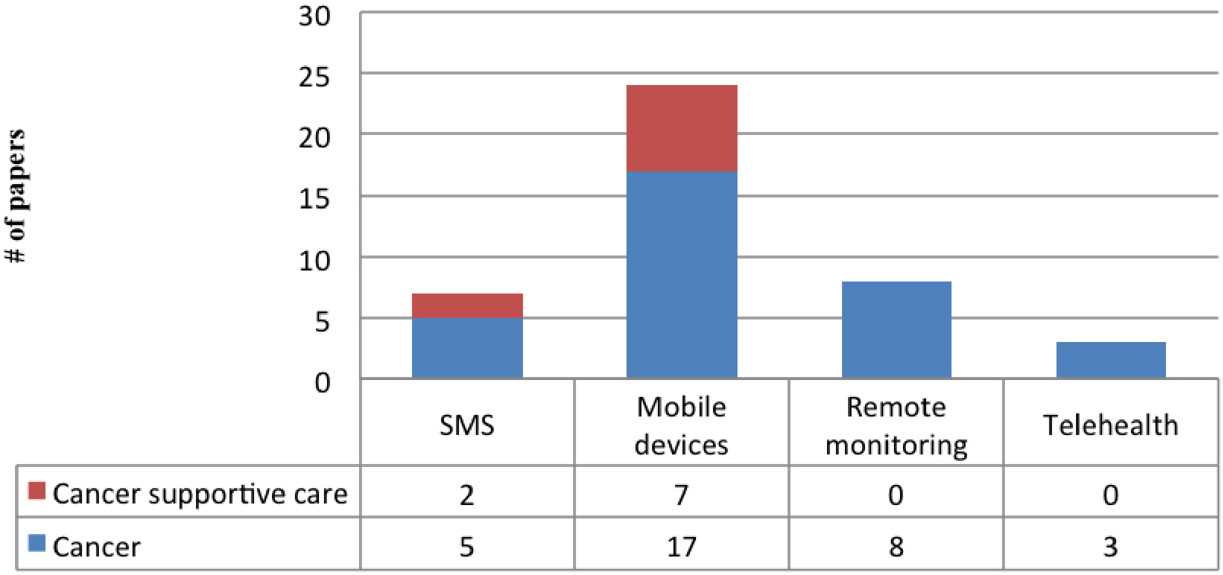
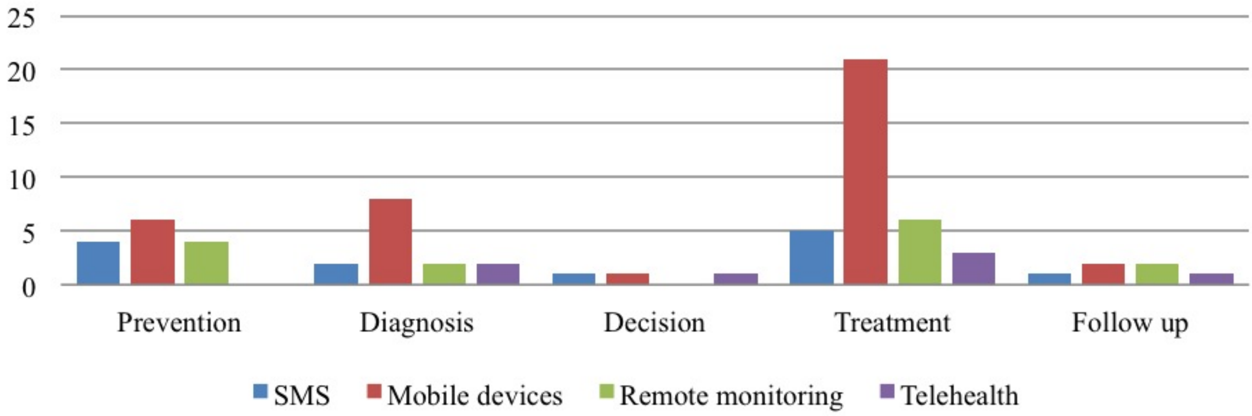


Figure 11. Mobile technologies in the phase of health care processes: focus on cancer care.



Discussion

Principal Findings

Our analysis of the use of mHealth in cancer supportive care revealed that few papers focus on this particular field, despite the fact that cancer affects more and more people every day. Looking at cancer care in general, we found that the use of mHealth is limited to certain technologies and certain phases of the care process. In particular, we observed that the main technology used consists of mobile devices, and the most explored stage in the health care process is the treatment phase.

The prevalent use of smartphones and remote monitoring devices indicates that mHealth typically supports the automation of processes, focusing on structured activities, such as the automatic transmission of a patient’s vital signs, and in some cases on semi-structured activities. Consequently, it seems that remote monitoring devices are used mainly in the treatment phase, even if this type of technology could also be used in the follow-up phase. Unstructured activities, mainly consisting of human-executed activities, are supported by mobile technology to a lesser degree, as we found for telehealth and remote surgery.

Regarding the stages in the health care process, not all of them feel the impact of mHealth. The use of mobile technologies concentrates on the treatment phase, mainly because of the extensive use for self-management activities. On the other hand, the decision, prevention, and follow-up phases are hardly affected by the use of mobile technologies, both for cancer and diabetes cases, but this can be explained by the fact they are also the least analyzed by selected literature.

In introducing mHealth, it should be remembered that some uses of mHealth have limited potential. For instance, productivity and efficiency goals can be met if mHealth is used for data collection or to support structured activities. Goals, such as improved effectiveness, can be met if it is used to support clinical decision making, for example, more prompt decision making with an impact on increasing the life expectancy of a cancer patient.

Consequently, if the objective of mHealth is to contribute to an organization's efficiency, in terms of cost cutting and time saving, it can be used to support data collection in a reliable, accurate, and validated way. If the objective is to reduce the length of hospital stays or re-hospitalization rates, it should be embedded into care process activities. Along with productivity and efficiency goals, mHealth can also make a contribution to the outcomes and results achieved, mainly related to the patient's perspective and the benefits they can achieve by means of mobile technologies. The concept of the quality of life thus gains importance and is mainly related to improvements to a patient's health and behavior.

Conclusions

The results of our analysis show that mHealth is a broad concept that can have several uses and different degrees of pervasiveness in the health care process. Nowadays, mHealth is used in various fields related to chronic diseases, such as diabetes and cancer. However, it is still underutilized in cancer supportive care compared to its potential contribution and mHealth will only be able to support new models of care if it has a high degree of pervasiveness and a wider range of applications. Since mHealth is used for limited purposes and only in some stages of the care process, it is unlikely that it will make a real contribution in achieving new models of care.

This underutilization may depend on many issues, including environmental, regulatory, technological, organizational, and opportunistic questions [55]. It may also depend on the vision shared by health care providers with regard to the actual potential of mHealth and other technologies if applied to care processes, and the strategy they put in place in order to move in that direction. This underuse of mHealth could be due to a failure to embed it into broader information systems [56].

We suggest that we need a better understanding of the reasons for introducing mHealth: if the aim is to achieve integrated models of care, using mHealth should not be limited to certain activities or phases of the health care process. Together with other technologies, mHealth can really make a difference by enhancing performance [57,58] and improving the quality of life of cancer patients. However, this implies adequate use as part of the care process, along with adequate vision, systematic and consistent use, and alignment with the actual objectives that organizations, decision makers, and stakeholders [59,60] really want to achieve with the use of mHealth and any other technologies.

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Conflicts of Interest

None declared.

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Abbreviations

SMS: short message service

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Original Paper

Impact of mHealth Chronic Disease Management on Treatment Adherence and Patient Outcomes: A Systematic Review

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Abstract

Background: Adherence to chronic disease management is critical to achieving improved health outcomes, quality of life, and cost-effective health care. As the burden of chronic diseases continues to grow globally, so does the impact of non-adherence. Mobile technologies are increasingly being used in health care and public health practice (mHealth) for patient communication, monitoring, and education, and to facilitate adherence to chronic diseases management.

Objective: We conducted a systematic review of the literature to evaluate the effectiveness of mHealth in supporting the adherence of patients to chronic diseases management (“mAdherence”), and the usability, feasibility, and acceptability of mAdherence tools and platforms in chronic disease management among patients and health care providers.

Methods: We searched PubMed, Embase, and EBSCO databases for studies that assessed the role of mAdherence in chronic disease management of diabetes mellitus, cardiovascular disease, and chronic lung diseases from 1980 through May 2014. Outcomes of interest included effect of mHealth on patient adherence to chronic diseases management, disease-specific clinical outcomes after intervention, and the usability, feasibility, and acceptability of mAdherence tools and platforms in chronic disease management among target end-users.

Results: In all, 107 articles met all inclusion criteria. Short message service was the most commonly used mAdherence tool in 40.2% (43/107) of studies. Usability, feasibility, and acceptability or patient preferences for mAdherence interventions were assessed in 57.9% (62/107) of studies and found to be generally high. A total of 27 studies employed randomized controlled trial (RCT) methods to assess impact on adherence behaviors, and significant improvements were observed in 15 of those studies (56%). Of the 41 RCTs that measured effects on disease-specific clinical outcomes, significant improvements between groups were reported in 16 studies (39%).

Conclusions: There is potential for mHealth tools to better facilitate adherence to chronic disease management, but the evidence supporting its current effectiveness is mixed. Further research should focus on understanding and improving how mHealth tools can overcome specific barriers to adherence.

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KEYWORDS

telemedicine; mHealth; mobile health; patient compliance; patient adherence; chronic disease; diabetes mellitus; cardiovascular diseases; lung diseases

Introduction

Chronic diseases are the most common causes of death and disability worldwide [1]. Chronic disease management often requires a long-term care plan. Adherence to chronic disease management is critical to achieving improved health outcomes, quality of life, and cost-effective health care [1]. A World Health Organization review of adherence behaviors noted that, “increasing adherence may have a greater effect on health than improvements in specific medical therapy” [2]. With an average adherence rate of only 50% among patients with chronic diseases, non-adherence is a serious challenge to chronic disease management [3]. The extent of non-adherence is even higher in developing countries [3-5]. The long-term nature and frequent need for continuous monitoring in chronic disease management gave rise to early developments in telehealth and telemonitoring. These innovations, which seek to improve chronic disease management and prevent death and disability, are improved by ongoing technological advancements.

One such advancement is mHealth—health care and public health practice supported by mobile devices [6]. Close to three-quarters of the world’s population has access to a mobile phone with increasingly powerful technical capacities [7]. More than 6.9 billion mobile subscriptions were in use as of May 2014, 5.4 billion of which were in developing countries [8]. Based on their popularity, availability, portability, and technological capacity, mobile phones and mHealth have enormous potential to impact chronic disease management around the globe. A World Health Organization survey of global mHealth initiatives published in 2011 reported a “groundswell” of activity in both developed and developing countries [6]. Mobile technologies such as phones and wireless monitoring devices are increasingly being used in health care and public health practice for communication, data collection, patient monitoring, and education, and to facilitate adherence to chronic disease management [6]. mHealth devices can improve service delivery and impact patient outcomes [6]. Sensors and context-awareness features allow for individualization and real-time information submission delivery. Moreover, the strong attachment people have to mobile phones and the tendency to carry them everywhere, opens up opportunities for continuous symptom monitoring and connecting patients with providers outside of health care facilities.

While the growing popularity of mHealth is evident, its impact is not. The reported impact of mHealth interventions is mixed, with studies showing modest benefits for some clinical diagnosis and management support outcomes [9,10]. Studies have shown the positive impact of mHealth on adherence-related behavior among patients with human immunodeficiency virus (HIV) and tuberculosis. For example, short message service (SMS) appointment reminders have led to an increase in attendance among children exposed to or infected with HIV in Cameroon [11]. However, criticism of mHealth includes its implementation through small pilot initiatives that address a single disease or issue in service delivery and lack of globally accepted ways to evaluate effectiveness [7]. Systematic reviews to date are indicative of mHealth’s segmented nature, which may include a single technology or a single chronic disease or a specific mHealth application [12-14]. Another review, focused on the impact of SMS interventions, found that text messaging increased adherence to antiretroviral treatment with reductions in viral load and biochemically verified smoking cessation, yet these effects were “small and of borderline clinical importance” [9]. A more comprehensive Cochrane review assessed the health impact of SMS on any type of long-term illness, but found only four comparative effectiveness trials able to address the impact of mobile services on self-management [14]. Moreover, the literature search did not go past 2009, and we are unaware of any updates.

The impact of these mHealth tools on adherence to treatment regimens may be overlooked, as mHealth promoters are eager to demonstrate their effect on clinical outcomes (eg, morbidity, mortality, and biometric markers of clinical disease). Adherence to treatment, and specifically adherence to treatment of chronic diseases, is a critical link that connects the promise of mHealth to the ultimate goal of improved clinical outcomes. This review builds the evidence base of mHealth by updating previous reviews and assessing a broad range of outcomes from usability to impact on health outcomes. This enables us to consider mHealth tools at all stages of development and gauge the effectiveness of mHealth interventions across a range of technologies and chronic diseases, many of which have overlapping treatment regimens and require similar adherence behaviors. This review aims to evaluate the effectiveness of mHealth in supporting adherence of patients to chronic disease management—which we call “mAdherence”—and the usability, feasibility, and acceptability of mAdherence tools and platforms for chronic disease management.

Methods

Overview

We undertook a systematic review of mHealth interventions used to facilitate adherence to chronic disease management. The chronic diseases included are diabetes mellitus (DM), cardiovascular diseases (CVDs), and chronic lung diseases (CLDs). CVDs include hypertension (HTN), coronary artery disease, and congestive heart failure. CLDs include asthma and chronic obstructive pulmonary disease (COPD). These chronic diseases were chosen based on their high global burden [15]. Our definition of mHealth was adopted from the Global Observatory for eHealth definition: “medical and public health practice supported by mobile devices” [6]. We use the term “mAdherence” to refer to any use of mHealth tools by patients and health care providers to improve adherence to chronic disease management. Given the comprehensive nature of chronic disease management, this review goes beyond defining adherence as compliance with a treatment regimen and includes a wide range of interventions, such as medication reminders, symptom monitoring, educational tools, and facilitated patient-provider communication [16].

Employing Boolean phrases, we searched PubMed, Embase, and EBSCO databases for studies that assessed the role of mAdherence in chronic disease management of DM, CVD, and CLD. MeSH terms (Medical Subject Headings) and advanced search-builder features were used for the PubMed searches.

Emtree terms using the explosion function to extend the search were employed to build a multi-term query along with advanced searches in Embase. Finally, CINAHL, PsychInfo, and PsychArticles were included for searches in the EBSCO database. EndnoteWeb was used for sorting and removal of duplicates. We searched databases for articles published from 1980 through May 2014.

Inclusion and Exclusion Criteria

We included original research published in peer-reviewed journals that evaluated mHealth tools for effect on patient adherence to chronic disease management, disease-specific clinical outcomes, and usability, feasibility, and acceptability features. mHealth interventions aimed at improving chronic disease management were included even if the research did not address adherence specifically. Usability, feasibility, and acceptability studies that focused on the design and development stages of mAdherence interventions were included as a necessary precursor to future evaluation. Studies that measured adherence included outcomes such as use of the mHealth tool for monitoring and reporting symptoms, compliance with medication regimens, and engagement in healthy behaviors. Studies that focused on clinical measures, such as hemoglobin A1c (HbA1c) or blood pressure (BP), were included, as improved clinical outcomes are the eventual goal of improving adherence and often indicate adherence to chronic disease management indirectly. Allowing for flexibility in the outcomes measured was necessary for an inclusive view of mAdherence technologies in all stages of design, development, and evaluation.

mHealth included any mobile device or service, such as mobile phones, SMS, smartphones, personal digital assistants, and devices that work on wireless technology or Bluetooth-compatible devices. These devices and services allowed patients to monitor their health, access health information, and communicate with their health care provider without requiring a wired connection to the Internet. We included interventions delivered using a Web-based platform only if it was specified that the patient accessed the service via a mobile phone or other mobile device. It was required that patients be the primary users of the mAdherence tools.

Only articles reporting that the mAdherence intervention was designed for secondary prevention targeting chronic disease patients were included. We excluded reports of studies on primary prevention among healthy or at-risk groups. We also excluded articles regarding interventions that were not tested in a sample population with clearly described methods and results. In addition, review articles, editorials, commentaries, dissertations, poster presentations, abstracts only, proposals for future studies, study protocols, and descriptive articles describing new tools but not testing them in a sample population were excluded. Publication language was restricted to English only.

Data Extraction and Analysis

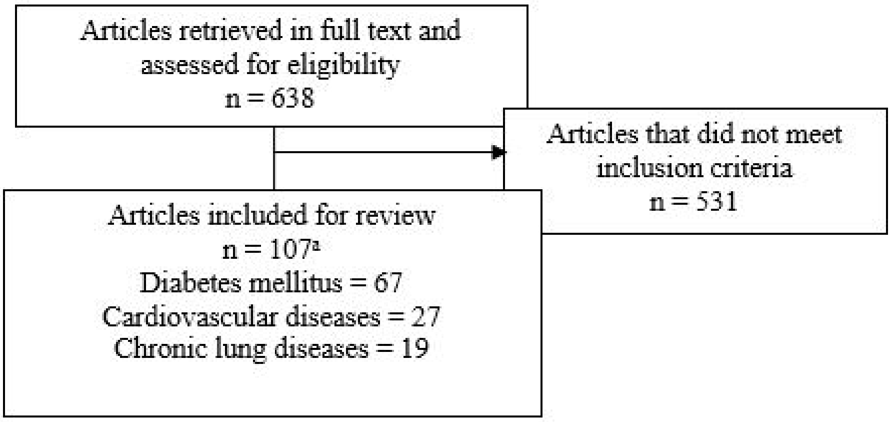
Publications were initially screened for potential inclusion based on simultaneous review of title and abstract by two reviewers. Any discrepancies were resolved by consensus among the researchers. Information including objectives, types of mobile technology used, role of mAdherence tools in chronic diseases management, setting, study sample characteristics, outcomes measured, and results reported were extracted using Microsoft Excel. Studies were organized for analysis based on the primary objective of the study and the key outcomes measured. Outcomes were organized into qualitative usability, feasibility, and acceptability of the mAdherence tool or platform among target end-users, the effect of mAdherence on patient adherence to chronic diseases management, and disease-specific clinical outcomes of the mAdherence intervention. We performed descriptive analyses of the data and summarized the findings from these studies, with emphasis on statistical results reported in randomized controlled trials (RCTs). We highlighted differences between groups when these results were available.

Results

Summary

In all, 638 articles were retrieved in full text and assessed for eligibility. Based on the search criteria, 531 articles were excluded. Of the excluded articles, many did not meet the study design criteria (n=225) or did not align with the definition of mHealth used here (n=199). A total of 60 articles were beyond the scope of the chronic diseases considered in this review, and 116 articles did not include any adherence component. An additional 20 articles were excluded because they were not available in English or a full text version was not obtainable despite all reasonable attempts. A total of 107 articles met all inclusion criteria. Figure 1 illustrates the selection process.

Figure 1. Study selection process.



[a] Six articles studied both diabetes mellitus and cardiovascular diseases.

Study Characteristics

Publication years ranged from 2003 to 2014, with an overall increase in articles published more recently (Figure 2). None of the studies published before 2003 met our inclusion criteria. A total of 34.6% (37/107) of studies were conducted in the United States, followed by 10.3% (11/107) in the United Kingdom, and 10.3% (11/107) in South Korea (Figure 3). Of note, only one study was conducted in India, one in China, and one in Africa. RCTs (46.7%, 50/107) that assessed the differences between mAdherence tools or between an mAdherence tool and standard care were the most common study design. DM (62.6%, 67/107) interventions were the most common, followed by CVD (25.2%, 27/107) and CLD (17.8%, 19/107) interventions (Table 1). Six studies targeted both DM and CVDs and were included in both categories. Study durations ranged from just a few hours to 18 months, with an average duration of around 6 months. Sample sizes also varied widely, ranging from 4 to 710 participants.

Table 1. Study designs by chronic disease (n=107).

Study design	Diabetes mellitus,n (%)	Cardiovascular disease,n (%)	Chronic lung diseases,n (%)
Randomized controlled trial	29[a] (27.1%)	17[a] (15.9%)	9 (8.4%)
Descriptive/feasibility	16[b] (15.0%)	2[b] (1.9%)	9 (8.4%)
Longitudinal/Pre- and Post-	7 (6.5%)	6 (5.6%)	0 (0%)
Quasi-experimental	8 (7.5%)	1 (0.9%)	1 (0.9%)
Crossover	7 (6.5%)	0 (0%)	0 (0%)
Retrospective	0 (0%)	1 (0.9%)	0 (0%)
Total	67 (62.6%)	27 (25.2%)	19 (17.8%)

[a] Five articles included here considered both cardiovascular disease and diabetes mellitus.

[b] One article included here considered both cardiovascular disease and diabetes mellitus.

Figure 2. mAdherence studies published over time.

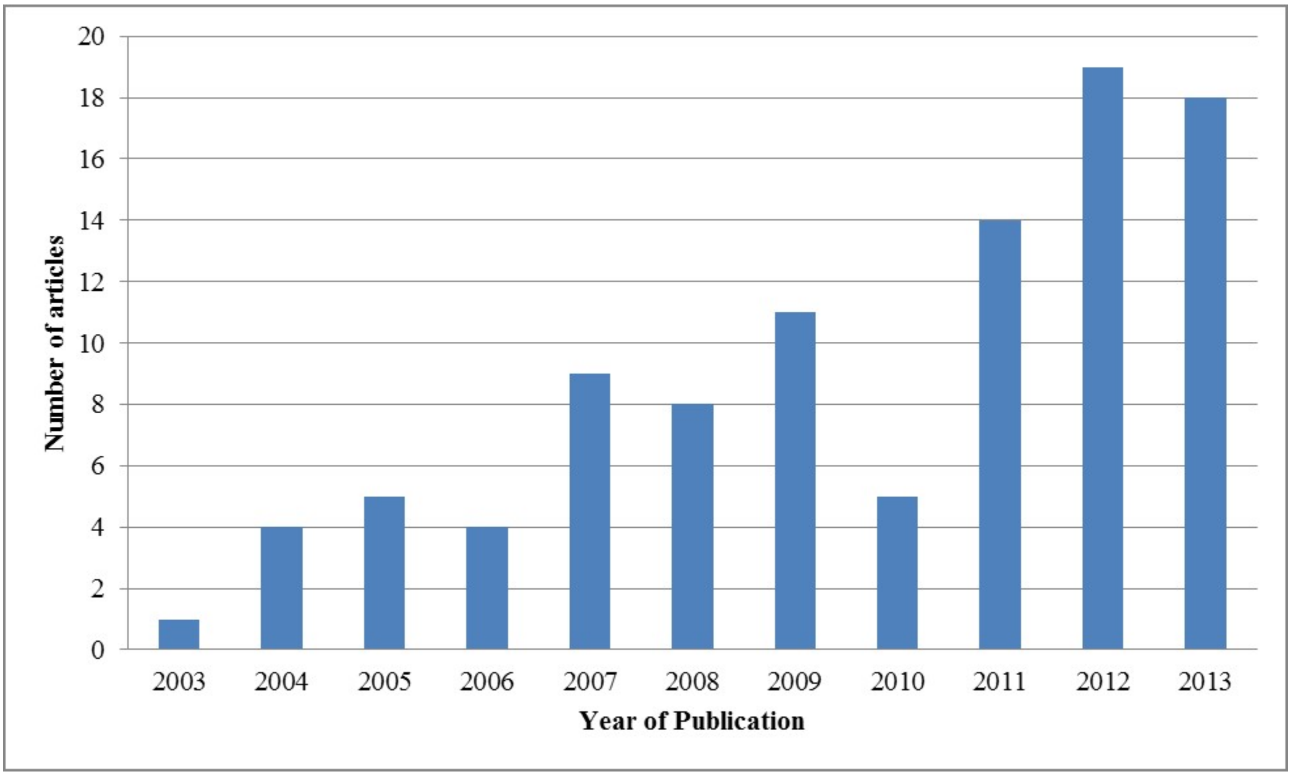


Figure 3. mAdherence studies published by country.

mAdherence Users

Several of the studies focused on the use of mAdherence tools by vulnerable, hard-to-reach, or otherwise high-risk patient populations. This included elderly patients, members of minority ethnic and racial groups, and low-income adults. The characteristics of the target user group was often the impetus for the development of the mAdherence tool. For example, researchers noted that travel to a health care provider's office can be difficult for older patients, and that mAdherence tools could lessen that burden [17]. Some studies also considered specific design considerations, such as larger device screens, that could make mAdherence tools easier to use by older adults [18]. In general, mAdherence tools targeting low-income, elderly, and minority groups were found to be usable with high satisfaction ratings [17-21]. In most of these interventions, mobile phones or other devices were either provided to users or considered a requirement for study participation. In a study that did not provide a mobile device to participants, access to mobile phones was noted to be a significant barrier [22].

In a study addressing the lack of knowledge in designing mHealth interventions for low-income and racial or ethnic minorities with DM, the authors noted that very little is known about decisions made in the mHealth design process for these patient populations [23]. An iterative design process involving systems and content development and multiple stages of user experience testing was recommended as a template for future mAdherence tools aimed at similar patient populations [23]. Ultimately, it appears that diverse individuals can use mAdherence tools as long as the tools are tailored to the needs of the population and sufficient training and support are provided [18,23].

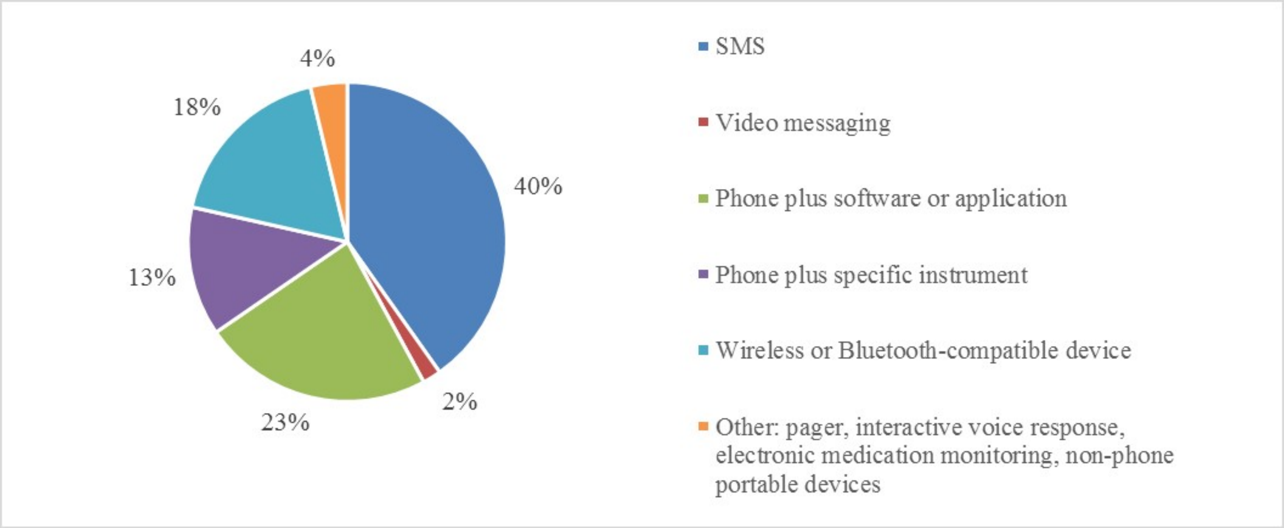
Mobile Tools Used in mAdherence

For the purposes of this analysis, we classified mAdherence tools and platforms into four main categories: SMS; phone plus software or application; phone plus specific instrument (medical device connected to phone via a cord); or phone plus wireless or Bluetooth-compatible device (Figure 4). SMS interventions require the least sophisticated hardware and can be used to transmit simple information from patients on their personal phones. Specialized software or applications including patient portals, management systems, and other complex communication platforms require only a commercially available smartphone. Here, patients generally need to manually input information. Wireless or Bluetooth-compatible refers to medical devices used by patients that transmit information wirelessly to mobile phones and computers for viewing by both patients and health care providers. Phones plus a specific instrument require additional medical hardware usually not available on a commercial smartphone.

SMS (40.2%, 43/107) was the most commonly used tool and the primary platform. SMS facilitated patient-provider communication, medication reminders, and data collection and exchange on disease-specific measurements, as well as delivered patient education and motivation [24-26]. It is important to note that while SMS was often a feature of more complex patient-provider communication platforms, the 40.2% (43/107) of studies here used SMS exclusively. The next most common mAdherence tool was specialized software or a smartphone app, used in 23.4% (25/107) of studies. Use of specialized software applications was high among patients with DM. For example, mAdherence software could be installed on the patient's mobile phone to help remember to check symptoms, maintain a food diary, or connect patients to DM educators in real time.

A wireless or Bluetooth-compatible device was used in 17.8% (19/107) of studies and a specific instrument connected to a phone, such as a blood glucose (BG) meter, was used in 13.1% (14/107) of studies. These mAdherence programs focused mainly on a combination of devices such as an electrocardiogram, BP monitor, and weighing machine with a wireless or Bluetooth interface, thus facilitating transfer of data automatically without requiring the patient to manually submit the data [27]. Data could then be reviewed by the health care provider and used to recommend an appropriate course of action. In some systems, automated criteria-based alerts were created, initiating an immediate response from the provider when measurements fell outside the target range [27,28]. CVD mAdherence programs also allowed for supervised cardiac rehabilitation by a remote monitoring system for those unable to access hospital-based programs [19].

Figure 4. Types of mobile tools used in mAdherence.



Study Outcomes and Indicators

Multiple outcome measures were used to evaluate mAdherence depending on stated study objectives. For the purposes of this analysis, the outcomes are organized into three categories: usability, feasibility, and acceptability of the mAdherence tool; effect of the mAdherence intervention on adherence to chronic disease management; and effect of the mAdherence intervention on disease-specific outcomes. In all, 62 studies (57.9%, 62/107) assessed usability, feasibility, and acceptability using qualitative methods and compiled usage data. These data ranged from patient satisfaction to cost-effectiveness estimations as well as timing and frequency of engagement with mobile tools and platforms. A total of 73 studies (68.2%, 73/107) evaluated the effect of an mAdherence intervention on adherence to chronic disease management, including medication adherence, engagement in healthy behaviors, frequency of symptom monitoring, and gains in knowledge and perceived self-efficacy. A total of 60 studies (56.1%, 60/107) assessed the effect of mAdherence on disease-specific clinical outcomes. Common clinical outcomes for DM included HbA1c, frequency of hypoglycemic events, and changes in insulin dosage. CVD measurements included changes in BP, lipid profile, and other biomarkers, as well as CVD risk profile. Examples of improved management of CLDs included indications of lung function, use of nebulizers, and exercise tests.

Usability, Feasibility, and Acceptability

A total of 57.9% (62/107) of studies assessed usability, feasibility, and acceptability or patient preferences for mAdherence interventions. In general, the studies found mAdherence tools and platforms to be usable, feasible, acceptable, and appreciated among users. The majority of studies focused on the patient as the end-user of mAdherence, though some also looked at acceptability from the provider perspective. Features of mAdherence tools such as automated reminders, text messages with educational and motivational content, healthy living challenges, and wireless transmission of data contributed to increased self-care awareness and knowledge about chronic diseases [29-33]. mAdherence tools facilitated better management and improved patient confidence to monitor chronic diseases, making the patients feel in control and strengthening coping mechanisms [34]. Patients expressed feeling reassured, with decreased anxiety, knowing that their health symptoms were regularly monitored [28]. Often, having the mAdherence system as an interface between the patient and the provider was perceived as less burdensome and judgmental compared to face-to-face contact, particularly in situations in which the patients were not fully adherent to the recommended treatment [34].

The feasibility and acceptability of mAdherence tools were evaluated across diverse patient populations, including low-income, bilingual populations, and otherwise difficult-to-reach patients. The majority of participants included in these studies reported good comprehension and satisfaction [20,21,35-37]. For example, both adolescent patients with DM and their parents perceived that using an mAdherence system increased the adolescent’s independence and confidence in disease management [25,37,38]. Adolescent patients gave high ratings regarding the usefulness and feasibility of mAdherence systems to help them remember to take their medications and be attentive to their symptoms [21,25,26,36,39]. Parents of adolescent patients appreciated the decreased burden of reminding their children to perform required testing and self-care and noted decreased parent-adolescent conflict [25]. Among elderly populations, mAdherence was accepted and considered especially useful among older patients living alone and/or with memory issues [17]. One study found that the use of the mHealth DM tool studied was conditioned by gender [40]. Men and women were motivated by different priorities in their dietary self-efficacy and wanted different information, and the authors urge that gender be taken into account for future mHealth interventions. Physician providers also favored an mAdherence system that provided patient data and supported clinical decision-making [28].

Though mAdherence tools were generally accepted, patients and providers documented a number of negative elements and perceptions. Patients’ primary concerns included dependence on professional supervision, unnecessary medicalization, and undue anxiety if technology failed [30,34]. Difficulty in understanding and using the technology were reported, including technical issues such as too many menus to navigate and small buttons on the mobile phone [31]. Some patients who had not used smartphones before found them frustrating to use [32]. Among providers, concerns included the amount of time and effort required to review data and respond in time [41]. While studies confirmed that mAdherence tools are feasible in low-income populations, cost remains a barrier to more widespread use [22]. Factors such as the cost of implementing the system, increased clinical workload and workflow, maintaining up-to-date records, and concerns about being supervised and depending too much on technology were some of the main concerns regarding implementation of mAdherence interventions [28,30,34].

Impact on Adherence

Only the subset of studies that employed a randomized comparison between two groups was included in this analysis. Descriptive studies and studies that did not involve a comparison group were excluded, as their diverse designs and methods prevented meaningful comparisons. Of the 27 RCTs that measured the effect of mAdherence on adherence behaviors, a statistically significant change or difference between groups ($P<.05$ to $P<.001$) was observed in 15 studies (56%) (Table 2). Multimedia Appendix 1 provides an overview of the methods and outcomes of these studies [18,33,35,37,42-64].

Two studies (4%, 2/27) found mixed results and 10 (37%, 10/27) showed no difference. Use of daily SMS reminders for medication intake with and without real-time medication monitoring showed significant improvements in patient adherence rates [42-46]. Text messaging tailored to counteract negative beliefs about asthma and education to overcome external barriers were associated with improved adherence to medication [43,47]. One study demonstrated the dual benefits of both better access to patient data and mobile coaching [65]. For adolescent patients with DM, employing automated, scheduled SMS programs providing motivational support was associated with improved adherence, understanding, and attention to DM care [45,48]. SMS notifications were particularly effective in increasing adherence to medication after a cardiac event [49,50]. Notably in one study, the use of an electronic blister pack with SMS communication significantly improved adherence to DM medication only and not to other types of medication [51].

Table 2. Effectiveness of mAdherence on adherence outcomes.

	Significant effect,n (%)	No significant effect,n (%)	Mixed results,n (%)	Total
Diabetes mellitus	7[a] (50%)	5 (36%)	2 (14%)	14[a]
Cardiovascular disease	5[a] (83%)	1 (17%)	0 (0%)	6[a]
Chronic lung diseases	4 (50%)	4 (50%)	0 (0%)	8
Total adherence outcome studies	15 (56%)	10 (37%)	2 (7%)	27

[a] One article is included here in both cardiovascular disease and diabetes mellitus.

Impact on Clinical Outcomes

In all, 41 studies (38.3%, 41/107) evaluated the impact of mAdherence tools on clinical outcomes (Table 3). Of the RCTs that measured the effect of mAdherence on disease-specific clinical outcomes, significant differences between groups (*P*<.05 to *P*<.001) were reported in 16 studies (39%, 16/41). No significant differences were found in 14 studies (34%, 14/41), and mixed results were observed in 11 (27%). Multimedia Appendix 2 provides an overview of the methods and outcomes of these studies [18,23,27,30,33,35,39,42,43,45,46,48,49,52-55,57-61,65-83].

A total of 26 of the RCT interventions were related to improving DM management and care. Significant improvements in DM-specific clinical outcomes such as BG, HbA1c, and two-hour postprandial BG were reported in 11 studies (42%, 11/26). Both adolescents and elderly patients receiving messages with tailored instructions on DM care experienced statistically significant improvements in their HbA1c levels [18,31,45,46,66,67,84]. A total of 13 studies evaluated mAdherence tools for CVDs. Significant improvements in clinical outcomes such as BP, weight, and lipid profile were reported in 7 studies (54%, 7/13). In one study, SMS enabled interactive monitoring so that the provider could set reminders for patients with HTN, collect data, and schedule visits for treatment adjustments [68]. This resulted in 77% of patients achieving goal BP levels. Pairing data transfer with a criteria-based alarm system that alerted and initiated contact from the physician was associated with a significant decrease in systolic BP [27]. Significant reduction in BP was also observed among HTN patients using an electronic salt sensor and mobile phone [69]. Patients with risk factors for coronary artery disease showed significant improvement after using an mHealth system consisting of an automatic sphygmomanometer, BG and lipid meter, and mobile phone [70]. Four interventions were designed to improve outcomes for patients with both DM and CVD and half these studies showed significant improvements in clinical outcomes, including HbA1c and BP control [71-74]. Mixed results in CLD clinical outcomes, mainly lung function parameters, were reported in 3 (50%) of 6 RCTs that evaluated mAdherence for CLD, and the other 3 RCTs found non-significant results. SMS interventions improved cough symptoms and sleep quality [52]. Among COPD patients, use of mobile phones installed with music software to record respiratory symptoms during their exercise training showed a significant increase in the walking distance of the incremental shuttle walk test compared to the control group [53].

Table 3. Effectiveness of mAdherence on clinical outcomes (n=41).

	Significant effect,n (%)	No significant effect,n (%)	Mixed results,n (%)	Total
Diabetes mellitus	11[a] (42%)	9 (35%)	6[a] (23%)	26[b]
Cardiovascular disease	7[a] (54%)	2 (15%)	4[a] (31%)	13[b]
Chronic lung diseases	0 (0%)	3 (50%)	3 (50%)	6
Total clinical outcome studies	16 (39%)	14 (34%)	11 (27%)	41

[a] Two articles are included here in both cardiovascular disease and diabetes mellitus.

[b] Four articles are included here in both cardiovascular disease and diabetes mellitus.

Discussion

Principal Findings

The evidence presented here indicates that while the potential of mAdherence tools is high, their implementation and execution is mixed. In all, 50 of the studies employed RCT methodology, and of those, just more than half demonstrated significant effects on adherence (56%) and less than half (40%) on clinical outcomes. SMS is the mHealth tool most widely, frequently, and successfully used to facilitate adherence to chronic disease management. Able to be used by those with little technology experience or familiarity, SMS can be made available relatively inexpensively on any mobile phone, and can be automated, personalized, and easily integrated into existing health systems. However, it is highly operator dependent, relying on the active engagement of patients and providers to monitor symptoms and exchange information, and there is clearly room for improvement. The freedom and portability of mobile devices combined with the advanced capacity to facilitate two-way communication and collect and analyze data for a real-time response offer enormous potential to patients and providers. The potential complexity of today's mAdherence tools and the mixed evidence in support of their effectiveness call for a renewed focus on understanding the connection between patient experience, adherence, and health outcomes.

More than half of the studies employed qualitative methods that yielded rich data that can be used to better understand how and why mAdherence tools impact adherence behaviors and clinical outcomes. User feedback can inform hypotheses that can then be tested. There is a growing understanding of barriers to adherence and ways to overcome them. mAdherence tools should be conceived, designed, developed, and evaluated with these barriers in mind. Research that seeks to understand how and why mAdherence works will deliver on the broader promise of mHealth. Future mHealth tools will be able to draw on the knowledge generated when discrete hypotheses around the relative importance of, for example, patient-provider communication, optimal user-interfaces, or targeted motivational messages are tested. This could lead to better mAdherence tools that deliver improved health outcomes.

This review found that the usability, feasibility, and acceptability of mHealth tools for chronic disease management adherence were generally high among both patients and providers. Innovative mAherence tools could unintentionally increase health disparities due to unequal access to technology. Vulnerable, hard-to-reach, or otherwise high-risk patient populations were the target audiences for several mAdherence interventions. There is a clear recognition that mHealth tools have the potential to impact patients who are less inclined to engage traditional health services. mAdherence offers a way to address barriers to care and to reduce health disparities. There is also some recognition that unequal access to, use of, and knowledge of information and communication technology can influence the uptake and use of mHealth tools. These inequalities and the needs of the target user group should be taken into consideration early in the design and development of the mAdherence tool. However, none of the studies included in this review addressed systematic differences in usability between diverse patient groups. Future research can be designed to better understand these differences and to encourage the development of mAdherence tools that address the needs of diverse patient groups.

Of note, few studies take seriously the issue of cost. In many of the small pilot studies, expensive devices or vouchers were given to study participants. When implemented at scale, interventions that use patients’ existing mobile devices rather than relying on gifted devices will go further toward explaining feasibility and improving adherence. Though currently concentrated in the developed world, pockets of mAdherence innovations are expanding around the globe. As developing countries work to address the burden of chronic disease, they may look to the potential of mHealth to lessen that burden. Part of that potential is to reduce costs and expand outreach. More mAdherence studies from resource-limited settings, especially in Africa and Asia, are needed. Rigorous cost-effectiveness analyses will be necessary to demonstrate not only the health impact but also the value of investing in these innovations now.

Besides cost, language, and literacy barriers, availability and connectivity issues are also potential barriers to consider. Perhaps most critically, if adherence to chronic disease management is not encouraged and actively practiced, it is very unlikely that mAdherence will be successful. mHealth tools are communication platforms and delivery mechanisms, not solutions in and of themselves. mAdherence will only work where there is already a functioning adherence program in place. Our review demonstrates that mAdherence can play a key role in translating mHealth technologies into better health outcomes. This role is becoming more explicit as mHealth research moves forward.

Limitations

There are limitations to this systematic review. It is not a meta-analysis, and we did not weigh the quality of evidence or study design against reported results. We also did not include non-English literature, and some of the studies included as few as four participants. The diversity of study objectives, designs, and outcomes made clear comparisons difficult and the quality of evidence was variable.

Our review expands the current evidence base regarding the impact of mHealth on chronic disease management adherence by including common chronic diseases, extending the definition of mHealth beyond SMS to other types of mobile and wireless communication, and by assessing both self-management outcomes and the nascent literature regarding mHealth feasibility, usability, and acceptability.

Conclusion

mAdherence is a potential high-impact tool to improve health outcomes among those living with chronic diseases through enhanced chronic disease management adherence. Further evaluation of mAdherence tools will be critical, especially research that informs how these tools overcome barriers to chronic disease management. More innovation, optimization, and high-quality research in mAdherence has the potential to transform the promise of mHealth technology into the reality of improved health care delivery and outcomes.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Randomized controlled trials that measured impact of mHealth tools on patient adherence (n=27).

[PDF File (Adobe PDF File), 101KB - jmir_v17i2e52_app1.pdf]

Multimedia Appendix 2

Randomized controlled trials that measured impact of mHealth tools on patient clinical outcomes (n=41).

[PDF File (Adobe PDF File), 136KB - jmir_v17i2e52_app2.pdf]

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Abbreviations

2Hpg: two-hour plasma glucose
AACM: active ambulatory care management
ACQ: asthma control questionnaire
ACS: acute coronary syndrome
ACT: asthma control test
AQLQ: asthma-specific quality-of-life questionnaire
baPWV: brachial-ankle pulse wave velocity
BG: blood glucose
BMI: body mass index
BNP: brain natriuretic peptide
BP: blood pressure
CARDS: Computerized Automated Reminder Diabetes System
CDSS: clinical decision support system
CGM: continuous glucose monitoring
CHD: coronary heart disease
CI: confidence interval
CIT: conventional insulin therapy
CLD: chronic lung disease
COPD: chronic obstructive pulmonary disease
CPDS: coach PCP portal with decision support
CPP: coach PCP portal
CRF: cardiovascular risk factors
CVD: cardiovascular disease
DBP: diastolic blood pressure
DID: diabetes interactive diary
DM: diabetes mellitus
ECG: electrocardiogram/electrocardiography
eNO: exhaled nitric oxide
FEV1: forced expiratory volume in one second
HbA1c: hemoglobin A1c
HCP: health care provider
HDL: high-density lipoprotein
HIV: human immunodeficiency virus
HRQL: health-related quality of life
HTN: hypertension
KASE-AQ: knowledge, attitude, and self-efficacy asthma questionnaire
LDL: low-density lipoprotein
LVEF: left ventricular ejection fraction

MEMS: Medication Event Monitoring System
MeSH: Medical Subject Headings
NICHE: Novel, Interactive Cell-phone Technology for Health Enhancement
PCA: perceived control of asthma
PCAQ-6: six-item PCA questionnaire
PCP: primary care provider
PDA: personal digital assistant
PEF: peak expiratory flow
RCT: randomized controlled trial
RR: risk ratio
RTM: remote telemedical management
RTMM: real-time medication monitoring
SBP: systolic blood pressure
SD: standard deviation
SMBG: self-monitoring of blood glucose
SMS: short message service
TACM: traditional ambulatory care management
TExT-MED: text message-based mHealth program to improve diabetes management
TM: telemonitoring
UCDC: ubiquitous chronic disease care
WAP: wireless application protocol

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Review

Medical Wikis Dedicated to Clinical Practice: A Systematic Review

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Abstract

Background: Wikis may give clinician communities the opportunity to build knowledge relevant to their practice. The only previous study reviewing a set of health-related wikis, without specification of purpose or audience, globally showed a poor reliability.

Objective: Our aim was to review medical wiki websites dedicated to clinical practices.

Methods: We used Google in ten languages, PubMed, Embase, Lilacs, and Web of Science to identify websites. The review included wiki sites, accessible and operating, having a topic relevant for clinical medicine, targeting physicians or medical students. Wikis were described according to their purposes, platform, management, information framework, contributions, content, and activity. Purposes were classified as "encyclopedic" or "non-encyclopedic". The information framework quality was assessed based on the Health On the Net (HONcode) principles for collaborative websites, with additional criteria related to users' transparency and editorial policy. From a sample of five articles per wikis, we assessed the readability using the Flesch test and compared articles according to the wikis' main purpose. Annual editorial activities were estimated using the Google engine.

Results: Among 25 wikis included, 11 aimed at building an encyclopedia, five a textbook, three lessons, two oncology protocols, one a single article, and three at reporting clinical cases. Sixteen wikis were specialized with specific themes or disciplines. Fifteen wikis were using MediaWiki software as-is, three were hosted by online wiki farms, and seven were purpose-built. Except for one MediaWiki-based site, only purpose-built platforms managed detailed user disclosures. The owners were ten organizations, six individuals, four private companies, two universities, two scientific societies, and one unknown. Among 21 open communities, 10 required users' credentials to give editing rights. The median information framework quality score was 6 out of 16 (range 0-15). Beyond this score, only one wiki had standardized peer-reviews. Physicians contributed to 22 wikis, medical learners to nine, and lay persons to four. Among 116 sampled articles, those from encyclopedic wikis had more videos, pictures, and external resources, whereas others had more posology details and better readability. The median creation year was 2007 (1997-2011), the median number of content pages was 620.5 (3-98,039), the median of revisions per article was 17.7 (3.6-180.5) and 0.015 of talk pages per article (0-0.42). Five wikis were particularly active, whereas six were declining. Two wikis have been discontinued after the completion of the study.

Conclusions: The 25 medical wikis we studied present various limitations in their format, management, and collaborative features. Professional medical wikis may be improved by using clinical cases, developing more detailed transparency and editorial policies, and involving postgraduate and continuing medical education learners.

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KEYWORDS

wikis; clinical medicine; review

Introduction

Access to information is a daily concern for clinicians, especially in general practice where the expertise field is particularly wide. Clinicians have to apply evidence-based knowledge as far as possible to manage varied and complex medical issues [1]. The medical information they use for practice must be accurate, readable, reliable, and up to date. As the use of primary sources requires documentary research methods and is time-consuming, clinicians usually refer to available syntheses such as practice guidelines, educational journals, or medical textbooks. However, these resources are often limited by language barriers [2], missing evidence [3], low acceptability [4], and conflicts of interest [5].

Wikis are websites characterized by a collaborative edition between users. A “wiki” is a type of content managing system differing from others in that the content is created without any defined owner [6]. Wikis belong to Web 2.0, which includes other interactive Web tools such as blogs (where users edit their own content), forums (where users discuss), and social networks (where users post comments) [7]. Since the wiki principle was initiated in 1995 on WikiWikiWeb, a site dedicated to programmers, hundreds of types of software have been developed to operate it [8]. Among them, MediaWiki is a worldwide reference that supports the 285 languages of the general encyclopedia Wikipedia. Subsequently, various medical wikis have emerged, including orphan diseases’ resources, terminology databases, care decision supports, and medical teaching resources [9-12]. Wikis may help to remediate other medical resources’ limitations by giving clinician communities the opportunity to build knowledge relevant to their practice [13].

The recent review of the literature about wikis and collaborative writing applications in health care by Archambault et al broadly explored use patterns, quality of information, and knowledge translation interests, and brought out a need for primary research on these applications [14]. Among the 25 articles in this review assessing the quality of the information, all but one targeted Wikipedia [15], whose medical content is controversial [16-18]. In the study published in 2009 by Dobrogowska-Schlebusch [15], 52 health-related wikis were included without specification of purpose or audience and assessed using the online Health Summit Working Group Information Quality tool (HSWG IQ tool) [19]. It globally showed poor quality scores, except for a few wikis having implemented expert moderation or peer reviews. The “quality of information” in a website actually refers either to its framework, including transparency and policy considerations such as in the HSWG IQ tool, or to its content, especially its scientific value. Assessing the content in wikis is problematic as it is only a snapshot of a long-lasting interaction [20-22].

Our study aimed at systematically reviewing medical wikis dedicated to clinical practices according to their purposes, platform, management, information framework, contributions, content, and activity.

Methods

Screening Strategy

In October 2011, we performed Google queries searching for the phrase “list of medical wikis” translated in the 10 most spoken languages on the Internet (English, Chinese, Spanish, Japanese, French, Portuguese, German, Arabic, Russian, and Korean), using the Google translation tool when necessary [23]. The phrase was expanded as far as possible within the limit of 500 resulting pages. The English query was filtered in order to remove an extensively cited page, which has been kept once for data extraction [24]. Every resulting page was browsed in order to extract Internet addresses (uniform resource locators [URLs]) linking to potentially relevant sites (Multimedia Appendix 1).

Second, we searched PubMed and Web of Science (using “wiki” AND [“medic*” OR “clinic*”]) and Literatura Latino-Americana e do Caribe em Ciências da Saúde (LILACS) (using “wiki”) in full texts for articles published until September 2012. Every open-access abstract and open access article was read, coupled with Web searches when necessary, in order to identify any potentially relevant URL (Multimedia Appendix 2).

Finally, we included any other potentially relevant URL retrieved through Web extra-browsing or expert advice, until September 2012. One author (AB) made all data extractions of the screening.

Sites’ Inclusion and Exclusion

Websites were included if they were (1) accessible from a public Internet protocol address; (2) operating a wiki tool, defining a “wiki” as “a type of content managing system (CMS) used for collaborative edition, where the content is created without any defined owner” [6], excluding wiki-based platforms used as non-collaborative CMS, like Wikinu [25], and websites where a collaborative edition was allowed on owned contents, like Google Knols [26]; (3) aimed at building some knowledge relevant for a clinical practice, defining “clinical” as “of or relating to the bedside of a patient, the course of a disease, or the observation and treatment of patients directly” [27], excluding medical topics not directly linked to the care of patients (medical research, medical informatics, biomedical sciences, medical curriculums, pharmacology, public health), and topics not specifically interesting physicians (other health care disciplines, patient information, first aid); and (4) explicitly targeting physicians or medical students in audiences. Wikis orientated toward general public, like Wikipedia, were excluded [28]. In addition, websites were excluded if they were dysfunctional, explicitly interrupted, only aiming at displaying external resources. Some clinical-oriented wikis, like Medical Matters Wiki, were excluded as bibliographic resources [29].

The inclusion and exclusion was done by 2 authors (AB and LL), and disagreements were solved by discussion.

Sites' Description and Assessment

Overview

All data collections from the included sites were performed in October and November 2012. The main language interface of each wiki, that is, the one having the biggest amount of content, was used as a reference to collect data. No direct contact to sites' administrators was undertaken. The data retrieval was done by 1 author (AB), and their assessments were performed by 2 authors (AB and LL). Disagreements were solved by discussion.

Purposes

Wikis' main purposes were described on the basis of sites' disclosures. Defining the term "encyclopedic" as a comprehensive reference work within a knowledge field [30], wikis were classified as "encyclopedic" or "non-encyclopedic" according to their statement of main purpose. Target audiences were described on the basis of sites' disclosures, considering only physicians, medical students, and lay persons.

Platform

Platforms were described according to software, user data, ergonomics, and clinically relevant utilities, by systematically browsing sites and using their functionalities.

Management

Management was described on the basis of sites' disclosures and technical characteristics. The access for editing was systematically tested anonymously and after login whenever registration was possible. A user community was defined as "closed" when the editing rights accreditation was not publicly opened. The registration process was defined as "automated" when filling out a form triggered the login access, and "on credentials" when some personal information had to be first checked. In case of hierarchy between registered users, those having special rights were consistently named "super-users", and their nomination procedure and specific roles were described. We named "administrators" those super-users having enlarged rights such as deleting or massively editing content, assigning or removing rights to users, blocking pages, blocking users, etc.

Information Framework

The Health On the Net ethical code of conduct (HONcode), as adapted for collaborative websites, was used as a reference to perform the information framework quality assessment [31]. However, the adaptation of its principle about the authoritativeness of the information only makes mandatory the disclosure of the credentials of "moderators". The wiki context makes every editing user responsible for edited content, and in a professional context, more author details than just credentials should be disclosed. We therefore built a set of 16 criteria for assessing the information framework quality, including 11 derived from the HONcode and 5 fitted to medical wikis. An operational definition was assigned to each of these criteria, including four definitions validated by Bernstam et al (Table 1) [32]. The assessment of these criteria was performed by 2 authors (AB and LL). Their agreement was measured by calculating an *r* correlation coefficient [33].

Table 1. The 16 information framework quality criteria.

Screened criteria[a]		Operational definition[b]
Owner disclosures		
1	Identity (p2)	Indication of the entity that owns the information presented on the website (o1).
2	Contact details (p6)	The webmaster or other official can be contacted. The presence of email address, telephone, fax, or online form (o2).
3	Funding (p7)	The presence of a disclosure about owner's funding.
4	Conflicts of interest (p7)	The presence of a disclosure about owner's conflicts of interest.
Disclaimers		
5	Medical advisory statement (p2)	The presence of a statement about the value of the medical content displayed on the website.
6	Users privacy policy (p3)	The presence of a disclosure about the management of the users' personal information.
7	Advertising policy (p8)	The presence of a disclosure about the advertising displayed (or not) in the website.
Editorial policy		
8	Review policy (p1)	The presence of a claim of use of an editorial review process or the listing of an editorial review committee or medical advisory board (o3).
9	Patients data protection rule (p3)	The presence of a rule for using patients' data.
10	Information referencing rule (p4)	The presence of a rule for referencing information.
11	True statement rule (p5)	The presence of a rule for editing with honesty.
12	Content organization rule	The presence of a rule for organizing the content.
User disclosures		
13	Editing users' identity	The presence of the disclosure of the identity, mandatory for every editing user.
14	Editing users' credentials	The presence of the disclosure of the authority and qualification (o4), mandatory for every editing user.
15	Editing users' conflicts of interest	The presence of the disclosure of eventual conflicts of interest, mandatory for every editing user.
16	Administrators' identity	The presence of the disclosure of the identity, mandatory for every administrator.

[a] Criteria referring to the HONcode principles [31]: p1=Information must be authoritative; p2=Purpose of the website; p3=Confidentiality; p4=Documented information; p5=Claims justification; p6=Website contact details; p7=Funding source disclosure; p8=Advertising policy.

[b] Operational definitions validated by Bernstam et al [32]: o1=Disclosure of ownership; o2=Feedback mechanism provided; o3=Editorial review process; o4=Author's credentials disclosed.

Contributions

Physicians were considered as contributors by default, except when they were not targeted in the audience. The contributions of medical learners (students or physicians) were described based on educational objectives, or when mentioned in super-users' credentials. Lay persons' contributions were described according to the registration requirements. The presence of clinical case reports was systematically searched by querying sites with the key word "case". Any content reporting some clinical materials issued from users' practice was considered.

Content

This part of the study aimed at describing the characteristics of the contents and assessing their readability. However, the scientific value of contents in itself was not assessed. From each wiki, we selected a sample of the 5 most revised articles. Articles were included if they had a clinically relevant topic and were written in the main language of the wiki. In sites where the numbers of revisions were not available, we subjectively selected the most finalized articles. We described characteristics related to content (presence of pictures, videos, diagrams, posology details, evidence levels and external resources, and numbers of words and references per article) and data related to edition (numbers of revisions and authors per article, and related talks). The sampled articles were assessed with Flesch's reading ease test adapted to each language and performed with automated hyphenation [34]. Characteristics of articles were compared between encyclopedic and non-encyclopedic groups by using Fisher's exact test for qualitative data and the Wilcoxon rank test for quantitative data.

Activity

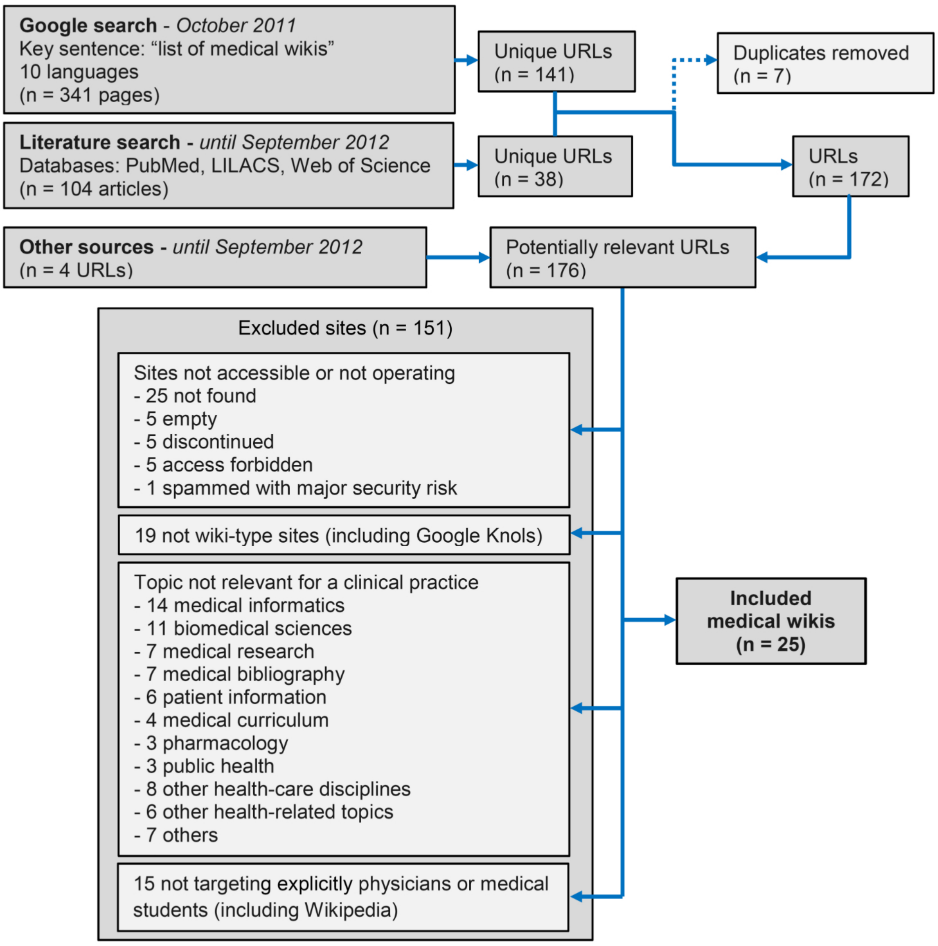
Wikis' global activities were described on the basis of available data from sites (absolute numbers of content pages, revisions, and talk pages). Displayed numbers of users were considered globally inaccurate since we suspected tens of false user registrations across several sites, presumably due to vandalism attacks. In order to estimate annual activity, content pages were counted according to their last edition date by performing empty queries on Google, filtered on each URL, and for each year since the wiki's creation. A recent editorial rate was estimated by reporting the number of pages last edited in the 365 previous days to that edited since creation. Rates higher than 50% were considered as "very high", and rates lower than 10% were considered as "very low". A recent editorial trend was estimated by reporting the number of pages last edited in the 365 previous days to that last edited in the 365 days before. Trends higher than 300% were considered as "sharply increasing" and trends lower than 33% as "sharply decreasing".

Results

Sites' Screening

The Google search yielded 341 pages, including 27 linking to some potentially relevant URLs. After extraction and removing duplicates, 141 URLs were collected (Multimedia Appendix 1). The literature search yielded 133 articles, 104 after removing duplicates. After identification of potentially relevant URLs and removing duplicates, 38 URLs were collected (Multimedia Appendix 2). Four additional potentially relevant URLs were retrieved from other sources. Merging all results and removing duplicates, 176 potentially relevant URLs were finally collected (Figure 1, Multimedia Appendix 3).

Figure 1. Site screening, exclusion, and inclusion flow diagram.



Sites' Exclusion and Inclusion

Of the 176 collected URLs, 31 met the inclusion criteria. Six of them became inoperative during the study. Finally, 25 wikis were retained for analysis [35-59] (Figure 1; Multimedia Appendix 3).

Sites' Description and Assessment

Purposes

The main languages were English (19 wikis), German (3), French (2), and Chinese (1), and four wikis had a second language interface. The purpose was encyclopedic for 11 wikis, including one also aiming at reporting clinical cases. Among the 14 wikis having a non-encyclopedic purpose, five aimed at editing a textbook, three medical lessons, two oncology protocols, one a single focused article, and three at reporting clinical cases, including one also displaying a textbook-like wiki area. Whereas 16 wikis were specialized to specific themes or disciplines, nine were not. Physicians were explicitly targeted by 22 wikis, medical learners by 18, and lay persons by five (Table 2).

Table 2. Wikis' purposes.

Wiki	Language	Main purpose(s)	Target audience
Encyclopedic			
Medpedia [35]	English	Medical encyclopedia	Physicians, Learners, Laypeople
Ganfyd [36]	English	Medical knowledge base	Physicians
AskDrWiki [37]	English	Medicine	Physicians, Learners
DocCheck Flexikon [38]	German, English	Medical lexicon	Physicians
Toxipedia [39]	English, Spanish	Toxicology encyclopedia	Physicians, Learners
EyeWiki [40]	English	Ophthalmology encyclopedia	Physicians, Learners
Radiopaedia [41]	English	Radiology encyclopedia & clinical case reports	Physicians
Wikiecho [42]	English	Echography encyclopedia	Physicians
wikiRadiography [43]	English	Radiography resource	Physicians
Pathowiki [44]	German	Pathology encyclopedia	Physicians, Learners
Pathpedia [45]	English	Pathology wikibook	Physicians, Learners, Laypeople
Non-Encyclopedic			
Textbook			
WikiDoc [46]	English	Medical textbook	Physicians, Learners, Laypeople
WardWiki [47]	English	Junior doctors help	Physicians, Learners
WikEM [48]	English	Emergency Medicine point of care reference	Physicians, Learners
Open Anesthesia [49]	English	Anesthesia textbook & critical care manual	Physicians, Learners
ECGpedia [50]	English, Dutch	ECG textbook & tutorial	Physicians, Learners
Lessons			
MedRevise [51]	English	Medical course revision	Learners
Mediwiki.fr [52]	French	Medical course revision	Learners
Wikia Biomedwiki [53]	German	Bio-medical learning aid	Physicians, Learners
Protocols			
Oncologik [54]	French	Oncology protocols	Physicians
OncoWiki [55]	English	Oncology regimens	Physicians
Single article			
Open Medicine Live Wiki [56]	English	Second line oral therapy in type 2 diabetes	Physicians, Learners, Laypeople
Clinical cases reports			
Dermpedia [57]	English	Dermatology knowledge and experience sharing	Physicians, Learners
Orthochina [58]	Chinese, English	Orthopedic clinical cases	Physicians, Learners, Laypeople
UCLA Radiology Residents Pediatric Imaging [59]	English	Radiology clinical cases	Learners

Platform

MediaWiki in its native form was supporting 15 sites. Three sites were hosted by online "wiki farms", that are ready-to-use multifunctional platforms [60-62]. The remaining seven sites had purpose-built platforms, including two developed upon MediaWiki. As opposed to every purpose-built platform, only one site using MediaWiki natively systematically managed users' real names and credentials. Wiki farms and purpose-built platforms included various forms of forums and social networks. Editing on MediaWiki required using a specific mark-up language, whereas all other software had a "What You See is What You Get" editing interface. Three wikis had automated links to PubMed or Cochrane library external databases. Two wikis operated a semantic management for synonyms or keywords. Two wikis provided some medical imaging facilities (Table 3).

Table 3. Wikis' platform.

Wiki	Software	Purpose-built	User disclosures management	Relevant utilities[a]
Encyclopedic				
Medpedia [35]	MediaWiki	✓	✓	
Ganfyd [36]	MediaWiki			Bibl. links
AskDrWiki [37]	MediaWiki			
DocCheck Flexikon [38]	MediaWiki	✓	✓	
Toxipedia [39]	Other	✓	✓	
EyeWiki [40]	MediaWiki			
Radiopaedia [41]	Other	✓	✓	Imaging + semantics
Wikiecho [42]	MediaWiki			
wikiRadiography [43]	Online wiki farm			
Pathowiki [44]	MediaWiki			
Pathpedia [45]	Other	✓	✓	
Non-Encyclopedic				
Textbook				
WikiDoc [46]	MediaWiki			Bibl. links + semantics
WardWiki [47]	MediaWiki			
WikEM [48]	MediaWiki		✓	
Open Anesthesia [49]	MediaWiki			
ECGpedia [50]	MediaWiki			
Lessons				
MedRevise [51]	MediaWiki			
Mediwiki.fr [52]	MediaWiki			
Wikia Biomedwiki [53]	Online wiki farm			
Protocols				
Oncologik [54]	MediaWiki			Bibl. links
OncoWiki [55]	MediaWiki			
Single article				
Open Medicine Live Wiki [56]	MediaWiki			
Clinical case reports				
Dermpedia [57]	Other	✓	✓	
Orthochina [58]	Other	✓	✓	Imaging
UCLA Radiology Residents Pediatric Imaging [59]	Online wiki farm			

[a] Bibl. links=automatized links to external resources (PubMed, Cochrane, etc); Semantics=key words management; Imaging=medical imaging facilities.

Management

Sites' owners were non-profit organizations (n=10), individuals (n=6), private companies (n=4), scientific societies (n=2) or universities (n=2), and one could not be identified. Six wikis restricted access to their talk pages and users' profile areas, and one wiki restricted access to its articles. Two wikis allowed any visitor to edit without registering. Registration was automated in 11 wikis, based upon credentials in 10, and limited to a closed community in four. A hierarchy between registered users existed in 14 wikis, among which three restricted the edition (or the validation of edition proposals) to super-users only. Super-users could be organized in "editorial boards" (n=9), responsible for the whole content, in "lead authors" (n=4), responsible for some articles, or in "moderators" (n=2), responding on call. Super-users were nominated without any explicit procedure in 10 wikis, subjectively in consideration of users' credentials or activity in two wikis, and following a systematic procedure based on a score or a vote in two wikis. Super-users were divided in more than two types of roles in four wikis (Table 4).

Table 4. Wikis' management.

Wiki	Governance[a]	Edit right accreditation	Authoring structure	Super-users nomination	>2 super-user roles
Encyclopedic					
Medpedia [35]	Universities	Super-uservonly	Lead authoring	On credentials[b] + on score[c]	
Ganfyd [36]	NPO	On credentials[b]	None	-	
AskDrWiki [37]	NPO	Super-user only	Lead authoring	On credentials	✓
DocCheck Flexikon [38]	PC	(any visitor)	None	-	
Toxipedia [39]	NPO	Automated	Editorial board	N/A	
EyeWiki [40]	SS	On credentials	Editorial board	N/A	
Radiopaedia [41]	PC	Automated	Editorial board	N/A	
Wikiecho [42]	NPO	Automated	Editorial board	N/A	
wikiRadiography [43]	Individuals	Automated	Moderators	N/A	
Pathowiki [44]	University	On credentials	None	-	
Pathpedia [45]	PC	Automated	Editorial board	N/A	
Non-Encyclopedic					
Textbook					
WikiDoc [46]	NPO	On credentials	Editorial board	N/A	✓
WardWiki [47]	N/A	Closed	-	-	
WikEM [48]	NPO	Automated	Editorial board	On credentials + editorial activity	✓
Open Anesthesia [49]	SS	Automated	Editorial board	N/A	
ECGpedia [50]	NPO	On credentials	Lead authoring	N/A	
Lessons					
MedRevise [51]	Individuals	On credentials	None	-	
Mediwiki.fr [52]	Individuals	On credentials	None	-	
Wikia Biomedwiki [53]	Individual	(any visitor)	None	-	
Protocols					
Oncologik [54]	NPO	Closed	-	-	
OncoWiki [55]	Individual	Closed	-	-	
Single article					
Open Medicine Live Wiki [56]	NPO	Automated	None	-	
Clinical case reports					
Dermpedia [57]	PC	Automated	Editorial board + lead authoring	N/A	
Orthochina [58]	NPO	Super-user only	Moderators + editorial board	Automated + on score[d] + vote	✓
UCLA Radiology Residents Pediatric Imaging [59]	Individual	Closed	-	-	

[a] NPO=non-profit organization; PC=private company; SS=scientific society

[b] Proof of credentials required.

[c] Score based on forum contributions and edit proposals.

[d] Score based on a multiple choice test and forum contributions.

Information Framework

The owner's identity was displayed on 19 wikis, its contact details on 21, its funding sources on 14, and its potential conflicts of interest on seven. A medical advisory statement was displayed on 17 wikis, a policy for users' privacy on 17, and a policy about advertising on 10. A review policy was displayed on 10 wikis, a rule for the protection of patients' data on 11, a rule for referencing information on nine, a rule for delivering true information on 11, and a rule for organizing content on five. The editing users' identity was systematically displayed on nine wikis, their credentials on seven, their potential conflicts of interest on two, and the administrators' identity was systematically displayed on three wikis, which were all made by students [51,52,59]. The total information framework quality score ranged from zero to 15 out of 16, with a median score of 6 (Table 5). The correlation between raters was fair (R^2=.68). Beyond these criteria, only one wiki organized standardized peer-reviews [39].

Table 5. Wikis' information framework quality assessment.

Wiki	Owner disclosures (n=4)	Disclaimers (n=3)	Editorial policy (n=5)	User disclosures (n=4)	Total (n=16)
Encyclopedic					
Medpedia [35]	4	3	5	3	15
Ganfyd [36]	3	2	2	0	7
AskDrWiki [37]	4	1	2	0	7
DocCheck Flexikon [38]	3	2	0	0	5
Toxipedia [39]	4	3	3	3	13
EyeWiki [40]	4	3	3	0	10
Radiopaedia [41]	4	3	4	2	13
Wikiecho [42]	2	2	1	0	5
wikiRadiography [43]	0	2	0	0	2
Pathowiki [44]	3	2	3	0	8
Pathpedia [45]	4	2	3	2	11
Non-Encyclopedic					
Textbook					
WikiDoc [46]	4	3	5	0	12
WardWiki [47]	0	2	3	0	5
WikEM [48]	2	1	0	3	6
Open Anesthesia [49]	3	0	2	0	5
ECGpedia [50]	3	2	2	0	7
Lessons					
MedRevise [51]	3	2	2	1	8
Mediwiki.fr [52]	2	1	1	1	5
Wikia Biomedwiki [53]	0	2	0	0	2
Protocols					
Oncologik [54]	2	0	1	1	4
OncoWiki [55]	1	1	0	0	2
Single article					
Open Medicine Live Wiki [56]	0	0	0	0	0
Clinical case reports					
Dermpedia [57]	3	2	2	2	9
Orthochina [58]	1	2	1	2	6
UCLA Radiology Residents Pediatric Imaging [59]	2	1	1	1	5

Contributions

Physicians were considered as contributors by default in all wikis except the three made by and for students [51,52,59]. Medical learners contributed according to a formal educational goal on four wikis, and as super-users on five wikis. Lay persons contributed to four wikis. Clinical cases were reported on nine wikis (Table 6).

Table 6. Wikis' contributions.

Wiki	Lay people	Learners[a]	Formal educational goal	Clinical case reports
Encyclopedic				
Medpedia [35]				✓
Ganfyd [36]				
AskDrWiki [37]				
DocCheck Flexikon [38]	Free edition			
Toxipedia [39]	Registered only			
EyeWiki [40]				
Radiopaedia [41]				✓
Wikiecho [42]				
wikiRadiography [43]				✓
Pathowiki [44]		PG		✓
Pathpedia [45]				
Non-Encyclopedic				
Textbook				
WikiDoc [46]				✓
WardWiki [47]				
WikEM [48]		PG	✓	
Open Anesthesia [49]		PG	✓	
ECGpedia [50]		PG		✓
Lessons				
MedRevise [51]		UG		✓
Mediwiki.fr [52]		UG + PG		
Wikia Biomedwiki [53]	Free edition	UG		
Protocols				
Oncologik [54]				
OncoWiki [55]				
Single article				
Open Medicine Live Wiki [56]	Registered only			
Clinical case reports				
Dermpedia [57]				✓
Orthochina [58]		CME	✓	✓
UCLA Radiology Residents Pediatric Imaging [59]		PG	✓	✓

[a] UG=undergraduate, PG=postgraduate, CME=practicing physicians in continuing medical education.

Content

As only one wiki displayed a single article and another did not allow access to its relevant content, 116 articles were sampled, including 58 most revised and 58 most finalized. Numbers of authors were not available for five encyclopedic articles. Numbers of revisions and of authors were not available for five non-encyclopedic articles. Pictures, videos, and external resources were more frequent in articles from encyclopedic wikis. Posology details were more frequent in articles from non-encyclopedic wikis ($P<.01$). The Flesch reading ease scores were lower in encyclopedic wikis (Table 7).

Table 7. Features of content, of edition, and readability of articles according to wiki purpose (N=116 articles).

Wiki purpose	Encyclopedic (n=55)	Non-encyclopedic (n=61)	*P* value
	n (%) or median (min-max)	n (%) or median (min-max)	
Content			
Pictures, n (%)	33 (60.0)	23 (37.7)	.025
Videos, n (%)	7 (12.7)	0 (0.0)	.004
Diagrams, n (%)	3 (5.5)	8 (13.1)	.211
Posology, n (%)	5 (9.1)	24 (39.3)	< .001
Evidence levels, n (%)	0 (0.0)	2 (3.3)	.497
External resources, n (%)	33 (60.0)	21 (34.4)	.009
References, median (min-max)	3 (0-87)	2 (0-105)	.400
Words, median (min-max)	1248 (94-4945)	654 (38-16265)	.353
Edition, median (min-max)			
Revisions	40 (2-261)	40.5 (2-516)	.953
Authors	3 (1-34)	3 (1-6)	.067
Talks	0 (0-24)	0 (0-2)	.099
Readability, median (min-max)			
Flesch's reading ease score	26.1 (-11.4-50.6) (college graduate)	33.9 (-55.5-87.6) (college)	.041

Activities

Wikis had been created between 1997 and 2011 (median year: 2007). Content pages per wiki varied from 3 to 98,039 (median 620.5), revisions per content page from 3.6 to 180.5 (median 17.7), and talk pages per content page from 0 to 0.42 (median 0.015). Among five particularly active wikis, three had a high previous year editorial rate and three a sharply increasing editorial trend. Among six wikis almost unused, six had a low previous year editorial rate, and three a sharply decreasing editorial trend. The activity of one wiki having a sharply increasing trend upon a very low previous editorial rate was not interpreted (Table 8). Two wikis included in this review were discontinued after the completion of the study [35,47].

Table 8. Wikis' activities.

Wiki	Year of creation	Content pages	Revisions / content pages	Talk pages / content pages	2011-12 editorial rate[a,b], %	2010-12 editorial trend[a,c]
Encyclopedic						
Medpedia [35]	2002	4000	85.3	0.02	36	→
Ganfyd [36]	2005	7979	6.7	0.14	18	→
AskDrWiki [37]	2006	1406	4.8	< 0.01	4	→
DocCheck Flexikon [38]	2002	18,017	8.5	0.02	73	↗
Toxipedia [39]	2006	1910[a]	N/A	N/A	34	→
EyeWiki [40]	2010	142	79.2	0.20	41	→
Radiopaedia [41]	2005	5131	N/A	N/A	44	→
Wikiecho [42]	2007	N/A	N/A	N/A	N/A	N/A
wikiRadiography [43]	2006	1730[a]	N/A	N/A	10	↘
Pathowiki [44]	2010	425	11	< 0.01	27	→
Pathpedia [45]	2006	N/A	N/A	N/A	0	N/A
Non-Encyclopedic						
Textbook						
WikiDoc [46]	2006	98,039	6.7	< 0.01	38	↗
WardWiki [47]	2010	324	11.4	0	0	↘
WikEM [48]	2010	126	N/A	0.01	64	→
Open Anesthesia [49]	2008	1023	N/A	0.02	60	→
ECGpedia [50]	2006	1241	17.7	0.02	16	→
Lessons						
MedRevise [51]	2008	597	21.8	0.01	8	→
Mediwiki.fr [52]	2008	216	29.4	0.02	32	↗
Wikia Biomedwiki [53]	2006	75	36.0	0.02	4	↗
Protocols						
Oncologik [54]	2011	152	180.5	0.42	48	→
OncoWiki [55]	2011	112	3.6	0.01	N/A	N/A
Single article						
Open Medicine Live Wiki [56]	2011	3	29.0	0	0	↘
Clinical case reports						
Dermpedia [57]	2008	601	N/A	N/A	18	→
Orthochina [58]	1997	N/A	N/A	N/A	N/A	N/A
UCLA Radiology Residents Pediatric Imaging [59]	2008	640	N/A	0	17	→

[a] Estimated with Google.

[b] [Last year edited pages]/[total pages]: >50%=high rate; <10%=low rate

[c] [Last year edited pages]/[year before edited pages]: ↗=sharply increasing trend (>300 %); ↘=sharply decreasing trend (<33 %); →=stable trend.

Discussion

Principal Findings

From this international review, we identified 25 medical wikis dedicated to clinical practices. The majority were in English and four were bilingual. They had various purposes, dominated by encyclopedic perspectives (44%), and most were specialized (64%). The MediaWiki software was commonly used (68%), often in its native form (60%). Site owners were mostly non-profit organizations (40%) and individuals (24%); only two were universities. While practicing physicians were major contributors (88%), medical learners (36%) and lay persons (16%) sometimes contributed.

Cross-reading our results, the relevancy for clinicians of the medical wikis can be discussed according to four information properties: accuracy, readability, reliability, and currency. Accuracy may be impaired in wikis not displaying a review policy (60%) and in those not delivering rules for organizing content (80%) [63,64]. The articles from encyclopedic wikis presented characteristics less relevant for professional use than the others, including more pictures, videos, and external resources but fewer posology details. The Flesch reading ease scores were globally low, especially for encyclopedic articles. In regard to reliability, 64% of wikis fulfilled less than half of the information framework quality criteria. In addition, articles were poorly referenced, and evidence level notifications were exceptional. Finally, 88% of the wikis had fewer than 50% of articles revised in the last year, and 24% of the sites were almost unused.

Strengths and Limitations

Our review may not have been exhaustive as the Google search was restricted to lists of medical wikis and several sites reported in the health literature were not accessible. Furthermore, the Web 2.0 field is rapidly changing, and some new medical wikis may have emerged since October 2012. Re-browsing the lists of medical wikis used in this study, we found only one relevant wiki after the inclusion period: the Australian Cancer Guidelines Wiki [65]. Among the 25 included sites, Medpedia and WardWiki have been discontinued [35,47], and a few changes occurred in the structure of the others: Open Anesthesia has been reorganized [49], WikiEcho and MedRevise changed their “skin” [42,51], and Oncologik added a missing link to its owner [54].

Among the tools available for assessing the quality of health information on websites, none is currently validated and none is fitted either to wikis or to a professional audience [66,67]. The HSWG IQ tool does not take into account collaborative features, as acknowledged by Dobrogowska-Schlebusch [15], and it has been removed from the Web [19]; the DISCERN tool targets health consumers and is restricted to information on treatments [68]; and the Bomba and Land Index has also been designed for health consumers [69]. Numerous items are common between these questionnaires and major guidelines such as the eHealth code of ethics [70], the American Medical Association guideline [71], or the eEurope 2002 quality criteria [72]. The HONcode ethical code of conduct is unique to provide specifications for collaborative websites [31,73]. For example, the item “is the information referenced?” will be transposed for collaborative websites as “is there a statement asking platform users to give references to the information they provide?”. Such specifications do not directly apply to the content, but indirectly through the editorial framework. However, the right influence of the framework on the content deserves to be investigated in future research projects.

The relevancy of low readability scores, corresponding to college and higher, is arguable since medical doctors have *de facto* a high level of reading. It has been long demonstrated that readability impacts both the understanding and the cross-reading ability, even for highly educated readers [74], and the need for simplicity is expressed by clinicians themselves for practice guidelines [4]. The relevancy of the Flesch reading ease test for medical writings is also debatable, but more specific tools are not yet validated [75]. Although it includes adjustment parameters adapted to several languages [34], a linguistic bias cannot be excluded in this study since multilingual comparisons have not been documented.

To check the validity of the estimation of annual editorial activities using Google, we measured the agreement between the number of content pages declared on the site and the corresponding estimate from the Google search engine, for 20 wikis. Although there was a strong agreement (Spearman correlation coefficient=.88, P<.001), automated page creation and vandalism may bias both figures.

Unmet Clinical Needs

Our results suggest that no medical wiki meets all four information properties needed by clinicians. The encyclopedic format does not seem to fit in terms of both accuracy and readability. However, whatever the wikis’ purposes, the organization of contents is often unclear, apart from very focused purposes such as oncology protocols, where the knowledge granularity is adapted to a particular audience [54]. The Medical Subject Headings (MeSH) indexing system is sometimes integrated, but it requires specific training for contributors, which is challenging in a multi-authoring context [76]. Whereas some semantic utilities can help manage indexation constraints [10,77], add-ons aimed at improving either medical knowledge management or ergonomics are rarely implemented in medical wikis. If such gaps impact both accuracy and readability, they may also hamper the involvement of users. Contrary to pure knowledge content, the frequent clinical case reports in medical wikis, supporting the emergence of concrete questions of practice, are likely to meet strong clinical interest.

Reliability is widely, and sometimes critically, impaired by lack of management. Although authoring transparency requires both technical and policy supports [5], our framework assessment particularly shows gaps in users’ disclosures and editorial policies. Since almost only purpose-built platforms are able to manage detailed user data, technical issues are important. Among open communities, only 48% of medical wikis ask for credentials to register, with two requiring some proof [35,36]. As an alternative, users’ medical skills can be assessed during an automated registration including medical tests [58,78]. Interestingly, the fully opened Wikipedia’s articles are commonly consulted by clinicians and medical students [79], while their relevancy has been recurrently questioned [7,14,16-18,21]. However, Wikipedia, including its Wikiproject Medicine, cannot respond to specific clinical needs as it does not target any specific audience [28]. As an encyclopedic media, it is also likely to meet the limitations highlighted in this study.

In most wikis, weak and poorly collaborative activity jeopardizes content updates. The talk pages, when available, are exceptionally used, and the discussion threads included in forums or social networks are not directly connected to content pages [80]. As a consequence, adversarial debates are lacking, although they are a foundation for building evidence [3].

The Open Community Challenge

Users' regulation in wikis is complex since the lower the control of their editors, the higher their growth [81]. For example, Wikipedia's English article on atrial fibrillation has been revised approximately 1345 times and discussed 150 times [82], and the article on the recent drug dabigatran 555 times and 35 times respectively [83]. Apart from the severe reliability issues due to anonymity in Wikipedia [84], it has been shown that its development, based only on volunteering, leads articles to be unevenly readable, complete, and reliable [17,20,85]. In our study, we paradoxically observed the highest page revision and discussion levels in a small wiki reserved to a closed community [54]. This finding suggests that a strong user commitment can overcome volunteering limitations.

Although multi-authoring requires a thorough organization [86], communities attached to medical wikis are often poorly structured. Super-user nominations are usually opaque, and only one wiki provides a standardized peer-review process [39]. As implemented in two wikis, the extent of users' rights can depend on their participation level [35,58], which represents a reward for authors [87]. However, in order to open scientific debates, the organization of bottom-up relations between users should be further considered [88]. In this way, the public expertise promoted by Wikipedia, which is based on consensus, uses a complex and democratic moderation system, detailed editorial rules, and standardized peer-reviews [21].

While the HONcode principle about the authoritativeness of the information protects the moderators' privacy by allowing their anonymity [31], it cannot guarantee the trustworthiness of what they have written [84,89]. The professional scope of our review highlights a lack of audience specifications in health information quality initiatives, in particular for collaborative applications where readers and writers are mixed altogether. The extensive review of social media by Grajales et al provides a useful tutorial for health care professional end users, which may be a first step to building more detailed guidelines for professional health information on the Internet [7]. Indeed, some professional knowledge may generate adverse outcomes, as information on drugs with potential for misuse is commonly sought on the Internet [90]. Therefore, as included in the wikiproject Medicine of Wikipedia [21], a policy specifying the nature and the limits of publicly accessible content is critical, and a model for displaying health information is needed [67,73].

Educational Value Added

Among eight medical wikis including learners' contributions, five include spontaneous undergraduate or postgraduate students' contributions. The three others have a formal educational goal, targeting postgraduate students or practicing physicians in continuous medical education [49,58,59]. Educational goals may represent an alternative to mere volunteering since learners' contributions can be part of their curricula. As works performed in training are frequently based on clinical cases as starting points for gathering scientific evidence [91,92], the wiki principle seems particularly fitted to archive, share, discuss, and gradually improve the related materials [93]. From a theoretical point of view, the wiki medium, as an asynchronous communication tool, embodies learning principles based on constructivism and cooperation [94]. Nevertheless, if Internet-based educational programs can be an alternative to live interactive workshops [95], the effectiveness of collaborative writing applications in medical education requires further research [12,14].

Conclusions

The 25 medical wikis reviewed present various limitations in their format, management, and collaborative features. Encyclopedic wikis have less accurate and readable content. Reliability is widely impaired by lack of transparency. Currency is commonly jeopardized by low editorial activity. Professional medical wikis may be improved by using clinical cases, developing more detailed transparency and editorial policies, and involving postgraduate and continuing medical education learners.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Google search.

[PDF File (Adobe PDF File), 245KB - jmir_v17i2e48_app1.pdf]

Multimedia Appendix 2

Literature search.

[PDF File (Adobe PDF File), 81KB - jmir_v17i2e48_app2.pdf]

Multimedia Appendix 3

Site exclusions and inclusions.

[PDF File (Adobe PDF File), 186KB - jmir_v17i2e48_app3.pdf]

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Abbreviations

CMS: Content Managing System
HONcode: Health On the Net code of ethics
HSWG IQ tool: Health Summit Working Group Information Quality tool
MeSH: Medical Subject Headings
URL: Uniform Resource Locator

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Original Paper

Twitter Sentiment Predicts Affordable Care Act Marketplace Enrollment

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Abstract

Background: Traditional metrics of the impact of the Affordable Care Act (ACA) and health insurance marketplaces in the United States include public opinion polls and marketplace enrollment, which are published with a lag of weeks to months. In this rapidly changing environment, a real-time barometer of public opinion with a mechanism to identify emerging issues would be valuable.

Objective: We sought to evaluate Twitter's role as a real-time barometer of public sentiment on the ACA and to determine if Twitter sentiment (the positivity or negativity of tweets) could be predictive of state-level marketplace enrollment.

Methods: We retrospectively collected 977,303 ACA-related tweets in March 2014 and then tested a correlation of Twitter sentiment with marketplace enrollment by state.

Results: A 0.10 increase in the sentiment score was associated with an 8.7% increase in enrollment at the state level (95% CI 1.32-16.13; *P*=.02), a correlation that remained significant when adjusting for state Medicaid expansion (*P*=.02) or use of a state-based marketplace (*P*=.03).

Conclusions: This correlation indicates Twitter's potential as a real-time monitoring strategy for future marketplace enrollment periods; marketplaces could systematically track Twitter sentiment to more rapidly identify enrollment changes and potentially emerging issues. As a repository of free and accessible consumer-generated opinions, this study reveals a novel role for Twitter in the health policy landscape.

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KEYWORDS

affordable care act; social media; health insurance marketplace

Introduction

The Patient Protection and Affordable Care Act (ACA), often referred to as Obamacare, established health insurance marketplaces in 2013 to extend coverage to more Americans. The health insurance marketplaces, also known as “exchanges”, are Web-based platforms where consumers can compare and purchase health insurance plans [1]. In the marketplaces’ first year, the majority of US states used the federal marketplace on HealthCare.gov (eg, federally facilitated marketplace), while 17 states set up their own health insurance exchange websites (eg, state-based marketplace) [2]. However, the ACA has been publicly debated, and the marketplaces struggled with technical issues in the first open enrollment period from October 2013 to April 2014, which was the time period designated for consumers to purchase a new health insurance plan in the marketplaces [3-10].

With such monumental and sometimes controversial changes, both supporters and opponents awaited measures of success or failure that included surveys of public support for the ACA and reports of marketplace enrollment, meaning the number of people purchasing health insurance plans in the marketplace (eg, marketplace plans) by state [11-14]. The release of these traditional metrics, however, lagged weeks to months. This delay was particularly relevant for the marketplaces as federal and state agencies worked to understand what was happening and address issues as they arose. In this rapidly changing environment, a real-time barometer of public opinion with a mechanism to identify emerging issues would have been valuable.

Twitter, an online micro-blogging social media outlet that allows for measure of public sentiment, is a potential new tool to monitor the rollout of major health policy. Twitter sentiment (the positivity or negativity of tweets) has previously been used to measure public perception on a range of health topics, from disease outbreaks and disaster response to health care quality and health reform [15-18]. In the debate around the ACA, Twitter became a prominent platform for scrutiny and praise. Twitter members used hashtag terms #ACA and #Obamacare to track these conversations. In this study, we sought to evaluate Twitter’s role as a real-time barometer of public sentiment on the ACA and to determine if Twitter sentiment could be predictive of state-level marketplace enrollment.

Methods

Overview

To evaluate the relationship between Twitter sentiment and marketplace enrollment, we retrospectively collected ACA-related tweets by state and then tested a correlation of Twitter sentiment with marketplace enrollment by state.

Twitter Data Collection

We collected ACA-related tweets from March 1-31, 2014, using the Twitter Search Application Programming Interface [19]. Specifically, we selected all tweets containing the terms “ACA”, “#ACA”, “Obamacare”, and “#Obamacare” (a total of 977,303 tweets) as well as those that were directed toward the Twitter account handles for HealthCare.gov (eg, @HealthCaregov) and the 17 state-based marketplace Twitter accounts (an additional 34,605 tweets; see Multimedia Appendix 1). Additionally, we collected a random sample of 977,303 tweets from March 2014 to use as a comparison group for the sentiment of ACA and Obamacare tweets.

Tweet content and geolocation data, when available, were extracted. Twitter provides latitude and longitude coordinates or the self-reported location of the Twitter user. For the self-reported location, we matched the location text with state names, state abbreviations, and the 60 most populated cities in the United States. To verify this automatic technique, we manually examined 400 randomly selected mappings and found 99% accuracy.

Twitter Sentiment

Twitter sentiment was measured using the National Research Council (NRC) sentiment lexicon [20]. The lexicon contains a list of 54,120 words along with sentiment weights ranging from positive values for positive sentiment to negative values for negative sentiment (eg, the word “excellent” has a positive sentiment weight, while “awful” is negative). The NRC lexicon was created in a data-driven fashion by analyzing tweets with positive and negative sentiment hashtags. Specifically, Mohammad et al use the point-wise mutual information metric to find an association between words and their being a part of a tweet with a positive or negative sentiment hashtag [20]. The lexicon was validated against a hand-annotated set of tweets as part of the SemEval-2012 sentiment task and was found to perform with an F1 value of 0.65. We are not aware of any lexicon achieving better accuracy over a standard set of Twitter data.

To apply the lexicon to a tweet, we computed the *relative frequency* for each word in the tweet (eg, the word frequency divided by total number of words in the tweet) and *word sentiment scores* per tweet by multiplying the *sentiment weight* by the *relative frequency* of each word. A single sentiment score for each tweet was produced by summing all *word sentiment scores* for the tweet. This is illustrated in the following equation where *sentiment(word)* is the NRC lexicon sentiment score for the word, *frequency* is the number of times the word occurred in the tweet, and *frequency_all_words* gives the number of (non unique) word instances in the tweet:

$$\textit{sentiment score(tweet)} = \Sigma_{\text{word}\varepsilon\text{tweet}} \text{sentiment(word)} * \text{frequency(word, tweet)/frequency\_all\_words(tweet)}$$

These scores were then standardized by *Z* scores, and a state’s sentiment score was calculated as the average sentiment of tweets in the state.

The NRC sentiment lexicon has been used to produce state-of-the-art accuracies for general domain tweets [20]. However, because our ACA corpus of tweets is biased compared to general tweets, we validate the NRC sentiment lexicon over our tweets. We randomly sampled 300 tweets from our corpus and had 2 raters score the sentiment from -3 (extremely negative) to 0 (neutral) to 3 (extremely positive); interrater reliability was strong (intraclass correlation=.72). We found the

NRC sentiment lexicon was significantly correlated with the mean of the human ratings (r=.26; P<.001).

Marketplace Enrollment Data

We used health insurance marketplace enrollment data by state from the Office of the Assistant Secretary for Planning and Evaluation and the Kaiser Family Foundation, which provides the number of people who selected a new health insurance plan in the marketplaces through March 31 and the special extended enrollment period through April 19, 2014 [12,21]. The total number of consumers eligible to enroll in a marketplace plan included legally residing individuals who were uninsured or purchased non-group coverage, had incomes above Medicaid/CHIP eligibility levels, and who did not have access to employer-sponsored coverage. The estimate excluded uninsured individuals with incomes below the federal poverty level in states that did not expand Medicaid [12,22]. The percent eligible who selected a plan represented the number of participants who selected a marketplace plan (with or without receipt of the first premium payment) divided by the total number of consumers eligible to enroll in a marketplace plan.

Data Analysis

Descriptive statistics and paired t tests were used to assess Twitter sentiment for ACA and Obamacare tweets, tweets directed to (eg @) the HealthCare.gov handle and state-based marketplace handles, and the random sample of comparator tweets. State Twitter sentiment for tweets containing ACA, #ACA, Obamacare, or #Obamacare were mapped using ArcGIS version 10.1.

The correlation between sentiment for ACA and Obamacare tweets and the percent of eligible individuals who selected a marketplace plan was assessed using a linear regression with robust standard errors. Adjusted analysis controlling for state Medicaid expansion [22] and if a state had a state-based or federally facilitated marketplace [2] were also conducted. Vermont was excluded as an outlier since their enrollment rate was over 2.5 standard deviations above the mean.

All analyses were conducted using STATA 13.1. The study was deemed exempt by the University of Pennsylvania Institutional Review Board.

Results

Sentiment for ACA and Obamacare tweets was significantly more negative compared to the random sample of tweets (0.44 standard deviations [SD] lower, P<.001). Tweets containing ACA or #ACA had a higher sentiment compared to those with Obamacare or #Obamacare (0.46 SD higher; P<.001). The sentiment of tweets at the HealthCare.gov handle was 0.20 SD lower than tweets at the state-based marketplace handles (P<.001). Table 1 provides examples of positive and negative sentiment tweets.

Of the 977,303 tweets, 449,553 (46.00%) were geocoded to the state level. Figure 1 shows the state-level distribution of Twitter sentiment for ACA and Obamacare. The mean percent eligible enrolled across states was 23.5% (SD 11.7%).

A 0.10 increase in sentiment score was associated with an 8.7% increase in enrollment at the state level (95% CI 1.32-16.13; P=.02) (Figure 2). The correlation remained significant when adjusting for state Medicaid expansion (P=.02) or whether states had a state-based or federally facilitated marketplace (P=.03).

Table 1. Sample tweets with positive and negative sentiment for ACA, Obamacare, and the health insurance marketplaces.

	Positive sentiment	Negative sentiment
#ACA or ACA	It's such a relief to have AFFORDABLE health insurance while just working part-time. My policy starts 4/1 and I'm so grateful for the ACA!	His 38% approval belies an unprecedented level of distrust. His hyper partisanship has destroyed his credibility! @GOP #IRS #ACA #Benghazi
	Another family covered under ACA in Texas -- my son & his family with pre-existing conditions of asthma & epilepsy! #ACAworks	RT If you are a Victim of ObamaCare #ACA #ObamaCare #CNN #Tcot #Pjnet #Hannity #NRA #Benghazi #NSA #IRS @CNN #Obama
Obamacare or #Obamacare	Healthy citizens are the greatest asset any country can have. ~Winston Churchill~ #GetCovered #ObamaCare	Once again @BarackObama is breaking the law by telling illegals to enroll in ObamaCare and the taxpayer will pay their insurance cost
	#Obamacare is a #HUGE Success! Run on that record!	@BarackObama I rather pay penalty then enroll to expensive #obamacare sucks
Tweets at state-based marketplaces (eg, @NYStateofHealth, @MarylandConnect)	Thanks to @CoveredCA, my mom has insurance for the 1st time in 3 years & can get new glasses for the first time in +10 years #ACA #thankyou	@NMHIX -Obamacare is a joke. Should trash what is left of it and leave the folks alone to figure their needs.
	@AccessHealthCT I am excited to share that we will be having an ACA recognition brunch this weekend here at CHC-Middletown #enrollCT	Concerning how I CANT get #ObamaCare in #Maryland NO customer service for password issues. BIG #FAIL for @MarylandConnect
Tweets at HealthCare.gov (@HealthCaregov)	@HealthCareGov I found a plan (or two) for less than $50... praise God, cause lord knows I'm broke phi broke. #ACA #ThankYou	@HealthCareGov @BarackObama How is Obamacare going to work if u can't even get the website or the enroll by phone to work? I want to sign up
	Best part of my week: When I took out my wallet for copay at the dr. and was reminded checkups now free. Thanks @HealthCareGov! #ACA	@HealthCareGov @WhiteHouse Obamacare is anti-choice and hurts people…

Figure 1. Sentiment of tweets about the Affordable Care Act or Obamacare by state, March 2014. Twitter sentiment (the positivity or negativity of tweets with higher sentiment scores indicating more positive sentiment) are presented in quartiles.

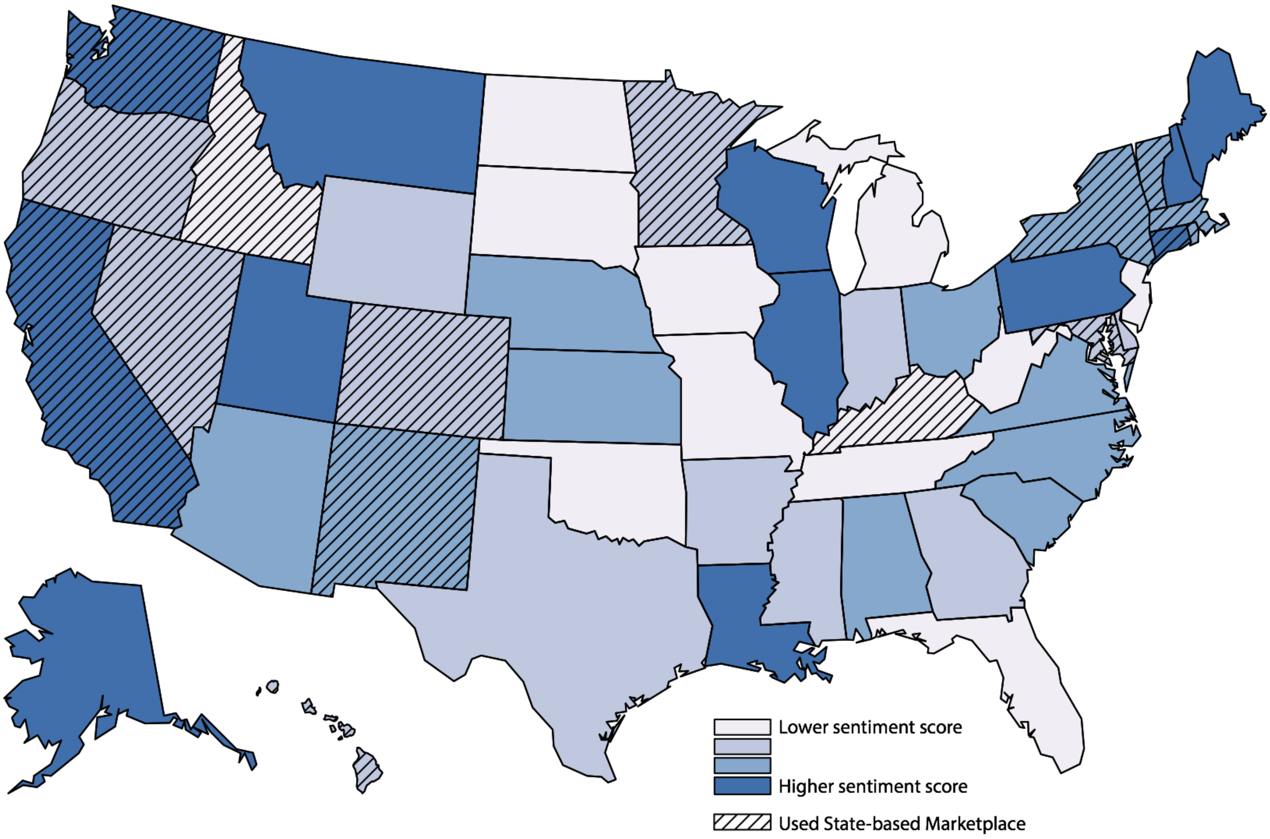
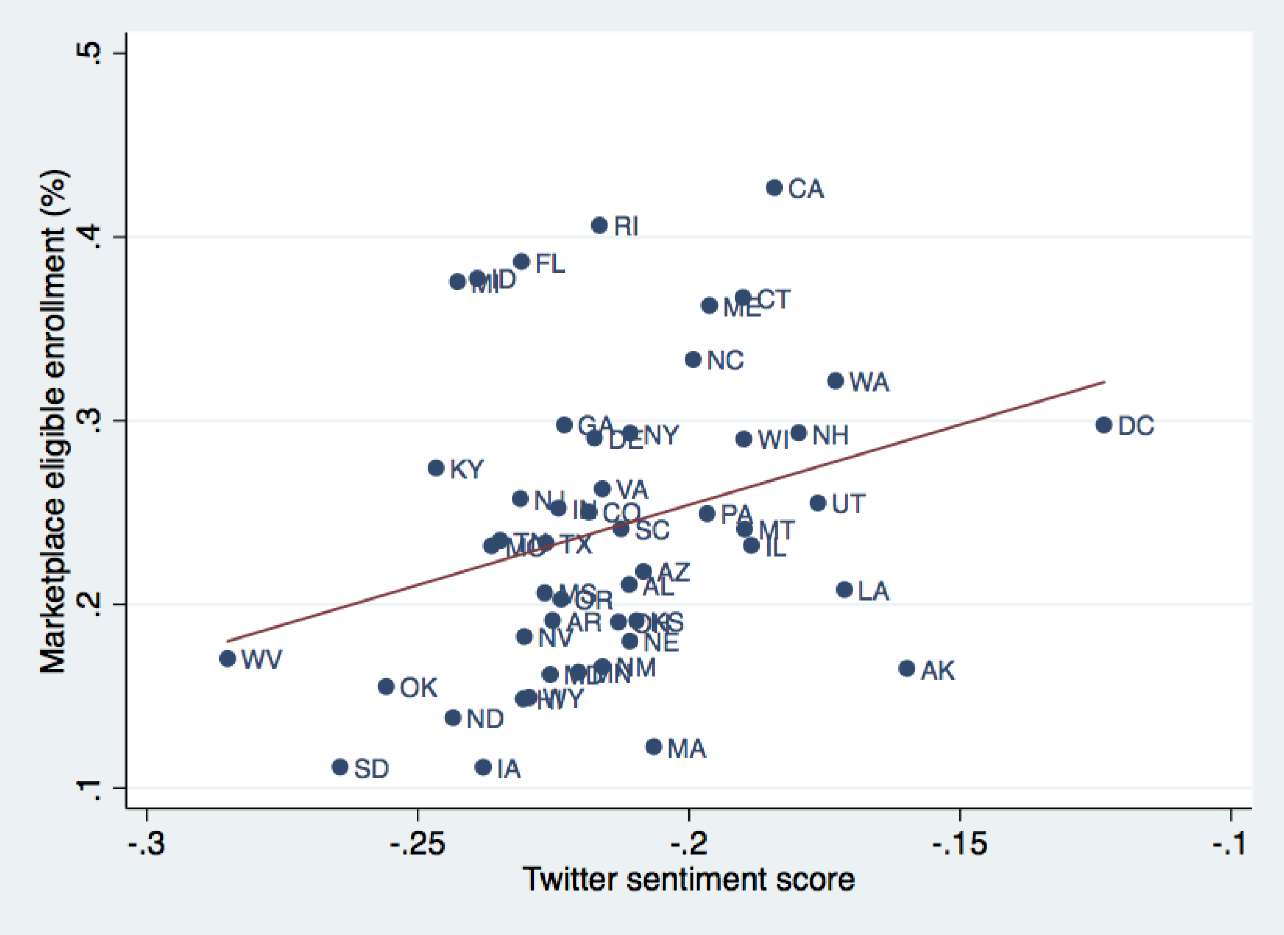


Figure 2. Correlation between Twitter sentiment and health insurance marketplace enrollment by state, March 2014. Abbreviations indicate US state. Vermont excluded due to outlier marketplace enrollment.



Discussion

Principal Findings

In our study conducted during the first open enrollment period of the health insurance marketplaces, we identified a significant correlation at the US state level between the ACA-related Twitter sentiment and the percent of eligible individuals who enrolled in a marketplace plan under the ACA. This correlation indicates the potential for Twitter to be a real-time monitoring strategy for future health insurance marketplace enrollment periods. Marketplaces could leverage systematic tracking of Twitter sentiment through commercially available software packages to more rapidly identify signals that indicate changes in marketplace enrollment, including emerging issues [23]. For example, a down-trending Twitter sentiment may indicate a problem in the marketplace, which could be further delineated by examining the content of negatively skewed tweets.

Strengths and Limitations

Our study was limited by examination of a single month of Twitter and marketplace enrollment data, though March 2014 enrollment surpassed all prior months [21]. Further analyses are needed to assess if the correlation remains robust in the next open enrollment period and if content analyses could be used to address emerging issues in real time. Additionally, non-geocoded tweets that were excluded from analysis may have differed from those that were geocoded, though the absolute Twitter sentiment for each group was similar. Finally, further examination of states in which Twitter sentiment and marketplace enrollment were discordant are needed.

Of note, some studies using social media have recently come under scrutiny for manipulating people and violating their privacy [24,25]. Concern for such research was directed toward both the use of private data and the performance of an intervention without a clear informed consent. Neither of those properties apply to this study: we used public archival data and did not attempt to intervene on Twitter users' lives. We believe studies like ours, which simply present statically grounded observations over public data, pose no risk to individuals and present no ethical concerns. Our study was approved by the University of Pennsylvania's Institutional Review Board under "exempt" status.

Conclusions

Twitter is a repository of free and accessible consumer-generated opinions [26]. Our study adds to a body of work indicating that Twitter is an emerging part of the health and health policy landscape [15,27-30]. The novel methodology used in our study linking Twitter sentiment to ACA implementation data may be an innovative way to inform how to improve the health care system in real time and may be applicable to other settings as health policy is implemented [15]. As the public debate over the ACA continues and federal and state marketplaces deal with the November 2014 open enrollment session, those managing the marketplaces and monitoring the ACA rollout may consider adding Twitter to their data and evaluation toolkit.

Acknowledgments

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Conflicts of Interest

Tom Baker and Robert Town are two of the co-founders of Picwell, Inc., a health information/technology company that leverages big data and predictive analytics to help consumers optimize health plan choice.

Multimedia Appendix 1

Twitter handles for state-based health insurance marketplaces.

[PDF File (Adobe PDF File), 3KB - jmir_v17i2e51_app1.pdf]

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Abbreviations

ACA: Affordable Care Act
NRC: National Research Council

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Original Paper

How Computer Literacy and Socioeconomic Status Affect Attitudes Toward a Web-Based Cohort: Results From the NutriNet-Santé Study

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Abstract

Background: In spite of the growing literature in the field of e-epidemiology, clear evidence about computer literacy or attitudes toward respondent burden among e-cohort participants is largely lacking.

Objective: We assessed the computer and Internet skills of participants in the NutriNet-Santé Web-based cohort. We then explored attitudes toward the study demands/respondent burden according to levels of computer literacy and sociodemographic status.

Methods: Self-reported data from 43,028 e-cohort participants were collected in 2013 via a Web-based questionnaire. We employed unconditional logistic and linear regression analyses.

Results: Approximately one-quarter of participants (23.79%, 10,235/43,028) reported being inexperienced in terms of computer use. Regarding attitudes toward participant burden, women tended to be more favorable (eg, “The overall website use is easy”) than were men (OR 0.65, 95% CI 0.59-0.71, *P*<.001), whereas better educated participants (>12 years of schooling) were less likely to accept the demands associated with participation (eg, “I receive questionnaires too often”) compared to their less educated counterparts (OR 1.62, 95% CI 1.48-1.76, *P*<.001).

Conclusions: A substantial proportion of participants had low computer/Internet skills, suggesting that this does not represent a barrier to participation in Web-based cohorts. Our study also suggests that several subgroups of participants with lower computer skills (eg, women or those with lower educational level) might more readily accept the demands associated with participation in the Web cohort. These findings can help guide future Web-based research strategies.

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KEYWORDS

computer literacy; Internet; cohort study; attitudes

Introduction

The use of Web-based questionnaires in prospective epidemiological studies has increased steadily over the past decade [1-11], driven by substantial logistic simplification (cost-effectiveness, convenience regarding place/time of survey completion, ease of converting data to an analyzable format) and scientific advantages (improved quality and quantity of exposure measurement, complex research designs, study of sensitive topics or rare conditions) of Web compared to traditional methods (paper-and-pencil questionnaires, face-to-face interviews). Other features, such as recruitment of very large samples and hard-to-reach populations (low socioeconomic strata, risky behavior profiles), quick returns, and data management facility and flexibility, are also strengths of e-epidemiology [12,13]. This medium for data collection is being increasingly favored given the growth of Web access and the use of personal computers [2]. In the United States, 75% of households were connected to the Internet in 2012 [14]. In France, this proportion was similar in 2012 (78%) compared to 54% in 2007 [15]. In this context, it remains unknown the extent to which low computer and Internet literacy represent a barrier to participation in Web-based studies. Very few Web-based epidemiological studies have provided information about the level of computer and Internet skills of their participants [16].

Another key question pertains to perceived respondent burden in Web-based studies (eg, regarding frequency and length of questionnaires) and its variability according to computer skills, age, gender, and the educational level of participants. Indeed, it has been shown that perceived ease and user-friendliness of the study website and the level of perceived difficulty of questionnaire completion may have a major impact on response and completion rates in e-epidemiology [17-19]. However, data are lacking in the literature regarding opinions and acceptance of respondent burden in Web-based studies and its correlation with computer skills of participants. Filling this knowledge gap would be useful for ongoing and future Web-based cohort studies, for instance, for improving and adapting the design of questionnaires according to the target population.

Thus, our objectives were (1) to assess computer and Internet skills of participants in a large Web-based cohort (the NutriNet-Santé study) and (2) to compare their attitude toward study demands according to sociodemographic background and computer literacy.

Methods

Participants

The ongoing NutriNet-Santé study is the first large-scale Web cohort set up to investigate the relationships between nutrition and health in the general population [4]. It was launched in France in May 2009 to evaluate the determinants and characteristics of eating behavior and the relationship between nutrition and chronic disease risk. Participants are recruited by a vast multimedia campaign. Inclusion criteria are age ≥18 years and access to the Internet. Registration and participation take place online using a dedicated and secure website. Participants receive regular emails informing them about a new questionnaire available for completion and communicating study results and newsletters. The study website also provides general information on health and nutrition topics and on scientific publications related to the cohort. Contact between investigators and study participants is established by the Internet (dedicated website and emails). This study was approved by the Institutional Review Board of the French Institute for Health and Medical Research (IRB Inserm No 0000388FWA00005831) and the “Comission Nationale de l’Informatique et des Libertés” (CNIL No 908450 and No 909216).

Data Collection

Participants completed a baseline set of 5 self-administered, Web-based questionnaires on sociodemographic and lifestyle characteristics, anthropometrics, dietary intake (using repeated 24-hour dietary records), and physical activity along with health status. Thereafter, these baseline questionnaires are administered each year to update the information. All these instruments have been tested against traditional assessment methods (paper questionnaires or interview by a health professional) [20-22].

Data on sociodemographic characteristics included age, gender, education, and occupation. In October 2013, participants were sent a computer literacy Web questionnaire in which they were asked to self-evaluate their level of computer skills (novice, inexperienced, experienced, or expert) and to report if they were able to perform specific computer/Internet tasks in order to evaluate their computer literacy profile. This questionnaire also aimed to gather information on perceived respondent burden in the NutriNet-Santé study (ease of website use, interest in the information section, acceptable frequency and completion time of the questionnaires, satisfaction with the communication between study staff and participants, potential interest in a NutriNet-Santé smartphone application). This questionnaire was not mandatory and no reminders were sent to nonresponders.

Statistical Analyses

From the 123,984 participants included in the NutriNet-Santé study between May 2009 and October 2013, 43,028 individuals (34.70%) returned the optional questionnaire on computer skills and Internet use.

Sociodemographic characteristics are presented in a frequency/percent format for the entire sample: gender, age (<30 years, 30-44 years, 45-59 years, ≥60 years), educational level (>12 or ≤12 years of schooling), and occupational category (farmers, manual workers, employees, intermediate professions/skilled office work, self-employed, managerial staff, never employed). Similarly, overall and task-specific computer skills are presented in a frequency/percent format.

Opinions about respondent burden in the NutriNet-Santé study were compared by multivariate unconditional logistic regression analyses according to sociodemographic characteristics (gender: women vs men; age: >50 years vs ≤50 years; education: >12 years vs ≤12 years of schooling) and self-evaluated level of computer skills (experienced-expert vs novice-inexperienced). Actual and self-perceived acceptable questionnaire completion times were compared by multivariate linear regression analyses according to the same sociodemographic characteristics and self-evaluated level of computer skills. These variables were log-transformed to improve normality. Adjusted means and standard errors (SE) were reported. Multivariate models were mutually adjusted for gender, age, educational level, and self-evaluated level of computer skills.

A *P* value <.05 was considered statistically significant. Analyses were carried out with SAS version 9.3 (SAS Institute Inc, Cary, NC, USA).

Results

Sociodemographic characteristics of the study population (N=43,028) are presented in Table 1. In all, 76.07% (32,731/43,028) of the participants were women and the mean age was 51.2 years (SD 14.5). The sample included 35.16% (15,130/43,028) managerial staff, 28.37% (12,209/43,028) intermediate professions/skilled office work, 26.83% (11,544/43,028) technical/routine occupations, 2.83% (1217/43,028) self-employed, 2.77% (1191/43,028) farmers and manual workers, and 4.04% (1737/43,028) never-employed participants (current occupation or most recent job for retired or currently unemployed participants).

Table 1. Baseline characteristics of respondents to the computer literacy questionnaire, NutriNet-Santé cohort, France, 2013.

Individual characteristics	French population,[a] % (N=48,730,086)	Full NutriNet-Santé cohort, n (%) (N=123,984)	Respondents to the computer literacy questionnaire, n (%) (N=43,028)
Gender			
Female	52.4	96,912 (78.16)	32,731 (76.07)
Male	47.6	27,072 (21.84)	10,297 (23.93)
Age categories (years)			
<30	22.8	18,518 (14.94)	4298 (9.99)
30-44	24.8	40,432 (32.61)	10,626 (24.70)
45-59	24.8	35,923 (28.97)	13,623 (31.66)
≥60	27.6	29,111 (23.48)	14,481 (33.65)
Educational level			
Advanced/graduate degree (≥17 y of schooling)	13.0	40,274 (32.48)	14,457 (33.60)
Undergraduate degree (13-16 y of schooling)	11.9	36,579 (29.50)	12,663 (29.43)
Secondary degree (≤12 y of schooling)	17.6	43,070 (34.74)	14,526 (33.76)
Elementary degree (≤5 y of schooling)	40.2	2375 (1.92)	942 (2.19)
No degree	17.3	1686 (1.36)	440 (1.02)
Level of computer skills			
Expert			5365 (12.47)
Experienced			27,428 (63.74)
Novice			9288 (21.59)
Inexperienced			947 (2.20)

[a] National Institute of Statistics and Economic Studies (INSEE), 2014.

Computer and Internet Skills

A substantial proportion of the participants (23.79%, 10,235/43,028) evaluated themselves as novice or inexperienced in computer use. This was illustrated by the description of specific skills (Table 2). For instance, 36.42% (14,881/43,028) did not know usual keyboard shortcuts (eg, CTRL+C, CTRL+V), 38.74% (16,667/43,028) did not know how to post messages on discussion forums, and 37.53% (16,147/43,028) did not know how to place a telephone call by the Internet.

Table 2. Self-reported computer and Internet skills of participants (n=43,028), NutriNet-Santé Study, France, 2013.

Self-reported computer and Internet skills	Positive responses, n (%)
Computer skills	
Copy or move a file or folder	39,693 (92.25)
Transfer files between a computer and a device (digital camera, USB stick, cell phone, etc)	37,827 (87.91)
Burn or copy a CD/DVD	32,466 (75.45)
Install new devices (modem, printer, scanner, webcam, etc)	31,465 (73.13)
Use basic arithmetic formulas in a spreadsheet (Excel, Open Office Calc, etc)	27,357 (63.58)
Create electronic presentation	25,102 (58.34)
Use keyboard shortcuts (CTRL+C, CTRL+V, CTRL+X, etc)	28,147 (65.42)
Compress/decompress (or zip) files	23,794 (55.30)
Install or update an operating system (Windows XP, Windows 7, Windows 8, Mac OS, Linux)	18,992 (44.14)
Change or check the configuration settings for a software	18,352 (42.65)
Upgrade a computer (desktop or laptop) by changing the hard disk or memory (RAM)	6614 (15.37)
Write a computer program (C, C++, PHP, HTML, Java, etc)	3359 (7.81)
Internet skills	
Use a search engine (Google, Yahoo, Bing, etc)	42,288 (98.28)
Send emails with attached files (document, photo, etc)	41,333 (96.06)
Fill in administrative forms online	39,718 (92.31)
Buy or sell goods and services online	36,509 (84.85)
Use instant messaging software (Yahoo, Facebook, Skype, Windows Messenger, Google Talk, etc)	29,522 (68.61)
Phone by connecting to the Internet (Skype, Yahoo Messenger, Google Talk, etc)	26,881 (62.47)
Post messages in online discussion forum or chat site	26,361 (61.26)
Download movies, music, games, etc	26,019 (60.47)
Change the security parameters of a Web browser	24,019 (55.82)
Upload text, games, photos, movies or music (on social networks like Facebook or Twitter, for example)	21,025 (48.86)
Create and manage a blog	10,158 (23.61)
Create and manage a website	6435 (14.96)

Opinions and Attitudes Toward Study Demands

Overall acceptance of the study was high: 94.50% (40,662/43,028) reported that the website use was easy, 91.32% (39,293/43,028) were satisfied with the current frequency of questionnaire administration, and 25.22% (10,852/43,028) reported that even a higher frequency than the one currently employed (ie, 1 questionnaire/month) would be acceptable (Tables 3 and 4).

Table 3. Opinions and attitudes toward the NutriNet-Santé Study demands according to gender and age, NutriNet-Santé Study, France, 2013.[a]

Opinions and attitudes	n (%)	Gender (female vs male)		Age (>50 y vs ≤50 y)	
		OR (95% CI)	*P* [b]	OR (95% CI)	*P* [b]
The overall website use is easy			<.001		.06
Agree	40,662 (94.50)	1.00 (Reference)		1.00 (Reference)	
Disagree	2366 (5.50)	0.65 (0.59, 0.71)		1.09 (1.00, 1.19)	
The information section is interesting			<.001		<.001
Agree	29,231 (67.93)	1.00 (Reference)		1.00 (Reference)	
Disagree	2042 (4.75)	0.61 (0.55, 0.68)		0.62 (0.56, 0.68)	
I don’t read these sections	11,755 (27.32)	0.90 (0.86, 0.95)		0.52 (0.50, 0.55)	
What do you think about the frequency of the questionnaire mailing?			<.001		<.001
The current frequency suits me	39,293 (91.32)	1.00 (Reference)		1.00 (Reference)	
I receive questionnaires too often	2900 (6.74)	0.80 (0.73, 0.87)		1.25 (1.15, 1.35)	
I would like to receive questionnaires more often	835 (1.94)	1.01 (0.85, 1.21)		0.30 (0.25, 0.35)	
What is the maximum acceptable frequency to complete a questionnaire?			.07		<.001
Once per week	2126 (4.94)	0.96 (0.86, 1.07)		0.32 (0.29, 0.36)	
Once every 2 weeks	8726 (20.28)	0.99 (0.94, 1.06)		0.51 (0.49, 0.54)	
Once per month (ie, current frequency)	24,936 (57.95)	1.00 (Reference)		1.00 (Reference)	
Once every 3 months	6138 (14.27)	1.00 (0.94, 1.07)		1.37 (1.29, 1.46)	
Once every 6 months	829 (1.93)	0.75 (0.64, 0.88)		1.53 (1.31, 1.80)	
Once per year	273 (0.63)	0.67 (0.52, 0.87)		1.85 (1.39, 2.47)	
Would you prefer to be contacted by means other than the Internet?					
Yes, by mail	2206 (5.13)	1.35 (1.20, 1.52)	<.001	0.57 (0.52, 0.62)	<.001
Yes, by phone	1123 (2.61)	0.83 (0.73, 0.96)	.01	0.78 (0.69, 0.89)	<.001
Yes, with a personal appointment	1441 (3.35)	0.77 (0.69, 0.87)	<.001	1.08 (0.96, 1.21)	.20
Yes, at a meeting	1037 (2.41)	1.31 (1.12, 1.53)	<.001	1.89 (1.64, 2.17)	<.001
No, the current method suits me	37,221 (86.50)	0.96 (0.89, 1.02)	.20	1.16 (1.10, 1.24)	<.001
Are you interested in the development of a NutriNet smartphone application?			<.001		<.001
Yes	8970 (20.85)	1.00 (Reference)		1.00 (Reference)	
No	27,385 (63.64)	1.25 (1.18, 1.33)		3.24 (3.07, 3.42)	
I don’t know	6673 (15.51)	1.10 (1.02, 1.19)		2.28 (2.13, 2.44)	

[a] Logistic regression analyses mutually adjusted for gender, age, education, and level of computer skills.

[b] Tests for linear trend were performed using the ordinal score for each category. *P* values for trend are reported.

Table 4. Opinions and attitudes toward the NutriNet-Santé Study demands according to education and self-evaluated level of computer skills, NutriNet-Santé Study, France, 2013.[a]

Opinions and attitudes	n (%)	Educational level (>12 y vs ≤12 y of schooling)		Level of computer skills (experienced vs novice)	
		OR (95%CI)	P [b]	OR (95%CI)	P [b]
The overall website use is easy			<.001		<.001
Agree	40,662 (94.50)	1.00 (Reference)		1.00 (Reference)	
Disagree	2366 (5.50)	1.45 (1.32, 1.59)		0.82 (0.74, 0.91)	
The information section is interesting			<.001		<.001
Agree	29,231 (67.93)	1.00 (Reference)		1.00 (Reference)	
Disagree	2042 (4.75)	2.05 (1.85, 2.28)		1.16 (1.03, 1.31)	
I don’t read these sections	11,755 (27.32)	2.17 (2.07, 2.28)		1.14 (1.07, 1.20)	
What do you think about the frequency of the questionnaire mailing?			<.001		.10
The current frequency suits me	39,293 (91.32)	1.00 (Reference)		1.00 (Reference)	
I receive questionnaires too often	2900 (6.74)	1.62 (1.48, 1.76)		0.95 (0.86, 1.04)	
I would like to receive questionnaires more often	835 (1.94)	0.61 (0.53, 0.70)		1.18 (0.98, 1.42)	
What is the maximum acceptable frequency to complete a questionnaire?			<.001		<.001
Once per week	2126 (4.94)	0.68 (0.62, 0.74)		1.14 (1.01, 1.28)	
Once every 2 weeks	8726 (20.28)	0.98 (0.93, 1.04)		1.18 (1.11, 1.26)	
Once per month (ie, current frequency)	24,936 (57.95)	1.00 (Reference)		1.00 (Reference)	
Once every 3 months	6138 (14.27)	1.03 (0.97, 1.09)		0.95 (0.89, 1.01)	
Once every 6 months	829 (1.93)	1.15 (0.99, 1.33)		0.83 (0.71, 0.98)	
Once per year	273 (0.63)	1.04 (0.82, 1.35)		0.87 (0.66, 1.15)	
Would you prefer to be contacted by means other than the Internet?					
Yes, by mail	2206 (5.13)	0.70 (0.64, 0.76)	<.001	0.50 (0.46, 0.55)	<.001
Yes, by phone	1123 (2.61)	0.85 (0.75, 0.96)	.01	0.67 (0.59, 0.77)	<.001
Yes, with a personal appointment	1441 (3.35)	0.97 (0.86, 1.08)	.50	0.71 (0.63, 0.80)	<.001
Yes, at a meeting	1037 (2.41)	0.87 (0.77, 0.99)	.04	0.97 (0.84, 1.12)	.70
No, the current method suits me	37,221 (86.50)	1.25 (1.18, 1.33)	<.001	1.62 (1.52, 1.72)	<.001
Are you interested in the development of a NutriNet smartphone application?			.001		<.001
Yes	8970 (20.85)	1.00 (Reference)		1.00 (Reference)	
No	27,385 (63.64)	1.00 (0.95, 1.06)		0.40 (0.38, 0.43)	
I don’t know	6673 (15.51)	0.90 (0.84, 0.97)		0.52 (0.48, 0.57)	

[a] Logistic regression analyses mutually adjusted for gender, age, education and level of computer skills.

[b] Tests for linear trend were performed using the ordinal score for each category. *P* values for trend are reported.

In all, 86.50% (37,221/43,028) of the respondents preferred the current communication modes (email and Internet website) and did not wish to be contacted by any other means (telephone, postal mail, or face-to-face interaction).

Despite their relatively lower computer skills (*P*<.001), women were more positive than men regarding facility of use of the study website (“The overall website use is easy” OR 0.65, 95% CI 0.59-0.71, *P*<.001), reported more interest in the information section (*P*<.001) and supported the current frequency of questionnaire administration (*P*<.001) (Table 3). Alternative contact modes (eg, postal mail or participant in-person meetings) were more frequently endorsed by women, whereas other communication modalities (eg, telephone or direct appointments with study staff) were more likely to be endorsed by men.

Older participants (>50 years) were more interested in the information section on the website (*P*<.001, Table 3) yet also more inclined to report dissatisfaction with the number of administered questionnaires (“I receive questionnaires too often”) compared with participants aged 50 years or younger (OR 1.25, 95% CI 1.15-1.35, *P*<.001).

Despite having higher computer skills (*P*<.001), participants with higher educational levels appeared to be more demanding regarding the study format compared with participants with ≤12 years of schooling: they were more likely to judge unfavorably the ease of use of the website (OR 1.45, 95% CI 1.32-1.59, *P*<.001) and reported lower interest in the information section as well as dissatisfaction with the number of administered questionnaires (*P*<.001 for all, Table 4). In contrast, the Internet communication mode was preferred over more direct contacts by participants with higher education (*P*<.001).

Participants with higher computer skills were more likely to feel comfortable with the website and with online communication regarding their study participation (both *P*<.001, Table 4).

Overall, 20.85% (8970/43,028) of participants reported being interested in the development of a NutriNet-Santé smartphone app. Men, younger people, and participants with higher self-reported computer skills were more interested in such an app (all *P*<.001).

Actual and Self-Perceived Acceptable Questionnaire Completion Time

Questionnaire completion time was higher for women, older participants, those with lower educational levels, and lower computer skills (Tables 5 and 6). These categories of participants were more disposed to spend time answering questionnaires, with higher acceptable completion durations declared (*P*=.004 for gender and *P*<.001 for age, educational level, and computer skills).

Table 5. Comparison of mean response time for questionnaires (in minutes) according to gender and age, NutriNet-Santé Study, France, 2013.[a]

Type of questionnaire	Gender					Age				
	Female		Male		*P*	>50 y		≤50 y		*P*
	Mean	SEM	Mean	SEM		Mean	SEM	Mean	SEM	
Sociodemographic	14.0	0.05	13.3	0.09	<.001	14.9	0.06	12.4	0.08	<.001
Anthropometric	10.9	0.05	10.4	0.08	<.001	11.6	0.05	9.6	0.07	<.001
Health	12.1	0.05	12.0	0.09	.40	13.6	0.06	10.5	0.08	<.001
Physical activity	12.2	0.05	11.4	0.08	<.001	12.7	0.06	10.9	0.07	<.001
Dietary intake	22.6	0.08	22.5	0.15	.50	24.5	0.10	20.5	0.13	<.001
Completion time deemed acceptable for a NutriNet-Santé questionnaire	33.9	0.44	31.6	0.77	.004	36.4	0.51	29.2	0.68	<.001

[a] Linear regression analyses mutually adjusted for gender, age, education, and level of computer skills. Mean completion time of questionnaires was log-transformed to improve normality.

Table 6. Comparison of mean response time for questionnaires (in minutes) according to educational level and self-evaluated computer skills, NutriNet-Santé Study, France, 2013.[a]

Type of questionnaire	Educational level					Level of computer skills				
	>12 y		≤12 y		*P*	Experienced		Novice		*P*
	Mean	SEM	Mean	SEM		Mean	SEM	Mean	SEM	
Sociodemographic	12.9	0.07	14.4	0.08	<.001	12.7	0.05	14.6	0.09	<.001
Anthropometric	9.6	0.06	11.6	0.07	<.001	9.9	0.05	11.3	0.08	<.001
Health	10.9	0.07	13.2	0.08	<.001	11.2	0.05	13.0	0.09	<.001
Physical activity	11.2	0.06	12.4	0.07	<.001	11.0	0.05	12.6	0.08	<.001
Dietary intake	22.5	0.11	22.5	0.12	.90	21.0	0.09	24.0	0.15	<.001
Completion time deemed acceptable for a NutriNet-Santé questionnaire	29.3	0.55	36.3	0.64	<.001	29.7	0.44	35.9	0.77	<.001

[a] Linear regression analyses mutually adjusted for gender, age, education, and level of computer skills. Mean completion time of questionnaires was log-transformed to improve normality.

Discussion

To our knowledge, this study is the first to shed light on computer skills and attitudes toward study demands of a large sample of French volunteers in a Web-based cohort. The main results showed that a substantial proportion of the participants (approximately one-quarter) declared being inexperienced or novice in computer use. Women tended to be more positive than men toward the study and its format, whereas participants with higher educational levels were less likely to be satisfied with the study demands, notably regarding the frequency and completion time of the questionnaires.

A key question in e-epidemiology pertains to the extent to which low computer skills represents a barrier to participation. Every year, the European Union Commission collects data on the digital skills of the population, measured by asking individuals if they had ever performed certain computer and/or Internet-related activities (Eurostat). In their 2012 report, 41% of the French population reported having either low or no computer skills [23]. The proportion of novice/inexperienced computer users was lower in our study population (24%). This was expected because access to the Internet was an inclusion criterion and since higher socio-professional categories were slightly (and commonly) overrepresented. Individuals in the latter category may have acquired a more practical and administrative use of the Web [24] given its regular use in the framework of their professional activity or during their university studies. Likewise, the proportion of NutriNet-Santé participants who could "install new devices," "compress/decompress files," or "use basic arithmetic formulas in a spreadsheet" was higher than observed in the French general population [25,26]. Our study population seemed to be better qualified for a more practical/working use of the Internet than for a leisure/entertainment use, with higher proportions of participants who could "send emails with attached files" or "fill in administrative forms online" and lower proportions of participants who could "download movies, music, games" or "upload texts, games, photos, movies, or music." The older age of our cohort compared to the French general population probably contributes to explain these differences. However, a notable finding was that the proportion of computer novice/inexperienced participants was non-negligible suggesting that participation in Web-based cohorts is not restricted to computer experts. Given the rapid increase in digital skills among EU citizens [23], there is a marked trend of ever decreasing barriers related to computer literacy.

Interestingly, several categories of participants with lower computer skills (eg, women or participants with lower educational levels) were more positive toward the study and more accepting of the respondent burden. Indeed, overall satisfaction was high regarding the design of the study, with the majority of participants reporting support for parameters that are currently in effect in terms of questionnaire frequency (about 1/month) and time needed for completion (less than 30 minutes/questionnaire). However, sociodemographic characteristics modulated these opinions. In addition to their higher participation (76%, which was expected for a study related to nutrition questions), females tended to be more motivated and satisfied by the study than were their male counterparts. Unlike older adults (>50 years), younger adults felt more comfortable with the website and the questionnaires. Interestingly, participants with higher levels of education were somewhat less satisfied with the demands of study participation. This could be explained by several reasons. First, participants with higher educational levels are usually exposed to a variety of digital activities and Internet websites during their professional activities and their leisure time [24] and, thus, may be more demanding on the design and the usability of questionnaires. Second, as they spend more time on the Internet [27], they are more often deluged with all types of questionnaires via spam, making them less receptive to the questionnaires of the study. These results provide useful information for Web-based study protocol optimization. For instance, when applicable, ancillary protocols that are optional and do not necessarily necessitate the recruitment of representative subsamples of the cohort should only be geared toward the most receptive categories of participants identified in this study.

The proportion of respondents who preferred the current communication modes (email and Internet website compared to telephone, postal mail, or face-to-face interactions) was high (87%), especially in older participants, better educated and with higher computer skills. However, unlike some previous studies [28-30], this one was not designed as an experiment to test response rates according to survey mode, but only to evaluate the overall satisfaction level of participants regarding the survey mode. Thus, this figure should be toned down by the fact prior research indicates that respondents tend to prefer the mode they were interviewed in [31]. Overall, the proportion of participants interested in the development of a NutriNet-Santé smartphone app was relatively limited (21%). In fact, smartphone use in our study (34% in 2013, data not shown) was less widespread than in the general French population (50%) [32]. In our sample, interest in a smartphone app was strongly modulated by several parameters; notably, men and younger adults were those who demonstrated the highest interest. Thus, given the opportunity to participate in a research study via a smartphone application would provide a strategic opportunity to recruit participants who are currently underrepresented in the cohort.

Strengths of this study pertain to the use of a large population-based cohort sample and availability of detailed information on computer/Internet skills and attitude toward demands of an Internet-based study, in the context of growing interest in e-epidemiology coupled with scarce knowledge about these parameters.

Several limitations should be acknowledged. First, caution is needed in extrapolating our results to all Web-based investigations because the NutriNet-Santé study involved a sample of volunteers who accepted to participate in a survey on nutrition and health. Compared to national estimates [33], the NutriNet-Santé study included more women, older participants, and individuals belonging to higher socio-professional categories. Second, response rate to this specific nonmandatory computer/Internet skills questionnaire was 35%. In fact, nonresponse to this questionnaire did not alter the enrollment status of the participants. Compared to nonresponders, responders were more likely to be men, younger, and better educated. Thus, we may have underestimated the proportions of novice/inexperienced computer users. In addition, the questionnaire was administered 4 years after the launch of the cohort. Thus, it is possible that this survey underrepresented participants who might have dropped out of the study due to difficulties related to computer/Internet use. As is usually the case in prospective cohorts in which mandatory and nonmandatory questionnaires are sent to participants, the level of involvement varies between participants. When the computer literacy questionnaire was administered in October 2013, 78,380 participants were regular respondents to optional questionnaires (at least 1 questionnaire filled in over the last 6 months). Based on this population, response rate to the present questionnaire was higher (55%). Lastly, a social desirability bias may have occurred since computer and Internet skills were self-evaluated, which may have led to an overestimation of expertise. However, our method was similar to the one used by the EU Commission for such assessment [23].

In conclusion, this study provided new information on computer skills and attitude toward study demands according to sociodemographic profiles of participants involved in a large population-based Web cohort. These results are useful for optimizing current and future Web-based investigations, in the context of rapid development of e-epidemiology and the currently scarce e-methodology literature. A substantial part of the study population reported low computer/Internet skills, suggesting that this characteristic does not constitute a barrier to participation in Web-based cohorts. The finding further suggested that several categories of participants with lower computer skills (eg, women or participants with lower educational levels) were more positive toward the study and less reluctant to comply with its demands. This study also highlighted that developing a dedicated smartphone app may boost interest in participation among categories of participants who are relatively less represented in health-related e-cohorts, such as men and young adults.

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Authors' Contributions

Contributors CP and MT designed the research; CP, MT, and SH conducted the research; CP analyzed the data and led the writing; MT supervised the study; CM, VAA, EKG, PF, PG, SH, and MT contributed to the data interpretation and revised each draft for important intellectual content; MT had primary responsibility for the final content. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

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Abbreviations

CNAM: Conservatoire National des Arts et Métiers
FRM: Fondation pour la Recherche Médicale
INPES: Institut National de la Prévention et de l’Education pour la Santé
INRA: Institut National de la Recherche Agronomique
INSERM: Institut National de la Santé et de la Recherche Médicale
InVS: Institut de Veille Sanitaire
SEM: standard error of the mean

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Original Paper

Assessment of Unconscious Decision Aids Applied to Complex Patient-Centered Medical Decisions

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Abstract

Background: To improve patient health, recent research urges for medical decision aids that are designed to enhance the effectiveness of specific medically related decisions. Many such decisions involve complex information, and decision aids that independently use deliberative (analytical and slower) or intuitive (more affective and automatic) cognitive processes for such decisions result in suboptimal decisions. Unconscious thought can arguably use both intuitive and deliberative (slow and analytic) processes, and this combination may further benefit complex patient (or practitioner) decisions as medical decision aids. Indeed, mounting research demonstrates that individuals render better decisions generally if they are distracted from thinking consciously about complex information after it is presented (but can think unconsciously), relative to thinking about that information consciously or not at all.

Objective: The current research tested whether the benefits of unconscious thought processes can be replicated using an Internet platform for a patient medical decision involving complex information. This research also explored the possibility that judgments reported after a period of unconscious thought are actually the result of a short period of conscious deliberation occurring during the decision report phase.

Methods: A total of 173 participants in a Web-based experiment received information about four medical treatments, the best (worst) associated with mostly positive (negative) side-effects/attributes and the others with equal positive-negative ratios. Next, participants were either distracted for 3 minutes (unconscious thought), instructed to think about the information for 3 minutes (conscious thought), or moved directly to the decision task (immediate decision). Finally, participants reported their choice of, and attitudes toward, the treatments while experiencing high, low, or no cognitive load, which varied their ability to think consciously while reporting judgments. Cognitive load was manipulated by having participants memorize semi-random (high), line structured (low), or no dot patterns and recall these intermittently with their decision reports. Overall then, participants were randomly assigned to the conditions of a 3 (thought condition) by 3 (cognitive-load level) between-subjects design.

Results: A logistic regression analysis indicated that the odds of participants choosing the best treatment were 2.25 times higher in the unconscious-thought condition compared to the immediate-decision condition (b=.81, Wald=4.32, P=.04, 95% CI 1.048-4.836), and 2.39 times greater compared to the conscious-thought condition (b=.87, Wald=4.87, P=.027, 95% CI 1.103-5.186). No difference was observed between the conscious-thought condition compared to the immediate-decision condition, and cognitive load manipulations did not affect choices or alter the above finding.

Conclusions: This research demonstrates a plausible benefit of unconscious thinking as a decision aid for complex medical decisions, and represents the first use of unconscious thought processes as a patient-centered medical decision aid. Further, the quality of decisions reached unconsciously does not appear to be affected by the amount of cognitive load participants experienced.

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KEYWORDS

unconscious; thought; intuition; medical; decision; judgment; cognitive load; patient-centered

Introduction

Background

To improve or maintain patient health and well-being, it is of course important that patients and/or health-care providers make the best (or at least beneficial) decisions regarding treatment options, behaviors, diagnoses, test options, and so forth. Complicating this, however, these individuals must commonly consider very complex information to make medical decisions. Thus, growing research has investigated decision aids that might benefit patients and health-care providers as they consider complex medical information [1]. Decision aids are generally used to engage both patients and practitioners in the decision process, and allow patients to understand the potential risks and benefits of a given medical choice. Additionally, decision aids often incorporate value clarification exercises to help patients consider the personal values they place on potential risks and benefits. For example, patients may go through a list of values, select the five most important ones, and bear those in mind while making a medical decision. De Vries et al [1] suggest that decision aids can make use of deliberative processes (requiring intentional and analytical thinking) or intuitive processes (which are more affective, unconscious, or automatic) to consider decision-relevant information. Although decision aids that make use of deliberative processes are more common, both types of processes have strengths and weaknesses for medical decisions. Regarding this, De Vries et al warn that decision aid developers “should be aware that the current common practice to encourage patients to extensively analyze available choice options, typically immediately after information exposure, lacks solid theoretical and empirical grounding…and may even have some harmful side effects to preference construction processes” (p. 159 [1]) and suggest that optimal decision aids would take advantage of the complementarity of the two systems [1]. Consistent with this later suggestion, the current paper explores the possibility that unconscious-thinking processes [2]—which theoretically incorporate intuitive processes as well as more time-demanding and analytic unconscious deliberation processes [3-5]—can provide patients with a valuable decision aid for complex medical information.

According to Dijksterhuis and Nordgren [2], unconscious thought is the “object-relevant or task-relevant cognitive or affective thought processes that occur while conscious attention is directed elsewhere” (p. 96 [2]), whereas conscious thought involves these same processes, but within conscious awareness. They suggest that unconscious thinking processes make use of vast mental resources, whereas conscious thinking processes rely on limited resources such as working and short-term memory. Thus, they argue, individuals often arrive at better decisions from complex information when they process information unconsciously (while conscious thinking processes are distracted from the relevant decision task). Much research supports this possibility [2,6-11], and generally follows a paradigm established by Dijksterhuis [6]. In this paradigm, individuals receive much information about 3-4 targets (eg, roommates). Further, one target is associated with mostly positive attributes, one with mostly negative attributes, and the other(s) with a balance of positive and negative attributes. Next, participants report their decisions regarding, or preferences for, targets either immediately (allowing for minimal conscious or unconscious thinking), after 3 minutes in which they think about the presented information (ie, think consciously), or after 3 minutes in which they engage in an unrelated task that distracts them from thinking consciously about the presented information (but can still think unconsciously). Typical results demonstrate an “Unconscious Thought Effect” (UTE) such that participants in the “unconscious thought” condition arrive at better decisions (prefer the best over the worst target) relative to participants in the immediate-decision condition. As well, participants in conscious-thought conditions often arrive at decisions comparable to those in the immediate-decision conditions.

Since Dijkterhuis’s first article reporting the UTE [6], much research has either replicated the effect or called the effect into question. A recent Bayesian meta-analysis of 16 studies conducted by Newell and Rakow [12] does not support the existence of the UTE, and a study by Huizenga and colleagues [13] provides additional evidence against the merits of unconscious thought processes. Conversely, a meta-analysis of 92 studies conducted by Stick et al [14] suggest that the UTE is modest but reliable, and research by Creswell and colleagues [15] provides strong fMRI (functional magnetic resonance imaging) evidence consistent with the UTE. Creswell and colleagues addressed important critiques of the UTE by providing physiological evidence that the UTE relies on specific neural reactivation to occur, and that conscious and unconscious thought processes recruit non-overlapping neural regions [15]. Nevertheless, when considering unconscious thought as a potential decision aid, developers ought to consider the present paper as part of a growing literature that deserves a thorough review before justifying any reforms.

The meta-analysis conducted by Strick et al [14] demonstrated that the UTE is stronger when the presented information is complex, the goal to make a decision is emphasized and formulated in a holistic fashion, and the decision task is ecologically valid. Thus, unconscious thought may be particularly suited to aid sound medical decisions; medical decisions are typically complex (eg, involving a large number of trade-offs between length and quality of life [1]), patients and health-care providers are generally motivated to find the best course of treatment, and the outcomes of such decisions bear real-life consequences that ensure a level of ecological validity. In fact, an experiment by DeVries and colleagues investigated the UTE in a health context, and demonstrated that in-training clinical-psychologists (graduate students) achieve more accurate psychiatric diagnoses following a period of unconscious versus conscious thinking. However, the present research sought to investigate the potential benefit of unconscious thinking as a decision aid for the broad population of patients (and is the first to our knowledge to do so), without specific health or medical training. This is noteworthy because experts within a given decision domain (eg, training clinicians) demonstrate the UTE more than non-experts [16] (eg, patients and the lay-public generally). Thus, demonstrating this effect on medically related decisions—relative to a “non-thinking” control group—even among a general sample could reveal that unconscious thought is a useful decision aid for making complex medical decisions that affect patient health and well-being. Further, the reported research addresses a potential methodological criticism of past unconscious-thought research: participants could theoretically think consciously while reporting their decisions (ie, during the decision phase of the experiment), even following a period of distraction. If true, the UTE might actually result from conscious thinking processes. We explore this possibility by manipulating the amount of cognitive load participants experience during the decision phase of the experiment. This is a relevant and ecologically valid manipulation given the cognitively demanding context of many medical environments, and is novel within the unconscious-thought literature.

Current Aims, Experiment Overview, and Hypotheses

The aim of the current research was to test whether patient-centered decisions regarding complex treatment options are better following a period of unconscious thought relative to immediate decisions, indicating unconscious thought can be a beneficial decision aid. For this initial investigation, a Web-based sample of participants received a cover story entailing “their” recent hospital admission and diagnosis. Next, all participants received side-effect/attribute information for four potential treatments, one of which was the best, one the worst, and two of which were in the middle. Following this, participants were randomly assigned to a thought condition in which they completed a distraction task for 3 minutes (unconscious), deliberated for 3 minutes (conscious), or were given no time (immediate decision), before reporting their judgments about the treatments. Finally, participants rendered their judgments while under a high, low, or no cognitive load. Thus, overall, participants were randomly assigned to the conditions of a 3 (thought condition) by 3 (cognitive-load level) between-subjects design. Participant’s choice of treatment, and attitude ratings of each treatment, were recorded.

The primary hypothesis was that we would observe a UTE such that participants in the unconscious-thought condition (but not participants in the conscious-thought condition) would choose the best treatment relative to the immediate-decision condition (control group). This same effect was predicted for participants’ treatment attitudes, although this measure is less critical than investigating actual treatment choices; the choices patients and health practitioners make tend to be more consequential to health outcomes than their attitudes toward various treatments. Additionally, we predicted that participants in the unconscious-thought condition would choose (and form more favorable attitudes toward) the best treatment relative to the conscious-thought condition. Although this is not critical to demonstrating the UTE per se, this prediction is consistent with much of the unconscious-thought literature [14], and speaks directly to the possibility that unconscious thought may be an effective decision aid relative to purely deliberative decision aids.

Further, we propose two competing exploratory hypotheses regarding the effect of cognitive load during the decision phase. First, if participants in the unconscious-thought condition actually generate their decisions consciously during the decision phase, then their decisions should become worse as cognitive load increases, and the UTE should only manifest under no- and low-load conditions. Second, if participants in the unconscious-thought condition truly generate their decisions unconsciously, then their decisions should be comparable across load conditions, and the UTE should occur unaffected by cognitive load.

Methods

Participants

A total of 173 Amazon Mechanical Turk workers participated in this Web-based experiment. The Institutional Review Board of the Montana State University approved all procedures in advance. Participants were compensated with US $0.50, and (retroactively) an additional $1.00 bonus for choosing the best treatment option. Participants were 87 males (50.3%) and 86 females (49.7%) with ages ranging from 18 to 73 years (mean 28.38, SD 8.18). One participant reported that he/she was 2 years old (we assumed this was a “typo” and the individual intended to report an age in the twenties); excluding this participant from the analyses had no effect on the results. In total, 135 participants categorized their ethnicity as White/Caucasian (78.0%), 12 as Black/African American (6.9%), 11 as Asian (6.4%), 3 as Native American (1.7%), and 12 as “other” (6.9%). Further, we analyzed these participant characteristics independently as a function of the independent variables, and found no significant effects (all *P*s>.15). Thus, our random assignment procedure succeeded at distributing participants evenly across the experiment conditions.

Materials

Treatment side-effects/attributes were first pretested using a separate sample of 52 Amazon Mechanical Turk workers. Participants from this sample rated each of 75 side-effects/attributes on valence and importance. Specifically, participants were asked to “Rate the following side effect in terms of how positive/negative it is”, then were randomly shown one of the 75 side-effects/attributes and responded on a 9-point scale ranging from 1 (very negative) to 9 (very positive). Following, participants were shown the same side-effect/attribute and asked to “Rate the following side effect in terms of how important it is” on a 9-point scale ranging from 1 (very unimportant) to 9 (very important). Of note, positive side effects/attributes in the present design were independent of the intended treatment effects (to cure the patient), but were considered to be positive or beneficial.

A total of 35 (17 positive and 18 negative) side-effects/attributes were selected as stimuli for the current experiment (see Multimedia Appendix 1 for selected side-effects/attributes and pre-test ratings). We chose side-effects/attributes with moderate pre-test ratings on both valence and importance dimensions to ensure that one or a few side-effects/attributes would not dominate choices, thereby oversimplifying the decision process. Using these pre-test data, we then assessed the actual quality of each treatment that was used in the main experiment by weighting the valance of treatment side-effects/attributes by importance. This follows logically from research conducted by Bos and colleagues [5], which demonstrates that unconscious thought makes use of valance and importance information in a logical way (approximately weighting valance by importance) to make sound decisions. For example, a highly positive side-effect/attribute of low importance can affect decisions less than a mildly positive side-effect/attribute of high importance. Thus, for each treatment, we first multiplied the valance rating by the importance rating for each positive side-effect/attribute, then summed these products. We did this again for each negative side-effect/attribute, independently for each treatment. Next, for each treatment, we subtracted the resulting sum for the negative side-effects/attributes from the sum for the positive side-effects/attributes. This created a “quality rating” for each treatment (more positive numbers indicate higher quality), which was analyzed using contrasts within a repeated-measure ANOVA (analysis of variance). These contrasts confirmed that the best treatment was viewed as having better quality (mean 297.75, SD 139.32) than the two balanced treatments (mean 128.92, SD 110.67 and mean 137.48, SD 117.76; $F_{1,51}$=366.95, P<.001), and the worst treatment was viewed as having lower quality (mean=−48.71, SD 88.73) than the two balanced treatments ($F_{1,51}$=308.51, P<.001). Further, the two balanced treatments were rated comparably, F<1.

Procedure

Internet Sample and Platform

Participants were recruited through Amazon Mechanical Turk (a Web-based crowdsourcing marketplace), and redirected to Qualtrics (a survey website) to complete the experiment. Amazon Mechanical Turk users were eligible to participate if they resided in the United States, had completed over 100 remunerated tasks (known as Amazon Mechanical Turk HITS), and had an approval rating over 90% (meaning that 90% of tasks completed by users where deemed worthy of remuneration by previous employers). Data collection started on April 30, 2014 and finished on May 9, 2014; participants had the option of leaving the experiment at any time but were unable to return to previous pages. A completeness check was automatically recorded by Qualtrics (dependent upon viewing the last page of the survey), and the completion rate was 59.6% (173/290). Incomplete surveys were not included in the final analyses. Amazon Mechanical Turk’s account registration system was used to prevent multiple entries (a given account could only complete the experiment once). The average time of survey completion was 13.5 minutes; no atypical timestamp surveys were excluded.

Experiment Flow

Participants were first presented with a consent form, completed a demographic questionnaire, and then read the following scenario:

> *Please imagine yourself as a recently admitted patient at a hospital. The doctors have diagnosed you with a Campylobacter infection. They then present you with different treatment options which all have a large number of positive and negative side effects. Since all of the treatments will treat the Campylobacter infection, the only basis for comparison are their associated side effects. Also, given the progression of the infection, a decision must be taken in the next few minutes. This part of the experiment is concerned with the way in which we form an impression on the basis of a number of attributes. In a few moments you will be presented with four treatments along with side effects that each of the treatments possess. Please read these sentences carefully, study each one until the next appears. Later, we will ask you a series of questions concerning the impressions that you have formed of the four different treatments.*

Following, participants were told that choosing the best treatment option would grant them a $1 bonus. The possibility for bonus remuneration helped ensure that participants were motivated to choose the best treatment. Subsequently, each participant was sequentially shown 48 side-effects/attributes in random order. Each side-effect/attribute was presented for 4 seconds and attributed to one of four treatment options. Overall, one option was best (8 positive and 4 negative side-effects/attributes), one was worst (4 positive and 8 negative side-effects/attributes), and the other two were balanced (6 positive and 6 negative side-effects/attributes). This type of stimuli presentation was used to ensure decision complexity following past research methods [6-8]. Next, participants were randomly assigned to either an unconscious-thought, conscious-thought, or immediate-decision condition. Finally, participants were randomly assigned to render their treatment choices and attitudes while experiencing high, low, or no cognitive load (details for all manipulations provided below). Last, participants were debriefed, thanked for their participation, and given a code to redeem compensation through Amazon Mechanical Turk.

Independent Variables

Thought Condition

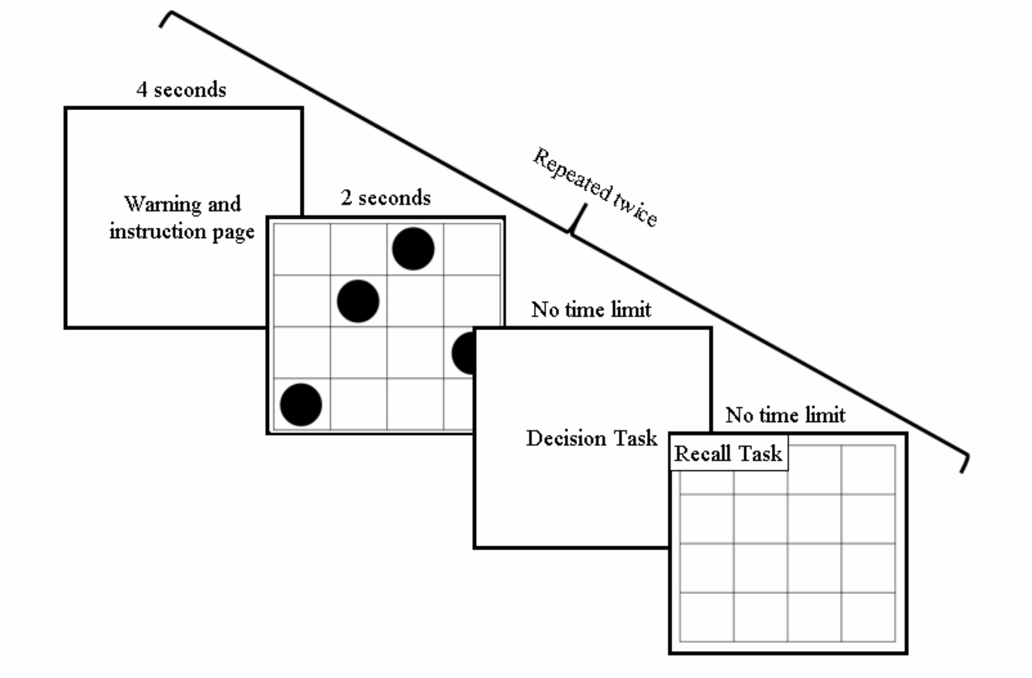
After participants received all of the side-effect/attribute information, they were randomly assigned to one of three thought conditions. Participants in the unconscious-thought (or distraction) condition were instructed to complete as many anagrams as they could within 3 minutes, and were presented with a list of 36 anagrams. This task is commonly used in unconscious-thought experiments to consume and distract conscious thought, yet allows unconscious thought to continue processing decision-relevant information. Participants in the conscious-thought condition read the following instructions: “For the next 3 minutes, consider the four different treatments and the side effects you read about. Think about which treatment is the best and/or which treatment you like the most. Try to only think of the treatments and which treatment you might personally prefer.” Thus, these participants were specifically instructed to think consciously about the side-effect/attribute information, and had time to do so. Finally, participants in the immediate-decision condition directly moved on to the judgment task, and had insufficient time to think consciously or unconsciously about the side-effect/attribute information.

Cognitive Load

Cognitive load was manipulated using 4 x 4 matrices with 4 dots presented within 16 possible locations. The manipulation stimuli were modeled after Haymen et al [17], who demonstrated their effectiveness in producing high or low cognitive load. High cognitive-load manipulations consisted of a semi-random scatter, whereas the low cognitive-load manipulation consisted of a 4 dot line (see Multimedia Appendix 2 for actual stimuli). Participants were instructed to memorize the exact pattern and warned that they would later be asked to reproduce it. Ultimately, participants reported judgments about the treatments interspersed with the load manipulations. Specifically, the decision phase entailed a repeated sequence of events: pattern exposure, treatment choice, pattern recall, new pattern exposure, treatment evaluations, pattern recall (see Figure 1). Participants in the no cognitive-load condition were only presented with the judgment tasks.

We reasoned that the semi-random dot patterns were difficult to memorize and that participants in the high cognitive-load condition would not be able to consciously process the side-effects/attributes information and rehearse the dot pattern as they were reporting their choice/attitude ratings. Conversely, the linear dot patterns (low cognitive load) would require little active cognition to maintain in working memory and therefore could allow participants to engage in conscious deliberation.

Figure 1. Flow of the decision phase. The first decision task consisted of the choice variable while the second decision task consisted of the attitude rating. The high cognitive load is displayed for illustrative purposes; the actual pattern depended on cognitive load condition.



Dependent Measures

Choice

Participants were asked to make two main treatment judgments. First, participants were instructed to: “Choose a treatment” and could click on one of the four treatment options. This is the primary dependent measure, as this choice directly affects patient health outcomes and experienced side-effects. For this measure, participants who chose the best treatment option were scored “1”, whereas participants who chose any of the other options were scored “0”.

Attitude Measure

Next, participants separately rated each of the four treatments (eg, “Your impression of Treatment A was…”) on scales ranging from −25 (very negative) to 25 (very positive). Following previous research in the unconscious-thought literature, participants’ rating for the worst treatment was subtracted from their rating for the best treatment, resulting in an attitude preference measure. Higher numbers on this measure indicate a more positive rating for the best over the worst option.

Results

Manipulation Check

On average, participants in the low cognitive-load condition correctly recalled significantly more dots (mean 6.91, SE 0.29) than participants in the high cognitive load condition (mean 5.73, SE 0.25; t_{110}=−3.031, P=.003). This worse recall in the high versus low cognitive-load conditions supports the idea that the pattern task was more cognitively demanding than in the former, and is consistent with the results and interpretation of Heyman et al [17].

Dependent Variables

Choice

We conducted a hierarchical logistic regression to predict participants’ choice for the best treatment, entering Thought Condition as a predictor in the first step (given this was a theoretically important variable), Cognitive-Load Condition as an additional predictor in the second step (given it was exploratory), and the interaction between these two factors as yet an additional predictor in the third step. As hypothesized, the first step revealed a main effect of thought condition; this predictor demonstrated a significant improvement over the constant-only model (χ^2_2=6.39, *P*=.04, Nagelkerke R^2=.05), and this single-predictor model fit the data well (for the Hosmer and Lemeshow test, *P*=.81). Further, there was no main effect of cognitive-load condition, nor a Thought Condition by Cognitive-Load Condition interaction. Adding Cognitive-Load in the second step revealed no improvement in the model (χ^2_2=1.54, *P*=.46), nor did adding the interaction term in the third step (χ^2_4=3.83, *P*=.43). Given this, we interpreted the main effect of thought condition based on the first step of the analysis. Demonstrating a UTE, the odds of participants choosing the best treatment were 2.25 times higher in the unconscious-thought condition compared to the immediate-decision condition (*b*=.81, Wald=4.32, *P*=.04, 95% CI 1.048-4.836), and 2.39 times greater in the unconscious-thought condition compared to the conscious-thought condition (*b*=.87, Wald=4.87, *P*=.027, 95% CI 1.103-5.186). Further, the odds of choosing the best treatment were comparable across the conscious-thought and immediate-decision conditions (*b*=−.06, Wald=0.22, *P*=.88; for the constant, *b*=−.88, Wald=9.31, *P*=.002). Overall, thought condition was the only significant predictor of choice, and participants in the unconscious-thought condition demonstrated a higher probability of making the correct choice versus the control condition (see Table 1 for choice contingency table). Further, participants overall found the decision task quite complex, given 112 of 173 participants (64.7%) chose an incorrect treatment option. This is important given UTEs tend to manifest in complex decision tasks.

We also explored choice as a function of cognitive-load condition separately for each thought condition. None of these analyses demonstrated a significant effect of cognitive load (all X^2< 2.56, all *Ps*>.05).Of note, if correct decisions arising from unconscious thought actually result from conscious thought during the decision phase, then higher levels of load should result in worsening decisions within the unconscious thought conditions. But, if anything, load resulted in better choices in the unconscious thought conditions (see Table 1). Nonetheless, so as to fully assess the interaction of cognitive load and thought conditions, we also reanalyzed our data after combining the immediate and conscious-thought conditions (unconscious thought vs others), and after combining the low- and high-load conditions (no load vs load). Again, this analysis revealed an effect of thought condition (*b*=.84, Wald=6.34, *P*=.012, 95% CI 1.205-4.463), and again the effect of load condition and the interaction of thought and load were not significant (all *Ps*>.28). Further, we found the power of our experiment to be .73 for this simplified interaction. Thus, our experiment had reasonable power to detect an effect of load on the UTE.

Table 1. Contingency table for choice broken down by thought condition and cognitive-load condition (n=173).

Thought Condition	Cognitive Load	Choice		Totals
		Correct	Incorrect	
Unconscious				
	No Load	10	13	23
	Low Load	10	8	18
	High Load	8	9	17
	Total	28 (48.3%)	30 (51.7%)	58
Immediate				
	No Load	3	9	12
	Low Load	4	20	24
	High Load	10	12	22
	Total	17 (29.3%)	41 (70.7%)	58
Conscious				
	No Load	7	19	26
	Low Load	4	10	14
	High Load	5	12	17
	Total	16 (28.1%)	41 (71.9%)	57

Attitude Measure

The attitude measure was analyzed using a 3 (thought condition) by 3 (cognitive load condition) between-subjects ANOVA. This analysis revealed no significant effects (all *F*s<1.42), and no planned comparisons were significant (*t*s<1).

Discussion

Principal Findings

In this experiment, participants who were distracted for 3 minutes after receiving treatment information—and thus had the opportunity to think unconsciously—were significantly more likely to choose the best treatment option relative to participants who made their choices immediately following the information (or thought consciously). To our knowledge, this is the first replication of the UTE using a patient-oriented medically related decision task. Further, no such advantage was observed for participants who consciously thought about the information for 3 minutes after receiving treatment information. These trends were mirrored in participants' attitudes toward the best versus worst treatment, although not significantly. In the field, however, the choices patients and health practitioners make are more consequential to health outcomes than their attitudes toward various treatments. The choice results are strongly in line with a growing body of evidence demonstrating that individuals are more likely to make the best decisions when they think unconsciously, provided the decision task is complex, they are motivated to be accurate, and the task has ecological validity. These conditions were met in the current research: the task was complex and most participants chose an incorrect treatment, participants were motivated to choose the correct treatment (with a US $1 incentive), and the task was constructed to represent a real-life medical decision (albeit, with fictitious treatment information and a fictitious medical condition). Further, these conditions are clearly met in many medical contexts, as treatment information is often complex and all parties involved are motivated to arrive at correct treatment choice. Thus, unconscious thinking processes may greatly aid decision making within many medical contexts.

The present research also explored the possibility that UTEs are not actually the result of unconscious thinking that occurs while people are distracted, but of conscious processes that occur while people solidify and report a judgment. And, to our knowledge, this is the first experiment to investigate this potential alternative account for the UTE. To test this possibility, we varied the cognitive load participants experienced while they reported their choice and attitude judgments, and this manipulation was successful. If the UTE actually results from conscious thinking at the time of judgment, then participants in the unconscious-thought conditions should do worse if they experience high load (compared to low or no load) while reporting their judgments. However, the cognitive-load manipulation had no effect on either of the dependent measures, nor did it interact with thought condition. This overall null effect of cognitive load suggests the UTE does not result from conscious processing at the time of judgment, and judgments are accessed with negligible effort during the decision phase.

Limitations and Future Directions

The reported results indicate that unconscious thought may serve as a beneficial decision aid for patients facing complex medical decisions. But, of course, this initial investigation has limitations and we encourage further research into unconscious thinking in medical contexts before advocating any decision-making reform. Foremost, the tested decision task involved an imaginary scenario and not a personal health event. Still, participants were motivated to arrive at the correct decision and the greater motivation real patients likely experience should theoretically enhance the UTE [5]. Related, the stimuli used in this experiment were fictitious, although designed to appear medically relevant. Future research should employ real information as the basis of decisions and focus on adapting the unconscious thought paradigm to real-life examples such as the trade-offs between length and quality of life faced by older or terminally ill populations or the time-sensitive medical decisions that one may face in an emergency room. Furthermore, the side-effect/attribute information was presented randomly rather than organized by treatment as would normally happen. This was important to create the decision difficulty needed to verify the results stemmed from unconscious, and not conscious, processes in this initial investigation. However, given the present results, future research could further test the benefit of unconscious thought as a decision aid under more realistic informational settings. Finally, we tested our predictions using a geographically dispersed Web-based sample, not with participants in a controlled environment, and cannot ensure strict instruction compliance. An exact laboratory replication could easily address this limitation. At the same time, however, the present results demonstrate the UTE for medical decisions using a Web-based sample, and suggest that a Web-based platform could be used to create decision aids that foster unconscious thinking.

Ultimately, it will be critical to demonstrate the UTE in actual medical contexts with participants facing real decisions for themselves or others. As of now, the present research reveals a plausible benefit of unconscious thought as an aid for patients' medical decisions and future research will have to confirm that benefit in commonplace settings, with real information, and with vested decision-makers.

The present claim that unconscious judgments come to awareness relatively independently of cognitive load entails several limitations. First, the cognitive load manipulation used in the present experiment was comprised of visuospatial dot patterns whereas the decision task was primarily verbal. To the extent that visuospatial and verbal processing may employ different cognitive resources, it is possible that the present cognitive load manipulation did not interfere with the decision task enough to adequately test our hypotheses. Although visuospatial stimuli were preferred in the present study to help ensure instruction compliance (reporting random dot patterns requires memory processes because they are difficult to reproduce or write down), future studies should make use of verbal cognitive-load manipulations to address this issue. Additionally, participants were instructed to memorize dot patterns and report their judgments intermittently, but were not instructed to focus primarily on one task or the other. As such, participants had the opportunity to neglect the cognitive task so as to minimize its impact on their performance on the decision task. This eventuality may account for the difference in mean recall observed between the high and low cognitive-load conditions (of note, however, this difference replicates Heyman et al, who interpreted these differences as indicating greater task difficulty rather than decreased task compliance). Future studies could address this issue by specifically stating the primary and secondary task in the instructions. Finally, a baseline assessment of performance on the cognitive load task could also be implemented to assess the extent to which it is affected by the decision task. As ours is the first experiment to explore the influence of cognitive load during the decision phase on UTEs, we strongly encourage future research to address these issues to better couch our current findings.

Conclusion and Implications

Patients and health practitioners alike commonly consider a vast amount of information to reach optimal medical decisions. Unfortunately, considerable evidence now indicates that conscious processes can be ill-equipped to integrate complex information, at least without aids (eg, notes, computers, etc). Quite simply, people cannot consciously retain and process vast amounts of information, and thus often form poor decisions via conscious processes. But, according to Dijksterhuis and Nordgren [2], unconscious thinking can process vast amounts of information with just a little time (eg, 3 minutes), and thus somewhat counterintuitively, individuals often come to better decisions when they are distracted from consciously considering decision-relevant information. The current research demonstrates this can also be true for patient-centered medical decisions.

A hypothetical (and relatively long-term) implication of the current research lies in the type of media used to test the UTE. Unconscious thought research readily utilizes computer and research software platforms, and a Web-based platform was used presently. Demonstrating the UTE in this fashion may constitute evidence that unconscious-thinking decision aids and value clarification exercises may be integrated with Web and mobile technologies within health care realms (given that current limitations are addressed of course). For example, a Web or mobile phone app may in some instances present the relevant information to a medical decision maker, provide a timed and cognitively consuming distraction, then solicit a decision. That is, it is conceivable that a Web or mobile app could model the stages used in the current research for real medical-decision tasks in a way that fosters unconscious thought, and thus better decisions. Further, the merits of unconscious thought should not be limited to treatment side-effects/attributes. Personal values could (theoretically) also be processed unconsciously. This implication is particularly relevant because unconscious thought can process decisional factors that are difficult to articulate or too numerous to maintain in conscious awareness [1-3]. Patients may therefore be able to use an “unconscious thought mobile app” as a beneficial value clarification exercise and successfully incorporate numerous personal values in their decision.

Finally, unconscious thinking may instill further benefits in medical contexts. First, other research demonstrates that individuals are more satisfied with the choices they make via unconscious thinking [7]. Thus, patients might experience more satisfaction with a treatment, and thus better adhere to it, if they chose that treatment following unconscious thought. Second, we investigated mock-patient decisions, but health practitioners might experience the greatest benefit from unconscious thought for complex medical decisions. For instance, research by Dijksterhuis and colleagues [8] showed that participants with more (vs little) expertise in a domain reach higher quality judgments after a period of unconscious thought. Thus, medical experts may realize the most advantage for choosing optimal treatments or generating accurate diagnoses in the face of complex and numerous symptoms, complications, side-effects, and risks, and some research already supports this possibility [16]. Given this, exploring the UTE in medical decision making for health care providers and patients has the potential to greatly and broadly enhance patient health and well-being.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Treatment side effects and relative mean (M) and standard derivation (SD) ratings of valence and importance.

[XLSX File (Microsoft Excel File), 12KB - jmir_v17i2e37_app1.xlsx]

Multimedia Appendix 2

High and low cognitive load dot patterns.

[PDF File (Adobe PDF File), 198KB - jmir_v17i2e37_app2.pdf]

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Abbreviations

ANOVA: analysis of variance
UTE: unconscious thought effect

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Original Paper

Multiple Comorbidities of 21 Psychological Disorders and Relationships With Psychosocial Variables: A Study of the Online Assessment and Diagnostic System Within a Web-Based Population

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Abstract

Background: While research in the area of e-mental health has received considerable attention over the last decade, there are still many areas that have not been addressed. One such area is the comorbidity of psychological disorders in a Web-based sample using online assessment and diagnostic tools, and the relationships between comorbidities and psychosocial variables.

Objective: We aimed to identify comorbidities of psychological disorders of an online sample using an online diagnostic tool. Based on diagnoses made by an automated online assessment and diagnostic system administered to a large group of online participants, multiple comorbidities (co-occurrences) of 21 psychological disorders for males and females were identified. We examined the relationships between dyadic comorbidities of anxiety and depressive disorders and the psychosocial variables sex, age, suicidal ideation, social support, and quality of life.

Methods: An online complex algorithm based on the criteria of the Diagnostic and Statistical Manual of Mental Disorders, 4th edition, Text Revision, was used to assign primary and secondary diagnoses of 21 psychological disorders to 12,665 online participants. The frequency of co-occurrences of psychological disorders for males and females were calculated for all disorders. A series of hierarchical loglinear analyses were performed to examine the relationships between the dyadic comorbidities of depression and various anxiety disorders and the variables suicidal ideation, social support, quality of life, sex, and age.

Results: A 21-by-21 frequency of co-occurrences of psychological disorders matrix revealed the presence of multiple significant dyadic comorbidities for males and females. Also, for those with some of the dyadic depression and the anxiety disorders, the odds for having suicidal ideation, reporting inadequate social support, and poorer quality of life increased for those with two-disorder comorbidity than for those with only one of the same two disorders.

Conclusions: Comorbidities of several psychological disorders using an online assessment tool within a Web-based population were similar to those found in face-to-face clinics using traditional assessment tools. Results provided support for the transdiagnostic approaches and confirmed the positive relationship between comorbidity and suicidal ideation, the negative relationship between comorbidity and social support, and the negative relationship comorbidity and quality of life.

Trial Registration: Australian and New Zealand Clinical Trials Registry ACTRN121611000704998; http://www.anzctr.org.au/trial_view.aspx?ID=336143 (Archived by WebCite at http://www.webcitation.org/618r3wvOG)

(J Med Internet Res 2015;17(3):e55) doi:10.2196/jmir.4143

KEYWORDS

comorbidity; multiple comorbidities; co-occurrences; e-mental health; online; fully automated; generalized anxiety disorder; obsessive-compulsive disorder; social anxiety disorder; posttraumatic stress disorder; panic disorder, major depressive episode; insomnia, hypersomnia, dependency; alcohol; drug; suicidal ideation; social support; quality of life; sex; age

Introduction

The comorbidity of psychological disorders is a common problem that has serious implications for the delivery of health care. The lifetime prevalence of any disorder has been reported to be 46.4%, while the lifetime prevalence of 2 and 3 disorders were found to be 27.7% and 17.3%, respectively [1]. The 12-month prevalence of any disorder was found to be 26.2%, while the 12-month prevalence of 2 and more disorders were reported to be 5.8% and 6%, respectively, and over the same period, more than 40% of those with one diagnosis met the criteria for a second diagnosis [2].

Studies on comorbidity have found strong relationships between comorbidity and higher rates of suicide [3,4], suicidal ideation [5], greater symptom severity [2,5], and poorer quality of life and social support [5]. Patients diagnosed with multiple disorders also tend to have a poorer prognosis, are less responsive to intervention, and generally exert a greater demand on the health care sector [3,4,6].

Two approaches have been used to investigate comorbidity. The co-occurrence, or frequency approach, identifies individuals with a particular diagnosis and then counts how many of them meet the diagnostic criteria of another diagnosis. The resulting comorbidity proportions therefore depend on the reference group. For example, the proportion of people diagnosed with an anxiety disorder who also meet the diagnostic criteria for an eating disorder will be different than the proportion of people diagnosed with an eating disorder who also meet the criteria for that same anxiety disorder. Moreover, because there are more people diagnosed with anxiety disorders than people diagnosed with eating disorders, it is easier to have larger samples, and hence more accuracy, when the reference group is anxiety-disordered rather than eating-disordered. The second approach identifies the psychological disorders of a group of individuals, based on discrete or dimensional scales, and then uses factor analysis to identify clusters of disorders, hence the underlying structure or dimensions of comorbidity is addressed.

While comorbidity, and the structure of comorbidity using in-clinic samples, has been the focus of many investigations for several decades, investigating comorbidity using an online sample is relatively new. We are not aware of any study on comorbidity using individuals who received diagnoses based on online diagnostic tools. The e-PASS data of the Mental Health Online Platform (formerly Anxiety Online) (Figure 1) [7] provide us with a unique opportunity to investigate many facets of online therapy and assessment. We have recently reported on the structure of comorbidity of 21 psychological disorders, using online diagnostic assessment, based on severity dimensional scales [5]. In this paper, we present the frequencies of co-occurrences of 21 psychological disorders using an online assessment tool within a Web-based sample and relate the identified anxiety-depression clusters to suicidal ideation, social support, and quality of life.

The comorbidities of anxiety disorders with one another are common and have long been documented, and for some anxiety diagnoses, the lack of discriminant validly was criticized [5,8-13]. The presence of anxiety disorders in clinically depressed patients is most common [14] with at least 50% of all patients diagnosed with depression meeting the diagnostic criteria for at least one anxiety disorder [15-17] and 46% of those diagnosed with major depressive disorder (MDD) showing high levels of anxiety symptoms [18]. Estimates of anxiety disorders and MDD vary based on the age of and the target population under study. For example, the comorbidity of anxiety disorders and MDD in samples of children and adolescents ranges from 15.9% to 61.9% [19,20] and 14.5% to 57% in specific populations of adult samples [21,22]. Almeida-Filho et al [23] found 74% of the depressed sample reported symptoms of anxiety disorders and 61% of those with anxiety disorders were depressed. Feva et al [24] found 50.6% of those diagnosed with MDD met the criteria for one or more anxiety disorders. Zimmerman et al [15] found 57.4% of 373 MDD outpatients meeting the criteria for at least one of the anxiety disorders. This finding was confirmed later by a meta-analysis study that concluded that 50% of individuals with MDD met the criteria for one or more anxiety disorders [25]. More specifically, Fava et al [18] found that 46% of MDD patients were significantly more likely to report symptoms associated with generalized anxiety disorder (GAD), obsessive-compulsive disorder (OCD), posttraumatic stress disorder (PTSD), agoraphobia without panic disorder (AwoPD), and panic disorder with or without agoraphobia (PD/A) than individuals without comorbid anxiety. In addition, 57% of the depressed outpatients with an anxiety disorder met the criteria for more than one anxiety disorder. In their sample, the most common comorbid anxiety disorders were social anxiety disorder (SAD) (33%), specific phobia (SP) (13.7%), PTSD (13.4%), GAD (15%), and PD/A (14.2%) [15]. Furthermore, symptoms of insomnia and hypersomnia have also been consistently present with anxiety disorders and MDD [26-30].

Although research on the comorbidity of eating disorders with other psychological disorders has produced mixed and inconsistent results, there is sufficient empirical evidence supporting the co-occurrence of eating disorders with other disorders like anxiety disorders [31,32], MDD [31,33,34], body dysmorphic disorder (BDD) [35], and substance use (drugs and alcohol) [36,37]. The estimates of these comorbidities are generally moderate to high with a wide range. For example, 55%-98% of those diagnosed with anorexia nervosa meet the diagnostic criteria for another Axis I disorder [38,39].

MDD has been found to be prevalent in individuals diagnosed with eating disorders. Estimates of the lifetime prevalence of MDD range from 50%-71% in anorexia nervosa and 50%-65% in bulimia nervosa [33,40,41]. A more recent study by Jordan et al [34] reported 63% and 51% lifetime prevalence of major depression in a 56-female anorexia nervosa sample and a 132-female bulimia nervosa sample, aged 17-40 years, respectively. On the higher end, Blinder et al [38] reported that for a female sample aged 11-68 years, 92% of the 956 patients diagnosed with anorexia nervosa and 92% of the 882 patients diagnosed with bulimia nervosa had unipolar depression disorder, while Salbach-Andrae et al [42] reported that 60% of their adolescent girls aged 12-18 years exhibited comorbid mood disorder. Conversely, among women with MDD, the lifetime prevalence rate of anorexia nervosa was estimated at 1-7% and of bulimia nervosa at 9-21% [43,44].

Anxiety disorders are also prevalent in individuals diagnosed with eating disorders, although studies on anxiety disorders and eating disorders have produced mixed results [32,45,46]. Studies that used controlled groups reported significant comorbidities between anxiety disorders and eating disorders [32,47-50]. Depending on which one of the anxiety disorders is under investigation, estimates of the lifetime prevalence of anxiety disorders in eating disorders range from as low as 0% for specific phobia in anorexia nervosa [51] to as high as 79% for OCD in anorexia nervosa [52], and from as low as 2% for agoraphobia without panic disorder in bulimia nervosa [53] to as high as 59% for SAD in bulimia nervosa [54]. A summary of life prevalence rates of MDD and various anxiety disorders in anorexia nervosa and bulimia nervosa is shown in Table 1 [33,34,38,47,51-59].

Table 1. Comorbidity of various anxiety disorders with anorexic nervosa and bulimia nervosa.

Anxiety disorders/MDD	Lowest, % [reference #]	Highest, % [reference #]
Anorexia nervosa		
OCD	14% [51]	79% [52]
SAD	38% [47]	55% [54]
Agoraphobia without panic disorder	3% [54]	27% [47]
Simple/Specific Phobia	0% [51]	45% [54]
GAD	24% [54]	49% [47]
PD/A	13% [47]	43% [51]
PTSD	2% [47]	7% [47]
MDD	46% [33] 63% [34]	74% [33] 92% [38]
Bulimia nervosa		
OCD	4% [53]	43% [55]
SAD	30% [53]	59% [54]
Agoraphobia without panic disorder	2% [53]	35% [56]
Simple/Specific Phobia	3% [51]	46% [57]
GAD	2% [53]	55% [58]
PD/A	10% [53]	53% [51]
PTSD	5% [47]	37% [59]
MDD	46% [33] 63% [34]	74% [33] 92% [38]

It should be noted that the time of onset for anxiety disorders, MDD, and eating disorders are not the same. Some anxiety disorders are associated with early childhood onset while others are associated with onset during adolescence. However, Pallister and Waller [46] concluded that while the relative time of onset was inconsistent, females with eating disorders exhibited higher rates of anxiety disorders compared to controls, and suggested that eating disorders and anxiety disorders might have some common underlying factors.

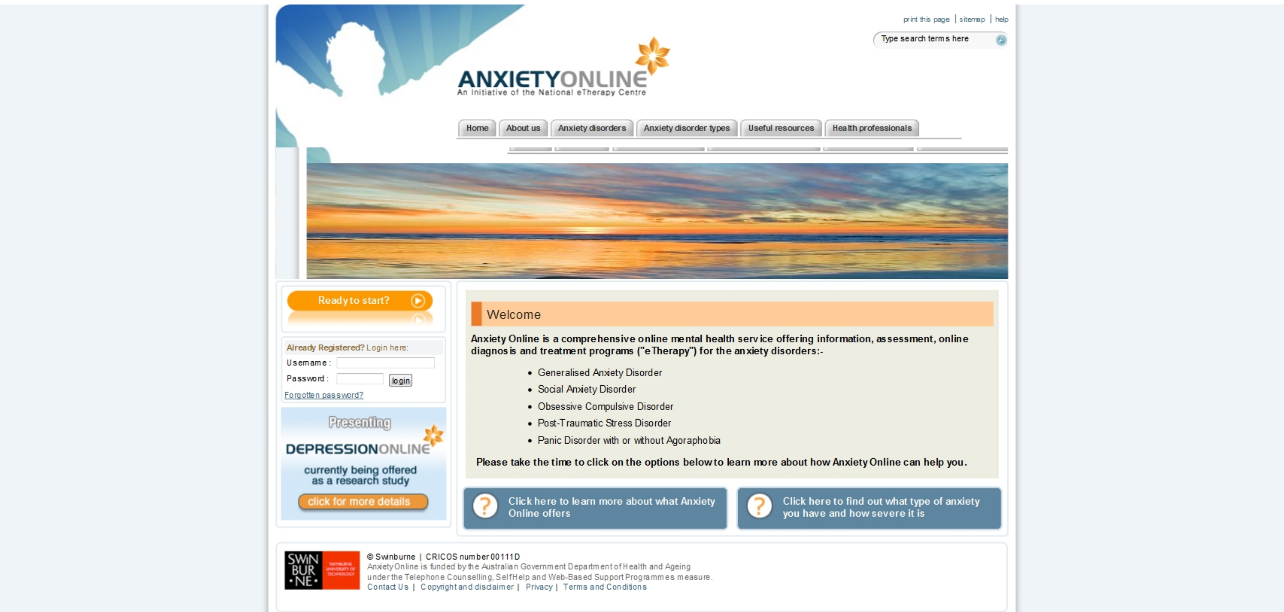
Another disorder that seems to be present in eating disorders, particularly in anorexia nervosa, is BDD [35,60], coupled with features of OCD engaging in ritualistic-like behaviors to reduce anxiety generated by thoughts of one's poor self-image [35,61,62].

Finally, the substance use by individuals with psychological disorders has long been investigated [36,63,64]. The rates of substance use disorders in patients diagnosed with mood disorders and anxiety disorders were reported to be 42% and 27%, respectively [37].

In summary, the comorbidities of anxiety disorders, MDD, eating disorders, and substance use have long been established in clinical samples using traditional face-to-face assessment and diagnosis. Comorbidity estimates vary depending on the psychological disorder, age of the sample, and the specific population sample. There are no data available on the comorbidity of psychological disorders using online assessment and diagnostic tools with online samples.

The first purpose of this study is to report on the co-occurrences of 21 psychological disorders diagnosed in an online sample using an online assessment and diagnostic tool, e-PASS. While we will present the entire matrix of co-occurrences, we will focus on the comorbidities of anxiety disorders, major depressive episode (MDE), eating disorders, BDD, insomnia, hypersomnia, and alcohol use disorder. We will also report these comorbidities for males, females, separately, and together. The second purpose of this study is to examine the relationships between the identified anxiety-depression comorbidity clusters and three variables: suicidal ideation, social support, and quality of life.

Figure 1. Anxiety Online homepage image.



Welcome

Anxiety Online is a comprehensive online mental health service offering information, assessment, online diagnosis and treatment programs ("eTherapy") for the anxiety disorders:-

- Generalised Anxiety Disorder
- Social Anxiety Disorder
- Obsessive Compulsive Disorder
- Post-Traumatic Stress Disorder
- Panic Disorder with or without Agoraphobia

Please take the time to click on the options below to learn more about how Anxiety Online can help you.

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Anxiety Online is funded by the Australian Government Department of Health and Ageing under the Telephone Counselling, SelfHelp and Web-Based Support Programmes measure.

Methods

Procedure

The Mental Health Online platform consists of four centers, one of which is the assessment center containing the e-PASS (electronic psychological assessment screening system). The e-PASS includes a variety of demographic and personal questions and the Kessler-6 and Suicidal Warnings measure, as well as the online diagnostic program. Individuals can access the Mental Health Online service from anywhere in the world provided they have an Internet connection. People can complete e-PASS if they are interested in the psychological assessment function and/or if they are interested in online treatment. Those who undertook the e-PASS were first required to register and consent to the Mental Health Online terms and conditions [7]. The procedures for collection and reporting of the Mental Health Online data were approved by the Swinburne University Human Research Ethics Committee.

Diagnostic Assessment

Based on an individual's response to some of the e-PASS questions, a person may be given a primary diagnosis and/or multiple secondary diagnoses. Primary or secondary diagnosis is determined by the reported presence of *Diagnostic and Statistical Manual of Mental Disorders* (4th edition, Text Revision) (DSM-IV-TR) symptoms and the average score on severity scales, each of which assesses the level of distress and interference caused by the symptoms of a particular disorder. A total of 21 clinical disorders are assessed by the e-PASS (see [5,65] for more details). The 21 psychological disorders and their abbreviations are shown in Multimedia Appendix 1.

The disorder specific severity score is the average of the scores on six questions that assess how distressed one is and how much the symptoms of a given disorder interfere in one's life (using a scale 0=no interference/distress to 8=severe interference/distress). A person who does not endorse enough of the initial DSM-IV-TR symptom criteria questions for a particular disorder is not presented with the questions assessing their level of distress and interference of those symptoms and is assigned a severity score of zero. Those who endorse the DSM-IV symptom criteria questions for a particular disorder are presented with the six distress and interference questions allowing the calculation of an averaged severity score ranging from 0-8. An averaged distress and interference severity score of 3.5 or above is considered sufficient to warrant a clinical diagnosis. Those whose average distress and interference severity scores are less than 3.5 are considered to warrant a subclinical (or subthreshold) diagnosis.

The e-PASS diagnostic system was informed by the Anxiety Disorders Interview Schedule (ADIS) clinician rating scale (a Likert scale from 0=no symptoms, to 4=mild presence of the disorder, to 8=very severe presence of the disorder). Most "total scores" would not be a whole number because the system used six rating scales and then averaged them. Thus, 4 is the typical score by a clinician using the ADIS that indicates the "presence" of a disorder. However, considering the decimal places resulting from the e-PASS averaging of the six rating scales, those scoring 3.5 and above were deemed clinical.

The psychometric properties of the e-PASS measures were shown to have high test-retest reliability and reasonable convergent validity with the structured clinical interviews (Nguyen, unpublished PhD thesis 2013). However, the small sample size and some disagreement with the structured clinical interviews in terms of the severity levels required for a clinical diagnosis, suggest that further validation studies with large sample sizes are needed.

For the purpose of this work, we will construct a frequency matrix representing the co-occurrences of all 21 psychological disorders diagnosed by the e-PASS system. We will identify the number of participants who met the criteria for a primary disorder (reference group) and then establish the proportion of the reference group who were given a secondary diagnosis for each of the remaining 21 disorders. We will also calculate these frequencies for males and females.

Participants

A total of 13,414 individuals completed the e-PASS phase between October 2009 and October 2012 and received at least one clinical diagnosis. The sample consisted of 3974 (29.6%) males whose ages ranged between 18-85 years old with a mean of 36.88 (SD 12.59) years, and 9440 (70.4%) females whose ages ranged between 18-86 years old with a mean of 33.66 (SD 11.57) years. A total of 749 individuals received a clinical diagnosis (severity score greater than 3.5) of only one disorder, leaving 12,665 individuals who were classified as having a clinical or subclinical diagnosis for two or more of the 21 disorders assessed by e-PASS.

Analysis

The frequency of male and female participants who received a primary diagnosis on any particular disorder was first identified. Then, for each group, the frequencies of receiving secondary diagnoses for all 21 disorders were calculated. A series of hierarchical loglinear regression procedures were used to examine the relationships between anxiety-depression disorders and suicidal ideation, social support, and quality of life. For the significant comorbidity relationships with suicidal ideation, social support, and quality of life, demographic variables will also be explored.

Results

Overview

A frequency matrix of 21-by-21 disorders is shown in Multimedia Appendix 2. The number of cases of males and females receiving a primary disorder is shown in column 3 for each disorder shown column 1. Columns 4 and onward in Multimedia Appendix 2 show the number of males, females, and total and their associated percentages of those receiving secondary diagnoses. For example, of the 858 males, 1761 females, and 2649 overall who received a primary diagnosis of MDE, there were 207 (24.13%) males, 505 (28.68%) females, and 712 (26.88%) overall who received a secondary diagnosis of PD/A, respectively. Conversely, of the 478 males, 1000 females, and 1478 overall who received a primary diagnosis of PD/A, there were 289 (60.46%) males, 615 (61.50%) females, and 904 (61.16%) overall who received a secondary diagnosis of MDE, respectively.

Comorbidities of Primary Anxiety Disorders

As shown in Multimedia Appendix 2, each anxiety disorder was comorbid with other anxiety disorders. GAD was the most comorbid anxiety disorder with other anxiety disorders ranging from 58.0% (327/564) with specific phobia to 62.31% (921/1478) with PD/A. SAD was the second most comorbid anxiety disorder with other anxiety disorders ranging from 39.5% (183/463) with OCD to 65.1% (334/513) with agoraphobia without panic disorder. The third was specific phobia with a range from 31.6% (162/513) with agoraphobia without panic disorder to 44.25% (654/1478) with PD/A. The fourth was PD/A with a range from 28.25% (378/1338) with SAD to 41.0% (231/564) with specific phobia. The fifth was PTSD with a range from 20.7% (96/463) with OCD to 31.39% (464/1478) with PD/A. The sixth was OCD with a range from 8.95% (184/2056) with GAD to 34.9% (176/504) with PTSD. The seventh was agoraphobia without panic disorder with a range from 13.8% (64/463) with OCD to 28.10% (376/1338) with SAD.

Comorbidities of Depression, Anxiety Disorders, Insomnia/Hypersomnia, and Drug and Alcohol Abuse

We first note that there were 858 males and 1761 females who received a primary diagnosis of MDE—a 2 to 1 female to male ratio. We also note the difference in comorbidity between males and females who have been diagnosed with MDE and one of the anxiety disorders. In all cases, except for OCD, the comorbidities of MDE with PD/A, agoraphobia without panic disorder, specific phobia, PTSD, GAD, and SAD among females are greater than the comorbidity among males. In addition, about 65.50% (1735/2649) of those diagnosed with MDE suffer from insomnia, whereas about 19.29% (511/2649) suffer from hypersomnia, with females reporting symptoms of insomnia and hypersomnia in greater numbers. Also, 21.10% (559/2649) of those diagnosed with MDE report alcohol abuse with males reporting alcohol use in greater numbers.

On average, we found 58.38% of those receiving a primary diagnosis of one of the anxiety disorders also received a secondary diagnosis of MDE. Conversely, on average, we found approximately 35% of those who received a primary diagnosis of MDE also received a secondary diagnosis of one or more anxiety disorders. The lowest comorbidity was between MDE and agoraphobia without panic disorder at about 17.93% (475/2649), whereas the highest comorbidity was between MDE and GAD at about 59.61% (1579/2649). The remaining anxiety disorders in order of frequency magnitude were OCD (710/26.80%), PD/A (712/2649, 26.88%), specific phobia (803/2649, 30.31%), PTSD (883/2649, 33.33%), and SAD (1336/2649, 50.43%).

Results show the presence of the following substance dependency in participants who received a primary diagnosis of MDE: cannabis (202/2649, 7.63%), stimulant (114/2649, 4.3%), opioid (71/2649, 2.68%), sedative (252/2649, 9.51%), and alcohol (559/2649, 21.10%). Most significant was the difference between depressed males and females in alcohol dependence (25.76% (221/858) for males vs 19.19% (338/1761) for females).

The highest percentage of substance dependency present in all anxiety disorders diagnosed by e-PASS was found for males with GAD and alcohol dependence at 24.06% (141/586), for females with specific phobia and alcohol dependence at 15.10% (61/404), and for both males and females with GAD and alcohol dependence at 17.41% (358/2056).

Results indicate insomnia was present in all disorders ranging from 41.25% to 83.67% for the combined male/female samples. For males, the co-occurrence of insomnia was found highest with somatization disorder at 100% and lowest with opioid dependency and OCD at 33.33% and 33.71%, respectively. For females, the co-occurrence of insomnia was found highest with somatization disorder at 80.0% (32/40) and lowest with alcohol dependency at 42.1% (40/95).

Comorbidities of Eating Disorders With Anxiety and Major Depressive Disorders

There were a total of 14 participants (3 males and 11 females) diagnosed with anorexia nervosa, whereas 505 participants (26 males and 479 females) diagnosed with bulimia nervosa. Results showed that 71.43% (0% males vs 90.91% females) and 71.68% (80.77% males vs 71.19% females) of those receiving a primary diagnosis of anorexia nervosa and bulimia nervosa, respectively, also received a secondary diagnosis of MDE. The co-occurrences of primary diagnosis of anorexia nervosa or bulimia nervosa with the presence of a secondary diagnosis of 1 of 7 anxiety disorders for males, females, and the total sample are extracted from Multimedia Appendix 2 and are shown in Table 2.

Table 2. Comorbidities of anxiety disorders, MDE in anorexia nervosa and bulimia nervosa groups.

Anxiety disorders	Anorexia nervosa, n (%)			Bulimia nervosa, n (%)		
	Male (n=3)	Female (n=11)	Total (N=14)	Male (n=26)	Female (n=479)	Total (N=505)
OCD	1 (33.3)	5 (45.5)	6 (42.9)	12 (46.2)	171 (35.7)	183 (36.2)
SAD	1 (33.3)	7 (63.6)	8 (57.1)	13 (50.0)	239 (49.9)	252 (49.9)
GAD	1 (33.3)	8 (72.7)	9 (64.3)	15 (57.7)	248 (51.8)	263 (52.1)
PD/A	0 (0.0)	3 (27.3)	3 (21.4)	5 (19.2)	126 (26.3)	131 (25.9)
PTSD	1 (33.3)	2 (18.2)	3 (21.4)	7 (26.9)	160 (33.4)	167 (33.1)
SP	0 (0.0)	4 (36.4)	4 (28.6)	9 (34.6)	127 (26.5)	136 (26.9)
AwoPD	1 (33.3)	1 (9.1)	2 (14.3)	7 (26.9)	64 (13.4)	71 (14.1)

As shown in Table 2, the comorbidity rate of anorexia nervosa with any of the 7 anxiety disorders was highest for females diagnosed with GAD at 72.7% and lowest for females diagnosed with agoraphobia without panic disorder at 9.1%. Similarly, the comorbidity rate of bulimia nervosa with any of the 7 anxiety disorders was highest for females diagnosed with GAD at 51.8% and lowest for females diagnosed with PD/A at 26.3%.

It should be noted that the rate of comorbidity depends on the reference group. For example, as shown in Multimedia Appendix 2, the rate of co-occurrence of MDE in the bulimia nervosa group was 80.8% (21/26) for males, 71.2% (341/479) for females, and 71.7% (362/505) for both. However, the rate of co-occurrence of bulimia nervosa in the MDE group was found to be 4.6% (39/858) for males, 14.82% (261/1761) for females, and 11.33% (300/2649) for both, and the rate of co-occurrence of anorexia nervosa in the MDE group was found to be 0% for males, 1% for females, and 1% for both.

Relationships Between Comorbidities of Anxiety and Depressive Disorders and Psychosocial Variables

The data contained 6 anxiety disorders with the following primary diagnoses frequencies: GAD (n=2056), PD/A (n=1478), SAD (n=1338), specific phobia (n=564), PTSD (n=504), and OCD (n=463). The data also contained 2649 participants who received a primary diagnosis of MDE. Cross-tabulation of these 7 disorders resulted in cells with fewer than 5 participants. To maintain a cell count of 5 or greater, specific phobia, PTSD, and OCD were removed from further analyses. For the next several hierarchical loglinear analyses, MDE, GAD, PD/A, and SAD were used with each of the following variables: suicidal ideation, social support, and quality of life. In addition, age was split into young (those between 18 and 35 years old) and older (those over 35 years old). Sex of participants was also split into males and females.

Anxiety, Depression, and Suicidal Ideation

Three anxiety disorders (PD/A, SAD, GAD) and MDE with suicidal ideation were entered into a hierarchical loglinear regression. The 5-way loglinear analyses resulted in a model with a non-significant likelihood ratio (χ^2_{10}=9.6, P=.476) that retained 3-way effects (χ^2_{16}=97.7, P<.001). Results of the backward elimination showed 2 significant triads that contained suicidal ideation: PD/A*SAD*suicidal ideation and PD/A*MDE*suicidal ideation. Two new hierarchical loglinear models were constructed. The first model was based on PD/A, SAD, suicidal ideation, age, and sex that resulted in a non-significant likelihood ratio (χ^2_{10}=12.7, P=.240) that retained 3-way effects (χ^2_{16}=81.5, P<.001). The second model was based on PD/A, MDE, suicidal ideation, age, and sex which resulted in a non-significant likelihood ratio (χ^2_{10}=6.5, P=.772) that retained 3-way effects (χ^2_{16}=34.8, P=.004). Consequently, a new model with PD/A, SAD, MDE, suicidal ideation, age, and sex with only 3-way effects resulted in a non-significant likelihood ratio (χ^2_{32}=22.4, *P*=.90). Backward elimination resulted in 2 significant triads that included suicidal ideation, MDE-PD/A comorbidity dyad and PD/A-SAD comorbidity dyad, as shown in Table 3. A 2x2 cross-tabulation for those who reported no suicidal ideation and for those who reported suicidal ideation was performed separately for the MDE-PD/A comorbidity dyad and for the PD/A-SAD comorbidity dyad.

Table 3. Values and significance of chi square test for 3-way interactional terms for MDE, PD/A, SAD, sex, and age with suicidal ideation.

3-way interaction	χ^2(df=1)	*P*
MDE*PD/A*SAD	13.7	.000
MDE*PD/A*suicidal ideation	7.6	.006
MDE*SAD*Sex	8.3	.004
PD/A*SAD*Suicidal ideation	14.3	.000
PD*SAD*Age	22.7	.000
Suicidal Ideation*Sex*Age	6.0	.014

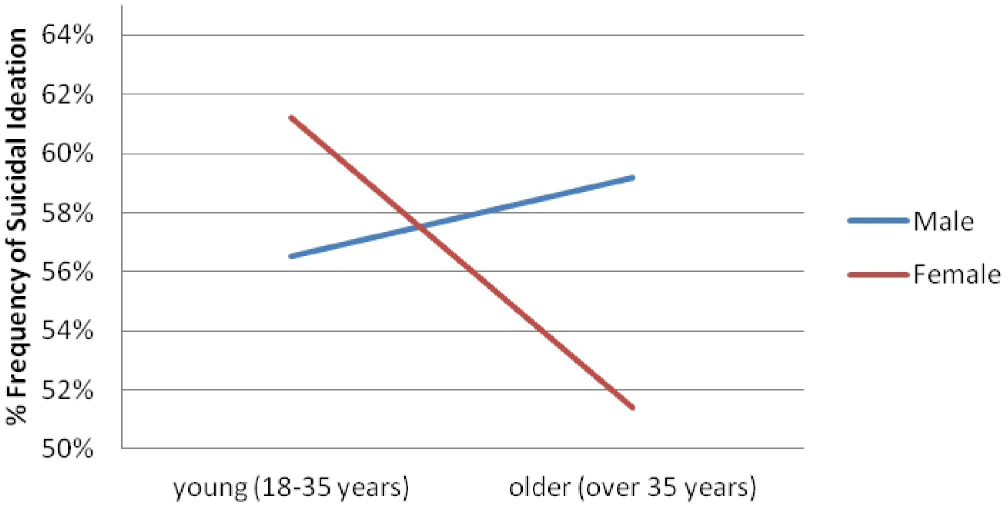
MDE-PD/A Comorbidity Dyad

For the non-suicidal ideation group, there was a significant association between MDE and whether or not PD/A was endorsed (χ^2_1=11.1, *P*=.001). The odds for the non-suicidal ideation group endorsing both MDE and PD/A were 1.18 times higher than if they had endorsed MDE only. For the suicidal ideation group, there was a significant association between MDE and whether or not PD/A was endorsed (χ^2_1=21.0, *P*<.001). This was based on the finding that the odds of the suicidal ideation group endorsing both MDE and PD/A were 1.84 times higher than if they had endorsed MDE only. The frequencies of all combinations of PD/A, MDE, sex, and age of those who reported suicidal ideation are shown in Table 4, and a graph illustrating the effect of sex and age on suicidal ideation when there is PD/A and MDE comorbidity is shown in Figure 2.

Table 4. Frequencies (%) of those endorsing suicidal ideation by PD/A*MDE*Sex*Age.

PD/A	MDE	Sex	Age	Suicidal ideation, n/N (%)
Yes	Yes	M	Y (≤35)	309/547 (56.5)
Yes	Yes	M	O (>35)	266/449 (59.2)
Yes	Yes	F	Y	1075/1757 (61.18)
Yes	Yes	F	O	416/809 (51.4)
Yes	No	M	Y	15/183 (8.2)
Yes	No	M	O	12/170 (7.1)
Yes	No	F	Y	40/550 (7.3)
Yes	No	F	O	18/314 (5.7)
No	Yes	M	Y	455/908 (50.1)
No	Yes	M	O	416/883 (47.1)
No	Yes	F	Y	1194/2419 (49.36)
No	Yes	F	O	676/1547 (43.70)

Figure 2. Sex by age for those who endorsed suicidal ideation (% frequency) and endorsed PD/A and MDE.



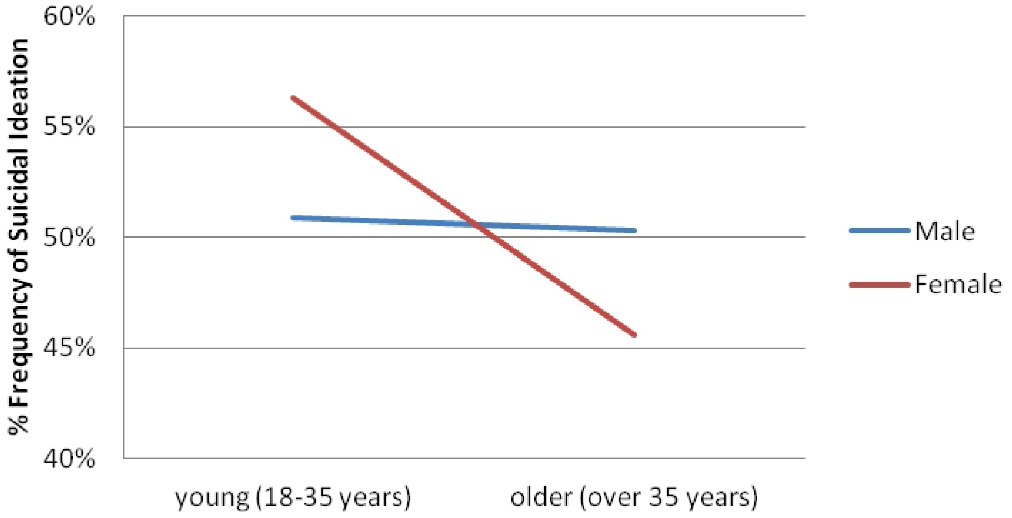
PD/A-SAD Comorbidity Dyad

For the non-suicidal ideation group, there was a significant association between PD/A and whether or not SAD was endorsed (χ^2_1=34.6, *P*<.001). The odds of the non-suicidal ideation group endorsing both PD/A and SAD were 1.32 times higher than if they had endorsed PD/A only. For the suicidal ideation group, there was a significant association between PD/A and whether or not SAD was endorsed by this group (χ^2_1=140.4, *P*<.001). The odds of the suicidal ideation group endorsing both PD/A and SAD were 2.07 times higher than if they had endorsed PD/A only. The frequencies of all combinations of PD/A, SAD, sex, and age of those who reported suicidal ideation are shown in Table 5, and a graph of the effect of age and sex on suicidal ideation in the presence of a PD/A and SAD comorbidity is shown in Figure 3.

Table 5. Frequencies (%) of those endorsing suicidal ideation by PD/A*SAD*Sex*Age.

PD/A	SAD	Sex	Age	Suicidal ideation, n/N (%)
yes	yes	M	Y (≤35)	244/479 (50.9)
yes	yes	M	O (>35)	197/392 (50.28)
yes	yes	F	Y	842/1496 (56.3)
yes	yes	F	O	314/689 (45.6)
yes	no	M	Y	80/251 (31.9)
yes	no	M	O	81/227 (35.7)
yes	no	F	Y	273/811 (33.7)
yes	no	F	O	120/434 (27.6)
no	yes	M	Y	303/776 (39)
no	yes	M	O	247/633 (39)
no	yes	F	Y	804/2021 (39.78)
no	yes	F	O	361/1049 (34.41)

Figure 3. Sex by age for those who endorsed suicidal ideation (% frequency) and endorsed PD/A and SAD.



Anxiety, Depression, and Social Support

Three anxiety disorders (PD/A, SAD, GAD) and MDE with social support were entered into a hierarchical loglinear regression. The 5-way loglinear resulted in a model, with a non-significant likelihood ratio (χ^2_{10}=7.1, *P*=.72), which retained 3-way effects (χ^2_{16}=86.5, *P*<.001). Results of the backward elimination showed 1 significant triad that contained social support, PD/A*GAD*social support (χ^2_1=4.3, *P*=.038). The remaining 4 significant triads were the 3-way interactions of MDE*GAD*PD/A, MDE*GAD*SAD, GAD*PD/A*SAD, and MDE*PD/A*SAD that did not include social support. A hierarchical loglinear model was constructed using PD/A, GAD, and social support with sex and age. The resulting model had a non-significant likelihood ratio (χ^2_{10}=2.2, *P*=.994) that retained 3-way effects (χ^2_{16}=40.4, *P*=.001). A new model with only 3-way effects resulted in a non-significant likelihood ratio (χ^2_{16}=17.7, *P*=.35). Backward elimination resulted in one significant triad that included social support and GAD-PD/A comorbidity dyad, as shown in Table 6.

Table 6. Values and significance of chi square test for 3-way interactional terms for GAD, PD/A, sex, and age with social support.

3-way interaction	χ^2(df=1)	*P*
GAD*PD/A*Social Support	9.6	.002
GAD*Sex*Age	19.6	.000
PD*Age	42.5	.000
Social Support*Sex	14.9	.000

A 2x2 cross-tabulation for those who reported inadequate social support and for those who reported adequate social support was performed separately for the GAD-PD/A comorbidity dyad. For those who reported inadequate social support, there was a significant association between GAD and whether or not PD/A was endorsed (χ^2_1=119.12, *P*<.001). This was based on the finding that the odds of inadequate social support group endorsing both GAD and PD/A were 1.84 times higher than if they had endorsed GAD only. For those who reported adequate social support, there was a significant association between GAD and whether or not PD/A was endorsed (χ^2_1=40.31, *P*<.001). The odds of the adequate social support group endorsing both GAD and PD/A were 1.42 times higher than if they had endorsed GAD only. Table 7 shows the frequencies of all combinations of PD/A, GAD, sex, and age of those who endorsed adequate social support.

Table 7. Frequencies (%) of those endorsing social support by PD/A*GAD*Sex*Age.

PD/A	GAD	Sex	Age	Social support, n/N (%)
Yes	Yes	M	Y (≤35)	189/507 (37.3)
Yes	Yes	M	O (>35)	166/435 (38.2)
Yes	Yes	F	Y	671/1744 (38.47)
Yes	Yes	F	O	304/793 (38.3)
Yes	No	M	Y	116/223 (52.0)
Yes	No	M	O	97/184 (52.7)
Yes	No	F	Y	294/563 (52.2)
Yes	No	F	O	193/330 (58.5)
No	Yes	M	Y	301/781 (38.5)
No	Yes	M	O	306/787 (38.9)
No	Yes	F	Y	1032/2362 (43.69)
No	Yes	F	O	639/1421 (44.97)

Anxiety, Depression, and Quality of Life

Three anxiety disorders (PD/A, SAD, GAD) and MDE with quality of life were entered into a hierarchical loglinear regression. The 5-way loglinear resulted in a model, with a non-significant likelihood ratio (χ^2_{10}=11.1, *P*=.35) that retained 3-way effects (χ^2_{16}=92.6, *P*<.001). Results of the backward elimination showed 1 significant triad that contained quality of life, PD/A*SAD*quality of life (χ^2_1=4.6, *P*=.031). The remaining 3 significant triads were the 3-way interactions of MDE*PD/A*SAD, MDE*GAD*SAD, and MDE*GAD*PD/A that did not include quality of life. A hierarchical loglinear model was constructed using PD/A, SAD, and quality of life with sex and age. The resulting model had a non-significant likelihood ratio (χ^2_{10}=7.7, *P*=.66) that retained 3-way effects (χ^2_{16}=56.0, *P*<.001). A new model with only 3-way effects resulted in a non-significant likelihood ratio (χ^2_{13}=14.1, *P*=.37). Backward elimination resulted in one significant triad that included quality of life and PD/A-SAD comorbidity dyad. The rest of the 5 significant triads did not include any comorbidity dyad with the quality of life term, as shown in Table 8.

Table 8. Values and significance of chi square test for 3-way interactional terms for SAD, PD/A, sex, and age with quality of life.

3-way interaction	χ^2(df=1)	*P*
PD*Quality of Life*SAD	16.4	.000
PD*Quality of Life*Sex	4.1	.042
PD*SAD*Age	18.0	.000
PD*Sex*Age	4.2	.040
SAD*Sex	5.4	.020

A 2x2 cross-tabulation for those who reported poor quality of life and for those who reported good quality of life was performed separately for PD/A-SAD comorbidity dyad. For those who reported poor quality of life, there was a significant association between PD/A and whether or not SAD was endorsed (χ^2_1=130.1, *P*<.001). This was based on the finding that the odds of poor quality of life group endorsing both PD/A and SAD were 1.87 times higher than if they had endorsed PD/A only. For those who reported good quality of life, there was a significant association between PD/A and whether or not SAD was endorsed by this group (χ^2_1=34.3, *P*<.001). The odds of the good quality of life group endorsing both PD/A and SAD were 1.35 times higher than if they had endorsed PD/A only. The frequencies of all combinations of PD/A, SAD, sex, and age of those who endorsed good quality of life are shown in Table 9.

Table 9. Frequencies (%) of those endorsing quality of life by PD/A, SAD, sex, and age.

PD/A	SAD	Sex	Age	Quality of life, n/N (%)
Yes	Yes	M	Y (≤35)	188/479 (39.2)
Yes	Yes	M	O (>35)	145/392 (37.0)
Yes	Yes	F	Y	567/1496 (37.90)
Yes	Yes	F	O	270/689 (39.2)
Yes	No	M	Y	147/251 (58.6)
Yes	No	M	O	113/227 (54.4)
Yes	No	F	Y	503/811 (62.0)
Yes	No	F	O	253/434 (58.3)
No	Yes	M	Y	339/776 (43.7)
No	Yes	M	O	386/663 (45.2)
No	Yes	F	Y	1011/2021 (50.02)
No	Yes	F	O	519/1049 (49.48)

Discussion

Principal Findings

A frequency matrix of the co-occurrence of 21 psychological disorders based on primary and secondary diagnoses of 12,665 individuals who were assessed using the e-PASS online diagnostic system was constructed. To the best of our knowledge, such a matrix for this many psychological disorders has not been presented before for traditional in-clinic diagnosis or for any online diagnostic tools. As such, comparisons with existing literature should be viewed with caution. We present this matrix to serve as a preliminary and potentially useful reference for future works in the area of online assessment and diagnosis.

Given the high number of disorders in the matrix and limited discussion space, we will focus on a few disorders that are of most interest and/or have been studied before in in-clinic samples.

Depression, Anxiety Disorders, Insomnia/Hypersomnia, and Drug and Alcohol Abuse

One area that has been studied extensively is the comorbidity of MDE and the various anxiety disorders, and alcohol abuse. We found the number of females receiving a primary diagnosis of MDE was twice the number of males receiving a primary diagnosis of MDE. This ratio of about 2:1 females to males is consistent with in-clinic samples and face-to-face diagnostic tools. We also found the comorbidities of MDE with all anxiety disorders, except for OCD, among females to be greater than the same comorbidities among males. In addition, the majority (2 in 3) of those diagnosed with MDE reported insomnia, whereas 1 in 5 reported hypersomnia, with greater numbers of females than males reporting symptoms of insomnia and hypersomnia. Moreover, 1 in 5 of those diagnosed with MDE reported alcohol abuse with greater numbers of males than females reporting alcohol abuse.

On average, we found approximately 1 in 3 of those who received a primary diagnosis of MDE also received a secondary diagnosis of one or more anxiety disorders. The lowest comorbidity was found between MDE and agoraphobia without panic disorder whereas the highest comorbidity was between MDE and GAD. These results are consisted with findings based on in-clinic samples [15,21,24,25,66]. Our findings are also consistent with Fava et al [24] who found that 46% of MDD patients were significantly more likely to report symptoms associated with GAD, OCD, PTSD, agoraphobia without panic disorder, and PD/A than individuals without comorbid anxiety. On the higher end, Almeida-Filho et al [23] found 74% of a depressed Brazilian sample reported symptoms of anxiety disorders, which is much higher than our results of 35%. This discrepancy is possibly due to the fact that they used reported symptoms of anxiety disorders, whereas this study used adherence to the DSM-IV-TR diagnostic criteria. On the other hand, our result that almost 2 in 3 of those receiving a primary diagnosis of one of the anxiety disorders was also receiving a secondary diagnosis of MDE is consistent with Almeida-Filho et al's [23] results that 61% of those with anxiety disorders were depressed.

We also found high rates of comorbidities among anxiety disorders with GAD being the most comorbid anxiety disorder with other anxiety disorders followed by SAD, specific phobia, PD/A, PTSD, OCD, and agoraphobia without panic disorder. These results are consistent with previous research findings that found anxiety disorders to have high comorbidities with each other and that questioned the discriminant validity of some anxiety diagnoses such as GAD [5,8-13]. This consistency may suggest that there are no differences between online and in-clinic assessment systems and online and in-clinic populations.

The comorbidities between MDE and various substance dependency (ranging between 3% to 21%) found in this study are much lower than the 42% of mood disordered patients who had substance use disorders as reported by McGovern et al [37]. Again, this discrepancy may be due to this study's strict adherence to the diagnostic criteria.

The highest comorbidity of substance dependency present in all anxiety disorders was found for males who received a primary diagnosis of GAD and a secondary diagnosis of alcohol dependence at 24.06%, and for females who received a primary diagnosis of specific phobia and a secondary diagnosis of alcohol dependence at 15.10%. McGovern et al [37], without examining males and females separately, found substance use disorders present in 27% of patients diagnosed with anxiety disorders, which is, again, slightly greater than results of this study of about 17% for the combined male and female samples. Almeida-Filho et al [23] found 20% of cases of alcoholism co-occurring with anxiety disorders and MDD diagnoses.

This study also found insomnia to be present in all disorders ranging from 41.25% to 83.67% for the combined male/female samples across all disorders. This association between insomnia and psychological disorders is consistent with the literature. For example, the presence of sleep problems has been consistently found in patients with anxiety and mood disorders [5,26-30].

Eating Disorders, Anxiety Disorders, and Major Depression

The interpretation of the comorbidities of anorexia nervosa with other disorders should be viewed with caution because of the small number of participants who were diagnosed with anorexia nervosa. Overall, our results are consistent with the previously found rates of anorexia nervosa and bulimia nervosa comorbidities with MDE and anxiety disorders. Specifically, we found 71.43% and 71.68% of those receiving a primary diagnosis of anorexia nervosa and bulimia nervosa, respectively, also received a secondary diagnosis of MDE. The comorbidity of anorexia nervosa and MDE found in this study is within the range of 50%-71% reported by previous studies [33,34,40-42]. However, the result for the comorbidity of bulimia nervosa and MDE found in this study is slightly greater than the range of 50%-65% reported by previous investigations [33,34,40,41].

The rates of co-occurrence of bulimia nervosa and anorexia nervosa in the MDE group found in this study are consistent with the estimated lifetime prevalence of anorexia nervosa in MDD (1%-7%) and of bulimia nervosa in MDD (9%-21%) reported by Carter et al [43] and Fava et al [44]. It is expected that a larger proportion of bulimia nervosa individuals experience symptoms of depression while a much smaller percentage of depressed individuals experience symptoms of bulimia nervosa.

While the choice of the reference group is very important in establishing comorbidity rates, it varies in importance. For example, while defining the reference group in the case of MDE or anxiety disorders and bulimia nervosa or anorexia nervosa is important, it is less so when defining the reference group for MDE and GAD. As shown in Multimedia Appendix 2, the co-occurrence of MDE in the GAD group is 66.83% whereas the co-occurrence of GAD in the MDE group is 59.61% for combined male and female sample.

For the most part, results of this study are consistent with previous findings. However, results do not fall within the range found in previous studies on three occasions. The comorbidity rate for anorexia nervosa with GAD (64%) found by this study is outside the range of 24%-49% reported by Godart et al [47,54]. Similarly the comorbidity rate for anorexia nervosa with PTSD (21%) is outside the range of 2%-7% given by Godart et al [47]. In both cases, the results of this study are based on very few participants with anorexia nervosa and therefore should be interpreted with caution. Finally, the comorbidity rate for bulimia nervosa with MDE (72%) is slightly outside the range of 61%-65% reported by Jordan et al [34] and Casper [33].

This study also examined the interactional relationships between GAD, SAD, PD/A, MDE, sex, and age and three variables: suicidal ideation, social support, and quality of life using a series of hierarchical loglinear analyses. In each case, 3-way interaction effects were found. For suicidal ideation, the odds of endorsing having suicidal ideation was greater for those diagnosed with depression and PD/A than depression only, and for those diagnosed with PD/A and SAD than PD/A only. These results suggest that comorbidity, even for two disorders, increases the risk of having suicidal thoughts, as indicated by previous research [3-5]. We also found a significant interactional effect for sex by age. The frequency of younger females (18-35 years old) diagnosed with MDE and PD/A or PD/A and SAD endorsing suicidal ideation was about 10% greater than older females (over 35 years old) and about 5% greater than their counterpart younger or older males. These results suggest that younger females who have these comorbidity dyads are at greater risk of having suicidal ideation.

The results of this study found the GAD and PD/A dyad to be the only one to have a significant relationship with social support. The odds for reporting having inadequate social support was greater for those diagnosed with GAD and PD/A than GAD only. There are not many studies that examined the relationship between comorbidity and social support, but one recent study reported a negative relationship between comorbidity and social support [5]. We should note here that this study found no significant interactional effect between GAD and PD/A comorbidity dyad and sex, age, and social support. These results suggest that sex and age have little effect on the relationship between this dyadic comorbidity and social support.

Finally, the results suggested that the PD/A and SAD dyad was the only dyad to have a significant relationship with quality of life. The odds for reporting having a poor quality of life was greater for those diagnosed with PD/A and SAD than PD/A only. Again, only one study reported a negative relationship between comorbidity and quality of life [5]. Also, as was the case with social support, we found no significant interactional effect between the PD/A-SAD comorbidity dyad and sex, age, and quality of life. These results suggest that sex and age have no effect on the relationship between this dyadic comorbidity and quality of life.

Transdiagnostic Approaches

There is growing support for using transdiagnostic approaches for the assessment and treatment of psychological disorders. AL-Asadi et al [5] using dimensional scales found overlapping dimensions underlying the various psychological disorders. Moses and Barlow [67] and Barlow et al [68] concluded that at a minimum, a diagnostic specific approach and transdiagnostic approaches to treatments are equally effective. AL-Asadi et al [69] found significant reduction in the severity of symptoms of depression as a result of participants receiving anxiety-specific treatment and supported the efficacy of online therapy to provide transdiagnostic treatment. McEvoy et al's [70] review of the literature concluded that transdiagnostic treatments were associated with improvements in comorbidity disorders and with high client satisfaction, therapeutic alliance, group cohesion, and positive treatment expectations. McManus et al [71] pointed out the potential of transdiagnostic approaches in addressing multiple comorbid anxiety disorders. Wade et al [72] found support for using transdiagnostic approaches to understanding eating disorders. Results of this study provide further support for the use of transdiagnostic approaches to the assessment and treatment of psychological disorders.

Limitations

One of the major limitations of this study is the lack of a control group. The online system does not require the inclusion of a control group and consequently any conclusion must be taken as preliminary. Another limitation is the lack of research on the sensitivity and the psychometric properties of the e-PASS system. There is only one unpublished study that found the e-PASS system to have high test-retest reliability and adequate convergent validity (Nguyen, unpublished PhD thesis, 2013). Unfortunately, even this one study has used a small sample size and found disagreement between e-PASS and structured clinical interviews when it came to the level of severity required for a clinical diagnosis. More validation studies with larger samples and using the newly released DSM-5 criteria are required before definitive conclusions can be made. The last limitation is inherent to all self-report instruments such as e-PASS. The exclusive reliance of e-PASS on automated online self-report measures brings into question the extent to which diagnosing individuals is reliable. Concerns have been raised regarding the reliability of online diagnostic tools [73].

Conclusions

In summary, overlap between psychological disorders for our online sample using the online assessment tool, e-PASS, was confirmed and was found to be similar to in-clinic samples using face-to-face assessment tools. Overall, there did not appear to be much difference in the rates of comorbidities of psychological disorders between in-clinic samples using face-to-face assessment and diagnostic tools and our online sample using the online assessment and diagnostic tool, e-PASS. The results of this study showed that the comorbidity rates for the online sample using e-PASS commonly fell within the range found for in-clinic samples using in-clinic assessment tools. The observation that e-PASS and face-to-face assessment tools generally yielded the same result may provide further evidence to the validity and the utility of the Anxiety Online Platform and the e-PASS assessment tool. Findings of this study supported the use of transdiagnostic approaches in the assessment and treatment of psychological disorders. Moreover, dyadic disorder comorbidities of some anxiety disorders and MDE were found to increase the odds for having suicidal ideation, inadequate social support, and poorer quality of life than a diagnosis of only one of the two making up the dyadic disorder.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Abbreviations for the 21 psychological disorders diagnosed by e-PASS.

[PDF File (Adobe PDF File), 29KB - jmir_v17i3e55_app1.pdf]

Multimedia Appendix 2

Table - Frequency of co-occurrences of 21 psychological disorders for males, females, and both.

[XLSX File (Microsoft Excel File), 20KB - jmir_v17i3e55_app2.xlsx]

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Abbreviations

ADIS: Anxiety Disorders Interview Schedule
AwoPD: agoraphobia without panic disorder
BDD: body dysmorphic disorder
DSM-5: Diagnostic and Statistical Manual of Mental Disorders (5th edition)
DSM-IV-TR: Diagnostic and Statistical Manual of Mental Disorders (4th edition, Text Revision)
e-PASS: electronic psychological assessment screening system
GAD: generalized anxiety disorder
MDD: major depressive disorder
MDE: major depressive episode
OCD: obsessive compulsive disorder
PD/A: panic disorder with or without agoraphobia
PTSD: posttraumatic stress disorder
SAD: social anxiety disorder

SP: specific phobia

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Review

The Effect of Patient Portals on Quality Outcomes and Its Implications to Meaningful Use: A Systematic Review

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Abstract

Background: The Health Information Technology for Economic and Clinical Health (HITECH) Act imposes pressure on health care organizations to qualify for “Meaningful Use”. It is assumed that portals should increase patient participation in medical decisions, but whether or not the use of portals improves outcomes remains to be seen.

Objective: The purpose of this systemic review is to outline and summarize study results on the effect of patient portals on quality, or chronic-condition outcomes as defined by the Agency for Healthcare Research and Quality, and its implications to Meaningful Use since the beginning of 2011. This review updates and builds on the work by Ammenwerth, Schnell-Inderst, and Hoerbst.

Methods: We performed a systematic literature search in PubMed, CINAHL, and Google Scholar. We identified any data-driven study, quantitative or qualitative, that examined a relationship between patient portals, or patient portal features, and outcomes. We also wanted to relate the findings back to Meaningful Use criteria. Over 4000 articles were screened, and 27 were analyzed and summarized for this systematic review.

Results: We identified 26 studies and 1 review, and we summarized their findings and applicability to our research question. Very few studies associated use of the patient portal, or its features, to improved outcomes; 37% (10/27) of papers reported improvements in medication adherence, disease awareness, self-management of disease, a decrease of office visits, an increase in preventative medicine, and an increase in extended office visits, at the patient’s request for additional information. The results also show an increase in quality in terms of patient satisfaction and customer retention, but there are weak results on medical outcomes.

Conclusions: The results of this review demonstrate that more health care organizations today offer features of a patient portal than in the review published in 2011. Articles reviewed rarely analyzed a full patient portal but instead analyzed features of a portal such as secure messaging, as well as disease management and monitoring. The ability of patients to be able to view their health information electronically meets the intent of Meaningful Use, Stage 2 requirements, but the ability to transmit to a third party was not found in the review.

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KEYWORDS

patient portal; medical record systems computerized; access to information; patient participation; quality, outcomes; meaningful use

Introduction

The 2009 Health Information Technology for Economic and Clinical Health (HITECH) Act placed new requirements on health care organizations in terms of Meaningful Use criteria, which drive reimbursements from the US government for patient-centered care [1]. Appropriate use of patient portals enables health care organizations to meet Stage 2 criteria for patient and family engagement [2]. Despite the advantages of a patient portal, there has not been widespread adoption of this patient-centered tool in the United States [3]. Additionally, research shows that although a provider can make a patient portal available to a patient, it does not necessarily result in a healthier patient [4]. As incentives came to a close at the end of 2014, the authors pondered if there had been any improvement from additional research conducted on the topic.

The US government defines a patient portal as “a secure online website that gives patients convenient 24-hour access to personal health information from anywhere with an Internet connection” [5]. The data are managed by the health care organization, and even the most rudimentary portals enable patients to access information like recent doctor visits, discharge summaries, medications, immunizations, allergies, and lab results. More advanced portals enable patients to request prescription refills, schedule non-urgent appointments, and exchange secure messaging (SM) with their provider [5].

The Meaningful Use criteria are a set of requirements that health care organizations must meet in order to qualify for incentives for the *meaningful* adoption of health information technology (HIT) [6]. Stage 1 criteria focused on data capture and sharing, while Stage 2 (current stage) focuses on advanced clinical processes such as health information exchange and increased patient-controlled data; the latter is specific to patient portals [6].

While most online patient portal programs are still in their infancy, the overall advantage that they provide will need to be benchmarked to determine how to improve not only the flow of information, but to also provide the patient with tools to take part in their care [7]. To be fully utilized in the future, these applications should be implemented to allow for fewer time consuming encounters between patients and providers as well as to enhance the accuracy of information being exchanged.

The ownership of a patient portal distinguishes it from a personal health record (PHR); while the PHR is owned and managed by the patient, a patient portal is owned and managed by the health care organization. A main advantage of the patient portal is that the data are current, while the data in the PHR are current only when the patient updates it. Without a patient portal as an intermediary, the patient would not be able to access the data in the electronic health record (EHR).

Ammenwerth, Schnell-Inderst, and Hoerbst conducted a systematic review on patient portals through a pilot study in 2011 [4]. The authors used medical subject headings (MeSH) terms to focus their research on studies that measured the impact of a patient portal on outcome criteria such as patient satisfaction with the provided care, patient empowerment, costs and resource consumption, mortality, or other relevant clinical parameters. The authors identified 603 papers, 13 of which were experimental or quasi-experimental. Of the 13 papers, five studies were deemed eligible and further analyzed, and four of which were randomized controlled trials (RCTs). Sample sizes ranged from 6-81 participants. A significant flaw in their research was to include the PHR in their search, which, as mentioned above, is significantly different from a patient portal in terms of ownership and management. The features of the patient portal, such as disease management, SM, and the ability to view current personal medical information, are not only key distinguishing details between the patient portal and the PHR, but they also identify features that align with Meaningful Use criteria in Stage 2. Results of this study showed an association between portal use and the following: decrease in office visits rates and telephone contacts, increase in number of messages sent, changes of medication regimen, and better adherence to treatment. The authors summarized their results as a very small effect of patient portals on patient empowerment.

This study intends to duplicate their systemic review with material published from 2011-2014. In light of the HITECH Act, it is expected that patient portals in the current market have evolved to the point that patient empowerment is evident, and medical outcomes can be more readily associated with the use of patient portals. All studies included in the systemic review will evaluate participants, interventions, comparisons, outcomes, and study design (PICOS), as appropriate.

Methods

The structure and content of this systematic review were loosely adopted from the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) [7]. Three search engines were queried for literature related to patient portals, outcomes (quality), and Meaningful Use. The literature search process, the inclusion and exclusion criteria, and final sample size is illustrated in Figure 1.

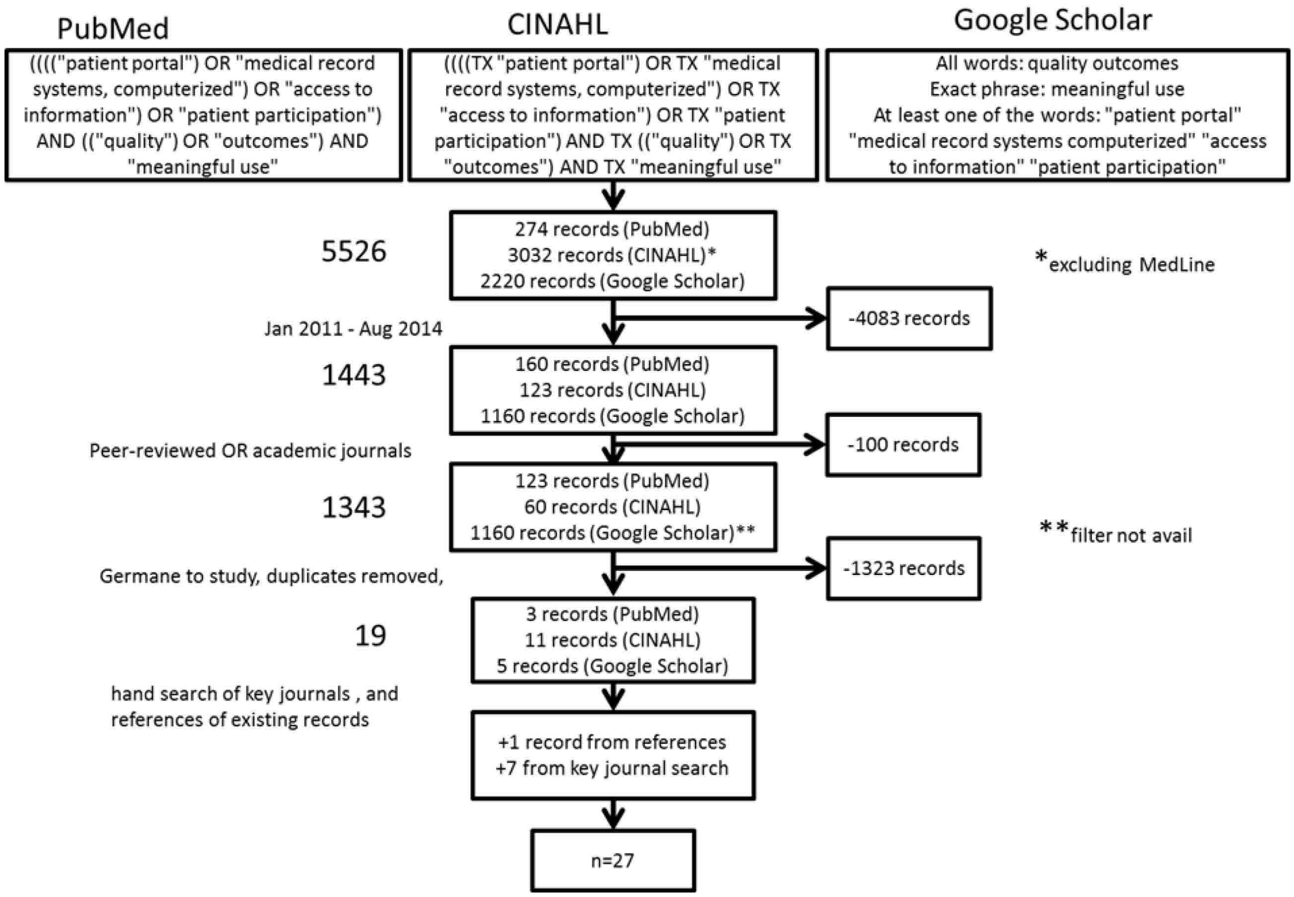
MeSH terms from PubMed (MEDLINE) were used as key words in the search. Unfortunately, MeSH does not contain the term “patient portal”. Keywords from the Ammenwerth et al study were all used, with the exception of “health record, personal”. The latter term was not used because of the clear ownership difference between the PHR and the patient portal. As illustrated, Boolean search operators were used to ensure proper terms were used and associated. The three search engines used were PubMed (including MEDLINE), CINAHL (excluding MEDLINE), and Google Scholar.

As depicted in the Ammenwerth et al review, experimental and non-experimental, as well as randomized and non-randomized studies published in academic journals were queried. The RCT and quasi-experimental designs are strong research designs, but we chose a wider array of publications, including those of weaker research designs such as observational studies. In order to be included in our review, publications must have occurred between January 1, 2011, and August 24, 2014. Editorials, government reports, letters to the editor, or non–data-driven studies were not considered, as in the Ammenwerth et al review. Studies for this review must include full text of the article so that the researchers could be certain that the manuscript addressed our research questions. Once studies were identified (N=19), the bibliography/references of each of the chosen articles were reviewed for seminal research otherwise missed. This search yielded one additional article. A key-journal search was also performed in the *Journal of Medical Internet Research*, because it is a prolific publisher of innovative research. This search added six studies and one review, for a final sample size of 27.

Rejection criteria comprised the following. Studies used in this review must have evaluated patient portals used by patients, access to information by patients, or patient participation (in medical decision making). Papers about PHRs or those that confused the line between portals and PHRs were rejected for aforementioned reasons. Studies presented at conferences but not published in peer-reviewed or other academic journals were rejected. The Ammenwerth et al review was not included because we were trying to update their review, and we did not want the results of their review to skew the results of our own.

There were no human subjects in this study; all information came from secondary data sources. The studies used in this research were sources that were publically available, and the subjects could not be identified either directly or through identifiers linked to the subject. This qualifies under “exempt” status in 45 Code of Federal Regulations 46. Therefore, Institutional Review Board review was not required, and consent from subjects was not applicable.

Figure 1. Search criteria and filters by search engine.



Results

Overview

As depicted in Figure 1, 5526 results from the initial search were narrowed down to 19 data-driven studies. From the references of the 19 studies, one additional study was identified. From the targeted-journal search, six studies and one review were added [8-34]. A brief summary of each of the 27 final manuscripts was compiled for analysis and is presented in Multimedia Appendix 1. Results from the searches are generally organized by year of publication. Approximately 22% were published in both 2011 and 2012, 37% were published in 2013, and 41% were published in 2014. Multimedia Appendix 2 provides an in-depth analysis of the studies, interventions, controls, outcomes, populations, and years conducted.

The studies from 2011 that were reviewed covered a wide range of objectives, and all were non-experimental. Goel et al analyzed age and race among portal users [8]. Nijland et al analyzed barriers to use of the patient portal [9]. Horvath et al used a much larger sample to evaluate the association between portal users and adherence to clinic appointments [10]. Results from these studies identified the demographics most commonly associated with use of the patient portal, that the primary barrier to adoption is lack of Internet use, and that the odds of arrival at an appointment increased 39.0% for portal users relative to nonusers of the portal.

In 2012, two of three studies were non-experimental. Palen et al conducted a retrospective study on portal enrollees to associate their rate of use of medical facilities [11]. Urowitz et al identified themes for appropriate use of the patient portal [12]. Debalco et al measured the frequency of access of provider notes by patients [13]. The latter study was able to record significantly positive, clinically relevant benefits by using a patient portal, but the study stopped short of measuring the positive benefit.

Ten studies were reviewed from 2013. Osborn et al used mixed methods to identify demographic differences between portal and non-portal users [14]. Portal users also noted greater medication adherence, particularly for those individuals with chronic illnesses like diabetes. Providers did not perceive a significant increase in workload. Wade-Vuturo et al reported greater patient engagement through the use of the portal [16]. Patients felt that medical decision making was more collaborative between them and their providers, increasing their sense of autonomy.

Several studies from 2013 evaluated the use of the secure messaging feature of a patient portal [15,16,20,22,23]. These studies all demonstrated a high level of patient satisfaction with the feature, and the users did not feel the process to exchange SMs was too complicated. Common to these studies was the perception of high-quality care, better patient-to-provider communication, greater levels of patient education, and a high level of patient engagement/empowerment.

Studies from 2013 also demonstrated several barriers to use of the patient portal; most common were lack of Internet access and lack of technical support [19,20,22,23]. Another significant finding in 2013 was the association of patient portal use with medication adherence, disease control, self-maintenance of health, and including the patient in the medical decision [16,19,22,23].

Ten studies and one review were analyzed from 2014. Researchers found an increase in communication between patients and provider through SM, as well as an increase in communication between patients and their health system, which resulted in an increase in customer retention through use of the patient portal [27,29]. Patients continued to respond positively about the SM feature of a portal or a portal-like app [24,26,32,33]. Use of the portal increased the number of office visits and phone contacts in one study [28], but in the review published in 2014, de Jong et al reported a decrease in the number of office visits. Last, Zikmund-Fisher et al evaluated portal user access to lab test results [30]. The portal users could not accurately interpret lab results that indicated level of disease management in diabetes patients. They concluded that health literacy and numeracy skills serve as barriers to full utility of the patient portal. If the patient can view the information but cannot interpret the numbers, they would in turn contact their provider for an interpretation, which defeats the goal of the patients being able to interpret their lab results without the provider having to call.

Bias, Validity, and Reliability

Several studies evaluated did not use randomization nor did they manipulate an independent variable. Studies without randomization of participants run the risk of selection bias, which, in turn, affects the internal validity. The articles reviewed did not provide a discussion section on bias or their efforts to compensate for the same. Non-experimental designs do not manipulate the independent variable (use of the patient portal) on a dependent variable (quality or Meaningful Use). Lack of a strong research design also reduces the internal validity of the study.

The risk of detection bias, or bias in how outcomes are ascertained, should not be low due to a common standard of care for chronic conditions; however, not all studies reviewed empirically measured outcomes. Reports of improved quality were primarily self-reported by users of the patient portal or portal-like apps.

Most studies that we reviewed provided sufficient detail for other researchers to duplicate their research, therefore the reliability of what they measured is strong. In the Methods section, we summarized our search criteria, and in Multimedia Appendix 1 we summarized results and applicability, loosely following the PICOS model identified in the PRISMA checklist. This review took extra care to ensure the consistency of measurement and reproducibility; we summarized the findings of previous studies and reviews, and we related these findings to our research questions pertaining to quality and Meaningful Use. Therefore, the reliability of this review should be acceptable. Unfortunately, our review did not record the specifics from each researcher on article selection. As in the Ammenwerth et al review, articles were reviewed by 2 researchers, and any differences in judgment were resolved by discussion.

Discussion

Summary of Evidence

The US Agency for Healthcare Research and Quality (AHRQ) lists several indicators of quality [35]. Most of these indicators surround the management of chronic conditions like diabetes and hypertension, as well as preventative care. The US Health Resources and Services Administration (HRSA) identifies quality improvement initiatives in health care, namely patient satisfaction and including the patient in medical decisions. This review identifies several quality indicators that are generated from both AHRQ and HRSA.

The use of the patient portals in this review illustrates a higher retention rate of patient loyalty [29] and lower appointment no-show rates [9]. Portal users tend to be female, Caucasian, under 65 years old, well educated, and prefer electronic means of communication [8,16,26,29]. Studies documented a high rate of patient satisfaction with the portal, which enables patients to take a more active role in medical decision making [16,17,24]. Sociodemographic disparities exist for portal use, and users need to improve their health literacy in order to better interpret the medical information they are viewing [8,10,16,18,21,30]. Portal use also seems to increase patient-to-provider communication with only a slight increase in workload or office visits [13,15,23,26,28,29]. Results varied on improved outcomes [14,16,24].

Patient portals seem to offer great potential for higher quality care, but it is unknown whether providers who offer the portals will be able to capitalize on the Meaningful Use, stage 2 incentive due to lack of awareness of the patient portal service [24,25,27]. Measure seven of 17 states requires eligible professionals (EP) to "provide patients the ability to view online, download and transmit their health information within four business days of the information being available to the EP" [2]. In this review, there was insufficient data to associate the use of the patient portal with Meaningful Use.

To improve the association of use of the patient portal with Meaningful Use, hospital administrators should focus heavily on the incorporation of training in proper portal use for patients. Portal developers should conduct ease-of-use studies on their products. If the portal is not easy to navigate, it will not be used. Policy makers should consider the extension of Meaningful Use incentives in the area that affects patient portals. The market has been slow to adapt, and as a result, the maturity of the portal is not where it needs to be in order to improve quality of care and more deeply involve the patient in the medical decision.

Limitations

It is important to stress the broader scope of study design analyzed in this review compared to that of Ammenwerth et al. When our team initially attempted to duplicate the original study, we did not find any RCTs, and we found only one quasi-experimental study. We chose to open the search criteria to observational studies. The results of studies with weaker designs is weaker results to analyze.

A large limitation to this study was the lack of the key term "patient portal" in MeSH. As depicted by Figure 1, we searched for this key term in all three research databases, but this portion of the search in PubMed resulted in an error. We sent a message to the Library of Medicine to call attention to this fact.

As a result of the absence of "patient portal" in MeSH, as well as differences in syntax required by each database, the queries from PubMed and CINAHL were not matched exactly with the same queries from Google Scholar. Boolean search operators were used in PubMed and CINAHL, but Google Scholar does not enable the use of this basic search method.

The limited ability of Google Scholar to filter and save searches could greatly limit the effectiveness of the search itself. Fewer than 2% of the queries on Google Scholar matched the selection criteria for this study, and the search engine's rudimentary filters forced a manual process of review for inclusion/exclusion criteria. Ammenwerth et al and this study share a common limitation on this issue; we undoubtedly omitted key research in our reviews.

The differences in search strategies for different databases, the absence of filters in Google Scholar, and the manual process of review for the Google Scholar results could easily affect the quality of analysis of this review. A key-journal search could have been used as a form of validation for the Google Scholar results. For instance, from the initial searches, a list of the top three journals that publish material on patient portals could be identified for a targeted search, as we did with the *Journal of Medical Internet Research*. That search would help validate or highlight weaknesses in the search terms used. If results from the key-journal search highlight a significant number of articles that were not picked up by the other queries, then search terms would need to be added to the initial queries.

Conclusions

This study systematically reviewed literature from January 1, 2011, to August 24, 2014, to assess the outcome of patient portal use and its effect on quality of care and medical outcomes, effectively duplicating the study by Ammenwerth et al. Approximately 89% of papers reviewed were non-experimental, 52% were qualitative, 67% were quantitative, and 22% were mixed-methods. The mixed-method studies reflect those that were both quantitative and qualitative. Only two studies were quasi-experimental, and no studies used the RCT study design. Ammenwerth et al were able to find four RCTs for their study. We did not identify any RCTs.

The Ammenwerth et al review did not identify any improvements in health outcomes, but it analyzed only RCTs. In contrast, this review identified several clinical and administrative improvements that qualify as quality, as defined by the AHRQ and HRSA, but our review did not include any RCTs. Improvements were identified in medication adherence and the management of chronic disease [5,9,13,22], disease awareness [33], improved self-care [19,22], general "clinically relevant benefits" [13], and a decrease in the number of office visits [33]. Use of the patient portal also increased customer retention [29], which is related to continuity of care. The use of the patient portal was also associated with extended office visits to ask questions of the providers, and an increase in preventative medicine [19]. Although each article talked about application features related to Meaningful Use, only one study specifically used the term [24]. Meaningful Use incentives outlined by the HITECH Act provide money to health care organizations for specific adoption and use of HIT. Features of a patient portal would help organizations meet some of the qualifications for the incentives. Specific to this review would be features of the patient portal such as disease management and secure messaging between patient and provider [36].

Future research should focus on use of the patient portal and empirically measured quality indicators such as medical outcomes, medication adherence, and patient satisfaction. Preferably, the study designs should be RCTs, or at a minimum, an experimental design. The Meaningful Use criteria are designed to improve quality and increase patient involvement in the medical decision. Not all EHRs offer a patient portal, but as seen in this review, there are features of portals that are offered as eHealth apps. The patient portal has great potential to meet both intents of Meaningful Use, but there is not sufficient evidence to declare its efficacy.

Authors' Contributions

Authors contributed equally in the preparation of this review. The topic began as a directed research in partial fulfillment of a Masters of Health Administration (MHA) at Texas State University. The manuscript developed further after the conclusion of the class.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Summary of the studies in the review.

[PDF File (Adobe PDF File), 51KB - jmir_v17i2e44_app1.pdf]

Multimedia Appendix 2

Full spreadsheet with intervention, control, outcome, and population of each study.

[XLSX File (Microsoft Excel File), 26KB - jmir_v17i2e44_app2.xlsx]

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Abbreviations

AHRQ: US Agency for Healthcare Research and Quality
CINAHL: Cumulative Index to Nursing and Allied Health Literature

EHR: electronic health record
EP: eligible professionals
HIT: health information technology
HITECH: Health Information Technology for Economic and Clinical Health
HRSA: US Health Resources and Services Administration
MeSH: Medical Subject Headings
PHR: personal health record
RCT: randomized control trial
SM: secure messaging

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Review

Patient and Provider Attitudes Toward the Use of Patient Portals for the Management of Chronic Disease: A Systematic Review

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Abstract

Background: Patient portals provide patients with the tools to better manage and understand their health status. However, widespread adoption of patient portals faces resistance from patients and providers for a number of reasons, and there is limited evidence evaluating the characteristics of patient portals that received positive remarks from patients and providers.

Objective: The objectives of this systematic review are to identify the shared characteristics of portals that receive favorable responses from patients and providers and to identify the elements that patients and providers believe need improvement.

Methods: The authors conducted a systematic search of the CINAHL and PubMed databases to gather data about the use of patient portals in the management of chronic disease. Two reviewers analyzed the articles collected in the search process in order remove irrelevant articles. The authors selected 27 articles to use in the literature review.

Results: Results of this systematic review conclude that patient portals show significant improvements in patient self-management of chronic disease and improve the quality of care provided by providers. The most prevalent positive attribute was patient-provider communication, which appeared in 10 of 27 articles (37%). This was noted by both patients and providers. The most prevalent negative perceptions are security (concerns) and user-friendliness, both of which occurred in 11 of 27 articles (41%). The user-friendliness quality was a concern for patients and providers who are not familiar with advanced technology and therefore find it difficult to navigate the patient portal. The high cost of installation and maintenance of a portal system, not surprisingly, deters some providers from implementing such technology into their practice, but this was only mentioned in 3 of the 27 articles (11%). It is possible that the incentives for meaningful use assuage the barrier of cost.

Conclusions: This systematic review revealed mixed attitudes from patients and their providers regarding the use of patient portals to manage their chronic disease. The authors suggest that a standard patient portal design providing patients with the resources to understand and manage their chronic conditions will promote the adoption of patient portals in health care organizations.

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KEYWORDS

electronic health record (EHR); health information technology (HIT); internet; patient portal; chronic disease; disease management; self-management

Introduction

As of 2012, about half of all adults in the United States suffer from one or more chronic diseases [1]. The top 10 chronic conditions are hypertension, coronary heart disease, stroke, diabetes, cancer, arthritis, and hepatitis [1,2]. Chronic conditions affect any individual regardless of age, race, or socioeconomic status, although it was noted that co-morbidity increases with age and prevalence is higher among non-Hispanic white adults [1]. Individuals suffering from more than one chronic disease usually have multiple providers and consume more medical services such as hospitalizations, office visits, and medications, which lead to higher health expenditures [2,3].

The concept of a patient portal has asserted its presence in literature for the last several years. The US government provides a rather clear definition of a patient portal: “a secure online website that gives patients convenient 24-hour access to personal health information from anywhere with an Internet connection” [4]. The patient portal differs from a personal health record (PHR), however, in terms of ownership. The data in a patient portal are owned and managed by the health care organization along with the electronic health record (EHR) [4]. The advantage of a portal over a PHR is that the data are updated whenever there are updates on the EHR, while the data in a PHR are only updated when the patient updates them. Patient portals offer many features, and health care organizations can choose different features of even the same vendor solution. The basic portal enables a patient to access his/her information such as recent office visits, discharge summaries, medications, immunizations, allergies, and lab results, and the more advanced portals enable a patient to request prescription refills, schedule non-urgent appointments, and exchange secure messaging with his/her provider [4].

Features enabled by patient portals are intended to improve quality and access to health care by engaging patients to be more active in managing and monitoring their health [3-6]. Many health care systems have piloted or implemented patient portals with emphasis on secure communication to assist patients with the management of their own health and to improve the coordination of care across multiple providers [3,7,8]. Patients may communicate electronically with their provider, access personal health records (PHR), receive lab results, request for medication refills, schedule appointments, and learn more about their health [7,9,10]. Some portals allow patients to monitor their own health by entering their daily blood sugar levels or weight loss progress, which give patients a greater sense of empowerment in the management of their conditions [10-12].

In 2009, less than 5% of hospitals utilized a Web-based patient portal [13]. Since Congress passed the Health Information Technology for Economic and Clinical Health Act (HITECH) in 2009, patient portal adoption has gained greater attention as it enables a secure means of continuous patient-centered care [3,8,10,11]. Innovations in health information technologies (HIT) allow providers to implement electronic PHRs to deliver targeted patient education for disease management and to support provider decision-making [14-16]. Patient health coaching has emerged as an effective service to educate patients on their chronic conditions, provide eVisits, and strengthen the patient and provider relationship [17-19].

Current research of patient portals has revealed mixed feelings among patients and providers who use Web-based patient portals to monitor their chronic conditions [20]. Despite potential advantages to providing personalized patient-centered care, health care providers are concerned about the increasing workloads to meet patient demands, lost profits, insufficient security, and the high cost of acquiring and maintaining a patient portal system [8,13,16,21].

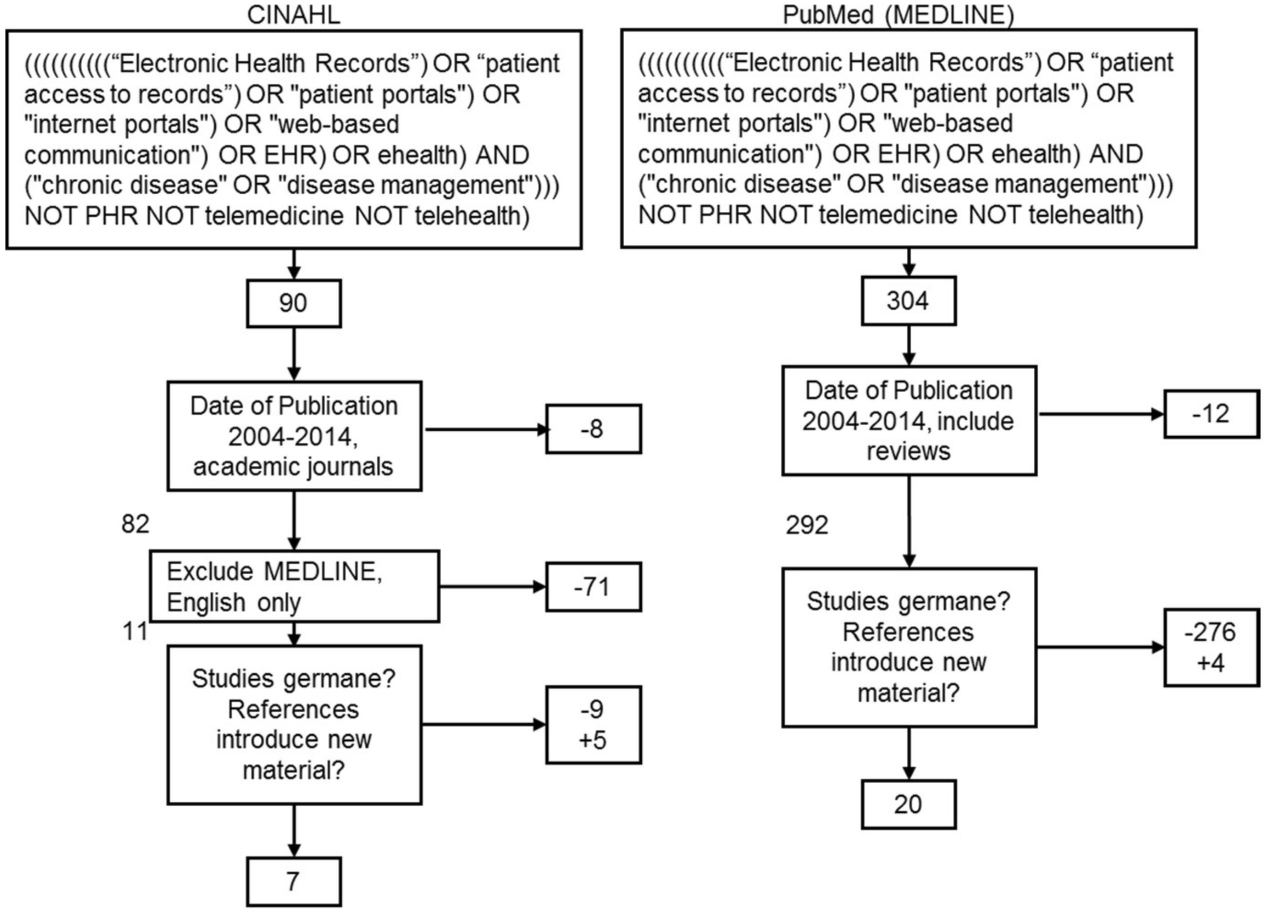
The purpose of this research is to conduct a systematic literature review to identify provider/patient attitudes toward the use of patient portals for the management of chronic disease. The review will also identify portal features that received favorable responses from patients and providers, and it identifies the portal services that patients and providers find valuable but believe need improvement.

Methods

Overview

The search and selection process of the articles used for this review are illustrated in Figure 1. The authors conducted a systematic search using PubMed and CINAHL research databases. A conscious decision was mutually made between researchers to omit Google Scholar in the search because it has an extremely primitive filter capability. The number of key search terms, even when incorporating Boolean operators, creates a highly complex query. Qualitative and quantitative studies and reviews published between January 2004 and July 2014 were included to increase the chance of capture of academic articles on the topic. The broad search terms used included “patient portals”, “internet portals”, “web-based communication”, and “chronic disease”. These terms were chosen from MeSH. Quotation marks for exact phrases and Boolean search operators were included. Because PubMed queries MEDLINE, we excluded MEDLINE from the CINAHL search. The initial search yielded 394 results.

Figure 1. Literature review process.



Exclusion Criteria

Filters were applied to exclude articles outside the period of study (2004-2014) and those not published in academic, peer-reviewed journals. Because PubMed automatically queries MEDLINE, a filter was used in CINAHL to exclude MEDLINE results. A final filter on CINAHL excluded all studies except those published in English. These filters removed 91 articles.

The remaining 303 articles were examined by at least one reviewer. A determination was made whether the article was germane to the study. This exclusion process was entirely manual, and it removed 285 articles. Of the articles excluded from the study, some only included patient portals as a small part of a broader topic of technological advances in patient care, while others focused on EHRs in conjunction with patient portals. One of the articles excluded from the literature review was a comparative study of various portal systems, which did not comment on the patient or provider attitudes toward the use and adoption of a portal system. Our screening criteria primarily revolved around our research question concerning the attitudes of patients and providers toward the use of patient portals for the management of chronic disease. Articles not related to the objective of this literature review were excluded. The remaining articles and their references were examined by at least two reviewers. An additional nine articles were added to the study from the references, but only if they fell within the 10-year date range. The final sample was 27. A table was built to summarize the observations from the authors on the 27 articles under study.

Results

The wide search criteria enabled a well-rounded evaluation of patient portals across multiple chronic diseases: diabetes, obesity, heart health, cancer, etc. Not surprisingly, there are both positive and negative attitudes presented by patients and providers using a patient portal or a Web-based communication system.

A total of 27 articles were carefully read for common themes. At least two reviewers made and compared notes on the articles for consensus. A more detailed summary of the individual articles is provided in Table 1.

An affinity matrix has been used by other research to illustrate frequency of mention or discussion of a particular topic [22]. For this review, an affinity matrix was created to identify the occurrences of both positive and negative aspects in the literature. This matrix can be found in Table 2. Overall, seven positive qualities and eight negative qualities of patient portals were common threads throughout the literature. In all, there were approximately 105 instances of both positive and negative perceptions of the patient portals.

A total of 11 out of 27 articles (41%) reported an improvement of patient-provider communication as a result of using a patient portal [4,5,7,15,16,18,19,23-26]. Ten of 27 articles (37%) reported a positive association with the secure messaging offered by the patient portal [4,5,7,12,18-20,23-25]. Ten out of 27 articles (37%) mentioned improvements in quality of care as reported by both patient and provider [4,5,7,13,16,18,20,23,25,27]. Ten of 27 articles (37%) reported an increase in disease outcomes as a result of using the patient portal. Nine out of 21 articles (33%) attributed greater self-management of chronic conditions through the presence of educational resources presented through a patient portal [4,7,12,13,16,18,21,23,28]. Seven out of 27 articles (26%) reported from both patients and providers of the ease of navigation and user-friendliness of the portals [4,13,15,21,23,26,28].

Several positive and negative attributes overlapped within the same study. For instance, while the respondents perceived an element from their patient portal as being beneficial, other respondents had a negative experience with a similar element in their portals. Even though patients and providers view secure messaging capabilities in patient portals as a beneficial attribute, 11 of the 27 articles (41%) stated that there was insufficient security in the portal design [7,8,10,12,15,16,20,24,25,27,29]. Also in 11 of 27 articles, patients did not perceive the patient portal as user-friendly and had difficulty navigating Web applications due to a lack of patient technical support, education, and access to the Internet [6,8-10,16-18,21,28-30].

Secure messaging and time management were both mentioned in five of the 27 articles (19%). The latter was most often mentioned by providers as an expression of frustration that they would not have sufficient time to take care of business that is reimbursable. Surprisingly, only three in 27 articles (11%) identified cost as a concern [7,8,14]. This is a surprise because cost is mentioned consistently in the literature relating to cost of other aspects of health information technology [31]. Three of 27 articles (19%) reported a sharp decrease in patient to provider communication after implementing a patient portal due to patients cancelling office visits [10,19,27]. Although patients value the educational resources provided in their patient portal, in three articles, many patients reported difficulty understanding and navigating interactive resources such as health libraries in their patient portal [9,10,15]. Only two of 27 articles (7%) reported negative medical outcomes as a result of using a patient portal [4,5].

Table 1. Summarized findings of the literature.[a]

Title	Findings
Primary-care physician attitudes towards the use of a secure web-based portal designed to facilitate electronic communication with patients [32].	Prior to using the patient portal, physicians demonstrated concern of work overload, lower reimbursement, and issues of security. After using the patient portal, physicians reported time savings, ease of documentation, improved quality of patient care, and improved communication.
Enhancing access to patient education information: a pilot usability study [33].	Patients learned more about their disease and how to manage it with the help of the educational links in their patient portal.
DIADEM: Implementation of a comprehensive disease management programme for type 2 diabetes [30].	User response was very positive. Patients entered their own glucose information into the Web-based interface
Interest in the use of computerized patient portals: role of the provider-patient relationship [13]	There was dissatisfaction in the provider-patient relationship with the use of the patient portal. Providers were not satisfied with its communication capabilities or responsiveness, and they reported having difficulty obtaining patient specific medical information.
Measuring the impact of patient portals: what the literature tells us [9]	The implementation of patient portals decreased office visits and increased the number of telephone calls and email from patients.
Patient use of secure electronic messaging within a shared medical record: A cross sectional study [10]	Patients over the age of 65 and covered by Medicaid are less likely to use secure messaging due to problems understanding the information, difficulty using technology, physical disabilities, and inability to access the Internet.
The new age of healthcare communications [16]	Portals increase the use of email communication, online appointment scheduling, and electronic health records among patients. Physicians are concerned about the loss of profitability that results from heavy use of portals, the breach of patient privacy, and the increased workload in responding to patient emails.
Health coaching via an internet portal for primary care patients with chronic conditions: a randomized controlled trial [20]	Patients experienced a higher quality, more informative clinic visit after using a patient portal because they were better informed about their health.
Usability testing finds problems for novice users of pediatric portals [28]	Despite prior heuristic testing, users found navigation of a portal to be difficult; however, it is clear that portals have the potential to assist in making health care system interfaces for laypersons more user-friendly and functional.
The literacy divide: health literacy and the use of an internet-based patient portal in an integrated health system-results from the diabetes study of northern California (DISTANCE) [8]	There is a distinction among users and non-users with respect to health literacy, educational resources, and ability to navigate and use the technology effectively.
Patient web portals to improve diabetes outcomes (systematic review) [18]	A review of 26 articles illustrates the value of patient portals to both patient and provider. Portals have a positive effect on outcomes of users.
Factors influencing the use of a web-based application for supporting the self-care of patients with type 2 diabetes: a longitudinal study [19]	Web-based applications improve patient access to care and enhanced the patient-nurse communication process. Timely feedback from providers allowed patients to better manage their diabetes.
Patient reported barriers to enrolling in a patient portal [29]	User training must include the value of different features of a portal, and reminders should be sent often.
Variation in use of internet-based patient portals by parents of children with chronic disease [26]	Only 15.9% of portal users were still using the portals after 3 months of initial registration. Education about the benefits of the portal is necessary for patients to fully understand the value of portals in patient care.
Impact of health portal enrollment with email reminders on adherence to clinic appointments: a pilot study [34]	Portal users were more engaged with their own care. When the healthcare organization combined email reminders with the portal use, monthly no-show rates were significantly reduced across multiple clinics.
Improving diabetes management with a patient portal: a qualitative study of diabetes self-management portal [12]	Patients were satisfied overall with features presented in the portal: users stated that they were more aware of their health status. The study stated that some portal features were too difficult for the patients to understand and navigate.
Internet use by primary care patients: Where is the digital divide [24]	Internet use is high among the sample (n=777). Major difference between users with chronic conditions was age. Older generations need more training.
The impact of electronic patient portals on patient care: a systematic review of controlled trials [31]	There are very few scientific studies that examine the relationship of portal use to health outcomes or patient empowerment. There is insufficient evidence to suggest any relationship, positive or negative.

Title	Findings
A national action plan to support consumer engagement via ehealth [5].	The use of eHealth can augment patient engagement, improve individual health, and achieve broader health care system improvements. Patient users of patient portals feel better prepared for the medical encounter, as relevant questions, are better informed about their health, and are more likely to take steps to improve their health.
Secure messaging between providers and patients, and patients' access to their own medical record (systematic review) [7]	Data exists to support a positive support between the use of a patient portal and the improvement of glucose outcomes and patient satisfaction.
Electronic patient portals: evidence on health outcomes, satisfaction, efficiency, and attitudes: a systematic review [11]	The systematic review shows that patient portals improve patient health outcomes. There are concerns regarding the high cost of the patient portal and the low utilization by patients.
Patient-provider communication and trust in relation to use of an online patient portal among diabetes: the diabetes and aging study [21]	Patients who trusted their health care providers were more likely to use the secure messaging application of the patient portal.
Patient-generated secure messages and eVisits on a patient portal: are patients at risk [27]?	Secure messages and eVisits are intended for low-risk symptoms and regular queries. Over 75% of the patients used these services for the intended purpose, but some used these services to communicate high-risk symptoms, such as chest pain. Services should be expanded and monitored 24/7 in order to expedite the response time.
Parents' perceptions of a patient portal for managing their child's chronic illness [25]	Portals seemed to remove barriers to communication, reduced hassle, maximized convenience, and provided a sense of control and independence, reducing anxiety, and providing reassurance.
Consumers' perceptions of patient-accessible electronic medical record [35]	Low-education, English-speaking health care consumers (n=28) were queried in four focus groups in New York City on perceptions of utility and value of patient portals. Most demonstrated high levels of enthusiasm about the portal's utility and value. Researchers noted that designers of portals must consider low reading levels and ease of use in order to capture enthusiasm and move the portal movement forward.
Understanding patient portal use: implications for medication management [36]	Portal users demonstrated better A1C (blood sugar) (P=.02). Users reported frequent use of medication refill capability, and they were enthusiastic about refill reminders. Portal users were more likely to be Caucasian/white (P<.001), have higher incomes (P=.005), be privately insured (P<.001), and have more education (P=.05). Patients uses the portal to manage medication refills and adherence. Additional focus on education may be necessary to reach non-white, low income, and underinsured.
Patient experiences with full electronic access to health records and clinical notes through the My Health*e*Vet Personal Health Record Pilot: qualitative study [37]	Patients reported positive experiences with the transparency that the portal provided. Viewing their records seemed to improve patient empowerment and engagement in their own medical decisions.
Does the use of consumer health information technology improve outcomes in the patient self-management of diabetes? A meta-analysis and narrative review of randomized controlled trials [6]	Health information technology improves patient self-management of diabetes. Further research needed to study the effectiveness of the technology.
Impact of patient use of an online patient portal on diabetes outcomes [14]	Results indicated that patients who access a patient portal were more likely to achieve their target A1C.
Mobile and ubiquitous architecture for the medical control of chronic diseases through the use of intelligent devices: Using the architecture for patients with diabetes [15]	Using the mobile monitoring apps allow patients to access their patient portal at their own convenience. Patients enjoyed the ease of use and the real-time functionality of the portal.
Family perceptions of the usability and value of chronic disease web-based patient portals [17]	Parents agreed that data displayed by the portal was accurate, timely, and useful. Confidentiality was not a major concern. The portal augmented understanding of their child's condition and their ability to manage it.
Family perceptions of the usability and value of chronic-disease, web-based patient portals [23]	Parents of patients perceived the portal as useful, accurate and timely. Parents using the portal felt confident in the confidentiality of their child's information on the portal.
Technology-assisted patient access to clinical information: an evaluation framework for Blue Button [38]	The implementation of Veterans Affairs (VA) Blue Button is a landmark event for both patients and the VA as an organization. Designers should focus on ease-of-use, low medical literacy, and carefully evaluate potential unintended consequences.
Evaluating user experiences of the secure messaging tool on the Veterans Affairs' patient portal system [39]	Patients reported positive experiences with increased communication through the VA's My Health*e*Vet portal. In order to capitalize on this positive enthusiasm, designers should focus on marketing, education, skill-building, and associated system modifications.

Title	Findings
The effects on health behavior and health outcomes of Internet-based asynchronous communication between health providers and patients with a chronic condition: a systematic review [40]	Any effect of asynchronous communication enabled through a portal is not clearly demonstrated among the chronically ill sample of patients in this study. Patients seemed to appreciate the secure messaging capability, and they are willing to take initiative to discuss health issues with their providers. Results were not significant.
Impact of patient access to Internet health records on glaucoma medication: randomized controlled trial [41]	Patients with access to an Internet-based glaucoma care support system on glaucoma use demonstrated significant improvement (P=.0002) in appropriate use of glaucoma medication, resulting in lower intraocular pressure. While this finding is not directly a patient portal, it does demonstrate a higher level of patient involvement and better outcomes with access to clinical data and care support through the Internet.

[a] Additional articles, beyond the 27 referenced in the text, were added in the peer-review process.

Table 2. Affinity matrix illustrating the frequency of factors identified in the literature (n=27).

Factor	Occurrences	Instances of the barrier n (%)
+ (positive)		
Patient-provider communication	[4],[5],[7],[15],[16],[18],[19],[23],[24],[25],[26]	11 (41%)
Secure messaging	[4],[5],[7],[12],[18-20],[23],[24],[25]	10 (37%)
Quality of care	[4],[5],[7],[13],[16],[18],[20],[27],[23],[25]	10 (37%)
Disease outcomes	[4],[5],[6],[7],[12],[15],[16],[21],[30],[23]	10 (37%)
Educational resources	[4],[7],[12],[13],[16],[18],[21],[28],[23]	9 (33%)
User-friendliness	[4],[13],[15],[21],[28],[23],[26]	7 (26%)
Time	[5],[7],[15],[20],[25]	5 (19%)
− (negative)		
Security	[7],[8],[10],[12],[15],[16],[20],[27],[29],[24],[25]	11 (41%)
User-friendliness	[6],[8],[9],[10],[16],[17],[18],[21],[30],[28],[29]	11 (41%)
Secure messaging	[8],[10],[20],[27],[29]	5 (19%)
Time management	[7],[9],[27],[30],[23]	5 (19%)
Cost	[7],[8],[14]	3 (11%)
Patient-provider communication	[10],[19],[27]	3 (11%)
Educational resources	[9],[10],[15]	3 (11%)
Disease outcomes	[4],[5]	2 (7%)

Discussion

Principal Findings

In this systematic review, the authors sought to understand the characteristics of patient portals that cause mixed feelings among patients and providers using patient portals. The authors identified the shared characteristics of patient portals that received favorable responses from patients and providers. The authors also identified the elements that patients and providers believe need to be improved or included in the portal design.

Successful patient portals and Web-based portals are user-friendly and empower patients to take responsibility for managing their health. However, it is evident from the literature reviewed in this study that attitudes toward patient portals differ. There is a lack of clarity regarding the portal design used among respondents; it is unknown whether the portals are designed the same, or whether they differ from one to another. For instance, while one portal may offer immediate access to laboratory results, it may not provide the patient with explanatory material to educate the patient on the meaning of his/her lab results. Another portal may provide an explanation of the lab results but the medical terminology used may cause further confusion for the patient.

Although this manuscript examines the same overall topic of portals from Ammenwerth et al (2007), our findings differ in many ways [31]. Ammenwerth et al did not find statistically significant effect of the portal on medical outcomes. Our study identified positive disease outcomes across 10 of 27 articles (37%) [4-7,12,15,16,21,23,30]. Ammenwerth et al reviewed only randomized controlled trials, however, and they did not broaden their search to encompass the breadth of this study. A common thread through the Ammenwerth et al study and ours is that security concerns rank very highly in the list of negative perceptions about patient portals. This manuscript did not set out to duplicate the work of Ammenwerth, but their work is raised for comparison purposes.

Patients are concerned about the safety of secure messaging on an Internet application, the complexity of the portal design, the lack of guidance in how to use the portal, and the inability to understand the information presented in the educational resources. Patients over the age of 65 years are more likely to have trouble using advanced technology than patients who are more technologically inclined. The gap among users who have different levels of expertise in using advanced technology is called the "digital divide". The authors believe that by providing patients with a tutorial prior to using the patient portal, patients who have little knowledge of technology will better understand how to operate the portal.

A recurring theme in the literature is the inability of patients to understand medical terminology presented in the patient portal and not being knowledgeable about their own condition. Some patient portals offered a Health Library, which is an interactive educational resource enabling patients to have a bettering understanding of their conditions and how to better manage their health. The resources educate patients on the importance of taking their prescribed medications and changing their behavior in order to improve their health. An advantage of using electronic educational resources is that by providing an electronic version of an information pamphlet covering a patient's condition, patients will no longer be at risk of losing their information packet.

Patient portals are an effective way to improve communication between patients and their health care providers. However, the large volume of electronic messages sent to providers from their patients may overwhelm providers who must respond to the messages as well as conduct office visits during their workday. In addition to being very expensive to install and maintain, patient portal systems require training for providers who may or may not be willing to shift from paper records to electronic health records. The ease of learning a new technology for the provider is, no doubt, an important factor in the acceptance and adoption of patient portals in health care organizations.

Conclusions

Innovations in health information technologies improve the quality of and access to health care. Web-based portals provide patients with access to their health record, improve the patient-provider communication, and enable patients to take control of their chronic condition(s). In order to enable the acceptance of patient portals among health care organizations, the portals must be redesigned to be both user-friendly and aesthetically appealing. The authors suggest that a standard patient portal design providing patients with the resources to understand and manage their chronic condition(s) will promote the diffusion of this important technology.

Authors' Contributions

Authors contributed equally in the preparation of this review. The topic began as a directed research in partial fulfillment of a Masters of Health Administration (MHA) at Texas State University. The manuscript developed further after the conclusion of the class.

Conflicts of Interest

None declared.

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Abbreviations

EHR: electronic health record
HIT: health information technology
HITECH: Health Information Technology for Economic and Clinical Health
PHR: personal health record

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Original Paper

The Wired Patient: Patterns of Electronic Patient Portal Use Among Patients With Cardiac Disease or Diabetes

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Abstract

Background: As providers develop an electronic health record–based infrastructure, patients are increasingly using Web portals to access their health information and participate electronically in the health care process. Little is known about how such portals are actually used.

Objective: In this paper, our goal was to describe the types and patterns of portal users in an integrated delivery system.

Methods: We analyzed 12 months of data from Web server log files on 2282 patients using a Web-based portal to their electronic health record (EHR). We obtained data for patients with cardiovascular disease and/or diabetes who had a Geisinger Clinic primary care provider and were registered "MyGeisinger" Web portal users. Hierarchical cluster analysis was applied to longitudinal data to profile users based on their frequency, intensity, and consistency of use. User types were characterized by basic demographic data from the EHR.

Results: We identified eight distinct portal user groups. The two largest groups (41.98%, 948/2258 and 24.84%, 561/2258) logged into the portal infrequently but had markedly different levels of engagement with their medical record. Other distinct groups were characterized by tracking biometric measures (10.54%, 238/2258), sending electronic messages to their provider (9.25%, 209/2258), preparing for an office visit (5.98%, 135/2258), and tracking laboratory results (4.16%, 94/2258).

Conclusions: There are naturally occurring groups of EHR Web portal users within a population of adult primary care patients with chronic conditions. More than half of the patient cohort exhibited distinct patterns of portal use linked to key features. These patterns of portal access and interaction provide insight into opportunities for electronic patient engagement strategies.

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KEYWORDS

electronic health record; eHealth; patient Web portal; electronic patient portal; personal health record

Introduction

The adoption of health information technology (HIT), particularly electronic health records (EHR) and personal health records (PHR), is widely viewed as a critical step towards achieving improvements in the quality and efficiency of the US health care system. The rapid growth of the Internet has made it possible for patients to independently obtain medical information and increasingly obtain health care on a temporally asynchronous basis. The Internet is widely used for seeking health-related information and patients are demanding access to physician email, Web-based appointment scheduling, and laboratory results online [1-4]. In response, structured health systems and academic centers with EHR-based HIT infrastructures are implementing Web-based patient portals that give patients access to their EHRs and other electronic care functions [5,6]. There is an expectation that these new approaches to clinical interaction increase access and reduce costs. Relatively little is known about how patients electronically access their provider's HIT system via the portal. Deploying and maintaining a portal requires substantial investments of time, capital, and technical resources. Understanding how users interact with the portal is fundamentally important to evolving features that meet user needs and incorporate electronically supported services into existing clinician and patient workflows. Indeed, current and proposed criteria for “meaningful use” include functionality currently available in many portals. As these criteria are finalized, they should be informed by experience with the first generation of portals now in use [7,8]. Moreover, Web portal experience will have considerable implications for patient controlled personal health records (PHRs) as they are integrated with provider-based EHR systems.

What is currently known about portal users, or more broadly, individuals who use the Internet for health and health care-related purposes, is based mainly on self-reported patient attitudes and expectations [9-13], with few empirical assessments of actual use [14-19]. A recent review found little evidence to support the association between portal use and improvement in patient care. The authors found that few studies actually provided usage information, and the degree to which patients “exploited the offered functionalities” is unknown [20]. Relatively little is known about actual use because most portal interactions are difficult to track longitudinally at the individual level. To address this gap in our understanding of portal use, we used the audit trail function of the Web server transaction log file data from the Geisinger Clinic's portal to understand how patients actually used the system over a long-term (12-month) period. Similar analyses have been used to improve the utility of other types of information systems such as medical library websites [21-25]. We hypothesized that patients have different motivations and expectations for use that are manifest in their unique transaction patterns.

Methods

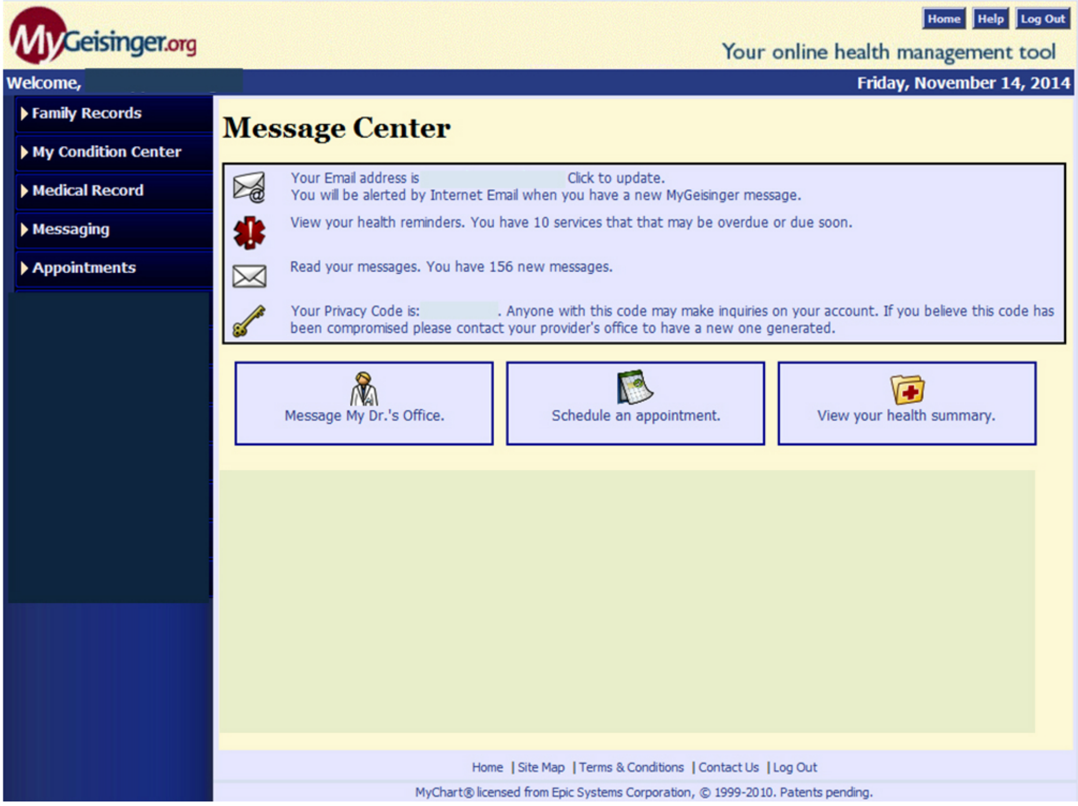
Overview

This study is a secondary analysis of administrative and EHR data for a cohort of 4945 Geisinger Clinic (GC) patients with cardiovascular disease and/or diabetes. GC is a network of more than 40 community practice sites in Central and Northeastern Pennsylvania, each of which uses the EpicCare EHR. The analysis cohort consisted of 3297 patients who were users of “MyGeisinger”, a Web-based electronic patient portal, and a comparison-matched group of 1648 patients who did not use MyGeisinger. This research was approved by the Institutional Review Boards of both Geisinger Health System and the Johns Hopkins University, and patient anonymity was strictly maintained.

MyGeisinger Patient Portal

MyGeisinger is a secure, no-cost (to the patient) Web-based portal that allows a patient to access portions of their EHR (Figure 1). MyGeisinger can be used to access medical record information including medications, allergy, and problem lists; view preventive health reminders, provider information, and details of previous office visits; review, track, and graph laboratory test results and clinical measures (eg, blood pressure, weight); and interact with a provider via secure messaging. Patients can also use MyGeisinger to complete administrative tasks (eg, refilling medications, scheduling appointments, requesting referrals). MyGeisinger use is voluntary. The availability of these functions was consistent over the study period. Information is available in all clinic sites. To register, patients can either register at a kiosk in a GC site or request an account online, after which a letter with an activation code and instructions for completing the registration process online is mailed to their home address.

Figure 1. Screenshot of the MyGeisinger Patient Portal.



Welcome, [redacted]

Friday, November 14, 2014

Your Email address is [redacted] Click to update.
You will be alerted by Internet Email when you have a new MyGeisinger message.

View your health reminders. You have 10 services that that may be overdue or due soon.

Read your messages. You have 156 new messages.

Your Privacy Code is: [redacted]. Anyone with this code may make inquiries on your account. If you believe this code has been compromised please contact your provider's office to have a new one generated.

Study Population

The analysis cohort consisted of patients who met the following inclusion criteria: (1) had a confirmed diagnosis, by International Classification of Diseases (ICD)-9 codes of diabetes, heart failure, and/or cardiovascular disease, (2) had an assigned primary care physician (PCP) in a GC community practice site, (3) had a visit with their PCP in the prior year, and (4) were registered users of the MyGeisinger portal. For comparison purposes, we also identified a matched (based on age, sex, and comorbid conditions) random sample of patients who met the first three inclusion criteria but had not registered to use MyGeisinger.

Data Sources

The two sources of data used in this study were MyGeisinger Web server log files and Geisinger's electronic health record.

All patient level MyGeisinger usage and interactions (ie, accessing a specific function by clicking on a link within MyGeisinger) are automatically recorded and time stamped in the log files maintained by the MyGeisinger Web server. For this study, we used MyGeisinger server logs from November 1, 2005, through October 31, 2006.

Information obtained from the EHR included body mass index (BMI), age, sex, comorbidities, and laboratory values relevant to chronic disease care (eg, HbA1c, low and high density lipoprotein values, blood pressure).

Analysis

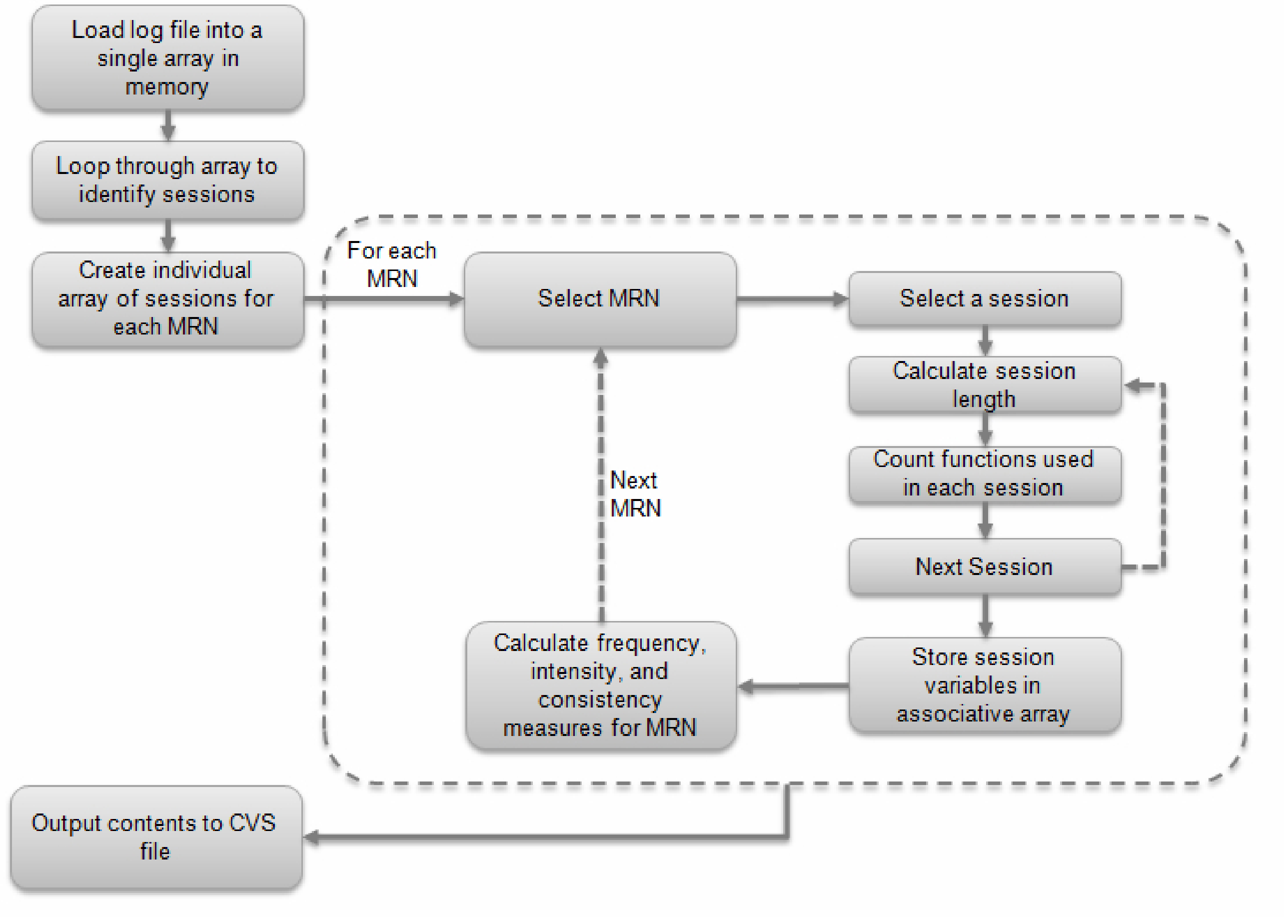
We approached the analysis in four steps. First, we used Web server log files to obtain detailed portal use information on a cohort of MyGeisinger users. Second, we developed a set of variables that quantitatively described the frequency, intensity, and types of portal use. Third, in order to determine whether there were similar groups of portal users, we used factor analysis to reduce the number of variables and then performed a cluster analysis to identify similar types of portal users. Fourth, to characterize the resulting clusters, we used a separate data source that included demographic and limited data from the EHR to profile the clusters.

MyGeisinger Log Files

For each patient, the log file was transformed into a longitudinal series of records for the 12-month study period, where each record corresponds to a discrete portal session. A portal "session" begins when a patient logs in with a username and password and ends when the patient logs out or is inactive for more than 20 minutes (a "time-out"). Study participants for whom longitudinal data were unavailable (ie, ≤1 session during the study period) were considered "non-users" and excluded from the analysis. Multiple sessions were allowed per day or "hit-day" [26] (ie, a day with at least one portal session). In some cases, sessions recorded in the log file occurred in very close proximity to one another (ie, logout followed by login after a very short duration). For analytic purposes, we assumed that sessions in very close temporal proximity (≤3 minutes apart) were indicative of a single instance of portal activity and combined them accordingly.

For each session, variables were created to quantify the length of the session (with adjustments made to account for time-outs) and to count the number of times each function (eg, checking lab results, emailing a physician) was used over the course of the study period. In this context, "use" of a function meant that a patient clicked on a link on the main MyGeisinger menu (eg, "Lab Results") or a link available from within a specific menu option (eg, a link to review a specific lab result). Patients were able to access each function multiple times during a session. For each patient, we counted each time a link was clicked and summed these at the session level for each function. In addition, we created variables to describe the frequency, consistency, intensity, and duration of portal use. Portal transactions were classified as administrative (ie, appointment-related functions, driving directions to a Geisinger Clinic, provider details, proxy functions, and referral functions) or otherwise categorized as clinical. We counted the total number of administrative and clinical transactions across all sessions in the study period and calculated the administrative-to-care ratio (a ratio >1.0 indicates that participants used more administrative functions). The log file was processed using a custom-programmed script (available on request) written in the Perl programming language. A schematic overview of the way the Perl script processed the log file is shown in Figure 2.

Figure 2. Summary of the process for parsing the log file using Perl. MRN: medical record number.



Variable Creation and Factor and Cluster Analysis

As the basis for our typology, we extracted 41 variables derived from the log files that quantify: (1) the number of times patients used individual portal functions during the study period, and (2) the frequency, consistency, duration, and intensity of use (Table 1). We defined frequency on the basis of the total number of sessions during the study period and on the total number of "hit-days". A hit-day is defined as any day on which a patient accesses the portal, regardless of the number of individual sessions on a given day [26]. Because session counts alone do not characterize use over a longer-term period (eg, a user could have many sessions during a single month and then never use the portal again), we defined a measure of consistency to distinguish users who might have a similar number of sessions overall, but with a different distribution across the study period. Similar to the concept of a hit-day, we measured consistency as the total number of hit-months, which, in turn, were defined as any individual month in which a patient had at least one portal session (eg, 12 hit-months meant that a user accessed the portal at least one time during each month of the study period). Intensity of use was defined as the number of functions accessed by a user during an individual session, as well as by the average page view length (ie, the average number of minutes between the time a user clicks on a link to a specific portal function and the time when they click to go to the next function or to log out of the session) and the total number of functions accessed during the study period. Duration was defined by two variables: the average length of an individual session and the total length of all sessions over the course of the study period.

Table 1. Variables extracted from the log file.

Variable (Category/Name)	Description/Definition
Frequency	
sess	Total number of sessions during study period
hitdays	Hit days (days during study period with ≥1 session)
Consistency	
hitmo	Hit months (months during study period with ≥1 session)
Duration	
avg_sess_len_mins	Average session length (minutes)
tot_len_mins	Total length of all sessions (minutes)
Intensity	
avg_view_mins	Average length of each page view (minutes)
totfxn	Total number of functions used
avgfxnses	Average number of functions accessed per session
Administrative use ratio	
adminfxn	Total administrative functions accessed during study period
carefxn	Total of care-related functions accessed during study period
ratioac	Ratio of number of administrative-to-care functions accessed
Use of individual portal functions (measured as total times accessed during the study period)	
labresults	Review specific lab results
labtests	Review lab tests
resultcomponentgraphing	Graph specific test results
encounterreview	Review list of all previous physician visits
encounterdetails	Review details of specific physician visit
allergies	Review list of allergies
immunizations	Review immunization history
problemlist	Review problem list
messaging	Review message inbox
flowsheetreportslist	View list of trackable clinical measures
flowsheetreportdetails	Graph specific clinical measures (weight, blood pressure)
healthmaintenance	Review all preventive care reminders
healthmaintenanceschedule	Review preventive care reminder
healthsnapshot	Review summary of preventive health information
histories	Review patient history
letters	Review list of referral letters
medication	Review list of current medications
medicationrenewalrequest	Renew medication via secure message
patientnotes	Enter notes viewable only by patient
personlpreferences	Review/update demographic information
demographics	Update patient demographic info (email address)
providerdetails	View detailed information about a provider
addresschangerequest	Update address information
referralreview	View referrals to other providers
referralrequest	Request referral

Variable (Category/Name)	Description/Definition
appt_final	Appointment-related functions (schedule, review, cancel)
proxyaccessview	View another individual's medical record
customerservicerequest	Send message to customer service
drivingdirections	View directions to physician/specialist office
switchcontext	Switch to proxy view

We explored typologies in two steps. First, we used principal components factor analysis with a varimax rotation to reduce the 41 variables in the analytic dataset to 10 composite factor scores (results available on request). Second, we conducted a cluster analysis of individual patient factor scores to identify similar types of MyGeisinger users. Cluster analysis encompasses a variety of mathematical methods for classifying groups of similar entities (eg, portal users), often for the development of typologies [27]. We sought to determine whether there are distinct groups of portal users, where similarity within a group is measured by both the number of specific portal functions they use over time and by measures of the frequency, consistency, duration, and intensity of their use. We used a hierarchical agglomerative clustering algorithm that initially places each patient in a separate cluster and then iteratively joins the two most similar clusters. "Similarity" was assessed using Ward's minimum variance method. The final cluster analysis solution places each patient into one of a set of mutually exclusive groups or "clusters" designed to minimize the differences between patients within a cluster and maximize the differences between patients in all other clusters. Because the cluster analysis is based on variables that describe study participant's use of the portal over the 12-month course of the study and not on patient-level variables such as age, sex, or health status, the resulting clusters will be based on similarity of portal use patterns, *not* on similarities between patient-specific variables such as age, sex, or health status. Our final typology was developed by summarizing the patient-level data (eg, age, sex, clinical characteristics) and portal use data for distinct groups of portal users identified by the clustering algorithm in order to develop summary descriptions of each group.

Our analysis used an empirical, hierarchical approach [27,28] rather than an iterative partitioning [29] approach because we did not make a priori assumptions about the number of clusters we expected to identify in our dataset. The cubic clustering criterion and pseudo t-statistics were used to make the final determination of the optimal number of user types (ie, clusters) underlying our typology [30]. To minimize the influence of outliers, we calculated the distribution of the total number of sessions for all portal users and removed those individuals (n=24) whose total number of sessions was greater than the 99th percentile of total number of portal session. Factor and cluster analyses were completed using SAS 9.1; all other statistical analyses used Stata 10.1.

Results

We identified a total of 3297 study participants who met inclusion criteria and were registered MyGeisinger users ("portal registrants"). Of these, 2282 (69.21%) actually logged in and used the portal at least two times ("registered active users") during the 12-month study period (Table 2). After excluding 24 patients whose total number of sessions was greater than the 99th percentile, 2258 patients were included in the cluster analysis. Of the remaining 1015 registered patients who were classified as "registered non-users", 183 used the portal for a single session. "Active users" (ie, ≥2 sessions) were more likely to be male. Age distributions, although statistically different, were largely similar between active users, non-users, and non-registered matched controls (Table 2).

Table 2. Characteristics of Web portal registrants who access the site at least 2 times compared with non-registrants and registrants who used the site minimally.

Characteristics	Portal registrants (N=1015): Non-users (≤1 session)		Portal registrants (N=2282): Active users (≥2 sessions)		Portal non-registrants (N=1649): Matched controls	
	n	%	n	%	n	%
Sex						
Female	459	45.22	974	42.68	717	43.48
Male	556	54.78	1308	57.32	932	56.52
Age [a]						
<44	103	10.15	237	10.39	190	11.52
45-54	202	19.90	472	20.68	318	19.28
55-64	295	29.06	755	33.09	488	29.59
65-74	221	21.77	525	23.01	389	23.59
75-84	149	14.68	249	10.91	215	13.04
85+	45	4.43	44	1.93	49	2.97
Chronic disease						
Diabetes only	433	42.66	1071	46.93	748	45.36
Cardiovascular only	311	30.64	637	27.91	470	28.50
Heart failure only	48	4.73	66	2.89	63	3.82
≥2 chronic conditions	223	21.97	508	22.26	368	22.32
Mean Body Mass Index	31.36		31.34		32.4	

[a] $P<.01$.

Principal components analysis identified 10 factors. Each patient's factor scores, which represent estimates of the scores study participants would have received on each of the extracted factors if the factors were measured directly, were used in the cluster analysis model [31]. Using the pseudo t^2 criteria as a guide, we selected an eight-cluster solution. Two major categories of usage measures (Table 3) were used to characterize portal activity for each of the eight clusters over the entire 12-month study period: (1) "portal use" measures (eg, frequency, consistency, duration, and intensity) that characterize overall use during the entire study period, and (2) "functional use" measures that describe the average number of times that members of a cluster used a specific function (eg, electronic messaging, viewing lab results) over the course of the 12-month study period. Each of the eight clusters was distinguished primarily by the constellation of portal use and functional use measures for which the cluster had either the highest or lowest average value relative to every other cluster (Table 3). For example, the largest cluster, number 1, accounted for 41.98% (948/2258) of the population, had the lowest average measure of intensity of use (7.4 functions per session), and had the lowest average use of the majority of individual portal functions (eg, members of this group accessed the lab results function an average of 20.5 times during the study period). In contrast, Cluster 7 members used the proxy access function 13 times more often (on average) than the members of Cluster 5, which had the second highest average proxy use (54.2 vs 4.2 times) during the study period. Cluster 5 had the highest frequency and consistency of use and the highest average use of the function that allowed users to view and track their lab results (Table 3). Table 4 profiles each cluster on the basis of demographic and clinical characteristics.

Based on the usage patterns and the demographic and clinical characteristics of this cohort of patients with chronic conditions, we offer a typology of eHealth users (Table 5). Type 1 members ("eDabblers") are low frequency and low intensity users. Members of type 2 ("infrequent intense users") are similar to Type 1 but have the highest intensity of use as measured by the average number of functions that members of this group access each time they use MyGeisinger. Members of Type 3 ("electronic messengers") are very high users of secure messaging, including requests for referrals and to renew medications.

Type 4 ("appointment preparers") is distinguished by frequent use of the portal for appointment scheduling, reviewing information on specific doctors, and viewing directions to a specific clinic location, functions that a patient is expected to use prior to an office visit. Type 5 ("lab trackers") is characterized by its high use of laboratory test review and tracking functions. Type 6 ("biometric monitors") is distinguished by its use of the function for tracking weight and blood pressure. Type 7 ("proxy moms") is predominantly female (80%, 12/15), has the youngest average age (39 years), and demonstrates very high use of the proxy function. Type 8 members ("record updaters") used the email and address update functions.

Table 3. Clustering of patients into eight user types based on cluster analysis of Web portal use patterns (total users N=2258).

	Cluster #							
	1	2	3	4	5	6	7	8
Cluster size								
Number in cluster, n	948	561	209	135	94	238	15	58
Percent in cluster, %	41.98	24.84	9.26	5.98	4.16	10.54	0.66	2.57
Web portal use measures								
Frequency								
Mean number of sessions	18.5	7.8[a]	46.2	46.0	58.2[b]	20.9	53.3	28.8
Consistency								
Mean hit-days[c]	15.1	6.9[a]	35.2	36.4	43.3[b]	16.7	37.7	22.8
Mean hit-months[c]	6.4	4.1[a]	9.3	9.3	10.2[b]	6.8	10.2	7.5
Duration								
Mean session length, minutes	4.7[a]	10.6[b]	6.9	5.2	6.5	7.5	7.1	6.8
Mean page view length, minutes	0.6	0.7	0.6	0.8	0.6	0.6	1.4[b]	0.5[a]
Intensity								
Mean number of functions/session	7.4[a]	18.3[b]	10.1	8.3	14.5	14.3	9.9	12.6
Administrative vs Care-related use								
Mean ratio of administrative:care use	0.3	0.2[a]	0.3	1.3[b]	0.2[a]	0.2	0.7	0.3
Review specific lab results	13.9[a]	19.2	30.6	32.7	98.0[b]	29.1	31.5	26.2
Review list of available lab tests	20.5[a]	23.9	43.8	48.3	143.4[b]	38.6	45.5	36.7
Graph specific lab test results	2.1[a]	3.3	6.1	5.1	17.5[b]	6.0	7.7	5.0
Review list of all prior provider visits	4.1[a]	6.7	15.5	23.8	29.8[b]	14.3	29.7	12.2
Review details of prior provider visit	2.7[a]	4.4	10.6	15.6	19.7[b]	9.7	18.9	8.2
Review electronic message inbox	28.7	14.4[a]	104.7[b]	55.6	68.1	32.8	54.3	43.6
View list of graphable values (weight, bp)	0.3[a]	0.4	1.2	1.1	1.5	3.1[b]	2.1	0.9
View specific graphs (weight, bp)	0.4[a]	0.5	1.6	1.7	2.2	4.7[b]	2.7	1.4
Review past medical history	0.7[a]	1.1	2.4	1.8	5.2[b]	2.5	1.7	2.2
View received letters	1.4[a]	1.5	6.9[b]	3.0	5.7	2.7	1.7	3.2
Review list of current meds	6.3[a]	6.7	20.6	16.5	38.4[b]	12.3	17.0	16.6
Renew med(s) via electronic message	1.9	0.5[a]	5.0[b]	1.9	2.3	1.3	3.3	2.1
Update email address[e]	0.5	0.3[a]	1.0[b]	0.5	0.7	0.5	0.7	0.8
Update address[e]	0.1[a]	0.1[a]	0.3	0.2	0.3	0.3	0.5	2.4[b]
View detailed provider information[e]	0.7[a]	1.1	2.8	10.0[b]	4.5	2.0	1.9	3.5
Review approved referrals[e]	1.1[a]	1.6	12.5[b]	7.6	12.3	4.3	3.1	5.9
Request specialty referral[e]	0.3	0.2[a]	5.5 [b]	2.6	1.9	0.6	1.4	1.3
Proxy use (view another's record)[e]	1.3[a]	1.6	4.1	3.1	4.2	2.5	54.2[b]	3.4
Send message to customer service[e]	0.7	0.4[a]	5.5[b]	1.7	2.5	1.3	1.7	1.6
View directions to provider's office[e]	0.2[a]	0.2	0.8	2.9[b]	1.1	0.4	0.5	0.8

	Cluster #							
	1	2	3	4	5	6	7	8
Schedule/change/cancel appointment[e]	16.5	8.8[a]	46.4	93.3[b]	59.2	24.5	41.1	35.3

[a] Lowest value relative to other clusters.

[b] Highest value relative to other clusters.

[c] Number of individual days/months during study period with ≥1 session.

[d] Administrative function (all others classified as care-related).

[e] The average was calculated based on the total number of times a function was used (ie, a portal menu option was clicked) by each patient in the specified cluster and dividing by the number of patients in the cluster. A function could be used multiple times per session. Not all functions accessible via the portal are listed in this Table.

Table 4. Characteristics of patients in each of the eight clusters of user types.

	Cluster # (size)							
	1 (n=948)	2 (n=561)	3 (n=209)	4 (n=135)	5 (n=94)	6 (n=238)	7 (n=15)	8 (n=58)
Patient characteristics								
Mean age, in years	61.0	60.8	61.2	59.3	61.3	57.2	39.5	53.2
Gender, % female	41.4	39.6	48.3	42.2	44.7	44.5	80.0	48.3
Mean Body Mass Index	31.1	30.5	31.0	33.0	29.7	35.2	31.8	27.5
Chronic conditions, n (%)								
Diabetes mellitus	430 (45.4)	254 (45.3)	103 (49.3)	61 (45.2)	44 (46.8)	124 (52.1)	10 (66.7)	32 (55.2)
Cardiovascular disease	270 (28.5)	175 (31.2)	50 (23.9)	31 (23.0)	27 (28.7)	63 (26.5)	3 (20.0)	13 (22.4)
Chronic heart failure	25 (2.6)	18 (3.2)	5 (2.4)	4 (3.0)	2 (2.1)	8 (3.4)	1 (6.7)	2 (3.4)
≥2 Chronic conditions	223 (23.5)	114 (20.3)	51 (24.4)	39 (28.9)	21 (22.3)	43 (18.1)	1 (6.7)	11 (19.0)

Table 5. Eight eHealth patient types based on Web portal use patterns.

Cluster/type # (population %)	Label	Key attributes
1 (42%)	eDabblers	Largest cluster Shortest average session length Second-lowest average number of sessions Lowest intensity use
2 (25%)	Infrequent, intense users	Infrequent but meaningful visits (ie, highest intensity of use) Lowest frequency (hit days) of use Lowest consistency (hit months) of use Highest percentage of male users
3 (9%)	Electronic messenger	Highest use of the secure messaging function Highest use of the referral review and request functions Highest use of the medication renewal function Second-lowest average patient activation score
4 (6%)	Appointment preparers	Highest use of appointment scheduling functions Highest ratio of administrative-to-care use (only cluster >1.0) Highest use of function that displays provider information Highest use of function that provides driving directions to clinic
5 (4%)	Lab trackers	Highest use of the lab results and lab test review functions Highest frequency and consistency of use Lowest administrative-to-care ratio (ie, more care-related use) Second-highest average patient activation score, highest average age
6 (11%)	Biometric monitors	Highest use of weight/blood pressure tracking and graphing Second-highest average session length Lowest use of most portal functions Highest average BMI
7 (1%)	Proxy moms	Highest use of proxy functions (ie, view another person's record) Second-highest frequency and consistency of use Second-highest use of function to review list/details of office visits Highest proportion of female user, lowest average age
8 (3%)	Record updaters	Highest use of email/address updating functions Third-lowest frequency and consistency of use Shortest average page view time Highest average patient activation score

Discussion

Principal Findings

The conceptual model for understanding users of eHealth technologies such as portals, and for understanding the link between portal use and changes in patient outcomes, is not adequately developed and is often categorized along a single dimension. The amount of use (eg, number of logins, page views, time online) is frequently evaluated as the dominant mediator of outcomes associated with eHealth interventions [32]. Our data indicate that portal users are highly heterogeneous. Amount of use captures one of a number of dimensions of effective or meaningful use. User phenotypes may capture unique combinations of known and latent reasons for how eHealth is used because patients appear to exhibit distinct patterns of use. These patterns of use (reflected in the groups identified in Table 5) are characterized not solely by "high" or "low" use, but by variability in the frequency, consistency, and intensity of use over time, as well as by the specific features or functions that they tend to use repeatedly over time. By identifying distinct usage patterns, our typology may offer a tool for articulating more robust hypotheses about why patients use eHealth tools (eg, portals, PHRs) and, therefore, the types of outcomes that may be relevant. For example, there is a conceptual rationale for examining the relationship between portal use and clinical outcomes (eg, HbA1c) for “lab trackers”. Patients who monitor their HbA1c may be more likely to reach their clinical goal. However, a similar rationale may not be valid for “appointment preparers” because there is not a clear rationale for expecting that the way they use the portal (to prepare for an appointment) is likely to directly influence a clinical outcome such as HbA1c. We note that the groups identified in Table 5 are characterized by the portal features they tend to use (or not use) over time, but use of functions within an identified group is not exclusive (eg, patients in the “lab tracker” group are also likely to use the secure messaging function even if their overall pattern of use is different from the “secure messengers”). As portals become more prevalent, payers and providers will be concerned about the value provided by these technologies. Value can be defined based on improvements in patient outcomes, patient satisfaction, market share, or as a combination of measures such as return-on-investment. To establish the relationship between value-focused outcomes and portal use, we need to first understand and design measures that account for, or are the result of, the different patterns of use we have identified. Our results should also inform the development of patient-specific measures of meaningful use [33].

Our results indicate that there appear to be naturally occurring groups of portal users in a primary care patient population. We expected that frequency and intensity of portal use could serve as factors that discriminate various types of eHealth users, and this is partially supported by the data. In addition, several other distinguishing features of users are apparent; for example, proxy users represent a distinct group, as do users who focus on administrative versus care-related functions. Our findings are limited by both our patient selection criteria and by the current structure and features of the institution’s portal. However, our results offer a potential guide to areas where portal redesign can foster greater patient engagement and use. Moreover, our data indicate that the “if you build it, they will come” assumption so often associated with HIT may be a false hope, at least for the types of patients studied. Notably, approximately one-third of patients registered to use the portal never actually accessed it during the course of the study period. Even among “active users”, whom we defined as having at least 2 portal sessions during the study period, more than 65% were relatively infrequent and inconsistent in their use of the portal. Polls have consistently found that patients want the ability to use online tools to schedule appointments, communicate with their physician, receive their lab results, and have access to an EHR [3,34]. More than 50% of respondents in one poll said the ability to engage in such online activities would affect their choice of a physician [2]. While the demand appears to exist for Internet-based tools such as a portal, the form and types of interactions allowed by the current generation of tools may not yet be well defined or developed. Moreover, relatively few patients have access to these tools, and even among those who do have access, our data suggest that there remains an opportunity to develop features that foster more substantial engagement.

Our typology offers insight into potential enhancements to better engage, support, and guide patients in health-related activities. We next consider the distinguishing usage features and patterns of each type of eHealth user and identify the enhanced functions and features that are relevant to each group’s specific usage patterns.

The “appointment preparers” present an opportunity to engage these patients in potentially beneficial activities prior to their visit. For example, these users can, via the portal, be invited to complete electronic versions of data collection instruments (eg, administrative forms, patient-reported outcomes) that, if collected at all, are usually administered by paper during the office visit. Engaging patients prior to the visit has the potential to reduce costs by streamlining clinic workflows and to improve quality as additional data relevant to patient care are made available to the physician at the time of the office visit [35]. Similarly, “lab trackers” have a pattern that presents a low-cost, efficient opportunity to improve quality of care by engaging patients in self-management behaviors at a time when the patient has, by virtue of their decision to access their lab data, indicated an interest in their own health.

“Proxy moms” have the highest proportion of individuals with diabetes. Given their relatively young age, it is likely that these users have a dual role, managing their own chronic condition, and as indicated by their use of the proxy function, the care of a child or elderly parent. These users appear to be motivated to use the portal by their role as a caregiver and additional features relevant to this role may enhance engagement and offer a means for more virtual encounters, including joint virtual encounters where both the patient and the caregiver can participate from separate locations.

The secure messaging function was used by patients in all clusters. However, the “electronic messenger” cluster, characterized by the highest use of this function, was relatively small (9.26%, 209/2258). This was surprising given survey data showing strong interest in this feature. Evidence is mixed on portal-based and/or a standalone (ie, without access to medical record data) secure messaging tools, with one randomized controlled study [36] finding no reduction in telephone calls, versus another study finding a reduction in office visits but not in the number of telephone calls to the clinic [37]. Non-randomized studies evaluating the relationship between portal use (including secure messaging) and measures of utilization have shown a range of results, including a reduction in telephone calls [38], an increased use of clinical services [39], an absence of any significant change in face-to-face visits [40], increases in utilization of specialty and emergency department visits among diabetic patients [41], and increases in in-person and telephone clinical services [42]. Our data suggest that the lack of a clear relationship between portal use and calls/visit is not surprising because the messaging function is heavily used by only a small subset of patients. Earlier studies may fail to show an effect because the messaging function is either not targeted to appropriate user types, the targeted user base is too small to show an effect, or the function is not designed with other features that can increase interest in the use of virtual rather than in-person encounters.

In this study, we chose patients as the unit of analysis. The clustering algorithm identifies groups of similar patients based largely on the "bundle" of different portal functions they use over the course of the study period. Individual patients in one typological group, however, are likely to engage in behaviors associated with other typological groups (eg, lab trackers may also use secure messaging). An alternative approach that should be considered for future research is to consider "sessions" as the unit of analysis. In this case, the clustering algorithm will identify whether there are distinct types of sessions (as opposed to patients) characterized by the use of certain portal functions alone or in combination (eg, secure messages and laboratory results review), and patients can be described on the basis of the types of sessions that they use over time, which may be associated with the need for clinical services, disease severity, demographic characteristics, and other factors.

Although beyond the scope of this study, it is possible to determine which patient characteristics predict a patient's eHealth user type. Such predictive capabilities will allow organizations to develop targeted approaches to engaging different segments of their population with messages and incentives that can motivate eHealth adoption and use. It may also spur the development of new types of technologies. Many of the currently installed portals function primarily as a read-only view of the data in an individual's medical record. Although we have described the potential to improve outcomes through a better understanding of the way patients use portals, many of the advances we outlined (eg, using the portal to collect pre-visit data from "appointment preparers") require functionality not available in the current generation of deployed portals.

Limitations

This study is subject to several limitations. We have speculated about the relationship between portal use, cluster types, and outcomes; however, conducting a detailed assessment of outcomes and the relationship to our typology was beyond the scope of this study. Data from this study were collected from 2005-2006. Although Geisinger's portal has changed relatively little in terms of the overall core functionality offered to patients (eg, secure messaging, laboratory results), we believe that over the past 7 years patients have likely become more familiar and comfortable with eHealth tools like the portal. It is likely that this familiarity would, if we re-ran the analysis using data from 2012-2013, change the frequency and consistency with which patients use the portal. Because our typology is based both on the features used and how they are used over time, it is possible that Cluster 1 ("eDabblers"), which is defined by relatively low use, would be smaller, although it is hard to know if/how these users would be distributed among the other clusters. Although the data are older, Geisinger was an early adopter of the patient portal and we believe that the results are relevant to the many health care systems that are implementing EHRs and portals in response to meaningful use incentives.

Our analysis focused on use of MyGeisinger, and our data sources did not include other measures of non-portal patient activity such as office visits, telephone calls, or hospital admissions. This limitation precludes the ability to explore the relationship between portal use and "real-world" office or telephone utilization. We also focused only on patients with chronic disease because we expected that they would have reasonable cause to use the portal repeatedly over time. Our typology cannot be reliably extrapolated to patients without chronic disease because the motivation to use the portal and utility of specific functions is likely to be different from chronically ill patients.

In our study, there are unmeasured provider behaviors (eg, quality and timeliness of provider and staff responses to secure messages), clinic-level behaviors (eg, scheduling and phone practices), and system-wide activities (eg, broadcast and/or targeted preventive care reminders sent to patients) that may have impacted whether and how often patients use the portal. In subsequent analyses, it will be important to incorporate measures of these behaviors and assess their impact on the size, number, and nature of user types identified by our method. Although the portal functions we analyzed are typical of many portals, our typology will need to be updated as current generation portals evolve to provide new and/or more advanced functions. We were limited in our ability to fully characterize cluster members using demographic and EHR data. Notably, like Roblin et al, we did not find evidence of an age disparity in terms of portal use by older patients; more than one-third of portal users (Table 2) were 65 years or older [43]. Some of the naturally occurring variability in portal use may be due to differences in disease severity or physician practice, and these factors should be explored in subsequent studies. To validate our findings, we used a method similar to Coste et al in which we re-ran the analysis on 10 random subsamples of the entire population [44]. We also re-ran the analysis using a partitioning cluster algorithm (k-means), which should replicate the results of the hierarchical approach if the hierarchical approach accurately identified the structure of the underlying data. Both validation approaches yielded acceptable results. However, we consider our results to be a preliminary typology that will likely be refined by similar research using different populations and different types of portals. Regardless of whether our typology is replicated in different populations, our results suggest that Web server log files can serve as a valuable secondary data source for eHealth services research.

The method we have described can be applied more broadly to studies of other types of eHealth technologies. For example, the "lifelong personal health record" described by Barbarito et al, as well as other personal health record systems, may have novel usage patterns because data are owned by the patient rather than a specific health care system (as are many of today's portals) and the potential for a longitudinal, provider-agnostic view may present new use cases from the patient's perspective [45].

Conclusion

Our preliminary typology offers a guide to developing additional features and functionalities that can support patients in their meaningful use of online health-related tools. By identifying distinct patterns of use that may be linked to relevant outcomes, our typology can form a framework around which to design future research focused on the next generation of burgeoning eHealth technologies.

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Conflicts of Interest

None declared.

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Abbreviations

BMI: body mass index
EHR: electronic health record
GC: Geisinger Clinic
HIT: health information technology
ICD: International Classification of Diseases
PCP: primary care physician
PHR: personal health record

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Original Paper

FRAT-up, a Web-based Fall-Risk Assessment Tool for Elderly People Living in the Community

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Abstract

Background: About 30% of people over 65 are subject to at least one unintentional fall a year. Fall prevention protocols and interventions can decrease the number of falls. To be effective, a prevention strategy requires a prior step to evaluate the fall risk of the subjects. Despite extensive research, existing assessment tools for fall risk have been insufficient for predicting falls.

Objective: The goal of this study is to present a novel web-based fall-risk assessment tool (FRAT-up) and to evaluate its accuracy in predicting falls, within a context of community-dwelling persons aged 65 and up.

Methods: FRAT-up is based on the assumption that a subject's fall risk is given by the contribution of their exposure to each of the known fall-risk factors. Many scientific studies have investigated the relationship between falls and risk factors. The majority of these studies adopted statistical approaches, usually providing quantitative information such as odds ratios. FRAT-up exploits these numerical results to compute how each single factor contributes to the overall fall risk. FRAT-up is based on a formal ontology that enlists a number of known risk factors, together with quantitative findings in terms of odds ratios. From such information, an automatic algorithm generates a rule-based probabilistic logic program, that is, a set of rules for each risk factor. The rule-based program takes the health profile of the subject (in terms of exposure to the risk factors) and computes the fall risk. A Web-based interface allows users to input health profiles and to visualize the risk assessment for the given subject. FRAT-up has been evaluated on the InCHIANTI Study dataset, a representative population-based study of older persons living in the Chianti area (Tuscany, Italy). We compared reported falls with predicted ones and computed performance indicators.

Results: The obtained area under curve of the receiver operating characteristic was 0.642 (95% CI 0.614-0.669), while the Brier score was 0.174. The Hosmer-Lemeshow test indicated statistical significance of miscalibration.

Conclusions: FRAT-up is a web-based tool for evaluating the fall risk of people aged 65 or up living in the community. Validation results of fall risks computed by FRAT-up show that its performance is comparable to externally validated state-of-the-art tools. A prototype is freely available through a web-based interface.

Trial Registration: ClinicalTrials.gov NCT01331512 (The InChianti Follow-Up Study); http://clinicaltrials.gov/show/NCT01331512 (Archived by WebCite at http://www.webcitation.org/6UDrrRuaR).

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KEYWORDS

accidental falls; odds ratio; risk assessment; risk factors; ROC curve; aged

Introduction

Background

About 30% of community-dwelling people aged 65 or more experience at least one unintentional fall a year [1], and the annual fall rate in this cohort is about 0.65 falls per person [2]. Falls can result in injuries and are a leading cause of activity restriction, hospitalization, and disability [3,4]. Falling is the tenth leading cause of global years lived with disability (YLD). Worldwide, it accounts for about 20 million YLD [5] and a total of 35 million disability-adjusted life years [6]. Its burden is even more pronounced in countries with an older population; in Italy it is estimated to be the third leading cause of YLD [7].

Many preventive strategies have been proposed, and some of them have been shown to be effective [8-10]. Their implementation, however, has been slow and the coverage in Europe is insufficient [11-13]. The individual and societal costs of these interventions are often among the factors that hinder their implementation. In order to make use of available resources and intervene only with subjects at increased risk, medical associations and national health authorities recommend the adoption of fall-risk assessment tools [14-17].

Existing Tools

Reviews of fall-risk assessment tools and their accuracy are available in the literature [18-23]. Among the most used and validated tools are the Timed Up and Go Test (TUG), the Performance Oriented Mobility Assessment (POMA), and the Physiological Profile Assessment (PPA) [24]. Despite extensive research, existing assessment tools for fall risk have been insufficient for predicting falls [23,25-28].

Existing Knowledge and Ontologies

An impressive number of scientific publications have identified statistical correlation between the exposure to risk factors and the risk of falling, in terms of odds ratios. Moreover, several reviews and meta-analyses are available, thus providing a solid scientific base about fall-risk factors [29-35].

In our Fall-Risk Assessment Tool (FRAT-up), we faced the issue of representing the information available from scientific literature in a structured manner. In computer science, an ontology is a formal, explicit specification of a shared conceptualization [36]; ontologies are widely used in artificial intelligence, the semantic Web, and biomedical informatics as a form of knowledge representation. Formal approaches, like ontologies and the semantic Web, are important instruments also in epidemiology research [37].

Aims of the Study

The goal of FRAT-up is to provide a tool for the fall-risk assessment of subjects aged 65 or up and living in a community dwelling. The tool is mainly intended for two different health professional roles: (1) general practitioners (GPs) delivering primary care provisions, with no specific knowledge about falls, who need an assessment tool for evaluating subjects' fall risk and possible early interventions, and (2) professionals involved in fall prevention and treatment, who need a tool for constantly assessing the fall risk in a reliable and quantitative manner. We identified the following requirements: (1) the assessment tool should identify people at high risk of falling, (2) the tool should exploit existing knowledge about fall-risk factors, (3) the tool should be sufficiently flexible to allow the use of different clinical tests for the estimate of each risk factor, and (4) the assessment tool should be robust with respect to the unavailability of complete information about the subject.

FRAT-up has been developed within the FARSEEING Project [38], and it aims to meet all the requirements listed above.

Methods

Overview

The FRAT-up fundamental hypothesis is to consider the fall risk as being directly related to the subject's exposure to known risk factors. Thus, the starting point is the scientific literature that lists risk factors, together with quantitative information on their association with falls (usually in terms of odds ratios). However, such literature does not provide any structured definition of risk factors and related information. Hence, the first building block of the FRAT-up approach consists of a formal ontology listing risk factors and related data.

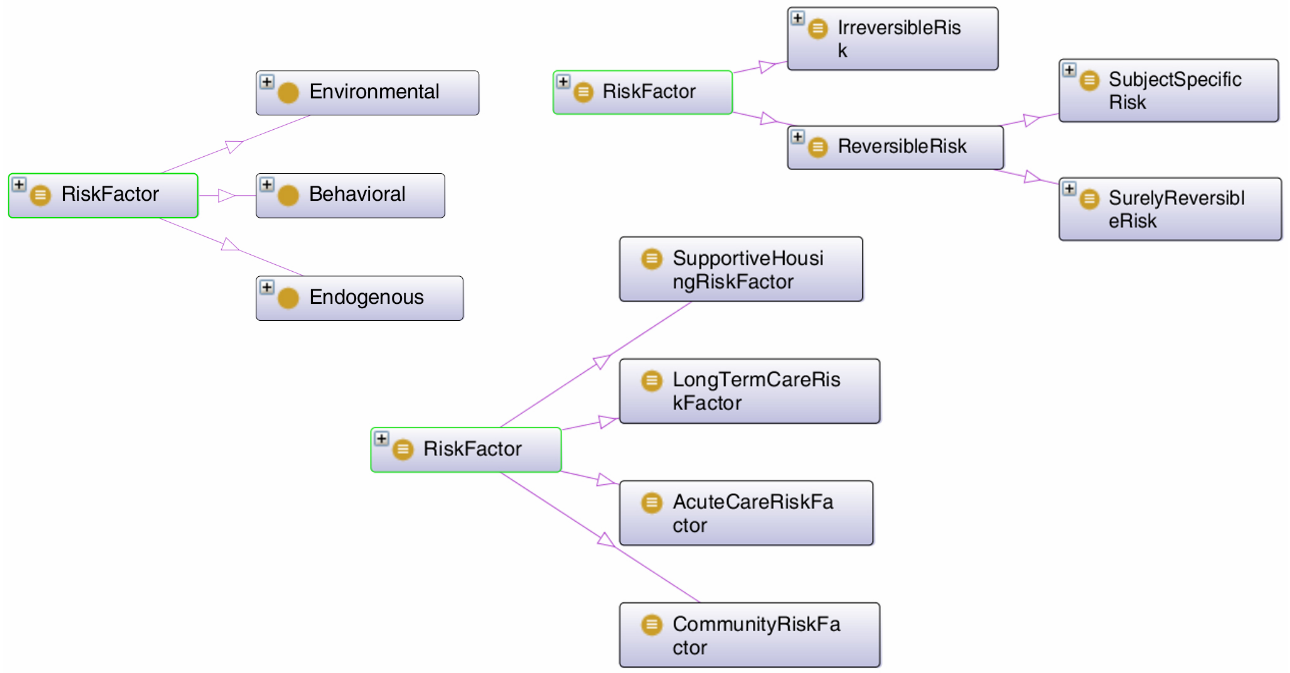
Once quantitative information is available through the FRAT-up risk factor ontology, we need to decide how (the exposure to) each risk factor contributes to the overall risk. Our approach is based on probabilities, while epidemiological studies on risk factors usually provide information in terms of odds ratios. Hence, the second building block is a mathematical transformation from odds ratios to probabilities under a few assumptions, as explained further in this section.

The third building block of FRAT-up is a Logic Programming with Annotated Disjunctions (LPAD) program that allows representation of the contribution of each risk factor in terms of probabilistic rules and probabilistic reasoning.

A Formal Ontology for Fall-Risk Factors

In FRAT-up, a fall-risk factor ontology has been defined, taking into account several domains. For example, the classification of risk factors by reversibility (surely reversible, subject specific reversible, or irreversible) and setting (community dwelling, acute care, etc) is shown in Figure 1.

Figure 1. Classification of risk factors by kind, reversibility, and setting. While the InCHIANTI dataset is about community dwellings, the ontology covers other settings, too.



Within the ontology, risk factors are distinguished as *dichotomous*, *scalar,* and *synergy* factors. Dichotomous risk factors indicate whether a risky condition is present or not, without taking into account its severity. Scalar risk factors also indicate the magnitude of the subject's exposure to the risky condition. Since synergism between risk factors is well known [39], synergy factors make it explicit if two or more risk factors, due to their simultaneous presence, determine a higher risk than if present alone.

The set of risk factors we include in the ontology comes from a well-established meta-analysis on known risk factors for falls in community-dwelling older people by Deandrea et al [29] (see Table 1).

The ontology also includes the odds ratio for each risk factor, taken from Deandrea et al [29]. Moreover, we introduced in the ontology a clear distinction between a risk factor and the corresponding *estimators*. An estimator is a method to assess the presence and, when necessary, the severity of a risk factor (possibly in combination with other estimators).

Additional data contained in the ontology are the risk factors' prevalence and procedures to map estimators into factors. Complete information, including sources for quantitative data, is reported in Multimedia Appendix 1.

Table 1. Risk factor names and types.

Name	Type
age	scalar
cognition impairment	dichotomous
depression	dichotomous
diabetes	dichotomous
comorbidity	synergy
dizziness and vertigo	dichotomous
fear of falling	dichotomous
female sex	dichotomous
gait problems	dichotomous
hearing impairment	dichotomous
history of falls	dichotomous
history of stroke	dichotomous
instrumental disability	dichotomous
living alone	dichotomous
number of medications	scalar
pain	dichotomous
parkinson	dichotomous
physical activity limitation	dichotomous
physical disability	dichotomous
poor self-perceived health status	dichotomous
rheumatic disease	dichotomous
urinary incontinence	dichotomous
use of antiepileptics	dichotomous
use of antihypertensives	dichotomous
use of sedatives	dichotomous
vision impairment	dichotomous
walking aid use	dichotomous

From Odds Ratios to Probabilities

Overview

The FRAT-up risk-assessment algorithm is based on probability contributions from single risk factors. In the following, we show how we extract probabilities from odds ratios by means of a few mathematical steps.

Initially, we assume that each risk factor is dichotomous; we explain this further in the section on how to generalize to cases with scalar and synergy risk factors. Let $E_0, E_1,\ldots, E_n$ be $n + 1$ dichotomous random variables with values in {0;1}, and $E=(E_0, E_1,\ldots, E_n)$. We say that the i^{th} risk factor is present if $E_i=1$. Let $d_0, d_1,\ldots, d_n$ be $n + 1$ events. We assume the following conditional independence relations:

Equation 1: $d_i \mid E_i \perp d_j, E_j \ \forall j \neq i$

We call d_i a fall event specific to risk factor E_i. Assumptions from Equation 1 can be phrased saying that risk factor–specific falls are mutually independent conditional on their associated risk factor. We define the event d as the union of the factor-specific events, d_i's (Figure 2). That is, d is verified if at least one of the d_i's is verified. This is an assumption of causal independence where the “causes”, $E_0, E_1,\ldots, E_n$, contribute independently to the probability of the effect d; for a complete formal definition see [40]. In our case study, d is the presence of at least one fall event during a given time span (if there is no fall, it is not verified), while E is an observation of the risk factor exposures of a subject before the time span.

The conditional probability of d given E can then be calculated as in Figure 3, by De Morgan laws and assumptions in Equation 1. This function models the probability of an event given a set of possible causes and is known as noisy-OR gate [41] (in this case OR refers to the logical operator). We make the assumption in Figure 4. C_i is a quantity yet to determine. C_i is the contribution to the probability of the effect *d* given by the exposure to the risk factor E_i. A method to assign values to the contributions C_i is introduced in the following. Using the equation in Figure 4, the equation in Figure 3 becomes the one depicted in Figure 5. Since we want to model a minimum probability of the adverse event that is applied even in the absence of any observation-specific exposures, we assign $P(E_0=1)=1$. C_0 is the risk that is present in this case. To assign values to the contributions of the exposures, we start from the OR. The OR relative to risk factor E_i, with $i=1,\dots,n$, is defined as in Figure 6. Note that the condition $E_0=1$ is always true and is highlighted above just for convenience.

There is no single way of translating odds ratios to probabilities, since an exact function would require more information than what is conveyed by the odds ratios alone, so some assumptions are needed. We present a possible set of assumptions that leads to a univocal way of computing exposure contributions.

Figure 2. Definition of fall event.

$$d := \bigcup_{i=0}^{n} d_i$$

Figure 3. Probability to fall from risk factor specific probabilities.

$$\begin{aligned}
P(d \mid E) &= P\left(\bigcup_{i=0}^{n} d_i \mid E\right) = 1 - P\left(\overline{\bigcup_{i=0}^{n} d_i} \mid E\right) = && (a)\\
&= 1 - P\left(\bigcap_{i=0}^{n} \overline{d_i} \mid E\right) = && (b)\\
&= 1 - \prod_{i=0}^{n} P\left(\overline{d_i} \mid E_i\right) = && (c)\\
&= 1 - \prod_{i=0}^{n} \left[1 - P\left(d_i \mid E_i\right)\right] && (d)
\end{aligned}$$

Assumption (a)

We assume that OR_i may be approximated as in Figure 7. Informally, Assumption (a) states that the odds ratio computed on the whole population is similar to the odds ratio computed restricting the population to subjects having at most one exposure. This assumption is obviously true in models where each subject has at most one exposure; otherwise there is a difference in the two values. This has not been quantified yet; the quality of the approximation will be experimentally compared with other methods as a future development.

Given the assumptions in Equation 1 and Figure 4, the derivation depicted in Figure 8 follows. Substituting the equation in Figure 8 in the equation in Figure 7 and solving for C_i, we finally get the equation depicted in Figure 9. We substitute it in the equation in Figure 5, with a result that is depicted in Figure 10.

Figure 4. Probability of factor specific fall event given exposure.

$$P(d_i \mid E_i) = \begin{cases} 0 & \text{if} \quad E_i = 0 \\ C_i & \text{if} \quad E_i = 1 \end{cases}$$

Figure 5. Probability to fall given exposures and contributions.

$$P(d \mid E) = 1 - \prod_{i=0}^{n} \left(1 - E_i C_i\right)$$

Figure 6. Odds ratio definition.

$$OR_i := \frac{P(d \mid E_0 = 1, E_i = 1)}{1 - P(d \mid E_0 = 1, E_i = 1)} \, \frac{1 - P(d \mid E_0 = 1, E_i = 0)}{P(d \mid E_0 = 1, E_i = 0)}$$

Figure 7. Approximated odds ratio.

$$OR_i = \frac{P\left(d \mid E_0 = 1, E_i = 1, E_{j\neq 0,i} = 0\right)}{1 - P\left(d \mid E_0 = 1, E_i = 1, E_{j\neq 0,i} = 0\right)} \frac{1 - C_0}{C_0}$$

Figure 8. Probability to fall with exposure to exactly 1 risk factor.

$$\begin{aligned} &P\left(d \mid E_0 = 1, E_i = 1, E_{j\neq 0,i} = 0\right) = && (a) \\ &= P\left(d_0 \vee d_i \mid E_0 = 1, E_i = 1, E_{j\neq 0,i} = 0\right) = && (b) \\ &P\left(d_0 \mid E_0 = 1\right) + P\left(d_i \mid E_i = 1\right) - P\left(d_0 \mid E_0 = 1\right) P\left(d_i \mid E_i = 1\right) = && (c) \\ &C_0 + C_i - C_0 C_i && (d) \end{aligned}$$

Figure 9. Contribution to fall probability from exposure to a single risk factor given odds ratio.

$$C_i = C_0 \frac{OR_i - 1}{1 - C_0 + C_0 OR_i}$$

Figure 10. Probability to fall from risk factor odds ratios.

$$P\left(d \mid E\right) = 1 - \left(1 - C_0\right) \prod_{i=1}^{n} \left(1 - E_i C_0 \frac{OR_i - 1}{1 - C_0 + C_0 OR_i}\right)$$

Assumption (b)

We assume to know C_0, which was calculated by leaving it as a free parameter and then learning it with an equation-solving algorithm. In particular, we used the bisection method, imposing the reported number of total falls from [1].

This model requires that we know for every risk factor if it is present or not. In the following section, we present the way FRAT-up deals with missing values.

For a general reference on how to get relative risk from odds ratio and the incidence of the outcome of interest in the unexposed group, see [42].

LPAD Structure and Handling of Unknown Exposures, and Scalar and Synergy Risk Factors

LPADs are logic programs [43] where the head of a clause is a disjunction of annotated atoms. The clauses are of the form:

$h_1: p_1 \vee \ldots \vee h_n: p_n \leftarrow b_1 \wedge \ldots \wedge b_m \wedge\ c_1 \wedge \ldots \wedge\ c_l$

where $h_1,\ldots,\ h_n$ are the atoms, and $p_1,\ldots,\ p_n$ are the probabilities related to each disjunct. Each atom h_i has probability p_i if the body is true, and the atom does not appear in the head of any other clause. When it does, the intended semantics are the distribution semantics as in [44], with the bodies contributing independently to the probability of the atom [40]. The probabilities $p_1,\ldots,\ p_n$ should sum up to 1, with an implicit “null” atom when the explicit probabilities sum up to less than 1.

Roughly speaking, for each clause containing a disjunction in its head, different instances are generated, each containing the clause with exactly one disjunct. The probability of a query would be given by the sum of all the probabilities of the instances whose models contain it.

We adopt the syntax of the *cplint* [45] implementation. Note that the disjunction in the head of clauses is indicated with the symbol “;”, while the conjunction is indicated as usual in Prolog with “,”. The equation in Figure 5 can be easily implemented with LPAD rules (Code 1 LPAD template with computed fall probability contributions):

```
fall(X) : c0.

fall(X) : c1 :- e1(X).

fall(X) : c2 :- e2(X).

...
```

Where c0≡C_0, c1≡ C_1, e1(X)≡ (E_1=1), c2≡ C_2, e2(X)≡ (E_2=1) ...

The assessment tool should provide reliable information even when part of the subject’s data is missing. Missing values may arise when a test has not been (or cannot be) performed or the involved clinical professional does not consider its outcome decisive and reliable. In these cases, we have used the prevalence of the risk factors extending Code 1 as follows:

```
fall(X) : c0.

e1(X) : p1 :- u1(X).

fall(X) : c1 :- e1(X).

e2(X) : p2 :- u2(X).

fall(X) : c2 :- e2(X).

...
```

where u1(X), u2(X)… is true when the existence of the factor 1, 2… for subject *X* is not determined.

A scalar factor, with exposure levels from 0 (no exposure) to *m* (maximum exposure), is implemented similarly to a set of *m* dichotomous factors, one for each exposure level starting from level 1. The LPAD rule related to level *k* fires if the scalar risk factor has a level of *k* or higher.

Positive synergies (eg, comorbidities) between risk factors are well documented in the scientific literature. Since this would violate the causal independence assumption made before, we adjusted the model, following the Deandrea meta-analysis [29], introducing synergy factors.

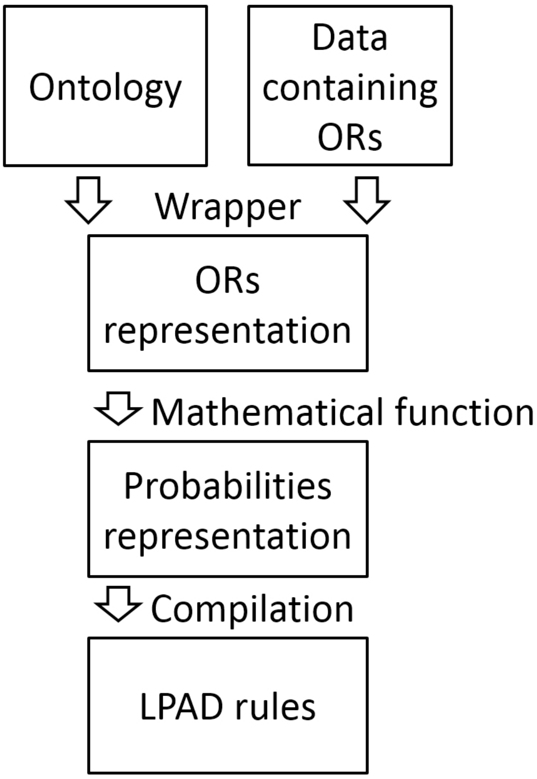
A synergy factor, representing the potential synergies between *S* dichotomous risk factors, is implemented similarly to a scalar risk factor having a maximum possible level of $S - 1$ where, having a number of exposures equal to *q*, with $0 \leq q \leq S$, the level is 0 if $q=0 \vee q=1$ and is $q - 1$ otherwise. So the risk starts increasing when there is a synergy between at least two factors.

Automatic Generation of the LPAD

The methodology that leads from risk factor odds ratio to LPAD rules is fully automatized. A working prototype has been produced and tested in the Java programming language (version 1.7); it may read risk factor odds ratios from an ontology or another source and outputs an LPAD program directly usable for risk assessment.

Synthetically (see Figure 11), risk factors data complete with odds ratio are read from an ontology or other data source; a data structure containing odds ratios is created and then transformed (by means of the equation in Figure 9) in another containing probability values. Finally LPAD rules are compiled: these rules are applied to a subject to give their probability of falling in a given time span.

Figure 11. Steps in generating the LPAD rules.



Dataset and Validation Procedure

FRAT-up discriminative performance and calibration have been tested on the InCHIANTI dataset (NCT01331512), where 1453 persons have been initially enrolled (1150 subjects aged 65 or more) and have undergone four consecutive visits globally covering a 9-year follow-up. It is a population-based epidemiologic study conducted in the Chianti region of Italy in two sites: Greve in Chianti (Area 1; 11,709 inhabitants; >65 years: 19.3%) and Bagno a Ripoli (Village of Antella, Area 2, 4704 inhabitants; >65 years: 20.3%). This study investigates age-related decline in mobility [46].

The InCHIANTI study started in September 1998 with the baseline assessment (first wave), which was completed in March 2000. Every 3 years, a follow-up assessment was performed. So, 3-year and 6-year follow-up assessments were performed respectively in 2001-2003 and 2004-2006 (second and third wave). A 9-year follow-up was then performed in 2007-2009 (fourth wave). The fifth wave is now ongoing.

At each wave, subjects were asked about the occurrence of any fall in the previous 12 months. In addition, clinical evaluation of the subjects was performed to collect information on fall-risk factors (other clinical variables were also collected, which are not of interest for this work [46]).

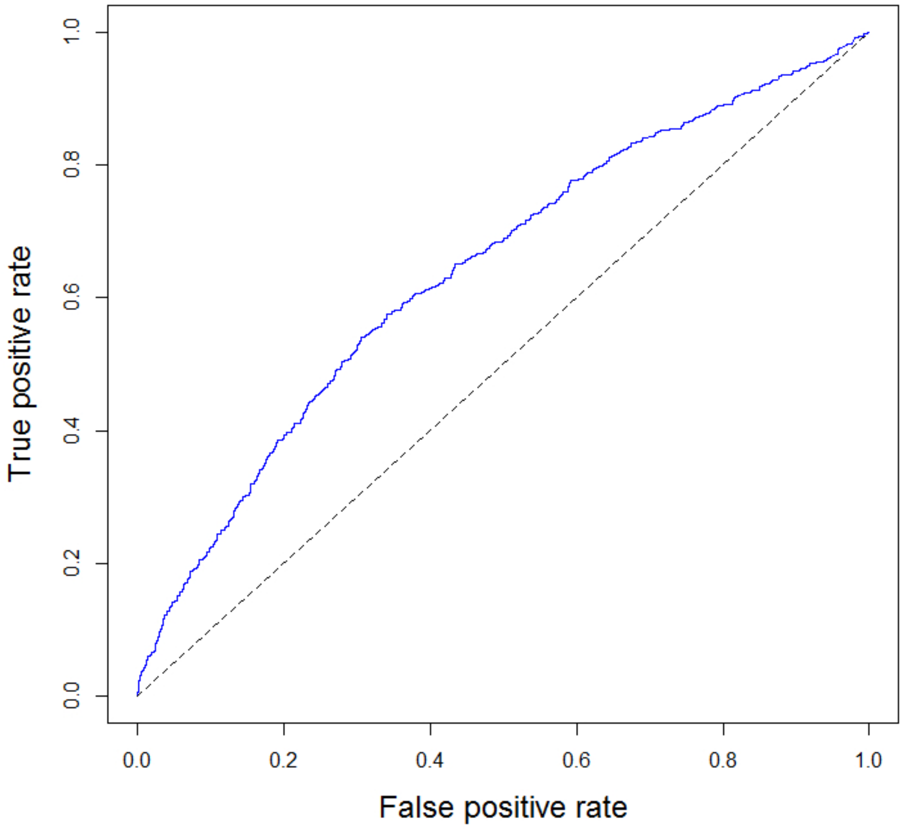
Our study used the information about risk factors from the first three waves, considering only subjects aged 65 or up. By doing so, we obtained 2319 samples from 977 subjects (every subject can have up to three samples).

At each wave, the risk factors of each subject were used prospectively to calculate their risk of falling at the subsequent wave (eg, the risk factors from the clinical evaluation at baseline were used to calculate the future risk of falling, which was compared with the recorded information on the occurrence of any falls in the 12 months before follow-up 1, and so on).

The estimators present in the InCHIANTI dataset and the algorithms to derive the risk factors from them are listed in Multimedia Appendix 1.

The discriminative ability and calibration of FRAT-up were validated by means of receiver operating characteristic (ROC) curve, area under the ROC curve (AUC), Brier score, and the Hosmer-Lemeshow test [47]. Since FRAT-up requires no training of the algorithm based on the available data, these metrics were computed by using all the available data as the test set.

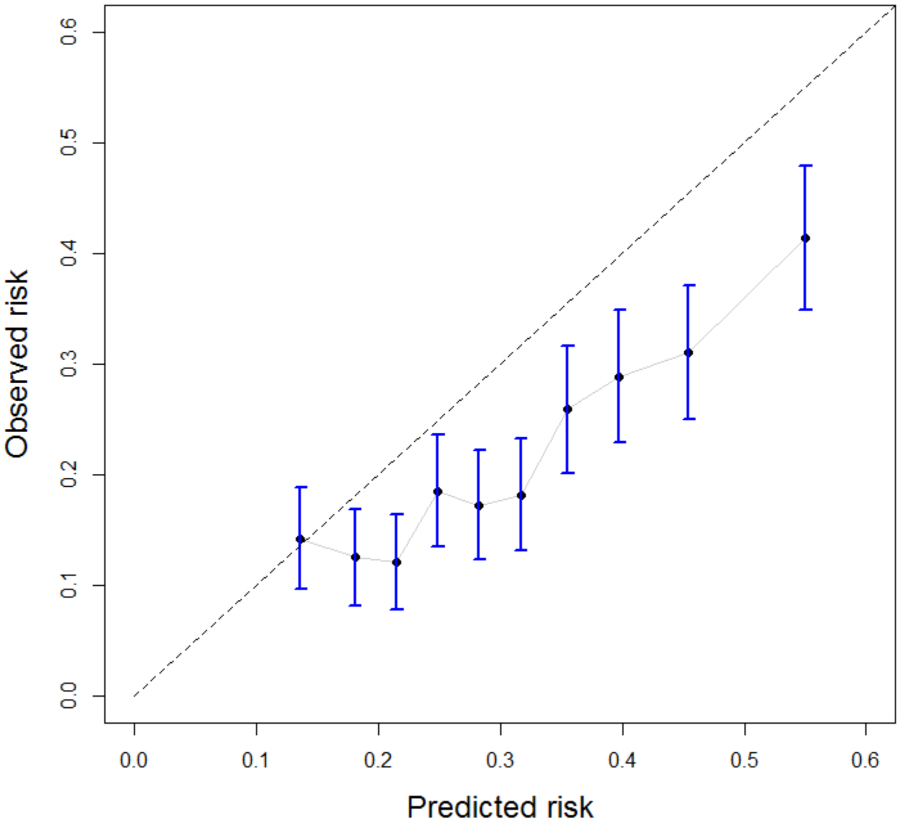
Figure 12. ROC curve obtained on the InCHIANTI dataset.



Results

The ROC curve can be seen in Figure 12; the AUC value is 0.642 (95% CI 0.614-0.669). The Hosmer-Lemeshow test produces a very low *P* value (<.001) indicating statistical significance of miscalibration. As shown by the calibration plot in Figure 13, this miscalibration is due to risk overestimation that is consistent over the risk strata. The Brier score is 0.174.

Figure 13. Calibration plot; sample (N=2319) used for validation where divided in 10 deciles, according to their predicted risk. For each decile, the mean predicted risk and the observed proportion of positive cases (proportion of fallers) are shown on the X and Y axes, respectively. Bars indicate 95% confidence intervals.



Discussion

Principal Findings

The ability to discriminate between subjects who fall and subjects who do not fall, as operationalized by the AUC (0.642), compares favorably with other commonly used screening tools: a recent meta-analysis has estimated that the AUC of the TUG is between 0.54 and 0.59 [28], while the POMA-balance (also known as Tinetti balance scale) has AUC around 0.56 [23]. Since at each wave of the study, each subject was asked whether they had fallen in the last 12 months and the waves were about 3 years apart, this means we evaluated a prediction for an event that materializes between about 24 and 36 months after the assessment of the risk factors. Had the information about falls been available for the year just after the assessment, the results would likely have been better. Additionally, it is worth noting that the InCHIANTI dataset was not specifically designed to investigate fall risk. Because of these limitations, validation on other datasets would be desirable.

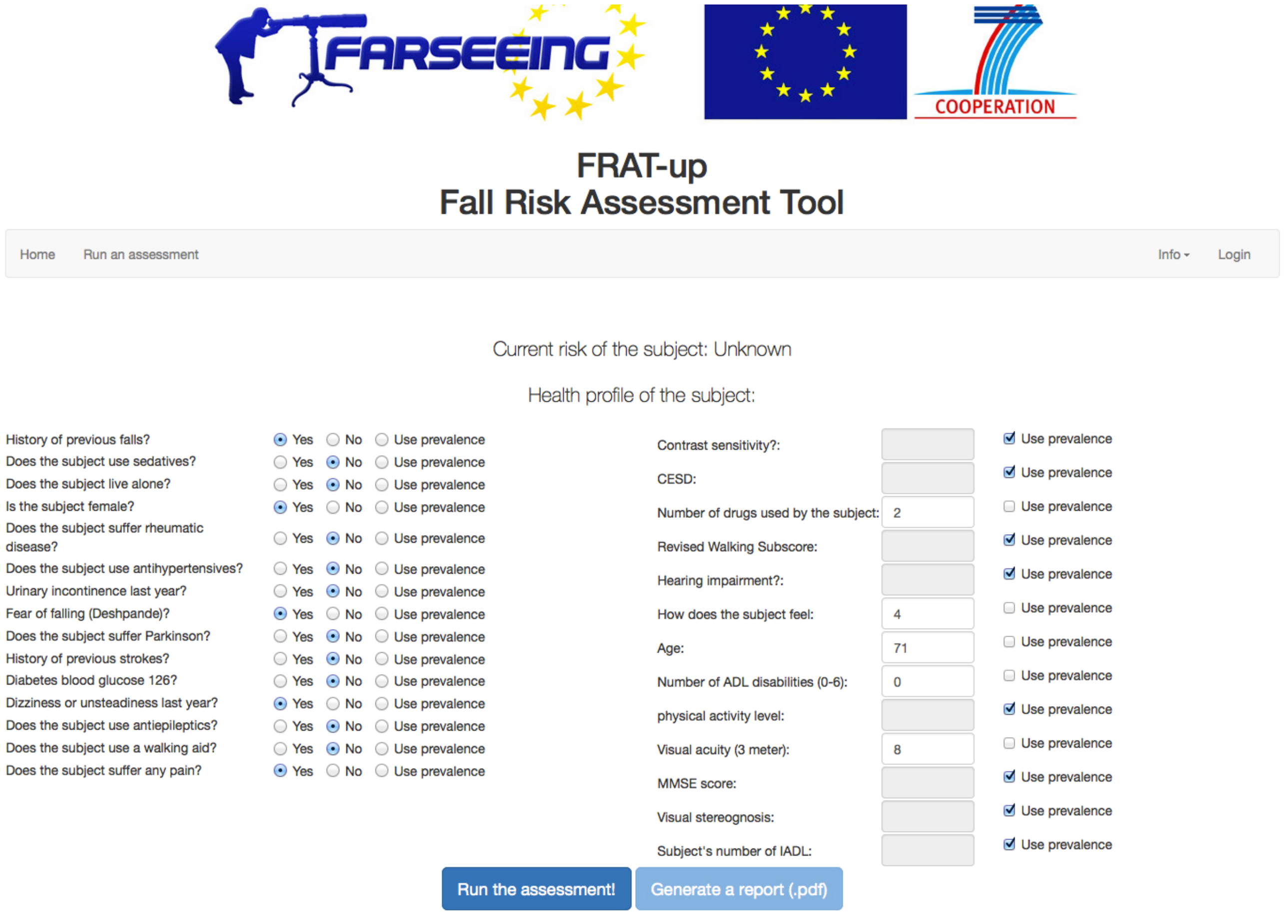
FRAT-up overestimates the fall risk. Since this overestimation, as shown in Figure 13, is consistent across deciles, the miscalibration is of less concern. The main reason behind this overestimation could be that the incidence of falls from [1] (31% subjects fallen at least once in a year), which was used for calculating the term C_0, is higher than the observed incidence of falls in the InCHIANTI population (22%). A possible way to reduce overestimation would be multiplying the output by a constant, but we did not exploit this kind of learning on the dataset.

FRAT-up does exploit existing knowledge as it was built only from information derived from the literature, which was systematized in a meta-analysis. By doing so, it avoids overfitting and overoptimism, problems well known to affect predictive models [48].

Although the validation on the InCHIANTI dataset is based on a specific set of estimators, the architecture allows for the use of different estimators. The results of the validation have been obtained from the InCHIANTI dataset, where the percentage of missing values ranges from 0% on some variables (eg, sex and age) to 17% on vision impairment.

The interactive prototype of the FRAT-up algorithm is freely available online [49]. Its interface is depicted in Figure 14.

Figure 14. Screenshot of the Web-based interface.



FRAT-up
Fall Risk Assessment Tool

Current risk of the subject: Unknown

Health profile of the subject:

History of previous falls?	● Yes	○ No	○ Use prevalence
Does the subject use sedatives?	○ Yes	● No	○ Use prevalence
Does the subject live alone?	○ Yes	● No	○ Use prevalence
Is the subject female?	● Yes	○ No	○ Use prevalence
Does the subject suffer rheumatic disease?	○ Yes	● No	○ Use prevalence
Does the subject use antihypertensives?	○ Yes	● No	○ Use prevalence
Urinary incontinence last year?	○ Yes	● No	○ Use prevalence
Fear of falling (Deshpande)?	● Yes	○ No	○ Use prevalence
Does the subject suffer Parkinson?	○ Yes	● No	○ Use prevalence
History of previous strokes?	○ Yes	● No	○ Use prevalence
Diabetes blood glucose 126?	○ Yes	● No	○ Use prevalence
Dizziness or unsteadiness last year?	● Yes	○ No	○ Use prevalence
Does the subject use antiepileptics?	○ Yes	● No	○ Use prevalence
Does the subject use a walking aid?	○ Yes	● No	○ Use prevalence
Does the subject suffer any pain?	● Yes	○ No	○ Use prevalence

Contrast sensitivity?:		☑ Use prevalence
CESD:		☑ Use prevalence
Number of drugs used by the subject:	2	☐ Use prevalence
Revised Walking Subscore:		☑ Use prevalence
Hearing impairment?:		☑ Use prevalence
How does the subject feel:	4	☐ Use prevalence
Age:	71	☐ Use prevalence
Number of ADL disabilities (0-6):	0	☐ Use prevalence
physical activity level:		☑ Use prevalence
Visual acuity (3 meter):	8	☐ Use prevalence
MMSE score:		☑ Use prevalence
Visual stereognosis:		☑ Use prevalence
Subject's number of IADL:		☑ Use prevalence

Limitations and Future Developments of FRAT-up

FRAT-up is based on the simplifying assumption that the risk factors contribute independently to the probability of falling. Following Deandrea et al [29] and to partially relax this assumption, we introduced the synergy factors in the methods section. However, different approaches may be investigated.

Our method showed robustness with respect to the missing values present in the InCHIANTI dataset. However, the extent to which the presence of missing values impacts the performance should be further investigated. In the future, FRAT-up will be tested on other datasets of different populations, possibly with different estimators for the risk factors, and compared with alternative risk assessment tools. Additionally, considering confidence intervals of the odds ratios could allow us in the future to assess the uncertainty associated with the fall-risk estimation.

Risk factors not reported in the meta-review by Deandrea et al [29] (such as rare risk factors) are not considered. Also, other information sources like experts' opinion and administrative/demographic data are currently ignored. Ongoing work is devoted to extend the risk factor ontology with this additional information. The evaluation of the tool should go beyond statistical assessment alone. Usability and usefulness, which are increasingly acknowledged as important in the literature of prognostic models [50], will hence be evaluated.

Within the framework of a fall-prevention strategy, information would be useful on the indication of the modifiable risk factors of a specific subject and their quantitative impact on their risk. Practically, we foresee integration of the tool within electronic medical records, tools of general practitioners, as well as its adoption in public health bodies for population-wide evaluation.

The versatility of the presented solution will allow combining clinical information (that was used in this study) with other sources of data such as ambient sensor information or wearable sensors recording unsupervised long-term physical activity and/or quantitatively evaluating supervised or unsupervised physical performance by instrumented motor assessment [51-55].

An interesting extension of FRAT-up would be to implement it as an app for “smart” devices such as smartphones. The tool might be fed with rich sensor-based information and could be extended to provide “real-time” risk evaluation based on the subject’s current physical activity. Although from the technical viewpoint, such an extension would be easy and straightforward, using smartphone sensor data (in the fall-risk estimation) is still an open research issue.

Finally, since FRAT-up is based on a general methodology, it may be extended/applied in different ways, such as estimating fall risks in different settings (eg, acute care or nursing homes). Another extension would be to estimate outcomes other than falling, such as stroke risk, and more generally, estimate any risks directly related to the presence/absence of risk factors.

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Conflicts of Interest

Clemens Becker has received consultation fees by Eli Lilly and Robert Bosch GmbH.

Multimedia Appendix 1

FRAT-up estimators, factors, and procedures to produce factor values starting from estimator values.

[PDF File (Adobe PDF File), 153KB - jmir_v17i2e41_app1.pdf]

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Abbreviations

AUC: area under the ROC curve
FRAT-up: Fall-Risk Assessment Tool
LPAD: Logic Programming with Annotated Disjunctions
OR: odds ratio
POMA: Performance Oriented Mobility Assessment
ROC: receiver operating characteristic
TUG: Timed Up and Go Test

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Original Paper

Training With Virtual Patients in Transcultural Psychiatry: Do the Learners Actually Learn?

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Abstract

Background: The rapid increase in the number of patients with diverse ethnic backgrounds and previous exposure to severe mental trauma dictates the need for improvement in the quality of transcultural psychiatric health care through the development of relevant and effective training tools.

Objective: This study aimed to evaluate the impact of training with a virtual patient on the learner's knowledge of posttraumatic stress disorder symptoms, clinical management, and basic communication skills.

Methods: The authors constructed an interactive educational tool based on virtual patient methodology that portrayed a refugee with severe symptoms of posttraumatic stress disorder and depression. A total of 32 resident psychiatrists tested the tool and completed a pre-interaction and post-interaction knowledge test, including skills, at the time and several weeks later.

Results: All of the participants (N=32) completed the pre-interaction and post-interaction test, and 26 (81%) of them completed the online follow-up test. The mean pre-interaction score was 7.44 (male: 7.08, female: 7.65, no statistical significance). The mean post-interaction score was 8.47, which was significantly higher (P<.001) than the pre-interaction score (mean score 7.44). The mean score for the follow-up test several weeks later was 8.38, higher than the pre-interaction score by 0.69 points but not statistically significant.

Conclusions: Our results suggest that virtual patients can successfully facilitate the acquisition of core knowledge in the field of psychiatry, in addition to developing skills such as clinical reasoning, decision making, and history taking. Repeated training sessions with virtual patients are proposed in order to achieve sustainable educational effects.

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KEYWORDS

mental health; transcultural psychiatry; virtual systems; PTSD; medical informatics; education; patient simulation

Introduction

The number of patients with diverse ethnic backgrounds (often having been exposed to severe mental trauma) is rapidly increasing [1,2], which highlights the crucial need for effective training platforms that can provide essential knowledge and skills to care for this vulnerable group. Immigrants have higher rates of disability than host populations: social disability including unemployment [3], mental disability such as posttraumatic stress disorder (PTSD) and major depression [4,5], as well as physical disability such as cardiovascular disease [6] and metabolic syndrome [7]. Unfortunately, trauma-related diagnoses are often missed in primary care [8]. The need for new methods of acquiring proper communication skills is considered crucial, since most current systems incorporate these important skills informally in clinical training under supervision but with no direct focus on them.

Rapid technological progress during the last few decades has enabled the development of innovative educational tools, most often to supplement traditional medical curricula. Virtual patients (VPs) are broadly defined as “interactive computer simulations of real-life clinical scenarios for the purpose of medical training, education, or assessment” [9]. They include a highly diverse group of platforms that, since the first published description in the early 1970s (10), have been developed and studied thoroughly and shown to provide a realistic, reliable, safe, and consistent learning environment for enhancing various aspects of knowledge and skills, including clinical reasoning, clinical decision making, communication, and history taking [10-15].

Very few studies have explored implementation of VPs by psychiatrists [16-19], and to the best of our knowledge, no other VP system dedicated to traumatized refugees has been described, although virtual reality has recently been used and studied as a means of providing exposure therapy for veterans with combat-related PTSD [20]. Previous papers published by our research team examined our system in terms of various aspects of user acceptance, expectations, attitudes, and educational potentials [21-23] and obtained promising results. This study examined the impact of a training session with the VP system on core knowledge related to PTSD symptomatology and clinical management, as well as basic communication skills.

Methods

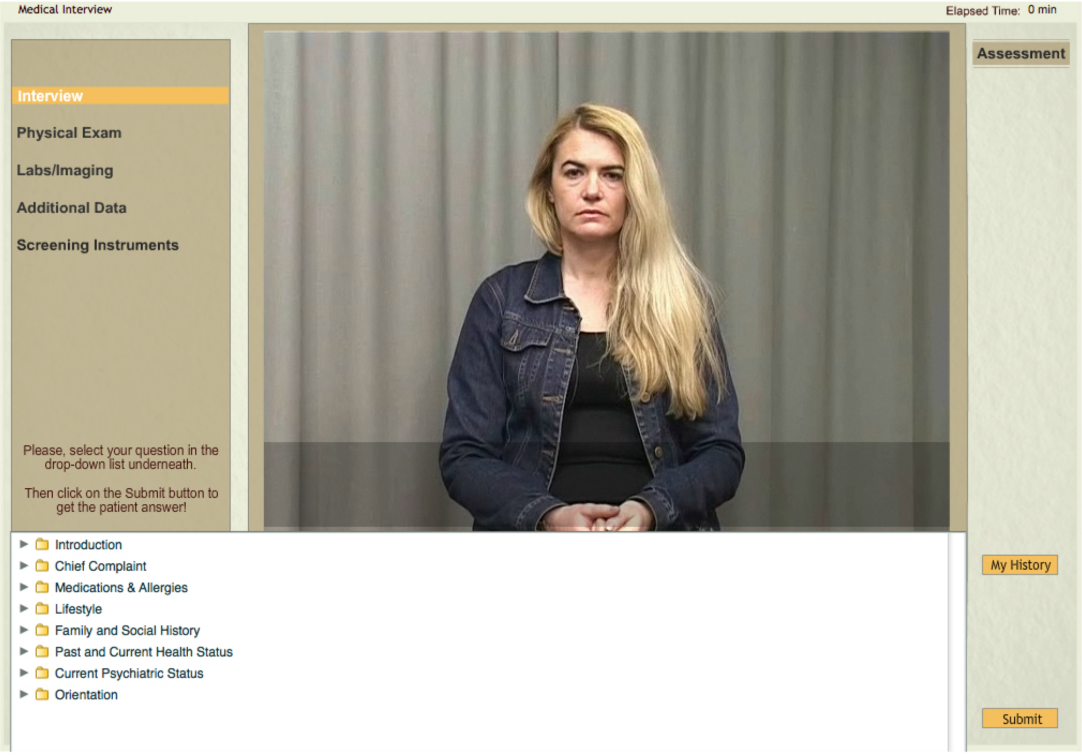
Refugee Trauma Simulation System

We developed a VP system called Refugee Trauma Simulation (RT-SIM) that portrays an adult Bosnian refugee (“Mrs K.”) who presents severe symptoms of PTSD and major depression (Figure 1). The VP is shown in video format by displaying appropriate prerecorded sequences depending on the questions asked by the user. The medical interview is conducted by selecting questions from a list based on suitable categories. The user can physically examine the VP, as well as order laboratory and imaging tests (Figure 2). A preliminary assessment, including a summary of the patient’s history, differential diagnosis, and treatment plan is filled out by the learner upon completion of the virtual consultation.

An individualized, automated feedback module provided by both the VP and a virtual advisor (VA) follows. The feedback by the VP gives the patient’s perspective of the consultation, while the feedback by the VA focuses on more technical and clinical aspects of PTSD diagnostic criteria, clinical management, and basic communication skills. The feedback is designed in accordance with the learner’s actual performance and provides a brief and relevant theoretical background.

For example, if the learner did not sufficiently examine the patient’s trauma history, the VA commented: “I do not think that you sufficiently examined the patient’s trauma history by asking enough relevant questions about traumatic events. This is important in order to investigate exposure to events that could involve actual or threatened death or serious injury, or a threat to the physical integrity of self or others. If the patient reacted with intense fear, helplessness, or horror during such exposure, the first criterion for PTSD according to DSM-IV has been fulfilled”. A more detailed description of the construction of the feedback module was presented in a previously published study [23].

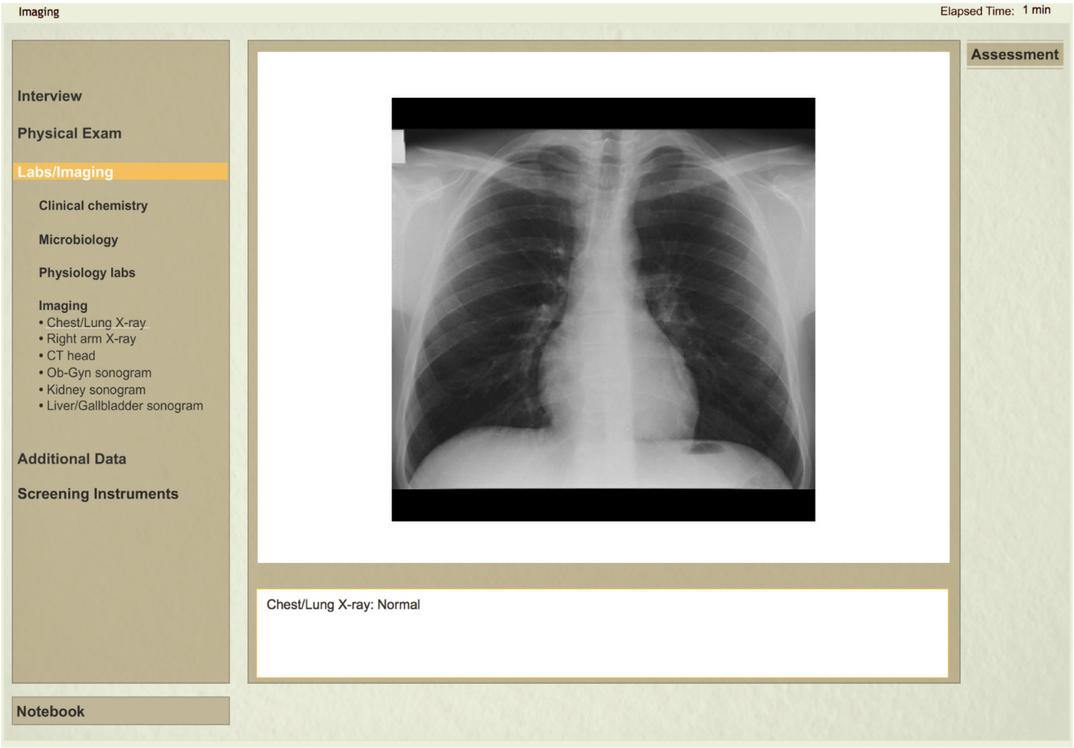
Figure 1. Screenshot of the RT-Sim system presenting the history-taking interview module.



Please, select your question in the drop-down list underneath.

Then click on the Submit button to get the patient answer!

Figure 2. Screenshot of the RT-Sim system presenting the laboratory and imaging module.



Chest/Lung X-ray: Normal

Design and Evaluation Outcomes

In response to email invitations sent by the department heads at three major university hospitals in Sweden, 32 psychiatric residents agreed to participate in our study. The participants sat in silent group rooms under supervision and were asked to interact with the VP for up to 45 minutes as they would in a real-life clinical encounter.

The pre-interaction and post-interaction outcome was a knowledge test consisting of 11 multiple-choice questions that were linked to the following fields: diagnostic criteria of PTSD according to the *Diagnostic and Statistical Manual of Mental Disorders*, 4th edition (DSM-IV), clinical management of patients with PTSD, and theoretical aspects of basic communication skills. The highest possible score for each test was 11 (each correct answer generating 1 point). Multiple response items, for which more than one answer was keyed as correct, were so indicated. A follow-up test, hosted by the Karolinska Institutet online learning management system (Ping-Pong), was given several weeks later. All three tests (pre-interaction, post-interaction, and follow-up) consisted of identical multiple-choice questions, though appearing in different orders. After completion of the tests, no feedback about the success rate or correct answers was provided to the participants. Explicit instructions stated that no outside help was allowed during the follow-up online test. An advisory opinion by the Stockholm Regional Ethical Review Board (2011/321-31/3) was obtained for this study, and informed consent was obtained from all of the participants.

Statistical Analysis

Stata/IC 12.1 for Mac was used for statistical analysis of the data. We used descriptive statistics to analyze demographic data and the matched-pair *t* test in order to estimate changes in the scores between pre-interaction, post-interaction, and follow-up tests. Participants who did not complete the follow-up test were excluded from that particular analysis. *P* values ≤.05 were regarded as evidence of statistical significance.

Results

All of the participants (N=32; 12 males, 20 females) completed the pre-interaction and post-interaction knowledge test. Twenty-six (81%) of the participants completed the online follow-up knowledge test (9 males, 17 females). The mean age was 35.6 (female: 35.5, men: 35.9; range 28-51), while their mean experience as psychiatric residents was 2.3 years (female: 2.4, men: 2.1; range 0-5). No statistically significant differences in age and work experience between male and female participants were found. The mean duration of the interactive session with the patient was 68 minutes (min: 25; max: 110). The mean time between the interactive session with the VP and the online follow-up test was 79 days: 78 days for men and 79 days for women (not significant, *P*=.78).

Table 1. Scores on pre-interaction (Pre), post-interaction (Post), and follow-up (FU) knowledge test, overall, and by gender.

Participants	Data	N	Mean	SD	CI	*t*	df	*P*
All								
	Pre	32	7.44	0.31	6.8-8.07			
	Post	32	8.47	1.65	7.86-9.06			
	FU	26	8.38	2.02	7.57-9.20			
	Pre vs Post		-1.03	1.33	-1.51 to -0.55	-4.38	31	<.001[a]
	Post vs FU		0.35	1.74	-0.36 to 1.05	1.01	25	.32
	Pre vs FU		-0.69	2.29	-1.61 to 0.23	-1.54	25	.14
Male								
	Pre	12	7.08	2.02	5.80-8.37			
	Post	12	7.92	2.02	6.63-9.2			
	FU	9	8	2.45	6.12-9.89			
	Pre vs Post		-0.83	1.19	-1.59 to -0.08	-2.42	11	.03[a]
	Post vs FU		0.11	2.02	-1.45 to1.67	0.16	8	.87
	Pre vs FU		-0.67	2.00	-2.20 to 0.87	-1.00	8	.35
Female								
	Pre	20	7.65	1.60	6.90-8.40			
	Post	20	8.80	1.32	8.18-9.42			
	FU	17	8.59	1.80	7.66-9.52			
	Pre vs Post		-1.15	1.42	-1.82 to -0.48	-3.61	11	.002[a]
	Post vs FU		0.47	1.62	-0.36 to 1.31	1.19	8	.25
	Pre vs FU		-0.71	2.49	-1.99 to 0.58	-1.17	8	.26

[a] Statistically significant.

Table 1 shows the mean scores on the pre-interaction, post-interaction, and follow-up knowledge test, both overall and by gender. The mean pre-interaction score was 7.44 (male: 7.08, female: 7.65, non significant), and the mean post-interaction score was 8.47, demonstrating an improvement of 1.03 points, which was highly statistically significant overall (*P*<.001) and by gender (male: *P*=.03, female: *P*=.002). The mean score on the follow-up knowledge test was 8.38, higher than the pre-interaction score by 0.69 points, which was not statistically significant. The follow-up score was 0.35 points lower than the post-interaction score, which was not statistically significant. Similar results were found when the data were analyzed by gender.

Discussion

Principal Findings

This paper describes a VP system that was constructed as a platform for training clinical management of traumatized refugees and was evaluated in terms of impact on the learner's core knowledge of PTSD symptomatology and clinical management, as well as basic communication skills.

To the best of our knowledge, only one published study has previously evaluated how VPs facilitate core knowledge in the field of psychiatry in general, finding no change in knowledge of PTSD symptoms pre-intervention and post-intervention [24]. Our results indicated a highly significant improvement on the knowledge test immediately after the training session with the VP. The fact that our participants did not receive any feedback about the success rate or correct answers after completion of the tests dramatically reduces the possibility that the improvement was due to recall rather than actual knowledge gain. The results were better on the follow-up test than the pre-interaction test but had declined and the improvement was no longer statistically significant. As far as our rather small sample allows, we can therefore conclude that a single session with the VP is not sufficient to produce a long-term impact on knowledge, which is consistent with previous findings that improvements in the performance of diagnostic tasks due to short-term training are not long-lasting [25]. We propose research about the impact of repeated sessions over a course of several months on the durability of acquired knowledge.

It has been suggested that VPs are not an ideal methodology for facilitating core knowledge, given potential cognitive overload and the fact that less interactive methods might be more effective [26]. Based on the system described above, we propose a VP model that combines experiential learning, as presented by Kolb [27], through active training in a realistic and appealing virtual environment, enhanced by short theoretical frameworks integrated into automated feedback. Our results support the hypothesis that this additional element can make VP systems valuable in the acquisition of core knowledge in addition to developing skills such as clinical reasoning and decision-making.

Limitations

A limitation on the generalizability of our conclusions was the rather small sample of resident psychiatrists with similar work experience and expertise. Moreover, although the pre-interaction and post-interaction tests were conducted in a strictly controlled environment with no access to outside help, the possibility that participants, despite clear instructions, obtained such help during the follow-up test in an online, non-controlled environment cannot be ruled out.

For this prospective study, we used a single-subject design, which is common in applied fields of education and psychology for which subjects serve as their own controls [28]. This design can be effectively used to evaluate the impact of an intervention (such as virtual patients) that has not been widely studied and provide an initial clue as to its effectiveness before planning larger-scale studies with other designs and populations. However, a limitation of this methodology is its inability to know how a control group receiving another form of intervention would perform. On the other hand, a review [26] showed that it is difficult to make a comparison with a control group that receives traditional forms of education, such as lectures, in this area since clinical reasoning demands exposure to the actual situation (as provided by clinical practice or various forms of simulation).

Conclusion

As a next step, we intend to conduct a randomized controlled trial that examines cognitive outcomes of using several VP cases, as well as actual patient outcomes. Future studies should also include the impact of working with the VP in pairs or groups, either at a local level or online.

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Conflicts of Interest

None declared.

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Abbreviations

DSM-IV: Diagnostic and Statistical Manual of Mental Disorders 4th edition
PTSD: posttraumatic stress disorder
VA: virtual advisor
VP: virtual patient

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Viewpoint

Advantages and Disadvantages of Educational Email Alerts for Family Physicians: Viewpoint

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Abstract

Background: Electronic knowledge resources constitute an important channel for accredited Continuing Medical Education (CME) activities. However, email usage for educational purposes is controversial. On the one hand, family physicians become aware of new information, confirm what they already know, and obtain reassurance by reading educational email alerts. Email alerts can also encourage physicians to search Web-based resources. On the other hand, technical difficulties and privacy issues are common obstacles.

Objective: The purpose of this discussion paper, informed by a literature review and a small qualitative study, was to understand family physicians' knowledge, attitudes, and behavior in regard to email in general and educational emails in particular, and to explore the advantages and disadvantages of educational email alerts. In addition, we documented participants' suggestions to improve email alert services for CME.

Methods: We conducted a qualitative descriptive study using the "Knowledge, Attitude, Behavior" model. We conducted semi-structured face-to-face interviews with 15 family physicians. We analyzed the collected data using inductive-deductive thematic qualitative data analysis.

Results: All 15 participants scanned and prioritized their email, and 13 of them checked their email daily. Participants mentioned (1) advantages of educational email alerts such as saving time, convenience and valid information, and (2) disadvantages such as an overwhelming number of emails and irrelevance. They offered suggestions to improve educational email.

Conclusions: The advantages of email alerts seem to compensate for their disadvantages. Suggestions proposed by family physicians can help to improve educational email alerts.

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KEYWORDS

theory of planned behavior; continuing medical education; educational email alerts; electronic knowledge resources; family physicians; health informatics; knowledge translation; primary health care

Introduction

Background

Educational email alerts have the potential to improve the quality of health care services, but present some disadvantages. Email alerts have been associated with learning, practice change, and expected benefits for patient health, among other outcomes [1,2]. They can be used for two-way knowledge translation, a process that involves sending evidence-based clinical recommendations to physicians and then receiving their constructive feedback [3,4].

Two examples of educational email alerts are “Daily-POEMs” (Patient-Oriented Evidence that Matters) and “Highlights from e-Therapeutics+” [1,3,5]. These alerts support continuing education programs that involve more than 10,000 Canadian physicians and pharmacists [3]. First, Daily-POEMs are tailored for family physicians. POEMs are synopses of original research and systematic reviews, selected after scanning and critically appraising new articles from more than 100 journals. Second, Highlights are treatment recommendations tailored for a primary care audience. They are based on a synthesis of research results and systematic reviews, and graded using the Strength of Recommendation Taxonomy System. They consist of key updated paragraphs from a Web-based text called e-Therapeutics+, published by the Canadian Pharmacists Association (CPhA). Highlights have been delivered to members of the College of Family Physicians of Canada since 2010 and to CPhA members since 2012.

However, physicians face email-related obstacles such as technical difficulties [3]. Privacy and security of email communication remain of major concern [6]. Other issues are changes of email address or service provider [7]. In addition, physicians complain about “email fatigue”, that is, too many emails and lack of time [8].

Understanding physicians’ knowledge, attitude, and behavior regarding email alerts can help to address obstacles associated with email as an educational channel. We found studies on the use of information derived from educational emails by physicians, but no studies on the advantages or disadvantages of email for the delivery of educational material. Therefore, our main objective was to explore the viewpoint of family physicians on advantages and disadvantages of educational email alerts.

By 2009, 80.3% of Canadians were using the Internet on a regular basis; the main reason for Internet usage was email, with 93.0% of Canadians using it for email [9]. Almost all physicians use email as do 94.7% of Canadians with a university degree [9]. In the clinical setting, physicians use email to consult with colleagues, obtain laboratory data, follow up with staff about patient care issues, and learn about new research findings [3,10]. When used as a method of communication between physician and patient, email can improve the doctor patient relationship, despite privacy and security concerns [6,11]. According to the 2010 Canadian National Physician Survey, 50.1% of family physicians email their colleagues for clinical purposes [12]. Increasingly, family physicians are using email for their continuing education [13]. However, in a review of the literature guided by a specialized librarian, we found no studies on family physicians’ perception about positive and negative aspects of educational emails. This justifies our exploratory work on the family physician viewpoint.

Educational Email Alerts

We identified nine studies on physicians’ use of information from educational email alerts. Three studies globally evaluated satisfaction and usefulness of receiving health information via email [14-16]. In these studies, users of email alerts reported high levels of satisfaction and perceived them to be useful for continuing education. A fourth study evaluated the effect of email alerts on information awareness and knowledge acquisition [17]. While subscribers of email alerts became more familiar with the recent literature, their medical knowledge was not improved. A fifth study evaluated the effect of email alerts on subsequent information retrieval by physicians and demonstrated that users of email alerts are more likely to search for information [18]. The sixth study examined self-reported cognitive impact of emailed synopses of recently published clinical research, and indicated that email alerts have a positive impact [19]. Subsequently, another study indicated that email alerts are infrequently retrieved after initial reading [20]. Finally, two studies suggested that email dissemination of synopses of systematic literature reviews [21], and of treatment recommendations is associated with anticipated benefits for patient health [3].

Advantages and Disadvantages of Educational Email Alerts

While we found no studies that specifically focused on advantages and disadvantages of emails according to health care professionals, four studies and one literature review on email [2,7,8,11,22] did mention this in passing (Table 1). For example, physicians are knowledgeable and familiar with email as a way of educating and communicating with medical students, by sending evidence-based clinical recommendations and individualized feedback [2]. In contrast, physicians can face technical difficulties when using email, because of slow Internet connections or software incompatibility. They complain about receiving too much information by email while not having time to read it [8]. Therefore, our research questions were: what are the advantages and disadvantages of educational email alerts from the physicians’ viewpoint?

Table 1. Advantages and disadvantages of email, as mentioned in the literature.

First author and date of study	Design, participants, setting, intervention, data collection and analysis	Types of advantage	Types of disadvantage
Barnhart 2010	Design: Cross-sectional Participants: 69 medical students Setting: Illinois University, Department of Family and Community Medicine Intervention: Educational emails containing clinical questions from standardized patients Data collection: Email replies Data analysis: Descriptive statistical	Good for training purposes. Possibility to receive feedback to improve the content. Easy to manage, as medical students are familiar with email.	Emails did not cover all educational topics.
Bennett 2005	Design: Survey Participants: 2200 community-based physicians Intervention: Survey Setting: United States Data collection: Survey responses Data analysis: Descriptive statistical	The Internet is an important tool for practice. Hand-held computers are useful educational tools, especially for drug information.	Information overload. Specific information often not found. Socio-technical difficulties eg, navigation, and searching. Internet connection sometimes too slow.
Kenny 2000	Design: Literature review of the usage of telecommunication (including email) Participants: Primary research studies involving general practitioners	Can be used anytime. Enhances the relationship between the doctor and the patient.	Family physicians fear being overwhelmed by patient inquires by email. The medical defense union has concerns about the security of email.
Moyer 2002	Design: Cross-sectional survey Participants: 476 outpatients, 126 family physicians, and 16 clinical staff. Setting: United States Intervention: Survey Data collection: Survey responses Data analysis: Descriptive statistical	Improves the relationship with patients. A good way to follow up with patients. A fast way to communicate with colleagues for consultation and lab results.	Email from patients would add to work load and not substitute for other tasks. Fear of being overwhelmed by patient email. Security concerns. Costs for implementation, integration, and maintenance of new systems.
Seguin 2004	Design: Randomized controlled trial Setting: Ontario, Canada Participants: 2397 family physicians Intervention: Survey Data collection: Survey responses Data analysis: Descriptive statistical	All physicians with academic practices had email addresses. Rapid method to obtain survey data. Email encourages physicians to write more than they would by regular mail.	Email addresses are subject to rapid change. Email messages are too easy to delete. Joint (family or business email) accounts reduce the chance of checking email.

Methods

Study Design

A qualitative descriptive study [23] was conducted through semi-structured face-to-face interviews with 15 family physicians. Participants were members of the Department of Family Medicine, McGill University, who had received an email to briefly explain the study. An invitation to participate in the study was emailed to 290 family physicians affiliated with this department. Of 17 family physicians who replied, two were not interviewed because we could not arrange an interview. Yet, the saturation of data was confirmed during the interviews, through the repetition of similar answers to our interview questions. We decided to conduct semi-structured face-to-face individual interviews because we were interested mainly in their individual experience and perceptions. The interview was conducted in four main parts (see Multimedia Appendix 1).

Part 1. Demographic Questions

In this part, four demographic questions were asked (ie, age, years of practice, practice setting (s), and special interests).

Part 2. Participants' Knowledge, Attitude, and Behavior (Theory of Planned Behavior) Regarding Email

In this part, four questions were asked to assess participants' experience (knowledge, attitude, and behavior) with email in general and educational email in particular. Using the Theory of Planned Behavior [24], we explored the daily experience of participants with email (knowledge), their psychological reaction toward email (attitude), and their behavior when they received an email. This theory was chosen because it is validated and commonly used for assessing health education programs and health care professional behavior [25]. The interview questions included: *Knowledge:* Please describe your daily experience with email, *Attitude:* How do you usually feel about email, eg, welcoming, disliking, feeling overwhelmed, or something else?, and *Behavior:* What do you usually do when you receive email, eg, reading, deleting, flagging, ignoring, saving, classifying, or anything else?

Part 3. Perception of the Advantages and Disadvantages of Educational Email

In this part, participants were asked three questions about their preferences for Continuing Medical Education (CME), specifically, the advantages and disadvantages of educational email.

Part 4. Recommendations to Improve Educational Email

In this part, participants were asked about their recommendations to improve educational email alerts.

Data Analysis

Interviews were transcribed, reviewed, summarized, and then a deductive-inductive thematic analysis was conducted [26]. To this end, we assigned preliminary themes based on the Theory of Planned Behavior, the literature review, and the interview guide, and then searched for emerging themes. The inductive process involved the identification of themes through careful reading and re-reading of the data in six sessions. The coding process was conducted in six stages [26]: (1) we developed the code manual, (2) we tested the reliability of the codes, (3) we summarized the data and identified the initial themes, (4) we applied a template, (5) we connected the codes in accordance with the process of discovering themes and patterns in the data, and (6) we corroborated and legitimated coded themes, especially the item-related codes.

Finally, the results were reviewed by two of us (PP, RG). We prepared a table of findings for each group of questions related to: (1) demographic data, (2) participants' preference for continuing education activities, (3) participants' experience with email, (4) participants' perception of the advantages and disadvantages of educational email, and (5) participants' recommendations to improve educational email. The data analysis process and final results were discussed with colleagues who conduct research in the fields of Information Technology and Primary Health Care. We distributed a report of the data analysis process and our results to members of the Information Technology Primary Care Research Group, and we allowed a week for detailed reading and commenting. Then, at one meeting, group members helped to interpret the results.

Ethical Approval

This study was conducted according to the ethical principles stated in the declaration of Helsinki. Ethical approval was obtained from the McGill University Institutional Review Board (IRB).

Results

Part 1. Demographic Results

A total of 15 family physicians were interviewed (nine male and six female). Nine family physicians were working in academic health science centers, university, or teaching units while the other six worked in community-based clinics. The participants' number of years in practice ranged from 9 to 38. Five participants indicated no clinical focus to their practice, while 10 expressed a special focus such as maternity and newborn care (Table 2).

Participants were involved in many CME activities (eg, conferences and Web-based activities) (see Table 3). While six family physicians mentioned no specific preference for CME activities, five family physicians expressed interest in Web-based activities (eg, educational email), three expressed interest in group learning (eg, conferences and clinical rounds), and one family physician expressed interest in reading magazines and journals.

All interviews were done face-to-face in participants' offices. Interviewees were welcoming and co-operative: 11 of 15 gave adequate time for the interview while only four seemed rushed. All interviewees answered all questions. Based on our interpretation of viewpoints, results are presented in three parts. First, participants reported their knowledge, attitude, and behavior regarding email in general, and educational email in particular. Second, they specifically reported advantages and disadvantages of educational email. Third, they proposed recommendations to improve educational email.

Table 2. Participants' demographic data.

Participant	Years of practice	Special focus	Work setting
P1	38	No	AHSC[a](university affiliated teaching hospital)
P2	37	No	AHSC (university)
P3	36	No	Private office
P4	35	Global health; health care of the elderly; mental health	University affiliated teaching hospital
P5	34	Health care of the elderly; home care	AHSC
P6	32	No	Private office
P7	31	No	AHSC
P8	30+	Adult ADHD	Private office
P9	23	Child and adolescent health care	Private office
P10	20	Maternity and newborn care	AHSC (university)
P11	20	Maternity and newborn care; immigrant and refugee care	Community clinic; AHSC (Family medicine teaching unit)
P12	12	Hospital medicine	Private office
P13	9	Health care of the elderly; hospital medicine; diabetic foot and wound clinic	AHSC (university); Nursing home
P14	9	Care of patients with sexually transmitted disease	Private office
P15	7	Maternity and newborn care; tropical and travel medicine	AHSC

[a] AHSC: academic health science center

Table 3. Continuing medical education (CME) activities reported by the participants (n=15).

Type of CME activities	n (%)
Group learning (eg, conferences)	13 (87%)
Online learning (eg, email alerts)	11 (73%)
Self-learning (eg, reading journals)	9 (60%)
Teaching or research	9 (60%)
Journal club / lunch time meetings	4 (27%)
University courses	3 (20%)
Clinical rounds	3 (20%)

Part 2. Participants' Knowledge, Attitude, and Behavior Regarding Email

Knowledge

Of 15 family physicians, 13 said they were familiar with email and checked their email from one to four times per day. These regular users checked email for clinical, educational, and personal reasons. Regular users received from 10 to 100 emails per day. In contrast, the two family physicians who were not familiar with email, used email for personal communication and checked it two or three times a week. Their two main reasons for not being regular users were (1) limited time because of family obligations, and (2) issues with technology (such as familiarity).

Attitude

Of 15 family physicians, nine family physicians felt comfortable with and liked email, three expressed a neutral attitude, and three disliked or felt overwhelmed by email. Only three family physicians were not overwhelmed by the volume of email, and only one family physician expressed a concern regarding confidentiality when using email in communication with patients.

Behavior

The 15 family physicians mentioned they scanned emails by reading the title, and prioritized them according to urgency and relevance. First, they replied to the urgent emails, then, time permitting, they replied to others. Second, they deleted irrelevant email. In addition, 13 family physicians mentioned that they archive important email in a folder, while the other two delete all email after reading. Regarding participants' behavior toward educational email, all 15 family physicians mentioned they follow the same procedure, namely scan and prioritize.

Part 3. Perceptions of the Advantages and Disadvantages of Educational Email

Advantages

Participants mentioned six types of advantages (see Table 4).

Disadvantages

Of 15 family physicians, 12 mentioned disadvantages that we grouped into six main types (see Table 5).

Table 4. Advantages of educational email as reported by the participants (n=15).

Advantages	n (%)
Convenient: they are brief and can be "read 24/7"	11 (73%)
Contain valid information family physicians can trust	5 (33%)
Give family physicians the option to use the information	4 (27%)
Constitute an easy way to disseminate information	2 (13%)
Broaden family physician knowledge, eg, raise their awareness	2 (13%)
Regularly received at a specific time	2 (13%)

Table 5. Disadvantages of educational emails as reported by the participants (n=15).

Disadvantages	n (%)
Overwhelming, eg, email difficult to manage	6 (40%)
Not relevant to specialized practice	2 (13%)
Time consuming	1 (7%)
Email may cost to use and to maintain	1 (7%)
Educational email is sometimes confused with commercial email (spam)	1 (7%)
Email readability is affected when writers are not professional editors	1 (7%)

Part 4. Recommendations to Improve Educational Email

Participants provided 23 recommendations, presented in Textbox 1. They suggested five general recommendations such as "Avoid sponsorship by pharmaceutical companies". They provided six recommendations regarding the informational content of email, for example, "Add a description of the writers' affiliation". There were 11 recommendations concerning the design of educational email, such as "Add a link to a discussion board on the topic".

Textbox 1. Participants’ recommendations to improve educational email.

General recommendations:

1. Avoid pharmaceutical sponsorship.
2. Clarify the subscription procedure.
3. Maintain the continuity and regularity of the emails.
4. Reduce the price.
5. Send email at a specific time of the day.

Recommendations related to the content:

1. Add a description of the writers’ affiliation.
2. Briefly describe the pathophysiology of the condition.
3. Concentrate on local health and system issues.
4. Email only clinically relevant content.
5. Email only validated content from high quality primary research or knowledge syntheses.
6. Email only up to date content.
7. Provide a summary and a link to the original article(s).

Recommendations related to the email design:

1. Adapt educational email for older readers (eg, larger font).
2. Add a link to a discussion board on the topic.
3. Add a link to archived topics from previous email.
4. Add a printable one page summary.
5. Add a way for readers to ask questions or send inquiries.
6. Avoid complex graphics and provide very simple text.
7. Avoid highly specialized technical functions associated with email.
8. Distinguish the appearance of educational from commercial email.
9. Provide the conclusion and summary in separate sections.
10. Include all information content in the email.
11. Send a reminder email with peer feedback (after few months).

Discussion

Principal Findings

No previous studies have specifically focused on the pros and cons of email from a physicians’ viewpoint, although four studies and one review [2,7,8,11,22] have mentioned this in passing (Table 1). This literature suggests physicians are familiar with email for their education and for communication [2]. In addition, it shows that some physicians face technical difficulties when using email, and complain about receiving too much information by email while not having time to read it [8]. Our results are aligned with the literature in that most of our participants were familiar with email, while many felt comfortable and liked using email in their professional life, and some felt overwhelmed by the volume of email they receive.

In addition, our results suggest types of advantages and disadvantages of educational email that were not previously mentioned in the literature. First, with respect to the advantages: (1) educational email can contain valid and trustworthy information, (2) is an easy way to disseminate information to multiple recipients, (3) broadens the spectrum of family physician knowledge, (4) is regularly sent at a specific time, (5) contains brief clinical synopses, and (6) gives the reader an option to use them.

Second, with respect to the disadvantages of educational email not previously mentioned in the literature: (1) educational emails are overwhelming in number and because of the information they contain, (2) they are not relevant to specialized practice, (3) they can resemble commercial email, and (4) some writers of educational email are not professionals.

However, there were two contradictions in the viewpoints expressed. First, physicians do not want advertisements within educational email, in line with Canadian CME policies [27], while they want this service for free. Second, they want brief “bottom-line” information, while asking for more information about the underlying “black-box” process surrounding the submission, peer-review, and editing of research articles.

Similar to usual qualitative research, our exploratory study faces two main limitations: small sample size and researchers' interpretation. As researchers, we are involved in the evaluation of email-based CME programs [3,4,28]. In addition, the homogeneity of participants and investigators may have limited the scope of participants' comments. This experience influenced our interpretation of participant viewpoints. In line with the "blind-spot" effect proposed by the anthropologist George Devereux [29], this might have lead us to miss some issues reported by participants. Participants were recruited by email invitation. We interviewed them in their offices. They were very welcoming, interested in our research topic, and 11 of 15 gave plenty of time to the interview. Having said this, in-depth face-to-face interviews with 15 family physicians provided rich data, as participants had a wide range of familiarity with email. In addition, we obtained redundant answers from participants suggesting data saturation was reached.

Finally, all participants made suggestions for improving educational email such as enabling links to a discussion board. A number of their suggestions are relevant to the providers of educational email alerts, namely to use valid studies, to add background information on pathophysiology, to enable a printable summary, and to provide comment boxes.

Conclusion

Given email still has some disadvantages as an educational channel, there is room to improve educational email alerts. Hence, information providers would be well advised to consider both the advantages and disadvantages of educational email as suggested by physicians.

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Authors' Contributions

Badran carried out the study. Pluye and Grad supervised the work and contributed to all stages of the research. All authors participated in drafting the manuscript. All authors read and approved the final version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

The interview guide.

[PDF File (Adobe PDF File), 22KB - jmir_v17i2e49_app1.pdf]

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Abbreviations

CME: Continuing Medical Education
CPhA: Canadian Pharmacists Association
IAM: Information Assessment Method
POEM: Patient-Oriented Evidence that Matters

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Original Paper

The Contribution of Online Peer-to-Peer Communication Among Patients With Adrenal Disease to Patient-Centered Care

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Abstract

Background: Addison’s disease and Cushing’s syndrome are rare. The Dutch Adrenal Society offers an online forum for Dutch adrenal patients to meet and communicate. However, little is known about the added value such a forum has for the delivery of patient-centered care.

Objective: Our aim was to analyze the purposes of online patient-to-patient forum conversations, within the context of patient-centered care.

Methods: For this study a consecutive sample of 300 questions (“threads”) from the past 3.5 years was selected from the forum. The content of these patient-driven questions was analyzed based on the dimensions of patient-centeredness of the Picker Institute. This analysis was performed using ATLAS.ti.

Results: From the 390 questions analyzed, 80.8% (N=315) were intended to gain more information about the disease, the treatment, and to verify if other patients had similar complaints. To a much lesser extent (38/390, 9.7%), questions expressed a call for emotional support. Patients answered primarily by giving practical tips to fellow patients and to share their own experiences.

Conclusions: On an online patient forum for Cushing’s syndrome and Addison’s disease, patients appear to primarily gain knowledge and, to a lesser extent, emotional support from their peers. This experience-based knowledge has become a very important information source. As such, patients can make a substantial contribution to the creation of patient-centered care if this knowledge is integrated into the care provided by health care professionals.

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KEYWORDS

online forum; self care; Cushing’s syndrome; Addison’s disease

Introduction

Addison’s disease and Cushing’s syndrome are rare disorders, characterized by abnormal secretion of adrenal hormones. Patients with Addison’s disease, but also many patients with Cushing’s syndrome after treatment, require long-term substitutional therapy [1]. It affects their lives dramatically, either physically, emotionally, or both [2-6]. Both conditions have a significant impact on patients’ quality of life. Patients treated for Cushing’s syndrome, for example, show increased levels of anxiety and symptoms of depression [2,4-6].

With long-term substitutional therapy, a certain amount of self-care and knowledge is expected from the patient. The level of knowledge in patients and the ability to react adequately in critical situations is often insufficient [7]. Not recognizing predictive signs of an adrenal crisis or not knowing when to increase the dosage of the medication is detrimental for these patient groups. This lack of knowledge sometimes even leads to hospitalizations and life-threatening events [8,9]. Patients with substitutional therapy are advised to carry a medicine passport with them and an “SOS medallion”, but not every patient follows this advice [8]. Group education and other educational programs can increase the quality of self-management and the use of self-management tools like the SOS medallion and the medicine card in adrenal patients [7,10].

To support self-management effectively, patient-centeredness should be a cornerstone of the health care delivery model [11]. Patient-centeredness is usually considered to be merely a task for health care providers. However, in the past decade the role of peer-to-peer support by means of online forums has gained tremendous ground, offering the potential to support self-management [12]. Online support groups can be described as “weak tie” networks, as the majority of the users only communicate through online messages. The people on the forum can have daily contact but are not necessarily close [13]. Patients use online forums to post messages and ask questions. Previous forum analyses revealed that patients primarily retrieve two main types of support from online support groups: experiential information and emotional support [14-17]. This type of online support cannot be acquired in the consultation with the doctor or taught in educational programs, but it can contribute to aspects of patient-centered care [18].

The aim of this study was to analyze the purpose of peer-to-peer communication, that is, what is the communication being used for, within the context of patient-centered care. The study is meant to show the potential contribution of online peer-to-peer communication to the delivery of patient-centered care.

Methods

Data

Conversation data were obtained from the online forum moderated by the Dutch Adrenal Society (NVACP). This is a member-only forum, requiring user login, except for the subforum “Public”, which is open to everyone. This forum is moderated by a team of volunteers, and rules are stated on the website to make sure the forum is used appropriately. For example, if a user wants to post medical information, references are demanded. If the requirements are not met or rules are violated, the message gets deleted or modified. There were 1210 registered members of the NVACP on January 1, 2014. For the purpose of our study, we created a static database to prevent any changes that could be made to the posts on the forum by the members or the administrators of the forum. We did this by downloading the posts into an Excel file. We used a sample of 300 consecutive questions (“threads”) in this study, consisting of 100 threads from three subforums each—Public, Addison, and Cushing—as these were the three most active subforums. For every thread we included, we also analyzed every first answer that was posted. The oldest thread dated from June 2010, and the most recent thread dated from January 2014.

To prevent any violation of privacy and to protect the identity of the members of the forum, no names of individuals or personal information were included or used in the analysis. A message was posted on the general subforum on the site on January 14, 2014, informing the forum members about this study and also that their identities and their personal information would not be used in the study. This procedure was presented to the local medical ethics committee and approved.

Analysis

We performed a deductive qualitative framework analysis for the 300 selected threads [19]. As a theoretically informed framework, the eight principles of patient-centered care of Picker guided the analysis: access to care, coordination and integration of care, emotional support, involvement of family and friends, information, communication and education, physical comfort, respect for patients’ values, and transition and continuity of care [20]. Every thread was labeled with one or more of the principles. In case one thread contained multiple subquestions, all subquestions were included.

For analyzing the answers to the questions, we used open coding [19]. Driven by the list of answers, we created a list of response themes that represented the aim of the answer. This list was created in an iterative manner, after reading through the answers multiple times.

Two researchers independently analyzed the data (DK, HR-W). Both had to agree on the principle that was selected for each question and theme for the answer. If both researchers did not agree, a third researcher (MF) joined the discussion until consensus was reached. We used the program ATLAS.ti for coding and supporting the analysis.

If questions were posted twice on the same subforum, for example due to a mistake by the poster or a technical error, these duplicate questions were analyzed only once to prevent biased results. If questions were posted twice but on different subforums, this was most likely done deliberately to get more views and replies to the question. These duplicate questions were therefore included in the analysis.

Results

The time span in which 100 threads were posted differed per subforum. The Cushing subforum was less active than the Addison and Public subforum. The 100 threads from the Cushing subforum were created in a time span of 3 years, whereas the 100 Public and Addison threads were created in a time span of just over 1 year.

Questions

The 300 threads included a total of 390 separate questions. Taking the three forums together, 80.8% (315/390) of questions fitted into one Picker principle, that is, “Information, communication, and education”. Because of the large number of issues, we created subthemes: treatment, the facility, medication, practical questions, similar complaints, suspected disease, and the disease itself. On every subforum, “similar complaints” (26.3%, 23.5%, 26.9% for Public, Addison, and Cushing respectively) and “question about the disease” (15.3%, 18.5%, 20.1%) were the most common used subthemes. “Emotional support” was the second most important principle, represented in 38 threads (9.7%), whereas no questions related to the principles “physical comfort” and “transition and continuity of care”. A small number of 17 threads did not fit any of the principles and were therefore labeled as “Miscellaneous” (4.6%) (see Table 1). The “Miscellaneous” category covered threads about the forum itself and about meetings of the NVACP.

Table 1. Total amount of questions, categorized per Picker principle.

Picker principles	Public (N=137), n (%)	Addison (N=119), n (%)	Cushing (N=134), n (%)	Total (N=390), n (%)
Access to care	3 (2.2)	1 (1.0)	2 (1.5)	6 (2)
Coordination and integration of care	0 (0.0)	1 (1.0)	0 (0.0)	1 (0.0)
Emotional support	11 (8.0)	11 (9.2)	16 (11.9)	38 (9.7)
Involvement of family and friends	2 (1.5)	3 (2.5)	0 (0.0)	5 (1.3)
Information, communication, and education	108 (78.8)	97 (81.5)	110 (82.1)	315 (80.8)
Question about treatment	15 (10.9)[a]	13 (10.9)	25 (18.7)[a]	53 (13.6)
Question about the facility	4 (2.9)	3 (2.5)	7 (5.2)	14 (3.6)
Medication	10 (7.3)	22 (18.5)[a]	14 (10.4)	46 (11.8)
Practical questions	9 (6.6)	7 (5.9)	0 (0.0)	16 (4.1)
Similar complaints	36 (26.3)[a]	28 (23.5)[a]	36 (26.9)[a]	100 (25.6)
Suspected disease	13 (9.5)	2 (1.7)	1 (1.0)	16 (4.1)
Question about the disease	21 (15.3)	22 (18.5)	27 (20.1)	70 (17.9)
Physical comfort	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Respect for patients’ values	3 (2.2)	3 (2.5)	2 (1.5)	8 (2.1)
Transition and continuity of care	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Miscellaneous	10 (7.3)	3 (2.5)	4 (3.0)	17 (4.6)

[a] The three most frequent question themes per subforum.

A frequent example of a question that was coded as “similar complaint” was “Does anyone have a similar experience?” Two more specific examples of “similar complaint” questions are:

> *I do a lot of exercise, everything gets toned, but my stomach remains swollen. I also find that I get more and more stretch marks on my stomach though not growing anymore and not gaining any weight. I would like to know who has experienced this and what can be done about it.*
>
> *1 year ago I had surgery. My ACTH-producing adenoma was successfully removed. I’m still phasing out with HC and now use 10 mg. per day. Every reduction of dosage is hard. Lately I’ve noticed that I have more energy at night than during the day. My own theory is that this is because a healthy person also has low cortisol levels in the evening. I wonder if there are more people who recognize this.*

On the Public and Cushing subforums, the “treatment” subtheme was also quite frequent, with respectively 11.1% of the questions (15/135) and 18.7% of the questions (25/134) from these specific subforums. On the Addison subforum, “medication” was more frequent than on the other subforums: 18.5% of questions (22/119), compared to 7.3% (10/137), and 10.4% (14/134) for the Public and Cushing subforums, respectively.

Answers

The final list of response themes contained 12 items, and an answer could have multiple themes assigned to it. The response themes were to emphatically urge, to provide medical information, to provide practical information, a counter-question, share own experiences, be motivational, to set at ease, to support, to hint, give advice to consult the doctor, miscellaneous, and questions answered by the poster themselves. A total of 29 (7.2%) questions remained unanswered (see Table 2). Quite often, regardless of the subforum, answers were provided that related to “own experiences” (21.5%, 23.9%, 26.6% for Public, Addison, and Cushing, respectively).

Table 2. Total amount of answers, categorized per theme.

Goal of the answer	Public (N=130), n (%)	Addison (N=130), n (%)	Cushing (N=143), n (%)	Total (N=403), n (%)
Emphatically urge	3 (2.3)	2 (1.5)	1 (0.6)	6 (1.5)
Medical information	16 (12.3)	12 (9.70)	13 (9.1)	41 (10.2)
Practical information	3 (2.3)	4 (3.1)	2 (1.4)	9 (2.2)
Counter-question	18 (13.8)[a]	24 (18.5)[a]	15 (10.5)	57 (14.1)[a]
Own experiences	28 (21.5)[a]	31 (23.9)[a]	38 (26.6)[a]	97 (24.1)[a]
Motivational	0 (0.0)	0 (0.0)	1 (0.6)	1 (0.0)
Set at ease	1 (1.0)	0 (0.0)	0 (0.0)	1 (0.0)
Support	11 (8.5)	13 (10)	20 (14)[a]	44 (11.0)
Hint	20 (15.4)[a]	33 (25.4)[a]	28 (19.6)[a]	81 (20.1)[a]
Advice to consult the doctor	16 (12.3)	2 (1.5)	7 (4.9)	25 (6.2)
Miscellaneous	4 (3.1)	0 (0.0)	0 (0.0)	4 (0.9)
Answered by poster	2 (1.5)	3 (2.3)	3 (2.1)	8 (2.0)
Question unanswered	8 (6.2)	6 (4.6)	15 (10.5)	29 (7.2)

[a] The three most frequent answer themes per subforum.

A good example of an “own experience” answer is “I recognize it and I have the same complaints”. The following is an example of a conversation with a “similar complaint” question and an “own experience” answer:

> *Q: Dear people, are there people with Addison who can sleep fast at night?? Whatever I try, I always wake up in the middle of the night and then I have a lot of trouble falling asleep again. Again who oh who can help me with some good advice eg one or other substance, or dietary supplement or whatever, I would be very happy.*
>
> *A: I have also tried…before and I had a dull feeling in the morning. If I’m still really busy I get out of bed and I use…(also homeopathic), walk outside with my dog as a distraction and then get back into bed. It doesn’t always work, but usually it does. Hopefully this can be useful to you. Greeting and a happy and above all a healthy 2014!*

“Hint” (33/130, 25.4%; 28/143, 19.6%) and “counter-question” (24/130, 18.5%; 15/143, 10.5%) were mainly frequent on the Addison and Cushing subforums respectively. The advice to consult a doctor was more often provided in the Public subforum (16/130, 12.3%) compared to the members-only subforums of Addison (2/130; 1.5%) and Cushing (7/143; 4.9%).

Discussion

Principal Results

This is the first study of online peer-to-peer communication in Addison’s disease and Cushing’s syndrome patients. The forum we studied was mainly used to express informational cues, and many of these questions were answered by sharing own experiences, that is, sharing experienced-based knowledge. An online peer-to-peer communication forum has the potential to provide a meaningful, but narrowly focused, contribution to patient-centered care, as over 90% of the questions related to two of the eight Picker principles for patient-centeredness.

Comparison With Prior Work

In the research on peer-to-peer communities, two methods are used to gain insight in these forums. The content of the forums can be analyzed in a qualitative analysis or information is gained by means of questionnaires or interviewing users of peer-to-peer forums. The first provides insight into what kind of purpose the forum has for the patients, whereas the second focuses more on the psychological and patient empowerment outcomes that patients experience.

The results of our study give us insight into the needs of Dutch patients with Addison’s disease or Cushing’s syndrome. The diseases are rare and complicated, and the number of patients is relatively low. Online these patients seek information support and, to a much lesser extent, emotional support. Multiple other patient forums, for a range of diseases, have been analyzed, and they also show the role of informational and emotional support of online forums [15,16,21]. In the NVACP forums, the balance between informational and emotional cues heavily leans towards the informational cues, which mimics the type of questions patients ask during a doctor consultation. In such a doctor-to-patient setting, emotional cues are about half as frequent compared to informational and illness-related cues [22].

Health can be positively affected by sharing experiences with peers, as described by Ziebland and Wyke [17]. Acquiring information, getting emotional support and supporting one another, describing your disease, and motivating each other to take actions as mechanisms for such positive influence were found in our results. However, evidence for positive outcomes of online support groups on health is inconclusive. In a systematic review about online support groups among cancer survivors, most studies report positive effects on psychosocial outcomes, but none of them reported significant outcomes [23].

Online Support Groups as Contributors to Patient-Centered Care

Our study shows the potential that online peer-to-peer support has in making a contribution to patient-centered care. Apart from the contribution to the "Information, communication, and education" principle, online forums can be accessed any time of the day, every day, and from anywhere. As such, it improves "Access to care" by removing geographical and social barriers and making communication more convenient and accessible. Also, online support groups are not constrained by space, as happens online. At the same time, it eliminates many people globally that do not have access to the Internet on a daily basis or who are not able to read and write.

A very important benefit of online support groups is that patients become engaged in their care, just by gaining experiential information and receiving emotional support from their peers. The interaction between the health care professional and the patient versus the interaction between patients on online forums are therefore interesting to compare. In a consultation of a patient with a physician, the physician usually fulfils two roles: an instrumental role and an affective role. Instrumental means the information exchange between the physician and the patient, and affective means building up an emotional relationship with the patient [24]. It is not clear to what extent both roles could be displayed during online conversations. Vennik et al [18] analyzed doctor-patient conversations in online forums. Patients value doctors' feedback differently from feedback received by peers. Peer-to-peer support usually is used as experiential information, whereas feedback by health care professionals is considered more reliable and evidence based.

Another reason for patients to seek information on forums could be because of inadequate information provision channels (eg, verbal or written folders) provided by professionals or inadequate informational content in existing materials. Van de Belt et al [25] analyzed whether the questions patients asked on an online forum could be answered with the information that was provided in the patient folders. About half of the patients' questions could not be answered with the information from the patient folders. As a result, questions concerning medical information arise on patient forums and then can be satisfactorily answered by peers, acknowledging the experienced-based value of information from peers. Therefore, it seems likely that patient forums are perceived as useful and even indispensable to patients.

Limitations

There are some limitations to this study. We analyzed only every first answer of every question. This excludes the remainder of the conversation. Also in this study, the posters of the messages were made anonymous. This was done to protect the identity and privacy of the posters. As a consequence, however, it excluded some interesting data for analysis. For example, we could not differentiate posters from lurkers or distinguish very active posters from one-time posters. Some patients are more active on forums than others. These active forum users who post messages regularly are called posters, and the forum users who mostly read the messages on the forum rather than posting new messages themselves are called lurkers. However, both groups seem to profit equally from peer-support via forums [26]. Also, only the 100 newest threads from the three subforums were analyzed. This excludes older threads that could still be very up to date and very active. Also the true meaning of each post could never be totally clear to the researchers, as the expression of the poster fully depends on how they formulate their posts. Finally, we did not rate the quality of the responses, that is, was the experienced-based knowledge in line with evidence-based guidelines, or was the response appropriate for the expressed cue?

Conclusions

In conclusion, on an online patient forum for Cushing's syndrome and Addison's disease, patients primarily gained knowledge and emotional support from their peers. Patients are therefore able to provide a significant contribution to the creation of patient-centered care. Moreover, the questions raised in an online forum revealed unmet needs and issues that matter to patients. As such, online peer-to-peer communication is an excellent resource for improving the delivery of patient-centered care tailored to the unmet needs of patients.

Acknowledgments

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Conflicts of Interest

AN is the administrator of the NVACP forum.

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Original Paper

SimQ: Real-Time Retrieval of Similar Consumer Health Questions

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Abstract

Background: There has been a significant increase in the popularity of Web-based question-and-answer (Q&A) services that provide health care information for consumers. Large amounts of Q&As have been archived in these online communities, which form a valuable knowledge base for consumers who seek answers to their health care concerns. However, due to consumers' possible lack of professional knowledge, it is still very challenging for them to find Q&As that are closely relevant to their own health problems. Consumers often repeatedly ask similar questions that have already been answered previously by other users.

Objective: In this study, we aim to develop efficient informatics methods that can retrieve similar Web-based consumer health questions using syntactic and semantic analysis.

Methods: We propose the "SimQ" to achieve this objective. SimQ is an informatics framework that compares the similarity of archived health questions and retrieves answers to satisfy consumers' information needs. Statistical syntactic parsing was used to analyze each question's syntactic structure. Standardized Unified Medical Language System (UMLS) was employed to annotate semantic types and extract medical concepts. Finally, the similarity between sentences was calculated using both semantic and syntactic features.

Results: We used 2000 randomly selected consumer questions to evaluate the system's performance. The results show that SimQ reached the highest precision of 72.2%, recall of 78.0%, and F-score of 75.0% when using compositional feature representations.

Conclusions: We demonstrated that SimQ complements the existing Q&A services of Netwellness, a not-for-profit community-based consumer health information service that consists of nearly 70,000 Q&As and serves over 3 million users each year. SimQ not only reduces response delay by instantly providing closely related questions and answers, but also helps consumers to improve the understanding of their health concerns.

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KEYWORDS

Online Health Information Seeking; Health Information Delivery; Consumer Health Informatics; Consumer Question Retrieval; Similarity Analysis; Netwellness.org; Health Care Questions; Search and Query

Introduction

Web-based health-related question and answering (Q&A) services are becoming more and more popular. Some consumer health websites receive millions of page views each year, such as NetWellness, WebMed, and EverydayHealth. Thousands of users visit these websites to search for answers related to their health problems [1]. Many of these health information websites are community-based, which means a user can submit a question to public forums and wait for that question to be answered by other users or experts.

The service model of community-based Q&A platforms has several unique advantages. First, users keep their identity anonymous, which protects the users' privacy and encourages information sharing. For example, many people who feel too stressed or embarrassed to ask certain types of questions during face-to-face physician consultations (eg, sex-related issues, weight-related concerns, or emotional problems) can seek help from the online community. Second, the Q&A platform can serve as an information source for acquiring new knowledge. It enhances a user's understanding of health care on many different topics, such as nutrition, patient care, or disease management. Third, compared to face-to-face physician consultation, a community-based service normally provides a quicker response and a wider range of perspectives. For example, a user who asks a question about "children nutrition" may receive answers from both child-care experts and nutritionists. Finally, the online community provides a platform for consumers to share their health concerns and wellness interests. This creates an environment that not only shares new knowledge, but also provides emotional support for health care consumers. Therefore, a community based Q&A is an excellent way of delivering health care information to a wide range of public users. It could help reduce the time and cost of information delivery, such as those services provided by MIMIR [2] and Yahoo Answers [3].

Despite the fact that an online community-based health information service has many advantages, there are still many challenging problems that need to be addressed to improve the service's quality and accessibility [4]. Consumers are often unaware of the great value of archived historical questions. Also, many consumers may lack professional knowledge, making it challenging for them to find Q&As that are relevant to their own particular health concerns. Often times, these users post similar questions that have been answered previously. As a result, duplicate questions delay service responses and create additional burdens for the service platform, which then becomes a significant waste of valuable resources. Furthermore, domain experts and administrators also have a strong need to retrieve and group similar Q&As to support content management. To address these problems, a similarity-based Q&A retrieval system is highly desirable both for health consumers and domain administrators to accommodate their specific needs.

Many community-based service platforms have now archived thousands of Q&As, which creates a valuable knowledge base. Berland et al published a study [4] on evaluating consumer health platforms on the Internet. The results show that the retrieval of relevant information is a critical factor for effectively delivering health information to consumers. Developing efficient methods to retrieve similar questions on the Q&A platforms can help unleash the power of the archived Q&A as important knowledge bases, and make the archived information more accessible to consumers. In this paper, the SimQ project is proposed as a useful framework that focuses on developing new methods to retrieve similar questions from the large health information platform, NetWellness [5,6].

NetWellness is a not-for-profit health information website, which has been providing consistent and high quality services for consumers since 1995. This service platform is operated by professional health care experts from three universities, including Case Western Reserve University, Ohio State University, and the University of Cincinnati. The health information provided by the NetWellness website has been evaluated and maintained at high quality standards by experts who periodically review the content to ensure that the information is up-to-date. Over 500 health experts, including physicians, nurses, pharmacists, dieticians, dentists, genetics counselors, optometrists, athletic trainers, and social workers have contributed to the public Q&A, and more importantly, provide professional health care information that directly addresses consumers' health concerns. Over 70,000 consumer questions have been answered with approximately 1,400,000 [7] visits reaching the website each month. NetWellness continuously collects user feedback through Web-based surveys. Close to 80% (28,137/35,719) of the users said that NetWellness Q&As were very useful for them but, surprisingly, about 67% (17,647/26,257) of users reported that the health information they found on the site was "new" to them. Similar to Lau and Coiera's report [8], the survey clearly indicates a strong need for developing advanced informatics tools to provide more informative and relevant knowledge to educate users and to fulfill consumers' health information needs. The goal of the present paper is to develop a *semantic similarity analysis* method to support the need for retrieving similar questions from NetWellness, that complements existing services, and that enables efficient reuse of the accumulated Q&A knowledge (source code available in Multimedia Appendix 1).

Similarity analysis of Q&As remains a challenging task [9]. There are several related studies that aim to develop new methods to improve the Q&A systems in the information retrieval research field. Metzler and Croft [10] presented a support vector machine (SVM) based question classification method, in which the trained classifier facilitates the determination of fact-based question types, such as the question, "What is the world's highest peak?", which can be classified to "location" question types. Sneiders [11] proposed a method that uses question templates to transfer questions into database queries, which query the answers based on the predefined variable slots into the templates. This method provides a formal way to construct a database query from structured question variables. However, due to the requirement of laborious effort for developing templates for each type of question, that method is not scalable for large and open question databases. More recently, a ranking framework [12] was proposed to retrieve relevant content from social media by using community feedback, such as the user's experience, reputation, and vote. This method is typically effective when the community allows users to evaluate the questions openly and provide feedback. Wang et al [13] proposed a method that uses syntactic structure to find similar questions. This method was tested on Yahoo Answers, which showed that the use of syntactic structure performed better than the traditional "bag-of-words" feature representation. Cui et al [6,14] recently proposed another method that uses multi-topic navigation to help consumers navigate question archives.

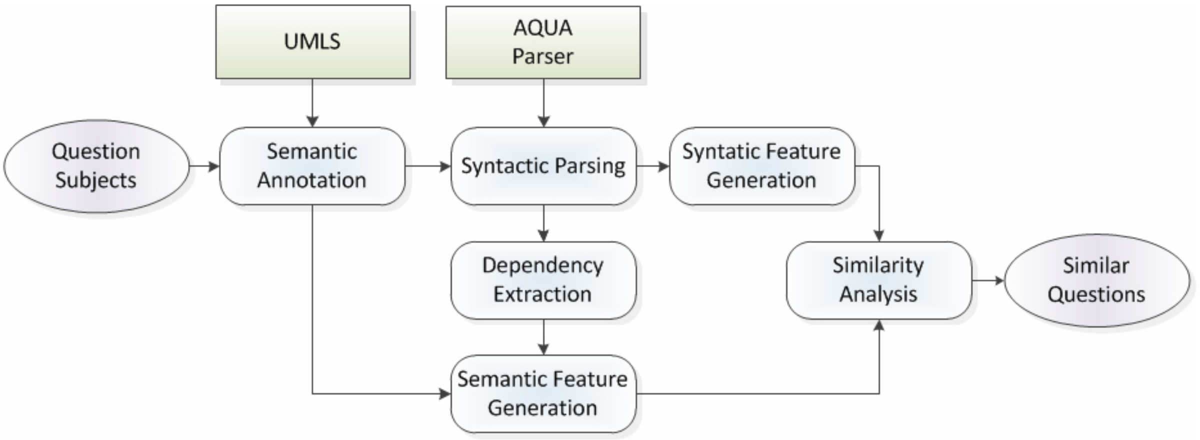
These methods provide different solutions to improve Q&A retrieval on various domains, such as question classification and ranking. However, health care Q&As often contain challenging medical information that are too difficult to encapsulate for standard language processing and information retrieval to be effective [14-16] (eg, description of diseases, signs and symptoms, pharmacological reactions, etc). In this paper, we propose a different method that takes advantage of the semantic network of the Unified Medical Language System (UMLS) [17] to assign semantic annotations to consumer health questions. The semantic features combined with statistical syntactic parsing results are then used to calculate similarity scores and retrieve similar questions. The goal is to provide similar Q&As that can help consumers better understand their own health concerns.

Methods

Challenge

Questions submitted to the NetWellness website are written in free-text, which contains complex syntactic structure and semantic elements. Analyzing the similarity of consumer questions is not a simple task, so we propose a method that combines semantic annotation techniques and syntactic natural language processing methods to analyze the question similarity. Figure 1 shows the overall framework of our method, called SimQ. We used the "AQUA" parser [18] to extract sentence syntactic structure. The UMLS [17] was used to annotate the sentences and generate semantic features. The Natural Language Parser (NLP) parsing results and semantic annotation were combined to create features for estimating similarity scores among question sentences.

Figure 1. Overview of the SimQ framework for analyzing similarity of consumer health question.



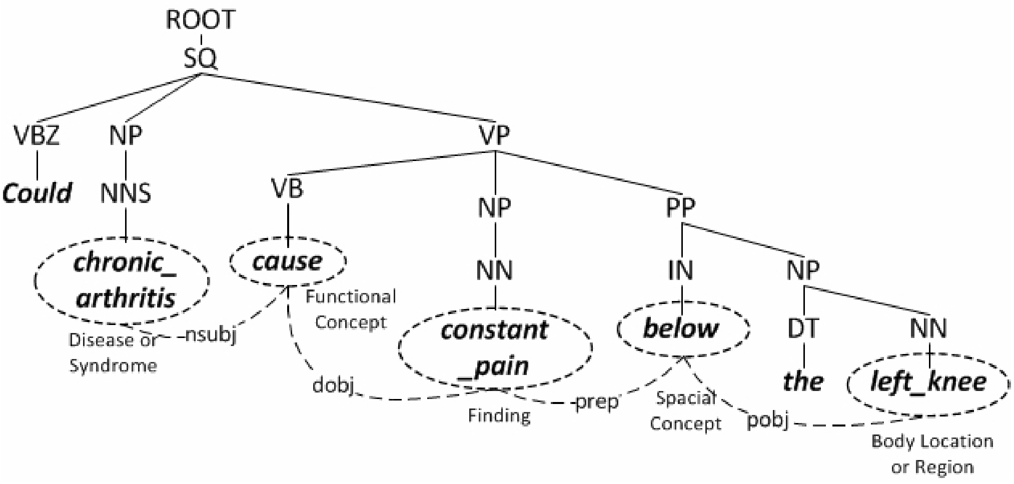
Semantic Annotation and Medical Entity Recognition

Semantic annotation is a fundamental step of the proposed Q&A similarity analysis. The annotation procedure aims to identify health-related entities from the free-text consumer questions and assign semantic types to the identified entities. We performed named entity identification using an adapted semantic annotation tool that was developed from UMLS [19,20]. The annotation tool mapped the biomedical terms to the UMLS concepts and semantic types [17]. It has been demonstrated that UMLS-based lexicons cover a wide range of medical concepts [19-21] that can be annotated. Each of the extracted entities was assigned a Concept Unique Identifier (CUI) as defined in UMLS. Subsequently, we chunked the sentence into smaller segments based on the identified phrases and words [19]. For example, the question, "Could folic acid cause a bitter taste and body odor?" would be annotated and chunked as: "could// | folic acid/C0016410/Pharmacologic Substance | cause/C0678227/Functional Concept | a// | bitter taste/C0235290/Sign and Symptom | and// | body odor/C0085595/Finding". Each chunk was separated by the "|" mark and consisted of three elements: the name entities (eg, folic acid, bitter taste), the concept identifiers (eg, C0016410, C0235290), and the semantic types (eg, Pharmacologic Substance, Sign and Symptom). Words without corresponding semantic mappings in UMLS were also kept to maintain sentence syntactic structure, such as the auxiliary verb "could" and the connector "and". In this step, the identified name entities enhanced the following syntactic parsing. The annotated semantic types were then used for generating semantic features to analyze the question similarities of the consumer questions.

Syntactic Features

To analyze the linguistic structure and the constituents of consumer questions, we parsed the question sentences into syntactic trees. The AQUA parser [18] was extended from the Stanford parser [22], and then used to construct syntactic trees and assign part-of-speech (POS) tagging. A parsed tree is a formalized structure that represents the syntactic relationship of the sentence constituents. For example, the syntactic tree in Figure 2 shows the parsing result of the sample sentence, "Could chronic arthritis cause constant pain below the left knee?". The sentence root is tagged as a SQ (Simple Question). It is further parsed into three parts: VBZ (3rd person verb), NP (noun phrase), and VP (verb phrase). The syntactic tree is expanded until all leaves contain a single constituent. Unlike standard syntactic parsing that treats each of the words as a constituent, our method uses the semantic annotation results and treats the UMLS recognizable entities as syntactic constituents. This last step enabled us to retrieve relationships between the identified named entities.

Figure 2. Parsed syntactic tree and semantic dependency.



Semantic Features

We constructed dependency grammars [22] from the syntactic tree, which represent grammatical relationships between the identified constituents. Studies have shown that dependency parsing can facilitate retrieving information from free-text within medical notes, such as from discharge summaries [18] or clinical research eligibility criteria [23]. A dependency grammar construct consists of a governor, a dependent, and a relationship name. In Figure 2, the governor and the dependent elements are encircled by dotted lines and linked together. For example, dependent “chronic arthritis” is a nominal subject (nsubj) of the governor “cause”, while “constant pain” is a direct object (dobj) of the governor “cause”. By applying the dependency relationship to the semantic annotation, we can extract semantic relationships between the entities. For example, we can extract the semantic relationship, “Disease or Syndrome (chronic arthritis) - Functional Concept (cause) - Finding (constant pain)”, which indicates that the disease has a functional influence on the clinical finding. Similarly, we can extract another relationship, “Finding (constant pain) - Spatial Concept (below) - Body Location or Region (left knee)”, which designates the spatial location of the clinical finding. The semantic-type pairs in the extracted semantic relationship were then used to represent semantic features for similarity calculation.

Question Similarity

Dice coefficient and cosine similarity are the algorithms that are employed for calculating similarity in this paper. Dice coefficient (DC) and cosine similarity (CS) (see Figure 3) were used to evaluate the similarity score between questions. The similarity score has a value range of 0-1. A score of zero means two questions are not similar at all, and a score of one means that they are completely the same. Assuming that there are two feature sets Q_1 and Q_2 that are generated from two different consumer questions, we can then calculate the DC and CS similarity scores through the formulas in Figure 3.

We use binary representation for both syntactic and semantic features. If a feature appears to a consumer in a question, then it has a value of 1; otherwise, the value is 0. From the binary representation, we can generate vectors containing both syntactic and semantic features to compare the similarity between these two questions as indicated in formulas 1 and 2 in Figure 3.

Figure 3. Dice coefficient (1) and cosine similarity (2) formulas.

$$DC(Q_1, Q_2) = \frac{2|Q_1 \cap Q_2|}{|Q_1| + |Q_2|} \quad (1)$$

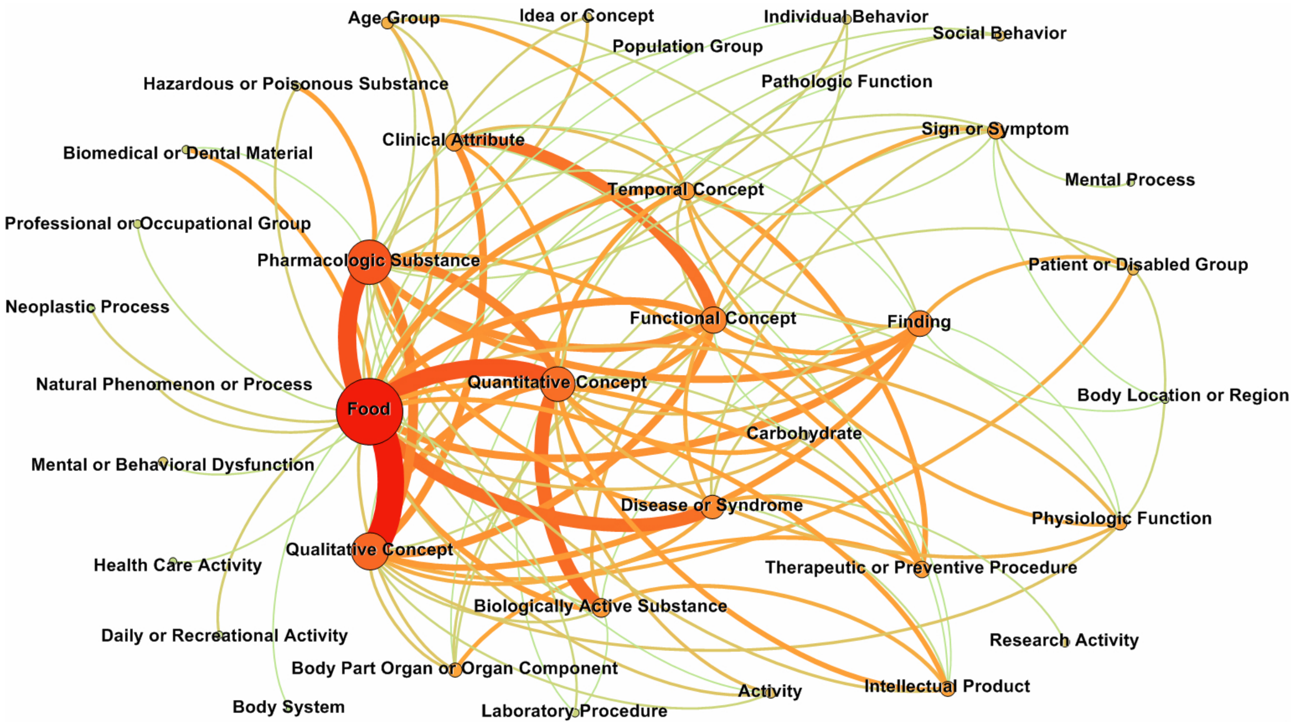
$$CS(Q_1, Q_2) = \frac{|Q_1 \cap Q_2|}{\sqrt{|Q_1| \times |Q_2|}} \quad (2)$$

Results

Data Source

We applied our method (SimQ) to the consumer questions posted on the Netwellness website, which has archived over 70,000 Q&As and more than 600 health information articles that were written by domain experts. All of the Q&As and articles were categorized into 121 health topics. The performance of the proposed SimQ method was then evaluated by using 2000 random selected NetWellness questions. The precision, recall, and *F*-score were measured. Also, we created an illustration for the aggregated semantic type patterns of the “Diet and Nutrition” category, which contained 2335 questions (see Figure 4).

Figure 4. Overview of the semantic dependency network of the “Diet and Nutrition” topic.



Semantic Dependency Overview

Figure 4 shows the overview of semantic type patterns in the topic group “Diet and Nutrition”. The nodes in the figure represent semantic types (eg, Food, Population Group, and Qualitative Concept, etc), while the edge that connects the two nodes indicates a dependency relationship between two types. The size of a node represents the frequency of the semantic types within the questions, and the width of an edge represents the frequency of the dependency relationships between two types. By connecting all semantic types (nodes) using their dependency relationships (edges), we were able to produce an overview of the semantic patterns. The result clearly shows the major topics and their connections in the “Diet and Nutrition” category. Among all 135 semantic types defined in UMLS, only 37 are used in this category. For example, in the semantic type, “Foods and medical substances”, quality and quantity attributes are the most prominent topics, such as dependency pairs “garlic − benefit”, “protein – amount”, and “grape seed extract − benefits and risks”. Diseases, symptoms, and medical findings associated with foods are also very popular questions, such as “gallstones − diet”, “heart disease − wine”, and “low blood sugar − food”. This result indicates that consumer questions within the same topic group share many similar patterns. We hypothesize that semantic features could be used further to improve similarity analysis.

Example Results of Similar Questions

Table 1 shows some example results of similar questions retrieved from the NetWellness website. Given a particular consumer question, our algorithm will run through all of the archived questions on NetWellness to retrieve the top ranked similar questions. The top 5 similar questions and their similarity scores are shown in Table 1 using two examples of consumer health questions: “My throat glands feel swollen, help?” and “Low platelet counts”.

Table 1. Examples of SimQ calculated similar questions.

Rank	Similar questions	Similarity score
	Input question: "My throat glands feel swollen, help?"	
1	Swollen throat glands are sore?	0.7368
2	Sore throat and swollen glands?	0.6718
3	Swollen feeling in throat, can`t swallow well?	0.6545
4	My throat is sore all the time and also my glands?	0.5901
5	Painful swollen uvula, please help?	0.5611
	Input question: "Low platelet counts?"	
1	Less platelet count?	0.8235
2	What causes low platelet count?	0.7906
3	Extremely low platelet count?	0.7726
4	Decreased platelet count?	0.7003
5	Food for increase in platelet count?	0.5957

Evaluation

To evaluate the performance of the SimQ method, 12 seed consumer questions were selected from Yahoo Answers as input questions. These questions were selected from different categories, such as women's health, diseases and conditions, and mental health. Two biomedical informaticians, who were independent to this project, were recruited to generate a gold standard to evaluate the results of the SimQ question retrieval engine. They were asked to manually select Netwellness questions that were closely similar to the seed questions. A total of 2000 randomly selected Netwellness questions were used as the candidate pool. In total, 246 consumer questions were selected by the evaluators as the positive gold standard to evaluate SimQ's retrieval performance. The initial agreement between the two evaluators was 83%. However, they were allowed to discuss and reach a final unanimous agreement on all the similar consumer questions, which were then used as the gold standard.

We also compared the performance of similarity analysis using different feature representations. Table 2 shows the results of SimQ using the Dice coefficient and cosine similarity algorithms. The baseline features (B) are the bag-of-words representation of a question, which is the standard representation of NLP analysis. The normalized features (N) are words that have been normalized by the Specialist Lexical Tool. The lexical tool normalizes plural terms and past tenses to their stem form. The concept features (C) are the UMLS concepts identified in the process of semantic annotation. The N+POS (P) features are the combination of normalized terms and their syntactic part-of-speech tagging. The N+Concept (NC) features are the combination of normalized terms and their mapped UMLS concepts. The N+C+Type (NCT) features are the combination of the precious feature (NC) and the extracted semantic type features described in the Semantic Features section.

In Table 2, we can see that Dice similarity performs better than cosine similarity in this task. The results indicate that word normalization, UMLS concepts, and semantic types improve similarity analysis. Part-of-speech tagging has no contribution to the similarity analysis. The best performing representation is the N+C+Type (NCT) features, with which the system achieved 75.0% *F*-score, 72.2% precision, and 78.0% recall.

Syntactic parsing is used to facilitate the identification of named entities and to support the construction of semantic features [24]. Part-of-speech tagging was evaluated as a syntactic feature. The evaluation result shows that part-of-speech did not improve the performance of retrieval. The semantic features are constructed from the semantic type pairs, which have been extracted from the parsed dependency tree. The evaluation result shown indicates that the semantic features improved the retrieval results, while syntactic parsing had little effect. From our analysis, the contributions of semantic features work in two aspects: (1) the semantic features strengthen key medical concepts and reduce the weight of non-medical concepts, and (2) the semantic features improve semantic similarity analysis of consumer questions that cannot be ascertained directly from the text. For example, questions such as "Could my blurred eyes caused by hypertension?" and "HBP lead to blurry vision?" share the same semantic concepts, Blurred Vision (CID:C0344232) Hypertensive Disease (CID:C0020538), and the same semantic type pattern, Disease_or_Syndrome - cause - Sign_or_Symptom. Figure 4 shows that there are many overlapping semantic relationships (semantic dependency pairs) within a closely related topic group.

Table 2. Evaluation of different feature representations for consumer Q&A similarity analysis (average of 12 experiments using 12 seed questions).

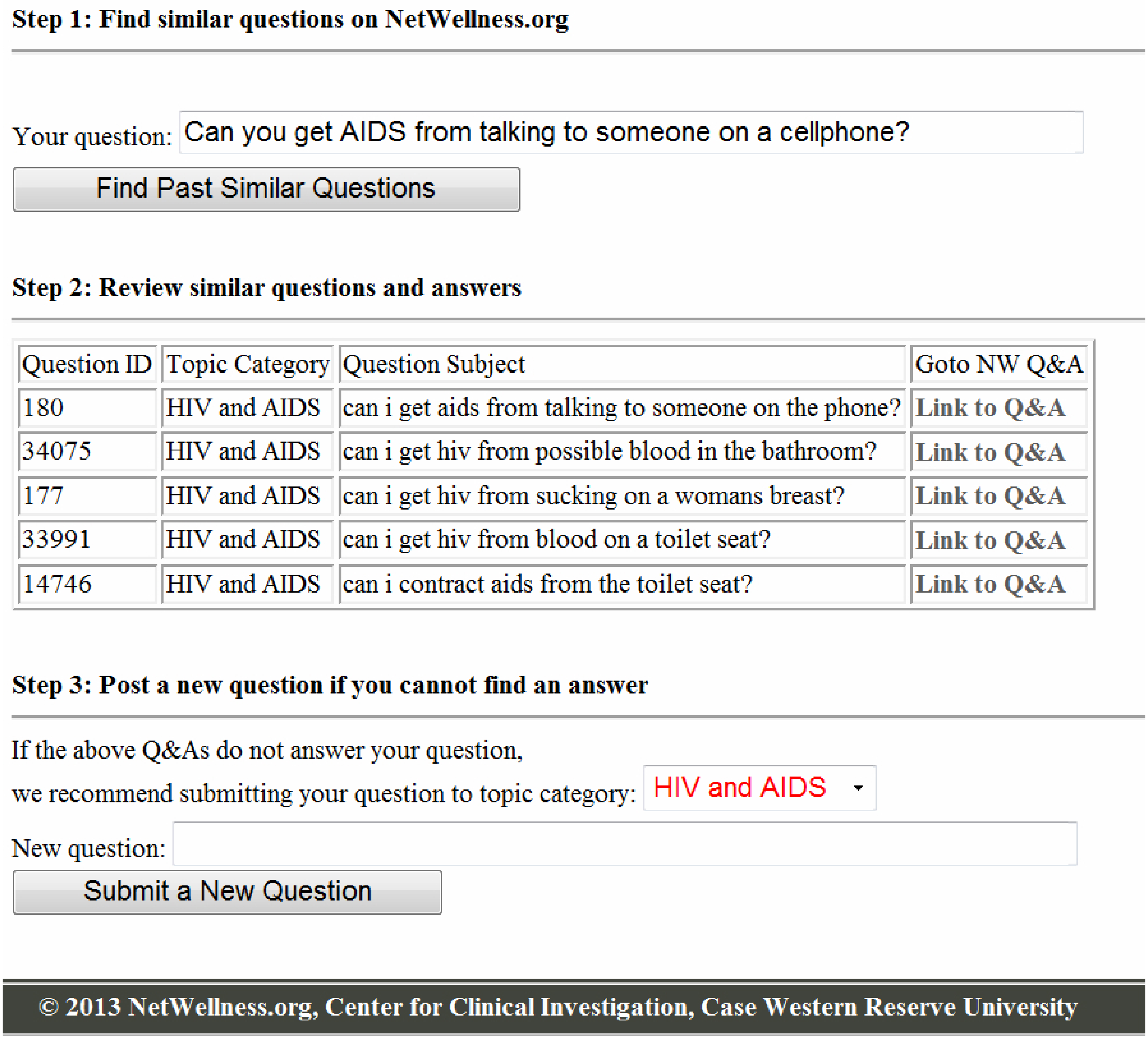
Feature	True positive	False positive	True negative	False negative	Precision %	Recall %	*F*-score %
Algorithm - Cosine Similarity							
Baseline (B)	12.83	7.67	1969.33	7.67	62.6%	62.6%	62.6%
Normalized (N)	12.67	6.67	1970.33	7.83	65.5%	61.8%	63.6%
Concept (C)	14.00	8.33	1968.67	6.50	62.7%	68.3%	65.4%
N+POS (P)	11.67	7.67	1969.33	8.83	60.3%	56.9%	58.6%
N+ Concept (NC)	15.00	7.50	1969.50	5.50	66.7%	73.2%	69.8%
N+C+Type (NCT)	15.33	6.67	1970.33	5.17	69.7%	74.8%	72.1%
Algorithm - Dice Similarity							
Baseline (B)	11.33	3.17	1973.83	9.17	78.1%	55.3%	64.7%
Normalized (N)	15.50	10.33	1966.67	5.00	60.0%	75.6%	66.9%
Concept (C)	15.33	8.00	1969.00	5.17	65.7%	74.8%	70.0%
N+POS (P)	11.67	5.67	1971.33	8.83	67.3%	56.9%	61.7%
N+ Concept (NC)	14.33	3.83	1973.17	6.17	78.9%	69.9%	74.1%
N+C+Type (NCT)	16.00	6.17	1970.83	4.50	72.2%	78.0%	75.0%

SimQ Application

To demonstrate the use of SimQ, we developed an application that complemented the existing Q&A services on the NetWellness website. Figure 5 shows the Web interface of SimQ. The original Q&A service on NetWellness prompts users to select a topic category among 120 categories, and subsequently allows consumers to submit their question to a specific category. A coordinator reviews the question and then determines whether the user-assigned category is correct. If the question is submitted to the correct category, the coordinator will forward the question to a health expert.

This new application enhances the workflow through semantic similarity analysis (see Figure 5, Step 1). Consumers first submit their health concerns to the SimQ question retrieval engine. SimQ analyzes the question and calculates the similarities against all the questions that have been archived on Netwellness (Figure 5, Step 2). A list of closely related similar questions will be retrieved for the consumer. The user can then browse through similar questions that were posted in the past and read the related Q&As. This step improves the consumer's understanding of the health problem using historical knowledge. The consumer could also find the right answer for their problem directly from the archived Q&As. After the consumers have read through the similar Q&As, and have determined that they wish to continue submitting a new question, the system will automatically recommend one or more topic categories for them to consider using the most frequent topics that have been assigned in the past applying similar questions (Figure 5, Step 3). This important step addresses the problem of wrong category selection, which is very commonly encountered on public Web-based Q&A services. Wrong category submission may lead to no answer or even require manual correction. The application described above demonstrates that our method can be integrated into existing systems to improve the service quality of the Q&A workflow.

Figure 5. Application of SimQ for NetWellness.



Step 1: Find similar questions on NetWellness.org

Your question: Can you get AIDS from talking to someone on a cellphone?

Step 2: Review similar questions and answers

Question ID	Topic Category	Question Subject	Goto NW Q&A
180	HIV and AIDS	can i get aids from talking to someone on the phone?	Link to Q&A
34075	HIV and AIDS	can i get hiv from possible blood in the bathroom?	Link to Q&A
177	HIV and AIDS	can i get hiv from sucking on a womans breast?	Link to Q&A
33991	HIV and AIDS	can i get hiv from blood on a toilet seat?	Link to Q&A
14746	HIV and AIDS	can i contract aids from the toilet seat?	Link to Q&A

Step 3: Post a new question if you cannot find an answer

If the above Q&As do not answer your question,
we recommend submitting your question to topic category: HIV and AIDS

New question:

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Discussion

Q&A Retrieval

At present, one of the most common ways to find health information online is through search engines. Search engines use keyword-based information retrieval techniques [25], which return ranked Web pages that contain the searched keyword. While returning top-ranked documents can be useful in some cases, frequently this type of search does not satisfy the user's information needs [26], as has been discussed in TREC, an international information retrieval consortium. Hence, despite the common use of search engines, community-based Q&A platforms are becoming more popular because they address the fundamental need to get human (consumer or expert) answers for health questions [7,27]. NetWellness is a not-for-profit platform that provides expert-answered recommendations to consumers for solving their health questions, which provides an invaluable resource for consumers.

Related Prior Work

The SimQ method is related to but fundamentally different than Question Answering Machines (QAMs) [16,26]. QAMs aim to automatically answer human questions by using computer programs supported by artificial intelligence techniques [28]. There are various types of QAMs in existence today. In the biomedical information domain, AskHERMES [29] is an automated system that finds and filters clinical information to help physicians obtain relevant information. Patrick and Li [30] developed an ontology to classify questions from intensive care units. MiPACQ [31,32] is a system that integrates different data sources to answer clinical questions. MEDLINE is the largest QAM database, and contains 20 million references to PubMed articles. Sneiderman et al [33] evaluated the performance of three methods in answering clinical queries using MEDLINE and found that external semantic knowledge improved the performance of two of these methods. Automatic machine question answering is still a very challenging task, especially for health informatics applications. Most of the machine answering systems can only provide factual answers to the questions. For tasks that involve questions about advice and/or opinions for consumer health problems, especially when the question is presented in a free-text format, the performance of these systems is still not satisfactory [34]. For example, one would need sophisticated reasoning ability and professional pharmaceutical knowledge to answer the question: "Why Fosamax should not be taken with estrogen?" SimQ is fundamentally different, since it reuses similar questions from the archived knowledge base to satisfy consumers' information needs to complement the existing research of machine answering systems. Therefore, our study is specifically focused on improving the information retrieval of community-based Q&A services instead of QAMs. The SimQ method analyzes question-to-question similarities in the archived Q&A database and retrieves relevant Q&As to address consumers' health concern. As far as we know, this is the first research study with a primary focus on analyzing the similarity of consumer health questions.

Error Analysis

We observed two types of errors from the SimQ retrieval results: false positive results and false negative results. False positive results, which are incorrectly included questions, were often created by questions with small but important differences. For example, SimQ retrieves the query, "How can I lose weight in one month?" for the question, "How I can gain weight quickly", because both "lose weight" and "gain weight" have the same semantic type, Findings. Both questions contain the same semantic types, Patient Group and Temporal Concept. The only major difference is seen in the concepts of "lose weight (CUI:C0043096)" and "gain weight (CUI:C0043094)". One potential solution for this type of error is to incorporate concept importance ranking into the similarity analysis. When generating feature vectors, important concepts have higher weights for calculating the similarity score, which can improve the retrieval results. False negative results (incorrectly excluded questions) are often caused by complex questions. For example, the question "I have a breast lump, could it be a lymph node or tumor?" is semantically close to "Is swelling breast a sign of breast cancer?" by human standards. However, the SimQ similarity score is not very high. To address this problem, we need to add concept reasoning ability to the similarity analysis. In this example, the concept "breast lump (CUI:C0424849)" is a descendent of the concept "swelling (CUI:C0038999)", and "breast cancer (CUI:C0006142)" is a descendent of "tumor (CUI:C0027651)".

Short ambiguous questions can also lead to both false negative and false positive errors. For example, when analyzing the question, "Vitamin B6 deficiency", SimQ retrieved the false positive result "Vitamin B12 deficiency?" and the false negative result "What are the symptoms of Vitamin B6 deficiency?" We believe that potential methods to address errors created by short ambiguous questions include weighting the question elements by importance and/or applying a query expansion technique. For example, an intuitive way to expand the question for Netwellness is to include previous answers from similarity analysis. However, the answers usually are much more complex and longer than the question, so it is still challenging to achieve a good result, especially since real-time retrieval response is needed. Integrating both questions and answers to improve retrieval results will be examined in subsequent studies that we plan to undertake.

Limitations

SimQ uses UMLS as a standardized semantic knowledge source. In the future, we plan to exploit other medical knowledge sources for semantic annotation, which could provide finer granularity of the semantic assignment and improve semantic analysis. Additionally, some researchers have pointed out that Consumer Health Vocabularies (CHV) [35] may facilitate natural language processing of consumer-related free text. Because most questions submitted to NetWellness are consumer questions about health, a natural extension to our current approach will be to evaluate the effectiveness of consumer health vocabularies in future studies.

Conclusions

Similarity analysis of consumer health questions can significantly improve the quality and accessibility of online community-based question answering (Q&A) services. In this study, we proposed a new application called SimQ, which analyzes the semantic similarity of consumer health questions by combining natural language processing and semantic pattern techniques. The evaluation results show that our approach effectively retrieves similar questions on NetWellness. The results show that SimQ reached the highest precision of 72.2%, recall of 78.0%, and *F*-score of 75.0%. We demonstrated a use case application by designing a new Q&A pipeline for the NetWellness website, which retrieves previous Q&As similar to the user's health care. We designed a new Q&A pipeline for NetWellness, which retrieves previous Q&As similar to the user's health care question. Then we demonstrated by using a particular case how the additional features of SimQ would be applied to a health consumer's inquiry and integrated into the existing system to improve the service quality of the Q&A workflow. Therefore, we have shown that SimQ not only reduces response delay by instantly providing closely related question and answers, but also helps consumers improve the understanding of their health concerns.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Source code for similarity analysis.

[ZIP File (Zip Archive), 27KB - jmir_v17i2e43_app1.zip]

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Abbreviations

CTSC: Clinical and Translational Science Collaborative Cleveland
NCATS: National Center for Advancing Translational Science
NLP: natural language processing
NP: noun phrase
POS: part-of-speech
Q&A: question-and-answer
SQ: Simple Question
UMLS: Unified Medical Language System
VB: verb phrase
VBZ: 3rd person verb

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Original Paper

The Chronic Care Model and Technological Research and Innovation: A Scoping Review at the Crossroads

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Abstract

Background: Information and communication technologies (ICT) are key to optimizing the outcomes of the Chronic Care Model (CCM), currently acknowledged as the best synthesis of available evidence for chronic illness prevention and management. At the same time, CCM can offer a needed framework for increasing the relevance and feasibility of ICT innovation and research in health care. Little is known about how and to what extent CCM and ICT research inform each other to leverage mutual strengths. The current study examines: What characterizes work being done at the crossroads of CCM and ICT research and innovation?

Objective: Our aim is identify the gaps and potential that lie between the research domains CCM and ICT, thus enabling more substantive questions and opportunities for accelerating improvements in ICT-supported chronic care.

Methods: Using a scoping study approach, we developed a search strategy applied to medical and technical databases resulting in 1054 titles and abstracts that address CCM and ICT. After iteratively adapting our inclusion/exclusion criteria to balance between breadth and feasibility, 26 publications from 20 studies were found to fulfill our criteria. Following initial coding of each article according to predefined categories (eg, type of article, CCM component, ICT, health issue), a 1st level analysis was conducted resulting in a broad range of categories. These were gradually reduced by constantly comparing them for underlying commonalities and discrepancies.

Results: None of the studies included were from technical databases and interventions relied mostly on “old-fashioned” technologies. Technologies supporting “productive interactions” were often one-way (provider to patient), and it was sometimes difficult to decipher how CCM was guiding intervention design. In particular, the major focus on ICT to support providers did not appear unique to the challenges of chronic care. Challenges in facilitating CCM components through ICT included poorly designed user interfaces, digital divide issues, and lack of integration with existing infrastructure.

Conclusions: The CCM is a highly influential guide for health care development, which recognizes the need for alignment of system tools such as ICT. Yet, there seem to be alarmingly few touch points between the subject fields of “health service development” and “ICT-innovation”. Bridging these gaps needs explicit and urgent attention as the synergies between these domains have enormous potential. Policy makers and funding agencies need to facilitate the joining of forces between high-tech innovative expertise and experts in the chronic care system redesign that is required for tackling the current epidemic of long-term multiple conditions.

(J Med Internet Res 2015;17(2):e25) doi:10.2196/jmir.3547

KEYWORDS

chronic care model; chronic disease management; information and communication technology; telemedicine; ehealth; computer science; medical informatics; scoping review

Introduction

One of the biggest health care challenges worldwide is the growing number of persons with chronic or lifestyle-related illness, which is threatening the infrastructure of health care systems by rising demands and unsustainable costs [1]. Today's fragmented service delivery between levels of care is partly blamed for the escalation of health care costs seen internationally. The Chronic Care Model (CCM) is acknowledged currently as the best synthesis of available evidence for chronic illness prevention and management interventions [2,3] (see Figure 1). Since launched by Wagner and colleagues in the late 1990s [4,5], the model has been extensively elaborated and expanded upon, for example, by the World Health Organization to highlight macro issues related to population health and health promotion [6,7].

Nevertheless, the basic components of the original CCM remain core to modern chronic care system redesign of clinical practices. The model comprises six components, each of which are supported by evidence as contributing toward productive patient-provider interactions and improved outcomes.

While questions still remain about whether sequential versus full implementation of the components are associated with differences in outcomes [2], orchestration of the six components are assessed in terms of how well they support productive interactions between the informed, activated patient and the prepared proactive practice team. Key to the model is an acknowledgement of the patient's own role in self-management as a vital, but under-focused, resource in chronic care. This entails a fundamental shift for health care that is traditionally built around acute, episodic encounters. Long-term and individualized support for self-management, in partnership with a proactive (rather than reactive) multi-professional team, is thus a central feature of this model and the evidence that supports it [8].

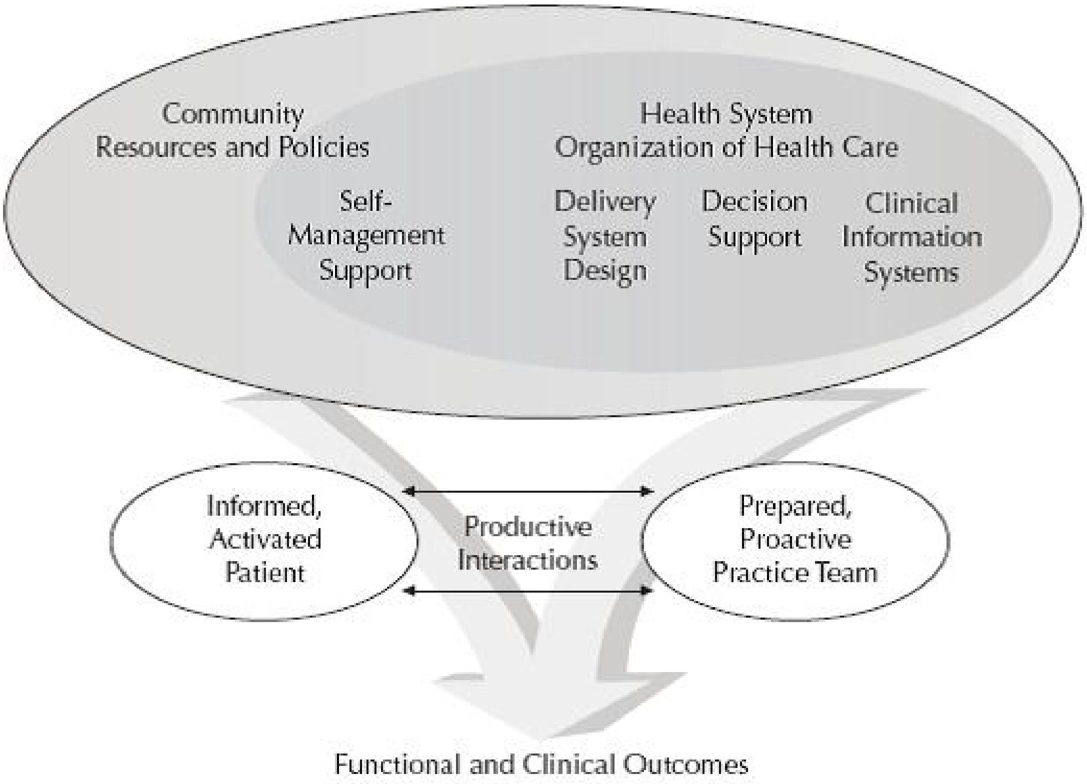
Information and communication technologies (ICT) are becoming ubiquitous to the information infrastructure of health care. While the CCM-component "clinical information systems" (electronic medical records, disease registries) is by definition ICT-based, several call for increased use of ICT to facilitate implementation and fidelity of the other CCM-components [9,10]. Advancements in the technological domains of computer science and information technology are fast-paced, as indicated by the last 10-20 years of high-tech products that have altered everyday life in Western civilization. Indeed, the market of direct-to-consumer mobile health and wellness products and apps is estimated to reach US $26 billion globally by 2017 [11]. Similar developments are gaining momentum under headings such as "assisted or independent living" and "welfare technologies" [12], many of which are potentially well-suited for patient-centric solutions within a CCM framework.

Nevertheless, similar to the gap between medical evidence and practice [13], there is a gap between technological research and innovation, and applications in health care. This is evident in that telemedicine and eHealth systems with documented benefits often fail to become incorporated into routine clinical practice [14]. Explanations offered include a mismatch between accepted methods in medicine (eg, randomized controlled trials) and the socio-technical nature of ICT systems, as well as a neglect in medical informatics and telemedicine to articulate theoretical rationales for the systems they design and expected outcomes. This undermines an ability to communicate between stakeholders, prioritize innovations, sort out critical variables in adapting them, and explain successful and unsuccessful outcomes [15]. Others note a lack of attention to contextual issues during implementation [14]. Thus, while many ICT innovations may be well-suited for facilitating CCM, they often end as pilots, detached from the broader movement toward improving chronic care in line with available evidence.

Arguably, CCM represents a type of framework that can aid in increasing the relevance and implementation of technological research and innovation to health care. First, it is comprehensive as well as intuitive, thus enabling a common language that may bridge the communication difficulties between health care stakeholders (patients, providers, funders) and technologists. Second, often framed as quality improvement, CCM can be linked to approaches that health care professionals are increasingly acquainted with (quality collaborative, breakthrough methodologies) and that are well-suited for ICT implementations [16-18]. Third, as the evidence-base of CCM increases, an increasing number of national and regional health care organizations are redesigning their health care services in accordance with CCM [2]. This provides a broader and more cohesive framework for the piloting and implementation of large-scale trials of innovative ICT applications. Further, while some ICT applications may only target one or two CCM components, adherence to the CCM framework should nevertheless enable better integration between applications supporting the other components.

These observations led us to examine the state of work being done at the crossroads of CCM and ICT research domains by examining how ICT is used to support the six domains of the CCM. Our overall motivation is identify the gaps and potential that lie between these research domains, thus enabling more substantive questions and opportunities for accelerating improvements in ICT-supported chronic care.

Figure 1. The Chronic Care Model. (Reprinted with permission from American College of Physicians).



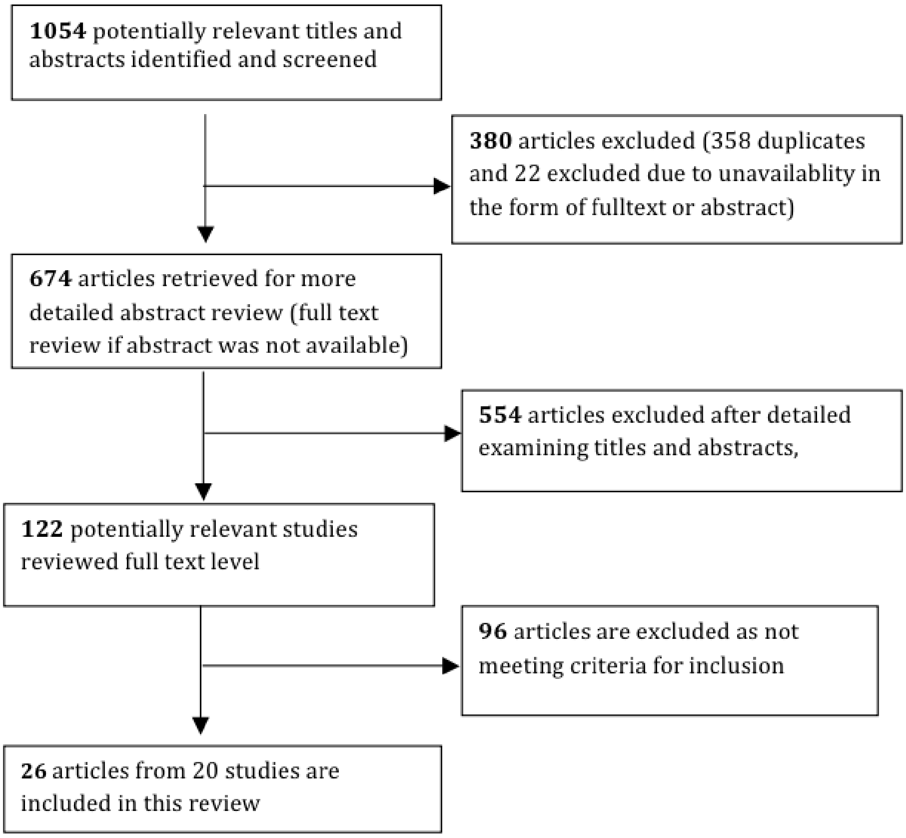
Methods

Study Design

A scoping study approach is a type of review that helps rapidly identify gaps in existing literature and points out areas worth further attention [19,20]. We initially considered conducting a broader scope of the chronic care literature than CCM. It became readily apparent, however, that inclusion of related concepts (chronic care, integrated care, coordinated care, disease management, shared decision making) resulted in a magnitude of literature that was unlikely to offer the types of insights we were seeking, even if we had the resources to analyze it conscientiously. This included extensions of CCM such as that of the World Health Organization, which emphasizes public health and health promotion in communities [6]. Our specific interest in clinical system redesign, coupled with the above arguments about the role of models such as CCM in facilitating stakeholder communication, led us to limit our focus to the basic CCM components. The process of determining inclusion and exclusion criteria was a team process that evolved iteratively during the initial broad searches of key concepts.

The following inclusion and exclusion criteria were applied. Inclusion criteria were: (1) a general focus that is apparent in the abstract on both CCM-theory/ implementation/ practice within a health care setting, and ICT-research and innovation, including innovative use of mature ICT-tools, with a purpose of supporting CCM-practice, and (2) any type of study (review, field study, theoretical analysis, randomized controlled trials). Exclusion criteria were: (1) papers where the CCM or ICT innovation was only peripherally mentioned and was not integral to the main focus of the paper, (2) protocols or abstracts not followed by a peer-reviewed full text publication, (3) commentaries, editorials, letters, and (4) technical feasibility trials. (See Figure 2.)

Figure 2. Flow chart of search results.



Information Sources and Search Strategy

The “Chronic Care Model” was used as the main search term combined with ICT. However, similar to what Coleman found [2], variations in nomenclature used by authors and imprecise descriptions of interventions made it difficult to meaningfully identify CCM-based interventions. Thus, to facilitate the search for and collection of relevant articles, we used the Science Citation Index-Web of Knowledge search tool to gather articles that cite one of five seminal articles [4,21-24] that together originally described the CCM.

In other databases, we searched for English-language publications in a selection of medical/health (Medline, Embase, PsycINFO, Cinahl, and Cochrane Library) and technical (IEEE, ACM Digital Libraries) databases. In the medical/health databases, any paper that included a title, abstract, or keyword referring to ICT-synonyms was considered to be a health ICT-paper. In technical databases, we considered the subset of papers with a health focus to be health ICT-papers either including health-ICT synonyms (eg, health informatics, telemedicine), subject headings, title, or abstract such as “telemedicine”, or papers including a “health” synonym. See Multimedia Appendix 1 for a complete list of search terms. The first search was conducted in October 2011, and last updated in October 2013.

Review of Eligible Papers

Search results were exported to EndNote (X6) (Thomson Reuters, Carlsbad, CA, USA) for merging of databases, identification and deletion of duplicates, and review management. Papers that were identified by database search algorithms as belonging to both the CCM and the health-ICT domain were collected in one common reference database for all CCM and health ICT-papers. In all, 1054 references were identified in all eight databases, of which 358 were identified as duplicates, and 22 excluded due to unavailability in the form of an abstract or full text, leaving 674 unique references eligible for abstract evaluation. In line with scoping studies [19], inclusion was not restricted to specific types of studies (eg, qualitative and quantitative), participants, types of intervention, or type of outcome.

A total of 122 articles were compliant with the above criteria and retrieved in full text for evaluation of eligibility.

Study Selection and Data Collection Process

If the publication did not have an abstract or the abstract was unclear with respect to the degree of CCM focus, the full text was retrieved. Otherwise, eligibility of all papers was primarily based on abstract evaluation.

The validity and reliability of the above inclusion/exclusion criteria was tested in a subset of 40 full-text references that were reviewed both in abstract and in full text, independently by two authors (DG/GB). Of 40 papers, both DG and GB agreed on inclusion of nine papers, exclusion of 30 papers, and disagreed on one paper. Further evaluation of inclusions were done by GB alone, and discussed with DG in cases of ambiguity. The two authors (ATK and KS) extracted data based on the inclusion and exclusion criteria into a structured spreadsheet. All disagreements were resolved by consensus discussion and four articles were discussed in a mini workshop by four authors (ATK, GB, KS, DG) for the final inclusion decision.

When authors reported primary and secondary analyses from the same study in two separate articles, we present them as one study and two articles.

Data Extraction and Management

Authors ATK or KS extracted the following variables from each included article: (1) eligibility criteria, (2) study design, (3) methodology, (4) target groups and topics, (5) the type of ICT used, (6) how the study integrated CCM and all its components, (7) the scale of the implementation, and (8) outcome measures and results relevant to the CCM-ICT implementation.

Analysis Process

In line with scoping studies and the aim of this study, we combined quantitative and qualitative analysis of selected articles resulting in both a descriptive numerical summary and a thematic analysis [19]. Predefined descriptive categories were applied to the initial coding of all articles: to type of article (eg, conceptual and intervention study), topic (eg, disease, technology, patient, provider, both), and issues addressed. All included articles were then examined by ATK and KS using a qualitative content analysis approach [25] resulting in a broad range of dimensions and categories. These were gradually reduced by constantly comparing them for underlying commonalities and discrepancies. Analysis notes and emerging categories were linked to the articles and concepts supporting each category. This allowed co-authors (DG, KS, GB, and CR) to discuss categories and alternative descriptions, although this was only done when co-authors did not intuitively understand the proposed categories. Any disagreement between the reviewers was resolved by consensus discussions.

Results

Descriptive Numerical Summary

The 26 included publications described 20 different studies, all of which were from medical databases. A total of 80% (16/20) of the studies were conducted in the United States, and the rest of the studies were from The Netherlands (n=1), Italy (n=1), Cyprus (n=1), and one study from six Asian countries. Eight studies had been published between 2004 and 2008 and 12 between 2009 and October 2013.

Of the total 20 included studies, 14 used quantitative methodology, four used qualitative methodology, and two studies combined quantitative and qualitative methodologies.

Patient groups were all defined by their health conditions. Diabetes was by far the most common disease type targeted by ICT-CCM implementation studies and accounts for 10 studies of the 20 included studies.

The summary of studies and the diseases that they looked at, the components of the CCM they focused on, and the type of ICT intervention they implemented are presented in Multimedia Appendix 2.

Presentation and Discussion of Thematic Analysis

ICT to Support Patient-Provider Interaction

“Productive interactions” is a critical dimension of CCM and thus of particular interest in this study. A total of 13 out of the 20 papers had ICT-CCM interventions that supported communication between patients and health care providers. Seven of these were one way (from providers to patients), while six offered patients the option to communicate with their providers using the designated ICT. However, for the most part, patients were involved by submitting predefined measures such as signs and symptoms, that is, providing clinical decision support for clinicians and/or patients.

Emails or text messages using mobile phones, secure Web-based systems, and telephone lines were found in 62% (8/13) of the studies that had a primary focus on patient-provider communication [26-33]. This included secure communications that also allowed patients to have full [30] or partial [27,29] access to their electronic health records (EHRs). Additional support included functions such as preventive health reminders, disease-specific information, self-care advice as a response to symptoms and test results, medication refill, appointment booking, laboratory test results, clinic visit summaries, lists of allergies, immunization status, and biometrics [27,31,34]. (See Multimedia Appendix 2.)

The second most common means of patient-provider communications were telephones (n=5), which we included to capture usage of mobile phones. However, only one study [30] used smartphones, two studies used text messaging [32,33], one used analogue telephone lines to transfer data [26], while three used ordinary voice telephony [35-37]. In some of these studies, telephone calls were the only means health care providers had to reach their patients [34-36]. This was done to remind patients when their tests were overdue [34], to provide self-management support to patients using either computer-assisted health education scripts [35], or as scheduled weekly calls to support self-management [36].

Video technology was only used in the Darkins and colleagues [26] study, and only as a tool to support patients needing assistance on how to use their other communication devices and biometric devices to send data to their health care providers. It was reported that it was hardly used. Finally, fax was used for daily data feeds from independent laboratories and automatic test interpretations were sent by fax and mail to providers and patients if not easily reached by electronic networks [31].

In light of the importance CCM places on “productive interactions” and facilitating self-management, it is somewhat surprising that so few studies (six) in our sample appear to leverage ICT for this purpose. Seven of the studies had one-way communication (provider to patient) without offering rationales. The degree to which patients actually were engaged in the management of their care is apparently assumed, but little illuminated.

ICT for Providers Across CCM Components

Seven of the 20 papers primarily focused on communication between health care providers and/or targeted the “clinical decision-making” component. Interventions in this category included physician education and feedback to physicians [38], provider feedback with guideline-driven medication assistance prompts [39], Web-based clinical decision support for providers [40], specialist and primary care physician email communication [41], and secure communication between psychiatric care team composed of primary care physicians, psychiatrists, and supporting nurses [42]. Other similar interventions included a Web-based decision support program that also provided feedback report to patients [43], a Web-based decision support system [40,42], and a Web-based feedback to clinicians with a simultaneous feedback report system for patients [39]. Implementation of EMRs and computerized disease registries to help support clinical data collection [24,38,42] were also among the ICT interventions.

While clinical decision support and effective provider-provider communication are vital components in CCM, it was often difficult to decipher how the interventions were expected to more specifically contribute either to the “informed activated patient”, the “prepared proactive team”, or both. Further, descriptions of how the interventions were expected to interact with, or at least complement, other CCM-components such as “self-management support” or “delivery system design” were typically lacking. In these cases, it was not apparent why CCM was used as a framework at all.

The CCM − ICT Gap

The ICTs in the included studies can be characterized as “old-fashioned” (with the exception of an unsuccessful experiment with gaming technology [30]). None of the studies in our sample were published in technical research venues. This apparent neglect of ICT research and innovation to embrace state-of-the-art approaches to solutions for chronic care is worth noting and may reflect a number of factors.

First, ICT innovations that are introduced into health care typically need to interact with pre-existing, often highly complex and inflexible systems, such as EHR. Testing ICT innovations in real-life clinical practices, even “simple” plug-in interventions, often require developing interfaces with EHR systems, which in itself can be costly and complex both legally and organizationally. This may discourage decision-makers in health care organizations from embarking on innovation processes. Technologists on the other hand need expeditious environments where they can iteratively test and evolve innovations before market deployment.

Second, ICT research faces the same type of “translational” challenge as medical research. ICT research typically tests “hypotheses” through prototypes which, as with medical research findings, often fail to translate into contexts of practice [44]. It can be argued that many ICTs could be well suited for solutions in chronic care, had broader frameworks (eg, CCM) been used to facilitate the multidisciplinary and stakeholder dialogue necessary for adapting and applying innovative solutions to contexts of practice.

Third, ICT-interventions involving patients face digital divide issues related to accessibility regardless of income and digital literacy. Important work in addressing this challenge is found in ICT research and innovation explicitly targeting elderly populations, and is often referred to as “independent or assisted-living technologies” [45] and “welfare technologies” [12]. Inspired by disability research, these domains more explicitly adhere to universal design principles and low-cost accessibility. We were somewhat surprised that our study did not detect any work from this area, possibly reflecting sectorial distinctions between health care (from which CCM emerged) and disability/social services (from which welfare technologies emerged).

It would be worthwhile to explore more closely the causes of the apparent gap between CCM and ICT innovation, as well as the potential of CCM to facilitate productive synergies with work being conducted on welfare technologies.

CCM Lost in Translation

In most of the articles in this review, authors start by describing thoroughly all the components of the CCM and how important it is to integrate them in their upcoming implementation. However, there was a tendency to restrict the interventions to selected CCM components during the course of the implementation process. For example, Samoutis and colleagues [46] discussed all the components of the CCM in the planning phase, but dropped self-management support and utilization of community resources during the intervention, without offering rationales. Some explicitly limited their focus to certain components of the CCM, while the study by Darkins and colleagues was the only study where ICT interventions supported more or less all six components of the CCM [26].

The CCM components most focused upon in our included studies were delivery system design, decision support, and self-management support. The CCM components that were least associated with ICT implementation were community resources and health system organization. While the first is an obvious candidate for facilitation through social media, none of the studies reviewed suggested this.

Inconsistency in the integration and application of the CCM components was observed throughout our sample. Almost none of the CCM-ICT interventions that we have included are alike, or follow the same pattern of implementation. Also, CCM’s basic principles of patient engagement, that is, shared decision making toward a care plan aligned with patient needs, values, and preferences were barely detected in our sample.

These observations probably reflect the nature of CCM. It is an overarching framework for entire health care system design. To be useful, it needs to be operationalized and tailored to local context. This process has no guidelines. We see that the dual focus on the two main components (patients and teams) is often lost in this process.

CCM’s strength is its general and overarching focus on all system components, which has inspired health care reforms across the world. We have identified an important gap between the agenda of health care and the agenda of ICI research domains. The ICT world does not seem to know or understand the language and challenges represented by the CCM. Equally, the CCM champions do not seem to be aware of or capable of applying novel technologies in their approaches.

Organizational and ICT Challenges

While few of the studies offered details about challenges, we noted the following: only a few studies managed to fund the interventions after the research/pilot projects ended [35,47]. Handing over the programs to non-profit managed care organizations was found to be one solution to sustain the programs [35]. Challenges also included provider resistance to using secure electronic messaging [29], along with challenges with the ICT itself, which ranged from minor technical problems [28] to absence of ICT resources (eg, computers, patient websites, and medical records) for successful integration of CCM-ICT interventions [27,24,47].

The lack of access to, for example, the Internet was also mentioned as a challenge, particularly for patients with low socioeconomic status or old age [27]. Individuals who are uninsured or publicly insured or those with communication barriers with limited literacy or limited language proficiency were also seen to be challenged by traditional mobile text messaging [36]. Similarly, use of unfamiliar ICT for patients and non-age appropriate ICT caused intermittent technical difficulties in uploading self-monitored blood glucose values [30]. Innovations to lessen the digital divide should be a major concern for further policies in chronic care.

Discussion

Principal Findings

This scoping study offers insights into the state of work being done at the crossroads of CCM and ICT with the intention of pinpointing possible gaps and synergies. The following is worth noting from this study.

The identified gap between CCM-inspired policy reforms and research and ICT research and innovation gives rise to important questions. What significant synergies can be leveraged by explicitly linking ICT research and innovation to CCM-based interventions? For example, what can the ICT research domain of Computer Supported Cooperative Work contribute in enhancing CCM’s productive interactions between patients and proactive care teams? The introduction of patients into cooperative work processes raises a range of issues that are both exciting and potentially of enormous impact. Exploring this potential would be worthwhile.

ICT innovations championed under headings such as “assisted living” and “welfare technologies” would seem well suited in supporting informed and active patients, and linking them to proactive care teams. Arguably, this would also help address digital divide issues noted in this review. Nevertheless, our study did not detect that this is happening. Rather, much of the work can be characterized by traditional medical informatics that supports the clinical work of providers.

Existing ICT infrastructures in health care (eg, EMR, data security issues) and the complexities, costs, and risks involved in changing them probably represent major barriers to innovation. It is perhaps not a coincidence that the Darkins study from the Veterans Administration was the most comprehensive both in terms of CCM and ICT. For health system organizations built around separate administrative levels of care, the complexities of negotiating innovative models of care across entities are even greater. Establishing large-scale living labs [48] or intermediate platforms for research and innovation that can safely interact with existing systems without disrupting ordinary clinical services may be one way of facilitating iterative innovation processes.

CCM offers a framework to aid communication across research domains and stakeholders. Other frameworks (eg, Patient-Centered Medical Homes [49]) can serve the same purpose assuming that they are supported by evidence and can facilitate communication between research domains and stakeholders. Given the complexities of chronic care, and the enormity of efforts needed to improve it, common frameworks such as CCM can increase the likelihood that the multitude of projects and innovations can be more systematically applied and assessed in terms of how well they contribute to improving the overall care delivered.

Strengths and Limitations

Limiting our search to CCM is both a strength and weakness. The obvious weakness is that relevant work using similar models and concepts referred to in the chronic care literature are not included in the study. Thus, we cannot claim to offer a total overview of what is happening at the crossroads of chronic care and ICT research and innovation. The strength of limiting our search to CCM is that it is clearly defined, it is currently recognized as the best synthesis of evidence, and it serves as a framework for health system redesign in Western countries [2,3]. Also, most other system models for chronic care build on, or are an adaptation of, the CCM in some way. Thus, we are confident that our observations are relevant and worth attention also for those applying other chronic care frameworks. Another strength of this study is the novel approach to identifying synergies between domains of chronic care and ICT research and innovation. Identifying gaps and synergies is an important step in leveraging the resources of these domains to meet the massive challenges of chronic and lifestyle-related diseases.

Conclusions

Efforts to bridge the gaps identified in this study need explicit and urgent attention as the synergies between domains of research have enormous potential. Policy makers, journals in the health-ICT field, and funding agencies need to facilitate the joining of forces between high-tech innovative expertise and experts in chronic care health system redesign that is required for tackling the epidemic of long-term multiple conditions in populations.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Search terms.

[PDF File (Adobe PDF File), 37KB - jmir_v17i2e25_app1.pdf]

Multimedia Appendix 2

Included articles.

[XLSX File (Microsoft Excel File), 16KB - jmir_v17i2e25_app2.xlsx]

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Abbreviations

CCM: Chronic Care Model
EHR: electronic health record
EMR: electronic medical record
ICT: information communication technology

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Original Paper

Integrating Health Belief Model and Technology Acceptance Model: An Investigation of Health-Related Internet Use

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Abstract

Background: Today, people use the Internet to satisfy health-related information and communication needs. In Malaysia, Internet use for health management has become increasingly significant due to the increase in the incidence of chronic diseases, in particular among urban women and their desire to stay healthy. Past studies adopted the Technology Acceptance Model (TAM) and Health Belief Model (HBM) independently to explain Internet use for health-related purposes. Although both the TAM and HBM have their own merits, independently they lack the ability to explain the cognition and the related mechanism in which individuals use the Internet for health purposes.

Objective: This study aimed to examine the influence of perceived health risk and health consciousness on health-related Internet use based on the HBM. Drawing on the TAM, it also tested the mediating effects of perceived usefulness of the Internet for health information and attitude toward Internet use for health purposes for the relationship between health-related factors, namely perceived health risk and health consciousness on health-related Internet use.

Methods: Data obtained for the current study were collected using purposive sampling; the sample consisted of women in Malaysia who had Internet access. The partial least squares structural equation modeling method was used to test the research hypotheses developed.

Results: Perceived health risk (β=.135, t_{1999}=2.676) and health consciousness (β=.447, t_{1999}=9.168) had a positive influence on health-related Internet use. Moreover, perceived usefulness of the Internet and attitude toward Internet use for health-related purposes partially mediated the influence of health consciousness on health-related Internet use (β=.025, t_{1999}=3.234), whereas the effect of perceived health risk on health-related Internet use was fully mediated by perceived usefulness of the Internet and attitude (β=.029, t_{1999}=3.609). These results suggest the central role of perceived usefulness of the Internet and attitude toward Internet use for health purposes for women who were health conscious and who perceived their health to be at risk.

Conclusions: The integrated model proposed and tested in this study shows that the HBM, when combined with the TAM, is able to predict Internet use for health purposes. For women who subjectively evaluate their health as vulnerable to diseases and are concerned about their health, cognition beliefs in and positive affective feelings about the Internet come into play in determining the use of health-related Internet use. Furthermore, this study shows that engaging in health-related Internet use is a proactive behavior rather than a reactive behavior, suggesting that TAM dimensions have a significant mediating role in Internet health management.

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KEYWORDS

health beliefs; Technology Acceptance Model; health-related Internet use behavior; mediation effect

Introduction

Health-Related Internet Use

Millions of people throughout the world use the Internet and much of this activity is focused on health [1,2]. The Internet is frequently used for seeking health information and communicating for health-related purposes [3-5]. Information seeking refers to the "purposive seeking for information as a consequence of a need to satisfy some goal" [6]. Individuals seek information to fill gaps between what they know and what they need to know in various fields including health. Health information seeking takes place in an environment where different sources are available [7] and information seekers consciously select 1 or more sources to meet their informational need [8]. Among formal and informal health information sources, however, mass media play a vital role in the dissemination of information: the Internet is a key source for information. The Internet as the largest online medical library contains more than 100,000 health-related websites [9]. Internet-based dissemination of health-related information is often suggested as an optimal way to spread health information [10] because the Internet provides privacy, immediacy, faster and easy access to a wide variety of health information, and a variety of perspectives on health-related issues [11,12].

The Internet not only functions as a rich source of health information, but it also provides interactivity between professionals and health seekers through an electronic or communication tool to gain and convey health information [13]. The interactive features of the Internet, such as emailing, chatting, and discussion forums, provide users with the opportunity to leave their questions related to their health and to contact with others, to share and exchange their experiences about a disease, to ask for the best physicians in the field, and to get and give psychological, emotional, and spiritual support from support groups such as bulletin boards and chat rooms [4,5,14,15]. All these communication-based activities on the Internet are not so easily performed through other media forms such as newspapers, radio, or television [16]. Internet use helps people make key health care decisions by connecting with those who access health information, and interacting with health professionals and social support groups [17].

Such importance placed on the Internet as a health-seeking platform helps people maintain, promote, and manage their health. Past research shows that women are more likely to use the Internet for health-related purposes than men [1,2]. In Malaysia, the use of the Internet to manage health and to learn more about diseases has become increasingly important [18] due to the increase in the incidence of chronic diseases, in particular among urban women [19]. Malaysian women, like women in other parts of the world, live longer than men, but are more susceptible to chronic diseases that are preventable [19]. The Internet can be beneficial for empowering women to take responsibility for their own health, decreasing the incidence of illness, and enhancing well-being. This could possibly explain why women are the dominant Internet users in terms of health information seeking even though the number of male Internet users is higher than that of female users [20].

Health-Related Internet Use From the Health Belief Model Perspective

Although an abundance of research can be found on Internet health care information-seeking behavior, a major focus of these studies tends to concentrate on understanding the use of the Internet for health information-seeking behavior based on the Health Belief Model (HBM). The HBM was initially developed to predict the behavioral reaction of individuals with acute or chronic diseases to the treatment they receive [21], but the model was later employed to predict more general health behavior [22,23]. The basic assumption of the HBM is that, in the absence of any symptoms, individuals will not take health or preventive measures unless that they are psychologically ready (eg, they feel vulnerable to a disease) [21]. The HBM suggests that belief in health risk predicts the likelihood of engaging in health behavior [21]. Perceived health risks consist of 2 dimensions: perceived susceptibility to disease and perceived severity of disease. *Perceived susceptibility to disease* refers to "beliefs about the likelihood of getting a disease or condition" [21]. *Perceived severity of disease*, on the other hand, is defined as "feelings about the seriousness of contracting an illness or of leaving it untreated include evaluations of both medical and clinical consequences (eg, death, disability, and pain) and possible social consequences (eg, the effect of the condition on work, family life, and social relations)" [21].

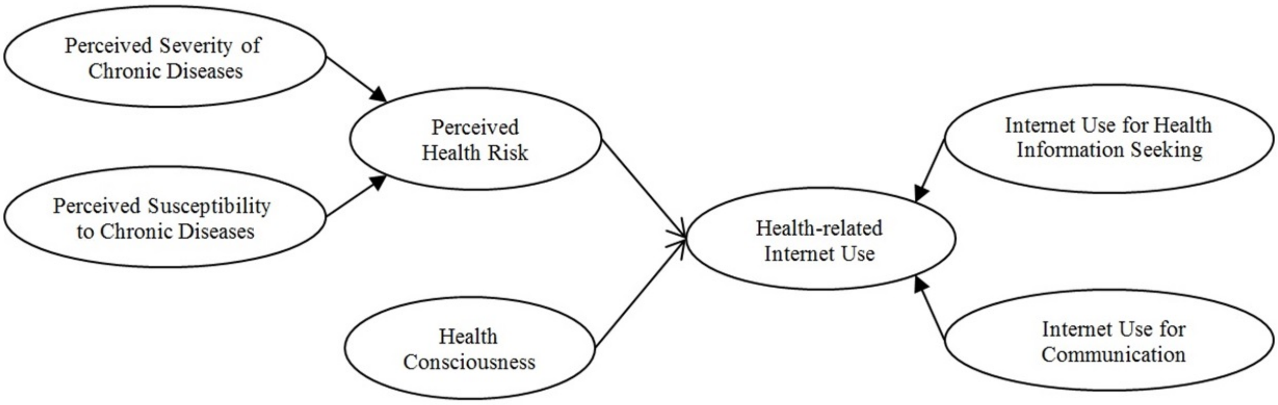
Individuals with higher perceived health risk have greater motivation to change or adopt a health-oriented behavior, including adopting a preventive health behavior such as seeking information and using information and communication channels (eg, the Internet) to satisfy health-related information and communication needs [24-27] (Figure 1).

Results of past studies found that women tend to have a higher perceived health risk than men [28,29]. Moreover, perceived health risk is the most important and noticeable predictor in determining women's health behavior adoption [30].

As well as perceived health risk, health consciousness is another dimension that influences health-seeking behavior. *Health consciousness* is defined as "the degree to which health concerns are integrated into a person's daily activities" [31]. Health-conscious people are aware of and concerned about their wellness; therefore, they are motivated to improve and/or maintain their health.

Health consciousness is a predictor of the use of communication channels for health information seeking [32-34]. Health consciousness increases the amount of health-related information obtained from media sources such as television, radio programs, books, newspapers, magazines, advertising, and pamphlets about health [35]. The positive attitude toward the Internet has made it a primary health information source (Figure 1), in comparison to mass media (eg, television and radio), for learning about health-related issues [4,5,33] as previously discussed. In essence, the Internet has enabled individuals to be proactive in managing their health through seeking, exchanging, and communicating health-related information via the e-platforms.

Figure 1. Hypothesized model based on the Health Belief Model.



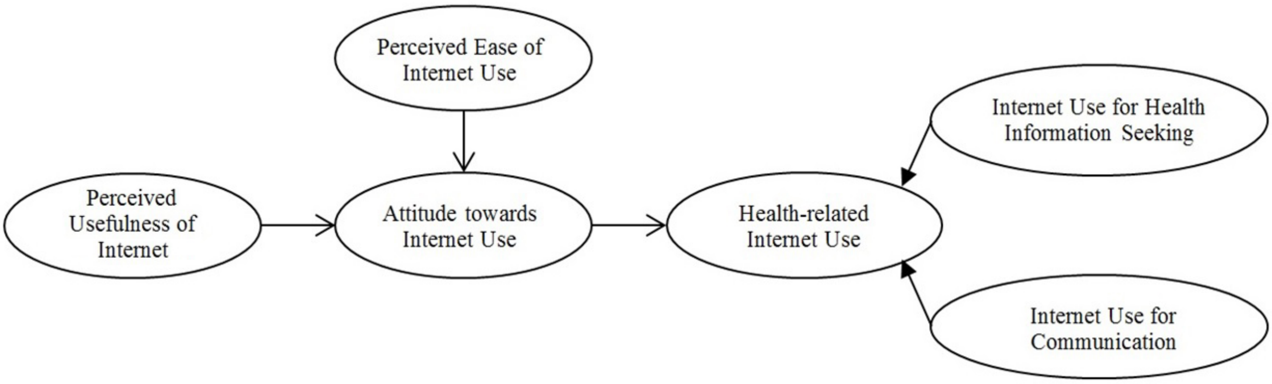
Health-Related Internet Use From the Technology Acceptance Model

Other studies that contribute toward the extant literature include those that are based on the Technology Acceptance Model (TAM) [36,37]. Although the HBM perspective explains health-related Internet use via the subjective assessment of an individual's vulnerability to health risks and one's consciousness toward health, the TAM views health-related Internet use behavior from the technology perspective (ie, the usefulness and ease of use of the Internet and one's attitude toward Internet use) [38].

The TAM was developed to enable understanding of the use of technology [38] and is most commonly used for studying technology-related behavior such as the Internet and computer use in different contexts including health. The TAM has 3 dimensions: perceived usefulness, perceived ease of use, and attitude toward technology use. *Perceived usefulness* is defined "as the belief about using the technology that would bring benefits to the user," whereas *perceived ease of use* refers to "the belief about using the technology that involves little effort" [36]. Perceived usefulness and perceived ease of use both affect attitude toward using the technology, which in turn influences behavioral intention to adopt the technology [36]. Attitude involves an individual's belief about the consequences of performing a behavior (eg, technology use), whether it is good or bad, and the general evaluation influences an individual's inclination to use or not to use a particular technology [39]. Attitude guides an individual's behaviors by shaping perception [39].

Using the TAM framework, studies showed that perceived usefulness, perceived ease of use and attitude, positively influence behavioral intention to use health information technologies such as the Internet and mobile phones [36,40]. Furthermore, all studies that applied the TAM in the health care domain included behavioral intention to use health information technology, which is driven by the Internet [24,36,37] (Figure 2).

Figure 2. Hypothesized model based on Technology Acceptance Model.



Integrating the Health Belief Model and the Technology Acceptance Model

Although many past studies on Internet use for health-related purposes adopted the TAM or HBM, the use of these theories independently has not been able to explain fully Internet health-seeking behavior. The TAM has been used to predict an individual's technology use; however, it is an inadequate model for health-related Web use because of its heavy dependence on 2 factors: perceived usefulness and perceived ease of use of technology [38]. The HBM attempts to explain the factors that influence health-related Internet use from purely the health perspective and it does not explain the mechanism or the process that lead to the behavior. Although the TAM has been widely used in explaining behavior that relates to technology [36,38,40], its effect on Internet use for health-related purposes could only be fully understood by incorporating dimensions of the HMB that explain individuals' belief about health into the model. In short, there is a need to examine health-related Internet use from an integrated perspective that combines cognition, attitude, and behavior as well as the subjective evaluation of the psychological states of individuals regarding their perception of their health status.

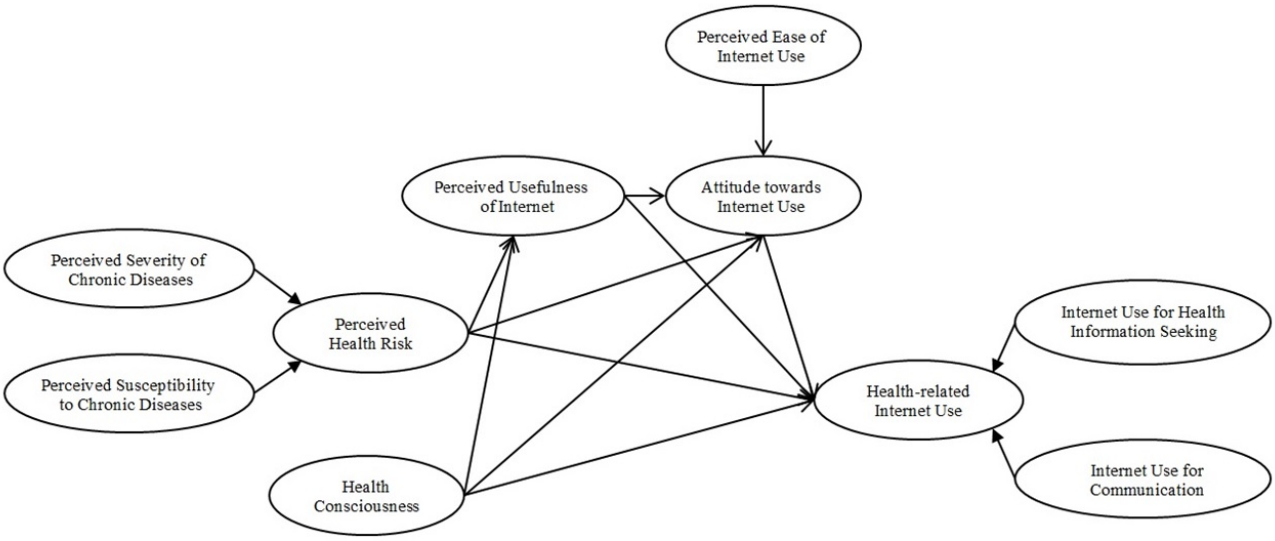
By incorporating constructs of technology acceptance based on the TAM and perceived health risk and health consciousness as explained by the HBM, an integrated model of health-related Internet use behavior is proposed whereby perceived usefulness of the Internet and attitude toward the Internet for health purposes mediate the relationship between perceived health risks as well as health consciousness and health-related Internet use behavior (Figure 3). In this model, individuals who perceive their health to be at risk or are motivated to use the Internet when they believe that the Internet is useful for providing information on health and health management would be expected to have a positive attitude toward Internet use for health purposes. In other words, cognitive and affective beliefs toward the Internet become central to a person who perceives his/her health to be at risk or is conscious about health. Therefore, these individuals would have greater technology usage (ie, the Internet).

This study aimed to examine the influence of perceived health risk and health consciousness on health-related Internet use based on the HBM. The model developed for the purpose of this study incorporated the TAM to provide a better understanding of the process that affects the adoption of Internet use for health purposes. Based on the integrated model, this study set out to test the mediating effect of TAM constructs, perceived usefulness of the Internet, and attitude toward Internet use on the relationship between perceived health risk and health consciousness on Internet use for health purposes. Table 1 shows the 4 hypotheses developed for the purpose of this study based on the literature reviewed previously.

Table 1. Research hypotheses for explaining health-related Internet use drawing upon the Health Belief Model and the Technology Acceptance Model.

Research hypotheses	Path (causal effect)	Sources
H_1: Perceived health risk toward chronic diseases consisted of perceived susceptibility to chronic diseases and perceived severity of chronic diseases has a positive effect on health-related Internet use	Perceived health risk → health-related Internet use	[21,25,26]
H_2: Health consciousness has a positive effect on health-related Internet use	Health consciousness → health-related Internet use	[31-33]
H_3: The effect of perceived health risk, consisted of perceived susceptibility to chronic diseases and perceived severity of chronic diseases, on health-related Internet use is mediated by perceived usefulness of the Internet, and attitude toward Internet use for health information and health management	Perceived health risk → perceived usefulness of the Internet → attitude toward Internet use → health-related Internet use	[36-38]
H_4: The influence of health consciousness on health-related Internet use is mediated by perceived usefulness of the Internet, and attitude toward Internet use for health information and health management	Health consciousness → perceived usefulness of the Internet → attitude toward Internet use → health-related Internet use	[24,38]

Figure 3. Integrated model based on the Health Belief Model and the Technology Acceptance Model.



Methods

Sample and Data Collection

The participants in this study consisted of Malaysian females living in the state of Selangor, the most urbanized state in Malaysia. Purposive sampling was used. Women who were Internet users were selected as the sample for the purpose of this study because past research found that they tend to be educated, married, and live in urban areas [15,41,42]. Furthermore, they tend to search for information regarding health [1,2,43]. Using the drop-and-collect method, a questionnaire was distributed to only those who expressed their willingness to be respondents. The purposive samples were sourced from women working in governmental institutions located in Selangor state through friends' contacts.

Out of 380 questionnaires distributed, 330 completed questionnaires were obtained. From the 330 sets of questionnaires returned, 293 responses were usable after excluding cases that had not used the Internet for health-related purposes and cases with incomplete information.

As shown in Table 2, 127 of 293 respondents (43.0%) were in the 30 to 39 age group, 193 of 293 (66.5%) were married, 138 of 291 (47.5%) reported that they had a college or university degree, and 133 of 288 participants (46.0%) had an income in the range of 3000-5999 Malaysian Ringgit (RM) (US $882-$1764).

Table 2. Descriptive statistics of demographic characteristics of participants (N=293).

Characteristics	n (%)
Age (years)	
20-29	110 (37.5)
30-39	127 (43.0)
40-49	43 (15.0)
≥50	13 (4.5)
Marital status	
Single	92 (31.5)
Married	195 (66.5)
Others	6 (2.0)
Education level	
Primary school	18 (6.0)
Secondary school	138 (47.5)
College/university	135 (46.5)
Household income (RM)	
1000-2999	114 (39.5)
3000-5999	133 (46.2)
6000-8999	39 (13.5)
≥9000	2 (0.7)

Measures

Perceived Health Risk

Perceived health risk contains 2 subdimensions: perceived susceptibility to chronic diseases and perceived severity of chronic diseases. Perceived susceptibility to chronic diseases was measured by 6 items adopted from Kim and Park [37] and Bryan et al [44]. Perceived severity to chronic diseases was measured by 4 items adopted from the Kim and Park study [37]. All items of these constructs were rated on a 5-point Likert-type scale (1=strongly disagree, 2=disagree, 3 =neutral, 4=agree, and 5=strongly agree) (Multimedia Appendix 1).

Health Consciousness

Participants' health consciousness was measured by 11 items covering most facets of health consciousness adopted from Chen [45] and modified for this study. All items of these constructs were rated on a 5-point Likert-type scale (1=strongly disagree, 2=disagree, 3=neutral, 4=agree, and 5=strongly agree) (Multimedia Appendix 1).

Perceived Usefulness of the Internet for Health Information and Health Management

Items that measured perceived usefulness of the Internet for health information and health management were adopted from Davis [38]. All items of these constructs were rated on a 5-point Likert-type scale (1=strongly disagree, 2=disagree, 3=neutral, 4=agree, and 5=strongly agree) (Multimedia Appendix 1).

Perceived Ease of Internet Use

Perceived ease of Internet use was assessed by the 4 items developed by Davis [38]. All items of these constructs were rated on a 5-point Likert-type scale (1=strongly disagree, 2=disagree, 3=neutral, 4=agree, and 5=strongly agree) (Multimedia Appendix 1).

Attitude Toward Internet Use for Health Issues

Four items on attitudes toward Internet use for health information were adopted from the study by Wong et al [36]. All items of these constructs were rated on a 5-point Likert-type scale (1=strongly disagree, 2=disagree, 3=neutral, 4=agree, and 5=strongly agree) (Multimedia Appendix 1).

Health-Related Internet Use

Health-related Internet use had 2 subdimensions: Internet for seeking health and medical information and Internet use to communicate health-related issues. Internet use for health information seeking was measured by 11 items and Internet usage for communication on health-related issues was measured by 5 items adopted from past studies [5,37,46]. Respondents were asked to indicate how frequently they use the Internet for health and medical information and to communicate on health-related issues. All 16 items were rated on a 5-point Likert-type scale (5=always, 4=often, 3=sometimes, 2=rarely, and 1=never). A higher score indicated a higher frequency of Internet usage for health information seeking and communication for health-related issues (Multimedia Appendix 1).

Results

We used the partial least squares structural equation modeling (PLS-SEM) method and SmartPLS software 2.0 [47] to estimate the structural model paths (Figure 4) and test the research hypotheses. PLS-SEM can cope with formative constructs and is appropriate for assessing relatively new measurement models. Both the constructs health-related Internet use (a second-order formative-formative construct) and perceived health risk (a second-order reflective-formative construct) justified the use of PLS-SEM for data analysis.

There are 3 different approaches to estimate parameters in models with second-order constructs: (1) the repeated indicator approach, (2) the 2-stage approach, and (3) the hybrid approach [48]. For the purpose of this study, a 2-stage approach was used. This is because the endogenous variable in the model of this study (health-related Internet use) is a formative second-order construct, which requires a 2-stage approach [48]. In the 2-stage method, first we specified the model with first-order constructs. Subsequently we estimated the latent variable scores of the first-order constructs and used these scores as indicators for the second-order constructs [48].

In order to discover the structure of reflective latent variables and to identify the underlying variance structure of a set of indicators, this research used exploratory factor analysis (EFA) [49]. Using oblique rotation, maximum likelihood factor extraction was performed on the 33 items of reflective constructs (refer to Table 2 for reflective constructs).

The Kaiser-Meyer-Olkin measure of sampling adequacy (0.816) and Bartlett’s test of sphericity results ($P<.001$) indicated the suitability of the data for factor analysis [50]. There were 54 (14.0%) nonredundant residuals with absolute values greater than .05 and the factors explain 63.71% of total variance. We excluded 5 items due to their low factor loadings and cross loadings over factors (ie, 1 item from perceived usefulness of the Internet, 1 item from perceived ease of Internet use, and 3 items from health consciousness). The details of the measurement properties of each reflective construct are reported in Table 3.

Table 3. Reflective constructs assessment.

Construct/measure	Factor loading[a]	Construct reliability	Average variance extracted	Maximum shared squared variance	Average shared square variance
Perceived susceptibility to chronic diseases		0.916	0.646	0.092	0.042
I have a higher likelihood of getting chronic diseases	0.873				
There is a great chance that I will be exposed to a chronic disease	0.808				
I would say that I am the type of person who is likely to get chronic diseases	0.891				
There is a person with chronic disease among my family members	0.759				
I have a strong possibility of attack or deterioration of chronic disease due to improper daily habits (drinking, smoking, dietary habit, lack of exercise, etc)	0.707				
It is most likely that I will catch chronic diseases in my lifetime	0.771				
Perceived severity of chronic diseases		0.900	0.694	0.022	0.011
I am afraid of facing attack or deterioration of chronic diseases	0.756				
If I face attack or deterioration of chronic disease, I will have difficulty with my work life (or domestic affairs)	0.807				
If I face attack or deterioration of chronic disease, it will hinder my personal relationships	0.896				
If I face attack or deterioration of chronic disease, I will be long haunted by resultant problems	0.865				
Health consciousness		0.925	0.608	0.228	0.140
I have the impression that I sacrifice a lot for my health	0.791				
I consider myself very health conscious	0.837				
I think that I take health into account a lot in my life	0.876				
I think it is important to know well how to stay healthy	0.883				
My health is so valuable to me that I am prepared to sacrifice many things for it	0.766				
I have the impression that other people pay more attention to their health than I do	0.767				
I do not continually ask myself whether something is good for me	0.665				
I often dwell on my health	0.610				
Perceived ease of Internet use		0.905	0.760	0.336	0.221
My interaction with the Internet for health information is clear and understandable	0.857				
I find the Internet for health information to be flexible to interact with	0.880				
It is easy for me to become skillful at using the Internet for health information	0.878				
Perceived usefulness of the Internet		0.928	0.811	0.344	0.218
Using the Internet is useful in managing my daily health	0.873				
Using the Internet for health information is advantageous in better managing my health	0.937				

Construct/measure	Factor loading[a]	Construct reliability	Average variance extracted	Maximum shared squared variance	Average shared square variance
Using the Internet for health information is beneficial to me	0.890				
Attitude toward health-related Internet use		0.933	0.777	0.344	0.303
Using the Internet for health information and health management would be a good idea	0.894				
Using the Internet for health information and health management would be a wise idea	0.872				
I like the idea of using the Internet for health information and health management	0.895				
Using the Internet for health information and health management would be a pleasant experience	0.865				

[a] The total variance explained by factors=63.713%. All factor loadings were more than 0.5 and significant (*P*<.05).

Subsequently, we assessed the construct reliability, convergent validity, and discriminant validity of reflective constructs [51]. Construct reliability greater than 0.7 is an acceptable reliability coefficient [51,52]. As shown in Table 3, the construct reliability of all reflective constructs varied from 0.900 to 0.933, which indicates good reliability. Then we assessed convergent and discriminant validity by estimating average variance extracted (AVE), maximum shared squared variance (MSV) and average shared square variance (ASV) [51,53]. For convergent validity, the results of this study show that the AVE of constructs exceeded 0.5 and construct reliability was greater than AVE, fulfilling the requirements of convergent validity [53].

To establish discriminant validity, both MSV and ASV should be less than the value of AVE. As shown in Table 2, MSV and ASV were less than AVE, indicating that there were no convergent and discriminant validity issues for the reflective constructs in this study.

In contrast to reflective constructs, indicators of formative constructs are not interchangeable and they do not necessarily have high intercorrelation [54]. In fact, high intercorrelation between indicators of formative constructs can increase the standard error, which results in instability of item coefficients [55]. Hence, instead of assessing reliability, convergent validity, and discriminant validity of formative constructs by conventional methods, we assessed them for collinearity issues [56,57].

In order to assess formative constructs, the collinearity issue was examined by computing correlation and the variance inflation factor (VIF). Table 4 shows maximum VIF and correlation between indicators of each formative construct. Because the maximum VIF for Internet usage for health information seeking and Internet usage to communicate for health indicators was less than 5, and indicators do not have high intercorrelation, this indicates an absence of a collinearity issue [58]. Further, to evaluate the contribution of formative indicators and their relevance, the factor weight of each indicator was assessed. As shown in Table 3, although only 3 indicators of Internet usage for health information seeking have significant weights, all outer loadings were greater than 0.5 (range 0.505-0.836). In addition, although Internet usage to communicate had 1 indicator with significant weight, factor loadings for all indicators were greater than 0.5 (range 0.655-0.931). Thus, all indicators of Internet usage for health information seeking and Internet usage to communicate made an absolute contribution to their respective constructs [58].

In the second stage of the 2-stage method, latent variable scores of perceived susceptibility to chronic disease and perceived severity of chronic disease as well as latent variable scores of Internet usage for health information seeking and Internet usage for communication were estimated and used to evaluate the formative second level of perceived health risks and health-related Internet use, respectively. The VIF of indicators of health-related Internet use and PHR was less than 5, which indicates an absence of collinearity issue. Moreover, the significant factor weights of perceived susceptibility to chronic disease, perceived severity of chronic disease, Internet usage for health information seeking, and Internet usage for communication show that they make a significant contribution to perceived health risks and health-related Internet use.

Table 4. Formative constructs assessment.

Construct/measure	Indicator weight	t_{1999}	Indicator outer loading	Interitem correlation, mean (range)	Variance inflation factor, maximum
Internet usage for medical and health information seeking				0.536 (0.312-0.774)	30.665
I use the Internet to get general health information	0.161	1.501	0.594		
I use the Internet to get information on medicine/drugs	0.450	3.945	0.836		
I use the Internet to be equipped with information before/after doctor's appointment	–0.348	1.877	0.595		
I use the Internet to get descriptions of various diseases	0.115	0.793	0.717		
I use the Internet to get information on treatments/therapy/diagnosis	0.121	0.883	0.708		
I use the Internet to get information on how to care for oneself	–0.201	1.468	0.567		
I use the Internet to decide about how to treat an illness	0.444	3.011	0.803		
I use the Internet to decide about whether or not to visit a doctor	0.097	0.735	0.735		
I use the Internet to understand how to deal with an illness	0.111	0.610	0.643		
I use the Internet to get information on hospitals/clinics/other health care facilities	0.257	2.112	0.717		
I use the Internet to get information on health management (exercise, abstinence from drinking, smoking, diet, nutrition, stress, mental health, etc)	–0.002	0.015	0.505		
Internet usage to communicate about health				0.572 (0.441-0.685)	20.779
I use the Internet to get online medical consultation from medical professionals	0.601	3.433	0.931		
I use the Internet to interact with people with similar health conditions	0.280	1.462	0.833		
I use the Internet to use mail to communicate with a doctor or a doctor's office	–0.021	0.129	0.655		
I use the Internet to share and exchange experiences about health and diseases	0.289	1.312	0.765		
Health-related Internet use				0.595	10.549
Internet usage for medical and health information seeking	0.853	10.766	0.984		
Internet usage to communicate for health	0.221	2.021	0.728		
Perceived health risk				0.005	10.000
Perceived susceptibility to chronic diseases	0.946	14.430	0.948		
Perceived severity of chronic diseases	0.319	1.967	0.324		

Next, in testing the hypotheses developed for this study, a bootstrapping resampling method with 2000 replications was performed [59]. Bootstrapping is a nonparametric approach that makes no distributional assumptions of variables and lets us estimate standard errors and confidence intervals and test the research hypotheses. In testing the mediation effect, a bootstrapping approach is more accurate and has higher statistical power than the approaches of Barron and Kenny [60], Sobel [61], and Taylor et al [62-64].

Standardized path coefficients, *t* value, and the percentile bootstrap 95% confidence interval of total, direct, and indirect effects on health-related Internet use are shown in Table 5.

Table 5. Direct, indirect, and total effects.[a]

Path	R^2	Q^2	Standardized path coefficient, β (95% CI)	t_{1999}(bootstrap)
Total effect				
Health-related Internet use	.2395	.1531		
Perceived health risk (c_1)			.135*(.036, 234)	2.676
Health consciousness (c_2)			.447***(.351, .542)	9.168
Direct effect				
Perceived usefulness of the Internet	.1821	.1460		
Perceived health risk (a_{11})			.309***(.216, .401)	6.538
Health consciousness (a_{21})			.269***(.165, .373)	5.063
Attitude toward Internet use	.5284	.4074		
Perceived usefulness of the Internet (d)			.334***(.224, .443)	5.955
Perceived health risk (a_{12})			.063 (–.034, .160)	1.278
Health consciousness (a_{22})			.270***(.167, .374)	5.118
Perceived ease of Internet use (e)			.322***(.215, .429)	5.910
Health-related Internet use	.3827	.2767		
Attitude toward Internet use (b_1)			.284***(.175, .392)	5.123
Perceived usefulness of the Internet (b_2)			.266**(.155, .377)	4.681
Perceived health risk (c'_1)			.019 (–.079, .117)	.383
Health consciousness (c'_2)			.211***(.107, .316)	3.958
Indirect effect				
Health-related Internet use	.3827	.2767		
Attitude toward Internet use, perceived usefulness of the Internet, perceived health risk (a_{11}.d.b_1)			.029**(.013, .045)	3.609
Attitude toward Internet use, perceived usefulness of the Internet, health consciousness (a_{21}.d.b_1)			.025*(.010, .041)	3.234

[a] Arrows show the influence direction in the hypotheses. For example, perceived health risk influences (⟶) health-related Internet use.

* $P<.05$, ** $P<.01$, *** $P<.001$.

In testing hypotheses 1 and 2 on the effect of perceived health risk to chronic disease and health consciousness on health-related Internet use, the results show support for these 2 hypotheses as perceived health risk (β=.135, t_{1999}=2.676) and health consciousness (β=.447, t_{1999}=9.168) have significant positive influences on health-related Internet use (Figure 5).

Hypothesis 3 was developed to test the mediation role of perceived usefulness of the Internet and attitude in the relationship between perceived health risk and Internet use for health information seeking. Results showed that 8 of 10 direct effects described in the structural mediated effect model in Figure 4 were significant at the 95% confidence level or higher, whereas the direct effect of perceived health risk on attitude toward Internet use and health-related Internet use was not significant.

The indirect effect of perceived health risk on health-related Internet use through perceived usefulness of the Internet and attitude toward Internet use was significant at the 95% confidence level (β=.029, t_{1999}=3.609). However, by controlling the mediators, the direct effect of perceived health risk on health-related Internet use was not significant and this indicated that perceived usefulness of the Internet and attitude toward Internet use fully mediated the effect of perceived health risk on health-related Internet use and hypothesis 3 was supported (Figure 5).

For hypothesis 4, the results showed that the indirect effect of health consciousness on health-related Internet use through perceived usefulness of the Internet and attitude toward Internet use was significant at the 95% confidence level (β=.025, t_{1999}=3.234). Because the direct effect of health consciousness on health-related Internet use was significant (β=.211,

t_{1999}=3.958), perceived usefulness of the Internet and attitude toward Internet use partially mediated the effect of health consciousness on health-related Internet use, supporting hypothesis 4 (Figure 5).

The results showed support for all the hypotheses developed in the study. Further, the model explained 38.27% of the variance in health-related Internet use. To assess the predictive accuracy of endogenous variables, we used Stone-Geisser’s Q^2 [65,66], which was implemented by a blindfolding procedure in SmartPLS 2.0. The results of predictive accuracy, shown in Table 4, indicated appropriate predictive power for all endogenous variables in the model (range 0.1460-0.4074) [67].

Figure 4. Structural research model.

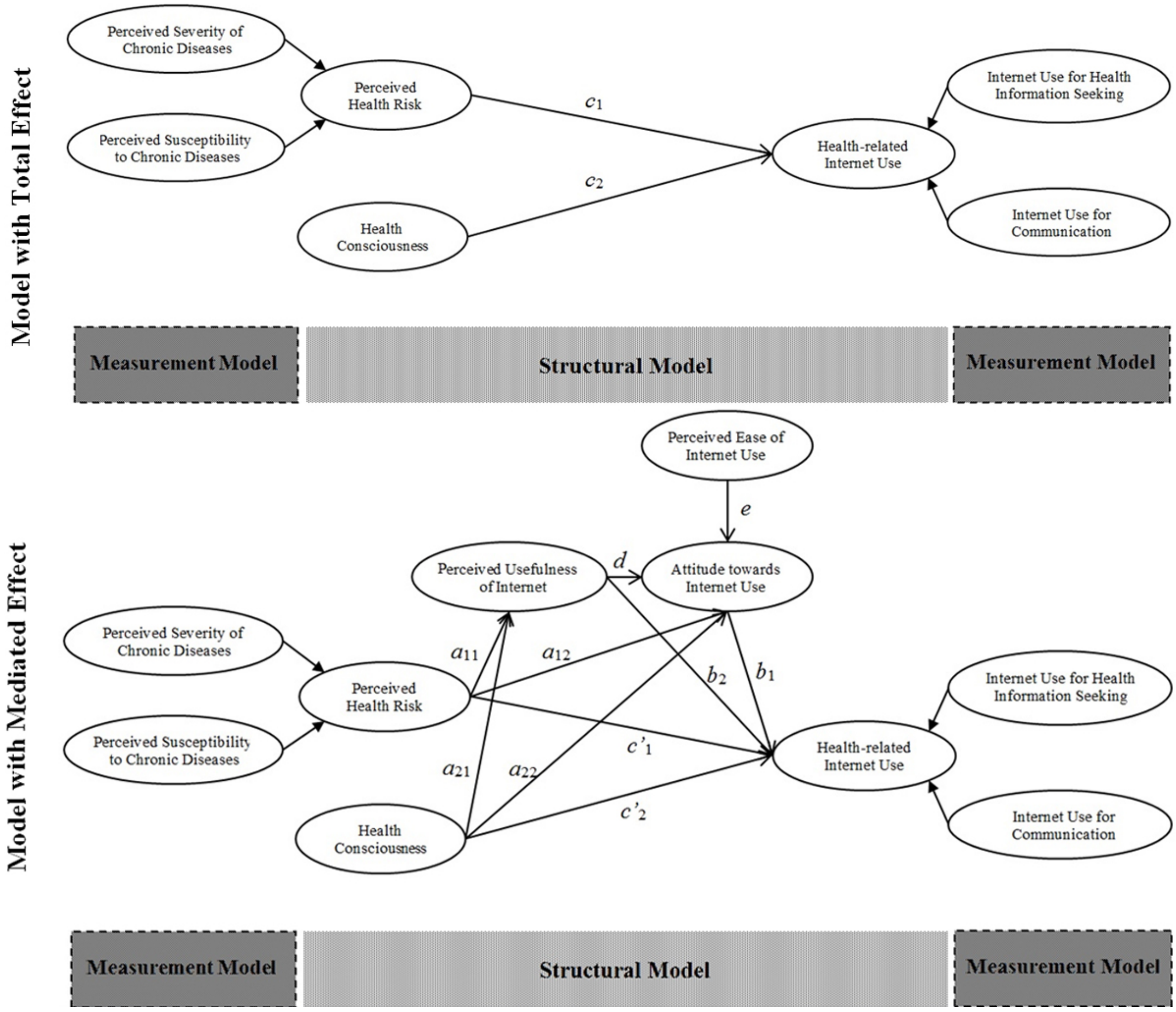
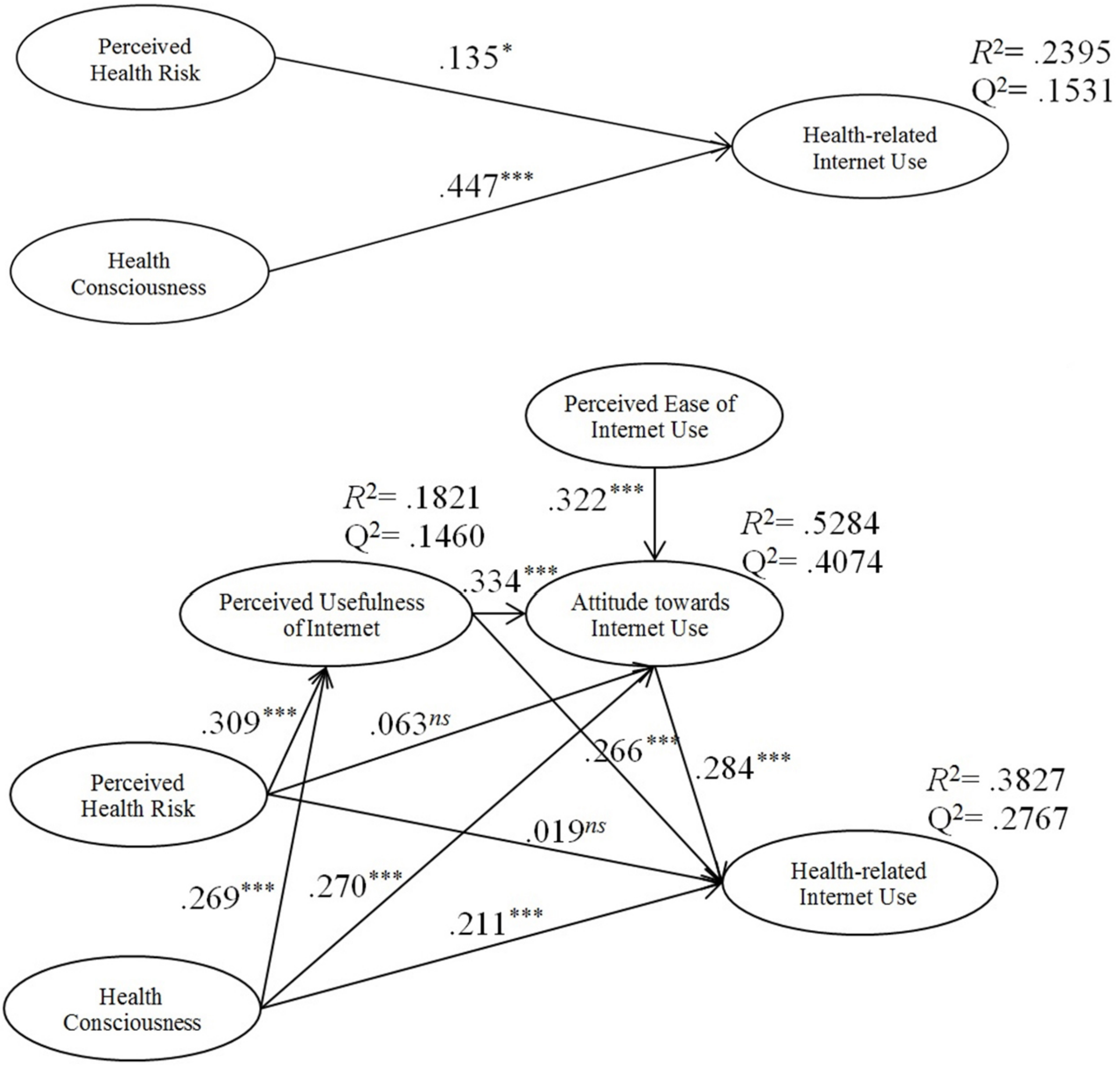


Figure 5. Path coefficients of the structural research model.



Discussion

Principal Findings

This study showed that there is a positive influence of perceived health risk and health consciousness on health-related Internet use, supporting hypotheses 1 and 2. It was also found that the effect of perceived health risk on health-related Internet use is fully mediated by perceived usefulness of the Internet and attitude toward Internet use for health information and health management as hypothesized in hypothesis 3. The study also supported that perceived usefulness of the Internet and attitude toward Internet use for health information and health management partially mediates the influence of health consciousness on health-related Internet use as proposed in hypothesis 4.

This study showed that perceived health risk positively affects health-related Internet use, confirming that perceived health risk is significant in influencing women's Internet use for health-related purposes. This finding is consistent with Dillard et al's study [26]. In addition, the results of the present study are in-line with Kim and Park's study, which found that behavioral intention to use health information technology was influenced by perceived health risk [37]. However, the results of Kim and Park [37] showed a smaller impact of perceived health risk on intention to use health information technology (β=.016) than in this study (β=.135) One explanation for this could be related to the perceived health risk level of the participants, whereby the present study is based on urban women who tend to assess their health as being more at risk, whereas the sample of Kim and Park's study consisted of both men and women [37].

The results of this study also showed that health consciousness has a significant positive effect on health-related Internet use, supporting the relevance of the HBM, which asserts that health consciousness contributes to health behavior adoption [31].

Additionally, it is consistent with prior research that revealed that health-conscious people engage more in health information-seeking behavior [32,33], prefer health information sources [68] and information oriented on the Internet [33], and tend to take part in both offline and online health communities [69].

The findings show that perceived usefulness of the Internet for health management and attitude toward Internet use for health-related purposes become central to women who perceive their health to be at risk and have the consciousness to seek information on health and health-related issues to manage their health and to stay healthy. Therefore, Internet use for health-related purposes is a process with perceived health risk and health consciousness as antecedents, but for this psychological orientation to translate into health-related Internet use behavior, perceived usefulness of the Internet and perceived ease of Internet use as well as attitude toward Internet use for health purposes provide the mechanism that explains health-related Internet use. In other words, for those who subjectively assess their health as susceptible to diseases and are concerned about their health, cognitive beliefs and positive affective feelings about the Internet come into play in the use of the Internet for health-related purposes.

Additionally, this integrated model shows that as health-related Internet use is predicted more by health consciousness than perceived health risk, it can be said that Internet usage for health purposes is a proactive health behavior driven by consciousness rather than a reactive health behavior. This result suggests that the Internet has become a necessary part of life for women who are health conscious and who prefer to be empowered by seeking health information online. Based on the findings of this study, the implications tend toward further promotion of Internet use for health purposes by individuals, health care service providers, and public policy makers. Knowing that health-related factors (ie, perceived health risk and health consciousness), technology-related cognitive beliefs (ie, perceived usefulness and perceived ease of use), and affective feelings toward Internet usage for health information positively influence Internet usage for searching health information, health care service providers could make greater use of the Internet to disseminate health-related information. Furthermore, health care providers can promote the use of online patient support systems or online self-care for a more seamless operation of their services. Individuals, especially women, would be motivated to seek information about health care by using the Internet, acting as opinion leaders in health and health-related issues for their family members and friends. Since the governments of all countries are keen to promote a healthy lifestyle, public policy makers could make use of the Internet to promote good health behavior, through women as the gatekeepers and as opinion leaders.

Limitations

The present study has several limitations. First, the sample population focused only on working women living in urban areas. The sample was not representative of the Malaysian female population. Therefore, a more comprehensive future study is suggested to include both men and women with different ethnicities, age groups, household income levels, educational attainment levels, and place of residence for a more representative study. Second, apart from perceived health risk and health consciousness examined in this study, there are other health-related factors such as health locus of control, and health informational and decisional involvement that could be included in the deliberate reasoning process of health-related Internet use as moderator or exogenous constructs. Further, this study did not examine the influence of possible predictors of perceived ease of Internet use for health such as eHealth literacy. Therefore, we suggest that future studies could be devoted to examining the influence of these suggested constructs on health-related Internet use. Finally, based on the commonly known health-related activities that are most often performed on the Internet (namely health information seeking, communicating for health-related purposes, and purchasing drugs and health products), further studies could include purchase of drugs and other health care products as variables to enable better understanding of the use of the Internet for health maintenance activities.

Conclusions

Although the present study supported past research that perceived health risk and health consciousness can operate as determinants of health-related Internet use as underpinned by HBM, the HBM model is insufficient to explain the mechanism for the adoption of the Internet for health purposes. By integrating HBM and TAM, results of this study provided the insight and an understanding that perceived usefulness of the Internet for health information and attitude toward Internet usage for health purposes act as mediators on the effect of health-related factors on health-related Internet use.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Questionnaire.

[PDF File (Adobe PDF File), 52KB - jmir_v17i2e45_app1.pdf]

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Abbreviations

ASV: average shared square variance
AVE: average variance extracted
HBM: Health Belief Model
MSV: maximum shared squared variance
TAM: Technology Acceptance Model
VIF: variance inflation factor

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Original Paper

Predictors for Assessing Electronic Messaging Between Nurses and General Practitioners as a Useful Tool for Communication in Home Health Care Services: A Cross-Sectional Study

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Abstract

Background: Nurses providing home health care services are dependent on access to patient information and communicating with general practitioners (GPs) to deliver safe and effective health care to patients. Information and communication technology (ICT) systems are viewed as powerful tools for this purpose. In Norway, a standardized electronic messaging (e-messaging) system is currently being established in health care.

Objective: The aim of this study was to explore home health care nurses' assessments of the utility of the e-messaging system for communicating with GPs and identify elements that influence the assessment of e-messaging as a useful communication tool.

Methods: The data were collected using a self-developed questionnaire based on variables identified by focus group interviews with home health care nurses (n=425) who used e-messaging and existing research. Data were analyzed using logistic regression analyses.

Results: Over two-thirds (425/632, 67.2%) of the home health care nurses returned the questionnaire. A high proportion (388/399, 97.2%) of the home health care nurses who returned the questionnaire found the e-messaging system to be a useful tool for communication with GPs. The odds of reporting that e-messaging was a useful tool were over five times higher (OR 5.1, CI 2.489-10.631, *P*<.001) if the nurses agreed or strongly agreed that e-messaging was easy to use. The odds of finding e-messaging easy to use were nearly seven times higher (OR 6.9, CI 1.713-27.899, *P*=.007) if the nurses did not consider the system functionality poor. If the nurses had received training in the use of e-messaging, the odds were over six times higher (OR 6.6, CI 2.515-17.437, *P*<.001) that they would consider e-messaging easy to use. The odds that a home health care nurse would experience e-messaging as easy to use increased as the full-time equivalent percentage of the nurses increased (OR 1.032, CI 1.001-1.064, *P*=.045).

Conclusions: This study has shown that technical (ease of use and system functionality), organizational (training), and individual (full-time equivalent percentage) elements had an impact on home health care nurses' assessments of using e-messaging to communicate with GPs. By identifying these elements, it is easier to determine which interventions are the most important for the development and implementation of ICT systems in home health care services.

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KEYWORDS

electronic mail; home healthcare nursing; collaborating; general practitioners

Introduction

Health care services are characterized as fragmented and dispersed [1,2]. This issue is particularly challenging for the delivery of safe and effective health care to patients who receive home health care services. Nurses in home health care services are dependent on access to accurate and relevant patient information [3]. It is also essential that nurses in home health care services have the opportunity for clinical communication and discussions about patient care with general practitioners (GPs) [2,4].

The current study was conducted in Norway, where home health care service is managed by municipalities; furthermore, GPs are self-employed [5] and each municipality can use different electronic health record (EHR) systems [6]. Thus, new methods for information exchange and clinical communication between GPs and home health care nurses are needed. Information and communication technology (ICT) systems are viewed as powerful tools that can solve this problem [7]. One of the most important goals for ICT development and implementation in health care is to improve the exchange of information, care coordination, and communication between health care workers [7,8]. However, implementing new electronic tools in health care has not always been successful [9,10]. Studies have shown that health care professionals may assess the tools as inefficient or believe that the tools do not align with their work practices [11-13]. Health care professionals' beliefs, assessments, and satisfaction with the ICT systems influence the structure, process, and outcome of care, which can affect the safety of patients and their next of kin [3,14,15]. Developing and implementing new electronic tools for communication has high costs; therefore, it is important to reduce the risks of low, incorrect, or incomplete use of the systems [9,16].

A sociotechnical perspective aims to understand how ICT systems are developed, implemented, and become a part of standard work practices [17]. The integration of ICT systems into work practices is dependent on the interaction between individual, organizational, and technological elements. These elements determine whether the implementation and use of ICT systems will be successful [16]. Therefore, a technical system cannot be isolated and function on its own and instead needs to be shaped and reshaped by the people and organizations in the social environments and contexts in which it is used [17]. The sociotechnical perspective emphasizes the need for active user involvement in an iterative development and implementation process and considers strong user involvement for adopting ICT systems, and for assessing them as useful [8,15,18-20].

Previous studies have shown that several elements impact health care professionals' assessments of the usability of ICT systems. These elements include the health professionals' participation in the development of the ICT system [19], the design of the ICT system [11,12,21], the user interface and functionality of the ICT system [15], the ease of use [20-24], the compatibility with work practices [11,15,21,22,25], and how the ICT systems are put into practice (eg, training, user support, technical infrastructure, and resources) [7,11,15,21,23,26-28].

In Norway, a standardized electronic messaging (e-messaging) system is currently being implemented in primary health services [29]. The e-messaging system has been integrated into all of the major EHR systems used in home health care services and GP offices in Norway, meaning that it is a module of the EHR systems that can be procured from vendors. The e-messaging system consists of six standardized, semistructured message types that can be sent from home health care nurses to GPs and five semistructured message types that can be sent from GPs to home health care nurses. The e-message types are customized for different purposes, including the patients' health information and medication lists. A dialogue message was designed for requests, inquiries, and discussions about patients' health issues and special care needs, administrative information on the type of home health care services provided to the patient and information about errors and omission in the treatment and care of the patient [30]. The e-messages are sent between the different health care providers' EHR systems via the Norwegian Health Net, which is a secure and closed net used solely for health information exchange and clinical communication.

The development of the e-messaging system was initiated and managed by health care professionals in close cooperation with vendors [31]. Several home health care nurses specified the requirements of the e-messaging system and participated in the development and implementation phases of the e-messaging system [31]. Thus, the system was adjusted by strong user involvement as suggested in other studies [15,19,20,22]. The Norwegian government aims to implement e-messaging in home health care services, nursing homes, GP offices, and hospitals by the end of 2014 [6].

The aim of this paper was to describe home health care nurses' assessments of using the e-messaging system to communicate with GPs and identify which elements predict that e-messaging will be considered a useful tool.

Methods

The study used a cross-sectional approach with a questionnaire administered between November 2011 and February 2012.

The Questionnaire

We searched the literature but did not find any questionnaires that measured the use of e-messaging between home health care services and GPs. Therefore, we developed a questionnaire in two phases [32]. In the first phase, we explored the recommended guidelines for the use of e-messages [33], the description of the standards for the e-messaging system [30], and the results from previous contiguous research [34-37]. We then conducted focus groups and semistructured interviews with home health care nurses from two municipalities. The results from the interviews showed that both organizational and technical elements were assessed as important dimensions for the use of e-messaging [38].

The second phase consisted of the questionnaire development. The questionnaire was reviewed by 6 registered nurses with clinical, ICT, and research skills, and it was pilot tested by 15 registered nurses who worked in home health care services. These steps provided significant and valuable information that was used to revise the questionnaire. The final version of the questionnaire contained 62 items in six sections: (1) Demographic information, eight items, (2) Procedures for and amount of information exchange and communication with GPs, 19 items, (3) Information content, 12 items, (4) Expectations for electronic communication with GPs, 10 items, (5) Electronic communication, three items, and (6) Experiences of the use of electronic communication, 10 items (see Multimedia Appendix 1). Six items were negatively worded: Items 19 (a)-(d) and Items 20 (d) and (e). Here, we report the demographic, electronic communication, and experiences of the use of e-messaging results from Sections 1, 5, and 6, respectively.

The items selected for this study have been previously documented as important factors for health care providers' assessments of health information systems [7,9,11,15,21,26-28]. These items can be grouped as individual, organizational, and technological elements. The individual element consists of Items 2-6 from Section 1 and Item 16 from Section 5 of the questionnaire. The organizational element consists of Items 20 (a) and (b) from Section 6 of the questionnaire. The technological element consists of Items 19 (b)-(d) and 20 (c) from Section 6 of the questionnaire.

The questionnaire items were rated on a 5-point Likert scale as follows: (1) strongly disagree, (2) disagree, (3) neither agree or disagree, (4) agree, and (5) strongly agree. The Cronbach alpha exceeded .7, indicating acceptable reliability [39].

To test the validity of the questionnaire, a selection of the items from the main study was summarized and correlated with the item "useful tool for communication with GPs", which is the questionnaire's concluding question. Pearson's *r* was .57 (*P*<.001), indicating a fairly strong correlation between the overarching concept of usefulness of the e-messaging tool and the selected questionnaire items, but also that there may be items or facets of items that should have been addressed in the questionnaire. However, we wanted to keep the questionnaire short to achieve a high response rate. The pilot test showed that it took approximately 10 minutes to complete the questionnaire.

Data Collection

The questionnaire data were collected from home health care nurses in 12 out of 428 municipalities in Norway. The inclusion criterion for the municipalities required that the e-messaging system had been in use for more than 6 months. We assumed that system usage would be stable after this time frame [40]. The 12 municipalities were the first in Norway to introduce e-messaging to support communication between home health care nurses and GPs, and they were the only municipalities that met this inclusion criteria at the time of our study. All of the home health care nurses were employed in a 50% or greater full-time equivalent position, had been using e-messaging for at least 3 months, and were able to read and write Norwegian. The home health care nurses received the questionnaire, information letter, and return envelope at their workplace from a designated contact person in each municipality. The contacts were responsible for distributing collective reminders and for collecting the envelopes with the completed questionnaire. There were 681 nurses qualified to answer the questionnaire, and the questionnaire was distributed to 632 (92.8%) nurses.

Ethical Considerations

The home health care nurses who were invited to answer the questionnaire received written information explaining that their participation was anonymous and that returning the questionnaire meant that they agreed to participate in the study. The methods for data collection and handling the interviews and the questionnaire were approved by the Norwegian Social Science Data Services, which is the official data protection agency for research at the University of Oslo (reference no. 26230).

Data Analysis

We used a descriptive analysis to determine the characteristics of the sample and the nurses' assessments of using e-messaging. Scores for negatively worded items were reversed. Two logistic regression models were developed to determine the extent to which specific elements influenced the odds that the nurses would report that e-messaging was a useful and easy tool for communication with GPs.

In the first logistic regression model, "the useful tool model", we chose to include the independent variables of "easy to use" and the home health care nurses' demographic characteristics of "age", "gender", "full-time equivalent percentages", "years of experience as a registered nurse (RN)", "years in current position", and "number of months using e-messaging". The reason for choosing these variables is based on results from previous research [3,8,21,26,38].

In the second logistic regression model, "the ease-of-use model", the dependent variable of "easy to use" was combined with the independent variables of "received training", "access to user support", "hindered by poor functionality", "hindered by low system performance", and "hindered by software error", and the home health care nurses' characteristics. These variables have been shown to have an impact of the assessment and adoption of ICT systems [3,7-9,11,15,21,26-28,38].

In the pre-analysis of the data, we searched for outliers in continuous variables. The results showed that it was not necessary to transform any of the data. We used ±3.30 standard deviations (SD) to check for outliers, as suggested by Altman [41]. Two variables had outliers: "years in current position" with 24 years (0.9%) in the positive direction and "number of months using e-messaging" with 37 months (1.3%). However, working for an extended period of time in the same position or using the e-messaging system for 37 months is unlikely to affect the results.

Homoscedasticity in both logistic regression models was assessed by a one-way analysis of variance of the standardized residuals to establish that their variance was approximately the same for all values of the predictor variables. No homoscedasticity was found. The first model was used to predict if the e-messaging system was a useful tool for communication with GPs. The item "easy to use" did not show statistically significant differences (*P*=.76) between the prediction errors in the group that found the e-messaging system to be a useful tool and the group that did not find the tool to be useful. The second model was used to predict if the e-messaging system was easy to use. The items "received training" (*P*=.88), "hindered by poor functionality” (*P*=.84), and “full-time equivalent percentage” (*P*=.77) did not show statistically significant differences between the prediction errors in the group that found the e-messaging system easy to use and the group that did not find the tool easy to use.

We tested for possible multicollinearity among the independent variables in both models using the Pearson correlation to exclude that the independent variables were highly correlated. The highest correlation was .76 for age and years of experience as an RN; therefore, no significant multicollinearity was found [42].

In the logistic regression analysis, we dichotomized the variables because of their skewed distribution. The variable “useful tool” was dichotomized as strongly disagree, disagree, neutral, and agree (0=1-4) and strongly agree (1=5). The rest of the ordinal variables were dichotomized as strongly disagree, disagree, neutral (0=1-3), agree, and strongly agree (1=4-5).

The *P* value of the Hosmer and Lemeshow goodness of fit statistic for “the useful tool model” was .317, and for “the ease-of-use model” the *P* value was .650. The data were analyzed using IBM SPSS Statistics version 20.0.

Results

Characteristics of Home Health Care Nurses

A total of 425 (67.2%) of the 632 home health care nurses who received the questionnaire completed it. The demographic information is presented in Table 1.

Table 1. Demographic information of home health care nurses (N=425).

Demographic characteristics	Mean	n (%)
Gender, n (%)		
Female		383 (90.4)
Male		41 (9.6)
Age, mean (SD)	39.6 (10.1)	424 (99.8)
Years of experience, mean (SD)	11.5 (9.1)	421 (99.1)
Full-time equivalent percentage, mean (SD)	90.9 (14.2)	425 (100.0)
Years in current position, mean (SD)	5.8 (5.6)	422 (99.3)
Number of months using e-messaging, mean (SD)	10.21 (7.5)	382 (89.9)

Home Health Care Nurses’ Assessments of e-Messaging

The vast majority of the responding home health care nurses (388/399, 97.2%) agreed or strongly agreed that e-messaging was a useful tool for communication with GPs. Table 2 presents all responses in order to show the complete distribution of the responses.

For the “easy to use e-messaging” item, the majority of home health care nurses agreed or strongly agreed (357/398, 89.7%) that e-messaging was easy to use. A high proportion of the home health care nurses agreed or strongly agreed that they had received training (333/399, 83.5%), while the remaining nurses were neutral or disagreed. The home health care nurses agreed to a lower degree that they had access to user support (256/389, 65.8%).

A relatively high proportion of the home health care nurses were neutral or agreed that they were hindered when using e-messaging because of poor functionality (123/395, 31.1%), low system performance (123/396, 31.1%), or software errors (129/395, 32.7%).

Table 2. Assessments of using e-messaging (N=425).

Item	Strongly disagree, % (n)	Disagree, % (n)	Neutral, % (n)	Agree, % (n)	Strongly agree, % (n)	Missing, n
Received training	1.7 (7)	6.0 (24)	8.8 (35)	50.9 (203)	32.6 (130)	26
Access to user support	1.2 (5)	3.6 (14)	29.3(114)	52.9 (206)	12.9 (50)	36
Hindered by poor functionality	18.7 (74)	50.1 (198)	23.3 (92)	6.6 (26)	1.2 (5)	30
Hindered by low system performance	19.4 (77)	49.5 (196)	23.5 (93)	6.3 (25)	1.2 (5)	29
Hindered by software error	21.5 (85)	45.8 (181)	17.2 (68)	13.1 (52)	2.3 (9)	30
Easy to use	0.2 (1)	1.5 (6)	8.5 (34)	52.8 (210)	36.9 (147)	27
Useful tool	-	0.7 (3)	2 (8)	31.8 (127)	65.4 (261)	26

Predictors That Affected Nurses’ Assessment of e-Messaging as a Useful Tool for Communication With GPs

The logistic regression model showed that the “easy to use” item gave a statistically significant contribution to the model (Table 3).

The odds of reporting that e-messaging was a useful tool were over five times higher if the nurses agreed or strongly agreed that e-messaging was easy to use. The “useful tool model” was controlled for the demographic variables of gender, age, years of experience as an RN, full-time equivalent percentage, and years in current position.

Table 3. Logistic regression model examining predictors affecting the assessment of e-messaging as a useful tool (N=391).

	B (SE)	*P* value	Odds ratio (95% CI)
Gender	.041 (0.402)	.920	1.041 (0.473-2.291)
Age	.009 (0.018)	.621	1.009 (0.974-1.045)
Years of experience as an RN	-.014 (0.021)	.505	0.986 (0.948-1.027)
Full-time equivalent percentage	.006 (0.008)	.505	1.006 (0.989-1.022)
Years in current position	.001 (0.024)	.973	1.1001 (0.955-1.049)
Easy to use	1.638 (0.370)	.000	5.144 (2.489-10.631)
Constant	-1.555	.134	0.211

Predictors That Affected the Nurses’ Assessment of e-Messaging as Easy to Use

The “ease-of-use model” determined which elements influenced the assessment of e-messaging as easy to use. The results from the logistic regression model (Table 4) showed that the independent variables “hindered by poor functionality”, “training received”, and “full-time equivalent percentage” were statistically significant.

The odds that a home health care nurse would experience e-messaging as easy to use increased as the full-time equivalent percentage of the nurses increased. If the home health care nurses agreed that they were not hindered by poor e-messaging functionality, the odds of agreeing that e-messaging was easy to use were over 6.9 times higher than if they did not agree. The home health care nurses who agreed that they had received training had odds over 6.6 times higher of agreeing that e-messaging was easy to use. The home health care nurses’ gender, number of months using e-messaging, being hindered by low system performance or software errors, or having access to user support were not statistically significant predictors for the assessment of e-messaging as easy to use.

Table 4. Logistic regression model examining predictors affecting assessments of e-messaging as easy to use (N=364).

	B (SE)	*P* value	Odds ratio (95% CI)
Gender	-.561 (0.796)	.480	0.570 (0.120-2.713)
Age	-.049 (0.038)	.193	0.952 (0.884-1.025)
Years of experience	-.015 (0.039)	.701	0.985 (0.913-1.063)
Full-time equivalent percentage	.031 (0.016)	.045	1.032 (1.001-1.064)
Years in current position	-.030 (0.043)	.488	0.971 (0.893-1.056)
Number of months using e-messaging	-.030 (0.030)	.318	0.971 (0.915-1.029)
Hindered by low system performance	-.633 (0.731)	.387	0.531 (0.127-2.226)
Hindered by software error	-.094 (0.548)	.863	0.910 (0.311-2.664)
Hindered by poor functionality	1.933 (0.712)	.007	6.914 (1.713-27.899)
Received training	1.890 (0.494)	<.001	6.622 (2.515-17.437)
Having access to user support	.170 (0.479)	.722	1.186 (.464-3.031)
Constant	1.053 (2.001)	.599	2.867

Discussion

Principal Findings

The results from this study showed that individual, organizational, and technological elements are interrelated and affect home health care nurses’ assessments of using e-messaging to communicate with GPs. This is in line with a sociotechnical perspective [20]. This study demonstrated that the majority of the home health care nurses assessed the e-messaging system as a useful tool for communication with GPs.

Several home health care nurses cooperated with the vendors in the development and implementation of the e-messaging system. The realization of an ICT system relies on the participation of the people who will ultimately use it [19]. This is important because the system must fit the needs and working practices of the users. ICT development and implementation projects in health care can be controversial because ICT systems change organizational routines and relationships between different health care professionals. To prevent resistance and non-utilization of the ICT systems, users need to be thoroughly and systematically involved at an early stage in the development and implementation process [20]. The involvement of home health care nurses in the development and implementation of the e-messaging system may have resulted in a system that was better aligned with nurses' needs and working practices; therefore, a positive assessment of the e-messaging system could be anticipated.

The only statistically significant predictor of e-messaging as a useful tool for communication with GPs was that nurses assessed e-messaging as easy to use. This is supported by a study of health care professionals' adoption and use of a clinical information system that found that the ease of use of the system was required for it to be considered as a beneficial tool for their clinical practice [24].

Ease of use is one of the most frequent elements reported among studies of facilitators and barriers of the adoption of ICT systems in health care [21,22,24]. Ease of use is related to individual characteristics of the people who are using ICT systems, technical features of the ICT system such as the software and hardware, and organizational implementation of the ICT system in terms of training, procedures, user support, and configuration of the system. We found that only one individual element, full-time equivalent percentage, was a statistically significant predictor for e-messaging being easy to use. Previous research has reported opposing evidence that multiple individual elements, such as age, gender, years of experience as a nurse, and full-time or part-time work, affect the assessment of ICT systems [3,8,43-45]. However, we found that the higher the full-time equivalent percentage of the home health care nurses, the more likely they were to assess e-messaging as easy to use. One explanation for this finding is that the more time home health care nurses spend at work, the more they have access to training, user support, and help from their colleagues; thus, the nurse is more familiar with the use of e-messaging, which may result in a positive experience and assessment of the e-messaging system. Another explanation could be that the more time spent at work, the more time is spent using the system, and the more adept the user becomes with the system.

Tools/technical concerns, such as functionality and system design, are important elements that can act as barriers and facilitators for the implementation and use of ICT systems in health care [28]. In our study, a lack of poor functionality was the strongest predictor for the home health care nurses' assessments of e-messaging as easy to use. This finding is supported by another study on nurses' assessments of health care technology, which revealed that poor system design was among the most common elements for negative attitudes [12]. Ease of use is also related to the technical environment and the integration between ICT systems. In a study on usability, the results showed that physicians rated ICT systems as low because the integration between the ICT systems was insufficient [11]. In this study, the technological environment was important in the way that the e-messaging system was integrated into the EHR systems that home health care nurses were already using. The user interface was well known, which lowered the threshold for implementing and adopting the e-messaging system [16].

Assessments of ICT systems are affected by organizational aspects, such as offering user support and training [11]. Our results show that a high proportion of the home health care nurses had received initial training in the use of the e-messaging system, which was a strong predictor for assessing the e-messaging system as easy to use. Training has previously been identified as a key element for the successful implementation of ICT systems in complex systems such as health care services [7,9,15,46,47]. Training is important in ensuring that the systems are used in the intended way and reducing the risk of incorrect use, which could jeopardize patient safety [7,15,27]. Nurses' use of ICT systems is affected by training in both basic ICT and specific software [3,28,48]. Training at different levels should be offered by organizations and must be tailored to the individual needs of home health care nurses [49].

By applying a sociotechnical perspective, we were able to detect and predict which elements were important for the development and implementation of e-messaging. All of these elements are interrelated and shape the sociotechnical system; furthermore, these elements should be considered when developing and implementing new technology in home health care services [20].

Limitations

This study has several limitations. The best methodology to develop a questionnaire is to include a pilot study with a smaller sample using all possible variables and subsequently identifying the relevant ones. However, we did not complete this type of study because of our limited time frame. As an alternative, we based the questionnaire on explanatory variables identified by the focus group interviews and existing research.

The questionnaire was not assessed across all dimensions of validity and reliability. However, the aim of the study did not include a complete psychometric testing of the questionnaire.

The mean full-time equivalent percentage may have been falsely high because one of the inclusion criteria for participation in the study was that the nurses had to be engaged in a 50% or greater full-time equivalent position. This was necessary to ensure that the nurses had enough experience in using e-messaging. According to the Norwegian Nurses Organization in 2011, 56% of the nurses in primary care in Norway did not work in a full-time positon, and 15% of those had less than a 50% full-time equivalent position [50]. The odds ratio of the full-time equivalent percentage predictor may be higher than our results suggest; thus, the results in our study may understate the odds of the full-time equivalent predictor in the general population. Another element that may have biased the results was that the home health care nurses who participated in this study worked in the first municipalities in Norway to implement e-messaging. Being among the early adopters may have caused the home health care nurses to be especially encouraged, enthusiastic, technologically optimistic, and positive toward e-messaging. These characteristics could differ in populations that were late to adopt the system.

The strength of this study is that we questioned home health care nurses in all of the municipalities that had used the e-messaging system for at least 6 months at the time of the study. The response rate of the study was 67.2%, which can be considered fairly good for a questionnaire study [51].

Conclusions

By identifying elements that affect home health care nurses' assessments of e-messaging for communication with GPs, we are better able to determine which interventions are most important for the development and implementation of e-messaging. This study demonstrated that home health care nurses assessed e-messaging as a useful tool for communication with GPs. It also shows that ICT systems must be easy to use to be assessed as a useful tool and that a higher full-time equivalent percentage, having received training, and not being hindered by poor functionality are important predictors for the assessment of the e-messaging system as easy to use. Our results imply that users should be actively involved in the development and implementation of ICT systems. Future studies should use a sociotechnical approach to consideration the complete range of elements that can affect working practices and the outcomes for the patients and organizations involved. These insights may help to increase the understanding of effective strategies for developing and implementing ICT systems in home health care services.

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Authors' Contributions

ML designed the work, conducted the analysis, and wrote the first draft of the paper. DH and AG contributed to the design of the study and the statistical analysis. RH contributed to the design of the study, the data collection, and the statistical analysis. All of the authors revised the manuscript and read and approved the final version.

Conflicts of Interest

None declared.

Multimedia Appendix 1

The questionnaire.

[PDF File (Adobe PDF File), 158KB - jmir_v17i2e47_app1.pdf]

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Abbreviations

GP: general practitioner
ICT: information and communication technology
RN: registered nurse

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Original Paper

The Performance of mHealth in Cancer Supportive Care: A Research Agenda

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Abstract

Background: Since the advent of smartphones, mHealth has risen to the attention of the health care system as something that could radically change the way health care has been viewed, managed, and delivered to date. This is particularly relevant for cancer, as one of the leading causes of death worldwide, and for cancer supportive care, since patients and caregivers have key roles in managing side effects. Given adequate knowledge, they are able to expect appropriate assessments and interventions. In this scenario, mHealth has great potential for linking patients, caregivers, and health care professionals; for enabling early detection and intervention; for lowering costs; and achieving better quality of life. Given its great potential, it is important to evaluate the performance of mHealth. This can be considered from several perspectives, of which organizational performance is particularly relevant, since mHealth may increase the productivity of health care providers and as a result even the productivity of health care systems.

Objective: This paper aims to review studies on the evaluation of the performance of mHealth, with particular focus on cancer care and cancer supportive care processes, concentrating on its contribution to organizational performance, as well as identifying some indications for a further research agenda.

Methods: We carried out a review of literature, aimed at identifying studies related to the performance of mHealth in general or focusing on cancer care and cancer supportive care.

Results: Our analysis revealed that studies are almost always based on a single dimension of performance. Any evaluations of the performance of mHealth are based on very different methods and measures, with a prevailing focus on issues linked to efficiency. This fails to consider the real contribution that mHealth can offer for improving the performance of health care providers, health care systems, and the quality of life in general.

Conclusions: Further research should start by stating and explaining what is meant by the evaluation of mHealth’s performance and then conduct more in-depth analysis in order to create shared frameworks to specifically identify the different dimensions of mHealth’s performance.

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KEYWORDS

mHealth; performance; organizational performance; efficiency; effectiveness; clinical effectiveness; quality of life

Introduction

Health care is undergoing an evolutionary phase worldwide aimed at facing multiple challenges: (1) the aging global population is increasingly affected by chronic diseases for much longer [1,2], (2) health care delivery costs are becoming unsustainable [3], (3) societies are becoming more and more mobile [4], and (4) being cared for at home is increasingly the preferred mode of health care delivery [2,5]. The unsustainability of current health care spending has led to the need for disruptive solutions, capable of controlling costs without diminishing quality of service and quality of life.

Chronic diseases are becoming the heaviest burden on health care systems worldwide, and cancer is one of these. A chronic disease can be defined as a condition that lasts a year or longer and requires ongoing monitoring and treatment [6]. Although cancer continues to be one of the main causes of death, efforts have been made in several fields of medicine in order to reduce cancer mortality every year [7].

This scenario has witnessed the rapid and ongoing growth in mobile technologies, especially mobile health (mHealth) defined as “medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants (PDAs), and other wireless devices” [8]. According to this definition, mHealth includes short messaging services (SMS) as well as more complex applications like general packet radio service (GPRS), third and fourth generation mobile telecommunications (3G and 4G systems), global positioning systems (GPS), and Bluetooth technology [8].

Furthermore, major advances have been carried out into two subfields: wearable and body area sensor networks, and mobile broadband and wireless Internet mHealth systems [9]. An example of the former is the innovative WE-CARE system: an intelligent telecardiology system that exploits mobile wireless networks in order to provide benefits in detection rate and time savings [10]. An example of the second subfield is the concept of 4G health. The introduction of the fourth-generation mobile communication system led to a turning point and “the evolution of mHealth towards targeted personalized medical systems with adaptable functionalities and compatibility with the future 4G networks” [9]. The prospect of managing health care via mobile platforms has resulted in a momentous technology drive and the implementation of thousands of mobile apps, mainly designed for a single condition or aspect of disease management.

Over the past decade, especially since the advent of smartphones, mHealth has come to the attention of the health care system as something that could radically change the way health care has been viewed, managed, and delivered to date. By exploiting their technical capabilities, mobile phones can be used to implement several health care interventions, ranging from increasing the accessibility of health care information (eg, short messages or reminders) to involving the health care team (eg, remote monitoring) [11]. To this extent, a mobile phone with a wireless connection is an essential prerequisite because, as Huang et al state: “a wireless network may be not mobile, but a mobile network must be wireless” [10]. In the case of cancer, hundreds of apps have already been designed and implemented with several purposes, such as raising awareness about chronic disease, providing information about cancer, or for managing cancer [12].

mHealth has generated a surge of positivistic policy documents, such as the Digital Agenda for Europe [13] and the Federal Health IT Strategic Plan [14] in the United States, and this emerging industry has attracted large investments. mHealth makes it possible to follow the shifting focus of health care from “cure” to “care” thanks to its tendency to support the entire care process, including wellness and prevention. This is important in the case of cancer, one of the leading causes of death worldwide, accounting for 8.2 million deaths in 2012 [15].

mHealth may play a particularly significant role in cancer supportive care, dealing with the management of the side effects of cancer treatment, since patients and caregivers play a role in managing side effects and, given adequate knowledge, are able to demand appropriate assessments and intervention. In this scenario, mHealth has great potential for linking patients, caregivers, and health care professionals, for enabling early detection and intervention, for cutting costs, and achieving better quality of life.

Given its huge potential, it is important to evaluate the performance of mHealth. Literature has shown that the performance of mHealth can be assessed from several perspectives. It can be seen as a return on integrated care processes, since it can improve communication and enhance integration among those involved in health care processes [16,17]. In terms of organizational performance, mHealth can increase the productivity of health care providers and possibly even the productivity of health care systems as a result [18-20]. For external relations, mHealth can enhance transparency, increasing the accountability of health care providers and systems [21,22], and it can also empower patients [1,23-25]. Finally, the greatest promise of mHealth is that it may boost the appropriateness of care and possibly the quality of life [26,27].

This paper intends to review studies on the evaluation of the performance of mHealth, with a particular focus on cancer care and cancer supportive care processes, concentrating on its contribution to organizational performance. It also aims to identify elements for a further research agenda.

Methods

We carried out a review of papers from three bodies of literature: medical informatics, health care management, and medicine, with particular reference to oncology journals. The first step of our research strategy (Table 1) was aimed at identifying and collecting all existing studies on the evaluation of mHealth’s performance in cancer and cancer supportive care. We started by identifying a number of keywords and entered them in our selected computerized bibliographical databases, resulting in a total of 1698 papers, including 106 that were relevant in terms of mHealth and performance and were used for our assessment. We then narrowed down this result to cancer supportive care, leading to a total of 67 papers, including 15 that were useful for our analysis.

We subsequently used a “bibliographic network approach” to track the articles in the references in the works we considered fundamental for our research. We retrieved papers and studies published after 1999 in academic reviews and journals that were not listed in the database at the time of the analysis, but which were known among academics.

Table 1. Research strategy to identify and collect relevant studies.

Search strategy	Detailed information
Keywords	Generic search using concept words: “mHealth”, “cancer”, “quality of life”, Specific searches : “mHealth” (mHealth OR mHealth OR “mobile health” OR “mobile health care”) + “cancer” (cancer OR “cancer care” OR “cancer supportive care” OR “supportive care in cancer” OR “chemotherapy” OR “side effects” OR “adverse effects” OR “integrated care” OR “cancer integrated care”) + “Quality of life” (“quality of life” OR “quality of service” OR “quality of care” OR “health care delivery” OR “health care management” OR “care management” OR “health policy” OR promises OR “continuity of care” OR “lean health care” OR “lean health care” OR “lean thinking” OR “patient-centered”) + “performance” (“performance” OR “evaluation” OR “impact” OR “assessment” OR “return” OR “promises” OR “adoption”)
Databases	BioMed Central, Business Source Complete, IEEE Xplore, PLOS (One, Medicine and Clinical Trials), PubMed, Science Direct, Web of Science (which embeds Elsevier, Wiley, JMIR, JAMIA), Cochrane Library
Specific journals	JAMIA, JMIR, BMJ, Health affairs, Health care management review, Health Policy, Health Policy and Technology, Value in Health (ISPOR), Journal of Cancer Policy, Academy of Management Journal, Journal of Management studies, Journal of Health Economics, Health economics, Canadian Medical Association Journal, Health Informatics Journal, Journal of Clinical Oncology (ASCO), Annals of Oncology (ESMO), Supportive Care in Cancer (MASCC), European Journal of Cancer (published by Elsevier, official journal of EORTC, ECCO, EACR and EUSOMA), Critical Reviews in Oncology and Hematology (ESO), Health Services Management Review (EHMA), IEEE Journal of Biomedical and Health Informatics, IEEE Transactions on Information Technology in Biomedicine, Journal of Biomedical Informatics
Inclusion criteria	Peer-reviewed published articles
	Published since 1999
Exclusion criteria	Grey literature (blogs, newsletters, videos)
	Provisional or structured abstracts
	Poster sessions, presentations, comments, opinions, discussions, editorials, prefaces, summaries, interviews, correspondence, tutorials
	Studies focused only on (1) design of the device or the app, (2) technology (communication and Web protocols, standards, platforms), and (3) characteristics of the technology (eg, wireless technology, bandwidth, battery life, connectivity, signal quality)
	Studies on psychology, ie, behavioral models and theory of psychology
	Studies on definition of new quality of life measurements as influenced by the technology
	Studies set in low resource settings or developing countries, except when talking about implementation of new technologies in low resource settings (sustainability, etc)
	Studies where mobile health means mobile clinics or mobility of professionals or mobile screening units
	Studies or articles with no author
	Studies or articles with no abstract

Results

Performance of mHealth

Study Characteristics

Our first finding is that there is a very limited amount of literature on mHealth’s performance. Our analysis revealed that only 35.8% (38/106) of our selected papers looked at mHealth’s performance in some way, as most of the studies focused on the use of mHealth, and less on adoption and its determinants and barriers.

More frequently, studies offered an assessment of the performance of technology rather than an evaluation of the contribution to organizational performance and the quality of life of patients. According to the categorization provided by the World Bank [8], countries can be classified according to three “income-classes”: high, medium, and low income. Most studies referred to high income countries (61%, 28/38 papers) and less to low income (8%, 3/38 papers) and middle income countries (5%, 2/38 papers). We should mention that 13% of papers referred to different type of countries (5/38 papers) and 13% (5/38 papers) of our selected studies did not refer to any specific country or region (Figure 1) since their contribution was based on a literature review with no specific reference to any country.

Most papers were empirical in methodology (about 73%, 28/38 papers) (see Figure 2). Other specific methodologies were used, some taking a more qualitative research design, such as literature review, case studies, tool description, and focus groups. However, most were based on more quantitative designs, like randomized controlled trials, systematic reviews, surveys, and pilot studies.

Looking in greater depth at the health condition under analysis (Figure 3), only 5% (2/38 papers) of the papers focused on acute care, 18% (7/38 papers) did not focus on any specific condition, and the majority of papers (77%, 29/38 papers) looked at chronic care. Chronic care includes cancer and cancer supportive care, which accounted for 37% (14/38 papers) of the papers on performance in our analysis, as well as several other diseases, such as asthma, diabetes, and obesity.

Looking at the type of mobile technologies analyzed relating to performance, 61% (23/38 papers) of papers discussed mobile devices (like smartphones and tablets) and apps, 18% (7/38 papers) remote monitoring technologies, 37% (14/38 papers) SMS technologies, and only 3% (1/38 paper) focused on telehealth (Figure 4). We should mention that some papers referred to several types of mobile technologies.

Figure 1. Type of country.

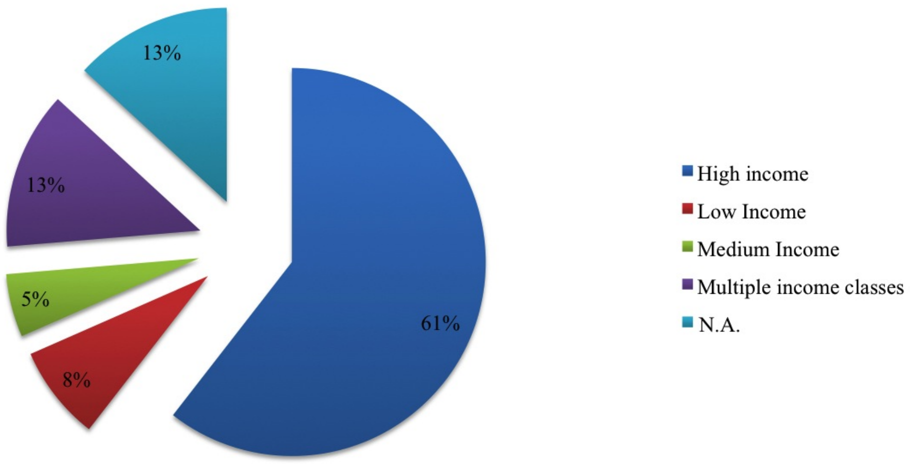


Figure 2. Methodology of studies.

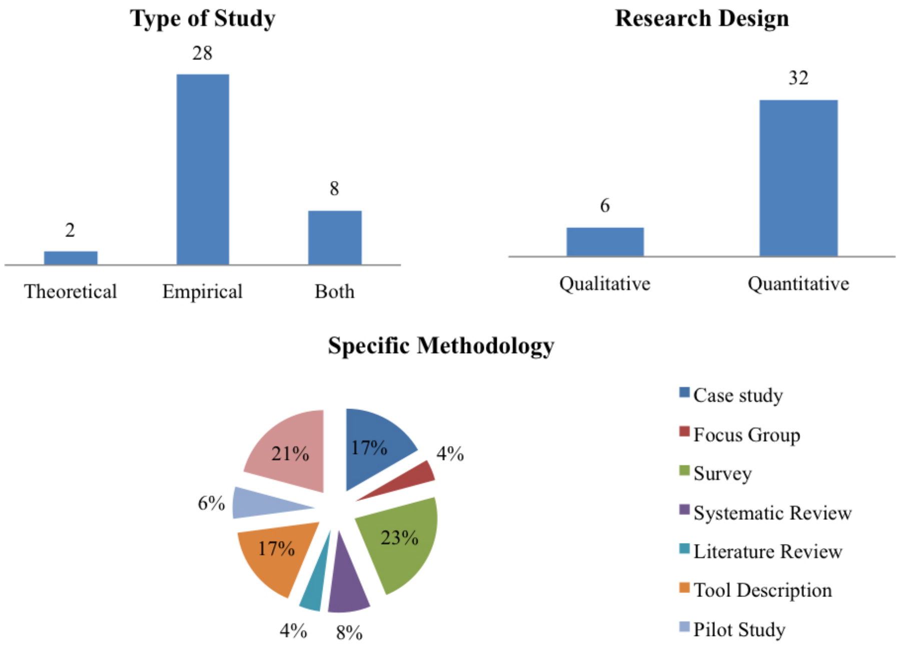


Figure 3. Health condition.

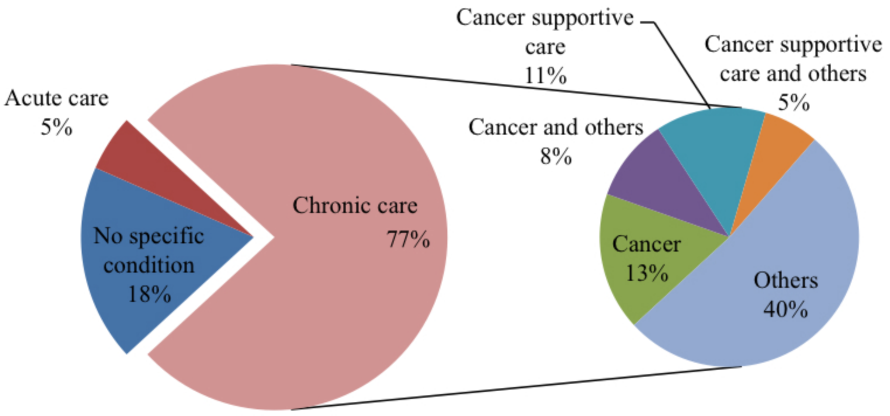
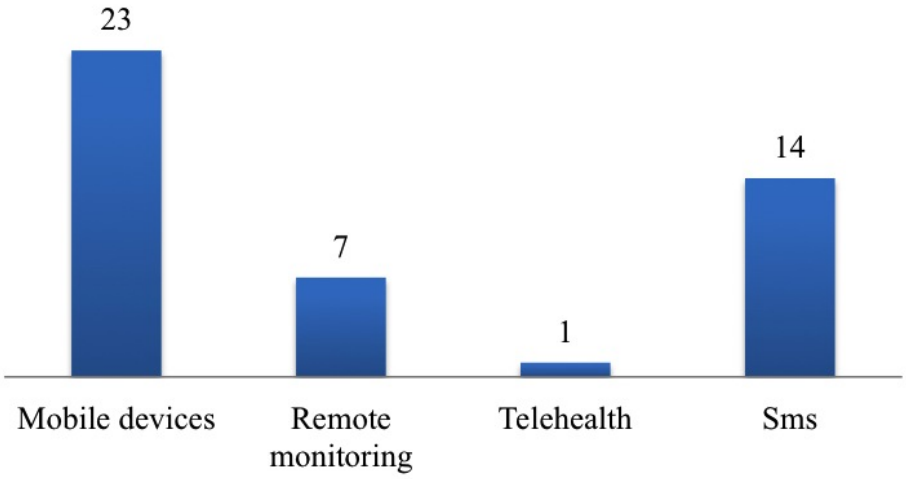


Figure 4. Type of technology.



Evaluation of mHealth's Performance

The assessment of mHealth's performance is based on the use of multiple measures. It is mainly measured in terms of better quality information [3,16,17,28-30]. Baumgart analyzed information-sharing, showing that the quality of information increased for certain activities as a result of using PDAs and tablets, such as billing, prescription writing, medical calculation, scheduling, and drug reference [31]. A study by Hamou et al showed that using mobile technologies for collecting patient data and feedback could promote better information when used in a clinical setting [20].

Another measure of performance often analyzed is cost savings [25,32,33]. A report by Boston Consulting Group and Telenor, for example, analyzed the role of mHealth in homecare for the elderly [34]. According to this report, costs savings for caring for the elderly varied in three different countries, with amounts ranging from €1.25 billion in Denmark to €2.4 billion in Sweden.

Other studies have shown that mHealth may make patient assessment more straightforward and less time consuming [17,35,36]. Some studies examined mHealth's performance with respect to improvements in medical treatment adherence rates [37,38] and consequent re-hospitalization rates [39-41]. Other papers studied the quality of service [42-44], but they often had a specific and narrow scope of mHealth use (eg, mHealth offers patients improved mobility and comfort thanks to wireless technology) [45]. Some papers analyzed mHealth's performance by looking at the enhanced monitoring of patients that also led to better disease management [46].

Using mobile technologies to collect up-to-date data can help patients regain functional independence and help hospitals determine the appropriate length of stay for a patient [47] and thus help cut the cost of hospitalization [25]. Finally, some studies have shown that health care communities created via mHealth can enhance quality of life by providing peer support, whereby patients are able to exchange opinions with regard to a certain drug, physician, therapy, or share personal experiences [27,48].

Discussion of Findings

Although there is not necessarily a common assessment of the measures of performance to be found in literature, they can be grouped into main dimensions based on other studies assessing innovation and technological innovations [49,50]. For instance, papers that measured performance in terms of the quality of information, cost savings, and time savings actually focused on efficiency measures [21]. Other studies related to effectiveness

[39,51], and some of these focused on dimensions of organizational performance from the health care provider's viewpoint. In particular, the focus was on cutting re-hospitalization rates or other indirect effects associated with improved integration of health care. With regard to effectiveness, another limited body of research focused on quality of service. Finally, very few papers analyzed clinical effectiveness in public health [26] and the role of mHealth for enhancing quality of life [26].

In particular, research considering quality of life focused on a single dimension, that is, enhancing the social relationships of patients. However, quality of life was typically associated with other dimensions, like a person's physical health, psychological state, level of independence, personal beliefs, and local environment [52].

Performance of mHealth in Cancer Care

We subsequently studied papers assessing the performance of mHealth in cancer supportive care. Unfortunately, there were very few papers on this important care process (5.6% of total papers, 6 papers), and so we extended our analysis to include all papers assessing mHealth's performance in cancer care. These studies were mainly empirical, and most of them identified similar measures of performance (Figure 5).

First, the dimensions discussed above must be defined [53]. The framework consists of four performance dimensions: efficiency and effectiveness, which are output measures, and clinical effectiveness and quality of life, which are outcome measures.

Efficiency focuses on the evaluation of mHealth in terms of quality of information, time saving, and cost savings. Effectiveness is related to the contribution that mHealth gives to the process of integration and improvement of patient care processes, evaluated from the health care provider's perspective. To this extent, this dimension can be divided into two measures, namely organizational performance and quality of service.

Clinical effectiveness deals with the evaluation of the effects produced on clinical activities, such as improvements in the adherence rate to medical treatment. Finally, quality of life measurements refer to the evaluation of mHealth in terms of physical and psychological state.

Figure 6 shows the different measures of performance of mHealth in cancer care grouped by these dimensions.

Figure 5. mHealth performance in cancer and cancer supportive care: empirical studies.

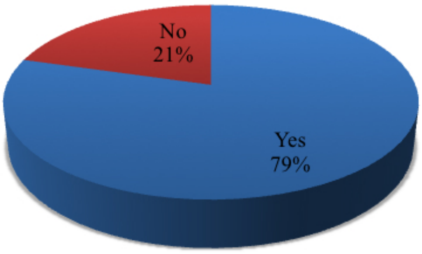
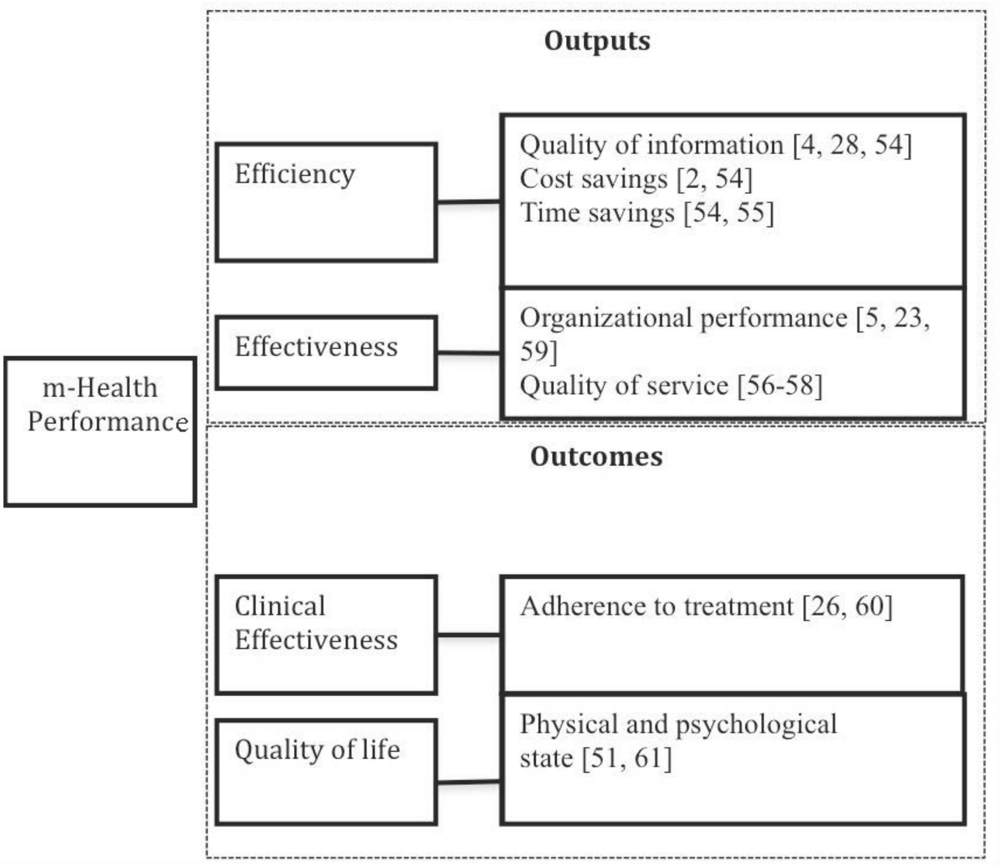


Figure 6. Dimensions and measures of mHealth performance in cancer care.



Efficiency

Most papers focused on better quality information with respect to efficiency [4,54]. A 2001 study, for example, found that many clinical procedures relating to patient management are repetitive and Workflow Management Systems for oncology can automate these repeated activities by using mobile applications to transfer data services, like remote monitoring. Workflow implies the automation of business processes in order to promote the transition of information within the organization and can enable health care institutions to transform large amounts of medical data into contextually relevant clinical information [28].

Literature on mHealth's performance in cancer analyzed other measures of efficiency, including cost savings [2,54] and time savings [54,55]. Holzinger analyzed the impacts of a new method for collecting skin cancer data [54]. Patients filled out a questionnaire on a tablet personal computer, and the medical data collected became part of the electronic patient record made directly available to physicians. The author found this instrument generated annual savings worth up to €40,000 compared to the estimated annual cost of €55,000 if mHealth were not used.

Holzinger's research [54] also showed another measure of efficiency, that is, time savings. His study actually found data indicating up to 90% reduction in the time needed for data entry. This may be particularly significant if mHealth can make it possible to save time by sharing information generated by central hospitals located in big cities with remote care centers [55]. Furthermore, ready access to patient data by means of mobile devices and technologies can lead to a significant reduction in medical errors.

Effectiveness

Quality of service is one measure of effectiveness [56-58]. Lamber et al showed how mobile technologies can help monitor oncological patients during day hospital therapies if a mobile service is an integral part of the hospital's information system. This instrument guides patients at hospital by means of a "patient guidance service" telling them what they have to do next [56].

Many papers, however, focus on better monitoring, especially those related to cancer supportive care [5,23,59]. For example, Kearney evaluated the impact of a remote monitoring system based on mobile technology assessing the effects of six common side effects of chemotherapy [23]. In the same way, Mooney tested the feasibility of a telephone-based computerized system used for monitoring chemotherapy symptoms by generating alerts to health care providers [59]. More specifically, Mooney illustrated the usefulness of mHealth for assessing less common symptoms that are usually poorly controlled.

Clinical Effectiveness

Clinical effectiveness seems to be mainly related to the appropriateness of care, often measured through the adherence rate to medical treatment [26,60]. Heinrich evaluated the use of handheld devices that provide electronic reminders for medication to a sample of adults suffering chronic illness [26]. Moreover, adherence to medical treatment may be improved through a software app developed for a mobile phone platform to support regular and correct drug intake, also leading to better disease management [60].

Quality of Life

Finally, quality of life is a poorly investigated dimension of performance with specific reference to cancer. We found only two papers assessing this dimension, which examined several chronic conditions, including cancer [51,61]. They discussed the contribution of mHealth to a patient's health and behavior in general terms.

Discussion

Principal Findings

This paper helps investigate the performance of mHealth, with particular reference to mHealth in cancer supportive care. Although there is abundant literature on mHealth, it is lacking with regard to mHealth's performance, especially in relation to cancer and cancer supportive care. Most mHealth studies focus more on the mobile technology itself, rather than on its adoption and performance, as confirmed by Van Heerden et al [62]. However, introducing systems like mHealth for managing health care-related information is not limited to technology, since it demands the capacity to integrate technology, people, and processes.

Most papers that we reviewed focused on the use of mHealth, some looked at the performance of mHealth, and very few papers looked at the determinants of mHealth. The papers on the early stages of the innovation process actually focused on pilot projects rarely leading to wide-scale adoption. Pilot studies have been carried out, and mobile apps have been developed and tested on specific contexts. According to Tomlinson et al [63], there are more than 500 mHealth studies on pilot projects, but almost nothing is known about the likely uptake of these initiatives after the pilot projects are completed. As a result, it is clear that there are huge scaling-up problems.

If we have to determine whether mHealth can actually meet its promise, our analysis found very limited evidence when it comes to mHealth in general and its contribution to better quality of life. Research is almost always based on single studies and on a single dimension of return. For example, papers often do not analyze efficiency, but focus on cost- or time savings. Any evaluation of the performance of mHealth is based on very different methods and measures, with a prevailing focus on the quality of information. This fails to consider the contribution that mHealth may offer to improving the performance of health care providers, health care systems, and to quality of life in general.

Technically, there is little evidence of evaluation processes based on structured, solid, consistent, and mature methodologies. Furthermore, the evaluations were not part of larger and more extensive performance measurement processes, starting with defining goals for mHealth supporting a given health care process, cancer care processes in particular, and then systematically and continuously analyzing what happens next. This approach to evaluation is crucial because effects may not necessarily be evident immediately after the introduction of innovation; evaluation should be monitored over time to allow for effects that become visible in the short, medium, and long term.

The existing literature also usually involved a single specific stakeholder, whereas our vision takes in multiple types of stakeholders [64,65] working in this specific field, who all perceive benefits resulting from their involvement. Thus, all these benefits should be analyzed.

Possible Future Research Agenda

Overview

This paper is a preliminary study that analyzes the performance of mHealth in cancer supportive care. To date, there is limited published research in this field. Consequently, we identified some areas for further research.

Systematic Review of Definitions for the Evaluation of mHealth's Performance

A first substantial contribution to assessing mHealth's performance would be a systematic assessment and review of the current definitions of the scope and boundaries of the evaluation processes. In the private sector, a substantial body of empirical and theoretically informed research has led to discussion on return of investment measures and key performance and success indicators. A main motivation for evaluation is the need to monitor profitability results, in turn providing an incentive for further innovation in order to cut costs and improve market share, which fits the purpose of some higher-income countries with private health care systems. However, the adoption of mHealth is generally supported for more general purposes, such as improving the efficiency, productivity, and adequacy of care services. This leads to benefits going beyond organizational results, with more social-related outputs and outcomes, and impacts such as quality of life.

Development of Solid Frameworks to Measure the Performance of mHealth

There is a prevailing focus on empirical studies, each adopting its own measures of performance. Theoretical studies should be carried out in order to better understand the performance of mHealth. There is a need to develop and consolidate more systematic frameworks since most studies focus on single measures of performance, although we grouped them into dimensions, with the aim of providing measurement systems of mHealth performance. This is fundamental for depicting results and for creating opportunities for comparing evidence and generalizing findings.

Multi-Stakeholder Expectations and Multi-Stakeholder Assessment of mHealth Performance

mHealth is a technological innovation that could affect multiple stakeholders. This has at least two implications for a research agenda. First, it suggests an investigation of the expectations of stakeholders with the purpose of prioritizing mHealth adoption where there is a need for it. This may lead to favorable and supportive opinions relating to the adoption process and to the identification of mechanisms to generate value and stimulate commitment towards mHealth. Second, evidence regarding the expectations of stakeholders should be considered in order to set goals and define targets for results that should be reflected in the measurement frameworks.

Systematic Performance Measurement Cycles

Most studies analyzed were based on empirical work on pilot projects and tests of mHealth adoption. Evidence [63] suggests that this does not always lead to wide-scale adoption. Literature on performance measurement [49,50] suggests that evaluating innovation performance should be an ongoing activity. Not all effects of mHealth embedded in a care process may be measurable at the same time. Most technological innovations produce multiple effects at different times after adoption [66-68], so it seems relevant to systematically and repeatedly collect data on the impacts of this innovation.

Methods

Some studies [43,59] are based on perceptions and limited interviews. Further research should address the question of methods that are more fit for purpose.

Finally, it seems appropriate to link the evaluation of mHealth's performance to the scope and use of mHealth. This might provide an honest assessment of the actual contribution that mHealth can offer.

Conclusions

Our analysis revealed that studies evaluating the performance of mHealth are based on very different methods and measures, with a prevailing focus on issues linked to efficiency. This fails to consider the real contribution that mHealth can offer for improving the performance of health care providers, health care systems, and the quality of life for patients.

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Conflicts of Interest

None declared.

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Abbreviations

mHealth: mobile health
PDA: personal digital assistant
SMS: short message service

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Corrigenda and Addenda

Correction: The Psychometric Properties of CollaboRATE: A Fast and Frugal Patient-Reported Measure of the Shared Decision-Making Process

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The authors of “The Psychometric Properties of CollaboRATE: A Fast and Frugal Patient-Reported Measure of the Shared Decision-Making Process” (http://www.jmir.org/2014/1/e2/) have overlooked an error in the Methods section during the submission process. The sentence “We administered 2 different response scales to examine their psychometric properties separately. CollaboRATE-10 was a 10-point anchored scale, ranging from 0 (no effort at all)” should have been “...ranging from 0 (no effort was made)”. This change is also needed in: “CollaboRATE-5 was a 5-point Likert scale, with responses of 0 (no effort at all),” to read “...with responses of 0 (no effort was made)”. These errors have been corrected in the online version of the paper on the JMIR website on February 6, 2015, together with publishing this correction notice. A correction notice has been sent to PubMed and the correct full-text has been resubmitted to Pubmed Central and other full-text repositories.

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