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Contents

Viewpoints

Original Papers

Review

Viewpoint

The Role of eHealth in Optimizing Preventive Care in the Primary Care Setting

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Abstract

Modifiable health risk behaviors such as smoking, overweight and obesity, risky alcohol consumption, physical inactivity, and poor nutrition contribute to a substantial proportion of the world's morbidity and mortality burden. General practitioners (GPs) play a key role in identifying and managing modifiable health risk behaviors. However, these are often underdetected and undermanaged in the primary care setting. We describe the potential of eHealth to help patients and GPs to overcome some of the barriers to managing health risk behaviors. In particular, we discuss (1) the role of eHealth in facilitating routine collection of patient-reported data on lifestyle risk factors, and (2) the role of eHealth in improving clinical management of identified risk factors through provision of tailored feedback, point-of-care reminders, tailored educational materials, and referral to online self-management programs. Strategies to harness the capacity of the eHealth medium, including the use of dynamic features and tailoring to help end users engage with, understand, and apply information need to be considered and maximized. Finally, the potential challenges in implementing eHealth solutions in the primary care setting are discussed. In conclusion, there is significant potential for innovative eHealth solutions to make a contribution to improving preventive care in the primary care setting. However, attention to issues such as data security and designing eHealth interfaces that maximize engagement from end users will be important to moving this field forward.

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KEYWORDS

eHealth; Internet; prevention; general practice; family practice; evidence-based practice

Importance of Preventive Care in Optimizing Health Outcomes

Background

Modifiable lifestyle risk factors such as being overweight, smoking, poor nutrition, excess alcohol consumption, and physical inactivity are among the major causes of morbidity and mortality worldwide [1,2]. These risk factors contribute significantly to the development of chronic diseases [3], which are the leading causes of death globally [4]. In 2002, chronic diseases including cardiovascular disease, cancer, chronic respiratory disease, and diabetes caused 29 million deaths worldwide [5]. The estimated annual economic impact of chronic diseases including cancer, heart disease, and diabetes in the United States in 2007 was US $1.3 trillion, including US $277 billion in direct treatment costs [6].

Role of General Practice in Delivery of Preventive Care

Implementation of best practice preventive care has the potential to substantially improve health outcomes by reducing the prevalence of modifiable risk factors. Primary health care is well positioned to address the challenges of chronic disease prevention and management [7], with each health care visit being a potential opportunity to provide preventive care [8].

Prevention is recognized by both general practitioners (GPs) and patients as one of the key roles of GPs [9,10]. The effectiveness of brief interventions (defined as short, motivational, patient-centered interactions) by GPs in encouraging changes in weight, alcohol, smoking, and physical activity behaviors has been demonstrated [11-13].

Improvements in Preventive Care Urgently Needed

Despite the development of national guidelines and acknowledgement by GPs of their professional responsibility in management of lifestyle risk factors [14], actual rates of preventive risk factor screening and management remain low [15,16]. For example, GPs rarely engage in lifestyle counseling with obese patients during their regular consultations [17]. Further, while many GPs report using verbal counseling for risk factors such as lack of physical activity, they rarely provide referrals or written action plans [18]. The gap between recommended care and actual delivery rates is further underscored by patient reports of a desire for more lifestyle advice [16]. Such findings indicate that there may be barriers affecting GPs' ability to screen for and provide advice on risk factors.

Barriers to Best Practice Preventive Care in Primary Care

Barriers to best practice preventive care include a lack of practitioner time, skills and reimbursement, and low patient motivation [19-21]. A recent review showed that practitioner time was the most frequently cited barrier to detection of lifestyle risk factors [22]. Preventive care must be balanced with already limited time available to deal with both immediate and ongoing health conditions. One US study estimated that in order to provide all the preventive services recommended by the US Preventive Services Task Force, each physician would be required to spend 7.4 hours per working day on prevention alone, highlighting the difficulties in meeting current preventive care recommendations [23]. Strategies for delivering time-efficient yet comprehensive lifestyle risk factor management in primary care are therefore required.

The Promise of eHealth in Improving Preventive Care

The disparity between recommended preventive care and actual screening behavior has prompted a call for alternative methods for collecting patient health information. eHealth technologies represent one strategy for improving the accuracy and completeness of clinical information collected from patients. eHealth is the "intersection of medical informatics, public health, and business, referring to health services and information delivered or enhanced through the Internet and related technologies" [24]. The use of information and communication technologies to improve health is rapidly expanding. These technologies can be used to gather, manage, and disseminate health information via computers, tablets, and mobile devices [25]. Electronic data collection via these portable devices offers a number of significant advantages for the assessment and management of patient lifestyle risk factors. eHealth technologies can support clinical practice by facilitating the accessibility of patient data and appropriate evidence-based guidelines, offering a potential strategy for improving the safety, quality, and efficiency of care [26,27].

Improving the Comprehensiveness and Accuracy of Clinical Information

Assessments of Lifestyle Risk Factors

Electronic assessment of lifestyle risk factors can be implemented prior to a patient's consultation with their GP, so that the information can be transmitted instantaneously to the GP and addressed during routine encounters. These assessments therefore provide valuable real-time clinical information that can help guide the consultation and facilitate opportunistic intervention. Multiple risk factors can be assessed simultaneously to ensure that a comprehensive picture of the patient's situation is available.

Acceptability to Users

Several studies have demonstrated the acceptability of electronic health assessments administered in waiting rooms in general practice clinics. Our study of over 4000 patients from 12 Australian general practices found that 86% of those eligible were willing to complete an electronic health risk assessment on a touchscreen computer in the waiting room [28]. The vast majority of patients reported that the system was easy to use (94%), and 77% of patients were willing to have GPs keep their survey responses on file [28]. Similar findings have been reported in studies from New Zealand, the United Kingdom, and the United States [29,30]. Patients report that electronic assessments are sufficiently private (91%) [30] and indicate a preference for electronic approaches over paper and pen assessments. Support for the implementation of repeated assessment is also available, with 86% of patients and 90% of GPs indicating tht they would be willing to complete electronic assessments at future consultations [31].

Feasibility and Acceptability to Clinic

GPs have expressed concerns in relation to the integration of patient risk factor assessments into routine practice, perceiving potential burden on staff and disruptions to the clinic, such as increased waiting times and consultation length. However, our data showed 89% of patients were able to complete a comprehensive health risk survey in less than 15 minutes, and 99% were able to do so prior to their consultation [28]. Given that the majority of general practice patients wait on average 11-30 minutes before an appointment [32], the completion of electronic assessments prior to consultation is highly feasible. Our data indicate that this approach does not disrupt the clinic, increase patient waiting times, or increase staff burden [28]. As many patients consult their GP several times a year (on average in Australia, 6.5 times per year [33]), implementation of this approach enables tracking of health risk factors over time.

Accuracy of Self-Reported Data

Clinicians primarily rely on patient self-reported risk factors when assessing a patient's medical history. While more accurate assessments such as cotinine analysis for smoking [34] or blood alcohol tests may be used [35], these are generally too intrusive, expensive, and time consuming to be used for routine screening of health risk factors. Although the accuracy of self-report data may be affected by factors such as social desirability and recall biases, for many lifestyle risk factors, self-report is the most feasible method of assessment [34,35]. Inconsistencies in questions used by clinicians, however, can result in variable accuracy of self-reported health behaviors [36]. The use of an electronic health risk assessment may help overcome this by allowing standardized questions, with established reliability and accuracy, to be used across all patients.

Simplification of Complex Assessments

The assessment of some lifestyle behaviors can be complex. For example, quantity and frequency assessments of alcohol intake require the respondent to not only recall the frequency of intake, but also to accurately assess what volume of different types of alcohol constitutes a standard drink [35]. Some of these complexities can be overcome in electronic risk assessment by using dynamic elements to simplify assessment. For example, electronic assessment tools for alcohol may allow participants to select the type and number of drinks they have consumed, with the program automatically converting these into standard drinks [35]. These types of strategies have been used in electronic surveys to help improve accuracy of reporting [35].

More Comprehensive Assessment of Risks

As noted above, GPs often have limited time for preventive care during a consultation and therefore may screen for only a limited range of risk factors, if at all. In contrast, electronic health assessments completed prior to a consultation can efficiently cover a standardized and comprehensive range of risk factors. Branching algorithms can be used to tailor the assessment and ensure participants are not required to answer irrelevant questions, thereby minimizing required assessment time. This information can then be automatically summarized and fed back to GPs prior to the patient's consultation, with areas that require risk management flagged.

Improving Provision of Clinical Care, Including Self-Management Advice

Point-of-Care Feedback

Computing systems have the capacity to use collected information to design personalized health programs or provide point-of-care individualized feedback [37]. If appropriate risk behavior information is collected, point-of-care feedback on patient risk factors can be provided to both the patient and clinician in real time, either as an onscreen display or in print [37,38]. Such feedback can be used as a reminder to prompt discussion of preventive care issues within the consultation. One review found that computerized feedback produced modest changes in clinical behavior [38]. However, it is notable that the review focused on a range of clinical behaviors, with only a few preventive care activities included. This suggests that there is a need to further investigate the impact of computerized feedback on a broader range of preventive care practices. This process can assist in streamlining consultations, increasing the time available for the delivery of advice or referral to other services or specialist providers. If consultation time is particularly limited or other urgent health care issues need to be addressed, there is potential for patient feedback to be uploaded to the patient's electronic medical record for discussion at a subsequent appointment.

Focused Secondary Screening by General Practitioner

By providing GPs and patients with the results of the electronic assessment, GPs can quickly identify which health issues are of concern and provide a more in-depth assessment, such as exploring the severity and impact of the health risk, as well as the social, psychological, medical, and environmental context that contributes to or exacerbates the risk factor. Through reducing the time burden associated with risk assessment and summarizing existing risk behaviors, electronic screening and feedback maximizes the time available for the provision of preventive care, thus allowing GPs to use their consultation time more effectively.

Results Available to Multiple Health Providers

If the GP refers their patient to specialist or other follow-up care, electronic screening results can also be made available to the other relevant providers. This reduces the need for replication of risk assessment by additional providers, again allowing other health care providers to use their time with the patient more effectively. There is some evidence that electronic sharing of medical information among clinicians within and across settings improves continuity of care [39].

Promoting Patient-Centered Care

Patient-centered care is concerned with ensuring that care provided is in accordance with patients' needs, values, and preferences [40]. Given that changing lifestyle behaviors require active and ongoing partnership from the patient, it is particularly important that preventive care takes a patient-centered approach that incorporates the needs and goals of the person [41]. Interventions that are matched to a participant's stage of change have shown promise for improving some behaviors [42,43]. It follows that adherence is likely to be greater if the recommendations are congruent with patient values and motivations. However, clinicians also have limited time to identify patients' preferences and needs in order to tailor their care. Electronic health assessments can help overcome this by including a systematic assessment of patients' priorities or readiness to change with regard to lifestyle risk factors. In situations with no clear clinical reason for prioritizing change of one lifestyle risk factor over another, this information is likely to be useful in guiding clinicians to target discussion or advice towards patient priorities or readiness to change.

Recall and Reminder Systems for Patients

Recall and reminder systems involve an automated system to trigger a reminder to the patient to perform a routine action or test. These systems may trigger a letter, telephone call, short message service (SMS), or email prompt. Recall and reminders have been used successfully to help patients manage chronic and complex diseases such as diabetes [44,45]. Although applications to preventive care have been less widespread, reviews suggest that recall and reminder systems are also likely to be effective in preventive care [46,47]. A Cochrane review found that recall and reminder systems were effective in improving immunization rates among both adults and children [46]. Multiple reminders were more effective than single reminders, and telephone reminders were more effective than mailed reminders [30]. Reminder systems for breast and colorectal screening have also been shown to improve patient uptake of such tests [47]. Potential applications of recall and reminder systems to prevention of lifestyle risk behaviors include providing automated reminders to clinicians to follow up on advice provided in previous consultations and prompting the provision of additional tips or suggestions that encourage the patient to adhere to treatment plans.

Reminder Systems for Clinicians

Computerized reminder systems for clinicians may involve reminders delivered electronically (eg, an alert on the computer screen) or via paper. Point-of-care reminders have been shown to be effective in prompting health care providers to perform a patient- or encounter-specific clinical action [48] and in improving physician adherence to processes of care [38]. Computerized reminders delivered on paper have been shown to improve care by a median of 7% [49]. Reminders that provided space for the clinician to record a response or explanation were more effective than those without this feature [49]. While studies to date have demonstrated that this type of intervention can be effective for increasing some preventive care behaviors such as participation in screening for cancer [49], there is a need for examination of how this can be applied to other types of preventive care such as addressing lifestyle risk factors. In the context of a broader range of preventive care, clinician reminder systems could be used to remind clinicians to monitor progress with lifestyle changes, reassess risk factors, or to administer a test or specific clinical action.

Provision of Tailored Educational Materials and Web-Based Resources

Self-management is the frontline intervention for most lifestyle risk factors. Even when risk factor severity indicates the need for pharmacological intervention, self-management is still required to ensure adherence to a recommended medication regime. The ability to initiate and sustain risk factor change depends on several factors, including patient awareness of the harm caused to health by particular behaviors, and the desire and ability to change [50]. Lack of knowledge about disease and treatment is one of the major obstacles to compliance with treatment [51]. There is also evidence to indicate that patients are often ill informed about their risk factors and how to manage them. For example, Silagy et al reported low awareness of the risks associated with a high fat diet [52]. Similarly, only one out of three established cancer risk factors for five common cancers were identified by British adults [53], and the majority of Americans were unable to identify major risk factors for breast, cervical, and colon cancers [54]. Therefore, patients may need information about their risk factors as well as the changes they should make to reduce these risk factors.

Electronic risk assessments may be programmed so that they either (1) generate tailored information on self-management of risk factors that can be printed in clinic, or (2) refer patients to specific online eHealth programs that provide advice and interactive self-management tools to help manage risk factors. The latter can be done by sending links to relevant programs to the patient's email address.

There is emerging evidence for the effectiveness of eHealth interventions for a range of health behaviors. For example, systematic reviews have found that interactive computer-based interventions are effective in producing small reductions in weight among overweight and obese people [55] and increasing knowledge about sexual health among various populations [56]. However, more evidence is needed, particularly evidence specific to the primary care setting. A recent review identified that no studies had evaluated the impact of Web-delivered physical activity interventions over a 12-month period or longer, and none in general practice settings [57]. Similarly, another review found only mixed evidence for the impact of Web-based interventions for smoking cessation; however, none of these studies were specific to the primary care setting [58]. This suggests that there is considerable scope to develop and test eHealth interventions for primary care populations.

Potential Advantages of Web-Based Self-Management Resources

Flexibility of Presentation

Web-based materials can be presented in a variety and combination of formats including text-based, verbal (eg, audio or embedded videos), and visual (eg, graphs, pictures, or animations) information. Provision of information in multiple formats improves comprehension, particularly for less literate patients [59].

Enhanced Relevance to the Reader

Web-based programs can be interactive such that the user can input details about their health concerns or health status and be directed to tailored information. In addition to saving the user time in searching through irrelevant information, there is strong evidence that tailoring improves recall and comprehension of medical information [59]. Studies also indicate that there is variation among individual patients in the level of detail that they prefer [60] and that tailoring to such preferences reduces patient anxiety [61].

Standardization of Care

There is considerable variation with respect to many aspects of health care delivery, including within primary care. This is in part due to the time pressures of clinical practice, differences with respect to services and systems within health care organizations, and differences in the skills and knowledge of clinicians [62]. There is also evidence that patients residing in rural areas, for example, experience more difficulties in accessing face-to-face services due to limited availability of primary care services [63]. Online approaches can ensure that high-quality, evidence-based information is made available to all patients, overcoming potential inconsistencies including those due to geographical barriers.

Adopting Evidence Into Practice

eHealth applications provide a central mechanism for disseminating and maintaining evidence-based information with broad population reach. Information can be centrally updated to correspond with changes in guidelines to ensure that the latest and best-evidence practices are disseminated to patients.

Accessibility in a Range of Languages

Interactive Web-based programs can be programmed so that the user can select the language the material is presented in on screen. This has advantages for multicultural countries such as Australia, the United Kingdom, and United States and can help ensure that people who are not fluent in English are not disadvantaged.

Enhanced Recall and Understanding

Strategies used for written materials to enhance comprehension and recall can also be applied online. These include explicit categorization [64,65], use of plain language [66], and repetition of important pieces of information [67].

Linkage to Data Provided in Other Websites

Web-based programs can be configured to collect and display information from other credible websites. This could include, for example, presentation of up-to-date health statistics, clinical information, and research and policy information.

Challenges of Using eHealth in Primary Care

Will eHealth Exacerbate Disparities in Care?

According to the World Bank, Internet access continues to rise globally. In 2011-2013, high rates of Internet access were reported for developed countries such as the United States (84%), Australia (83%), Germany (84%), Japan (86%), and the United Kingdom (90%) [68]. However, there is a risk that eHealth applications will exacerbate health disparities among groups with lower Internet access and/or skills. One potential risk is that particular patients will be unwilling or unable to use computer-based health assessments administered in clinic. Our pioneering work in the late 1990s, however, indicated the acceptability of touchscreen computers in a variety of community and specialist health care settings including general practice [69], drug and alcohol clinics [70], and oncology settings [71]. Since then, the mainstream use of touchscreen technology on computer tablets and mobile phones has increased considerably. Our recent multisite study of general practice care indicated that more than 90% of patients rated the touchscreen health assessment administered in the waiting room as highly acceptable [28]. High rates of acceptability ranging from 88% to over 90% have also been confirmed in community settings serving socioeconomically disadvantaged clients [72,73]. This suggests that with appropriate survey tools, socioeconomic factors will not necessarily be a barrier to the implementation of this technology as part of standard clinic care.

There are perhaps greater risks of disparities where patients are referred to use eHealth applications outside the clinic. These relate to both disparities in access to the Internet, and in engagement with, and ability to apply, the information provided, in order to improve health. Several studies have reported differences in Internet access among subgroups of the population such as older people [74,75], racial minorities [76], and people who are socioeconomically disadvantaged [75,76]. However, there is evidence to suggest that the “digital divide” is becoming narrower as more people gain access to the Internet [77].

In relation to engagement and use of information, developers of eHealth programs can potentially incorporate design features to overcome such barriers. As described earlier, there are many features that can be built into the design of eHealth programs such as the use of language, layout, and graphics that can mitigate poor health literacy. As the digital divide narrows, the issue of how to ensure that information can be understood and applied by a wide range of people is likely to become increasingly prominent [77,78]. A client-centered approach that maximizes the user’s experience of interacting with the technology and enhances its ease of use is needed. This involves iterative development that incorporates user feedback [79]. Human factors research advocates a range of factors that need to be taken into account when designing eHealth applications including readability and ease of navigation of the interface, user skills training needs, and how easily and efficiently the interface allows the user to complete necessary tasks [80].

Integrating Patient Electronic Assessments Into Existing Practice Software Systems

Data obtained using electronic assessment tools can be initially collected and stored by the Web server software executing on the server that provides the webpages. The data are aggregated on a per-page basis during communication between the server and the device (eg, tablet computer) on which the patient performs their assessment. Ideally, the collected assessment data would then be made available on each respective patient’s medical record. This copying of patient data between software systems is similar to the current widely implemented transfer of pathology, radiology, and other data/images from laboratories and collection centers to GP practice software.

Implementation of the transfer of data is typically achieved by transfer of messages between the data producer (in this case the Web-based assessment system) and the practice software. As envisaged by McDonald et al, both parties to the data transfer need to “understand” an agreed upon message format used by the Web-based assessment system to send the assessment data to the practice [81]. The ANSI-accredited Health Level 7 standards development organization (HL7) [82] aims to standardize interoperability, so that transfer between medical software systems is straightforward. For example, the practice software may “understand” the HL7 compliant Medical-Objects [83] format for medical message transfer. While most current medical practice software would support HL7 communication, if the practice software does not support such message transfer, the Web-based assessment system could automatically send each patient’s assessment (in a format such as csv) to a provided email address (representing the practice) for manual import into the practice software. It is expected that manual import would, however, be required only as an interim solution for the minority of practices using out-of-date, non-connected software.

Ensure Use of Electronic Assessment Results by General Practitioners

Simply providing risk factor results to GPs may not ensure that results are utilized by GPs (although as noted above, the use of point-of-care reminders have been shown to be effective in improving care). For example, Brindle et al found no strong evidence that cardiovascular risk assessment performed by a clinician improved patient health outcomes, possibly due to the poor uptake of computerized clinical decision support systems [84]. Therefore, electronic risk factor assessment results need to be seen as relevant and useful by GPs. Including clinicians in the design of the assessment or results may improve their use [84]. Providing links to relevant guidelines, and/or advice for GPs about recommended actions or next steps, may also help ensure the clinical utility of electronic risk assessment results.

Ensuring Security of Patient Data

Security of data is three-fold: (1) the device on which the data are collected must prevent unauthorized users from accessing data or immediately transfer the data to another site so it is not locally stored, (2) any devices used to store data must control physical access by implementing, for example, password-based access control, and be protected against unauthorized external access using mechanisms such as firewalls controlling Internet traffic, and (3) data must be rendered unreadable using encryption techniques that allow decoding by the correct recipient and prevent decoding by unauthorized interceptors of the data. Each of these methods of securing data is currently available. For example, an electronic risk assessment on a portable device (such as tablet computer) could use a local Web browser to receive webpage content from the Web server and send patient responses back to the Web server at the completion of each page of the assessment (signaled when the patient clicks the “next” button on their screen). In this way, no patient data need be stored on the tablet between assessments, and access by unauthorized persons would be impossible on the data collection device. A patient’s response to each page of the risk assessment would be encrypted while in transit between the tablet computer and the Web server, thus preventing its being understood in the event of interception. The centralized server would be positioned within a secure data center with appropriate access control preventing unauthorized internal and/or external access to patient data. Such methods could be used to ensure security of patient data within the electronic risk assessment approach proposed in this paper.

Conclusion

There is great potential for eHealth to assist clinicians in assessing preventive health care needs and in enhancing the delivery of care to manage such risks. While there are practical challenges that need to be considered in the implementation of eHealth programs, these are not insurmountable. Engagement of end users (patients and clinicians) in the development of such applications, and ensuring data security concerns are addressed will be crucial to advancing this field.

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Conflicts of Interest

None declared.

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Abbreviations

GP: general practitioners
SMS: short message service

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Original Paper

Childcare Service Centers' Preferences and Intentions to Use a Web-Based Program to Implement Healthy Eating and Physical Activity Policies and Practices: A Cross-Sectional Study

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Abstract

Background: Overweight and obesity is a significant public health problem that impacts a large number of children globally. Supporting childcare centers to deliver healthy eating and physical activity-promoting policies and practices is a recommended strategy for obesity prevention, given that such services provide access to a substantial proportion of children during a key developmental period. Electronic Web-based interventions represent a novel way to support childcare service providers to implement such policies and practices.

Objective: This study aimed to assess: (1) childcare centers' current use of technology, (2) factors associated with intention to use electronic Web-based interventions, and (3) Web-based features that managers rated as useful to support staff with implementing healthy eating and physical activity-promoting policies and practices.

Methods: A computer-assisted telephone interview (CATI) was conducted with service managers from long day care centers and preschools. The CATI assessed the following: (1) childcare center characteristics, (2) childcare centers' use of electronic devices, (3) intention to use a hypothetical electronic Web-based program—assessed using the Technology Acceptance Model (TAM) with ratings between 1 (strongly disagree) and 7 (strongly agree), and (4) features rated as useful to include in a Web-based program.

Results: Overall, 214 service centers out of 277 (77.3%) consented to participate. All service centers except 2 reported using computers (212/214, 99.1%), whereas 40.2% (86/214) used portable tablets. A total of 71.9% (151/210) of childcare service managers reported a score of 6 or more for intention to use a hypothetical electronic Web-based program. In a multivariable logistic regression analysis, intention to use the program was significantly associated with perceived ease of use (*P*=.002, odds ratio [OR] 3.9, 95% CI 1.6-9.2) and perceived usefulness (*P*<.001, OR 28,95% CI 8.0-95.2). Features reported by service managers as useful or very useful for a Web-based program included decision-support tools to support staff with menu planning (117/129, 90.7%), links to relevant resources (212/212, 100%), updated information on guidelines (208/212, 98.1%), and feedback regarding childcare center performance in relation to other childcare centers (212/212, 100%).

Conclusions: Childcare service managers reported high intention to use a Web-based program and identified several useful features to support staff to implement healthy eating and physical activity policies and practices. Further descriptive and intervention research examining the development and use of such a program to support childcare centers with the implementation of healthy eating and physical activity-promoting policies and practices is warranted.

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KEYWORDS

obesity; long day care centers; childcare centers; guideline adherence

Introduction

Overweight and obesity adversely impacts a large proportion of the population globally, accounting for at least 2.8 million deaths annually and 35.8 million disability-adjusted life years [1]. It is estimated that approximately 60% of adults in developing countries are overweight or obese [2]. Globally, approximately 43 million preschool-aged children were overweight or obese in 2010, with this figure projected to reach 60 million by 2020 [3]. Children who are overweight or obese are up to ten times more likely to develop non-insulin-dependent diabetes and eight times more likely to develop cardiovascular disease during childhood [4]. Overweight or obese children also have a significantly increased risk of adult morbidity and up to three times increased risk of adult mortality as compared to children within the healthy weight range [4]. As a consequence, interventions to reduce childhood overweight and obesity are recommended to reduce the risk of chronic disease in both childhood and adulthood [5,6].

Center-based childcare services represent a promising setting for obesity prevention interventions targeting young children, with between 60% and 80% of young children in countries including Australia and the United States attending these centers [7,8]. Recognizing this opportunity, guidelines for childcare centers recommend the implementation of healthy eating and physical activity-promoting policies and practices [9,10]. Findings from reviews of randomized and quasi-experimental trials suggest that the implementation of a number of policies and practices in childcare, including providing programmed time for physical activity and improving nutritional quality of food provided, are effective in improving child diet and physical activity levels, and preventing unhealthy weight gain [5,11,12].

Although research supports the implementation of healthy eating and physical activity policies and practices in childcare service settings [9,10], their adoption by childcare centers is suboptimal. A study conducted in 20 childcare centers in the United States found that approximately 30% of childcare centers met guideline recommendations for the provision of fruit and vegetables [13]. Further, in a sample of 96 childcare centers in the United States, only 14% of childcare centers provided 120 minutes of active play per day and 40% provided two or more occasions of teacher-led physical activity [14]. Similarly, a study of 261 Australian childcare centers reported that only 41% of preschools and 48% of long day care centers had a written physical activity policy, and between 46% and 60% undertook daily, programmed, fundamental movement skills programs for children aged 2 to 3 years and 3 to 5 years [15].

A small number of trials have been conducted to improve the implementation of healthy eating and physical activity-promoting practices in the childcare setting [16,17]. Interventions which included multiple organizational change strategies, such as the provision of regular face-to-face or telephone support by qualified health staff and the provision of feedback and resources, have been shown to be effective [17-19]. However, such interventions are often resource intensive, and expensive to deliver to large numbers of centers. Most previous trials have also been conducted on a small number of childcare centers (ie, less than 30) [16,20,21], providing limited information regarding the effectiveness of such interventions when scaled up and delivered to all eligible centers [22].

Web-based interventions, including the provision of online training and resources, and interactive tools, represent a promising way of providing population-wide support to childcare centers. Such interventions enable the provision of support to large numbers of childcare centers at a fraction of the cost of other modalities. Further, childcare centers report having existing computing infrastructure and are familiar with the use of Web-based technology, thus increasing the likelihood of engaging in such interventions [8,23,24]. Research examining the effectiveness of such electronic interventions in facilitating the implementation of health-promoting policies and practices in community-based settings is scarce, with an updated Agency for Healthcare and Research Quality review failing to identify such interventions in the childcare setting [25]. Research from primary care and hospital settings, however, demonstrate that electronic interventions can be used to improve clinicians' practices through decision-support tools, performance monitoring and feedback, information communication and prompts, and reminder functions [26,27].

Despite the promise of using electronic modalities, the public health impacts of such interventions are often impeded by low uptake and dropout or attrition in use [28,29]. Frequently reported barriers to uptake include the lack of access to appropriate infrastructure, setup costs, limited integration with existing operating electronic systems, lack of considered implementation, and failure of interventions to meet the immediate needs of users (eg, program being too complex and including features not acceptable or relevant to end users [13,30]) [29,31]. Recognizing such challenges, theories such as the Technology Acceptance Model (TAM) recommend that formative examination of factors associated with end-user intention to use a new electronic system be conducted to maximize the likelihood of end-user adoption [32,33]. Further, assessment of users' preferences regarding the content and type of features they would like available in a Web-based intervention is likely to facilitate uptake and ongoing user engagement [13,34].

To provide relevant information to guide the design and implementation of a Web-based intervention for childcare centers, a survey was conducted with childcare center managers to (1) identify centers' access to the Web and Web-access devices, and (2) identify factors associated with managers' intention to use a Web-based program designed to support implementation of healthy eating and physical activity-promoting policies and practices. Further, the study examined managers' preferences for features to include in a Web-based program to support the implementation of such policies and practices in childcare centers.

Methods

Ethics Approval

Ethics approval was obtained from Hunter New England Local Health District (HNELHD) Human Research Ethics Committee (06/07/26/4.04) and the University of Newcastle (H-2008-0341).

Design and Setting

A cross-sectional study was conducted in the state of New South Wales (NSW), Australia. There were approximately 566,862 children aged between 0 and 5 years [35], and 2587 childcare centers—preschools and long day care centers—in the state [36].

Sample

Childcare centers, including preschools and long day care centers, in NSW provide education and center-based care for children aged 0 to 5 years. Childcare centers in NSW were identified from a list of all licensed centers supplied by the regulator—The State Office of Childcare. Using the RAND function in Microsoft Excel, a random sample of 277 out of 2587 (10.71%) eligible childcare centers within NSW were selected to participate in the study. Childcare centers that catered exclusively to children with special needs or that operated within a primary school were ineligible for participation. Childcare centers located within a particular region of the state were also excluded due to their participation in a separate implementation trial [37]. Licensing and accreditation requirements regarding healthy eating and physical activity are identical for both preschools and long day care centers [38]. As such, preferences for Web-based features to support implementation of obesity prevention policies and practices were not examined separately for the two types of childcare centers. In Australia, all childcare centers that provide government-subsidized childcare benefits are required by federal legislation to use a government-mandated, Web-based Child Care Management System (CCMS) to log enrolments, store essential service information, and enable calculation of childcare benefits [24]. All centers, regardless of whether they had access to CCMS software, were eligible to participate in this study.

Recruitment and Data Collection

Service managers of all selected childcare centers were sent an information letter inviting them to participate in the study survey, which was conducted from October to December 2013. Up to 2 weeks following the mailing of the invitations, research assistants telephoned the service managers to confirm eligibility and to gain consent. If a service manager was unavailable to complete the survey, an alternative staff member was nominated to participate in the survey. Data was collected via a 25-minute computer-assisted telephone interview (CATI).

Measures

Service Characteristics

Service managers were asked to report the following: the center operating times, number of children enrolled, number of educators (ie, carers with primary contact role), and whether they were a childcare benefit-approved center using CCMS to report child enrolment details.

Access and Use of Internet and Associated Equipment

Service managers were asked to report whether they had access to the Internet, and whether they used computers and tablets in their center. If such infrastructure existed, service managers were asked to identify the purposes for using such infrastructure including the following: administrative tasks, completion of reporting requirements, staff education, child education, searching for information, accessing emails, recording and planning of daily program and activities, reporting progress to parents, taking photographs of children's activities, and other purposes.

Factors Associated With Intention to Use a Web-Based Program to Implement Policies and Practices

Items from the Technology Acceptance Model were used to assess intention to use the hypothetical electronic Web-based program. TAM is one of the most parsimonious models assessing end-user intentions to adopt a new information technology system [39]. This model posits that attitudinal characteristics of end users, including perceived usefulness and perceived ease of use, are predictors of intentions to adopt new information technology systems. Reviews of empirical studies report that TAM accounts for between 40% and 70% of variance in explaining intention to use new electronic systems in health care, university, and commercial work settings [33,39,40]. Such studies report high internal consistency for each item (ie, Cronbach alpha >.8 for each item) [39]. This model has also shown high validity when used in countries external to Northern America, where originally developed [41], including China [42] and Switzerland [43]. Further, systematic reviews also report positive associations between behavioral intention to use and TAM constructs, with actual use of program [44,45]. Specifically, systematic reviews examining the relationship between behavioral intentions—as measured by TAM—and actual use of technology found a positive association for approximately 90% of included studies [44,45].

Similar to other studies utilizing TAM [46], service managers were asked to rate on a 7-point scale—1 (strongly disagree) to 7 (strongly agree)—the perceived usefulness, perceived ease of use, and intention to use an electronic online system to support implementation of healthy eating and physical activity policies and practices. The questionnaire was pilot-tested with 6 childcare center managers and, as a result, some minor modifications to the wording of the questions were made to increase relevance to the setting. Perceived usefulness (ie, the perception that using this system will help users achieve gains in job performance) [41] was assessed by the following statements: It would be useful to *assist staff*, *improve staff performance*, *increase staff productivity*, and *enhance effectiveness of staff delivery of healthy eating and physical* *activity-promoting policies and practices*. Perceived ease of use (ie, the degree of ease associated with using a system) [41] examined the following: *ease of interaction with the program*, *mental effort required*, *ease of use of program*, and *ease to get the program to do what they wanted it to do*. Intention to use were assessed by asking managers whether they: *intended to use the system*, *predicted they would use the system*, and *planned to use such a system if it were made available to them* (see Multimedia Appendix 1 for questionnaire).

Features to Support Healthy Eating and Physical Activity Policy and Practice Implementation

Center managers were asked to rate on a 4-point scale—1 (very unhelpful) to 4 (very helpful)—whether they perceived the following features as helpful to support staff implement healthy eating and physical activity-promoting policies and practices: *interaction and communication tools*, including (1) chat rooms, (2) discussion boards, and (3) email feedback or phone support from health care service staff, *provision of educational materials* (ie, lunchbox or menu-planning ideas, physical activity ideas, links to other helpful websites), *decision-support systems* (ie, menu-planning tool), *performance feedback and monitoring tools* (ie, features to monitor progress over time and in relation to other services, and tools to help staff with prioritizing tasks), and *prompts and reminders* [18]. Such questions were based on consultations with childcare center managers, health promotion practitioners who support services to implement such practices, and a review of the literature examining Web-based applications used to support practice change in other settings [47,48].

Statistical Analysis

Descriptive statistics were generated for service characteristics, access, and use of electronic devices. Childcare centers with postcodes ranked in the top 50% of NSW postcodes based on their socioeconomic status (SES) were grouped as being located in *higher socioeconomic areas*, while those in the lower 50% were categorized as being located in *lower socioeconomic areas* using the 2009 Socio-Economic Indexes For Areas (SEIFA), Australia. Childcare centers were categorized as either *rural* (ie, those located in outer regional, remote, and very remote areas) or *urban* (ie, those in regional cities and inner regional areas) based on their postcode using the Accessibility/Remoteness Index of Australia (ARIA).

Similar to that previously used in other studies, TAM subscale scores—perceived usefulness, perceived ease of use, and intention to use—were derived by summing responses—1 to 7—to all items in the subscale and dividing by the number of items within the scale [46]. Descriptive statistics, including mean and standard deviation, and median and interquartile range (IQR), were reported. TAM subscales were dichotomized into a score of 1 (strongly disagree) to 5.9 (slightly agree) or more than or equal to 6 (strongly agree or agree). This cut-point was chosen based on the median score of the subscales and corresponds to those who agree or strongly agree with the items examined within the subscales, providing a clinically meaningful way of interpreting the results.

To examine factors associated with intention to use, a multivariable logistic regression was conducted using the backward stepwise method to exclude variables where $P>.1$. The dependent variable was intention to use, and factors examined were the following: perceived ease of use, perceived usefulness, locality (rural/urban), socioeconomic status (high/low), service type (preschool/nonpreschool), number of children enrolled, number of primary contact staff, number of computers, and whether the center used a childcare management enrolment system software. All significance tests were two-tailed, with an alpha of .05. The proportion and 95% confidence intervals of center managers reporting a system feature as useful/very useful in assisting with the implementation of healthy eating and physical activity-promoting policies and practices were calculated.

Results

Service Characteristics

Overall, 277 centers were approached, and 214 (77.3%) consented to participate in the telephone survey. Of the participating centers, 36.9% (79/214) were preschools and 70.6% (151) were long day care centers (see Table 1). Of the centers, 7.5% (16/214) were both preschools and long day care centers. Almost all centers were open for 5 days per week and 77.6% (166/214) were open 8 or more hours per day. Of the centers, 81.8% (175/214) reported being approved under the childcare benefit scheme, and of those, 159/175 (90.9%) reported using a CCMS-approved software program to manage enrolments.

Table 1. Descriptive characteristics of participating center-based childcare services (n=214).

Service characteristics	n (%) or mean (SD)
Preschools, n (%)	79 (36.9)
Long day care centers, n (%)	151 (70.6)
Number of children enrolled, mean (SD)	77 (34)
Usual number of primary contact educators, mean (SD)	8.9 (5.2)
Average daily opening hours, mean (SD)	9.6 (1.9)
Open 5 days per week, n (%)	207 (96.7)
Open 8 hours or more per day, n (%)	166 (77.6)
Used CCMS[a]software, n (%)	159 (74.3)

[a] Child Care Management System (CCMS).

Access and Use of Internet and Associated Equipment

All but two services reported using computers at their center (212/214, 99.1%), with 58.9% (126/214) of all services reporting having access to three or more computers in their center. A total of 40.2% (86/214) of service managers reported using portable tablets in their center. Almost all centers (205/214, 95.8%) had Internet access for at least 1 year and the majority (160/214, 74.8%) reported having Internet access for 5 or more years. More than 90% of service managers reported using computers for administrative and reporting tasks (210/212, 99.1%), to search for information (204/212, 96.2%), and to access emails (206/212, 97.2%), whereas portable tablets were used most frequently to assist with child education (76/86, 88%) (see Table 2).

Table 2. Use of computers and portable tablets by childcare center staff.

Tasks	Computer (n=212), n (%, 95% CI)	Portable tablet (n=86), n (%, 95% CI)
Administrative tasks	210 (99.1, 97.9-100)	9 (10, 4-17)
To complete reporting requirements	210 (99.1, 97.8-100)	11 (13, 6-20)
For staff education	193 (91.0, 87.2-94.9)	22 (26, 16-35)
To assist with child education in the classroom	174 (82.1, 76.9-87.2)	76 (88, 82-95)
To search for information	204 (96.2, 93.6-98.8)	42 (49, 38-60)
To access emails	206 (97.2, 94.9-9.49)	12 (14, 7-21)
For planning and recording daily programming of service and children's activities	180 (84.9, 80.1-89.7)	34 (40, 29-50)
To report progress and provide information to parents or staff	187 (88.2, 83.9-92.5)	19 (22, 13-31)
Other[a]	2 (0.9, 0-2.2)	8 (9, 3-16)

[a] Includes use for networking or linking to other services, to play music, as a communication aid for special-needs children, and to display graphs.

Factors Associated With Intention to Use a Web-Based Program to Implement Policies and Practices

The mean score for intention to use a Web-based program (n=210) was 5.9 (SD 1.5), for perceived usefulness was 5.3 (SD 1.6), and for perceived ease of use was 5.5 (SD 1.1). The median score for intention to use was 6.0 (IQR 5.3-7.0), for perceived usefulness was 5.7 (IQR 4.8-6.8), and for perceived ease of use was 5.7 (IQR 4.8-6.3). Table 3 shows the factors that were associated with intention to use a Web-based program.

Perceived ease of use, perceived usefulness, and number of children enrolled had *P* values less than .1 in the univariate analyses (see Table 3) and were included in the multivariable logistic regression. In the final model, only perceived ease of use (odds ratio [OR] 3.9, 95% CI 1.6-9.2, *P*=.002) and perceived usefulness (OR 28, 95% CI 8.0-95.2, *P*<.001) were significantly associated with a score of more than or equal to 6 for intention to use.

Table 3. Factors associated with intention to use a Web-based program to support staff with implementing healthy eating and physical activity policies and practices (n=210).

Factors		Intention to use[a]		Univariate analysis	
		Mean score of 1.0-5.9 (n=59), n (%)	Mean score of 6.0-7.0 (n=151), n (%)	X^2_1	*P*
Locality (n=200) [b]				1.2	.30
	Urban	53/56 (95)	130/144 (90.3)		
	Rural	3/56 (5)	14/144 (9.7)		
Type of childcare center				1.2	.30
	Preschool	25 (42)	51 (33.8)		
	Nonpreschool	34 (58)	100 (66.2)		
Use of CCMS [c] **software**				2.4	.10
	Yes	40 (68)	118 (78.1)		
	No/don't know	19 (32)	33 (21.9)		
Number of children enrolled				3.5	.06
	75 or less	27 (46)	90 (59.6)		
	>75	33 (54)	60 (39.7)		
Number of staff members				1.4	.20
	1 to 8	32 (54)	96 (63.6)		
	>8	27 (46)	55 (36.4)		
Disadvantage (n=201) [b]				2.6	.11
	Low SES[d]	17/56 (30)	62/145 (42.8)		
	High SES	39/56 (70)	83/145 (57.2)		
Perceived ease of use [e]				21.4	<.001
	1.0-5.9	50 (85)	74 (49.0)		
	6.0-7.0	9 (15)	77 (51.0)		
Perceived usefulness [e]				53.1	<.001
	1.0-5.9	56 (95)	58 (38.4)		
	6.0-7.0	3 (5)	93 (61.6)		

[a] Score of 1.0-5.9 indicates response to statements of strongly disagree to slightly agree, and score of 6.0-7.0 indicates response to statements of agree and strongly agree.

[b] Center number is less than the total as no Socio-Economic Indexes For Areas (SEIFA) and Accessibility/Remoteness Index of Australia (ARIA) score matched the center postcode.

[c] Child Care Management System (CCMS).

[d] Socioeconomic status (SES).

[e] Significant variables in multivariable model, *P*<.05.

Features to Support Healthy Eating and Physical Activity Policy and Practice Implementation

More than 90% of service managers reported the following features to be useful/very useful in supporting the implementation of healthy eating and physical activity policies and practices: decision-support systems to help support staff with planning a healthy menu (117/129, 90.7%), having links to useful nutrition and physical activity resources (212/212, 100%), updated information on nutrition and physical activity guidelines (208/212, 98.1%), and a having a feature which provided updated feedback on how their center was performing in relation to other centers (212/212, 100%) (see Table 4).

Table 4. Features of a Web-based program reported by service managers as useful or very useful to help their staff implement healthy eating and physical activity policies and practices (n=212).

Features of Web-based program	n (%)	95% CI
Performance monitoring and feedback		
Allows staff to input nutrition and physical activity information and monitor service's progress over time.	187 (88.2)	83.9-92.5
Provides updated information on how your center is performing in relation to other centers.	212 (100)	99.3-100
Provides staff with tailored feedback based on your service's needs, and suggested strategies to implement.	198 (93.4)	90.1-96.7
Allows staff to prioritize which nutrition or physical activity practice they would like to work on.	201 (94.8)	91.8-97.8
Interaction and communication tools, prompts		
Allows staff to ask a member of their local health promotion team for advice.	208 (98.1)	96.2-100
Allows staff to communicate with staff from other childcare centers via online chat rooms, discussion boards, or blogs.	165 (77.8)	72.2-83.4
Allows staff to communicate with parents about physical activity and nutrition or via online chat rooms, discussion boards, or blogs.	143 (67.5)	61.5-73.7
Reminds or prompts staff to deliver a physical activity or nutrition session, based on your service's daily schedule.	182 (85.8)	81.2-90.5
Provision of education materials		
Uses videos or interactive activities, including games, to demonstrate an activity.	194 (91.5)	87.8-95.3
Includes a database of healthy lunchbox options, which is regularly updated (n=116)[a].	113 (97.5)	94.5-100
Provides links to useful physical activity and nutrition resources.	212 (100)	99.3-100
Provides updated information on nutrition and physical activity guidelines relevant to preschools.	208 (98.1)	96.3-100
Decision-support systems		
Supports you and your staff in planning a healthy menu for your childcare center (n=129)[b].	117 (90.7)	85.7-95.7

[a] Only services that required parents to provide food for their children answered this question.

[b] Only services that provided food for children answered this question.

Discussion

Principal Findings

Almost all childcare center managers had access to computers and the Internet, with 40.2% (86/214) of centers also reporting having access to portable tablets. The majority of service managers reported high behavioral intention to use an electronic Web-based program to support their service with implementing healthy eating and physical activity-promoting policies and practices—71.9% (151/210) of service managers scored an average of 6 or more on intention to use. Constructs within the TAM—perceived ease of use and perceived usefulness—were significantly associated with intention to use. Several preferred features, including the capacity to provide feedback on how the service was performing, providing updated links to physical activity and nutrition resources, and use of decision-support systems to assist with planning menus, were consistently rated as useful or very useful to support practice improvement in this setting. The universal access that childcare center managers have to computers, the high proportion reporting intending to use such systems, and high acceptability of Web-based features suggest that there is considerable potential for electronic programs to be developed to support childcare center staff with implementation of healthy eating and physical activity-promoting policies and practices.

Comparisons With Prior Work

The near universal access that childcare center managers have to computers and the Internet is not surprising given the introduction of mandatory online recording systems for childcare benefit-approved services in Australia since 2009 [24] . The potential of newer forms of computer technology such as tablets to provide implementation support may increase the appeal of Web-based support programs given their portability, capacity to provide tailored interactive information in multiple formats, ease of navigation, and potential effectiveness in modifying other health behaviors [49].

Consistent with previous research using TAM [40] and other research assessing characteristics associated with uptake of electronic interventions [50], perceived ease of use and perceived usefulness were significantly associated with service managers' intention to use a Web-based program. Intention to use scores reported in this study are higher than those documented among students [33] and clinicians [40]. While these samples are not directly comparable, such findings suggest greater intention to use electronic Web-based programs among childcare center managers and are encouraging, given findings that behavioral intention to use scores, as measured by TAM, are associated with actual use of the program [44,45]. TAM may be a useful model to inform the design, implementation, and evaluation of electronic Web-based programs in childcare centers.

The provision of training and educational materials, including guidelines and updated links to healthy eating and physical activity resources, were rated as useful by almost all service managers, a finding consistent with other studies which report that childcare center staff find training and resources useful to support their delivery of healthy eating and physical activity policies and practices [51,52]. Communications features which allowed staff to interact with parents and staff from other childcare centers were the least preferred function. This may reflect a preference for more conventional methods—face-to-face, telephone, or one-on-one communication methods—rather than chat rooms or forums as examined in this study. Previous studies in childcare centers have reported using Web-based resources largely for dissemination of information [23,53]. However, these findings suggest that an opportunity exists to use more interactive training resources and decision-support tools to support childcare centers with implementing healthy eating and physical activity-supporting policies and practices.

Implications

To ensure that the design characteristics of Web-based programs are both functional and easy to use, end-user engagement and feedback on the utility of such interventions need to be undertaken prior to introduction of new electronic interventions [41]. Further examination of the specific design characteristics that are associated with ease of use and perceived usefulness is needed to inform the development of Web-based programs that are most likely to be adopted by childcare center staff. Strategies to increase usefulness, such as incorporating features within the program that deal with tasks currently performed with computers or tablets (eg, reporting or administrative tasks) and engaging end users in development and pilot-testing of the program, could potentially be useful in facilitating uptake [41,45]. Research with clinicians suggest that the provision of staff training, establishing organizational support, and encouraging peer uptake and support may be useful to facilitate uptake of electronic interventions [41,45]. Further descriptive and intervention research examining the association between TAM constructs—perceived ease of use and perceived usefulness—and actual use of an electronic, Web-based program in childcare centers is needed.

Strengths and Limitations

Strengths of the study include the use of a large, randomly selected sample of centers from across an Australian state and the adaptation of a previously validated tool to assess intention to use a Web-based program. To our knowledge, this is the first study to describe childcare centers' access to Web-based devices and factors associated with childcare service managers' intention to use a Web-based program internationally. Nonetheless, a number of study limitations warrant mention. This study assessed intention to use, rather than actual use of electronic Web-based programs. While there is empirical evidence supporting the relationship between intention and actual use [44], and assessments of intention to use provide important formative information for program development [41], rates of actual use are likely to differ from those reported here. Childcare centers within a particular region of NSW—approximately 10% of centers—were also excluded due to participation in another trial [37]. A comparison between excluded centers (n=26) and those in this study found no significant difference in the number of usual providers (*P*=.22) and number of children enrolled (*P*=.88). A significantly larger proportion of centers located in this region were located in lower SES areas (*P*=.003) and rural areas (*P*=.015). As such, findings reported in this study are only likely to be representative of the 90% of centers in NSW from where the centers were randomly sampled. The survey was conducted with service managers of childcare centers who are likely to be involved in overseeing and coordinating the introduction of electronic Web-based interventions in their centers. Future assessments with childcare staff who may be primarily involved in the delivery of healthy eating and physical activity practices are likely to provide useful complementary information on how best to implement such programs in childcare centers. Notwithstanding these limitations, the study provides support for the potential of Web-based technology to make a significant contribution to the translation of evidence-based obesity prevention interventions in this setting.

Conclusions

Findings reported in this paper highlight the potential for electronic Web-based interventions to be used to support the implementation of healthy eating and physical activity-promoting policies and practices in childcare centers. Further research examining the development and effectiveness of using such modalities to support practice change within childcare centers is warranted to realize the potential of childcare centers for obesity prevention in the community.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Modified TAM questionnaire (administered via computer-assisted telephone interview).

[PDF File (Adobe PDF File), 103KB - jmir_v17i5e108_app1.pdf]

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Abbreviations

ARIA: Accessibility/Remoteness Index of Australia
CATI: computer-assisted telephone interview
CCMS: Child Care Management System
HMRI: Hunter Medical Research Institute
HNELHD: Hunter New England Local Health District
HNEPH: Hunter New England Population Health
IQR: interquartile range
NHMRC: National Health and Medical Research Council
NSW: New South Wales
OR: odds ratio
SEIFA: Socio-Economic Indexes For Areas
TAM: Technology Acceptance Model

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Original Paper

Comparative and Cost Effectiveness of Telemedicine Versus Telephone Counseling for Smoking Cessation

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Abstract

Background: In rural America, cigarette smoking is prevalent and health care providers lack the time and resources to help smokers quit. Telephone quitlines are important avenues for cessation services in rural areas, but they are poorly integrated with local health care resources.

Objective: The intent of the study was to assess the comparative effectiveness and cost effectiveness of two models for delivering expert tobacco treatment at a distance: telemedicine counseling that was integrated into smokers' primary care clinics (Integrated Telemedicine—ITM) versus telephone counseling, similar to telephone quitline counseling, delivered to smokers in their homes (Phone).

Methods: Smokers (n=566) were recruited offline from 20 primary care and safety net clinics across Kansas. They were randomly assigned to receive 4 sessions of ITM or 4 sessions of Phone counseling. Patients in ITM received real-time video counseling, similar to Skype, delivered by computer/webcams in clinic exam rooms. Three full-time equivalent trained counselors delivered the counseling. The counseling duration and content was the same in both groups and was available in Spanish or English. Both groups also received identical materials and assistance in selecting and obtaining cessation medications. The primary outcome was verified 7-day point prevalence smoking abstinence at month 12, using an intent-to-treat analysis.

Results: There were no significant baseline differences between groups, and the trial achieved 88% follow-up at 12 months. Verified abstinence at 12 months did not significantly differ between ITM or Phone (9.8%, 27/280 vs 12%, 34/286; *P*=.406). Phone participants completed somewhat more counseling sessions than ITM (mean 2.6, SD 1.5 vs mean 2.4, SD 1.5; *P*=.0837); however, participants in ITM were significantly more likely to use cessation medications than participants in Phone (55.9%, 128/280 vs 46.1%, 107/286; *P*=.03). Compared to Phone participants, ITM participants were significantly more likely to recommend the program to a family member or friend (*P*=.0075). From the combined provider plus participant (societal) perspective, Phone was significantly less costly than ITM. Participants in ITM had to incur time and mileage costs to travel to clinics for ITM sessions.

From the provider perspective, counseling costs were similar between ITM (US $45.46, SD 31.50) and Phone (US $49.58, SD 33.35); however, total provider costs varied widely depending on how the clinic space for delivering ITM was valued.

Conclusions: Findings did not support the superiority of ITM over telephone counseling for helping rural patients quit smoking. ITM increased utilization of cessation pharmacotherapy and produced higher participant satisfaction, but Phone counseling was significantly less expensive. Future interventions could combine elements of both approaches to optimize pharmacotherapy utilization, counseling adherence, and satisfaction. Such an approach could commence with a telemedicine-delivered clinic office visit for pharmacotherapy guidance, and continue with telephone or real-time video counseling delivered via mobile phones to flexibly deliver behavioral support to patients where they most need it—in their homes and communities.

Trial Registration: Clinicaltrials.gov NCT00843505; http://clinicaltrials.gov/ct2/show/NCT00843505 (Archived by WebCite at http://www.webcitation.org/6YKSinVZ9).

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KEYWORDS

telemedicine; Internet; rural; smoking cessation, RCT; primary care

Introduction

Background

Globally, an estimated 1 billion people will die from tobacco-related illnesses this century [1]. Although some progress has been made in driving down the prevalence of tobacco use, in rural areas headway lags. For example, the prevalence of smoking in US rural areas was 26% in 2009—equivalent to overall US smoking rates in 1990 [2]. Despite this, few initiatives focus on helping rural smokers quit.

Rural primary care is a good conduit for cessation efforts. Approximately 70% of smokers visit their health care provider in any given year [3]. Unfortunately, during primary care encounters few receive clear advice to quit, only 1 in 5 identified smokers receive cessation counseling, and less than 5% receive pharmacotherapy [4-6]. Barriers to providing tobacco treatment include constraints on time, lack of counseling skills, and poor office systems for conducting intensive, longitudinal behavior change intervention, such as cessation counseling [7-10].

To work around these barriers, primary care providers are increasingly referring patients to proactive tobacco quitlines. Quitlines are available in nearly all US states and many countries, they reach rural areas, and they are effective for smoking cessation [11]. They are, however, poorly utilized—only 1-2% of smokers in the United States have reported trying the quitline [12]. In addition, quitlines operate parallel to the health care system, and in general provide access to cessation medications to only a small subset of callers who meet criteria. Physician-office delivered telemedicine, as delivered by real-time, two-way video counseling, is another promising system for delivering expert care at a distance.

Telemedicine has been shown to deliver effective care for multiple health behaviors and outcomes [13]. A Cochrane review of telemedicine versus in-person patient care found telemedicine and in-person treatment to be equally effective, and both achieved high levels of satisfaction among patients and providers [14]. To date, the only large-scale study evaluating telemedicine for smoking cessation is a group-based intervention trial conducted by Carlson and colleagues in Canada, which achieved equivalent quit rates between groups receiving in-person versus telemedicine-delivered interventions [15]. However, in this study, participants were not randomized into groups and quit rates were based on self-report.

Our objective in “Connect2Quit” was to determine the comparative effectiveness and cost-effectiveness of two ways of delivering expert cessation services at a distance: telemedicine-delivered counseling, integrated into clinical practices (ITM) and quitline-like telephone counseling (Phone). We also examined participant satisfaction with the two approaches. The study employed a two-arm, individually randomized design that examined the impact of ITM on verified cessation at 12 months post-enrollment. We designed ITM to optimize use of the two cornerstones of evidence-based tobacco treatment: counseling and pharmacotherapy [3]. We also designed ITM to be fully integrated into the patients’ routine clinical care. ITM counselors delivered all sessions in participants’ physician offices—counselors scheduled sessions with clinic receptionists, updated the primary care team on participants’ progress, and worked with rural providers to help participants select and obtain medication prescriptions. Because telemedicine counseling occurred in the medical home, participants had the opportunity to immediately ask their health care providers for additional advice regarding pharmacotherapy and prescriptions for smoking cessation medication.

We hypothesized that ITM would outperform Phone by providing much more comprehensive support than could be achieved by Phone alone. Our ITM intervention was designed to (1) deliver a very high-quality, supportive counseling interaction by creating a more personal bond by enabling counselors to respond to important non-verbal cues during counseling, and (2) remove barriers to high-quality advice on prescription and non-prescription cessation medications by creating multiple opportunities for patients to interact with their health care providers over medication choices. For a detailed description of the study design and underlying theory, please see Mussulman et al, 2014 [16].

Hypotheses

Our study hypotheses addressed outcomes and costs (Textbox 1). These hypotheses are based on several features of the study design. We co-located video counseling in the doctor’s office in order to enable all rural smokers, even those with no computers or poor access to high-speed Internet, to participate.

Co-location also created better access to providers and support in obtaining prescription medications. In addition, the visual connection afforded by ITM could result in better counseling adherence and participant satisfaction. To ensure that outcomes could be attributed to the intervention, and not differences in the content or quality of counseling delivery, we also assessed fidelity to the counseling protocols.

Textbox 1. Study aims and hypotheses.

First Aim: To test the effects of Integrated Telemedicine (ITM) versus Phone on smoking cessation and other smoking outcomes. Compared to participants in Phone, at 12 months following randomization:

Hypothesis 1: Smokers receiving ITM will have significantly higher 7-day point prevalence abstinence (defined as no cigarettes in the past 7 days, biochemically verified).

Hypothesis 2: Smokers receiving ITM will have significantly higher prolonged abstinence.

Hypothesis 3: Smokers receiving ITM will have participated in more counseling sessions and been more likely to use cessation medications.

Hypothesis 4: Among those who continue to smoke, persons receiving ITM will have more quit attempts and will smoke fewer cigarettes.

Second Aim: To examine the costs and cost-effectiveness of ITM versus Phone.

Hypothesis 5: ITM will be more costly, but more cost-effective than Phone from provider, participant, and societal (combined) perspectives. Relative costs of care will be assessed by examining quit rates for ITM and Phone per combined provider and/or participant costs to assess the cost per quit in the two treatment arms from the three perspectives.

Methods

Design and Overview

We employed a control group design with individual randomization to study arms. Study staff screened patients for eligibility, collected informed consent, and administered baseline data collection. The counseling approach, content, and educational materials were the same across both ITM and Phone conditions. Within both treatment arms, all participants received the same educational materials and individually tailored pharmacotherapy guidance to help them select and obtain cessation medications. Patients in ITM received 4 sessions of telemedicine counseling integrated into the patient's primary care office, in examining rooms equipped with 2-way webcams mounted on desktop computers. Participants assigned to Phone received 4 sessions of in-home telephone counseling. Study assessments were conducted at baseline and months 3, 6, and 12. The University of Kansas Medical Center Ethics Committee approved all study procedures. A detailed description of the study intervention, design, and participant baseline characteristics have been published previously [16].

Setting

Participants were patients of 20 primary care clinics in the state of Kansas. The clinics were located in a wide range of rural counties, half were in cities with a population of less than 1800, and three were federally-qualified health clinics for the medically underserved. We used the Health Resources and Services Administration (HRSA) guidelines to define rural areas; at the time of the study in Kansas, this included 88 non-metropolitan counties and other regions [17].

Participant Eligibility

Eligible smokers were required to have a primary care physician who was participating in the study, be 18 years of age or older, smoke 5 or more cigarettes per day for at least 1 year, smoke 25 out of the past 30 days, speak English or Spanish, and have a telephone. We opted to take all smokers willing to participate, regardless of level of motivation to quit, in order to maximize the generalizability of the trial. Individuals were excluded if they used other tobacco products, were currently taking smoking cessation medications or participating in another quit smoking program, were breast feeding, were pregnant or planning to become pregnant, were planning on moving in the next year, or lived with a smoker already enrolled in the study.

Participant Identification, Recruitment, and Randomization

Patients from clinic sites were recruited on site by clinic staff and via mailings from clinic directors. In order to ensure adequate representation of Latino patients, study staff conducted community-based recruitment activities through radio interviews, health fairs, community newsletters, and staff recruitment tables at Latino worksites, religious organizations, and businesses. During on-site recruitment, clinic staff or medical student volunteers identified smokers, screened for eligibility, invited smokers to participate, and sent participant information to study staff who collected informed consent and baseline study data. In recruitment via mailings, letters from clinic leaders informed patients that they would be contacted about a research opportunity from study staff; the letters also provided a number for patients to call in order to proactively opt in or opt out of the trial. Study staff called all smokers and performed screening, consent, and baseline data collection. The project director allocated enrolled participants to study arm by opening sealed envelopes that contained randomly generated group assignments created in advance by the study statistician (KJP) and database manager (NN). Participants were recruited from June 2009 through June 2011.

Equipment and Site Orientation

Video counseling was delivered via Polycom PVX, a program installed on desktop computers and linked to the University of Kansas Medical Center study staff via the Internet. Each participating site received a desktop computer, webcam, and Polycom PVX software. A study technician installed equipment, tested connections with the site delivering the intervention, and trained clinic staff in equipment use and troubleshooting. The technician placed a binder with connection checklists, troubleshooting tips, and emergency phone numbers next to the study equipment. The technician also met with Internet service managers at each site to set up lines of communication for problem-solving connection issues that might arise throughout the trial. Once equipment was installed, the study project director conducted clinic staff training with each site via the Polycom system, in order to reinforce skills and build confidence in using the system. During this meeting, the project director reviewed study materials with the clinic staff, focusing on the clinic role in care such as reviewing prescription requests and providing medication prescriptions, as outlined below.

Interventions

Overview

Within the first week after enrollment, all study participants received a mailed packet of study materials. The packet included educational materials on smoking cessation and a timeline of study activities, including counseling sessions and follow-up.

The packet also included a pharmacotherapy guidance form, which provided individually tailored information on what medications were covered by the participants' insurance plan or public assistance program. The guidance form also indicated for what medications patients were medically eligible. Medical eligibility was ascertained by a study pharmacist by entering participants' prescription medication use and pre-existing health conditions into a pharmacy database to identify contraindications and cautions for each cessation medication. Counselors then called participants to advise them of their group assignment and to schedule the first counseling session. In both study conditions, study staff assisted income-eligible participants with no insurance coverage to apply for cessation medication from the pharmacy assistance programs (PAPs) of pharmaceutical drug companies. Study staff worked with participants and providers to complete these forms and apply to companies for medications.

The counseling approach used across both conditions—ITM and Phone—was based on Combined Behavioral Intervention (CBI), a combination of Motivational Interviewing and Cognitive Behavior Therapy (CBT) [18-20]. The counseling content was designed to adapt to smokers' level of motivation. The first session included assessment of participants' readiness to quit, motivational counseling among those not ready to quit, and development of a quit plan among those ready to quit. As part of the quit plan, counselors reviewed participants' pharmacotherapy options and helped participants select and obtain a cessation medication to aid in quitting. In subsequent sessions, counselors reviewed participants' progress, helped troubleshoot difficulties, and, time permitting, invited participants to choose a topic for discussion from a list of common barriers to cessation such as “triggers” for smoking or avoiding weight gain. Three full-time equivalent trained counselors delivered the counseling. Prior to each counseling session, counselors telephoned participants to remind them of the session.

Integrated Telemedicine (ITM)

Participants in ITM received 4 sessions of clinic-based video telemedicine counseling for smoking cessation. Because most ITM computers were located in dedicated rooms in study clinics, participants could sign in at the clinic reception and go directly to the ITM room for their session. Clinic staff, either a receptionist or a nurse, called the study counselor at the medical center via Polycom PVX to initiate the session. At the close of the counseling session, study counselors directed participants to go to the clinic receptionist. Counselors then telephoned the front desk to schedule the next appointment with the participant and receptionist. If the participant created a quit plan and/or expressed interest in pharmacotherapy, the quit plan and a medication prescription request form were faxed to the receptionist for placement in the participants' medical record and for review/prescription approval by the participants' primary care provider.

Phone (Telephone Counseling)

Participants in Phone received 4 counseling sessions via their home or mobile phones. At the end of each session, counselors scheduled the next counseling session with the participant. If the participant created a quit plan and/or expressed interest in pharmacotherapy, the quit plan and a medication prescription request form were mailed to the participant, with instructions to take the forms to their health care provider for placement in their medical records and review/prescription approval by their primary care providers.

Data Collection and Reimbursement

All assessments were conducted via telephone and mail by trained study staff. Assessments occurred at the following times and were reimbursed (US $) at the following levels: baseline ($20), 3 months ($20), 6 months ($20), and 12 months ($50). Clinics that participated in the study received a $1000 reimbursement for incidental costs associated with the trial. In addition, intervention sites received a computer and Polycom PVX software used to implement the intervention. Clinics dedicated the equipment to the telemedicine trial for the duration of the study but kept the equipment at the end of the trial. Prior to the 6- and 12-month follow-up assessments, participants received reminder postcards.

Measures

Baseline Characteristics and Computer/Telemedicine Use

We collected general demographic variables such as age, gender, marital status, education, employment status, income, race, and ethnicity. Smoking history included number of cigarettes per day, quitting history, previous quit smoking medication use, and age of smoking initiation. Nicotine dependence was assessed with the 6-item Fagerström Test for Nicotine Dependence scale (FTND) [21]. Stage of behavioral change was determined using a 4-item algorithm that defines pre-contemplation as having no interest in quitting in the next 6 months, contemplation as strong interest in quitting in the next 6 months, and preparation as strong interest in quitting in the next month coupled with a serious quit attempt in the past year [22]. Motivation and confidence to quit smoking were measured using 10-point Likert scales with higher scores indicating greater motivation and confidence [23]. We summarized income into a dichotomous variable of whether or not income was less than 200% of the 2009 US Federal Poverty guideline.

Participants were also asked four questions related to their perceptions of using computer technology such as telemedicine for the delivery of health care [16]. Computer and Internet availability within the home were also assessed [16].

Intervention Fidelity

To assess whether counseling was the same across ITM and Phone sessions, we obtained independent ratings of counselor adherence on a 10% randomly selected subset of sessions. These audio files were encrypted, blinded regarding group assignment, and emailed to an independent expert rater for evaluation via the Motivational Interviewing Treatment Integrity (MITI) coding system [24]. Four variables from this coding system were used to compute a score of adherence to counseling style: (1) Empathy, in which coders assigned a global rating of empathy to the counselor's style), (2) Spirit, in which coders assigned a global rating of MI spirit to the counselor's style, (3) MI adherent, a sum of the frequency MI adherent utterances, and (4) MI non-adherent, similarly, a sum of the frequency non-MI adherent utterances. To test for differences between groups on each of these variables, we took clustering (both within participant and within counselor) into account using the multilevel regression module available in SPSS (MIXED) [25].

Hypothesis 1: Primary Outcome

The main outcome measure was verified 7-day point prevalence smoking cessation at 12 months. Abstinence verification was assessed via salivary cotinine, carbon monoxide (CO), or proxy. All participants who self-reported being abstinent from cigarettes for the 7 days preceding their 12-month survey, and who were not taking nicotine replacement therapy, were asked to provide a mailed salivary cotinine sample, for which they were reimbursed an additional $50. To reduce any incentive to misreport smoking status, participants were not informed of the $50 additional incentive for verification until after they completed the 12-month questionnaire. Participants meeting the recommended salivary cotinine cut point of <15 ng/ml were considered abstinent [26]. Participants reporting abstinence who were taking nicotine replacement were asked to meet staff at the clinic or at a community location to provide an expired CO (carbon monoxide) sample. Participants meeting the recommended CO cut point of <10 ppm were considered abstinent [27]. Staff contacted proxies to verify abstinence among participants who did not provide cotinine or carbon monoxide. All participants who failed to verify abstinence were counted as smokers. To explore group differences in outcome throughout the follow-up period, we also report self-reported quit rates at months 3, 6, and 12.

Hypotheses 2-3: Prolonged Abstinence, Counseling Adherence, Pharmacotherapy Use

Prolonged abstinence as defined in this study included a "grace period" of 1 month at the beginning of treatment to allow the treatment to take effect followed by continuous abstinence [27]. Counseling adherence was collected from counselor records of completed sessions. Pharmacotherapy use was collected via participant self-reports of any prescription or non-prescription use at any time between baseline and follow up.

Hypothesis 4: Quit Attempts and Number of Cigarettes Smoked Among Continued Smokers

Quit attempts were assessed by self-report of the number of times patients tried to quit for 24 hours or more since the beginning of the study. Cigarettes per day were self-reported by participants who continued to smoke at month 12.

Hypothesis 5: Costs

After itemizing the resources needed for each arm of the intervention, we selected only those items that differed between treatment arms for the variable cost analysis. The fixed costs stemming from the Polycom PVX technology were not included in the cost analysis, consistent with current guidelines for short-run cost analyses. We included costs from both the provider and participant perspectives. All costs were calculated based on 2011 dollars. Since the intervention was completed in less than one year, no discounting was applied. While there may have been limited price inflation during the time period of study recruitment, we did not adjust for inflation that might occur with recruitment of subjects across different years. We used two-tailed *t* tests to examine differences in costs.

Provider's Perspective

From the provider's perspective, a major potential cost difference was counselor's time. Counselors' time was summed across the intervention sessions (the date and time of individual sessions were recorded in a database by study staff) and valued at the median national wage plus 25% fringe rate for a health educator (occupation code 21-1091) from the Bureau of Labor Statistics National Occupational Employment and Wage Estimates [28].

For the Phone arm, the communication between counselor and study participant took place over the telephone: we used our local, institutional phone charge rate (US $0.0355/minute). For the ITM arm, communication occurred via the Internet: we collected data from Internet providers in each of the clinic locations on average monthly charges. These charges were converted to hourly rates assuming the clinics were open 9 hours per day, 5 days per week. Given that most clinics may have multiple computers with Internet access, this rate likely overstates the actual cost of Internet-based communication (US $0.37/hour=$0.0062/minute).

Finally, the need for office space to deliver ITM incurred space allocation costs not encountered in the Phone arm. Generally, in cost analyses, space is valued on the basis of opportunity—what the space is normally used for when it is not being used for the intervention being evaluated. In sites where telemedicine was delivered in examining rooms, it should rightfully be valued as the cost of a medical visit. However, some of our sites used other space, either administrative or even storage space, for telemedicine visits. A few, based on changing needs of the clinic, moved telemedicine equipment between administrative and examining room space. We were not always able to determine the space used for every telemedicine visit.

In order to estimate the costs of the space under these varying scenarios, we made two quite different assumptions in assigning a value for this space. First, a functioning exam room could be used to generate billable physician services: therefore, we applied the American Medical Association's CPT (Current Procedural Terminology) rates for patient visits based upon the length of the visit and 2011 Medicare rates for the facility charges in Kansas (CPT codes=99211, <5 minutes; 99212, 5-10 minutes; 99213, 10-15 minutes; 99214, 15-25 minutes; 99215, 25+ minutes) [29].

Second, for a more conservative estimate, we assumed that the ITM could be delivered in a more general office space; to arrive at this value, we applied local rent costs (US $). Since all sites were rural, we used a rent plus maintenance/utility rate of $10/square foot per year and measured the square footage for each of the clinic sites (mean 148 sq. ft.). We then applied an average rent charge per minute of counseling ($0.0105/min).

Participants' Perspective

To capture the participants' perspective, we valued their time spent in counseling, travel time and costs, and the cost of pharmacotherapy, if applicable. Participants were asked to provide their hourly wage rate: for those who did not, we used age- and gender-adjusted wage rates (minimum wage=US $7.25) from the 2007 Bureau of Labor Statistics [28]. These rates were applied to counseling time. In addition, participants in ITM incurred costs travelling to and from clinic offices for sessions that were not incurred by Phone participants. Travel time was calculated based upon the distance from the participant's residence to and from the clinic site for the ITM arm using Google maps (maps.google.com). Mileage costs were added as vehicle costs using the state-based reimbursement rate for travel (US $0.54/mile). Finally, we collected self-reported (out-of-pocket) pharmacotherapy costs from participants.

Societal Perspective and Cost Per Quit

We calculated the society perspective on costs by summing provider and participant perspectives. To facilitate comparison with other interventions, we also report the cost per quit for each study arm.

Satisfaction with the Counseling and Overall Intervention

Six items administered at month 3 assessed participant satisfaction with the number and length of counseling sessions; overall satisfaction with the entire intervention; whether the participant would recommend the program to a friend or family member; and which component of the intervention (counseling, pharmacotherapy guidance, educational materials, or support from health care providers) was most useful.

Statistical Analyses

All data analyses, except where specified, were conducted using SAS 9.3 [30]. We examined pretreatment differences between groups on demographic, psychosocial, and computer use characteristics using analysis of variance for continuous variables and χ^2 statistics for categorical variables. To test our primary hypothesis, we compared verified 7-day point-prevalence abstinence at 12 months using the χ^2 statistic in an intent-to-treat (ITT) analysis, with all non-responders counted as smokers. We repeated our outcome analysis as a multilevel model that controlled for clustering by site using Mplus 6.12 [31]. We also used the χ^2 statistic and *t* tests, as appropriate, to examine differences between groups for self-reported abstinence, prolonged abstinence, counseling adherence, pharmacotherapy use, quit attempts, and cigarettes per day. We examined differences between groups on participant satisfaction using analysis of variance for continuous variables and χ^2 test for categorical variables. We compared differences in cost by perspective between the treatment arms using *t* tests. A priori, we specified that if there were a significant difference in outcomes, we would perform an incremental analysis.

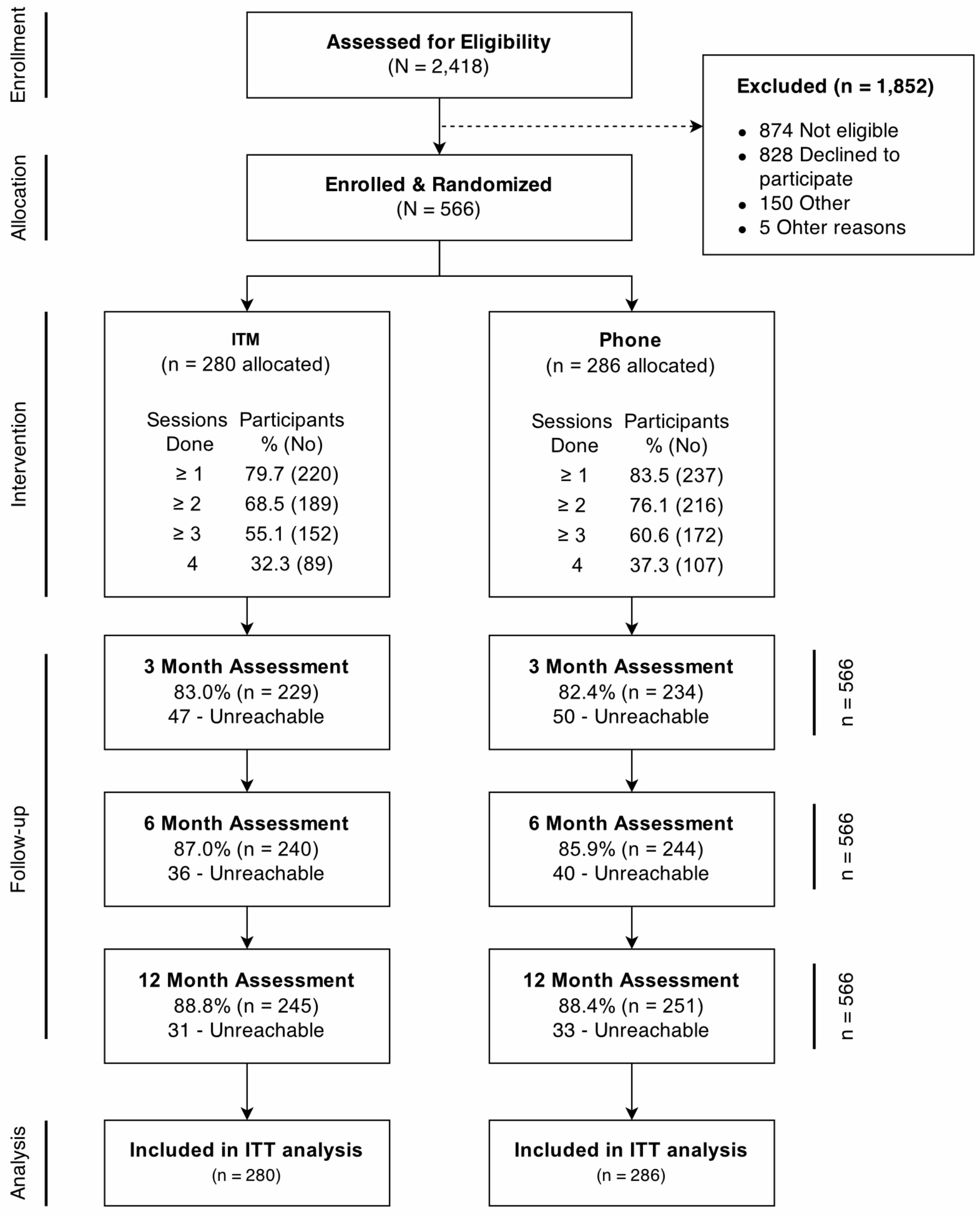
Based on a sample size of 283 participants in each group, this study had 80% statistical power at an alpha of .05 to detect a 50% difference between groups in the proportion of participants making a quit attempt (16% in the ITM group and 8% in the Phone group). These quit rates were based on prior studies of in-home telephone counseling referred from primary care providers (Phone) and in-person counseling (ITM) [32,33].

Results

Overview

Of 2418 individuals assessed for eligibility, 1544 were deemed eligible, and 566 provided consent and were respectively randomly assigned to either ITM (280) or Phone (286) (Figure 1). Top reasons for ineligibility included no longer being a smoker (481/874, 55.0%), not having a regular health care provider at the clinic (85/874, 9.7%), and smoking fewer than 5 cigarettes per day (72/874, 8.2%). Follow-up ranged from 83% (470/566) at month 3 to 88% (498/566) at month 12.

Figure 1. Flow of participants through the trial. Reasons for being dropped from enrolment are not mutually exclusive. Values next to the number of sessions completed represent the cumulative number of participants who completed at least that many treatment sessions. ITT denotes intention to treat.



Baseline Characteristics, Computer/Telemedicine Use, and Intervention Fidelity

Randomization resulted in groups with similar baseline characteristics (Table 1). Most (464/566, 82.9%) participants were Caucasian and 9.0% (50/566) were Latino. Most (361/566, 64.5%) had incomes of <200% of the federal poverty level. Chronic diseases including hypertension, chronic lung disease, and diabetes were highly prevalent. Participants smoked on average 19.7 (SD 10.3) cigarettes per day and had moderate nicotine dependence. They began smoking on average at 17.1 (SD 5.0) years of age and most had tried some form of smoking cessation medication in the past. Participants were highly motivated to stop smoking.

There were no differences in computer use variables across groups (Table 1). Although most (70.0%, 391/566) had a working computer at home, one out of three lacked home Internet access, nearly half were not comfortable using computers, and only 4.5% (25/566) had been seen by a doctor via telemedicine in the past. Many were not confident that personal information was kept private via technology, were not comfortable using newer communication technologies, and were not interested in receiving telecare in the home. Analysis of fidelity data found no significant differences in counseling style across the groups.

Table 1. Baseline characteristics.

		ITM n=280 n (%) or mean (SD)	Phone n=286 n (%) or mean (SD)	Total n=566 n (%) or mean (SD)
Sociodemographics				
Age, yrs, mean (SD)		47.27 (12.8)	47.51 (13.0)	47.4 (12.9)
Female		173 (62.7)	190 (66.9)	363 (64.8)
Caucasian		228 (82.6)	236 (83.1)	464 (82.9)
Hispanic/Latino		23 (8.3)	27 (9.6)	50 (9.0)
Married		123 (44.6)	115 (40.6)	238 (42.6)
High school education or less		161 (58.3)	156 (55.2)	317 (56.8)
Employed full time		110 (39.9)	123 (43.5)	233 (41.7)
<200% Federal Poverty Level		177 (64.1)	184 (64.8)	361 (64.5)
Health insurance		174 (63.0)	178 (62.7)	352 (62.9)
Prescription cessation medication coverage		161 (58.3)	159 (56.2)	320 (57.3)
Medical history				
Hypertension		121 (43.8)	121 (42.8)	242 (43.3)
High cholesterol		119 (43.1)	103 (36.4)	222 (39.7)
Chronic lung disease		91 (33.0)	98 (34.6)	189 (33.8)
Diabetes		55 (19.9)	48 (17.0)	103 (18.4)
Heart disease		30 (10.9)	28 (9.9)	58 (10.4)
Cancer		23 (8.3)	25 (8.8)	48 (8.6)
Stroke		8 (2.9)	15 (5.3)	23 (4.1)
Mental health co-morbidities				
PHQ-2, depression[a]		137 (49.6)	142 (50.2)	279 (49.9)
AUDIT-C, high risk drinking[b]		58 (21.0)	71 (25.0)	129 (23.0)
GAD-2[c]		115 (41.7)	111 (39.2)	226 (40.4)
Current smoking				
Current cigarettes per day, mean (SD)		20.3 (10.7)	19.2 (9.8)	19.7 (10.3)
Nicotine dependence (FTND), mean (SD)		4.91 (2.2)	4.85 (2.4)	4.9 (2.3)
Smoking history				
Age started smoking regularly, yrs, mean (SD)		16.9 (4.4)	17.4 (5.5)	17.1 (5.0)
No. quit attempts, past 12 months, mean (SD)		2.0 (3.2)	2.1 (2.9)	2.0 (3.1)
Prior use of cessation pharmacotherapy (any)		210 (76.1)	200 (70.7)	410 (73.4)
Longest period of past abstinence in days, mean (SD)		331.9 (768.2)	432.6 (1016.2)	382.9 (902.9)
Interest in quitting				
Readiness to stop smoking				
	Pre-contemplation	7 (2.5)	7 (2.5)	14 (2.5)
	Contemplation	105 (38.0)	113 (39.9)	218 (39.0)
	Preparation	164 (59.4)	163 (57.6)	327 (58.5)
Importance of quitting (0-10 low-high), mean (SD)		9.4 (1.5)	9.3 (1.5)	9.4 (1.5)
PCSC (1-7 low-high), mean (SD)[d]		5.0 (1.5)	5.0 (1.5)	5.0 (1.5)
Computer, Internet, and telemedicine use				

	ITM n=280 n (%) or mean (SD)	Phone n=286 n (%) or mean (SD)	Total n=566 n (%) or mean (SD)
Currently have a functional computer in home	203 (73.6)	188 (66.4)	391 (70.0)
Currently have Internet access in home	193 (69.3)	182 (64.3)	375 (67.1)
Ever been seen by a doctor via telemedicine, ITV, or web-cam	11 (4.0)	14 (5.0)	25 (4.5)
Attitudes toward computers, communication technology, and health technology			
I am comfortable using computers, (% agree-strongly agree)	161 (58.3)	173 (61.1)	334 (59.8)
I am comfortable using other communication technologies, such as mobile phones, mp3 players, or Web cameras, (% agree-strongly agree)	179 (64.9)	172 (60.8)	351 (62.8)
I am interested in receiving health care in my home using computers or communication technologies, (% agree-strongly agree)	155 (56.2)	168 (59.4)	323 (57.8)
I am confident my personal information is kept private when using communication technologies, (% agree-strongly agree)	194 (70.3)	183 (64.7)	377 (67.4)

[a] PHQ-2: Patient Health Questionnaire, 2-item version.

[b] AUDIT-C: Alcohol Use Disorders Identification Test - Consumption, with a binge drinking cutoff of >4 Males, >3 Females.

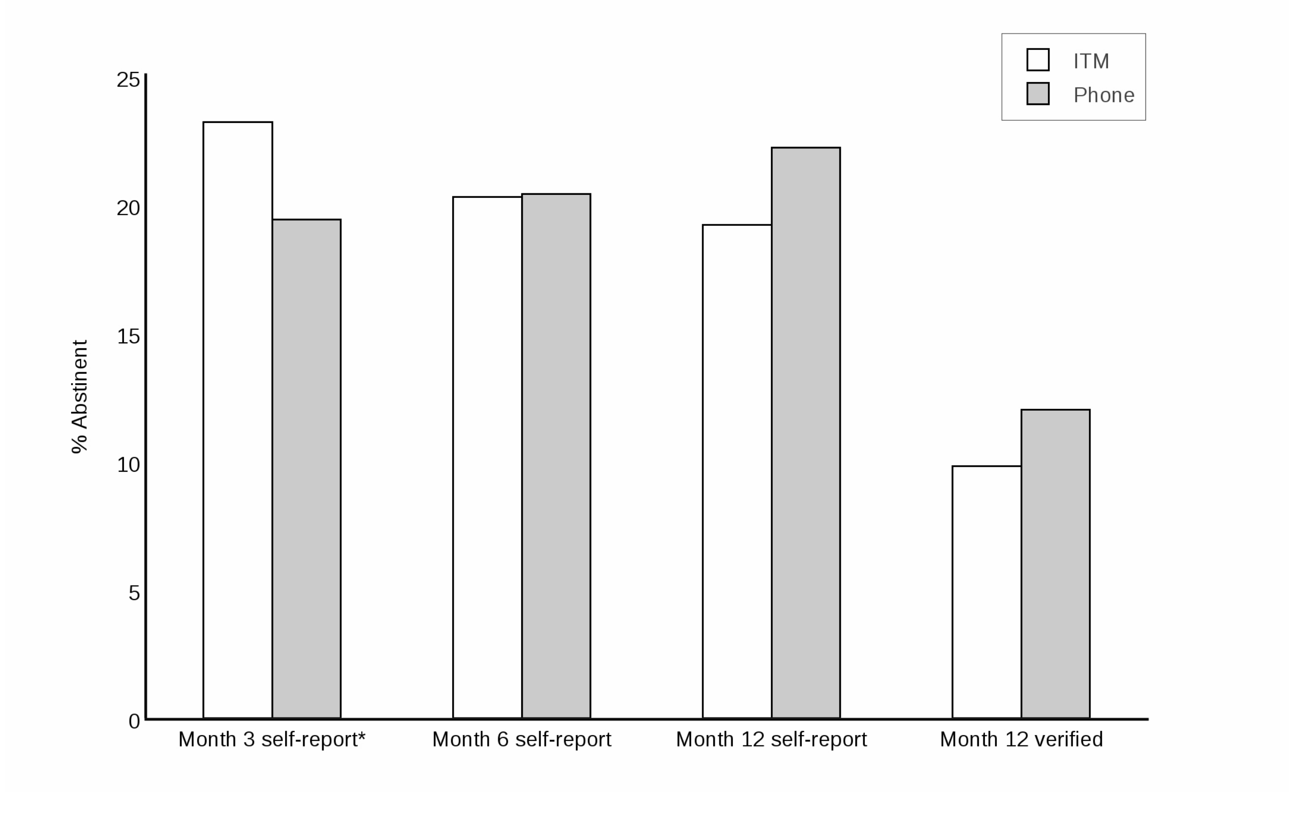
[c] GAD-2: Generalized Anxiety Disorder questionnaire, 2-item version.

[d] PCSC: Perceived Competence Scale for Cessation.

Hypothesis 1: Primary Outcome

The main outcome of biochemically verified 7-day point prevalence did not significantly differ between ITM and Phone at 12 months (9.8% vs 12.0%, 27/566 vs 34/566; *P*=.406) (Table 2). These rates were also not different when treated as a multi-level model that controlled for clustering (*P*=.554). Participants in ITM reported higher abstinence rates at month 3, similar rates at month 6, and lower rates at month 12 compared to Phone; none of these differences, however, were statistically significant (Figure 2).

Figure 2. Primary outcomes.



Hypotheses 2-3: Prolonged Abstinence, Counseling Adherence, Pharmacotherapy Use

Likewise, prolonged abstinence did not differ significantly between ITM and Phone (*P*=.8394) (Table 2). Phone participants completed slightly more counseling sessions than ITM. Significantly more participants in ITM used cessation medications, compared to Phone (*P*=.03).

Hypothesis 4: Quit Attempts and Number of Cigarettes Smoked Among Continued Smokers

Among participants who continued to smoke, those in ITM made somewhat more attempts to quit compared to those in Phone (4.8, SD 6.8 vs 4.3, SD 5.7); this difference, however, was not significant (Table 2). Continued smokers in both study arms reported smoking similar numbers of cigarettes per day.

Table 2. Outcomes: Hypotheses 1-4.

Hypothesis		ITM n=280	Phone n=286	*P* value
Main outcomes, n=566				
1	Biochemically verified 7-day point prevalence, 12 months, n (%)	27 (9.8)	34 (12.0)	.406
2	Prolonged abstinence, n (%)	23 (8.1)	21 (7.6)	.8394
3	Average number of counseling sessions, mean (SD)	2.4 (1.5)	2.6 (1.5)	.083
3	Used cessation medication, n (%)	128 (55.9)	107 (46.1)	.03
Outcomes among participants continuing to smoke at 12 months, n=499				
4	Average number of quit attempts, mean (SD)	4.8 (6.8)	4.3 (5.7)	.3469
4	Average number of cigarettes smoked per day at 12 months, mean (SD)	10.2 (8.1)	10.0 (7.5)	.7212

Hypothesis 5: Costs

Provider Perspective

Costs are summarized in Table 3 (US $). Counseling time costs differed by 9% (US $4.12) between the treatment arms. Communication (Internet or phone) costs were lower for the ITM arm. The cost for the clinic space used to deliver ITM had a large impact on provider costs, depending on how the space was valued. When the space was valued as local rental space, the cost was $0.99 per person; when valued as a medical visit, the cost was $226.61 per participant. Summing all provider costs, the mean cost for the Phone arm was $53.25 as compared to $47.04 for ITM when space was valued at rental rate. When physician office visit rates were used to value the space, the cost of ITM increased substantially to $272.65.

Participant Perspective

From the participant's perspective, counseling time costs were roughly 10% higher in the Phone arm, consistent with the counselor time costs. Participants bore a much heavier burden in ITM, though, because of the travel-related time and mileage costs, which added almost $94 to ITM participant costs.

Societal Perspective and Cost Per Quit

After summing across provider and participant costs, Phone was less costly than ITM regardless of underlying assumptions ($81.61, SD 58.70 per participant for Phone). The magnitude of the difference between approaches differed greatly depending on how we valued the clinic space used to deliver ITM ($166.04, SD 347.90 if rental cost basis or $390.20, SD 415.40 if CPT cost basis for clinic space). We did not compute an incremental cost-effectiveness ratio, as there was no significant difference in the primary outcomes between ITM and Phone. The cost per quit from the provider perspective was $444/quit for Phone and $480/quit for ITM in provider costs. Adding patients' costs increased those values to $680/quit (Phone) and $1694/quit (ITM).

Satisfaction With Counseling and Overall Intervention

Satisfaction with the study was high. Overall, participants were somewhat satisfied (26.8%, 99/369) or very satisfied (73.2%, 270/369) with the program. Most (72.6%, 281/387) reported the length of sessions was about right. When asked to choose the most helpful part of the program, most (61.2%, 243/392) participants chose counseling. The only difference between study arms was the proportion of participants who would recommend the program to a friend or family member: 97% (194/200) of ITM participants reported they would recommend (74.5%, 149/200) or had already recommended it (22.5%, 45/200) compared to 91.9% (182/198) in the Phone arm reported that they would recommend (78.8%, 156/198) or had already recommended it (13.1%, 26/198) to a friend or a family member (*P*=.0075).

Table 3. Input valuations and results for variable cost components by intervention arm (US $).

Variable costs	Unit costs	Phone (n=284)	ITM (n=276)	*P* value
		Mean (SD) in $		
Provider perspective				
Counselor cost	$28.81/hour	49.58 (33.35)	45.46 (31.50)	.133
Internet access	$0.37/hour	n/a	0.58 (0.40)	
Telephone charges	$2.13/hour	3.67 (2.47)	n/a	
Facility costs	rent basis	n/a	0.99 (0.69)	
Facility costs	CPT basis	n/a	226.61 (148.08)	
Total provider variable costs				
Calculated based on costs to rent space		53.25 (35.82)	47.04 (32.59)	.032
Calculated based on costs for medical visit		53.25 (35.82)	272.65 (178.29)	<.001
Participant perspective				
Time in counseling	Hourly wage	28.36 (27.83)	25.81 (21.24)[a]	.224
Travel time cost	Hourly wage	n/a	33.38 (101.27)[a]	
Mileage costs	$0.54/mile	n/a	60.59 (239.93)[a]	
Pharmacotherapy	out-of-pocket costs	113.87=16,852 total (n=148)	92.21=6544 total (n=150)	
		59.34/participant	51.04/participant[a]	
Total participant variable costs				
Without pharmacotherapy		28.36 (27.80)	119.44[a] (341.00)	<.001
With pharmacotherapy		75.29 (169.10)	124.55[a] (259.10)	.008
Combined societal (modified) perspective				
Rent basis		81.61 (58.70)	166.04[a] (347.90)	<.001
Facility CPT basis		81.61 (58.70)	390.20[a] (415.40)	<.001

[a] n=271: 5 additional ITM participants had missing self-reported participant perspective cost data.

Discussion

Principal Findings

Integrated telemedicine was not superior to phone-delivered counseling for smoking cessation. While telemedicine had the added benefit of increasing pharmacotherapy utilization, telephone counseling facilitated adherence to counseling sessions. There are relative benefits to each intervention approach, and both promote smoking abstinence, but telephone counseling was significantly less expensive. In our trial, the provider cost of telemedicine-delivered counseling was either equivalent to phone or much more expensive, depending on the assumption underlying the cost of the space used to deliver the telemedicine-based intervention.

Limitations

Because the study tested the effects of telemedicine integrated into physician practices, versus telephone counseling delivered to patients' homes, it is impossible to isolate the effects of video- versus phone-based counseling. Moreover, we limited our study to rural practices in the Midwest. These findings might not generalize to other settings. We opted to test integrated telemedicine in part because we were concerned that our rural population might have difficulty navigating a home-based telemedicine intervention, or a video intervention via smartphones. As of 2011, only 21% of rural adults were smartphone users [34]. We believe this concern was borne out by our participants' low rates of comfort using computers and familiarity with smartphone technology. We were not always able to determine the space used for the telemedicine encounter, which necessitated calculating costs under two different space assumptions. While our intervention included components of both MI and CBT, our fidelity assessment was limited to adherence to MI procedures alone, and did not include a component assessing fidelity of CBT across arms. Last, one rationale for this study was that quitlines have low rates of utilization by smokers. This study, however, does not determine whether integrated telemedicine would have higher utilization.

Comparison With Prior Work

Our biochemically verified quit rates, in both study arms, are similar to self-reported long-term quit rates reported by smokers using telephone quitlines [3]. Likewise, our 3-month self-reported quit rate of 23% in our ITM arm was similar to the 25% self-reported 3-month quit rate reported by Carlson et al, in their rural telemedicine group-based cessation intervention [15].

In comparison with recent studies, our cost per quit values are consistent: $444/quit for Phone and $480/quit for ITM in provider costs. Adding patients' costs increased those values to $680/quit (Phone) and $1694/quit (ITM). A telephone-based counseling approach from Veterans Affairs reported $1092/quit (2009 dollars) and an Australian quitline reported $680/quit (converted Australian to US dollars) [35,36]. Unlike most telemedicine trials, we compared our telemedicine intervention to a telephone intervention, *not* to a face-to-face intervention [14]. Undoubtedly, the telemedicine would have been less expensive compared to the cost of traveling to a location for equivalent quality face-to-face counseling—which would have been Kansas City.

From a provider's perspective (the organization proposing to deliver the intervention), if they have an appropriate space to perform the telemedicine intervention that would not influence the clinic's revenue generation, then ITM would be the preferred approach, given the higher propensity of participants to refer ITM to family and friends. From a patient's perspective, attending a face-to-face or a telemedicine intervention outside the home imposes a substantial burden in time and travel costs. This may well, in practice, ultimately limit attendance. From a societal perspective, applying limited resources to the best yield tips the balance to the current phone-based quitline as most cost-effective.

Conclusions

Findings did not support the superiority of telemedicine smoking cessation counseling, integrated into patients' medical homes, over quitline counseling. Participants in the telemedicine arm, however, were significantly more likely to recommend the program to family and friends, in spite of the fact that ITM placed considerably higher burden on participants. This is important. Although all states provide free access to telephone quitlines, very few smokers choose to use quitlines. Telemedicine-based counseling, integrated into medical homes, could be another option for behavioral counseling for smokers who might not opt for phone counseling. The opportunity costs associated with using clinic exam rooms for delivering telemedicine counseling made this approach far less favorable economically, however. Identifying a less costly space to deliver telemedicine within patients' medical homes would maximize the efficiency of this approach.

Future research could include preference trials, in which smokers are provided the option of choosing between telemedicine and quitline counseling, to examine whether the higher proportion of participants who would refer to family and friends translates into higher rates of utilization. Moreover, there may be sub-populations of smokers for whom this form of telemedicine might be more attractive or more effective. Future studies, perhaps involving mixed modeling or classification and regression tree (CART) analyses might identify such groups.

Because our trial was designed as a test of superiority and not equivalence, it is premature to assume that the effects of quitline and ITM are equivalent. In our trial, differences between the groups consisted of (1) participant willingness to refer others to the study, and (2) costs. It would be misleading, however, to suggest that decisions about implementation be made on the basis of these differences alone. A future equivalence trial would better determine the relative effectiveness of each approach and might uncover other implementation considerations. In addition, future interventions could combine and test elements of both approaches to optimize pharmacotherapy utilization, counseling adherence, and satisfaction. Such an approach could commence with a telemedicine-delivered clinic office visit for pharmacotherapy guidance, and continue with either telephone or video counseling delivered via traditional or mobile phones to flexibly deliver behavioral support to patients where they most need it—in their homes and communities.

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Authors' Contributions

KR oversaw all aspects of the study, completed the first draft of the manuscript, collected feedback and approval from all authors, and submitted the final version of the manuscript. TS designed and conducted the cost-effectiveness analyses. EFE contributed to the study design and assisted in recruitment of clinics. APC helped design the analysis oversaw all aspects of Spanish translation and recruiting Hispanic and Latino smokers. DC and LSC designed the counseling protocol, fidelity procedures, provided counseling supervision, and assisted in the drafting of the manuscript. KJP designed study analyses. RS supervised telemedicine technicians and oversaw all aspects of telemedicine implementation. LM served as project director for the first year of the project and provided extensive feedback on drafts of the manuscript. NN managed the study database and generated all descriptive data. JH directed data collection and entry and worked with NN and KJP to ensure data accuracy. LL served as project director for 3 years and oversaw all aspects of study implementation. All authors have seen and approved of the final manuscript.

Conflicts of Interest

None declared.

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Abbreviations

AUDIT-C: Alcohol Use Disorders Identification Test, alcohol consumption questions
CART: Classification and Regression Tree
CBT: Cognitive Behavior Therapy
CO: carbon monoxide (expired)
CPT: American Medical Association’s Current Procedural Terminology
FTND: Fagerström Test for Nicotine Dependence
GAD-2: Generalized Anxiety Disorder questionnaire, 2-item version
ITM: integrated telemedicine
ITT: intent-to-treat
MI: motivational interviewing
MITI: Motivational Interviewing Treatment Integrity
PCSC: Perceived Competence Scale for Cessation
Phone: telephone treatment arm

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Original Paper

Who Follows eHealth Interventions as Recommended? A Study of Participants' Personal Characteristics From the Experimental Arm of a Randomized Controlled Trial

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Abstract

Background: Computer-tailored eHealth interventions to improve health behavior have been demonstrated to be effective and cost-effective if they are used as recommended. However, different subgroups may use the Internet differently, which might also affect intervention use and effectiveness. To date, there is little research available depicting whether adherence to intervention recommendations differs according to personal characteristics.

Objective: The aim was to assess which personal characteristics are associated with using an eHealth intervention as recommended.

Methods: A randomized controlled trial was conducted among a sample of the adult Dutch population (N=1638) testing an intervention aimed at improving 5 healthy lifestyle behaviors: increasing fruit and vegetable consumption, increasing physical activity, reducing alcohol intake, and promoting smoking cessation. Participants were asked to participate in those specific online modules for which they did not meet the national guideline(s) for the respective behavior(s). Participants who started with fewer than the recommended number of modules of the intervention were defined as users who did not follow the intervention recommendation.

Results: The fewer modules recommended to participants, the better participants adhered to the intervention modules. Following the intervention recommendation increased when participants were older (χ^2_1=39.8, *P*<.001), female (χ^2_1=15.8, *P*<.001), unemployed (χ^2_1=7.9, *P*=.003), ill (χ^2_1=4.5, *P*=.02), or in a relationship (χ^2_1=7.8, *P*=.003). No significant relevant differences were found between groups with different levels of education, incomes, or quality of life.

Conclusion: Our findings indicate that eHealth interventions were used differently by subgroups. The more frequent as-recommended intervention use by unemployed, older, and ill participants may be an indication that these eHealth interventions are attractive to people with a greater need for health care information. Further research is necessary to make intervention use more attractive for people with unhealthy lifestyle patterns.

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KEYWORDS

eHealth; Web-based intervention; intervention use; computer tailoring; personal characteristics; health lifestyle; multiple health behaviors; intervention adherence; socioeconomic status

Introduction

New eHealth interventions are an important tool to improve public health by providing people with information, skills, and support needed for a positive health-related lifestyle change [1,2]. These eHealth interventions provide the opportunity to use computer tailoring to provide highly personalized information to a respondent without face-to-face counseling [3-5]. With the use of computer tailoring, participants receive information derived from an individual assessment, attuned to their individual answers, and, in our case, aimed at motivating individuals to adopt 1 or more healthy behaviors [6]. Consequently, computer-tailored interventions provide feedback that is more relevant to the individual, contains less redundant information, and is more likely to be processed and remembered than generic information [7-10]. Furthermore, eHealth interventions are easily accessible and have the potential to reach a wide population [11,12].

Numerous studies have demonstrated that computer-tailored interventions are effective in motivating individuals to adopt health behaviors [1,13-15], including increased physical activity [16-20], healthy nutrition [5,20-24], smoking prevention and cessation [25-28], and decreasing alcohol intake [29-31]. Moreover, interventions to change multiple health behaviors have also been shown to be effective [32-35]. Studies also showed that computer-tailored interventions are more cost-effective than typical health care [36-38].

People of a low socioeconomic status (SES) often have unhealthy lifestyle behaviors [39,40]. They often eat fewer fruits and vegetables [41], are less physically active (eg, [42]), consume more alcohol (eg, [43]), and smoke more tobacco (eg, [44]) compared to people with higher SES.

Although there is evidence that Web-based interventions are effective in improving health behavior, these interventions come with high dropout rates and the problem that participants often do not use the intervention as recommended [45-47]. Although studies have investigated characteristics of dropout and nonusage of eHealth interventions (eg, [45,48]), it is equally important to know more about the participants who use these interventions as recommended. It is conceivable that people with different sociodemographic profiles may use these Web-based interventions differently because of general differences in online behavior and Internet usage between certain groups. This digital divide, for example, refers to unequal access to and use of the Internet among people with a lower SES [49-53].

More than 90% of the general Dutch population has access to the Internet and 86% of Dutch people use the Internet every day [54,55]. Although the gap between people with and without Internet access seems to be closing, there is still a difference in Internet use between certain sociodemographic groups [56]. People with a higher SES use the Internet more often than people with a lower SES to achieve personal development (eg, getting a new job), whereas people with a lower SES use the Internet primarily for other purposes, such as entertainment [57,58].

Education is often used as a proxy to measure SES; therefore, the literature about education and Internet use is extensive. People with a higher educational level have been found to use the Internet more frequently to gain health-related information, for work, and for shopping or product information. People with a lower educational level use the Internet more often with other objectives, such as browsing the Web or playing online games [59-62]. Educational level might also play a role in online behavior because most information on the Internet is written at a high literacy level whereas nearly half of the people do not understand this level of written information [63]. Moreover, employed people spend less of their leisure time online [57]. People with a lower income use the Internet more often for entertainment purposes, such as downloading music [64-66], whereas people with a higher income spend more of their time online searching for news or information [57].

Age- and gender-based differences in Internet use also exist. Although the majority (80%) of Dutch people aged 65 years or older have access to the Internet [67], they are less familiar with routine daily use of the Internet [56,68] and use the Internet primarily as an information source [69] in contrast to younger Internet users who primarily understand the Internet as an entertainment medium [70]. Males have been found to use the Internet more often, are more experienced with Internet use, and feel more comfortable with it [56,71]. This is in contrast to women, who spend less time online when having to take care of their family [72], but seek health information online more often than men [64]. In addition to these, other personal factors, such as a lower quality of life [73,74] or being married, are related to less Internet usage [75].

Because SES is an important predictor of how people use the Internet [56], it is conceivable that people with a lower SES may not implement eHealth interventions as intended by the intervention developer and may be unlikely to follow intervention recommendations, which makes behavior change less likely [76]. However, because people with a lower SES are a high-risk group for unhealthy behaviors [44,77-79], they are a highly relevant target group that might benefit from eHealth behavior change interventions. The same reasoning might hold for other personal characteristics, such as age, perceived health, or quality of life.

Therefore, this study investigates whether people are following the recommendations of how to use eHealth interventions. The purpose of our study is to identify personal and socioeconomic characteristics associated with recommended eHealth intervention use. Based on findings from the literature, we hypothesize that people with a higher education, who do not have paid work, those who have a lower income, who are younger, female, have a high perceived quality of life, and are not in a relationship are more likely to use the intervention as recommended.

Methods

Overview

A detailed description of the study protocol has been published elsewhere [80]; only those study methodology details relevant to the study at hand are described here.

Participants, Procedure, Study Design, and Intervention Content

This study is part of a randomized controlled trial that was conducted in the Netherlands between 2009 and 2012. The study received ethics approval from the Medical Ethics Committee of Maastricht University and the University Hospital Maastricht (MEC) and has been registered by the Dutch Trial Register (NTR 2168). Participants were recruited through different Dutch Regional Health Authorities (RHAs) in the Netherlands [80]. These RHAs periodically monitor the health status, health behaviors, and related aspects of the adult population. At the end of this monitor, people were asked if they were interested in participating in this study. They were told that they would be invited to take part in a free online program that provides participants with tailored feedback about their health behavior. Internet access, a computer, basic Internet skills, and sufficient Dutch language skills were required preconditions for participating. The intervention consisted of 2 parts and focused on 5 health behaviors: fruit consumption, vegetable consumption, physical activity, smoking behavior, and alcohol intake. During the first part of the intervention, participants had to answer questionnaires about their health behaviors. The answers were used to provide participants with their personalized risk appraisal, which provided feedback by comparing the respondents' behavior to the Dutch guidelines defined for the 5 behaviors, such as (1) being physically active for at least 30 minutes on at least 5 days a week, (2) eating at least 200 grams of vegetables, (3) eating at least 2 pieces of fruit each day, (4) drinking no more than 2 glasses of alcohol a day (for men; 1 glass for women), and (5) not smoking at all.

The second part of the intervention consisted of 5 lifestyle modules. Participants who were interested in participation in the program received an email with their personalized link to log on to the computer-tailoring program. Based on the first part, the questionnaire assessment as part of the RHA monitor, participants were provided with tailored feedback concerning their behavior. They received an overview about all 5 behaviors and whether they met the guidelines or not. In the second part of the program, participants were asked to complete all modules for which they did not meet the guidelines. For example, in case a participant reported smoking and eating less than 2 pieces of fruit a day, he/she was advised to participate in the modules for smoking and fruit consumption. All modules included tailored feedback based on the determinants specified in the I-Change Model [81]: attitudes, social influence, self-efficacy, and preparatory and coping planning. The order of the modules was counterbalanced, either starting with preventive behaviors and addiction behaviors (ie, physical activity/vegetable consumption/fruit consumption and alcohol intake/smoking), or vice versa (alcohol intake/smoking followed by physical activity/vegetable consumption/fruit consumption).

Measures

Demographic Information

The following demographic information were assessed: age, gender (1=male; 2=female), education (1=low: no education, primary, or lower vocational school; 2=middle: secondary vocational school or high school; 3=high: higher professional education or university), monthly income (1≤€1751; 2=€1751-€3050; 3≥€3050), work situation (1=no paid job; 2=paid job) [82], family status (1=single; 2=relationship), number of persons living in the household, and country of birth (1=the Netherlands; 2=other).

Health Status

Participants were asked whether they suffered from (any of) the following diseases: diabetes mellitus, myocardial infarction, stroke, high blood pressure, other cardiovascular diseases, and/or cancer. Participants were categorized as ill (1=suffering from at least 1 of the diseases) or healthy (0). To assess quality of life, the Short Form Health Survey (SF-12) questionnaire was used [83-85] (ranging from 18 to 48; based on a mean split of 24, we defined 0=a low quality of life score and 1=a high quality of life score).

Health Behaviors

All 5 health behaviors were assessed with the use of validated questionnaires. Physical activity was assessed with the Short Questionnaire to Assess Health-Enhancing Physical Activity (SQUASH) [86]. Weekly vegetable intake (raw, boiled, baked, or salad), weekly fruit intake, and fruit juice consumption were assessed with the Food Frequency Questionnaire (FFQ) [87]. Alcohol consumption was assessed with the 5-item Dutch Quantity-Frequency-Variability (QFV) questionnaire [88]. Smoking behavior was assessed by asking if, what (eg, cigarettes, shag), and in what quantities participants smoke and their answers were converted into a score for tobacco consumption according to the recommendations by Mudde and colleagues [89].

Intervention Use

We defined someone as using the intervention as recommended if he/she started with the suggested number of lifestyle modules based on his/her assessed behavior. Answering the first question within the specific module was defined as starting the module. For example, if a participant did not meet the guideline for smoking, vegetable consumption, and physical activity, this person was expected to start with 3 lifestyle modules (more than 3 modules were also counted as using the intervention as recommended) to be classified as a participant who uses the intervention as recommended. If this participant only started 2 or less modules, he/she was classified as not meeting the intervention recommendation.

Statistical Analyses

The data was analyzed with SPSS 20.0 (IBM Corp, Armonk, NY, USA). Descriptive statistics were used to describe participants' characteristics.

Frequency analyses were performed to identify the number of participants who used the intervention as recommended (1) and those who did not (0), as defined by the intervention recommendation. Only participants who got the advice to complete at least 1 module were included in analysis of intervention use as recommended. Differentiations were made between different subgroups for age, gender, education, income, working situation, health status, family status, and quality of life. We used chi-square tests to explore the differences among these groups.

Logistic regression analyses using the Enter method were used to predict intervention use as recommended among different personal characteristics. The number of the received intervention modules, based on the amount of health behaviors that did not met the national guidelines, was used as a dependent variable. Separate logistic regression analyses were carried out dependent on the amount of lifestyle modules participants were advised to complete. One logistic regression analysis including all respondents was conducted with as-recommended program use as a dependent variable to detect characteristics that predict intervention use in general. Age, gender, level of education, income, employment status, family status, household size, country of birth, diseases, and quality of life were included as predictors in all models. The recommended number of modules was also taken into account in the model. Tests were performed at alpha=.05 to indicate statistical significance.

Results

Sample Characteristics

A total of 1638 participants were included in this study (Table 1). Variables with missing data were not filled up (maximum missing values of 2.4%). The mean age was 43.9 years (SD 12.6) and slightly more men (53.60%, 878/1638) than women (46.40%, 760/1638) participated in the trial. A minority of the participants had a low educational level (10.84%, 174/1605). The majority had a middle income (46.83%, 767/1606), were in a relationship (75.94%, 1215/1600), and came originally from the Netherlands (95.27%, 1531/1607). Most participants were healthy (79.84%, 1283/1607) and reported a high quality of life (58.51%, 935/1598).

Intervention Use

Figure 1 represents the percentages of participants who used the intervention in the recommended way. For example, 414 of 585 participants (70.8%, red bar) who were advised to complete at least 2 lifestyle modules did not do so, 162 participants (27.7%, blue bar) followed the recommendation, and a minority (9/585, 1.5%, green bar), attended more than 2 modules. These percentages indicate that the healthier their lifestyle and the fewer modules participants were advised to complete, the more participants followed the intervention guideline.

Figure 1. Percentage of participants who used the intervention in the recommended way.

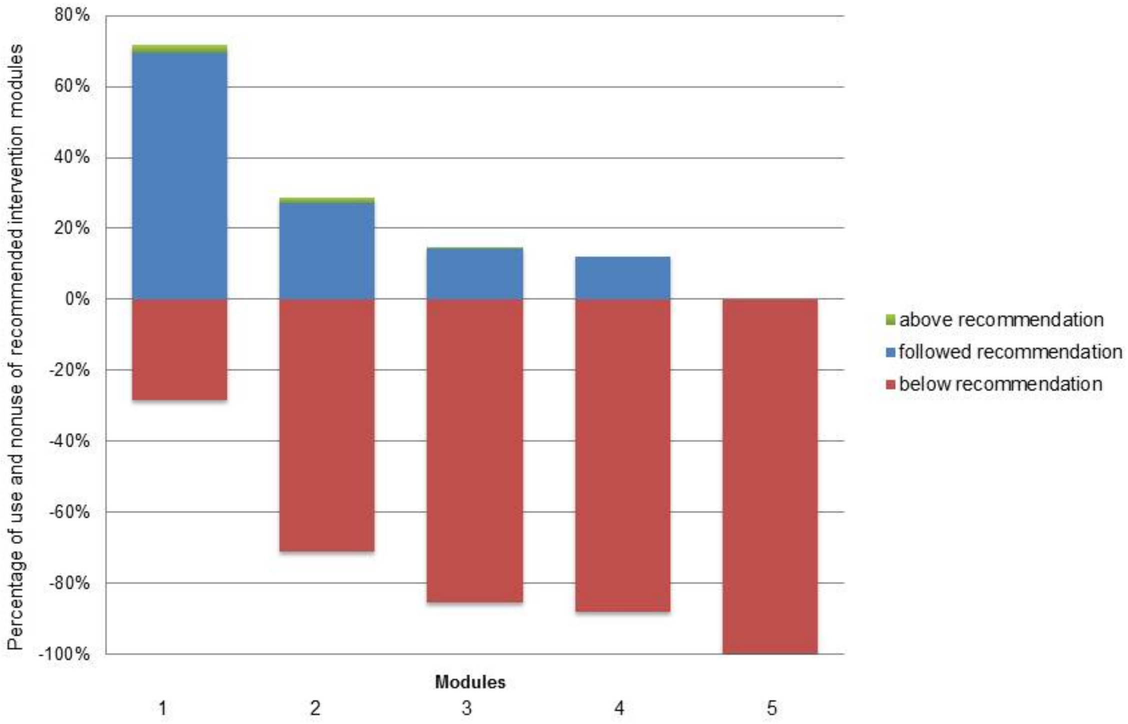


Table 1. Sample characteristics (N=1638).

Characteristics	n (%)	Mean (SD)	Range
Age (years)		43.94 (12.57)	19-65
Gender			
Male	878 (53.60)		
Female	760 (46.40)		
Educational level			
High	700 (43.16)		
Middle	731 (45.55)		
Low	177 (10.84)		
Income (€)			
<1750	373 (22.77)		
1751-3050	767 (46.83)		
>3051	466 (28.45)		
Working situation			
Paid job	1240 (77.26)		
Nonpaid job	365 (22.74)		
Family status			
Single	385 (24.06)		
In relationship	1215 (75.94)		
Number of people in household		2.89 (1.37)	1-11
Country of birth			
The Netherlands	1531 (95.27)		
Other	76 (4.73)		
Disease status			
Ill	324 (20.16)		
Healthy	1283 (79.84)		
Quality of life (SF-12)		40.19 (5.08)	18-48
High	935 (58.51)		
Low	663 (41.49)		
Number of modules recommended			
0	174 (10.62)		
1	451 (27.53		
2	585 (35.71)		
3	315 (19.23)		
4	100 (6.11)		
5	13 (0.79)		

Intervention Use by Different Subgroups

The table in Multimedia Appendix 1 gives an overview of the number of unhealthy behaviors and the number of started modules, differentiated by several personal variables. Figure 2 graphically summarizes the difference between the subgroups and the number of participants who did not comply with the intervention recommendation compared to those who used the intervention as recommended.

Significantly more older (39.50%, 361/914) than younger participants (26.3%, 191/726; χ^2_1=44.8, P<.001) and significantly more women (50.66%, 385/760) than men (38.8%, 341/878; χ^2_1=23.0, P<.001) used the intervention as recommended.

People with low education (42.0%, 73/174) adhered best to the recommendation to participate in the suggested modules depending on their health behavior compared with participants with middle (33.2%, 243/174) or high education (32.6%, 228/700). However, no significant differences among these 3 educational levels were found with regard to recommended intervention use (χ^2_1=2.9, *P*=.23).

Participants with a low income (33.24%, 124/373), middle income (34.29%, 263/767), and high income (33.26%, 155/466) also did not differ significantly from one another with regard to intervention use (χ^2_2=0.6, *P*=.72).

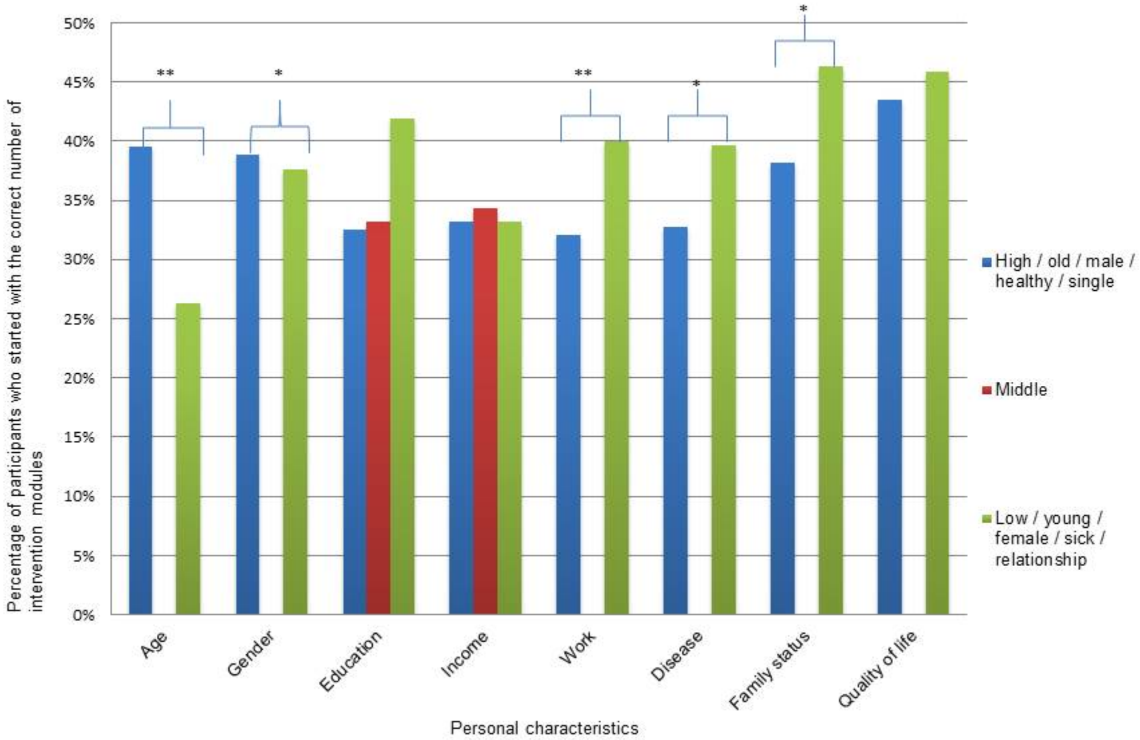
However, participants without a paid job (40.0%, 146/365) followed the recommendation of the intervention significantly more often than participants with a paid job (32.02%, 397/1240; χ^2_1=7.9, *P*=.01).

Those participants who were ill (37.7%, 123/324) did use the intervention as recommended significantly more often compared to healthy participants (32.74%, 420/1283; χ^2_1=4.5, *P*=.02).

Participants in a relationship (46.34%, 563/1215) followed the intervention recommendation significantly more often than single participants (38.2%, 147/385; χ^2_1=7.8, *P*=.003).

Finally, no significant differences were found for participants with a high quality of life (43.5%, 407/935) compared to those with a low quality of life (45.9%, 304/663; χ^2_1=0.9, *P*=.19).

Figure 2. Percentage of participants who followed the recommendation to start with the correct number of intervention modules differentiated by education, income, work, age, gender, and disease status. Age was categorized as 1=young and 2=old based on a mean split of 44 years. **P*<.05, ***P*<.001.



Predictors of Intervention Use

As indicated in Table 2, higher age at baseline was a significant predictor of following the relevant recommendation to start with 1 or more modules. This was found for those who were recommended to follow 1, 2, and 3 modules, and in general. Age did not predict intervention use as recommended for respondents who were recommended to follow 4 lifestyle modules.

Table 2. Logistic regression results for the relationship between socioeconomic variables, personal characteristics, and following the intervention recommendation.

Predictor[a]	Number of modules recommended to start with											
	1 module (n=427)			2 modules (n=556)			3 modules (n=302)			4 modules (n=108)		
	β	*P*	OR (95% CI)	β	*P*	OR (95% CI)	β	*P*	OR (95% CI)	β	*P*	OR (95% CI)
Age (cont)	0.04	<.001	1.05 (10.02-10.07)	0.04	<.001	1.04 (1.02-1.05)	0.05	.002	1.06 (1.02-1.09)	–0.03	.30	0.97 (0.90-1.04)
Gender (ref=female)	0.17	.62	1.13 (0.71-10.78)	0.54	.007	1.16 (1.24-2.54)	0.41	.22	1.60 (0.76-3.24)	–0.91	.24	0.41 (0.05-3.07)
Diseases (ref=healthy)	0.08	.82	1.09 (0.57-2.04)	–0.17	.50	0.84 (0.51-1.39)	0.40	.24	1.72 (0.69-4.2)	–1.36	.37	0.26 (0.05-1.41)
Country of birth (ref=other than NL)[b]	–0.32	.52	0.73 (0.27-1.95)	–0.46	.31	0.63 (0.27-1.53)						
Family status (ref=relationship)	–0.68	.03	0.50 (0.27-0.94)	0.35	.21	1.42 (0.82-2.25)	0.68	.16	2.12 (0.71-6.03)	–1.24	.41	0.29 (0.04-2.18)
Household (cont)	–0.10	.25	0.90 (0.76-1.07)	–0.04	.69	0.96 (0.83-1.13)	–0.12	.42	0.88 (0.66-1.21)	–0.80	.07	0.45 (0.20-1.05)
Income (ref=low)												
Low		.33			.25			.59			.12	
Middle	0.46	.21	1.59 (0.77-3.29)	–0.48	.15	0.62 (0.33-1.2)	–0.16	.53	0.67 (0.26-2.85)	–1.25	.15	0.06 (0.02-4.18)
High	0.37	.17	1.45 (0.85-2.50)	–0.36	.13	0.70 (0.43-1.11)	0.21	.81	1.12 (0.51-2.99)	1.01	.55	1.86 (0.39-19.44)
Work situation (ref=unemployed)	–0.23	.45	0.79 (0.44-1.44)	–0.001	.99	0.99 (0.62-1.61)	–0.27	.68	0.84 (0.36-1.9)	–1.26	.14	0.20 (0.04-1.99)
Education (ref=low)												
Low		.65			.74			.70			.08	
Middle	0.15	.73	1.16 (0.50-2.70)	–0.26	.44	0.77 (0.40-1.5)	0.40	.40	1.60 (0.57-4.67)	2.84	.08	10.99 (1.38-212.83)
High	0.24	.36	1.27 (0.77-2.08)	–0.06	.79	0.94 (0.62-1.49)	0.08	.71	1.17 (0.52-2.54)	–0.26	.65	0.65 (0.13-4.65)
QOL (cont)	–0.02	.37	0.98 (0.93-1.03)	–0.07	.002	0.93 (0.89-0.98)		.22	0.96 (0.9-1.03)	–0.09	.24	0.92 (0.8-1.06)

[a] Cont=continuous; ref=reference group for categorical variables.

[b] Analysis of country of birth not possible for those in 3 and 4 modules because number of participants not from the Netherlands<10.

Being single significantly predicted recommended intervention use, but only for those participants who were advised to start with 1 module. However, none of the socioeconomic variables (education, income, and work) had a significant influence on the intervention use behavior regardless of the number of unhealthy behaviors.

A low quality of life (SF-12) was associated with being more likely to use the intervention as recommended for only people who received the advice to start with 2 modules. It should be noticed that the analysis of country of birth was not possible for the model with 3 and 4 recommended modules because the number of participants not from the Netherlands was less than 10.

The regression analysis of intervention use in general indicated that being older, female, having a lower quality of life, and given the recommendation to complete fewer lifestyle modules were significant predictors of intervention use according to recommendations (see Table 3).

Table 3. Logistic regression results for the relationship between socioeconomic variables, personal characteristics, and following the intervention recommendation within the complete sample (N=1586).

Predictor	β	*P*	OR (95% CI)
Age (cont)	0.04	<.001	1.04 (1.02-1.05)
Gender (ref=female)	0.34	.02	1.40 (1.08-1.80)
Diseases (ref=healthy)	–0.18	.71	0.94 (0.67-1.31)
Country of birth (ref=not NL)	–0.26	.40	0.77 (0.42-1.41)
Family status (ref=in relationship)	0.01	.97	1.0 (0.67-1.46)
Household (cont)	–0.09	.07	0.91 (0.82-1.01)
Income (ref=high)			
Low		.67	
Middle	–0.16	.47	0.86 (0.56-1.31)
High	0.01	.98	1.06 (0.74-1.34)
Work situation (ref=unemployed)	–0.15	.35	0.86 (0.62-1.19)
Education (ref=high)			
Low		.78	
Middle	0.06	.79	1.06 (0.68-1.67)
High	0.08	.58	1.08 (0.82-1.43)
QOL (cont)	–0.04	.002	0.96 (0.93-0.98)
Module recommendation (cont)	–1.59	<.001	0.20 (0.17-0.24)

[a] Cont=continuous; ref=reference group for categorical variables.

Discussion

Principal Findings

Because eHealth intervention use as recommended increases the effectiveness of behavior change [76], it is of high importance that people at a high risk of unhealthy lifestyle behaviors use those interventions in such a way. Our analysis of a sample of the general Dutch population revealed that there was a difference in intervention use among people grouped by different personal characteristics.

Contrary to earlier findings regarding Internet use and age (eg, [56,59]), we found that more older than younger participants used the intervention as recommended. It might be possible that older people were less familiar with eHealth interventions and, therefore, gained more information that was new and relevant to them resulting in more frequent use of the intervention modules.

Women in our study used the intervention as recommended more often, which could be explained by the fact that women use the Internet to seek health information more frequently than men [90]. Females tend to be more interested in health topics [91,92] and rely more often on the Internet as a trustful source [59,93]. These explanations might be possible reasons why women used the intervention as recommended more frequently compared to men in our study. In addition, males have been found to evaluate the Internet as a less valuable source of health information than women do [59], which might include eHealth interventions, and this may be another reason for the lower intervention adherence by men in our study.

Participants within a relationship have been found to use the intervention as recommended more frequently compared to singles. People within a relationship have been found to have healthier behavior and health might be something in their interest which could explain why they are more interested in using the intervention [94]. Further research should explore the importance of family status as well as health behaviors of other family members in more depth because it might be that family members are more likely to behave alike, which might ultimately affect (the need for) intervention use.

People with a lower educational level used more intervention modules than those with a higher education level did. This result is surprising because it is known from the literature that higher-educated people spend more time online to seek health information [62,95]. One explanation is that the lower-educated participants may lack prior knowledge and may have used this intervention to gain more knowledge about a healthy lifestyle [59]. Another explanation could be that people with a lower SES use the Internet primarily to gain information, whereas people with a high SES make use of different sources, including professionals or their social environment, and thus rely less on the Internet for information [93]. But these results must be interpreted with caution because although we found higher as-recommended intervention use, education was not a significant predictor within the regression analysis. Furthermore, our data indicated that income is not a predictor for recommended intervention use, which might indicate that income level might not be important with regard to intervention use as recommended.

This study revealed that unemployed people used the intervention as recommended more frequently. Participation in the intervention is time-consuming and it may be that employed people adhered less to the intervention recommendations because they had less leisure time. Previously, van Deursen and van Dijk [57] reported that unemployed people spent more time online than employed people did.

The fact that participants who reported having a disease used our intervention more frequently is in-line with previous literature findings. Individuals who perceive themselves as more ill have been found to use the Internet as a source of health information [96,97]. This might also be an explanation for our finding that participants with a lower level of quality of life used the intervention as recommended. It might be plausible that these participants look for health information and tips about how to change their lifestyle to gain a better health condition and a higher quality of life.

We also found the more modules recommended to complete, the fewer were done by participants. Following the recommendations of an eHealth intervention requires a significant investment of time for reading and processing information and interacting with the program. Participants who received the recommendation to use many modules might be at greater risk of being overwhelmed by those requirements. If an eHealth program demands too much cognitive effort from their participants, ego depletion [98,99] can arise and participants might be more inclined not to use the program as recommended.

To summarize, we have found differences in intervention use as recommended among participants with different personal characteristics. We know that especially younger people, males, people who have a job, people with illnesses, and singles did not use the intervention as recommended. Furthermore, our analysis revealed that being older, female, having a low quality of life, and a healthier lifestyle are predictors of intervention use as recommended when all personal characteristics are taken into account.

Strengths, Limitations, and Further Implications

One of the strengths of this study is the multiple-behavior approach because previous studies have demonstrated that those interventions have a high impact on behavior change [2]. Furthermore, we assessed several indications to measure SES, which allows us to compare the impacts of education, income, and occupational status.

In addition to the randomization of the started behaviors, either preventive or addictive modules, one of the limitations of this study is that participants could not choose on their own which module they wanted to begin with in the given module block. This might have increased the risk of participants not using the intervention because they might have disliked a given sequence. Furthermore, a predefined order of the modules may have led to reduced feelings of choice. We were not able to analyze potential consequences of this reduction and further studies may explore this issue at greater depth. Participants could have also misinterpreted a predefined order as an order of importance. Providing the module about fruit consumption first and then smoking might have created the impression that changing fruit consumption is more important than smoking cessation. Another limitation of the predefined order of the modules might be that some participants had to start with a behavior that they experienced as difficult, which may have led to reduced motivation to complete the full program. Future intervention studies should study under which conditions the utilization of a simultaneous strategy favoring multiple behaviors simultaneously or sequentially are preferred by participants.

Although this study used the term “following interventions as recommended,” we can only say for sure that participants started with the recommended amount of modules and not whether they finished the modules or how they used the modules. Next, the aim of the study was to look at differences in people of this intervention group in regards to following intervention recommendations. Yet, participants of an intervention are often preselected, implying that people who are healthier and more interested in health are more willing to participate.

Another limitation of the study at hand is the use of self-reported questionnaires, which could result in an overestimation of healthy lifestyles and participants being given the recommendation to start with fewer intervention modules. Self-reported questionnaires with regard to education, income, and working situation might also result in an underestimation of people with a low SES (eg, false information about income).

Finally, we did not analyze whether following the intervention recommendation resulted in behavior change or not. However, in one of our studies [2], it was investigated that a longer visiting time and greater number of visits in the intervention resulted in higher likelihood of behavior change. To our knowledge, this is one of the first studies focusing on socioeconomic and personal characteristics as a predictor of recommended intervention use. Because we found that older participants, females, unemployed people, ill participants, and people in a relationship more often use the intervention as recommended, we should ask ourselves what strategies can be taken to make interventions more attractive to use for those who did not use the intervention as recommended. Our intervention included several strategies that are known to increase intervention use, such as giving tailored feedback, using goal-setting strategies, action planning, self-efficacy monitoring, and the use of reminders [100,101]. On the other hand, the intervention might be more attractive if interactive elements and communication tools to facilitate social support were used, when involving the social environment, or if entertaining elements (eg, additional games, quizzes) were added [100,101]. Furthermore, the health modules were very similar in terms of structure and type of feedback, and it might be that participants disliked the repetition (which also increases participants’ burden). Future research is warranted to investigate whether improving the flow experiences of participants by using strategies to attract participants’ attention and make interventions more entertaining increases recommended intervention use [102,103].

Conclusion

Our findings indicate that different subgroups use eHealth interventions in different ways. The more frequent as-recommended intervention use by unemployed, older, and ill participants may be an indication that these eHealth interventions are attractive to people with a greater need for health care information. Therefore, computer-tailored eHealth interventions might be a promising tool to increase health status and maintain healthy lifestyles.

Conflicts of Interest

Hein de Vries is the scientific director of Vision2Health, a company aimed at implementing evidence-based eHealth programs. All other authors have no conflicts of interests.

Multimedia Appendix 1

Number of started intervention lifestyle modules separated personal characteristics.

[PDF File (Adobe PDF File), 89KB - jmir_v17i5e115_app1.pdf]

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Abbreviations

FFQ: Food Frequency Questionnaire
RHA: Regional Health Authorities
SES: socioeconomic status
SF-12: Short Form Health Survey questionnaire
SQUASH: Short Questionnaire to Assess Health-Enhancing Physical Activity
QFV: Quantity-Frequency-Variability

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Original Paper

A Web-Based Psychoeducational Program for Informal Caregivers of Patients With Alzheimer's Disease: A Pilot Randomized Controlled Trial

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Abstract

Background: Although several face-to-face programs are dedicated to informal caregivers of persons with dementia, they are not always accessible to overburdened or isolated caregivers. Based on a face-to-face intervention program, we adapted and designed a Web-based fully automated psychoeducational program (called Diapason) inspired by a cognitive approach.

Objective: This study aimed to evaluate through a pilot unblinded randomized controlled trial the efficacy and acceptability of a Web-based psychoeducational program for informal caregivers of persons with Alzheimer's disease (PWAD) based on a mixed methods research design.

Methods: We recruited and randomized offline 49 informal caregivers of a PWAD in a day care center in Paris, France. They either received the Web-based intervention and usual care for 3 months (experimental group, n=25) or only usual care (control group, n=24). Caregivers' perceived stress (PSS-14, primary outcome), self-efficacy, burden, perceived health status, and depression (secondary outcomes) were measured during 3 face-to-face on-site visits: at baseline, at the end of the program (month 3), and after follow-up (month 6). Additionally, semistructured interviews were conducted with experimental group caregivers at month 6 and examined with thematic analysis.

Results: Intention-to-treat analysis did not show significant differences in self-perceived stress between the experimental and control groups (P=.98). The experimental group significantly improved their knowledge of the illness (d=.79, P=.008) from baseline to month 3. Of the 25 participants allocated to the experimental group, 17 (71%) finished the protocol and entirely viewed at least 10 of 12 online sessions. On average, participants used the website 19.72 times (SD 12.88) and were connected for 262.20 minutes (SD 270.74). The results of the satisfaction questionnaire showed that most participants considered the program to be useful (95%, 19/20), clear (100%, 20/20), and comprehensive (85%, 17/20). Significant correlations were found between relationship and caregivers' program opinion (P=.01). Thus, positive opinions were provided by husbands and sons (3/3), whereas qualified opinions were primarily reported by daughters (8/11). Female spouses expressed negative (2/3) or neutral opinions (1/3). Caregivers expected more dynamic content and further interaction with staff and peers.

Conclusions: In this study, quantitative results were inconclusive owing to small sample size. Qualitative results indicated/showed little acceptance of the program and high expectations from caregivers. Caregivers did not rule out their interest in this kind of intervention provided that it met their needs. More dynamic, personalized, and social interventions are desirable. Our recruitment issues pointed out the necessity of in-depth studies about caregivers' help-seeking behaviors and readiness factors.

Trial Registration: Clinicaltrials.gov NCT01430286; http://clinicaltrials.gov/ct2/show/NCT01430286 (Archived by WebCite at http://www.webcitation/6KxHaRspL).

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KEYWORDS

family caregivers; psychological education; eHealth; Alzheimer disease; emotional stress; qualitative research; Internet; randomized controlled trials

Introduction

Due to the worldwide aging population, the number of persons with dementia (35.6 million currently) is expected to double by 2030. The socioeconomic consequences of this rapid rise and the absence of an effective pharmacotherapy have positioned dementia as a major public health concern in recent years [1]. The Alzheimer's Association reported that in 2012 more than 15 million caregivers provided an estimated 17.5 billion hours of unpaid care, representing US $216 billion [2]. Today, the majority of persons with Alzheimer's disease (PWAD) living at home are cared for by their spouses, children, or friends [3]. Nevertheless, the amount of time dedicated to their relative, the physical efforts, and the strong emotional involvement associated with caregiving may induce chronic stress in caregivers and weaken their physical and mental health [4-7]. Such repercussions can also negatively affect other areas of their lives (eg, professional or social) [8].

Various nonpharmacological intervention programs for caregivers are available on-site (ie, [9,10]). Nevertheless, some caregivers are not willing or available to attend a face-to-face program due to a lack of respite, the distance, or owing to care-recipients' behavioral or physical problems. For them, technology-based programs may represent an interesting complementary strategy to regular care management [11,12].

Based on a face-to-face psychoeducational program [13], we adapted and developed the Diapason program, based on a user-centered design, including a proof of concept and 2 usability tests [14]. Although other recent Internet-based programs have been tested [15,16], to our knowledge, the use of mixed research methods still remains rare in randomized controlled trials (RCTs) [17]. Yet, including qualitative analysis in the evaluation of these programs may improve results interpretation, help "trialists" become more sensitive to individual differences, and save money "by steering researchers toward interventions more likely to be effective in future trials" [18].

The main aim of this pilot RCT was to evaluate the impact of the Diapason program on caregivers' perceived stress. We hypothesized that this program offering information, skills training, and a forum for caregivers would significantly reduce their perceived stress and burden, and enhance caregivers' self-efficacy, self-perceived health, and self-perceived knowledge about the disease. Qualitative analyses would facilitate the identification of subgroups benefiting from the program and would guide us to improve content and methods to evaluate this type of intervention.

Methods

Study Design

We carried out an unblinded monocentric pilot RCT (NCT01430286) between 2011 and 2014 in a day care center geriatric unit (Paris, France). Informed consent was obtained before participation. French ethical CPP approved this protocol in July 2011. The in-depth description of the protocol study has been reported elsewhere [19].

Recruitment and Participants

The recruitment strategy included flyers and posters placed in the hospital. During the consultations, geriatricians proposed this protocol to caregivers of PWAD. The caregivers interested in the study filled out a contact form. Then a psychologist provided them with the information form, confirmed inclusion criteria, and collected the signed informed consent.

Eligible participants were required to be French-speaking caregivers of community-dwelling PWAD who met the criteria of the *Diagnostic and Statistical Manual of Mental Disorders*, 4th Edition [20]. Caregivers had to spend at least 4 hours per week with their relative, be aged 18 years or older, scored 12 or more on the Perceived Stress Scale (PSS-14), and to have access to a computer with Internet connection. Professional caregivers were ineligible.

Based on the literature, a 6-point difference on PSS-14 was expected between the experimental and control groups at 3 months [21]. With an assumed SD of 9, 40 participants per group needed to be included to detect this difference with an 80% power (Cronbach alpha=.05; 2-tailed).

Intervention

The Diapason program [22] was delivered in a free, password-protected, fully automated website to be used in an individual fashion, at home, by the caregivers. The program's content was based on cognitive theories of stress, a literature review [23], and the results of a study conducted by our team [13]. In the latter, caregivers who improved their understanding of cognitive and behavioral symptoms reported feeling less stressed. Furthermore, caregivers with a perceived personal time restriction or poor social support suffer more stress, burden, and depression [24,25]. Consequently, our intervention targeted (1) caregivers' beliefs about the illness and the caregiving role, (2) caregivers' skills to manage daily life difficulties, and (3) caregivers' social support and help-seeking behavior to obtain respite or financial support, and to meet and discuss with peers through a forum. Twelve thematic sessions were sequentially and weekly unblocked once the previous one was entirely viewed (see layout in Figure 1). Owing to the variability of behavioral and psychological symptoms depending on the type of dementia and the important impact of some of them on caregivers' stress (eg, hallucinations, delusions), only Alzheimer's disease was targeted by this program.

Each session included theoretical and practical information, videos of health professionals, and a practice guide for applying the session's content in real life. The length of the intervention was 3 months, with each weekly session lasting 15 to 30 minutes on average, but there was no time limit and the participants could access different website sections (eg, relaxation training, forum) for as long as they wished at any time. The program content is summarized in Textbox 1.

Textbox 1. Overview of Diapason program contents.

Weekly Sessions

One session per week had to be entirely viewed at least once to unblock the next session

Session 1. Caregiver stress: this session presents a definition of stress, its causes and consequences on caregivers, the risk factors for chronic stress, and the mechanisms and effects of relaxation (includes a link to the relaxation training in the Diapason website), as well as strategies for managing stress underlining the importance of looking for respite.

Session 2. Understanding the disease: in this session, the Alzheimer's disease diagnosis procedure, the symptoms, the progression of the illness, and the consequences on daily life activities for persons with Alzheimer's disease (PWAD) are explained.

Session 3. Maintaining the loved ones' autonomy: this session presents the reasons and strategies to involve loved ones in the process of care in order to stimulate the preserved functions and compensate for the lost ones. The session underlines the importance of maintaining the self-esteem of PWAD.

Session 4. Understanding their reactions: in this session, the most frequent behavioral and psychological symptoms of dementia (BPSD) and their characteristics are succinctly described and illustrated by examples from daily life. The contextual and intrinsic factors that might be associated with them are also described.

Session 5. Coping with behavioral and emotional troubles: this session presents practical advice on how to cope vis-à-vis the BPSD described in the previous session.

Session 6. Communicating with loved ones: this session includes the description of the most frequent language troubles and the strategies to modulate and adapt communication to the preserved skills of PWAD.

Session 7. Improving their daily lives: this session presents strategies to facilitate the performance of activities that become difficult or impossible to execute due to apraxia, illustrating them with examples adapted to daily life.

Session 8. Avoiding falls: the session includes practical advice for maintaining and stimulating the relative's balance and actions to adopt in the event of a fall. In addition, various actions are described to adapt the relative's home.

Session 9. Pharmacological and nonpharmacological interventions: this session includes a brief presentation of different interventions available for caregivers in France with pharmacological treatment as well as cognitive and psychological support.

Session 10. Social and financial support: this session presents the different stakeholders and services that may help caregivers in their daily life. The financial and social support provided by the French government is also overviewed.

Session 11. About the future: this session provides caregivers with information about the role of disease progression anticipation, inviting them to try and foresee solutions keeping a prospective vision, encouraging them to look for further sources of information, and social support to reduce the uncertainty of caregiving situations.

Session 12. In a nutshell: the last session encompasses a summary of the Diapason program, emphasizing the acceptance of support and help and the importance of obtaining more information to anticipate and avoid stressful circumstances.

Additionally the website contains other sections that can be consulted at any time.

Relaxation training: guidelines for learning relaxation as well as 2 videos for the modeling of Schultz's Autogenic Training and Jacobson's method.

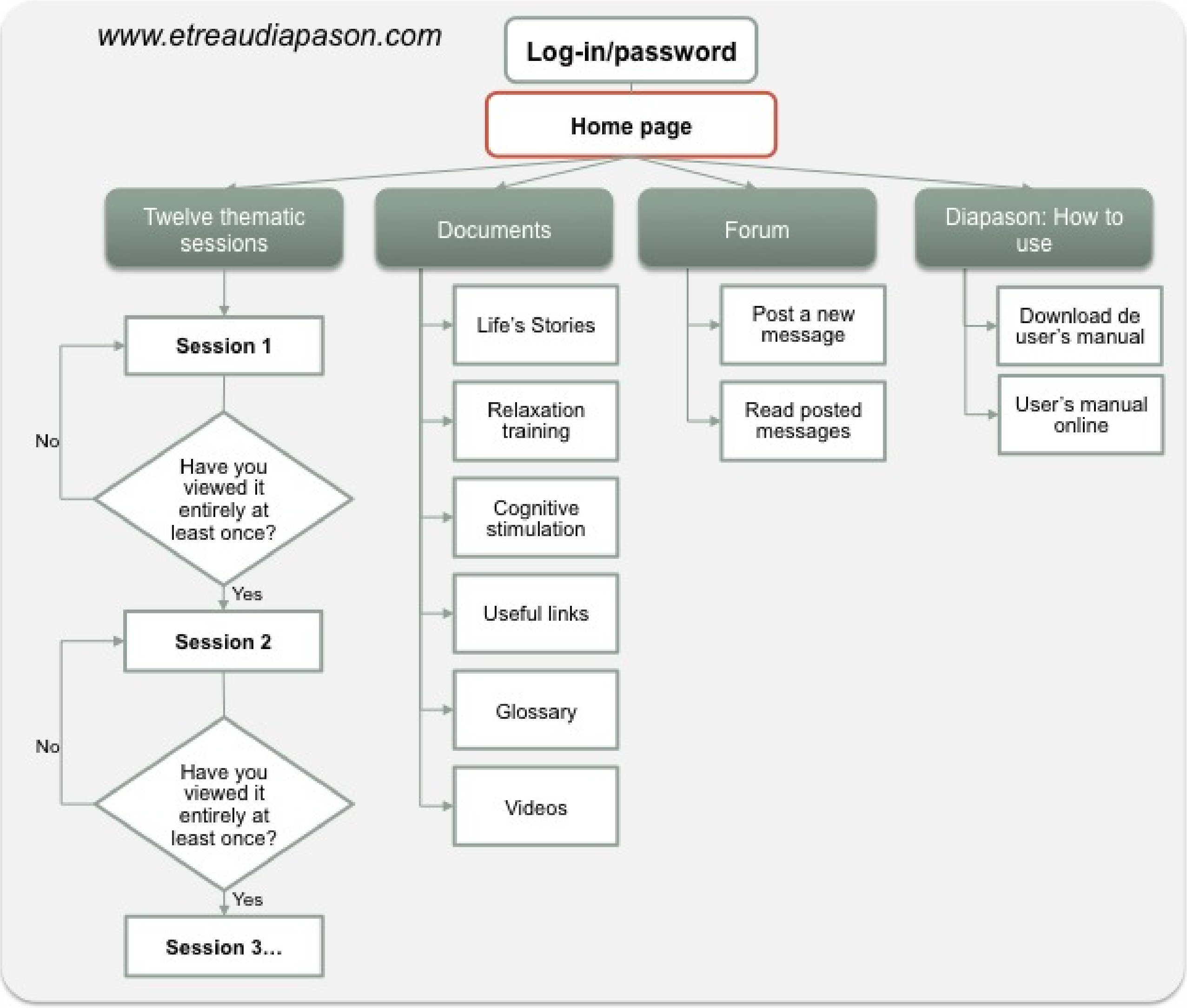
Life Stories: stories about 4 couples, based on testimonials of caregivers, in which difficult situations are illustrated and possible solutions to manage them are discussed (eg, apathy of patient, caregivers' isolation).

Glossary: a glossary for technical words (eg, neuropsychological assessment, aphasia)

Stimulation: practical activities to stimulate autonomy and share pleasant activities with the relatives in daily life.

Forum: a private and anonymous forum to interact with peers, to express their concerns, discuss solutions to daily problems, and share their feelings and experiences. The participants use nicknames to protect their privacy. A clinical psychologist participates in the discussions if necessary (ie, avoiding aggressive or inappropriate comments).

Figure 1. Layout of the Diapason program and process for viewing weekly sessions.



Procedure

Participants were recruited and randomized offline in 2 parallel groups based on a computer-generated randomization list using blocking and stratification by sex and relationship (spouses vs nonspouses).

The experimental group participants received at baseline a 10-minute training session on how to use the website, a log-in and password, a printed version of the user's manual, and a notebook to write personal ideas about their application of the program's content. Each week, participants had to read through an entire thematic session and fill out a printed satisfaction questionnaire. Other website sections (eg, relaxation training, forum) were available but not mandatory to complete the program. No modification regarding methodology, program content (except for forum discussions), or the website was done during the course of the study.

The control and experimental group participants received usual care, in which they were provided with information about the illness during their semiannual follow-up with their geriatrician. The control group participants were given access to the Diapason program at the end of their participation. All participants were advised to look for additional help if necessary and were asked to inform the researcher about it.

An individual face-to-face assessment was conducted at the Broca hospital by research psychologists (VCL or JW) at baseline, at the end of the program (at month 3), and after 3 months of follow-up (at month 6). Each 90-minute assessment visit consisted of a structured interview, standardized questionnaires, and visual analog scales (VAS). Additionally, experimental group volunteers participated in an optional one-to-one semistructured interview at the 3-month follow-up.

Measures

Based on a cognitive approach inspired by Lazarus and Folkman's [26] stress and coping theory and Bandura's [27] self-efficacy model, we hypothesized the program would have a direct impact on perceived stress levels, self-efficacy, and burden, and may influence depression and self-perceived health status.

To evaluate the perceived stress of caregivers (primary outcome), we used the 14-item Perceived Stress Scale (PSS-14) [28]. The total score ranges from 0 to 56, higher scores representing higher stress levels. In order to target the caregiving stress, we adapted the instruction by proceeding with heteroevaluation and adding the following underlined text: "This scale asks you about your feelings and thoughts about your experience with your relative during the last 4 weeks."

The secondary outcomes were:

1. Self-efficacy measured by the Revised Scale for Caregiving Self-Efficacy (RSCS) [29], which distinguishes 3 self-efficacy domains: obtaining respite, responding to disruptive behavior, and controlling upsetting thoughts. Scores in each domain range from 0 to 100, higher scores indicating a higher degree of confidence for each situation.
2. Perception and reaction to cognitive or behavioral symptoms of PWAD were evaluated with the Revised Memory and Behavior Problems Checklist (RMBPC) [30]. This instrument rates 24 problems on 2 scales. They evaluate (5-point scale) frequency and caregiver's bother or strain for each problem. A global score ranging from 0 to 4 was calculated for both scales. Higher scores indicate higher frequency or higher emotional effects.
3. Subjective burden was evaluated with the French version of the Zarit Burden Interview [31]. The total score ranges from 0 to 88, a higher score meaning a higher burden level.
4. Depressive symptoms were measured with the second version of the Beck Depression Inventory (BDI-II) [32] including 21 items with a total score range from 0 to 63. Higher scores indicate higher levels of depressive symptoms.
5. Self-perceived health was measured with the French version of the Nottingham Health Profile (NHP) [33]. We analyzed social isolation, emotional reactions, and sleep quality subscores and rated each from 0 to 100, which provided a percentage of the perceived illness impact.

At each visit, we collected information on caregiving variables (structured questionnaire). On the 4 VAS, caregivers evaluated their current levels (from 0=low to 100=high) of (1) knowledge about Alzheimer's disease, (2) overall stress, (3) self-efficacy for coping with the illness, and (4) the caregivers-PWAD relationship quality.

Web metrics (session length and rate of visits) were collected for each experimental group participant automatically and anonymously. Participants completed a weekly satisfaction questionnaire focused on utility, clarity, and comprehensiveness (5-point Likert scale). They rated from 0 to 100 the applicability and positive emotional impact of each session and reported their opinion of the program (open-ended question). At the end of their participation, we proposed a semistructured interview exploring their opinion of the program.

Concerning the PWAD, we collected at baseline the Mini-Mental State Examination (MMSE) [34] from the medical record and Instrumental Activities of Daily Living (IADL [35]) and the date of symptom onset (reported by the caregiver).

Data Analysis

All available data at baseline were analyzed by intention-to-treat analysis. Descriptive statistics (means and percentages) were calculated for caregivers' and PWAD's characteristics. Moreover, *t* tests (or Mann-Whitney tests) and Spearman or polyserial correlations were used to assess associations between variables. The missing data within each scale were treated according to the recommendations of the literature when available. Otherwise, simple mean imputation was used. The last observation carried forward method was used for participants who dropped out. After checking normality and homoscedasticity of primary outcome (PSS-14), we conducted an analysis of covariance (ANCOVA), controlling for regression to mean phenomenon and effects of potential confounders at baseline on primary outcome. All analyses were conducted using *R* Software for Windows (version 3.0.0).

Interviews and open-ended questions were concurrently analyzed by two trained psychologists (JW and VCL) following the thematic analysis method, using a semantic approach, driven by analytic interests and an essentialist/realist approach [36].

Results

Participants

As summarized in the flowchart (Figure 2), of the caregivers met by the physicians, 129 were prescreened between December 2011 and August 2013. Among them, 40 did not meet inclusion criteria (ie, did not use the Internet, did not accept/know the diagnosis, were not available for 3 assessments at the hospital), 23 were unreachable, and 17 declined. After an 8-month recruitment extension, the main investigators (ASR and VCL) stopped recruitment (in total 20 months) because the rate of inclusions did not exceed 2 persons per month on average.

We randomized 49 participants. Of the 25 participants allocated to the experimental group, 17 (71%) finished the protocol and validated at least 10 of 12 online sessions. Four participants ended their participation in the study without withdrawing consent.

Demographics and other characteristics of participants are summarized in Table 1. At baseline, the groups were imbalanced regarding the number of weekly hours of professional help and IADL and BDI-II scores. The PSS-14 scores were correlated with weekly professional help received (ρ=.33) and BDI-II scores (ρ=.49), whereas the correlation with IADL scores was weak (ρ=–.11).

Table 1. Demographics and key characteristics at baseline by group (N=49).

Characteristics	Experimental group	Control group
Caregivers' characteristics, n	25	24
Caregiver age (years), mean (SD)	64.2 (10.3)	59.0 (12.4)
Female caregiver, n (%)	16 (64)	16 (67)
Children of PWAD,[b] n (%)	16 (64)	13 (54)
High level of education, n (%)	19 (76)	18 (75)
Middle level of education, n (%)	6 (24)	3 (12)
Living with the PWAD, n (%)	12 (48)	10 (41)
Visiting the PWAD daily, n (%)	4 (16)	2 (8)
Visiting the PWAD at least once per week, n (%)	9 (36)	9 (38)
Psychological/ psychiatric treatment, n (%)	3 (12)	2 (8)
Psychotropic treatment, n (%)	6 (24)	7 (29)
Caregivers with at least another source of stress different to caregiving (eg, work, relationship, family), n (%)	18 (72)	14 (56)
Caregivers with ≥1 professional help,[c] n (%)	18 (72)	18 (75)
Weekly hours of professional help,[d] mean (SD)	26.7 (28.7)	8.2 (9.7)
Suffering from a chronic pathology, n (%)	9 (36)	8 (33)
Patients' characteristics, n	25	24
Onset of symptoms (years), mean (SD), range	4.62 (3.53), 0.55-14.05	4.11 (3), 0.39-12.03
MMSE, mean (SD)	18.5 (5.4)	19.0 (4.6)
IADL scale, mean (SD)	0.6 (0.8)	1.1 (1.1)

[a] IADL: Instrumental Activities of Daily Living; MMSE: Mini-Mental State Examination; PWAD: persons with Alzheimer's disease.

[b] Two participants were not children or spouses (1 daughter-in-law and 1 friend).

[c] Professional help=housekeeper, nurse, day care, meal delivery.

[d] Among caregivers receiving respite help.

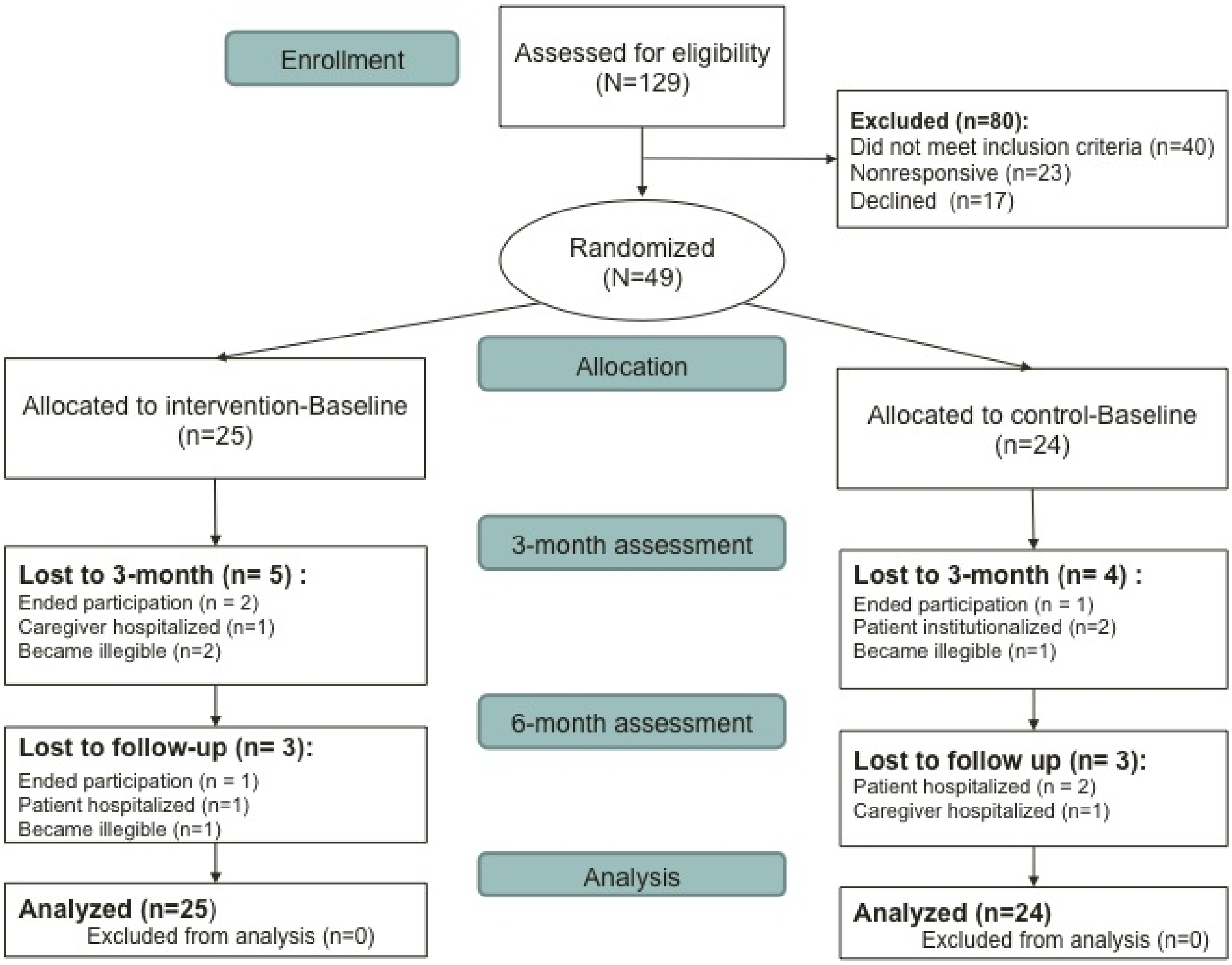


Figure 2. Flowchart of the Diapason pilot randomized controlled trial.

Primary Outcome: Self-Perceived Stress

Mann-Whitney tests did not show significant differences between the experimental and control groups over time (Table 2). We conducted ANCOVA with the PSS-14 at month 3 as dependent variable and the PSS-14 at baseline, group, stratification factors (sex and relationship), and potential confounders at baseline (BDI-II and professional help received) as independent variables. Only the PSS-14 at baseline (*P*<.001) and weekly help received (*P*=.01) were significantly associated with PSS-14 at month 3. Thus, no significant relationship was found with the intervention (*P*=.34). ANCOVA showed similar results when stratification factors were not included.

Table 2. Outcome measures (means and SDs) for assessments at baseline (M0), after intervention (M3), and at 6-month follow-up (M6) per group.

Scales and subscores[a]	Experimental, mean (SD)				Control, mean (SD)				*P* [b]
	M0	M3	M6	Diff[c]	M0	M3	M6	Diff[c]	
PSS-14	24.2 (9.0)	23.7 (9.2)	25.0 (9.9)	–0.5 (8.0)	24.5 (6.7)	23.8 (6.2)	23.8 (6.9)	–0.7 (4.5)	.98
RSCS									
Obtaining respite	55.0 (26.9)	51.7 (29.3)	54.7 (30.6)	–3.3 (18.3)	49.2 (22.4)	48.9 (26.8)	48.6 (24.5)	–0.4 (24.1)	>.99
Responding to patients' behaviors	72.2 (17.0)	69.0 (19.7)	71.5 (23.1)	–3.2 (14.1)	66.3 (18.2)	65.8 (22.7)	68.4 (15.3)	–0.5 (15.5)	.52
Controlling upsetting thoughts	62.6 (21.3)	63.2 (19.7)	63.4 (20.8)	0.5 (17.0)	64.7 (18.1)	66.3 (14.9)	64.0 (13.7)	1.5 (16.1)	.83
RMBPC									
Frequency	1.6 (0.5)	1.8 (0.6)	1.8 (0.6)	0.1 (0.4)	1.5 (0.6)	1.6 (0.6)	1.6 (0.7)	0.0 (0.3)	.72
Reaction	2.2 (0.4)	2.2 (0.6)	2.3 (0.5)	0.0 (0.4)	2.2 (0.6)	2.1 (0.6)	2.1 (0.6)	–0.1 (0.5)	.66
ZBI	38.0 (14.5)	38.3 (14.9)	39.6 (15.7)	0.3 (6.6)	35.0 (15.0)	33.5 (15.3)	34.8 (15.9)	–1.5 (6.1)	.74
BDI-II	11.2 (10.1)	11.5 (9.2)	12.4 (11.6)	0.3 (4.6)	9.0 (7.4)	8.9 (6.5)	8.8 (7.2)	–0.1 (2.7)	.56
NHP									
Social isolation	14.1 (20.4)	15.9 (21.7)	16.5 (23.4)	1.9 (9.7)	12.5 (17.2)	15.5 (19.9)	14.8 (20.7)	3.0 (14.9)	.79
Emotions	20.6 (22.4)	18.6 (18.09)	26.6 (25.6)	–2.1 (16.4)	18.6 (20.3)	19.0 (19.5)	17.2 (19.2)	0.4 (12.9)	.84
Energy	27.9 (39.1)	25.3 (33.6)	35.9 (39.4)	–2.6 (30.6)	26.6 (31.7)	38.5 (38.8)	35.6 (41.6)	11.9 (34.2)	.22
VAS									
Knowledge	45.4 (23.2)	59.2 (25.9)	58.6 (24.4)	13.8 (15.1)	44.5 (23.5)	44.4 (21.6)	51.7 (18.8)	–0.0 (17.4)	.008
Coping	67.4 (15.8)	67.6 (13.3)	67.2 (17.6)	–0.2 (13.8)	61.4 (21.8)	61.4 (15.7)	61.8 (17.5)	0.0 (16.5)	.71
Stress	40.7 (23.0)	48.6 (24.3)	50.6 (23.2)	7.9 (23.8)	50.2 (15.3)	46.7 (16.7)	50.3 (17.0)	–3.5 (16.5)	.05
QR	71.4 (20.5)	73.8 (21.5)	72.7 (17.9)	2.4 (13.5)	72.1 (16.9)	69.0 (23.8)	69.3 (18.0)	–3.0 (19.5)	.36

[a] BDI-II: Beck Depression Inventory-second version; NHP: Nottingham Health Profile; PSS-14: self-perceived stress; QR: quality of relationship between caregiver and the patient; RMBPC: Revised Memory and Behavior Problem Checklist; RSCS: Revised Scale for Caregiving Self-Efficacy; VAS: visual analog scale; ZBI: Zarit Burden Interview.

[b] Comparing means differences (M3 – M0) of experimental and control groups by Mann-Whitney tests.

[c] Means difference (M3 – M0).

Secondary Outcomes

Only the VAS evaluating knowledge of the disease showed significant change at month 3 scored a high effect size (Cohen's *d*=.79, *P*=.008). Indeed, the experimental group scores increased by 13.8 points (SD 15.1), whereas the control group scores decreased by 0.04 points (SD 17.4) (Table 2). However, no significant differences were found between the groups from baseline to month 6.

Only one user reported problems watching the videos (Flashplayer was not installed on computer) and another with little experience using the Internet could not use it unaided. The high scores on the weekly satisfaction questionnaire showed that nearly all participants considered Diapason topics to be useful (95%, 19/20), clear (100%, 20/20), and comprehensive (85%, 17/20). Topics describing strategies to maintain relatives' autonomy and coping skills with the PWAD's behavioral troubles fostered higher levels of positive emotional impact (mean 61.50, SD 22.83 and mean 61.90, SD 26.68, respectively). The most applicable session was focused on coping skills of the PWAD's behavioral troubles (mean 72.25, SD 15.22). In contrast, the session describing caregiving stress factors and protectors received the lowest scores for positive emotional impact (mean 49.25, SD 21.75) and applicability (mean 61.00, SD 17.67).

On average, participants used the website 19.72 times (SD 12.88) and for 262.20 minutes (SD 270.74) during the first 3 months. The most frequently visited section was the forum (mean 24.86 times, SD 40.95), whereas only 10 messages and 10 answers were posted. Four spouses (45%) and 4 daughters (33%) visited the website 26 times or more (third quartile). No significant correlation was found between the PSS-14 score (M3–M0) and frequency (ρ=–.15) or duration (ρ=–.05) using the website. After month 3, connection times were near zero.

Qualitative Analysis

Thematic analysis on the participants' impressions underlined four trends: caregivers without a clear opinion toward the program (5/25, 20%) and those with a clearly positive (3/25, 12%), qualified (11/25, 44%) or negative (6/25, 24%) opinion. These trends were significantly associated to the relationship (Fisher's exact test, *P*=.01). Thus, most wives had a negative opinion, whereas daughters primarily expressed a qualified opinion about the program. Only male caregivers expressed a positive opinion (see Table 3). As shown in Figure 3, reasons varied between caregivers of a single category.

Table 3. Caregivers' profiles and opinions about the Web-based program (N=25).

Demographics	None	Negative	Qualified	Positive
Age, mean (SD)	58.00 (4.24)	66.83 (11.81)	62.45 (9.36)	72.00 (13.45)
Relationship, n				
Wife	1	3	0	0
Husband	1	1	1	2
Daughter	2	2	8	0
Son	1	0	2	1
Total, n (%)	5 (20)	6 (24)	11 (44)	3 (12)

Figure 3. Thematic map of opinions and reasons given by users.

Moreover, we distinguished 4 topics comprising caregivers' opinions (examples in Table 4):

1. "It was useful for me." A few participants reported having benefited from the program. They said it improved their understanding on the disease or changed their initial beliefs about the disease or diagnosis.
2. "It would be better for others." Participants considered the program would be better attuned to the needs of a PWAD in other (earlier or more advanced) stages of the disease than their relatives. Most children thought the overall "message" was more adapted for spouses rather than for them. The contrary was not stated.
3. "I expected something else." Some participants found the content was not in-depth enough. They expected more specific and individualized advice, and more "human interaction" with professionals or peers.
4. "This is not for me." Other participants preferred another kind of intervention (eg, individual therapy, respite, financial support) or reported not feeling a need for help. Others considered the program had come too late or did not believe that someone/something could help them. Most of them ended their participation.

Additionally, many experimental and control group participants reported having used other resources to better understand the disease and adapt their behavior (eg, reading books, asking for help, or contacting associations).

Table 4. Categories and examples of qualitative data.

Topic	Example quote (verbatim)
It was useful for me	Mr. P, husband, 83 y/o: “The topics were highly interesting and useful for me. Advice is clear and helpful for improving communication with my wife”
	Mr. R, son, 51 y/o: “The more I read the more I found it interesting. Sometimes I came back (to the first sessions) and I found that my perception of the topics had changed (...) I’ve understood that my mother behaves like this because of the illness, and her reactions are not against me”
	Mr. L, husband, 80 y/o: “At the beginning I did not feel concerned, I was wrong. Maybe I was in denial. Now I find (in the program) a lot of interesting advice”
The program would be better for others	Mrs. L., daughter, 55y/o: “I did not feel concerned at all, not yet (...) my mother is in the earliest stages”
	Mrs. R, wife, 75 y/o: “This program is not adapted to the current state of my husband, he was diagnosed 7 years ago, I’ve already experienced these situations”
	Mrs. FR, daughter, 55 y/o: “(...) some ideas and solutions are more adapted for spouses or for someone living with the person”
I expected something else	Mrs. L, daughter, 56 y/o: “The content is almost superficial, it lacks more information about books, addresses, events (...)”
	Mrs. R, daughter, 55 y/o: “I wished to know how to accurately behave or react when my mother upsets me, when she repeats the same question”
	Mr. L, husband, 81 y/o: “(Diapason) is too impersonal and “cold,” I tried to use the forum, but I need to look at the person in front of me (...)”
This is not for me	Mr. C, husband, 71 y/o: “I still don’t understand why the doctor said she had Alzheimer’s. For me she is depressed, that is all, this is normal after retirement (...)”
	Mrs. C, daughter, 56 y/o: “I know how to manage my mother, I have acquired some more experience in my professional life (Professor in Economics) The most important is to be organized, I am not stressed (...) the reason why I’ve participated is only to contribute to research”
	Mrs. M, daughter, 60 y/o: “I’ve tried to use the website, but reading how my mother will lose her memory, her abilities is painful for me, (...) I am anxious, I’d preferred a psychotherapy. Finally I am not ready for that (...)”

Discussion

Principal Findings

Statistical analysis did not show significant differences in self-perceived stress (PSS-14) between the groups over time. This result is most likely due to low statistical power. Perceived stress levels remained stable over time in PSS-14 scores although the disease progressed. This stabilization has been observed in control groups from similar studies, suggesting that caregiving stress rarely increases over a period of 3 months [16]. After 6 months, a few experimental group participants had heightened stress levels. This may be due to a raised awareness of their loved one’s diagnosis. Even if it is a major source of stress, being aware of diagnosis might help caregivers to deploy adapted coping strategies (eg, self-regulation, problem-focused coping, positive emotion) [37], whereas those using avoidance-escape strategies (eg, denial of diagnosis) may suffer from more negative long-term consequences (eg, inability to cope with behavioral problems) [38].

As in other studies [13], the experimental group participants’ self-perceived level of disease knowledge was significantly improved between baseline and month 3, with control group participants reaching similar levels at month 6. During the first 3 months, the program may have accelerated the learning process, but the control group may have improved their perception of disease knowledge at month 6 based on their experience and information from other sources (eg, websites, books, professionals/institutions, friends).

During the first 3 months, the program was highly used, in contrast with other studies [39], most likely due to mandatory reading of weekly sessions. Nevertheless, once the program was finished (after 3 months) almost none of the participants used the website, probably due to the stasis of the program’s content. No significant correlation was found between frequency or duration of website use and stress levels (PSS-14).

Qualitative Results

Our qualitative findings are comparable to previous works. Caregivers considered the program could be useful for people other than themselves [11]. They wished to receive personalized support, extensive information, specific assistance, and more communication with professionals and peers [40]. They preferred the topics offering strategies to maintain the PWAD’s autonomy and teaching skills for coping with behavioral problems [41], but were less interested in self-care [7]. Furthermore, specific subgroups of caregivers benefited from the program [42,43]. Some reported having a better perception of the disease or accepted diagnosis after the program [13]. In contrast with other studies [11], the most interested users were male caregivers. Probably linked to their preference for information and skills-centered interventions (such as Diapason) rather than emotional-focused ones [44]. In our study, daughters expressed more qualified opinions about the program compared to female spouses. In our view, because children caregivers are often active workers, they may recognize distance-based interventions as an interesting alternative for them. Moreover, female spouses facing greater caregiving challenges may be less aware of caregiving consequences for themselves [45] and may need more personalized interventions.

Strengths of the Study

To our knowledge, this is the first pilot RCT based on a mixed methods research design evaluating an online program for caregivers of PWAD. By using a mixed method research design, this program follows current methodological trends [46] using qualitative data to complement and contextualize RCT results [18]. Based on literature recommendations [47], Diapason adopted a multicomponent structure combining information and interaction between caregivers. Furthermore, this study met almost all the “best practice” criteria for a RCT (ie, randomization, intention-to-treat analysis, prior sample size calculation, and restriction of analysis to primary outcomes) [9] and controlled the intervention’s implementation errors [48]. Indeed, we paid particular attention to control implementation error. For instance, we controlled the information viewed by the caregiver according to a specific schedule. Additionally, the website content remained static during the study offering the same content to all participants. Finally, in order to avoid bias associated with the hypothetical imbalance of number of messages exchanged with the professional at the beginning and at the end of the protocol (eg, the first participants would not have benefited from discussions published later in the study), professionals only acted as moderators.

Limits and Lessons Learned

In spite of using different strategies, the recruitment for this study was difficult; only 38.0% (49/129) of prescreened caregivers were actually enrolled. These difficulties occur in Internet-based intervention studies [16], suggesting it may be due to caregivers’ attitudes toward these programs [49]. Nevertheless, their reluctance to face-to-face services was also described [49-51]. Thus, further studies about caregivers’ help-seeking behaviors and readiness facilitators or predictors are warranted [52].

Although face-to-face trials allowed the control of bias, isolated caregivers and those living in remote regions could participate more easily if the trials were conducted online only. In any case, replication with larger samples is necessary to complement our results. In addition, due to the heterogeneity of caregiver populations, we advise limiting the number of inclusion criteria [42] and the number of variables measured to reduce analysis bias. Finally, we pointed out the risk of bias owing to nonblinded assessments in this study [53].

This pilot study evaluated the first online version of the Diapason program. Qualitative results revealed little acceptance of the program and high expectations from caregivers. The Diapason program needs to evolve toward dynamic, flexible, and more customizable content based on a structure that favors interaction with professionals and peers, such as online community support [54].

Conclusions

Although a lack of statistical power prevents any definitive conclusions being reached about the efficacy of this program, the mixed research analysis provided us with valuable information for improving content and methods. Caregivers outlined high expectations about the program’s functionalities and showed little acceptance of our program. Dynamism, flexibility, personalization, and socialization appeared as key characteristics expected by caregivers. Overall, further studies about caregivers’ help-seeking behaviors and readiness facilitators or predictors are warranted.

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Conflicts of Interest

Some authors and researchers (VCL, JW, IC, and ASR) were also involved in the development of the Diapason program.

Multimedia Appendix 1

CONSORT-EHEALTH checklist V1.6.2 [55].

[PDF File (Adobe PDF File), 82KB - jmir_v17i5e117_app1.pdf]

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Abbreviations

BDI-II: Beck Depression Inventory-second version
BPSD: behavioral and psychological symptoms of dementia
IADL: Instrumental Activities of Daily Living
MMSE: Mini-Mental State Examination
NHP: Nottingham Health Profile
PSS-14: Perceived Stress Scale
PWAD: persons with Alzheimer’s disease
RCT: randomized controlled trial
RMBPC: Revised Memory and Behavior Problems Checklist
RSCS: Revised Scale for Caregiving Self-Efficacy
VAS: visual analog scales
ZBI: Zarit Burden Interview

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Original Paper

Effectiveness of a Blended Web-Based Intervention on Return to Work for Sick-Listed Employees With Common Mental Disorders: Results of a Cluster Randomized Controlled Trial

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Abstract

Background: Common mental disorders are strongly associated with long-term sickness absence, which has negative consequences for the individual employee’s quality of life and leads to substantial costs for society. It is important to focus on return to work (RTW) during treatment of sick-listed employees with common mental disorders. Factors such as self-efficacy and the intention to resume work despite having symptoms are important in the RTW process. We developed “E-health module embedded in Collaborative Occupational health care” (ECO) as a blended Web-based intervention with 2 parts: an eHealth module (Return@Work) for the employee aimed at changing cognitions of the employee regarding RTW and a decision aid via email supporting the occupational physician with advice regarding treatment and referral options based on monitoring the employee’s progress during treatment.

Objective: This study evaluated the effect of a blended eHealth intervention (ECO) versus care as usual on time to RTW of sick-listed employees with common mental disorders.

Methods: The study was a 2-armed cluster randomized controlled trial. Employees sick-listed between 4 and 26 weeks with common mental disorder symptoms were recruited by their occupational health service or employer. The employees were followed up to 12 months. The primary outcome measures were time to first RTW (partial or full) and time to full RTW. Secondary outcomes were response and remission of the common mental disorder symptoms (self-assessed).

Results: A total of 220 employees were included: 131 participants were randomized to the ECO intervention and 89 to care as usual (CAU). The duration until first RTW differed significantly between the groups. The median duration was 77.0 (IQR 29.0-152.3) days in the CAU group and 50.0 (IQR 20.8-99.0) days in the ECO group (hazard ratio [HR] 1.390, 95% CI 1.034-1.870, *P*=.03). No significant difference was found for duration until full RTW. Treatment response of common mental disorder symptoms did not differ significantly between the groups, but at 9 months after baseline significantly more participants in the ECO group achieved remission than in the CAU group (OR 2.228, 95% CI 1.115-4.453, *P*=.02).

Conclusions: The results of this study showed that in a group of sick-listed employees with common mental disorders, applying the blended eHealth ECO intervention led to faster first RTW and more remission of common mental disorder symptoms than CAU.

Trial Registration: Netherlands Trial Register NTR2108; http://www.trialregister.nl/trialreg/admin/rctview.asp?TC=2108. (Archived by WebCite at http://www.webcitation.org/6YBSnNx3P).

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KEYWORDS

occupational health; randomized controlled trial; mental health; depression; anxiety; sick leave

Introduction

Common Mental Disorders and Sickness Absence

Common mental disorders, such as depression, anxiety, and somatization disorders, are strongly associated with long-term sickness absence [1,2] and have negative consequences for the quality of life of the sick-listed employee. Prolonged sickness absence can lead to social isolation, income reduction, reduction of meaningful activity, and anxiety to return to work (RTW) [3,4]. The longer the duration of sickness absence, the more difficult RTW may become. In addition to the consequences of sickness absence for the individual employee, sickness absence also leads to substantial costs for society. Sickness absence due to common mental disorders leads to one-third of all disability benefits in The Netherlands [5]. Estimated annual costs of sickness absence in The Netherlands due to mental disorders are €2.7 billion [2].

Return to Work

Several studies have shown that a reduction of common mental disorder symptoms was not enough to reduce sickness absence [6,7]. Moreover, interventions focusing on symptoms alone did not have an effect on sickness absence [6-9]. Therefore, it is important to also focus on RTW during treatment of sick-listed employees with common mental disorders. However, in Dutch social security legislation, treatment sickness certification is separated with occupational physicians playing an important role in the guidance of sickness absence while the curative sector provides treatment. Although this legislation was introduced to protect the employee, RTW is hampered as a result due to a lack of collaboration and communication between occupational physicians and the curative sector. Also, RTW is often not addressed in the treatment of sick-listed employees [10,11]. Another study showed that the occupational physicians often neither monitor symptoms nor evaluate the initiated treatment [12]. To overcome these barriers, Van der Feltz et al [13] studied a form of collaboration in which occupational physicians worked together with consultant psychiatrists in the guidance of employees with common mental disorders. Although this form of collaboration did not reveal a statistically significant reduction in the duration of sickness absence until RTW, the results were promising [13]. Vlasveld et al [14] studied the effectiveness of an even more elaborated form of collaboration, namely a collaborative care model. In this model, an occupational physician trained in this model provided the treatment for major depressive disorder and the regular occupational physician provided the guidance in sickness absence. Despite the dual focus on RTW and symptoms, the results of this study showed an improvement of depressive symptoms but not of RTW [14]. These results may reflect implementation problems, which in turn could be explained by the fact that the employees and the occupational physicians felt uncomfortable with the occupational physician in the role of treatment provider, although the occupational physicians had received specialized training [15]. Nevertheless, the dual focus on RTW and the recovery of symptoms remains important and efforts need to be made to improve that dual focus [15]. A better model could be one in which the occupational physician is supported in the referral of the employee to adequate treatment in the curative sector by decision support based on monitoring of common mental disorder symptoms of the employee. This calls for a low-access intervention, such as eHealth, including a decision aid for the occupational physician.

Self-Efficacy

Recent studies have shown the importance of factors such as self-efficacy and the intention to resume work despite having symptoms [16-19]. Return-to-work self-efficacy (RTW-SE) is the belief that employees have in their own ability to meet the demands required to RTW [17]. Several studies have shown that RTW-SE is a predictor of actual RTW [17,18,20]. Van Oostrom et al [16] found that a workplace intervention was effective on lasting RTW only for employees who at baseline intended to RTW while still having symptoms. The results of this study suggest that a negative intention regarding RTW while having symptoms will probably hinder the RTW process and a lack of focus on factors such as RTW-SE in treatment may lead to unnecessary sickness absence. This would have important policy implications if factors such as RTW-SE could be influenced by interventions working on these cognitions.

Web-Based Intervention

To our knowledge, no intervention exists that specifically focuses on advancing RTW and cognitions regarding RTW for sick-listed employees with common mental disorders combined with monitoring of progress in their mental health and a decision aid for the occupational physician [21]. Because there is a need for highly available, low-threshold, low-cost interventions and more than 90% of Dutch households have Internet access, a Web-based intervention was developed [22]. The intervention was named “E-health module embedded in Collaborative Occupational health care” (ECO). The aim of ECO was to guide sick-listed employees with common mental disorders to RTW. The employee follows an eHealth module, known as Return@Work, which focuses on the employees’ cognitions regarding RTW with physical or psychological symptoms and options to resume work at least on a partial basis while symptoms are still present. Also, the recovery process of the employee is monitored in the eHealth module. An integral part of the intervention is that the occupational physician of the sick-listed employee with a common mental disorder receives automated suggestions by email for referral to adequate treatment in the curative sector from a decision aid when the monitoring of symptoms indicates a lack of progress. Progress is monitored in terms of physical and mental well-being and functioning [23].

The aim of the current study was to evaluate the effects of the ECO intervention on time to RTW and mental health outcomes. It was hypothesized that the ECO intervention would lead to a faster RTW and less common mental disorder symptoms than usual care.

Methods

Study Design

Overview

The study was a 2-armed cluster randomized controlled trial. Randomization took place at the level of occupational physician. Employees in both conditions received sickness absence guidance as usual. Employees in the intervention condition received the ECO intervention in addition. The design of this study has been extensively described in Volker et al [23]. The study protocol was approved by the Medical Ethics Committee of the University Medical Center Utrecht, The Netherlands, in February 2011.

Randomization of Clusters

The participants were sick-listed employees in small- to medium-sized companies visiting their occupational physician at Arbo Vitale (a large occupational health service) and sick-listed employees of GGz Breburg (a large mental health service employer) visiting their occupational physician, both in The Netherlands. Cluster randomization took place at the level of the occupational physicians to prevent contamination and thus to prevent dilution of the effect. At Arbo Vitale, occupational physicians working in the same region were clustered to reduce contamination due to occupational physicians who take over each other’s caseloads when necessary. The clusters of occupational physicians were randomized by an independent statistician using a computer algorithm for randomization. Six regions (31 occupational physicians) were allocated to the ECO group and 6 regions (29 occupational physicians) were allocated to the control group.

At GGz Breburg, only 1 occupational physician was available. For this reason, a cluster crossover design was used at first with the first 100 employees approached as the control condition and subsequently the second 100 employees approached as the intervention condition. However, at the end of the planned control condition, the occupational physician was replaced with another occupational physician, with whom the intervention condition was conducted. Therefore, this can be considered as a pseudo-randomization design in GGz Breburg.

Because the occupational physicians had to guide the intervention, they could not be blinded to the group assignment after randomization. However, they participated in only 1 experimental condition: either ECO or care as usual (CAU). The research assistants and the participants were blind to the allocation when assessing the eligibility of sick-listed employees for participating in this study. If the participant met the inclusion criteria for this study and agreed to participate, the baseline questionnaire was sent by email. After the questionnaire was filled out and informed consent was given, the participant was informed by the researchers via telephone about the allocation.

Sample Size

A power calculation prior to the study indicated that a sample size of 200 participants was needed to have at least .80 power to detect differences in time to RTW given a hazard ratio (HR) of 1.6 [23].

Participants

Recruitment Procedure

All employees on sickness absence for any cause between 4 and 26 weeks who gave informed consent were screened for depression (Patient Health Questionnaire 9-item; PHQ-9), somatization (PHQ-15), and anxiety (Generalized Anxiety Disorder 7-item; GAD-7). Employees who were considered as screen-positive on any of the 3 screening instruments were contacted by a research assistant, who was blinded to group assignment, by telephone. The research assistants checked for inclusion and exclusion criteria and provided information about the study.

Sick-listed employees who did not meet any of the exclusion criteria received the baseline questionnaire and a second informed consent form. Employees who completed the baseline questionnaire and gave their informed consent were included in the study.

Inclusion Criteria

Employees (aged ≥18 years) who were on sickness absence between 4 and 26 weeks and screened positive (score ≥10) on either the depression scale of the PHQ-9 and/or the somatization scale of the PHQ-15 and/or the GAD-7 were included. These instruments have shown good psychometric properties for the screening of depression, somatization, and anxiety [24-26].

Exclusion Criteria

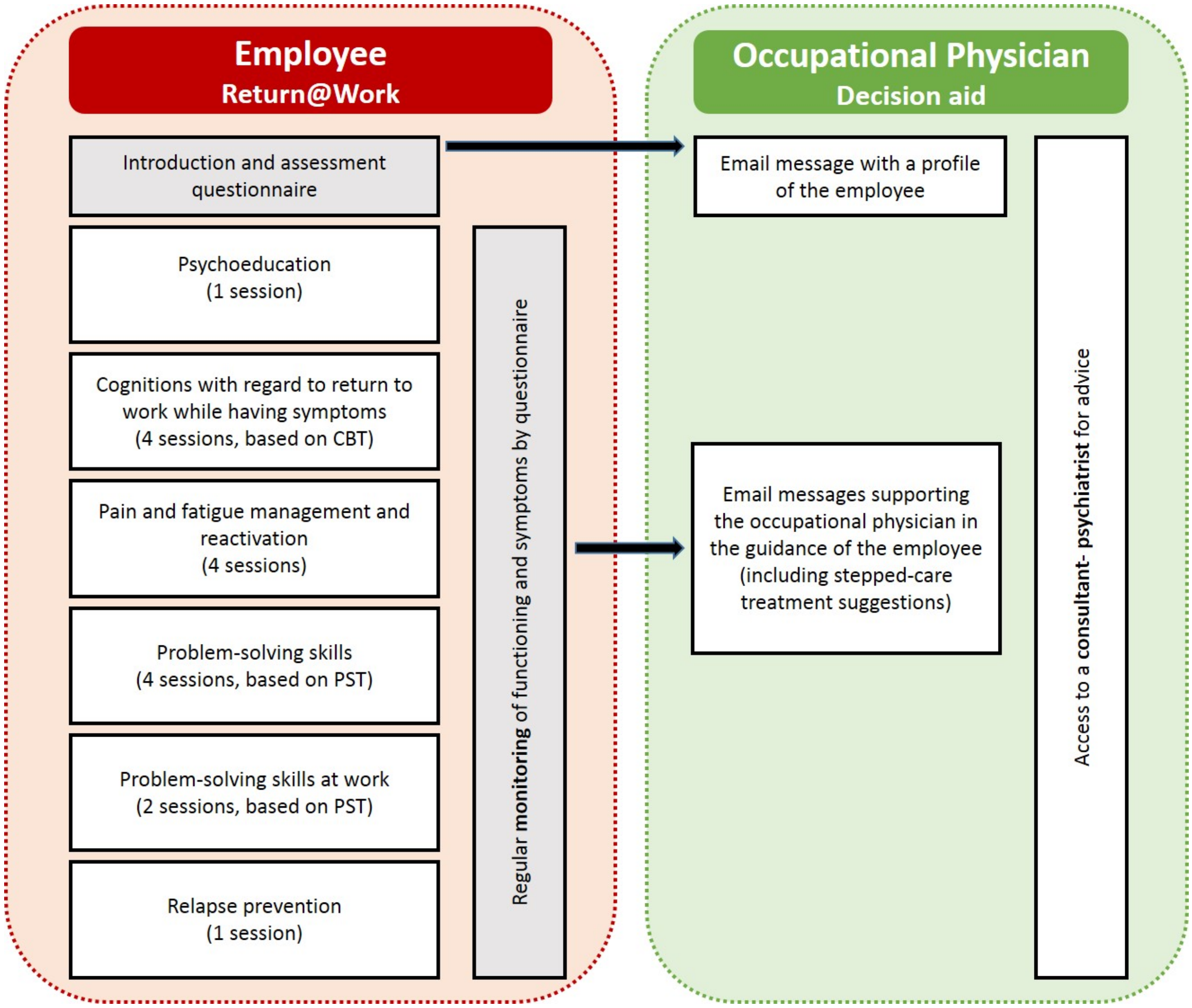
Employees were excluded for participating in this study if they had insufficient knowledge of the Dutch language, were pregnant, or were involved in legal action against their employer. Furthermore, employees without access to the Internet were excluded.

Intervention

ECO

The ECO intervention included 2 elements (an illustration of the ECO intervention can be found in Figure 1): (1) the Return@Work eHealth module and (2) an email decision aid for the occupation physician. Both are described subsequently.

Figure 1. Overview of the ECO intervention.



Return@Work eHealth Module

The employee received an individual log-in code for the eHealth RTW module Return@Work. Return@Work included the following 5 modules: (1) psychoeducation, (2) a module aimed at cognitions with regard to RTW while having symptoms (based on cognitive behavioral therapy [CBT] principles), (3) a module aimed at increasing problem-solving skills with problem-solving treatment (PST) exercises, (4) a module for pain and fatigue management and for reactivation, and (5) a module for relapse prevention. In total, the modules included 16 sessions. The content of Return@Work was tailor-made to the individual employee, depending on the symptoms and cognitions about RTW of the employee. As a consequence, not every employee received all modules; therefore, the total number of sessions ranged from 6 to 17. Furthermore, functioning and symptoms were monitored on a regular basis in Return@Work. A screenshot of Return@Work can be found in Figure 2.

The employees worked through Return@Work individually, but were free to discuss topics or assignments with the occupational physician. The occupational physicians were asked to follow the guidelines of the Dutch Board for Occupational Medicine (NVAB); thus, as in usual sickness guidance, the occupational physician and employee met each other face-to-face on a regular basis [27]. The occupational physicians were instructed to inquire about the employee’s progress in Return@Work during those meetings and to support the employee if necessary [23].

Figure 2. Screenshot of Return@Work.

Return @ Work

SESSIE 1 – Helpende en niet-helpende gedachten

Gebeurtenis -> gedachten -> gevoelens

Vaak ontstaan de gedachten die u over uzelf en de gebeurtenissen die u meegemaakt hebt zo snel dat het lijkt alsof deze gedachten 'automatisch' opkomen in uw hoofd. Doordat dit proces zo snel verloopt is het erg moeilijk om deze gedachten te herkennen. Soms lijkt het alsof een gebeurtenis direct een gevoel veroorzaakt. Hoe gebeurtenissen, gedachten en gevoelens met elkaar samenhangen wordt hieronder uitgelegd.

Een voorbeeld:

Willem voelt zich ellendig. Sinds hij zich op zijn werk heeft ziekgemeld, heeft hij geen enkel telefoontje van zijn collega's gehad. Hij voelt zich verschrikkelijk eenzaam en somber. Hij belt echter zelf ook niemand op. Hij wéét immers dat zijn collega's het met hem gehad hebben!

In de beleving van Willem wordt zijn eenzame gevoel dus direct veroorzaakt door het feit dat zijn collega's hem niet bellen. Onderstaand figuur geeft dat weer:

Toch kan een gebeurtenis nooit *direct* een gevoel veroorzaken. Het zijn de gedachten die u heeft over wat er gebeurt, die uw gevoelens bepalen.

Als Willem stilstaat bij zijn gevoel, ontdekt hij dat hij verschillende gedachten over de situatie heeft. Hij is ervan overtuigd dat

Email Decision Aid for the Occupational Physician

Furthermore, the occupational physicians received automated email messages that were based on a decision aid with principles of stepped collaborative care. The decision aid supported the occupational physicians in the sickness guidance of the employees, in the monitoring of symptoms, functioning, and RTW. The outcomes of the monitor in Return@Work were used in the fully automated email messages for the occupational physician to give advice for stepped care treatment. Furthermore, the decision aid gave the occupational physician access to a consultant psychiatrist who, when needed, gave advice in case of stagnation [23].

Training

The occupational physicians in the intervention group were trained by the researchers and a consultant psychiatrist before recruitment of participants began. The training lasted half a day. In the training, occupational physicians were taught about the background and content of Return@Work and were instructed on how to guide employees through Return@Work and how to work with the decision aid. They were taught the basic principles of PST and CBT and how to apply these principles in the guidance of the employee.

Care as Usual

The occupational physicians in the control group provided usual sickness guidance to their employees. CAU was protocoled according to the guidelines of the NVAB [27]. However, several studies showed that adherence to this guideline was minimal [28,29]. For the process evaluation, actual provided care was assessed with a questionnaire by the participants in both groups.

Outcomes

Overview

Data were collected by the research staff of The Netherlands Institute of Mental Health and Addiction. Participants completed online self-report questionnaires at baseline (T0) and at 3 (T1), 6 (T2), 9 (T3), and 12 months (T4) after inclusion. Data about RTW were derived from the registers of the occupational health service (Arbo Vitale) or employer (GGzBreburg).

Primary Outcome Measure

The primary outcome measure was duration until first RTW defined as the duration of sickness absence in calendar days from the day of randomization until the moment of first partial or full RTW. Subsequently, full RTW was analyzed. In accordance with the Dutch Sickness Benefits legislation, sickness absence within 4 weeks of full RTW was considered as belonging to the initial period of sickness absence. Furthermore, the total number of days of sickness absence in the first year follow-up period was tracked.

Secondary Outcome Measures

Secondary outcome measures were the severity of depression, anxiety, and somatization symptoms as measured with the PHQ-9, GAD-7, and PHQ-15 in terms of response and remission. Response was defined as a 50% reduction in symptoms on the PHQ-9, GAD-7, or PHQ-15, with the restriction that the baseline score on the questionnaire on which response was evaluated was above the cut-off point of 10 (otherwise it was defined as no response). Remission was defined as a score lower than 5 on the PHQ-9, GAD-7, or PHQ-15, with the restriction that the baseline score on the questionnaire on which remission was evaluated was above the cut-off point of 10 [24-26].

Covariates

All relevant covariates were measured at baseline. Demographic data such as age, gender, marital status, education level, and nationality were collected. Comorbid chronic medical illness was measured using a 28-item questionnaire developed by Statistics Netherlands. Job characteristics were measured by the Job Content Questionnaire (JCQ) [30]. Intention to RTW despite the existence of symptoms was measured on a 5-point Likert scale, with a response category varying from 1=certainly to 5=certainly not.

Process Outcomes

The actual health care utilization in both groups was assessed with the Trimbos/iMTA questionnaire for Costs associated with Psychiatric illness (TiC-P) [31]. The participants in the ECO condition received additional questions about the use of the intervention at the 3-month questionnaire. Furthermore, we recorded the number of log-ins per participant, the number of modules of the Return@Work intervention that they started, and the number of times the psychiatrist was consulted by the occupational physicians to assess adherence to the intervention.

Data Analysis

All analyses were conducted according to the intention-to-treat principle. Baseline measurements of the participants were compared between the CAU and ECO condition using chi-square tests and independent samples *t* tests. The analyses of the primary outcomes, time to partial and full RTW, were performed with Kaplan-Meier time-to-event curves and Cox proportional hazards models. The shared-frailty procedure was used to account for clustering in the Cox proportional hazard models [32]. The Mann-Whitney *U* test was used to test the between-group difference in the average total number of sickness absence days during the 1-year follow-up.

Potential effect modification by severity of depression (PHQ-9), somatization (PHQ-15), and anxiety (GAD-7) at baseline as well as modification by company (Arbovitale and GGz Breburg) and intention to RTW in the presence of common mental disorder symptoms were evaluated. Interactions were tested for significance at the 5% significance level. Furthermore, a test of the proportional hazard assumption was conducted.

The analyses of the secondary outcomes were performed using multilevel logistic regression analysis with 3 levels: level of occupational physicians, level of employees within the cluster of occupational physicians, and level of number of measurements within the employees. First, the estimates of the intraclass correlation coefficients (ICCs) using the random intercept logistic-normal was assessed [33,34]. Then, the analysis of the outcomes was performed. For all analyses, all statistical tests were computed at the 5% significance level.

Per-protocol analyses were performed on the primary outcomes. In these analyses, the participants in the ECO condition who finished at least the introduction session of Return@Work were compared with the CAU participants.

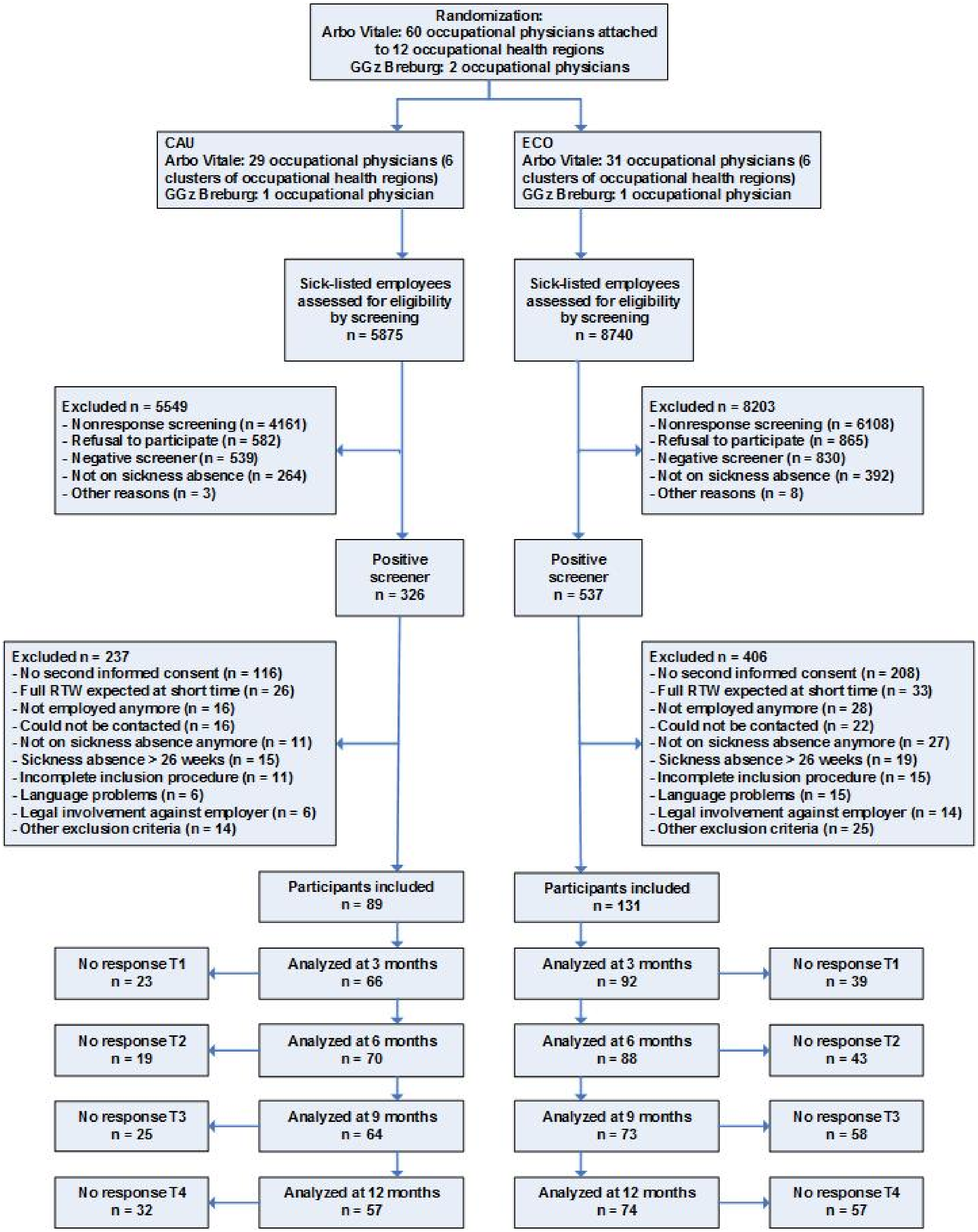
The R package survival was used to test for clustering in the Cox regression analyses. The multilevel logistic regression analyses were performed in LME4 package of R [35]. All other analyses were performed in SPSS version 22.0 (IBM Corp, Armonk, NY, USA).

Results

Recruitment of Participants

In total, 14,615 all-cause sick-listed employees were approached between July 2011 and January 2013. Of this total group, 2232 of 14,615 employees (15.27%) participated in the screening. Of all 2232 screened participants, 863 (38.66%) positively screened for depression, somatization, or anxiety. Due to various reasons, 643 employees were excluded (see Figure 3). Finally, 220 employees who met all inclusion criteria were included in the study: 131 employees in the intervention condition and 89 employees in the control condition. The number of employees in the intervention and control condition were unequal due to the cluster randomization. Of all participants, 210 employees were included by the occupational health service (Arbo Vitale) and 10 employees by their employer (GGz Breburg). Figure 3 shows an overview of the recruitment flow.

Figure 3. Flowchart of the clusters and participants.



Loss to Follow-Up

Data about RTW were obtained from the registers of the OHS or employer. Sickness absence data were available for 86 employees in the control condition and for 130 employees in the intervention condition. For unknown reasons, the sickness absence data of 4 participants could not be found in the registers. These 4 participants did not differ significantly on average at baseline on sickness absence duration, depressive, somatization, or anxiety symptoms from the other participants.

For the self-reported secondary outcomes, follow-up questionnaires were returned by 158 of 220 participants (71.8%) at 3 months, 158 participants (71.8%) at 6 months, 137 participants (62.3%) at 9 months, and 131 participants (59.5%) at 12 months. At 9 months, the loss to follow-up rate was significantly higher in the ECO condition (44.3%, 58/131) than in the CAU condition (28%, 25/89, *P*=.02). However, the participants who did return the questionnaire at 9 months did not differ significantly at baseline on sickness absence duration, depression, somatization, or anxiety symptoms from the participants who did not return the questionnaire. This was the case in the ECO condition and in the control condition. From these results, we concluded that there was no evidence for selective dropout in this study.

Baseline Characteristics

Table 1 shows a summary of the baseline characteristics of the participating employees. None of the baseline characteristics differed significantly between the intervention (ECO) and control (CAU) condition. This suggests that the randomization was successful.

As shown in Table 1, approximately half of the participants scored positive (≥10) on depression and somatization and anxiety symptoms (54%, 48/89 in the CAU group and 49.6%, 65/131 in the ECO group). Only 18.2% (40/220) of the participants scored positive on depressive, somatization, or anxiety symptoms alone (17%, 15/89 in the CAU group and 19.1%, 25/131 in the ECO group).

Table 1. Baseline characteristics of the participants in the care as usual (CAU) control and the ECO intervention groups (N=220).

Baseline characteristics	CAU (n=89)	ECO (n=131)	*P*
Demographics			
Age (years), mean (SD)	45.5 (10.7)	43.4 (9.5)	.14
Gender (female), n (%)	53 (60)	77 (58.8)	.91
Married / living together, n (%)	62 (70)	91 (69.5)	.98
Educational level, n (%)			.96
Low	32 (36)	48 (36.6)	
Average	31 (35)	47 (35.9)	
High	26 (29)	36 (27.5)	
Dutch nationality, n (%)	88 (99)	127 (96.9)	.65
Symptoms and conditions			
Common mental disorders symptoms, n (%)			
Only depressive symptoms (PHQ-9 ≥10)	5 (6)	11 (8.4)	.44
Only somatization symptoms (PHQ-15 ≥10)	7 (8)	8 (6.1)	.61
Only anxiety symptoms (GAD-7 ≥10)	3 (3)	6 (4.6)	.74
Depressive and somatization symptoms	12 (14)	16 (12.2)	.78
Depressive and anxiety symptoms	8 (9)	16 (12.2)	.45
Somatization and anxiety symptoms	6 (7)	9 (6.9)	.97
Depression, somatization and anxiety symptoms	48 (54)	65 (49.6)	.53
Number of chronic medical conditions, mean (SD)	2.4 (3.0)	1.9 (1.7)	.10
Job characteristics (JCQ), mean (SD)			
Decision latitude (range 24-96)	68.2 (10.6)	68.6 (12.3)	.81
Psychological job demands (range 12-48)	33.4 (6.2)	34.6 (6.5)	.15
Physical job demands (range 5-20)	10.9 (3.4)	11.6 (3.9)	.21
Social support (range 8-32)	21.6 (4.2)	21.3 (4.0)	.61
Job insecurity (range 3-12)	8.1 (0.8)	8.1 (0.9)	.97
Sickness absence			
Duration at baseline in days, median (IQR)	70.0 (55.5-106.5)	73.0 (56.0-110.0)	.87
Partial sickness absence at baseline, n (%)	27 (30)	36 (27.5)	.61
Intention to RTW despite symptoms (range 1-5), mean (SD)	2.7 (1.3)	2.8 (1.2)	.53

Primary Outcome

Overview

The shared-frailty procedure was used to account for clustering in the Cox proportional hazard models. The results, however, showed that there was no evidence of a clustering effect at the level of occupational physician regions (*P*=.92).

Figure 4 shows the Kaplan-Meier curves for the time until first RTW (partial or full) for both groups. Within the 1-year follow-up, 84% (72/86) of the CAU participants and 87.7% (114/130) of the ECO participants had achieved partial or full RTW. The median duration from baseline until first RTW (partial or full) was 77.0 days (IQR 29.0-152.3) in the CAU group and 50.0 days (IQR 20.8-99.0) in the ECO group (mean 99.0, SD 78.8 days and mean 72.5, SD 71.1 days, respectively). In total, 14 participants were censored because they resigned, 6 participants from the CAU group and 8 participants from the ECO group.

Figure 5 shows the Kaplan-Meier curves for the time to full RTW. In all, 61% (52/86) of CAU participants and 67.7% (88/130) of the ECO participants achieved full RTW within the 1-year follow-up. The median duration from baseline to full RTW was 178.0 days (IQR 72.0-243.3) in the CAU group and 131.0 days (IQR 68.5-198.0) in the ECO group (mean 164.8, SD 93.4 days and mean 146.3, SD 91.2 days, respectively).

The results of the Cox regression analysis on first RTW showed a significant effect of ECO intervention compared with usual care (HR 1.390, 95% CI 1.034-1.870, *P*=.03). The results of the Cox regression analysis on full RTW showed that the groups did not differ significantly from each other in duration until full lasting RTW (HR 1.287, 95% CI 0.913-1.814, *P*=.15). Because no differences were found between the CAU and ECO group for baseline characteristics, the Cox regression models were not adjusted for possible covariates.

To check whether the proportional hazard assumption was violated in the Cox regression analyses, log-minus-log plots were conducted. The log-minus-log plot for time to first RTW showed that the proportional hazard assumption was not violated. The log-minus-log curves of the CAU and ECO group for the time to full RTW crossed at approximately 40 days. Therefore, a Cox regression with time-dependent covariate was conducted. The time-dependent covariate was not significant (*P*=.26), indicating that the proportional hazard assumption for time to full RTW was also not violated.

The median total number of sickness absence days in the 1-year follow-up period was 228.0 days (IQR 111.0-365.0) in the CAU group and 174.0 days (IQR 100.0-321.0) in the ECO group (Mann-Whitney test; *P*=.10), and did not differ significantly between both groups (mean total number of sickness absence days was 225.3, SD 118.1 and mean 198.3, SD 116.0 days, respectively).

Figure 4. Kaplan-Meier curve of time to first partial or full return to work (RTW).

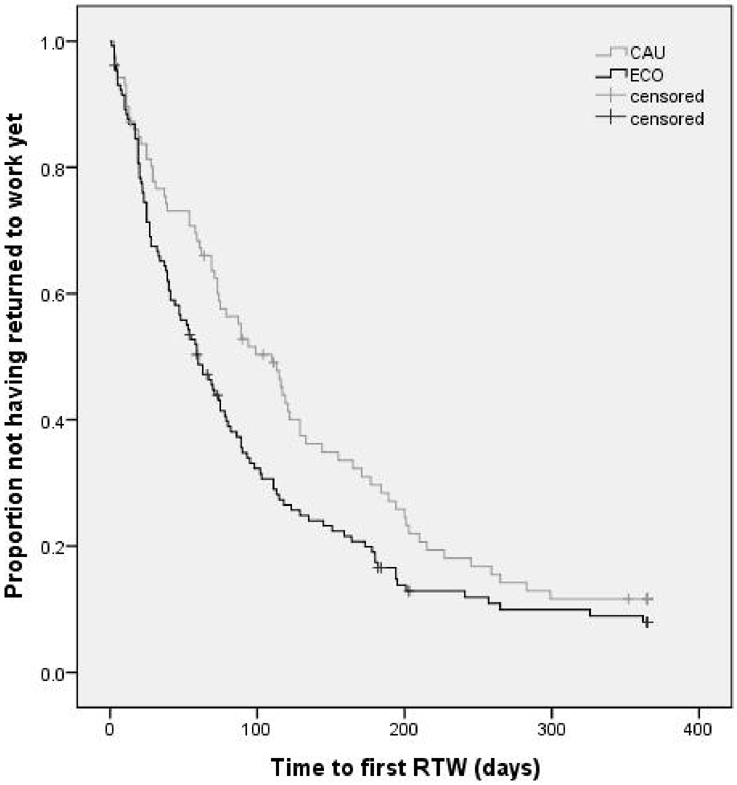
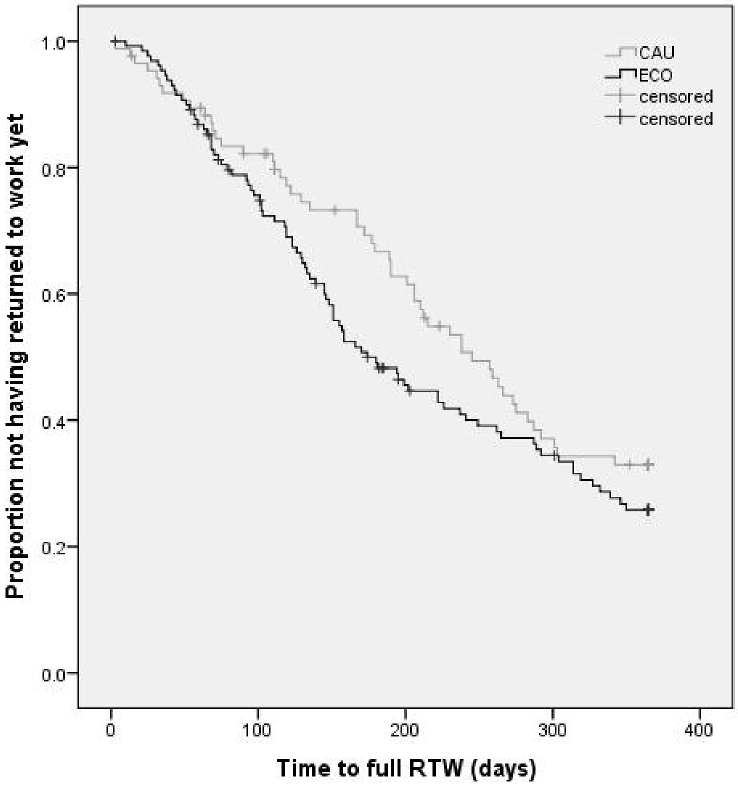


Figure 5. Kaplan-Meier curve of time to full return to work (RTW).



Effect Modification Primary Outcome

Having a depression (score ≥10 on the PHQ-9), somatization (score ≥10 on the PHQ-15), or anxiety disorder (score ≥10 on the GAD-7) at baseline were added separately as potential effect modifiers in the Cox proportional hazard model for first RTW and in the model for full RTW. No significant interaction effects were found.

Furthermore, the company (Arbo Vitale or GGz Breburg) and the intention to RTW despite having symptoms were added as potential effect modifiers in the Cox proportional hazard model for first RTW and in the model for full RTW. Again, no significant interaction effects were found.

Secondary Outcomes

Table 2 shows the estimates of the ICCs using the random intercept logistic-normal model [33,34]. All ICCs were very close to zero. The largest ICC was found for response at 6 months, indicating that clusters explained 4.5% of the variance at most in the log odds-transformed outcome measures. Even though the ICC estimates suggested that the cluster effects were minor, we nevertheless used the random intercept logistic-normal model for estimating the effect of the treatment on the secondary outcomes to avoid inflated type I error rates.

Table 2. Estimated intraclass correlation coefficients (ICCs) for remission and response for each measurement occasion.[a]

Follow-up	Remission	Response
3 months	.007	.000
6 months	.000	.045
9 months	.000	.010
12 months	.038	.000

[a] Intraclass correlations based on random intercept multilevel model [33].

Table 3 shows the percentage of employees in both groups who achieved remission and/or response. No significant differences between ECO and CAU were found for response. For remission, a significant difference was found at 9 months (T3) after baseline with the ECO group having a larger proportion achieving remission than the control group (OR 2.228, 95% CI 1.115-4.453, *P*=.02).

Table 3. Results on remission and response for both groups.

Follow-up	Remission				Response			
	CAU, n (%)	ECO, n (%)	OR[a] (95% CI)	*P*	CAU, n (%)	ECO, n (%)	OR[a] (95% CI)	*P*
3 months	16 (24)	25 (28)	1.180 (0.543-2.562)	.68	33 (50)	44 (49)	0.957 (0.507-1.806)	.89
6 months	20 (29)	36 (41)	1.731 (0.885-3.384)	.11	39 (56)	58 (66)	1.611 (0.694-3.742)	.27
9 months	23 (37)	41 (56)	2.228 (1.115-4.453)	.02	35 (56)	51 (70)	1.874 (0.879-3.996)	.12
12 months	25 (45)	36 (49)	1.157 (0.492-2.719)	.74	37 (66)	52 (70)	1.214 (0.576-2.556)	.61

[a] Reference group is CAU.

Process Outcomes

Health Care Utilization

Table 4 presents the proportion of participants in the CAU and ECO conditions that had contact with different health care professionals during the follow-up year. Generally, care in both groups consisted of contact with the occupational physician, general practitioner, and a mental health professional. There were no significant differences in health care use between the CAU and ECO participants.

Table 4. Health care utilization within 12 months after baseline.

Health care	CAU, n (%) (n=66)	ECO, n (%) (n=91)	*P*
Contact with occupational physician	61 (92)	81 (89)	.47
Contact with general practitioner	59 (89)	75 (82)	.22
Contact with mental health professional	51 (77)	63 (69)	.27
Day treatment for mental health problems	4 (6)	8 (9)	.53
Contact with social worker	6 (9)	6 (7)	.56
Participation in a self-help group	3 (5)	5 (6)	>.99

Adherence to the ECO Intervention

Of the 131 participants in the intervention group, 31 participants (23.7%) never logged in at Return@Work. Of the 100 participants who did log in at Return@Work, 10.0% (10/100) did not finish the introduction (which included information about Return@Work and a questionnaire). The mean number of total log-ins of the 90 participants who finished the introduction and actually started Return@Work was 7.8 (SD 6.1). Furthermore, 40% (36/90) of the participants minimally completed half of the modules of Return@Work.

For the 3-month questionnaire, 69 participants in the ECO condition answered additional questions about their experiences with Return@Work. Of these, 29% (20/69) reported that they discussed Return@Work with their occupational physician, initiated by themselves or their occupational physician. Furthermore, 15% (10/69) of the participants stated that Return@Work did not fit with their situation/problems, 61% (42/69) stated that Return@Work somewhat fit, and 24% (17/69) stated that Return@Work fit (quite) well. The psychiatrist was consulted only once by the occupational physicians.

Per-Protocol Analyses

In the per-protocol analyses, the analyses on the primary outcomes were repeated, comparing the participants in the ECO condition who finished the introduction of Return@Work (n=90) with the CAU participants (n=89). The results of the per-protocol analyses did not differ from the results of the intention-to-treat analyses. The ECO participants who finished the introduction of Return@Work differed significantly from the CAU participants in duration until first RTW (HR 1.447, 95% CI 1.051-1.991; B=.369, SE=0.163; *P*=.02); however, they did not differ significantly from the CAU participants in duration until full RTW (HR 1.370, 95% CI 0.951-1.974; B=.315, SE=0.186; *P*=.09).

Discussion

Interpretation and Comparison With Other Studies

This study showed a positive effect of the ECO intervention on the duration until first RTW. On average, the participants in the ECO group returned to work (either partial or full) 27 days earlier than the participants in the control group receiving CAU did. Because eHealth focuses on the importance of RTW and on the employees' perceptions regarding RTW with symptoms, we expected that the intervention would lead to a faster first RTW than CAU. However, we also expected that the partial RTW would lead to full RTW. On average, the participants in the ECO condition achieved full RTW 47 days earlier than the participants in the control condition, but this difference was not significant at the 5% level (2-tailed test). It may be that to reliably assess the effect on full RTW, larger comparison groups or a longer follow-up would be needed. However, another explanation may be that full RTW did not differ significantly between the 2 groups because the intervention primarily focused on enhancing partial RTW in a patient group that is known from the literature to have long-term full sickness absence and low full RTW. Time lag for RTW in patients with depression in remission has been found to be at least a year in general [36]. Maybe, in order to attain faster full RTW, the intervention should be longer and more explicitly focus on full RTW.

Additionally, Hees et al [37] examined the perspectives of some key stakeholders regarding the definition of successful RTW outcome after sickness absence due to common mental disorders. One of the results of this study was that the stakeholders did not necessarily consider full RTW as a prerequisite for successful RTW, but instead regarded a subjective criterion (ie, consensus between supervisor and employee) as more important for successful RTW [37]. Partial RTW could even be a long-term solution of employees with reduced work ability [38]. Because of the relatively long sickness duration of the participants at the start of our study, this could be the case in this study. Unfortunately, it is unknown whether partial RTW was a satisfactory outcome for all parties concerned.

The intervention was not intended to be a treatment for common mental disorders, but we expected that the feedback and support that the occupational physicians received from the decision aid would lead to a reduction of common mental disorder symptoms for the sick-listed employees. Also, a faster RTW might have a positive effect on the recovery from symptoms. For remission, at 9 months after baseline a significant difference was found between the 2 groups in favor of the ECO intervention. However, no effect was found on treatment response and the effect on remission did not persist through 12 months after baseline. This might be explained by the low adherence of the occupational physicians to the intervention. The eHealth module for the employee, Return@Work, was meant to be blended. The occupational physicians were instructed to inquire about the employee’s progress in Return@Work at the regular consults. However, the process outcomes showed that only 29% of the employees reported that they discussed the intervention with the occupational physician. Another signal of low adherence by the occupational physicians was the fact that only 1 occupational physician contacted the consultant psychiatrist during this study. It is unknown why the occupational physicians did not consult the psychiatrist more often. Another component of the ECO intervention was the decision aid. The decision aid supported the occupational physicians in the monitoring of symptoms, functioning, and RTW, and gave advice for stepped care treatment and referral to the curative sector. Unfortunately, it is unknown if the occupational physicians did adhere to the email messages from the decision aid. But the fact that the process outcomes showed that there were no differences in health care use between the ECO and CAU groups is an indication that the intervention did not lead to more referrals.

Strengths and Limitations

This study discussed an innovative approach to reduce sickness absence because of its combination of an eHealth intervention aimed at RTW for sick-listed employees with a decision aid via email and the possibility of consulting a psychiatrist for the occupational physicians. However, the study design made it difficult to make inferences about the effectiveness of the different components of the intervention. However, there were several (mentioned previously) signals that the occupational physicians did not adhere to the intervention very well; therefore, it could be expected that the significant differences were mostly due to the Return@Work eHealth module.

The possible limited adherence of the occupational physician to the intervention could be caused by the design of this study. The participants were recruited by the researchers and the occupational physician was not informed (because of ethical reasons) about the participation of the employee until the employee started the eHealth module. The occupational physicians were informed by email and it is possible that they sometimes missed this notification. Furthermore, due to a reorganization by Arbo Vitale during this study, some of the sick-listed employees were not guided by 1 occupational physician, but by several occupational physicians. This was not helpful for the adherence of the occupational physicians to the ECO intervention.

Another limitation was that a relatively high proportion of the participants did not return 1 or more of the follow-up questionnaires. At 9 months, the loss to follow-up rate was significantly higher in the ECO condition than the CAU condition. Also at 9 months, significantly more participants in the ECO condition achieved remission than in the control condition. It might be the case that many participants who did not fill out the questionnaire at 9 months were not recovered, but it was also possible that the recovered participants did not feel the urge to fill out the questionnaires anymore. However, at baseline there were no differences between the participants who did or did not fill out the questionnaire at 9 months. Thus, no indications for selective dropout could be found in this study.

Furthermore, to achieve a successful RTW, it is important that all relevant stakeholders facilitate RTW [39]. A limitation of the ECO intervention was that the employers have no active role in the intervention. The cognitions that employees have about not being able to resume work while having symptoms is a cognition that employers/managers could also have. This could be one of the reasons why there was no effect of the ECO intervention on full RTW.

Generalizability

A rather large population was screened for eligibility for participation in this study (N=14,615). From this population, 10,269 employees did not respond to screening, which might limit the generalizability of the findings of this study. It is unknown for what reasons employees did not respond. However, the employees who received a screener were on sickness absence for any cause and the focus of the study was explained as being on psychiatric symptoms, so it is possible that a large proportion of the nonresponders did not respond because they did not fit the description of the study. Also, it is possible that they may not have been on sickness absence anymore.

The participants in this study were mainly sick-listed employees of Dutch nationality, working in small- to medium-sized companies whose employer had insurance for the costs of sickness absence and sickness guidance. There is no indication that these employees would react differently to the intervention than employees from, for example, large companies. However, the organization of the sickness guidance in the company might have an effect on the ECO intervention. In this study, the sick-listed employees were not always guided by the same occupational physician. It might be the case that in larger companies where 1 occupational physician gives guidance to all sick-listed employees, the ECO intervention would be better guided by the sole occupational physician than the multiple occupational physicians did in this study. Continuity and accessibility of the occupational physician are important aspects for successful implementation of the ECO intervention.

Conclusions

To our knowledge, this is the first study to combine an (eHealth) intervention specifically focused on RTW and cognitions regarding RTW while still having symptoms for sick-listed employees with common mental disorders with a decision aid for the occupational physician. It is promising that even though the adherence of the occupational physician to the ECO intervention was not optimal, ECO led to a faster first RTW and more remission of common mental disorder symptoms. This suggests that the potential of the ECO intervention might be better exploited with better continuity in and adherence of occupational physicians. Future research on optimizing the benefits of the ECO intervention should focus on improving the involvement of the occupational physician throughout the intervention, involving the employer/manager of the sick-listed employee, and monitoring the adherence of the occupational physicians to the decision aid.

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Conflicts of Interest

D Volker, Dr MC Zijlstra-Vlasveld, and Prof Dr CM van der Feltz-Cornelis reported that their employer (Trimbos-institute) received grants from ZonMw and grants from Achmea SZ when conducting this study. Prof Dr CM van der Feltz-Cornelis reported grants from Eli Lilly outside the submitted work. Prof Dr JR Anema reported being a chair in Insurance Medicine paid by the Dutch Social Security Agency and is a stockholder of Evalua LTD. Dr ATF Beekman reported grants from Eli Lilly, grants from Astra Zeneca, grants from Jansen, grants from Shire, personal fees from Eli Lilly, and personal fees from Lundbeck when conducting this study. Dr EPM Brouwers, Dr WHM Emons, and Dr AGC van Lomwel had nothing to disclose.

Multimedia Appendix 1

CONSORT-EHEALTH checklist V1.6.2 [40].

[PDF File (Adobe PDF File), 75KB - jmir_v17i5e116_app1.pdf]

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Abbreviations

CAU: care as usual
CBT: cognitive behavioral therapy
ECO: E-health module embedded in Collaborative Occupational health care
HR: hazard ratio
ICC: intraclass correlation coefficient
JCQ: Job Content Questionnaire
PST: problem-solving treatment
RTW: return to work
RTW-SE: return-to-work self-efficacy

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Original Paper

Integrating mHealth in Oncology: Experience in the Province of Trento

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Abstract

Background: The potential benefits of the introduction of electronic and mobile health (mHealth) information technologies, to support the safe delivery of intravenous chemotherapy or oral anticancer therapies, could be exponential in the context of a highly integrated computerized system.

Objective: Here we describe a safe therapy mobile (STM) system for the safe delivery of intravenous chemotherapy, and a home monitoring system for monitoring and managing toxicity and improving adherence in patients receiving oral anticancer therapies at home.

Methods: The STM system is fully integrated with the electronic oncological patient record. After the prescription of chemotherapy, specific barcodes are automatically associated with the patient and each drug, and a bedside barcode reader checks the patient, nurse, infusion bag, and drug sequence in order to trace the entire administration process, which is then entered in the patient's record. The usability and acceptability of the system was investigated by means of a modified questionnaire administered to nurses. The home monitoring system consists of a mobile phone or tablet diary app, which allows patients to record their state of health, the medications taken, their side effects, and a Web dashboard that allows health professionals to check the patient data and monitor toxicity and treatment adherence. A built-in rule-based alarm module notifies health care professionals of critical conditions. Initially developed for chronic patients, the system has been subsequently customized in order to monitor home treatments with capecitabine or sunitinib in cancer patients (Onco-TreC).

Results: The STM system never failed to match the patient/nurse/drug sequence association correctly, and proved to be accurate and reliable in tracing and recording the entire administration process. The questionnaires revealed that the users were generally satisfied and had a positive perception of the system's usefulness and ease of use, and the quality of their working lives. The pilot studies with the home monitoring system with 43 chronic patients have shown that the approach is reliable and useful for clinicians and patients, but it is also necessary to pay attention to the expectations that mHealth solutions may raise in users. The Onco-TreC version has been successfully laboratory tested, and is now ready for validation.

Conclusions: The STM and Onco-TreC systems are fully integrated with our complex and composite information system, which guarantees privacy, security, interoperability, and real-time communications between patients and health professionals. They need to be validated in order to confirm their positive contribution to the safer administration of anticancer drugs.

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KEYWORDS

health informatics; mobile health; home monitoring; supportive care; patient safety; safe chemotherapy

Introduction

Delivering effective and safe treatment is one of the main challenges facing health professionals, and this is particularly important in medical oncology because chemotherapy and target therapies are generally characterized by complex regimens, a high degree of toxicity rates, and a narrow therapeutic window [1]. The process of prescribing, preparing, and administering current chemotherapy treatments is complex, and prescription and administration errors are still common: 7% in the case of adult chemotherapy to 19% in a pediatric setting, and fewer than 2% of these errors are intercepted at the patient bedside [2-4].

The development of new technologies, a safety culture, and evolving workflows have been widely reported, and have been shown to have the potential for reducing medication errors in various health care settings [5]. The information technologies (ITs) introduced over the past 20 years have facilitated patient management, improved the safety and precision of administering cancer treatments safer, and increased the efficiency of the process of ordering, preparing, and administering antineoplastic drugs [5,6]. The use of electronic patient records (EPRs), clinical decision support systems (CDSS), computerized prescriber order entry (CPOE), barcode-assisted medication administration (BCMA) systems, intravenous infusion safety systems (smart pumps), electronic medication administration records (eMARs), and telepharmacy have all been extensively described [5-8] and, although evidence supporting their use in preventing medication errors is limited (particularly in oncology), their potential benefits could become exponential if incorporated in an integrated technological system [5]. This has been highlighted by the Institute of Medicine (IOM), which has recently defined electronic medical record (EMR) systems in which clinical information, decision support tools, and CPOE are closely integrated: “a vital piece of the health information system needed to improve cancer care” [9].

CPOE is the only technology that has been demonstrated to contribute to reducing medication errors in oncology [8,10-14], and is therefore being increasingly used in the case of anti-neoplastic drugs. This has prompted the American Society of Health-System Pharmacists (ASHP) to publish guidelines concerning its use, particularly when integrated with a pharmacy information system [15]. Although it has been reported that CPOE may sometimes lead to increased errors (most of which consist of the wrong cycle number or stage, or wrong height or weight), these can be easily prevented by optimally designed CPOEs integrated in EMR systems, which significantly improve the quality, safety, and efficiency of the complex medication of cancer patients [8,11,13,14,16].

BCMA is the second most frequently implemented technology and is intended to reduce medication errors at a patient’s bedside [17-19]. Its value has been proved in a broad range of patients and numerous organizations including the Food and Drug Administration (FDA), IOM, and ASHP have urged its adoption, although there is a lack of concrete supporting it in anticancer therapy [5,6,18-20]. However, its integration with other systems, such as EMR, CPOE, and eMAR, which can also track appropriate medication use, has been found to be effective in many areas [5,6,21,22] including oncology [7]. Moreover, if CPOE is integrated with a pharmacy information system, BCMA and eMAR are both automatically updated whenever new medication orders are entered or existing orders are modified [6,21].

New developments in cancer treatment have significantly increased the use of oral therapies, and there are a number of new chemotherapeutic and biological drugs that are generally more convenient for health care institutions and patients, most of whom are treated at home. This has led to a major shift from directly observed, intermittent intravenous therapy to self-administered oral treatment, and raised the problem of adherence and safety. This is important in the case of oral anti-cancer drugs, whose poor tolerability and limited dosing options mean that they need to be actively monitored in order to avoid any serious complications or toxicities, unnecessary hospital visits or admissions, and unnecessary treatment reductions or interruptions, and maintain treatment activity [23-29].

The safety of home treatment has traditionally been handled by measures such as frequent medical visits, information leaflets, patient-held diaries, and phone contacts between clinicians/nurses and patients [30]. The key aspects of these processes are information and communication between patients and health professionals, but patient empowerment also plays a central role in the daily self-administration and management of oral therapies.

Telephone follow-ups for purposes of monitoring and providing health care advice have been widely used for many years but tend to be non-specific and time consuming [26,27,31]; however, mobile computing and communication technologies are beginning to play an increasing role in health care. There are a very few cases in which mobile phone messaging has been found to be beneficial in supporting the self-management of chronic diseases [32], but more advanced mobile phone systems that allow patients to alert health care professionals automatically in real time and only when necessary have been successfully piloted in the case of diabetes [33] and asthma [34].

The introduction of new-generation smartphones with computer-like features has made it possible to monitor of a whole series of behaviors using a wide range of sophisticated mobile-health (mHealth) apps designed to be used by health care professionals, patients, and even healthy people [5,35,36]. However, there has been a clear focus on chronic diseases (63%, primarily diabetes) and only 5% relate to cancer, as pointed in a recent review, although these have so far had little impact on public health outcomes [37]. A number of studies of the mobile monitoring of cancer patients have been published, including one randomized clinical trial, and the results have shown it can be effective, may reduce chemotherapy- or radiotherapy-related toxicity [38-41], and can even help to maintain maximum dose intensity in patients treated with oral capecitabine [42]. The patients involved in all of these studies generally felt reassured to be monitored at home, and the health professionals found that the system helped in the management of symptoms and promotion of timely interventions.

It has been argued that the contribution of eHealth technologies and mHealth apps to creating a more efficient and safer health care process can be maximized in a highly computerized setting [5,21,37]. This is the case in the province of Trento in northern Italy, where the regional health authority has introduced various eHealth solutions over the past 15 years that cover all public health activities, and are characterized by a high degree of integration and interoperability. They are not only routinely used to manage patients and support citizen and patient empowerment, but have also provided an opportunity for the development of new health care applications.

The aim of this paper is to describe two of these applications: the Safe Therapy Mobile (STM) system for the safe delivery of infusion chemotherapy in hospital wards, and the Onco-TreC home monitoring system, which has been designed to increase patient/health professional interactions in such a way as to improve the self-care capabilities and treatment adherence of cancer patients receiving oral therapies at home, and reduce or prevent the occurrence of toxicity and complications.

Methods

Information Technology Systems

The backbone of health technology in Trento is its hospital information system (SIO), which handles all of the patients' clinical and administrative data, and is used by all of the public health care professionals working in the province. It can be accessed from every public health care facility, and supports various functions and activities including digital agendas and the paperless prescription of tests and drugs. General practitioners and primary care pediatricians are connected to the SIO by means of a virtual private network (VPN), which allows them to issue paperless drug prescriptions and receive all of their patients' clinical data directly on their electronic desks.

A citizen-controlled clinical record system called the TreC ("three C") system after its Italian name (*Cartella Clinica del Cittadino*) has been more recently introduced and integrated with the SIO, with the aim of empowering all citizens to manage their own health and facilitating communications with health care professionals and institutions [43]. The rationale underlying it is to provide a "safe place" in which to store personal health information and allow access to health-related public services such as their medical reports or monitoring services for chronic patients. The platform has two layers: "basic TreC services", which consists of data management and other common Web-based functions, the most important of which is the authentication and authorization of users in order to ensure the security, integrity, and privacy of sensitive personal data, and "composite TreC services", which includes higher integrated functions such as a structured health diary and monitoring tools for specific pathologies. Both layers interact with other mHealth solutions ("TreC access services and applications") in order to allow users to take full advantage of them. The TreC platform is increasingly used and, as of 30 September 2014, more than 37,000 citizens had accessed more than 400,000 reports.

Finally, as long ago as July 2000, a Web-based, user-centered electronic Oncological Patient Record (eOPR) system (OncoSys) was developed in order to facilitate the clinical, organizational, and administrative management of all oncological patients in the region. It is integrated with the SIO and routinely used by our Medical Oncology and Radiotherapy units and six oncological day hospitals, and so far managed more than 27,000 oncological patients (for a total of 359,600 individual accesses). The characteristics and functions of the eOPRs (particularly the management of therapeutic regimens) have been previously described [44].

The STM System

The STM system is a new application of our eOPR that has been designed and developed to support and monitor the entire process of drug medication in the hospital, from prescription to administration and reporting. Its design was preceded by modelling the workflow of patient therapy using Business Process Modelling Notation (BPMN), version 2.0 [45], and analyzing different tracking systems for mobile platforms and devices. It has a Web-based, multi-tier architecture: at the *business layer*, server and client interact to process the data in the *data layer*, which is visible to the user in the *presentation layer*. The system is cookie-free and no sensitive data can be intercepted because they remain on the server or are encrypted. One of its basic components is the eOPR, which includes a library of all the chemotherapy regimens currently being used, which have been reviewed by a group of experienced oncologists and pharmacists and electronically uploaded by informatic researchers, and support CPOE. The other components of the system are a radio frequency identification (RFID)/barcode reader, bar-coded drug labels, disposable RFID bracelets for patients, RFID tags for nurses, and a mobile device such as a tablet. The tablet communicates via Bluetooth with the RFID/barcode reader and via Wi-Fi with the server of the eOPR, in order to import the CPOE and export the eMAR, which contains the tracking data (Figure 1). When a chemotherapy regimen is prescribed, the eOPR originates a CPOE that is uniquely associated with the RFID bracelet of the specific patient. The CPOE details every single chemotherapy and ancillary drug (and the washing solution) in terms of dose, dilution volume, sequence, and infusion rate, which is also automatically associated with a specific barcode. The CPOE is sent via Web to the pharmacy for evaluation and drug preparation, and via Wi-Fi to the tablet. At the patient's bedside, the RFID/barcode reader checks the patient's RFID bracelet, the nurse's RFID, and the barcode on the infusion bag before each drug administration in order to verify that the right drugs are administered to the right patient in the right sequence. In the case of an error (eg, wrong drug, wrong sequence, etc), the system blocks the procedure and prompts the nurse to correct it. The system tracks every drug administration: which nurse has administered which drug to which patient, the duration of each infusion, and the total duration of therapy. All of this information is entered in the eMAR and automatically recorded in the patient's eOPR (becoming part of his/her oncological history), and may be used for clinical and/or organizational analyses.

The STM system was first repeatedly laboratory tested and then, in February 2014, was introduced into a day hospital with limited daily activities. At the beginning, the previous usual administration procedure and the STM system were used together in the same few volunteer patients but, after a few minor technical adjustments, the STM system was used alone for a total of 176 administrations. At the end of the testing period, it was adopted for routine chemotherapy administration in the initial day hospital and the more active day hospital of the Medical Oncology Unit of Trento.

The usability of the system and its acceptance by the nurses involved in the administration process was investigated using a modified questionnaire based on the "health IT usability evaluation scale" [46], which explored the three dimensions of the quality of working life, and the perceived usefulness and ease of use of the system (the fourth dimension of user control was not explored because the system had been designed in collaboration with the department and its introduction was preceded by extensive training of the nurses). The questionnaire was administered to all 15 nurses in both day hospitals after each had used the STM system for at least 2 months. An oral informed consent was obtained from nurses, whose participation was entirely voluntary.

Figure 1. The basic components of the STM system. The eOPR originates a CPOE that is univocally associated with the patient's RFID bracelet and the barcodes of the individual chemotherapy and ancillary drug, and washing solution. The RFID/barcode communicates via Bluetooth with the tablet, which communicates via Wi-Fi with the server of the OPR. The RFID/barcode reader checks the patient's RFID bracelet, the nurse's RFID, and the barcode on the infusion bag before each drug administration.

The Home Monitoring System

The home monitoring system was developed in order to deliver mHealth services in various medical contexts, and so relatively few technical enhancements are necessary to allow the same core components to be used for different clinical purposes and to support the different aspects of patient/doctor relationships. Based on the TreC platform, the architecture of the monitoring service is common to all chronic diseases, but the mobile phone or tablet user interfaces and parameters are specific for each condition.

The system consists of a mobile diary and the Web dashboard. The mobile diary is an Android app that allows patients to record parameters related to their health (eg, blood pressure, weight, fever, specific disease symptoms, or therapy-related side effects) and the medications they have taken (see Figure 2); it also has a built-in rule-based alarm module that notifies health care professionals of critical conditions via email. All of the data are stored in a central database and made available in real time by means of the Web dashboard or a tablet. The Web dashboard allows health care professionals to check their patients' data any time, and to monitor adherence to prescriptions and possible side effects. If a patient's condition is a cause for alarm, he or she can be promptly contacted by a doctor or nurse.

The TreC home monitoring system has been tested in three pilot studies that used a living lab approach in real-life settings [47] and involved patients with chronic type I or II diabetes, hypertension, or youth asthma. The three studies were conducted on the basis of a similar 3-step evaluation process: (1) technical testing with a few (2-3) users, (2) qualitative evaluations based on a small sample of 10-12 patients, and (3) a validation clinical trial. The qualitative evaluations were made before and after the studies and consisted of audio-recorded, semi-structured interviews that were analyzed by means of template analysis [48] in order to evaluate the patients' and clinicians' perception of acceptability and usefulness.

The system has since been customized to meet the home management and remote monitoring needs of cancer patients treated with cytotoxic capecitabine or the biological agent sunitinib. Both drugs are widely used in clinical practice on a sufficiently long-term basis, and frequently require dose adjustments or support interventions in order to ensure patient safety and compliance, and maintain treatment activity.

This Onco-TreC system consists of the mobile diary app and Web dashboard, based on the TreC platform, which are closely integrated with the eOPR, which originates the CPOE and records the administered therapy and related events. The mobile oncological diary app is deployed on a tablet to be used by the patient, and contains sections relating to the prescribed drugs, symptoms, general data, and day-by-day notes.

In the drug section, the CPOE is automatically converted to the number and type of pills that the patient has to take each day throughout the duration of the treatment. The patients are required to enter data into the system manually at least once a day by clicking on specific buttons each time they take the drug or not for any reason (Figure 3).

In the symptoms section, patients can choose from a number of predefined, drug-specific side effects. Adverse events are graded and summarized on the basis of the NCI-CTCAE, Version 4.02 [49], which is available in the app: the patients are asked to indicate the grade with the help of a scale defined in simple language and, in the case of skin toxicities, illustrated by pictures (Figure 4).

Every time such data is entered, the patient is given suggestions for action (eg, stop/continue the therapy or follow instructions), a feature that integrates and reinforces the patient information provided during a preliminary education phase [50]. All of the toxicity data, together with general data such as blood pressure, weight, fever, and patient notes, appear in the patient's diary and on the Web dashboard, and are recorded in the patient's eOPR.

The alarm module has also been customized using oncological drug-specific rules, which generally define any grade 3 toxicity symptom as an alarm signal that is automatically notified by email to the health professional responsible for monitoring the patient and displayed on the dashboard (Figure 5).

The Web-based dashboard (Figure 6) consists of a set of horizontally tiled time-based charts that show the programmed therapy and the set of monitored data entered by the patients via their mobile diaries, thus allowing oncologists and nurses to check the patients undergoing treatment at a glance, in a defined time window (eg, 3 days, 1-3 weeks, 1 month), assess any problems, and provide appropriate and timely indications. The nurses are organized on a rotating basis in order to ensure the 24-hour coverage of alarms.

The development and lab testing of Onco-TreC have now been completed, and the system will soon be validated by means of a prospective study of 60 consecutive patients designed to verify adherence to therapy, the prevention of home complications, dose reductions, or treatment interruptions, and any unscheduled access to a day hospital or emergency room, and assess its usability and acceptance by patients and health care professionals. The evaluation will be made using a customized version of the "health IT usability evaluation scale" [46] in order to investigate the four dimensions of the quality of working life (for health care professionals), communication (for patients), perceived usefulness and ease of use, and user control. We will also investigate the patients' perceived quality of life using the Functional Assessment of Cancer Therapy-General (FACT-G) questionnaire [51], and anxiety levels using the Hospital Anxiety and Depression Scale (HADS) questionnaire [52], both of which will be administered in a training phase at baseline, and after 6 and 12 weeks of treatment.

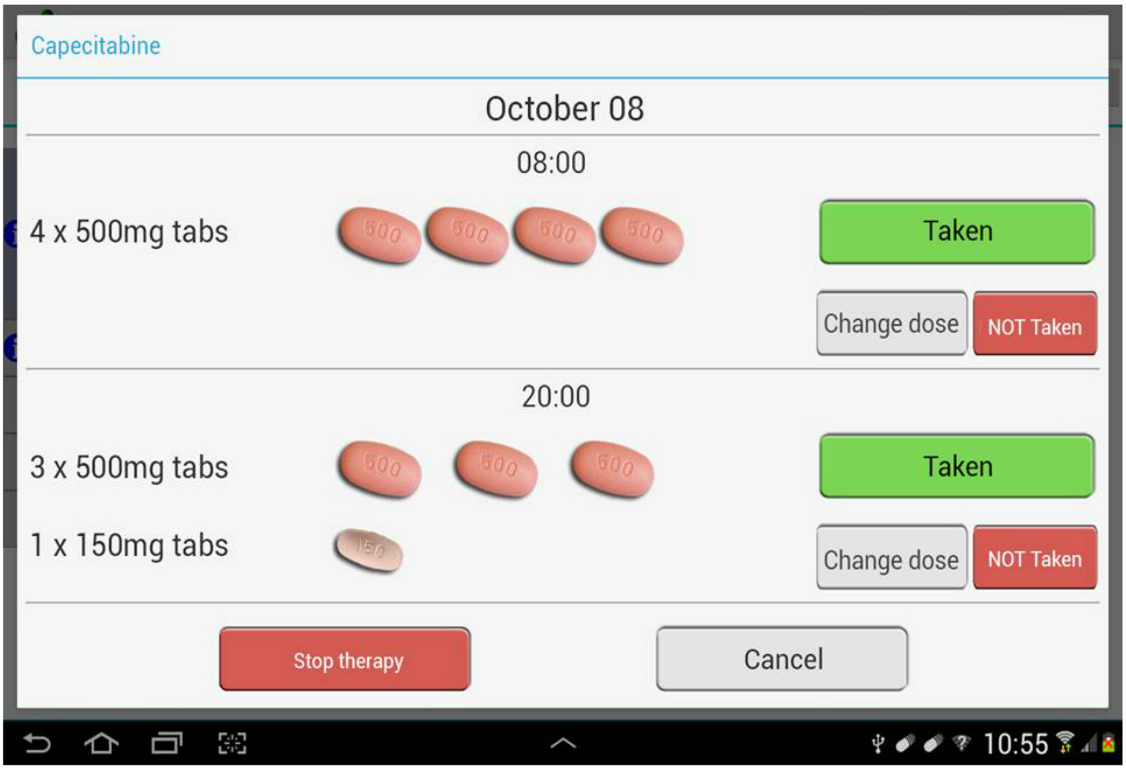
The following results therefore refer to the testing and validation of the original systems.

Figure 2. Screenshot of the mobile oncological diary showing patient’s prescribed therapy, self-assessed symptoms, and general data.

from October 06 to October 12

	Monday 06	Tuesday 07	Wednesday 08	Thursday 09	Friday 10	Saturday 11	Sunday 12
Capecitabine	**8:00** 3 tabs 500 1 tab 150 **20:00** 3 tabs 500 1 tab 150	**8:00** 3 tabs 500 1 tab 150 **20:00** not taken	**8:00** 3 tabs 500 1 tab 150 **20:00** 3 tabs 500 1 tab 150	**8:00** 3 tabs 500 1 tab 150 **20:00** 3 tabs 500 1 tab 150	**8:00** 3 tabs 500 2 tab 150 **20:00** 3 tabs 500 2 tab 150	**8:00** 3 tabs 500 1 tab 150 **20:00** 3 tabs 500 1 tab 150	**8:00** 3 tabs 500 1 tab 150 **20:00** 3 tabs 500 1 tab 150
LASIX		08:00 1 tab 20:00 1 tab	08:00 1 tab 20:00 1 tab	08:00 1 tab	08:00 1 tab	08:00 1 tab	08:00 1 tab
Symptoms	Diarrhea 2 Weakness 1	Diarrhea 2 Weakness 1	Diarrhea 1 Weakness 1				
Measurements		180/100mH	82.0Kg 140/90mH				
Notes							

Figure 3. Screenshot of pills and buttons.



Capecitabine

October 08

08:00

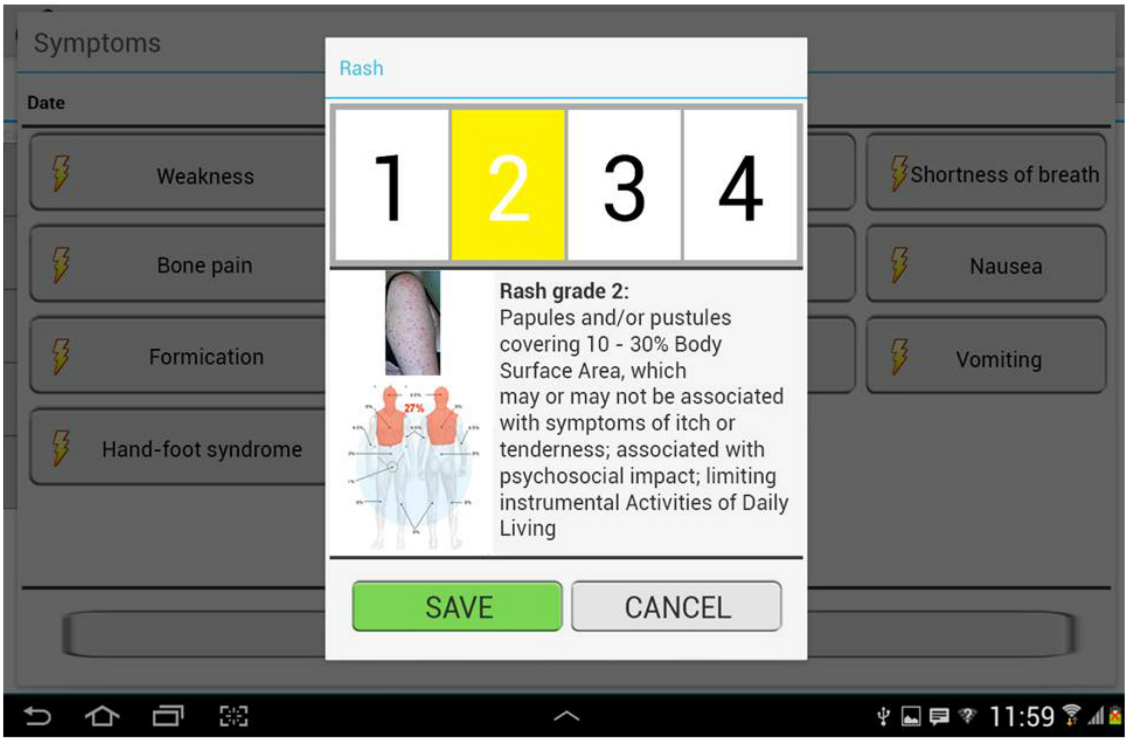
4 x 500mg tabs

20:00

3 x 500mg tabs

1 x 150mg tabs

Figure 4. Screenshot of mobile oncological diary showing the window that allows patients to input onset and intensity of therapy-related rash. The app helps patients determine grade of toxicity by displaying explanatory texts and pictures.



Rash grade 2:
Papules and/or pustules covering 10 - 30% Body Surface Area, which may or may not be associated with symptoms of itch or tenderness; associated with psychosocial impact; limiting instrumental Activities of Daily Living

Figure 5. Conceptual model of cancer patient home monitoring: (1) diary compilation - data are stored in central database and displayed on dashboard; (2) real- time analysis by rule-based alarm module; (3) If “critical event” is detected, alarm signal is automatically generated and displayed on dashboard; (4) message service alerts competent health professional; (5) doctor/nurse accesses patient dashboard to evaluate patient’s problems; (6) dashboard shows patient’s data and alarms; (7) they can contact patient directly if necessary.

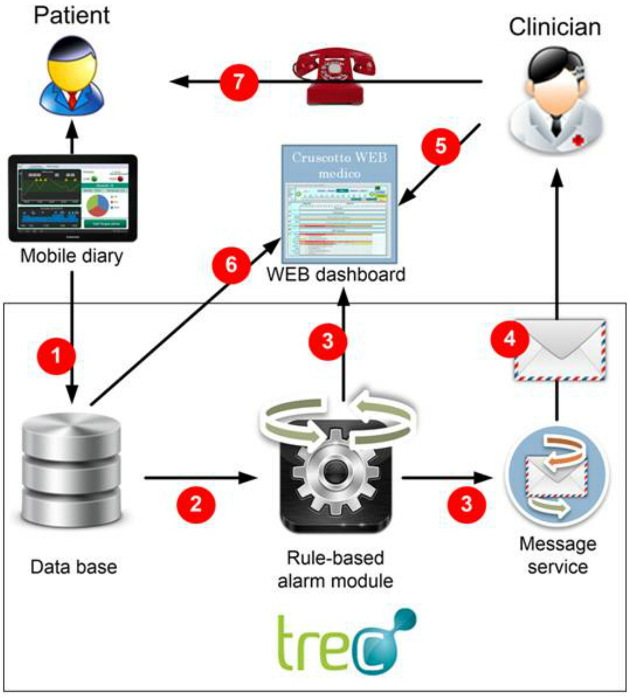
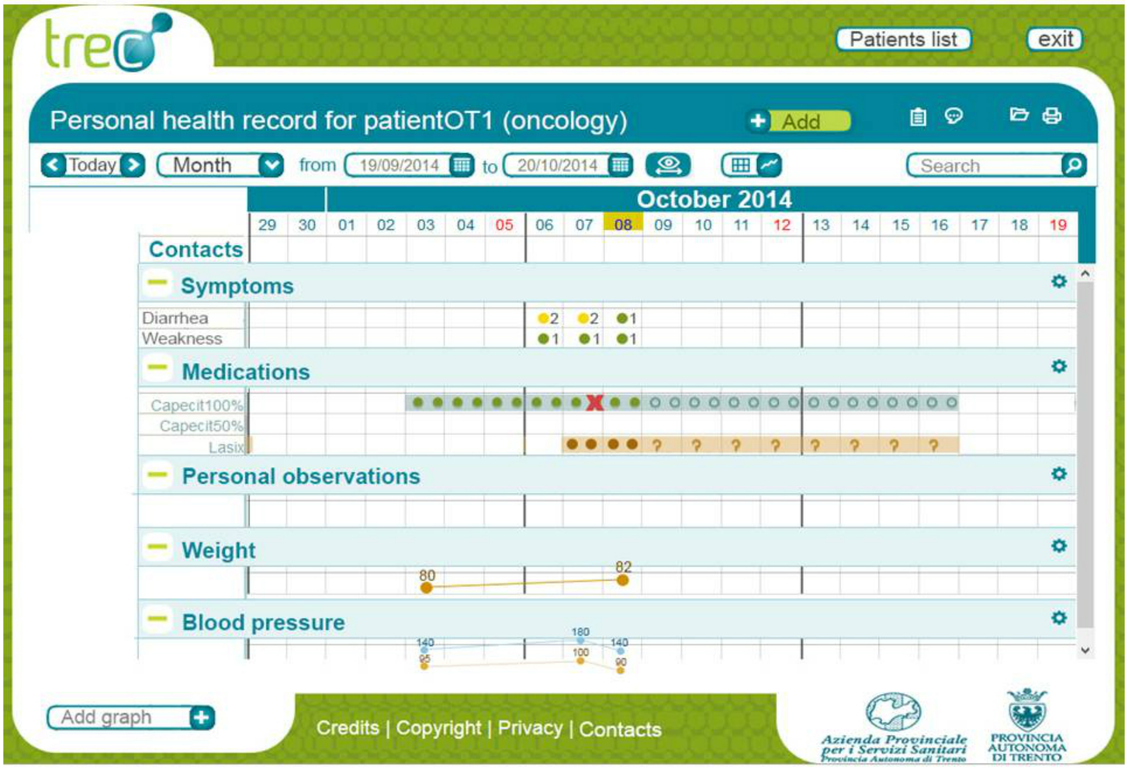


Figure 6. The oncological dashboard via Web browser. The horizontally tiled charts show general data, eg, weight, fever, symptoms, personal observations, and drugs (taken or discontinued).



Results

The STM System

By the end of the testing period, the system had been used to administer a total of 176 treatments to 59 patients. Only nine of the treatments were not completed during the first 2 weeks because of minor technical reasons such as a few short periods of weak Wi-Fi network signals and some difficult to read drug label barcodes, all of which were easily resolved. The system never failed to match the patient/drug/nurse combination correctly (and recognized errors when we voluntarily tried to change a drug or sequence), and proved to be accurate in tracking the time and duration of any single drug administration, the name of administering nurse, and the duration of the entire treatment. In order to test impact of the system on hospital workflows (the duration of the visits, therapies, and waiting times of each patient), we evaluated the duration of the entire administration process in a few patients who received the same chemotherapy regimen before and after the system was introduced into routine practice: there were no significant differences in the duration of chemotherapy administration, although this was not the perception of the majority of the nurses.

Analysis of the questionnaires showed that the users were generally satisfied with the use of STM (13/15, 87%; Q.8) and positively perceived all of the considered dimensions (the quality of working life, and the perceived usefulness and ease of use of the system) (Table 1).

For the purposes of this paper, the most interesting data concerning the perceived usefulness of the system when managing therapy administration (87% (13/15); Q.7); the improvement in information sharing (93% (14/15); Q.6); and the general perception of greater safety when administering the therapies (87% (13/15); Q.11) as the system is perceived as helping to associate the prescribed drugs with the right patient (73% (11/15); Q.9), and respect the correct sequence of administration (93% (14/15); Q.10).

It is more difficult to evaluate the nurses' perception of the system's impact on the speed of executing nursing tasks: 60% (9/15), said that it slowed down operations at the patients' bedsides (Q.4), but 80% (12/15) said that it speeds up recording the details of the administered therapies in the eOPR (Q.5). Before the introduction of the system, the nurses wrote the time they started the infusion of each drug on a paper form and, at the end of their shift, manually entered the data in the OPR, whereas the STM system relieves them of these tasks by automatically recording the data and entering them in the eOPR (thus also eliminating possible transcription errors).

Table 1. Results of the nurses' administered questionnaire on the STM (Safe Therapy Mobile) system (n=15).

		Strongly disagree n (%)	Disagree n (%)	Agree n (%)	Strongly agree n (%)
Quality of working life					
1	STM has improved a nurse's work	1 (7)	1 (7)	12 (80)	1 (7)
2	STM has improved the work of our ward	1 (7)	2 (13)	11 (73)	1 (7)
3	STM is important in treatment management	0 (0)	2 (13)	6 (40)	7 (47)
Perceived usefulness					
4	Using STM quickens the management of therapies at the patient's beside	4 (27)	5 (33)	6 (40)	0 (0)
5	Using STM quickens the recording of therapy details in the OPR	0 (0)	3 (20)	6 (40)	6 (40)
6	Using STM improves the sharing of information about the administration process	1 (7)	0 (0)	10 (7)	4 (27)
7	STM is useful when managing the administration of therapies	0 (0)	2 (13)	5 (33)	8 (53)
8	I am generally satisfied with STM	1 (7)	1 (7)	12 (80)	1 (7)
9	STM makes it more difficult to make a mistake in associating therapy and patient	0 (0)	4 (27)	3 (20)	8 (53)
10	STM makes it more difficult to make a mistake in the sequence of the administered drugs	0 (0)	1 (7)	5 (33)	9 (60)
11	Using STM makes me feel safer when administering the therapies	2 (13)	0 (0)	5 (33)	8 (53)
Perceived ease of use					
12	Learning to use STM was easy	0 (0)	3 (20)	9 (60)	3 (20)
13	STM is easy to use	0 (0)	2 (13)	10 (67)	3 (20)
14	I can always remember how to use STM	0 (0)	0 (0)	12 (80)	3 (20)

Home Monitoring of Chronic Patients

A total of 43 patients were involved in the three pilot studies: 20 with type I or type II diabetes, 15 with hypertension, and eight with youth asthma. These pathologies were chosen in order to include different mixes of patient self-care and empowerment and the direct intervention of doctors and nurses: type I diabetes and youth asthma are mainly managed autonomously by patients and their families, whereas type II diabetes and hypertension require health care professionals to play a more active role in monitoring and evaluating data.

Some of the results were common to all studies, whereas others show that the mobile remote monitoring app has different effects depending on the duration of the study and the distribution of the workload between doctors and patients.

All of the studies found that the system was well accepted by patients for up to 3 months [53-55], and the health care professionals were positive toward the system because of its novelty (type 1 diabetes [56]), its potential for reducing unnecessary face-to-face encounters (type 2 diabetes: submitted), and its diagnostic reliability (hypertension [53]).

However, the patients involved in two studies perceived the system as intruding on their everyday lives and causing an additional burden [53,55]. This tension between potential benefits and perceived intrusiveness is well described by a simulation based on the real data of patients with type I diabetes, a chronic disease which is usually managed by the patients themselves. During the 6 months of the test, the system alerted doctors 95 times and, each time, the doctors were asked what they would have done had the system been implemented in clinical practice. In 14% of cases (13/95), they would have contacted the patient (or his/her parents) straight away and, in 58% of cases (55/95), they would have closely monitored the patient's data; in the remaining 28% of cases (27/95), they would have simply waited for the next visit. These data were presented to the patients at a project meeting, and it became clear that patients thought they could manage by themselves the condition that had triggered the alarm to doctors, and that they considered the system as a means of supporting self-management rather than remote monitoring. This led to a request that doctors intervene only on call [51] and a request to redesign the alarm module to receive notifications on any conditions of attention and limiting to a small fraction the number of alarms automatically sent to health professionals.

With regard to the conditions characterized by a greater need for remote monitoring, the patients appreciated the closer medical supervision, and considered the system a useful means of reducing the need for direct contacts with health professionals and increasing their perception of safety [53]. This situation can be considered very similar to that of oncological patients treated with oral anticancer therapies at home.

The preliminary results of these pilot studies show that clinicians and patients perceive the approach as useful and reliable, but it is also necessary to pay attention to the expectations that mHealth solutions may raise in users [53-56].

Discussion

The STM System

The published data clearly suggest that the integration of EMR, CPOE, and BCMA systems can decrease medication errors and help to deliver safer and more efficient care. This makes it highly suitable in oncology because specifically designed, integrated, and interoperable systems, together with good patient/health professional communications and robust Web or Wi-Fi connectivity, are vital components ensuring the safety of the administration of chemotherapy [5,6,7].

Bearing these principles in mind, our STM system is fully integrated with the eOPR that we routinely use for the total management of all oncological patients, and so any chemotherapy treatment can be entirely managed from prescription (automatically transformed into a CPOE for the pharmacy) to administration at the patient’s bedside, where each single drug is checked by the barcode reader in order to verify that the right drug is administered to the right patient in the right sequence. The system has proved to be accurate, reliable, and capable of guaranteeing the safety, monitoring, tracking, and recording of the entire treatment for each patient, and has been successfully used for the last 5 months at a busy day hospital for adult oncological patients.

Even the best health technology is designed not to replace health care professionals, but to enhance their ability to care for their patients, and so it is always important to consider its impact on the workflow of health care providers and the way in which it is perceived. In addition to verifying its ability to guarantee the safe administration of chemotherapy, the STM has been evaluated in terms of its usability and acceptability in a department staffed by a quite stable group of specialized and experienced nurses who are able to ensure a high standard of care. These nurses have found that it supports their work in at least three ways. First of all, its use removes a potential source of clerical errors by digitalizing and automatically transferring information from the barcode/RFID scanner to a tablet and then the eOPR, thus replacing the previous paper-based system. Second, the system monitors and tracks the entire infusion process, and all of the information is transferred to the eMAR and automatically recorded in the patient’s eOPR to became a part of his/her oncological history; this means that all of the nurses are aware of every stage in the administration process in real time, thus increasing the sharing of information. Third, the questionnaire data suggest that the introduction of the technology is perceived by nurses as improving the quality of their work and professional skills.

Our nurses had a positive perception of all of the dimensions considered in the questionnaire (the quality of their working life, and the usefulness and ease of use of the system), except for the fact that the system appeared to slow down bedside operations. This observation is not new and probably reflects the impact of the new technology on the workflow of health professionals, who are generally reassured as soon as they become more familiar with the technology and more efficient at using the system [7]. This view is supported by the fact no significant objective differences in the duration of chemotherapy administration were found after the system was introduced.

In conclusion, it seems that our STM system can simplify the medication process by eliminating some unnecessary steps, and that its safety features not only make cancer treatments safer for patients, but improve the accuracy and efficiency of the process of ordering, preparing, and administering antineoplastic drugs for health care workers.

Home Monitoring

The use of mobile health apps is not new in the field of home monitoring of chronically ill and oncologic patients as well [37,42,57-60]. In this context, mHealth seems to be a particularly attractive means of managing conditions that require patients to be monitored or cared for at home because, given the widespread use of mobile connectivity, it can enhance information sharing with clinicians as a result of real-time communications. The greatest perceived benefits of the more widespread adoption of mHealth solutions included improvements in health care system processes, the collection and retrieval of crucial medical data, and the ability of patients to manage chronic conditions [61]. Specifically, some of these studies have shown that mobile monitoring of cancer patients can be effective, may reduce chemotherapy- or radiotherapy-related toxicity [38-41], and can even help to maintain maximum dose intensity in patients treated with oral capecitabine [42]. Although eHealth technologies and mHealth apps have so far had little impact on public health outcomes [37], it has been argued that their contribution to creating a more efficient and safer health care process can be maximized in a highly computerized setting [5,21,37].

The architecture of the home monitoring system described in this paper is not new, but its use has been extended. It is based on the broad, multipurpose TreC platform, which was designed to deliver mHealth services in various medical contexts, which means that relatively few technical enhancements were necessary to allow the same core components to be used in the setting of oncology. The minimum set of basic components (mobile phone or tablet apps) to be used by patients have been previously evaluated in three different patient populations involving different mixes of patient empowerment and self-care, and different interventions by doctors and nurses [53-55]. All of these studies showed that the system was well accepted by patients and considered useful by physicians, although they also showed that attention needs to be paid to the expectations that mHealth solutions may raise in users as the remote monitoring led to different effects depending on the duration of the study and the distribution of the workload between doctors and patients [53].

Nevertheless, the results were sufficient to provide a rationale for developing the Onco-TreC system for monitoring patients treated at home with oral capecitabine and sunitinib. Such patients are traditionally given appropriate education and information, and are always asked to call health staff in the case of problems. However, this obviously excludes off-duty hours, holidays and nights, and, together with the difficulties that may occur when communicating with a hospital, may give rise to feelings of abandonment and, in some cases, the need to seek access to the Emergency Department.

However, what makes Onco-TreC quite different from other apps is the fact that it is integrated in a system that has been specifically developed for the total management of cancer patients. The patient-held diary combines patient-reported symptoms with the real-time detection and communication of potentially serious adverse events [28], and gives doctors better information concerning toxicity and compliance to therapy, thus allowing prompt intervention and supporting patient adherence. All of the information automatically becomes part of each patient's clinical history and is immediately available whenever any decision-making support is needed.

Moreover, this highly integrated, complex, and composite information system guarantees privacy, security, interoperability, and (particularly) connectivity, thus real-time patient/health professional communication. All of these features, together with the automatic alarm system should have a beneficial impact on the quality and efficiency of health care. Our home monitoring app certainly still has to be validated before it can be considered helpful in clinical practice, but this will soon be done in a prospective study of patients treated with oral oncological drugs.

In conclusion, our approach to designing and implementing an integrated oncology management system using mobile apps was aimed at ensuring the safer in-hospital delivery of infusion chemotherapy and empowering cancer patients to manage their disease and treatment at home.

Mobile apps such as STM and Onco-TreC may play a role in creating an organizational culture of safety, but it needs to be remembered that, even when human processes are replaced by integrated, computerized activities in order to increase safety, a major element remains the importance of staff training and patient education and empowerment.

Conflicts of Interest

Santi J and Galvagni M are co-owners and active workers in the company (MTT-pro) involved in the development of our oncological patient record and the safe therapy mobile application. None of the other co-authors has any conflict of interest in relation to this paper.

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Abbreviations

ASHP: American Society of Health-System Pharmacists
BCMA: barcode-assisted medication administration
BPMN: business process modelling notation
CDSS: clinical decision support systems
CPOE: computerized prescriber order entry
eMARs: electronic medication administration records
eOPR: electronic oncological patient record
EMR: electronic medical record
EPRs: electronic patient records
IOM: institute of medicine
ITs: information technologies
mHealth: mobile Health
RFID: radio frequency identification
SIO: hospital information system
STM: safe therapy mobile

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Original Paper

Behavior Change Techniques in Popular Alcohol Reduction Apps: Content Analysis

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Abstract

Background: Mobile phone apps have the potential to reduce excessive alcohol consumption cost-effectively. Although hundreds of alcohol-related apps are available, there is little information about the behavior change techniques (BCTs) they contain, or the extent to which they are based on evidence or theory and how this relates to their popularity and user ratings.

Objective: Our aim was to assess the proportion of popular alcohol-related apps available in the United Kingdom that focus on alcohol reduction, identify the BCTs they contain, and explore whether BCTs or the mention of theory or evidence is associated with app popularity and user ratings.

Methods: We searched the iTunes and Google Play stores with the terms “alcohol” and “drink”, and the first 800 results were classified into alcohol reduction, entertainment, or blood alcohol content measurement. Of those classified as alcohol reduction, all free apps and the top 10 paid apps were coded for BCTs and for reference to evidence or theory. Measures of popularity and user ratings were extracted.

Results: Of the 800 apps identified, 662 were unique. Of these, 13.7% (91/662) were classified as alcohol reduction (95% CI 11.3-16.6), 53.9% (357/662) entertainment (95% CI 50.1-57.7), 18.9% (125/662) blood alcohol content measurement (95% CI 16.1-22.0) and 13.4% (89/662) other (95% CI 11.1-16.3). The 51 free alcohol reduction apps and the top 10 paid apps contained a mean of 3.6 BCTs (SD 3.4), with approximately 12% (7/61) not including any BCTs. The BCTs used most often were “facilitate self-recording” (54%, 33/61), “provide information on consequences of excessive alcohol use and drinking cessation” (43%, 26/61), “provide feedback on performance” (41%, 25/61), “give options for additional and later support” (25%, 15/61) and “offer/direct towards appropriate written materials” (23%, 14/61). These apps also rarely included any of the 22 BCTs frequently used in other health behavior change interventions (mean 2.46, SD 2.06). Evidence was mentioned by 16.4% of apps, and theory was not mentioned by any app. Multivariable regression showed that apps including advice on environmental restructuring were associated with lower user ratings (B=-46.61, *P*=.04, 95% CI -91.77 to -1.45) and that both the techniques of “advise on/facilitate the use of social support” (B=2549.21, *P*=.04, 95% CI 96.75-5001.67) and the mention of evidence (B=1376.74, *P*=.02, 95%, CI 208.62-2544.86) were associated with the popularity of the app.

Conclusions: Only a minority of alcohol-related apps promoted health while the majority implicitly or explicitly promoted the use of alcohol. Alcohol-related apps that promoted health contained few BCTs and none referred to theory. The mention of evidence was associated with more popular apps, but popularity and user ratings were only weakly associated with the BCT content.

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KEYWORDS

alcohol; behaviour change; mHealth; smartphone; iPhone; android; apps; digital; intervention

Introduction

Excessive alcohol use causes approximately 3.3 million deaths each year, and more than 5% of the global burden of disease is attributable to its consumption [1]. Brief interventions delivered by health care workers to hazardous drinkers are effective [2]. However, there is little understanding of their mechanisms of action [3], and barriers to their delivery such as lack of time, training, and financial resources mean they have limited reach [4,5].

Mobile phones offer the potential to reduce these barriers as they are relatively cheap, accessible to users, and deliver support when and where needed. Mobile phone apps for mobile health (mHealth) enable disease monitoring, management, and education; improve health behavior assessment; and facilitate more frequent user-to-user or practitioner-to-user communication [6-8]. Thousands of mHealth apps are available; as of June 2013, there were over 40,000 mHealth apps in the US English-language iTunes Store alone [9]. Approximately 20% of smartphone users have downloaded an mHealth app [10]; this figure is expected to rise as both smartphone ownership and the number of apps increase. According to industry estimates, 1.7 billion smartphone users worldwide will have downloaded an mHealth app by 2018 [11].

Smartphone use is increasing rapidly among young people, but older people are also using apps in increasing numbers [12]. App-delivered interventions to reduce excessive alcohol consumption could potentially be targeted at a range of age groups, as younger people tend to drink more heavily but older people tend to drink more regularly [1].

Despite the proliferation of mHealth apps, there has been little research investigating their mechanisms of action or efficacy and they are often developed without reference to evidence base or theory [13]. Reviews of apps for smoking cessation [14], weight loss [15-17], diabetes management [18], healthy eating and physical activity [19,20], breast disease management [21], and melanoma detection [22] have found the majority fail to conform to guidelines, lack evidence-based content, and/or provide inaccurate information. Concern about the content of mHealth apps has led to calls for regulation to improve patient safety [23,24].

Moreover, the most popular apps—as defined by the approximate number of installations on the Google Play store or by their position in the search results in the iTunes Store—have been found to contain fewer evidence-based techniques [15], lower levels of adherence to guidelines [14], or information that may encourage risky behavior [25] than less popular apps. User ratings are a different measure of popularity and reflect a user's judgment about the quality of the app (eg, an app may be highly rated but used by only a small number of people). User ratings have been found to be associated with high levels of adherence to guidelines in smoking cessation apps [14], although not in weight loss [17] or physical activity apps [20].

A review of 767 alcohol apps available in the US version of the iTunes Store found that 71% facilitated the use of alcohol and 29% aimed to reduce its consumption [26], though many of the alcohol reduction apps simply attempted to measure a user's blood alcohol content (BAC). A review of 384 BAC apps available in the Australian iTunes and Google Play stores found that most were inaccurate, with some purporting to measure BAC by asking users to blow into the microphone, and only 11% of all the apps examined had an alcohol reduction focus [25].

Of the US and Australian alcohol-reduction apps identified in previous studies [25,26], little is known about their potential active ingredients and mechanisms of action. A useful method for describing the potentially active ingredients of apps is to assess the behavior change techniques (BCTs) they contain [27-29]. A BCT is "an observable, replicable, and irreducible component of an intervention designed to alter or redirect causal processes that regulate behavior; that is, a technique is proposed to be an 'active ingredient' (eg, feedback, self-monitoring, and reinforcement)" (p. 82, [27]).

A taxonomy of 42 BCTs to reduce excessive alcohol consumption has been developed from guidance documents and treatment manuals identified by expert consultation [30]. The taxonomy has been reliably applied to identifying BCTs in brief alcohol interventions, and meta-regression revealed that those that included self-monitoring were associated with larger effect sizes [30]. Similar taxonomies have been used to reliably identify BCTs contained in physical activity and dietary apps [31,32].

An additional aim of this study was to identify whether there were BCTs widely used in domains other than alcohol consumption that could be considered for alcohol apps. Analysis of the BCTs used in 40 published descriptions of behavior change interventions to prevent illness, improve illness management, or improve the behaviors of health care professionals found that 22 of a possible 93 BCTs were frequently used. A comparison with those used in alcohol apps would indicate potentially useful BCTs not frequently used in alcohol apps.

The current study should yield benefits for research and practice. Coding alcohol apps for BCTs allows (1) researchers to identify BCTs and establish which ones are based on theory and/or evidence and to conduct evaluations in terms of BCTs, (2) users to be better informed about which BCTs are present and enable them to choose ones suited to their needs, (3) health care practitioners to make more informed recommendations to patients [33], and (4) app developers to make decisions about which BCTs to include.

This study builds on previous work [25,26] by providing an up-to-date estimate of the relative prevalence of alcohol-related apps available in the United Kingdom that focus on reducing excessive alcohol consumption and by coding those apps for their component BCTs [30]. We also explored associations between the presence of BCTs, the mention of theory or evidence, and the popularity and user ratings of the app.

The research questions addressed by this study are (1) What proportion of alcohol-related apps available in the UK version of the iTunes and Google Play stores focus on alcohol reduction?, (2) Which BCTs are contained within alcohol-related apps focusing on alcohol reduction?, (3) To what extent do alcohol-related apps focusing on alcohol reduction use BCTs commonly found in other types of behavior change intervention?, and (4) What are the associations between the presence of BCTs, the mention of theory or evidence, and the popularity and user ratings of the apps?

Methods

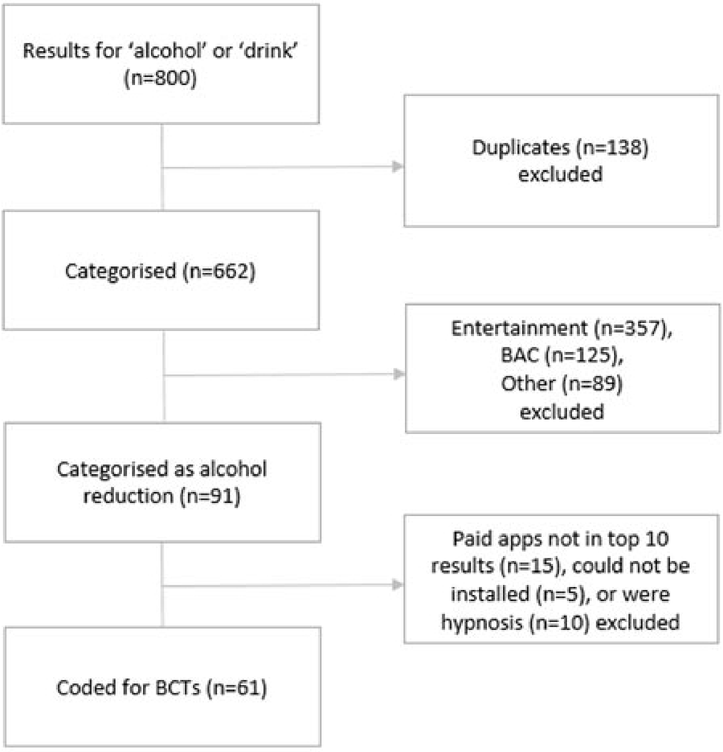
Search Strategy and Data Extraction

Alcohol-related apps were identified by searching the UK versions of the iTunes and Google Play stores in April and May 2014 for the terms “alcohol” and “drink”. The following data were extracted from the first 200 results found for each term in each app store (4 x 200): time and location of search, app name, developer name, ranking in the search results, cost, and classification. We considered 200 search results for each search term comprehensive as users rarely examine search results thoroughly [34].

Duplicate apps were removed from the 800 search results and the unique apps were classified as either alcohol reduction (apps that aim to reduce drinking-related behavior and those that track consumption), entertainment (drinking games, cocktail recipes, bar finders); BAC measurement; or other (apps not about alcohol, apps not in English, information for employers, etc).

Of the 91 alcohol reduction apps, we installed, examined, and coded all 51 free apps as users prefer apps that are free to download [35]. However, 10 paid apps were installed, examined, and coded as a sensitivity check of the BCTs included. The remaining paid apps (n=15), apps that could not be installed (n=5), or those that focused on hypnosis (n=10) were excluded (see Figure 1). Included apps were coded for the presence of BCTs [30], mention of theory, mention of evidence, number of installations, and user ratings. Ratings were taken from all versions of the app in the iTunes store (rather than the current version). We did not base our coding on any other information (such as descriptions in the app stores or on Web pages, or within developers’ protocols or published papers).

Figure 1. Flow diagram of apps selected for coding.



Behavior Change Technique Coding

The taxonomy of BCTs to reduce excessive alcohol consumption and the associated coding manual were used for our evaluation [30]. The coding manual includes definitions and examples of BCTs and guidelines for identifying them in intervention descriptions. For each app, BCTs were coded as 0: no evidence of BCT, 1: BCT present in all probability but evidence unclear; and 2: BCT present beyond all reasonable doubt and clear evidence. For all analyses, the presence of a BCT was dichotomized, with only those receiving a “2” being classified as containing the BCT. The BCT “build general rapport” was excluded from coding because it could not be appropriately coded for a digital intervention.

The coding manual was used independently by 2 trained coders (DC and CG) to code 11 of the included apps. There was “outstanding” agreement: prevalance and bias adjusted kappa (PABAK)=.89, kappa=.65 [36] for this first round of coding. Discrepancies were discussed and the coding guidelines were refined. After the coding manual was updated, the remaining apps were coded by 1 coder (DC) with 15% also coded by the second coder (CG) to assess rater drift. There was “outstanding” agreement for the subsequent ratings of the eight apps coded by both raters (PABAK=.89, kappa=.81 [36]).

Of the 93 BCTs described by a general taxonomy of behavior change (BCTTv1) [27], 22 have been found to be frequently used in a variety of health behavior change interventions [37]. In order to establish the extent to which the included apps contained these BCTs, 1 coder (DC) and an independent behavior change expert mapped the 22 frequently used BCTs to the alcohol taxonomy [30]. This allowed us to determine the prevalence of those BCTs in these apps.

The full content of the apps was coded. Alcohol consumption spanning numerous days was entered in order to determine if the app included graphs that displayed progress over time. If the app was tailored on the basis of personal details, the characteristics of a female alcohol consumer in the United Kingdom drinking moderately above guidelines were used (30 years, consumed 16 units of alcohol over 3 days in the previous week). Theory was coded if the app made reference to theory as a factor informing its development. Evidence was coded if the app made reference to empirical evidence relating to behavior change. Apps were coded on an iPhone running iOS7 and a Samsung Galaxy S3 running Android 4.3.

Popularity and User Ratings

The popularity of apps was operationalized as the overall number of ratings received. User ratings of the apps were operationalized by assessing the proportion of ratings that were four or five star and calculating the associated lower 95% confidence interval (CI). Mean ratings were not used because they do not reflect the uncertainty associated with a very small number of ratings [38]. For example, an app with 2 five-star reviews and no other reviews would receive a mean rating of 5 and an app with 900 five-star reviews and 100 one-star reviews would receive a mean rating of 4.6. Whereas, if using a lower bound CI, an app with 2 five-star reviews would have a lower bound CI of .34, and an app with 900 five-star reviews and 100 one-star reviews would have a lower bound CI of .88. This approach has been adopted by websites such as reddit and Yelp, which depend on accurately ranking user ratings [39,40].

Analyses

All statistical analyses were conducted using SPSS version 20.0. Frequencies, percentages, and associated 95% CIs were calculated for the categories of alcohol-related apps (alcohol reduction, entertainment, blood alcohol content, other), for each of the 41 BCTs, and for the mention of theory or the mention of evidence contained within the alcohol reduction apps. To assess interrater reliability, kappa and PABAK were calculated. PABAK is an adjusted kappa statistic that accounts for coders agreeing on the presence or the absence of codes [41]. PABAK was used in addition to Cohen's kappa, which only accounts for coders agreeing on the presence of codes.

We examined (1) all BCTs in Table 1 for their frequency in alcohol reduction apps, (2) associations between the presence of BCTs and the mention of theory or evidence listed in Table 2 with the popularity of the app in a series of univariable logistic regressions, and (3) the independent association after mutual adjustment for all variables listed in Table 2 in a multivariable logistic regression. BCTs that were present in two or fewer apps were excluded. We repeated similar analyses to examine the univariable and multivariable associations between the presence of BCTs and the mention of theory or evidence listed in Table 3 with the user ratings.

Results

Overview

Of the 800 apps returned from the searches, 662 unique apps were identified (see Figure 1). Of these, 13.7% were classified as alcohol reduction (91/662, 95% CI 11.3-16.6), 53.9% entertainment (357/662, 95% CI 50.1-57.7), 18.9% blood alcohol content measurement (125/662, 95% CI 16.1-22.0), and 13.4% other (89/662, 95% CI 11.1-16.3). A total of 61 apps were coded: all 51 free apps and the first 10 paid apps found in the search results. The remaining paid apps (n=15), apps that could not be installed (n=5), and those that focused on hypnosis (n=10) were excluded.

Behavior Change Techniques in Alcohol Reduction Apps

A sensitivity check indicated that the number and type of BCTs in free and paid apps was broadly similar, so they were treated as a single group (data not shown). The mean number of BCTs from the alcohol taxonomy [30] used in apps was 3.56 (SD 3.39, median 2). Seven apps did not include any BCTs and 30 apps (49.2%) included only one, two, or three BCTs. Five apps included 10 or more BCTs. The maximum number of BCTs included was 13 (n=3), and 26 BCTs were used in at least one app.

The frequency with which BCTs were included by different apps is shown in Table 1. The most frequent BCTs were "facilitate self-recording" (54.1%, 33/61), "provide information on consequences of excessive alcohol use and drinking cessation" (42.6%, 26/61), "provide feedback on performance" (41.0%, 25/61), "give options for additional and later support" (24.6%, 15/61), and "offer/direct towards appropriate written materials" (23.0%, 14/61).

Table 1. BCTs included in alcohol reduction apps (N=61 apps).

BCT		n (%)
15	Facilitate self-recording	33 (54.1)
1	Provide information on consequences of excessive alcohol use and drinking cessation	26 (42.6)
3	Provide feedback on performance	25 (41.0)
22	Give options for additional and later support	15 (24.6)
32	Offer/direct towards appropriate written materials	14 (23.0)
23	Tailor interactions appropriately	13 (21.3)
2	Boost motivation and self‐efficacy	9 (14.8)
14	Prompt review of goals	8 (13.1)
4	Provide rewards contingent on successfully reducing excessive alcohol use/abstaining	8 (13.1)
13	Facilitate goal setting	7 (11.5)
33	Provide information on withdrawal symptoms	6 (9.8)
17	Advise on environmental restructuring	5 (8.2)
42	Behavior substitution	5 (8.2)
10	Facilitate barrier identification and problem solving	4 (6.6)
11	Facilitate relapse prevention and coping	4 (6.6)
20	Advise on avoidance of social cues for drinking	4 (6.6)
21	Advise on/facilitate use of social support	4 (6.6)
6	Prompt commitment from the user there and then	4 (6.6)
12	Facilitate action planning/know how to help identify relapse triggers	3 (4.9)
25	Assess current and past drinking behavior	3 (4.9)
5	Provide normative information about others' behavior and experiences	3 (4.9)
16	Change routine	2 (3.3)
24	Emphasize choice	2 (3.3)
37	Provide reassurance	2 (3.3)
7	Provide rewards contingent on effort or progress	2 (3.3)
8	Identify reasons for wanting and not wanting to reduce excessive alcohol use	2 (3.3)
18	Set graded tasks	1 (1.6)
26	Assess current readiness and ability to reduce excessive alcohol use	1 (1.6)
31	Explain expectations regarding treatment programme	1 (1.6)
9	Explain the importance of abrupt cessation	1 (1.6)
19	Advise on conserving mental resources	0 (0)
27	Assess past history of attempts to reduce excessive alcohol use	0 (0)
28	Assess withdrawal symptoms	0 (0)
30	Elicit and answer questions	0 (0)
34	Use reflective listening	0 (0)
35	Elicit user views	0 (0)
36	Summarize information/confirm user decisions	0 (0)
38	Model/demonstrate the behavior	0 (0)
39	Prompt use of imagery	0 (0)
40	Motivational interviewing	0 (0)
41	General communication skills training	0 (0)

Eleven BCTs were not used in any app: “advise on conserving mental resources”, “assess past history of attempts to reduce excessive alcohol use”, “assess withdrawal symptoms”, “elicit and answer questions”, “use reflective listening”, “elicit user views”, “summarize information/confirm user decisions”, “model/demonstrate the behavior”, “prompt use of imagery”, “motivational interviewing”, and “general communication skills training”.

Behavior Change Techniques Frequently Found in Other Interventions and Used in Alcohol Apps

Of the 22 BCTs frequently found in other health behavior change interventions, the mean number included in alcohol-reduction apps was 2.46 (SD 2.06, median 2). Of these 22, the five most often included in alcohol apps were “facilitate self-recording” (54.1%, 33/61), “provide information on consequences of excessive alcohol use and drinking cessation” (42.6%, 26/61), “provide feedback on performance” (41.0%, 25/61), “give options for additional and later support” (24.6%, 15/61), and “offer/direct towards appropriate written materials” (23.0%, 14/61). Three of the BCTs frequently found in other health behavior change interventions were not used in any app “motivational interviewing”, “use reflective listening”, and “model/demonstrate the behavior”.

Associations Between Behavior Change Techniques, Theory, and Evidence With Popularity and User Ratings

The mean user rating for apps was 2.64 (SD 1.71), and the mean number of ratings was 234.46 (SD 1272.08). Evidence was mentioned in 16.4% of apps (n=10), most usually evidence about the recommended guidelines for the consumption of alcohol. Theory was not mentioned by any app.

The BCT “prompt review of goals” (B=0.41, *P*=.001, 95% CI 11.88-44.79) was positively associated with user ratings in univariable regression models (Table 2); no other significant associations between BCTs and user ratings were found. In multivariable linear regression models, the only significant association was a negative one: apps that advised on environmental restructuring had marginally lower user ratings (B=-46.61, *P*=.04, 95% CI -91.77 to -1.45).

Table 2. The association between BCTs, theory/evidence with ratings (lower 95% CI of the proportion of ratings >3/5).[a]

BCT		Unadjusted B (CI)	Adjusted B (CI)
1	Provide information on consequences of excessive alcohol use and drinking cessation	0.08 (-8.59 to 15.96)	-6.54 (-32.64 to 19.56)
2	Boost motivation and self‐efficacy	0.13 (-8.78 to 25.29)	17.88 (-9.77 to 45.53)
3	Provide feedback on performance	0.23 (-1.25 to 22.86)	-14.28 (-43.21 to 14.65)
4	Provide rewards contingent on successfully reducing excessive alcohol use/abstaining	0.18 (-5.25 to 30.23)	4.73 (-25.16 to 34.62)
6	Prompt commitment from the user there and then	0.18 (-7.21 to 41.18)	-31.96 (-83.87 to 19.94)
10	Facilitate barrier identification and problem solving	-0.03 (-27.15 to 22.03)	-62.14 (-139.39 to 15.12)
11	Facilitate relapse prevention and coping	-0.17 (-39.96 to 8.55)	-17.62 (-94.96 to 59.71)
13	Facilitate goal setting	0.19 (-4.96 to 32.57)	15.19 (-16.26 to 46.64)
14	Prompt review of goals	0.41 (11.88 to 44.79)[b]	24.34 (-3.67 to 52.34)
15	Facilitate self-recording	0.17 (-4.01 to 20.07)	-0.92 (-27.75 to 25.91)
17	Advise on environmental restructuring	-0.1 (-30.69 to 13.48)	-46.61 (-91.77 to -1.45)[b]
20	Advise on avoidance of social cues for drinking	0.06 (-18.82 to 30.28)	18.98 (-38.64 to 76.61)
21	Advise on/facilitate use of social support	0.05 (-19.66 to 29.46)	2.39 (-42.95 to 47.73)
22	Give options for additional and later support	0.05 (-11.55 to 16.7)	-2.04 (-44.97 to 40.89)
23	Tailor interactions appropriately	0.23 (-1.16 to 27.76)	-0.89 (-26.32 to 24.54)
32	Offer/direct towards appropriate written materials	0.02 (-13.51 to 15.44)	-16.25 (-50.57 to 18.07)
33	Provide information on withdrawal symptoms	-0.06 (-25.39 to 15.42)	-6.91 (-54.04 to 40.22)
42	Behavior substitution	-0.07 (-27.65 to 16.65)	-5.25 (-64.82 to 54.32)
	Total BCTs	0.16 (-0.66 to 2.91)	6.29 (-13.28 to 25.87)
	Mention of evidence	0.22 (-2.25 to 29.85)	18.15 (-3.45 to 39.74)

[a] BCTs only included for analysis if present in more than two apps. The adjusted models included all variables listed in this table.

[b] Indicates *P*<.05.

The mention of evidence (B=0.26, *P*=.04, 95% CI 24.28-1739.31) was positively associated with the popularity of the apps in univariable regression models (Table 3). In a multivariable linear regression models, both “advise on/facilitate the use of social support” (B=2549.21, *P*=.04, 95% CI 96.75-5001.67) and the mention of evidence (B=1376.74, *P*=.02, 95% CI 208.62-2544.86) were positively associated with popularity.

Table 3. The association between BCTs, theory/evidence with popularity (number of ratings).

BCT		Unadjusted B (CI)	Adjusted B (CI)
1	Provide information on consequences of excessive alcohol use and drinking cessation	0.19 (-155.79 to 1148.02)	906.92 (-504.77 to 2318.61)
2	Boost motivation and self-efficacy	-0.06 (-1143.07 to 706.91)	-228.05 (-1723.82 to 1267.72)
3	Provide feedback on performance	0.2 (-138.23 to 1170.96)	410.01 (-1154.91 to 1974.93)
4	Provide rewards contingent on successfully reducing excessive alcohol use/abstaining	-0.03 (-1101.77 to 844.34)	-1362.93 (-2979.54 to 253.69)
6	Prompt commitment from the user there and then	-0.05 (-1563.56 to 1089.02)	-644.43 (-3452.1 to 2163.25)
10	Facilitate barrier identification and problem solving	-0.05 (-1570.16 to 1082.25)	-2150.59 (-6329.64 to 2028.46)
11	Facilitate relapse prevention and coping	-0.05 (-1574.65 to 1077.64)	2175.79 (-2007.23 to 6358.81)
13	Facilitate goal setting	0.05 (-849.23 to 1210.96)	828.87 (-872.37 to 2530.11)
14	Prompt review of goals	0.04 (-838.87 to 1107.13)	-751.26 (-2266.15 to 763.63)
15	Facilitate self-recording	0.15 (-264.74 to 1038.84)	547.11 (-904.17 to 1998.39)
17	Advise on environmental restructuring	-0.05 (-1441.99 to 950.81)	-1189.63 (-3632.18 to 1252.92)
20	Advise on avoidance of social cues for drinking	-0.05 (-1564.35 to 1088.21)	-2799.6 (-5916.7 to 317.49)
21	Advise on/facilitate use of social support	-0.05 (-1562.23 to 1090.37)	2549.21 (96.75 to 5001.67)[b]
22	Give options for additional and later support	0.2 (-149.92 to 1344.47)	-61.18 (-2383.46 to 2261.1)
23	Tailor interactions appropriately	-0.06 (-984.06 to 618.26)	-778.78 (-2154.21 to 596.65)
32	Offer/direct towards appropriate written materials	0.22 (-115.64 to 1410.65)	666.27 (-1190.03 to 2522.58)
33	Provide information on withdrawal symptoms	-0.06 (-1355.21 to 848.07)	-1868.23 (-4417.4 to 680.94)
42	Behavior substitution	-0.05 (-1440.49 to 952.36)	-1442.94 (-4665.2 to 1779.31)
	Total BCTs	0.07 (-70.01 to 124.48)	150.73 (-908.13 to 1209.58)
	Mention of evidence	0.26 (24.28 to 1739.31)[b]	1376.74 (208.62 to 2544.86)[b]

[a] BCTs only included for analysis if present in more than two apps. The adjusted models included all variables listed in this table.

[b] Indicates *P*<.05.

Discussion

Principal Findings

A review of 662 alcohol-related apps in the UK version of the iTunes and Google Play stores found that more than half were classified as entertainment apps that promoted drinking, 19% were BAC calculators, and 14% had an alcohol reduction focus. This is consistent with findings on alcohol-related apps available in the United States and Australian app stores [25,26] and indicates that potential app users who search for terms such as "alcohol" will be primarily exposed to apps encouraging increased alcohol consumption.

The BCTs most often used in alcohol reduction alcohol apps were (1) "facilitate self-recording" (included in 54% of apps), (2) "provide information on consequences of excessive alcohol use" (43%), (3) "provide feedback on performance" (41%), (4) "give options for additional and later support" (25%), and (5) "offer/direct towards appropriate written materials" (23%). The second, fourth, and fifth of these are information-based. This finding may indicate a missed opportunity for app developers, as interventions that require interaction from participants are associated with increased amounts of behavior change than interventions that passively present information [42].

Behavior change interventions are often complex and consist of a number of BCTs [43], which may interact additively or synergistically. For example, Control Theory [44] posits that goal-setting, feedback/self-monitoring, action planning, and goal review have synergistic effects. Interventions using a group of these techniques have been found to be more effective than interventions that used only one [45-47]. In alcohol reduction apps, "facilitate self-recording" and "provide feedback on performance" were found to be frequently used BCTs. However, other theory-linked BCTs were often not included: "prompt review of goals" was used in only 13% of apps, "facilitate goal setting" in 12%, and "facilitate action planning" in 5%.

The number of apps prompting the review of behavioral goals was greater than the number that facilitated goal setting, as in many cases apps assumed a user's behavioral goal was to get their drinking below recommended daily or weekly guidelines and displayed a graph to indicate how current levels of drinking compared to guidelines. Apps that facilitated goal setting allowed users to set their own goals, for example, to have a set number of non-drinking days each week. People are motivated by different types of goals [48] and self-set goals tend to result in greater commitment to goal achievement than assigned goals [49]. Together these studies suggest that apps that allow users to set their own goals and review their performance against them would be more successful, but only three apps met this criteria.

The mean number of BCTs from the alcohol taxonomy [30] included in the reviewed apps was less than four. Five apps included more than 10 BCTs, three of which were book or pamphlet-type apps that passively provided information or advice. More BCTs does not necessarily equate to more effective interventions; interventions that targeted lower-income groups to reduce smoking or increase physical activity and/or healthy eating were found to be more effective when they contained fewer BCTs [50]. Other reviews have found a positive relationship between the number of BCTs and weight loss [45] and that health behavior change interventions that included more BCTs tended to have larger effect sizes [51].

The relatively low number of BCTs used in the majority of apps in this study suggests there is scope to investigate whether including more BCTs could increase effectiveness and additionally, whether BCTs found to be effective when delivered face-to-face could be effective when delivered digitally. For example, “provide normative information about others’ behavior and experiences” has been found effective in reducing alcohol consumption when delivered digitally [52,53] but was used in less than 5% of the apps reviewed in the current study. “Motivational interviewing” is another frequently used BCT and has been used in a Web-based intervention to reduce alcohol consumption [54] indicating the possibility for it to be delivered digitally, but no apps included this technique. It will be important to establish whether any BCTs found to be effective in other modes of delivery generalize to app-based interventions.

The 22 BCTs frequently found in other health behavior change interventions [37] were rarely used in alcohol apps (mean 2.5). Social support is the BCT most frequently found in other interventions but was only used in 7% of alcohol apps. “Facilitate action planning” is a frequently used BCT in other interventions but was included in less than 5% of apps. Action planning has been found effective when combined with feedback [46], but none of the apps in this study included both techniques. This finding suggests that developers of alcohol apps may benefit from looking across other domains. In doing so, it is useful to draw on theory to guide the selection of BCTs for any given intervention.

The BCT “prompt review of goals” was positively associated with user ratings in univariable models, and “advise on environmental restructuring” was negatively associated with user ratings in multivariable models. The mention of evidence was positively associated with the popularity of the app in univariable models, and both the mention of evidence and “advise on/facilitate the use of social support” were positively associated with popularity in multivariable models. Apps that mentioned evidence usually referred to evidence relating to the recommended guidelines for consumption rather than evidence about the approach to behavior change adopted by the app. No app mentioned theory.

The current study provided relatively little evidence of association between BCTs, mention of theory or evidence, and the popularity or user ratings of apps. However, the failure to identify evidence of associations should not be taken as evidence that there are not true associations. The relatively small number of alcohol reduction apps available for analysis meant the study was exploratory and had only limited power.

It may be that other BCTs are associated with user ratings and popularity, but the large variation in the design, complexity, and functionality of apps and the contexts in which use occurs may be masking such associations [55]. An app with a large number of BCTs could be poorly built and so result in a poor user experience, negative ratings, and few downloads, whereas an app with few BCTs could be well built and result in a good user experience, positive ratings, and increased downloads. Careful experimental work in factorial designs is required to isolate and test the impact of BCTs and other app characteristics.

Strengths and Limitations

While previous studies have examined the type of alcohol-related apps that are available, this is the first to our knowledge to have examined the BCTs present in alcohol apps with an alcohol reduction focus. Documenting their content allows researchers to refine their future evaluations in terms of active ingredients and may help users to be better informed. It may also allow for future regulation of apps to be facilitated [23,24].

This study has several limitations. First, the presence of BCTs was coded but not their “dose” [56], that is, their intensity and whether or how often it was repeated, nor the quality with which it was delivered [57], which is likely to influence the degree with which it was engaged with by users. Engagement with a BCT is important if behavior change is to occur, but many digital interventions experience high levels of attrition [58]; more understanding of the ways in which users engage with mHealth apps is required. Second, the mHealth market is constantly evolving. New apps are added on a regular basis, and both Google and Apple frequently change their algorithms for returning search results. Therefore, these findings should be seen as representing a snapshot in time. Finally, the BCTs were identified by a taxonomy developed for face-to-face rather than digital interventions [30]. While an acceptable interrater reliability was established, the list may not be exhaustive and a similar method designed specifically for digital interventions is needed.

Conclusions

While a minority of alcohol-related apps promoted health, the majority implicitly or explicitly promoted the use of alcohol. Alcohol-related apps that focused on alcohol reduction usually contained few BCTs or few BCTs frequently found in other interventions, and their popularity or user ratings were only weakly related to their BCT content. None of the apps mentioned theory, and the few apps that mentioned evidence usually referred to evidence about guidelines. The popularity of these apps suggests that users may value content that makes explicit reference to evidence.

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Conflicts of Interest

JB has received an unrestricted research grant from Pfizer related to the surveillance of smoking cessation trends. RW has received research funding and undertaken consultancy for companies that manufacture smoking cessation medications.

Multimedia Appendix 1

Taxonomy of 42 BCTs used to treat excessive alcohol use. Tailored for apps.

[PDF File (Adobe PDF File), 23KB - jmir_v17i5e118_app1.pdf]

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Abbreviations

BAC: blood alcohol content
BCT: behavior change technique
PABAK: prevalance and bias adjusted kappa

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Original Paper

E-Mental Health Care Among Young Adults and Help-Seeking Behaviors: A Transversal Study in a Community Sample

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Abstract

Background: The Internet is widely used by young people and could serve to improve insufficient access to mental health care. Previous information on this topic comes from selected samples (students or self-selected individuals) and is incomplete.

Objective: In a community sample of young adults, we aimed to describe frequency of e-mental health care study-associated factors and to determine if e-mental health care was associated with the use of conventional services for mental health care.

Methods: Using data from the 2011 wave of the TEMPO cohort study of French young adults (N=1214, aged 18-37 years), we examined e-mental health care and associated factors following Andersen's behavioral model: predisposing factors (age, sex, educational attainment, professional activity, living with a partner, children, childhood negative events, chronic somatic disease, parental history of depression), enabling factors (social support, financial difficulties, parents' income), and needs-related factors (lifetime major depression or anxiety disorders, suicidal ideation, ADHD, cannabis use). We compared traditional service use (seeking help from a general practitioner, a psychiatrist, a psychologist; antidepressant or anxiolytics/hypnotics use) between participants who used e-mental health care versus those who did not.

Results: Overall, 8.65% (105/1214) of participants reported seeking e-mental health care in case of psychological difficulties in the preceding 12 months and 15.7% (104/664) reported psychological difficulties. Controlling for all covariates, the likelihood of e-mental health care was positively associated with 2 needs-related factors, lifetime major depression or anxiety disorder (OR 2.36, 95% CI 1.36-4.09) and lifetime suicidal ideation (OR 1.91, 95% CI 1.40-2.60), and negatively associated with a predisposing factor: childhood life events (OR 0.60, 95% CI 0.38-0.93). E-mental health care did not hinder traditional care, but was associated with face-to-face psychotherapy (66.2%, 51/77 vs 52.4%, 186/355, *P*=.03).

Conclusions: E-mental health care represents an important form of help-seeking behavior for young adults. Professionals and policy makers should take note of this and aim to improve the quality of online information on mental health care and to use this fact in clinical care.

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KEYWORDS

Internet; mental health services; young adult; epidemiology; health care disparities

Introduction

Background

As written by Hartzband and Groopman [1]: “Medicine has built on a long history of innovation, from the stethoscope and roentgenogram to magnetic resonance imaging and robotics. Doctors have embraced each new technology to advance patient care. But nothing has changed clinical practice more fundamentally than one recent innovation: the Internet. Its profound effects derive from the fact that while previous technologies were fully under doctors’ control, the Internet is equally in the hands of patients. Such access is redefining the roles of physician and patient.” The main impact of the Internet is through the virtually exponentially growing amounts of heath information [2]. The proportion of households with Internet access in Europe is high: 73% are equipped, 68% of Europeans use the Internet at least once a week, and 56% use it daily, although significant disparities are reported between countries [3].

E-mental health care, defined as “mental health services and information delivered or enhanced through the Internet and related technologies,” comprises 4 areas: information provision, screening, assessment and monitoring, and intervention and social support [4]. At present, the Internet is ranked higher as a source of information than as a source to trust, with health professionals remaining the most trusted sources of information for mental health problems [5]. A population survey conducted in the United Kingdom reported that 10.6% of youths had used the Internet to find out about mental health and this level reached 20.5% among those with a history of mental health problems [6]. Potential benefits of online health-information seeking are easy accessibility; absence of geographical boundaries; free access; interactivity; potential social support, personalization, anonymity, and privacy; and potential to address the gap between identified needs and limited resources. Nevertheless, several concerns exist: disparities in access to computers and the Internet, quality of online health information even though several studies show that it is reasonable [7-9], financial interests, and competition with conventional services [2,4]. Furthermore, there is insufficient evidence that e-mental health interventions are efficacious and valid, especially social media and communication sites [10]. However, for psychiatric patients, the importance of the Internet is now unquestionable, regardless of diagnosis, primarily for information provision [11].

The Internet is seen as a major medium for reaching contemporary young people [12]. There is no consensus regarding the definition of young adulthood in the 2 dominant life models of adulthood defined by Erikson (age range 20-40 years) [13] and Levinson (20-24, 24-29, and 30-39 years) [14] and in research (eg, 18-25 [15], 16-20 [16], 18-34 [17], or 15-39 [18] years have previously been considered as young adults). A recent paper defined young adulthood as the period between ages 20 and 24 years, arguing about the relevance of this period regarding development: physical development (young women are typically fully developed physically; young men continue to gain height, weight, muscle mass, and body hair), cognitive development (ability to think ideas through from beginning to end, to delay gratification, to examine inner experiences, increased concern for the future, continued interest in moral reasoning), and social and emotional development (sense of identity, including sexual; increased emotional stability, concern for others, and independence and self-reliance; importance on peer relationships; more serious relationships; regain some interest in social and cultural traditions) [19].

Mental heath issues are challenging at that age because anxiety, mood, or substance use disorders tend to be frequent (75% of lifetime cases emerge by age 24 years, most anxiety disorders occur between 11 and 15 years, most substance-misuse disorders between 19 and 21 years, and mood disorders between 24 and 30 years [19-21]). Because of unsatisfactory mental health care access, only 18% to 34% of young people with high levels of symptoms of depression or anxiety seek professional help [15]. In the European Study of the Epidemiology of Mental Disorders (ESEMeD) survey conducted in Europe, compared to participants older than 65 years, participants aged 18 to 24 years were least likely to get care for mental health problems followed by participants aged 25 to 34 years [22]. Young adults born after 1993 (when the Internet became widely available) have been referred to as digital natives because they are fundamentally different from previous generations in that they grew up with the Internet. The Internet is completely natural to digital natives, is a key part of their lives, and a predominant source of health information [23]. A recent systematic review investigated the effectiveness of online services in facilitating mental health help seeking in young people aged 14-25 years [24]. In all, 38.4% reported seeking mental health information on the Internet, but these data came from selected samples (students or self-selected individuals) and from selected countries (9 studies were conducted within Australia; 3 in the United States; 2 in Canada; 1 in Germany, Ireland, Norway, United Kingdom; and none in France). This review concluded that online mental health services may conceivably assist in all elements of the help-seeking process and invited further research to examine the effectiveness of e-mental health care, how it interacts with face-to-face services, and whether the use of online services can overcome barriers to mental health care and increase help-seeking behavior.

Since this review was published, 2 studies provided more information about the use of the Internet by young adults for mental health difficulties. According to a Spanish study conducted among a sample of students, entering keywords into a search engine, portal, or Internet Service Provider was the most frequently used procedure, with usually no attention to the date or the origin of the information and with a strong distrust in online mental health information [25]. According to a Canadian study among youth aged 17-24 years (87% students), when using the Internet for information-seeking purposes, the 3 most common features were looking for information about symptoms (52.4%), for treatment options (47.4%), and for assessment tests (23.8%) [26]. In France, 99% of people aged 12-24 years and 96% of those aged 25-39 years have access to the Internet [27]. A nationally representative study conducted in France established that 48.5% of young adults aged 15-30 years used the Internet to look for health information and one-third report having changed their health behaviors because of their online searches; however, this study did not investigate e-mental health care [28].

Objectives

In this investigation, conducted in a community sample of young adults in France, we aimed to (1) describe the frequency of e-mental health care for psychological difficulties; (2) determine associated health access factors according to Andersen's behavioral model: predisposing, enabling, and needs-related factors [29]; and (3) determine the association between e-mental health care and conventional services.

Methods

Study Sample

Our sample comes from the Trajectoires Épidémiologiques en Population (TEMPO) study and comprised young adults defined as ages 18-37 years within the classes of the 2 dominant life models of adulthood: Erikson (age range 20-40 years) [13] and Levinson (20-24, 24-29, and 30-39 years) [14], and larger than a more recent definition (20-24 years) [19]. The TEMPO study launched in 2009 and includes a sample of young adults in France whose parents took part in the Gaz et Electricité (GAZEL) epidemiological cohort study, composed of 20,625 employees of a large French public sector utility company, Électricité de France-Gaz de France (EDF-GDF), the French national gas and electricity companies [30-37]. The TEMPO cohort has been described in detail elsewhere [38]. Briefly, the study was set up in 2009 among young adults aged 22-35 years, whose parents participated in the GAZEL cohort study and who took part in a study of children's mental health in 1991 and 1999 (the GAZEL Youth study). In 2011, all TEMPO study participants and other offspring of GAZEL cohort participants aged 18-37 years were invited to take part in the TEMPO study. The 2011 sample (n=1214) included 526 individuals who took part in the 2009 TEMPO study assessment and agreed to be followed up (70.1% participation) and 688 new members (14.4% participation). In 2011, data were collected via a 30-minute phone interview assessing their health, health behaviors, access to health care, and socioeconomic and life circumstances. Study participants unable to take part in the phone interview were invited to complete the study questionnaire online [38-42]. The TEMPO study received approval from France's national committees for data protection (Comité Consultatif sur le Traitement des Informations pour la Recherche en Santé, Commission Nationale Informatique et Liberté).

Measures

E-mental health care was assessed by the following question: "In the preceding 12 months, did you consult the Internet for a psychological problem?" (yes/no/I did not have psychological problem). In addition, several factors potentially associated with e-mental health care use were investigated:

1. Predisposing factors: sex, age in 2011(<30 or ≥30 years; we chose arbitrarily to split at 30 years because it was in the middle of the age range of our sample), educational attainment (<high school diploma vs ≥high school diploma), family situation living with a partner (yes vs no), lifetime unemployment (yes vs no), childhood negative events (family conflicts, bullying, lack of affection; yes vs no), chronic somatic disease (obesity, diabetes, digestive disease, cancer, and epilepsy), and parental depression based on parents' reports of treated depression on the yearly GAZEL study assessments from 1989 to 2011 (yes vs no) [43,44] and TEMPO participants' reports regarding their parents on the Family Interview for Genetic Studies (yes vs no) [45].
2. Enabling factors: self-reported financial difficulties (yes vs no), self-reported income (<€2600 vs >€2600 per month), and social support as measured using the Berkman Social Networks and Social Support questionnaire (insufficient vs sufficient) [46].
3. Needs-related factors: presence of a mental health disorder ascertained using the Mini-International Neuropsychiatric Interview (MINI), a short structured clinical interview allowing researchers to diagnose psychiatric disorders according to the International Classification of Diseases (ICD-10). We assessed whether participants had major depression, panic, phobia, or generalized anxiety disorder in the preceding 12 months [47]. Additionally, lifetime suicidal ideation, attention deficit and hyperactivity disorder (ADHD) using the French version of the ADHD Self-Report Scale (ASRS) [48], and lifetime cannabis abuse were ascertained.

Help seeking from a general practitioner (GP), a psychiatrist, or a psychologist and antidepressant or anxiolytics/hypnotics use in lifetime were also assessed.

Statistical Analysis

Following descriptive analyses, we tested associations between factors described in Andersen's model and e-mental health care using (1) bivariate chi-square tests (categorical variables) and *t* tests (continuous variables) and (2) logistic regression models controlled for all factors associated with the study outcome in bivariate models (significant at $P<.20$ in order to control for as many potentially relevant covariates as possible). We repeated analyses weighing factors associated with study participation to verify the robustness of our results after correction for selection bias [49]. Then we compared traditional service use between participants who used online information versus those who did not with bivariate chi-square tests. Data were analyzed using SAS v9.3 (SAS Institute Inc, Cary, NC, USA).

Results

Of the 1214 TEMPO Participants, 664 reported psychological difficulties and documented whether they used the Internet or not. Their mean age was 30.8 (SD 3.8) years, 72.7% (483/664) were female, 5.0% (33/657) were students, 63.7% (389/611) worked in a high occupational grade, 43.7% (290/664) lived with a partner, 66.0% (438/664) reported sufficient social support, and 12.4% (82/664) had a common mental health disorder (Table 1).

Table 1. Descriptive analyses of TEMPO young adults who reported psychological difficulties and comparison analyses between those who used and did not use e-mental health.

Associated factors	Total sample, n (%) N=664	E-mental health, n (%) n=104	No e-mental health, n (%) n=560	χ^2 (*df*)[a]	*P*
Predisposing factors					
Age (years)				0.5 (1)	.49
<30	198 (29.8)	34 (17.2)	164 (82.8)		
≥30	466 (70.2)	70 (15.0)	396 (85.0)		
Gender				0.2 (1)	.69
Female	483 (72.7)	74 (15.3)	409 (84.7)		
Male	181 (27.3)	30 (16.6)	151 (83.4)		
Education				0.5 (1)	.47
High school or less	238 (35.8)	34 (14.3)	204 (85.7)		
Beyond high school	426 (64.2)	70 (16.4)	356 (83.6)		
Marital status				0.9 (1)	.34
Living in couple	290 (43.7)	41 (14.1)	249 (85.9)		
Living alone	374 (56.3)	63 (16.8)	311 (83.2)		
Students				0.3 (1)	.56
Yes	33 (5.0)	4 (12.1)	29 (87.9)		
No	624 (95.0)	99 (15.9)	525 (84.1)		
Unemployed				0.7 (1)	.40
Yes	332 (50.1)	56 (16.9)	276 (83.1)		
No	331 (49.9)	48 (14.5)	283 (85.5)		
Child event				1.8 (1)	.18
Yes	334 (50.3)	46 (13.8)	288 86.2		
No	330 (49.7)	58 (17.6)	272 82.4		
Somatic chronic disease				2.3 (1)	.13
Yes	159 (24.0)	31 (19.5)	128 (80.5)		
No	505 (76.1)	73 (14.5)	432 (85.5)		
Parental depression				0.8 (1)	.38
Yes	112 (20.0)	20 (17.9)	92 (82.1)		
No	447 (80.0)	65 (14.5)	382 (85.5)		
Enabling factors					
Financial difficulties				0.1 (1)	.82
Yes	155 (23.4)	25 (16.1)	130 (83.9)		
No	508 (76.6)	78 (15.4)	430 (84.7)		
Parental income (€)				0.6 (1)	.43
<2600	384 (59.6)	52 (13.5)	332 (86.5)		
≥2600	260 (40.4)	41 (15.8)	219 (84.2)		
Social support				0.7 (1)	.42
Sufficient	438 (66.0)	65 (14.8)	373 (85.2)		
Insufficient	226 (34.0)	39 (17.3)	187 (82.7)		
Needs factors					
Depression or anxiety disorder				13.1 (1)	<.001

Associated factors	Total sample, n (%) N=664	E-mental health, n (%) n=104	No e-mental health, n (%) n=560	χ^2 (*df*)[a]	*P*
Yes	82 (12.4)	24 (29.3)	58 (70.7)		
No	582 (87.7)	80 (13.8)	502 (86.3)		
Lifetime cannabis use				0.0 (1)	.99
Yes	418 (63.3)	64 (15.3)	354 (84.7)		
No	242 (36.7)	37 (15.3)	205 (84.7)		
ADHD				3.3 (1)	.07
Yes	57 (11.6)	14 (24.6)	43 (75.4)		
No	435 (88.4)	66 (15.2)	369 (84.8)		
Suicidal ideation				12.7 (1)	<.001
Yes	260 (39.2)	57 (21.9)	203 (78.1)		
No	404 (60.8)	47 (11.6)	357 (88.4)		

[a] Chi-square test between young adults who reported using e-mental health care and young adults who did not use e-mental health care.

In all, 8.65% (105/1214) of study participants reported ever using the Internet for psychological difficulties. Among participants who reported psychological difficulties, the prevalence was 15.7% (104/664).

In the bivariate analyses (Table 1), e-mental health care was not significantly associated with any of the predisposing or enabling factors studied but was associated with 2 needs-related factors: the presence of a common depressive or anxious mental health disorder (*P*<.001) and lifetime suicidal ideation (*P*<.001).

In the multivariate analyses (Table 2), 3 variables were significantly associated with e-mental health care: childhood negative events (OR 0.6, 95% CI 0.38-0.93), the presence of a common mental health problems (OR 2.36, 95% CI 1.36-4.09), and lifetime suicidal ideation (OR 2.07, 95% CI 1.33-3.23). This model explained 9.3% of the total variance.

Table 2. Factors associated with seeking e-mental health care through multiple logistic regression analysis (N=664).

Factors	OR (95% CI)	*P*
Gender		.81
Male	1	
Female	0.95 (0.59-1.52)	
Age (years)		.52
<30	1	
≥30	0.86 (0.54-1.36)	
Negative childhood event		.02
No	1	
Yes	0.60 (0.38-0.93)	
Anxiety or depressive disorder		.002
No	1	
Yes	2.36 (1.36-4.09)	
Suicidal ideation		.001
No	1	
Yes	2.07 (1.33-3.23)	

Young adults who reported using e-mental health care were not different from those who did not report use in terms of actual help seeking from GPs or from psychiatrists, and in antidepressant or anxiolytics/hypnotics use. Young adults who reported using e-mental health care sought more help from psychologists than those without e-mental health care (66.2%, 51/77 vs 52.4%, 186/355, *P*=.03) (Table 3).

Table 3. E-mental health care use and seeking help in traditional health care (N=664).

Mental health care	E-mental health, n (%) n=104	No e-mental health, n (%) n=560	*P*
GP help seeking			.07
No	25 (32.0)	154 (43.1)	
Yes	53 (68.0)	203 (56.9)	
Psychiatrist help seeking			.43
No	44 (59.5)	229 (64.3)	
Yes	30 (40.5)	127 (35.7)	
Psychologist help seeking			.03
No	26 (33.8)	169 (47.6)	
Yes	51 (66.2)	186 (52.4)	
Antidepressant use			.99
No	76 (73.1)	409 (73.0)	
Yes	28 (26.9)	151 (27.0)	
Anxiolytics/hypnotics use			.11
No	52 (50.0)	327 (58.4)	
Yes	52 (50.0)	233 (41.6)	

Discussion

Principal Findings

In a community sample of French young adults, we found that 8.65% (105/1214) reported seeking e-mental health care in the preceding 12 months and this prevalence reached 15.7% (104/664) in the case of common mental health problems. The likelihood of e-mental health care was associated with 2 needs-related factors, common mental health problems (OR 2.36, 95% CI 1.36-4.09) and lifetime suicidal ideation (OR 2.07, 95% CI 1.33-3.23), and was negatively associated with a predisposing factor, childhood negative events (OR 0.6, 95% CI 0.38-0.93). E-mental health care does not hinder conventional care; young adults who reported using e-mental health care were not different from those who did not in terms of seeking help from a GP, a psychiatrist, or in terms of antidepressant or anxiolytics/hypnotics use. To the contrary, they sought help from psychologists more frequently than young adults who did not seek e-mental health care (66.2%, 51/77 vs 52.4%, 186/355, *P*=.03).

Frequency of E-Mental Health Care

The frequency of e-mental health care use is lower than reported in other countries for young people (mean 38.4%, range 18%-53% according to a recent review) [24]. This may be due to differences between study samples (students, self-selected samples, sample drawn from the community with only 5% students and differences in age range; mean age of participants for the studies was 16.5-26.2 years vs 18-37 years in this study). Our percentage is closer to the 10.6% (20.0% in case of mental health problems) reported in England in young adults older than 18 years [6]. At the international level, lower Internet use has already been reported in France for health information provision among young people in a representative sample from the general population [28].

Andersen’s Model for Young Adults’ E-Mental Health Care

Results about factors associated with Internet use are in-line with previous studies. We verified that needs factors are the most important, common mental health disorders and lifetime suicidal ideation, and contrary to previous studies, we measured for the first time mental health disorders with specific standardized tools [6,50]. Our results are also in-line with previous studies of Andersen’s model applied to traditional health care service utilization for the most prevalent mental disorders, showing 2 major needs-related factors (emotional problems, number of mental disorders) [29,51,52]. If personal income was a barrier in service utilization, it is not a barrier for Internet use [51]. Additionally, we did not find the gender barrier to online services reported elsewhere [12,24,25,28,50,53].

It is the first time that a study examined the relative role of childhood negative events as a predisposing factor for e-mental health care. Previous studies found that childhood adverse experiences were associated in adulthood with higher care use, for somatic care [54], or for mental health care [55]. Our results, indicating a weaker utilization of e-mental health care, could signify less active treatment seeking among adults with a history of childhood adverse experiences and is associated with an increased risk of multiple health risk behaviors [56,57].

Association With Traditional Services

As reported in previous studies, e-mental health care does not hinder traditional care [58]. We confirm that young people are “using online help seeking in combination with other services, rather than substituting online services for other resources” [24].

To the contrary, e-mental health care appears to be a step in the help-seeking process toward conventional mental health care. Several reasons can be proposed. First, e-mental health care could enhance mental health literacy [59]. Second, it could increase health empowerment and contribute to a more active attitude, which is necessary in psychotherapy [60]. The Spanish study among nursing students identified a profile of the few young adults (approximately 14%) who reviewed mental health information on the Internet instead of going to a doctor: mainly female, aged between 18 and 24 years, not living with their family, and living in the countryside [25]. In this Spanish student sample, the use of at least 1 online tool for mental health care concerned 97.7% of people having seen at least 1 health professional in the past year and 11.5% of those who has seen 1 psychologist or psychiatrist or counselor in the past year [25].

Limitations

We acknowledge some limitations. The first is selective nonresponse in our community sample, which resulted in a higher proportion of young adults in high occupational grade jobs and with higher education than among young adults in France; nonetheless, unemployment rates in the study were comparable to the general population [61] and our main results were unchanged even when analyses were weighted to correct for factors associated with study participation. Second, we were not able to measure all Andersen's model factors because we did not have information about important Internet-specific enabling factors (access, familiarity, and high-speed access) [6,50]. We hypothesize that they are unlikely to show high levels of variation and we were able to consider the model's main factors [29]. Third, we lack information about the types of online services young people consulted and whether they were satisfied with the e-mental health care.

Conclusion

In France, e-mental health care is a method of help-seeking behavior for young adults, even for those in the general population. Mental health professionals and policy makers must take note of its role. To begin, physicians have to figure out how best to use this fact to foster therapeutic alliance. They are in the best position to weigh information from the Internet and to advise patients in their particular situations [1].

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Authors' Contributions

NY conceived of the study, participated in its design, and drafted the manuscript. AC participated in the design of the study and supervised the study and statistical analyses. EM performed statistical analyses. MM is the scientific director of the TEMPO study and participated in the design, in the analyses of the study, and in the English revision. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

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Abbreviations

ADHD: attention deficit and hyperactivity disorder
ASRS: ADHD Self-Report Scale
ESEMeD: European Study of the Epidemiology of Mental Disorders
GAZEL cohort: Gaz et Electricité cohort
GP: general practitioner
IReSP: Institut de la Recherche en Sante Publique
MINI: Mini-International Neuropsychiatric Interview
TEMPO cohort: Trajectoires Épidémiologiques en Population cohort

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Original Paper

Disease Detection or Public Opinion Reflection? Content Analysis of Tweets, Other Social Media, and Online Newspapers During the Measles Outbreak in the Netherlands in 2013

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Abstract

Background: In May 2013, a measles outbreak began in the Netherlands among Orthodox Protestants who often refuse vaccination for religious reasons.

Objective: Our aim was to compare the number of messages expressed on Twitter and other social media during the measles outbreak with the number of online news articles and the number of reported measles cases to answer the question if and when social media reflect public opinion patterns versus disease patterns.

Methods: We analyzed measles-related tweets, other social media messages, and online newspaper articles over a 7-month period (April 15 to November 11, 2013) with regard to topic and sentiment. Thematic analysis was used to structure and analyze the topics.

Results: There was a stronger correlation between the weekly number of social media messages and the weekly number of online news articles (*P*<.001 for both tweets and other social media messages) than between the weekly number of social media messages and the weekly number of reported measles cases (*P*=.003 and *P*=.048 for tweets and other social media messages, respectively), especially after the summer break. All data sources showed 3 large peaks, possibly triggered by announcements about the measles outbreak by the Dutch National Institute for Public Health and the Environment and statements made by well-known politicians. Most messages informed the public about the measles outbreak (ie, about the number of measles cases) (93/165, 56.4%) followed by messages about preventive measures taken to control the measles spread (47/132, 35.6%). The leading opinion expressed was frustration regarding people who do not vaccinate because of religious reasons (42/88, 48%).

Conclusions: The monitoring of online (social) media might be useful for improving communication policies aiming to preserve vaccination acceptability among the general public. Data extracted from online (social) media provide insight into the opinions that are at a certain moment salient among the public, which enables public health institutes to respond immediately and appropriately to those public concerns. More research is required to develop an automatic coding system that captures content and user's characteristics that are most relevant to the diseases within the National Immunization Program and related public health events and can inform official responses.

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KEYWORDS

Internet; Web 2.0; measles; infectious disease outbreak; Netherlands; vaccination

Introduction

In May 2013, a measles outbreak began in the Netherlands among Orthodox Protestants who often refuse vaccination for religious reasons [1].

In the Netherlands, the National Immunization Program (NIP) offers childhood vaccinations free of charge and vaccinations are not compulsory. Overall, the vaccination coverage among children up to age 4 years is high in the Netherlands and somewhat lower for boosters in children aged 4 and 9 years [2]. Since 1987, children have been offered vaccination against measles, mumps, and rubella in a 2-dose schedule at 14 months and 9 years of age, with a coverage of 96% and 93%, respectively [2]. Vaccination coverage among Orthodox Protestants was assessed in 2006-2008 and was found to be approximately 60% [3]. Orthodox Protestants are a close-knit community in the Netherlands, consisting of approximately 250,000 individuals. Predestination is an important doctrine in their belief and refusal of vaccination is based on the idea that people should not interfere with divine providence [4]. Other groups in the Netherlands that partly refuse measles vaccination include Anthroposophists and those with critical stances toward vaccination in general [5-6].

At the end of the outbreak, in February 2014, the incidence of measles was 0.16 per 1000 (2640 measles cases) in the Netherlands, resulting in more than 180 hospitalizations (approximately 7% of measles cases). In October 2013, a death occurred in a girl aged 17 years who was not vaccinated for religious reasons. The number of reported cases began to decline in October 2013 and at the end of February 2014, the National Institute for Public Health and the Environment (RIVM) announced the outbreak was over. Additional control measures implemented in July 2013, such as offering early vaccinations to children aged between 6 and 14 months of age living in municipalities with a low vaccination coverage (<90%), were ended.

The outbreak led to heated debates in traditional and social media. At the start of the measles outbreak, RIVM was asked for weekly updates of reported measles cases. In addition, some well-known politicians made public statements, such as “parents should take their responsibility and vaccinate their children” [7] and “clergymen should call for vaccinating their religious community” [8].

Outbreak patterns and related public opinions expressed in mass media channels are likely to diverge simply because not all epidemiological data are equally relevant in terms of news value. The traditional media agenda is determined by news value [9]; for example, the first severe case in an outbreak generally generates more media attention than later reported cases even if later cases are higher in numbers. Likewise, the start of an epidemic is generally more newsworthy than the peak of an epidemic because of the uncertainty involved at the beginning of an outbreak. Agenda-setting theory proposes that public opinion generally follows the (traditional) media agenda; the media does not determine what people think, but they do determine what people think about [10].

Social media can also be a rich source for researchers. Previous research has suggested a relationship between the number of influenza-related tweets and reported number of influenza-like illness [11-13]. Previous research has also suggested a relationship between social media and public opinion for influenza outbreaks such as H1N1 [13,14]. Results from these studies showed that H1N1-related tweets were primarily used to spread information from credible sources, but it also offered a platform for the exchange of opinions and experiences among the public. Variations in responses to different disease outbreaks was shown by Fung et al [15] who found the social media response among Chinese people to the H7N9 outbreak was 2-fold higher compared to the Middle East Respiratory Syndrome Coronavirus (MERS-CoV) outbreak. Therefore, analyzing social media appears useful in gaining insight into public opinion and/or disease patterns although it remains unclear to what extent previous findings generalize across different outbreaks.

Given that epidemiological patterns are likely to diverge from traditional media patterns and that previous social media research has focused on either disease detection or public opinion, the question remains if and when social media data reflect public opinion patterns versus disease patterns. This research aims to answer this question for the measles outbreak by investigating traditional and social media patterns across time and comparing these to reported measles cases. Our hypothesis is that because people generally use Twitter for spreading news and because the measles outbreak was highly publicized, the number of social media messages will show stronger convergence with the number of traditional media messages than with the epidemic curve (number of reported cases).

A second goal of this research was to analyze the content and specific sentiments expressed on Twitter, other social media, and online newspapers to detect factors that might affect intentions to vaccinate [16] and emotional states that might mediate vaccination behavior [17,18], and meaningful fluctuations in these factors over time. Jones et al [17] found that levels of anxiety waned along with the perception of the influenza A (H1N1) virus as an immediate threat. Translated to the measles outbreak, this research aimed to assess whether real-world events trigger significant increases or decreases in vaccination behavior-related sentiment such as expressed concern.

To summarize, adding to previous analyses of social media with regard to infectious disease outbreaks, this study aimed to compare the number of social media messages with the number of online news articles and with the epidemiological curve (ie, the number of reported measles cases) and assess the usefulness of social media in tracking factors that might affect vaccination behavior.

Methods

Data From Online (Social) Media

Because we were interested in discussions on online (social) media during the measles outbreak in the Netherlands in 2013, we used the search term “mazelen” (ie, measles; there are no synonyms used in the Dutch language) to select messages from online media. Data were gathered from April 15, 2013 (ie, 15 days before the start of the measles outbreak) to November 11, 2013 (ie, 14 days after the report of the measles-related death on October 28, 2013).

Articles from online newspapers were retrieved via LexisNexis and HowardsHome [19], tweets were retrieved via Twiqs.nl (free analytic Dutch tool for tweets [20]) and HowardsHome, and messages from other social media were also retrieved from HowardsHome. We could not get information about the data mining approaches used by the 2 companies LexisNexis and HowardsHome. For Twiqs.nl we used the data mining approach as has been described by Tjong Kim Sang [20]. Social media included messages from websites such as forums, weblogs, Facebook, and others (eg, advertisements, comments, information sites, status updates, podcasts, reviews/evaluation of products, social photo websites, social video websites, and wikis). For the selected articles in the newspapers (which were published online but were also available in paper version), all the national newspapers in the Netherlands were checked (ie, *NRC Handelsblad*, *De Volkskrant*, *Trouw*, *De Telegraaf*, *Algemeen Dagblad*, *Spits*, and *Metro*). We also included the religious-oriented newspapers *Reformatorisch Dagblad* and *Nederlands Dagblad*.

Data on Measles Cases

Data on the number of measles cases were retrieved from the notification data of measles by the RIVM. The measles case definition of the European Centre for Disease Prevention and Control was used [21]. A measles case was defined if the person met the clinical criteria: fever and maculopapular rash and at least one of (1) cough, (2) coryza, or (3) conjunctivitis, and at least one of the laboratory criteria (1) isolation of measles virus from a clinical specimen, (2) detection of measles virus nucleic acid in a clinical specimen, (3) measles virus-specific antibody response in serum or saliva, or (4) detection of measles virus antigen by direct fluorescent antibody in a clinical specimen using measles-specific monoclonal antibodies (laboratory results need to be interpreted according to the vaccination status). A measles case could also be defined if the reported case did not meet the clinical and laboratory criteria but met the epidemiological criteria: an epidemiological link by human-to-human transmission (ie, contact less than 3 weeks ago with an identified measles case).

Manual Topic and Sentiment Analyses

Data analysis was started by estimating the relative proportion of weekly online media messages and reported measles cases from April 15 to November 11, 2013, by scaling the numbers to the highest peak for all 4 data sources. The highest peak was assigned a score of 100. The reported measles cases by week of onset of exanthema were gathered to plot against the number of weekly media messages to see whether media followed the epidemiological curve. Tweets and retweets were analyzed together. To compare weekly number of online (social) media messages with one another and with weekly number of reported measles cases, Pearson correlations were calculated between the different sources using SAS 9.1.3 (SAS Institute Inc, Cary, NC, USA).

Furthermore, we analyzed the content of the messages (ie, topic) and how the messages were expressed (ie, sentiment). For each data source, the title was used for determining the topic and sentiment; if this was not clear or did not match with the summary, then the summary was used for determining the topic and sentiment. Note, for tweets, both title and summary contained the whole tweet. For newspaper articles and other social media messages retrieved via HowardsHome, the summary contained a maximum of 500 words. There was no minimum number of words. To identify the topics, thematic analysis was performed [22]. The process of coding and the development of themes were inductive in nature. A codebook was developed and initial codes provided various topics (n=25). On review and discussion, infrequently used (sub) topics were collapsed into larger (main) topics (n=8). Table 1 shows the topics and subtopics that emerged from the data with examples from tweets, other social media, and online newspapers.

The sentiments in the online newspaper articles generally differed from the sentiments in tweets and other social media messages. The sentiments for online newspaper articles fit better with objective nonjudgmental messages, whereas the sentiments for social media fit better with more personal and opinionated messages. Sentiments for online newspaper articles were, therefore, based on the classification used by Vasterman & Ruigrok [23], which included the following 3 sentiments: alarming (eg, “Teenager dead by measles infection”), reassuring (eg, “Start of extra vaccinations against measles”), and neutral / no sentiment / both alarming and reassuring (eg, “Measles epidemic has stabilized”). The sentiments for tweets and other social media messages were based on the article by Chew & Eysenbach [14], which emerged from analyzing their H1N1-related tweets. The sentiments included, among others, frustration, humor/sarcasm, concern, relief, question, minimized risk, information, and personal experiences. If the message contained more than one sentiment, the first sentiment identified was chosen. Table 2 shows examples of tweets and other social media messages for these various sentiments.

Table 1. Topics and subtopics (between parentheses) of tweets, other social media, and online newspapers about the measles outbreak or perceived risks.

Topic	Definition	Example (tweet, other social media, online newspaper)
Measles outbreak (including number of reported measles cases, measles deaths, people experiencing measles, and consequences of measles infection [including hospitalizations])	Objective information about the measles outbreak	“Number of measles cases has increased to 161” (online newspaper)
Refusing vaccination because of religious reasons	Opinions about persons refusing vaccination for religious reasons	“Unbelievable that the love for God can be greater than the love for your own child” (tweet)
Critical toward vaccination	Opinions about persons who are critical toward vaccination (eg, Anthroposophists)	“To remember: also followers of Rudolf Steiner (anthroposophical theory) and the Dutch society for conscientious vaccination are very much against vaccination! Also their children are taking a risk at getting measles” (other social media)
Perceived risks (including perceived severity of measles disease and not vaccinating against measles, adverse events, effectiveness of measles vaccine)	How public perceives risks of measles disease and measles vaccine	“That [ie, measles] was not that severe at all, I have experienced flu disease, which was much more severe” (other social media)
Measles prevention (including additional vaccinations, maternal measles antibodies, obligatory vaccination, vaccinating secretly, vaccinating employees, vaccinating religious people)	Preventive measures taken to control the measles spread	“Young adult without a measles vaccination cannot camp during summer” (tweet)
Trust and role institutions (including role of government, role of media, conspiracies)	No trust in information supply, should government interfere in whether people should vaccinate or not, and allegations about production of vaccines and vaccine components	“Subtle lies about measles by the RIVM? Naïveté?” (tweet)
Other	If it did not belong to one of the topics above	“What makes that the school exam and a measles infection are similar? Only children are affected!” (tweet)
Information not related to measles outbreak	If it had nothing to do with the measles outbreak or a relation with the measles outbreak could not be found	“The mortality of dolphins on the East coast of the USA is caused by a measles-related virus” (tweet)

Table 2. Sentiments of tweets and other social media messages about information or frustration.

Sentiment	Definition	Example (tweet/other social media)
Frustration	Tweet/message contains anger, irritation, contempt, criticism, or source is flabbergasted	"How stupid can you be by not vaccinating your children against measles" (tweet)
Humor/sarcasm	Tweet/message is funny or expresses sarcasm	"HAHAHAHAHAHA. He had drawn red spots on his head and said: 'oooooh I have measles'" (tweet)
Concern	Tweet/message contains fear, concern, anxiety, worry, or grief about themselves or others	"Around me many vaccinated children with measles. A bit strange and alarming I think. Is there something known about this by the RIVM?" (tweet)
Relief	Tweet/message contains joy, happiness, or relief	"Thank God we are a liberal country (ie, that we have a choice to vaccinate or not)" (other social media)
Question	Tweet/message contains a question or questions for which the user would like to receive an answer	"This you probably know: what happens when you get measles? Do you need treatment or does it go away spontaneously" (tweet)
Minimized risk	Tweet/message minimizes the risk of measles infection and/or the possible complications	"That [ie, measles] was not that severe at all, I have experienced flu disease, which was much more severe" (other social media)
Information	Tweet/message contains information, informative retweets, and/or other information sources about measles	"RIVM expects more measles cases because school holidays are over" (tweet)
Personal experience	Tweet/message contains a personal experience/story about the disease without expressing any concerns	"My daughter has had encephalitis as a complication of an unknown virus infection" (other social media)
Other	Tweet contains none of the above 8 sentiments	"At the left wing also a number of persons are not vaccinating because of other reasons" (other social media)
Information not related to measles outbreak	Tweet has nothing to do with the measles outbreak or a relation with the measles outbreak could not be found	"The mortality of dolphins on the East coast of the USA is caused by a measles-related virus" (tweet)

For coding purposes, we limited the number of tweets and other social media messages by selecting every tenth tweet or message. This resulted in 2020 of 20,201 tweets in total and 552 of 5521 other social media messages in total. The number of tweets not related to the measles outbreak was 38 of 2020 (1.88%); therefore, the total number of tweets used for the analyses was 1982 of which 626 (31.58%) were retweets. The number of other social media messages unrelated to the measles outbreak was 88 of 5521 (15.94%); therefore, the total number of messages used for the analyses was 464. To be able to compare the topics of tweets with the topics of other social media messages and online newspaper articles, we again selected every tenth tweet of the 2020 tweets mentioned previously, which resulted in 202 tweets of which 6 tweets were not related to the measles outbreak and were excluded from the analysis. We analyzed retweets separately from tweets because retweets might provide insight into what people find interesting and important.

The topics and sentiments were coded for all measles-related online newspaper articles found (n=351). The number of online newspaper articles analyzed was 282 because 69 (19.7%) were unrelated to the measles outbreak. Of the 282 articles, 79 were published in the 2 religious-oriented newspapers and 203 were published in the 7 nonreligious-oriented newspapers. Both the topic and sentiment were only available for the articles in these 2 religious-oriented newspapers.

Each message was coded independently by 2 raters to establish coding reliability (ie, Cohen's kappa with values <0 indicating no agreement, 0-.20 indicating slight agreement, .21-.40 indicating fair agreement, .41-.60 indicating moderate agreement, .61-.80 indicating substantial agreement, and .81-1 indicating almost perfect agreement [24]). During coding of the sentiments of tweets and coding of the sentiments and topics of other social media messages, there were some differences in insights between the raters. Regarding interpretation of tweets, one of the raters coded part of the tweets as concerned tweets whereas the other 2 raters (ie, each rater coded two-thirds of the tweets) coded these tweets as informative tweets. Regarding interpretation of other social media messages, one of the raters interpreted the other social media messages about refusing vaccination because of religious reasons differently compared to other raters. Another rater interpreted informative messages as neutral messages. After discussing these differences, informative messages (both tweets and other social media messages) and the other social media messages with the topic refusing vaccination because of religious reasons were recoded and the kappa was estimated. For tweets, the kappas for sentiment and topic were .79 and .77, respectively. For other social media, the kappas for sentiment and topic were .58 and .65, respectively. For online newspapers, the kappas for sentiment and topic were .80 and .81, respectively.

Results

Comparing Number of Measles Cases and Online (Social) Media Messages

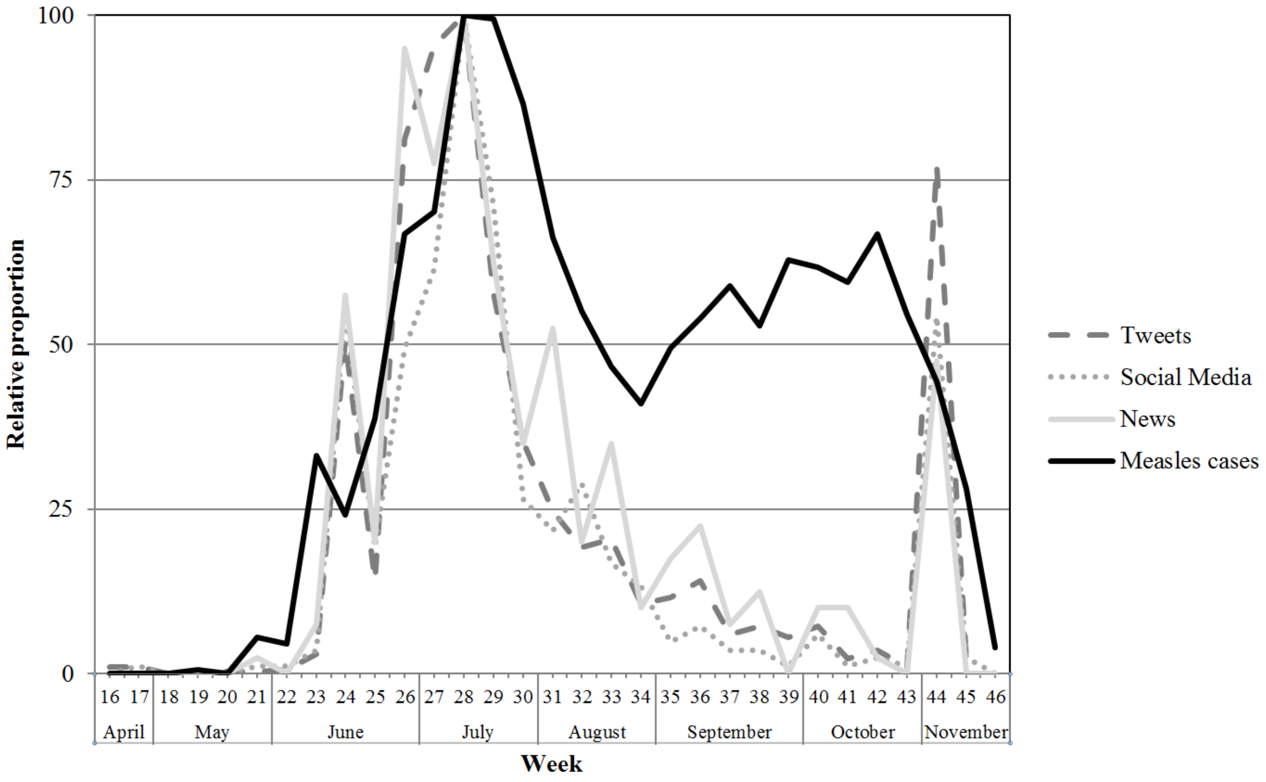
During the measles outbreak, 3 large peaks in the number of messages with a small width were observed for all 3 types of online media data, which coincided with announcements about the measles outbreak by the RIVM and statements made by well-known politicians (Figure 1). The first peak in mid-June coincided with the announcement of the start of the measles outbreak. The second peak in mid-July corresponded with the announcement that additional control measures were to be implemented (ie, additional vaccinations for groups considered most at risk) by RIVM. The second peak also corresponded with public statements made by well-known politicians. The third peak coincided with the announcement that an unvaccinated adolescent had died due to measles complications.

The number of measles cases peaked in mid-July, which was reflected by the peaks in the media reports. However, from the end of August (week 34: 73/2378, 30.70%, 95% CI 24.31%-38.22%) to the end of October (week 42: 119/2378, 50.04%, 95% CI 41.81%-59.37%), a significant increase was shown in the number of measles cases. In the same period, the number of online media messages continued to gradually decrease. Furthermore, after the announcement of the measles-related death on October 28, a steep significant increase from week 43 (eg, for tweets: 3/1982, 0.15%, 95% CI 0.04%-0.41%) to week 44 (for tweets: 234/1982, 11.81%, 95% CI 10.44%-13.28%) in the number of media messages was observed. In the same period, the number of measles cases decreased. Table 3 shows a stronger convergence between the number of social media messages and the number of news messages than between the number of social media messages and the number of reported measles cases.

Table 3. Pearson correlations between weekly number of online (social) media messages and weekly number of reported measles cases for the observation period (31 weeks between April 15 and November 11, 2013).

Data source	Tweets		Other social media		Online newspapers	
	r	*P*	*r*	*P*	*r*	*P*
Tweets	—	—	—	—	—	—
Other social media	.96	<.001	—	—	—	—
Online newspapers	.96	<.001	.90	<.001	—	—
Reported measles cases	.56	.003	.40	.048	.44	.045

Figure 1. Comparison of relative proportions of weekly tweets, other social media messages, and online newspaper articles to measles cases from April 15 to November 11, 2013. Graph is scaled to the highest peak at week 28 for all 4 data sources (peak assigned a score of 100).



Manual Topic Analyses

Most tweets and online news articles were about the measles outbreak. Also, most other social media messages addressed the topic measles outbreak but the number did not significantly differ from the number of messages related to other topics. Most retweets addressed the topic of measles prevention, but this was also not statistically significant (Table 4). Overall, perceived risks of measles disease and measles vaccine and refusing vaccination because of religious reasons were also frequently reported topics, but did not significantly differ from the other topics, such as opinions of those who are critical toward vaccination and the trust and role of institutions (eg, government or media).

Comparing the topics of religious- versus nonreligious-oriented newspapers showed that most articles in both types of newspapers were about the measles outbreak and measles prevention (Table 5). The percentages of the topics did not differ significantly between the religious- and nonreligious-oriented newspapers.

Table 4. Topics of coded measles-related tweets, retweets, other social media messages, and online newspaper articles.

Topic	Tweets		Retweets		Other social media		Online newspapers		Total	
	n=136		n=60		n=464		n=282		N=942	
	n (%)	95% CI	n (%)	95% CI	n (%)	95% CI	n (%)	95% CI	n (%)	95% CI
Measles outbreak	56 (41.2)	33.1-49.6	14 (23)	14-35	95 (20.5)	17.0-24.3	150 (53.2)	47.3-59.0	315 (33.4)	30.5-36.5
Measles prevention	23 (16.9)	11.3-23.9	17 (28)	18-41	92 (19.8)	16.4-23.6	76 (27.0)	22.0-32.4	208 (22.1)	19.5-24.8
Perceived risk	13 (9.6)	5.4-15.4	3 (5)	1-13	90 (19.4)	16.0-23.2	14 (5.0)	2.9-8.0	120 (12.7)	10.7-15.0
Refusing vaccination because of religion	21 (15.4)	10.1-22.3	9 (15)	8-26	58 (12.5)	9.7-15.7	15 (5.3)	3.1-8.4	103 (10.9)	9.1-13.0
Other	16 (11.8)	7.1-18.0	7 (12)	5-22	50 (10.7)	8.2-13.8	3 (1.1)	0.3-2.9	76 (8.1)	6.5-9.9
Critical toward vaccination	3 (2.2)	0.6-5.9	4 (7)	2-15	49 (10.6)	8.0-13.6	16 (5.7)	3.4-8.9	72 (7.6)	6.1-9.5
Trust and role of institutions	4 (2.9)	0.9-6.9	6 (10)	4-20	30 (6.5)	4.5-9.0	8 (2.8)	1.3-5.3	48 (5.1)	3.8-6.6

Table 5. Topics of coded measles-related articles in religious- and nonreligious-oriented newspapers.

Topic	Religious newspapers		Nonreligious newspapers		Total	
	n=79		n=203		N=282	
	n (%)	95% CI	n (%)	95% CI	n (%)	95% CI
Measles outbreak	35 (44)	34-55	115 (56.7)	49.8-63.3	150 (53.2)	47.3-59.0
Measles prevention	24 (30)	21-41	52 (25.6)	20.0-32.0	76 (27.0)	22.0-32.4
Critical toward vaccination	5 (6)	2-13	11 (5.4)	2.9-9.2	16 (5.7)	3.4-8.9
Refusing vaccination because of religious reasons	8 (10)	5-18	7 (3.5)	1.5-6.7	15 (5.3)	3.1-8.4
Perceived risk	5 (6)	2-13	9 (4.4)	2.2-8.0	14 (5.0)	2.9-8.0
Trust and role institutions	0 (0)	0-4	8 (3.9)	1.8-7.3	8 (2.8)	1.3-5.3
Other	2 (3)	0-8	1 (0.5)	0.0-2.4	3 (1.1)	0.3-2.9

Manual Sentiment Analyses

Sentiment information was most frequently found in tweets (49.19%, 667/1356 messages) and the number of tweets with information differed significantly from the number of tweets expressing other sentiments (see Table 6). In retweets and other social media messages, the sentiment relating to frustration was highest, but the number did not significantly differ from the sentiment information. Overall, the sentiments relating to humor/sarcasm and “other” were expressed in the messages of the different data sources but to a lesser extent than sentiments relating to information and frustration. Sentiments relating to concern, question, minimized risk, relief, and personal experience were hardly expressed in the tweets and other social media messages.

We also analyzed how content was expressed in online news articles and compared religious- with nonreligious-oriented newspapers (Table 7). It was observed that measles-related articles in religious newspapers were more neutral, less alarming, and more reassuring than articles in nonreligious newspapers, but not significantly so. Overall, and within the nonreligious newspapers, the number of neutral and alarming articles was significantly higher than the number of reassuring articles.

We also analyzed the weekly number of messages expressing one of the previously defined sentiments for the 3 data sources, but the numbers were too low to draw conclusions on.

Table 6. Sentiments of coded measles-related tweets, retweets, and other social media messages.

Sentiment	Tweets n=1356		Retweets n=626		Other social media n=464		Total N=2446	
	n (%)	95% CI	n (%)	95% CI	n (%)	95% CI	n (%)	95% CI
Information	667 (49.19)	46.53-51.85	214 (34.2)	30.5-38.0	82 (17.7)	14.4-21.3	963 (39.37)	37.45-41.32
Frustration	238 (17.55)	15.60-19.65	232 (37.1)	33.3-40.9	106 (22.8)	19.2-26.8	576 (23.55)	21.90-25.26
Other	123 (9.07)	7.63-10.69	46 (7.4)	5.5-9.6	128 (27.6)	23.7-31.8	297 (12.14)	10.89-13.48
Humor/ Sarcasm	144 (10.62)	9.06-12.34	78 (12.5)	10.0-15.2	46 (9.9)	7.4-12.9	268 (10.96)	9.76-12.24
Concern	59 (4.35)	3.36-5.54	24 (3.8)	2.5-5.6	37 (8.0)	5.8-10.7	120 (4.91)	4.10-5.82
Question	78 (5.75)	4.60-7.09	15 (2.4)	1.4-3.8	13 (2.8)	1.6-4.6	106 (4.33)	3.58-5.20
Minimized risk	23 (1.70)	1.10-2.49	8 (1.3)	0.6-2.4	27 (5.8)	3.9-8.2	58 (2.37)	1.82-3.03
Personal experience	12 (0.88)	0.48-1.50	1 (0.2)	0.0-0.8	19 (4.1)	2.6-6.2	32 (1.31)	0.91-1.82
Relief	12 (0.88)	0.48-1.50	8 (1.3)	0.6-2.4	6 (1.3)	0.5-2.7	26 (1.06)	0.71-1.53

Table 7. Sentiments of coded measles-related articles in religious- and nonreligious-oriented newspapers.

Sentiment	Religious newspapers n=79		Nonreligious newspapers n=150		Total N=229	
	n (%)	95% CI	n (%)	95% CI	n (%)	95% CI
Neutral/no sentiment/both alarming and reassuring	37 (47)	36-58	62 (41.3)	33.7-49.3	99 (43.2)	36.9-49.7
Alarming	23 (30)	20-40	69 (46.0)	38.1-54.0	92 (40.2)	34.0-46.6
Reassuring	19 (24)	16-34	19 (12.7)	8.0-18.7	38 (17.0)	12.2-21.8

Combining the Manual Analyses of Topics and Sentiments

Of the tweets (retweets included) and other social media messages with topics relating to measles incidence or measles prevention, we found that 56.4% (93/165) of messages were informative for measles outbreak and 35.6% (47/132) for measles prevention. In all, 48% (16/33) of the messages with the subtopic of measles-related death within the topic measles outbreak were related to the sentiment of frustration (ie, frustration about persons not vaccinating their child). Of the messages with the topic of refusing vaccination because of religious reasons, we found that 48% (42/88) of the sentiments qualified as frustration.

Of the other social media messages with the topic of perceived risk, we found that 30% (27/90) of messages qualified as minimized risk (ie, in combination with subtopic of measles disease is not severe), 22% (20/90) as concern (ie, in combination with the subtopic of measles disease is severe), and 19% (17/90) as neutral (ie, in combination with the subtopics of adverse events and perceived effectiveness of vaccine). Of the other social media messages with the topic regarding opinions of those who are critical toward vaccination, 43% (21/49) of the messages qualified as neutral and 39% (19/49) as frustration. Of the other social media messages with the topic relating to trust and the role of institutions (eg, government or media), 53% (16/30) of the messages qualified as frustration and 30% (9/30) as neutral.

Both the topic and sentiment were only available for the articles in the religious-oriented newspapers. Of the online newspaper articles with the topic of measles outbreak, we found that 49% (17/35) of the articles qualified as neutral and 46% (16/35) as alarming. Of the articles with the topic regarding measles prevention, 50% (12/24) of the articles qualified as reassuring and 29% (7/24) as neutral. Of the online newspaper articles with the topic of refusing vaccination because of religious reasons, all (n=8) qualified as neutral.

Discussion

Principal Findings

The weekly number of social media messages was related more strongly to the number of online news articles than to the number of reported measles cases, supporting the public opinion function of social media more than the disease detection function. In addition, the number of tweets, other social media messages, and online news articles showed a similar distribution over time with 3 large peaks. These findings support the agenda-setting function of the media, showing that the media determine to a large extent what people talk about on social media. Important events with high news values, such as the death of a young girl, resulted in a significant increase in the number of social media messages: people seemed to share their frustration about this measles-related death of a girl who was not vaccinated for religious reasons. The second and largest peak in response to the announcement of additional control measures and statements made by well-known politicians occurred at the same time for both the number of social media messages and reported number of measles cases, but overall patterns between social media and outbreak data diverge.

Particularly interesting is the finding that (social) media attention shows a steep drop after the second peak, whereas the number of reported measles cases remained relatively high. This suggests that the news value of the measles outbreak had dropped and other topics gained prominence. Thus, our findings suggest that social media followed the traditional media agenda for the measles outbreak rather than the measles pattern. It should also be noted that the significant increase in the number of reported measles cases at the end of August may be due to the commencement of schools after the summer break. The spread of the measles virus has been found to occur mostly at schools [1].

Various studies [11-13] showed that estimates of influenza-like illness derived from Twitter accurately track reported disease levels, which is partly the case in our study. Vasterman & Ruigrok [23] showed that it was not the reported number of cases but the number of hospitalizations during the epidemic stage that was in-line with media coverage. Vasterman & Ruigrokl [23] argued that this was probably because almost 50% of the hospitalized patients were children, which made this extra newsworthy. Our findings point to the importance of differentiating between illnesses; for some illnesses, social media may reflect outbreak patterns, whereas for other illnesses social media are more likely to reflect public opinion patterns. Future studies should look further into this issue by examining the role of media hype and news value (eg, it may be that illnesses with low news value such as seasonal flu may more accurately reflect disease levels than illnesses with high news value). It may also be that large international outbreaks follow different rules than smaller local outbreaks. Finally, the present outbreak concerned a specific-risk group, which may also have played a role in the observed patterns.

We also showed that most tweets were about the measles outbreak and were informative, and most newspaper articles were about the measles outbreak and were neutral or alarming. For retweets and other social media, the topics and sentiments were less distinct. Taking all data sources together, the topics of measles outbreak and measles prevention and the sentiments information and frustration were the most present in the messages. People were informing others about the measles outbreak and preventive measures such as vaccination, but also expressed their frustration regarding persons who did not vaccinate because of religious reasons. Some differences were also observed between tweets and retweets. Most tweets were informative, whereas most retweets qualified as frustration. Therefore, it seemed that people found it more important to express their frustration than informing others about the measles outbreak. No significant differences in topic and sentiment were found between religious- and nonreligious-oriented newspapers. Similar to the study by Chew & Eysenbach [14] about H1N1, our study showed that tweets primarily contained news, updates, and information about the outbreak. Chew & Eysenbach [14] also suggested that tweets are a source of experiences. In our study, this was less the case (experiencing measles is a subtopic within the topic measles outbreak) and which was shared more by social media (24/95 messages) than by Twitter (6/70 messages). Regarding sentiments expressed in messages, Chew & Eysenbach [14] found that tweets expressing humor, concern, and questions were the most common, whereas we found the sentiments information and frustration were the most common. The sentiment information is not very surprising because tweets expressed news primarily. Despite that they did not find many informative tweets, they did show that the proportion of tweets containing news increased over time, which was probably because more information about the disease and the vaccine became available. The differences with the study of Chew & Eysenbach [14] might be explained because they analyzed tweets related to an unknown disease and vaccine (ie, H1N1 pandemic) and to a disease spread throughout the entire population. Our study, in contrast, was about a well-known disease and vaccine, and the outbreak mostly affected unvaccinated Orthodox Protestants.

This study did not provide new insights into factors possibly related to intention to vaccination and/or vaccination behavior and could not detect increases or decreases in the number of messages expressing a specific sentiment over time. The fact that we found the leading sentiment was frustration regarding people who refuse vaccinations based on religious grounds might confirm the high vaccination coverage for measles vaccination indicating that our study population favors measles vaccination.

Limitations

A limitation of this study is that our study population is not well defined, which may underestimate or overestimate the results toward the general public causing a misinterpretation of results. Social media have fast become an important area for the acquisition of new information. Almost 90% of the Dutch population aged 12 years and older use the Internet; of those, 70% are active on social media, particularly Facebook and Twitter (ie, Web 2.0) [25]. It was beyond the scope of this study to identify characteristics of our study population. However, it has been shown that the use of social media does not vary much by gender, ethnicity, and educational level [25], but this may not be the case for those who write about measles on social media. Furthermore, we had no insight into whether the sentiments about the measles outbreak we identified in our data sources were in-line with the sentiment of the general public. More research is needed to ascertain if an association can be found between the topics and sentiments of messages presented in media messages and among the general public. Another remark that has to be made is that we could not get information about the data mining approaches by the companies we retrieved the data from. A last limitation was the relative low kappa for coding sentiments expressed in the social media messages. Overall, social media messages contain larger volumes of text stories and personal experiences compared with tweets and online news articles. This led to difficulties in coding. Sometimes several sentiments were expressed in the same message; in those cases, the first sentiment identified was chosen. Despite these limitations, the biggest advantage of using online data is the continuous data collection and the user-generated content.

Practical Implications and Future Work

We also wanted to explore whether and how we should monitor the online (social) media data about the NIP for harvesting public opinions possibly related to intention to vaccinate during and in-between outbreaks so that interventions can be made, such as adapting communication to the public. An important real-time worldwide Internet monitor for vaccine concerns that already exists is The Vaccine Confidence Project [26]. However, it could not be used directly for the Netherlands because it does not contain search words in Dutch, but because similar vaccine concerns may be present in various countries, it will be interesting to compare our findings with their findings. Additionally, they developed a typology of concerns and a way to assess the priority of each concern, which might be very useful for us as well as for others. Furthermore, The European Commission's Joint Research Centre has developed a number of news aggregation and analysis systems (Europe Media Monitor [EMM]) to support EU institutions and Member State organizations with, for example, analyzing real-time news for medical- and health-related topics and providing early warning alerts per category and country. The advantage of this EMM is that it is already an automated process and that it covers many languages, including Dutch. They plan to add an opinion-mining functionality to the existing information extraction components, but this might not be specific enough for our purposes [27].

We believe that real-time monitoring of online (social) media data is important so that the RIVM is aware of the beliefs and opinions of the public about the NIP and is able to detect and respond to possible vaccine concerns in a timely manner. The online (social) media monitoring has an added value to the parental questionnaire sent at regular intervals in the system to monitor the intention and their determinants to vaccinate within the NIP [28] because the online media monitoring generates continuous data and consists of user-generated content. This study addressed various specific topics about a measles outbreak among Orthodox Protestants; therefore, a next step is to explore the public's opinion about other NIP diseases using similar methodology. Additionally, this study showed that the announcements by the RIVM on their website had a considerable effect on the message volume and posting behavior, which could also be used to generate attention for other health messages related to that particular subject (eg, taking preventive measures). Therefore, the use of these online data may have potential usefulness in public health. In the near future, we will start developing a system that automatically codes messages relating to various NIP diseases. This system would enable the analysis of large amounts of data and allow detection of differences in thoughts and emotions people share on the Internet and will provide insight into user's characteristics.

Conclusions

The number of social media messages was related more strongly to the number of online news articles than to the number of reported measles cases. Furthermore, the number of tweets, other social media messages, and online newspaper articles showed a similar distribution over time with 3 large peaks. The peaks in the number of online news articles could very well be explained by announcements by the RIVM (ie, start of the outbreak, additional vaccinations, and a measles-related death) and statements made by well-known politicians. Most messages were about informing people about the measles outbreak and the leading sentiment was frustration regarding people who do not vaccinate for religious reasons. Monitoring online (social) media might be useful for RIVM in deciding whether and how to respond to the public about infectious disease outbreaks. Additionally, the data provide insight into the opinions of the public about infectious diseases outbreaks, which could enable the RIVM to respond appropriately to possible concerns.

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Authors' Contributions

All authors discussed the study design. LM, IH, EB, and RC all assisted in coding of a subset of the data. LM wrote the first version of the manuscript. All authors contributed to the draft of the final manuscript; their remarks were discussed and processed into the final version that was approved by all authors.

Conflicts of Interest

None declared.

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Abbreviations

EMM: Europe Media Monitor
NIP: National Immunization Program
RIVM: The National Institute for Public Health and the Environment

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Original Paper

Sources of Traffic and Visitors' Preferences Regarding Online Public Reports of Quality: Web Analytics and Online Survey Results

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Abstract

Background: In the context of the Affordable Care Act, there is extensive emphasis on making provider quality transparent and publicly available. Online public reports of quality exist, but little is known about how visitors find reports or about their purpose in visiting.

Objective: To address this gap, we gathered website analytics data from a national group of online public reports of hospital or physician quality and surveyed real-time visitors to those websites.

Methods: Websites were recruited from a national group of online public reports of hospital or physician quality. Analytics data were gathered from each website: number of unique visitors, method of arrival for each unique visitor, and search terms resulting in visits. Depending on the website, a survey invitation was launched for unique visitors on landing pages or on pages with quality information. Survey topics included type of respondent (eg, consumer, health care professional), purpose of visit, areas of interest, website experience, and demographics.

Results: There were 116,657 unique visitors to the 18 participating websites (1440 unique visitors/month per website), with most unique visitors arriving through search (63.95%, 74,606/116,657). Websites with a higher percent of traffic from search engines garnered more unique visitors (*P*=.001). The most common search terms were for individual hospitals (23.25%, 27,122/74,606) and website names (19.43%, 22,672/74,606); medical condition terms were uncommon (0.81%, 605/74,606). Survey view rate was 42.48% (49,560/116,657 invited) resulting in 1755 respondents (participation rate=3.6%). There were substantial proportions of consumer (48.43%, 850/1755) and health care professional respondents (31.39%, 551/1755). Across websites, proportions of consumer (21%-71%) and health care professional respondents (16%-48%) varied. Consumers were frequently interested in using the information to choose providers or assess the quality of their provider (52.7%, 225/427); the majority of those choosing a provider reported that they had used the information to do so (78%, 40/51). Health care professional (26.6%, 115/443) and consumer (20.8%, 92/442) respondents wanted cost information and consumers wanted patient narrative comments (31.5%, 139/442) on the public reports. Health care professional respondents rated the experience on the reports higher than consumers did (mean 7.2, SD 2.2 vs mean 6.2, SD 2.7; scale 0-10; *P*<.001).

Conclusions: Report sponsors interested in increasing the influence of their reports could consider using techniques to improve search engine traffic, providing cost information and patient comments, and improving the website experience for both consumers and health care professionals.

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KEYWORDS

consumer health information; Internet/statistics and numerical data; search engine; quality of health care; consumer behavior

Introduction

There is unprecedented interest in making information about provider cost and quality of care publicly available. The Affordable Care Act (ACA) expands coverage to millions, with variable levels of deductibles, leading to increased demand from consumers for cost and quality data [1,2]. In addition, the ACA requires insurance exchanges to create websites that provide comparative health plan performance on quality and cost [3]. As physician performance metrics become publicly available under the ACA's Value-Based Payment Modifier program [4], the hope is that public reporting will drive provider choice and stimulate greater quality improvement efforts among providers to a degree not seen before. And yet, consumers have been slow to use this information to inform choices [5-7]. However, there is evidence that well-designed reports of quality can influence consumers to choose higher quality providers [8]. Because public reporting has the potential to improve quality, multiple stakeholders are interested in understanding how best to reach consumers and how to provide relevant quality information [1]. This study aims to add to that understanding.

Prior work about the users of public reports of quality has focused on specific user segments (eg, clinicians or patients) and predictors of consumer use. Some clinicians use public reports for internal quality improvement [9,10]. A small proportion of US consumers report seeing comparative hospital or physician quality information, although that number appears to be increasing [5,6]. Studies of sociodemographic predictors of physician rating websites for German consumers were mixed regarding whether education, age, gender, or chronic disease predicted use and awareness of the physician rating websites [11-13].

Despite knowledge that people find online information through a variety of routes, there is no peer-reviewed literature of which we are aware about how people find public quality and cost reports (eg, via search engines searches, links on other websites, direct emails) or whether specific traffic sources are associated with overall traffic. In addition, there has been no information gathered in real time from US online visitors to the reports, which limits our understanding of what is relevant to users as they interact with the reports. Lastly, prior work has not described differences in website experience for different visitors (eg, consumers compared to physicians), not their areas of interest. Because the influence of these reports depends on who finds and uses them, improving the reports' impact will be difficult without understanding how reports currently garner an audience and without knowing the needs of consumer and physician visitors who find the reports.

In order to address this knowledge gap, we used 2 types of data gathered from a group of public reporting websites of hospital or outpatient provider quality: Web analytics data that passively tracks website visitor traffic and behavior, and an online survey of website visitors. We describe overall traffic to the sites, how visitors arrive at the websites, differences between the sites in traffic sources and types of visitors (eg, consumers vs physicians), visitors' purposes in going to the website, and their experience while there. The objective of this study is to inform transparency efforts by assessing for potential ways to increase traffic to online public reports of provider-level quality and cost as well as meet the needs of the visitors who find them.

Methods

Setting

The Learning Network of Chartered Value Exchanges (CVEs) is a program that has supported transparency since 2004 and is sponsored by the Agency for Healthcare Research and Quality (AHRQ). The CVEs are multistakeholder state or local quality collaboratives that are investing significant resources in online public reports of hospital and physician quality in their communities. The CVEs involve more than 550 health care leaders and represent more than 124 million lives, more than one-third of the US population [14]. Because of the CVEs' long experience and broad catchment area, we used the network of CVEs for this study.

All 24 CVE's were invited to participate, with 22 CVE or CVE-affiliated websites active. Of these, 18 websites participated. The websites were public quality reports of hospitals, outpatient providers (medical groups or clinics), or both. Websites reported on providers within a state, a region in a state, or a county. Quality measures for hospitals were commonly Center for Medicaid and Medicare Services (CMS) measures, although some websites also included measures of maternity and neonatal care. Quality measures for outpatient providers were often Healthcare Effectiveness Data and Information Set (HEDIS) measures and Consumer Assessment of Healthcare Providers and Systems (CAHPS) patient experience measures. Narrative patient comments were not shown on any participating website.

Further descriptions of CVE groups and websites are available [14]. Participating websites agreed to participate on the condition that we not identify the websites and their performance individually. Multimedia Appendix 1 shows a screenshot from one of the websites at the time of the study, whose sponsors gave permission to share it.

Website Analytics Data Collection and Search Term Coding

We gathered Web analytics data from February to August 2011 using Google Analytics [15]. We excluded data from the IP addresses of computers of the report sponsor organization and of any external vendors hosting the online reports.

Collected variables were number of unique visitors and percent of unique visitors arriving via 3 methods: search engine queries ("search traffic"), clicking on a link from a different website ("referral traffic"), or directly entering a URL into a Web browser or clicking on a link in an email, word processing document, or document in Portable Document Format (PDF) ("direct traffic").

The population density varied among the catchment areas the websites served. To generate population-adjusted website traffic from the absolute number of unique visitors, we used Census Bureau catchment area counts of 100,000 Internet-using households as the denominator under total number of unique visitors to calculate "per capita traffic" to each website [16,17].

We also collected search terms (eg, "best doctors San Francisco") for all search engine traffic. The primary author (NSB) and a research staff member (RAP) organized the search terms into categories using an iterative process: both investigators read the 50 most common search terms for each website then discussed the various categories of search terms to create a codebook for categories. RAP then coded the top 50 search terms for each website and NSB reviewed the initial coding and discussed any code changes. They then combined codes into larger groupings for the final analysis. The codebook and documentation of the coding process is available on request.

We could not link the Web analytics data to survey responses because the analytics data do not include visitor IP addresses and because they are reported in aggregate.

Survey Development and Content

The primary aim of the survey was to provide information on report visitors' use and perceptions of the value of the public reporting websites. See Multimedia Appendix 2 for the full Checklist for Reporting Results of Internet E-Surveys (CHERRIES) checklist for reporting of Internet e-surveys and for additional description of survey development [18]. We drafted the AHRQ Public Report [19] surveys based on the authors' expert knowledge about online public reports and drawing from existing surveys that participating public reporting websites were using.

Survey items fell into the following categories: demographics, purpose of the visit, medical topics of interest, and areas of quality measurement of interest. Visitors were shown questions within each topic tailored to their persona type (eg, patient, friend or family member, health care professional, insurer, employer or labor union, researcher, media, lawyer, legislator). We focused on the results for the consumers (patients or friends or family members) and health care professionals in this paper because these were the largest groups of respondents and are the ones most likely to use the reports for choice or for performance improvement. The surveys are available in Multimedia Appendix 2.

Survey Data Collection and Response Coding

We surveyed participating website visitors from February to August 2011. We used an "open survey" design in which all visitors viewing at least 1 page with access to quality performance measures were offered the opportunity to take the survey. The invitation appeared in a pop-up window with directions to take the survey at the end of the session. See Multimedia Appendix 1 for images of invitation and survey.

We framed the survey respondents as a group interested enough in the website content to spend time on an online survey afterward. The implication is that although there might be a low response rate, the responses we received would be from people who are more likely to be potentially influenced by the report. We adopted this frame because low response rates are a known limitation for website surveys because a proportion of website visitors are searching for other content or have limited attention or time for a survey while online. For instance, Kaiser researchers had a 17% response rate in an online survey of users of a secure online personal health record who were presumably more engaged than one-time visitors to a website [20]. One approach to the known low response rate is to invite only visitors who interact extensively with a website to answer a survey, thus creating a smaller response rate denominator. We chose to invite all visitors because some websites have quality information on only 1 or 2 pages.

To decrease response burden, we programmed the survey software to show each consumer (patient or friend/family member) a randomized set of 3 of 5 item groupings (eg, purpose of visit, demographics, topics of interest), leading to smaller consumer sample sizes for each set of questions than if all consumers had answered all items. As noted in our results, the denominators for each of these item sets only included those who were randomized to see those questions.

We coded free-text survey responses using the existing survey item options and categorizing responses that did not fit into an existing option as "other." We allowed a new category to be formed if it occurred more than 10 times and put the answers for an existing option into "other" if the option was chosen less than 10 times. The only option affected was the consumer primary purpose of visit, for which "learn about a disease" was included in "other."

Statistical Analysis

Analysis of Traffic to the Websites

We assessed 2 potential predictors of per capita traffic on the websites. We used the same approach in 2 separate models and websites were the unit of analysis. The predictors were the percent of visitors to the website that were from search engines and, for the websites with >15 survey respondents, the percent of consumer respondents to the survey. We estimated linear regression models. In each model, we included a term for report type (hospital only, physician only, or both), assuming that reports with both types might have higher traffic. We performed sensitivity analyses allowing for clustering by website and using a binary variable for report type (1 provider type vs both provider types).

Analysis of Survey Responses

We calculated response rate statistics: view rate (unique visitors shown the survey/all unique site visitors) and participation rate (number of surveys with at least 1 question answered/unique visitors shown the survey) [18]. See Multimedia Appendix 2 for response rate analysis details. We used a t test to compare health care professional and consumer website experience scores. We used chi-square tests to compare health care professional and consumer primary purposes of visit and other areas of interest. As a sensitivity analysis, to assess whether the associations differed by report type (physician or hospital report), we performed the same analyses using survey responses stratified according to whether the survey was answered from a hospital or a physician reporting page.

All analyses were conducted using Stata 12 (StataCorp LP, College Station, TX, USA). The University of California San Francisco Committee on Human Research approved this study.

Results

Website Analytics Data on Volume and Sources of Visitors

For the 18 websites, there was an average of 1440 unique visitors per month per website, with a total of 116,657 unique visitors to all websites. There was substantial variability in website per capita traffic (range 1-167 unique visitors/100,000 Internet users per month; median 31.8, IQR 15.7-47.2).

The websites commonly reported on hospital quality (89%, 16/18), with 61% (11/18) also reporting on clinic or medical group quality (Table 1). There were fewer reports from the Southern region compared to other regions, with reports approximately evenly split through the rest of the regions. Most reports had a state as a catchment area, with all websites reporting at the provider level (hospitals, clinics, or medical groups).

Table 1. Characteristics of participating websites (N=18).

Characteristics	Websites, n (%)
Public report type	
Hospital	7 (39%)
Clinic or medical group	2 (11%)
Both	9 (50%)
Region	
West	5 (27%)
Northeast	5 (28%)
Midwest	6 (33%)
South	2 (11%)
Catchment area	
State	13 (72%)
County	5 (27%)
Number of per capita monthly unique visitors [a]	
1-20	7 (39%)
21-50	6 (33%)
>50	5 (28%)

[a] These are the numbers of unique visitors/100,000 Internet users in the catchment area arriving at the websites per month.

Visitors arrived most often through a search engine query (63.95%, 74,606/116,657 of unique visitors) (Table 2) and less often through referral from another website (15.80%, 18,432/116,657) or direct links received in an email or in an electronic document (19.99%, 74,606/116,657). There was a positive association between percent of unique visitors arriving from search engines and total unique monthly visitors per 100,000 Internet-using households in the catchment area, adjusted for report type (hospital only, outpatient group only, or both), with a 1-point increase in traffic for every 1.8% point increase in proportion of search traffic (P=.002) (Figure 1). The sensitivity analysis that allowed clustering by website returned similar results.

Table 2. How visitors arrived at the websites and categories of search terms used by those arriving via search engines (N=116,657 unique visitors).

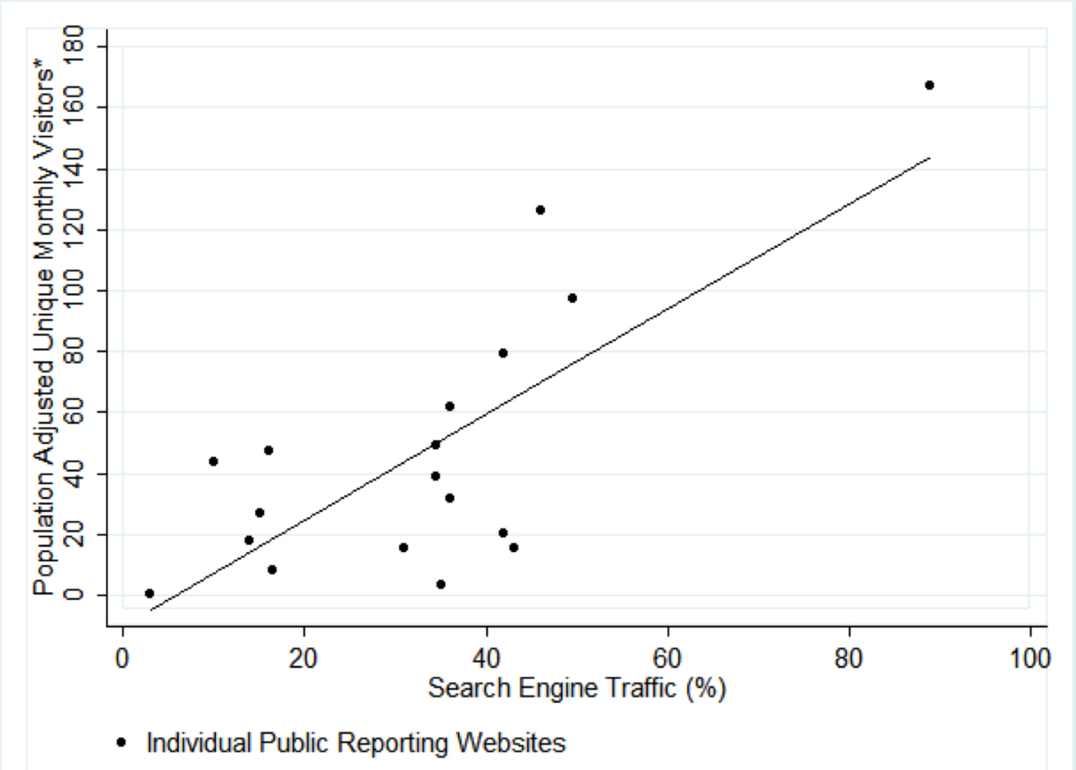
Traffic sources	Total traffic, n (%)
Route of arrival (N=116,657)	
Direct traffic	23,331 (20.00%)
Referral traffic	18,432 (15.80%)
Search engine traffic	74,606 (63.95%)
Search terms used (n=74,606)	
Hospital name	27,122 (23.25%)
Website name	22,672 (19.43%)
Website to compare providers	15,998 (13.71%)
Other	4988 (6.69%)
Medical condition	605 (0.81%)

[a] Direct traffic arrives by directly entering the website URL into the browser or by clicking on a link in an email, word processing document, or PDF document. Referral traffic arrives at the websites through clicking on a link from a different website. Search engine traffic arrives via Web search engines (eg, Google, Yahoo, or Bing).

[b] “Search terms used” refers to phrases or words used by search engine traffic visitors (eg, “best doctors XXX city”). “Website to compare providers” refers to search terms for hospital comparison such as “best hospitals in Maine.”

For most websites (61%, 11/18), the search term by which visitors arrived most often was the name of the website. However, collectively, searches for individual hospitals by name were the bulk of the searches that led to visits across all participating websites (Table 2). Among the 2 websites with the highest traffic, responsible for 56.55% (65,967/116,657) of all unique visitors, the hospital name was the most common search term (37.00%, 17,205/46,500 and 97.23%, 9891/10,172 of search terms used), and search was the most common source of traffic (89.00%, 46,500/52,247 and 74.14%, 10,172/13,720 of unique visitors, respectively).

Figure 1. Relationship between proportion of traffic from search engines and population-adjusted number of unique monthly visitors to public reporting websites of hospital and outpatient provider quality. *This is the per capita traffic: the number of unique monthly visitors per 100,000 Internet-using households in the catchment area of the individual public reporting website.



Survey Data on Consumer and Health Care Professional Visitors

Of all unique visitors (N=116,657), 49,560 were presented the option to take the survey, resulting in a view rate of 42.48%. Of those who viewed the invitation, 1755 responded, resulting in a participation rate of 3.54%. The number of responses from the websites ranged from 2-287 (mean 97.5, SD 98.6; median 49.5, IQR: 26-143).

There were more consumer respondents (850/1755, 48.43%) than health care professional respondents (551/1755, 31.39%). The remaining respondents were members of the media, employers or labor union members, researchers, insurers, or others who chose a free-text option (354/1755, 20.17%). There was wide variation across websites in proportions of respondents who were consumers (21%-71%) and health care professionals (16%-48%). Figure 2 displays that variation and shows ranking according to per capita traffic. Figure 2 illustrates that there is no association between audience composition and website traffic (*P*=.56 for regression of proportion of consumers and per capita traffic, with similar results in the clustered sensitivity analysis).

More health care professionals than consumers had a primary purpose of choosing or comparing providers (38.8%, 168/433 vs 25.3%, 108/427) (Table 3), whereas more consumers than health care professionals (27.4%, 117/433 vs 20.3%, 88/427) had a primary purpose of finding quality information on a specific provider (*P*<.001 for overall comparison). For consumers with a primary purpose to “choose providers” who were also asked whether they did so (n=51), 78.4% (40/51) were likely or very likely to use the information to choose a provider. Only 4.2% (18/433) of health care professionals said that they came to the websites for the purpose of patient referral to a hospital or other health care provider (Table 3). Sensitivity analysis found that these patterns were similar by report type (data not shown).

Few providers (0.9%, 4/433) or consumers (2.6%, 11/427) had a primary purpose of looking at cost information. The interest in this information was more common, with both providers (26.6%, 115/433) and consumers (20.8%, 92/442) desiring cost content to be added to the websites (Table 3). Approximately one-third of consumer respondents indicated interest in adding measures about diseases relevant to them (36.4%, 161/442) or adding written comments from other patients (31.5%, 139/442). Consumer respondents rated their experiences using the website lower than did health care professional respondents (mean 6.2, SD 2.7 vs mean 7.2, SD 2.2 on a scale 0-10, *P*<.001).

Sensitivity analysis found that these differences in primary purpose by respondent type and in mean experience scores were similar in analyses stratified by report type (hospital report vs outpatient quality report, data not shown).

Consumer respondents were commonly middle aged (58.1%, 194/334 were 45-64 years), white (84.4%, 217/257), and many had private insurance (74.1%, 238/321). Additional respondent characteristics are in Multimedia Appendix 3.

Figure 2. Variation in proportions of consumer and health care professional respondents across websites.

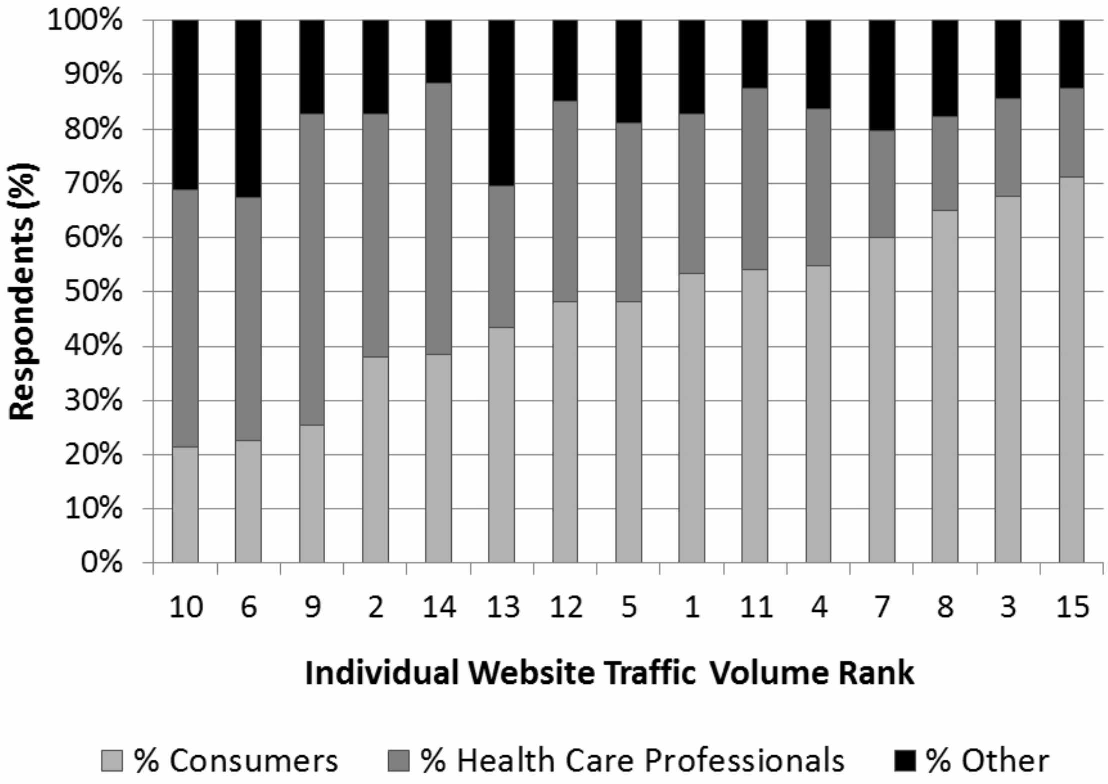


Table 3. Comparison of health care professionals' and consumers' primary purposes for visits to public reports and overall website experiences.

Survey topics	Consumers	Health care professionals
Primary purpose, n (%) [a]		
Choose or compare providers[b]	108 (25.3)	168 (38.8)
Find quality information on a specific provider[c]	117 (27.4)	88 (20.3)
Cost information	11 (2.6)	4 (0.9)
Referral to another provider	—[h]	18 (4.2)
Get practical information[d]	25 (5.9)	20 (4.6)
General interest in website content	10 (2.3)	26 (6.0)
Other[e]	68 (15.9)	52 (12.0)
No answer	88 (20.6)	57 (13.2)
Overall website experience,[f] mean (SD)	6.2 (2.7)	7.2 (2.2)
Additional content endorsed, [g] **n (%)**		
Measures about other diagnoses, relevant to their condition	161 (36.4)	—[i]
Patient comments	139 (31.5)	—[i]
Practical information[d]	48 (10.9)	—[i]
Additional providers	45 (10.2)	43 (9.9)
Costs	92 (20.8)	115 (26.6)
Additional measures, n (%)	—[h]	99 (22.9)
More methods (eg, risk adjustment model)	—[h]	113 (26.1)
More detailed results (eg, 95% CIs)	—[h]	112 (25.9)
Physician-level data	—[h]	81 (18.7)

[a] $P<.001$ for differences between categories of Primary purpose by persona. Consumers n=427; health care professionals n=433.

[b] This could be choosing a provider for oneself or a friend or family member. For providers, this included comparing oneself to other providers.

[c] For providers, this included looking at one's own performance only.

[d] For example: address, hours of operation, services available.

[e] Only 2.1% (7/427) of consumers chose the primary purpose of "learn about a disease" and so it was included in "other."

[f] $P<.001$ for difference in overall experience on website between health care professionals and consumers. Consumers: n=697; health care professionals: n=499.

[g] Respondents could choose more than 1 answer leading to total percentages >100%. Consumers: n=442.

[h] These options not presented to consumers.

[i] These options not presented to health care professionals.

Discussion

Principal Findings

In this study of Web analytics data and real-time survey data from a multistate group of public reports of quality, we analyze variations in sources of traffic across websites as well as audience type and purpose. We found that overall traffic to the sites is low. Per capita Internet traffic varied extensively across sites, with higher traffic on websites associated with higher proportion of traffic from search engines. Most visitors arrived after a Web search, frequently using search terms for a specific hospital. Although both consumers and health care professionals use the websites to assess provider quality and choose a provider, websites varied substantially in the proportion of consumer or health care professional respondents, and consumer respondents had a less positive experience on average than health care professionals. Our findings speak to 2 mechanisms through which a public report can be influential: achieving a larger audience and meeting the needs of the audience that arrives.

Achieving a Larger Audience

The number of visitors to these websites was low (1440 unique visitors/month) compared to a similar site in the United Kingdom, the NHS Choices website, which posts numerical ratings of hospitals and physicians as well as written comments from patients. NHS Choices has 250,000 page views per month (some of which could be repeat visitors) to the pages that show comparative provider performance [21]. To the extent that public reports influence choice [22], leading to better health, or that public reporting can incentivize providers to improve care [23,24], increasing the use of US public reporting websites will be important. The UK experience implies that it is potentially possible to do so.

In our group of websites, the range of per capita traffic was large, with the 2 websites with the highest per capita traffic achieving most of their traffic via search queries. This, taken with the finding that search traffic was >60% of traffic overall and that a higher proportion of search traffic is statistically significantly associated with higher overall traffic, suggests that increasing search engine traffic is a potentially powerful approach to increase traffic overall. This is supported by data that in 2012-2013 there were 97,000 monthly Google searches using keywords related to hospital quality, suggesting that consumers are actively searching for this information [25].

We also found that very few visits to the websites came from searches for specific diseases. A similar finding in the survey was that few consumer respondents chose “learn about a disease” as their primary purpose for their visit. Taken together, these findings imply that the provision of disease-specific information only (eg, sections titled “learn about your diabetes” without performance measures) may not increase traffic to the site.

Lastly, we found that the 2 websites with the highest search traffic and the highest traffic overall had hospital names as the most common search terms leading to their visits. These websites had also “tagged” (ie, made visible to search engines) the hospital names, whereas the other websites did not. Hence, our data suggest that tagging provider names on a public reporting website may increase the chances of the website being found in a search and lead to more visitors.

Visitor Experience and Preferences

The influence of a public report also depends on the types of people who find the report and whether the content meets their needs. Prior work in this area includes assessments of predictors of reported past use of online physician rating websites and willingness to pay for physician rating sites, examining consumer demographics as well as models of underlying factors motivating consumer use of physician rating websites (digital literacy, perceived ease of use of Internet) [12,26,27]. Our findings add to this work by surveying visitors in real time, including visitors to hospital public reporting websites, assessing physician and consumer perspectives separately, and assessing the purpose of website visitors and their areas of interest. These new contributions may be useful to report sponsors who would like to not only understand predictors of use, but also preferences of their current audience in order to meet their needs. If the traffic on these sites grows, report sponsors or researchers could track whether the user composition changes and whether audience preferences change.

We found that consumer survey respondents on these websites were predominantly older, white, and privately insured. The high proportion of privately insured respondents could be due to low response rate among other respondents or due to low numbers of uninsured or publicly insured visitors. Should the latter be true, one implication is that vulnerable populations who have historically received lower quality of care may access quality information for provider choice less often. Prior research found that African American survey respondents were less likely than white survey respondents to report seeing comparative quality information for hospitals and doctors [28], even though once minorities are aware of reports, they are more likely to use the information [28,29]. To the degree that use of quality information drives health outcomes, disseminating the information to vulnerable populations, as some communities are already trying to do [30], is one approach to avoid widening existing disparities. Additional research is needed regarding whether vulnerable populations have a choice of provider and, if so, the most effective way to disseminate and encourage the use of the quality information to this group [11].

Websites vary in the proportion of consumer and health care professional respondents. Berwick and Coye [31] and Hibbard [9] describe differences in consumer and health care professional pathways through which quality reports may stimulate improvement; hence, both audience types are important. Future research could assess for potential differences between the marketing approaches or website features to explain differences in report visitor composition. We did not find a relationship between the proportion of consumer respondents and per capita traffic, implying that the higher traffic sites are not necessarily succeeding in the consumer populations. Our findings on website experience suggest that additional research is needed to improve the experience for both audiences. Our data show that although there is some overlap in interests between consumers and health care professionals, the consumer website experience was worse than the experience of health care professionals. The needs of health care professionals and consumers may be different enough that a single report will not be adequate to effectively drive quality improvement through the separate pathways Hibbard and Berwick and Coye describe, but additional research is sorely needed in this area.

Few survey respondents indicated that the primary purpose of their visit was to obtain cost information, likely reflecting that most websites lacked cost information. However, 21% of consumers and 27% of health care professionals indicated interest in adding cost information. Since we collected our data, the insurance market has evolved with greater use of high deductible plans and more cost shifting to consumers. In this context, consumer interest in costs may increase [1], especially if there is increased awareness of variation among providers in cost of care [32]. Our data suggest that providing cost information on the websites may be an opportunity to meet the needs of visitors to the public reports.

Consumer respondents reported an interest in seeing patient comments. This is similar to prior literature showing that consumers find patient stories to be as persuasive as quantitative assessments of patient experience [33]. Providing patient comments on provider quality may better meet the needs of consumer visitors. Additional research is needed to understand how to best elicit narrative comments and how to display narrative and quantitative data together to facilitate optimal choices [8,11].

Limitations

The survey participation rate was low (3.6%) leading to a risk of nonresponse bias. This is a known limitation for website surveys in real time [20] and the results represent the only available data from recent visitors to online public reports. The nonresponse bias in our survey might be particularly relevant in the younger age groups who are poorly represented in these data and are often poor responders to Internet and other types of surveys [34]. This is supported by our findings in Multimedia Appendix 3 showing that the consumer respondents were older than the population in the catchment areas who reported using the Internet to research health plans or practitioners in 2011. Additional methods to gather data from consumer groups who do not answer surveys may be necessary to complete our understanding of visitors to public reports. Response bias does not affect the Web analytics data.

Conclusions

Under the ACA, there is new support for health care transparency and a unique opportunity to help consumers choose higher quality providers. If public reports of provider performance and cost are to be effective, consumers and health care professionals need to find them and visitors to the sites need to find what they need there. These new data suggest that online performance reports of physicians and hospitals are not frequently found and, when found, that the website experience can be improved for both health care professionals and consumers. Using specific search engine techniques may garner a larger audience. Developing reports that cover a broader set of medical conditions, that include patient comments, or that provide cost information could enable website sponsors to better meet visitors’ needs.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Example of a comparative online public report of hospital quality and screenshots of the survey invitation and an example survey question.

[pptx file (PowerPoint File), 1MB - jmir_v17i5e102_app1.pptx]

Multimedia Appendix 2

(1) CHERRIES Checklist for Reporting Results of Internet E-Surveys; (2) Description of Survey Development; (3) AHRQ Hospital-Public Report Survey; (4) AHRQ Physician-Public Report Survey; (5) Response Rate Description.

[PDF File (Adobe PDF File), 141KB - jmir_v17i5e102_app2.pdf]

Multimedia Appendix 3

Description of website survey respondents.

[PDF File (Adobe PDF File), 69KB - jmir_v17i5e102_app3.pdf]

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Abbreviations

ACA: Affordable Care Act
AHRQ: Agency for Healthcare Research and Quality
CAHPS: Consumer Assessment of Healthcare Providers and Systems
CVE: Chartered Value Exchanges
HEDIS: Healthcare Effectiveness Data and Information Set
PDF: Portable Document Format

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Original Paper

Older People Going Online: Its Value and Before-After Evaluation of Volunteer Support

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Abstract

Background: Although Internet usage can benefit older people by reducing social isolation, increasing access to services, and improving health and well-being, only a minority are online. Barriers to Internet uptake include attitude and a lack of knowledge and help. We have evaluated volunteer support in helping older people go online. Knowing what value the Internet has been to older people who have just gone online should guide how it is “sold” to those remaining offline.

Objective: Objectives of this study are (1) to assess the feasibility of recruiting volunteers aged 50 years and older and supporting them in helping people (ie, beneficiaries) aged 65 years and older go online, (2) to assess the impact of beneficiaries using the Internet on contacts with others, loneliness, and mental health, and (3) to assess the perceived value to beneficiaries of going online.

Methods: Beneficiaries received help in using the Internet from 32 volunteers in one of two ways: (1) one-on-one in their own homes, receiving an average of 12 hours of help over eight visits, or (2) in small group sessions, receiving 12 hours of help over six visits. We assessed, at registration and follow-up, the number of contacts with others, using Lubben’s 6-item Lubben Social Network Scale (LBNS-6), loneliness, using De Jong Gierveld’s 6-item De Jong Gierveld loneliness scale (DJG-6), and mental well-being, using Tennant’s Short Warwick-Edinburgh Mental Well-Being Scale (SWEMWBS). We also assessed how beneficiaries valued going online using a Social Return on Investment (SROI) approach by postal survey.

Results: A total of 144 beneficiaries were recruited with the aim of helping them go online via one-on-one (n=58) or small group (n=86) sessions. Data through to follow-up were available on 76.4% (110/144) of participants. From baseline to follow-up, the number of contacts with others was significantly increased—LBNS-6, mean 13.7 to mean 17.6—loneliness scores were reduced—DJG-6, mean 2.38 to mean 1.80—and mental well-being improved—SWEMWBS, mean 24.06 to mean 24.96. Out of six options, beneficiaries valued better communication with family and friends most and better health care least as a benefit of using the Internet. Out of nine options, having the Internet was valued less than having TV, but more than, for example, having a weekly visit from a cleaner. There were no associations between values placed on Internet use or volunteer help and psychological improvements.

Conclusions: Volunteer help to go online seemed to result in increased social contacts, reduced loneliness, and improved mental well-being and was valued quite highly by beneficiaries. Although the use of the Internet for health care was the least valued, improved social contact can improve health. Contacting family is likely to be the best “selling point” of the Internet for older people.

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KEYWORDS

digital inclusion; health informatics; social return on investment; older people

Introduction

Background

Governments and others are concerned about the digital divide and are funding initiatives to try to close the gap [1]. Age is the biggest predictor of not using the Internet in the United Kingdom (UK). In 2011, only 33% of those aged 65 years and older used the Internet compared to 99% of those aged 14 to 17 [2]. The barriers to Internet uptake include attitudes towards technology, limited experience, lack of physical access, confidence or self-efficacy, knowledge, and social help [3-6].

Studies have shown that older people can benefit from using the Internet. In particular, using the Internet for communication (eg, email) and facilitating contact with friends and family is associated with reduced feelings of social isolation [7-10]. Using the Internet for communication and information is associated with improved general mental well-being and self-efficacy [11,12]. Online access to an increasing range of goods and services (eg, online banking, home delivery, and information) can provide more opportunity to live independently [8,13]. The Internet is, of course, also used for health purposes, including providing online information, peer support, communication with health care professionals, access to medical records, and for repeat prescriptions, as this journal regularly demonstrates.

On the other hand, for some people, emphasis on technology may be the “final straw” in their alienation from modern culture [14], so we need to carefully consider whether, and how, to engage older people in using the Internet. Furthermore, there are many ways to tackle isolation and loneliness [15], and promoting Internet access may not be an obvious choice.

Assuming there are still many older people who are open to the possibility of using the Internet, what would persuade them to go online? Helsper and Reisdorf [4] found that the oldest age group was more likely to indicate a lack of interest and skills as the reason for nonuse. Lack of interest in, or having no need for the Internet was also the main reason cited in 2013 by UK households [16] and in a Scottish study [17].

Although factors such as help-seeking behaviors [18] and demographics [19] may influence the uptake of Internet use, Rogers’ theory suggests that knowing what value an innovation—such as the Internet—has been to other older people who are now online, is a necessary component of discussion with those remaining offline [20]. Older people who have recently gone online are more likely than longer-term users to be like those who continue to be nonusers.

Various projects have sought to address the digital divide through social marketing, training at local centers [21], providing Internet access points at local libraries [22,23], and various community projects, for example, the health communication project by Chu et al [24]. Conducting training and support sessions with older people may improve self-reported measures of Internet confidence, knowledge, and self-efficacy, which can ultimately lead to increased Internet use [23]. Such tuition may be more effective if received from peers of similar age [25].

We have assessed the impact on loneliness, well-being, and perceived value of using the Internet in a project in which peer volunteers helped older people go online.

Aims

This study had the following three aims:

1. To assess the feasibility and workloads of recruiting volunteers aged 50 years and older, and to support them to help people (ie, beneficiaries) aged 65 and older go online.

2. To assess the impact of using the Internet on contact with others, loneliness, mental health, life satisfaction, and independence using standardized measures.

3. To assess how beneficiaries perceived the value of going online.

Methods

Context

Plymouth SeniorNet (PSN) was set up in 2012, funded by the UK’s Big Lottery as part of the Silver Dreams program of interventions to help older people [26]. The estimated population of Plymouth residents aged 65 and older who were non-Internet users was 28,000.

Ethics

The evaluation project was approved by Plymouth University Faculty of Health, Education, and Society Ethics Committee (28/1/13).

Interventions

There were two main interventions—volunteers supported beneficiaries (1) one-on-one in their own homes, spending an average of 12 hours together over eight visits, and (2) in 90 small groups spending 12 hours with participants per group. Participants thought to be more physically isolated as determined by PSN were allocated to one-on-one support. Sessions in both settings covered basic computer use, how to get online and search the Internet, online shopping, email, Skype or FaceTime, and online news and entertainment. Volunteers supported some participants in choosing and setting up equipment and broadband. PSN supplied 9 participants with computers on long-term loan agreements and 3 participants received support with broadband costs. The elapsed time for the intervention depended on an agreement between volunteers and beneficiaries about whether they had had sufficient support.

Recruitment of Volunteers

A total of 36 people responded to local advertisements expressing an interest to become PSN volunteers. Their mean age was 63 years (SD 8.13, range 49 to 84), and most were male (26/36, 72%) and white British (35/36, 97%). Two-thirds (21/33, 64%) had prior volunteering experience and two-thirds (17/27, 63%) used the Internet many times a day. Out of 36 respondents, 4 of them (11%) dropped out during the recruitment process, 31 (86%) proceeded to provide computer support to beneficiaries, and 1 (3%) to manage a PSN online forum. Volunteers attended an introductory training session, which included project overview, an explanation of available roles, safeguarding, and lone working. They were also invited to four quarterly networking events and three technical training sessions.

Recruitment of Beneficiaries

Awareness of the project was raised through existing contacts with older people through Age UK—UK's largest charity for older people—tenants of Plymouth Community Homes, advertisements in community newspapers and on bus shelters, attendance at other local events, and other personal contacts. Beneficiaries were recruited by referral from Age UK Plymouth to PSN.

Data Collection

The PSN team documented recruitment, the intervention process, support, and training. Volunteers recorded the number, duration, and content of sessions with beneficiaries. Data from beneficiaries were collected by self-completed questionnaires with assistance where needed. Costs related to PSN staff activities were estimated over the duration of the PSN project and used to model an extension of the project to help 3000 older people get online in Devon, Cornwall, and Somerset, UK.

Baseline questionnaires included demographic data, use of health and social care services, the 6-item Lubben Social Network Scale (LBNS-6) [27]—range 0 to 30, where a high score indicates more connection—the 6-item De Jong Gierveld loneliness scale (DJG-6)—range 0 to 6, where a high score indicates more loneliness [28]—the Short Warwick-Edinburgh Mental Well-Being Scale (SWEMWBS)—range 7 to 35, presenting both raw scores and metric (converted) scores, where a high score indicates better well-being [29-31]—life satisfaction [32], independence using a question from the Investigating Choice Experiments for the Preferences of Older People CAPability measure (ICECAP) index—range 1 to 4, where a high score indicates more independence [33]—and questions from the Personal eHealth Readiness Questionnaire (PERQ) [3]. The first follow-up questionnaire was administered to beneficiaries within a few weeks of their volunteer help coming to an end, which varied between 5 and 42 weeks after completing the baseline questionnaire due to varying periods of volunteer support. It repeated questions from the baseline questionnaire with additional self-reported effects of the intervention on contacts with family and friends.

A second follow-up questionnaire (see Multimedia Appendix 1), a Value of Participation postal survey, which followed the principles of the Social Return on Investment (SROI) [34,35] approach and, in particular, Scholten’s Value Game [36], collected data to evaluate the “worth” to beneficiaries of having computer and Internet tuition. The questionnaire was developed with a small group of older people and volunteers. For each of the four questions in the survey, beneficiaries were asked to distribute 100 tokens based on personal value between a range of activities, at least some of which would be relevant to each participant. We wanted to know about (1) being on the Internet, and (2) getting help to be on the Internet so that we could, to some degree, differentiate between the perceived value of contact with the volunteer and the perceived value of being on the Internet. Question 4 addressed being on the Internet and question 3 addressed receiving help to start using the Internet. The survey was posted simultaneously to all beneficiaries in January 2014. This varied from 1 to 44 weeks—mean of 11 weeks—after completing the follow-up questionnaires.

Analysis

We explored changes in five main self-reported outcomes from baseline to follow-up by intervention group, gender, age, length of follow-up, and prior Internet connection by paired *t* tests and general linear models. In the general linear models, differences in scores from baseline to follow-up were modelled on intervention, gender, and previous Internet connection (ie, fixed factors), as well as on age and length of follow-up (ie, covariates). This was undertaken with and without the baseline value of the outcome as covariate. We examined both the values placed on Internet use and PSN volunteer help as the raw score and grouped raw scores as more or less than the median compared with improvements in the five main outcomes, and grouped them by intervention group using *t* tests and logistic regression.

Results

Beneficiaries Recruited

In total, 144 older people living in the Plymouth area with an interest in learning how to use the Internet were recruited to be supported by home (58/144, 40.3%) or small group (86/144, 59.7%) sessions. Although the target age group was 65 years and older, 14 (9.7%) younger beneficiaries aged 57 to 64 registered and, rather than be turned away, were included. Typically, beneficiaries were aged 75 to 84, were female (103/144, 71.5%), and white British (139/144, 96.5%), which reflected the ethnicity of the older population of Plymouth (see Figure 1). Of the 144 participants, 3 (2.1%) did not receive tuition due to health reasons, leaving 141 (97.9%) who received Internet help. Of the 141 remaining participants, 11 (7.8%) did not take part in the evaluation after the intervention due to health or personal reasons, and 20 (14.2%) did not respond to the follow-up questionnaire requests. Psychological data through to follow-up were, therefore, available on 78.0% (110/141) of beneficiaries, with missing values on some variables. The 3 participants who dropped out were older than the 141 who participated in the intervention (t_{142}=2.9, *P*=.004) and less independent (t_{135}=3.5, *P*=.001). The 96 out of the 141 participants (68.1%) who returned the Value of Participation postal survey were more likely to have had the one-on-one home intervention—81.0% home versus 59.0% group, χ^2_1=7.6, *P*=.006—and were older—77.5 (SD 8.2) home versus 72.6 (SD 6.7) group, t_{139}=3.5, *P*=.001—than the 45 (31.9%) who did not complete that questionnaire. There were no other differences by psychological or demographic characteristics at baseline for the groups shown in Figure 1.

The 58 beneficiaries due to be helped at home had been classified as isolated by PSN, based on who they lived with, how easily they could get out and about, and their contact with others. These were older participants and were more likely to have a disability and home help compared to the 86 not considered to be isolated, and who were due to be helped in group settings (see Table 1). All but one of those seen in group settings said they could leave the house unsupported, whereas nearly half of the isolated participants needed support. However, from the standardized questionnaires at baseline, the home-based participants had similar strengths of social networks as the group participants, were not lonelier, had similar mental well-being, and similar satisfaction with life, but were slightly less independent. Those classified as isolated were less likely to see economic barriers to using the Internet for health.

Table 1. Comparison of beneficiaries receiving one-on-one help at home with those due to receive group help.

Characteristics	One-on-one help (n=58), mean (SD) or n (%)	Group help (n=86), mean (SD) or n (%)	Test of difference	*P*
Age in years, mean (SD)	79.0 (7.5)	74.3 (8.2)	t_{142}=3.4	.001
Disability, n (%)	43 (74)	45 (52)	χ^2_1=6.9	.008
Home help, n (%)	43 (74)	33 (40) (3 MV[a])	χ^2_1=16.2	<.001
Can leave the house unsupported, n (%)	36 (62)	85 (99)	χ^2_1=34.9	<.001
Social network [28] LBNS-6[b], mean score (SD)	12.3 (6.3)	14.0 (6.8)	No difference	N/A[c]
Loneliness scale DJG-6[b][29], mean score (SD)	2.4 (1.6) (2 MV)	2.4 (1.7) (18 MV)	No difference	N/A
Mental well-being SWEMWBS[b], mean score (SD)	24.0 (3.6) (2 MV)	24.0 (5.3) (13 MV)	No difference	N/A
Satisfaction with life [32], mean score (SD)	7.1 (2.0)	7.6 (2.4) (2 MV)	No difference	N/A
Independence [33], mean score (SD)	3.0 (0.7)	3.2 (0.8) (7 MV)	t_{132}=1.98	.05
Perceived economic barriers to using the Internet for health [3], mean score (SD)	3.55 (1.7)	2.44 (1.6)	t_{142}=3.9	<.001

[a] Missing values (MV).

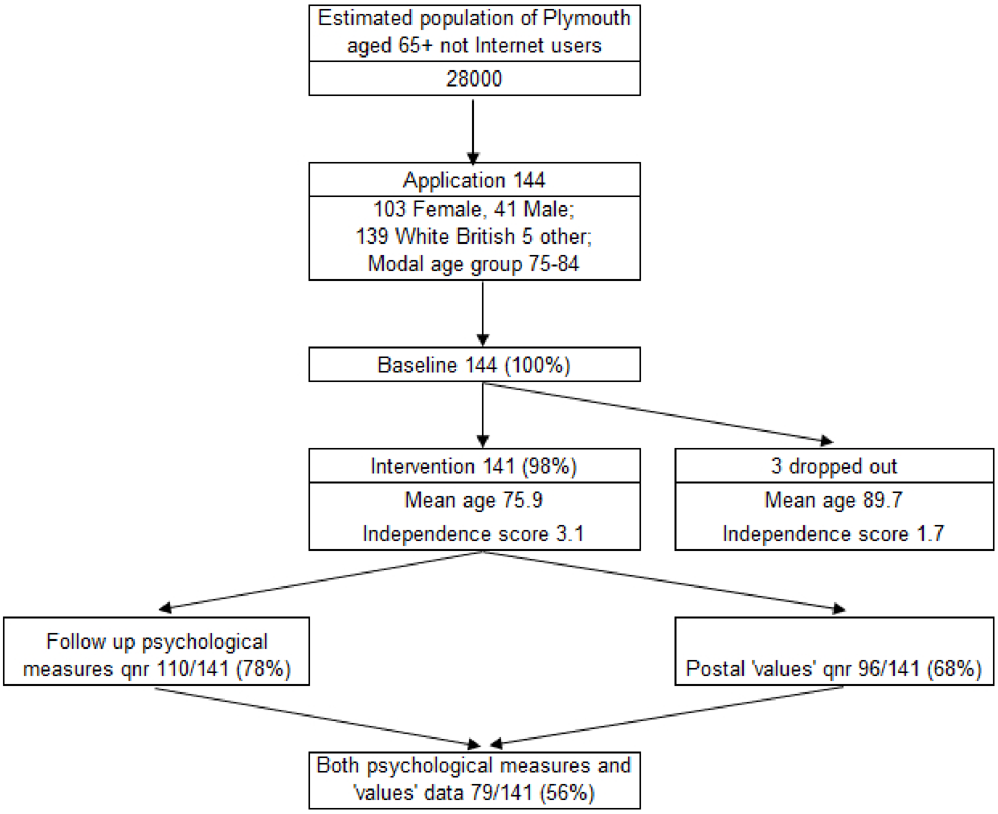
[b] 6-item Lubben Social Network Scale (LBNS-6), 6-item De Jong Gierveld loneliness scale (DJG-6), Short Warwick-Edinburgh Mental Well-Being Scale (SWEMWBS).

[c] Not applicable (N/A).

Just under half (61/138, 44.2%) of the beneficiaries had never used the Internet, a third (45/138, 32.6%) had used it a few times, and 23.2% (32/138) claimed to have used it fairly often, although not in the last 3 months, prior to the project. More than a third (53/141, 37.6%) had previously attended a computer class and two-thirds (93/138, 67.4%) had asked someone else to use the Internet on their behalf. As all were responding to an offer of help with skills, we might assume (1) that they were interested in trying the Internet, perhaps again, and (2) that skills rather than lack of access or cost may be the main reason for current Internet nonuse [4].

Two-thirds of beneficiaries (95/138, 68.8%) had home Internet connections and three-quarters (105/143, 73.4%) had a home computer. Laptops were the most common device (62/104, 59.6%), followed by desktop computers (19/104, 18.3%), tablets (16/104, 15.4%), and multiple devices, such as a laptop and a tablet (7/104, 6.7%). Most beneficiaries were interested to learn about using email (127/140, 90.7%), followed by Skype (100/140, 71.4%), online shopping (100/144, 69.4%), then games (67/140, 47.9%), and social networking (55/140, 39.3%).

Figure 1. Participant recruitment and dropout.



Intervention Resources and Feedback

In total, volunteers had 974 contacts with 141 beneficiaries—498 contacts in group sessions, 476 contacts in one-on-one sessions—and an average of 6.9 contacts per beneficiary. In total, there were 996 hours of contact with groups and 702 hours of one-on-one contact. The total period (ie, elapsed time) over which volunteers were in contact with beneficiaries, and hence the gap between completing the baseline and follow-up questionnaires, varied considerably from 5 to 42 weeks. Beneficiaries who received one-on-one contact received this over a longer period—mean 18.5 (SD 7.4) weeks—than those attending group sessions—mean 10.7 (SD 4.2) weeks—(t_{108}=7.0, P<.001). Several beneficiaries remarked that they felt less intimidated by the prospect of working with older volunteers.

Internet Use at Follow-Up

At follow-up, one-fifth (22/107, 20.6%) of beneficiaries reported using the Internet less than once a week, while four-fifths used it quite frequently—14.0% (15/107) used it many times a day, 34.6% (37/107) used it at least once a day, and 30.8% (33/107) used it at least once a week. Of those who had never used the Internet prior to Internet tuition, 68% (32/47) now used it at least once a week, including 28% (13/47) who used it at least once a day and 9% (4/47) who used it many times a day.

Most (100/109, 91.7%) beneficiaries now had a home Internet connection. Of those who did not have an Internet connection at the start of the project, 83% (29/35) did at follow-up, accounting for 30% (29/96) of those who reported having a home connection following tuition. However, 4% (3/70) of those with an Internet connection, initially, terminated their connection after the project.

Most beneficiaries had used the Internet for information (90/108, 83.3%) and email (82/108, 75.9%). The next most frequent use was Skype (42/108, 38.9%). Most beneficiaries accessed the Internet using a home desktop computer or laptop (66/108, 61.1%), followed by a mobile device, such as a tablet (23/108, 21.3%). Only a few reported not having accessed the Internet since the project (6/108, 5.6%).

Impact of Internet Use

At baseline, more than two-thirds (86/124, 69.4%) of beneficiaries were lonely—DJG-6 score of 0 to 1 [26]—compared to 52% of older people in Spain [37] and New Zealand [38]. However, the baseline mental well-being scores of the Plymouth SeniorNet population were better than the overall scores for all Silver Dreams projects—24.3 versus 21.78 [26].

Simple before-after analysis (see Table 2) suggested that participants had increased social networks, reduced loneliness, and improved mental well-being after the intervention. There was no measurable impact on satisfaction with life or independence scores, even though 46.8% (51/109) reported that involvement in the project had made a difference to their satisfaction with life, and most of those with limited independence at baseline reported an improvement (13/17, 76%) at follow-up.

Table 2. Mean scores and significance of score changes from baseline to follow-up for up to 110 participants for various measurements by intervention and for all participants.

Scale	Scores, mean (SD)		Mean change	n	*t* [a]	*df*	*P*	Impact of intervention
	Baseline	Follow-up						
One-on-one sessions (n=45)								
Contacts[b]	12.25 (6.18)	13.82 (6.17)	1.57	44	2.05	43	.05	Increased social networks
Loneliness[c]	2.42 (1.66)	2.34 (1.64)	-0.08	41	0.30	40	.76	No difference
Mental well-being [d]								
Raw score	26.90 (3.49)	27.64 (3.28)	0.74	39	1.32	38	.19	No difference
Metric score	24.30 (3.35)	24.95 (3.16)	0.65	39	1.15	38	.26	No difference
Satisfaction[e]	7.09 (2.11)	7.16 (2.35)	0.07	45	0.17	44	.86	No difference
Independence[f]	3.00 (0.62)	2.95 (0.65)	-0.05	43	0.50	42	.62	No difference
Group sessions (n=65)								
Contacts	15.03 (6.42)	16.69 (5.57)	1.66	65	3.50	64	.04	Increased social networks
Loneliness	2.35 (1.65)	1.37 (1.43)	-0.98	51	3.39	50	.001	Reduced loneliness
Mental well-being								
Raw score	25.96 (5.73)	27.63 (2.97)	1.67	54	2.19	53	.03	Improved mental well-being
Metric score	23.89 (4.91)	24.97 (3.18)	1.08	54	1.68	53	.10	No difference
Satisfaction	7.60 (2.33)	8.14 (1.22)	0.54	63	2.00	62	.05	Improved satisfaction
Independence	3.27 (0.76)	3.29 (0.59)	0.02	59	0.16	58	.87	No difference
All participants (n=110)								
Contacts	13.91 (6.44)	15.53 (5.56)	1.62	109	2.87	108	.005	Increased social networks
Loneliness	2.38 (1.64)	1.80 (1.59)	-0.58	92	2.92	91	.004	Reduced loneliness
Mental well-being								
Raw score	26.36 (4.92)	27.63 (3.09)	1.27	93	2.56	92	.01	Improved mental well-being
Metric score	24.06 (4.31)	24.96 (3.16)	0.90	93	2.04	92	.04	Improved mental well-being
Satisfaction	7.39 (2.24)	7.73 (1.83)	0.34	108	1.53	107	.13	No difference
Independence	3.16 (0.71)	3.15 (0.64)	-0.01	102	0.13	101	.89	No difference

[a] Paired *t* tests.

[b] Number of contacts measured with the 6-item Lubben Social Network Scale (LBNS-6) [27].

[c] Loneliness measured with the 6-item De Jong Gierveld loneliness scale (DJG-6) [28].

[d] Mental well-being measured with the Short Warwick-Edinburgh Mental Well-Being Scale (SWEMWBS) [29-31].

[e] Satisfaction with life [32].

[f] Independence as in Coast et al [33].

When viewed by intervention type, the pattern of change was consistent with the overall change in these five variables (see Table 2). In paired *t* tests, those in the group intervention showed a greater reduction in loneliness—0.98 group versus 0.07 home, t_{90}=2.41, *P*=.018—but not in the other four main outcomes, compared to those in the one-on-one intervention.

Modelling changes in the five outcomes by demographics, length of follow-up, prior Internet connection, and intervention group, did not identify any major predictors (see Table 3). However, in all cases the baseline value of the outcome was a significant predictor at *P*<.01, suggesting that all improvements seen may just be "regression to the mean." Length of follow-up was a significant predictor of increased connections (F_{109}=5.21, *P*=.025) and intervention type was a predictor of increased independence (F_{140}=4.75, *P*=.03).

Table 3. Significant predictor variables in general linear models predicting improvement in five outcome variables.

Improved outcome	Predictors	
	Not including baseline as covariate	Including baseline as covariate
Contacts	No predictors	Baseline value (*P*<.001) Length of follow-up (*P*=.03)
Loneliness	Intervention*previous connection (*P*=.04)	Baseline value (*P*<.001)
Mental well-being (metric)	No predictors	Baseline value (*P*<.001)
Satisfaction	No predictors	Baseline value (*P*<.001) Intervention*gender (*P*=.05)
Independence	No predictors	Baseline value (*P*<.001) Intervention (*P*=.03)

Value of Participation

Of the 141 beneficiaries, 101 (71.6%) responded to the Value of Participation postal survey but 5 (3.5%) returned incomplete questionnaires—1 participant was ill, 1 had died, 1 was no longer using the Internet, 1 was dissatisfied with the intervention and did not want to complete the questionnaire, and for 1 the reasons were unknown. Data from this survey were, therefore, available for 68.1% (96/141) of the beneficiaries (Figure 1).

Better communication with family and friends was ranked highest out of six options by beneficiaries as a benefit from using the Internet (mean 35.63, SD 21.60), followed by being entertained or stimulated (mean 21.96, SD 22.80), and feeling more confident because of their newly learned skills (mean 18.18, SD 18.95) (see Table 4). Better health care was seen as the least important. Beneficiaries also thought that the tuition they received had also benefited their family and friends, most notably better communication with them was ranked highest (mean 49.50, SD 28.38) out of four options (see Table 5). Receiving help from a PSN volunteer in using the Internet was ranked highest out of nine options in terms of value to them (mean 21.55, SD 20.93). This was followed by receiving a phone call each week from a family member or friend (mean 20.21, SD 16.96), and being able to get out and about by themselves (mean 14.54, SD 15.65) (see Table 6). Finally, giving up the Internet for 1 week was ranked second highest (mean 16.49, SD 15.89), following giving up their TV for a week (mean 23.63, SD 16.75) out of nine options of things they did not want to give up (see Table 7).

Those who had one-on-one tuition at home were more likely to value the PSN volunteer than those helped in group settings—25.89 (SD 19.98) home versus 17.39 group (21.18), t_{94}=2.0, *P*=.046—but there was no difference in the value placed on being online between the two interventions. There were no associations between values placed and the five main psychological outcomes from logistic regression analysis.

Table 4. Values assigned to personal use of the Internet based on answers to question 1 from the Value of Participation postal survey: Have you benefited from using the Internet in any of these ways?

Benefits from using the Internet (n=90)	Score out of 100, mean (SD)
Better communication	35.63 (21.60)
Being entertained or stimulated	21.96 (22.80)
Feeling more confident	18.18 (18.95)
Being more independent	11.18 (14.98)
Saving money or having a better range of goods	7.03 (11.85)
Better health care	6.02 (9.77)

Table 5. Perceived value for family members of older person's Internet use based on answers to question 2 from the Value of Participation postal survey: Have your family or friends benefited from you using the Internet?

Benefits by family or friends from you using the Internet (n=83)	Score out of 100, mean (SD)
Better communication	49.50 (28.38)
Saving money or having a better range of goods	17.69 (19.84)
Being entertained or stimulated	17.40 (21.54)
Not having to do things for me	15.41 (20.79)

Table 6. Help using the Internet compared to other activities based on answers to question 3 from the Value of Participation postal survey: How much are the following activities worth to you?

Internet help and other activities (n=96)	Score out of 100, mean (SD)
Receiving help from a Plymouth SeniorNet volunteer	21.55 (20.93)
Having a phone call from my family/friend each week	20.21 (16.96)
Being able to get out and about on my own	14.54 (15.65)
Having someone clean my house/flat	13.82 (18.36)
Being taken out to a nice pub in the country for lunch	7.83 (10.20)
Getting a letter or postcard from my family/friend	7.53 (10.77)
Spending an afternoon enjoying the garden	6.92 (10.17)
Having someone help sort out bills, investments, or finance	4.38 (8.62)
Having someone cook me lunch at home	3.24 (7.75)

Table 7. Value of keeping Internet access compared to other activities based on answers to question 4 from the Value of Participation postal survey: Which of these do you really not want to give up?

Continued Internet access and other activities (n=95)	Score out of 100, mean (SD)
TV for a week	23.63 (16.75)
Internet for a week	16.49 (15.89)
Bus pass for a week	15.70 (18.65)
Reading the newspaper for a week	9.78 (10.97)
One weekly visit from my cleaner	9.53 (13.90)
One weekly tea and biscuits with a friend	7.61 (10.76)
A social event for a week (eg, bowling, bridge, pub)	7.14 (10.39)
One weekly visit from my gardener	5.50 (9.92)
Going to church for a week	4.63 (9.14)

Costs

PSN received funding of £172,000. Setup and learning costs to get the project started were estimated as £50,000. Costs for taster sessions—105 people not reported in this paper—were estimated as £20,000. Therefore, the cost to help 144 people online was £102,000, or £708 per person. This did not include the costs of volunteers, but if we assume that volunteers benefited themselves from their activity we might exclude those costs. Based on workloads for PSN and how these might have scaled up—with economies of scale—in a 4-year project for the largely rural counties of Devon, Cornwall, and Somerset, UK, we estimated a project cost of £1 million to help 3000 people, or £333 per person.

Social Return on Investment

Having the Internet is valued by participants more than items such as cleaning and meals out that can be valued at £20 to £25 per week (see Table 6). An annual value for being online might, therefore, be £1000 to £1300. An intervention such as PSN would, therefore, "pay for itself" in under a year.

Discussion

Principal Findings

The longer-term aim of PSN was that going online would help older people be better connected with their peers, family, and sources of support, have a greater sense of control in their lives through the use of computers, have a greater sense of belonging to a community, be able to use information technology to improve health and well-being, and build resilience to manage change effectively. The indications from the before-after scores for social network, loneliness, and mental well-being for the beneficiaries, along with the value they placed on using the Internet for communication suggest that helping older people to use the Internet is of considerable value. Social isolation has mortality risks as great as smoking and obesity [39,40]. Reducing social isolation is, therefore, a health issue, but may not be seen as such either by older people themselves or by policy makers.

The PSN intervention of recruiting people aged 50 years and older to help those aged 65 years and older get online seemed to work well. Volunteers were relatively easily recruited and retained, however the project itself terminated with the end of Lottery funding for the supporting PSN team, although some volunteers may have continued informally to help older people go online. Some PSN volunteers transferred to Age UK Plymouth as IT trainers/facilitators after the project ended. PSN funding had been substantial, but a large proportion of these funds were used in setting up the project and learning what worked in establishing the recruitment and training of volunteers and recruitment of beneficiaries. This method of getting people online is still relatively expensive compared to some other methods, such as group drop-in sessions. However, that some people needed support over quite long periods (ie, up to 42 weeks) suggests that assumptions that older people can become Internet users after one or two sessions may be overoptimistic.

We demonstrated two approaches to help older people get online—one-on-one and group sessions—but it is difficult to compare the two interventions, as allocation was based on perceived physical ability to get out of the house and, thereby, to attend group sessions. Those given one-on-one help were older, more likely to be disabled, and needed home help so it may not have been feasible for them to attend group sessions. However, those attending group sessions seemed, on simple paired *t* test analysis, to have a greater reduction in loneliness compared to those in one-on-one sessions.

One strength of the PSN approach may be the support offered by volunteers on practical aspects of equipment and getting online, for example, being there to oversee the installation of broadband and to set up new equipment. On joining PSN, two-thirds of beneficiaries already had Internet connections but were not sure how to use them and had not used the Internet in the previous 3 months. Although this was higher than in a cross-sectional household survey in the same town in which just under half (30/71, 42%) of non-Internet users had an Internet-connected computer at home [3], indicating that participants in that study were more predisposed to try using the Internet, half of non-Internet users may live in Internet-connected households. We did not collect data on bereavement, but it is possible that many non-Internet-using older people had previously relied on a now deceased partner for that "task" within their relationship [41] and now had to take on this new responsibility.

A quarter of the beneficiaries felt their involvement in the project had made a notable difference to the number of contacts with family and friends, in particular the number of relatives they felt close enough to that they could call on for help. This was supported by the Value of Participation survey in which better communication was the biggest benefit to them and their family and friends from learning to use the Internet. Receiving help from a volunteer in using the Internet was highly valued by beneficiaries and rated higher than other activities, such as getting out and about on their own or having a cleaner in to help.

Studies of this sort, including, for example, the overall evaluation of the Silver Dreams project [26], typically use a before-after design and attribute improvement to the intervention. On this same basis, using paired *t* test analysis, scale measures showed a significant decrease in loneliness and increase in mental well-being among beneficiaries—18% indicated that their involvement in the project had made a notable difference to their satisfaction with life. However, a linear model approach that included baseline values of each outcome variable suggested that at least part of this change may be "regression to the mean."

Limitations

There was no control group and participants volunteered for help to go online. Therefore, the participants still represented those who were willing to try the Internet. Although our before-after measures may, therefore, be partly explained by a Hawthorne effect, including the social aspects of being involved in the project, there is no reason to believe that their views on the value of being online are invalid.

As participants were chosen for each type of intervention and not randomized, it had not been our a priori intention to compare effectiveness of the two interventions. We assumed before the project that physical independence to get out of the house might be associated with psychological isolation, loneliness, and mental well-being. This proved not to be the case. We, therefore, took the opportunity to examine, post hoc, which approach seemed to work given the baseline psychological status of participants in the two groups. Some will argue that comparisons that were not predefined should not be made.

Fitting a model to the five main psychological outcomes including baseline values suggests that the improvements seen may just be "regression to the mean." We, therefore, may be overly optimistic in assuming that the PSN intervention had any effect. However, the simple before-after approach has been used for other studies, including from the Silver Dreams program [26], and our method of presentation allows comparison with those studies.

Other studies [4,5] have shown education to be a good predictor of the uptake of use of the Internet. However, we did not collect data on the educational level of beneficiaries and were unable to make such comparisons.

Recommendations

1. This project has shown that many older people can be helped to get online. They rated the value of being online highly compared to other daily activities, and using the Internet for communication with family was most valued, whereas using the Internet for health was not seen as particularly important. Although there is evidence from elsewhere that many older people are not interested in using the Internet, these findings suggest that campaigns to motivate those older people who are, as yet, not interested in going online should focus on communication with family.

2. Others have tried intergenerational support for older learners [42], but PSN beneficiaries indicated that support by someone closer to them in age was important.

3. Many of the older people we contacted were prepared to buy their own equipment, in particular, tablet computers proved popular. The decreasing cost of tablets suggests that, although cost may be important for some, volunteer support should be the focus.

4. A mix of one-on-one and group sessions is likely to be needed. Those with limited mobility may struggle to attend group sessions out of the home.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Extension to beneficiary follow-up questionnaire.

[PDF File (Adobe PDF File), 5MB - jmir_v17i5e122_app1.pdf]

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Abbreviations

DJG-6: 6-item De Jong Gierveld loneliness scale
ICECAP: Investigating Choice Experiments for the Preferences of Older People CAPability measure
LBNS-6: 6-item Lubben Social Network Scale
MV: missing values
N/A: not applicable
PERQ: Personal eHealth Readiness Questionnaire
PSN: Plymouth SeniorNet
SROI: Social Return on Investment
SWEMWBS: Short Warwick-Edinburgh Mental Well-Being Scale
UK: United Kingdom

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Original Paper

Seeking Health Information Online: Association With Young Australian Women's Physical, Mental, and Reproductive Health

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Abstract

Background: Relatively little is known about the extent to which young adults use the Internet as a health information resource and whether there are factors that distinguish between those who do and do not go online for health information.

Objective: The aim was to identify the sociodemographic, physical, mental, and reproductive health factors associated with young women's use of the Internet for health information.

Methods: We used data from 17,069 young women aged 18-23 years who participated in the Australian Longitudinal Study on Women's Health. Multivariable logistic regression was used to estimate the association between sociodemographic, physical, mental, and reproductive health factors associated with searching the Internet for health information.

Results: Overall, 43.54% (7433/17,069) of women used the Internet for health information. Women who used the Internet had higher odds of regular urinary or bowel symptoms (OR 1.44, 95% CI 1.36-1.54), psychological distress (very high distress: OR 1.24, 95% CI 1.13-1.37), self-reported mental health diagnoses (OR 1.16, 95% CI 1.09-1.23), and menstrual symptoms (OR 1.25, 95% CI 1.15-1.36) than women who did not use the Internet for health information. Internet users were less likely to have had blood pressure checks (OR 0.85, 95% CI 0.78-0.93) and skin cancer checks (OR 0.90, 95% CI 0.84-0.97) and to have had a live birth (OR 0.74, 95% CI 0.64-0.86) or pregnancy loss (OR 0.88, 95% CI 0.79-0.98) than non-Internet users.

Conclusions: Women experiencing "stigmatized" conditions or symptoms were more likely to search the Internet for health information. The Internet may be an acceptable resource that offers "anonymized" information or support to young women and this has important implications for health service providers and public health policy.

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KEYWORDS

Internet; women's health; young adults; health status; mental health; information seeking behavior

Introduction

The affordability and availability of the Internet make it a convenient resource that is increasingly used to offer information, support, and services to the population regarding their health. Recent estimates from the United States and Europe suggest that almost half of adults seek health information online [1-3], often before or after a visit to a health care professional to obtain further information or advice [2,4,5]. Certain subgroups appear more likely to access health information online, including younger adults, women, and those from higher socioeconomic backgrounds [1,4,6-9]. However, few studies have examined the characteristics of online health seekers beyond sociodemographic factors.

Going online for health information may be useful for a broad range of health issues. The Internet offers diversity in health information and support with numerous websites, blogs, and online support groups all dedicated to various aspects of health. Of the few studies examining the health status of those who search the Internet for health information, those experiencing socially embarrassing or "stigmatizing" symptoms or conditions (eg, urinary incontinence and mental health conditions) [10], those wanting sexual health information (eg, sexually transmitted infections) [11], and pregnant women and mothers [9,12] appear to be more likely to seek health information online. However, studies specifically focusing on online health-seeking behaviors among young adults are limited. A recent population-based study from France reported that young women aged 15-30 years who had children or who were psychologically distressed were more likely to seek health information online [1]. However, the health care needs of adolescents and young adults are likely to be diverse and there may be better insights offered by research that targets specific age groups [13].

In this paper, we describe the health information sources used by a national sample of young Australian women aged 18-23 years. We aim to identify the sociodemographic, physical, mental, and reproductive health factors associated with searching the Internet for health information to inform health care services and support for young women.

Methods

Overview

The Australian Longitudinal Study on Women's Health (ALSWH) is a national study focusing on the biological, psychological, social, and economic factors relevant to women's health [14]. Initially, ALSWH used mailed self-report surveys to explore the health and well-being of 3 cohorts of Australian women aged 18-23 years, 45-50 years, and 70-75 years when the project began in 1996. The 40,000 participants were randomly selected using the national health insurance database (Medicare), which includes all permanent residents of Australia. Since 1998, surveys have been conducted on a triennial basis [14]. Comparisons with Australian census data show that the 3 cohorts of women are broadly representative of the Australian population in these age groups [15].

In 2012-2013, ALSWH recruited a new cohort of young women born 1989-1995 and aged 18-23 years when they were first surveyed. Women were eligible if they lived in Australia, had a valid Medicare number, and if they consented to data linkage (linking survey data with administrative health data). Approval for the study was obtained from the Human Research Ethics Committee of the University of Newcastle and the University of Queensland, as well as the Department of Human Services and the Department of Health. Further details of the survey methodology are available from the study website [16].

Recruitment

Participants were recruited from October 2012 to December 2013 through conventional (ie, radio interviews and magazine advertising) and online social media (including YouTube videos), with full details reported elsewhere [17,18]. A total of 17,069 women completed a Web-based survey comprising 62 questions on sociodemographic characteristics (eg, educational qualifications), physical and mental health (eg, self-rated general health), anthropometric data (eg, height, weight), reproductive health (eg, pregnancy, birth outcomes), health behaviors (eg, physical activity levels, tobacco and illicit drug use), and experience of violence or abuse and access to health services (eg, screening services). Comparisons with national census data (2011) show that the 1989-1995 cohort is broadly representative of the Australian population of women aged 18-23 years, but with a slight overrepresentation of better-educated, Australian-born, and nonsmoking women [17].

Study Variables

Outcome Measure

A question asking women, "Where do you get information about your health? (mark all that apply)," was used to categorize women into those who did and did not use the Internet as a source of health information. Women chose from 10 information sources (eg, Internet, family, doctor, television/radio/magazines/posters/leaflet, other) and those who reported using the Internet (solely or in conjunction with other sources) were classified as "Internet users" and the remaining women were classified as "non-Internet users." We also calculated the number of health information sources used by summing together women's responses to the list of 10 sources (yes=1; no=0), creating an ordinal variable ranging from 0-10.

Sociodemographic Variables

We collected information on age (in years), area of residence based on an index of distance to the nearest urban center (major cities, inner regional, outer regional, remote/very remote) [19], highest level of education (less than year 12, year 12 or equivalent, certificate/diploma, university degree), current relationship status (never married, never married but in a relationship, married/engaged, separated/divorced/widowed), ability to manage on income (easy, not too bad, difficult some of the time, difficult all of time, impossible), and living arrangements (living with parents / not living with parents).

Health and Health Conditions

Women were asked to rate their general health (excellent, very good, good, fair or poor) and to report chronic health conditions (eg, diabetes, heart disease, cancer). Women reporting urinary/bowel symptoms (eg, urine that burns or stings, leaking urine, hemorrhoids, constipation), mental health conditions (eg, depression, anxiety, other), and who used preventative health services (eg, blood pressure or skin cancer checks in the last two years) were classified as "yes" or "no.".

Sexual and Reproductive Health

Women reported if they ever had a live birth, pregnancy loss (ectopic pregnancy, miscarriage, termination for medical or personal reasons, stillbirth), sexually transmitted infection (chlamydia, genital herpes, genital warts, human immunodeficiency virus [HIV] / acquired immune deficiency syndrome [AIDS], hepatitis B/C), or received a diagnosis of endometriosis or polycystic ovary syndrome, or had a Papanicolaou test in the last 2 years (yes/no). Women reporting menstrual symptoms "sometimes" or "often" in the last 12 months (eg, vaginal discharge, heavy periods, severe period pain) were categorized as suffering these symptoms regularly and classified as "yes" vs "no."

Statistical Analysis

Bivariate logistic regression was used to estimate odds ratios (ORs) and 95% confidence intervals (95% CIs) for the association between sociodemographic, physical, mental, and reproductive health factors and searching the Internet for health information. Sociodemographic variables were entered into a multivariable logistic regression model to examine their association with Internet use for health information. The ORs for the association between physical, mental, and reproductive health factors and Internet use, adjusted for key sociodemographic characteristics, were estimated by multivariable logistic regression models. Data analysis was conducted using SAS version 9.4 (TS1M0) for Windows (SAS Institute Inc, Cary, NC, USA).

Results

On average, women aged 18-23 accessed 3 sources of information for their health. Doctors (77.01%, 13,145/17,069) followed by family members (61.87%, 10,561/17,069) were the major sources of health information. The Internet and friends were identified by 43.55% (7433/17,069) and 43.25% (7383/17,069) of women, respectively, followed by school, university, and Technical and Further Education (TAFE; 39.55%, 6750/17,069), conventional media (32.18%, 5495/17,069; includes television, radio, magazines, posters, leaflets), and to a lesser extent, nurses (14.49%, 2474/17,069). A minority of women (5.90%, 1007/17,069) reported other sources of health information (results not shown).

Overall 43.55% (7433/17,069) of women identified the Internet as a source of health information (either alone or in conjunction with other sources) with the remaining 56.45% (9636/17,069) of women using non-Internet sources only. Stratifying by Internet use made little difference to the overall pattern of health sources accessed (Figure 1). However, Internet users were more likely to rely on friends, school, university, and TAFE or conventional media than non-Internet users, whereas non-Internet users sought advice more often from doctors.

Being older, having a university education, living in a major city, being in a relationship (never married), and not living with parents were significantly associated with using the Internet for health information (Table 1). Income management was not associated with accessing the Internet for health information. After adjusting for sociodemographics, having urinary or bowel symptoms, moderate or higher levels of psychological distress, a diagnosed mental health condition, or menstrual symptoms were associated with Internet use for health information (Table 2). Women who accessed preventive blood pressure and skin cancer checks or who had ever had a live birth or pregnancy loss were less likely to use the Internet for health information.

Figure 1. Sources of health information accessed by young women who do and do not use the Internet as a health information resource.

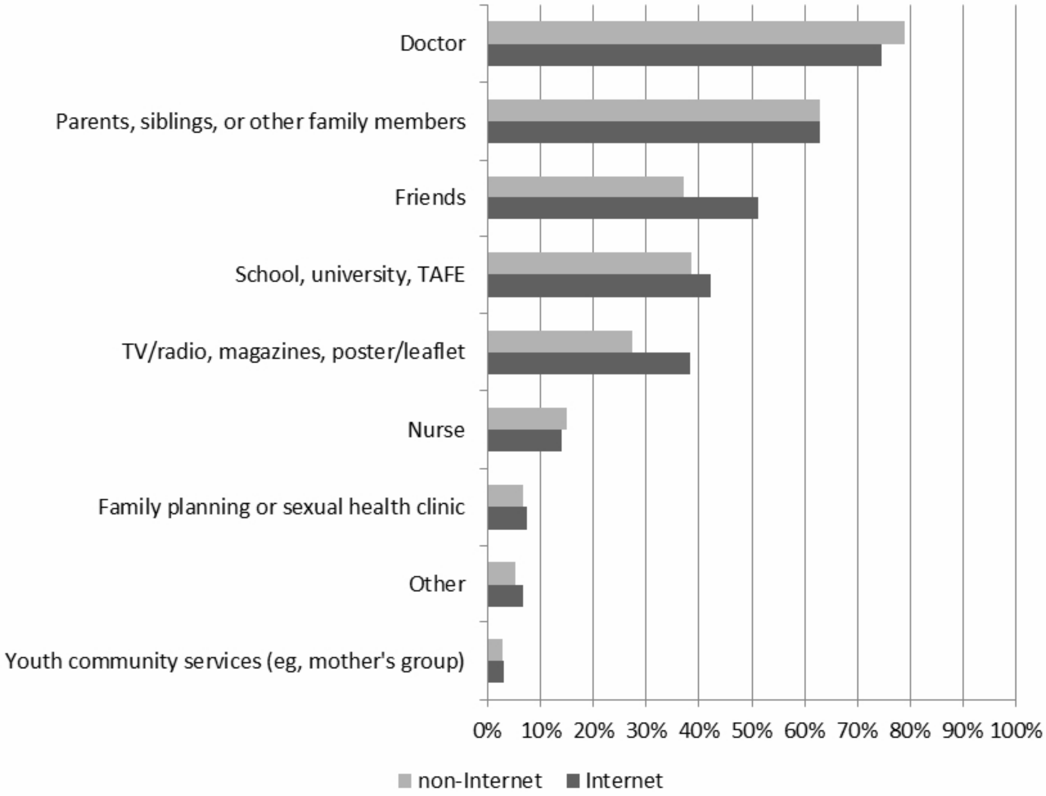

Table 1. Sociodemographic characteristics of women who do and do not use the Internet as a health information resource (N=17,069).

Sociodemographics	Internet	Non-Internet	Internet use	
	n=7433	n=9636	OR (95% CI)	AOR[a] (95% CI)
Age (years), mean (SD)	20.7 (1.67)	20.4 (1.69)	1.10 (1.08-1.12)	1.08 (1.06-1.11)
Education, n (%)				
<Year 12	477 (6.43)	794 (8.39)	0.79 (0.70-0.89)	0.79 (0.69-0.89)
Year 12	3170 (42.70)	4171 (44.09)	1	1
Certificate/diploma	1808 (24.35)	2620 (27.70)	0.91 (0.84-0.98)	0.83 (0.77-0.90)
University	1969 (26.52)	1875 (19.82)	1.38 (1.28-1.49)	1.17 (1.07-1.27)
Area of residence, n (%)				
Major city	5773 (77.91)	7076 (73.68)	1	1
Inner regional	1114 (15.03)	1717 (17.88)	0.80 (0.73-0.86)	0.82 (0.76-0.90)
Outer regional	444 (5.99)	707 (7.36)	0.77 (0.68-0.87)	0.79 (0.70-0.90)
Remote/very remote	79 (1.07)	104 (1.08)	0.93 (0.69-1.25)	0.96 (0.71-1.29)
Marital status, n (%)				
Never married-single	2771 (37.32)	3733 (39.46)	1	1
Never married-in a relationship	4031 (54.30)	4913 (51.93)	1.11 (1.04-1.18)	1.09 (1.02-1.16)
Engaged/married	558 (7.52)	744 (7.86)	1.01 (0.90-1.14)	0.96 (0.85-1.09)
Separated/divorced/other	64 (0.86)	70 (0.74)	1.23 (0.87-1.73)	1.31 (0.92-1.85)
Ability to manage on income, n (%)				
Easy/not bad	2955 (39.82	3623 (38.31)	1	1
Difficult some of the time	2619 (35.29)	3403 (35.98)	0.94 (0.88-1.01)	0.95 (0.87-1.02)
Difficult all of the time/impossible	1847 (24.89)	2432 (25.71)	0.93 (0.86-1.01)	0.98 (0.91-1.07)
Living arrangements, n (%)				
Living with parents	3639 (49.04)	4843 (51.21)	1	1
Not living with parents	3782 (50.96)	4615 (48.79)	1.09 (1.03-1.16)	1.05 (0.98-1.12)

[a] Mutually adjusted for other variables in the model.

Table 2. The association between physical, mental, and reproductive health and using the Internet as a health information resource (N=17,069).

Health-related variables	Internet, n (%)	Non-Internet, n (%)	Internet use	
	n=7433	n=9636	OR (95% CI)	AOR[a] (95% CI)
Physical health				
Self-rated general health				
Excellent/very good	3191 (42.93)	3987 (42.10)	1	1
Good	2982 (40.12)	3884 (41.01)	0.96 (0.90-1.03)	1.02 (0.95-1.09)
Fair/poor	1260 (16.95)	1599 (16.88)	0.98 (0.90-1.07)	1.08 (0.99-1.18)
Chronic condition				
None	3496 (47.04)	4425 (46.73)	1	1
1	2673 (35.97)	3407 (35.981)	0.99 (0.93-1.06)	0.99 (0.93-1.06)
≥2	1263 (16.99)	1638 (17.30)	0.97 (0.90-1.06)	0.97 (0.89-1.06)
Urinary/bowel symptoms				
Never/rarely	3782 (50.89)	5656 (59.73)	1	1
Sometimes/often	3650 (49.11)	3814 (40.27)	1.43 (1.35-1.52)	1.44 (1.36-1.54)
Blood pressure check				
No	1096 (14.75)	1288 (13.61)	1	1
Yes	6332 (85.25)	8177 (86.39)	0.91 (0.83-0.99)	0.85 (0.78-0.93)
Skin cancer check				
No	5297 (71.32)	6608 (69.87)	1	1
Yes	2130 (28.68)	2850 (30.13)	0.93 (0.87-1.00)	0.90 (0.84-0.97)
Mental health				
Psychological distress				
Low	1451 (19.54)	2078 (21.95)	1	1
Moderate	2178 (29.33)	2814 (29.72)	1.11 (1.02-1.21)	1.13 (1.04-1.24)
High	2173 (29.26)	2458 (25.96)	1.27 (1.16-1.38)	1.34 (1.23-1.47)
Very high	1625 (21.88)	2118 (22.37)	1.10 (1.00-1.21)	1.24 (1.13-1.37)
Diagnosed mental health condition				
No	4188 (56.36)	5559 (58.70)	1	1
Yes	3243 (43.64)	3911 (41.30)	1.10 (1.04-1.17)	1.16 (1.09-1.23)
Reproductive health				
Live birth				
No	7063 (95.20)	8835 (93.45)	1	1
Yes	356 (4.80)	619 (6.55)	0.72 (0.63-0.82)	0.74 (0.64-0.86)
Pregnancy loss or termination				
No	6777 (91.30)	8516 (90.01)	1	1
Yes	646 (8.70)	945 (9.99)	0.86 (0.77-0.95)	0.88 (0.79-0.98)
Endometriosis				
No	7196 (96.81)	9295 (96.46)	1	1
Yes	237 (3.19)	341 (3.54)	0.90 (0.76-1.06)	0.89 (0.75-1.05)
Polycystic ovary syndrome				
No	7023 (94.48)	9082 (94.25)	1	1
Yes	410 (5.52)	554 (5.75)	0.96 (0.84-1.09)	0.93 (0.82-1.07)
Sexually transmitted infection				

Health-related variables	Internet, n (%)	Non-Internet, n (%)	Internet use	
	n=7433	n=9636	OR (95% CI)	AOR[a] (95% CI)
No	6549 (88.13)	8420 (88.91)	1	1
Yes	882 (11.87)	1050 (11.09)	1.08 (0.98-1.19)	1.06 (0.96-1.16)
Menstrual symptoms				
Never/rarely	1165 (15.67)	1729 (18.26)	1	1
Sometimes/often	6268 (84.33)	7742 (81.74)	1.20 (1.11-1.30)	1.25 (1.15-1.36)
Pap test				
No	3796 (51.11)	4990 (52.72)	1	1
Yes	3631 (48.89)	4475 (47.28)	1.07 (1.00-1.13)	0.94 (0.88-1.01)

[a] Adjusted for age, education, area of residence, and marital status.

Discussion

This study describes the sources of health information accessed by young Australian women and identifies the sociodemographic, physical, mental, and reproductive health factors associated with searching the Internet for health information. Our findings suggest that although the majority of young Australian women rely on their doctor for health information, a large proportion (43.55%, 7433/17,069) also access health information online. Several other studies, including a previous survey of Australian women across a wide age range [9], reported that although doctors are rated as the preferred and most credible source of health information, the Internet is another common source [5,8,20]. There is evidence to suggest that between 40% and 66% of adults use the Internet for health information [1-3,5,11]. Our finding that 44% of women aged 18-23 years used the Internet as a source of health information is generally consistent with previous estimates, although slightly lower (48.5%) than a recent large study of young French adults [1].

Consistent with several other studies [1,4,6-8], there were sociodemographic differences between those who did and did not use the Internet as a source of health information. Although the association between age and Internet use for health is conflicting, Internet use increased with age in our study among young women in the age range of 18-23 years. Young women's preferences for online health information may increase in response to major life transitions and events that influence their health and well-being, including sexual and reproductive issues and events. Further, like other studies reporting a positive association between online health seeking and socioeconomic position [1,6,8], we found that young women who had a university qualification were more likely to search the Internet for health information. Women with higher educational qualifications are likely to have greater access to computers and the Internet and it is also possible that they find it easier to navigate the diversity of information offered by the Internet [20-22].

Women reporting "stigmatized" conditions or symptoms were more likely to search the Internet for health information. Consistent with other studies [1,10], we found that psychological distress and a diagnosis of a mental health condition were associated with Internet use. The stigma associated with mental illness is a common barrier to young adults' use of professional support services [23]; however, the Internet may be an acceptable "flexible" resource that can offer "anonymized" information or support [24,25]. In Australia, several government-supported organizations including "headspace," "beyondblue," and "Young and Well" offer online resources to people with mental health issues. It is possible that some young women in our study accessed these websites independently or were advised by a health professional. Further, young women experiencing urinary and/or bowel or menstrual symptoms—where discussions with health care professionals may be perceived as embarrassing—were more likely to use the Internet as a health information resource. A review of UK research regarding young adults' health care needs and preferences also described accessibility and confidentiality as important aspects of health care [13]. Thus, the Internet may play an important role in supporting young women with "sensitive" health issues.

Few studies have examined the relationship between health status and searching the Internet for health information and the evidence is somewhat inconsistent. In our study, we found that women with children, those who had experienced pregnancy losses, and those accessing preventive health services were least likely to use the Internet. These are all women who are likely to be in contact with health care professionals, so their need for health information may already be met. In contrast, we found no association between self-rated general health or chronic conditions and Internet use for health information. Although other studies have reported that use of computer-based resources or online support groups are associated with more visits to a health care professional [26] or poor self-rated general health [7], more recent studies have also found no association between Internet use for health and self-reported general health [1,6], chronic conditions [1], or number of visits to a health professional [3,6].

Although we assessed women's health status, we did not ask women about recent visits to a health care professional. Therefore, we cannot determine the impact of the Internet on health care use. Further, although we focused on women's use of information for their own health, other studies suggest that some people will use the Internet to seek information for another's health. This may be an important avenue for future research with young women as they transition through adulthood, particularly motherhood.

Internet availability and use has increased dramatically in Western countries in the last decade. Our findings suggest that the Internet may be an acceptable resource for young women experiencing stigmatized or sensitive health issues, which has important implications for the effectiveness of professionally supported self-care programs [27]. Although the Internet has great capacity as a health resource, the quality of the information offered varies considerably, and misinformation has the potential to negatively impact a person's health and well-being. Therefore, a better understanding of young women's online behaviors is important for developing strategies to assist and direct women to credible online health resources.

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Authors' Contributions

IJR conducted the statistical analyses and drafted the manuscript. GDM, DL, and AJD contributed to all stages of the study, interpretation of the results, and critical revision of the manuscript for intellectual content. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

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Abbreviations

ALSWH: Australian Longitudinal Study on Women’s Health
AIDS: acquired immune deficiency syndrome
HIV: human immunodeficiency virus
STI: sexually transmitted infection
TAFE: Technical and Further Education

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Original Paper

Women Veterans' Experience With a Web-Based Diabetes Prevention Program: A Qualitative Study to Inform Future Practice

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Abstract

Background: Diabetes prevention is a national goal and particularly important in the Veterans Health Administration (VHA) where 1 in 4 veterans has diabetes. There is growing evidence to support the use of Web-based diabetes prevention program (DPP) interventions, shown to be as effective and often more feasible than in-person interventions.

Objective: Our primary objective was to qualitatively explore women veterans' early experiences with a Web-based DPP intervention. Our secondary objective was to estimate weight loss, participation, and engagement to provide context for our qualitative findings.

Methods: We conducted and analyzed semistructured interviews and collected data on weight change, participation, and engagement. A total of 17 women veterans with prediabetes from a Midwest VA Women's Health Clinic were eligible to participate; 15 completed interviews.

Results: Participants perceived the DPP program as an appealing way of initiating lifestyle changes and made them feel accountable in achieving their daily goals. The online program was convenient because it could be accessed at any time, and many found that it integrated well into daily life. However, some did not like the logging aspect and some found it to be too impersonal. Participants logged in a mean 76 times, posted a mean 46 group messages, and sent a mean 20.5 private messages to the health coach over 16 weeks. Participants lost 5.24% of baseline weight, and 82% (14/17) of participants completed at least 9 of 16 core modules.

Conclusions: Women veterans' early experiences with a Web-based DPP intervention were generally positive. Accountability and convenience were key enabling factors for participation and engagement. A Web-based DPP intervention appears to be a promising means of translating the DPP for women veterans with prediabetes.

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KEYWORDS

prediabetic state; disease management; risk reduction behavior; program evaluation; patient satisfaction; attitude to computers; computers; Internet

Introduction

Type 2 diabetes is associated with significant morbidity and mortality. Nationally, diabetes affects 11% of women 45-64 years of age [1], but the prevalence has been estimated at 10% for women veterans between 45-54 years of age and 18% for those 55-64 years of age [2]. For women veterans, the burden of diabetes is further compounded by known gender disparities in the control of important modifiable risk factors shown in both Veterans Affairs (VA) [3] and non-VA studies [4,5].

Several randomized controlled trials, including the Diabetes Prevention Program (DPP) study, have demonstrated that lifestyle interventions promoting weight loss and increased physical activity significantly reduce the risk of progression to diabetes compared to placebo [6]. These landmark findings have been shown to persist up to 10 years in longitudinal observational studies [6-12]. However, translation of DPP-based lifestyle interventions has presented several challenges [13-15]. The most notable challenge is the substantial investment required to deliver—and for participants, attend—16 in-person lifestyle coaching sessions [13,16,17], resulting in significant barriers to reach and uptake among both health care systems and patients.

Women have repeatedly identified competing demands (such as caregiving) as a significant barrier to lifestyle intervention adherence [18,19]. For women veterans, distance may also be a barrier because up to one-third live in rural or highly rural areas [20]. Therefore, the time and expense of traveling to attend in-person interventions is likely to constrain participation. Furthermore, studies have shown that women veterans are more reluctant to regularly attend in-person VA-sponsored programs due to the nature of the predominantly male environment [21]. They may also feel uncomfortable discussing weight and exercise in groups that include face-to-face interaction with men [22].

Web-based DPP interventions have the potential to reduce or eliminate these barriers. Web-based DPP interventions are delivered asynchronously and are easily accessed, affording women greater convenience and flexibility. Web-based interventions can improve behavioral outcomes including increased exercise time, increased knowledge of nutritional status, and 18-month weight loss maintenance [23]. In addition, Web-based DPP interventions can produce similar weight loss compared to in-person interventions, but at a lower cost [13]. Thus, Web-based DPP interventions may be a feasible means of increasing reach and uptake of DPP interventions in the VA and an especially appealing option for women veterans with prediabetes.

To date, most of the literature related to DPP interventions has been quantitatively focused with little attention paid to participant experiences [13,24-30]. Overall, our goal was to generate rapid and relevant data on the early experiences of participants to inform future work in this area. Specifically, our primary objective was to qualitatively explore advantages and disadvantages of delivering a DPP in a Web-based format to the earliest cohort of women veterans with prediabetes in our study. Our secondary objective was to quantitatively estimate weight loss, participation, and engagement in this cohort to provide context for our qualitative findings. The rising prevalence of both prediabetes and diabetes, as well as the variable reach and uptake of in-person DPP, render our findings timely and relevant inside and outside VA.

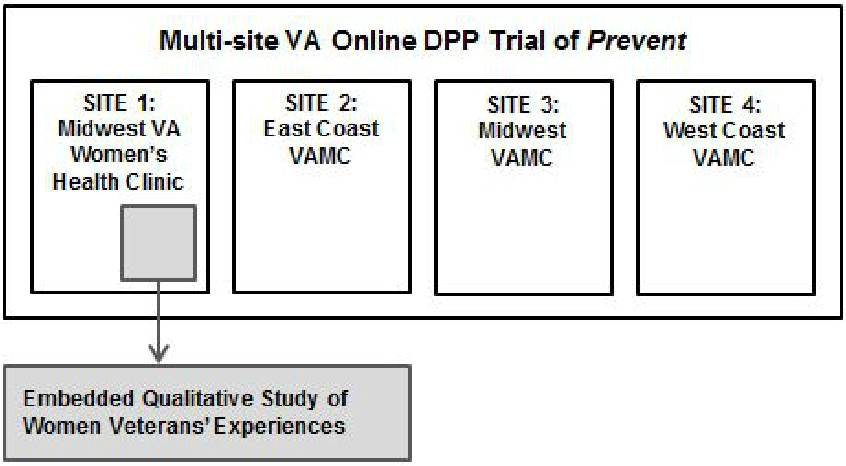
Methods

Setting and Design

Overview

This qualitative study was embedded within a larger, multisite VA trial of a Web-based DPP intervention, which used a commercially available Web-based, DPP-based group lifestyle intervention known as *Prevent*, described below. See Figure 1 for a diagram of the study design overview.

Figure 1. Study design overview.



Multisite VA Online DPP Trial

The Multisite VA Online DPP Trial was funded by the VA Diabetes QUERI (Quality Enhancement Research Initiative) and included 4 VA Medical Centers (VAMCs). One participating VAMC—a Midwest VA Women's Health Clinic—recruited only women veterans; the other 3 VAMCs in the study did not make a special effort to recruit women. The trial was initiated to explore alternative methods for DPP delivery. VA research funds were used to pay for 240 participant enrollment fees for 1-year access to Prevent, a commercially available Web-based diabetes prevention program developed by Omada Health (Omada Health, San Francisco, California).

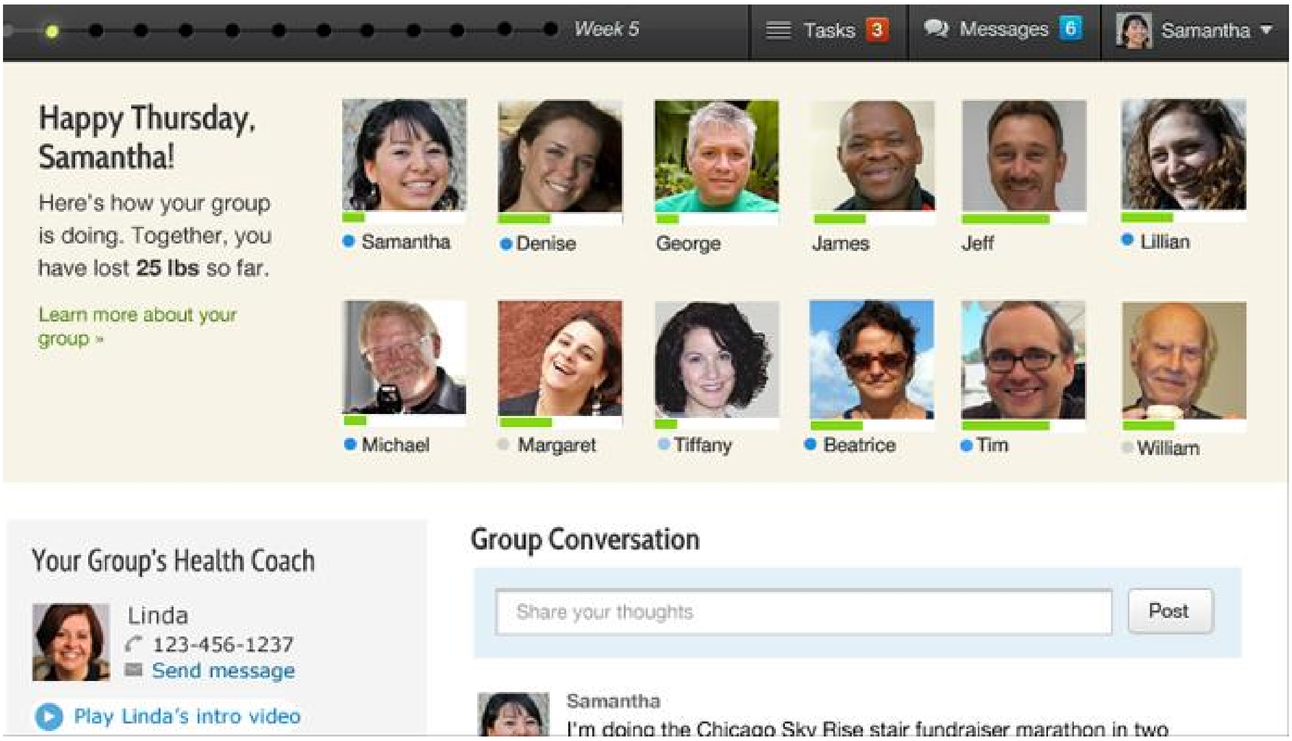
Prevent integrates educational modules, health coaching, and tracking tools [26]. A unique feature of this program is that it leverages social media principles to deliver a virtual DPP in a small group format, as shown in Figure 2.

Prevent has been shown to meet the Centers for Disease Control and Prevention (CDC) Diabetes Prevention and Recognition Program outcome standards [31] and weight loss outcomes of other DPP translations [26]. Prevent participants are assigned to small virtual groups based on a proprietary algorithm that uses individual characteristics including age, body mass index (BMI), and geographic location.

A 1-year membership to Prevent consists of 16 weekly modules of intensive core curriculum followed by an 8-month maintenance phase (8 “post-core” monthly modules). Over the first 16 weeks, a new core module is made available each week with new goals and encouragements to post responses to interactive exercises. Participants can choose when to log in and for how long. A certified professional health coach, affiliated with the Prevent program, is assigned to each group to help deliver the curriculum, answer questions, and monitor group interactions on a regular basis to ensure an appropriate and positive virtual group environment. Participants can post messages to the entire group or send private messages to the health coach. All participants receive a pedometer, food and exercise trackers, and a wireless scale that automatically uploads weight data to Prevent on a daily basis.

Omada Health agreed to transfer all participation data from consented study participants to the VA research team for analysis. The study team analyzed all data independently and retained sole authority over all publication-related decisions throughout the course of the study. Enrollment for the multisite VA DPP trial began in October 2013.

Figure 2. Prevent screenshot.



Happy Thursday, Samantha!

Here's how your group is doing. Together, you have lost **25 lbs** so far.

Samantha

I'm doing the Chicago Sky Rise stair fundraiser marathon in two

Embedded Qualitative Study of Women Veterans' Experiences

We used an exploratory mixed-methods study design to examine the early experiences of a subset of women veterans with prediabetes enrolled in the multisite VA online DPP trial [32].

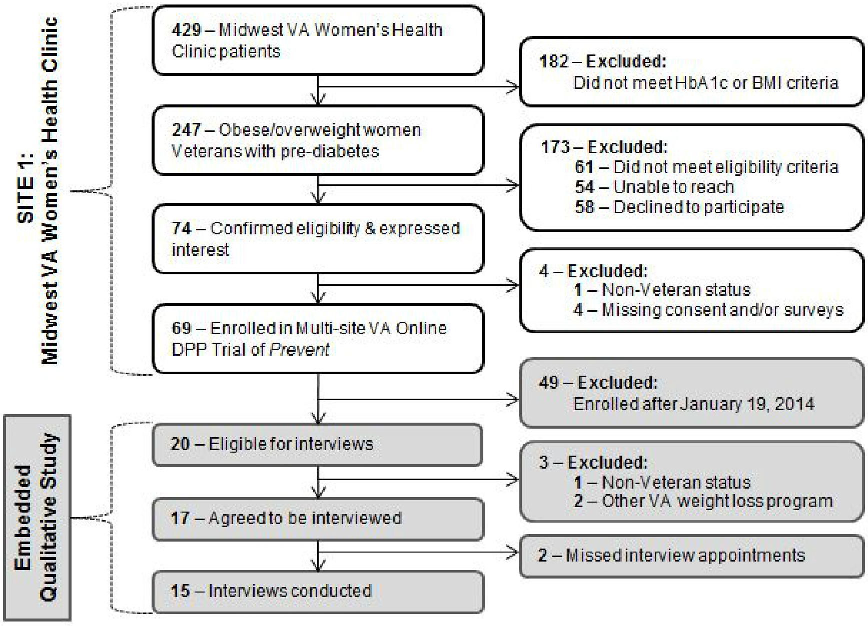
Participants and Recruitment

Women veterans with prediabetes from the Midwest VA Women's Health Clinic who had enrolled in *Prevent* by January 19, 2014, were invited to participate in interviews for this embedded qualitative study (Figure 3). Prediabetes was defined as fasting plasma glucose of 100-125 mg/dl or a hemoglobin A1c (A1c) of 5.7-6.4% in the past 12 months. All participants were obese (BMI >30 kg/m^2) or overweight (BMI >25 kg/m^2) with one cardiovascular risk factor (eg, hypertension). Participants with diabetes or eating disorders, use of antiglycemic medications (including metformin), pregnancy or a plan to become pregnant, a medical contraindication to lifestyle modification, lack of regular access to a computer with an Internet connection or email address, or participation in a VA weight management program within the prior 6 months were excluded.

Eligible participants were mailed invitation letters from their primary care providers and received follow-up phone calls from research staff. All participants were asked to sign informed consent. Consented participants were then assigned to a Prevent group on a rolling basis; groups included veterans and non-veterans and female and male participants.

Beginning in February 2014, the research team contacted women veterans with prediabetes from one Midwest VA Women's Health Clinic who had enrolled in Prevent by January 19, 2014, for interviews. All participants who expressed interest were scheduled for interviews with the investigator (JS). All participants who completed an interview received a US $25 gift card.

Figure 3. Study recruitment details.



Data Collection and Analysis

Qualitative data were collected through in-person semistructured interviews conducted in a private room by one investigator (JS) in March 2014. A copy of the interview guide is provided in Multimedia Appendix 1. We audio-recorded the interviews, which lasted 30-50 minutes, transcribed them verbatim, and manually coded the transcripts using a content analysis approach [33]. Codes were developed inductively by coding the first 6 interviews using a consensual process. Descriptive, inductive content analysis was used to identify common themes. Two coders independently coded each interview manually (JS, KE, KH, EV, TM) and analyzed them for common themes. While it was not a criterion for stopping interviews, we did reach thematic saturation. The analysis team (KE, KH, EV, TM) met regularly to iteratively reach consensus on any coding discrepancies [34].

General health information was collected from medical records (age, A1c, BMI, weight, and service connection) and an enrollment questionnaire (race/ethnicity, income, education, employment status, comorbidities, and self-rated health status). Weight data were objectively collected using data uploads from wireless scales. We assessed participation based on frequency of logins to Prevent, weight assessments, and messages sent. Engagement was assessed based on rates of module completion and mean percent weight loss over 16 weeks**.**

The study was approved by the local and coordinating center's Institutional Review Boards, and all participants completed a written informed consent process.

Results

By January 19, 2014, 20 women veterans with prediabetes had enrolled in Prevent. Our sample included the first 17 interview-eligible participants who enrolled in the program. All 17 agreed to be interviewed but two did not show up for interviews, leaving a final qualitative sample of 15 participants.

At baseline, participants had a mean age of 56.8 years, BMI of 35.6 (5.3) kg/m^2, and A1c of 6.0% (0.2) (Table 1); 41% were African American (n=7).

Table 1. Participant baseline[a] characteristics (n=17).

Characteristics	n (%) or mean (SD)
Age (years), mean (SD)	56.8 (7.0)
Race or ethnicity [b] , n (%)	
White	8 (47)
Black	7 (41)
Did not disclose	2 (12)
Education, n (%)	
Some college or 2-year degree	11 (64)
4-year college graduate	2 (12)
4-year college degree	3 (18)
Did not disclose	1 (6)
Annual income, US $ [b] , n (%)	
<50,000	8 (47)
≥50,000	6 (35)
Did not disclose	3 (18)
Employment status, n (%)	
Working part-time/full-time	7 (41)
Unemployed/disabled/unable to work	3 (18)
Retired	6 (35)
Did not disclose	1 (6)
Comorbidities	
Number[c], mean (SD)	1.9 (0.7)
Hypertension, n (%)	8 (47)
Mental health conditions[d], n (%)	5 (30)
Self-rated general health status, n (%)	
Good or better health	14 (82)
Fair or poor health	3 (18)
Physiological tests, mean (SD)	
A1c	6.0 (0.2)
BMI	35.6 (5.3)
Weight (lbs)	210.4 (38.6)

[a] Baseline characteristics are from surveys and labs taken prior to the first Web-based DPP module.

[b] One or more missing values.

[c] Comorbidities included hypertension, hyperlipidemia, coronary heart disease, heart failure, liver disease, lung disease, stroke, arthritis, and/or osteoporosis.

[d] Mental health conditions included depression, posttraumatic stress disorder, schizophrenia, and/or bipolar disorder.

Qualitative Findings

Overview

Qualitative interview data provided insights into the early experiences of women veterans in the Web-based DPP intervention. The women were enthusiastic about Prevent and described their experiences, highlighting both facilitators and challenges. We identified seven broad themes that emerged from the 15 interviews.

Theme 1: The Program Is a Good Fit With Perceived Health Needs

Overall, participants perceived the Web-based DPP as a good fit for their health needs. One participant stated: “I was just thinking and praying about the fact that I need to get my weight under control. Gotta get my health under control and I was just feeling so yucky and this program came along. And it was just perfect” [ID11]. Another participant explained: “You know, I’ve battled my weight all my life, you know, and I knew it was time to get back and start doing something but just kind of casting around and trying to find the right program and the right fit. So this [program] sounded good" [ID13].

Theme 2: The Program Is Convenient

Almost all participants emphasized the convenience of a Web-based delivery format. One participant explained:

> *Knowing I didn't have to leave out the house (sic); knowing I can participate with other people just via Internet, this was great. It was great doing [the program] by Internet. You didn't have to get up and go places all the time and do things and [could] keep…your own pace. The only thing I had to get up every morning and do is weigh in. That's not a problem so far.* [ID6]

Another participant highlighted the flexibility of the Web-based format: "…'unstructuredness:' Ability to go on at midnight and see what's going on. Not [being] tied to a schedule" [ID5].

Theme 3: The Program Integrates With Daily Life

Participants stressed the ease with which they could integrate the intervention into their existing daily routines and how integration in daily activities increased participation and engagement:

> *I get on the scale every day. That's a no-brainer 'cause it's in the bathroom, you know, after I brush my teeth and all that stuff just before I get in the shower I get on and then I get in the shower and I'm going about my day. No brain. Easiest thing in the world to do. So I've never missed getting on the scale.* [ID8]

Several participants specifically commented on the increased convenience of the Web-based format compared to previously attempted in-person programs, such as "I don't have to drive into the [medical center] every, you know, every day, that kind of thing. I have had to do that with other programs in the past and it's just, it can take up a lot of my time in the day" [ID7].

Theme 4: "I Feel Accountable"

All participants felt accountable to the Web-based DPP intervention, which was a significant motivation to meet daily goals including daily weighing. One participant stated:

> *I think that the program helped a lot. When I made a commitment to weigh myself every day that was huge, you know, that kept me honest. On the days I really didn't want to get on the scale—which was the day I really needed to be on the scale—that was good. Knowing I was sort of accountable to the program, that was a big motivator.* [ID13]

Another explained: "It's the accountability. A lot of this program is because of the accountability, having to put everything, having to get on the scale every morning, and I sleep and walk with my pedometer and to get my 5000 steps or more in a day and things like that" [ID11].

One participant stated: "Um…the daily weigh-in I think for me was just, was the biggest. Really the biggest and knowing that I was a part of a group and that we were all working towards the goals so I was part of something, was a big motivator. Having that goal set was also helpful" [ID13]. Another participant explained:

> *Well, there's a little bar that says what the group's goal is for steps and then there's like a, I think it's a green bar, that shows everybody's steps, and then there's like a little tiny bar that's you. So it will tell you how many steps if you hover over it. So I'll take and figure out the percentage because…I always want to look to make sure I'm keeping up my steps so I'm not the slacker in the group.* [ID10]

Theme 5: "I Hate Logging"

Though tracking and entering data fosters accountability, it also proved to be a deterrent for some participants. One example included the food and exercise trackers, which are ubiquitous in most weight loss programs whether they are online or not. Some participants did not welcome the logging that was needed, as described by one participant: "I'm not one to log. I hate logging stuff. I can't stand to log. I'm lazy. When it comes up to logging my activities, you know. I know what I'm doing, but I don't want to log my life. I'm not interested in logging my life" [ID4].

Theme 6: "If the Program Were In-Person, My Group Would Know Me Head-to-Toe"

Last, several participants viewed the Web-based group format as less interactive or intimate, as highlighted by one participant:

> *I'm a real talker. So if we were sitting in a room face-to-face, they'd know me from head to toe by now. Sitting before people I seem to be a little bit more open than online. Probably simply because I'm very conscious of my wording and so if I sit before you I may say a couple paragraphs, but typing it'll probably be a couple of sentences.* [ID8]

Another participant said: "Online: I didn't care for it. If we were all in one room it would be a different situation, you know. Body language says a lot to me. I mean you can say all the right words you want in black and white but body language tells me a lot" [ID14].

Theme 7: Difficult to Figure It Out

Computer literacy made the Web-based format more challenging for some, including one participant who stated: "There were some parts of the website I guess that I never did figure out. Well, I'm sure it's user friendly for most people. Not all of us have the same abilities when it comes to that" [ID5].

Several participants also described technical and/or equipment failures that interfered with engagement. "For instance, my scale got goofed up and I didn't know how to fix it and she [the health coach] finally helped me figure out what to do and it worked". Despite several participants encountering technical issues, most of them were resolved through responsive support services and generally, the convenience of the Web-based delivery format outweighed technical challenges. "My computer acts up a lot, so I don't get to log in and do all the stuff that they would like me to do, but versus going to meetings and all of that, I would prefer to do it online" [ID9].

At 16 weeks, participants lost an average of 5.24% (SD 0.05) from starting body weight. All participants completed at least 4 core modules, and 82% (14/17) completed at least 9 of the 16 core modules. On average, participants logged into the Web-based intervention 76 (SD 64.3) times, weighed in 89 (SD 34.8) times, posted 46.5 (SD 35.7) group messages, and sent 20.5 (SD 9.9) private messages to the health coach over 16 weeks (Table 2).

Table 2. Participation, engagement, and weight change over 16 weeks (n=17).

Measure	Result
Participation metrics over 16 weeks per participant, mean (SD)	
Logins[a]	76 (64.3)
Weight assessments[b]	88.5 (34.8)
Comments left on discussion board	46.5 (35.7)
Private message to health coach	20.5 (9.9)
Completion of 16 weekly core modules, n (%)	
Participants who completed at least 9 of 16 of modules	14 (82)
Participants who completed all 16 modules	7 (41)
Percent weight change from starting weight over 16 weeks, %	
All participants (n=17)	5.24
For participants completing ≥9 modules (n=14)	5.92
For participants completing all 16 modules (n=7)	8.59

[a] Logins refers to the number of times participants logged in to the program.

[b] Weight assessments were conducted using a home wireless scale.

Discussion

Principal Results

Our qualitative results showed participants perceived the Web-based DPP as an appealing way of initiating lifestyle changes. The program was convenient because it could be accessed at any time, it integrated well into daily life, and it made them feel accountable in achieving their daily goals. One way the program helped make participants feel accountable was through regular and ad hoc interactions with the health coach and members of their group. Participants posted messages about their progress (or lack thereof), which elicited supportive feedback from other group members and/or the health coach. Group members could see the progress each participant was making toward her goals (Figure 2). In addition, group progress was updated daily and helped participants see their contribution to their group's progress as a whole. However, some did not like logging and some felt the program was too impersonal. Our quantitative results indicated high levels of participation and engagement as measured by rates of educational module completion and the frequency of online interactions. These high levels of participation and engagement, including self-monitoring, are likely to have contributed toward weight loss [35-37].

Generally, little is known about participant experiences in diabetes prevention programs, which is an important gap in the existing literature [13,25-30], and even less is known about Web-based DPP interventions. Based on early experiences of a small cohort of women veterans with prediabetes, our findings suggest that a Web-based DPP intervention may be an especially appealing option for them. The challenges of delivering an in-person DPP intervention coupled with the rising prevalence of prediabetes and diabetes, place increasing urgency on learning about viable options to engage patients in effective non-traditional programs.

Our results provide several insights for future practice. First, offering a Web-based version of DPP may be an effective way to increase the repertoire of diabetes risk reduction strategies. From a health system perspective, a Web-based DPP intervention may be more feasible and sustainable to implement on a large scale given lower operating costs. The VA is a regionalized health care system where Internet-based health care delivery has great potential to increase access and sustainability of programs targeted to preventing diabetes. However, rates of health-related Internet use are relatively low among veterans [38,39]. Higher education and urban location are strongly and positively associated with veterans' health-related Internet use; even after controlling for socioeconomic characteristics, interventions may be needed to increase use among less educated and rural veterans [40].

Despite these challenges, our sample, albeit small, provides early evidence that well-designed Web-based DPP interventions may be welcomed and effectively utilized by women veterans. In fact, a Web-based delivery format may help increase participation and engagement in a DPP or weight management programs for all patients; traditional onsite programs struggle with low levels of participation in real-world settings [41-43]. A Web-based DPP intervention may increase enrollment, participation, and satisfaction among patients who are not able to participate in onsite programs because of distance, work schedules, or discomfort.

Second, unlike in-person DPP interventions with established standards for delivery, Web-based interventions are relatively new and necessitate evaluation. It is not yet clear how best to optimize this type of DPP delivery to enhance desired clinical outcomes. Evidence from our qualitative data suggests that accountability and automated real-time monitoring affected participants' early experiences and encouraged participation and engagement. Accountability was frequently described as a sense of obligation to the group or the health coach. Technological features of Prevent helped reinforce this feeling of accountability. A wireless scale automatically uploaded weight data and online tools displayed visual progress toward goals, individually and aggregated for the group in real-time. In contrast, diet and exercise trackers that required manual data entry were inconsistently used or not used at all. Thus, our early findings suggest that Web-based DPP interventions should strive to include elements of accountability and automated monitoring systems whenever possible.

Our qualitative results also allude to an important shortcoming that may occur in a virtual online group environment. The Web-based format felt less intimate to some participants who, for example, highlighted the importance of non-verbal communication that is possible only with face-to-face interventions. This raises interesting questions about the potential merging of in-person and Web-based programs to best meet patient needs while also maximizing available resources. For example, individuals assigned to a Web-based group might benefit, if geographically feasible, from having the option of a limited number of face-to-face meetings with their group. Future studies should help establish minimum standards and best practices for Web-based DPP delivery to help answer these critical questions.

Limitations

Our findings should be interpreted with several limitations in mind. First, our sample size was small. However, our qualitative data indicated thematic saturation (ie, no new themes emerged in the last five interviews that were analyzed). The small sample size limits generalizability of quantitative results, including estimates of weight loss, and will need to be confirmed in a larger study; these were included here to provide context for the qualitative results. Second, enrollment occurred on a rolling basis and our sample included the first 17 interview-eligible participants who enrolled in the program. These first participants may have been more highly motivated patients who completed the multistep recruitment process relatively quickly. It would be important to continue to assess participant experiences and collect data on reasons for non-participation in future studies.

Our participants were enrolled in the Web-based DPP intervention for a relatively short timeframe, so further studies are needed to assess longer-term experiences and outcomes. Our findings are also less generalizable because we included only women veterans from one VA Women's Health Clinic. Further studies are needed to assess the extent of applicability of these findings to other settings and populations. Last, comparing and contrasting qualitative and quantitative findings was outside the scope of this small study but will be the focus of future work in this area.

Conclusions

In conclusion, a Web-based DPP intervention appears to be a promising means of translating the DPP for women veterans with prediabetes in the VA. Our early qualitative findings provide a deeper understanding of participants' early experiences and reveal how the convenience, fit, and integration of the program into daily life, and feelings of accountability contributed to participation and engagement. Our quantitative findings demonstrate high levels of participation, engagement, and meaningful weight loss, which is often a challenge with in-person interventions. These findings are particularly valuable given the paucity of literature in this domain and the high prevalence of prediabetes [44]. Studies with larger and more diverse cohorts/settings, non-completers, and long-term follow-up are needed to provide a more definitive evidence base for Web-based DPP interventions.

Acknowledgments

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Conflicts of Interest

Authors KH, JS, and KE work at the recruitment site. KH directs the Midwest VA Women's Health Clinic and serves as primary provider for many of the women in that clinic. The rest of the research team had no direct ties to the recruitment site or patients.

Multimedia Appendix 1

Patient interview guide.

[PDF File (Adobe PDF File), 35KB - jmir_v17i5e127_app1.pdf]

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Abbreviations

A1c: hemoglobin A1c
BMI: body mass index
CDC: Centers for Disease Control and Prevention
DPP: Diabetes Prevention Program
QUERI: Quality Enhancement Research Initiative
VA: Veterans Affairs
VAMCs: VA Medical Centers

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Viewpoint

The Cancer Experience Map: An Approach to Including the Patient Voice in Supportive Care Solutions

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Abstract

The perspective of the patient, also called the “patient voice”, is an essential element in materials created for cancer supportive care. Identifying that voice, however, can be a challenge for researchers and developers. A multidisciplinary team at a health information company tasked with addressing this issue created a representational model they call the “cancer experience map”. This map, designed as a tool for content developers, offers a window into the complex perspectives inside the cancer experience. Informed by actual patient quotes, the map shows common overall themes for cancer patients, concerns at key treatment points, strategies for patient engagement, and targeted behavioral goals. In this article, the team members share the process by which they created the map as well as its first use as a resource for cancer support videos. The article also addresses the broader policy implications of including the patient voice in supportive cancer content, particularly with regard to mHealth apps.

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KEYWORDS

mHealth; patient participation; neoplasm; public policy; Internet intervention; cancer survivors; online interventions

Introduction

Background

“Patient voice” is a term that has become more common in health care contexts. It is often used to describe a compilation of many patients’ expressed feelings, concerns, and experiences during an illness. While “patient voice” sounds singular—as if all of these voices had somehow reached a consensus and blended into one voice—it is plural in that this “voice” reflects a span as wide as the vastness of human experience and response. For the purpose of this article, “patient voice” is defined as the perspective of a cancer patient, and acknowledging the voice of the cancer patient is synonymous with having a deep understanding of how cancer affects a person as a human being, including in physical, emotional, psychosocial, and spiritual ways.

When our team, consisting of a medical writer, an oncology content specialist, and two user experience researchers, set out to concretely represent the voice of the cancer patient, our goal was to build a tool for our company’s content developers. We call this new patient-voice model a “cancer experience map”. We believe that, in this time when technology makes very little seem impossible, the usefulness and long-term, proven success of mobile health apps (mHealth apps) will depend on the app developers’ willingness and ability to tailor their apps to the cancer patient. Here, we offer the cancer experience map as a new tool for mHealth app developers.

Mobile Health Apps: Benefits and Barriers

Mobile health apps (mHealth apps) not only can be a source of support for people who have cancer but also can improve their quality of life. During cancer treatment, this support can help a cancer patient manage health-related issues and promote better patient-provider communication, collaboration, and shared decision making [1]. After cancer treatment, an mHealth app can ease this transition by helping him or her deal with lingering side effects, such as insomnia, or make health behavior changes, such as trying a new exercise routine [2]. Also, mHealth apps that are online coaching programs can benefit family or friends who are caring for a person with cancer—lightening their burden, increasing their coping skills, and improving their mood [3].

Amidst all this promise, there are some real-world limitations. A systematic review of mobile phone apps found that while there are hundreds of apps covering a range of cancer-related support, there is a lack of evidence on how they are used and how effective and safe they are [4]. There is no index or repository where a person can go to see what apps are available, nor is there a standard rating system that includes reviews by cancer patients who have tried these apps. In addition, mHealth apps in the United States are subject to legal implications, so health care providers and app developers need guidance to comply with regulations [5].

Many barriers have been identified. A recent review of mobile phone apps for breast cancer noted as a barrier the lack of consumer confidence in these apps and pointed out the need for a robust framework for identifying high-quality cancer supportive care apps that could be used by patients and their medical providers [6]. The technology limitations of mobile devices pose another barrier, and app developers are advised to use cancer patients to test their apps and then implement the design and functionality features recommended by these patients [1]. The unmet supportive care needs of cancer survivors after treatment are also a barrier that is becoming increasingly more evident [7].

Capturing the Cancer Patient Voice

How can researchers and others who are interested in building mHealth apps for cancer supportive care know what cancer patients need the most? It may seem obvious that the first step would be to ask cancer patients what they need and want. But, surprisingly, the voice of the cancer patient is often absent from the conversations that lead to the design of supportive-care programs for this very population.

Some developers have invited cancer patients into their app development process, such as the researcher who created a real-time tracking tool for breast cancer patients and had patients try it out [8]. Others have created apps and then had cancer patients try them out, such as the researcher who made revisions after getting feedback from the adolescent cancer patients who tried out her game-type app for managing pain [9].

While the actual use and testing of mHealth apps with cancer patients during development and afterwards is essential, what about the initial steps in developing an app? A key starting point is a “rigorous evaluation of the consumer’s needs” [10]. Understanding “the nature and magnitude of the impact of cancer” is essential in planning supportive care [7].

Looking to gain entry into the mindset of cancer patients, our small team found ourselves at this very point when assigned the task of creating a suite of cancer support videos. In this paper, we share how we developed a representational model to reflect the cancer patient voice and how we used this model in our product development process. We also briefly discuss the broader concerns of the patient voice and recent steps that have been taken to represent that voice in health care public policy in the United States. The aim of this paper is to offer our process and the resulting cancer experience map as a resource for designers of mHealth apps specifically for this population. Our deepest hope is that ultimately cancer patients will benefit from the sharing of this story.

The Oncology Content Specialist: Hearing the Patient Voice

When our health information company decided to create supportive cancer content, an early assignment came to the oncology content specialist and the user experience researchers. Our task was to create a representational model to support script development for cancer support videos and for future cancer content development.

As the oncology content specialist, I was responsible for providing information, resources, and insight about cancer and cancer patients to the team. For over 6 years, I had followed the medical news on cancer and had been tracking the “consumer experience” of cancer patients online in blogs and forums as well as in other media. While my work often involved reviewing oncology content for medical accuracy with an eye to the patient perspective, my initial meeting with the user experience researchers was the first time I was part of a project where the scope of the discussion was the entire range of the cancer experience. Two questions were paramount in the conversation: Who is the person with cancer? And what does a person with cancer experience?

> *I remember the day that they diagnosed me. I left the hospital, and I couldn’t find my car. It was in a parking garage. I literally was bumping into cars. I was so broken up. I couldn’t see where I was walking. It was just like, ‘Oh, my God. This can’t be happening to me’.* [11]
>
> *Emotionally, you don’t drop to the bottom; you get thrown to the bottom.* [11]

When asked to summarize my informal observations, I talked about the patient interview I had recently read in which a man described losing his car in the hospital parking lot shortly after finding out he had cancer. This story brought up the striking contrast between reading research *about* people who had cancer and reading what was written *by* cancer patients about their experiences. It had to do with hearing the voice of the cancer patient. Having cancer isn’t like having another kind of illness but is an experience that only those who have had cancer seem to truly understand. There is also a considerable gap in perspective that appears to exist between people who have cancer and those who don’t. Sometimes it seems as if people with cancer are members, albeit unwilling members, of an exclusive club, and those outside—those who haven’t been “thrown to the bottom”—are left wondering what is happening.

> *It is hard to describe how unsafe, angry, depressed, and betrayed by my own body I felt when first diagnosed with cancer.* [12]

It was also fairly apparent from reading the stories of cancer patients that people don’t have uniform or parallel responses to having cancer. Individuals at one end of the spectrum experience empowering personality changes, while at the other end there are fiercely private individuals who are determined not to say anything about their cancer, who hope no one will find out.

A few weeks before my meeting with the user experience researchers, the medical writer [RSP] and I had talked about our hope that the cancer support videos would feature patients relating their experiences rather than actors reading a script. While our company’s process was underway for creating the necessary legal paperwork, we soon learned that the permission forms wouldn’t be ready in time for our project. With this change in plans, we now needed a representational model more than ever.

> *I was trying to find information about what treatments are available and things like that, but I kept on finding that every person is different. [13]*
>
> *I can’t be the only person who fought cancer and will never say ‘Well, in the end, it was a gift’. [14]*

The User Experience Researchers: Building the Cancer Experience Map

Overview

From the start of developing our cancer support videos, we planned to work with the oncology content specialist to develop personas to represent our target users. A persona is an archetype that is based on user research and that communicates user requirements [15]. Using a persona during product design helps writers and developers understand the information needs as well as the goals, challenges, motivations, hopes, and fears of their target audience.

Researching the Persona

While personas are very common in product development, most companies treat them as proprietary internal collateral and don’t share them outside the company. We suspect that many cancer personas exist, but we located only a few limited cancer personas online. It seemed clear that approaching something as complex as cancer would need a wider view than the view that our established persona process provided. A cancer patient’s needs and experience change dramatically over the course of time. We felt that our traditional single-point-in-time persona format would not be enough. A point-in-time persona, even brilliantly rendered, could not adequately represent the cancer patient’s experience.

To gain insight into an approach that would inform our team and fit both immediate and longer-term needs, we engaged friends and coworkers to chart their perceptions of *their* personal cancer journeys. These exercises reinforced the complexity of the cancer journey and hinted at common points of experience. We decided that the similarities in the experiences of different kinds of cancer warranted our pursuing a universal cancer experience map.

> *The hardest part was the waiting. I wasn't sure what it was going to do—if it was going to rapidly expand or slow down . . . If you’re not sure what's going on in your body, it's hard to sit down and think about anything that's going on around you. [16]*
>
> *After I got my cancer-free diagnosis, that's when I got depressed . . . Disease-free is the moment—it doesn't mean you're going to stay that way. Everyone around me was celebrating; they were happy, life was good, and I became completely depressed. [17]*

We noticed that the timeline created from the discovered common points followed a clinical path. This wasn’t surprising, given that the experience of cancer is often closely tied to what is happening clinically—for example, getting a diagnosis or making treatment decisions.

With the stages in the timeline identified, we again teamed up with the oncology content specialist to collaborate on how we could keep the patient voice in the forefront. In addition to talking to cancer patients, we had found that actual patient quotes seemed to be our best option for accurately capturing the patient voice, and our preference was to get this information first-hand, rather than as told by a clinician or other third party. So we combed the research sent to us by the oncology content specialist, pulled out the patient quotes, reviewed open-ended interviews our company had previously conducted with cancer survivors, and conducted additional literature reviews, as needed, to have patient quotes from across the stages of the timeline.

> *I experienced overwhelming distress at my cancer’s recurrence with metastatic disease. I cried buckets of tears with my husband, family, and friends. However, the support of those who love me enough to supply companionship and food helped me realize that I wasn’t dying today. [18]*
>
> *People say, ‘You have to be positive. You have to fight this.’ You’re sitting there, depressed, ill, and you just feel like saying, ‘I don’t feel positive.’ Then you feel guilty, ‘I should be positive to be healthy, but I don’t feel positive.’ There’s this whole Catch-22. [19]*

We also identified a variety of sources, including national cancer websites such as the LiveStrong Foundation and the American Cancer Society, articles from magazines like “Coping with Cancer”, and newspapers, including “The New York Times”. Our criteria for choosing an article or patient story was simply that it had to contain actual patient quotes. We also limited our selection to quotes in which a cancer patient described his or her own experiences. In addition, we sought out patient quotes from research articles that included the recorded comments of cancer patients who otherwise might not have spoken out.

> *My spouse, and most of my family and friends are supportive, but they don’t seem to really understand the constant lifetime struggle of my cancer walk. … I feel my best when I’m around other cancer survivors. [20]*
>
> *Initially . . . I couldn't put on earrings, hold a pencil, or button my pants with grace and dignity. Now, seven months out, I have full functionality but my fingertips feel waterlogged, like I've been swimming or hot-tubbing for too long. My doctor says that*

> *whatever you feel after a year will likely be permanent.* [21]

We followed a process for affinity sorting, as outlined in *Mental Models: Aligning Design Strategy with Human Behavior* [22]. The affinity of the quotes was validated by a team of three user experience researchers. Strong parallels across cancer types were evident, including shock at hearing the diagnosis, difficulty choosing from conflicting treatment options, the waiting and uncertainty inherent in treatment, pressure to be positive, and the benefits of connecting with others who have experienced cancer. The map summarizes those common experiences.

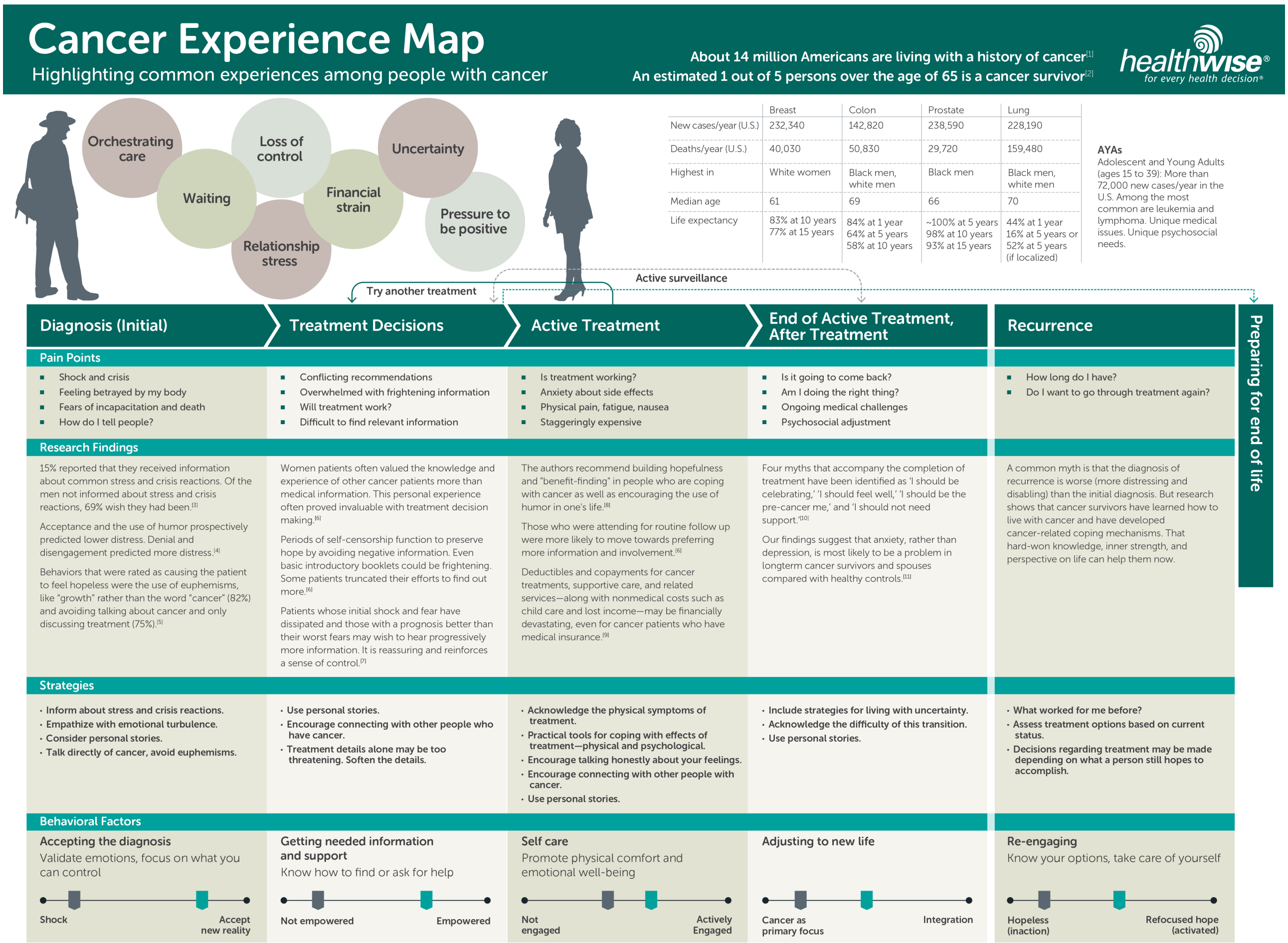
Insights from our research led us to propose actionable strategies for writers and developers. With the assistance of the oncology content specialist, a family medicine physician, and a behavioral health psychologist, we identified the single most important behavior for each stage. For example, “Getting needed information and support” is the behavior for the treatment decisions stage. Because research supporting how best to move this behavior is cited, the map is not only a summary of user research but a resource for content or product development.

Translating research into user-centered mHealth apps is not an easy task. Multidisciplinary teams are composed of individuals with varying familiarity of the topic, varying understanding of user-centered design, and different geographical locations. Development proceeds on many parts separately. Tight timelines are the norm. The voice of the patient can easily lose prominence. We created the cancer experience map in part to bridge these gaps.

The Cancer Experience Map

The cancer experience map represents the complexity of the cancer experience while capturing the common points of change and transition throughout. Based on direct quotes from cancer patients, the map provides design guidelines and identifies one behavioral factor for each stage. We found this combination to be an effective user-centered design strategy. The map is a tangible representation of the cancer patient voice, a solid and trustworthy resource for writers and developers tasked with creating supportive care materials for cancer patients. See Figure 1 and Multimedia Appendix 1.

Figure 1. Cancer experience map (see Multimedia Appendix 1).



Cancer Experience Map

Highlighting common experiences among people with cancer

About 14 million Americans are living with a history of cancer[1]

An estimated 1 out of 5 persons over the age of 65 is a cancer survivor[2]

	Breast	Colon	Prostate	Lung
New cases/year (U.S.)	232,340	142,820	238,590	228,190
Deaths/year (U.S.)	40,030	50,830	29,720	159,480
Highest in	White women	Black men, white men	Black men	Black men, white men
Median age	61	69	66	70
Life expectancy	83% at 10 years 77% at 15 years	84% at 1 year 64% at 5 years 58% at 10 years	~100% at 5 years 98% at 10 years 93% at 15 years	44% at 1 year 16% at 5 years or 52% at 5 years (if localized)

AYAs

Adolescent and Young Adults (ages 15 to 39): More than 72,000 new cases/year in the U.S. Among the most common are leukemia and lymphoma. Unique medical issues. Unique psychosocial needs.

	Diagnosis (Initial)	Treatment Decisions	Active Treatment	End of Active Treatment, After Treatment	Recurrence
Pain Points	▪ Shock and crisis ▪ Feeling betrayed by my body ▪ Fears of incapacitation and death ▪ How do I tell people?	▪ Conflicting recommendations ▪ Overwhelmed with frightening information ▪ Will treatment work? ▪ Difficult to find relevant information	▪ Is treatment working? ▪ Anxiety about side effects ▪ Physical pain, fatigue, nausea ▪ Staggeringly expensive	▪ Is it going to come back? ▪ Am I doing the right thing? ▪ Ongoing medical challenges ▪ Psychosocial adjustment	▪ How long do I have? ▪ Do I want to go through treatment again?
Research Findings	15% reported that they received information about common stress and crisis reactions. Of the men not informed about stress and crisis reactions, 69% wish they had been.[3] Acceptance and the use of humor prospectively predicted lower distress. Denial and disengagement predicted more distress.[4] Behaviors that were rated as causing the patient to feel hopeless were the use of euphemisms, like “growth” rather than the word “cancer” (82%) and avoiding talking about cancer and only discussing treatment (75%).[5]	Women patients often valued the knowledge and experience of other cancer patients more than medical information. This personal experience often proved invaluable with treatment decision making.[6] Periods of self-censorship function to preserve hope by avoiding negative information. Even basic introductory booklets could be frightening. Some patients truncated their efforts to find out more.[6] Patients whose initial shock and fear have dissipated and those with a prognosis better than their worst fears may wish to hear progressively more information. It is reassuring and reinforces a sense of control.[7]	The authors recommend building hopefulness and "benefit-finding" in people who are coping with cancer as well as encouraging the use of humor in one's life.[8] Those who were attending for routine follow up were more likely to move towards preferring more information and involvement.[6] Deductibles and copayments for cancer treatments, supportive care, and related services—along with nonmedical costs such as child care and lost income—may be financially devastating, even for cancer patients who have medical insurance.[9]	Four myths that accompany the completion of treatment have been identified as ‘I should be celebrating,’ ‘I should feel well,’ ‘I should be the pre-cancer me,’ and ‘I should not need support.’[10] Our findings suggest that anxiety, rather than depression, is most likely to be a problem in longterm cancer survivors and spouses compared with healthy controls.[11]	A common myth is that the diagnosis of recurrence is worse (more distressing and disabling) than the initial diagnosis. But research shows that cancer survivors have learned how to live with cancer and have developed cancer-related coping mechanisms. That hard-won knowledge, inner strength, and perspective on life can help them now.
Strategies	· Inform about stress and crisis reactions. · Empathize with emotional turbulence. · Consider personal stories. · Talk directly of cancer, avoid euphemisms.	· Use personal stories. · Encourage connecting with other people who have cancer. · Treatment details alone may be too threatening. Soften the details.	· Acknowledge the physical symptoms of treatment. · Practical tools for coping with effects of treatment—physical and psychological. · Encourage talking honestly about your feelings. · Encourage connecting with other people with cancer. · Use personal stories.	· Include strategies for living with uncertainty. · Acknowledge the difficulty of this transition. · Use personal stories.	· What worked for me before? · Assess treatment options based on current status. · Decisions regarding treatment may be made depending on what a person still hopes to accomplish.
Behavioral Factors	**Accepting the diagnosis** Validate emotions, focus on what you can control	**Getting needed information and support** Know how to find or ask for help	**Self care** Promote physical comfort and emotional well-being	**Adjusting to new life**	**Re-engaging** Know your options, take care of yourself

The Parts of the Map

The main part of the map (in shaded columns) is the experience timeline, which documents the continuum of stages from initial cancer diagnoses to possible recurrence.

Each stage is further broken down under the headings of Pain Points, Research Findings, Strategies, and Behavioral Factors.

- The Pain Points segment describes the very common situational stressors that someone in each stage is experiencing. For example, in the Diagnosis stage, people feel shock, fear of incapacitation and death, feel betrayed by their bodies, and wonder how to tell others about the diagnosis. In the Treatment Decisions stage, people grapple with conflicting treatment recommendations, get overwhelmed by frightening information, wonder whether a given treatment will work, and have a hard time finding relevant information to make an informed treatment choice. By referring to the pain points in a given stage, writers and developers can approach their work with a more holistic understanding of what the audience or end user is dealing with. Effective developers will keep in mind what is going on during the stage at which their product is aimed.

- The Research Findings segment lists cited information that supports our choice of pain points for each stage.
- The Strategies segment proposes best practices for addressing needs. For example, in the Diagnosis stage, shock and crisis are major stressors, yet research shows that only about 15% of testicular cancer patients report receiving information about common stress and crisis reactions [23]. This is clearly a gap, an unmet need for cancer patients. One of the strategies described, therefore, is to inform about common stress and crisis reactions and to empathize with emotional turbulence. Strategies are specific, actionable approaches to be considered by the developer of a solution for a given stage. The strategies vary significantly across the journey, just as the patient's experience and needs evolve.
- The Behavioral Factors segment identifies the primary objective at each stage. These designations are based on expertise from our in-house behavioral health psychologists. For example, in the Diagnosis stage, the most important behavioral factor to influence is acceptance—moving from shock toward an acceptance of reality. Validating emotions and reminding someone to focus on what they *can* control are listed as ideas for moving a person in that direction.

Patterns that are not stage-specific and that show up throughout the journey include relationship stress, loss of control, and uncertainty. These journey-spanning patterns are represented by the colored circles at the top of the timeline.

The top right of the map includes a data table with cancer statistics, including a breakdown for the four most prevalent cancers: breast, colon, prostate, and lung. This macro research is included as a reference to complement the detailed experience timeline.

How to Use the Map

A writer or developer creating materials or apps for cancer patients can refer to the map and see what a person is likely dealing with at each stage. Understanding stressors from the patient perspective, having research-based strategies, and knowing what behaviors to focus on: all of these help the writer or developer build effective products.

The Medical Writer: Using the Map to Inform Cancer Support Videos

Knowing your audience is fundamental to writing good content. By listening to the words—the voices—of real people, developers can gain a better understanding of the audience they're trying to reach. The cancer experience map—and the research that informed its development—helped give us insight into a large, diverse audience that would have otherwise been hard to represent.

The cancer experience map proved to be valuable for developing cancer support videos. The videos needed to be very short—at most three minutes—so we had to make hard decisions about what information to cut out or include to capture people's experiences with cancer and to address cancer's inherently difficult issues. The cancer experience map—and the verbatim quotes on which it is based—helped us decide what to focus on. The map helped to validate the choices we made about what would be most relevant to the most people.

Not everyone's experience with cancer is the same. While there are commonalities, people tend to approach cancer in different ways, face different struggles, and find different ways of coping. Essentially, the map helped us answer the question: How can we make the videos more relatable—and helpful—to a greater number of people?

By reflecting both concerns and coping strategies relevant to each stage of the experience, the map helped us create more targeted, tailored videos that could speak to a person's experience during different periods of time. The data also provided useful information on topics that aren't as prevalent in evidence-based research, such as the role of spirituality.

> *After battling cancer, I have a real appreciation for trees, chipmunks, our dog, shrubs, flowers, clouds, people, thunderstorms, the stars at night and life itself—all these things seem more intense to me now. [24]*

We also looked at various themes that emerged in the research, which were summarized in the map or, in many cases, represented by the actual patient quotes. They included the fear of the unknown, the pressure to act positive, the obligation to be strong for the sake of others, the importance of support from friends and family, ways of coping with difficult emotions, strength in one's faith, and an appreciation for the small things in life. We were able to address many of these themes in the videos.

We approached these issues through personal stories. Through short vignettes, we were able to convey concepts—for example, focusing on what gives you strength—in a way that would resonate more with users. The details of the cancer experience map helped us make these stories richer and more nuanced and to capture the right emotional tone.

> *I am a firm believer in prayer. It calms me and gives me peace in times that I am spinning with emotions. It gives me someone to tell everything – however I want to say it – rather than picking the things that are appropriate for the person I'm talking to or working to say what I mean without seeming ungrateful or selfish or rude. [25]*

The cancer experience map was a reliable guide for our approach to a difficult, complex subject. Our resulting set of 11 cancer support videos includes *Cancer: When You First Find Out*, *Cancer: Finding Your Strength*, and *Cancer: Life After Treatment.*

We want our cancer support videos to represent the patient voice as effectively as possible. And we want them to be shared with as many patients as possible. We are encouraged, knowing that policy can help make this happen.

The Policy Advisor: Promoting the Patient Voice Through Health Care Policy

The imperative to include the patient voice in cancer supportive care content, whether through the use of the cancer experience map or other patient voice approaches, resonates as well upstream in the realm of health for all patients, that is, in health care policy.

Health care in the United States is in a time of great change and opportunity. At the heart of it, amidst all the swirl that accompanies a transition of this magnitude, is the patient. Many policy leaders, providers, payers, and other health care stakeholders who are active participants in this change agree that patient involvement is critical to the progress of health care. A noted thought leader blogged, “If patient engagement were a drug, it would be the blockbuster drug of the century and malpractice not to use it” [26].

While the goal is full participation by patients, where does it all begin? Perhaps the first step is with the relationship between a patient and his or her health care provider. Respect, mutual trust, and empathy all play a role in creating a relationship of professional intimacy, where shared decisions can be made.

The consequences for a patient can be significant when the provider and a patient do *not* share common understanding, goals, values, and assumptions—or said in another way, when the patient’s voice is not considered. Such a disconnect has negative consequences for both patient and provider, and ultimately, for the health care system at large, undermining whatever benefit, care, or healing is being sought or otherwise may be possible.

How can the importance of patient voice affect policy? The patient voice is a key to effective care, to systems that support that care, and to policy that enforces care. And the patient voice has already informed some policy in the United States. The Health and Human Services, Office of the National Coordinator (ONC) Health Information Standards Committee’s Consumer/Patient Engagement Power Team brought a group of patients and advocates together and asked them what they would want from Health Information Technology (HIT). This was the result—a goal to “ensure that pending regulatory requirements and standards meet current opportunities for engaging patients and their families in their care, and anticipate future policy and technology that encourages further engagement” [27].

This group made recommendations that will enable patients to participate as partners in their care. Their work has subsequently informed policy and standards work, specifically within the ONC for Health Information Technology Meaningful Use criteria. This includes patients’ access to medical records to view, download, or transmit (Blue Button); secure messaging; patient-generated data; patient-specific education in English and other languages; and further clarity on privacy and security for patients/consumers in the Health Insurance Portability and Accountability Act (HIPAA) omnibus rule.

Policy-focused groups (such as the ONC team) that represent the patient/consumer voice will continue to put pressure on access, design, education, quality, and care. This will affect innovative mHealth apps being created to provide cancer supportive care. Why is this important? The patient voice must be heard. The cancer experience map is an example of a guide, a design tool to help mHealth apps succeed.

Discussion

We have described the development of the cancer experience map, which has value as a resource for mHealth app developers who are looking to include the voice and concerns of the cancer patient in the creation, development, and delivery of apps for cancer supportive care.

Cancer supportive care is an ideal focus for the development of mHealth apps. Cancer patients are a population of people who have been through a life-threatening and life-altering experience. In the United States, an estimated 14 million people live with a history of cancer. Many issues affect people who are in active treatment—hearing the diagnosis, making treatment decisions, dealing with side effects. Then another related but separate set of concerns arises after treatment: fear of recurrence, long-lasting or permanent effects from treatment, and the emotional and psychological consequences of going through such an experience. The transition in care from active treatment under an oncology care team back to a person’s former general practitioner can also be difficult for both patient and provider. Through all these stages, mHealth apps could offer seamless methods for patients to connect with their providers and vice versa. Issues such as how often checkups are needed or what symptoms are common or expected could be handled simply and quickly, and reassurance could replace worry or unneeded health care calls or office visits.

A major limitation to the current work is the lack of user-testing data thus far. User testing is important to find out if products are effective.

In our case, the cancer experience map was put to the test while the ink was still wet, so to speak. As the map was being assembled, our writer used parts of it in the scripts he wrote for the first six videos on coping with cancer. He then was able to use the entire cancer experience map for the next five scripts. However, the videos are still too recent to have accumulated enough user feedback to get a good sense of how they are perceived by viewers. Having sufficient user feedback will be key to knowing if we were successful in identifying commonalities in the cancer experience and addressing points of concern. We look forward to gathering this additional data.

Another limitation we encountered is that projects like the cancer experience map are ordinarily featured in product development materials rather than professional research journals; consequently, this article lacks a systematic literature review.

While the cancer experience map reflects the experience of Americans with cancer, it is likely that some of these traits are universal. Further research is needed to discover what those similarities and differences are and to see how our work compares with similar research projects in other parts of the world.

Conclusion

The cancer experience map presented in this paper is one way mHealth app developers can consider and include the voice of the cancer patient in their design, creation, testing, and utilization of apps for cancer supportive care. This is an exciting time for mHealth app developers, as rapid developments in technology are moving beyond those that seemed so novel just yesterday, and apps that offered limited fitness data or diet information are giving way to wearable motion sensor detectors and programs that seamlessly integrate mHealth apps with electronic health records systems. It is only a matter of time before current obstacles, such as security concerns and certification criteria, are resolved. With this article, we offer a contribution—the cancer experience map—to help developers create cancer supportive care apps that will assure patients that their voice is being heard.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Cancer experience map.

[PDF File (Adobe PDF File), 156KB - jmir_v17i5e132_app1.pdf]

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Abbreviations

ONC: Office of the National Coordinator, Health and Human Services

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Original Paper

Online and Offline Recruitment of Young Women for a Longitudinal Health Survey: Findings From the Australian Longitudinal Study on Women's Health 1989-95 Cohort

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Abstract

Background: In 2012, we set out to recruit a cohort of at least 10,000 women aged 18-23 from across Australia. With recent research demonstrating the inadequacy of traditional approaches to recruiting women in this age group, we elected to conduct open recruiting.

Objective: Our aim was to report on the overall success of open recruiting and to evaluate the relative success of a variety of recruitment methods in terms of numbers and demographics.

Methods: We used referrals, Facebook, formal advertising, and incentives in order to recruit the cohort.

Results: In all, 17,069 women were recruited for the longitudinal online survey, from 54,685 initiated surveys. Of these women, most (69.94%, n=11,799) who joined the longitudinal cohort were recruited via Facebook, 12.72% (n=2145) via the fashion promotion, 7.02% (n=1184) by referral, 4.9% (n=831) via other Web activities, and 5.4% (n=910) via traditional media.

Conclusions: Facebook was by far the most successful strategy, enrolling a cohort of women with a similar profile to the population of Australian women in terms of age, area of residence, and relationship status. Women recruited via fashion promotion were the least representative. All strategies underrepresented less educated women—a finding that is consistent with more traditional means of recruiting. In conclusion, flexibility in recruitment design, embracing new and traditional media, adopting a dynamic responsive approach, and monitoring the results of recruiting in terms of sample composition and number recruited led to the successful establishment of a new cohort.

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KEYWORDS

cohort studies; longitudinal studies; social media; women's health

Introduction

Recruiting participants has become increasingly challenging in the face of telemarketing, mass direct marketing, privacy concerns, and expectations of rewards for survey completion [1]. Traditional methods of recruiting participants, such as mailed invitations to random samples drawn from existing databases [2-4] have become less effective and more expensive [5]. Furthermore, changes to privacy laws have resulted in limited access to some national databases, even for the purposes of health research [6]. These findings point to the need for new methods that are tailored to recruit young people in the present day. This paper reports on the methods that were developed to recruit a new national cohort of women aged 18-23 into an existing longitudinal study on women's health.

Advances in technology offer opportunities for adapting recruitment methods to reach younger generations. Online recruitment has been shown to be more cost-effective than postal recruitment for young people [5,7,8]. Furthermore, social media, particularly Facebook [9], has been identified by young women as being a trusted communication channel that could entice them to participate in research [10]. Importantly, advertising on Facebook has been found to be an effective recruitment tool, with broad populations of young adults successfully recruited in Australia, Canada, and United States [8,11-13]. Additionally, there is some evidence that samples recruited through Facebook are ethnically diverse and geographically representative [8,11,12]. However, there are mixed results regarding whether Facebook advertising can be used to successfully recruit a sample that is demographically representative of the target population, particularly with regard to age, education level, and income [8,12,14]. In addition, not all young women use social media, and those who do not engage with social networking sites have been found to be less economically stable and less educated than those who participate in social media [15]. Therefore, recruiting entirely through social media may result in a biased sample.

There is some evidence that using a number of recruitment methods is an effective strategy. In the United States, smokers were successfully recruited via traditional and online methods including media, word of mouth, email referrals, medical Internet media, Google AdWords [16], and social networking sites [17]. Similarly, Ramo et al [18] successfully recruited young American adults into an online tobacco use survey through a variety of methods, including online classified advertisements, paid advertising through an Internet marketing company, and purchased completed surveys through an online survey sampling company. When specifically focused on young women, Harris et al [19] successfully recruited women aged 18-23 years into a study of contraception use using Facebook advertising supported by a social media presence, in conjunction with network snowballing, poster distribution, and attending tertiary education events to raise awareness of the study. Despite these findings, the relative success of each type of recruiting method in terms of demographic representativeness has not been examined.

The aim of this study was to recruit a cohort of at least 10,000 women aged 18-23 years into the Australian Longitudinal Study on Women's Health (ALSWH). This paper reports on the open recruiting campaign and the variety of methods that were used to recruit the cohort. The relative success of the different recruiting strategies in terms of the number of women recruited and the demographic representativeness of the subsamples that resulted from each strategy are reported.

Methods

Study Overview

The ALSWH is a national study that recruited over 40,000 women into three age cohorts in 1996 [20]. The original three cohorts, born 1973-78, 1946-51, and 1921-26, were randomly sampled from the Medicare (national health insurance) database and have completed mailed omnibus health surveys every 3 years [4,21,22]. Random sampling from the Medicare database for the new cohort was not feasible due to the very low response rate (6%) reported by another study that attempted to recruit women aged 18-23 years using this method [5]. The ALSWH aims to assess the health and well-being of Australian women to provide an evidence base for both policy and practice. The study measures multiple aspects of health including physical health, mental health, health service use, as well as the social and environmental determinants of health. In 2011, ALSWH was funded to incorporate the use of online surveys as well as to recruit a new cohort of women aged 18-23 years who would complete annual online health surveys.

Participants

Eligibility criteria for the 1989-95 cohort included living in Australia, being a female aged 18-23, possessing a Medicare (ie, Australian national health insurer) number (Australian and New Zealand citizens and permanent residents living in Australia are eligible for a Medicare number), and consenting to have survey data linked with administrative data (eg, records of health service use). The final inclusion criterion involved verification by the Australian Department of Human Services that sufficient details had been provided for data linkage to occur. Sufficient details included as many of the following as were needed for a match to be made with the administrative dataset: name, address, date of birth, Medicare number.

Recruitment Campaign

The recruitment campaign comprised two promotions: ALSWH and Women's Health of Australia! (WHoA!). Due to a slow rate of participation at the beginning of recruitment, it was decided that assistance from a marketing communications company could be beneficial for the second campaign. ALSWH ran for the total campaign (October 2012-December 2013) and was designed and implemented by ALSWH staff (see Figure 1 and Multimedia Appendices 1 and 2). WHoA! commenced October 2013 and was conducted by a marketing company with ALSWH staff support (see Figure 2 and Multimedia Appendices 3 and 4). Slogans, branding, and incentives differed for the two promotions. ALSWH offered the chance to win one of 100 AU $50 prepaid debit cards and WHoA! used a 1990s-themed fashion incentive of the chance to win one of 2000 exclusive items of clothing. Participants in South Australia were offered the chance to win one of 99 AU $50 prepaid debit cards instead of the fashion promotion due to the state's lotteries legislation.

Multiple recruitment strategies were used for both promotions and are summarized in (Table 1) (for examples of advertising and promotional materials, see Figures 1-3 and Multimedia Appendices 1-4). Strategies were categorized as Facebook, which included Facebook pages and advertising; other Web-based activities, which involved establishing accounts on other social media platforms as well as dedicated websites; referral, which utilized existing networks and snowballing; traditional media that included direct and mass marketing as well as bulk mailouts (eg, to tertiary institutions); and the WHoA! fashion company, which involved direct and indirect marketing focused on the fashion company's involvement with ALSWH.

Table 1. Strategies used to recruit the ALSWH 1989-95 cohort over the recruitment period October 2012 to December 2013.[a]

Strategy	Method[b]
Facebook	Facebook page
	Facebook advertising (paid and unpaid[c])
Other Web activities	Twitter
	Web forums
	Instagram
	Tumblr
	YouTube
	Web advertising/promotion
	ALSWH & WHoA! websites
Referral	Emails from ALSWH staff to personal/professional networks (ALSWH only)
	Emails to original ALSWH cohorts (ALSWH only)
	Emails to ALSWH collaborators and their networks (ALSWH only)
	Emails to professional bodies
	Snowballing (via participants who already completed the survey)
Traditional media	Posters
	Postcards
	Business cards
	Flyers
	Magazine
	Newspapers
	Television (ALSWH only)
	Radio (ALSWH only)
WHoA! fashion co.	Where the participant ascribed their participation to the involvement of the fashion company, eg, through emails sent on behalf of WHoA! by the fashion company to their subscribers (WHoA! only)

[a] Examples of materials and advertisements used for recruiting are available in Multimedia Appendices 1-4.

[b] Unless stated otherwise, methods were conducted under both ALSWH and WHoA! promotions.

[c] Unpaid Facebook advertising included posting information about the study on Facebook pages of other organizations.

The campaign was dynamic by design so that successful strategies could be augmented. To monitor the success of the campaign in relation to the strategies that were being used, responses to an item that asked participants how they had heard about the study were reviewed on a weekly basis. For the purposes of this paper, the response options for this item (which varied slightly between the two recruitment promotions) were allocated to one of the five recruitment strategies defined in Table 1. Demographic characteristics of the respondents were monitored on a weekly basis and compared to the Australian Census to examine demographic representativeness. So, as well as being responsive to the number of participants entering the study, it was also possible to target recruitment strategies to respond to the composition of the sample. In particular, paid Facebook advertisements targeted underrepresented groups throughout recruitment (see Figure 3 for an example of a Facebook advertisement targeting an underrepresented group). Overall, ads were targeted to augment particular ages, areas of residence, and level of education. The decision about when to target underrepresented groups was determined by there being at least a 2% difference between the sample category and equivalent category in the census.

Figure 1. A postcard created as part of the ALSWH promotion, distributed across 1439 venues, at events, and through mailouts.

Hey Ladies aged 18-23!
We need YOU!

You are more than the sum of your parts. You are a complicated being.

Help us understand young Australian women's health.

www.alswh.org.au/survey

Participate in a nationally important survey on women's health. Your generation is counting on you to have your say!

How? Just go to www.alswh.org.au/survey

Why? To help make the changes to women's health that will impact you and your generation.

It's quick. It's confidential.
100 $50 Eftpos vouchers to win.

Questions? info@alswh.org.au 1800 068 081

Prize terms and conditions see www.alswh.org.au/survey
Freecard Media ★ Australia ★ www.avantcard.com.au ★ All Rights Reserved ★ 2012 ★ #00000

women's health australia
the australian longitudinal study on women's health

Figure 2. A less successful Facebook advertisement created as part of the WHoA! promotion, targeted at women aged 18-23 living within 16 kilometres of Henley Beach South Australia (0 users clicked the link).

Women's Health of Australia

Sponsored ·

We need you! Speak up for your generation & do this health & lifestyle survey!

Ladies 18-23 from Henley!

You have the power to improve women's health for all Aussie women - just complete the WHoA! survey. You could win a limited edition pair of Black Milk Clothing leggings. Thanks for being awesome!

WWW.WHOALEGS.COM.AU | BY WOMEN'S HEALTH OF AUSTRALIA

Figure 3. A successful Facebook advertisement created as part of the ALSWH promotion, targeted at women living in Australia aged 19 (7669 users clicked the link). Copyright User:couscouschocolat / Wikimedia Commons / CC-BY-SA-2.0.

Australian Longitudinal Study on Women's Health (ALSWH)

Sponsored ·

We need you! Speak up for your generation & do this health & lifestyle survey!

Aussie? Female? 19?

ALSWH.ORG.AU

Procedure

In all promotional materials, potential participants were directed to a website that included a link to the survey and participant information, including the inclusion criteria, information statement, and details concerning incentives for participation. The documentation was updated once the WHoA! promotion started, but essentially participants experienced a similar process of reading documentation and then commencing the online survey.

The survey contained questions about health and well-being as well as items that concerned demographic characteristics and life experiences [23]. In addition, participants were asked to provide formal consent to their data being linked to administrative datasets and to provide compulsory contact details and their Medicare number to facilitate data linkage. Follow-up phone calls were made to participants who had provided contact details but who had not completed other survey requirements. Data were sent to the Department of Human Services to verify participants' Medicare numbers and personal details. All methods, including obtaining informed consent as implied by survey initiation, were approved by the University of Newcastle and the University of Queensland Human Research Ethics Committees.

Statistical Analysis

Sociodemographic characteristics (age, area of residence, education, study, and relationship status) were compared for each recruitment strategy with results for women in the same age group in the 2011 Australian Census. Multinomial logistic regression was used to compare sociodemographic characteristics for each strategy relative to the reference category (Facebook). These models simultaneously estimate the odds ratio for each characteristic for each recruitment strategy relative to an odds ratio of one for the same characteristic in the Facebook group. All analyses were conducted using SAS software, version 9.3. The significance level was set at .05.

Results

A total of 54,685 surveys were initiated; however, 16,753 exited before providing enough information to determine whether they belonged to valid survey respondents. Of the remaining 37,932 initiated surveys, 19,955 were considered invalid for the following reasons: 3148 excluded personal details needed to verify participants, 36 were not eligible for a Medicare number; 13,476 were excluded for issues relating to consent to data linkage (ie, did not answer consent item, refused data linkage); 3159 were excluded due to identity concerns (eg, survey completed by someone else, duplicate); and 9 were considered invalid for other reasons. Before the verification process, 127 survey respondents withdrew. Data from the remaining 17,977 potential participants were sent to the Department of Human Services to have their Medicare numbers and personal details verified. Of those, 255 failed the verification process and 155 were excluded post verification (eg, duplicate). That left a total of 17,567 verified participants, 498 of whom were allocated to the future pilot group, in keeping with ALSWH procedures of maintaining a separate group of participants for pilot testing each new survey. The final cohort was 17,069 participants.

Figure 4 shows the periods when various recruitment methods were active, along with the number of participants recruited each week. Women were exposed to Facebook pages with recruiting posts and advertisements, other online media, and ALSWH referral for the entire recruitment period. Facebook advertising was reasonably constant, with breaks due to technical issues, pricing, and the changeover from the ALSWH promotion to WHoA!. In June 2013, Facebook introduced newsfeed advertising, so that advertisements appeared in the central part of the screen (rather than to the side) and on mobile devices that used the Facebook app. Targeted Facebook advertising was also introduced in June 2013, whereby particular sections of the community were identified and advertisements were shown only to those people who met the specified criteria. For example, advertisements designed for women of a particular age (eg, 19 years) appeared only on the Facebook pages of women who were that age (see Figure 3).

The introduction of targeted newsfeed advertising in combination with increased advertising had a significant impact on participant responses. Prior to this time, an average of 10.5 women responded per day (2434 surveys over 232 days). After the introduction of targeted newsfeed advertisements and before the WHoA! promotion, responses rose to an average of 54.3 per day (6787 surveys over 125 days). The WHoA! promotion was officially launched in early October 2013, and the fashion company database was emailed late October 2013, resulting in a spike of responses. However, WHoA! prelaunch activities were conducted from July until the launch to engage the interest of potential participants in the WHoA! materials. During the WHoA! promotion, responses rose to an average of 100.6 per day (7849 surveys over 78 days). As can be seen in Figure 4, this was the most intensive period of recruiting activities during the campaign incorporating both ALSWH and WHoA! activities.

Of the 17,069 women enrolled in the 1989-95 cohort, 200 did not indicate how they heard about the survey. Of the remaining 16,869 women, 69.94% (n=11,799) indicated Facebook, 4.93% (n=831) other Web activities, 7.02% (n=1184) referral, 5.39% (n=910) traditional media, and 12.72% (n=2145) the fashion company (see Table 2). Compared with the 2011 Australian Census, respondents to each of the recruitment strategies were more likely to have a university degree and to be studying. Most of the strategies resulted in relatively representative samples of women with regards to age, except that referral and the fashion company overrepresented older women compared to the population. There was also a higher proportion of women living in urban areas among the women recruited via the fashion company. With regards to education, all recruitment strategies led to an underrepresentation of less educated women compared to the 2011 Australian Census; however, Facebook was the least biased in this regard. Facebook resulted in the most representative sample in relation to the Australian Census, whereas the fashion company sample was the least representative. As would be expected and has been reported in detail in Mishra et al [24], the overall sample was broadly representative of women in this age group with overrepresentation of women with higher levels of education.

Table 2. Demographic characteristics by recruitment strategy[a] of 18-23 year old women from the ALSWH 1989-95 cohort compared with 18-23 year old women from the 2011 Australian Census.

	Facebook (N=11,799)	Other Web activities (N=831)	Referral (N=1184)	Traditional media (N=910)	Fashion company (N=2145)	2011 Australian Census (N=847,042)
Age in years, %						
18	15.92	18.4	13.01	15.9	10.49	15.98
19	18.76	16.5	14.53	16.9	12.91	16.21
20	17.35	15.0	16.30	17.1	17.25	16.82
21	15.55	17.6	19.26	16.5	20.09	17.07
22	16.09	17.8	20.10	16.0	19.77	16.95
23	16.32	14.7	16.81	17.5	19.49	16.96
Area of residence, %						
Major city	74.17	78.1	74.83	73.1	80.98	74.52
Inner regional	17.50	14.6	15.46	17.1	13.10	15.95
Outer regional	6.86	5.9	8.36	8.0	5.08	7.23
Remote/ very remote	1.14	1.0	1.10	1.8	0.42	2.02
Missing/ migratory/ no usual address	0.33	0.5	0.25	0	0.42	0.28
Highest qualification achieved, %						
Less than Year 12	8.45	6.4	4.90	4.6	5.64	14.93
Year 12	43.22	47.3	46.20	47.1	40.23	46.09
Certificate/ Diploma	26.88	20.0	18.67	24.2	30.07	21.75
University degree	21.45	26.4	30.24	24.1	24.06	9.41
Missing	0.01	0	0	0	0	7.82
Studying, %						
No	34.74	26.6	26.94	30.6	37.44	47.36
Yes	65.16	73.4	73.06	69.3	62.42	47.44
Missing	0.10	0	0	0.1	0.14	5.20
Relationship status, %						
Never married	71.87	78.0	81.00	75.7	74.27	94.53
De facto[b]	24.32	19.6	15.88	21.0	24.20	
Married	3.37	2.3	3.04	2.9	1.45	4.89
Separated/ divorced/ widowed	0.43	0.1	0.08	0.4	0.09	0.59

[a] 200 missing information on what alerted them to the survey.

[b] De facto relationship is included with never married in the 2011 Australian Census.

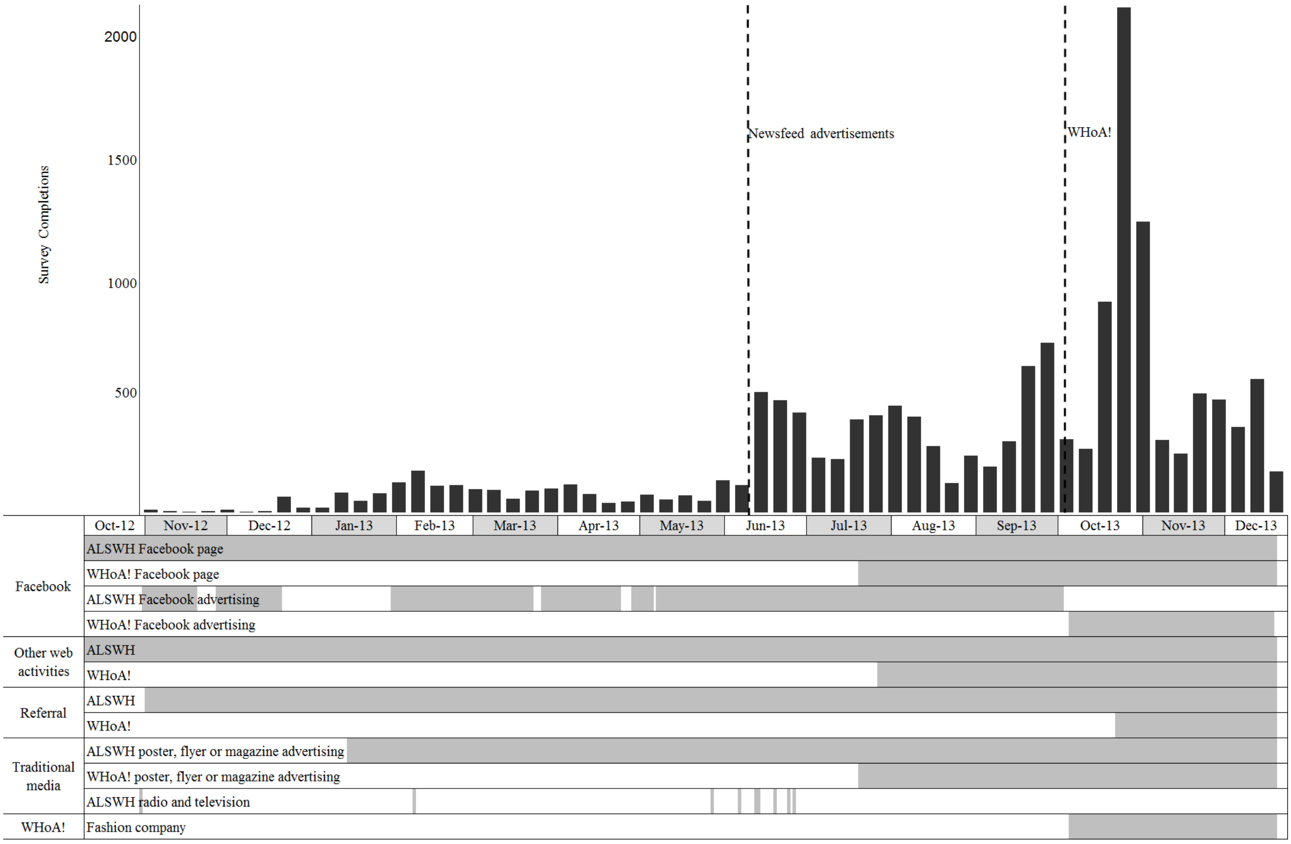
Odds ratios for sociodemographic characteristics of women in each recruitment group relative to women recruited via Facebook are shown in Table 3. Compared to women aged 20, women aged 21-23 were more likely to be recruited via other Web activities, referral, and through the fashion company than via Facebook (significant ORs between 1.20 and 1.33). Compared to women with Year 12 qualifications, less educated women were less likely to be recruited by strategies other than Facebook (ORs between 0.50 and 0.72). Women recruited via the fashion company also differed from those recruited via Facebook in that they were less likely to live outside a major city (ORs between 0.34 and 0.69), were less likely to be studying (OR 0.89), and were less likely to have a partner (OR 0.96 for in a de facto relationship and OR 0.42 for married).

Table 3. Odds ratios for demographic characteristics by recruitment strategy of 18-23 year old women from the ALSWH 1989-95 cohort recruited October 2012-December 2013, using Facebook as the reference category.

	Other Web activities (N=831) OR (95% CI)	Referral (N=1184) OR (95% CI)	Traditional media (N=910) OR (95% CI)	Fashion company (N=2145) OR (95% CI)
Age in years				
18	1.33 (1.04-1.70)[a]	0.87 (0.70-1.08)	1.01 (0.80-1.28)	0.66 (0.56-0.79)[a]
19	1.01 (0.79-1.30)	0.82 (0.66-1.02)	0.91 (0.72-1.15)	0.69 (0.59-0.82)[a]
20	reference	reference	reference	reference
21	1.30 (1.02-1.67)[a]	1.32 (1.08-1.61)[a]	1.07 (0.85-1.35)	1.30 (1.12-1.51)[a]
22	1.28 (0.99-1.63)	1.33 (1.09-1.62)[a]	1.01 (0.80-1.28)	1.24 (1.06-1.44)[a]
23	1.04 (0.80-1.34)	1.10 (0.89-1.35)	1.08 (0.86-1.36)	1.20 (1.03-1.40)[a]
Area of residence				
Major city	reference	reference	reference	reference
Inner regional	0.79 (0.65-0.97)[a]	0.88 (0.74-1.03)	0.99 (0.83-1.19)	0.69 (0.60-0.78)[a]
Outer regional	0.82 (0.60-1.10)	1.21 (0.97-1.50)	1.19 (0.92-1.53)	0.68 (0.55-0.83)[a]
Remote/ very remote	0.80 (0.39-1.65)	0.96 (0.54-1.70)	1.57 (0.93-2.66)	0.34 (0.17-0.67)[a]
Highest qualification achieved				
Less than Year 12	0.69 (0.51-0.93)[a]	0.54 (0.41-0.72)[a]	0.50 (0.36-0.69)[a]	0.72 (0.59-0.88)[a]
Year 12	reference	reference	reference	reference
Certificate/diploma	0.68 (0.56-0.82)[a]	0.65 (0.55-0.76)[a]	0.82 (0.70-0.98)[a]	1.20 (1.08-1.34)[a]
University degree	1.12 (0.94-1.33)	1.32 (1.14-1.52)[a]	1.03 (0.87-1.22)	1.20 (1.07-1.36)[a]
Studying				
No	reference	reference	reference	reference
Yes	1.47 (1.26-1.72)[a]	1.44 (1.26-1.65)[a]	1.21 (1.05-1.40)[a]	0.89 (0.81-0.98)[a]
Relationship status				
Never married	reference	reference	reference	reference
De facto relationship	0.74 (0.62-0.89)[a]	0.58 (0.49-0.68)[a]	0.82 (0.69-0.97)[a]	0.96 (0.86-1.07)[a]
Married	0.62 (0.39-0.99)[a]	0.80 (0.56-1.13)	0.80 (0.54-1.20)	0.42 (0.29-0.60)[a]
Separated/divorced/ widowed	0.26 (0.04-1.86)	0.18 (0.02-1.26)	0.96 (0.35-2.68)	0.21 (0.05-0.86)[a]

[a] Significant odds ratios.

Figure 4. Survey completions by week in relation to recruitment strategies for the ALSWH 1989-95 cohort over the recruitment period October 2012 to December 2013.



Discussion

Principal Findings

The primary aim of recruiting over 10,000 women aged 18-23 years was met, with 17,069 meeting the inclusion criteria and forming the 1989-95 ALSWH cohort. The most successful strategy used in terms of number of participants gained was Facebook, under both the ALSWH and WHoA! promotions. Direct marketing strategies were the next most successful, with the fashion company under the WHoA! promotion and the more general referral strategy together accounting for 20% of the final sample. While other Web activities and traditional media were the least successful activities, they still managed to attract 5% each of the final sample.

Comparison With Prior Work

Facebook was the most successful in recruiting a sample of young women that represented those in the Australian population. This was most likely due to the ability to constantly monitor women's particular characteristics in relation to the Australian Census and post Facebook advertising as necessary to target any underrepresented groups. Such a strategy most likely mitigated the age bias reported by past research, which found that Facebook attracted a lower proportion of older women (ie, aged 22-25) compared to Australian Census data [12]. There was, however, an age bias among those recruited via referral and the fashion company strategies. These strategies attracted a higher proportion (56.17% and 59.35% respectively) of women aged over 20 years than is apparent in the population (50.98%) and were more likely than Facebook to attract women aged over 20 years. The multiple strategies approach to the recruiting campaign resulted in a total sample that has been found to be representative of the population with regard to age [24].

Unfortunately, the same was not true for education. Compared with Australian Census data, all of the recruiting strategies resulted in subsamples that were overrepresentative of women with a tertiary education or who were studying. Overall, referral was the most likely and Facebook the least likely to attract women with a university degree. This is not surprising since referral largely consisted of using networks of people who worked on, participated in, or who were close to the ALSWH. It is noteworthy that Facebook achieved the highest proportion of women with less than a Year 12 education, although this was still 6% below the proportion indicated by the Australian Census as having this level of education. Education bias is a common occurrence for survey research [4,8,25], which warrants future research to utilize more refined targeting to recruit less educated individuals.

Facebook, referral, and traditional media attracted women in similar proportions by area as those that exist in the population. The most notable difference here was the tendency for the fashion company incentive to attract more women from urban areas than the other strategies. Nevertheless, the sample as a whole has been found to be representative of the population with regard to area [24].

It is difficult to compare relationship status with Australian Census data. The Australian Census records registered marital status, so that figures on the percentage of women living in de facto relationships were not available. Including women living in de facto relationships with those who had never married, the proportions are similar for all strategies. Fewer married women were recruited via the fashion company strategy, making these women the least representative of the population.

Limitations

In generalizing the results of our recruiting techniques to other situations, a number of limitations must be considered. First, the sample was limited to women aged 18-23 years. The strategies used may be more or less effective in recruiting males or other age groups. Second, the requirement that women had to consent to linking their survey data with administrative datasets reduced the number of eligible participants and might have resulted in differential participant bias for different strategies. However, Medicare verification is also a strength of this method in ensuring participants are valid and removing the risk of multiple survey submissions from any one participant. Our previous work determined that the ALSWH 1989-95 cohort were demographically representative overall and heterogeneous with respect to health and health behavior [24]. The diversity of the sample and the wide range of variables collected, including the use of well-recognized psychometric measures, allows for valid statistical comparisons to be made. Further, when compared with women who consented to data linkage, those who did not consent were not significantly different in terms of age, area of residence, income management, education, general health, or psychological distress [26]. Last, we were unable to assess the cumulative impact of multiple approaches on the individual and relied on a single response from participants as to what attracted them to the survey. Anecdotally, participants reported having multiple contacts with various recruiting materials before joining the study. It would be a useful avenue for future research to measure not only which strategies bring participants to a research project but how many strategies are encountered by an individual before they commit to participation.

Conclusions

Facebook was by far the most successful recruiting strategy, in line with other research results [19]. The current study found that the strengths of a Facebook recruiting approach included the reach of the advertising in terms of demographic diversity, the ability to target advertising to specific groups, and the capacity to be responsive to the sample composition as it was recruited. Weaknesses included a lack of control over how advertising is presented, variable costs that can be challenging to budget, and the inability to reach those who do not (or cannot) participate in Facebook [14,15]. Supporting Facebook advertising with a substantial social media platform assisted with recruiting and with study credibility [7,12], and the promotion of incentives via Facebook likely also increased the appeal and reach of the Facebook posts. We found that supplementing Facebook with other approaches helped to mitigate biases attributable to the use of a single method. This is in agreement with research that has recommended using social media to complement more traditional recruiting approaches [14].

The dynamic design allowed for successes to be augmented but also required almost constant contact with institutional ethics committees who needed to approve every material and individual procedure that involved recruiting. For example, every advertisement or post that mentioned recruiting had to be preapproved. In our original ethics application, we included examples of potential ads and posts in an effort to have materials readily available. However, the need to provide relevant and topical posts and ads on a frequent basis meant that this strategy was only partially successful in mitigating the need for ongoing ethics approvals. These types of delays are not in keeping with social media, where responsiveness is the key to success within the paradigm. It would be helpful for both ethics committees and researchers if clear guidelines with regard to ethical recruiting using social and other modern media were developed to prevent such labor intensive procedures.

The recruiting campaign resulted in the establishment of a national cohort of over 17,000 women aged 18-23 years. While some overrepresentation in tertiary-educated women is apparent and was unable to be fully mitigated by the multiple techniques employed, the sample is broadly representative across other demographic measures and has sufficient size and diversity to allow for subgroup comparisons [24]. In conclusion, flexibility in recruitment design, embracing new and traditional media, providing incentives, adopting a dynamic responsive approach, and monitoring the results of recruiting in terms of sample composition and number recruited led to the successful establishment of a new cohort.

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Members of the ALSWH recruitment team are Annette Dobson, and in alphabetical order: Ashleigh Baker, Catherine Chojenta, Katherine De Maria, Megan Ferguson, Leonie Gemmel, Anna Graves, Sheree Harris, Jayne Lucke, Clare Thomson, Britta Wigginton.

Authors' Contributions

DL was responsible for the study concept and design, acquisition of the data, interpretation of the data, drafting and revising the manuscript. JP contributed to the study design, acquisition of the data, analysis, and interpretation of the data as well as drafting and revising the manuscript. AA contributed to data acquisition, analysis, and interpretation of the data as well as drafting and revising the manuscript. NT and SP contributed to the study design, as well as drafting and revising the manuscript. MH contributed to data acquisition, interpretation of the data, as well as drafting and revising the manuscript. RT contributed to the study design, acquisition of the data, and revision of the manuscript. GM contributed to the acquisition of the data and revision of the manuscript. JB contributed to the study concept and design, data acquisition as well as drafting and revising the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Advertising and recruitment materials from the ALSWH promotion.

[PDF File (Adobe PDF File), 345KB - jmir_v17i5e109_app1.pdf]

Multimedia Appendix 2

Example of a YouTube video created as part of the ALSWH promotion.

[AVI File, 2MB - jmir_v17i5e109_app2.avi]

Multimedia Appendix 3

Advertising and recruitment materials from the WHoA! promotion.

[PDF File (Adobe PDF File), 239KB - jmir_v17i5e109_app3.pdf]

Multimedia Appendix 4

Example of a YouTube video created as part of the WHoA! promotion.

[AVI File, 2MB - jmir_v17i5e109_app4.avi]

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Abbreviations

ALSWH: Australian Longitudinal Study on Women’s Health
WHoA!: Women’s Health of Australia!

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Original Paper

Response Rates for Patient-Reported Outcomes Using Web-Based Versus Paper Questionnaires: Comparison of Two Invitational Methods in Older Colorectal Cancer Patients

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Abstract

Background: Improving questionnaire response rates is an everlasting issue for research. Today, the Internet can easily be used to collect data quickly. However, collecting data on the Internet can lead to biased samples because not everyone is able to access or use the Internet. The older population, for example, is much less likely to use the Internet. The Patient-Reported Outcomes Following Initial Treatment and Long-Term Evaluation of Survivorship (PROFILES) registry offers a platform to collect Web-based and paper questionnaires and to try different measures to improve response rates.

Objective: In this study, our aim was to study the influence of two methods of invitation on the response rate. Our second aim was to examine the preference of questionnaire mode of administration (paper or Web-based) for the older patient in particular.

Methods: To test these two invitational methods, 3406 colorectal cancer patients between ages 18 and 85 years received an invitation containing an access code for the Web-based questionnaire. They could also request a paper questionnaire with an included reply card (paper-optional group). In contrast, 179 randomly selected colorectal cancer patients received a paper questionnaire with the invitation (paper-included group). They could also choose to fill out the Web-based questionnaire with the included access code.

Results: Response rates did not differ between the paper-optional and the paper-included groups (73.14%, 2491/3406 and 74.9%, 134/179, *P*=.57). In the paper-optional group, online response was significantly higher when compared to the paper-included group (41.23%, 1027/2491 vs 12.7%, 17/134, *P*<.001). The majority of online respondents responded after the first invitation (95.33%, 979/1027), which was significantly higher than the paper respondents (52.19%, 764/1464, *P*<.001). Respondents aged 70 years and older chose to fill out a paper questionnaire more often (71.0%, 677/954). In the oldest age group (≥80 years), 18.2% (61/336) of the respondents filled out a Web-based questionnaire.

Conclusions: The lack of difference in response rates between invitation modes implies that researchers can leave out a paper questionnaire at invitation without lowering response rates. It may be preferable not to include a paper questionnaire because more respondents then will fill out a Web-based questionnaire, which will lead to faster available data. However, due to respondent preference, it is not likely that paper questionnaires can be left out completely in the near future.

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KEYWORDS

Internet; questionnaires; aged; aged, 80 and over; cancer, colon; cancer, rectum; characteristics, population; survey methods; respondents; patient-reported outcomes

Introduction

The first Web-based questionnaires were posted in the mid-1990s, but they were only available for a select few with access to a computer and to the Internet [1]. Today, the Internet is accessible for more and more households. In the Netherlands, access to the Internet is high with 97% of the households having an Internet connection in 2013 [2]. To optimally utilize this high level of access, the population-based Patient-Reported Outcomes Following Initial treatment and Long-Term Evaluation of Survivorship (PROFILES) registry was developed in 2010. Its goal is to collect, preferably, online data on patient-reported outcomes (PRO) of cancer patients at least once a year [3]. However, paper questionnaires can be provided if preferred by the respondent. Offering different modes of administration is a way to improve response as is offering incentives and sending reminders [4].

Although it is widely accepted that Web-based questionnaires offer advantages, these advantages are not all scientifically proven. Advantages of Web-based questionnaires compared to paper questionnaires that are supported by literature are more complete data [5], less data entry errors [6], and questionnaires returned more quickly [7]. Several studies also show that reliability of Web-based questionnaires and paper questionnaires is comparable [8-11]. An often-described disadvantage of Web-based questionnaires is sample bias [1] because not all population groups have access to or are proficient in using the Internet. Additionally, Web-based questionnaires often have lower response rates than paper questionnaires [12].

Recent literature shows that the online respondent is most likely to be young and highly educated [10,13,14]. On the other hand, cancer patients tend to be older. There are a few studies that report on Internet use of older patients, but these patients are described as one group (eg, 50 years and older or 65 years and older) with response percentages varying from 58% to 63% [15-20]. Studies on computer and Internet use that are stratified by age and include a group older than 60 years are sparse. We found 6 studies that stratified older age into groups for computer or Internet use [21-26]. Percentages varied from 10% for those aged ≥85 years for Internet use in 2007 [22] to 35% in the 60-69 years age range for computer use for email in 2011 [21]. A previous study from our group, performed in 2007, observed Internet access for 3 age groups (<50 years, 50-59 years, and 60-69 years) of 81%, 65%, and 47%, respectively [24]. According to Statistics Netherlands, 54% of Dutch individuals between ages 65 and 75 years had access to the Internet in 2007 [27]. Since 2007, access to the Internet in the Netherlands has increased rapidly. In the older population aged 65-75 years, 80% currently have access to the Internet [28]. Therefore, we expect that more older respondents will be able to fill out Web-based questionnaires.

This paper describes a study in which our primary aim was to investigate whether including a paper questionnaire in the initial invitation would lead to a higher response rate. Furthermore, we wanted to compare patient characteristics and response rates between different modes of administration (Web-based vs paper). Our second aim was to evaluate the preference of administration mode for the older patient in particular. We hypothesized that including a paper questionnaire would increase the overall response rate because it may still be the preferred mode of administration for many older adults.

Methods

Setting

We used data from a large population-based survey conducted in 2010 among colorectal cancer (CRC) patients. Data were collected within the PROFILES registry [3]. The PROFILES registry collects data for the study of the physical and psychosocial impact of cancer and its treatment from a population-based cohort of short- and long-term cancer survivors. PROFILES contains a large Web-based component. However, because a large percentage of cancer patients are older, PROFILES also collects PRO data using traditional paper questionnaires. Collected PRO data are directly linked to clinical data from the Eindhoven Cancer Registry (ECR).

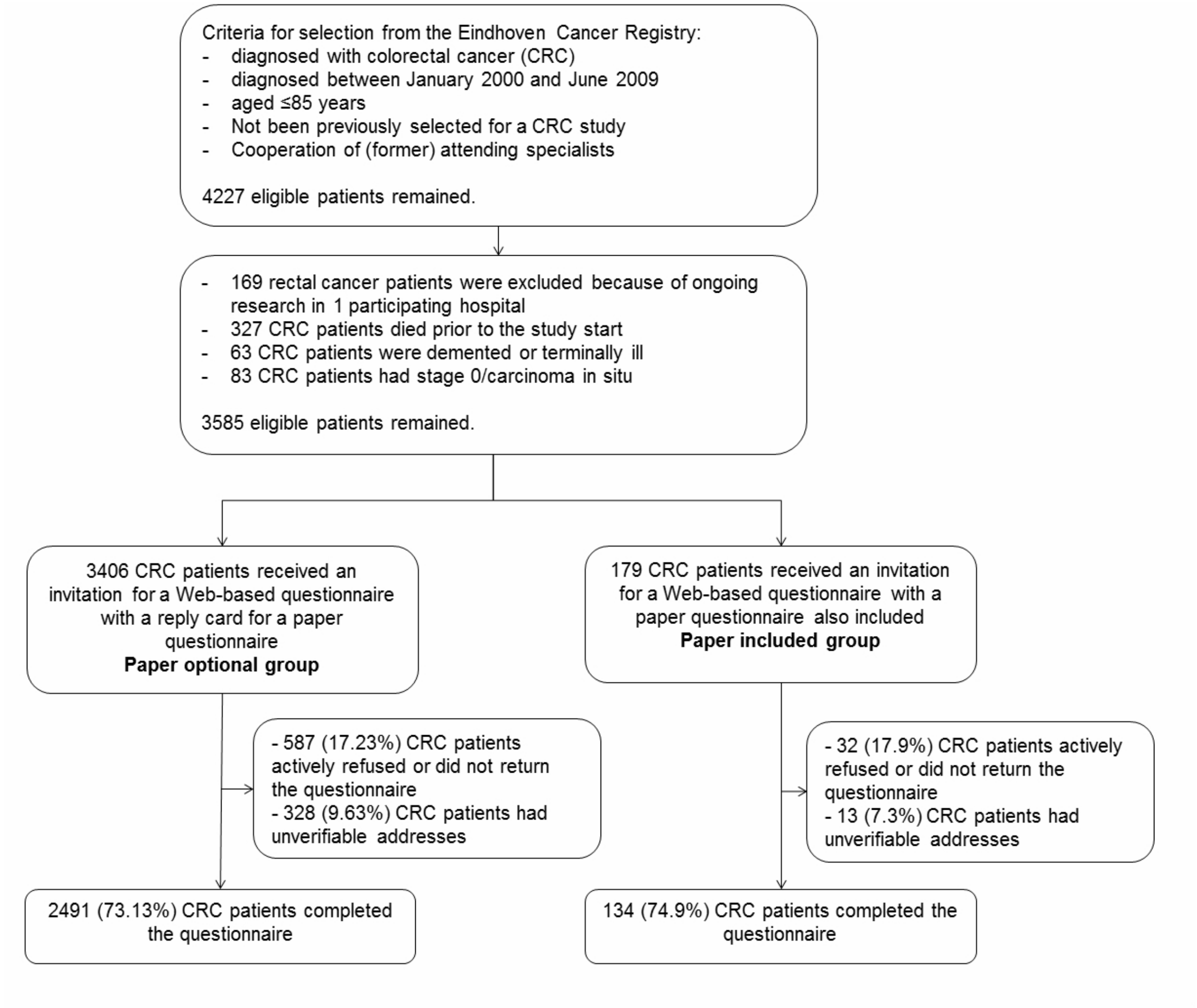
The questionnaire consisted of questions on work and lifestyle, health care use, comorbidity (the Self-Reported Comorbidity Questionnaire), diabetes (Problem Areas in Diabetes Questionnaire), quality of life (EORTC QLQ-C30), disease-specific symptoms (EORTC QLQ-CR38), health status (SF-12), personality (DS14), illness perception (Brief Illness Perception Questionnaire), fatigue (Fatigue Assessment Scale), and anxiety and depression (Hospital Anxiety and Depression Scale). A total of 182 items were to be answered. Respondents were informed that filling out the questionnaire could take up to 45 minutes. Online respondents could see the progress on a progress indicator and were able to log in again to continue completing the questionnaire from where they last left off. Online respondents were required to answer all questions, but could choose the option “I don’t want to say” when sensitive information was asked (eg, sexuality).

The ECR, which is part of the Comprehensive Cancer Center the Netherlands, compiles data of all newly diagnosed cancer patients in the southern part of the Netherlands, covering an area with 10 hospitals serving 2.3 million inhabitants [29]. All individuals aged between 18 and 85 years, diagnosed with CRC between January 2000 and June 2009, and registered in the ECR were eligible for participation in our study. Those with cognitive impairment, with stage 0/carcinoma in situ, and who died prior to start of the study were excluded, resulting in 3585 eligible patients. The CRC survey was approved by the Central Committee on Research Involving Human Subjects (approval number NL23463.015.08) and the Medical Ethics Committee of Máxima Medical Centre (approval number 0822). All patients signed informed consent. Further details on the method of data collection are published elsewhere [30].

Description of Study Groups

Patients were divided into 2 groups for this study (Figure 1). Patients in the paper-optional group (n=3406) were invited via a letter from their former attending specialist. The letter contained a website address and log-in instructions to fill out the Web-based questionnaire. It also contained a reply card with a return envelope (postage included) with which participants could request a paper version of the questionnaire. Patients in the paper-included group (n=179) received the same letter, but with a paper questionnaire and a return envelope (postage included) also included. Nonrespondents from both groups were sent a reminder letter together with a paper questionnaire and return envelope (postage included). A reminder was sent after 3 months, on average. The number of patients needed for the paper-included group was calculated in advance. We sampled the number of patients to be able to test a statistically significant higher (1-sided test based on our hypothesis) response rate of 10% between both groups, assuming a response rate of 75% in the paper-optional group (power 80%, alpha 10%).

Figure 1. Flowchart of the colorectal cancer patient selection.



Demographics and Clinical Characteristics

Patients' demographic and clinical information, including cancer stage, time since cancer diagnosis in years, and primary treatment were available from the ECR. The questionnaire contained questions about marital status and educational level. Information about response status, time of completion (either before or after the reminder), and the chosen mode of administration (paper or Web-based) was gathered from the PROFILES data manager application.

Statistical Analyses

Differences in characteristics of respondents and nonrespondents and between groups were analyzed using independent *t* tests and chi-square tests where appropriate. Further analyses within the paper-optional group were conducted to assess differences in clinical and demographic characteristics between online and paper respondents. All differences with a *P* value <.05 were considered statistically significant. To assess the difference in online response between the 2 groups, logistic regression models were constructed. An unadjusted and a logistic model adjusted for age, sex, educational level, and having a partner or not were used to assess differences in Web-based response. Odds ratios (ORs) and 95% confidence intervals (95% CI) were reported. All statistical analyses were performed using SAS v9.2 for Windows (SAS institute Inc, Cary, NC, USA).

Results

Of the 3406 invited CRC patients in the paper-optional group, 2491 (73.14%) responded. In the paper-included group, a similar response rate was found with 134 (74.9%) respondents of the 179 invited CRC patients.

Statistically significant differences in characteristics between respondents and nonrespondents were seen for gender (male: 55.16%, 1448/2625 vs 48.0%, 297/619, *P*<.001), age (mean 69.4, SD 9.53 vs mean 72.4, SD 9.9, *P*<.001), and cancer type (colon: 61.18%, 1606/2625 vs 66.9%, 414/619, *P*=.03) (Table 1). The age difference between the 2 groups was more pronounced after age was stratified into categories. The biggest response difference was found in the age category 60-70 years (32.27%, 847/2625 vs 23.4%, 145/619, *P*<.001) and ≥80 years (13.26%, 348/2625 vs 25.8%, 160/619, *P*<.001).

Table 1. Demographic and clinical characteristics of respondents and nonrespondents in a colorectal cancer population.

Characteristics	Respondents, n=2625		Nonrespondents, n=619		Unverifiable addresses, n=341		*P*
	Group	95% CI	Group	95% CI	Group	95% CI	
Gender, n (%)							
Male	1448 (55.16)	53.26-57.06	297 (48.0)	44.0-51.9	165 (48.4)	43.1-53.7	<.001
Female	1177 (44.84)	42.93-46.74	322 (52.0)	48.1-56.0	176 (51.6)	46.3-56.9	
Age (years), mean (SD)	69.41 (9.53)	69.05-69.78	72.4 (9.9)	71.7-73.2	68.1 (12.7)	66.8-69.5	<.001
Age range (years), n (%)							
<60	410 (15.62)	14.23-17.01	65 (10.5)	8.1-12.9	80 (23.5)	18.9-28.0	<.001
60-70	847 (32.27)	30.48-34.06	145 (23.4)	20.1-26.8	88 (25.6)	21.2-30.5	
70-80	1020 (38.82)	37.00-40.72	249 (40.2)	36.4-44.1	109 (32.1)	27.0-36.9	
≥80	348 (13.30)	11.96-14.55	160 (25.8)	22.4-29.3	64 (18.8)	14.6-22.9	
Cancer type, n (%)							
Colon cancer	1606 (61.18)	59.32-63.05	414 (66.9)	63.2-70.6	208 (61.0)	55.8-66.1	.03
Rectal cancer	1019 (38.82)	36.95-40.68	205 (33.1)	29.4-36.8	133 (39.0)	33.8-44.2	
Time since diagnosis (years), mean (SD)	5.16 (2.80)	5.06-5.27	5.3 (2.9)	4.9-5.4	5.5 (3.0)	5.2-5.9	.06
Invitational approach, n (%)							
Paper-optional	2491 (94.90)	94.05-95.73	587 (94.8)	93.1-96.6	328 (96.2)	94.2-98.2	.57
Paper-included	134 (5.10)	4.26-5.95	32 (5.2)	3.4-6.9	13 (3.8)	1.8-5.8	
Mode of completion, n (%)							
Paper	1581 (60.23)	58.36-62.10					
Online	1044 (39.77)	37.90-41.64					
Time of completion, n (%)							
After initial request	1836 (70.16)	68.19-71.70					
After reminder	781 (29.84)	28.00-31.50					

Differences in Response Rates Between Groups

No differences in overall response rate were found between the paper-optional and the paper-included groups, with 73.14% (2491/3406) and 74.9% (134/179, *P*=.57), respectively (Figure 2). For respondents aged 70 years and older, no difference in response rate was found, with a 68.84% (1290/1847) response rate in the paper-optional group and 75.7% (78/103) in the paper-included group (*P*=.38).

Characteristics of the respondents in the paper-optional group were comparable with those of the paper-included group, except for age which was slightly older in the paper-included group (≥70 years: 51.79%, 1290/2491 vs 58.2%, 78/134, *P*=.04) (Table 2). The unadjusted logistic regression model showed patients in the paper-optional group were 4.82 times (95% CI 2.88-8.07, *P*<.001) more likely to fill out the Web-based questionnaire compared to patients in the paper-included group; this effect remained after adjustments for age, sex, educational level, and having a partner or not (OR 5.81, 95% CI 3.37-10.01, *P*<.001). In the paper-optional group, online response was significantly higher compared to the paper-included group (41.23%, 1027/2491 vs 12.7%, 17/134, *P*<.001).

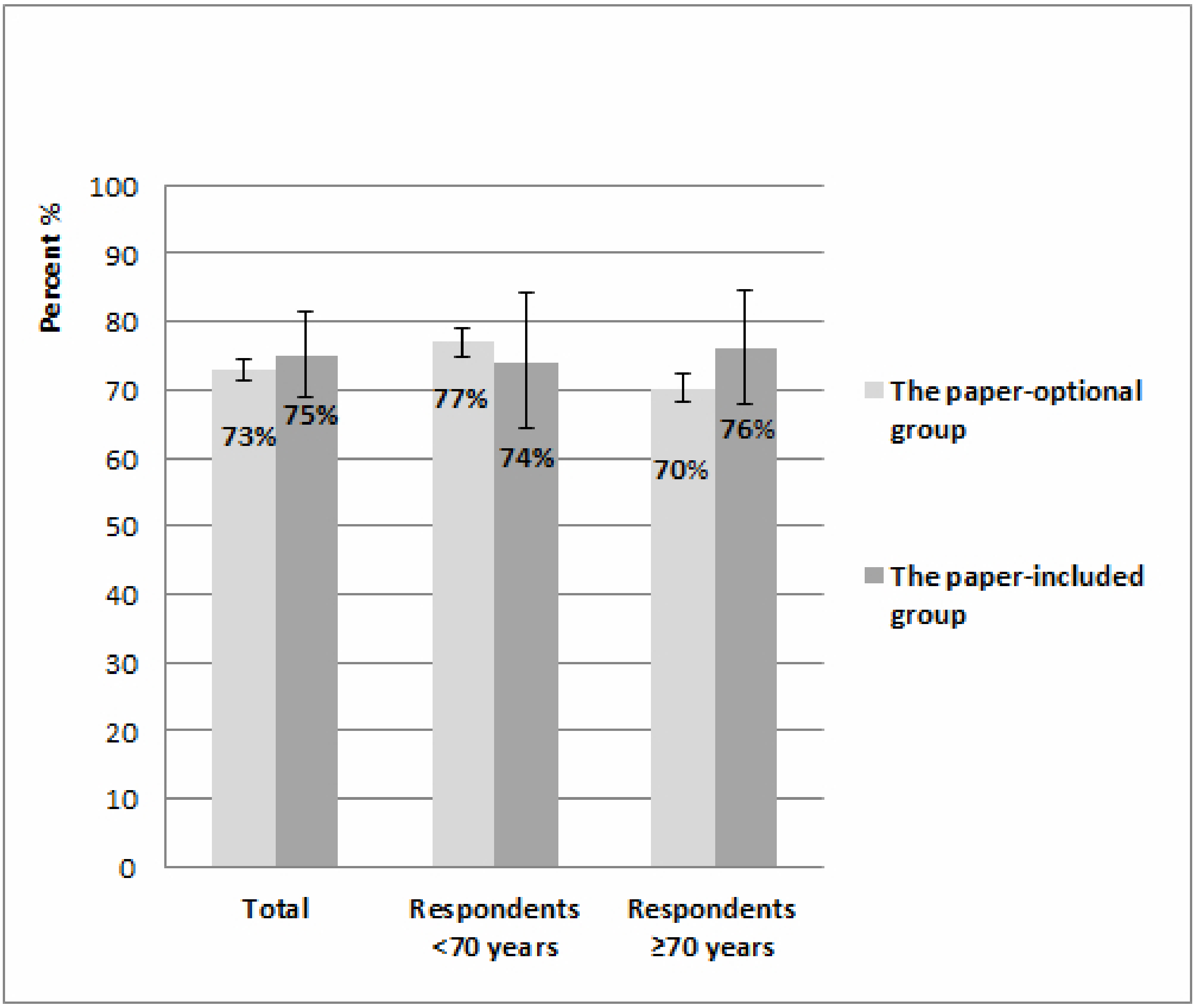
Sending a reminder increased the response by 30% in both arms. Due to local logistical issues, the time of sending a reminder varied between 2 and 5 months. However, this variation did not influence overall response rates (data not shown) or mean time until response (Table 2).

Table 2. Demographic and clinical characteristics of colorectal cancer patients in the paper-optional and the paper-included groups.

Characteristics	Paper-optional, n=2491		Paper-included, n=134		*P*
	Group	95% CI	Group	95% CI	
Gender, n (%)					
Male	1368 (54.92)	52.96-56.87	80 (59.7)	51.4-68.0	.28
Female	1123 (45.08)	43.13-47.04	54 (40.3)	32.0-48.6	
Age (years), mean (SD)	69.4 (9.59)	68.99-69.74	70.3 (8.5)	68.8-71.7	.29
Age range (years), n (%)					
<60	396 (15.90)	14.46-17.33	14 (10.4)	5.3-15.6	.04
60-70	805 (32.32)	30.48-34.15	42 (31.3)	23.5-39.2	
70-80	954 (38.26)	36.39-40.21	66 (49.3)	40.8-57.7	
≥80	336 (13.53)	12.15-14.83	12 (9.0)	4.1-13.8	
Education, n (%) [a]					
Low	494 (20.05))	18.27-21.40	26 (19.7)	12.7-26.1	>.99
Medium	1488 (60.39)	57.81-61.66	80 (60.6)	51.4-68.0	
High	482 (19.56)	17.80-20.90	26 (19.7)	12.7-26.1	
Marital status, n (%)					
Married	1882 (76.19)	73.86-77.24	102 (76.7)	68.9-83.3	.23
Divorced	136 (5.51)	4.57-6.35	8 (6.0)	2.0-10.0	
Widow	373 (15.10)	13.57-16.38	15 (11.3)	5.9-16.5	
Never married	79 (3.20)	2.48-3.86	8 (6.0)	2.0-10.0	
Time since diagnosis (years), mean (SD)	5.16 (2.80)	5.05-5.27	5.3 (2.7)	4.8-5.8	.58
Cancer type, n (%)					
Colon cancer	1528 (61.34)	59.43-63.25	78 (58.2)	49.9-66.6	.47
Rectum cancer	963 (38.66)	36.75-40.57	56 (41.8)	33.4-50.1	
Mode of completion, n (%)					
Online	1027 (41.23)	39.30-43.16	17 (12.7)	7.1-18.3	<.001
Paper	1464 (58.77)	56.84-60.70	117 (87.3)	81.7-93.0	
Time of completion, n (%)					
After first invitation	1743 (70.14)	68.17-71.77	93 (70.5)	61.6-77.2	.94
After reminder	742 (29.86)	27.99-31.58	39 (29.5)	21.4-36.8	
Time until response (days), mean (SD)					
After first invitation	21.46 (19.32)	20.56-22.37	19.1 (12.1)	16.6-21.6	.23
After reminder	20.11 (15.24)	19.01-21.21	19.4 (15.0)	14.5-24.2	.70

[a] Low: no/primary school; medium: lower general secondary education/vocational training; high: preuniversity education/high vocational training/university.

Figure 2. Overall response differences for the paper-optional (n=3406) and the paper-included (n=179) groups in a colorectal cancer population stratified by age groups.



Comparison of Characteristics of Online and Paper Respondents in the Paper-Optional Group With a Focus on Older Patients

In the paper-optional group, men were more likely to complete the Web-based questionnaire than to return the paper questionnaire (61.73%, 634/1027 vs 50.14%, 734/1464, *P*<.001) (Table 3). Compared to paper respondents, online respondents were younger (mean 65.72, SD 9.28 vs mean 71.85, SD 8.89, *P*<.001), more often highly educated (30.34%, 311/1027 vs 11.88%, 171/1464, *P*<.001), more often married (83.93%, 862/1027 vs 70.69%, 1020/1464, *P*<.001), more often recently diagnosed (time since diagnosis: mean 4.94, SD 2.74 vs mean 5.31, SD 2.83, *P*<.001), and more often had a rectal cancer diagnosis compared to paper respondents (41.38%, 425/1027 vs 36.75%, 538/1464, *P*=.02). The majority of the online respondents responded after the first invitation (95.42%, 979/1027), which was significantly higher than the paper respondents (52.36%, 764/1464, *P*<.001).

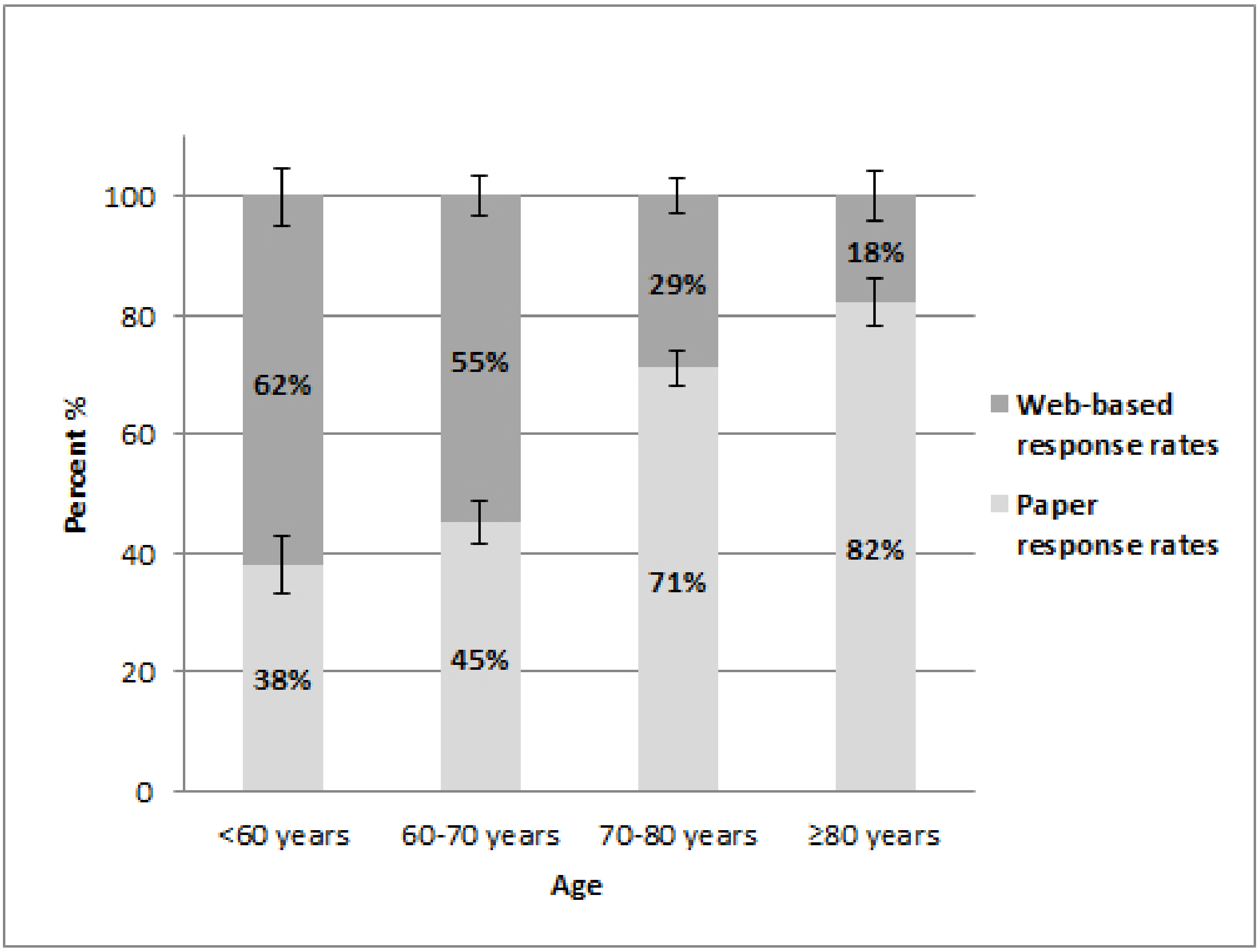
Table 3. Demographic and clinical characteristics of colorectal cancer patients in the paper-optional group stratified by questionnaire type used.

Characteristics	Paper questionnaire, n=1464		Web-based questionnaire, n=1027		*P*
	Group	95% CI	Group	95% CI	
Gender, n (%)					
Male	734 (50.14)	47.58-52.70	634 (61.73)	58.76-64.71	<.001
Female	730 (49.86)	47.30-52.42	393 (38.27)	35.29-41.24	
Age in years, mean (SD)	71.85 (8.89)	71.41-72.29	65.72 (9.28)	65.16-66.29	<.001
Age range (years), n (%)					
<60	150 (10.25)	8.70-11.80	246 (23.95)	21.34-26.56	<.001
60-70	362 (24.73)	22.52-26.94	443 (43.14)	40.11-46.16	
70-80	677 (46.17)	43.69-48.80	277 (26.97)	24.26-29.69	
≥80	275 (18.85)	16.78-20.78	61 (5.94)	4.49-7.39	
Education, n (%) [a]					
Low	400 (27.80)	25.04-29.61	94 (9.17)	7.39-10.92	<.001
Medium	868 (60.32)	56.77-61.81	620 (60.49)	57.38-63.36	
High	171 (11.88)	10.04-13.32	311 (30.34)	27.47-33.09	
Marital status, n (%)					
Married	1020 (70.69)	67.32-72.03	862 (83.93)	81.69-86.18	<.001
Divorced	82 (5.68)	4.42-6.78	54 (5.26)	3.89-6.62	
Widow	288 (19.96)	17.64-21.71	85 (8.28)	6.59-9.96	
Never married	53 (3.67)	2.66-4.58	26 (2.53)	1.57-3.49	
Time since diagnosis (years), mean (SD)	5.31 (2.83)	5.17-5.45	4.94 (2.74)	4.77-5.11	<.001
Cancer type, n (%)					
Colon cancer	926 (63.25)	60.78-65.72	602 (58.62)	55.61-61.63	.02
Rectal cancer	538 (36.75)	34.28-39.22	425 (41.38)	38.37-44.39	
Time of completion, n (%)					
After initial request	764 (52.36)	49.63-54.74	979 (95.42)	94.04-96.62	<.001
After reminder	695 (47.64)	44.91-50.03	47 (4.58)	3.30-5.85	
Time until response (days), mean (SD)					
After first invitation	36.08 (17.05)	34.87-37.29	10.03 (11.84)	9.29-10.77	<.001
After reminder	20.66 (15.21)	19.53-21.80	11.76 (13.34)	7.80-15.72	<.001

[a] Low=no/primary school; medium=lower general secondary education/vocational training; or high=preuniversity education/high vocational training/university.

After age was stratified, Web-based versus paper response differed per age group (*P*<.001, Figure 3). We saw that the turning point of filling out a Web-based questionnaire was approximately age 70 years: the majority of respondents younger than 70 years filled out a Web-based questionnaire and the majority older than 70 years chose a paper questionnaire. Among those aged ≥80 years, 18.2% (61/336) preferred a Web-based questionnaire.

Figure 3. Web-based and paper response rates in the paper-optional group among colorectal cancer patients stratified by age groups (n=2491).



Discussion

Principal Findings

Our study showed that including a paper questionnaire with the first invitation did not increase overall response rates. In contrast, it negatively influenced the online response. Sending a reminder improves response rates by 30%. Compared to patients responding on paper, online respondents were more often male, younger, married, and highly educated. The majority of respondents in both arms chose to fill out a paper questionnaire. The turning point of preference for a Web-based questionnaire was approximately age 70 years. The majority of respondents who were younger than 70 years preferred to fill out the Web-based questionnaire. The majority of respondents older than 70 years chose the paper questionnaire. We did not find evidence that including a paper questionnaire led to a higher response among older patients.

We expected the overall response rate in the paper-included group to be higher than in the paper-optional group because respondents in the paper-included group received the paper questionnaire immediately at invitation. However, we observed similar overall response rates. A previous review of the literature showed that when respondents can choose between paper and Web-based questionnaires, paper response is higher than online response in most studies [31]. A recent literature review confirmed this, although they expect the difference to diminish in the near future [6]. The absence of this expected difference in response rates in our study could not be explained by differences in patient characteristics between the 2 groups. A possible explanation for the comparable response rates could be the willingness of respondents to participate because the subject of the questionnaire (ie, cancer and health-related quality of life) felt relevant to them. Furthermore, the respondents received the invitation directly from their medical specialist, so they might have felt a moral obligation to participate. The lack of difference in response rates implies that researchers can leave out a questionnaire at first invitation without lowering response. It is preferable not to include a paper questionnaire because more respondents will fill out the Web-based version of a questionnaire, which will enable researchers to access data more quickly and to have a more complete dataset.

Several studies have compared response rates between patients invited via paper only and Web only, or mixed-mode and Web only, or paper only and mixed-mode [5,7,8,10,11,13,14,32-36]. However, few studies are available that address the influence of including a paper questionnaire on response rate in the invitation for a mixed-mode survey. We found an American study that compared the response rates of 3 modes of administration, namely paper only, paper with an Internet option, or Internet with a paper option [37]. The response for the Internet with a paper option and for the paper with an Internet option was 37% and 42%, respectively. These are the same manners of invitation we used in our study. The difference with our study is that instead of sending 1 reminder, the other study sent 4 reminders. Only the last reminder for the Internet with a paper option contained a paper questionnaire. A second difference is that this study was done in 2000 in the United States, so the use of Internet was lower than in 2010 in the Netherlands, when our study was done. Internet use in the United States in 2000 was 51% compared to 90% in the Netherlands in 2010 [38,39]. This might explain the lower response rates for both groups and the bigger difference in response rates between the groups in that study. A Dutch study among 277 long-term childhood cancer survivors in 2010 used a comparable invitation approach and mode of administration [40]. The study used a mixed invitation group (paper with the option of Internet) and a Web-only invitation group (Internet with the option of paper) leading to a response of 83% and 89%, respectively. A different approach with regard to reminders was chosen in that study compared to ours; after sending 1 reminder letter, nonrespondents were contacted by telephone in their study. Another difference is that only young women were included in that study. Both studies [37,40] did not address the (preference of) the older patient.

When studying different age groups, we found that almost 20% of the respondents aged ≥80 years filled out the questionnaire online. We expected a lower percentage because of the so-called “grey digital divide” referring to the low use of computers and the Internet in the older population [41]. This grey digital divide is also confirmed by a British study that found that only 10% of respondents aged ≥85 years have used the Internet at any point in their lives [22]. To fill out a Web-based questionnaire, a respondent must not only be able to use a computer, but also be skilled on the Internet. The high number of older respondents who used the Internet in our study might imply that the grey digital divide is closing in the Netherlands and more older people are becoming familiar with the Internet. Numbers from Statistics Netherlands (CBS) confirm this, showing that there is an increase in Internet use among individuals aged between 65 and 75 years in recent years [28]. Daily use of the Internet among these individuals increased from 15% in 2005 to 55% in 2013. Eurostat Statistics also show these numbers: a rise in frequent use of the Internet among people aged 65 to 74 years from 41% in 2008 to 73% in 2013 in the Netherlands [42]. Unfortunately, a group of users is left out in these statistics, namely the people older than 75 years. The statistics do, however, indicate a trend of older people being more online. With this in mind, researchers could more easily consider using the Internet as a primary mode for data collection without the inclusion of a paper questionnaire with the first invitation.

Strengths of this study are that it is population-based, including (very) older people, has a high overall response rate, and the cooperation of medical specialists. Furthermore, the influence of sending a paper questionnaire in 2 mixed-mode groups has rarely been studied. Thirdly, our results are more recent than other studies that compare paper versus Web-based questionnaires, which is important because of the rapid changes in Internet access. Lastly, we have looked at many patient characteristics to assess the differences in patient characteristics of online and paper respondents.

A limitation of this study is that the time a reminder was sent varied per hospital due to local logistical issues. However, analyses showed that the difference in reminder time did not have any effect on outcomes. A second limitation is that the comparison between the paper-optional group and the paper-included group shows a slight discrepancy in the age categories, although mean age did not differ. There is a slightly higher percentage of respondents older than 70 years in the paper-included group. Although an age difference existed before data collection in the initial random selection of this group, it was not significant (results not shown). Thus, the significant discrepancy found in our results after data collection is a consequence of (un)willingness to cooperate. In the future, further evaluation of nonrespondents may clarify this difference. It is not unlikely that the results found in our study are applicable to other populations, for example, patients with a different type of cancer, a different disease (eg, diabetes), or a normative population. However, further research is needed to confirm this.

Conclusion

Although this study was on a CRC survivor population, we are of the opinion that the significant lack of difference in response rates between invitation modes implies that researchers may leave out a paper questionnaire at invitation without lowering the response rate. It may even be more preferable not to include a paper questionnaire because more respondents then will fill out a questionnaire online, which will lead to faster available data. However, due to respondent preference, it is not likely that paper questionnaires can be left out completely in the near future.

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role in study design; in the collection, analysis, and interpretation of data; in the writing of the report; and in the decision to submit the paper for publication.

Conflicts of Interest

None declared.

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Abbreviations

CRC: colorectal cancer
ECR: Eindhoven Cancer Registry
PRO: patient-reported outcomes
PROFILES: Patient-Reported Outcomes Following Initial treatment and Long-Term Evaluation of Survivorship

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Original Paper

Personal Electronic Health Records: Understanding User Requirements and Needs in Chronic Cancer Care

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Abstract

Background: The integration of new information and communication technologies (ICTs) is becoming increasingly important in reorganizing health care. Adapting ICTs as supportive tools to users' needs and daily practices is vital for adoption and use.

Objective: In order to develop a Web-based personal electronic health record (PEPA), we explored user requirements and needs with regard to desired information and functions.

Methods: A qualitative study across health care sectors and health professions was conducted in a regional health care setting in Germany. Overall, 10 semistructured focus groups were performed, collecting views of 3 prospective user groups: patients with colorectal cancer (n=12) and representatives from patient support groups (n=2), physicians (n=17), and non-medical HCPs (n=16). Data were audio- and videotaped, transcribed verbatim, and thematically analyzed using qualitative content analysis.

Results: For both patients and HCPs, it was central to have a tool representing the chronology of illness and its care processes, for example, patients wanted to track their long-term laboratory findings (eg, tumor markers). Designing health information in a patient accessible way was highlighted as important. Users wanted to have general and tumor-specific health information available in a PEPA. Functions such as filtering information and adding information by patients (eg, on their well-being or electronic communication with HCPs via email) were discussed.

Conclusions: In order to develop a patient/user centered tool that is tailored to user needs, it is essential to address their perspectives. A challenge for implementation will be how to design PEPA's health data in a patient accessible way. Adequate patient support and technical advice for users have to be addressed.

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KEYWORDS

personal electronic health record; user requirements; functions; colorectal cancer; chronic care

Introduction

The integration of new information and communication technologies (ICTs) is becoming increasingly important in reshaping the way health care is understood and delivered [1]. Significant potential is seen in ICT concepts aiming to give patients access to their own health- and treatment-related information [2-5]. In particular, personal health records (PHRs) are seen as promising tools, ranging from standalone to tethered to integrated approaches [6,7]. PHR systems that often used in the United States allow patients to access primary data from an electronic health record managed by health care professionals (HCPs) through a patient portal (tethered PHRs) [8].

However, design and implementation of innovative patient-centered PHRs has not proven to be easy. Experiences from nationwide approaches such as the National Health Service implemented personal electronic health record HealthSpace (England) show that it failed due to a lack of usefulness and user friendliness, as well as poor alignment to users' expectations and self-management practices [9]. According to adoption and use, user orientation in ICT development, implementation, and evaluation is central [2,9].

Moreover, current literature shows that patients and health care professionals may have complementary perspectives regarding PHRs. In general, patients do have a positive attitude towards the use of a PHR [10-13] and are willing to share their health-related information via new ICTs [10,14-16]. However, health care professionals more often express concerns regarding PHRs instead of discussing possible benefits [13,17-19].

In our research project, we are developing a patient-controlled personal electronic health record (PEPA) in chronic care of patients with colorectal cancer. As a subset of PHRs, the Web-based PEPA would enable patients to access, maintain, and manage (including access management) a secure copy of their personal health information integrated from various HCP primary systems (eg, electronic medical records in hospital, electronic health records in general practice). Within the PEPA concept, patients are understood to be active partners who manage their personal health information across health care settings.

For an innovative ICT like PEPA to create added benefit and function as a supportive tool in managing complex chronic illness and care, it is essential that it fit into the real world, daily practices, and health care structures of patients with cancer and their HCPs. Therefore, it is important to better understand the needs and requirements of prospective users. The aim of this study was to explore needs and requirements of potential users with regard to the content and function of a PEPA.

Methods

Study Design

A pilot project called "Information technology for patient-centered health care" (INFOPAT), funded by the German Federal Ministry of Education and Research (2012-16), has been initiated in the Rhine-Neckar region (population: 2.3 million) in Germany aiming to improve cross-sectoral health care especially for patients with colorectal cancer. Within this project, a PEPA is being developed and implemented regionally.

In the first phase of this INFOPAT-project, a qualitative, exploratory study design using focus groups was chosen, to allow intensive exploration of requirements and needs of selected user groups. The following general research questions were explored within this analysis: (1) What requirements do potential users have regarding the PEPA content?, (2) What information do potential users perceive as relevant to have available in the PEPA?, and (3) Which PEPA functions do potential users perceive as useful?

Ethical approval was given by the Ethics Committee of the University Hospital Heidelberg (S-497-2012). All participants gave their written informed consent. The participants' anonymity and confidentiality was ensured throughout the study.

Study Sample

In a regional (Rhine-Neckar region in Baden-Wuerttemberg, Germany), cross-sectoral health care setting, prospective user groups of a PEPA were identified. The first user group comprised patients with colorectal cancer (ECOG Performance Status 0-1 [20]) as well as representatives (staff) from patient support groups. The second group was made up of physicians and the third group comprised other non-medical HCPs. Patients who fulfilled the following criteria were excluded: younger than 18 years, suffering from severe acute psychiatric disorders as well as moderately to severe dementia.

Patients were recruited through the National Center for Tumor Diseases (NCT) in Heidelberg, Germany, where they received their cancer treatment. Additionally, patients were recruited via an umbrella organization, Heidelberger Selbsthilfebüro, for patient support groups in Heidelberg. Clinicians (oncological specialists) and other non-medical HCPs (nurses, stoma therapist, social services, physiotherapists, and nutritionists) were also recruited at the NCT. General practitioners (GPs), registered medical specialists (eg, oncologists), and health care assistants from GP practices were recruited by the Department of General Practice and Health Services Research (University Hospital Heidelberg).

Data Collection

The decision to collect data through focus groups was based on the explorative character of the research topic. A focus group is a kind of group interview with participants who are involved in the research field of interest. The group processes that are evoked by focus groups can help participants explore and clarify their views, attitudes, and opinions, which would be less accessible in a one-to-one interview [21].

From March until October 2013, 10 focus groups with a total of 47 participants were conducted. For all user groups, separate focus groups were performed (3 with patients; 4 with physicians; 3 with other HCPs) (Table 1). On average, the focus groups lasted 120 minutes and took place in rooms at the University Hospital Heidelberg. All data were audio- and videotaped and transcribed verbatim.

An experienced researcher used a semistructured, pilot-tested interview guide based on a literature review and expert discussions for conducting the focus groups. At the beginning of the focus group, a small amount of information was given on the PEPA concept to all participants. At all focus groups, the moderator was supported by a co-moderator. A third researcher wrote a protocol that was integrated into the data analysis phase of this study. The focus group discussions lasted until the saturation of theoretical arguments was reached.

Table 1. Composition of focus groups (N=10).

User group	Focus groups, n	Participants (total), n	Description
Patients	3	14	Patients with colorectal cancer, representatives from patient support groups
Physicians	4	17	Oncological specialists, GPs, registered specialists
Other HCPs	3	16	Nurses, health care assistants, social services, nutritionists, physiotherapists
Total	10	47	

Data Analysis

The approach for the descriptive qualitative analysis used in this study [22,23] dealt with the transcribed texts of conducted focus groups as material, in which all data were embedded. To perform a qualitative content analysis, data were taken from the transcripts, edited, and analyzed. This was done by using a preliminary category system as search grid. The preliminary category system was based on theoretical considerations, expert discussions, and a literature review. During the entire process of analysis, the category system was adapted if the data revealed additional and new information that did not fit into the previous category system.

Therefore, the performed qualitative content analysis included inductive development of categories and a deductive application of categories. In a first step, three transcripts were reviewed independently by the first author (IB), a coauthor (MK), and the last author (DO) using the preliminary category system and additional key issues were identified. After summarizing and labeling key issues as codes, the codes were sorted into main and subcategories [23]. The codes were clearly defined and linked with representative examples from the original texts. The categories were discussed and further modified within the interprofessional researcher team until a consensus on the category system was achieved. Qualitative content analysis of the data was performed using the software ATLAS.ti (version 7.0.80).

Presentation of Results

In order to facilitate better readability, the key findings are presented in categories, subcategories, and aspects. Tables that present the categories enable differentiation between the user groups' perspectives with respective aspects mentioned. The quotations cited in this article were cross-checked by a native speaker in the Department of General Practice and Health Services Research after translation from German into English.

Results

Overview

Table 2 summarizes the characteristics of patients with colorectal cancer (n=12), representatives from patient support groups (n=2), physicians (GPs, registered specialists, oncological specialist) (n=17), and 16 other non-medical HCPs like nurses including a stoma therapist (n=7), health care assistants (n=4), social services (n=2), nutritionist (n=1), and physiotherapists (n=2).

Overall, the key results presented here show that focus group participants discussed user requirements like the presentation of information, tumor specific information that is needed, and possible useful functions (Figure 1).

Table 2. Sample characteristics of focus group participants (N=47).

	Patients (n=12)	HCPs (n=16)	Physicians (n=17)	Patient representatives[a] (n=2)
Sex (male), % (n)	83.3 (10)	18.8 (3)	58.8 (10)	50.0 (1)
Age (years), median (interquartile range)	61.5 (58.0-67.2)	38.0 (28.5-50.0)	43.0 (35-56.5)	(44;62)[b]
Living in rural area[c], % (n)	58.3 (7)	—	—	—
Living with a partner, % (n)	91.7 (11)	—	—	—
Education ≥12 years, % (n)	50.0 (6)	43.7 (7)	—	100.0 (2)
Duration since diagnosis (years), median (interquartile range)	1.7 (0.8-6.7)	—	—	—
Professional experience (years), median (interquartile range)	—	20 (5.0-26.0)	15 (5.0-26.5)	(10;38)[b]
Living with diagnosis, % (n)				
<1 year	33.3 (4)	—	—	—
1-2 years	33.3 (4)	—	—	—
≥6 years	33.3 (4)	—	—	—
Health care setting, % (n)				
NCT	—	75 (12)	29.4 (5)	—
Outpatient care[d]	—	25 (4)	70.6 (12)	—

[a] Patient representatives=staff from patient support groups.

[b] Minimum; maximum.

[c] Less than 15,000 inhabitants.

[d] General practitioners; registered specialists.

User Requirements: Personal Electronic Health Record Information and its Presentation

Overview

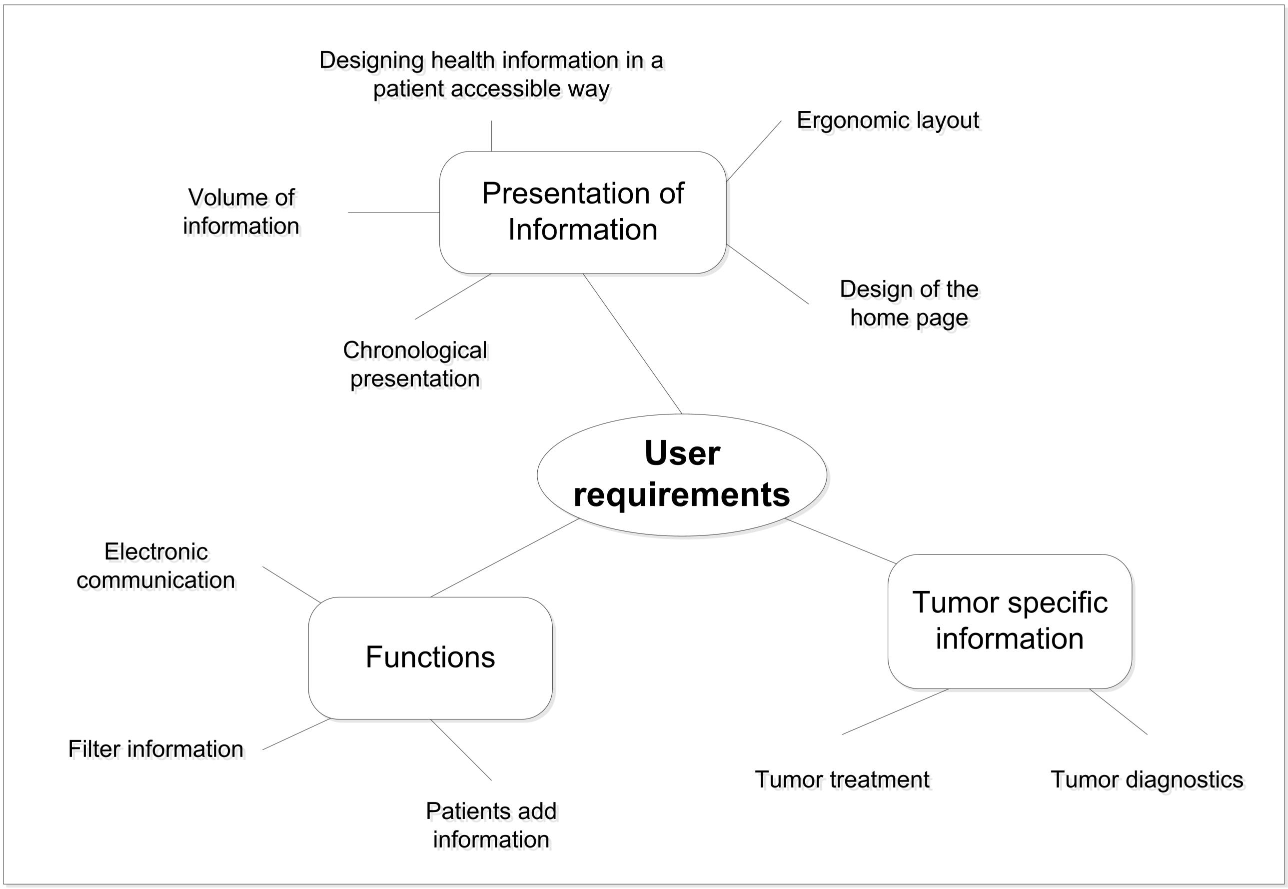
During the focus group discussions, issues on PEPA information and how it should be presented in a PEPA were central in all groups. The following user requirements on these issues were identified (Table 3).

Table 3. User requirements: PEPA information and its presentation.

Subcategory	Aspects	User group[a]
Volume of PEPA information	Need for complete data	b
	Manageability of large amounts of data	a/b
	Need for time and content-related limits	a/b/c
Designing health information in a patient accessible way	Information comprehensible to laypersons	a/b/c
	Adapting the presentation of medical results	b
	Glossary to support comprehensibility	a/c
Chronological presentation of illness related information	Tracking the course of illness and treatment	a/b/c
	Information in chronological order	a/b/c
	Identifying and utilizing unstructured information	b
	Tracking long-term laboratory findings	a
Ergonomic layout	Clarity	b/c
	Ease of use	b/c
Design of the home page	Key information on the home page	a/b/c
	Priority for current issues	a/b
	Highlighting entries	b/c

[a] User group: a=patients; b=physicians; c=other HCPs (eg, nurses).

Figure 1. Overview of identified key results regarding user requirements.



Volume of Information in a Personal Electronic Health Record

The volume of information that should be provided in a PEPA was discussed in all three user groups. Different needs regarding this issue emerged. In particular, participants from the physicians' focus groups expressed their need for complete data in a PEPA. They wished to have information available in the PEPA as much as possible: "I always expect all information from such a record" (GP1-F10).

On the other hand, other participants within the physicians' group and patients saw a challenge in manageability of large amounts of data: "It's just such an enormous thing…can you still manage it, do you want to manage it—everyone will have this huge thing to maintain" (Patient4-F01).

In all three user groups, the need for time and content-related limits in information volume was mentioned. Issues on limiting the volume with a timeline were addressed especially by patients, for example, only data from the last 10 years, although they were unsure about when to draw the line. Some patients mentioned that they did not want to have every detailed laboratory result in their PEPA. Similarly, participants from both professional user groups (medical and other HCPs) thought it would be useful to limit the amount of medical results for practical reasons: "Yes, but not everything…I don't need all 20 of those little blood exams" (Patient4-F01) and "It would perhaps be quite good if only a certain number of the results were in it" (HCP-F06).

Designing Health Information in a Patient Accessible Way

A central issue was how to present information in a PEPA for patients. Designing health information in a patient accessible way was discussed by all three user groups. Several patients emphasized their need for having comprehensible information in their PEPA. They highlighted the fact that patients are mostly laypersons who typically have problems understanding medical jargon. One patient suggested a copy of the record that is reworded in patient assessable language while realizing that the associated effort was significant: "I've often wished I had a, what shall I call it—a patient copy…to me that's something that summarizes the most important events of my own life in terms of illness, translated into a language that I can understand" (Patient2-F03).

Similarly, the HCPs user group saw the need for changing the way of presenting medical information in this patient-owned tool, and participants from the physicians' focus groups also required adapting the presentation of medical results to the patients' needs: "How the results are displayed needs to be changed completely so that it can be used for the patients" (Physician 3-F04).

Moreover, options were discussed for supporting the comprehensibility of medical terms in a PEPA for patients by the patient and non-medical HCPs focus groups. The usefulness of a glossary, especially in handling medical abbreviations was stressed:

> *But with the speed…at which the information is given in a one-off appointment, I at least am not able to take it all in. And then I sit at home and really don't know what this RT, all these abbreviations, what that means. Such a kind of glossary would be extremely helpful here.* [Patient2-F03]

Chronological Presentation of Illness-Related Information

During the focus group discussions, in all three user groups, themes related to chronological information recurrently cropped up. For patients as well as their HCPs, it was important that a PEPA structure would facilitate tracking the course of illness and treatment over time: "First of all, I want to see my medical history shown completely for myself" (Patient1-F02) and "I also think that it would be important to have the data in a way that you can track the progress/ process quite quickly" (GP1-F09).

Some physicians explicitly highlighted the need for presenting the PEPA information in chronological order for their daily practice in treating patients with colorectal cancer but concurrently stressed the big challenge in technological practicability:

> *The challenge certainly lies in putting individual results into a useful chronology.* [Physician3-F04]
>
> *I think it's sensible to categorize it (the information) and assign it to the different areas so that you really end up with this chronology…he had the last chemotherapy on day xy and this was the medication and a week ago he took a break because his blood values were bad.* [Physician3-F04]

A further issue pointed out in the physician focus groups was that physicians dealt with patients' health information in electronic patient records within their daily work where, currently a lot of necessary health information is provided in an unstructured way, for example, in medical reports or physician's letters (as PDF files). From their perspective, a PEPA would have a real benefit for their daily work if it could identify and utilize unstructured information from various information systems and present it in a structured form in the PEPA:

> *because if it can't do that, I end up with what feels like ten PDF files from the patient and one is the doctor's letter from the University Hospital and one is the doctor's letter from the oncologist and the third PDF is maybe a copy of a prescription…The question is, how do we make the new system more than just the scanned-in doctor's letters.* [Physician3-F04]

Patients focused more on the possibility of observing how their condition developed over time (eg, tumor markers). They would benefit from using a PEPA, for example, if tracking their long-term laboratory findings would be possible: "My tumor marker values, for instance, it would be really interesting to see how they progress" (Patient4-F01).

Ergonomic Layout

In general, issues with PEPAs related to design and layout were not central to discussions. In particular, patients did not have a detailed idea on how the PEPA layout and its user interface should appear: “The design isn’t that important to me” (Patient4-F01). However, participants from both professional user groups (medical and other HCPs) had several overall requirements regarding this issue. Both wished that a PEPA would have an ergonomic layout that is clearly structured: “The whole thing…really needs to be completely clear” (GP1-F05). Furthermore, the importance of the PEPA’s ease of use for a broad range of users was emphasized: “It needs to be very simple” (GP4-F05) and “understandable to everyone” (HCP1-F07).

Design of the Front Page

Regarding the design of the PEPA’s front page, participants from all three user groups, especially physicians mentioned that the information presented at the frontpage should be restricted to key information like administrative data, contact persons, diagnoses, or the current medication plan. Further information of interest they would like to open on sub-levels: “Really the most important...I mean name, address, relatives, telephone number, allergies, diagnoses, maybe the last medication plan—that’s it. And you can open the rest if you want to” (GP2-F05).

Some participants from the patient and the physician user groups pointed out a priority for current issues. They wished to view current information first on the front page. Some participants from both professional user groups (medical and other HCPs) suggested even highlighting important or new information, for example, in terms of color to highlight relevance.

> *If new entries are added, they need to be specially marked, not integrated into the mails, so that I don’t have to search and read through everything again to find out what’s new. It should be introduced somehow and indicated that it’s new.* [Patient6-F03]
>
> *that some things are highlighted in a different colour, important things.* [HCP6-F06]

Relevant Information in a Personal Electronic Health Record From Users’ Perspective

Tumor-specific information was identified as relevant to have available in the PEPA for care delivery in patients with colorectal cancer. Particularly, participants in the physicians focus groups focused on tumor-specific information related to tumor diagnostics and tumor treatment (Table 4).

Table 4. User requirements on available tumor specific information in the PEPA.

Categories	Contents	Specifics
Tumor diagnostics	Tumor diagnosis	Initial diagnosis including the date of assessment
	Tumor localization	Tumor localization including the date of assessment
	Tumor laboratory	Tumor marker
	Tumor stage	Information on tumor stage and metastases (TNM-classification); including the date of assessment; and staging or planned staging
Tumor treatment	Chemotherapy	Information on the application of chemotherapy; dose reduction; and status of chemotherapy
	Radiotherapy	Information on dose of radiotherapy

Moreover, general information was identified from the users’ perspective as relevant to have available in the PEPA (see Multimedia Appendix 1). The focus group participants from all three user groups required that a PEPA should provide at least a basic dataset of relevant information that would be crucial for everyone involved in the patients’ health care. Besides administrative data, information like allergies, diagnoses, and medication were highlighted as relevant. Patients were interested in accessing long-term diagnoses in their PEPA and information on their appointments. Accessing information on diagnostics and medical results including laboratory findings from different health care settings concerning the patients’ treatment were perceived as crucial by patients as well as both professional user groups. Information related to the patients’ medical history was mentioned several times. Patients perceived information regarding past family history like information on tumor diseases or congenital disease as relevant PEPA contents, whereas participants from the other HCP focus groups emphasized the importance of getting information on the patients’ social history.

Participants from both the patient focus groups and the physician focus groups thematized the potential of information regarding the patient that could be made available through a PEPA. A section for information on internal professional documentation in a PEPA was seen as critical especially by the group of other HCPs. They highlighted the need for HCPs to be able to exchange information with each other on the patients’ condition or behavior without general access being available.

User Requirements on Personal Electronic Health Record Functions

Overview

Identifying user requirements on PEPA functions revealed several topics that the focus group participants in the three user groups addressed. In addition to storage of and access to desired personal health information including clinical data, some identified central functions of a PEPA were selected and are presented in Table 5.

Table 5. User requirements on PEPA functions.

Subcategory	Aspects	User group[a]
Patients add information	Information on subjective well-being	a/b/c
	Patients could add commentaries	b/c
	Demand for separate section for patient entries	b
	Consequences on liability	b
Filter information	Filter large amount of data is crucial	b
	Filter for currentness	a/b/c
	Filter for diagnosis/topics	a/b/c
Electronic communication	Ambivalence towards messaging with patients	b/c
	Communication among HCPs	b
	Pressure by permanent availability	b
	Patients' high expectations and limited resources in time	b/c

[a] Which user group was responsible for the aspect presented: a=patients; b=physicians; c=other HCPs (eg, nurses).

Patients Add Information

One central issue discussed in all three user groups was the opportunity for patients to add information to a PEPA in addition to the HCPs. The usefulness of information on subjective well-being that patients could add to a PEPA was emphasized. Some patients expressed the wish to share information on their well-being with their HCPs. Participants from both professional user groups (medical and other HCPs) gave examples on information they perceived as clinically relevant that they would want to know from the patient (eg, information on pain, depressive feelings, and side effects from the chemotherapy like nausea): "Well, yes, it's data that the patient might generate themselves…It would be important to know that in terms of pain treatment, for instance" (GP2-F10).

A participant from a physician focus group suggested providing this function as a patient journal that would be kept by the patient in the PEPA: "Of course, that would be especially important, yes, if he could write a kind of journal…while he's undergoing chemotherapy about how it's going" (GP1-F09).

Furthermore, participants from both professional user groups mentioned the possibility for patients to add commentaries on medical results. For instance: "add something to it, a note/comment/commentary, if he wants, so that someone else who accesses it can either take it into account or not" (GP1-F05).

Critical comments were also made regarding patients' adding information. From the physician group, requirements for a separate section for patient entries were identified to ensure that data entered by patients are not mixed with those uploaded from professionals and further to ensure that patient-added information would be marked as such:

> *Is that really necessary?...Then we'd need to enter certain codes for the patient to show where in his record… such as Patient History, where he can only enter something himself there and not add in other things.* [GP1-F10]

Given the fact that several physicians from different health care settings would have PEPA access, participants from physician focus groups expressed concerns and uncertainty regarding negative consequences on professionals' liability for reacting to patient-added information or commentaries: "In theory you could go even further with the liability thing, if three or four doctors check the record and all saw that he was feeling worse and no one reacted, whose fault is it?" (GP1-F09).

Filter Information

Having the possibility to filter information in the PEPA was important to focus group participants from all three user groups: "But then there should be a filter function so you can filter out things fairly quickly, that would be important" (GP1-F09). Especially in terms of handling large amounts of data that a PEPA could provide, physicians perceived a filter function as essential: "The data volume soon won't be a problem…but you need to be able to filter really well." (GP4-F09).

Related to this topic, physicians perceived a filter function for currentness as useful, for example, listing medical results from the latest to the oldest: "Yeah, yeah, yeah. Well, I think the detailed filter function is very important too, eg to search for the latest results." (GP2-F09).

Also, having the opportunity to filter the PEPA information for a diagnosis, for example, colorectal carcinoma or a topic of interest was highlighted as useful:

> *and so I can say, only colorectal carcinoma, then I only see everything connected with this diagnosis. If he comes to me because of high blood pressure, then I click at the top on just this episode and only see these things, that would be the benefit of it.* [GP1-F10]

Electronic Communication

Electronic communication could be a PEPA feature provided to its users. Among both HCP user groups, especially among physicians, ambivalence towards messaging with patients was revealed during the discussions. Some participants perceived this function as useful whereas others did not: "A kind of messaging function, being able to send messages to the patient would be useful: ‘Attention: please do not eat anything before attending your CT appointment tomorrow’” (Physician1-F04) and “That doesn’t make any sense” (GP5-F05).

Some physicians saw the positive potential of this feature for enhancing communication among HCPs involved in the patients’ treatment: “And perhaps sometimes a better coordination or a note to the GP as the most important second contact, leaving short messages via both channels without having to hold long phone calls and so on. This would certainly be beneficial” (Physician3-F04).

Concerns regarding electronic communication with patients that were expressed by physicians during the discussions referred to a perceived pressure by permanent availability of HCPs: “And if I then need to look up who just wrote to me and who I need to write to now because something urgent has happened, then I don’t need an emergency service any more, then I’m permanently on call” (GP1-F10).

It was argued that patients would develop high expectations concerning the HCPs’ availability in terms of dealing promptly with patient concerns, if such communication features would be available. They feared that their limited time resources could be overstrained by providing this feature to patients:

> *They can order prescriptions from us by e-mail and pick them up the next day. It’s actually a great function, but the problem is that patients send prescriptions at midnight and want to have them ready at 7 a.m. They think we sit here all day just for that.* [HCP3-F07]

Discussion

Principal Findings

The aim of this study was to explore requirements and needs of potential users with regard to the content and function of a PEPA. In our study, key requirements and needs were identified from users’ perspective. Overall, our participants were very much focused on themes according to their daily routines. They wished for a PEPA that allows and facilitates tracking the course of illness and treatment over time. Professionals expressed the need for presenting PEPA information in chronological order for their daily practice in treating patients with colorectal cancer. In this context, one central desired function to our participants was the opportunity to filter information and thus to categorize information for several purposes like time or content.

Physicians specifically highlighted the potential of a PEPA if it would enable them to view all information as history related to one single episode, for example, colorectal cancer. Closely linked with this requirement was the need to identify and utilize unstructured information and present it in structured form. Currently, a problem in daily practice described by professionals is that a lot of necessary health information is provided in an unstructured way, for example, in medical reports or physician’s letters (as PDF file). A real benefit for their daily work would be if a PEPA could identify and utilize unstructured information from various IT systems and present it in a structured form in a PEPA. However, there is a lack of literature addressing this issue [24].

A significant issue for patients and their HCPs was that PEPA information including medical information will be accessible to patients in their patient-controlled tool. Consequently, if patients managed their PEPA, they required that the presentation of data has to be adapted to the patient’s needs as a layperson, in particular, comprehensibility. Problems in understanding clinical documentation have often been an issue reported by patients [15,25-27]. Our patients wished to have a patient copy that is designed to be understood and handled by patients or wished a supportive glossary. As described previously in literature, patients want adapted patient versions of the record including reduced medical terms or support to quickly find definitions of medical terms [17].

In addition to storage and access to personal health information including clinical information [28,29], several desired PEPA functions were discussed. The idea that patients could autonomously add information to the PEPA was discussed by our participants. In general, patients were open in terms of this and found it was a good idea as supported by literature [12]. In particular, they were interested in adding information on their subjective well-being, for example, nausea during chemotherapy. However, adding general information about lifestyle choices such as exercise and smoking history was described as less interesting by participants from another study [10]. Most of our professional participants supported that this function could have additional benefit, for example, if it were in the form of a patient journal, in particular regarding clinical relevant information on patient well-being. However, some of them tended to be critical regarding the liability of professionals relying on patient-added information.

Despite the fact that electronic communication with HCPs is an often required and provided function [4,10,28-31] and higher satisfaction or improved doctor-patient communication was observed [32-35], our user groups did address this function, in particular patients. One possible explanation could be that patients in particular had no concrete ideas about electronic communication as a feature of patient-controlled records, due to the early stage of our PEPA development. Ambivalence towards messaging with patients was expressed especially by physicians. Their concerns referred to a perceived pressure by permanent availability. Moreover, this “electronic communication function" was seen more as a positive feature to enhance communication among HCPs involved in the patient treatment rather than a communication tool with patients. Experiences from a study with messaging services showed that patients most frequently rated the administrative communication functions as valuable features, such as the ability to request appointments, renew prescriptions, ask an administrative question, or obtain referral approvals. One third of respondents sent messages containing questions about their medical care [34]. Patient disappointment if professionals do not answer their questions has been described before [36].

In line with other studies, our findings referred to treatment-related information (eg, major diagnosis, information on allergies, medication lists, laboratory results, as well as to more general health information like social history, immunizations [2,5,8,10,37,38]). In particular, tumor-specific health information was important to patients with colorectal cancer and their HCPs. To oversee appointments was addressed by our patients as beneficial [28,29]. Information regarding the patients' wishes were highlighted by both patients and HCPs. Similar findings are reported in a study of Patel [10].

Requirements regarding the layout were not specified by our participants, probably due to the early stage of technical development of the PEPA. However, our participants focused on general requirements like ergonomic issues, for example, clarity and ease of use. The ease of use of ICTs has been identified as a predictor for adoption [18,39-41], whereas complex portal interfaces were described as a barrier to use [8,42]. User-friendliness can be assumed as a central requirement for users' adoption and use [2].

Strengths and Limitations

As user acceptance has a significant impact on widespread implementation and use of a PEPA in health care, it is essential to involve users early in the technical development and evaluation processes in order to develop a patient/user-centered PEPA that addresses user needs. Consequently, exploring attitudes regarding the PEPA concept from the user perspective was an important first step in developing and implementing an innovative ICT into existing health care structures. The study was conducted by an interprofessional team of researchers (nursing, physiotherapy, medicine, philosophy) enabling a broad perspective during design and analysis stages. Some limitations in recruitment of participants have to be acknowledged. Most patients willing to participate in the study were men, and the level of education was relatively high. It can be assumed that the innovative and technical character of this approach attracted early adopters of ICT [4,8,43], therefore the findings may not be generalizable to the regional colorectal cancer patient population.

Conclusions

From the user perspective, a PEPA was seen as a potentially useful tool for patients with colorectal cancer and their HCPs in cross-sectoral cancer care. A PEPA has potential to support patients in managing their chronic illness and is conceptualized to facilitate information exchange between patients and their HCPs as well as among HCPs or institutions across health care sectors. However, chronic diseases do have a long-term and episodic character. In order to create an added benefit to its users, a PEPA has to be oriented to these phases and episodes of care. A challenge for implementation will be how to design a PEPA's health data in a patient accessible way. In order to create a real patient/user-centered tool that is tailored to user needs, patients and their HCPs have to be involved early in development, implementation, and evaluation processes. User preferences according to their daily routines in managing chronic illness have to be addressed. Furthermore, adequate patient support and technical advice for users have to be provided.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Relevant information in a personal electronic health record from users' perspective linked with quotations and user requirements on relevant available information.

[PDF File (Adobe PDF File), 254KB - jmir_v17i5e121_app1.pdf]

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Abbreviations

ECOG: Eastern Cooperative Oncology Group
GP: general practitioner
HCP: health care professional
ICT: information and communication technology
IQR: interquartile range
NCT: National Center for Tumor Diseases
INFOPAT: information technology for patient-centered health care
PEPA: name of the patient-controlled personal electronic health record which is developed within the INFOPAT project
PHR: personal electronic health record

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Original Paper

The Relationship Between Balance Measured With a Modified Bathroom Scale and Falls and Disability in Older Adults: A 6-Month Follow-Up Study

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Abstract

Background: There are indications that older adults who suffer from poor balance have an increased risk for adverse health outcomes, such as falls and disability. Monitoring the development of balance over time enables early detection of balance decline, which can identify older adults who could benefit from interventions aimed at prevention of these adverse outcomes. An innovative and easy-to-use device that can be used by older adults for home-based monitoring of balance is a modified bathroom scale.

Objective: The objective of this paper is to study the relationship between balance scores obtained with a modified bathroom scale and falls and disability in a sample of older adults.

Methods: For this 6-month follow-up study, participants were recruited via physiotherapists working in a nursing home, geriatricians, exercise classes, and at an event about health for older adults. Inclusion criteria were being aged 65 years or older, being able to stand on a bathroom scale independently, and able to provide informed consent. A total of 41 nursing home patients and 139 community-dwelling older adults stepped onto the modified bathroom scale three consecutive times at baseline to measure their balance. Their mean balance scores on a scale from 0 to 16 were calculated—higher scores indicated better balance. Questionnaires were used to study falls and disability at baseline and after 6 months of follow-up. The cross-sectional relationship between balance and falls and disability at baseline was studied using t tests and Spearman rank correlations. Univariate and multivariate logistic regression analyses were conducted to study the relationship between balance measured at baseline and falls and disability development after 6 months of follow-up.

Results: A total of 128 participants with complete datasets—25.8% (33/128) male—and a mean age of 75.33 years (SD 6.26) were included in the analyses of this study. Balance scores of participants who reported at baseline that they had fallen at least once in the past 6 months were lower compared to nonfallers—8.9 and 11.2, respectively ($P<.001$). The correlation between mean balance score and disability sum-score at baseline was -.51 ($P<.001$). No significant associations were found between balance at baseline and falls after 6 months of follow-up. Baseline balance scores were significantly associated with the development of disability after 6 months of follow-up in the univariate analysis—odds ratio (OR) 0.86 (95% CI 0.76-0.98)—but not in the multivariate analysis when correcting for age, gender, baseline disability, and falls at follow-up—OR 0.94 (95% CI 0.79-1.11).

Conclusions: There is a cross-sectional relationship between balance measured by a modified bathroom scale and falls and disability in older adults. Despite this cross-sectional relationship, longitudinal data showed that balance scores have no predictive value for falls and might only have limited predictive value for disability development after 6 months of follow-up.

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KEYWORDS

telemonitoring; balance; bathroom scale; older adults; falls; disability; validity

Introduction

There are indications that older adults who suffer from poor balance have an increased risk for adverse health outcomes, such as falls, mobility-related disability, and disability in daily activities [1-4]. Monitoring the development of balance over time enables early detection of balance decline. Providing interventions aimed at improving balance and preventing falls or disability could be beneficial to older adults with decreased balance because it can reduce their risk of these adverse outcomes [5-8].

Possibilities for monitoring the development of balance over time in older adults are clinical balance tests that are conducted by care professionals [9-11], (expensive) force plate equipment that is available in clinical/laboratory settings [12], and innovative telemonitoring devices [13-16]. The latter can be used by older adults in their own homes without the presence of a care professional. This can facilitate regular monitoring and early detection of change over time. Furthermore, such telemonitoring devices can provide direct information regarding balance changes to the user, which can support self-management.

A telemonitoring device appropriate for home-based self-monitoring of balance is a modified bathroom scale [13]. This device uses an algorithm to calculate balance parameters and is equipped with Bluetooth, which enables the transfer of balance and weight data to a mobile phone-based app. Via the app, older adults can receive information about their own balance scores, or changes in these scores. Furthermore, the data could be forwarded to a database that can be accessed by care professionals, which enables them to monitor the development of balance in their patients over time from a distance [17,18]. Older adults are able to use the modified bathroom scale for home-based self-monitoring of balance because it does not differ from a normal bathroom scale [13,19]. Previous research that compared balance scores of the modified bathroom scale to clinical balance tests, such as the Performance-Oriented Mobility Assessment or Timed Up and Go, suggests good construct validity, especially in older adults with slightly diminished balance [20]. Besides that, the modified bathroom scale provides estimates of balance-related parameters similar to a force plate [21].

Since the bathroom scale seems to be able to provide valid balance measurements, it can be used to identify balance decline in older adults. However, no studies have been conducted yet in which the predictive validity of balance scores of the modified bathroom scale on adverse outcomes has been studied. Information regarding predictive validity can help older adults and care professionals to interpret the balance scores. Furthermore, it is important to know whether lower balance scores are associated with adverse outcomes in order to decide whether, or which, preventive interventions would be justified when balance decline is detected. Therefore, the aim of this study is to explore the relationship between balance scores of the modified bathroom scale and falls and disability in older adults.

Methods

Design, Setting, and Participants

A longitudinal study with 6-month follow-up was conducted in two Southern provinces of the Netherlands between October 2012 and July 2013. Participants were recruited via different settings to ensure that older adults with different balance levels, ranging from very poor to very good, were represented in the study sample. Participants were recruited via physiotherapists working in two nursing homes, the outpatient clinic of a geriatrician, exercise classes for older adults, and at an event about health for older adults. To be eligible for inclusion, participants had to be aged above 65 years, able to stand on the bathroom scale independently, and able to provide written informed consent.

Potential participants who met the eligibility criteria mentioned above received an invitation letter from their physiotherapist (n=48), geriatrician (n=28), exercise instructor (n=72), or the researcher (n=60) that contained information regarding the study. Invitations were handed out during regular physiotherapy sessions, consultations with the geriatrician, exercise classes, and at an event about health for older adults. Before handing out the invitations, the physiotherapists, geriatricians, exercise instructor, and researcher checked whether a person was able to provide written informed consent. Those who met the eligibility criteria and signed informed consent documents were included in the study. Once written informed consent was provided, participants measured their balance using the modified bathroom scale and filled out a paper-based questionnaire. After 6 months of follow-up, the same questionnaire was sent to the participants. Nonresponders received a reminder after 3 weeks asking them to return the questionnaire. This study was approved by the Medical Ethical Committee Atrium-Orbis-Zuyd (Reference: NL 142245709, July 23, 2012).

Measurements

Participants conducted balance measurements at baseline and filled out a questionnaire regarding participant characteristics (ie, age, gender, chronic conditions, psychotropic drug use), falls, and disability at baseline and at the 6-month follow-up measurement.

Balance was measured using the modified bathroom scale (see Figure 1). The scale is equipped with an infrared sensor at the front which activates the bathroom scale. All participants were instructed to stand in front of the bathroom scale and to step onto it when the number “0.0” appeared on the display. They were instructed to step down backwards once their weight appeared on the screen. The modified bathroom scale uses the signals from four pressure sensors located in the corners of the scale to collect information regarding two dynamic and two static balance parameters. An overall balance score is calculated using the information regarding the following four parameters: step on delay, rise rate, surface under the stabilogram, and average velocity of the trajectory. Each parameter is scored on a scale from 0 to 4 which results in an overall balance score between 0 and 16—a higher score indicates better balance. Detailed information regarding the parameters and the calculation of the overall balance score is described by Duchêne and Hewson [13]. Participants stepped onto the bathroom scale three consecutive times which resulted in three balance scores. The mean balance score of these three measurements was calculated and used in the analyses. The researchers were present when participants used the bathroom scale to provide help and instructions when needed.

Falls were defined as unintentionally coming to rest on the ground, floor, or other lower level. Via the questionnaire, participants were asked to report whether they had fallen in the past 6 months. Those who had fallen at least once in the past 6 months were considered fallers.

Disability was measured using the Groningen Activity Restriction Scale (GARS), which is a valid and reliable measuring instrument [22]. The GARS consists of 18 items, 11 of which refer to activities of daily living (ADL) and seven of which refer to instrumental activities of daily living (IADL). A copy of the GARS is provided in Multimedia Appendix 1. For each item, participants indicated on a 4-point scale whether they could perform the activity independently without any difficulty (score of 1), independently with some difficulty (score of 2), independently with great difficulty (score of 3), or whether they could not execute the activity independently (score of 4). So, if participants scored 4, they depended on other people for the performance of that activity. Overall disability, ADL disability, and IADL disability sum-scores were calculated and ranged from 18 to 72, 11 to 44, and 7 to 28, respectively—higher scores indicated higher disability levels. Disability development after 6 months of follow-up was operationalized as increased dependence in daily activities—ADL and IADL combined—meaning that a participant was dependent in at least one more activity of the GARS at follow-up compared to baseline. This was calculated by subtracting the number of activities in which a participant was dependent at baseline from the number of activities in which a participant was dependent at follow-up.

Figure 1. Modified bathroom scale.

Statistical Analyses

Descriptive statistics were used to provide information regarding the baseline characteristics of the participants. Categorical variables were expressed with percentages and continuous variables with means and standard deviations.

To study the reliability of the modified bathroom scale, intraclass correlation coefficients (ICCs)—two-way random effects using absolute agreement—of the balance scores were calculated. ICCs were calculated for the three repeated balance scores and separately for each of the four balance parameters—step on delay, rise rate, surface under the stabilogram, and average velocity of the trajectory.

The independent samples *t* test was conducted to determine whether participants who reported at baseline that they had fallen at least once in the past 6 months had a lower mean balance score compared to participants who had not fallen in the 6 months before baseline. To study the relationship between balance and disability at baseline, Spearman rank correlations between the mean balance score and overall, ADL, and IADL disability sum-scores at baseline were calculated.

To study the relationship between balance scores at baseline and falls and disability after 6 months of follow-up, univariate and multivariate logistic regression analyses were conducted. Six univariate regression analyses were conducted with baseline balance scores of the modified bathroom scale, faller at baseline (1=yes, 0=no), baseline disability (ie, GARS overall sum-score), psychotropic drug use at baseline (1=yes, 0=no), gender (1=female, 0=male), and age as independent variables and faller after 6 months of follow-up as dependent variable. Five univariate regression analyses were conducted with baseline balance scores of the modified bathroom scale, baseline disability (ie, GARS overall sum-score), faller at follow-up (1=yes, 0 = no), gender, and age as independent variables and disability development after 6 months of follow-up as dependent variable. In addition, two multivariate logistic regression analyses were conducted to study the predictive value of the bathroom scale balance score at baseline on falling and development of disability after 6 months of follow-up, while correcting for relevant baseline variables—age, gender, faller at baseline, use of psychotropic drugs, GARS sum-score at baseline—and faller at follow-up.

Disability development after 6 months of follow-up was the primary outcome of our study. According to Green, at least 90 participants should be included in the multivariate analysis with five independent variables to ensure sufficient power [23]. To ensure that enough participants could be included in the analyses, 180 participants were recruited at baseline, taking into account a "worst-case scenario" of not being able to include 50% of the participants in the final analyses due to loss to follow-up or incomplete datasets. All analyses were conducted using SPSS version 19.0 (SPSS Inc, IBM Corp, Armoch, NY). Assumptions for the *t* tests and logistic regression models were checked and met.

Results

Participants

Figure 2 provides an overview of the inclusion process. A total of 208 participants received an invitation and 180 provided written informed consent and participated in the baseline measurement. After the 6-month follow-up, 4 participants had died and 2 could not be approached for the follow-up measurement due to advanced illness. Of the 174 participants who received the 6-month follow-up questionnaire, 143 returned it (82.2%). Finally, 15 participants were excluded from the analyses because they had four or more missing values on the GARS, or because they had not answered the question regarding falls. This resulted in a study sample of 128 participants with complete datasets—25.8% (33/128) male—and a mean age of 75.33 years (SD 6.26). More information regarding the baseline characteristics of the study sample is provided in Table 1.

Table 1. Baseline characteristics of participants (n=128).

Characteristics		Mean (SD) or n (%)
Age in years, mean (SD)		75.33 (6.26)
Gender, n (%)		
	Male	33 (25.8)
	Female	95 (74.2)
Chronic diseases, n (%)		
	Diabetes	21 (16.4)
	COPD[a]/asthma	7 (5.5)
	Cardiovascular diseases	39 (30.5)
	Arthritis	36 (28.1)
	Parkinson's disease/MS[b]	7 (5.5)
Balance score, mean (SD)		10.63 (3.17)
Falls in past 6 months, n (%)		31 (24.2)
Disability sum-scores, mean (SD)		
	GARS[c] overall sum-score (ADL[d] + IADL[e])	27.42 (12.00)
	GARS ADL sum-score	15.13 (5.96)
	GARS IADL sum-score	12.29 (6.61)
Dependence, n (%)		
	Dependent in one activity	20 (15.6)
	Dependent in two activities	12 (9.4)
	Dependent in three activities	10 (7.8)
	Dependent in four activities	25 (19.5)

[a] Chronic obstructive pulmonary disease (COPD).

[b] Multiple sclerosis (MS).

[c] Groningen Activity Restriction Scale (GARS), range 18 to 72.

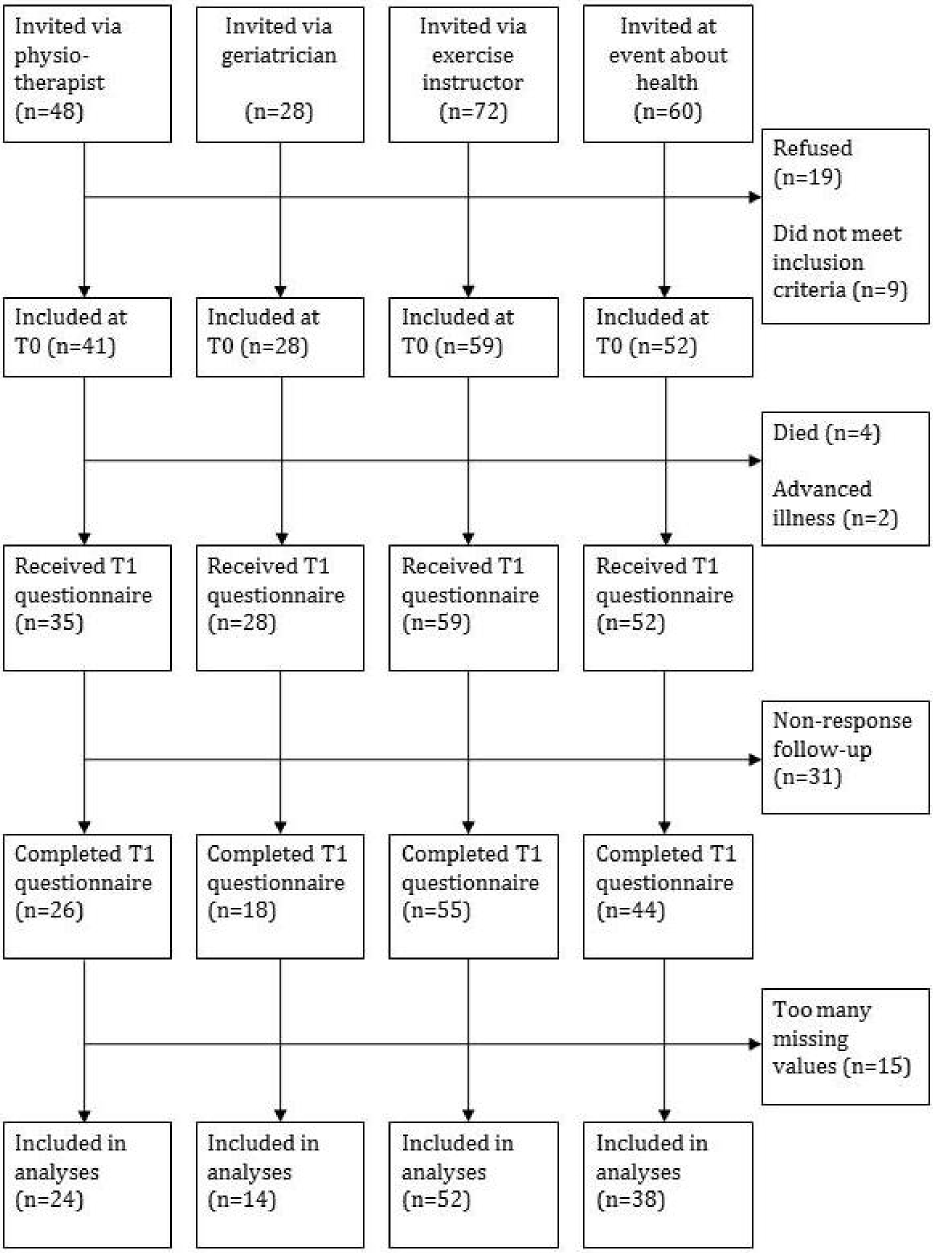
[d] Activities of daily living (ADL), range 11 to 44.

[e] Instrumental activities of daily living (IADL), range 7 to 28.

Out of 128 participants, 23 (18.0%) reported that they had fallen at least once during the follow-up period of the study. Of these 23 participants, 15 (65%) also reported a fall during the 6 months before the baseline measurement. After 6 months of follow-up, the level of dependence increased in 32 of the 128 participants (25.0%), meaning that these participants needed help from another person with at least one more activity compared to baseline.

There were no demographical differences between participants who completed the study and those who were lost to follow-up. The mean balance scores of participants who dropped out of the study after the baseline measurement were significantly lower, namely 9.26 (SD 3.69), compared to those of participants who were included in the analyses, namely 10.63 (SD 3.17) (*P*=.009). Furthermore, baseline IADL disability sum-scores were higher in the group of participants who were not included in the analyses of this study, namely 14.52 (SD 7.35), compared to those who were included in the study sample, namely 12.29 (SD 6.61) (*P*=.049). Dropout was highest among participants who were recruited via the physiotherapists working in a nursing home and via the geriatrician.

Figure 2. Flowchart of participants. Baseline (T0), 6-month follow-up (T1).



Reliability

The ICC for three consecutive balance scores of the modified bathroom scale was .70 (95% CI .62-.77). The ICCs for the four separate balance parameters—step on delay, rise rate, surface under the stabilogram, and average velocity of the trajectory—were .31 (95% CI .20-.43), .72 (95% CI .64-.79), .54 (95% CI .43-.63), and .54 (95% CI .44-.64), respectively.

Cross-Sectional Relationship Between Balance, Falls, and Disability

Balance scores of participants who had fallen at least once in the past 6 months before baseline were lower compared to nonfallers—8.9 and 11.2, respectively ($P<.001$, 95% CI 1.08-3.54). Correlations between mean balance score and overall, ADL, and IADL disability sum-scores at baseline were -.51, -.42, and -.46, respectively ($P<.001$).

Relationship Between Baseline Balance and Falls and Disability at Follow-Up

Results of the univariate regression analyses are presented in Table 2 and results of the multivariate regression analyses are presented in Table 3. Falls reported at baseline were significantly associated with falls during the 6-month follow-up in the univariate analyses—odds ratio (OR) 10.43 (95% CI 3.80-28.63)—and in the multivariate analysis—OR 14.02 (95% CI 4.06-48.50). Disability sum-score at baseline was also significantly associated with falls during the 6-month follow-up in the univariate analysis—OR 1.04 (95% CI 1.00-1.07)—but not in the multivariate analysis. Baseline balance scores were significantly associated with the development of disability after the 6-month follow-up in the univariate analyses—OR 0.86 (95% CI 0.76-0.98). Furthermore, disability level at baseline was significantly associated with disability development after 6 months of follow-up in the univariate analyses—OR 1.04 (95% CI 1.00-1.07). None of the variables entered into the multivariate regression model was predictive of disability development after 6 months of follow-up.

Table 2. Univariate association between baseline variables and falls and disability development after 6 months of follow-up (n=128).

Independent variable	Dependent variable			
	Falls at follow-up, OR[a] (95% CI)	*P*	Disability development at follow-up, OR (95% CI)	*P*
Mean balance score at baseline (scale 1 to 16)	0.96 (0.84-1.11)	.62	0.86 (0.76-0.98)	.03[b]
Age in years	1.00 (0.93-1.07)	.95	1.07 (1.00-1.14)	.05
Gender (0=male, 1=female)	0.59 (0.22-1.54)	.28	0.47 (0.20-1.11)	.08
Faller at baseline (0=no, 1=yes)	10.43 (3.80-28.63)	<.001	N/A[c]	N/A
Psychotropic drugs at baseline (0=no, 1=yes)	2.50 (0.76-8.19)	.13	N/A	N/A
GARS[d] sum-score at baseline (scale 18 to 72)	1.04 (1.00-1.07)	.03	1.04 (1.00-1.07)	*.03*
Faller at follow-up (0=no, 1=yes)	N/A	N/A	2.29 (0.88-5.97)	.09

[a] Odds ratio (OR).

[b] Significant associations (univariate) are shown in italics.

[c] Not applicable (N/A): variable not entered in analysis.

[d] Groningen Activity Restriction Scale (GARS).

Table 3. Multivariate predictors of falls and disability development after 6 months of follow-up (n=128).

Independent variable	Dependent variable			
	Falls at follow-up[a], OR[b] (95% CI)	*P*	Overall disability at follow-up[a], OR (95% CI)	*P*
Mean balance score at baseline (scale 1 to 16)	1.21 (0.95-1.57)	.13	0.94 (0.79-1.11)	.45
Age in years	1.00 (0.90-1.10)	.92	1.04 (0.97-1.12)	.29
Gender (0=male, 1=female)	0.51 (0.16-1.60)	.25	0.50 (0.20-1.24)	.13
Faller at baseline (0=no, 1=yes)	14.02 (4.06-48.50)	<.001 [c]	N/A[d]	N/A
Psychotropic drugs at baseline (0=no, 1=yes)	0.86 (0.18-4.28)	.86	N/A	N/A
GARS[e] sum-score at baseline (scale 18 to 72)	1.04 (0.98-1.09)	.17	1.02 (0.98-1.06)	.34
Faller at follow-up (0=no, 1=yes)	N/A	N/A	2.00 (0.72-5.54)	.19

[a] Adjusted R^2 for falls at follow-up was 0.30, adjusted R^2 for overall disability at follow-up was 0.11.

[b] Odds ratio (OR).

[c] Significant association (multivariate) is shown in italics.

[d] Not applicable (N/A): variable not entered in model.

[e] Groningen Activity Restriction Scale (GARS).

Discussion

Principal Findings and Comparison to Previous Research

The results of this study indicate that the reliability of the balance scores of the modified bathroom scale is acceptable since, according to Nunnally, ICCs at or above .70 are considered acceptable [24,25]. There seems to be a significant cross-sectional relationship between balance scores and falls since the group of participants who suffered a fall in the past 6 months before baseline had significantly lower balance scores compared to those who did not fall. The difference between these groups was 2.3 points on a scale from 0 to 16. Furthermore, there was a significant and substantial correlation between balance scores and disability sum-scores at baseline, which revealed that poorer balance was associated with higher disability levels. Despite this cross-sectional relationship, longitudinal data showed that balance scores have no predictive value for falls in the next 6 months, and maybe only limited predictive value for disability development after 6 months of follow-up. No significant relationship was found between balance at baseline and falls after 6 months of follow-up in the univariate and multivariate regression analyses. Baseline balance score was associated with disability development in the univariate regression analyses, which indicated that older adults with poorer balance had a higher risk of developing disability after 6 months of follow-up. However, when correcting for age, gender, and baseline disability in the multivariate regression analyses, this association was no longer significant.

Previous studies have been conducted regarding the relationship between balance measured by clinical balance tests, force plates, or telemonitoring devices and falls and disability in older adults. Most studies focused on the predictive validity of clinical balance tests and these studies suggested that poor balance predicts a moderately increased risk of these adverse outcomes in older adults [1-3,26]. Previous studies regarding the predictive value of balance-related parameters measured with a force plate on falls revealed contradictory results—some studies reported that force plate measurements predicted falls, whereas other studies reported that no associations were found [27,28]. Previous research regarding innovative telemonitoring technologies that can be used for home-based self-monitoring of balance mostly concerns the Nintendo Wii. A recent review regarding the use of the Nintendo Wii for the assessment and training of balance revealed that, despite the fact that the Wii Balance Board can be used as a proxy for measurements conducted with a force plate, its software is not very effective in determining balance status [29]. Furthermore, correlations between balance scores of the Wii Balance Board and clinical balance tests are low [30,31]. No previous studies have been conducted yet regarding the predictive value of the Wii Balance Board, or other home-based balance telemonitoring devices, on adverse health outcomes in older adults. The results of our study were in line with previous research that indicated that falls in the past are a strong predictor of falls in the future [32,33].

This study only partly confirmed findings from previous research, since it revealed a cross-sectional relationship between balance and falls and disability, but no association between balance scores at baseline and falls and disability development after 6 months of follow-up could be demonstrated. A possible explanation for this could be that the follow-up period of this study was short compared to other studies that focused on the predictive validity of clinical balance tests on falls and disability [34]. Due to this shorter follow-up period, not many falls or changes in the level of dependence occurred in this study. In addition, previous research suggests that balance is not always a very strong predictor of future falls and disability development, which could explain why no significant relationship was found when correcting for other relevant baseline characteristics. Another possible explanation of why studies focusing on clinical balance tests revealed moderate predictive value of balance in older adults, and why scores of the modified bathroom scale were not predictive of future falls and disability in this study, could be that professionals who conduct such clinical balance tests often take into account different aspects of balance, or physical functioning, and have their clinical expertise to rely on when estimating the risk for falls or disability development.

Strengths and Limitations

In total, 128 participants, which is 71.1% of the baseline study sample of 180, could be included in the analyses of this study. Dichotomization of dependent variables could have negatively influenced statistical power. The follow-up period of 6 months is relatively short compared to previous research regarding the predictive validity of balance in older adults. Possibly, as a result of the shorter follow-up period, only 23 out of 128 participants (18.0%) reported that they had suffered one or multiple falls during the study. No distinction was made in the analyses between participants who fell once during the follow-up period and those who fell multiple times because the groups would become even smaller, which would negatively influence the statistical power. The relatively short follow-up period of our study is not necessarily a limitation since, for the early identification of older adults with balance decline who could benefit from preventive intervention programs, it is more useful to know the short-term predictive value of the balance scores of the modified bathroom scale. It makes more sense to start with a preventive intervention when short-term predictors are present in older adults compared to a situation in which it will take a few years before adverse outcomes will develop.

The number of participants who reported increased overall disability after 6 months of follow-up was higher, namely 32 out of 128 (25.0%), compared to the number of participants who reported a fall. However, a possible limitation of this study could be that participants who were lost to follow-up reported higher disability levels and lower balance scores at baseline compared to those who remained in the sample. This may have influenced the results of our study because the disability levels at follow-up and the variation in scores on dependent and independent variables might have been higher if those participants could have been included in the analyses. Based on the available data, no firm conclusions can be drawn regarding the extent to which this selective loss to follow-up has influenced the results of our study.

It should be noted that all balance measurements were performed under the supervision of a researcher. This can yield different results compared to home-based measurements using the modified bathroom scale. Balance scores of the modified bathroom scale could have been higher during this study because participants might be more alert, step onto the bathroom scale quicker, or try to stand very still when the researcher is present, whereas they might not do this when performing home-based measurements alone. Based on this study, no estimates can be provided on how the reliability of balance scores of the modified bathroom scale are influenced by the setting in which they are conducted (ie, research setting vs home-based setting), and to what extent the setting might influence the relationship with falls and disability. The ICCs that were calculated to evaluate test-retest reliability of the four separate balance parameters revealed that three out of four were not adequate, taking into account the proposed cutoff point of .70 for minimum reliability by Nunnally [25]. The ICC of step on delay was lowest (.31), followed by surface under the stabilogram and average velocity of the trajectory (both .54). This means that the scores of these parameters differed considerably across the three consecutive measurements of a participant. To what extent these parameters, and thereby the balance scores, are influenced by the participant "learning" how to step onto the bathroom scale, presence of the researcher, cognitive functioning, or other factors cannot be concluded based on this study.

Conclusions

There is a cross-sectional relationship between balance measured with a modified bathroom scale and falls and disability in older adults. Longitudinal data did not confirm this, which suggests that balance scores of the modified bathroom scale have no predictive value for falls and might have only limited predictive value for disability development after 6 months of follow-up. Research with a larger sample and longer follow-up period is needed to confirm or contradict these findings, and to determine whether balance score cutoff points can be formulated, for different subpopulations, that identify older adults with increased risk for adverse health outcomes. Follow-up studies in which older adults use the bathroom scale on a regular basis (eg, daily or weekly) for home-based monitoring of balance would provide useful information regarding the variation in balance scores among older adults and regarding clinically relevant changes. Such information is needed before the bathroom scale can be implemented in practice.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Groningen Activity Restriction Scale (GARS).

[PDF File (Adobe PDF File), 10KB - jmir_v17i5e131_app1.pdf]

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Abbreviations

ADL: activities of daily living
COPD: chronic obstructive pulmonary disease
GARS: Groningen Activity Restriction Scale
IADL: instrumental activities of daily living
ICC: intraclass correlation coefficient
MS: multiple sclerosis
N/A: not applicable
OR: odds ratio
T0: baseline
T1: 6-month follow-up

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Original Paper

Vaccination Persuasion Online: A Qualitative Study of Two Provaccine and Two Vaccine-Skeptical Websites

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Abstract

Background: Current concerns about vaccination resistance often cite the Internet as a source of vaccine controversy. Most academic studies of vaccine resistance online use quantitative methods to describe misinformation on vaccine-skeptical websites. Findings from these studies are useful for categorizing the generic features of these websites, but they do not provide insights into why these websites successfully persuade their viewers. To date, there have been few attempts to understand, qualitatively, the persuasive features of provaccine or vaccine-skeptical websites.

Objective: The purpose of this research was to examine the persuasive features of provaccine and vaccine-skeptical websites. The qualitative analysis was conducted to generate hypotheses concerning what features of these websites are persuasive to people seeking information about vaccination and vaccine-related practices.

Methods: This study employed a fully qualitative case study methodology that used the anthropological method of thick description to detail and carefully review the rhetorical features of 1 provaccine government website, 1 provaccine hospital website, 1 vaccine-skeptical information website focused on general vaccine safety, and 1 vaccine-skeptical website focused on a specific vaccine. The data gathered were organized into 5 domains: website ownership, visual and textual content, user experience, hyperlinking, and social interactivity.

Results: The study found that the 2 provaccine websites analyzed functioned as encyclopedias of vaccine information. Both of the websites had relatively small digital ecologies because they only linked to government websites or websites that endorsed vaccination and evidence-based medicine. Neither of these websites offered visitors interactive features or made extensive use of the affordances of Web 2.0. The study also found that the 2 vaccine-skeptical websites had larger digital ecologies because they linked to a variety of vaccine-related websites, including government websites. They leveraged the affordances of Web 2.0 with their interactive features and digital media.

Conclusions: By employing a rhetorical framework, this study found that the provaccine websites analyzed concentrate on the accurate transmission of evidence-based scientific research about vaccines and government-endorsed vaccination-related practices, whereas the vaccine-skeptical websites focus on creating communities of people affected by vaccines and vaccine-related practices. From this personal framework, these websites then challenge the information presented in scientific literature and government documents. At the same time, the vaccine-skeptical websites in this study are repositories of vaccine information and vaccination-related resources. Future studies on vaccination and the Internet should take into consideration the rhetorical features of provaccine and vaccine-skeptical websites and further investigate the influence of Web 2.0 community-building features on people seeking information about vaccine-related practices.

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KEYWORDS

vaccination; communication; Internet; social networking; Web 2.0; qualitative research

Introduction

Background

Current concerns about vaccination resistance often cite the Internet as a source of vaccine controversy. Despite the United States' high vaccination rates among children and adults, physicians and researchers have perpetuated the belief that vaccine-skeptical websites contribute to lower levels of vaccination among children by effectively persuading parents against immunizing their children. Websites promoting vaccine-skeptical discourses are scrutinized routinely in the academic literature; however, the preponderance of this research aims at demonstrating that the information they circulate is inaccurate and deceptive to visitors seeking information on vaccines and vaccination-related practices. It is true that as a result of these studies, the medical community has gained a greater understanding of the types of information presented on vaccine-skeptical websites and deeper insights into how these websites deploy this information to make persuasive arguments against vaccines and vaccination. The majority of academic studies of vaccine-skeptical websites use quantitative methods to taxonomize arguments against vaccination on these websites. Although this information is useful for categorizing their generic features, it has not provided insights into why these websites successfully persuade their viewers.

To date, there has been no attempt to understand the qualitative features of vaccine-skeptical websites. The research presented in this paper attempts to fill this gap by employing a case study approach to a smaller number of websites than is typical of quantitative studies of vaccine skepticism on the Internet. In addition, this study examines both vaccine-skeptical and vaccine-promoting websites to compare the rhetorical features through which they attempt to reach their audiences. By deploying a qualitative methodology, researchers can better understand the rhetorical features of both types of websites. As a result of this study, we can better understand the specific mechanisms by which vaccine-skeptical organizations have been able to use the Internet to successfully spread their messages.

Literature Review

Since the United Kingdom passed the Vaccination Act of 1853, vaccine-skeptical groups have leveraged the available means of persuasion to voice their opposition to compulsory vaccination. Some groups resorted to public demonstrations, legal actions, and the occasional riot after the passage of the 1853 law, but others, such as the Anti-Compulsory Vaccination League, which formed in response to the 1867 Vaccination Act, found publishing their ideas in newsletters and journals to be a more effective means of responding to government vaccine mandates for children [1]. Other groups followed suit. The *Anti-Vaccinator* journal was founded in 1869 followed by the *National Anti-Compulsory Vaccination Reporter* in 1874 and the *Vaccination Inquirer* in 1879 [2]. After a smallpox epidemic in the 1870s, US vaccine-skeptical movements circulated pamphlets and journals in response to state attempts to pass new vaccine legislation or enforce extant laws. During the Progressive Era, regional antivaccination movements, such as the one in Portland, Oregon, assumed the political mantle of the populist democracy movement [3]. At that time, resistance to vaccination in the United States took 2 dominant forms: ordinary Americans who resisted compulsory vaccination and self-identified antivaccination activists who joined societies, wrote newsletters, and were largely middle class [4]. Political opposition to vaccine mandates and the circulation of populist information continued throughout the 20th century, although it changed as a result of the rapid development of many vaccines in the second half of the century.

In the late 20th century, the Internet transformed mass communication, affording its users new means of sharing information, forging interpersonal connections, and establishing association [5-8]. The relatively short history of the Internet can be divided into 2 epochs: Web 1.0, which emerged in the 1980s, and Web 2.0, which emerged in the mid-2000s. Web 1.0 is characterized by static webpages that display information [9,10] and text-based online virtual communities where users interact with one another on topics of mutual interest [6,8,11]. Web 1.0 also introduced hyperlinking, the now-familiar clicking process that redirects a Web user to another website. One static website could be hyperlinked to another for a myriad of rhetorical purposes, including demonstrating affinity, offering additional information, or leveraging another website's credibility [7]. Web 2.0 is best characterized as a platform for Internet applications that afford users the ability to "harness collective intelligence" [9]. Web 2.0 permits users to generate and post their own content and comment on what others have shared [9,10]. One of its most defining characteristics is that it affords 2-way communication via social media, such as blogs, Facebook, Twitter, YouTube, and other websites. Where the static Web pages of Web 1.0 allowed unidirectional communication (a user reading text on a screen), Web 2.0 promotes interactivity between users who can easily respond to one another via text and images.

The Internet and Web 2.0 have changed the way that people access health information. Ordinary people have greater access to medical information [12] and online patient communities have organized on websites [13] and social media [14] to provide information and support for many diagnoses. Easy access to information has led to both self-diagnosis and self-doctoring [15]. According to Pew Research's Health Online 2013 poll, 72% of Internet users surveyed looked for health information online and 35% opted to self-diagnose with Web-based information rather than visit a clinician [16]. It is estimated that 16% of those seeking online medical information searched for vaccination information, with 70% of this group stating that their findings influenced their vaccine decisions [17]. In addition to peer-reviewed medical information, Internet users also have access to health information generated by nonmedical practitioners, which has raised concerns about the quality of online medical information available on the Internet [18].

Online Vaccination Skepticism and Web 1.0

Current accounts of vaccine skepticism tend to identify its origins in the present period with the circulation of information on the Internet (eg, Kodish [19]). Although early proponents of the Internet saw its potential as a means of promoting democracy through the circulation of information [8,20], others viewed the Internet as a “Pandora’s box” of misinformation [21]. As Internet use proliferated at the end of the 20th and beginning of the 21st centuries, researchers began to pay attention to the World Wide Web as a site of information dissemination for vaccine skeptics. Many of these studies employed a Web 1.0 understanding of online communication even after Web 2.0′s social media paradigm was well in place (ie, they conceived the Internet as a repository of information and not a dynamic space were users interact with one another). The main objectives of these studies were to ascertain the philosophies of so-called antivaccination websites and point out the misleading or inaccurate information they circulated in cyberspace. A number of these studies created taxonomies or tried to identify specific features of the misunderstandings that these sites were thought to perpetuate. The article that best exemplifies this tendency is Jacobson et al [22], the title of which is indicative of the approach: “A Taxonomy of Reasoning Flaws in the Anti-Vaccine Movement.”

During this period, 2 studies about vaccination influenced by the Pandora’s box metaphor appeared in the pages of medical journals [23,24]. Taking as his exigence the concern that vaccine-skeptical groups were using the Internet to gain political momentum in the United States and Western Europe, Nasir [23] analyzed 51 websites that opposed routine childhood vaccination, addressing content, common themes, philosophy, links to other websites, and strategies to avoid routine immunization. Although the websites promoted a variety of philosophies, they exhibited some commonalities: they listed adverse effects of vaccines and presented themselves as unbiased toward vaccination [23]. Nasir found that clicking deeper into the websites revealed a strong bias against vaccines and vaccination and concluded that the availability of vaccine-skeptical information on the Internet is troublesome. Nasir expressed concern that Web surfers are ill equipped to assess its reliability, an argument that is nearly ubiquitous in subsequent studies of vaccine skepticism on the Internet [23].

Two years later, Davies et al [25] examined the content of 100 similar websites from a rhetorical perspective to better understand the social discourses in which vaccine-skeptical claims are embedded. Their rhetorical analysis revealed that vaccine-skeptical websites portrayed themselves as authorities on vaccination, appealed to viewers’ emotions through personal testimonies of vaccine injury and calls for parental responsibility, and maintained a discourse of truth seeking often advancing evidence of medical conspiracies bolstered by their own privileged information. Davies and colleagues caution medical practitioners from refuting vaccine-skeptical discourses based solely on “the facts,” suggesting instead that provaccination websites employ emotional counterappeals featuring “images and stories of children harmed by vaccine-preventable illnesses” [25].

Another study by Wolfe et al [26] made similar observations in its analyses of the content and design attributes of 22 vaccine-skeptical websites. From their content analyses, they found that all websites in their sample expressed “a variety of claims that are largely unsupported by peer-reviewed scientific literature,” including themes of concern about vaccine safety and efficacy, “governmental abuses” of civil liberties, and preferences for alternative (nonbiomedical) health practices. Their analyses of the websites’ design attributes resulted in a list of 10 common themes that, from a rhetorical perspective, conflate content (narratives of parents of vaccine-injured children), digital ecology (the content to which the website links), visual rhetoric (images of “scary needles” and “harmed children”), and commerce (solicitations of donations and merchandise for sale) [26]. The authors do note that defining what counts as content on a website is “a problem” [26]. Such a problem is likely to occur when websites are treated like pages in a book rather than interactive spaces where users connect to share experiences, expertise, and interpretations of information.

Online Vaccine Skepticism and Web 2.0

The ascendency of social media in the mid-2000s adds another layer of complexity to online vaccine discourses. The multimedia nature of Web 2.0 websites allows vaccine-skeptical groups a means of constructing more sophisticated arguments than a single medium could afford. One study notes that antivaccine movements are well versed in multimedia communication because the groups often are led by spokespersons who use a variety of media (eg, books, television appearances) to build their ethos (credibility) as whistleblowers [27]. Although researchers have created sophisticated taxonomies of static websites [22,28,29], the strategies they offer to counter vaccine-skeptical discourses either have not been adopted by provaccine websites or have not been effective in general. For instance, one strategy offered is mass education campaigns that share images and personal narratives of people affected by vaccine-preventable diseases, such as pertussis [28]. They also suggest communicating statistics that demonstrate how vaccine-preventable diseases increase as vaccination rates decline. Using scare tactics and arguing about facts has not proven to be an effective strategy for making vaccine-skeptical parents amenable to childhood vaccination [24,30]. One main reason is the social networking features of Web 2.0 [31] that transform static Web pages into information hubs where viewers can share personal experiences in the form of images and narrative to create or participate in a community with individuals who share their vaccination beliefs.

Web 2.0′s social networking capabilities have aided health communicators in targeting messages to specific audiences [32] and helped patients and medical practitioners to gather information about diseases and diagnoses [27]. Although social networking technologies make it easy for users to crowdsource information, there is widespread concern about the quality of the information that is circulated among users and the extent to which that information influences people’s decisions to vaccinate themselves [33] and their children [34]. As users grow more accustomed to Web 2.0 technologies, it becomes more difficult to impose the authority of establishment medicine on online discourse. Witteman and Zikmund-Fisher [35] suggest “in this Web environment, effective communication about vaccinations is not about controlling what is available but rather, it is about responding and participating in an interactive, user-responsive environment.” To this end, a growing number of studies attempt to understand the flow of information on specific Web 2.0 sites.

Research on vaccination and Web 2.0 suggests that websites featuring user-generated content are more likely to support vaccination viewpoints that counter or question medical science [36]. Venkatraman et al [36] found that websites that support greater freedom of speech (ie, the website’s content is not moderated, edited, or peer-reviewed), such as YouTube and Google, are more likely to contain antivaccination content than moderated websites such as Wikipedia and PubMed. Another study analyzed nearly 40,000 opinionated Twitter users’ posts about the H1N1 vaccine and found that more information was circulated among users who shared the same positive or negative sentiments about the vaccine [37], suggesting that social media is more of an echo chamber for circulating opinions among like minds than a means of randomly influencing less opinionated users. A study of 172 YouTube videos about the human papillomavirus (HPV) vaccines found that slightly more than half of the videos expressed explicitly negative sentiments about the vaccine and that negative videos garnered a higher number of average likes than videos endorsing the HPV vaccine [38]. Compared to previous studies of HPV vaccines on YouTube, which found that approximately one-quarter [39] to approximately one-third [40] of videos opposed the HPV vaccine, Briones et al’s [38] findings suggest that vaccine critics are more effective than vaccine promoters at using social media to communicate their messages. It is also worth noting that the shift from majority positive HPV vaccine sentiments to majority negative occurred in fewer than 5 years. The relatively short time span in which attitudes change also appears to be a feature of Web 2.0, where private and public discourses about vaccines can spread virally around the Internet [31].

In an effort to counter the rhetorical efficacy of online vaccine skepticism [25], provaccine researchers have developed a 2-pronged approach that is grounded in earlier Internet studies. It begins by first attributing contemporary vaccine skepticism to Wakefield et al’s [41] now discredited claim that the measles, mumps, and rubella (MMR) vaccine contributed to the development of autism in children and then calls for the medical community to do a better job of communicating accurate medical information about childhood vaccination [42-44]. This 2-step maneuver attempts to deny the premise of vaccine skepticism through a *reductio ad absurdum* argument and creates a space for new, more accurate facts to fill the social vacuum. This tactic seems logical to vaccine proponents, but it appears to be ineffective. Although some research suggests that psychological investments may be the cause of entrenchment in antivaccine positions [45], another reason may be that vaccine-skeptical discourses predate the Wakefield debacle [46]. After all, many 21st-century arguments against vaccines are rhetorically similar to discourses in the 19th and early 20th centuries [26,28,47].

Online Vaccination Skepticism and Postmodern Medicine

The strategy of correcting vaccine-skeptical beliefs appears to be based on a misreading of both the context of and reasons for those views. Public health attempts to correct so-called flawed reasoning are inadequate in the full context of vaccine skepticism in culture [48,49]. Hobson-West’s [30] study found that “vaccine-critical groups” tend to be differently oriented to issues of vaccination, with “radical” groups outright rejecting vaccine and “reformist” groups seeking changes to vaccination policy [30]. Both groups distrust provaccine discourses and policies and, as a result, they have reframed the notion of risk to be incommensurable with medicine’s traditional understanding [30]. Similarly, recent research suggests that corralling all discourse that does not promote vaccination under the big tent of the “antivaccination movement” collapses the variety of critical stances on vaccination [48,50-52]. Terms such as “vaccine selective” [50], “vaccine resistance” [51], and “vaccine hesitancy” [52] are used to reflect a spectrum of orientations rather than the catch-all “antivaccination.” We prefer the term “vaccine skeptical” because it denotes a variable attitude toward vaccines and vaccination versus a term, such as vaccine resistance, which forefronts an action taken against vaccines.

Beyond rejecting or reframing provaccine discourses, vaccine-skeptical websites do not subscribe to one notion of the truth; therefore, these websites’ adherents do not seem to be persuaded by claims that their beliefs are misinformed [45]. Under the current postmodern medical paradigm [53], doctors are no longer the sole arbiters of authoritative information about health and healing. The expectations that patients should inform themselves to take charge of their health decisions has resulted in “new priorities for health care” [54], such as medicine based on both social values and empirical evidence, an increased emphasis on the risks of treatment, and informed patients taking charge of their own health care decisions [53]. Kata [54] has articulated the relationship between postmodern medicine and Web 2.0 as one of flattened hierarchies where “infinite personal truths presented online are each portrayed as legitimate, thus supplanting the primacy of medical facts with a multiplicity of personal meanings and ways of knowing.” Thus, vaccine-skeptical groups appear to use the Internet to leverage postmodern notions of truth that are based on their own experiences with vaccines and their own understandings of medical science. Within the postmodern paradigm, the knowledge they generate and circulate online is not easily dismissible by attempts to better educate the public about vaccination.

Methods

Overview

Previous studies of vaccination information websites have taken objective approaches to locating websites via search engines. These methods included gathering and examining websites based on keyword searches. We opted for a fully qualitative case study methodology, choosing to carefully review the rhetorical features of 1 provaccine government website, 1 provaccine hospital website, 1 vaccine-skeptical information website, and 1 vaccine-skeptical website focused on a specific vaccine. The websites selected for analysis were the US Department of Health and Human Services (HHS) vaccine website Vaccines.gov [55], the Children's Hospital of Philadelphia (CHOP) Vaccine Education Center (VEC) [56], National Vaccine Information Center (NVIC) [57], and SANE Vax, Inc [58], respectively.

Website Selection

The websites were chosen specifically for their representativeness of specific positions in the current vaccination controversy—their choice was deliberate, not random, to demonstrate proof of concept in this pilot study. Both the Vaccines.gov and VEC websites are targeted to the general public and meant to educate. They were chosen as the representative provaccine websites because they are the US federal government's website for the education of its citizens and a hospital-based educational site developed overseen by one of the most prominent medical proponents of vaccination, Dr Paul A Offit [59-61]. The vaccine-skeptical websites included the most established vaccine-skeptical organization (NVIC) which began in the early 1980s as Dissatisfied Parents Together [57] and a newer organization targeting concerns about the HPV vaccine, SANE Vax. Opposition to the HPV vaccines Gardasil and Cervarix has coalesced around specific injury narratives [62], and SANE Vax is one of the prominent Web venues proffering a space for these discourses. Choosing these specific websites allowed us to focus on the specific rhetorical features of each website to determine if the provaccine and vaccine-skeptical sites differed in this regard.

Data Acquisition

To gather information from the websites, we adapted the qualitative research method of thick description to the online environment. Thick description requires the researcher to pay close attention to the contextual aspects of a research setting including minute details of the setting, the social events taking place therein, and the behaviors of the participants [63]. As a means of controlling data acquisition for consistency across the 4 websites, 5 categories of analysis were developed: information about the websites' owners, the visual and textual content of websites, user experience, hyperlinking, and social interactivity within the website. Each of these categories corresponds to a different rhetorical element of effective communication with respect to the interactive nature of Web 2.0.

Digital Ecologies

Aristotelian rhetoric holds that 3 modes are necessary for persuasion to take place [64]. These features are ethos, pathos, and logos. *Ethos* refers to the character of the speaker who attempts to persuade an audience. *Pathos* is the manner in which the speaker appeals to the audience's emotions. *Logos* refers to the types of information a speaker uses to make an argument. These modes linked to the 5 categories of analysis in the following way. The website's ownership and hyperlinks to other websites determined its ethos. The visual and textual content was the website's logos. Social interactivity and user experience lent to the website's pathos. Taken together, these features contributed to the website's rhetorical efficacy.

The theoretical framework that guided this study took these Aristotelian rhetorical elements as an analytical starting place. In the second half of the 20th century, rhetoricians came to understand that persuasion is situational [65-68]. Theorists first formulated the rhetorical situation as a response to a problem, or exigence, in the world that commanded a person to communicate to change it [65]. Yet despite the robust, multifactorial nature of theories of the rhetorical situation, such a framework cannot account for the fluidity of rhetoric in networked environments. To address this shortcoming and to create a notion of rhetoric that accounted for the interconnectedness of human communication and the viral circulation of information, Edbauer [69] developed the concept of rhetorical ecologies. In a rhetorical ecology, rhetoric is not limited to a taxonomy of tropes; instead, rhetorical ecologies enable the flow information from one part of an ecosystem, such as the Internet, to another.

Because the viral circulation of information is not bounded by specific media in Edbauer's model, we followed the lead of scholars of digital rhetoric who examined ecologies in online spaces, such as websites and gaming platforms [70,71]. Throughout this paper, we employ the term "digital ecology" to mean the discursive connections created and propagated by a website. There are 2 benefits to using the term digital ecologies to refer to rhetorical ecologies within digital spaces. The first is that the term suggests the active engagement of readers of online discourse as well as underscoring the rhetorical nature of hyperlinking [72]. The second benefit of using a term such as ecology to describe online activity is that it recalls ecosystems in nature. A website, through its links to other websites and its interactive features, can be analyzed by its size (the number it links it contains) and its diversity (whether it is open to discourses from vantage points other than its own or closed to differing opinions). For Web 2.0, an ecological model addresses the fact that the quality of information alone is insufficient to persuade someone. Rather, persuasion is effected by the information, where it is found online, how the user interacts with that information, how that information interacts with other information, and the community surrounding it.

Usability

In considering these factors, this study also took the usability of vaccine websites into account. Usability studies are traditionally focused on making a product or application more functional for the end user [73]. When applied to online health information, a usability perspective can highlight the ways that Web design and content presentation can deny users access to information because a website is visually overwhelming, difficult to navigate, or written in such a way that it misses its target audience [74,75]. Although the prime objective of usability studies is ease of use [76], the straightforward transmission of information online has the potential to make Internet users "passive consumers of digital content" [77]. More recent studies of the usability of websites evaluated the usefulness [78,79] of websites based on the website's ability to facilitate inquiry about the topic at hand, promote collaboration between the website's users, and offer a multidimensional perspective that extends beyond the mere transmission of information. For the purpose of our study, we used the website usability guidelines available at Usability.gov [80] because it incorporated aspects of both ease of use and usefulness; in addition, it provided the guidelines that the federal government uses itself to evaluate website information and user experience.

Data Analysis

Data analysis was conducted by a team of 4 advanced undergraduate researchers, who participated in Virginia Tech's Vaccination Research Group. Each researcher was assigned a website and asked to conduct 5 rounds of observation using the thick description criteria. After each round, the group convened to discuss the findings and develop an initial analysis. Through this iterative process, each researcher synthesized his or her findings into a preliminary report with brief conclusions. These reports were a starting point for the final analysis of each case as the primary author went back to each website to confirm the findings, deepen the interpretation, develop conclusions, and write the article.

Results

Overview

The results are brief descriptions of the websites examined in our study. Websites are content-rich, interactive genres that do not easily lend themselves to concise textual description. Rather than offering in-depth descriptions of all aspects of each website, we present 4 case studies of the salient features of Vaccines.gov [55], VEC [56], NVIC [57], and SANE Vax [58].

Case Study 1: Vaccines.gov

The US federal government's omnibus website, Vaccines.gov [55], bills itself as a "gateway" to information on vaccines and immunization for infants, children, teenagers, adults, and seniors" (Figure 1) The HHS National Vaccine Program Office (NVPO) coordinates the website and its content, which is created by US federal agencies including the Food and Drug Administration (FDA), Health Resources and Services Administration, National Institutes of Health, HHS, and NVPO. The intended audience of Vaccines.gov is the US general public and, as per federal mandate, the website is designed to be accessible to individuals of varying levels of literacy and ability [81]. Although all information on the website is sanctioned by the US federal government, the website carries several disclaimers, stating that the "site is not intended to be a substitute for professional medical advice, diagnosis, or treatment" and advising viewers to seek the advice of physicians and qualified health care providers regarding any questions or health concerns they may have.

Vaccines.gov contains general information about vaccines and vaccination-related practices, as well as vaccine-specific information for 22 diseases. General information is listed under 2 separate tabs on the website's toolbar. The "Basics" tab contains information on the safety of vaccines, the efficacy of vaccines, prevention of diseases, and community (or herd) immunity. The "Getting Vaccinated" tab contains information about what children and adults can expect during vaccination, an interactive section in which visitors can enter their zip codes to find providers of adult vaccines near them, an interactive map of the United States that links to each state's department of health, and information on how to pay for vaccinations with the Affordable Care Act and the Centers for Disease Control's (CDC) Vaccine for Children Program. There is also a separate "Travel" tab on the navigation bar with information that links to the CDC Travel Health site.

Vaccine-specific information is categorized under 2 tabs: "Diseases" and "Who and When." Under the "Diseases" tab, 22 vaccine-preventable diseases are listed. Each disease has its own page, most with subsections with information about the disease, information on its respective vaccine, and a tab labeled "Take Action" that includes additional government information about the disease and resources for finding where to get vaccinated. The "Who and When" tab contains vaccination schedules for 7 specific populations: infants, children, and teens aged 0 to 18 years; the Catch-up Schedule for Children aged 4 months to 18 years; college and young adults aged 19 to 24 years; adults aged 19 and older; seniors aged 65 years and older; pregnant women; and persons with health conditions.

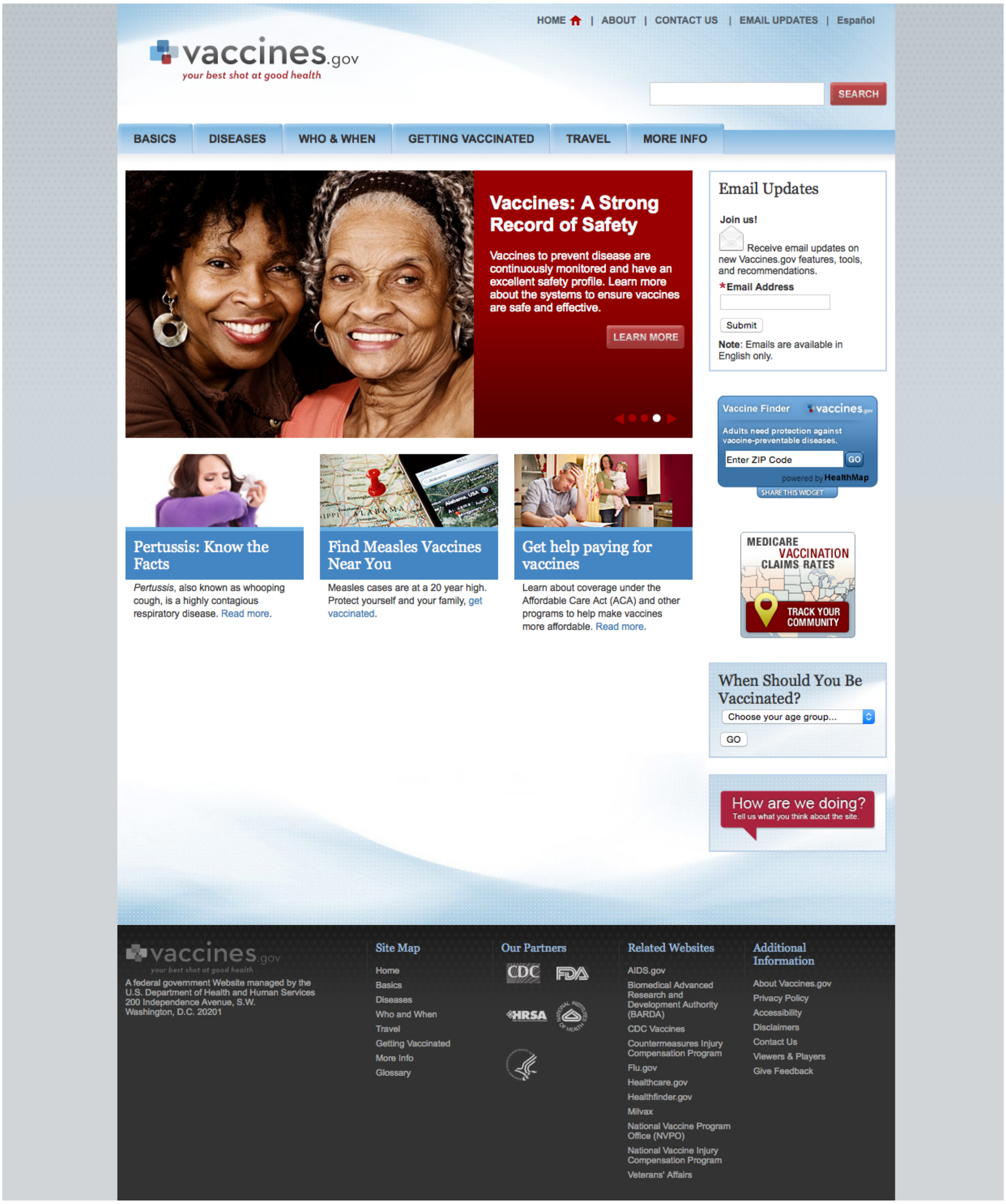
Vaccines.gov is predominantly text based and all information references either government or scientific literature. The website also includes a limited number of images, videos, spreadsheets, and an infographic. Images feature most prominently on the website's landing page, where they serve to illustrate the seasonal content Vaccines.gov promotes. The videos embedded on its "Features: News & Video" page offer flu vaccine information targeted at a variety of audiences, such as cartoons about the flu shot for children and scientific simulations of how the disease spreads for adults. All 19 videos are produced by government agencies.

As a repository of US federal government vaccine information, Vaccines.gov links exclusively to federal and state government websites. Although hyperlinks are numerous, the website functions as a hub for vaccine information within a relatively small network of websites.

Vaccines.gov's limited social interactivity mirrors the website's small digital ecology. The website's sole interactive feature is a checkbox at the bottom of each page that asks the user "Was this page helpful?" The results of these page-by-page surveys are not available on the website, so there is no means for a user to see the feedback left by others. Additionally, the website does not include any functions that would permit users to communicate directly or indirectly with one another.

Using the guidelines published on the US federal government's encyclopedic usability website, Usability.gov [80], as a heuristic, Vaccines.gov is best characterized as a website that employs a subject organizational scheme that organizes its content according to a variety of topics while also supporting task-oriented navigation. Visually, the website is uncluttered and easily legible due to its predominantly black text on a white background.

Figure 1. Screenshot of the Vaccine.gov home page.



Vaccines: A Strong Record of Safety

Vaccines to prevent disease are continuously monitored and have an excellent safety profile. Learn more about the systems to ensure vaccines are safe and effective.

Email Updates

Join us! Receive email updates on new Vaccines.gov features, tools, and recommendations.

***Email Address**

Note: Emails are available in English only.

Vaccine Finder

Adults need protection against vaccine-preventable diseases.

Enter ZIP Code

powered by **HealthMap**

Pertussis: Know the Facts

Pertussis, also known as whooping cough, is a highly contagious respiratory disease. Read more.

Find Measles Vaccines Near You

Measles cases are at a 20 year high. Protect yourself and your family, get vaccinated.

Get help paying for vaccines

Learn about coverage under the Affordable Care Act (ACA) and other programs to help make vaccines more affordable. Read more.

When Should You Be Vaccinated?

A federal government Website managed by the
U.S. Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Case Study 2: Children's Hospital of Philadelphia Vaccine Education Center

The VEC website was launched by CHOP in 2000 to "provide accurate, comprehensive, and up-to-date information about vaccines and the diseases they prevent to parents and health care professionals" [32] (Figure 2). The website's main goal is to correct "misinformation" and "misconceptions" about vaccines and vaccination practices. The VEC is a member of the World Health Organization's Vaccine Safety Net "because its website meets the criteria for credibility and content as defined by the Global Advisory Committee on Vaccine Safety" [56].

On the "About" page, VEC discloses that funding for the website comes entirely from CHOP and not from "vaccine manufacturers." Visitors have the option to donate to the CHOP Foundation via a button on the main CHOP website; however, there is no donation link displayed on the VEC website itself.

Additionally, the “About” page provides short biographies of the “team of scientists, physicians, mothers, and fathers” who administer, advise, and staff the VEC. The website also carries the disclaimer that none of its information is intended to be patient-specific or replace the viewer’s relationship with a qualified health care professional.

The VEC website contains information on 21 individual vaccines and 9 combination vaccines. Information on each vaccine is accessible either through the website’s sidebar or through a cluster of buttons within body of the landing page. Clicking on the “A Look at Each Vaccine” button in either location directs the viewer to a page with specific information about the vaccine and its corresponding disease. The pages are structured in a question-and-answer format, with questions moving from generic inquiries about what the disease is and how it is contracted to more population-specific questions. For instance, clicking on “Anthrax Vaccine” displays the question “Why should military personnel be vaccinated?” Similarly, “Meningococcus Vaccine” contains information targeted at college students.

The VEC uses a variety of textual and visual genres to provide information to visitors. Its landing page features links to 2 videos about infant and childhood vaccination, as well as downloadable materials for parents and health care providers. In addition to information on each vaccine, the website’s sidebar offers many other resources including vaccine schedules and vaccine safety information. There are also other scientific resources under tabs labeled “Vaccines: Practical Considerations,” “Vaccine Science,” and “Rash Information.” Information on all these pages is accompanied by references to scientific publications. The “Vaccine-Related News” tab directs users to information and resources from the CDC. Other than images of the CHOP app, links to downloadable documents, and links to videos, only one static image is used throughout the website. The VEC banner features a tightly cropped headshot of a smiling girl accented by a pink background with stars.

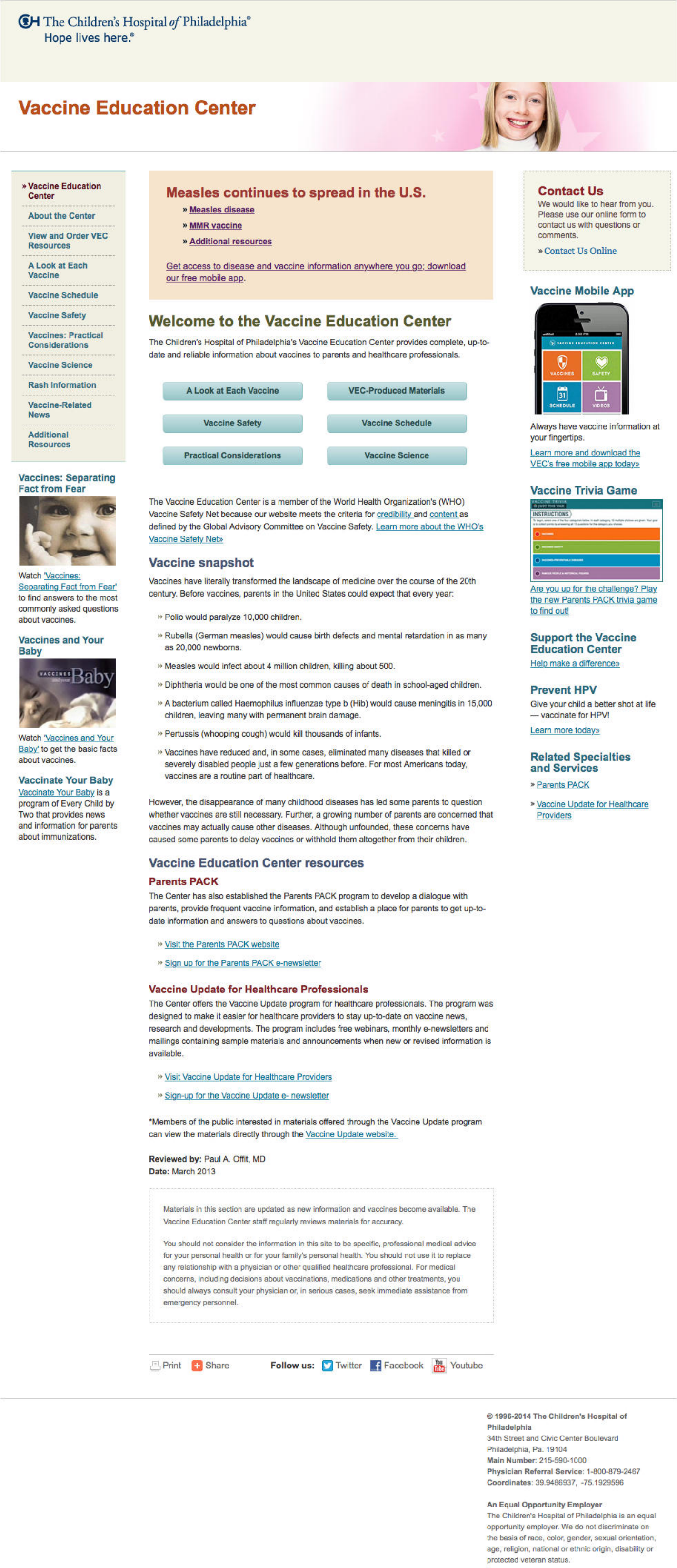
All content on the VEC website is created by the organization, including links to scholarly and popular press publications by the VEC’s staff, and all pages within the website are reviewed and dated by the VEC director, Dr Paul A Offit. Although the vast majority of hyperlinks direct the viewer to content within the VEC website, there are external links to “Professional and Parent Groups,” “Resources for Kids and Teens,” and “Further Reading” on the “Additional Resources” page. There are also downloadable PDF versions of CHOP’s booklets, pamphlets, and other brief communications in both English and Spanish.

The VEC website does not offer users any means of interacting with one another within its pages. Each page on the VEC website contains links to CHOP’s Twitter, Facebook, and YouTube sites; however, the content of these pages informs visitors about CHOP in general and is not specific to the VEC.

Although there is no social networking capability on the VEC website, it does offer some Web 2.0 features, such as an email newsletter, games, and a mobile app. The mobile app, called “Vaccines on the Go: What You Need to Know,” is available on both iOS and Android platforms. In addition to content from the VEC website, it includes “[a] place to save questions for the next doctor’s visit” and gives users “[t]he opportunity to easily email the VEC for answers to vaccine-related questions.”

Much like Vaccines.gov [55], the VEC website employs a combination topic and task schema. The website is easily legible with its use of black text on a white background; soft accent colors indicate items that can be clicked for more information. Its streamlined design omits a navigation bar; therefore, more content appears on screen. Despite the lack of this typical feature, its sidebar-content-sidebar layout makes the site easily navigable. The website extends its utility through its numerous downloads, which can be read offline.

Figure 2. Screenshot of the Vaccine Education Center home page.



Measles continues to spread in the U.S.

- » Measles disease
- » MMR vaccine
- » Additional resources

Get access to disease and vaccine information anywhere you go; download our free mobile app.

Welcome to the Vaccine Education Center

The Children's Hospital of Philadelphia's Vaccine Education Center provides complete, up-to-date and reliable information about vaccines to parents and healthcare professionals.

The Vaccine Education Center is a member of the World Health Organization's (WHO) Vaccine Safety Net because our website meets the criteria for credibility and content as defined by the Global Advisory Committee on Vaccine Safety. Learn more about the WHO's Vaccine Safety Net»

Vaccine snapshot

Vaccines have literally transformed the landscape of medicine over the course of the 20th century. Before vaccines, parents in the United States could expect that every year:

- » Polio would paralyze 10,000 children.
- » Rubella (German measles) would cause birth defects and mental retardation in as many as 20,000 newborns.
- » Measles would infect about 4 million children, killing about 500.
- » Diphtheria would be one of the most common causes of death in school-aged children.
- » A bacterium called Haemophilus influenzae type b (Hib) would cause meningitis in 15,000 children, leaving many with permanent brain damage.
- » Pertussis (whooping cough) would kill thousands of infants.
- » Vaccines have reduced and, in some cases, eliminated many diseases that killed or severely disabled people just a few generations before. For most Americans today, vaccines are a routine part of healthcare.

However, the disappearance of many childhood diseases has led some parents to question whether vaccines are still necessary. Further, a growing number of parents are concerned that vaccines may actually cause other diseases. Although unfounded, these concerns have caused some parents to delay vaccines or withhold them altogether from their children.

Vaccine Education Center resources

Parents PACK

The Center has also established the Parents PACK program to develop a dialogue with parents, provide frequent vaccine information, and establish a place for parents to get up-to-date information and answers to questions about vaccines.

- » Visit the Parents PACK website
- » Sign up for the Parents PACK e-newsletter

Vaccine Update for Healthcare Professionals

The Center offers the Vaccine Update program for healthcare professionals. The program was designed to make it easier for healthcare providers to stay up-to-date on vaccine news, research and developments. The program includes free webinars, monthly e-newsletters and mailings containing sample materials and announcements when new or revised information is available.

- » Visit Vaccine Update for Healthcare Providers
- » Sign-up for the Vaccine Update e- newsletter

*Members of the public interested in materials offered through the Vaccine Update program can view the materials directly through the Vaccine Update website.

Reviewed by: Paul A. Offit, MD
Date: March 2013

Materials in this section are updated as new information and vaccines become available. The Vaccine Education Center staff regularly reviews materials for accuracy.

You should not consider the information in this site to be specific, professional medical advice for your personal health or for your family's personal health. You should not use it to replace any relationship with a physician or other qualified healthcare professional. For medical concerns, including decisions about vaccinations, medications and other treatments, you should always consult your physician or, in serious cases, seek immediate assistance from emergency personnel.

Vaccines: Separating Fact from Fear

Watch 'Vaccines: Separating Fact from Fear' to find answers to the most commonly asked questions about vaccines.

Vaccines and Your Baby

Watch 'Vaccines and Your Baby' to get the basic facts about vaccines.

Vaccinate Your Baby

Vaccinate Your Baby is a program of Every Child by Two that provides news and information for parents about immunizations.

Contact Us

We would like to hear from you. Please use our online form to contact us with questions or comments.

» Contact Us Online

Vaccine Mobile App

Always have vaccine information at your fingertips.

Learn more and download the VEC's free mobile app today»

Vaccine Trivia Game

Are you up for the challenge? Play the new Parents PACK trivia game to find out!

Support the Vaccine Education Center

Help make a difference»

Prevent HPV

Give your child a better shot at life — vaccinate for HPV!

Learn more today»

Related Specialties and Services

- » Parents PACK
- » Vaccine Update for Healthcare Providers

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34th Street and Civic Center Boulevard
Philadelphia, Pa. 19104
Main Number: 215-590-1000
Physician Referral Service: 1-800-879-2467
Coordinates: 39.9486937, -75.1929596

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Case Study 3: National Vaccine Information Center

A nonprofit organization, NVIC describes itself as "the oldest and largest consumer-led organization advocating for the institution of vaccine safety and informed consent protections in the public health system" [57] (Figure 3). NVIC states that its mission is to prevent vaccine-related injuries and deaths through public education and to promote informed consent in medicine. Additionally, NVIC funds research on vaccines and vaccination and “provides assistance to those who have suffered vaccine reactions.”

Barbara Loe Fisher, NVIC’s founder, has a significant presence on the website because the current organization grew out of her advocacy against childhood vaccines in the 1980s. Fisher’s commentary runs throughout the website and much of the site is dedicated to documenting her past and present advocacy efforts. Although her presence is ubiquitous on the website, NVIC includes graphical links to its 2 partner organizations: Mercola.com, a self-described natural health information website, and the United Way of the National Capital Area.

The landing page of the NVIC website is separated into 2 columns under a navigation bar. Atop the broad left column headed is a set of links imbedded in a rotating picture box displaying links to the website’s subsections and a right side bar with Breaking News. Current News fills up the lower left-hand side. Along the bottom of the banner at the top of the page, a series of navigation tabs lead the user into the site: “Home,” “About Us,” “Vaccines,” “Law and Policy,” “News and Events,” “Resources,” “Vaccine Reactions,” and “FAQs.” “Subscribe Now!,” “Donate Now!,” “PayPal Donation,” and “Volunteer Now!” buttons appear above and below the picture on the left side of the screen, next to links for Facebook, Twitter, and YouTube. The links embedded in the rotating picture box include “Ask 8 Questions,” “Diseases and Vaccines,” “State Vaccine Law,” “NVIC Advocacy Portal,” “Vaccine Ingredients,” “Injury Compensation,” “Informed Consent,” “Vaccine Victim Memorial,” and “Vaccine Freedom Wall.”

Although the group states on its “About Us” webpage that it “does not advocate for or against the use of vaccines,” the preponderance of the content on its website questions the safety and efficacy of vaccines and vaccination practices, such as the CDC childhood vaccination schedule. Visitors can also download informational pamphlets designed by the organization. The downloadable literature is targeted at parents and is designed to raise questions about current vaccination practices, with emphatic titles such as “49 DOSES OF 14 VACCINES BEFORE AGE 6? 69 DOSES OF 16 VACCINES BY AGE 18? *Before you take the risk, find out what it is.*”

As an “information clearinghouse,” the NVIC website connects visitors to a diverse array of resources about vaccine safety, ranging from government agencies, such as the CDC and the Institute of Medicine, to news outlets that broadcast interviews with the group’s founder, Barbara Loe Fisher. It also provides links to vaccine advocacy events, such as Vaccine Awareness Week and antivaccination conferences.

The NVIC relies heavily on its social media outreach program, and much of its work is done through this outlet. Indeed, many of the sources on the traditional Web pages appear to be somewhat out of date, whereas its Facebook page is updated daily. In its 2011 Annual Report, NVIC states that “350,000 unique visitors accessed information on NVIC.org during FY2011,” [57], that the “Vaccine Ingredient Calculator (VIC) alone attracted more than 46,000 visits from users in 133 nations,” that its “online vaccine freedom wall saw an increase in reports of harassment by parents and health care professionals,” and that the NVIC’s “Facebook and social media outreach experience sustained growth in FY2011” [57]. Although NVIC’s traditional Web pages have as their purpose the dissemination of information about infectious disease and vaccination, the NVIC Facebook page contains posts about vaccination and other controversies in health, such as gluten allergy.

Although visitors to the NVIC website will find a great deal of governmental and scientific information on vaccines and vaccination, they are also faced with a vast number of resources that cast vaccines as dangerous. The landing page, as described previously, presents visitors with several types of information, which can make for less than straightforward navigation for the visitor seeking to learn more about a specific vaccine. The website is a repository for information on vaccine injury with links to state and federal legislation, such as the National Childhood Vaccine Injury Act of 1986, as well as links to agencies and groups that report and compensate vaccination injuries. To bolster its legitimacy, the website reflects the design choices typically employed on governmental and medical websites, replete with patriotic red, white, and blue accents on an easily legible white background, a layout resembling Vaccines.gov [55].

Figure 3. Screenshot of the National Vaccine Information Center home page.

Click here to view or post descriptions and photos of children and adults who have experienced vaccine reactions.

NVIC is 100% funded by donations. Please give.

Find All Items from Archive Here!

Current News

Measles in Disneyland: Third MMR, Vaccine Exemption Ban?

As the stories about measles and Disneyland spread like wildfire, Americans have a choice to make, to maintain their right to informed consent with medical and vaccine risk-taking ...

Special Report: The Emerging Risks of Live Virus & Virus Vectored Vaccines

This referenced report from the National Vaccine Information Center provides information on the emergine risks of live virus & virus vectored vaccines; including vaccine strain virus infection, shedding and transmission ...

ANOTHER Epic Fail for Influenza Vaccine

Flu vaccine effectiveness is measured from 0-62 percent as U.S. public health officials admit that the ineffective influenza vaccine is once again an epic fail ...

Proposed Changes Restrict Vaccine Reaction Reporting

Proposed changes by the CDC to the VAERS reporting form is likely to result in more underreporting of vaccine reactions ...

Grinches in Ohio Attack Vaccine Exemptions

As many families are making last minute holiday preparations, lawmakers in Ohio are rushing a new law through the legislature to add more vaccine requirements for children in daycare ...

Michigan Guts Vaccine Exemptions While Ohio Saves Them

Early in December Ohio legislators proposed reform to vaccination exemptions. NVIC posted an alert, and area residents took action to protect their right to informed consent. At the same time, Michigan lawmakers did not allow the public to participate ...

Vaccination: Defending Your right to Know and Freedom to Choose

The most divisive and hotly debated of all health freedom issues is the question of whether individuals should be at liberty to dissent from established medical and government health policy and exercise freedom of thought, speech and conscience when it comes to vaccination. At risk in this debate - every citizen's right to make voluntary medical risk-taking decisions without sanction...

Will There be an Ebola Outbreak in America?

Inquiring minds want to know the truth about why Ebola hemorrhagic fever has landed on American soil. Unfortunately, Congress and officials at the U.S. Department of Health and Human Services (DHHS), Departments of Defense (DOD) and Homeland Security are having a hard time coming up with answers that don't raise more questions...

New NVIC Pinterest Boards & Vaccine Failure Wall

Check out NVIC's new online forums recently launched to give the public more access to vaccine information and easier to share personal experiences with others. We've also recently launched a Pinterest account and added new information pages....

Remove Vaccine Safety Oversight from DHHS

The recent statement by a CDC senior scientist admitting that vaccine risk data is being withheld from the public is just one more piece of evidence that parents' questions and concerns about vaccine safety are legitimate...

An Inside Job: The DHHS Funded RAND Corp. Vaccine Safety Review

A vaccine safety review published in July 2014 by *Pedatrics* conducted by controversial corporate-funded think tank, RAND Corporation and funded by the U.S. Department of Health & Human Services (DHHS) was significantly influenced by federal government officials with a big stake in finding no significant vaccine safety science gaps...

Back to School Vaccines: Know the Risks & Failures

Denial of a public school education has been used like a club by public health and medical trade officials demanding that state legislators enact "No Shots, No School, No Exceptions" vaccine laws...

NVIC Calls for Vaccine Policy & Law Reform to Protect Human and Civil Rights

In America today, some citizens are being discriminated against and persecuted for following their conscience and making vaccine choices that do not conform with federal health policy. They are being targeted, bullied...

NVIC's "Know the Risks" Message on Times Square Jumbotron

In March 2013, the National Vaccine Information Center launched a national vaccine education billboard and ad campaign to advocate for vaccine risk awareness and the right to exercise voluntary, informed consent to vaccination...

USA Today: Eliminate Personal Belief Vaccine Exemptions

In a USA Today OpEd, NVIC's President, Barbara Loe Fisher opposed USA Today's call for an end to the personal belief exemption to vaccination in the U.S. and for narrowing of "strictly defined" religious and medical exemptions...

The Vaccine Culture War in America: Are You Ready?

NVIC's "No Forced Vaccination" Message in NYC Times Square, Philadelphia and New Jersey

Adults Targeted as Federal Government Prepares to Track the Unvaccinated

Click below to learn about NVIC's vaccine education campaigns!

Read our latest press releases and media coverage.

United Way of the National Capital Area CFC: 90527
NCA Designation Code: 8690

Shop at AmazonSmile and Amazon will make a donation to: National Vaccine Information Center

Copyright 1982-2015 **National Vaccine Information Center.** All Rights Reserved.
21525 Ridgetop Circle, Suite 100 Sterling, VA 20166

Case Study 4: SANE Vax, Inc

SANE Vax states that its mission is “to promote only safe, affordable, necessary, and effective vaccines and vaccination practices through education and information” [58] (Figure 4). The nonprofit organization espouses a belief in science-based medicine and states that it offers information necessary for its visitors to make informed health decisions. Of its 5 board members, 2 state in their biographies that they are the parents of vaccine-injured children. SANE Vax presents itself as a grassroots organization in need of financial support to keep up with “popular demand” and solicits donations via a PayPal link on each page.

The majority of content on the SANE Vax website focuses on the dangers of the HPV vaccines Cervarix and Gardasil (sold in some countries as Silgard). The website’s landing page is divided into several sections corresponding to the group’s mission. Against a purple background, the upper half of the page features 2 columns: “Victims,” which is a series of short, clickable posts featuring images of vaccine-injured young women and their stories, and “SANE Vax Press Releases,” a list of position papers on vaccine policy last updated in 2011. Atop the press release column, a rotating picture box displays images of young women with narrative descriptions of their lives before and after they were vaccinated against HPV. Visitors can explore the webpage via 2 navigation bars that categorize its almost overwhelming amount of content into a series of blogs, resource pages, press release pages, and video pages. Additionally, a sidebar on the right side of the page solicits donations, displays “This Week’s Victim,” additional links to HPV-related groups, and a table listing data about HPV claims from the most recent report of the Vaccine Adverse Event Reporting System, a surveillance program sponsored by the CDC and FDA which permits anyone to submit an incident report about vaccine-related adverse effects.

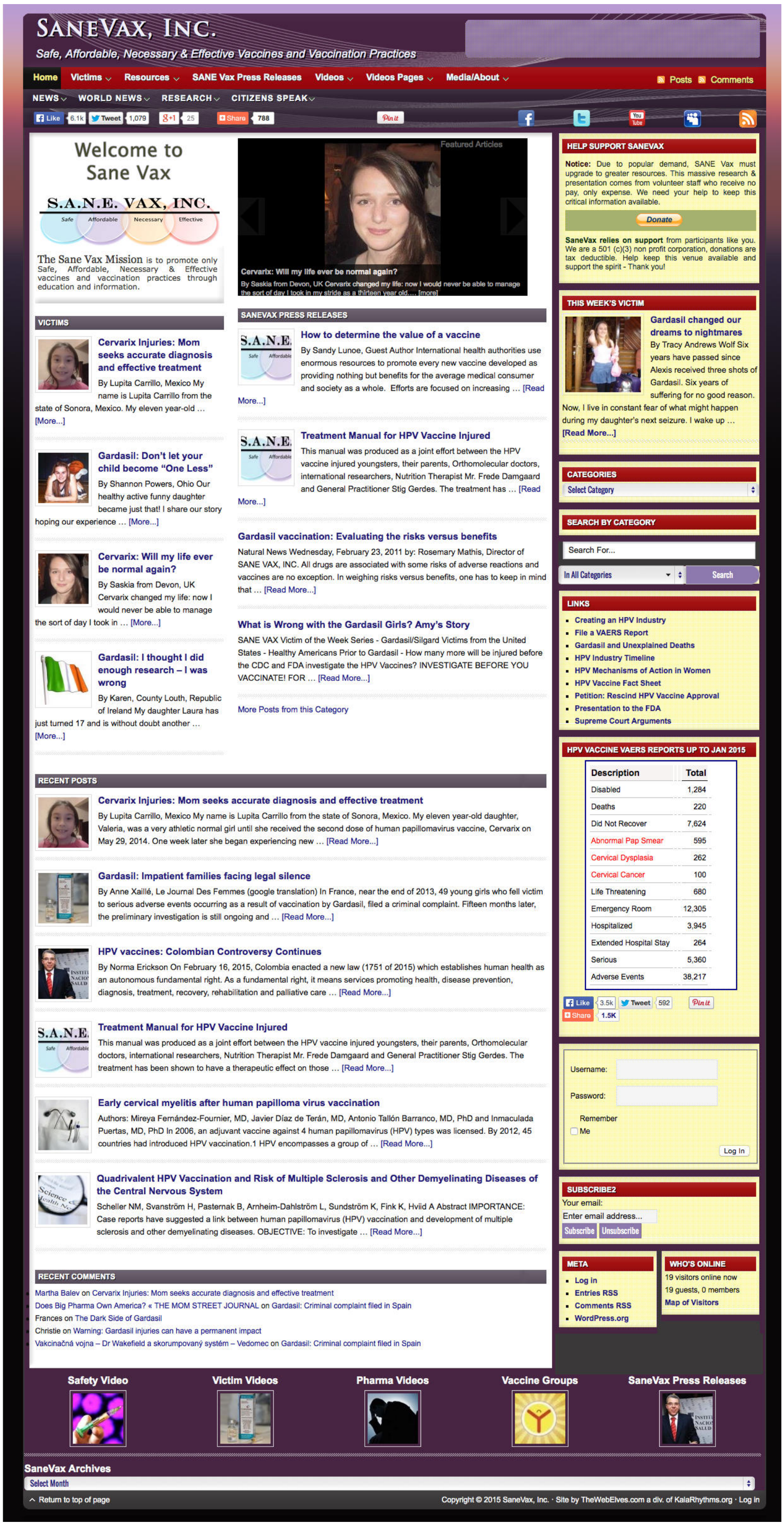
There are several ways for visitors to access victims’ stories. For example, clicking on the “Victims” tab at the top of the page drops down a list of pages including a “Victims Memorial” dedicated to family remembrances of young women who died after receiving an HPV vaccine and a blog page where users submit stories about their family members who died after receiving an HPV vaccine. Most of the information on the website is text based; however, SANE Vax contains a great deal of images and videos that illustrate the stories of vaccine-injured young women. These stories tend to be narrated by family members who chronicle the young women’s healthy lives before they received the vaccination and their subsequent declines postvaccination. The text and video narratives almost always conclude by urging viewers to “investigate before you vaccinate.” The narratives are structured to juxtapose emotional appeals of vaccine injury with logical appeals to scientific research. By placing these 2 forms of persuasion side-by-side, SANE Vax achieves 2 rhetorical effects. First, it makes the argument that the scientific record is inaccurate because it omits information about vaccine injury and, second, it hopes that the viewer will place personal narratives on equal footing with scientific studies. SANE Vax’s postmodern understanding of scientific truth enables it to construct a broad digital ecology where personal truths, clinical truths, and scientific truths coexist. Although the website privileges vaccine-skeptical information, it provides a space where information can be produced and consumed in a fluid, nonhierarchical manner that, in turn, creates a more capacious understanding of vaccine and vaccine-related practices.

Like NVIC [57], SANE Vax supports a considerable digital ecology. The website links to a variety of advocacy groups, news websites, and government agencies. Keeping in-line with the website’s content, all the external information presented focuses on the dangers of vaccine and vaccination. This information comes from news reports and personal accounts from several continents giving SANE Vax a global reach, despite its status as a US nonprofit organization.

SANE Vax houses several blogs to which users can contribute after they register for a free membership to the website. The membership also permits users to upload their own text and video HPV vaccine injury narratives as well as comment others’ content. In this regard, SANE Vax creates an online community of users from around the world who share personal stories and opine about current vaccine policies.

Unlike the Vaccines.gov [55] and VEC [56] websites, SANE Vax attempts to use an exact organization scheme. According to Usability.gov, “exact organization schemes objectively divide information into mutually exclusive sections” [80]. One of the challenges this type of website organization poses to visitors of SANE Vax is that they are presented with numerous discrete categories of information on the website’s many dropdown menus. Visitors to the Vaccines.gov [55] and VEC [56] websites can access all the information about a specific disease and its vaccine with a single click, whereas visitors to the SANE Vax website are presented with information about HPV vaccines in numerous tabs and dropdown menus. The implications of this organization scheme are discussed subsequently in “User Experience.”

Figure 4. Screenshot of the SANE Vax, Inc home page.



Welcome to Sane Vax

The Sane Vax Mission is to promote only Safe, Affordable, Necessary & Effective vaccines and vaccination practices through education and information.

Cervarix: Will my life ever be normal again?

By Saskia from Devon, UK Cervarix changed my life: now I would never be able to manage the sort of day I took in my stride as a thirteen year old.... [more]

HELP SUPPORT SANEVAX

Notice: Due to popular demand, SANE Vax must upgrade to greater resources. This massive research & presentation comes from volunteer staff who receive no pay, only expense. We need your help to keep this critical information available.

SaneVax relies on support from participants like you. We are a 501 (c)(3) non profit corporation, donations are tax deductible. Help keep this venue available and support the spirit - Thank you!

VICTIMS

Cervarix Injuries: Mom seeks accurate diagnosis and effective treatment

By Lupita Carrillo, Mexico My name is Lupita Carrillo from the state of Sonora, Mexico. My eleven year-old … [More...]

Gardasil: Don't let your child become "One Less"

By Shannon Powers, Ohio Our healthy active funny daughter became just that! I share our story hoping our experience … [More...]

Cervarix: Will my life ever be normal again?

By Saskia from Devon, UK Cervarix changed my life: now I would never be able to manage the sort of day I took in … [More...]

Gardasil: I thought I did enough research – I was wrong

By Karen, County Louth, Republic of Ireland My daughter Laura has just turned 17 and is without doubt another … [More...]

SANEVAX PRESS RELEASES

How to determine the value of a vaccine

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HPV VACCINE VAERS REPORTS UP TO JAN 2015

Description	Total
Disabled	1,284
Deaths	220
Did Not Recover	7,624
Abnormal Pap Smear	595
Cervical Dysplasia	262
Cervical Cancer	100
Life Threatening	680
Emergency Room	12,305
Hospitalized	3,945
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Serious	5,360
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By Lupita Carrillo, Mexico My name is Lupita Carrillo from the state of Sonora, Mexico. My eleven year-old daughter, Valeria, was a very athletic normal girl until she received the second dose of human papillomavirus vaccine, Cervarix on May 29, 2014. One week later she began experiencing new … [Read More...]

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By Anne Xaillé, Le Journal Des Femmes (google translation) In France, near the end of 2013, 49 young girls who fell victim to serious adverse events occurring as a result of vaccination by Gardasil, filed a criminal complaint. Fifteen months later, the preliminary investigation is still ongoing and … [Read More...]

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Early cervical myelitis after human papilloma virus vaccination

Authors: Mireya Fernández-Fournier, MD, Javier Díaz de Terán, MD, Antonio Tallón Barranco, MD, PhD and Inmaculada Puertas, MD, PhD In 2006, an adjuvant vaccine against 4 human papillomavirus (HPV) types was licensed. By 2012, 45 countries had introduced HPV vaccination.1 HPV encompasses a group of … [Read More...]

Quadrivalent HPV Vaccination and Risk of Multiple Sclerosis and Other Demyelinating Diseases of the Central Nervous System

Scheller NM, Svanström H, Pasternak B, Arnheim-Dahlström L, Sundström K, Fink K, Hviid A Abstract IMPORTANCE: Case reports have suggested a link between human papillomavirus (HPV) vaccination and development of multiple sclerosis and other demyelinating diseases. OBJECTIVE: To investigate … [Read More...]

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Map of Visitors

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Analysis

Ownership

Each of the websites presented in this study offered information about its sponsoring organization. Only VEC [56] and SANE Vax [58] offered biographical information about the personnel affiliated with the website and the organization it represents. Vaccines.org [55] presented disclosures of the institutions that created the content displayed on the website. As a governmental entity, it is more interested in presenting the positions of government agencies than the backgrounds of individuals holding positions within those agencies. On the other hand, the NVIC [57] "About Us" page offered no biographical data about the organization's founder, Barbara Loe Fisher. The only mention of Fisher in this section of the website was found in a list of Frequently Asked Questions: "How do I contact NVIC, Barbara Loe Fisher, or update my contact information with NVIC?" However, Fisher's writings and videos are showcased throughout the website.

VEC and SANE Vax disclosed their affiliated personnel's professional achievements and personal attachments, a feature that permits users to learn more about the people presenting them with information on vaccine and vaccination-related practices. This feature also allows the website's visitors to assess the ethos of the organizations in light of the people who founded and work for it. Although such an omission of data on Vaccines.gov is understandable because it is a convention of government agency websites, it raises questions with regard to the NVIC website. The majority of the content on NVIC was dedicated to Fisher's advocacy work. Omitting information about her role in the organization may appear to give NVIC an official, authoritative ethos, such as that of Vaccines.gov; however, it distances the organization from the actions and positions of its founder, a rhetorical maneuver that attempts to maintain the appearance of a balanced position on vaccines and vaccination that some viewers might question.

The Vaccines.gov and VEC websites were the only 2 that included disclaimers about the medical information they presented in their "About Us" sections (and in other parts of the websites). The disclaimers functioned in 3 rhetorical ways. First, the disclaimers underscored that the information presented was not a substitute for medical treatment and opinion. These websites endorsed vaccine and vaccination. Appealing to the authority of medical practitioners demonstrated that the content presented was aligned with best medical practices. It also assumed that medical practitioners endorse vaccine and vaccination. Second, the disclaimers offered visitors a means of finding further information in the form of a medical consultation specific to their health needs. Lastly, they signified that the information presented on the website was not monolithic despite the ethos of the organizations that presented it.

Textual and Visual Content

All the websites in this study presented findings from the scientific literature about vaccines and vaccination. The VEC [56] and Vaccines.gov [55] websites presented the scientific information either directly or in a synthesized form and offered no further commentary on it. Thus, the logos of VEC and Vaccines.gov relied on the straightforward distribution of scientific information and governmental policies. On the other hand, NVIC [57] and SANE Vax [58] tended to present scientific information indirectly and with commentary about its quality and the conflicts of interest of its authors. It was common to find allegations on these sites that research is sponsored by the pharmaceutical industry accompanying scientific data on vaccines and vaccination.

Both NVIC and SANE Vax constructed arguments in conjunction with the presentation of scientific information and government policy. These organizations created their logos through questioning, clarifying, and challenging scientific findings. Additionally, NVIC and SANE Vax promoted alternative scientific research that accorded with their vaccine-skeptical positions. These 2 organizations constructed their "watchdog" ethos through challenging scientific and governmental knowledge and, therefore, presented counterarguments in the form of differing scientific findings and opinions on vaccine and vaccination.

Visual content played a minor role on the VEC, Vaccines.gov, and NVIC websites. Because scientific information is disseminated in text form, these websites assumed the logos, or logical argument structure, of scientific medicine even when the mission was to challenge its findings. Text-based websites are easily skimmable and searchable, aiding visitors in finding the information they seek. The encyclopedic feel of these websites added to their ethos of reputable information providers.

SANE Vax was the only website in this study that presented large amounts of visual data to its viewers. Images are the currency of Web 2.0 because they can present a large amount of information in an efficient package. SANE Vax fused its logos with the pathos of emotionally charged images that display the dangers of HPV vaccine, effectively placing scientific logic on equal ground with the personal experiences of the lay visitors and thus building a community of lay experts sympathetic to vaccine injury. Its predominately text-based counterparts in this study tended to make assertions about vaccines and vaccination based on logic and scientific reasoning. SANE Vax subverted this way of understanding vaccines by linking the faces of human suffering to vaccine. This method of argumentation requires the viewer to construct meaning in a way that differs from reading text. Reading a video image calls on the viewer's personal knowledge, in this case about the human body and illness, thus creating a relationship between the viewer and the image. Compared to text-based reading, reading images is a more intersubjective and affective experience that makes the viewer empathize with the suffering and loss illustrated in the images. Thus, SANE Vax used pathos to build its arguments against vaccination.

As a comparison, Vaccines.gov included a few videos, but those watched by the research group seemed overly scripted and unnatural, limiting their rhetorical efficacy. This rather amateur use of video seemed half-hearted in its attempt to respond to authentic viewer concerns, presenting instead its own version of those concerns in a way that rang false. Because the videos seemed like attempts to engage viewers but were experienced as inauthentic, they not only failed to convince viewers but also diminished the ethos of the website overall.

Hyperlinking

The hyperlinking feature of websites (eg, its digital ecology) describes its interconnectivity with other sites. Of the 4 case studies presented, Vaccines.gov [55] contained the fewest hyperlinks to other websites. The few websites to which it linked were government agencies. The other websites in this study had considerably larger digital ecologies because they linked to numerous other websites. VEC linked to other vaccine-promoting websites, where viewers could find additional resources on special topics, such as vaccines for tween girls, and products such as provaccination children's books. Although VEC's [56] digital ecology may be larger than Vaccine.gov's, its overall ecology was somewhat closed because it omitted positions on vaccines that differed from its own.

Both NVIC [57] and SANE Vax [58] linked to websites that questioned vaccine and vaccination practices as well as vaccine-related medical journal articles and government websites. Viewers navigating these websites were exposed to a variety of resources and perspectives on vaccine. NVIC and SANE Vax adopted this logical strategy to familiarize viewers with the provaccine discourses they challenged. In turn, viewers learned argumentative strategies and counterpoints to challenge the messages of websites such as VEC and Vaccines.gov. Their rhetorical strategy for hyperlinking is to demonstrate that there are many available positions on vaccines and vaccination for viewers to take. Additionally, the hyperlinking strategy demonstrated that scientific and government information is open to interpretation. In this way, NVIC and SANE Vax acknowledged the breadth and diversity of thought on vaccines and vaccination on the Internet by representing and linking to a greater diversity of positions on the subject. That is, their rhetorical ecologies were open and diverse, encouraging a variety of viewpoints even as they focused more insistently on skeptical perspectives.

Social Interactivity

Each of the websites offered some kind of interactive feature for viewers. Vaccines.gov [55] offered viewers surveys at the bottom of each of its pages; however, it solicited feedback to make future design and content changes to its websites. This practice is typical of US government websites. VEC [56] offered a mobile app so that viewers could reference information from its website in a smartphone-friendly format, but it did not include any social networking functions. NVIC [57] and VEC [58] displayed links to their social media accounts, where users could interact with one another. SANE Vax was the only website that permitted users to contribute their own content to its website. The website also enabled users to comment on others' content. Contributing and commenting are 2 key community-building functions of Web 2.0 websites. The lack of interactivity of the provaccine websites seems to fit with their hierarchical understanding of scientific authority about vaccines and vaccination. The vaccine-skeptical websites allowed for more interaction and, thus, engaged the viewer in the coconstruction of knowledge about vaccination, especially with the links to social media. The most vaccine-skeptical of the websites, SANE Vax, allowed the most user engagement with content creation on the website.

As a result, SANE Vax built and supported a community of lay experts who circulated alternative knowledge about vaccines. Instead of presenting peer-reviewed scientific literature, the website created a community of peers who could view and comment on one another's narratives. Rather than reading information on vaccines, the community members shared their experiences with vaccines, adding another level of vaccine data that Vaccines.gov and VEC could not support with their Web architecture. On the other hand, Vaccines.gov and VEC directed users to seek personal support and information from medical practitioners. These differences in interactivity clearly affect user experience and help the vaccine-skeptical websites build loyal and engaged communities, whereas the provaccine websites merely exist as online information repositories. The NVIC website occupied a somewhat middle position in this regard.

User Experience

All 4 of the websites in this study presented themselves to their visitors as information resources. The organizational structure of Vaccines.org [55] and VEC [56] lent itself to targeted searches about specific vaccines and vaccination-related topics. Neither of these websites offered additional commentary about vaccines and vaccination outside the realms of science and government, nor did they offer news on current events pertaining to vaccines or vaccination.

NVIC [57] and SANE Vax [58] offered many types of information about vaccines and vaccination. As a result, the websites were more difficult to navigate and their overall purposes were more difficult to discern. The NVIC website was particularly interesting with regard to purpose because it presented a more neutral position concerning vaccination on its landing page than in the rest of the website. Navigating into the site revealed deeply antivaccination sentiments that were often presented through tautological citations and links to publications by Fisher and other prominent vaccine-skeptical figures (eg, Dr Mercola of Mercola.com).

As noted previously, SANE Vax used an exact organization scheme to organize its links and information. The exact organization scheme benefits visitors looking for specific information about political action groups, manufacturers of vaccines, and victims of Gardasil in different countries. Users seeking more general information were potentially overwhelmed with scientific and lay data on vaccines, vaccine news from governments around the world, and transmissions from the website's staff. However, SANE Vax's design reinforced the relationship between scientific and governmental literature and personal testimony that could be used for 2 purposes. A visitor interested in personal accounts of HPV vaccine injury would find that SANE Vax's research blogs and analyses of scientific literature reinforced the video accounts, whereas a visitor researching vaccines would find that the testimonials provided additional information to bolster SANE Vax's claims. Thus, despite the potential confusion, SANE Vax's architecture reflected its 2 purposes, which were to show that there are vast bodies of knowledge (in the form of personal accounts of vaccine injury) that are suppressed in the scientific and governmental literature and to demonstrate that HPV vaccines are controversial and injurious around the world. By placing personal accounts on equal footing with scientific information, the website invited visitors to share their own personal experiences in a manner that the other websites did not.

Discussion

The provaccine websites examined in this study do not leverage the affordances of Web 2.0. The primary purpose of

Vaccines.gov [55] and VEC [56] is to transmit medical and government information to viewers who are seeking specific vaccine information. Although they incorporate different types of media, those media reinforce the information-driven purposes of the websites. The unidirectional transmission of information denies viewers the opportunity to share their experiences with vaccines or to challenge the information that is presented to them. Their rhetorical ecologies are closed rather than open. The content on Vaccines.gov and VEC is vetted by physicians and government workers, but neither website acknowledges the effect that the information and policies have on the lived experiences of those who visit the websites. This unidirectional flow of information is reinforced by both websites' hyperlinking practices. Vaccines.gov only links to other government agencies; VEC only links to provaccine websites. This practice reinforces the websites' positions on public health while denying that there are members of the public who do not subscribe to their provaccine stances. Of course, it is not in the interest of either website to acknowledge positions that challenge their own, which may explain why neither website permits visitors to comment publicly on the information they present.

By not including interactive or community-building features on their websites, both Vaccines.gov and VEC attempt to solidify their positions as authorities on vaccines and vaccination-related practices. The obverse side of this decision is that the websites foster an image of unsympathetic authoritarians who only care about well-being at the level of the public instead of at the level of the individual. In effect, individuals whose experiences differ from the health outcomes presented on these websites have no means of interacting with those who tout vaccines and mandate vaccination practices. It is clear that many of these individuals seek an online forum where their experiences can be publicly presented and validated by a receptive community. As stated previously, according to a Pew Research's Health Online 2013 poll, 72% of Internet users surveyed looked for health information online and 35% opted to self-diagnose with Web-based information rather than visit a clinician [16]. Considering these statistics, the lack of interactivity on the Vaccines.gov and VEC websites may turn people who have had adverse experiences with vaccines into vaccine skeptics because the only online places where their alternative experiences will be acknowledged may be vaccine-skeptical websites.

Although the quality of online vaccination information is a constant concern for researchers and practitioners, both NVIC and SANE Vax demonstrate that studies conducted in the early 2000s are inaccurate in their claims that vaccine-skeptical websites misunderstand scientific information. Rather than circulating deliberate misunderstandings of medical research, both websites strip evidence-based scientific information of its authority by questioning its primacy and call for alternative scientific studies that are sympathetic to its claims. The websites substantiate their calls for alternative research by fostering a community of individuals whose experiences with vaccines counter the information transmitted by medical and governmental websites. Through the community-building functions of Web 2.0, they curate interactive accounts of vaccine injury and skepticism, thus providing a corpus of medical texts that adhere to a different standard for scientific information; that is, the personal experience of vaccination, a purview that is absent in the information offered by Vaccines.gov and VEC.

The research presented in this study is necessarily limited because it makes case studies of only 4 of the many vaccine-related websites on the World Wide Web. However, it presents an opportunity for future research on Internet vaccine information. By employing a rhetorical framework, this study found that both provaccine websites studied concentrate on the accurate transmission of evidence-based scientific research about vaccines and government-endorsed vaccination-related practices. On the other hand, the vaccine-skeptical websites investigated focus on creating communities of people affected by vaccines and vaccine-related practices. From this more personal framework (see also Lawrence et al [49]), the websites then challenge the information presented in scientific literature and government documents. At the same time, the vaccine-skeptical websites in this study are repositories of vaccine information and vaccination-related resources.

Future studies on vaccination and the Internet should take into consideration the rhetorical features of provaccine and vaccine-skeptical websites and further investigate the role of Web 2.0 community-building features on vaccine-related practices. More work needs to be done to determine if the findings of this small pilot study can be replicated across more provaccine and vaccine-skeptical websites; that is, whether the features identified here are generalizable.

Authors' Contributions

Lenny Grant is the primary author. Bernice Hausman is the second author. Margaret Cashion, Nicholas Lucchesi, Kelsey Patel, and Jonathan Roberts provided preliminary research for the study.

Conflicts of Interest

None declared.

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Abbreviations

CDC: Centers for Disease Control
CHOP: Children’s Hospital of Philadelphia
FDA: Food and Drug Administration
HHS: Health and Human Services
HPV: human papillomavirus
MMR: measles, mumps, rubella
NVIC: National Vaccine Information Center
NVPO: National Vaccine Program Office
VEC: Vaccine Education Center
VIC: Vaccine Ingredient Calculator

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Original Paper

Characteristics of Men Who Have Sex With Men in Southern Africa Who Seek Sex Online: A Cross-Sectional Study

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Abstract

Background: Use of the Internet for finding sexual partners is increasing, particularly among men who have sex with men (MSM). In particular, MSM who seek sex online are an important group to target for human immunodeficiency virus (HIV)/sexually transmitted infection (STI) interventions because they tend to have elevated levels of sexual risk behavior and because the Internet itself may serve as a promising intervention delivery mechanism. However, few studies have examined the correlates of online sexual partner seeking among MSM in sub-Saharan Africa.

Objective: These analyses aim to describe the prevalence of using the Internet to find new male sexual partners among MSM in two southern African countries. In addition, these analyses examine the sociodemographic characteristics, experiences of discrimination and stigma, mental health and substance use characteristics, and HIV-related knowledge, attitudes, and behaviors among MSM associated with meeting sex partners online.

Methods: MSM were enrolled into a cross-sectional study across two sites in Lesotho (N=530), and one in Swaziland (N=322) using respondent-driven sampling. Participants completed a survey and HIV testing. Data were analyzed using bivariate and multivariable logistic regression models to determine which factors were associated with using the Internet to meet sex partners among MSM.

Results: The prevalence of online sex-seeking was high, with 39.4% (209/530) of MSM in Lesotho and 43.8% (141/322) of MSM in Swaziland reporting meeting a new male sexual partner online. In the multivariable analysis, younger age (adjusted odds ratio [aOR] 0.37, 95% confidence interval [CI] 0.27-0.50 per 5 years in Lesotho; aOR 0.68, 95% CI 0.49-0.93 in Swaziland), having more than a high school education (aOR 18.2, 95% CI 7.09-46.62 in Lesotho; aOR 4.23, 95% CI 2.07-8.63 in Swaziland), feeling scared to walk around in public places (aOR 1.89, 95% CI 1.00-3.56 in Lesotho; aOR 2.06, 95% CI 1.23-3.46 in Swaziland), and higher numbers of male anal sex partners within the past 12 months (aOR 1.27, 95% CI 1.01-1.59 per 5 partners in Lesotho; aOR 2.98, 95% CI 1.51-5.89 in Swaziland) were significantly associated with meeting sex partners online in both countries. Additional country-specific associations included increasing knowledge about HIV transmission, feeling afraid to seek health care services, thinking that family members gossiped, and having a prevalent HIV infection among MSM in Lesotho.

Conclusions: Overall, a high proportion of MSM in Lesotho and Swaziland reported meeting male sex partners online, as in other parts of the world. The information in this study can be used to tailor interventions or to suggest modes of delivery of HIV prevention messaging to these MSM, who represent a young and highly stigmatized group. These data suggest that further research assessing the feasibility and acceptability of online interventions will be increasingly critical to addressing the HIV epidemic among MSM across sub-Saharan Africa.

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KEYWORDS

Internet; HIV; male homosexuality; southern Africa; social stigma; sexual behavior

Introduction

Globally, the Internet is becoming an increasingly popular platform for meeting new sexual partners, particularly among men who have sex with men (MSM) [1-6]. Recent studies conducted among MSM in Europe and North America indicate that 34-50% report having met a sexual partner online [1,2,4,5]. In particular, MSM who use the Internet to find sexual partners are an important group to target for human immunodeficiency virus (HIV)/sexually transmitted infection (STI) interventions because they tend to have elevated levels of sexual risk behavior and because the Internet itself may serve as a promising intervention delivery mechanism. For example, risk behaviors associated with using the Internet to find sexual partners include increased levels of methamphetamine use [1], higher numbers of sexual partners [1,4,7], and a higher frequency of unprotected anal intercourse [1,4,5,8-10].

In light of these observations, one study measured the acceptability of using Internet-based HIV testing among MSM in Canada and identified perceived benefits to this delivery method including privacy and convenience [11]. Another study conducted in the United States identified high levels of interest for multiple sexual health education topics delivered via the Internet [12]. Further, studies have pointed to the Internet's ability to enhance the discussion of HIV status and negotiate safer sex practices between partners before meeting [13-15], potentially because the anonymity of the Internet appears to facilitate more direct and less stigmatizing discussions of these complex issues. Finally, additional research suggests that use of the Internet for seeking HIV/STI information is common among MSM using the Internet to find sexual partners [16], further suggesting the potential effectiveness for the Internet to serve as a mechanism to deliver HIV/STI prevention.

However, the majority of research to date assessing the prevalence of, factors associated with, and potential interventions directed towards MSM using the Internet to find sex partners has occurred primarily in higher income settings such as the United States and Europe. Less is known about the Internet sex-seeking behaviors of MSM in sub-Saharan Africa, despite the high and consistent risk for HIV among MSM in this region [17]. In addition, stigma and discrimination may also play a particularly important role in Internet sex-seeking behavior due to high levels of homoprejudice [18-21], which may dissuade MSM from finding sex partners in other venues such as bars or clubs. Of the limited research conducted in sub-Saharan Africa, one study found that using the Internet to find sex partners was associated with testing positive for HIV among MSM in Malawi [21]. Further, having a higher level of education and increased numbers of recent sexual partners were associated with having met sex partners on the Internet among MSM in Cameroon [22]. However, there is a need for additional research to understand the feasibility of Internet-based intervention efforts in sub-Saharan Africa, especially given evidence to suggest that Internet use is growing in the region [23], and particularly among adolescents [24,25].

Because there is evidence suggesting that using the Internet to find sexual partners is associated with risk behaviors among MSM and that the Internet could serve as a promising HIV intervention delivery mechanism, and due to the lack of studies assessing Internet use among MSM in southern Africa, these analyses aim to describe the prevalence of using the Internet to find new male sexual partners online among MSM in two southern African countries. Furthermore, these analyses examine the demographic characteristics, experiences of discrimination and stigma, mental health and substance use characteristics, and HIV-related characteristics among MSM associated with meeting sex partners via the Internet. Taken together, these findings may be used to inform the development of tailored online HIV prevention interventions in southern Africa.

Methods

Study Population and Sampling Methods

Data were collected from February-September 2014 in Maseru and Maputsoe in Lesotho and July-December 2011 in Manzini, Swaziland. Participants were recruited in-person using respondent-driven sampling (RDS) [26,27]. Sampling methods are described in detail elsewhere [28]. In brief, initial recruits or “seeds” recruited peers who then recruited additional peers and so forth, until the desired sample size was reached. Each recruiter could recruit up to three peers. In Maseru, 9 seeds recruited participants through up to 13 waves of accrual, and 7 seeds in Maputsoe recruited participants through up to 17 waves. In Swaziland, 5 seeds recruited participants through up to 14 waves of accrual. In all study sites, equilibrium was reached for several sociodemographic characteristics including age, sexual orientation, and education. Equilibrium was defined using two criteria: (1) close approximation (± 0.03) of the sample proportion and corresponding equilibrium proportion [26], and (2) comparison of the required number of recruitment waves estimated using the respondent driven sampling analysis tool (RDSAT) with the actual number of recruitment waves in the RDS sample [29]. Specifically, the number of recruitment waves estimated to reach equilibrium in RDSAT had to be smaller than the number of waves in the RDS sample for equilibrium to be considered.

MSM were eligible to participate if they were aged 18 years or older, assigned male sex at birth, capable of providing informed consent, and reported having receptive or insertive anal intercourse with another man in the past 12 months. No exclusions were made on the basis of ethnicity, gender identity, or history of HIV testing and diagnosis.

In Swaziland, 4 participants did not answer the question pertaining to meeting partners online and were excluded, resulting in a final sample of 322. All participants in Lesotho answered the question pertaining to meeting partners online (n=530). Participants were reimbursed the equivalent of up to approximately US $10 for their time and travel to the study site. In addition, participants were compensated the equivalent of up to approximately US $2 for each eligible participant they recruited into the study. All participants provided informed oral consent prior to data collection. Data collection was approved by the Institutional Review Board of the Johns Hopkins Bloomberg School of Public Health, the Lesotho National Health Research Ethics Committee, and the Ministry of Health Scientific Ethics Committee in Swaziland.

Data Collection and Key Measures

During the study visit, trained interviewers administered a structured questionnaire including topics on demographics, social stigma and negative experiences with health care workers and other members of society, social cohesion, mental health and illicit substance use, sexual history, and HIV-related knowledge, attitudes, and behaviors. The primary outcome variable of interest was whether the participant reported meeting new male sexual partners on the Internet. In Lesotho, this was measured by asking, “Where (in what type of place) do you meet new male sexual partners?” Participants were read a list of possible places, and those who responded yes to “online” were indicated as having met male sex partners online. Participants could choose more than one place. In Swaziland, participants were asked, “In the past 12 months, how often have you used the Internet to look for male sexual partners?” and response options were “did not go”, “once a month of less”, “about once a week”, “several times a week”, “about once a day”, and “several times a day”. Those who reported having ever met a partner on the Internet were indicated as having met male sex partners online.

Stigma was measured by a series of “yes” or “no” questions that assessed whether the participant ever felt excluded from family gatherings, that family members gossiped or made discriminatory remarks, rejected by friends, or scared to walk around in public places because of their gender identity or sexual orientation, and if they knew of safe places in their community to socialize with other MSM or had ever been tortured because of their gender identity or sexual orientation. Torture could include both physical abuse such as being beaten or forced to have sex, as well as verbal abuse. In Lesotho, participants were additionally asked if they had ever overheard someone saying discriminatory things about MSM, if they did not feel protected by police, or were ever verbally harassed or blackmailed because of their gender identity or sexual orientation [19-21,30]. Health care stigma was measured by asking participants if they ever avoided (in Lesotho only) or felt afraid to go to health care services because they were worried that someone may learn that they have sex with men, or if they ever felt that they were not treated well in a health center because someone knew they had sex with men.

In Lesotho, depression was assessed using the Patient Health Questionnaire [31], and a positive screen was defined as receiving a score of 10 or greater. In Swaziland, a positive depressive symptoms screen was indicated by answering “yes” to the question, “Have you felt sad or had a depressed mood for more than 2 weeks at a time in the last 3 years?” and suicidal ideation was assessed by asking the participant if he had ever felt like he wanted to end his life. In both countries, drug use was assessed by asking the participant if he had injected any illicit drugs or used any non-injection drugs that were not prescribed to him for health reasons in the past 12 months.

HIV knowledge was assessed by asking participants what type of sex puts them most at risk for HIV, what type of anal sex (ie, insertive or receptive) puts them most at risk for HIV, and what is the safest lubricant to use during anal sex. Attitude towards HIV was measured by asking if they worried about HIV in the past 12 months. Finally, HIV-related behaviors were measured by asking participants if they had ever tested for HIV (in Lesotho) or tested within the past 12 months (in Swaziland), if they had any unprotected anal intercourse (receptive or insertive) in the past 12 months, if they had transactional sex (eg, sex in exchange for drugs or money) with a male partner in the past 12 months, and how many male anal sex partners they had in the past 12 months.

After completing the questionnaire, trained nurse counselors performed blood draws to test for HIV using the Determine Rapid Test (Alere). If tested positive, the sample was then tested using the Unigold Rapid Test (Trinity Biotech). Confirmatory testing was performed for discrepant or indeterminate HIV rapid tests in accordance with national guidelines [32,33].

Statistical Analysis

RDS-adjusted prevalence estimates for having met a sex partner online at each study site were generated using RDSAT [29]. In a sensitivity analysis, we performed RDS-adjusted bivariate and multivariable logistic regression analyses across each study site by weighting based on the outcome variable. However, because results were convergent and data from the two Lesotho sites were pooled, we present only the unadjusted results [34,35]. Variables were entered into the final logistic multivariable regression model based on a priori knowledge of existing potential confounders and the results of the bivariate analysis. These analyses were performed using SAS software version 9.4.

Results

Sociodemographic Characteristics of Study Sample

The prevalence of seeking partnerships on the Internet was high, with 39.4% (209/530) of MSM in Lesotho and 43.8% (141/322) of MSM in Swaziland reporting meeting a new male sexual partner online (Table 1). Among those who were asked what website they primarily used for meeting partners, the majority in Swaziland reported using Facebook (data not shown). Participants tended to be young overall, with a median age of 23 in Lesotho and 22 in Swaziland. A larger proportion of participants identified as gay or homosexual in Swaziland (202/320, 63.1%) as compared with Lesotho (215/519, 41.4%). In addition, more participants in Lesotho (111/529, 21.0%) reported ever being married to or cohabiting with a female partner as compared with Swaziland (12/318, 3.8%). The median MSM network size was similar across Lesotho (10) and Swaziland (12).

Table 1. Prevalence of sociodemographic characteristics and meeting sex partners online among MSM study participants in Lesotho and Swaziland.

Characteristics	Lesotho (N=530)	Swaziland (N=322)
Age in years, median (interquartile range)	23 (20-27)	22 (20-26)
Gender, n (%)		
Male	487 (91.9)	232 (72.7)
Female/intersex	43 (8.1)	87 (27.3)
Sexual orientation, n (%)		
Gay	215 (41.4)	202 (63.1)
Bisexual	286 (55.1)	114 (35.6)
Heterosexual	18 (3.5)	4 (1.3)
Education completed, n (%)		
Primary school or less	100 (18.9)	110 (34.2)
Secondary/High school	347 (65.6)	135 (41.9)
More than high school	82 (15.5)	77 (23.9)
Marital status, n (%)		
Single/never married	418 (79.0)	306 (96.2)
Ever married or cohabited	111 (21.0)	12 (3.8)
Network size, median (interquartile range)	10 (5-20)	12 (6-30)
Met male sex partner online, n (%)	209 (39.4)	141 (43.8)
RDS-adjusted % (95% CI)	35.7 (28-46)[a]	39.2 (31-49)
RDS-adjusted % (95% CI)	26.1 (17-36)[b]	

[a] Maseru.

[b] Maputsoe.

Sociodemographic Characteristics Associated With Meeting a Sex Partner Online

Older age was associated with being less likely to use the Internet to find new male sex partners among MSM in Lesotho (odds ratio [OR] 0.57, 95% confidence interval [CI] 0.47-0.70 per 5 years) (Table 2). In addition, participants who identified as female/intersex were more likely to use the Internet for male sex partners in Lesotho (OR 3.53, 95% CI 1.82-6.86). In both countries, reporting secondary/high school (OR 5.88, 95% CI 3.03-11.39 in Lesotho; OR 2.02, 95% CI 1.19-3.41 in Swaziland) and more than a high school level of education (OR 13.31, 95% CI 6.17-28.73 in Lesotho; OR 2.83, 95% CI 1.54-5.18 in Swaziland) were positively associated with using the Internet to find sex partners. Finally, reporting a larger network of MSM was also associated with using the Internet to find sex partners in Lesotho (OR 1.25, 95% CI 1.12-1.40 per 10 MSM).

Table 2. Bivariate associations between sociodemographic characteristics and meeting sex partners online, among MSM in Lesotho and Swaziland.

	Lesotho		Swaziland	
	OR	95% CI	OR	95% CI
Age, per 5 years	0.57	0.47-0.70[a]	0.91	0.72-1.15
Gender				
Male	Ref	—	Ref	—
Female/intersex	3.53	1.82-6.86[a]	1.48	0.90-2.42
Sexual orientation				
Gay	Ref	—	Ref	—
Bisexual	0.51	0.35-0.73[a]	0.76	0.48-1.21
Heterosexual[b]	0.20	0.06-0.70[a]	—	—
Education completed				
Primary school or less	Ref	—	Ref	—
Secondary/High school	5.88	3.03-11.39[a]	2.02	1.19-3.41[a]
More than high school	13.31	6.17-28.73[a]	2.83	1.54-5.18[a]
Marital status				
Single/never married	Ref	—	Ref	—
Ever married or cohabited	0.76	0.49-1.18	0.93	0.29-2.99
Network size, per 10 MSM	1.25	1.12-1.40[a]	1.03	0.99-1.07

[a] *P*<.05.

[b] Sample size was not large enough to generate OR in Swaziland.

Social and Health Care Stigma and Mental Health Factors

In Lesotho, meeting new male sex partners online was significantly associated with feeling that family members gossiped or made discriminatory remarks about the participant's sexual orientation or gender identity (OR 4.86, 95% CI 2.80-8.43), feeling excluded by family members (OR 2.53, 95% CI 1.29- 4.97), hearing discriminatory remarks about MSM (OR 2.34, 95% CI 1.48-3.72), being verbally harassed (OR 2.48, 95% CI 1.73-3.55), feeling scared to walk around in public (OR 3.20, 95% CI 1.94-5.30), and being tortured (OR 4.17, 95% CI 1.46-11.86) (Table 3). In Swaziland, feeling rejected by friends (OR 2.17, 95% CI 1.38-3.41) and feeling scared to walk around in public (OR 1.79, 95% CI 1.14-2.79) were associated with meeting a new male sex partner online. Finally, meeting sex partners online was associated with being afraid to seek health care services (OR 3.32, 95% CI 1.91-5.76), avoiding services (OR 2.43, 95% CI 1.28-4.62), and being treated poorly by a health care worker (OR 3.48, 95% CI 1.30-9.31) in Lesotho.

There was only one statistically significant association detected between mental health and substance use measures and meeting sex partners online (Table 4). In Lesotho, screening positive for depression was associated with using the Internet to meet sex partners (OR 1.77, 95% CI 1.11-2.83).

Table 3. Bivariate associations between stigma and meeting sex partners online, among MSM in Lesotho and Swaziland.

Explanatory variable	Lesotho			Swaziland		
	n[a]	OR	95% CI	n[a]	OR	95% CI
Social stigma						
Family exclusion	38	2.53	1.29-4.97[b]	81	1.11	0.67-1.84
Family gossiped	71	4.86	2.80-8.43[b]	157	1.39	0.90-2.17
Friend rejection	100	1.33	0.86-2.06	176	2.17	1.38-3.41[b]
No safe place to socialize with other MSM	160	1.05	0.72-1.54	200	1.09	0.69-1.73
Heard discriminatory remarks about MSM	413	2.34	1.48-3.72[b]	—	—	—
Did not feel protected by police	18	2.50	0.96-6.57	—	—	—
Felt scared to walk around in public	77	3.20	1.94-5.30[b]	145	1.79	1.14-2.79[b]
Verbally harassed	214	2.48	1.73-3.55[b]	—	—	—
Blackmailed	100	0.93	0.59-1.45	—	—	—
Tortured	18	4.17	1.46-11.86[b]	129	1.20	0.77-1.88
Health care stigma						
Afraid to seek services	63	3.32	1.91-5.76[b]	177	1.07	0.69-1.67
Avoided services	42	2.43	1.28-4.62[b]	—	—	—
Treated poorly	19	3.48	1.30-9.31[b]	54	0.86	0.48-1.56

[a] n refers to the number of participants who indicated “yes” for the explanatory variable.

[b] *P*<.05.

HIV Knowledge, Attitudes, and Behaviors and Prevalent HIV Infection

Overall, a greater knowledge about HIV transmission was associated with meeting sex partners online (Table 4). In particular, knowing that water-based lubrication is the safest to use during anal sex was significantly associated with finding partners online in both countries (OR 3.01, 95% CI 2.09-4.32 in Lesotho; OR 1.66, 95% CI 1.05-2.61 in Swaziland). In addition, knowing the correct answer to all three questions assessing HIV transmission knowledge was associated with meeting partners online in Lesotho (OR 2.72, 95% CI 1.55-4.79). Among those who had never been diagnosed with HIV, being worried about HIV infection was significantly associated with meeting partners online in Lesotho (OR 1.69, 95% CI 1.04-2.76).

There were no associations detected between meeting sex partners on the Internet and ever receiving an HIV test, reporting any recent unprotected anal intercourse, or engaging in transactional sex in either country. However, across both countries reporting a greater number of male anal sex partners in the past 12 months was associated with meeting sex partners online (OR 1.30, 95% CI 1.07-1.56 per 5 partners in Lesotho; OR 2.24, 95% CI 1.20-4.19 per 5 partners in Swaziland). Finally, testing positive for HIV was significantly associated with having met partners online in Lesotho (OR 1.50, 95% CI 1.04-2.17).

Table 4. Bivariate associations between HIV-related variables and meeting sex partners online, among MSM in Lesotho and Swaziland.

Explanatory variable	Lesotho			Swaziland		
	n[a]	OR	95% CI	n[a]	OR	95% CI
Mental health						
Depressed	84	1.77	1.11-2.83[b]	208	1.18	0.74-1.87
Suicidal ideation, ever	—	—	—	141	1.37	0.88-2.13
Substance use						
Any illicit drug use, past 12 months	89	0.79	0.49-1.28	113	1.52	0.96-2.40
HIV-related knowledge, attitudes, and behaviors						
Anal sex is riskier than vaginal or oral sex	138	2.28	1.54-3.39[b]	80	0.87	0.52-1.44
Receptive anal sex is riskier than insertive	267	0.78	0.55-1.11	96	1.00	0.62-1.62
Water-based lubricant is the safest to use during anal sex	219	3.01	2.09-4.32[b]	134	1.66	1.05-2.61[b]
All of the above	57	2.72	1.55-4.79[b]	23	0.81	0.34, 1.94
Worried about HIV[c]	84	1.69	1.04-2.76[b]	150	1.14	0.72-1.82
Tested for HIV[d]	366	1.57	0.97-2.56	161	1.08	0.68-1.70
Any unprotected AI, past 12 months	267	1.34	0.95-1.91	143	1.31	0.81-2.12
Transactional sex with male, past 12 months	170	1.11	0.77-1.61	84	0.83	0.50-1.38
Five additional male AI partners, past 12 months, median (IQR)	3 (1-4)	1.30	1.07-1.56[b]	2 (1-3)	2.24	1.20-4.19[b]
Laboratory testing						
Positive for HIV	173	1.50	1.04-2.17	55	1.07	0.60-1.92

[a] n refers to the number of participants who indicated "yes" for the explanatory variable.

[b] *P*<.05.

[c] Among those who have never been told that they have HIV.

[d] Refers to ever in Lesotho and past 12 months in Swaziland.

Factors Independently Associated With Meeting Sex Partners Online

In the multivariable analysis, younger age, increased level of education, feeling scared to walk around in public places, and higher numbers of male anal sex partners were significantly associated with meeting sex partners online in both countries (Table 5). Additional country-specific associations included increasing knowledge about HIV transmission (adjusted odds ratio [aOR] 1.29, 95% CI 1.02-1.64), feeling afraid to seek health care services (aOR 2.31, 95% CI 1.15-4.65), feeling that family members gossiped (aOR 3.42, 95% CI 1.76-6.67), and having a prevalent HIV infection (aOR 2.45, 95% CI 1.41-4.24) in Lesotho.

Table 5. Factors independently associated with meeting sex partners online, among MSM in Lesotho and Swaziland (variables entered into single logistic regression model for each country).

Explanatory variable	Lesotho		Swaziland	
	aOR	95% CI	aOR	95% CI
Age, per 5 years	0.37	0.27-0.50[a]	0.68	0.49-0.93[a]
Secondary/High school	6.15	2.74-13.78[a]	2.46	1.38-4.39[a]
More than high school	18.18	7.09-46.62[a]	4.23	2.07-8.63[a]
Female/other gender	2.03	0.87-4.74	1.50	0.85-2.65
Ever married or cohabited	2.15	1.23-3.76[a]	1.77	0.49-6.43
Ever felt scared to walk around in public	1.89	1.00-3.56[a]	2.06	1.23-3.46[a]
Ever felt that family members gossiped	3.42	1.76-6.67[a]	1.29	0.79-2.11
Ever felt afraid to go to health care services	2.31	1.15-4.65[a]	0.98	0.58-1.64
Increasing knowledge of HIV transmission[b]	1.29	1.02-1.64[a]	1.01	0.76-1.35
Five additional male AI partners, past 12 months	1.27	1.01-1.59[a]	2.98	1.51-5.89[a]
Tested positive for HIV	2.45	1.41-4.24[a]	1.39	0.68-2.84

[a] *P*<.05.

[b] Refers to number of HIV-related knowledge questions answered correctly.

Discussion

Principal Findings

In this study of MSM across two countries in southern Africa, we found that a high proportion reported using the Internet to meet new male sex partners, and the prevalence was similar to that observed among MSM across North America and Europe [1,2,4,5]. Southern African MSM who reported social and health care stigma, were younger, more educated, were knowledgeable about HIV transmission, and reported a greater number of recent anal sex partners were more likely to report using the Internet to meet male sex partners. Within Lesotho, MSM who had larger MSM networks screened positive for depression and tested positive for HIV were also more likely to meet partners online. These findings have implications for the future development of Internet-based HIV interventions.

Recent online HIV intervention efforts directed towards MSM are summarized in a 2007 literature review [36]. These efforts include feasibility studies of Internet- and mobile phone-based programs primarily designed to reduce HIV risk behavior, with overall high levels of feasibility noted thus far. However, most of this work has been conducted in the United States or Europe with limited focus on sub-Saharan Africa. One likely significant difference between populations of MSM in higher income settings as compared to MSM in sub-Saharan Africa is the level of stigma and discrimination. In particular, male homosexual acts are criminalized in Swaziland, and in Lesotho sodomy is still prohibited as a common-law offense [37]. Not only are stigma and discrimination likely to be higher in these countries, but these results suggest that those MSM who use the Internet to meet sex partners report even higher levels of stigma and discrimination than their peers. This suggests that there may be opportunities via Internet-based methods to link these individuals to social support networks, including cyber-support networks, to help increase skills for coping with stigma. For example, one study conducted among racial/ethnic minority MSM in Los Angeles, CA, indicated that social media-based HIV prevention interventions can increase community cohesion and facilitate discussions about HIV-related stigma and discrimination [38,39]. In contrast, because reporting a larger MSM network was also associated with Internet sex-seeking in Lesotho, existing Internet social networks could be used to deliver HIV interventions or to facilitate linkage to HIV testing and care in health care venues that are sensitive to the needs of MSM. The finding that larger sexual networks are associated with using the Internet to meet new sex partners has been identified previously by studies in higher income settings [1,8,40] and indicates that much of the knowledge attained from these studies might be applicable to Internet-using MSM in southern Africa. However, additional feasibility studies are needed for Internet-based HIV interventions among MSM in sub-Saharan Africa, including where and how these men access the Internet.

The finding that younger, more educated and informed individuals were using the Internet to meet sex partners may be reflective of the population subgroups who have better access to the Internet in general. However, the Internet may be particularly relevant to younger MSM in building and establishing peer networks that support sexual health and empowerment, in part because adolescence is an important time for development of self-acceptance and sexual identity [4,41,42]. Because of the positive association between existing HIV transmission knowledge and Internet sex-seeking, Internet-based interventions to increase HIV knowledge may be less effective for MSM using the Internet to find partners. Instead, efforts might be better focused towards the Internet's ability to facilitate safer sex negotiation and serostatus disclosure [13,14]. For example, MSM could be encouraged to disclose their HIV status on their online profile or to discuss their HIV status and preferences for condom use with potential sex partners before meeting. However, there is some concern for the potential misrepresentation of HIV status among those who have never tested or have tested positive, possibly as a result of HIV stigma or fear of losing sexual partners [43]. Because the Internet allows for the opportunity to interact with greater numbers of sexual partners, safer sex negotiation may be even more important as the opportunity for exposure to HIV and STIs is increased.

In addition, these findings suggest some variability by country. For example, testing positive for HIV was associated with meeting sex partners online among MSM in Lesotho but not in Swaziland. This speaks to the importance of tailoring online interventions for different groups of MSM by region, as MSM in one region may not have the same experiences or needs as MSM in other parts of southern Africa. However, we did find consistency in several of our results across countries, suggesting that MSM who use the Internet to find sex partners are a relatively defined group with specific characteristics and needs.

Limitations

There are several limitations of these analyses. First, data were cross-sectional and as such we make no effort to infer causality. Instead, our objective was to describe the prevalence of and characteristics associated with meeting a sex partner online among MSM in southern Africa because they represent an important understudied group with many untapped opportunities for intervention. Second, comparisons made across countries must be interpreted with caution as there was some variability in the phrasing of the question regarding Internet use to find sex partners. In particular, the Lesotho questionnaire asked about current online partner seeking and the Swaziland questionnaire asked about online partner seeking within the past 12 months. In addition, data were collected in 2014 in Lesotho and 2011 in Swaziland, which could account for some variation between countries because the Internet was less popular and more expensive in 2011 as compared with 2014 in this region. However, there were similarities in the response distribution and measures of associations between the two countries, which suggests that both questions similarly measured recent Internet use to find male sex partners.

Finally, the use of RDS requires certain underlying assumptions to be met [44]. Because of the difficulty involved with testing these assumptions, it is possible that not all assumptions were not met in this study. For example, participants were not explicitly asked during the interview how they knew their recruiter. However, recruiters were instructed to recruit only MSM who they knew and who also knew them. Further, because there are limited data available regarding the total number of MSM in Lesotho and Swaziland, it is difficult to test the assumption that the recruited sample size is small relative to the overall size of the target population. In addition, there can be bias introduced in RDS by the non-random selection of individuals out of a recruiter's social network [45]. However, results from our RDS-adjusted sensitivity analysis indicated similar results to the unadjusted estimates presented here. Because equilibrium was reached for several sociodemographic characteristics in this study, this further suggests a minimal overall bias due to non-random recruitment.

Conclusions

Overall, a high proportion of MSM in southern Africa report meeting male sex partners online, as in other parts of the world. The information in this study can be used to tailor interventions to young, educated, and stigmatized MSM who were most likely to report using the Internet to find sex partners. Internet use for meeting sexual partners is likely to increase in prevalence in coming years among MSM in southern Africa, as it is currently common among younger age groups. These trends reinforce the potential value of engaging MSM in these settings through online interventions. Moreover, interventions should draw from the lessons of online engagement of MSM in other parts of the world including North America, Europe, and Asia given the similarities observed. Ultimately, these analyses suggest that further research assessing the feasibility and acceptability of online interventions will be increasingly critical to addressing the HIV epidemic among MSM in sub-Saharan Africa.

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Authors' Contributions

SS led the analysis of the secondary datasets and manuscript writing. SB conceptualized and designed the study. Implementation of the study at the Lesotho sites were led by TM and NT, with substantial support from AG, SK, and JN. Implementation of the study in Swaziland was led by XM, BS, and ZM. All authors provided critical inputs for the interpretation of results, have read, and approved the final manuscript.

Conflicts of Interest

None declared.

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Abbreviations

AI: anal intercourse
aOR: adjusted odds ratio
HIV: human immunodeficiency virus
IQR: interquartile range
MSM: men who have sex with men
OR: odds ratio
RDS: respondent-driven sampling
RDSAT: respondent-driven sampling analysis tool
STI: sexually transmitted infection

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Original Paper

The Acceptability Among Health Researchers and Clinicians of Social Media to Translate Research Evidence to Clinical Practice: Mixed-Methods Survey and Interview Study

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Abstract

Background: Establishing and promoting connections between health researchers and health professional clinicians may help translate research evidence to clinical practice. Social media may have the capacity to enhance these connections.

Objective: The aim of this study was to explore health researchers' and clinicians' current use of social media and their beliefs and attitudes towards the use of social media for communicating research evidence.

Methods: This study used a mixed-methods approach to obtain qualitative and quantitative data. Participation was open to health researchers and clinicians. Data regarding demographic details, current use of social media, and beliefs and attitudes towards the use of social media for professional purposes were obtained through an anonymous Web-based survey. The survey was distributed via email to research centers, educational and clinical institutions, and health professional associations in Australia, India, and Malaysia. Consenting participants were stratified by country and role and selected at random for semistructured telephone interviews to explore themes arising from the survey.

Results: A total of 856 participants completed the questionnaire with 125 participants declining to participate, resulting in a response rate of 87.3%. 69 interviews were conducted with participants from Australia, India, and Malaysia. Social media was used for recreation by 89.2% (749/840) of participants and for professional purposes by 80.0% (682/852) of participants. Significant associations were found between frequency of professional social media use and age, gender, country of residence, and graduate status. Over a quarter (26.9%, 229/852) of participants used social media for obtaining research evidence, and 15.0% (128/852) of participants used social media for disseminating research evidence. Most participants (95.9%, 810/845) felt there was a role for social media in disseminating or obtaining research evidence. Over half of the participants (449/842, 53.3%) felt they had a need for training in the use of social media for professional development. A key barrier to the professional use of social media was concerns regarding trustworthiness of information.

Conclusions: A large majority of health researchers and clinicians use social media in recreational and professional contexts. Social media is less frequently used for communication of research evidence. Training in the use of social media for professional development and methods to improve the trustworthiness of information obtained via social media may enhance the utility of social media for communicating research evidence. Future studies should investigate the efficacy of social media in translating research evidence to clinical practice.

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KEYWORDS

social media; evidence-based medicine; communication; eLearning

Introduction

The importance of evidence-based practice (EBP) in health professions for providing patients with safe and effective care is well established [1]. Yet research that should change practice is often ignored, poorly implemented [1,2], or implemented only after significant time delay [3]. With an estimated 86% of relevant research evidence failing to be adopted into clinical practice [3], innovations to improve knowledge translation may assist in bridging the gap between health care knowledge and practice.

Barriers to the timely implementation of research into clinical practice include both a lack of awareness and acceptance of new research findings by those delivering patient care [1]. Establishing strong connections that enhance communication, collaboration, and education between health researchers, clinicians, health care organizations, educational institutions, and policy makers may foster practice that is grounded in evidence and ensure that ongoing research is relevant to clinicians. Social media may provide an avenue for these connections.

Social media has been defined as a “collection of Web-based technologies that share a user-focused approach to design and functionality, where users can actively participate in content creation and editing through open collaboration between members of communities of practice” [4]. Social networking sites, such as Facebook and Twitter, blogs, wiki’s and many other interactive Web-based technologies are encompassed by this term. Social media is already well established as a powerful communication tool. In 2012, Twitter grew to over 200 million monthly users, and Facebook hosted over one billion users [5]. In contrast to journal articles, which predominantly facilitate top-down and one-way communication, social media may provide a forum for two-way discussion and feedback. Social media provides an avenue for information sharing that is not limited by geographical borders, potentially providing a convenient and cost-effective alternative to attending face-to-face conferences.

There has been a substantial growth in the use of social media within health care [5-7]. Research has demonstrated over 140 uses in health care for Twitter alone [6]. Provision of health education resources for patients and professionals, recruitment of patients to research studies, reporting of real-time flu trends, public outreach campaigns, and online consultations are only a few of the applications of social media in health care [6,7]. However, few studies have investigated attitudes and motives behind social media engagement in the health professions [5,8,9]. Most literature on the use of social media in health education has focused on undergraduate medical education [4], and although favorable results have been reported with regard to learner attitudes, knowledge, skills, and satisfaction [4,10], many of these studies lack methodological rigor [4]. No studies to date have investigated the use of social media in translating research evidence to clinical practice incorporating perspectives of health professionals from differing roles, disciplines, and nationalities.

Social media may assist in enhancing interaction and collaboration between health researchers and clinicians. This research aimed to explore health researchers’ and health professional clinicians’ current use of social media and their beliefs and attitudes towards the use of social media in professional contexts. We were particularly interested in exploring factors that might influence the use of social media and the future potential of social media to convey research evidence to those at the point of care. This would help us understand and subsequently utilize opportunities that social media may provide in improving the translation of research evidence to clinical practice.

Methods

Participants

Health practitioners (clinicians) who practice in the professional disciplines registered by the Australian Health Practitioner Regulation Agency (AHPRA) [11] were invited to take part in this study. Undergraduate students were eligible to participate if they were actively engaged in providing clinical care in a professional health care setting. Health researchers involved in formalized health care research were also invited to participate. While the invitation to participate was distributed in Australia, Malaysia, and India, participants from any geographical location were eligible to participate.

Procedure

Ethical approval for the study was granted by the Monash University Human Ethics Committee (CF 14/1372 - 2014000640). The two phases of the data collection included an anonymous Web-based questionnaire and an interview. Since no existing validated survey was suitable for this study, an original questionnaire was developed by the researchers. The questionnaire consisted of 19 items with varying response types from which both quantitative and qualitative data were obtained (see Multimedia Appendix 1 for questions and response options). The questionnaire gathered demographic details on role, area of practice, age, gender, and country of residence. The questionnaire also gathered data on participants’ current social media use, and attitudes and beliefs regarding the use of social media in professional contexts, with an emphasis on using social media to communicate research evidence. At the close of the survey, participants were invited to provide contact details to participate in the interview phase of the data collection. Any contact details recorded were not linked to the previously recorded survey responses.

A link to the questionnaire was distributed by email. The email invited potential participants to take part in the questionnaire, as well as a link for those indicating that they were declining to participate. For those participants who chose to decline, an option was available for them to volunteer their reason for not participating.

The invitation to participate was distributed to research centers, clinical and educational affiliates, and departments of Monash University, Faculty of Medicine, Nursing and Health Sciences, Australia; Monash University Malaysia; and Swami Vivekanand National Institute of Rehabilitation Training and Research (SVNIRTAR), India. Health professional associations and peak bodies that represent professions registered with AHPRA were also contacted to distribute the invitation to participate.

As part of an action research cycle, results of preliminary data collection were used to develop semistructured interview questions for in-depth exploration of themes pertaining to professional development and professionalism arising from the questionnaire. The interview questions were an original script and are provided in Multimedia Appendix 2.

Participants from Australia, India, and Malaysia who consented to participate in an interview were stratified by country and role and selected at random. Individual interviews of approximately 20 minutes were conducted via telephone until saturation of themes occurred. Data collected in multiple countries allowed for validation of themes in international contexts. Data were audio recorded, transcribed, and de-identified prior to analysis.

The online questionnaires were open between June and November 2014. Interviews were conducted between July and October 2014.

Quantitative data were analysed using SAS statistical software [12]. The Cochran-Mantel-Haenszel (row mean scores) test was used to explore associations between demographic factors (country, age, gender, graduate status, and role) and the ordinal responses to questions. The corresponding *P* values were calculated using a chi-square distribution. Thematic analysis of qualitative data was conducted independently by 2 researchers who then discussed outcomes and arrived at a consensus regarding themes. Analysis was conducted according to the guidelines described by Braun and Clarke [13]. All representative quotes are reported verbatim to illustrate and provide context for derived themes.

Results

Overview

The invitation to participate was sent to 72 research centers, 65 heads of departments, 97 professional organizations, and 293 clinical or educational affiliates of Monash University Australia, Monash University Malaysia, and SVNIRTAR. Participants were able to select options within the emailed invitation to either accept or decline the invitation to participate. A total of 856 participants accepted the invitation to participate, which linked them through to the data collection survey; 125 potential participants elected to decline the invitation. Using the number of participants who accepted or declined the invitation to participate, the response rate for the survey was 87.3%. The reasons for declining to participate (participants could select more than one option) included lack of time (49/125, 39.2%), no interest in the study (40/125, 32.0%), felt the study was not relevant to them (31/125, 24.8%), and other reasons (15/125, 12.0%).

Demographics

Over half of the participants were from Australia (542/856, 63.3%) and over half of all participants were clinicians (536/856, 62.6%). There was a high representation of females (522/856, 61.0%) and those aged 34 or younger (562/856, 65.7%). The demographic details of participants are listed in Table 1.

Table 1. Demographic details of participants.

	Australia, n (%)[a]	India, n (%)	Malaysia, n (%)	Other, n (%)	Total, n (%)
Total participants by country	542 (63.3)	166 (19.4)	90 (10.5)	58 (6.8)	856 (100)
Role					
Clinician[b]	366 (42.8)	71 (8.3)	67 (7.8)	32 (3.7)	536 (62.6)
Researcher	76 (8.9)	30 (3.5)	14 (1.6)	7 (0.8)	127 (14.8)
Multiple[c]	76 (8.9)	61 (7.1)	4 (0.5)	13 (1.5)	154 (18.0)
Not stated	24 (2.8)	4 (0.5)	5 (0.6)	6 (0.7)	39 (4.6)
Student status					
Undergraduate	220 (25.7)	10 (1.2)	56 (6.5)	11 (1.3)	297 (34.7)
Discipline					
Medicine	134 (15.7)	28 (3.3)	51 (6.0)	10 (1.2)	223 (26.1)
Allied Health[d]	201 (23.5)	78 (9.1)	6 (0.7)	10 (1.2)	295 (34.5)
Nursing	28 (3.3)	1 (0.1)	0 (0.0)	7 (0.8)	36 (4.2)
Medical Research	54 (6.3)	4 (0.5)	8 (0.9)	4 (0.5)	70 (8.2)
Other[e]	104 (12.1)	50 (5.8)	14 (1.6)	20 (2.3)	188 (22.0)
Not stated	21 (2.5)	5 (0.6)	11 (1.3)	7 (0.8)	44 (5.1)
Age					
≤24	208 (24.3)	16 (1.9)	53 (6.2)	9 (1.1)	286 (33.4)
25-34	137 (16.0)	105 (12.3)	21 (2.5)	13 (1.5)	276 (32.2)
35-44	88 (10.3)	34 (4.0)	10 (1.2)	13 (1.5)	145 (16.9)
45-54	66 (7.7)	8 (0.9)	5 (0.6)	10 (1.2)	89 (10.4)
55-64	34 (4.0)	3 (0.4)	1 (0.1)	12 (1.4)	50 (5.8)
65+	8 (0.9)	0 (0.0)	0 (0.0)	0 (0.0)	8 (0.9)
Not stated	1 (0.1)	0 (0.0)	0 (0.0)	1 (0.1)	2 (0.2)
Gender					
Male	168 (19.6)	109 (12.7)	33 (3.9)	21(2.5)	331(38.7)
Female	372 (43.5)	56 (6.5)	57 (6.7)	37 (4.3)	522 (61.0)
Not stated	2 (0.2)	1 (0.1)	0 (0.0)	0 (0.0)	3 (0.4)

[a] All percentages are based on the total number of participants.

[b] The clinician category includes health practitioners in the professional disciplines registered by AHPRA and undergraduate students in those disciplines involved in clinical care.

[c] The multiple role category includes participants who identify as a clinician and researcher, or who have other roles in addition to clinician or researcher.

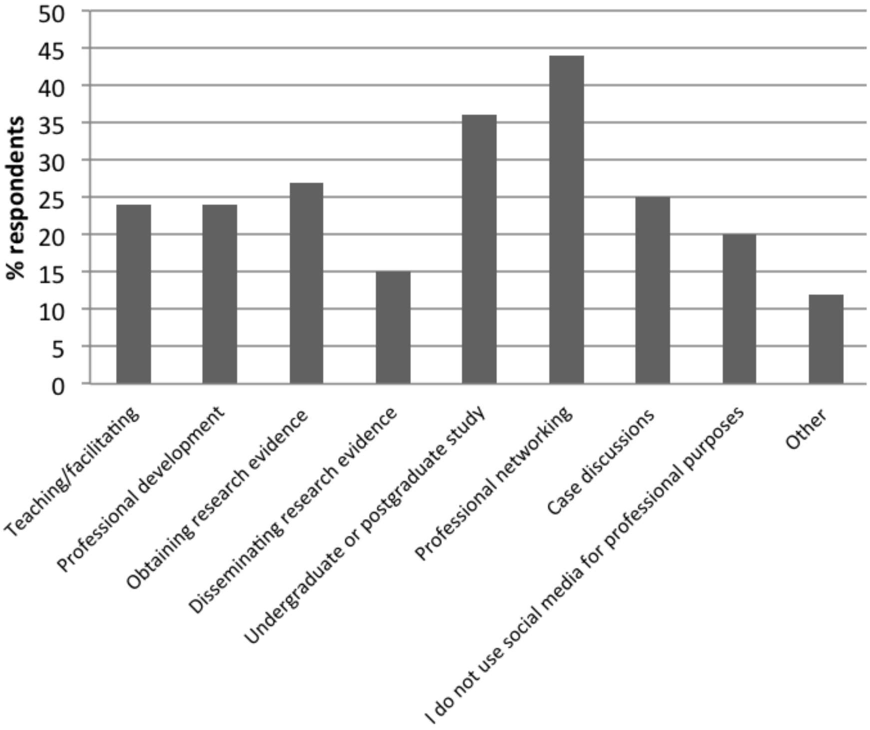
[d] The definition of Allied Health for this study is health care professions registered with AHPRA, excluding medicine and nursing.

[e] Includes responses where area of practice stated but discipline was unclear.

Use of Social Media

Most respondents (749/840, 89.2%) reported using social media for recreational purposes, with 80.0% (682/852) of participants reporting use for one or more professional purposes. The most frequent use of social media in a professional context was for professional networking (44.1%, 376/852), followed by undergraduate or postgraduate study (306/852, 35.9%). Over a quarter (229/852, 26.9%) of participants used social media for obtaining research evidence, and 15.0% (128/852) of participants used social media for disseminating research evidence. Almost a quarter (201/852, 23.6%) of participants used social media for other professional development. The use of social media by respondents for professional purposes is shown in Figure 1.

Figure 1. Categories of professional use of social media nominated by respondents.



Facebook was the social media platform most commonly used for both recreation (710/822, 86.4%) and professional purposes (363/779, 46.6%). YouTube was the second most used site for recreation (565/822, 68.7%) and professional purposes (359/779, 46.1%). When given a choice of platform for obtaining research information, Facebook was the most selected social media platform (227/848, 26.8%).

For respondents who accessed social media for recreation, the most frequent pattern of use, by 49.1% of participants (409/833), was to access social media more than once per day. For professional purposes the most frequent pattern of use, by 30.6% of participants (250/816), was to access social media a few times per week. A relationship between country and frequency of social media use for professional purposes was found. A total of 86.5% (77/89) of Malaysian and 76.7% (122/159) of Indian participants accessed social media a few times per week or more, compared to 56.1% (287/512) of Australian participants. A relationship between professional use and age, and professional use and graduate status was also found. Those in the <25 year age group were the most frequent users of social media for professional use, with 71.8% (199/277) using social media a few times a week or more. Professional usage frequency reduced with increasing age. More undergraduate students (221/291, 75.9%) used social media for professional purposes a few times per week or more compared to those who were not undergraduate students (292/525, 55.6%). While no difference was found between males and females for frequency of recreational use of social media, $\chi^2_1=1.38$, $P=.24$), 66.0% (204/309) of males used social media for professional purposes a few times a week or more compared with 60.7% (306/504) of females ($\chi^2_1=4.57$, $P=.03$). Professional usage patterns of social media were found to be unrelated to role ($\chi^2_2=2.76$, $P=.25$). Table 2 shows the frequency of social media use in professional contexts by category.

For recreational purposes, most respondents read online material only (357/833, 42.9%) or contributed small amounts (356/833, 42.7%). For professional purposes, most participants also read online material only (445/843, 52.8%) or contributed small amounts (265/843, 31.4%). Participants aged <25 years contributed least to professional on line material, compared with participants in other age categories, with 95.2% (259/272) only reading or contributing small amounts to online material ($\chi^2_4=11.2$, $P=.02$). Table 3 shows contributions to online material for professional purposes by age.

Table 2. Frequency of use of social media for professional purposes (the percentage shown is the percent of respondents for each row).

	Never, n (%)	Less than once month, n (%)	A few times per month, n (%)	A few times per week, n (%)	About once per day, n (%)	More once per day, n (%)	χ^2	DF	*P*
Country									
Australia	63 (12.3)	41 (8.0)	121 (23.6)	165 (32.2)	75 (14.7)	47 (9.2)	63.76	3	<.001
India	8 (5.0)	4 (2.5)	25 (15.7)	47 (29.6)	39 (24.5)	36 (22.7)			
Malaysia	4 (4.5)	1 (1.1)	7 (7.9)	28 (31.5)	26 (29.2)	23 (25.8)			
Other	13 (24.1)	5 (9.3)	11 (20.4)	9 (16.7)	5 (9.3)	11 (20.4)			
Age									
<25	18 (6.5)	9 (3.3)	51 (18.4)	96 (34.7)	64 (23.1)	39 (14.1)	20.1	4	<.001
25-34	29 (11.2)	16 (6.2)	52 (20.2)	70 (27.1)	48 (18.6)	43 (16.7)			
35-44	18 (13.0)	10 (7.2)	29 (20.9)	47 (33.8)	18 (13.0)	17 (12.2)			
45-54	15 (17.2)	8 (9.2)	20 (23.0)	24 (27.6)	11 (12.6)	9 (10.3)			
55+	8 (15.1)	8 (15.1)	11 (20.8)	12 (22.6)	4 (7.6)	10 (18.9)			
Gender									
Male	33 (10.7)	11 (3.6)	61 (19.7)	90 (29.1)	60 (19.4)	54 (17.5)	4.57	1	.03
Female	55 (10.9)	40 (7.9)	103 (20.4)	158 (31.4)	85 (16.9)	63 (12.5)			
Graduate status									
Undergraduate	16 (5.5)	9 (3.1)	45 (15.5)	116 (39.9)	66 (22.7)	39 (13.4)	18.46	1	<.001
Postgraduate / non student	72 (13.7)	42 (8.0)	119 (22.7)	134 (25.5)	79 (15.1)	79 (15.1)			

Table 3. Contribution to online material for professional purposes by age.

	I read online material only			I contribute small[b] amounts to online material			I contribute large amounts to online material		
Age[a]	n	% age group[c]	% total participants	n	% age group	% total participants	n	% age group	% total participants
<25	173	63.6	20.2	86	31.6	10.0	13	4.8	1.5
25-34	132	54.3	15.4	84	34.6	9.8	27	11.1	3.2
35-44	70	56.0	8.2	45	36.0	5.3	10	8.0	1.2
45-54	39	48.8	4.6	32	40.0	3.7	9	11.3	1.1
55+	30	60.0	3.5	17	34.0	2.0	3	6.0	0.4

[a] n=2 did not provide age and are not included in the analysis.

[b] Participants were not given a specific definition of a “small amount” or “large amount”.

[c] Percent of age group that reported interacting with online material.

Attitudes and Beliefs Toward Social Media for Professional Purposes

The majority (692/851, 81.3%) of respondents felt confident using social media for recreation compared with 58.2% (496/852) who felt confident using it for professional purposes. Confidence using social media for recreation and professional use reduced with increasing age (χ^2_4=134.5 and 31.7 respectively, *P*<.001 for both).

Just over half the participants (449/842, 53.3%) felt a need for further training to be able to use social media for professional development. Participants from all age categories expressed a need for training, but this was highest in the 45-54 years age category (60/83, 72.3%) and lowest in the <25 years age category (121/280, 43.2%; χ^2_4=34.1, *P*<.001).

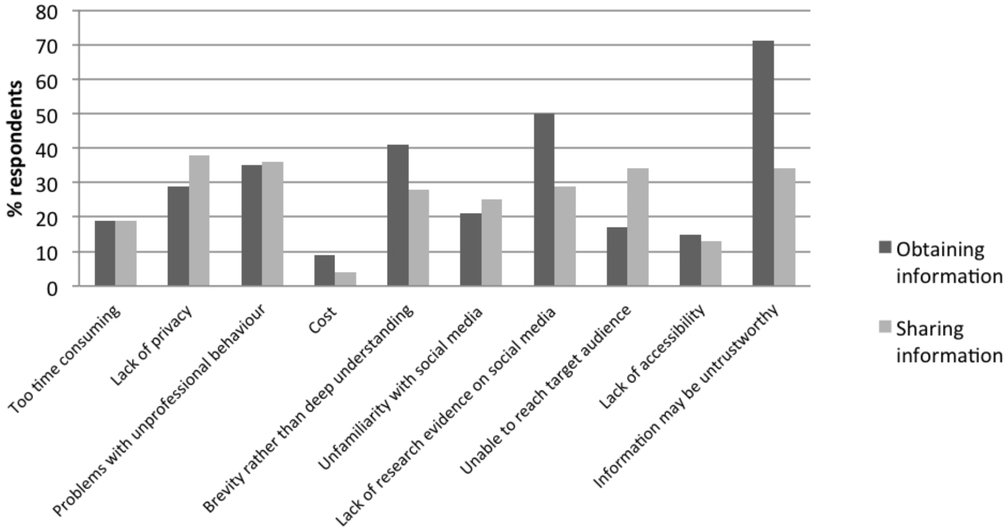
Participants rated social media as the least useful method for staying up to date with research evidence (average rating 2.8 where 1 is not at all useful and 4 is very useful) compared with journals (3.6), mentors (3.4), conferences (3.3), and in-service programs (3.1).

Most respondents (729/843, 86.5%) felt the need to create connections between health researchers and clinicians. Almost all participants (810/845, 95.9%) also saw a role for social media in disseminating research evidence or obtaining clinical information; however, 14.5% (123/848) reported that they would not use social media for obtaining research or clinical information.

The biggest obstacle to obtaining clinical or research information via social media was a felt to be information being untrustworthy (596/839, 71.0%), while the biggest obstacle to sharing clinical or research information via social media was a lack of privacy (305/807, 37.8%). Cost was identified as being the smallest barrier. Barriers to using social media for sharing or obtaining clinical or research information are described in Figure 2.

Most participants considered professionalism in their professional social media use. Most respondents (569/842, 67.6%) were concerned about how material they contribute to social media would represent them. Just over half of respondents (463/841, 55.1%) believed that the material they contributed to social media may positively influence their career and 45.5% (381/838) felt it may have a negative effect.

Figure 2. Obstacles to obtaining or sharing research or clinical information nominated by respondents.



Thematic Analysis

Overview

Interviews were conducted with 27 participants from Australia (9 researchers, 18 clinicians, including 10 students), 28 participants from India (5 researchers, 20 clinicians, including 10 students and 3 "other" roles), and 14 participants from Malaysia (14 clinicians, including 10 students). A saturation of themes was obtained within the clinician, student, and researcher subcategories, and between countries.

Thematic analysis of interviews from Australia, India, and Malaysia revealed three major themes. The themes were consistent between countries and roles. Quotes have been provided to illustrate each theme and are coded by country (A=Australia, I=India, M=Malaysia), role (C=clinician, S=student, R=researcher), and a participant number.

Profile of Social Media

Participants felt that the use of social media in health professions is still developing, particularly with regards to health professionals' understanding of how to use social media in professional contexts, ensuring professional conduct when using social media, and the regulation of professional social media environments: "I think there's a fledgling growth in using social media for some professional stuff but I think it's still in its infancy" (AC2) and "I think it will continue to grow and become a more—I think people will begin to view it as a more reputable source" (AS5).

Participants also felt that there was a stigma attached to using social media for professional use. They felt that using social media was seen as being unprofessional and that information obtained via social media was less valid than that from other sources such as peer-reviewed journals. This perception was held by participants from Australia, India, and Malaysia, and by students, clinicians, and researchers. Some participants also felt that it was a source of information that would be utilized by "younger" health researchers and clinicians only: "I don't think it's professional at all" (MS2) and "This is a generational thing…you can't teach an old dog a new trick" (IC1).

Contributions, Concerns, and Considerations

Participants felt that social media held value for health researchers and clinicians in professional contexts. Features such as accessibility and convenience, the ability to disseminate information quickly to a large audience, and the opportunity to develop networks were key benefits of social media: "One of the real values that I think that social media can offer is that trans-disciplinary and multi-disciplinary conversations in research" (AS10).

Participants were wary of the trustworthiness of the content of social media posts such as research reports due to its lack of regulation. They felt brevity of messages was a concern in establishing validity of information and that some information may be anecdotal or used to support certain agendas: "if you see something posted or shared or Tweeted or whatever...that doesn't mean it is the best evidence on something…You have to realize who is posting it, what potential agendas may be, or where that article or topic or information might fit within your field of practice" (AR5).

Respondents also reported apprehension over the mixing of personal and professional lives and the need to use social media in a manner that would allow distinction between the two. Participants were also concerned about their digital identity, including being misunderstood or misinterpreted, and being held accountable for their social media posts: “I think there’s always the worry that the lines might blur between professional and social. It only takes one mistake, one photo, one silly comment, and it can lead to a whole lot of other problems and outcry” (AS3).

Participants felt that social media could not replace face-to-face interactions. More than half (40/69, 58.0%) of participants interviewed would prefer to attend a conference in person rather than via social media. Reasons for this choice included the potential to build relationships with colleagues resulting from rich interactions that may arise from face-to-face exchanges. However, it was acknowledged that social media may be a more convenient and less expensive alternative to attending conferences face to face. Participants also felt that using social media to broadcast conference proceedings may also increase audience size and dissemination of information: “[social media is] more convenient and there’s no extra expenses in terms of travelling” (MS6).

Many participants felt they had not been “trained” to use social media for professional purposes. This included the choice of social media platforms to use and how to use them in professional contexts. If training in the professional use of social media were to occur, participants felt that this training could either be face to face or online.

> *I don’t think we’ve been really trained to use social media to look up articles or to look up research…So we just kind of fiddle around and we jump on things and we try out different things and we don’t know exactly if we’re using it to the full capacity…So there’s definitely a huge need for more training in this area* [AC5]

Best Practice for Professional Use of Social Media

Participants felt that social media could and should be used in professional contexts if there were specific platforms for professional use, run by accredited or respected bodies or peers. These platforms would be standardized, content controlled, restricted access, peer reviewed, and contain links to full sources of information: “Maybe it would be interesting to have some platforms from different institutions, like universities…That would also make trustworthiness increase” (AR6) and “there’d need to be really clear links, I think direct links, to the actual source of the evidence so that that could then be accessed directly” (AC3).

Discussion

Principal Findings

The results of this study demonstrate a high level of engagement by health researchers and clinicians with social media in both recreational (89.2%) and professional (80.0%) contexts. However, far fewer use social media for obtaining or distributing research evidence, and there are different patterns of use by country, age, gender, and graduate status. A key barrier in using research evidence obtained via social media may be the perceived untrustworthiness of information obtained via this medium.

Wide variation in rates of social media use are reported in existing literature with students showing higher use (64-97%) [14,15] than clinicians (13-47%) [14] and researchers (51.9%) [8]. This study also found a high level of professional social media use by undergraduate students and those in the <25 year age category. This result may be reflective of an increasing use of social media within health care education courses [4]. Although social media has been considered to be a “Generation Y” phenomenon [16], a need for training in the professional use of social media was expressed by participants of all ages, not just older subgroups. Few training programs in social media exist, but those that do, such as the “Friending Facebook” course at Penn State Hershey Medical Center have achieved favorable results [17].

Professional use was most frequent by Malaysian and Indian participants. This is reflective of worldwide trends of social media use, which demonstrate that the average number of daily hours spent on social media is highest in Malaysian residents, followed by Indian and Australian residents [18]. The higher proportion of participants in the 34 and under age category from Malaysia and India may also have influenced this result. Males were more frequent users of social media for professional purposes than females, despite similar rates of use for recreation. The high proportion of male compared with female participants from India, where professional use rates are high, may have influenced this result.

The results of this study demonstrate that networking was the predominant motive for social media use, a result comparable to previous studies [5,9]. Most health researchers and clinicians who participated in this study (86.5%) consider it important to create professional connections, which also correlates with this result. While networking may be useful in building a health professional’s profile or building relationships, social interaction via these networks may also impact upon the translation of evidence to clinical practice. Social influence is a powerful change inhibitor or facilitator [19] and the opinions of peers and leaders play a major part in influencing individual practitioners’ behavior, especially with regards to acting on new information [19].

Fifteen percent of health researchers and clinicians in this study indicated that they currently distribute research findings, while 26.9% obtain research evidence via social media. The rationale for the limited use of social media in conveying research evidence may lie within the perceived barriers to its use. Trustworthiness of information obtained via social media was a key concern for participants in this study. The open access environments of social media allow the circulation of both evidence-informed and opinion-informed messages. The quality and validity of Web-based health information has been of concern since the Internet became publicly accessible in the mid-1990s [6].While these concerns may be valid, obtaining evidence-based information from traditional sources such as academic journals does not necessarily guarantee its quality. “Predatory journals” may publish articles of poor quality in return for payment [20]. Clinicians must possess both the time and skills to decipher what is both valid and reliable, regardless of source. These barriers to social media use have been identified in previous research [5]. Participants in this study had specific ideals regarding best practice for the use of social media in disseminating and obtaining research evidence in future. These included particular standards such as content-controlled sites run by accredited or respected bodies. Those seeking to disseminate research evidence should consider these ideals in the development of social media platforms and content, and application of these standards may assist in reducing the "unprofessional" stigma of these media. Initiatives to improve the quality of Web-based information exist, such as validated information sites, for example Medpedia (a Harvard, Stanford, University of Michigan, and UC Berkley initiative) [6]. The World Health Organization has also proposed to instigate a regulated health domain for validated health information [6]. However, health professionals must be aware of these sites, and restricting user-generated content may limit peer interaction. As the uptake of evidence-based information is more likely from a participatory educational program [19], increased regulation may limit the educational value of these sites.

Despite the perceived barriers to using social media for communicating research or clinical information, most participants in this study saw a role for social media in obtaining or disseminating research evidence, which is considerably more than reported in previous literature [8]. Social media has several features that enhance its utility for dissemination of research evidence, which may have contributed to this result. Cost was identified as the smallest barrier to professional use. The cost of scholarly journals can be high and continue to increase in price [21]. A World Health Organization investigation of the lowest income countries reported that 56% of institutions had no subscription to international journals, and 21% had an average of only two subscriptions [22]. Social media may be a cost-effective alternative to journal subscription, as access to social media sites are free (given an Internet connection and Web-enabled device). This may enable greater equity in distribution of health information globally.

Participants also identified accessibility and the rapid dissemination of information as benefits of social media. Social media is available to anyone with an Internet connection and Web-enabled device, a feature of particular benefit to health professionals in geographically isolated areas. Online communities of practice have proven to enhance the use of EBP, which may be used within rural and remote areas [23], although paradoxically, these may be areas where technological infrastructure does not support fast or reliable Internet connections. Social media also distributes information rapidly. With a median time from study completion to journal publication of 2.4 years [24], social media may have the potential to reduce the time from knowledge creation to implementation in clinical practice, compared with traditional methods of evidence-based information dissemination.

Limitations

This study has several limitations. Although participation was open to participants from all geographical locations, the invitation to participate was distributed in Australia, India, and Malaysia, resulting in data predominantly from participants in these regions. Future studies should validate this study's findings with other populations. In addition to this, participant discipline could not always be ascertained, therefore the data may include responses from participants in professions other than those registered with AHPRA. The questionnaire was presented online, therefore participants with reduced information technology access or skill may have been unable to participate. This may have resulted in selection bias towards those who favor the use of social media. While an effort was made to calculate a response rate based on the two questionnaires used, not all non-responders will have been captured. Therefore, the response rate may be lower than that reported. Two research assistants conducted the interviews with participants in Australia; however, use of local interviewers in India and Malaysia may have affected the information generated from interview data. Poor phone connections in some cases may have led to misinterpretation of participant intention. A further limitation to this study is that the analysis of findings has remained broad, as many themes arising from the data were consistent between subgroups of participants. However, this limits the depth of understanding of the findings in relation to these subgroups. Future studies may include geographical or role-based analysis of findings on this topic to contribute to existing literature.

Conclusions

With an average of 17 years required to incorporate 14% of research findings into clinical practice [3], it is evident that there is a disparity between health care knowledge and health care practice. Social media may assist in "filling the gaps" left by traditional methods of research dissemination, by providing a rapid, accessible, cost-effective medium with which to disseminate information. Social media for knowledge translation may also provide an avenue for discussion, collaboration, and peer-review that may enhance learning and acceptance of new information.

This study found that a large majority of health researchers and clinicians use social media in recreational and professional contexts. This study has also found relationships between age, gender, country of residence, and graduate status with use of social media in professional contexts. Younger age, male gender, undergraduate status, and residency in Malaysia or India were indicators of high use of social media for professional purposes. However, this finding should not limit the investigation or use of social media in communicating research information to these subgroups. This study has also demonstrated that a vast majority of health researchers and clinicians feel that social media has a role to play in the communication of research evidence, but they lack trust in the reliability and validity of information on social media. This is a valid concern and may limit the use of social media in translating research evidence to clinical practice. Therefore, methods for improving the "reputation" of social media for professional use should be investigated. This study has found that these methods may include tailoring of social media platforms and content to enhance the utility for professional purposes and provide clinicians and researchers with greater trust and safety in use. Training programs may also assist in increasing the number of health professionals using social media for obtaining and communicating research evidence. Future research should also investigate the efficacy of social media in communicating research evidence and the impact on clinician's attitudes, knowledge, and clinical practice.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Study questionnaire.

[PDF File (Adobe PDF File), 49KB - jmir_v17i5e119_app1.pdf]

Multimedia Appendix 2

Semi-structured interview questions.

[PDF File (Adobe PDF File), 60KB - jmir_v17i5e119_app2.pdf]

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Abbreviations

AHPRA: Australian Health Practitioner Regulation Agency
EBP: evidence-based practice
SVNIRTAR: Swami Vivekanand National Institute of Rehabilitation Training and Research

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Review

Low Health Literacy and Evaluation of Online Health Information: A Systematic Review of the Literature

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Abstract

Background: Recent years have witnessed a dramatic increase in consumer online health information seeking. The quality of online health information, however, remains questionable. The issue of information evaluation has become a hot topic, leading to the development of guidelines and checklists to design high-quality online health information. However, little attention has been devoted to how consumers, in particular people with low health literacy, evaluate online health information.

Objective: The main aim of this study was to review existing evidence on the association between low health literacy and (1) people’s ability to evaluate online health information, (2) perceived quality of online health information, (3) trust in online health information, and (4) use of evaluation criteria for online health information.

Methods: Five academic databases (MEDLINE, PsycINFO, Web of Science, CINAHL, and Communication and Mass-media Complete) were systematically searched. We included peer-reviewed publications investigating differences in the evaluation of online information between people with different health literacy levels.

Results: After abstract and full-text screening, 38 articles were included in the review. Only four studies investigated the specific role of low health literacy in the evaluation of online health information. The other studies examined the association between educational level or other skills-based proxies for health literacy, such as general literacy, and outcomes. Results indicate that low health literacy (and related skills) are negatively related to the ability to evaluate online health information and trust in online health information. Evidence on the association with perceived quality of online health information and use of evaluation criteria is inconclusive.

Conclusions: The findings indicate that low health literacy (and related skills) play a role in the evaluation of online health information. This topic is therefore worth more scholarly attention. Based on the results of this review, future research in this field should (1) specifically focus on health literacy, (2) devote more attention to the identification of the different criteria people use to evaluate online health information, (3) develop shared definitions and measures for the most commonly used outcomes in the field of evaluation of online health information, and (4) assess the relationship between the different evaluative dimensions and the role played by health literacy in shaping their interplay.

(J Med Internet Res 2015;17(5):e112) doi:10.2196/jmir.4018

KEYWORDS

health information seeking; online health information; information quality; health literacy

Introduction

Recent years have witnessed a dramatic increase in consumer online health information seeking [1]. Online health information deserves particular attention because studies on the content of health-related websites have highlighted inaccuracies that raise concerns about the quality of the online health information encountered by consumers [2-6]. The limited accuracy of information is often the result of one of the distinctive features of the Internet, that is, that anyone can potentially publish health-related information. Online health information seeking thus poses several major challenges to health information users, as it requires them to undertake an active role in evaluating a vast amount of often unverified health information on the Internet [7]. As a result, people experiencing difficulties evaluating online health information may be exposed to wrong or incomplete information, which has been shown to be related to adverse health outcomes, such as low participation in screening programs or low adherence to treatments [8]. Evidently, more attention needs to be given to the issue of quality of online health information and in particular to people's ability to evaluate it [2-6].

Several guidelines and checklists to improve the quality of online health information have been developed, for example by the Standford Persuasive Tech Lab, the Health On the Net Foundation (HONcode), Web Médica Acreditada, and Centrale santé (Netscoring criteria) (see Kim et al [9] for a summary view). These tools can be useful for Web designers and providers of health information to develop high-quality health websites. At the same time, the guidelines could be used by users as evaluation criteria to assess online health information. However, these criteria are likely known and adopted only by specific segments of the population, resulting in disparities in people's ability to evaluate online health information. The knowledge gap hypothesis, for instance, states that as a result of increasing mass media exposure, individuals in the higher socioeconomic strata of society tend to acquire information faster than people in lower ones. So the gap in knowledge between the two tends to increase rather than decrease [10]. It is likely that traditionally disadvantaged groups—such as those with lower education or lower health literacy—will be the ones at higher risk for disparities in this context [11].

Among the determinants of health disparities, people's health literacy has been proven to play a crucial role in the context of health information seeking. Health literacy has originally been defined as "the cognitive and social skills which determine the motivation and ability of individuals to gain access, to understand, and use information in ways which promote and maintain good health" [12]. A closer look at the different conceptualizations of health literacy proposed in the last years (eg, [12-19]) shows that almost all of them explicitly or implicitly include people's ability to deal with (ie, obtain, process, evaluate, and use) health information among the skills a person should possess in order to be considered health literate. Several studies have provided evidence of differences in how people with different levels of health literacy seek, find, understand, and use online health information. For instance, low health literate people have been shown to search less for health information, choose different information sources, and have a poorer ability to interpret medication labels or health messages [20-23]. In contrast, little attention has been devoted to how consumers—and in particular those with low health literacy—evaluate online health information [24]. Additionally, to date, no studies have systematically summarized existing evidence on the role of health literacy in the context of the evaluation of online health information.

The main objective of this study was to address this research gap and provide a comprehensive description of how low health literacy impacts people's evaluation of online health information. This translates to four distinct research questions aimed at understanding whether and how people's health literacy is related to their ability to evaluate online health information (RQ1), perceived quality of online health information (RQ2), people's trust in the Internet as a source of online health information (RQ3), and the use of evaluation criteria for online health information (RQ4).

The rationale behind RQ1 is the fact that a relationship between health literacy and ability to evaluate the quality of health information has been explicitly or implicitly suggested by several health literacy conceptualizations [12-19] but has not been systematically verified so far.

Information evaluation, however, does not depend only on the characteristics of the audience (in our case, people's ability to evaluate online health information). As acknowledged already at the very beginning of scholarly interest in the field of credibility, characteristics of the message and the source can play a role as well [25-28]. This is the reason why RQ2 is about the relationship between health literacy and perceived quality of online health information (message level). Perceived information quality is a multifaceted concept encompassing several dimensions, which in turn can be grouped in different categories [29,30]. For the purposes of this review, we will focus on the dimensions of perceived reliability and accuracy, which Wang and Strong [31] have defined as intrinsic information quality.

It has been found that perceived information quality does not necessarily imply intention to rely on it [32]. Someone could, for instance, perceive a message as being of high quality but not trust the source because of external factors (such as previous negative experiences) and thus decide not to act on the information. Therefore, RQ3 concerns overall trust in the Internet as a source of health information. In the context of computer-mediated communication, trust has been defined in terms of dependability and is a subjective judgment about whether a person (or, in the case of online health information, a digital object) is worth being relied on [32,33].

Last, as past research in other fields has shown that people use several different criteria when evaluating online information, including relying on formal (eg, color of the webpage) or contextual (eg, position in Google search results) aspects of the website, or evaluating the information based on previous knowledge [34], RQ4 is aimed at understanding whether health literacy plays a role in the choice and use of these evaluation criteria.

Answers to these four questions will provide us with a new and more comprehensive understanding of the role played by low health literacy in the evaluation of online information. At the same time, the results of the review will allow us to identify possible areas where consumer education could have an impact on improving low health literate people’s ability to correctly evaluate online health information.

Methods

Data Sources and Search Strategy

During the third week of January 2014, five academic databases from different relevant disciplines (Medline, PsycINFO, CINAHL, Web of Science, and Communication and Mass Media Complete) were systematically searched for peer-reviewed literature describing consumers’ evaluation of online health information. No time limits were set because the topic of online health information seeking is relatively recent. Search terms used included a combination of Medical Subject Headings (MeSH) terms and free terms covering the four domains, “online information”, “health”, “evaluation”, and “health literacy”, combined with the Boolean operator AND (see Multimedia Appendix 1). A preliminary search showed that the number of articles explicitly mentioning health literacy was limited, so the search was modified to include some of its most common proxies or indicators. Since health literacy has been defined as a set of skills [12], only skills-based indicators (eg, educational attainment, reading ability, or general literacy) were included in the search. These indicators can be considered as proxies of health literacy because of their conceptual similarities (eg, they all refer to teachable skills) and the existence of a direct link between the concepts. Other common, mainly sociodemographic, indicators (eg, age, income, or ethnicity) were excluded because of the more complex nature of their relationship with health literacy. The original search strategy was developed for PsycINFO and subsequently adapted to the peculiarities and requirements of the other databases. These terms were included in the original search, allowing us to refine it. References cited in included articles were reviewed manually, and a Google Scholar and Web of Science search for recent articles citing the ones included in the review was performed in order to identify further additional articles relevant to this review (snowball method).

Study Inclusion/Exclusion Criteria

A two-phase screening process was conducted. After de-duplication, the first author (ND) screened titles and abstracts of all retrieved articles in order to identify possible relevant articles (first phase). Abstracts were selected for full text screening (second phase) if they (1) were written in English, (2) reported original results, qualitative or quantitative, (3) studied consumer online health information, (4) mentioned evaluation of the information by consumers/patients, and (5) had been conducted in a low health literacy population (or in a sample of the above-described proxies of low health literacy) OR subgroup analyses were conducted in a sample of low health literate people (or proxies of low health literacy). Excluded were non-empirical articles (such as reviews, commentaries, or editorials), articles describing empirical studies conducted among health care providers, content analyses of websites, quality assessments of websites, and articles reporting on research conducted in samples that were not explicitly described as low health literate (or proxies) and did not present subgroup analyses for the low health literacy (or proxies) group. No selection based on the country where the study was conducted was made, and the same inclusion criteria were used for each country. In order to estimate reliability of the screening process, 10% of the abstracts and all the selected full texts were independently assessed by a second researcher. Initial intercoder agreement (Cohen’s kappa >.70 for both title/abstract and full-text screening) was substantial [35], and all disagreements regarding full texts were resolved during consensus meetings that were held on a regular basis during the whole screening process.

Data Extraction

Overview

Besides the formal characteristics of the included papers—author(s), publication date, study design, study population, and sampling—data were extracted from all articles on the following aspects, which were deemed relevant to answer our research questions.

Predictors

Data were extracted about the predictors used in the study and the measures used to assess them. The main predictor of interest was health literacy, which can be assessed using different tools, for example, the Rapid Estimate of Adult Literacy in Medicine (REALM) [36], the Short Test of Functional Health Literacy in Adults (S-TOFHLA) [37,38], or the Newest Vital Signs (NVS) [39]. As mentioned earlier, however, included studies could also describe differences in one of the outcomes of interest related to differences in education or other skills-based proxies for health literacy [40]. Each study could address one or more predictors.

Outcomes

Data were extracted on the outcomes addressed in the studies and the measures used to assess them. The four outcomes of interest were (1) ability to evaluate online health information, (2) perceived quality of online health information, (3) trust in the Internet as a source of online health information, and (4) use of evaluation criteria for online health information. Each study could address one or more outcomes.

Association Between Predictors and Outcomes

All qualitative or quantitative evidence of (or lack of) an association between one of the predictors and one of the four outcomes of interest were extracted.

Data Synthesis

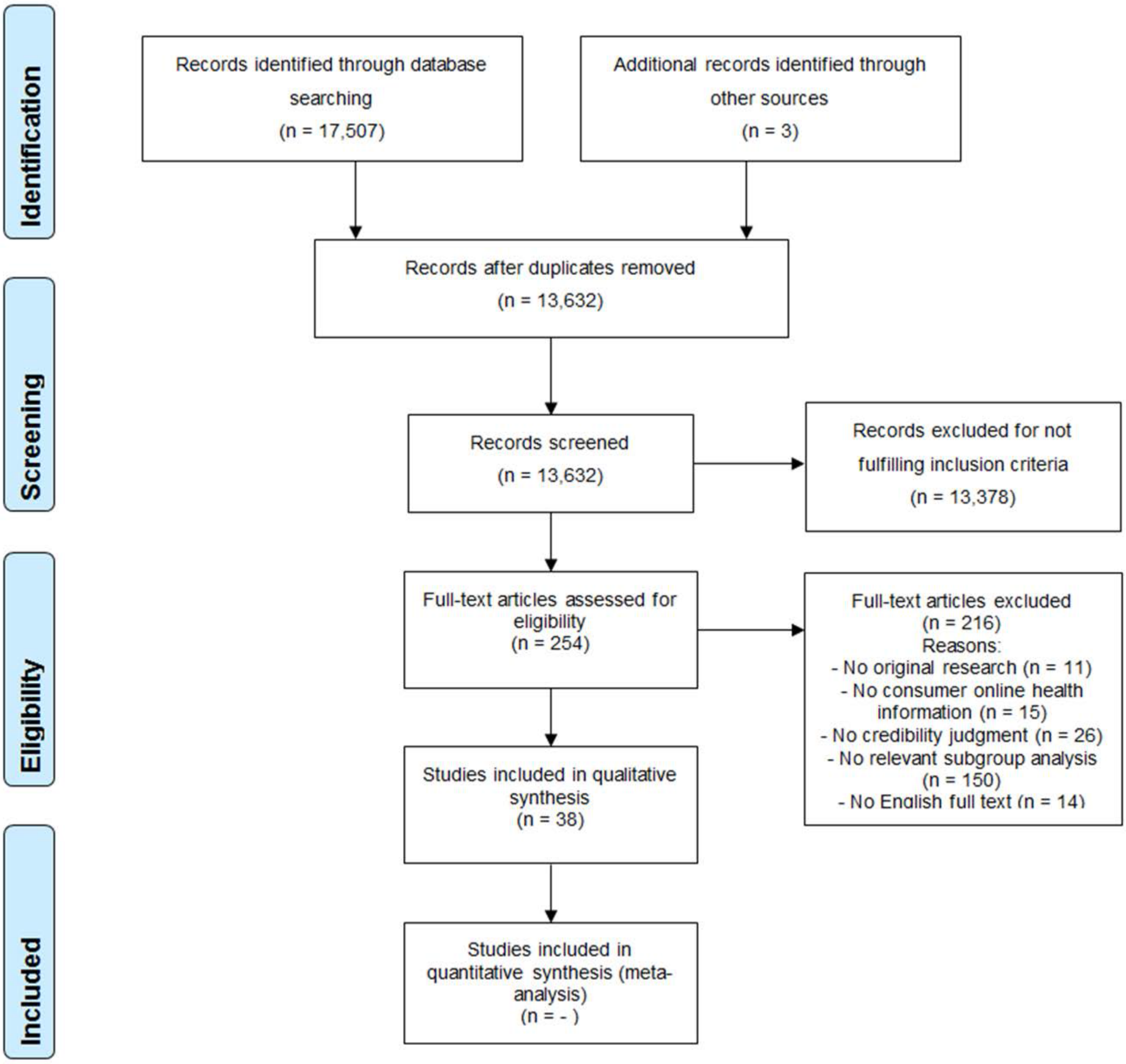
Given the heterogeneity of study designs, samples, predictors, and outcome measures in our articles pool, results could not be synthetized quantitatively using meta-analytic techniques. The findings were therefore synthetized narratively and structured according to the different outcomes under investigation.

Results

Included Studies

The initial search resulted in 17,507 articles. In the process of reviewing articles identified through the initial searches, 3 additional articles were identified through cited references, bringing the total to 17,510 articles. After duplicates were removed, the remaining number of articles was 13,632, of which 13,378 were discarded after reviewing titles and abstract. An additional 216 articles were discarded after reviewing the articles in their entirety, resulting in 38 articles [24,41-77]. The whole process is illustrated in detail by the flow diagram in Figure 1.

Figure 1. Flow diagram of the screening process.



Characteristics of Included Studies

The basic characteristics of the final pool of articles included in the systematic review are described in Table 1 [41-77]. The 38 studies were published between 2001 and 2013. Most of them were conducted in North America (24/38; 63%), five were conducted in Europe (13%), four (11%) in Asia, four (11%) in Australia, and one in Africa (3%). Study populations varied widely, ranging from the general population to specific patient groups, and so did sample sizes, ranging from N=8 up to N=8586. All studies were non-experimental, with the vast majority being cross-sectional surveys (35/38; 92%), and the remaining were qualitative studies (1 focus group study [60] and 2 qualitative observational studies [45,50]).

According to commonly used approaches for rating the quality of evidence in systematic reviews (eg, Grades of Recommendation, Assessment, Development and Evaluation [GRADE]; see [78]), the quality level of the evidence has to be considered low because all the studies included in this review are non-interventional in nature.

Table 1. Characteristics of included studies.

Author(s), date	Country	Study type	Sample	Sample size, N
AlGahmdi & Moussa, 2012 [41]	Saudi Arabia	Cross-sectional	Random sample of male and female outpatients and visitors attending a public University Hospital in Riyadh, Saudi Arabia	801
Bates et al, 2007 [42]	United States	Cross-sectional	Community-wide convenience sample through intercept survey methods. Participants were recruited at high-traffic areas in a regional hub city in southeastern Ohio	519
Benotsch et al, 2004 [43]	United States	Cross-sectional	Individuals with human immunodeficiency virus recruited from neighborhoods in inner city Atlanta, Georgia	324
Bernhardt et al, 2004 [44]	United States	Cross-sectional	In-person surveys administered to diverse respondents in four different locations in two states, including a small and large city in the Southeastern United States, and a small and large city in the Northeastern United States. Online surveys were administered on a webpage that was promoted to diverse respondents using emails and word-of-mouth	858
Birru et al, 2004 [45]	United States	Observational study	Subjects enrolled in a reading assistance program at Bidwell Training Center in Pittsburgh, PA	8
Borzekowski & Rickert, 2001 [46]	United States	Cross-sectional	Sample of 10th grade students from a diverse community near NY	412
Clayman et al, 2010 [47]	United States	Cross-sectional	Hispanics-Latinos of the 2005 Health Information National Trends Survey (HINTS) sample	496
Dart, 2008 [48]	Australia	Cross-sectional	Three different Australian communities: low socioeconomic sample, mid-high socioeconomic sample, and university sample	714
Dutta-Bergman, 2003 [49]	United States	Cross-sectional	Stratified random sample of approximately US adults (Porter Novelli HealthStyles database)	2636
Feufel & Stahl, 2012 [50]	Germany	Observational study	Native German-speaking adults	22
Gauld & Williams, 2009 [51]	Australia & New Zealand	Cross-sectional	Non-representative sample of Australians and New Zealanders	406
Ghaddar et al, 2012 [52]	United States	Cross-sectional	Random sample of high school students in South Texas	261
Helft et al, 2005 [53]	United States	Cross-sectional	Convenience sample of patients from the WMH Oncology Specialty Outpatient Clinic, Indianapolis	200
Hesse et al, 2005 [54]	United States	Cross-sectional	Nationally representative sample of US adults 18+ (HINTS 2002-03)	6369
Ishikawa et al, 2012 [55]	Japan	Cross-sectional	Nationally representative sample of people aged 15-75 years in Japan	1311
Kalichman et al, 2006 [56]	United States	Cross-sectional	HIV-positive men and women who use the Internet recruited from AIDS service organizations, health care providers, social service agencies, and infectious disease clinics in inner-city areas of Atlanta, GA	419
Knapp et al, 2011a [57]	United States	Cross-sectional	Parents whose children with special health care needs were enrolled in Florida’s Medicaid and State Children’s Health Insurance Plan (SCHIP)	2371
Knapp et al, 2011b [58]	United States	Cross-sectional	Parents whose children are in a pediatric palliative care program in Florida	129
Lawson et al, 2011 [59]	New Zealand	Cross-sectional	Sample of New Zealanders drawn from the electoral roll	8291
Mackert et al, 2009 [60]	United States	Focus groups	Parents from a midsized city in the southwestern United States 18 years of age or older, at or below median income for the area, who had not completed a 4-year college degree nor worked in the health care field	43
Maguire et al, 2011 [61]	Australia	Cross-sectional	Australian adults with schizophrenia (recruited from both community and inpatient settings) and general practice attendees	301

Author(s), date	Country	Study type	Sample	Sample size, N
Maraziene et al, 2012 [63]	Lithuania	Cross-sectional	Randomly selected sample of Lithuanian citizens	1763
Marrie et al, 2013 [63]	United States	Cross-sectional	US people with multiple sclerosis enrolled (voluntary) in the Consortium of MS Centers developed the North American Research Committee on Multiple Sclerosis (NARCOMS) Registry	8586
Murray et al, 2003 [64]	United States	Cross-sectional	Household probability sample of US adults (18+) from the 48 contiguous states	3209
Neter & Brainin, 2012 [65]	Israel	Cross-sectional	Adult (18+) Israeli population	4286
Nguyen & Bellamy, 2006 [66]	United States	Cross-sectional	Non-Hispanic Asians and non-Hispanic whites form the 2003 HINTS	4395
Nwagwu, 2007 [67]	Nigeria	Cross-sectional	In-school, and out-of-school adolescents in Owerri, Nigeria	1145
Oh et al, 2012 [68]	United States	Cross-sectional	Korean Americans ≥40 years	254
Richter et al, 2009 [69]	Germany	Cross-sectional	Patients with inflammatory rheumatic diseases (rheumatoid arthritis, systemic Lupus erythematosus (SLE), spondyloarthritis (SpA) regularly scheduled for a visit in our Rheumatology outpatient clinic at the University Clinic Düsseldorf	153
Smith, 2011 [70]	United States	Cross-sectional	Nationally representative sample of adults in the United States from the 2008 Annenberg National Health Communication Survey (ANHCS)	3656
Soederberg Miller & Bell, 2012 [71]	United States	Cross-sectional	Nationally representative sample of US adults from the Health Information National Trends Survey (HINTS)	3796
Van der Vaart et al, 2011 [72]	The Netherlands	Cross-sectional	Sample of patients with rheumatic diseases (Study 1) and stratified sample of the Dutch population (Study 2)	277
van Deursen & van Dijk, 2011 [73]	The Netherlands	Cross-sectional	Stratified random sample of adults (18+) living in the region of Twente, The Netherlands	88
Yan, 2010 [74]	Hong Kong & Kowloon	Cross-sectional	Convenience sample recruited in urban public areas including shopping locations (in Hong Kong Island and Kowloon) and subway stations	443
Ye, 2011 [24]	United States	Cross-sectional	Nationally representative sample of US adults (HINTS)	7674
Zhao, 2010 [75]	United States	Cross-sectional	2005 HINTS sample (foreign-born and US born)	5393
Zoellner et al, 2009 [76]	United States	Cross-sectional	Proportional quota sample of adult residents in the Mississippi Delta region.	177
Zulman et al, 2011 [77]	United States	Cross-sectional	Adults 50 years of age and older in the United States	1450

Predictors Included in the Studies

Only four of the included studies (4/38, 11%) specifically described the relationship between health literacy and one or more of the four outcomes of interest [45,52,60,76]. Health literacy was measured using different instruments: the NVS [52,76], the TOFHLA [43], and S-TOFHLA [60].

The majority of the included studies (33/38, 87%) described the relationship between educational level and one or more of the outcomes. In most of them, educational level was operationalized either as number of years of education or as the highest achieved degree. In some cases, however, other operational definitions were used. One study compared a university sample with a mid-high socioeconomic and a low socioeconomic sample [48], two compared different ethnic groups with different educational levels [66,75], one compared in-school versus out-of-school young people [67], and one last study compared students in different grades and enrolled in programs with or without a health focus within the same school [52].

Five studies (13%) described the relationship between other skills-based proxies for health literacy and one or more of the outcomes. These skills included reading comprehension [43], comfort speaking English [47], general literacy [45], and ability to understand health information [24]. Although it could be argued that this last skill is conceptually very similar to health literacy, the authors did not define it as such in their paper. In addition, health literacy was not measured with a recognized measure but by a single item. In the fifth study, a distinction was made between skilled (younger than 30 years, higher educational level and more experienced using the Web) and less-skilled (50 or older) participants [50]. As some studies reported results related to more than one predictor, percentages add up to more than 100%, and studies might be referred to more than once throughout the results.

Outcomes

Overview

The majority of the studies included in the review included trust in online health information as an outcome variable (53%, 20/38). The second most common outcome was evaluation ability, included in 26% of the studies (10/38), followed by perceived quality of online health information (defined in the studies as perceived credibility, reliability, accuracy, and worth), which was included in 21% of the studies (8/38). The least frequent outcome variable in the pool of articles was the use of evaluation criteria, which was included in 5 studies only (14%). As some studies reported results on more than one outcome, percentages add up to more than 100%, and studies might be referred to more than once throughout the results.

Ability to Evaluate Online Health Information

Our first research question focused on the relationship between health literacy and ability to evaluate online health information. This specific aspect was addressed in 10 (26%) of the 38 studies (see Table 2 [43,45,52,56-58,64,65,72,73]). Evaluation ability was mostly assessed using self-report measures. Five studies [52,57,58,65,72] used the eHealth Literacy scale (eHEALS)—a measure assessing several aspects related to online health information seeking, including people's perceived ability to evaluate online health resources and to distinguish high quality from low quality online health information—or some of its items [79]. Other studies asked the respondents to self-assess their ability to evaluate online health information by means of a single item measure [64] or qualitatively by means of an open question [45]. Among the studies using objective measures, van Deursen and van Dijk [73] asked their participants to perform an evaluation task derived from the eHEALS. In the other studies, the participants were asked to evaluate websites of varying quality [43,56].

Two studies assessed the role of health literacy in people's ability to evaluate online health information. The first study showed that low health literacy was associated with lower eHEALS scores [52], while in the second study low health literacy was shown to be associated with lower quality ratings of a high-quality website and higher quality ratings of a low-quality website [43].

Six out of the nine studies focusing on educational level showed a positive relationship between educational attainment and perceived or actual ability to evaluate online health information [43,52,57,58,65,73]. The studies by Murray et al [64] and van der Vaart et al [72] did not find any significant difference among different education groups. A last study found that lower education was associated with assigning a higher quality rating to a low-quality website but did not find any association between education and evaluation of a high-quality website [56].

Last, two studies reported on ability to evaluate online health information in relation to other skills. In a small qualitative study conducted in a sample with low general literacy, 7 out of the 8 respondents reported finding it very easy to locate trustworthy health information on the Internet [45]. The second study identified a positive association between reading ability and correct evaluation of the quality of a high-quality and a low-quality website [43].

Perceived Quality of Online Health Information

Eight studies (21%) reported on perceived quality of online health information. Except in one case where a multidimensional scale was used [46], this aspect was measured by means of single-item measures. Most studies did not refer directly to information quality but to one of its dimensions, that is, reliability [51,69,74], perceived accuracy [44,53,67], and perceived worth [46] (see Table 3 [44,46,50,51,53,67,69,74]). No studies on perceived information quality included health literacy as a predictor.

The majority of the studies focusing on educational level failed to find significant associations between education and perceived quality of online health information. One study found a positive association [53], and one a negative association [44]. Another study found contrasting results: while out-of-school adolescents tended to describe online health information as more accurate than in-school adolescents, the latter group assigned higher overall quality to online health information as compared to out-of-school adolescents [67].

Only one study reported on the relationship between skills-based proxies for health literacy and perceived quality of online health information. The study, however, did not find any differences among skilled and less-skilled participants: both groups doubted the quality of online health information [50].

Table 2. Outcome 1: Ability to evaluate online health information.

Author(s), date	Predictor	Specific measure used	Result
Benotsch et al, 2004[a][43]	Health literacy (TOFHLA)	Quality rating of health information from reputable (JAMA) and unfounded (AIDS cure) webpages (5 dimensions: accuracy, amount of detail, trustworthiness/credibility, relevance, and usefulness)	Lower health literacy scores predict higher quality ratings for the AIDS cure webpage (unfounded) and lower quality ratings for the JAMA webpage (reputable) (*P*<.01).
Ghaddar et al, 2012[b][52]	Health literacy (NVS)	eHEALS[c]	Students identified as possibly or likely low health literate present significantly lower eHEALS scores than those with adequate health literacy (*P*<.05).
Benotsch et al, 2004[a][43]	Educational level	Quality rating of health information from reputable (JAMA) and unfounded (AIDS cure) webpages (5 dimensions: accuracy, amount of detail, trustworthiness/credibility, relevance, and usefulness)	Individuals with fewer years of education assign more credibility to unfounded information (*P*<.01). Educational level is unrelated to perceived quality of the JAMA webpage.
Ghaddar et al, 2012[b][52]	Educational level (different grade levels; health classes)	eHEALS[c]	Freshmen and sophomore students and those who have not taken a health course have lower eHEALS scores relative to students in higher grade levels and those enrolled in a health course (*P*<.001). eHEALS scores are significantly lower among students from the non-medical focused campuses compared to the 2 high schools with a focus on medical education (*P*<.001).
Kalichman et al, 2006 [56]	Educational level	Quality rating of health information from reputable (JAMA) and unfounded (AIDS cure) web pages	Less education predicts assigning higher credibility to unfounded Internet information (*P*<.001). Education does not have an impact on the evaluation of the reputable webpage.
Knapp et al, 2011a[57]	Educational level	eHEALS (Item 6: “I have the skills I need to evaluate the health resources I find on the Internet” and Item 7: “I can tell high-quality health resources from low-quality health resources on the Internet”)	Parents without college education feel less confident in having the skills to evaluate the health resources they find on the Internet (*P*<.05) and feel less able to tell high-quality health resources from low-quality health resources on the Internet (*P*<.001) compared to those with college education.
Knapp et al, 2011b[58]	Educational level	eHEALS[c]	Not having a high school diploma is associated with a 2.5-point decrease in overall eHealth literacy (*P*<.05).
Murray et al, 2003 [64]	Educational level	Perceived ability to appraise online health information	No significant effect of education on self-rated ability in appraising online health information.
Neter & Brainin, 2012 [65]	Educational level	eHEALS[c]	Lower education is associated with lower eHealth literacy ($F_{1,1274}$=5.43, *P*<.02).
Van der Vaart et al, 2011 [72]	Educational level	eHEALS[c]	No significant correlation between educational level and eHEALS scores.
Van Deursen & Van Dijk, 2011 [73]	Educational level	Number of information tasks[d] (derived from the eHEALS) completed successfully	Educational level is positively correlated with the number of information tasks completed successfully (β=.56, *P*<.001).
Benotsch et al, 2004[a][43]	Other skills-based proxies for health literacy – Reading comprehension	Quality rating of health information from reputable (JAMA) and unfounded (AIDS cure) webpages (5 dimensions: accuracy, amount of detail, trustworthiness/credibility, relevance, and usefulness)	Poorer reading comprehension predicts higher quality ratings for the AIDS cure webpage, whereas higher reading comprehension predicts higher quality ratings for the JAMA webpage (*P*<.01).
Birru et al, 2004 [45]	Other skills-based proxies for health literacy – Low general literacy (3rd to 8th grade level) only sample	Perceived ability to locate trustworthy online health information	7 out of 8 subjects report that they find it very easy to locate trustworthy information on the Internet. The eighth subject notes that it is moderately easy to find information that is trustworthy on the Internet.

[a] Study reported three times because it described the impact of health literacy, educational level, and other skills-based proxies for health literacy on the ability to evaluate the credibility of online health information.

[b] Study reported twice because it described the impact of both health literacy and educational level on the ability to evaluate the credibility of online health information.

[c] The eHEALS (eHealth Literacy scale) includes specific items about people’s perceived ability to evaluate the quality of online health information (Item 6: “I have the skills I need to evaluate the health resources I find on the Internet” and Item 7: “I can tell high-quality health resources from low-quality health resources on the Internet”). Specific data for these items are, however, not presented in the paper.

[d] Information tasks included choosing a website or a search system to seek information, defining search options or queries, selecting information on websites or in search results, and evaluating information sources. Specific data for the task “Evaluating information sources” are not presented in the paper.

Table 3. Outcome 2: Perceived quality of online health information.

Author(s), date	Predictor	Specific measure used	Result
Bernhardt et al, 2004 [44]	Educational level	Perceived accuracy of online health information	Less educated respondents perceive online health information to be more accurate ($P<.05$).
Borzekowski & Rickert, 2001 [46]	Educational level	Composite assessing perceived worth, trustworthiness, use, and relevance of online health information	No significant effect of educational level on the outcome.
Gauld & Williams, 2009 [51]	Educational level	Perceived reliability of online health information	Educational level is not correlated to perceived reliability of online health information.
Helft et al, 2005 [53]	Educational level	Perceived accuracy of online health information	Less educated patients are less likely to believe that online health information is accurate (r=.0417; $P<.05$).
Nwagwu, 2007 [67]	Educational level – In-school vs Out-of-school	Perceived accuracy and quality of online health information	The out-of-school groups describes more often the information as accurate. Overall, however, the in-school group assess online health information to be of higher quality more often than the out-of-school.
Richter et al, 2009 [69]	Educational level	Perceived reliability of online information	No significant effect of education on perceived reliability of online information.
Yan, 2010 [74]	Educational level	Perceived reliability of online health information	No significant effect of educational level on perceived reliability of online health information.
Feufel & Stahl, 2012 [50]	Other skills-based proxies for health literacy – Skilled (30 years of age, had a higher level of education, and were more experienced using the Web) vs less-skilled (≥50 years of age)	Attitudes towards the quality of online health information	Health information seekers in both cohorts doubt the quality of information retrieved online; among poorly skilled seekers, this is mainly because they doubt their skills to navigate vast amounts of information; once a website is accessed, quality concerns disappear in both cohorts.

Trust in Online Health Information

Trust in online health information was the outcome measure of more than half of the studies included in this review (20/38, 53%) (Table 4 [24,41,47,48,54,55,59,61,63,66-71,74-76]). Among those, three studies asked the participants to rate their trust in online health information on specific health topics (cancer and nutrition [54,66,76]). All other studies referred to general trust in online health information and assessed it by means of a single-item measure.

Only one study investigated trust in online health information in relation to health literacy and did not find any significant relationship [76].

Ten out of the 17 studies reporting on the relationship between educational level and trust in online health information identified a positive association. Among the other studies, two found a negative association [59,66] and four found no significant association [24,48,69,74] between educational level and trust. One study reported contrasting results: Maguire et al [61] found a positive association between education and trust among respondents with schizophrenia but not among non-schizophrenia respondents.

Two studies reported on the relationship between skills-based proxies for health literacy and trust in online health information. A positive association between comfort speaking English [47] and ease in understanding health information [24] and trust was found.

Table 4. Outcome 3: Trust in online health information.

Author(s), date	Predictor	Specific measure used	Result
Zoellner et al, 2009 [76]	Health literacy (NVS)	Trust in food, diet, or nutrition-related online health information	No significant effect of health literacy on trust in online health information.
AlGahmdi & Moussa, 2012 [41]	Educational level	Trust in online health information	Fewer individuals with lower education always trust online health information (*P*<.001).
Dart, 2008 [48]	Low socioeconomic (LSE) vs mid-high (MSE) socioeconomic vs university	Trust in online health information	Most respondents in all three groups (LSE, 58.4%; MSE, 63.7%; university, 64.5%) are unsure of the trustworthiness or distrusted online health information (no significance level reported).
Hesse et al, 2005 [54]	Educational level	Trust in cancer-related online health information	Education is positively associated with trust in cancer-related online information (*P*<.01).
Ishikawa et al, 2012 [55]	Educational level	Trust in online health information	Participants with high school education or less report less trust in online health information than those with higher education (OR 0.68, 95% CI 0.51-0.92).
Lawson et al, 2011 [59]	Educational level	Trust in health information from media (including the Internet)	Education is negatively associated with trust in health information from media (no statistics reported).
Maguire et al, 2011 [61]	Educational level	Trust in online health information	A lower level of education makes it more than twice less likely that a person with schizophrenia would trust online health information (OR 2.24, *P*<.01). There are no education-related differences among respondents without schizophrenia.
Maraziene et al, 2012 [63]	Educational level	Trust in online health information	People with lower education tend to trust the Internet less than their better educated counterparts (*P*<.05).
Marrie et al, 2013 [63]	Educational level	Trust in online health information	Respondents with a high school degree or less are less likely to have some/a lot of trust in online health information compared to those with an associate’s degree (OR 1.31, 95% CI 1.10-1.57), bachelor’s degree (OR 1.37, 95% CI 1.17-1.61), and graduate degree (OR 1.30, 95% CI 1.10-1.55).
Nguyen & Bellamy, 2006 [66]	Whites vs Asians (significantly different educational background)	Trust in cancer-related online health information	Asians (lower educational level) are more likely to trust cancer-related online information than whites (OR 0.54, *P*<.05).
Nwagwu, 2007 [67]	In-school vs Out-of-school	Trust in online health information	Out-of-school respondents report the information as trustworthy less often than the in-schools (no statistics reported).
Oh et al, 2012 [68]	Educational level	Trust in online health information	Respondents with 12 or fewer years of education are 3.1 times less likely to trust online health information a lot than were those with more than 12 years (95% CI 1.1-8.6).
Richter et al, 2009 [69]	Educational level	Confidence in online health information	No significant effect of education on confidence in online health information.
Smith, 2011 [70]	Educational level	Trust in online health information	Education is positively associated with trust in online health information (*P*<.001).
Soederberg Miller & Bell, 2012 [71]	Educational level	Trust in online health information	Education is significantly correlated with trust in online health information (*P*<.01)
Yan, 2010 [74]	Educational level	Confidence in online health information	No significant effect of educational level on confidence in online health information.
Ye, 2011[a] [24]	Educational level	Trust in online health information	Educational level is not correlated to trust in online health information.

Author(s), date	Predictor	Specific measure used	Result
Zhao, 2010 [75]	US-born vs Foreign-born (significantly different educational background)	Trust in online health information	Foreign-born Hispanics have lower trust in online health information compared with their US-born counterparts (higher educational level) (55% vs 86%, P=.016).
Zulman et al, 2011 [77]	Educational level	Trust in online health information	Those with high school or less are significantly less likely to trust online health information than college graduates (OR 2.47, P<.001).
Clayman et al, 2010 [47]	Other skills-based proxies for health literacy – Comfort speaking English	Trust in online health information	Those less comfortable speaking English report lower trust in online health information compared with those more comfortable speaking English (P<.01).
Ye, 2011[a] [24]	Other skills-based proxies for health literacy – Hard to understand health information	Trust in online health information	The harder the health information is to understand, the less trust there is in online health information, $F_{1,100}$=11.85, P<.01; β=.07, SE 0.02).

[a] Study reported twice because it described the impact of both educational level and other skill-based proxies for health literacy on trust in online health information.

Use of Evaluation Criteria

Five studies (14%) investigated the last outcome of interest, namely people’s use of evaluation criteria for online health information (Table 5 [42,49-51,60]).

Only the study by Mackert et al [60] was about health literacy. This study, conducted in a low health literate-only sample, showed that low health literates used position in search results, quality of pictures, celebrity endorsement, and website authorship as criteria to evaluate online health information. With regard to website authorship, the study showed that almost all participants lacked trust in government or religious authorities as sources of online health information, whereas university researchers were generally considered trusted information providers.

Reliance on website authorship as an evaluation criterion was also found in one of the studies investigating the role of educational level. In his study, Dutta-Bergman [49] showed that educational level was positively associated with trust in information coming from medical universities and federal institutions and negatively associated with trust in information from health insurance companies. No differences related to education were found with regard to trust in online health information coming from the local doctor. Bates et al [42] showed that there was no consistent relationship between educational level and using readability of websites as a criterion to evaluate website quality. This finding suggests that ease of reading is not widely used as a criterion to evaluate the quality of the websites. Gauld and Williams [51] found that respondents with higher educational level were more likely to check credentials (eg, name or qualifications of the author) when evaluating health websites.

With regard to the role played by other skills-based proxies, Feufel and Stahl [50] showed in their study among skilled and less-skilled people that consistency with search intentions was used as a criterion to evaluate online health information. However, consistency referred to different things in the two groups: for the majority of less-skilled participants, this meant that a website confirmed a priori opinions, while for the majority of skilled participants, this meant that a website yielded the information that was searched for.

Table 5. Outcome 4: Use of evaluation criteria.

Author(s), date	Predictor	Evaluation criteria	Result
Mackert et al, 2009 [60]	Low health literacy (S-TOFHLA) only sample	Heuristics: Website position in search results; picture quality; celebrity endorsement; website authorship	Participants use heuristics to evaluate online health information quality: position in search results; quality of pictures; celebrity endorsement. Almost-universal lack of trust in the government and in religious figures as sources of online health information. University researchers are trusted sources as information providers.
Bates et al, 2007 [42]	Educational level	Website readability	No consistent relationship between educational level and using readability of websites as a criterion to evaluate website quality.
Dutta-Bergman, 2003 [49]	Educational level	Website authorship	Education does not impact trust on online health information from the local doctor. Trust in the local hospitals (*t*=3.83, *P*<.001) and in health insurance companies (*t*=1.90, *P*=.05) as sources of online health information is negatively associated with education. Individuals with higher trust in medical universities (*t*=11.83, *P*<.001) and federal sources (*t*=7.45, *P*<.001) are more educated than their counterparts.
Gauld & Williams, 2009 [51]	Educational level	Website credentials	Lower educational level decreases the likelihood to check credentials of health websites.
Feufel & Stahl, 2012 [50]	Other skills-based proxies for health literacy – Skilled (30 years of age, had a higher level of education, and were more experienced using the Web) vs less-skilled (≥50 years of age)	Consistency with search intentions	Overall, online health information is trusted if consistent with search intentions—among less-skilled participants this means if a website confirms a priori opinions (21/30, 70%) or yields search contents (9/30, 30%), and among skilled participants if a website confirms a priori opinions (4/28, 14%) or yields search contents (24/28, 86%).

Discussion

Principal Findings

People's health literacy is deemed to play an important role in the context of online health information seeking because according to most definitions it includes the ability to evaluate health information from different sources [12-19]. One of the main aims of this review was to identify and systematically summarize existing literature in order to collect evidence on the effect of low health literacy on the evaluation of online health information. The review provided us with indications of an overall (positive) association between health literacy (or one of its skills-based proxies) and both people's ability to evaluate online health information (RQ1) and trust in the Internet as a source of health information (RQ3). On the other hand, evidence on the association between health literacy and both perceived quality of online health information (RQ2) and people's use of evaluation criteria for online health information (RQ4) was inconsistent.

The limited number and the heterogeneity of studies using health literacy as a predictor makes it hard to get a clear picture of how people's health literacy levels impact the evaluation of online health information. However, the included studies give us some indications that low health literacy may have a negative impact. Indeed, low health literate individuals use evaluation criteria that do not correspond to the well-established quality criteria [9]. To illustrate, one study reports that they do not trust online health information from the government or that they use the position of a website in search results or the quality of images to evaluate the quality of online health information [60], whereas evidence shows that information provided from institutional sources is usually accurate [80,81] and that position in search results and image quality are not among the criteria that should be used to judge the quality of a website [9]. This could at least partly explain why, as reported in another study [43], low health literate respondents, compared to their high health literate counterparts, have been shown to give higher-quality ratings to low-quality websites, and lower ratings to high-quality websites. At the same time, it has also been found that low health literacy is correlated with lower eHEALS scores (which include people's perceived ability to evaluate online health information). Confidence in one's own information skills has been shown to be positively related to information use [82].

What was observed in the few studies about health literacy was mostly confirmed in the higher amount of studies investigating differences in the evaluation of online health information related to educational level or other health literacy-related skills. Although we recognize that the diversity of measures used and the reliance on dichotomous measures of educational level may limit the accuracy of the results [40], this gives us more confidence in our findings. Included studies have shown that, overall, individuals with lower educational levels have worse actual and self-rated skills to evaluate the quality of online health information and lower trust in online health information compared to their more educated counterparts. Regarding perceived quality of online health information or people's use of evaluation criteria, the limited number of studies and the diversity of samples and measures, however, does not allow us to draw conclusions about the impact of educational level or other skills-based proxies of health literacy, leaving two of the main research questions of this study mainly unanswered.

Besides providing us with indications on the role played by people's health literacy in their evaluation of online health information, our review also highlighted some important gaps and limitations of research in this field. The main gap identified is probably the fact that, despite the undeniable theoretical importance of health literacy for online health information seeking, only four studies have specifically investigated the association between health literacy and the evaluation of online health information. Moreover, one of these studies was conducted in a low health literacy-only sample [60], not allowing comparisons across different health literacy levels. All the other studies in our review compared people with different educational levels or different levels of other literacy-related skills.

A second important limitation of current research highlighted by the review is the lack of shared definitions and measures. This has been shown to be the case not only for health literacy but also for other more commonly used predictors such as educational level, making comparisons across studies and summaries of existing evidence almost impossible. Additionally, only a few studies measured actual online health information evaluation skills, asking their participants to perform actual evaluation tasks. All the other studies relied on the participants' self-rated ability. As shown in the study by van der Vaart et al [83], who compared their respondents' eHEALS scores with an Internet performance test, self-rated ability does not seem to adequately capture people's actual skills. Further research efforts should thus be devoted to the development and validation of a shared measure of online health information evaluation skills that is better able to reflect people's real ability in this context.

Last, among the studies investigating more than one outcome variable, no information was found on the relationship between them. For this reason, no conclusions can be drawn on the interplay among the different evaluative dimensions.

Limitations

This review has several limitations. The first limitation consists of the limited number of studies using health literacy as a predictor. Despite the fact that education has been shown to be related to (and it is often used as a proxy for) health literacy (eg, see [84]), this fact limits the extent to which our results can be generalized. A second important limitation of this review is the fact that all the included studies were non-interventional, with the consequence that the overall quality of the evidence has to be considered low [78]. Although causality is not an issue in this context (information evaluation cannot influence people's literacy level), the uncontrolled nature of cross-sectional studies might fail to account for alternative explanations for the phenomenon under investigation [85]. This adds to the limited generalizability of the findings of this review. Finally, due to the heterogeneity of samples and outcome measures, it was not possible to conduct a meta-synthesis, with the result that no quantitative summary of the evidence could be provided.

Conclusions and Future Directions

Despite its limitations, this systematic review on the role of health literacy in the evaluation of online health information has provided us with important insights on this topic. These insights have allowed us to draw some preliminary conclusions and, most importantly, have highlighted the main outcomes and limitations of current research in this relatively new and unexplored field.

From a research perspective, our findings are to be considered an indication of the fact that health literacy indeed plays a role in the evaluation of online health information and thus this topic is worth more scholarly attention. Based on the results of this review, the future research agenda in this field should include (1) a specific focus on health literacy, (2) more attention to the identification of the different criteria people use to evaluate online health information, (3) the development of shared definitions and measures for the most commonly used outcomes in the field of evaluation of online health information, and (4) the assessment of the relationship between the different evaluative dimensions and the role played by health literacy in shaping their interplay. Only by first addressing these research gaps will it be possible, in line with what has been called for in a recent Cochrane review [86], to develop high-quality interventions to enhance low health literacy individuals' ability to appraise online health information as well as to develop well-designed randomized controlled trials to investigate their effects. A better understanding of how people appraise online health information is also crucial in view of the investigation of the impact of their information evaluation ability on their interactions with health care providers and ultimately on health outcomes.

From a practice perspective, the results of this review should be sufficient to urge public health officials and health care providers to start devoting particular attention to the online health information seeking behavior of low health literate citizens and provide them with targeted advice on criteria to correctly assess the quality of the information they find online.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Search strategy.

[PDF File (Adobe PDF File), 34KB - jmir_v17i5e112_app1.pdf]

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Abbreviations

CINAHL: Cumulative Index to Nursing and Allied Health Literature
eHEALS: eHealth Literacy Scale
HINTS: Health Information National Trends Survey
MeSH: Medical Subject Headings
S-TOFHLA: Short Test of Functional Health Literacy in Adults
TOFHLA: Test of Functional Health Literacy in Adults

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Original Paper

Utilizing the Wikidata System to Improve the Quality of Medical Content in Wikipedia in Diverse Languages: A Pilot Study

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Abstract

Background: Wikipedia is an important source of medical information for both patients and medical professionals. Given its wide reach, improving the quality, completeness, and accessibility of medical information on Wikipedia could have a positive impact on global health.

Objective: We created a prototypical implementation of an automated system for keeping drug-drug interaction (DDI) information in Wikipedia up to date with current evidence about clinically significant drug interactions. Our work is based on Wikidata, a novel, graph-based database backend of Wikipedia currently in development.

Methods: We set up an automated process for integrating data from the Office of the National Coordinator for Health Information Technology (ONC) high priority DDI list into Wikidata. We set up exemplary implementations demonstrating how the DDI data we introduced into Wikidata could be displayed in Wikipedia articles in diverse languages. Finally, we conducted a pilot analysis to explore if adding the ONC high priority data would substantially enhance the information currently available on Wikipedia.

Results: We derived 1150 unique interactions from the ONC high priority list. Integration of the potential DDI data from Wikidata into Wikipedia articles proved to be straightforward and yielded useful results. We found that even though the majority of current English Wikipedia articles about pharmaceuticals contained sections detailing contraindications, only a small fraction of articles explicitly mentioned interaction partners from the ONC high priority list. For 91.30% (1050/1150) of the interaction pairs we tested, none of the 2 articles corresponding to the interacting substances explicitly mentioned the interaction partner. For 7.21% (83/1150) of the pairs, only 1 of the 2 associated Wikipedia articles mentioned the interaction partner; for only 1.48% (17/1150) of the pairs, both articles contained explicit mentions of the interaction partner.

Conclusions: Our prototype demonstrated that automated updating of medical content in Wikipedia through Wikidata is a viable option, albeit further refinements and community-wide consensus building are required before integration into public Wikipedia is possible. A long-term endeavor to improve the medical information in Wikipedia through structured data representation and automated workflows might lead to a significant improvement of the quality of medical information in one of the world's most popular Web resources.

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KEYWORDS

Internet; Wikipedia; drug information services; semantic networks; medical informatics; drug interactions

Introduction

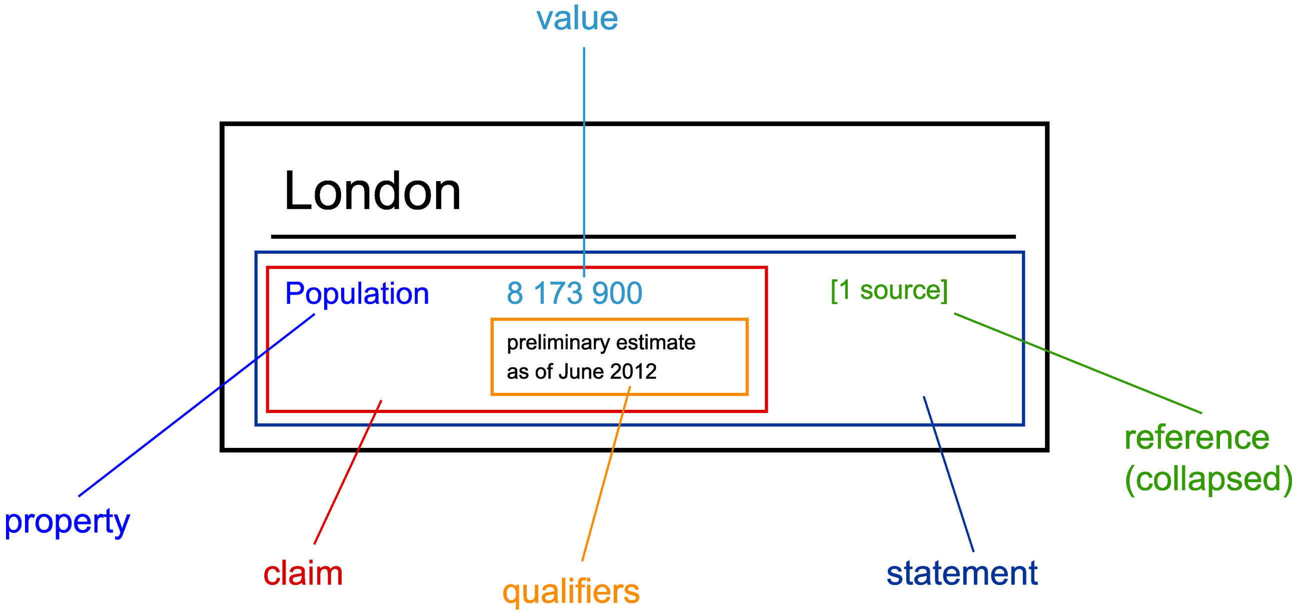
Wikipedia is an important source of medical information for both patients and medical professionals [1,2]. Medical Wikipedia content is made up of more than 150,000 articles in 255 languages [3]. Given its wide reach, improving the quality, completeness, and accessibility of medical information on Wikipedia could have a positive impact on global health. For example, adverse events caused by drug-drug interactions (DDIs) are a significant cause of morbidity [4], but adverse event data on Wikipedia is currently incomplete in ways that might cause harm to patients [5-7].

To address these issues, we created a prototypical implementation of an automated system for keeping drug information in Wikipedia up to date with current evidence about clinically significant drug interactions. Our work is based on Wikidata [8,9], a novel database backend of Wikipedia currently in development. Wikidata is a large, community-edited, multilingual graph database aiming to capture facts in a centralized store that can be dynamically queried and displayed by different language versions of Wikipedia. As such, Wikidata could emerge as a community-backed and highly visible structured knowledge base of medical and biological information, bringing concepts and methodologies such as controlled taxonomies, Semantic Web / semantic technologies and ontologies into mainstream use.

The data model of Wikidata is exemplified in Figure 1. The model differs from that of common databases in that information is captured through property-value pairs and each entry is individually sourced. A property resembles a field for a specific piece of information (eg, the population of a city). To complete the pair, a value is added for this property (eg, a population count of 8,173,900). Together this pair is called a *claim* and it is the smallest amount of information that can be added to Wikidata. A claim can also contain qualifiers that put the value into context (eg, the year of the population estimate is given). Each claim can have a multitude of qualifiers. The practice of using claims (instead of “facts”) reflects the notion that Wikidata anticipates and embraces situations in which conflicting claims are made when different sources might disagree. An advantage of this data model is that only claims with sources are considered as complete statements and that disagreement in the sources can be modeled by adding multiple statements.

At the time of this writing (November 2014), Wikidata contained 50 million statements about more than 12 million data items and had more than 13,000 active participants. However, the large-scale participative character of Wikidata and its integration with Wikipedia also lead to unprecedented challenges. In this paper, we describe a pilot project utilizing the Wikidata system to improve information on DDIs in Wikipedia. The aim of this pilot is to provide insights into strategies for improving drug safety data in Wikipedia and provide guidance on utilizing the Wikidata system for capturing, sharing, and accessing biomedical knowledge in general.

Figure 1. The structure of a statement in Wikidata. Source: [10].



Methods

Drug-Drug Interaction Data

We reviewed openly available DDI knowledge bases, including Drugbank [10], the National Drug File-Reference Terminology (NDF-RT) [11], a short list of clinically important and common DDIs maintained by the CredibleMeds nonprofit organization [12], the Office of the National Coordinator for Health Information Technology (ONC) “high priority” list of potential DDIs suggested as high priority to alert clinicians in any care environment [13], and the ONC “noninterruptive” list of potential DDIs not requiring interruptive alerting in any care environment [14]. We decided to include only clinically relevant potential DDIs that had high priority and were curated by teams of experts in order to avoid overloading the knowledge base with large numbers of interactions that were not critical or not backed by sufficient evidence [14]. We selected the ONC high priority list for these reasons, reserving the possibility of further extension of the knowledge base at a later point in time.

Adding Data to Wikidata and Wikipedia

The process for adding potential DDI data to Wikidata consisted of several steps and community interactions. First, we registered for accounts on the Wikidata system. In general, every person with or without an account can directly edit data pages via the Wikidata website. Complex contribution tasks are usually organized through WikiProjects (eg, WikiProject Medicine), which are the first points of contact for people who share a specific goal in Wikidata development. If users want to be part of a WikiProject, they simply have to add themselves to the project participant list. We joined the Wikidata Medicine project [15].

We researched if appropriate Wikidata properties currently existed or if it would be necessary to create a new Wikidata property. We found no existing property for capturing potential DDIs, so we drafted a proposal for a new property and submitted it for community discussion and voting (discussion archived at [16]). Three discussants participated in this discussion. After the name, description, and semantics were refined by us based on community feedback and the utility and novelty of the property were ascertained, the proposed property was accepted and added to the Wikidata system [17]. Major discussion points were the inclusion of food-drug interactions, whether the property should be symmetric or should be nonsymmetric to discern precipitant and objects drugs, and whether existing properties for physical interactions between objects could be reused. The entire process took 1 week. Minor backwards-compatible refinements to the property definition were conducted at later stages of the process based on requirements that became apparent during data loading. After a property is created, any user can translate it. Additionally, property constraint can be set that help to find mistakes in the data when such constraints are violated.

We created a Wikidata “bot” (a program that autonomously adds or edits content) for automatically adding and updating interactions from the larger ONC high priority list. The implementation and application of the bot was discussed with the Wikidata community until consensus on its utility and the scope of the imported data was reached (discussion archived at [18]). Eight discussants participated in this discussion.

To operate the bot, we registered a separate bot account and created a request for permission (as stated in the Wikipedia bot policy [19]). The request’s text included a description of our team and the bots main functionality and goals. The resulting discussion included 8 other Wikipedians (mainly members of the WikiProject Medicine) and spanned more than a month before the bot was approved by a Wikidata “bureaucrat” (the official title of members responsible for such decisions in the Wikipedia/Wikidata community). The bot was created by using the Pywikibot framework, which is a collection of Python scripts for maintaining different MediaWiki sites [20]. We derived the bot from a basic template script [21], which is part of the Pywikibot software package and used specific functionality geared toward Wikidata editing. The code of the bot we created is available on GitHub [22].

We created modified templates of drug infoboxes for the English and German Wikipedia that utilize potential DDI data from the Wikidata knowledge base; Infoboxes are templates that typically accompany a Wikipedia article and are usually displayed at the top-right of a page. They typically contain the most important facts about a Wikipedia entry. We copied selected Wikipedia articles into an online development environment and integrated the modified drug infobox templates so that potential DDI data from Wikidata were automatically shown in the resulting Wikipedia articles. This workflow can potentially be implemented for any of the more than 288 languages of Wikipedia as long as the property name and the statement’s values are translated. These articles were used as a proof of concept and to predict how information from Wikidata would be displayed in Wikipedia with current technologies.

For this pilot study, we implemented these changes in a segregated Wikipedia development environment instead of the main system because changes to widely used templates (eg, the drug infobox) usually require extensive discussion. Given that the Wikidata application program interface (API) is still not fully stable, large-scale adoption of Wikidata-based infoboxes are not yet approved by the community. The Wikipedia development environment is not technically different from normal Wikipedia, but it is less visible (eg, Web search engines do not usually point to pages in the development environment).

Analysis

We conducted a pilot analysis to explore if adding the ONC high priority data would significantly enhance the information currently available on Wikipedia in terms of coverage of significant potential drug interactions. We developed a simple script that analyzed English Wikipedia articles of substances in the ONC high priority list and checked if interacting substances were mentioned in the current Wikipedia article through string matching.

Finally, an expert clinical pharmacist (JH) conducted a detailed evaluation of the current Wikipedia DDI information available for 2 examples of drugs on the ONC list (ramelteon and warfarin). A standard reference for clinically important DDIs coauthored by the expert was used as basis for the evaluation [23].

Results

We derived 1150 unique interactions from the ONC high priority list. The coverage of active ingredients in Wikidata was exhaustive and we did not need to create new entities. A screenshot of an example of the data represented in Wikidata is shown in Figure 2 and screenshots of the same data as represented in an infobox in the German and English Wikipedia are shown in Figure 3.

Integration of the potential DDI data from Wikidata into the Wikipedia infobox proved to be straightforward and yielded useful results, but also highlighted potential shortcomings of the current system. We recognized difficulties with making long lists of interacting drugs accessible through the infoboxes because some drugs had interactions with up to 30 other drugs. This problem could be addressed by hiding long lists of interacting drugs behind expandable user interface elements, which is already done for other use cases (eg, gene ontology term annotations on protein articles), or by removing other information that might be of lower interest. Still, the existence of these long lists of interactions for some drugs might lead to unsatisfactory usability or reduced findability of important information. An alternative could be the integration of the Wikidata information into the main text of the Wikipedia article as exemplified in Figure 4.

Another shortcoming of the current integration of Wikidata into Wikipedia that was uncovered by our prototype is the way in which literature citations/evidence is rendered. Although backing evidence from Wikidata can be displayed through endnote references in Wikipedia, the Wikipedia system currently does not recognize that multiple citations may point to a single reference, leading to the creation of redundant reference list entries. Furthermore, the current system is only able to display the titles of literature references, but does not provide a formatted endnote with all bibliographic details (eg, authors, journal, and publication year). These current limitations reduce the ability of Wikipedia readers to efficiently check the evidence behind data from the Wikidata knowledge base. However, given the novelty of Wikidata and the ongoing development of the database interfaces, this limitation will soon disappear.

Figure 2. Screenshot of drug interaction data for the pharmaceutical ramelteon in the Wikidata system. A large number of other properties not pertaining to drug-drug interaction data have been removed from the screenshot.

Ramelteon (Q417689)

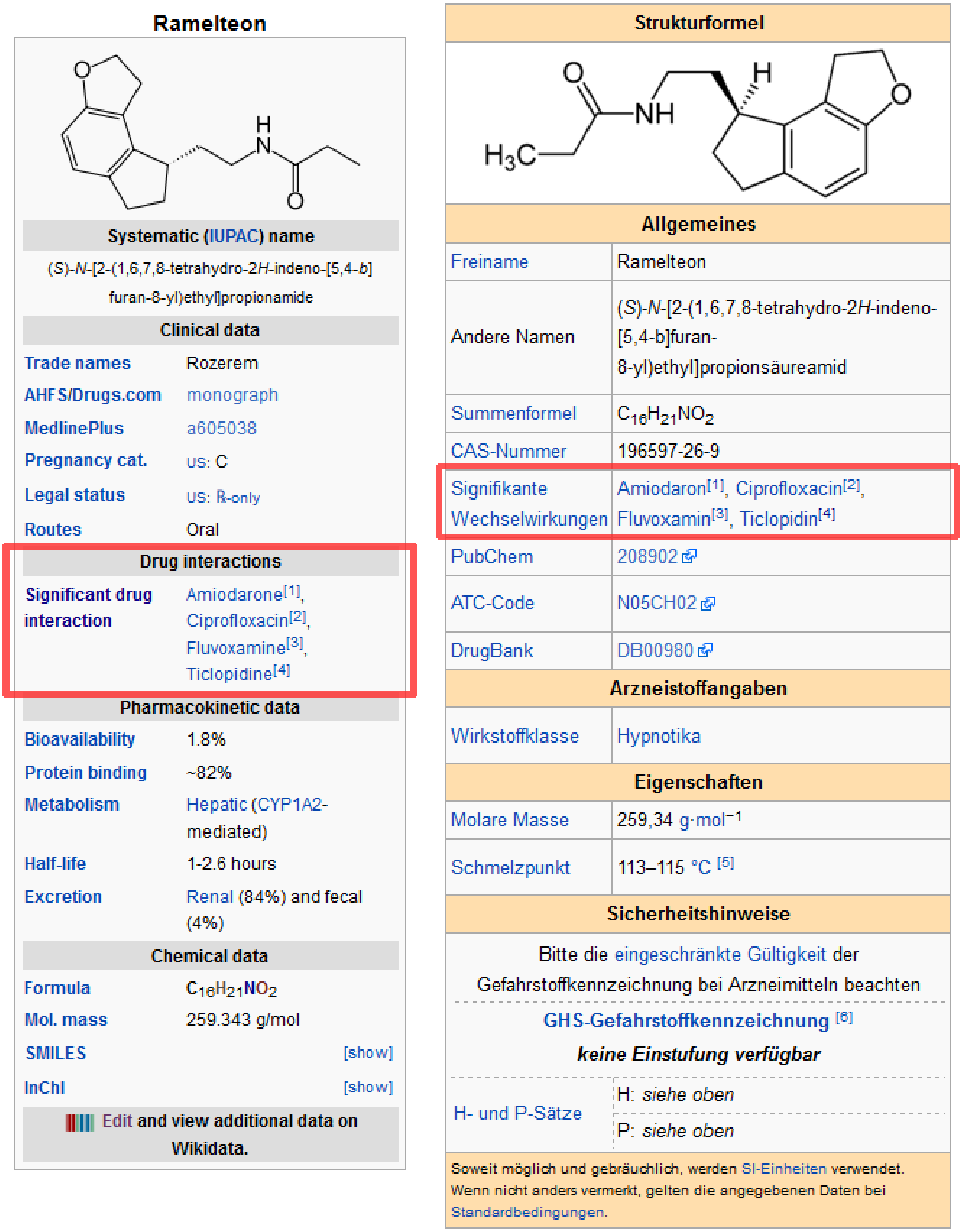
enter a description in English

Also known as:

significant drug interaction: Amiodarone; Ciprofloxacin; Fluvoxamine; Ticlopidine

Language	Code	Linked page
Deutsch	dewiki	Ramelteon
English	enwiki	Ramelteon
日本語	jawiki	ラメルテオン

Figure 3. Screenshots of the English and German infoboxes of the pharmaceutical ramelteon. Drug interaction data automatically queried from the Wikidata knowledge base is highlighted.



Ramelteon

Systematic (IUPAC) name

(*S*)-*N*-[2-(1,6,7,8-tetrahydro-2*H*-indeno-[5,4-*b*]furan-8-yl)ethyl]propionamide

Clinical data	
Trade names	Rozerem
AHFS/Drugs.com	monograph
MedlinePlus	a605038
Pregnancy cat.	US: C
Legal status	US: ℞-only
Routes	Oral
Drug interactions	
Significant drug interaction	Amiodarone[1], Ciprofloxacin[2], Fluvoxamine[3], Ticlopidine[4]
Pharmacokinetic data	
Bioavailability	1.8%
Protein binding	~82%
Metabolism	Hepatic (CYP1A2-mediated)
Half-life	1-2.6 hours
Excretion	Renal (84%) and fecal (4%)
Chemical data	
Formula	$C_{16}H_{21}NO_2$
Mol. mass	259.343 g/mol
SMILES	[show]
InChI	[show]

Edit and view additional data on Wikidata.

Strukturformel

Allgemeines	
Freiname	Ramelteon
Andere Namen	(*S*)-*N*-[2-(1,6,7,8-tetrahydro-2*H*-indeno-[5,4-b]furan-8-yl)ethyl]propionsäureamid
Summenformel	$C_{16}H_{21}NO_2$
CAS-Nummer	196597-26-9
Signifikante Wechselwirkungen	Amiodaron[1], Ciprofloxacin[2], Fluvoxamin[3], Ticlopidin[4]
PubChem	208902
ATC-Code	N05CH02
DrugBank	DB00980
Arzneistoffangaben	
Wirkstoffklasse	Hypnotika
Eigenschaften	
Molare Masse	259,34 g·mol⁻¹
Schmelzpunkt	113–115 °C [5]
Sicherheitshinweise	

Bitte die eingeschränkte Gültigkeit der Gefahrstoffkennzeichnung bei Arzneimitteln beachten

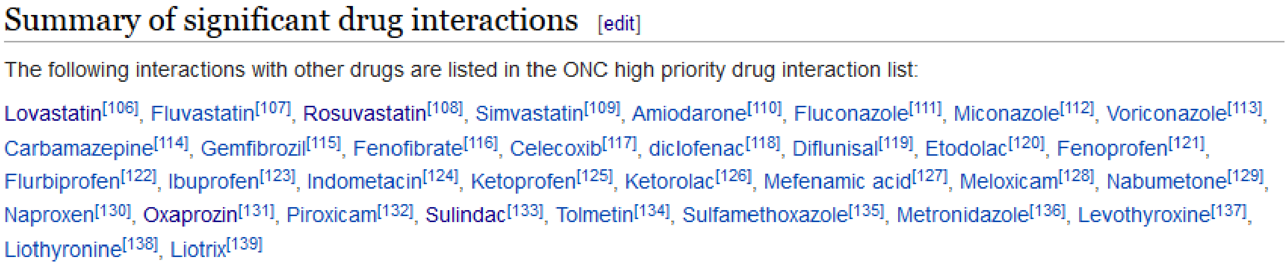
GHS-Gefahrstoffkennzeichnung [6]

keine Einstufung verfügbar

H- und P-Sätze	
H: *siehe oben*	
P: *siehe oben*	

Soweit möglich und gebräuchlich, werden SI-Einheiten verwendet. Wenn nicht anders vermerkt, gelten die angegebenen Daten bei Standardbedingungen.

Figure 4. Screenshot of a long list of drug interaction data from Wikidata embedded into the main text of a Wikipedia article. The example shows drugs interacting with warfarin.



Summary of significant drug interactions [edit]

The following interactions with other drugs are listed in the ONC high priority drug interaction list:

Lovastatin[106], Fluvastatin[107], Rosuvastatin[108], Simvastatin[109], Amiodarone[110], Fluconazole[111], Miconazole[112], Voriconazole[113], Carbamazepine[114], Gemfibrozil[115], Fenofibrate[116], Celecoxib[117], diclofenac[118], Diflunisal[119], Etodolac[120], Fenoprofen[121], Flurbiprofen[122], Ibuprofen[123], Indometacin[124], Ketoprofen[125], Ketorolac[126], Mefenamic acid[127], Meloxicam[128], Nabumetone[129], Naproxen[130], Oxaprozin[131], Piroxicam[132], Sulindac[133], Tolmetin[134], Sulfamethoxazole[135], Metronidazole[136], Levothyroxine[137], Liothyronine[138], Liotrix[139]

Statistics on Drug-Drug Interaction Information in Wikipedia

We found that even though the majority of current English Wikipedia articles about pharmaceuticals contained sections detailing contraindications, only a small fraction of articles explicitly mentioned interaction partners from the ONC high priority list in the article text (Table 1). For 91.30% (1050/1150) of the 1150 interaction pairs we tested, none of the 2 articles corresponding to the interacting substances explicitly mentioned the interaction partner. For 7.21% (83/1150) of the pairs, only 1 of the 2 associated Wikipedia articles mentioned the interaction partner, and for only 1.48% (17/1150) of the pairs both articles contained explicit mentions of the interaction partner.

Table 1. Statistics on coverage of drug-drug interaction (DDI) data in existing English Wikipedia articles compared to the ONC high priority list for 1150 DDI pairs tested.

Coverage	n (%)
Both articles of interacting pair contain explicit mention of interaction partner (symmetric occurrence). Example: amiodarone-simvastatin	17 (1.48)
Only 1 article of interacting pair contains explicit mention of interaction partner (asymmetric occurrence) Example: fluoxetine-phenelzine	83 (7.21)
None of the 2 articles of interacting pair contain explicit mention of interaction partner	1050 (91.30)

A review of randomly selected articles showed that many contained implicit information about drug interactions by providing information about interacting drug classes or interactions with enzymes. However, in many cases, readers might not have the background knowledge necessary to infer actionable information from these statements (eg, the warning that a drug significantly inhibits the cytochrome P450 3A4 [CYP3A4] enzyme requires the knowledge that a potentially coadministered drug is metabolized by CYP3A4 to be of practical utility). We also observed that many articles that did not contain explicit mentions of interacting drugs from the ONC high priority list did mention interactions with other drugs that were not on the list, suggesting a significant overall discordance between drug interaction information on Wikipedia and the ONC high priority list.

It is also important to keep in mind that the ONC list is not intended to be inclusive of all clinically relevant DDIs because it was developed from a short list of interacting drug pairs and then expanded to include related drugs that also interact. This makes the lack of DDIs in Wikipedia even more disturbing because many important DDIs are simply missing.

Detailed Analysis of Exemplary Wikipedia Drug Articles

The following detailed analyses of DDI information in Wikipedia articles for the drugs ramelteon and warfarin exemplify some of the limitations of the current Wikipedia article coverage of DDIs from the perspective of a professional pharmacologist.

As noted in Figure 3, ramelteon is primarily metabolized by CYP1A2. CYP3A4 and CYP2C9 also contribute to its metabolism. Thus, any drug that alters the activity of CYP1A2, CYP3A4, or CYP2C9 is likely to alter the elimination of ramelteon. Ramelteon also has a very low bioavailability (amount of oral drug reaching systemic circulation) of 1.8%. This means that if a 10 mg dose of ramelteon is taken orally, less than 0.2 mg will reach the systemic circulation and produce a pharmacologic response. If another drug inhibits the metabolism of ramelteon, the amount of ramelteon reaching the systemic circulation will be increased, potentially to a very large extent.

Currently, Wikipedia notes several drugs that do not interact with ramelteon; however, it is not clear if the drugs have no effect on ramelteon or that ramelteon has no effect on the listed drugs. Actually, both outcomes are true. None of the drugs listed as noninteracting with ramelteon would be expected to interact because they do not affect any of the metabolic pathways that metabolize ramelteon. The Wikipedia entry further states:

> *A drug interaction study showed that there were no clinically meaningful effects or an increase in adverse events when ramelteon and the SSRI Prozac (fluoxetine) were coadministered. Ramelteon and fluvoxamine should not be coadministered. Ramelteon should be administered with caution in patients taking other CYP1A2 inhibitors, strong CYP3A4 inhibitors such as ketoconazole, and strong CYP2C9 inhibitors such as fluconazole. Efficacy may be reduced when*

> *ramelteon is used in combination with potent CYP enzyme inducers such as rifampin, since ramelteon concentrations may be decreased.*

Although no references are provided for the preceding statements, they appear to be taken from the ramelteon product label. We agree that ramelteon should be avoided in patients taking fluvoxamine because the label notes a 190-fold increase in ramelteon levels resulting from the interaction. Fluvoxamine inhibits CYP1A2 as well as CYP2C9 and CYP3A4. As noted previously, CYP1A2 is the primary enzyme that metabolizes ramelteon. Other drugs that inhibit CYP1A2 include atazanavir, ciprofloxacin, amiodarone, enoxacin, mexiletine, tacrine, thiabendazole, cimetidine, ticlopidine, zileuton, and vemurafenib, yet none of these are mentioned in the Wikipedia article. Likewise, there are many drugs that inhibit both CYP3A4 and CYP2C9 other that the 2 drugs listed in the article. For example, atazanavir, ciprofloxacin, and cimetidine inhibit 2 of the metabolic pathways of ramelteon and would potentially cause large increases in ramelteon plasma concentrations.

Warfarin is primarily metabolized by CYP2C9 with CYP1A2 and CYP3A4 also contributing to its elimination. Although too lengthy to reproduce fully here, Wikipedia notes drugs that "can displace warfarin from serum albumin and cause an increase in the international normalized ratio (INR)" can interact with warfarin. This is theoretically true; however, because the clearance of warfarin from the blood is limited to drug that is not attached to albumin, displaced warfarin is metabolized and the amount of active warfarin at steady state does not change so the INR is also unchanged.

Antibiotics such as metronidazole and macrolides are noted to "greatly increase the effect of warfarin" by reducing its metabolism. Metronidazole will reduce the metabolism of warfarin, as will several other antibiotics and antifungal agents that are not mentioned in the article and are likely to be more commonly used and produce larger changes in warfarin concentrations than the drugs cited. Macrolides do not appear to alter warfarin metabolism. They have been associated with enhanced warfarin effect, but this is likely due to other causes including the infection itself or altered diet. Several cases of altered warfarin response associated with thyroid activity are also cited in the article. It has been demonstrated that the administration of thyroid supplementation does not alter patients' response to warfarin. The Wikipedia article notes that excessive use of alcohol can increase the response to warfarin. This is true for binge drinking; however, chronic alcohol consumption is likely to increase the metabolism of warfarin leading to reduced response.

Several paragraphs in the article recount selected reports of herb-warfarin interactions. Most of the reports cited do not meet even minimal standards for evidence of an interaction and none of the trials showing no or minimal effects of the herbals on warfarin are included. This is an example of selection bias in DDI reporting.

As with the ramelteon article, the warfarin article omits many important DDIs. No mention is made of potent inhibitors of CYP2C9, such as amiodarone, sulfamethoxazole, fluconazole, voriconazole, or fluoxetine. No mention is made of drugs that can increase the risk of bleeding in patients taking warfarin, such as the nonsteroidal antiinflammatory drugs or acetaminophen.

Discussion

Principal Results

We implemented a process for enriching medical data in the Wikidata knowledge base and demonstrated that automated updating of medical content in Wikipedia through Wikidata is a viable option, albeit further refinements and community-wide consensus building are required before integration into public Wikipedia is possible. Adding data to Wikidata and Wikipedia is a lengthy process that requires lots of community interactions and familiarity with customs and requirements of the respective communities. We expect that actual integration into the self-governed Wikipedias in each language will require further refinement and substantial dialog with the different WikiProject Medicine communities.

Better data quality in Wikidata can reduce the maintenance work required in Wikipedia, giving editors more time to focus on the quality of articles. If an article exists in all 288 languages of Wikipedia, keeping it up to date or adding a piece of data with Wikidata amounts to a single edit compared to 288 edits without Wikidata. This helps to improve the completeness and currentness of medical content on Wikipedia, a resource that has become central to health information seeking among patients and health professionals on a global scale.

We had the experience that the Wikidata community was very open toward novel participants and provided constructive feedback and assistance with the integration of novel data into the complex Wikidata knowledge base. We decided to invite one Wikipedia member who provided significant support to become a coauthor of this manuscript (TS). Based on our experiences, we strongly recommend the inclusion of long-term Wikidata and Wikipedia community members in scientific or medical projects such as this one.

Wikidata is a recent addition to the Wikipedia ecosystem and its strengths and weaknesses in routine widespread use for serving complex data to Wikipedia or as a general-purpose knowledge base have yet to be determined. Although centralized data management in Wikidata can improve efficiency of data management and quality in Wikipedia, its integration into Wikipedia might also be a source of problems. Of special concern is the fact that not all data in Wikidata are necessarily displayed in Wikipedia and that the "many eyeballs" principle that helps to correct errors in Wikipedia might not apply to some of the content in Wikidata. The inclusion of data without long-term plans of maintenance or inclusion in visible Wikipedia articles might lead to a problematic accumulation of outdated data.

The review of the DDI entries for warfarin and ramelteon reveals the severe limitations of the current system to provide clinically important and useful DDI information. This problem might be partially mitigated by the strong community interaction and feedback that helps to decide which data to include or not include into Wikidata to keep the knowledge base manageable.

Furthermore, the usage of automated bots to import and map data from primary sources into Wikidata might play an important role. The bots can also make routine checks to determine if the different Wikipedias use the same data and if the data are a subset of the data in Wikidata. Wikidata is also developing tools to check for inconsistencies in the data. Furthermore, the community is not only tending to the Wikipedia-wide data but is also encouraged to report mistakes to the source database, thereby improving databases that are willing to share their data.

When we compared explicit mentions of potential drug interactions in Wikipedia with interactions from the ONC high priority list, we found a large amount of missing information in English Wikipedia. This might be even more pronounced in other language versions of Wikipedia that have, in general, fewer editors and worse coverage than English Wikipedia. This finding resonates with prior research that found substantial differences in drug interaction pairs captured in DDI knowledge bases [24,25]. The inclusion and exclusion criteria of a DDI knowledge base are vital to its practical utility. Although failing to include highly significant DDI can have obvious negative consequences, the permissive inclusion of large numbers of DDI backed by insufficient evidence or of low clinical significance can have a negative impact as well because it can lead to cognitive overload and the inobservance of truly significant interactions [13], frustrating clinicians [26] and leading to inappropriate responses [27]. The inclusion of clinically important DDIs based on critical evaluation of primary DDI evidence or established expert-curated DDI resources should be a goal of the Wikipedia/Wikidata community.

Limitations

The publication of medical data on a public website that includes readers from the general public requires special attention to ensure proper understanding of the data and its implications. In this regard, further work is required to reduce the risk of improper utilization of the data (eg, making it clear that nonoccurrence in the list does not imply that a certain drug combination does not carry risks of adverse events). Furthermore, when the current implementation notes a potential interaction, it does not provide further information on the mechanism of the interaction or potential actions to mitigate patient risk.

A major limitation of our current implementation is the disjoint presentation of potential DDI data from Wikidata and potential DDI information in the main text of the Wikipedia article. The potential redundancies and differences between the 2 information sources might further add to this confusion and automatic checks comparing the Wikipedias to Wikidata are not in place yet for drug interactions. In order to have all potential DDI information in one place, integrating potential DDI data as a table into main text under a “drug interactions” heading might be preferable to the inclusion in the infobox on the upper right hand of the page. Furthermore, editing policies need to be set up to clarify the relation between structured data from Wikidata and unstructured text in Wikipedia. Routine checks by bots, possibly after every edit to a drug page, could potentially determine if the interactions listed are a subset of the data in Wikidata. We will investigate the automated inclusion of structured data into the main article once the necessary features in both Wikipedia and Wikidata have reached sufficient maturity, which was not yet the case at the time of this writing.

A limitation of our evaluation methodology was that the string matching approach used for identifying DDI mentions might have missed mentions that used drug class references rather than individual substances.

Comparison With Prior Work

The Wikidata WikiProject Medicine that we are participating in is also involved in other endeavors, such as managing sitelinks for medical topics or connecting medical topics with their corresponding identifiers in medical databases. Furthermore, a WikiProject for molecular biology content on Wikidata was recently established [28].

Wikidata might also become an interesting platform for large-scale, graph-based knowledge integration tasks in the biomedical field that have been realized with Semantic Web technologies in recent years, such as Linked Open Drug Data [29] or Bio2RDF [30]. Further research and pilot projects are needed to fathom the potential of Wikidata to become a centralized repository of large-scale medical and life science data.

Conclusions

We believe that this work provides a foundation for a long-term endeavor to improve the medical information in Wikipedia through structured data representation and automated workflows. It will strengthen the collaboration with the medical Wikipedia community to bring high-quality information on drug safety into production use as part of Wikipedia in diverse languages. We will also seek to align our work on drug safety information in Wikidata with projects in related domains, such as biomedical research and the life sciences [31,32].

Finally, we are currently preparing a collaboration with international experts in clinical pharmacology and drug safety to establish and maintain a machine-readable, open-source representation of important DDIs based on the ONC high priority list as well as other sources. The establishment of such a resource could not only benefit the quality of drug safety data in Wikipedia, but also improve the quality of clinical decision support interventions or even drug product labels [33].

To have a sustained impact, it is vital that the Wikipedia community carries this work further in both the structured world of Wikidata and the textual world of Wikipedia. We invite interested readers to join this effort.

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Authors' Contributions

MS devised the study and wrote major parts of the manuscript; AP and TS led Wikidata community interaction, design decisions, and technically implemented the pilot system; RB gave advice about DDI datasets and overall strategy; and JH conducted an in-depth review of 2 Wikipedia drug articles. All authors contributed to writing the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

API: application program interface
DDI: drug-drug interactions
INR: international normalized ratio
ONC: Office of the National Coordinator for Health Information Technology

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