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Editorial

Toward Impactful Collaborations on Computing and Mental Health

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Abstract

We describe an initiative to bring mental health researchers, computer scientists, human-computer interaction researchers, and other communities together to address the challenges of the global mental ill health epidemic. Two face-to-face events and one special issue of the *Journal of Medical Internet Research* were organized. The works presented in these events and publication reflect key state-of-the-art research in this interdisciplinary collaboration. We summarize the special issue articles and contextualize them to present a picture of the most recent research. In addition, we describe a series of collaborative activities held during the second symposium and where the community identified 5 challenges and their possible solutions.

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KEYWORDS

mental health; human-computer interaction; digital interventions; interdisciplinary collaboration

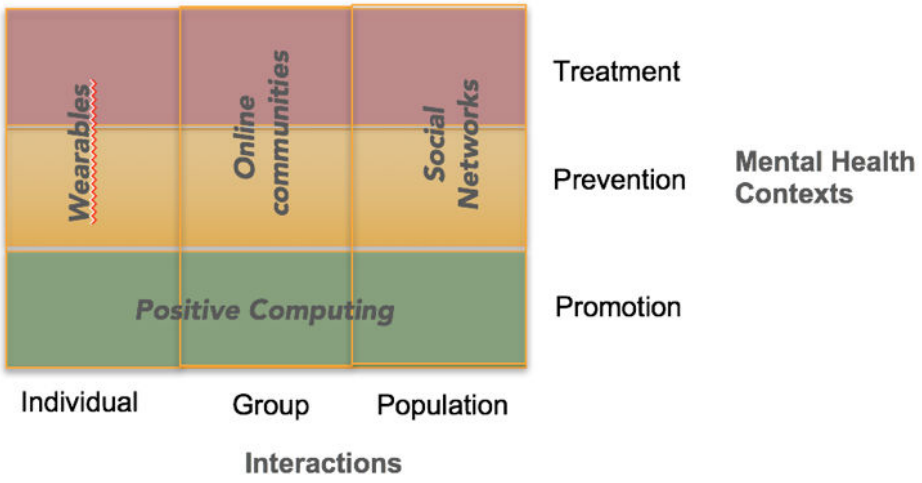
Introduction: Computing and Mental Health

Whether measured in terms of suffering, disability, or economics, the devastating impact of mental ill health continues to grow. In 2017, the World Health Organization labeled depression as the single leading cause of global disability [1], and in 2016 there were nearly 800,000 suicides worldwide [2]. With a projected global shortage of mental health clinicians, especially in low- and middle-income countries [3], new solutions are urgently needed. The uniting of computing and mental health fields offers the potential to bring easily accessible, scalable, affordable, and innovative tools for preventing mental health problems and for improving the overall mental health of the global population [4] as the articles in this special issue exemplify. However, the first step toward joint computing and mental health solutions is to actually bring these two often disparate communities together.

This joint community started as “a gathering of researchers from health, psychology, psychiatry, and human-computer interaction (HCI) meeting together to consider ways technology can be used to improve psychological wellbeing” (pg 3439) [5]. At the first gathering in 2016, we introduced a schematic and taxonomy to conceptualize technologies to support mental health and well-being (see Figure 1). In Figure 1, the vertical axis represents 3 commonly used categories in mental health care: treatment (interventions aimed at addressing illness), prevention (aiming to reduce risk), and promotion (fostering optimal mental health universally in line with the concept of mental health flourishing [6]). The horizontal axis indicates the target level of the intervention: individual (eg, one-to-one counseling session, journal writing), group (eg, online community intervention), or general population (eg, Facebook).

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Figure 1. Taxonomy for technologies in mental health and well-being (adapted from Calvo et al [5], with permission from the author).



Positive computing is defined as "the design and development of technology to support psychological well-being and human potential" [7]. While every taxonomy has limitations, this organizational structure for mental health technologies enables identification of well-researched areas, as well as those deserving of further investigation.

For the inaugural symposium held in Silicon Valley, California, USA, in May 2016, we received 72 submissions, reflecting a high level of interest in the topic. Most articles (n=47, 65%) focused on depression and anxiety. Interestingly, although the HCI community is paying increased attention to ways in which technology can support well-being and health promotion, only 22 (30%) of the total submissions to the first event addressed some aspect of mental health promotion or flourishing. Those submissions categorized as mental health promotion addressed physical health (n=10, 20%), sleep (n=8, 16%), strength (n=12, 24%), psychoeducation (n=14, 28%), and antistigma (n=6, 12%). This focus on illnesses versus health promotion and flourishing may reflect the representation of mental health researchers at the event. During the first event, participants expressed their interest in a follow up event and a special issue. These are described in the following sections.

The second Symposium on Computing and Mental Health was held in May 2017 [8]. It was organized in tandem with a special issue published by JMIR Publications. The symposium format allowed participants to meet face-to-face, discuss issues of significance to the community, and disseminate their work. This meeting was complemented by the special issue, which provided an easily accessible and archival publication of relevant peer-reviewed papers, while also maintaining the open access element that many participants thought was important for multidisciplinary collaborations. Participants with a paper accepted in this special issue were invited to give an oral presentation about their work, while other participants were invited to present a poster. In addition, some participants used the event as an educational or networking opportunity.

Further information about the symposiums and special issue can be found at the Computing and Mental Health website [9], and the call for papers for this special issue can be found at the JMIR website [10].

The Special Issue

The second workshop and associated special issue received 65 submissions, of which 20 were accepted for publication in the special issue. Here we use the taxonomy described in Figure 1 to guide discussion of these articles. Numerous articles actually addressed all 3 mental health contexts of the taxonomy (promotion, prevention, and treatment) but, to better organize this special issue, we have classified articles into a single context.

Promotion

Promotion, the support of positive mental health, focuses on strategies to improve quality of life rather than the reduction of symptoms. Thus, promotion, in line with the concept of mental health flourishing, aims at preventing future mental health problems and reducing the global burden of mental health. The HCI community has a fast-growing interest in how technologies can be designed to support positive mental health and flourishing [7]. Articles in this category of the special issue, and several other presented as posters, focused on how computing and mental health can be successfully combined to augment mental health and well-being.

Yarosh and Schueller [11] demonstrated how promoting mental health and wellness need not be limited to traditional adult populations. The authors used participatory design approaches to understand children's (N=12) interpretations of positive psychology concepts. They analyzed almost 500 artifacts produced by the children over the course of 14 participatory design sessions. The article provides insights into how children conceive mental health promotion skills such as gratitude, mindfulness, and problem solving. Peters and colleagues [12] also used participatory design approaches to explore how young people conceive their lives with asthma as a window into mental health promotion and understanding their psychological needs [13]. Participants produced artifacts (collages, paper prototypes, and concept maps) that provided evidence of how important basic psychological needs (eg, autonomy, competence, and relatedness) are for their quality of life. The focus here was an app, a technology to be used by a single individual. Also focusing on an individual device, Zhu and colleagues [14]

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evaluated a physical device to encourage mental health promotion, a mindful breathing tool (a single-user technology) for stress reduction. The evaluation consisted of a pilot study and structured interviews to learn how this device benefited mental health promotion. Paredes and team [15] explored how the daily commute could be used to improve mental health through mindfulness interventions. Participants described their individual perceptions of movements and vibrotactile patterns in a driving simulation.

Rather than talking directly with potential users, Huang and Bashir [16] explored how information cues, such as ratings and reviews in the app store, may affect mental health promotion through the adoption of mental health apps. Their results show that ratings and reviews have higher correlations with installs than price and privacy settings.

Saha and colleagues [17] studied mental health promotion through public awareness about schizophrenia using data from Facebook's advertising platform. Facebook collects data from within its products (eg, likes) and from websites that use its marketing tools. These data, which are generally used for personalizing ads, were used instead to estimate a schizophrenia awareness index. Finally, Nicholas and colleagues [18] presented results from a survey completed by experts examining what they thought were the key issues with electronic health in psychiatry, including how it could be used for mental health promotion. The study identified 10 issues: access to care, integration and collaboration, education and awareness, mental health stigma, data privacy, trust, understanding and assessment of mental health, government and policy, optimal design, and engagement.

Prevention and Monitoring

While a focus of the current mental health system is often treatment, prevention and monitoring are critical toward avoiding the need for treatment. For example, referring patients for early treatment can alter the entire course of chronic lifelong illnesses such as schizophrenia and minimize the severity and disability from the disease [19]. The articles discussed below offer innovative tools and approaches to better quantify and understand the lived experience of mental illness in ways that can enable early detection or real-time responses that are difficult for clinical care to offer today.

Haskins and colleagues [20] conducted a randomized trial of a Web app for alcohol screening, brief intervention, and referral to treatment versus a control condition. They found that participants using the Web app were more likely to seek help from an alcohol treatment provider, but the intervention did not lead to reduced risky alcohol use, suggesting the complexity of this issue. Web apps are not the only tools that can be used for prevention and monitoring. For instance, Delgado-Gomez and colleagues [21] used Microsoft Kinect sensors to develop a novel assessment of attention-deficit/hyperactivity disorder. The results suggest an innovative way for using consumer sensors in clinical assessment and how new information, including whole-body movements through space, can be important mental health metrics. Chow and colleagues [22] used the global positioning system sensors available in mobile phones to model the relationship between state affect and the duration of time spent at home. Their findings that depression and anxiety are associated with staying-at-home behavior patterns offer both a new tool to monitor risk and an actionable signal to guide real-time physical activity interventions. Parra and colleagues [23] studied new biometric approaches using a combination of facial expressions, voice recording, heart rate, and electrodermal activity to assess attachment security. The authors found evidence of unique physiological, behavioral, and linguistic markers of attachment security, offering a model of personalized digital biomarkers. Other groups also explored digital biomarkers, with Saeb and colleagues [24] pairing a mobile phone app to capture sleep data with machine learning algorithms that together achieved significant classification accuracy (88% on 10-minute windows). Aledavood and colleagues [25] also presented a novel mobile phone app designed for broad and customizable data capture in mental health. Their article describes the design of a software platform that integrates and manages mental health data from many sources, including mobile phones, Internet of things devices, surveys, actigraphs, and social media content. Social media also offers a novel space for prevention and monitoring, and Mowery and colleagues [26] contributed an innovative scheme for annotating signs and symptoms of depression: a dataset of 9300 tweets originally used in the 2015 Computational Linguistics and Clinical Psychology Shared Task. Park and Conway [27] used computational linguistic approaches to study how emotion-related language changes over time for members of a depression community on the widely used Internet forum Reddit. The diversity of tools and methods in the above articles represents the growing potential to soon offer mental health monitoring and prevention tools that are affordable, scalable, and personalized.

Clinical Interventions and Treatment

While the most frequent interventions in mental health today include face-to-face therapy or medications, or both, digital interventions are rapidly expanding. Presentations at the conference focused on novel ways to use current technologies to deliver more personalized, convenient, and affordable care.

Boudreaux and colleagues [28] designed, built, and tested a Web-based safety planning intervention. The design followed user-centered practices in a multidisciplinary team. Kaiser and Laireiter [29] described DynAMo, a tool that could help researchers and psychotherapy practitioners in treatment planning and monitoring of process and outcomes. This open source tool provides mechanisms for quantifying, modeling, and visualizing the progress of a patient while completing psychotherapy treatment. Mandryk and Birk [30], Aguilera and colleagues [31], and Hoermann and colleagues [32] focused on direct interactions with patients. Mandryk and Birk [30] described an approach to using games that can engage patients with interventions. Aguilera and colleagues [31] studied the impact of augmenting cognitive behavioral therapy through text messaging in a randomized controlled study among lower-income patients with depression compared with a control group receiving only cognitive behavioral therapy. Their finding of increased engagement with treatment in the text messaging group, though with similar clinical outcomes to those of the control group, suggests the potential of texting as an

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intervention. Hoermann and colleagues [32] systematically reviewed synchronous text-based dialogue systems. Dialogue systems can be of two types: fully automated, where end users chat with a bot; and augmentation systems, where they chat with a human. This literature review focused on how these systems are being used in mental health intervention.

Challenges and Solutions: The Research Community's Perspective

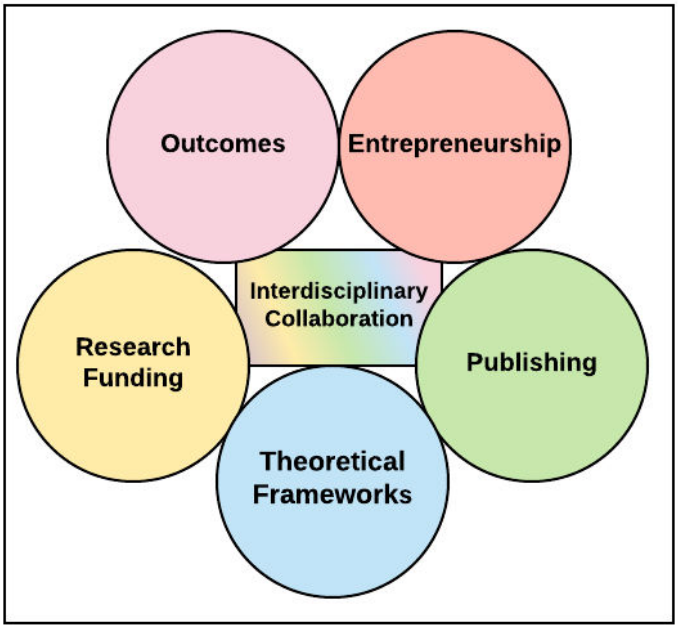
The symposium included several activities aimed at sharing experiences among the participants, discovering common challenges, and discussing possible solutions. In this section, we discuss the 5 themes of challenges discussed. Themes were picked ahead of time from an online poll completed by attendees 2 weeks prior to the symposium. Based on responses, the final themes selected were as follows: entrepreneurship, publishing, funding, theoretical frameworks, and outcomes. At the symposium, attendees separated into 5 groups, 1 group for each theme, with each group comprising approximately 15 members. The groups spent approximately 30 minutes brainstorming a list of challenges related to their theme and then shared their initial results on a large poster. All attendees were given 20 minutes to visit all 5 posters, leave comments, and offer solutions. After this period, each group then spent the next 30 minutes reviewing comments, brainstorming ideas, and listing potential solutions. This list of final solutions was presented and shared with the entire group, and everyone was invited to comment. Here we present only a summary (Figure 2) of those final outcomes based on an analysis of the artifacts and discussions by RAC and JT.

Challenges and Solutions #1: Entrepreneurship

While within this group there was general agreement on the need for greater academic and industry collaboration, numerous other issues were raised. One was that intellectual property in mental health is "soft," meaning that it can be difficult to patent or protect innovations in this space. Another discussion point centered on the difficulty in targeting entrepreneurship efforts to the correct audience, which may include governments, insurers, hospital systems, employee benefit programs, end users, and more. While the goal of all stakeholders is improved mental health, the approach, metrics of success, and business models dramatically differ by stakeholder. Another issue raised was that mental health stigma often drives away potential users and investors. Many recognized that creating successful products in this space requires diverse collaborations with mental health professionals, designers, data scientists, end users, and more. Building such teams is feasible but often requires significant effort, organization, and upfront cost. Many mental health professionals noted they might not even know where to start in building such a team or finding the right business partners with whom to connect. The different lexicons and priorities of stakeholders was raised as another set of barriers to forming teams. Finally, the frequent tension between industry incentives for return on investment and profit versus research goals and open dissemination of knowledge was also raised.

Numerous solutions to the entrepreneurship challenge were discussed. There was a general agreement that education about the entrepreneurship process by the mental health and HCI communities is needed. Many noted that they would like to attend workshops and sessions that introduced business concepts and taught the skills needed to navigate the entrepreneurial space. To better align incentives and goals, several suggested that social enterprise ventures are a good target for collaboration between academia and industry. Many also supported the creation of programs that would match clinicians and HCI professionals with potential business partners. Other also suggested that, by using crowdfunding, it might be possible to self-support early-stage efforts and thus bypass the need for entrepreneurship.

Figure 2. The 5 challenges presented at the symposium and the central role of interdisciplinary collaboration as a solution toward each.



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All of these above suggestions revolved around means to increase collaboration between the mental health, HCI, and entrepreneur communities.

Challenges and Solutions #2: Publishing

A second challenge addressed by the group involved publishing. Many noted that, while the academic publication process is often cumbersome and slow, mobile health research evolves rapidly. Waiting up to 6 months for peer review and then longer for actual publication can result in delays of more than 1 year from manuscript submission to published article. For work at the intersection of mental health and HCI, there are often few peer reviewers who can bridge both domains and offer balanced feedback. Many also noted the publication bias for positive results that has created a lack of knowledge regarding how many mobile health studies do not succeed. Others pointed out that many journals, especially HCI-focused ones, favor novelty in submissions and there is less incentive or ability to publish on actual implementation or reproducibility research. Concerns about how to maintain a human participants' privacy when publishing small case studies or N=1 experiments were also noted as a barrier for publication.

Numerous solutions toward publication challenges were presented. One novel concept was the notion of segmented peer review, with mental health and HCI experts each dividing responsibility for reviewing certain sections of a paper. There was also broad consensus on the need for more interdisciplinary journals that bring together expertise in mental health and HCI. Others suggested the promulgation of guaranteed publication for clinical studies with preapproved methods. While this would require careful screening of study design and approach, such a system would remove bias toward publishing only positive findings. Finally, many agreed on the need for further online prepublication distribution of papers (eg, through arxiv.org), and even the desire to make prepeer-review prints available in order to facilitate dissemination that can keep pace with innovation. Like the entrepreneurship challenge outlined above, new and expanded collaborations were noted as the key to sharing and publishing works at the intersection of HCI and mental health.

Challenges and Solutions #3: Research Funding

Related to entrepreneurship, the challenge of bringing the necessary funding resources to digital mental health projects was also raised. All agreed that a primary challenge of this space remains a funding gap for mental health works bridging academic disciplines, spanning multiple countries, and even involving multiple industries. Without a primary "home" in academia or industry, dedicated funding is a challenge. Many noted that, even among dedicated academic funding agencies, there are few well-aligned grant mechanisms to support this interdisciplinary work, and that grant-review panels often may not fully understand the unique needs or challenges of the mental health HCI space. Current research funding mechanisms often support a winner-takes-all approach that does not facilitate strong collaborations but instead tends toward supporting isolated efforts by small teams or even individuals. As alluded to above in the entrepreneurship section, a misalignment of incentives, timelines, and values (eg, seeking answers vs outcomes) further complicates the funding landscape. The true nature of many mental health HCI projects is often iterative, but funding for iterative and phased projects is often not available today.

Numerous solutions were described as a way to begin to address funding challenges. Many supported efforts by international centers and foundations that have a broad perspective and willingness to support novel mental health HCI projects. However, realizing that such programs are scarce today, all agreed there is a need for better lobbying for further funding resources from both governments and nonprofits. This could be accomplished by framing mental health as the key challenge of our times and underscoring the potential of this work to aid in recovery, reduce health care costs, and have broad global impact. Many noted that the physics community may serve as a model for building a successful funding message around often abstract and theoretical work. It was suggested the field should unify around a "big message" and present a more coherent message regarding funding priorities. Again, the topic of crowdfunding was raised as a means to provide early support to enable projects to complete pilot assessments. Similarly, all agreed that more education about entrepreneurship and collaboration with industry is necessary. New and stronger collaborations were also seen as the core of all solutions for uniting the right funding with the right opportunities in this space.

Challenges and Solutions #4: Theoretical Framework

Theory is necessary for hypothesis-driven research, and theory-driven research creates the necessary scaffold for research efforts to support or refute each other. Theories can also provide a framework to understand where studies fit in the larger context and what underpins our understanding of human nature. The current model of collecting numerous digital data streams and then searching for a statistically significant signal is important exploratory and foundational work for the mental health HCI space. The need for theoretical work arises from the fact that models of mental illness such as the biopsychosocial model were developed in an earlier era when the wealth of real-time sensor and survey data offered by the mobile phones of today was unimaginable. For example, new digital mental health data streams offer the potential to help advance the biopsychosocial model by offering a bridge to unite biological and behavioral theories of illness [4]. New and updated models are needed that better account for the novel longitudinal and environmentally aware information streams that current mental health HCI efforts enable. Such a theoretical model should not seek to reduce the understanding of human nature and mental illness to narrow concepts, but rather best use the multivariate nature of available data to increase and incorporate expanding knowledge. This work may thus lead to new digital mental health gold standards and the development of new measurement scales that will replace today's efforts to correlate digital mental health data to static time-point clinical scales.

Numerous solutions toward creating theoretical frameworks were discussed. One broad solution was to organize further joint conferences and publications between the mental health and HCI communities to encourage cross-pollination of theory and

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ideas. Another was to carefully search the existing literature for those projects and efforts already bridging the mental health and HCI worlds and review their framing. Others suggested the need to create new scales and outcome measurements for the field, in line with the development of US National Institutes of Health Patient-Reported Outcomes Measurement Information System measures. Another solution was to learn from the pioneering efforts of the Quantified Self community, which has already created its own framework and metrics. Still others noted that, by focusing efforts on solving clinical problems, there is less need to focus on theory, as a problem-focused mindset will naturally produce the desired frameworks. Again, the theme of interdisciplinary collaborations and partnerships was evident at the core of these proposed solutions.

Challenges and Solutions #5: Outcomes

Along with theory, another challenge considered was outcomes. Many raised the difficulties in establishing causality or casual inferences from predominantly observational studies. Other challenges included the generalizability of outcomes given that many studies are conducted on either proprietary or nonaccessible digital platforms, use statistical analyses that are often too vague to reproduce, and focus on small, nonrepresentative populations. Even if outcomes were well defined, many raised the concern that randomized controlled trials may not be the best method for studies, given that an advantage of digital mental health computing efforts is the ability to study mental illness at the personal level and provide individual assessments and recommendations. Further confounding outcomes, several noted that metrics such as reduction in symptom scores on standardized measurements are often of less utility outside of the clinic and that adaptive or functional outcomes such as employment may matter more. Often-secondary outcomes such as user adherence and engagement become of paramount importance when apps are deployed outside of clinical studies. Finally, the difficulties of any outcomes research in this space is compounded by a myriad of confounding variables, such as participants often receiving new mobile phones, additional clinical visits or attention, or payments for increased participation. Isolating the “active ingredient” or true effect size of digital mental health HCI efforts remains challenging, with reports varying wildly on the actual effect size and impact [33].

In response, the group raised several potential solutions. Many discussed the need for more dynamic randomized controlled trails and moving to more adaptive and iterative study designs. The agile science model proposed by Hekler and colleagues was cited as a viable alternative in which studies are more iterative [33]. All agreed on the need to further study and quantify engagement as a primary outcome and to understand how end users’ experience with the app or digital tool itself affects outcomes. Several also proposed, as noted above, that the field will have to develop new scales and outcome measures instead of seeking to match new digital data streams to traditional clinical scales that were developed in a different era and for use with different data. Along similar lines, it will be necessary to consider not only clinical outcomes that we can easily measure with scales but also real-world and adaptive or functional outcomes such as increased social engagement or cognition. Like for all the above challenges, new collaborations, including those with patient communities, were highlighted as the key to both finding and measuring the right outcomes.

Conclusions and Future Steps

Interdisciplinary collaborations are a powerful way to solve complex problems and emerged as the core solution in our workshop exploring challenges of entrepreneurship, publishing, funding, theory, and outcomes. Mental health and well-being is undoubtedly one of the most significant complex challenges of our generation, and collaboration, with supportive funding, may present the most important opportunity for progress. We know that our technological environments and tools can advance or improve mental health, as demonstrated in the articles included in this special issue. These promising results, and collaborations between the mental health and HCI communities, rely on development of interdisciplinary research communities that are achievable only through face-to-face and online conversations, collaborative projects, and deep thinking and writing. While the challenges discussed in this editorial are significant, the numerous proposed solutions, interdisciplinary collaborations, and enthusiasm of those partaking in the second Symposium on Computing and Mental Health suggest a bright future for this field. While this one symposium and special issue cannot alone speak for the CHI and mental health fields, we hope it offers a path for others to follow and build upon. The need for better mental health globally is growing and presents a serious challenge that can no longer be met by the mental health community working alone. We urge the communities of CHI and mental health to continue to come together to apply the lessons learned here, while continuing to expand and integrate knowledge and practice to achieve better global mental health.

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Conflicts of Interest

RP is a shareholder in 2 companies making technologies that are sometimes applied to mental health, Empatica Inc and Affectiva Inc.

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Abbreviations

HCI: human-computer interaction

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Review

Health Information Technology Continues to Show Positive Effect on Medical Outcomes: Systematic Review

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Abstract

Background: Health information technology (HIT) has been introduced into the health care industry since the 1960s when mainframes assisted with financial transactions, but questions remained about HIT's contribution to medical outcomes. Several systematic reviews since the 1990s have focused on this relationship. This review updates the literature.

Objective: The purpose of this review was to analyze the current literature for the impact of HIT on medical outcomes. We hypothesized that there is a positive association between the adoption of HIT and medical outcomes.

Methods: We queried the Cumulative Index of Nursing and Allied Health Literature (CINAHL) and Medical Literature Analysis and Retrieval System Online (MEDLINE) by PubMed databases for peer-reviewed publications in the last 5 years that defined an HIT intervention and an effect on medical outcomes in terms of efficiency or effectiveness. We structured the review from the Primary Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA), and we conducted the review in accordance with the Assessment for Multiple Systematic Reviews (AMSTAR).

Results: We narrowed our search from 3636 papers to 37 for final analysis. At least one improved medical outcome as a result of HIT adoption was identified in 81% (25/37) of research studies that met inclusion criteria, thus strongly supporting our hypothesis. No statistical difference in outcomes was identified as a result of HIT in 19% of included studies. Twelve categories of HIT and three categories of outcomes occurred 38 and 65 times, respectively.

Conclusions: A strong majority of the literature shows positive effects of HIT on the effectiveness of medical outcomes, which positively supports efforts that prepare for stage 3 of meaningful use. This aligns with previous reviews in other time frames.

(J Med Internet Res 2018;20(2):e41) doi:10.2196/jmir.8793

KEYWORDS

health information technology; treatment outcome; electronic health record

Introduction

Background

Health information technology (HIT) is an umbrella term that covers a wide range of technologies that store, share, and analyze health information [1,2]. In this role, HIT can influence service quality and provider performance [3]. As stated by Wagner et al, the adoption of HIT for the purpose of improving medical outcomes was touted by the Institute of Medicine in numerous reports, including "The Computer-based Patient Records: An Essential Technology for Health Care" in 1991, "To Err is Human: Building a Safer Health Care System" in 2002, and "Patient Safety: Achieving a New Standard for Care" in 2004 [4]. Due to the costs associated with implementing HIT, initially, health care payers seemed to be the only stakeholders benefiting from it [4].

In the United States in 2009, the Health Information Technology for Economic and Clinical Health (HITECH) Act made incentive

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payments available to providers who adopted the *meaningful use* of a certified electronic health record (EHR), stimulating widespread adoption of HIT across various health care settings [4]. Since the implementation of the HITECH Act, adoption rates of the electronic medical record in the United States have shown greater than arithmetic growth [5], but have patients experienced a commensurate increase in quality and decrease in errors as a result of the presence of that technology? The same question applies internationally. In 2014, Denmark instituted a regional patient record system. In 2015, Switzerland adopted a nationwide EHR, and Germany issued chip-based medical cards to all statutory health insurance beneficiaries for health care claims. In 2018, Germany will penalize providers who do not participate fully in this program. Have outcomes followed these programs?

Over the last several years, many studies have examined a relationship between the use of HIT and resulting health outcomes, administrative efficiencies, and cost [1,2]. Most studies that we found after our initial interest demonstrated a positive relationship between the use of HIT and medical outcomes, and these studies spanned seven countries [6-12]. However, all but three lacked quality metrics [1,2,11]. Three previous studies reviewed relative literature published in various but distinct time frames from 1995 and 2010.

Buntin et al [1] evaluated the benefits of health information technology in 2011 using data available from 2007 to 2010. This was a continuation of effort from Chaudhry et al, who examined literature from 1995 to 2004 and Goldzweig et al, who examined literature from 2004 to 2007 [2,11]. These three reviews demonstrated higher standards of science in their analysis, and therefore, this review will examine the years from January 1, 2011 to July 31, 2017 to update the literature. A good question to ask, however, is how has this changed since the HITECH Act? What has been the result of medical outcomes, specifically, since the last high quality review was conducted [1]?

Objective

The purpose of this review was to evaluate the current literature demonstrating the impact of HIT adoption on medical outcomes. Using the same methods as Buntin et al, Chaudhry et al, and Goldzweig et al (2004, 2007, and 2011, respectively), we intended to carry this research forward into 2017 [1]. What is the effect of the adoption of health information technology on medical outcomes since 2011? The hypotheses are as follows:

> Hypothesis 1: There is a positive association between the adoption of HIT and medical outcomes.
>
> Hypothesis 0: There is no positive association between the adoption of HIT and medical outcomes.

Methods

Eligibility Criteria

The conduct of our review followed a measurement tool for the "Assessment of Multiple Systematic Reviews" (AMSTAR) [13]. The format of the review follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) [14]. The search criteria matched that used by Chaudhry, Goldzweig, and Buntin and colleagues. Papers were eligible for selection in this systematic review if they were published in the last 5 years in academic (peer-reviewed) journals, in English, whose full-text was available for analysis, and the papers addressed implementation of HIT and an association with an effect on medical outcomes expressed in terms of efficiency or effectiveness. We chose 5 years because that is the amount of time since the last review was published on this topic. We limited the search to peer-reviewed journals to ensure an acceptable element of quality to the papers we were analyzing. We made the decision not to include other systematic reviews in the analysis, but they were used in the Discussion section for comparison.

Information Sources

We queried two common research databases: Medical Literature Analysis and Retrieval System Online (MEDLINE) by PubMed and the Cumulative Index of Nursing and Allied Health Literature (CINAHL). We used key terms from the US National Library of medicine's medical subject headings separated by Boolean terms. Searches were conducted from July 1, 2017 to July 4, 2017.

Search and Study Selection

Searches in each database were nearly identical. Due to the differences in indexing methods between the databases, we had to slightly modify the search string and filters for each. We screened for date of publication to begin in 2007 until the end of June 2017. The filters in PubMed enabled us to screen out reviews. In CINAHL, we excluded MEDLINE because it was being collected separately from PubMed, and this eliminated most duplicates. Papers were placed into an Excel (Microsoft) spreadsheet shared among the reviewers. Remaining duplicates were removed. As a quality measure, only peer-reviewed journals were used in the selection process.

Data Collection Process and Data Items

Reviewers agreed ahead of time what to look for in each abstract. We focused on papers that described a technological intervention that follows the definition of previous reviews [1,2,11] and that expressed medical outcomes in terms of either effectiveness or efficiency. After the initial search was completed, we removed duplicates and filtered. Each member of the review team read all of the remaining abstracts to ensure they were reviewed at least twice, as outlined by AMSTAR [15]. Independent notes were taken on a shared spreadsheet to inspire discussion. Two consensus meetings were held: one to identify the full-text papers for analysis and one to identify other observations for additional analysis. A statistic of agreement, *kappa*, was calculated.

Summary Measures, Synthesis of Results, and Bias

The summary measure used in this analysis was the medical outcome specified in terms of either efficiency or effectiveness. When clear statistics were listed, our team recorded them for our analysis. We also identified signs of bias that could have deleterious effect on the broad application of the results. Several papers only mentioned advantages of administrative efficiency, such as a shorter length of stay (LOS) and lower readmission rates. These were kept because, we reasoned, a shorter LOS

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could have been due to improved outcomes, and lower readmission rates could have been enabled with improved outcomes that would have otherwise caused the patient to return.

Results

Eligibility Criteria, Information Sources, and Search and Study Selection

Studies from PubMed and CINAHL that defined an HIT intervention and a corresponding effect on medical outcomes stated in terms of efficiency or effectiveness were eligible for selection. The search for this review was extensive, and the reviewers took care to be deliberate and thorough in their process.

Data Collection Process and Data Items

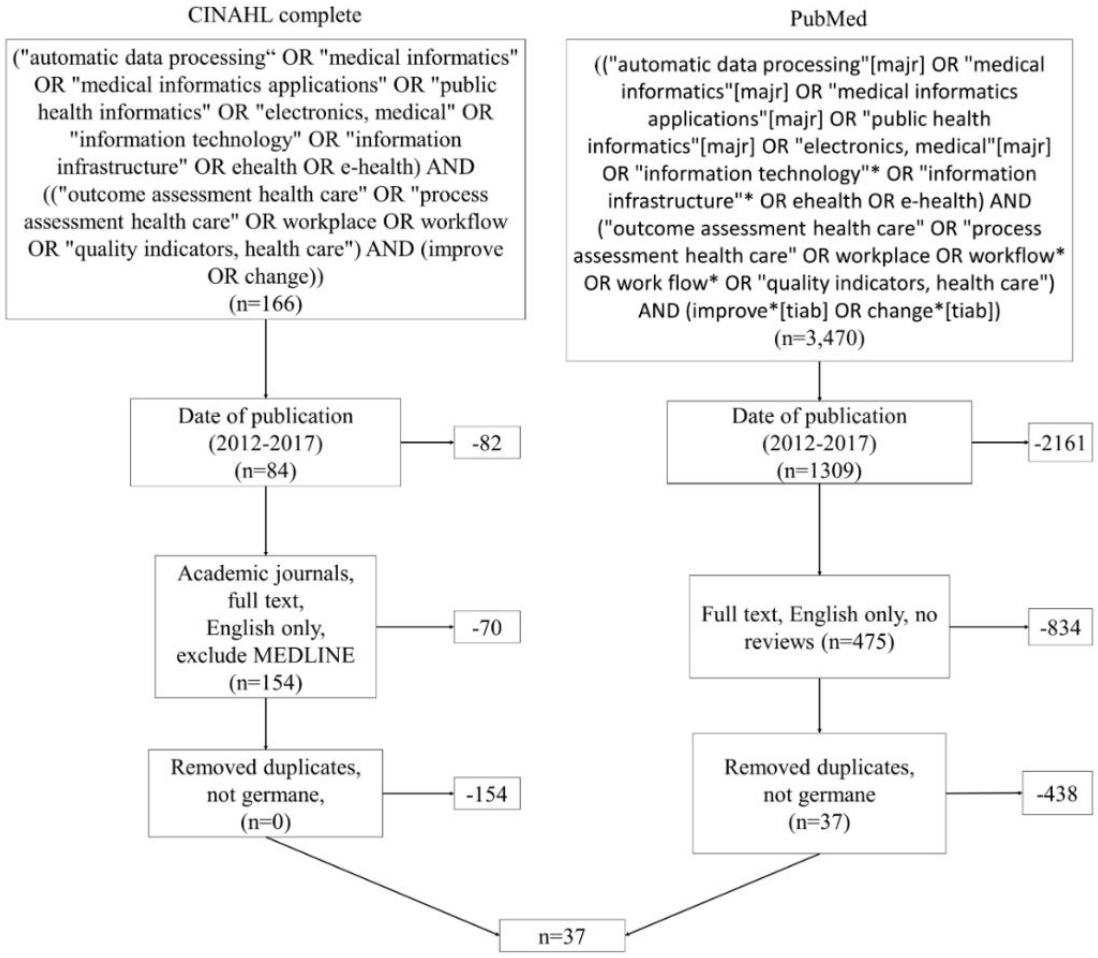
The initial search, as illustrated in Figure 1, resulted in 3636 results. After removing duplicates and filtering, the remaining 629 abstracts were read in their entirety by the two reviewers, as outlined by AMSTAR [15]. Independent notes were taken on a shared spreadsheet. After the first consensus meeting, 534 were eliminated because they did not report medical outcomes, 8 because they were editorials, 8 were protocols and reported no results, 6 were models without results, and 6 were not germane to the objective. A statistic of agreement, *kappa*, was calculated to be .966, which is indicative of a high level of agreement. Only 54 studies remained for full-text analysis, although some were kept under suspicion because the abstract was vague on whether or not outcomes were reported. A similar review approach was used for the analysis of the full-text papers. After the second consensus meeting, 15 more were removed for no medical outcomes and 2 removed for not being germane to the objective. The final set for analysis was 37.

Summary Measures, Synthesis of Results, and Bias

Multimedia Appendix 1 summarizes the results of the analysis of the 37 studies chosen. It lists the descriptive title of the study, the HIT intervention, the measures of efficiency or effectiveness, and any bias observed that could limit the applicability of the results [15-51].

After consensus meeting number two, the categories of HIT recorded by each reviewer were combined. We counted the number of times that a category occurred in the literature and sorted by frequency of occurrence. This data was placed into an affinity matrix for further analysis (see Table 1).

Figure 1. Literature search with inclusion and exclusion criteria.



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Table 1. The specific categories of health information technology (HIT) and their frequency of occurrence.

Category of HIT[a]	Paper in which category occurred	Frequency (n=38)
Web-based	[19,31,34,41,44,45,47,51]	8
Telemedicine	[16-18,21,32,40,46]	7
Software	[25,27,28,30,36,50]	6
CDSS[b]	[22,24,33,35,48]	5
mHealth[c]	[20,42,45]	3
Telemonitoring	[29,37]	2
Electronic ordering	[26,38]	2
HIT	[49]	1
HIE[d]	[43]	1
Robot assist	[15]	1
Videoconferencing	[23]	1
Remote screening	[39]	1

[a]HIT: health information technology.

[b]CDSS: clinical decision support systems.

[c]mHealth: mobile health.

[d]HIE: health information exchange.

Table 2. The specific categories of outcomes and their frequency of occurrence.

Category of outcome	Paper in which category occurred[a]	Frequency
Physical	[15-17,23-26,28,30-35,37,39,41,42,44,45,48,49,51]	39
Psychological	[17-19,21,27,40,47]	13
Continuity of care	[20,22,23,25,27,29,36,39,40,43,46,50]	13
Total	Multiple occurrences in same paper	65

[a]More than one occurrence was observed in the following papers in the categories of outcome; physical: 15-17, 23, 28, 37, 39, 41, 42; psychological: 18, 21, 27, 40; continuity of care: 23.

Twelve different categories of HIT were identified in our analysis with a total of 38 occurrences. Web-based interventions were analyzed most frequently at 8 of 38 occurrences (21%) [19,31,34,41,44,45,47,51]. Telemedicine and software programs were the next most frequently identified interventions, occurring 7 of 38 occurrences (18%) [16-18,21,32,40,46] and 6 of 38 occurrences (16%) [25,27,28,30,36,50], respectively. Clinical decision support systems were analyzed at a frequency of 5 of 38 occurrences (13%) [22,24,33,35,48]. mHealth occurred 3 of 38 occurrences (8%) [20,42,45]. Telemedicine [29,37] and electronic ordering [26,38] HIT interventions occurred 2 of 38 occurrences (5%). Health information exchange (HIE) [43], HIT [49], robot assistance [15], videoconferencing [23], and remote screening [39] were all identified once for the lowest frequency at 3% individually.

Table 2 tabulates the categories of outcomes and their frequency of occurrence.

The asterisks note that more than one occurrence was observed within the same paper. Evidence of efficiency or effectiveness that were grouped under physical outcomes included body mass index, blood pressure, hypertension, pain, infection, activities of daily living, mortality, vaccines nutrition, physical activity, cardiovascular disease, wound healing, diabetes distress, quality of life, A1C level, low-density lipoprotein, vaccination rate, sedation interruptions, spontaneous breathing trials, mechanical ventilations, asthma control, cholesterol, and cluster of differentiation 4 count. Occurrences grouped as psychological included depression, insomnia, self-efficacy, emotional stability, maintenance of motivation, upset, negative mood states, social outcomes, and eating disorder symptomatology. Continuity of care included medication administration, medication adherence, service utilization, readmission, length of stay, unmet needs, and reduced office visits. Although readmission, length of stay, and reduced utilization are qualities most often associated with administrative efficiencies, we chose to keep these in the review because these efficiencies could have been enabled because of improved medical outcomes. The most common outcome category was physical, which appeared 39 of 65 occurrences (60%) [15-17,23-26,28,30-35,37,39,41,42,44,45,48,49,51]. The other two categories tied for second most often were as follows: psychological [17-19,21,27,40,47] and continuity of care [20,22,23,25,27,29,36,39,40,43,46,50], which each occurrences 13 of 65 occurrences (20%). Table 3 illustrates the categories of outcomes and the outcome results and their frequency of occurrence.

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Table 3. Outcome results and their frequency of occurrence.

Result of outcome	Paper in which result occurred	Frequency (n=37)
Improved	[18,20-29,31-35,37-46,48-51]	30
No statistical difference	[15-17,19,30,36,47]	7

Of the 37 papers included, 30 (81%) reported an improvement in efficiency or effectiveness related to a medical outcome. No statistical difference in outcomes was reported in 7 of 37 occurrences (19%) studies. These results strongly support our hypothesis; therefore, we accept our hypothesis and reject the null. There is a positive association between the adoption of HIT and medical outcomes.

We made 15 comments related to bias in the original research, the majority of which were related to the lack of heterogeneity in characteristics of participants. Characteristics that were noted include socioeconomic status, gender, age, ethnicity, and geographical area. Small sample size was noted as a potential concern in 4 studies, and participation refusal or dropout was noted in 2 studies. In one study, participants received payment for participation, and in another study, two of the authors had invented the technology being evaluated. Other sources of bias identified included outcomes reported based on a quality manager's response to survey, seasonal influences not controlled for, and technical challenges experienced that resulted in delays.

Discussion

Summary of Evidence

Health care providers will continue to be incentivized to adopt HIT as policy makers respond to quality, and safety concerns and reimbursement methods transition toward value-based purchasing [4]. Providers, consumers, and policy makers alike stand to benefit from the further proliferation of HIT. Our research aligns with previous work that identified improvements achieved as the result of the adoption of HIT [1,2,11]. The majority of research we identified, 81%, in this review demonstrated improved medical outcomes in terms of efficiency or effectiveness as a result of HIT adoption. Although these findings are similar to the overall conclusions drawn by previous reviews, the adoption of HIT can have a positive impact on medical outcomes [1,2,11]. There are two key differences between our work and the three previous literature reviews.

First, Buntin et al reported that less than 10% of the studies included in their work demonstrated negative findings related to the adoption of HIT [1]. We identified a number of studies that demonstrated no statistical improvement, but we did not identify any negative impacts as a result of the adoption of HIT. Buntin et al noted that the majority of their negative findings were associated with provider satisfaction with HIT. We chose to only include papers that demonstrated effects of efficiency and effectiveness in terms of medical outcomes; this could account for the difference in our findings. Organizational factors related to the success of HIT implementation and improved medical outcomes is one area where further research is needed [1,2,11].

Second, the literature review conducted by Chaudhry et al in 2004 noted that the improved outcomes demonstrated were reported by a limited set of large benchmark organizations and cautioned on the ability to generalize positive findings to other institutions [2]. Goldzweig et al and Buntin and colleagues identified the emergence of more widespread research outside larger and more established organizations [11,1]. One important finding noted by Goldzweig et al was an increased focus on patient-focused HIT. We believe this trend has continued through 2017. We identified a greater variety in the types of HIT being studied than previous literature reviews; Web-based interventions being the most frequently researched. This may be an indication of an increased rate of adoption of HIT and perhaps improved efficiency and effectiveness across a wider variety of health care settings.

One common theme in all four literature reviews is the limited amount of research associated with HIE specifically [1,2,11]. HIE is at the forefront of technological advancement in the health care industry [4]. Only one study in our review of recent literature included HIE. More research is needed to identify the outcomes associated with the adoption of HIT systems that are capable of information exchange.

Limitations

Our literature review did not identify any studies demonstrating a negative impact on medical outcomes as the result of HIT adoption. The absence of negative findings may be because of publication bias [1] and should be considered in the interpretation of these results. This is supported by the finding of 19% of studies that found no statistical difference in outcomes as a result of HIT. Another limitation of this work is the diversity in types of medical outcomes examined and the uniqueness of each sample studied. This impacts the ability to generalize findings across the industry. Furthermore, limiting our search to MEDLINE by PubMed and CINAHL may have impacted the scope of our results.

Conclusions

HIT has the potential to improve the quality and safety of health care services. Providers who leverage HIT to improve medical outcomes can position themselves for sustainability in the future. Further research is needed to continue to reveal and define the relationship between the adoption of HIT and medical outcomes. This will be especially true as the industry establishes new and innovative ways to integrate technological advances and works toward greater interoperability as the United States prepares for stage 3 of meaningful use, as all providers seek a link between the application of HIT in health care and its effect on outcomes, and as other nations such as Switzerland, Denmark, and Germany reconcile national medical programs such as a nationwide EHR, regional electronic patient record system, and national medical chip cards, respectively, against outcomes.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Summary of analysis.

[PDF File (Adobe PDF File), 123KB - jmir_v20i2e41_app1.pdf]

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Abbreviations

AMSTAR: Assessment for Multiple Systematic Reviews
CINAHL: Cumulative Index of Nursing and Allied Health Literature
EHR: electronic health record
HIE: health information exchange
HIT: health information technology
HITECH: Health Information Technology for Economic and Clinical Health
LOS: length of stay
MEDLINE: Medical Literature Analysis and Retrieval System Online
mHealth: mobile health
PRISMA: Primary Reporting Items for Systematic Reviews and Meta-Analysis

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Review

Role of Social Media in Diabetes Management in the Middle East Region: Systematic Review

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Abstract

Background: Diabetes is a major health care burden in the Middle East region. Social networking tools can contribute to the management of diabetes with improved educational and care outcomes using these popular tools in the region.

Objective: The objective of this review was to evaluate the impact of social networking interventions on the improvement of diabetes management and health outcomes in patients with diabetes in the Middle East.

Methods: Peer-reviewed articles from PubMed (1990-2017) and Google Scholar (1990-2017) were identified using various combinations of predefined terms and search criteria. The main inclusion criterion consisted of the use of social networking apps on mobile phones as the primary intervention. Outcomes were grouped according to study design, type of diabetes, category of technological intervention, location, and sample size.

Results: This review included 5 articles evaluating the use of social media tools in the management of diabetes in the Middle East. In most studies, the acceptance rate for the use of social networking to optimize the management of diabetes was relatively high. Diabetes-specific management tools such as the Saudi Arabia Networking for Aiding Diabetes and Diabetes Intelligent Management System for Iraq systems helped collect patient information and lower hemoglobin A_{1c} (HbA_{1c}) levels, respectively.

Conclusions: The reviewed studies demonstrated the potential of social networking tools being adopted in regions in the Middle East to improve the management of diabetes. Future studies consisting of larger sample sizes spanning multiple regions would provide further insight into the use of social media for improving patient outcomes.

(J Med Internet Res 2018;20(2):e58) doi:10.2196/jmir.9190

KEYWORDS

social media; Saudi Arabia; eHealth; telemedicine; mobile phone; cell phone; outcome of care; Middle East

Introduction

Diabetes mellitus is a group of metabolic disorders characterized by high blood glucose levels and inflammation leading to long-term complications of obesity, heart disease, stroke, foot ulcers, and loss of eyesight and kidney function [1,2]. After a person consumes a meal, the pancreas releases the hormone insulin, which binds to cell receptors to signal uptake of glucose from the blood. However, in diabetes, the cells are unable to take up glucose from the blood. Type 1 and type 2 are the 2 most common forms of diabetes mellitus. Type 1 diabetes occurs due to the inability of the pancreas to produce insulin, whereas type 2 diabetes occurs due to cells developing a resistance to insulin.

Diabetes prevalence is rapidly increasing in developing countries, including those in South Asia, the Middle East, Sub–Saharan Africa, and Latin America [3]. Diabetes has various risk factors, including obesity for type 2 diabetes, where

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the body progressively develops insulin resistance [4]. In addition, there is an ethnic predisposition to type 2 diabetes that is most notably present in Asians [5]. A special case of concern is for the population in the Middle East, with one of the highest prevalences of overweight [5] due to a high prevalence of physical inactivity [6]. The countries in this region have boasted rapid economic growth in the last three decades. This has led to changes in lifestyle, with lower physical activity levels and an increase in dietary caloric intake, resulting in high incidences of obesity, diabetes, and cardiovascular diseases. For example, one nationwide study in Iran showed that the occurrence of metabolic syndrome is upward of 35%, and is higher in women and populations in urban areas [5]. This pattern is expected to impose an enormous burden on the health care system in the Middle East region and calls for an implementation of improved methods of self-care for disease management. Several large-scale clinical randomized trials have shown that type 2 diabetes can be prevented or the effects can be minimized through self-care by changing one's lifestyle with a low-calorie diet and increased physical activity [7].

Due to recent technological advances, more and more people are relying on new communication channels, such as online information and social media, than on traditional messages on television and in print media [8]. Consequently, there has been a growing effort to introduce efficient means of implementing electronic and digital processes in health care. This correlates with the high use of smartphones and the popularity of mobile phone–based apps developed for virtually all aspects of life. Social networking is dominated by apps, such as Facebook, Twitter, Snapchat, Instagram, and YouTube, with millions of subscribers. These apps have provided a means of communicating quickly and efficiently with the masses, at minimal cost, in a very short period of time. In health care, social networking is garnering more users, and its benefits in educating patients about their disease, dietary limitations, and physical activity are already proving their worth [8-11]. Due to high economic growth and the presence of a reliable network in the Middle East region, a large proportion of the population in the Middle East region own a smartphone. One example is that the Kingdom of Saudi Arabia (KSA) has the largest percentage of mobile phone users in the world, according to a United Nations Conference on Trade and Development report [12]. The increase in mobile phone use is accompanied by a spread of social networking apps, especially among the young and the educated population of the KSA.

Due to the far-reaching presence and ease of use of mobile phones and social media, many researchers and health care providers are encouraging the use of mobile phones in the Middle East to better educate patients on how to manage their disease. Previously, several studies had shown the benefit of using social media campaigns to educate patients about diabetes, obesity, antibiotic use, and adolescent dating violence [9,13,14]. For health promotion advocates, social media presents a platform that is highly cost efficient and delivers mass education that ultimately is responsible for lowering the burden on regional health care systems. From the user's perspective, social media platforms have several benefits, such as making open access information available, providing the option for dynamic conversations in a group, and keeping users connected with their topic of interest [13]. This paper presents the evidence on evaluating the impact of social media intervention in improving the health of patients with diabetes in the Middle East.

Methods

Search Strategy

Both PubMed (1990-2017) and Google Scholar (1990-2017) were searched for research studies using various combinations of the following search terms: "diabetes," "diabetes mellitus," "mobile phone," "cell phone," "cellular phone," "social media," "social network," "Facebook," "Twitter," and "Snapchat." References of the identified articles were also searched for potential articles for inclusion. Only articles published in English in peer-reviewed scientific journals were eligible for review. The main inclusion criterion was that studies used mobile social networking apps for diabetes care in the Middle East as the primary intervention approach.

Study Selection

The search successfully identified 26 unique articles that addressed the basic criterion of the search: diabetes with the use of mobile phones in the Middle East. A review of the titles and abstracts of all relevant search results identified 15 articles that were relevant to the objectives of this review and met the following inclusion criteria: (1) randomized controlled trials, (2) quasi-experimental studies, and (3) pre-post studies evaluating the use of mobile phones for improving the education and health care of patients with diabetes in the Middle East. Further refining of the search results excluded articles that did not incorporate a social network app in their study (n=9) or did not specify a location (n=1). A final selection of 5 articles [12,15-18] that met the above-mentioned criteria were included for the review and analysis. A thorough review of all articles collected the following information: descriptions of the study design, country in which the study was conducted, sample size, patient age, duration of the study, technology used, frequency of intervention, method of intervention, control groups, self-care management activities, educational content and delivery, process and outcome measures, and statistical significance.

Results

Study Designs and Participants

The participants in the 5 studies included in this review were primarily patients with type 2 diabetes (80% of the studies), while the other patients had both type 1 and type 2 diabetes. The duration of diabetes was reported in 3 of the selected studies [12,17,18], whereas additional clinical data such as hemoglobin A_{1c} (HbA_{1c}), body weight, body mass index, and cholesterol levels were reported in only 1 study [18]. In most of the studies, the sample sizes ranged from 12 to 33 participants, with ages extending from 10 to 68 years. However, in 1 particular study, the participant sample size was not directly assessed, as the method of data collection consisted of compiling information from 7 groups for a total of 1551 Facebook posts [17]. In this study, participant ages ranged from less than 20 to 80 years.

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Most of the reviewed studies used mixed methods of design interviews and surveys to gather data regarding the acceptance of social media for the management of diabetes. In 1 study [17], a mixed-methods quantitative and qualitative content analysis was conducted to assess data collected from Facebook posts. In other studies [12,15], the Questionnaire for User Interaction Satisfaction assessed users' satisfaction according to a 9-point Likert scale after using the Saudi Arabia Networking for Aiding Diabetes (SANAD) system [15].

Furthermore, in 1 study, patients randomly allocated to 2 groups (intervention vs control) were selected to evaluate the effectiveness of the Diabetes Intelligent Management System for Iraq (DIAR) system for mobile diabetes management [18]. Most of the selected studies were conducted in the KSA. However, 1 study [18] was conducted in Iraq, whereas another study [17] included data from a series of 22 Arabic-speaking countries. Multimedia Appendix 1 lists the reviewed studies and the social networking intervention used, together with each of the Middle Eastern countries where these studies were conducted.

Social Networking Apps in the Middle East

Social networking apps used to facilitate the management of diabetes from the patient's perspective included the SANAD system [12,15]. The SANAD system has 3 main entities: (1) a mobile diabetes management module, (2) a social networking module, and (3) a cognitive behavioral therapy module for behavioral change issues. Another study used the DIAR system for mobile diabetes management [3]. The DIAR system consisted of 2 main components: (1) a mobile self-monitoring of blood glucose system and (2) a remote Web interface and health management system. Other social network tools consisted of mobile phones [16] and social networking media such as Facebook [17].

Social Networking System in the Kingdom of Saudi Arabia

This review focused on the benefits of social networking and mobile diabetes management in the patient population of the Middle East region. In the first example, my group presented a mobile social networking system, SANAD, tailored for patients with type 2 diabetes in the KSA [12,15]. SANAD was designed to provide a smart social behavioral change intervention and management for Saudi patients with diabetes. To evaluate this system, 33 patients with diabetes were surveyed, and 80% indicated that the SANAD mobile system was effective in managing their diabetes [12,15]. However, the patients indicated that aspects relating to terminology and system information needed improvement.

In another study, we showed that a large number of patients in the KSA were open to using social networking as a tool for better management of their diabetes [16]. Specifically, the patients preferred the features that allowed them to speak to and obtain feedback from a medical professional in real time.

mHealth System in Iraq

To assess the effectiveness of a mobile health study in a conflict region, Istepanian et al designed and implemented a feasibility study on mobile diabetes management in Basra, southern Iraq [18]. This pilot study was set up as a model to test the effectiveness of mobile health technologies to improve health care in other postconflict regions. The study recruited a total of 12 patients with type 2 diabetes from 1 hospital. The patients were evaluated for HbA_{1c}, low-density lipoprotein cholesterol, and high-density lipoprotein cholesterol before and after commencing the study. The results showed a significant decrease in HbA_{1c} levels; however, no change was observed in other parameters. Overall, the patients were satisfied with the mobile health intervention and wished to continue it as part of their medical care [18]. The major limitation of this study was the small sample size and lack of regional diversity.

Social Media Platforms in Arabic-Speaking Countries

A study by AlQarni et al assessed the sharing of diabetes-related health information on the social media platform Facebook [17]. This study analyzed a total of 1551 Facebook posts originating in 22 countries. The principal focus of the posts was on sharing personal experiences with diabetes (n=423, 27.3%), followed by posts supporting patients and caregivers (n=220, 14.2%), raising awareness of the condition (n=210, 3.5%), providing spiritual support (n=162, 10.4%), sharing the latest research (n=147, 9.5%), and providing education (n=110, 7.1%) on diabetes. A large proportion of the posts by individuals aged between 40 and 60 years focused on finding out diagnosis-related information due to limited access to care in their home countries. These findings support the increasing rate of sharing information on social media to improve public health.

Discussion

Principal Findings

The purpose of this review was to assess the impact of social network platforms on the control and management of diabetes in the Middle East region. The use of technological devices as a means of providing effective health care solutions is rapidly increasing, especially in low- to middle-income countries [18]. Health education and awareness programs are being recognized as key players responsible for this rising trend. The studies evaluated in this review demonstrated that the acceptance of social networking tools for better management of diabetes is relatively high in the Middle East. Generally, newer networking system such as SANAD and DIAR, tailored for individuals with diabetes, were easily adopted and received high ratings. More specifically, patients reported a favorable overall impression and satisfaction in terms of aspects of screening and learning, and capabilities of the system. However, patients rated aspects of terminology and system information and learning factors poorly. Improving the factors that caused user dissatisfaction would promote further use of social networking tools to support disease management.

As in the case of more universal social media avenues such as Facebook, it is evident that the sharing of health information, especially for chronic diseases with a high global prevalence, such as diabetes, is also increasing. Patients are finding new ways to find answers via social media platforms to address health concerns with other users. It is noteworthy that there are

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several advantages to using social networking for the management of a disease. However, without the proper regulations and screening tools for social media sites in place, there is the potential of acquiring misleading management advice from an erroneous source.

From a clinical standpoint, provision of improved glycemic control and education through mobile phone technologies is an effective and available approach to provide knowledge to patients with type 2 diabetes. However, limited resources and deployment options are some of the challenges to getting the devices to areas in the Middle East region.

This review highlights that social media networking interventions are considered as acceptable approaches to improving management of and education about diabetes. However, there are some limitations that should be noted. Some of the studies included in the assessment did not report power calculations. Furthermore, several studies assessed in this review contained small sample sizes limited to 1 region. Therefore, further studies with larger sample sizes and spanning multiple cities and regions are required to fully evaluate the social network interventions for the management of diabetes.

Conclusion

This review evaluated the available data and studies of the impact of social networking on diabetes management in Middle Eastern countries. Considering the importance and the massive popularity of social networking tools in the region, only a few studies to date have addressed this important health care area. However, these studies indicated the potential impact of social networking tools in improving diabetes care and outcomes. Further studies consisting of larger sample sizes spanning multiple regions would provide further insight into the use of social network media for improving outcomes of patients with diabetes.

Conflicts of Interest

None declared.

Multimedia Appendix 1

List of reviewed studies.

[PDF File (Adobe PDF File), 27KB - jmir_v20i2e58_app1.pdf]

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Abbreviations

DIAR: Diabetes Intelligent Management System for Iraq
HbA_{1c}: hemoglobin A_{1c}
KSA: Kingdom of Saudi Arabia
SANAD: Saudi Arabia Networking for Aiding Diabetes

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Original Paper

Medicaid Becomes the First Third-Party Payer to Cover Passive Remote Monitoring for Home Care: Policy Analysis

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Abstract

Background: Recent years have seen an influx of location-tracking, activity-monitoring sensors, and Web-cameras to remotely monitor the safety of older adults in their homes and to reduce reliance on in-person assistance. The state of research on these monitoring technologies leaves open crucial financial, social, and ethical cost-benefit questions, which have prevented widespread use. Medicaid is now the first large third-party payer in the United States to pay for these technologies, and their use is likely to increase as states transition to managed long-term services and supports (MLTSS).

Objectives: This is the first study to examine how state Medicaid programs are treating passive remote monitoring technologies. This study identifies (1) which states allow location tracking, sensor systems, and cameras; (2) what policies are in place to track their use; (3) what implementation processes and program monitoring mechanisms are in place; and (4) what related insights Medicaid program stakeholders would like to learn from researchers.

Methods: Interviews were conducted with 43 state, federal, and managed care organization (MCO) Medicaid program stakeholders about how these technologies are used in state waivers serving community-dwelling older adults in 15 states, and what policies are in place to regulate them. The interviews were analyzed by the research team using the framework analysis method for applied policy research.

Results: Two-thirds of the states cover location tracking and activity-monitoring sensors and one-third cover cameras, but only 3 states have specific service categories that allow them to track when they are paying for any of these technologies, impeding regulation and understanding of their use at the state and federal level. Consideration of ethical and social risks is limited, and states struggle to understand which circumstances warrant use. They are further challenged by extreme resource restrictions and transitions to MLTSS by MCOs inexperienced in serving this growing “high-need, high-cost” population.

Conclusions: Decisions about Medicaid reimbursement of technologies that have the potential to dramatically alter the way older adults receive supportive services are being made without research on their use, social and ethical implications, or outcomes. At a minimum, new service categories are needed to enable oversight. Participants prioritized 3 research aims to inform practice: (1) determine cost-effectiveness; (2) identify what type of information beneficiaries want to be generated and whom they want it to be shared with; and (3) understand how to support ethical decision making for beneficiaries with cognitive impairment. These findings provide direction for future research and reveal that greater interaction between policy makers and researchers in this field is needed.

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KEYWORDS

policy making; Medicaid; long-term care; aging; information technology; passive remote monitoring; sensing; ethics; technology implementation

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Introduction

Most are aware of the statistic that by 2050, 20% of the US population will be aged 65 years or older [1]. The silver tsunami, age wave, and other catastrophic weather metaphors are commonly evoked along with the "care crisis" due to the changing ratio of elder care supply and demand. Among the 43+ million Americans who are over the age of 64 years today, nearly 1 in 3 live alone and half will experience severe cognitive impairment or need long-term care for at least 2 activities of daily living at some point over the remainder of their lives [2,3]. At a national average of US $20 per hour, having a regular home health aide to provide this care is costly [4], but it amounts to roughly half the cost of the median shared nursing home room at about $86,000 per year [4]. Enabling aging-in-place is widely considered a priority in the context of a shortage of human and financial resources for elder care [5-7]. The population of older adults living in nursing homes has declined significantly over the past few decades [8], and despite the rise of assisted living facilities, 80% of older adults who receive assistance live in private homes in the community [1].

While the majority of the population receives ongoing assistance in their own homes, this is not a covered service under Medicare. Medicaid pays for the largest share of long-term services and supports (LTSS), which includes both residential and home and community-based care. Two Medicaid LTSS trends are noteworthy. First, there has been an increase in the portion of Medicaid LTSS expenditures on home and community-based services (HCBS) compared with nursing homes, reflecting the goals of rebalancing initiatives. In 2015, 44% of LTSS expenditures on programs for older adults and people with physical disabilities were accounted for by HCBS [9], a portion that has more than doubled since 1995 [10]. A second trend is the expansion over a short period of time of managed long-term services and supports (MLTSS) where managed care organizations (MCOs) contract with states to provide services to Medicaid beneficiaries. As of February 2017, 19 states had transitioned to MLTSS [11].

State Medicaid waivers are a key component of many Centers for Medicaid and Medicare Services (CMS) and state rebalancing initiatives to reduce reliance on institutional care, with the 1915(c) waiver known as the "home and community-based services waiver" accounting for more than half of all HCBS Medicaid spending [9]. These waivers, whether contracted through providers or MCOs in MLTSS states, are states' most flexible mechanism to connect people with services such as case management, home health aides, personal care, and respite care, to prevent or delay nursing facility admissions or to move people out of institutions. Waivers are a source of variation in programs across states because they allow states to waive federal regulations to, for example, target services to specific populations such as those at risk for institutionalization and to demonstrate new methods for providing services [12].

The Rise of Passive Remote Monitoring Technology in Elder Care

Recent years have seen an influx of accessible, low-cost technologies for continuous passive remote monitoring in the form of Web-cameras and sensor systems that monitor activity and movement in and out of the home [13]. Passive remote monitoring systems collect and transmit a range of data, including location outside the home (GPS), movement and activity (sensor systems), and camera recordings of activity in intimate living spaces. With these technological developments, providers of Medicaid-funded LTSS are turning to passive remote monitoring technologies to enable what is referred to as "most integrated housing" and to reduce costs of services for waiver beneficiaries.

In the United States, barriers to widespread uptake of passive monitoring technology have been the lack of reimbursement by third-party payers and inadequate evidence of clinical and financial benefit [14,15]. Medicaid is the first large third-party payer to begin to formally reimburse these technologies for the care of older adults, but this trend has not been cited in academic literature, and virtually nothing is known about it. There are no national data on the prevalence of their use, nor are there state or federal administrative record capture systems on the use of this category of technology.

The introduction of passive remote monitoring technologies through Medicaid is important because these technologies' potential for revolutionizing independent living is one of the most widely discussed topics in aging health studies [16]. The past decade has seen a high level of innovation in technology for aging, with numerous governments investing in significant research collaborations, such as the cross-national Ambient Assisted Living Joint Platform of the European Union and the national AGE-WELL Initiative in Canada, launched in 2008 and 2015, respectively. Still, today's published research is more focused on development rather than the evaluation of impact of devices on health outcomes and lives of older adults [17]. These technologies hold promise to safely supplement and reduce in-person care, but reviews of the English language literature find that they are being deployed with neither evidence of benefit on individual nor systems outcomes [16-22]. Furthermore, while more attention is paid by researchers in Europe and in Canada to ethical challenges, we neither understand how to mitigate the risks that older adults face and which pose significant ethical concerns yet [23-25] nor do we know how to provide comprehensive and effective systems [6] or how to interpret changes detected by monitoring systems in ways that would enable the prediction of adverse events necessary for an intervention [15]. As a result, decisions about Medicaid reimbursement that could dramatically alter the way older adults receive supportive services are being made in the absence of research on the trade-offs in privacy, autonomy, and human interaction, as well as other risks identified by researchers [16]. This is compounded by a lack of clarity about the relevant stakeholders' perspectives, particularly those who are asked (though this step cannot be assumed) to subject themselves to remote monitoring.

What Are the Potential Risks and Benefits?

Potential benefits of passive remote monitoring include reduced health service use [26], enhanced emergency response, fall detection, independence and postponement of institutionalization [27], feelings of security and peace of mind [28], whereas

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potential risks include isolation through reduced human interaction and hands-on care, privacy invasion, loss of control, data inaccuracy [27,29-32], and reduced behavioral autonomy and access to services [29,33,34]. Reviews of the passive remote monitoring literature exhibit that ethical issues are treated superficially, and detailed consideration of serious ethical challenges is absent [23,35]. Authors of a review of ethics in the remote monitoring of those with memory loss conclude that these technologies "pose serious ethical challenges" that "urgently need further analysis" [23]. Gerontologists have also pointed toward the parallels between monitoring and "processes of institutionalization," whereby deviations from one's typical behavior or routine lead to the involvement of caregivers [29]. Weber and colleagues warn that individuals will "lack full autonomy in their decision making" when they "normalize" their behaviors while being monitored, thus impeding informational self-determination and the right to be nonconformist [36].

There are few studies of older adults' attitudes toward these technologies, and many of those that exist are of low methodological quality [37,38]. Small-scale studies of older adults indicate that they want control over decision making about who has access to what data and under what conditions [39,40]. They do not want passive remote monitoring to reduce social interaction, replace human contact, or replace hands-on care [18,39], and they largely reject the collection of visual or audio data recorded by cameras [41,42]. The majority of the research identifies tensions among values such as privacy, independence, and safety, referred to in the literature as "sacrifices" or "trade-offs," which older adults would make to forestall residential care [24,43,44]. This trade-off framing posits that diminished privacy, autonomy, human interaction, and other risks are outweighed by new efficient means of enhancing safety, reducing hospitalizations, and allowing people to remain living in the community.

These tensions and concerns cited by older adults are largely due to the shift from *active* emergency alarm systems to *passive* monitoring. Unlike personal emergency response systems (PERS) that require the user to push a button, passive monitoring systems collect and transmit data about the type and frequency of activity in a home without the beneficiary having to take any action or even be cognizant of the monitoring. Passive systems are unlike telehealth because there is no communication between patient and provider. Location tracking, activity monitoring sensor systems, and cameras are distinct from the category of remote patient monitoring that references biometrics monitoring, such as heart rate. Sensor-based passive monitoring, for example, uses algorithms to track behavior or movement for interpretation as behavioral biomarkers--in theory, a urinary tract infection might be detected if the activity monitoring system captures a change in an individual's frequency of bathroom use. Another option is monitoring cameras, which now come in many inexpensive forms purchased by family members, LTSS providers, or facilities wishing to keep an eye on vulnerable older adults. When implementation is advancing faster than the research on what constitutes appropriate and ethical use for different populations, it is important to explore what devices are being used and how.

The aim of this research is to begin casting light on the use and regulation of passive remote monitoring technologies by state Medicaid waiver programs for older adults. The Center for Connected Health Policy publishes state technology coverage based on publically available documents, but this information is incomplete because passive remote monitoring is rarely captured in waiver documentation, which CMS provides on their website. This interview-based policy analysis addressed the following questions in a sample of 15 diverse states:

- Which states allow GPS, sensor systems, and cameras, and under what conditions?
- What policies are in place to track and regulate their use?
- What implementation processes and program monitoring mechanisms are in place?

The urgency of these questions is heightened by both Medicaid HCBS expenditure growth and the possibility of Medicaid becoming a block grant program. These pressures and the absence of research on the circumstances under which passive remote monitoring is a viable and preferable HCBS policy option might propel states and MCOs to substitute it for costly in-person care. Proposals to limit funding growth based on medical inflation are projected to adversely impact the main drivers of state spending, particularly disabled LTSS beneficiaries [45]. Changes in Medicaid payment policy will likely foster greater growth in the use of monitoring technologies, including the prospect of monitoring being an allowable cost under dual eligible Medicaid Advantage Programs. As such, there is a pressing need to learn how these technologies are being used, how their outcomes are monitored, and how their deployment is overseen.

Methods

This targeted policy analysis included telephone interviews with 43 participants about GPS-based location tracking outside the home, activity monitoring sensor systems, and cameras in aging waivers. To ensure that the most knowledgeable people participated, those who held the following positions were recruited: (1) the manager of one or multiple Medicaid waivers that serve older adults in the community (1915b/c and 1115 waivers), (2) state employees suggested by managers for their institutional knowledge and content expertise, (3) state-level MCO representatives of the largest MLTSS programs referred by state managers, and (4) HCBS policy experts who study participants identified as their "go-to" resource on the use of remote monitoring technologies. In total, 7 participants were content and policy experts at the national level, and 36 participants represented state Medicaid waiver programs or MCOs serving older adults in a diverse sample of states.

The sample of states was selected to capture variation in LTSS policy and include those that are known to be taking the first steps toward expanding services, as well as those that are likely to be the most influential, based on their track records as innovators in HCBS. These 15 states included California, Florida, Illinois, Indiana, Kansas, Massachusetts, Michigan, Minnesota, Missouri, Montana, New York, Pennsylvania, Tennessee, Virginia, and Washington. In this study's sample, 8 of the 15 states had MLTSS programs, and 4 state branch

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representatives of large MCOs that provide MLTSS were interviewed about their state's coverage. The interview protocol is highly targeted because it was informed by pilot interviews with consultants who advise states on these issues, national membership associations, and federal policy makers.

Before each interview, we read each state's current CMS-approved aging waivers to understand under which service category, if any, that state had been approved to cover any of our 3 categories of technologies (location tracking, sensor systems, and cameras). We cross walked that information into the interviews to clarify discrepancies between what the participants were telling us and the content of the waivers. This also allowed us to confirm that we were speaking about the same specific service categories when participants described their content.

The author and 2 Master of Public Health student researchers analyzed all interview notes and approved waivers using the framework analysis method that was developed for applied policy research [46,47]. This method enables transparent interpretation of specific policies in relation to specific research questions [46]. Framework analysis involved 5 steps: familiarizing, identifying an analytical framework, indexing, charting, and interpreting [46]. We began by thoroughly reading the interview notes and waivers and noting initial analytic observations, followed by classifying the data through an a priori coding scheme based on the questions in the structured interview protocol. The research team met weekly to discuss these codes and applied this framework to a subset of interviews to reach consensus on its application. We then applied the analytical framework to all documents by connecting codes to corresponding portions of the data (indexing). Data from each state were then summarized and arranged into matrices with headings and subheadings developed according to the analytic framework. This visualization drew attention to patterns, trends, and differences between states that guided and clarified our interpretation [47].

Results

Coverage policies regarding these technologies ranged from explicitly and operationally prohibiting them to explicitly and operationally covering them. As depicted in Table 1, ten of the 15 states cover GPS location tracking systems. Nine states allow sensors, and an additional 3 states report that there is no policy in place regarding sensors. For the allowing states, sensors fall under a broad range of service categories. Sensor-based systems that track location and activity have been integrated into ubiquitous services such as PERS, so that companies now offer multiple functions in familiar products. Decision makers in aging services view these as promising tools. As one state manager explained, "This whole thing is in its infancy right now and we need to incorporate it into our program because it's one way to save costs, and it's less invasive and hopefully less costly and more convenient." MCO representatives echoed these sentiments.

Respondents report that providers of adult family homes originally promoted the use of cameras through the intellectual and developmental disability waivers. In the context of a workforce shortage, providers argued that replacing an aide who periodically checks in at night with a camera in residents' bedrooms is more efficient and less intrusive. This use of Web-based cameras is still more prevalent in disability waivers than aging waivers. Five of the 15 states cover cameras in at least one of their waivers for older adults. These include a state that covers cameras through an "in lieu of" clause for MCOs, one in the form of baby monitors that are paid for by a waiver, and a third with baby monitors allowable under "Specialized Medical Equipment and Supplies." Three additional states do not prohibit cameras and reported that they would fall under the "Assistive Technology" service category.

What Policies Are in Place to Track Their Use?

Service category titles under which passive remote monitoring technologies are covered in practice under the approved waivers are listed in Table 1. Only 3 states collect service data that allow them to track the number of beneficiaries using a particular technology. In Washington, PERS + GPS is assigned an extra "modifier" in administrative records that makes it possible to run a data search to learn the number of people using PERS + GPS tracking. Massachusetts covers GPS under a specific service category called "Home Based Wandering Response Systems," and "Telecare" is a unique service category in Pennsylvania for sensors. None of the respondents accessed these data for our interviews or at follow-up upon request, noting that it is an onerous process. In all other states, these technologies fall under broader service categories, so the precise type of technology (ie, GPS, sensor, or camera) is unknown to state administrative systems.

State representatives report struggling to collect data that can inform them about what is being used without causing the waivers to be restricted to specific technologies. They felt current service categories were inadequate. "Assistive Technology," for example, might encompass walkers, screen readers, brail embossers, and a range of other assistive technologies, which are defined as those that maintain or improve functional capabilities. One participant hoped that a specific service category or code for remote monitoring would be developed:

> *...because we now use the one code for assistive technology, but that doesn't give us access to the level of detail to understand how that benefit is being used.*

Worried about being able to keep up with tech innovation, the participant stated:

> *I never want what we can do to be limited if a code doesn't exist for it.*

Many wanted to know what other states were doing:

> *It would be easier if we had a broad category as new technology becomes available, rather than going through a new approval process, but knowing CMS, they want all kinds of specifics. We can't put just anything in there, of course. Have any states figured it out?*

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Table 1. Summary of state technology coverage, tracking, and policy.

Category	Location tracking	Sensors	Cameras or baby monitors
States prohibiting (15 possible), n	4	3	7
States that do not prohibit but lack policy, n	1	3	3
States covering, whether or not specified in waiver, n	10	9	5
States able to track use, n	2	1	1
States that require special committee, consenting, or rights notification process, n	0	1	1 (if camera is to be used in a bedroom)
Service categories used in practice	PERS; Specialized Medical Equipment and Supplies; Communication *Technology-Specific Categories:* "Home-based Wandering Response Systems" (MA); PERS+GPS modifier under "PERS" (WA)	Goods and Services; Specialized Medical Equipment and Supplies; Assistive Technology; Communication; Possible for MCOs under "Cost Effective Alternative Services" *Technology-Specific Category:* "Telecare" (PA)	Assistive Technology; Specialized Medical Equipment and Supplies; Communication; Environmental Modifications; Possible for MCOs under "In Lieu Of" Clause

Two managed LTSS states reported clauses that allow MCOs to provide services that may fall outside the approved program services, termed "cost-effective alternative services" in one and "the 'in lieu of' benefit" in the other. This provides flexibility for MCOs to integrate technologies and other alternatives to standard services outlined in the waivers. States' oversight of which specific services are provided is minimal. As one waiver manager explained:

> *What's hard is that while we get full encounters on their expenditures for "Assistive Technology," I have no way of knowing the kinds of things they are purchasing for members. I expect that many of these technologies are things they have and would purchase but my encounter data isn't that granular.*

In MLTSS states, MCOs authorize technology and directly contract with providers. States do not know what technology-based services they provide and access care plans only if an issue has been brought to their attention.

The finding that states are largely unable to track what technologies are being covered in practice supports one participant's characterization:

> *It's the wild West.*

The inclusion of passive monitoring technologies under broad service categories prevents states or CMS from knowing when providers use passive monitoring.

What Implementation and Oversight Mechanisms Are in Place?

The risks of these technologies identified in the extant research are not directly addressed by current state Medicaid policies, and there is limited discussion in state aging waiver programs about these risks. With just 1 exception, states that covered any of these technologies lacked consenting processes and monitoring mechanisms. Conditions for use are the same as those that would qualify beneficiaries for the broader service category under which a given technology might fall (eg, PERS), in addition to requirements for an associated behavior, such as wandering behavior when GPS is to be covered. States also report struggling with the weak evidence base and were unclear about which circumstances warranted use, and consequently, trainings were not provided to educate support coordinators who approve services. The additional barriers of a widespread shortage of qualified coordinators and uneven availability of technologies across various regions were often cited.

At the time of these interviews, Minnesota had made the most progress toward formalizing a process for approving cameras and sensors that collect data. Camera requests are reviewed by a committee, and a series of forms recently required by CMS are used to notify beneficiaries and roommates of their rights. Cameras were in use in other waivers where monitoring technology substitutes for staff, but an older adult case had not yet been reviewed. Minnesota was also in the process with CMS of reviewing forms for technology that collect data, including movement sensors, noting that they had always paid for such technology for older adults but had no way of monitoring it or explaining beneficiaries' rights. Apart from that, however, there are no processes in place to ensure informed consent, discuss the implications of being remotely monitored with beneficiaries, or guided dialogue about privacy or other impacted values. Requests from families, providers, or support coordinators are addressed on a case-by-case basis with no unique process.

The lack of process notwithstanding, the majority of individual respondents acknowledged the potential for ethical problems to arise, though one-third noted that their offices had never discussed or considered potential ethical issues related to these 3 categories of monitoring. Some felt that the inherent risks to privacy of sensors and GPS are outweighed by benefits to safety, offering examples where beneficiaries with dementia had wandered off and gotten lost. In some states where sensor-based systems are permitted, managers noted that restriction of patients' rights is a concern. Others had questions about efficacy:

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> *I think with the sensing, I guess what's the most effective. I mean with floor mats or bed mats, do you really just get someone's movement that's just normal movement, just restless or getting up and it's not necessarily an emergency? We don't want to install cameras, but I don't know without a camera how you would know that.*

The most common sentiment was that there is a balance to be struck between privacy and safety, though respondents indicated no process for achieving it.

Participants identified a tension between the needs and desires of beneficiaries and those of care providers:

> *There's a consent factor there, and understanding if the person knows they're being monitored, and if their representative is solely safety-driven and doesn't include evaluation of dignity at risk. So there are a lot of factors. How informed is the person?*

A state manager explained that they receive requests for cameras from family members to monitor people with Alzheimer's disease and related dementias while away at work, which raises similar questions.

> *I know that that's been a big trend in a lot of the different states. I know that it's something that we probably need to start venturing in here to looking at what would that look like, what would the reimbursement look like? Under what circumstances would we allow something like that? I think we've got to be careful too that just because the family gets peace of mind, it's like, well, we don't want to invade that person's right because we're also struggling with that whole person-centeredness and having to take everyone's perspective into account. You have to be very considerate of what that could look like. So I think there could be some ethical concerns and maybe some conflict.*

Others expressed similar concerns about the use of GPS for beneficiaries with dementia:

> *Yes it's great for family, but is it bad for a consumer who gets anxious?*

These concerns were not linked to formalized processes for mitigating them. With few exceptions, individual support coordinators determined and safeguarded the balance between privacy and safety without technology training, additional supports, or consent form processes. Participants noted the need for research on participants' experiences, ethical implications, and efficacy to help inform their decision making.

Discussion

Research and Policy Priorities

Service providers and policy makers recognize the need to monitor the safety of a growing population of older adults living alone in the community. The combination of looming federal cuts to Medicaid and a widespread shortage of attractive direct care jobs and workers have created a strong incentive to reduce reliance on personal aides [48].

In addition to these pressure points, the transition states are making to MLTSS is likely to increase the use of passive remote monitoring technologies. States have reported that they struggle with lack of data from MCOs to measure quality impact, particularly for duals [49]. Moreover, this research finds that critical feedback loops are lacking without mechanisms for tracking which beneficiaries are using which technologies in MLTSS and non-MLTSS states. Given the pace of innovation and onerous waiver application processes, states want service categories that do not restrict adoption of promising technologies, yet current categories do not accurately describe covered technologies. A move to categorize these by function (ie, scope of data collected; granularity; frequency) may help to solve both the flexibility problem and the information problem for overseers.

Ideally, those responsible for making policy decisions and for implementing policy through Medicaid programs would be in conversation with researchers on monitoring technologies; effective safeguards require knowledge of the nature of risks they are intended to mitigate. It is not unusual for research and research dissemination to lag behind policy and practice, but in this case, the conversation about the difficult trade-offs for Medicaid beneficiaries is lagging behind as well.

One place to start is the simple but profound acknowledgment that there is no such thing as technology [50]. Dutch anthropologist, Jeanette Pols reminds us that while there are many technologies, technology is just a concept. It is better to study and understand the implications of a specific technology than to place undirected hope in *technology* to categorically solve problems of resource restrictions in the face of demand growth. It is important, in other words, to distinguish an assistive technology like a brail embosser or a walker from a remote monitoring technology such as a movement sensor. The distinctions matter because their implications for actors and relationships differ. As participants pointed out, even within the category of passive remote monitoring, it is important to distinguish between GPS location tracking, sensors, and Web-camera monitoring. This study finds that this is not current practice. Participants prioritized 3 research aims that align with Pols' encouragement to capture specificity: (1) identify what type of information beneficiaries want to be generated, whom they want it to be shared with, and under what circumstances, (2) understand how to support decision making for beneficiaries with cognitive impairment, and (3) evaluate the efficacy of various categories of remote monitoring technologies in relation to the costs.

This research should also inform the following policy priorities: (1) regulatory checks on risks and negative impact of passive remote monitoring; (2) training for support coordinators (care managers) and state staff on ethical implications across settings and uses; and (3) cross-state sharing of best practices and lessons learned. Regulatory checks require specific coding to inform states and CMS when a given technology is in use. This would enable tracking these technologies' associations with positive or negative outcomes, which has the potential to greatly inform use in the absence of large randomized controlled trials. The implementation of such regulatory checks could also provide more intentional opportunities for beneficiaries and their families

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to request changes to their technology service according to their own experiences with it over time and as their conditions and situations change.

Across states, respondents reported uneven or nonexistent trainings for care coordinators and eagerness to learn from other states about emerging solutions to the difficulties of managing an ethically fraught intervention without a sound evidence base. Medicaid program managers are accustomed to difficult decisions forced by resource restrictions; however, the job of regulating the lesser of what may be considered two undesirable choices (being monitored remotely or move to a nursing home) may be especially complex. Put directly, a solution that is less bad than residence in a nursing home does not make it a sound ethical solution because beneficiaries may be made to accept undesirable circumstances [24]. In practice, for beneficiaries with decision-making capacity, ethical deployment of passive monitoring requires freely given informed consent and awareness that consent can be withdrawn [51]. One state was in the process of piloting a consent form, which included "privacy" as a checkbox; however, researchers are just beginning to learn what privacy means in relation to in-home monitoring and how to talk about it with older adults [31,52]. The known risks of passive remote monitoring, including loss of privacy, autonomy, control and human contact, require clear and careful articulation in relation to the nascent research. New efforts that are needed both to introduce training on ethical implications and to share best practices across states can be integrated, with opportunities for open discussion among practitioners about what they are encountering in the field.

Conclusions

Medicaid waiver programs require flexibility to meet beneficiaries' individual needs, and technology to support connectivity, well-being, and home care are important areas for growth in waiver programs. Nevertheless, when the economic logic of an intervention for "high-need, high-cost" individuals [53] is as powerful as it is in this case of Medicaid, we must be vigilant about what types of technologies are being integrated without an understanding of what constitutes appropriate use. Before investment in passive remote monitoring technology makes it difficult to reevaluate use, policy makers should heed gerontologists' concerns regarding the parallels between monitoring and "processes of institutionalization," cautioning that "careful consideration is necessary to ensure that programs, policies and technologies that are intended to contain costs by 'protecting' the health of older adults do not further disempower this already potentially marginalized group of individuals" [29]. The fact that struggling Medicaid programs are moving first into this uncharted territory adds weight to these concerns.

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Conflicts of Interest

None declared.

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Abbreviations

LTSS: long-term service and supports
MLTSS: managed long-term service and supports
PERS: personal emergency response systems
HCBS: home and community-based services
MCO: managed care organizations
CMS: Centers for Medicaid and Medicare Services

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Viewpoint

The Significance of Witness Sensors for Mass Casualty Incidents and Epidemic Outbreaks

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Abstract

Due to the increasing number of natural and man-made disasters, mass casualty incidents occur more often than ever before. As a result, health care providers need to adapt in order to cope with the overwhelming patient surge. To ensure quality and safety in health care, accurate information in pandemic disease control, death reduction, and health quality promotion should be highlighted. However, obtaining precise information in real time is an enormous challenge to all researchers of the field. In this paper, innovative strategies are presented to develop a sound information network using the concept of “witness sensors.” To overcome the reliability and quality limitations of information obtained through social media, researchers must focus on developing solutions that secure the authenticity of social media messages, especially for matters related to health. To address this challenge, we introduce a novel concept based on the two elements of “witness” and “sensor.” Witness sensors can be key players designated to minimize limitations to quality of information and to distinguish fact from fiction during critical events. In order to enhance health communication practices and deliver valid information to end users, the education and management of witness sensors should be further investigated, especially for implementation during mass casualty incidents and epidemic outbreaks.

(J Med Internet Res 2018;20(2):e39) doi:10.2196/jmir.8249

KEYWORDS

social media; mass casualty incident; internet; sensor

Background

Due to the increasing number of natural and man-made disasters, mass casualty incidents occur more often than ever before. As a result, health care providers need to adapt in order to cope with the overwhelming patient surge [1]. To ensure quality and safety in health care, accurate information in pandemic disease control, death reduction, and health quality promotion is critical [2-4]. However, obtaining precise information in real time during a mass casualty incident is an enormous challenge to all researchers in the field. In this paper, innovative strategies are presented, in order to develop a sound information network using the concept of “witness sensors.”

What Are Witness Sensors?

The term “witness” can be found in vital sectors of several medical fields, especially in emergency and disaster medicine. For instance, many reports emphasize the crucial role of

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bystanders in out-of-hospital cardiac arrests. These bystanders perform cardiopulmonary resuscitation or use automated external defibrillators [5-15]. When it comes to disaster medicine, the first witness usually initiates the systems of pre-hospital emergency medical services (EMS). However, while continuous messages from witnesses flood social media, a major dilemma arises. Should quantity of data be valued over quality? In order to overcome the reliability and quality limitations of the information emerging from social media, researchers must pay significant attention to developing solutions that verify the authenticity of the messages, especially for matters related to health. In this research, we introduce a novel concept that is based on the two elements of "witness" and "sensor" to address this challenge.

Witness sensors respond in a similar way to physical sensors, since they interact and report in real time. Physical sensors are calibrated and modulated prior to any operation so that only the signals from qualified physical sensors are accepted. Likewise, for the witness sensor, training, management, and accreditation policies are critical and should therefore be further investigated prior to executing this concept.

Why Witness Sensors?

These days, the use of social media is an integral part of our daily life. As a consequence, information from witnesses can spread fast and far during catastrophic events [16]. This active and multisourced information is essential during disasters, and it leads to a huge number of messages and posts flooding the Internet. However, the quality and accuracy of some of these data may be questionable.

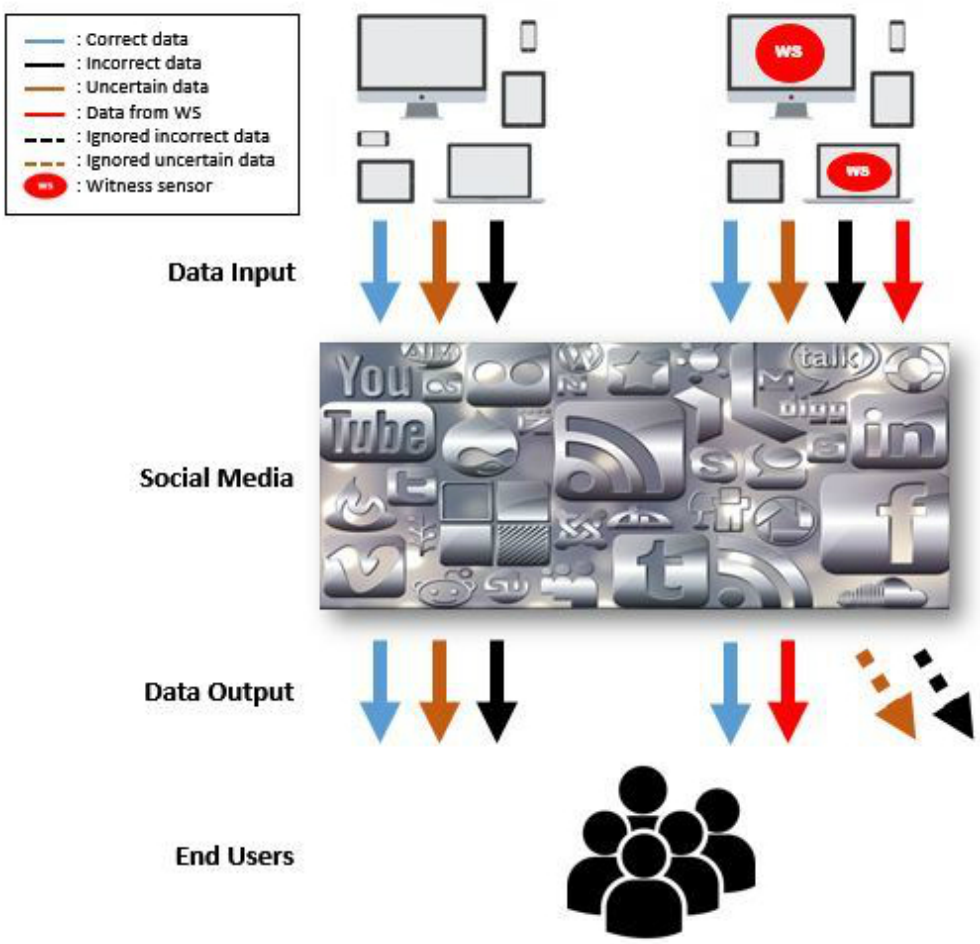
Nevertheless, the value of witnesses should not be ignored, especially in applied medical practices. For example, a magnitude 6.4 earthquake struck southern Taiwan at 03:57 on Feb. 6, 2016, and caused 513 injuries [17]. Remarkably at 04:05, several messages and images were reported in a discussion group on the widely used instant communication/social media app "LINE" in Taiwan, administered by local emergency medical technicians (EMTs). The major EMS responders were dispatched to the disaster area a few minutes later based on the details provided of the damage. Additionally, all the information was monitored by the fire department, response hospitals, and local government.

Owing to the high-quality information from the local EMTs, a temporary Emergency Response Center was set up immediately by the local government at 06:00 to manage and control the event. The incident command system responded efficiently, due to the precise information given primarily by specific witnesses.

However, this does not always apply in general witness cases. Two individuals shared fake posts on social media causing people to panic during a magnitude 6.0 earthquake that occurred in the same city a year later, at 01:12 on Feb. 11, 2017.

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Figure 1. The different information pathways during a disaster between witness sensors and non-witness sensors.



Such phenomena appear globally and although there are mechanisms to prevent such incidents, retrieving and verifying information from witnesses is still a challenge to researchers. The concept of witness sensors is illustrated in Figure 1. Incorrect and questionable information will be ignored while the data from witness sensors are applied as principal references. In addition, qualified witness sensors could ensure the validity and dependability of communication, potentially leading to a paradigm shift in social media.

Similar Cases of Witness Sensors

In Taiwan, several cases based on witnesses and/or volunteers have been applied successfully, mainly for the inspection of traffic and flood events. Real-time reporting of traffic conditions is one such case, which has been well implemented by the Police Broadcasting Service (National Police Agency, Ministry of Interior, Taiwan), online and on radio. The Police Broadcasting Service collects all the incoming information from witnesses and then disseminates that information to road users and to relevant agencies for adequate response and treatment. However, once again, the information quality from general witnesses is not always accurate and truthful, which leads to the need for additional confirmation and accreditation processes by other witnesses or traffic police officers.

This is one of the reasons why the witness sensors should be differentiated from general witnesses; qualification criteria are needed in order to be approved to provide valid information. The precise data collected from witness sensors could produce more reliable and valuable information for all users, especially during or after extreme events.

Training Plan for Witness Sensors

The central dogma of witness sensors is to prevent or reduce the loss of lives during extreme events. The information given by qualified witness sensors could act as a reliable and safe source to corresponding decision makers, compared to data obtained from average social media users. The information pathway is similar to that of social networks, but the response behavior and purpose aim to direct accurate observations to emergency needs instead of personal opinions and embellishments.

Based on our strategy, volunteers will be invited and classified to three levels of witness sensor (WS): WS I, WS II, and WS III. The training goal of WS I is to report on-scene events with true facts, while WS II must report substantial evidence, as well as participate in measurement and evaluation practices. The WS III is a professional level of witness sensors, responsible for in-depth investigations and comprehensive interpretations. In this case, EMTs and members of Disaster Medical Assistance

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Teams would be the most appropriate candidates for WS III. Each level of witness sensor may not only act as an information peer, but also contribute to the emergency response of affected groups, when necessary.

Benefits to Health Quality and Safety

Many researchers have welcomed the general benefits of social media to public health [18,19]. Some of the benefits include increased interaction with different groups, open source information, increased accessibility to global health information, support at multiple levels (eg, peer, social, emotional, as well as public health surveillance), and potential to enhance health policies. Even so, there are many limitations when using social media, especially in developing a robust and comprehensive evaluation mechanism to complement the quality concerns and lack of reliability [20].

Hence, the messages and details from witness sensors could not only promote quality information shared through social media, but also become a prototype model for screening the enormously uncertain health information that resides on the Internet. The witness sensors could improve the reliability of primary data and accelerate the tracking of information sources, since these are fundamental issues during pandemic outbreaks or catastrophic events.

Conclusions

Social media and information exchanges on the Internet have become a major communication tool for health providers and users. In this paper, we proposed witness sensors as key players designated to alleviate possible limitations to accuracy of information and to distinguish fact from fiction during critical events. In order to enhance health communication practices and deliver valid information to end users, the education and management of witness sensors should be further investigated, especially for implementation during mass casualty incidents and epidemic outbreaks.

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Authors' Contributions

C-LP and J-CW conceived the study, and this concept was first constructed by C-LP. C-HL and Y-RL collected the data and shared their experience in emergency medical responses during a disaster. Their contribution and ideas were extremely important to understanding the real conditions of medical information translation during catastrophic events. J-CW supervised all the details of this research. C-LP and H-YW performed a literature review and drafted the initial manuscript. All authors revised the manuscript. J-CW takes responsibility for the paper as a whole.

Conflicts of Interest

None declared.

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Abbreviations

EMS: emergency medical service
EMT: emergency medical technician
WS I-III: witness sensor level I to III

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Original Paper

Effect on the Metabolic Biomarkers in Schoolchildren After a Comprehensive Intervention Using Electronic Media and In-Person Sessions to Change Lifestyles: Community Trial

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Abstract

Background: Obesity is a chronic low-intensity state of inflammation with metabolic alterations that, when acquired during childhood, lead to severe illness in adults. Encouraging healthy eating habits and physical activity is the basis for preventing and treating obesity and its complications.

Objective: To evaluate how a comprehensive intervention promoting healthy eating habits and physical activities in schools affects children's metabolic biomarkers.

Methods: Of four Mexico City primary schools in this study, two groups of children that were recruited at their schools were assigned to a 12-month intervention group (IG) and the other two were assigned to control groups (CGs). The intervention had two components: (1) parents/schoolchildren attended in-person educational sessions promoting healthy eating and physical activity habits, and were provided printed information; and (2) parents were able to seek information through a website, and also received brief weekly mobile phone text messages. Anthropometric measurements and fasting blood samples were taken from both groups of children at baseline and again after 12 months.

Results: The study involved 187 children in the IG and 128 in the CG. Regardless of each child's nutritional status at the beginning of the study, the intervention improved metabolic parameters; the IG showed a negative effect on glucose concentrations (–1.83; CI 95% –3.06 to -0.60), low-density lipoprotein-cholesterol (–2.59; CI 95% –5.12 to –0.06), insulin (–0.84; CI 95% –1.31 to –0.37), and homeostasis model to assess the insulin resistance index (HOMA-IR; –0.21; CI 95% –0.32 to –0.09) in comparison to the CG. HOMA-IR improved in children who had higher than baseline body mass index *z-scores*.

Conclusions: Intervention through multiple components that promoted healthier eating and physical activity habits improved the metabolic parameters of the children in the study after one year, regardless of their nutritional status.

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KEYWORDS

obesity; child; early intervention (education); insulin resistance; biomarkers

Introduction

Over the last 25 years, the prevalence of overweight and obese persons has become a worldwide public health issue [1,2]. According to national surveys, the combined incidence of overweight and obese children in Mexico rose from 26.9% in 1999 to 34.8% in 2006, which is one of the highest increments in the world [3]. While surveys from 2012 and 2016 [3] revealed that the problem has not grown in the last ten years (34.4% and 33.2%, respectively), this percentage remains unacceptably high [4].

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In recent decades, adults and children have changed their eating and physical activity habits. Foods and beverages have become energy dense and high in saturated fats and refined carbohydrates, and these nutrients present cardiovascular risk factors [5-7]; meanwhile, consumption of fresh fruits, vegetables, and water has diminished [8]. Conversely, both children and adults have become less physically active and spend more time on sedentary activities [9,10].

Childhood obesity is associated with adverse health effects. Obesity is a state of low-intensity chronic inflammation, because adipose tissue produces proinflammatory cytokines that promote insulin resistance and metabolic syndrome [11-13]. These alterations precede the emergence of type 2 diabetes and other cardiovascular diseases [14], which are the most common causes of death. People suffering from obesity who have reduced their body weight have improved their metabolic and inflammatory biomarkers and increased their sensitivity to insulin [15]; however, very few studies have researched how community intervention on nutritional status can affect metabolic parameters.

Blood lipid concentrations in obese children have been positively correlated with blood lipid concentrations in adulthood [16], which is an indication of the long-term risk of these alterations for obese children. When comparing to children who are in a normal weight range, obesity affects blood pressure and blood lipid concentrations and increases insulin resistance [12,17-19]; however, children in a normal weight range can also present metabolic alterations. In a population similar to the one in this study, our research group found that 15% of children with normal weights exhibited low high-density lipoprotein cholesterol (HDL-C) concentrations and 6% had hypertriglyceridemia [11].

Diastolic blood pressure has been positively associated with the consumption of sugary drinks, insulin concentrations have been associated with foods containing refined flour, and triglyceride concentrations have been associated with foods with added fats [8]. Childhood obesity prevention programs promoting healthy eating and physical activity habits have achieved considerable improvements in lipid profiles (low-density lipoprotein cholesterol [LDL-C], HDL-C, and total cholesterol), even in children already in a healthy weight range [20]. These results are likely attributable to better eating habits and increasing physical activity, as opposed to a reduction in adipose tissue. This evidence highlights the importance of introducing prevention programs and healthy lifestyle interventions from an early age.

There are numerous studies in which interventions have aimed to improve metabolic parameters in obese children, mostly through calorie-restriction strategies as opposed to encouraging a change of habits. Conversely, few studies have focused on preventing obesity or target children who (despite being in a healthy weight range) are still at risk [21]. Preventing obesity and its severe health implications requires sustainable strategies. Therefore, elementary schools are an ideal context for providing children and households with trustworthy information regarding the importance of leading a healthy lifestyle [22]. We previously reported that handing parents information on healthy eating and physical activity in person, or sending it through electronic media, can improve their children's nutritional status [23]. Thus, the objective of this study is to evaluate how an educational intervention aimed at parents can encourage a change of lifestyle, and also modify metabolic biomarkers in schoolchildren.

Methods

Design and Study Population

As described by Vilchis-Gil et al [23], this study took place in two public and two private Mexico City elementary schools located in the same geographic area, which were selected for convenience and for their approximately similar number of students. Two of these schools were assigned to intervention activities (intervention group; IG) and two of these schools were used as control groups (CGs). Children of both sexes from grades 1-4 were included in the study. The nutritional status of the children could be eutrophic, overweight, or obese; however, children participating in weight loss programs, suffering from chronic illness, or taking prescription medicine that could affect their metabolic profile were not included. The research protocol was approved by the Hospital Infantil de México Federico Gómez (HIMFG) Research, Ethics, and Biosecurity Committee, and by school authorities. Before initiating the study, students and parents were asked to give written consent and approval. The study was not registered at ClinicalTrials.gov.

Intervention Implementation

The intervention took place between October 2013 and July 2014; parents were informed of health risks associated with obesity and the benefits of developing healthy eating and physical activity habits. Nutrition and health topics, mobile phone text messages, posters, and other learning materials were prepared in advance.

Long distance activities for parents took place on the website and through parents' mobile phones. The HIMFG website featured a window where parents could access all project information. The portal, which had several sections, was updated with new topics every 15 days for a total of 20 topics during the entire intervention. Topics included information on how to improve eating and physical activity habits, as well as links to electronic resources providing information on that same topic. Parents were sent weekly text messages of up to 25 words on their mobile phones. Each message encouraged and reinforced behavioral changes and was related to the latest topic on the website. Forty messages were sent in total.

Regarding in-person activities, parents of schoolchildren participating in the intervention attended three hour-long sessions, which were held every two months. Session contents were designed to strengthen their participation in the project and offer opportunities for parents to share their experiences, doubts, and opinions, and offer feedback for the project. Parents were also given two brochures offering information on healthy eating and physical activity.

The children participated in several activities. A team of two nutritionists and a physical education teacher held four bimonthly workshops with a 1.5-hour duration. Workshops

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incorporated board games, physical games, and learning materials designed to encourage and reinforce healthy eating habits and physical activity. Children were given laminated placemats with images such as the "Healthy Eating Dish" (Plato del Bien Comer) [24] and the physical activity pyramid. The children and their parents visited the Life and Health Balance Hall (Sala Salud Vida en Equilibrio) at Universum Science Museum located at the National Autonomous University of Mexico (UNAM; Universum, Museo de las Ciencias de la UNAM). Every month, posters promoting healthy habits related to the latest topic on the website were placed in visible places around the school, and proved to be very popular among students.

Sociodemographic Information

Mothers of participating students filled in forms that provided information on their education level and on their child's sex and age.

Measurement Anthropometrics

Two nutritionists who were familiar with standardized in international anthropometric procedures [25] measured and weighed the children at baseline and at the end of the study (12 months). Weight was measured on a digital scale (Seca model-882, SECA Corp., Hamburg, Germany) with 0.1 kg precision. Height was measured on a stadiometer (SECA model-225, SECA Corp., Hamburg, Germany) with 0.1 cm precision. Children were measured without shoes and wearing light clothing, standing in the middle of the scale platform or stadiometer, arms resting freely by their sides, with their heads in the Frankfurt horizontal plane.

Body mass index (BMI) *z-scores* were obtained using the children's age, height, and sex. Children were then classified as underweight (*z-score* < -2), normal weight (*z-score* > -2 to <1), overweight (*z-score* >1 to <2) and obese (*z-score* >2), according to standards provided by the World Health Organization in 2007 [26].

Biochemical Determinations

Children from both groups gave venous blood samples at baseline and after 12 months, in both cases having fasted for 12 hours. These samples were used to determine glucose, triglycerides, total cholesterol, and HDL-C (ILAB 300, Instrumentation Laboratory, Barcelona, Spain). For LDL-C, we utilized DeLong's modified Friedwald formula [27]. Insulin was determined by chemiluminescence immunoassay (IMMULITE 2000, Euro, DPC, Llanberis, UK). The following equation was used to obtain homeostasis model to assess the insulin resistance index (HOMA-IR): fasting glucose (mg/dL) x fasting insulin (μU/mL)/405 [28].

Data Analysis

The study population's baseline characteristics were described using descriptive statistics. Weight and height measurements were adjusted by age and sex using multiple linear regression. A student's t-test was used to compare groups' continuous variables at baseline and the Chi-square test was used for categorical data. The Mann-Whitney U test was used to compare metabolic parameters between groups at baseline.

Subsequently, the analysis was limited to participants whose data was complete at baseline and after 12 months. To evaluate changes in metabolic parameters at baseline and after 12 months, quotients were estimated using quantile regression models, adjusted for dependent variable baseline concentrations, baseline age, sex, and school. After these estimations were determined, the effect of the intervention on the change in metabolic parameters at the end of the study was evaluated. Quantile regression models were used to build two models, the first of which was adjusted for dependent variable baseline concentrations, baseline age, sex, and school; model 2 was adjusted for dependent variable baseline concentrations, baseline age, sex, school, and baseline BMI *z-score*. Finally, we studied the relationship between baseline BMI *z-scores* and changes in HOMA-IR at baseline and after 12 months for both the CG and the IG. *P*-values <.05 were considered significant. Data analysis was completed using STATA SE v.12.0 (Stata Corp, College Station, TX, USA).

Results

Of all the children participating in the study, 82.7% (187/226) of IG children and 70.7% (128/181) of CG children gave baseline blood samples (Figure 1); 68.5% (128/187) of IG children and 64.8% (83/128) of CG children gave blood samples at the end of the 12-month study. Table 1 shows baseline characteristics of the population. Both groups had similar anthropometric and socioeconomic characteristics and the median age was approximately 8 years (standard deviation [SD] 1.2). Data showed that 24.2% (31/128) of CG children and 25.1% (47/187) and IG children were overweight; 28.1% (36/128) of CG children and 21.9% (41/187) of IG children were classified as obese.

Some differences in baseline metabolic parameters were observed between each group (Table 2): the CG presented higher glucose concentrations in comparison to the IG (*P*=.03); while the IG, when compared to the CG, had higher concentrations of total cholesterol (*P*=.001), LDL-C (*P*=.03), insulin (*P*=.001) and HOMA-IR (*P*=.005).

Table 3 shows changes in metabolic parameters between baseline and 12 months for both the CG and IG children. Adjusting for baseline concentrations of each dependent variable, age, sex, and school (model 1), at the end of the intervention, IG children showed reduced glucose concentrations (-1.53; CI 95% -2.66 to -0.40), triglycerides (-5.76; CI 95% -9.90 to -1.62), total cholesterol (-3.36; CI 95% -6.66 to -0.05), LDL-C (-2.56; CI 95% -4.89 to -0.22), insulin (-0.97; CI 95% -1.54 to -0.40), and HOMA-IR (-0.22; CI 95% -0.34 to -0.11). Model 2 shows that regardless of children's BMI *z-score* at the start of the study, the intervention had beneficial effects on participants' metabolic parameters.

Figure 2 shows the relationship between changes in HOMA-IR at baseline and after 12 months, and children's BMI *z-scores* at baseline. HOMA-IR changes at the end of the study showed differences between study groups. Children in the CG showed an increase, which was higher when baseline BMI *z-scores* were higher, while children in the IG maintained stable HOMA-IR regardless of their BMI *z-score*.

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Figure 1. Study population.

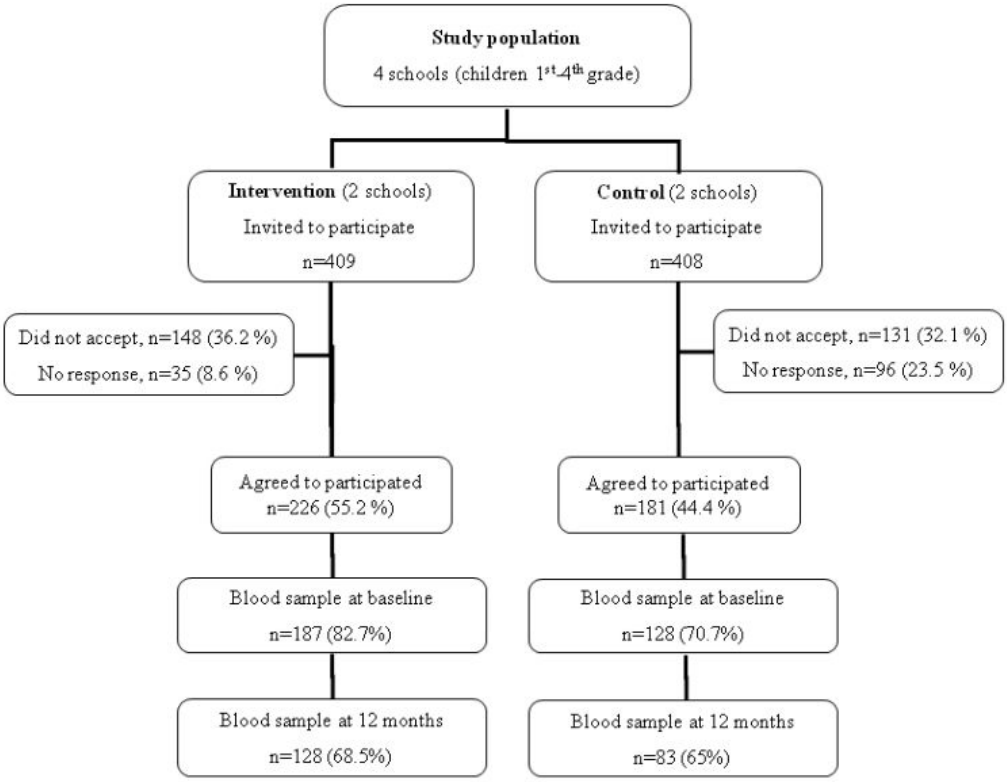


Table 1. Baseline characteristics of the study population (n=315).

Characteristic	Control (n=128)	Intervention (n=187)	*P* value[a]
Age in years, mean (SD)	8.1 (1.2)	7.9 (1.2)	.26
Sex (female), n (%)	70 (54.7)	85 (45.5)	.11
Anthropometric, mean (SD)			
Weight (kg)[b]	30.4 (5.0)	29.7 (5.0)	.26
Height (cm)[b]	127.5 (7.1)	126.6 (7.1)	.30
Body mass index (BMI) *z-score*[c]	1.07 (1.3)	0.94 (1.4)	.41
Classification of BMI *z-score*[a], n (%)			
Normal weight (*z-score* > –2 to <1)	61 (47.7)	99 (52.9)	
Overweight (*z-score* ≥1 to <2)	31 (24.2)	47 (25.1)	
Obesity (*z-score* ≥2)	36 (28.1)	41 (21.9)	.44
Maternal schooling, n (%)			
Middle school or less	15 (12.1)	34 (19.4)	
High school or technical school	55 (44.4)	67 (38.3)	
College career or postgraduate	54 (43.5)	74 (42.3)	.22
School, n (%)			
Public	63 (49.2)	112 (59.9)	
Private	65 (50.8)	75 (40.1)	.06

[a]*P* value according to Student´s *t* test and $\chi 2$ test.

[b]Means adjusted by age and sex.

[c]World Health Organization standard, 2007.

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Table 2. Metabolic parameters by study group at baseline.

Parameter	Control (n=128) Median (Q1-Q3)	Intervention (n=187) Median (Q1-Q3)	*P* value[a]
Glucose (mg/dL)	87 (82-93)	85 (81-90)	.03
Triglycerides (mg/dL)	67 (54-90)	73 (49-102)	.32
Total cholesterol (mg/dL)	155 (143-175)	170 (150-185)	.001
LDL-C[b] (mg/dL)	92.9 (81.7-110.3)	103.0 (85.4-117.4)	.03
HDL-C[c] (mg/dL)	47 (39-55)	50 (41-57)	.15
Insulin (µU/mL)	2.6 (1.9-5.1)	3.8 (2.2-6.6)	.001
HOMA-IR[d]	0.53 (0.43-1.21)	0.79 (0.46-1.39)	.005

[a]*P*-value according Mann-Whitney *U* test.

[b]LDL-C: low-density lipoprotein cholesterol.

[c]HDL-C: high-density lipoprotein cholesterol.

[d]HOMA-IR: homeostasis model to assess the insulin resistance index.

Table 3. Change in metabolic parameters from baseline to 12 months.

Parameter[a]	Control (n=74) change 0-12 months (95% CI)[b]	Intervention (n=119) change 0-12 months (95% CI)[b]	Intervention effect, model 1, β (95% CI)[c]	*P* value	Intervention effect, model 2, β (95% CI)[d]	*P* value
Glucose (mg/dL)	4.86 (3.84 to 5.88)	3.38 (2.79 to 3.98)	-1.53 (–2.66 to –0.40)	.008	–1.83 (–3.06 to –0.60)	.004
Triglycerides (mg/dL)	2.25 (–1.16 to 5.67)	–6.74 (–9.20 to –4.29)	-5.76 (-9.90 to -1.62)	.007	-5.25 (–1.46 to 0.97)	.01
Total cholesterol (mg/dL)	1.76 (–1.10 to 4.62)	-2.54 (–6.38 to 1.31)	-3.36 (–6.66 to –0.05)	.046	-3.22 (–7.11 to 0.67)	.10
LDL-C (mg/dL)	1.10 (–1.74 to 3.93)	-1.62 (–3.96 to 0.72)	-2.56 (–4.89 to –0.22)	.03	-2.59 (–5.12 to –0.06)	.045
HDL-C (mg/dL)	-0.47 (–1.31 to 0.37)	-0.14 (–0.74 to 0.49)	0.55 (–0.54 to 1.63)	.32	0.36 (–0.73 to 1.45)	.52
Insulin (µU/mL)	1.30 (0.60 to 1.99)	–0.09 (–0.29 to 0.11)	–0.97 (–1.54 to –0.40)	.001	-0.84 (–1.31 to –0.37)	.001
HOMA-IR	0.37 (0.16 to 0.58)	0.03 (–0.01 to 0.06)	-0.22 (–0.34 to –0.11)	<.001	–0.21 (–0.32 to –0.09)	.001

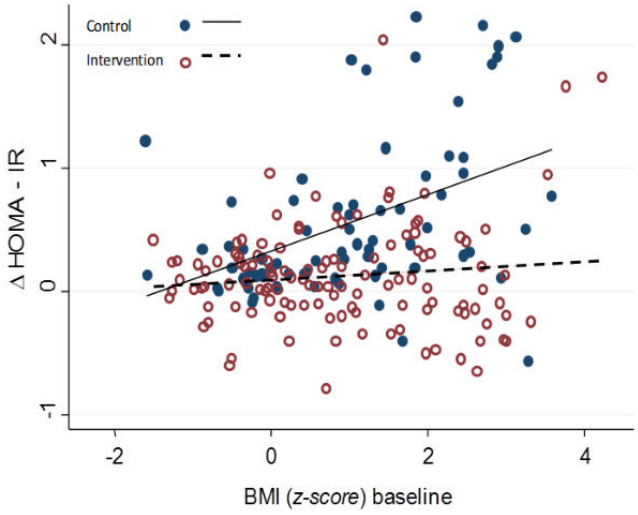
[a]LDL-C: low-density lipoprotein cholesterol; HDL-C: high-density lipoprotein cholesterol; HOMA-IR: homeostasis model to assess the insulin resistance index.

[b]Change from baseline at 12 months, adjusted for baseline data of the dependent variable, baseline age, and sex.

[c]Quantile regression models, adjusted for baseline data of the dependent variable, baseline age, sex, and public and private school.

[d]Quantile regression models, adjusted for baseline data of the dependent variable, baseline age, sex, public and private school, and baseline BMI *z-score.*

Figure 2. Change of baseline at 12 months in the homeostasis model assessment-estimated insulin resistance (HOMA-IR) and the relationship with body mass index (BMI) z-score baseline in the groups.



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Discussion

This study shows that an educational intervention focused on promoting healthy eating and physical activity habits aimed at parents and their children, through in-person and long-distance activities, can improve children's metabolic parameters regardless of their baseline nutritional status. Some studies have shown that diets low in saturated fats and rich in fruits and vegetables reduce the risk of cardiovascular disease [29], while an increase in physical aerobic activity reduces insulin levels regardless of weight loss [30]. Childhood overweight and obesity prevention programs promoting healthy eating and physical activity habits, in children of any nutritional status, have proven to significantly improve lipid profiles in children (LDL-C, HDL-C, and total cholesterol), including children who are within a healthy weight range [20,31,32]. Conversely, a meta-analysis has shown that interventions targeting multiple components (eg, diet and/or physical activity) in family or school contexts that improve body adiposity measurements (BMI, BMI *z-score*) also improve LDL-C, HDL-C, and triglycerides, as well as insulin sensitivity, while studies not targeting body adiposity measurements did not improve these factors [20]. Previously published anthropometric data from this study [23] showed that children in the IG, especially those suffering from obesity, reduced their BMI *z-scores*. In this study, greater HOMA-IR changes were observed in children presenting obesity; for this reason, changes in metabolic parameters reported here may be associated with a change in children's nutritional status and/or changes in eating and physical activity habits. It remains to be determined how long the effects of an educational intervention can last on metabolic parameters.

It is known that alterations in lipid profiles, insulin, and HOMA-IR during childhood are risk factors for cardiovascular diseases and generally carry over into adulthood [33,34]. Studies have shown that insulin and HOMA-IR levels increase during puberty [33]. In a study of healthy children by prospective cohort (EarlyBird) insulin resistance and HOMA-IR increased in a linear fashion as of age 7, and even before puberty [33]. This increase could be due to an increase in adiposity as of this age (and fat inhibiting the effect of insulin), or a progressive increase in insulin-like growth factor-1 that takes place as puberty approaches and has effects associated with insulin resistance [33,34]. In this study, in-person and distance learning programs focused on improving eating habits and physical activity proved to halt this possible age-related increase of insulin concentrations and HOMA-IR in the IG. Insulin resistance is considered an important physiopathological factor that underlies many complications that result from childhood obesity [16].

The change in the HOMA-IR biomarker found in this study is less significant than the findings of other studies [35]; this may be due to the changes achieved in the present study within a year of intervention, which included children who were of healthy weight, who were overweight, and who were obese, while studies with higher changes in HOMA-IR were focused on calorie restriction [36] and were directed specifically at children suffering from obesity [21,36,37]. However, it should be highlighted that in the present study, the effects on metabolic parameters were greater in obese children. Although small changes achieved in one year are important when improving lifestyles, a steady increase in unhealthy habits over time can contribute to the development of cardiovascular disease. Given the magnitude of the problem, individual treatment is unsustainable and low-cost community-wide measures that reach a greater number of people and promote better eating habits and physical activity in families become necessary [38]. This intervention sought the participation of parents, which is an important factor to improve adherence to changes in eating and physical activity habits in children.

Excess adipose tissue contributes to a chronic state of inflammation and increases insulin resistance, along with other metabolic complications [39]. Programs encouraging healthy eating and physical activity should be promoted among the population as a way of improving lipid profiles and preventing or reverting insulin resistance, as well as preventing chronic diseases such as metabolic syndrome, diabetes, and other comorbidities.

It is important to highlight that this study had certain limitations. Schools were not randomly assigned to study groups, and data on changes in eating habits and physical activity, which would explain changes in metabolic parameters, has not been presented. However, the intervention on multiple components also had some strengths, such as: (1) parents were treated as a household proxy, which is where children obtain their habits; (2) the study enabled parents to use their time more efficiently in this very complex city; (3) the study followed participants for 12 months, which is more time than other studies [21]; and (4) the use of technological resources was an innovative way to answer the problem of overweight and obese children.

Finally, our data indicates that strategies that imply adiposity reduction are likely to succeed in modifying lipid profiles and insulin resistance, which are sensitive to changes in body composition. However, these parameters are also independently sensitive to changes in diet and physical activity in children. This evidence highlights the importance of introducing early prevention programs and interventions aimed at promoting healthy lifestyles with the purpose of preventing adverse health effects in adult age. In conclusion, results found in this study suggest that educational interventions using electronic media and in-person sessions to promote healthy eating and physical activity habits improved children's metabolic parameters, and especially benefitted glucose metabolic parameters, independently of children's nutritional status at the start of the study.

Acknowledgments

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Authors' Contributions

JVG participated in the design and coordination of the study, supervised the fieldwork, and conducted the statistical analyses. MKK participated in the design and coordination of the study and critically revised the manuscript. SFH participated in the conception and design of the research question and provided critical comments on the manuscript. All authors were involved in drafting the manuscript, and read and approved the final version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

CONSORT - EHEALTH checklist (V 1.6.1).

[PDF File (Adobe PDF File), 706KB - jmir_v20i2e44_app1.pdf]

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Abbreviations

BMI: body mass index
CG: control group
HDL-C: high-density lipoprotein cholesterol
HIMFG: Hospital Infantil de México Federico Gómez
HOMA-IR: homeostasis model to assess the insulin resistance index
IG: intervention group
LDL-C: low-density lipoprotein cholesterol
UNAM: National Autonomous University of Mexico

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Original Paper

Using Relational Agents to Promote Exercise and Sun Protection: Assessment of Participants' Experiences With Two Interventions

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Abstract

Background: Relational agents (RAs) are electronic computational figures designed to engage participants in the change process. A recent study, Project RAISE, tested the effectiveness of RAs, combined with existing computer-based interventions to increase regular exercise and sun protection behaviors. Results showed these interventions can be effective but need further development.

Objective: The purpose of this study was to examine participants' experiences using RAs to increase participant engagement and promote behavior change .

Methods: A qualitative approach was primarily utilized. A 25-question interview guide assessed different components of participants' experiences with the intervention, including motivation, engagement, satisfaction or dissatisfaction, quality of their interaction with the RA, and behavior change. Quantitative assessment of satisfaction was based on a scale of 1 to 10, with 1 representing least satisfied and 10 representing most satisfied. A summative analytic approach was used to assess individuals' qualitative responses. A single analysis of variance (ANOVA) examined levels of satisfaction by gender.

Results: Of the original 1354 participants enrolled in Project RAISE, 490 of 1354 (36%) were assigned to the RA group. A sample of 216 out of 490 (44%) participants assigned to the RA group completed the interventions, and follow-up assessments were contacted to participate in the semistructured interview. A total of 34 out of 216 (16%) completed the interview. Participants were motivated by, and satisfied with, the intervention. Participants viewed the RA as supportive, informative, caring, and reported positive behavior change in both exercise and sun protection. Some participants (15/34, 44%) noted the RA was less judgmental and less "overbearing" compared with a human counselor; other participants (12/34, 35%) said that the interaction was sometimes repetitive or overly general. The majority of participants (22/34, 65%) viewed the RA as an important contributor to their behavior change for exercise, sun protection, or both. Levels of satisfaction ranged between 7 and 10. There were no gender differences noted in levels of satisfaction (P=.51).

Conclusions: RAs provide an innovative and attractive platform to increase exercise and sun protection behaviors and potentially other health behaviors.

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(J Med Internet Res 2018;20(2):e48) doi:10.2196/jmir.7640

KEYWORDS

relational agents; eHealth; exercise; sun protection; qualitative methods

Introduction

Background

During the last 30 years, numerous computer-based behavioral health interventions have been developed and have shown to be effective in clinical trials [1-4]. However, the effect sizes have been small due to a lack of engagement by a significant proportion of the population [3,4]. Relational agents (RAs) represent one of the recent innovative electronic communication technology approaches (electronic health) developed to increase engagement [5-9]. RA interventions for medication adherence and depression management have shown to be more efficacious in comparison with non-RA conditions [8,9]. A recent exercise and sun protection intervention tested the efficacy of RAs, combined with existing computer-based interventions, to increase participant engage and behavior change [9]. The study demonstrated that these interventions can be effective but need further development [9].

RAs are computational figures that incorporate information and communication technology to engage participants in the change process [5,7]. The RA uses speech, gaze, hand gesture, intonation, and other nonverbal modalities to emulate the experience of human face-to-face conversation with their users [5-9]. Specifically, the RA engages users through small talk, storytelling, humor, offering empathy, encouragement, and praise to help them to acquire and maintain the target behavior [6-9]. The interactions are in real time, allowing the user to ask the RA questions that may emerge during the session [6-9]. Furthermore, the RA is able to recall specific information, including trivial information, from a previous session to facilitate continuous engagement with the user. This feature of the RA provides the appearance of empathy and gives the impression that it (represented as he or she) is attentive to and thus cares about the user. This feature is vital to increasing engagement and building relationship overtime [6-9].

In-depth assessments of participants' experiences with these interventions could potentially provide a better understanding of particular tenets that underlie the RAs' interaction with participants that help to increase engagement and behavior change. Moreover, this knowledge can contribute to the improvement of specific functions or contents of these interventions that would further enhance participants' interactions with the RAs. This study examined participants' experiences with two longitudinal RA interventions for exercise and sun protection, titled Relational Agents Intervention for Sun Protection and Exercise (Project RAISE).

Project RAISE

Insufficient exercise and prolonged unprotected exposure to ultraviolet light are associated with numerous adverse health effects including certain cancers [10-13]. National survey data show that a majority of American adults are not meeting the recommendations for regular exercise [12,13] and sun protection behaviors [10,11].

Project RAISE was a randomized controlled clinical trial comparing computer-tailored interventions (one for exercise and one for sun protection) with the following 3-group experimental design: (1) a multiple risk Internet group, (2) multiple risk Internet with RA condition, and (3) a control group [9]. The interventions were developed based on the transtheoretical model (TTM; [14,15]). Briefly, the TTM is a comprehensive framework with multiple dimensions of behavior and behavior change [16]. This model has been applied to various health behaviors [14-23], including exercise [16-18] and sun protection [21-23]. The core TTM constructs include decisional balance, stages of change, self-efficacy, and processes of change. These constructs work in concert throughout the process of behavior change [14,15].

An expert system intervention approach provided participants with unique matched information and intervention based on their health risks and attitudes toward exercise and sun protection [9]. A tracking chart helped participants monitor their exercise and sun protection behaviors weekly and over the course of the 12-month intervention. A workbook provided participants with activities designed to help them reduce physical inactivity, unprotected sun exposure, and progress to the next stage of change. Lastly, participants received a personalized email reminder by the RA if they did not access the program for 7 days. These reminders continued once a week until they accessed the intervention to help participants remain on track with the program [9].

Demographic information for race and gender was used to match participants to one of four RAs (see Multimedia Appendix 1 for pictures of the RAs). The RA maintained a conversational approach with participants throughout the program, while providing them with support and encouragement to engage in regular exercise and sun protection behaviors and eventually maintenance. Specifically, the RA acknowledged participants' struggles or difficulties, showed empathy, and provided them with tailored strategies to overcome reported barriers for exercise (eg, finding the best time in your schedule to exercise or putting your sneakers in front your bed as a reminder or encouragement to exercise) and sun protection (eg, setting an alarm as a reminder to apply sunscreen before sun exposure) [9]. Participants who reached their weekly goals for exercise (eg, 30 min or more of moderate intensity level of physical activity (PA); [9]) or sun protection (eg, applied sunscreen regularly during the week before sun exposure; [9]) were acknowledged or complimented (eg, You did an excellent job! You should be proud of yourself) and given additional strategies for continued engagement [9]. Participants who did not reach their goals also received encouragement and tailored strategies that addressed related barriers. Moreover, the RA used small talk and storytelling about day-to-day life events (eg, how a friend resolves a problem with a coworker) throughout the

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intervention to engage users [9]. These conversation modalities also included humor or daily jokes. Participants interacted with the RA throughout the 12-month intervention. As previously noted, all interactions were in real time, allowing participants to ask the RA questions and receiving immediate answers [9].

The 12-months data showed that the RA intervention increased participant engagement [9]. The RA group viewed an average number of 0.142 sessions each week compared with the non-RA conditions, which viewed an average of 0.048 sessions [9]. A slightly higher percentage of RA participants (16.6) met recommended guidelines for regular PA (ie, 150 min of moderate to vigorous level of PA each week [15]) compared with the multiple risk Internet condition (16%) and control (14%) [9].

Methods

Study Design and Participants

A standardized open-ended qualitative interview was used to assess participants' experiences, including level of satisfaction with the interventions. The use of qualitative interviews facilitates a greater understanding of participants' experiences, including feelings, emotions, and opinions when compared with only quantitative assessments [24-26]. The following research questions were used to assess participants' experiences:

1. What was the experience of individuals who participated in the intervention?
2. What were their reasons for participating in the intervention?
3. What expectations did individuals have before participating in the interventions?
4. What was their reaction and interaction with the RA?
5. What promoted consistent and increased level of participation among individuals?
6. What was the level of trust individuals had with the information provided?
7. How did individuals' participation in the program influence their future behavior?
8. What intervention component or components id participants attribute most to their exercise and sun protection behaviors?
9. Did participants' level of satisfaction (or dissatisfaction) differ for gender and race based on a scale of 1 to 10, where 10 was the "most satisfied" and 1 the "least satisfied"?
10. Did participants' stage of change play a role in their experience with the interventions?

A pragmatic orientation paradigm consisting of three tenets was used to explore participants' experiences with the different components of the intervention: prospective, prescriptive, and constructive [27,28]. From a health behavior perspective, the three tenets work in concert to enable the researcher to grasp a greater understanding of the individuals' experiences by taking into account their expectations and assumptions regarding the approaches needed to help them engage and maintain the target behavior(s) [27]. Specifically, this approach assesses individuals' experiences or their application of the prescribed strategies for achieving regular engagement in the target health behavior(s) [27,28]. The prospective and perspective tenets address participants' levels of acceptability of the intervention design (eg, intervention content, length of intervention, delivery, and supportive function), their experience, and subsequent evaluation [27-30]. The constructive concept focuses on individuals' experiences, as they are related to behavior change, as well as their recommended improvements of future and similar interventions [29,30].

Participants were recruited from across the United States from 2010 to 2012 for the original Project RAISE [9,19]. Eligible participants were in the in preaction stages (precontemplation, contemplation, or preparation) for exercise and sun protection. Additional inclusion criteria included aged 18 to 75 years, willingness to provide demographic information, ability to participate in PA, and Internet access. Participants were assessed on three occasions: baseline, 12 months (end of treatment), and 24 month follow-up (12 months after end of treatment) [9]. All of the intervention materials and assessments were administered over the Internet. Consent and other human subject protocols were approved by the University of Rhode Island Institutional Review Board, and research was conducted according to the American Psychological Association's ethical guidelines. Participants completed surveys assessing key constructs of the TTM. The survey questions assessed behaviors relating to exercise, sun exposure, and behavior change constructs, including stage of change, decisional balance, self-efficacy, and processes of change [8].

A total of 1354 adults were enrolled in Project RAISE [9]. The RA condition consisted of 490 participants. Of that sample, 216 participants who completed the intervention, the 12-month and/or 24-month follow-ups were contacted over a 3-month period via telephone and/or mail to participate in this study.

Measures

Demographic data collected in the Project RAISE study included information pertaining to gender, age, race, and stages of change for both exercise and sun protection. Stages of change assessed an individual's level of readiness to engage in PA and sun protection behaviors. The stages were precontemplation (participants who were not consistently engaging in PA or protecting themselves from the sun, along with not intending to begin within the next 12 months); contemplation (participants not consistently engaging in PA or protective behaviors yet were seriously considering doing so within the next 12 months); and preparation (participants who were not currently engaging PA or protection but planned to start within the next 30 days). Satisfaction was assessed using a scale of 1 to 10, with 1 representing least satisfied and 10 representing most satisfied [9].

Interview Guide

The 25-question interview guide was developed based on several meetings with a team of researchers with expertise in health promotion, qualitative methods, clinical interviewing, and measurement development. Interview questions included "what" and "how" questions (instead of "why" questions) to help illicit in-depth information about participants' experience with the interventions [25,26]. The wording of questions and their order

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of presentation were consistent across participants. The guide included follow-up questions and probes developed to facilitate accuracy of information, including points for clarification. Two other researchers independently reviewed the interview guide for clarity. The first author completed all of the interviews. The interviews ranged between 12 to 30 min.

Analysis

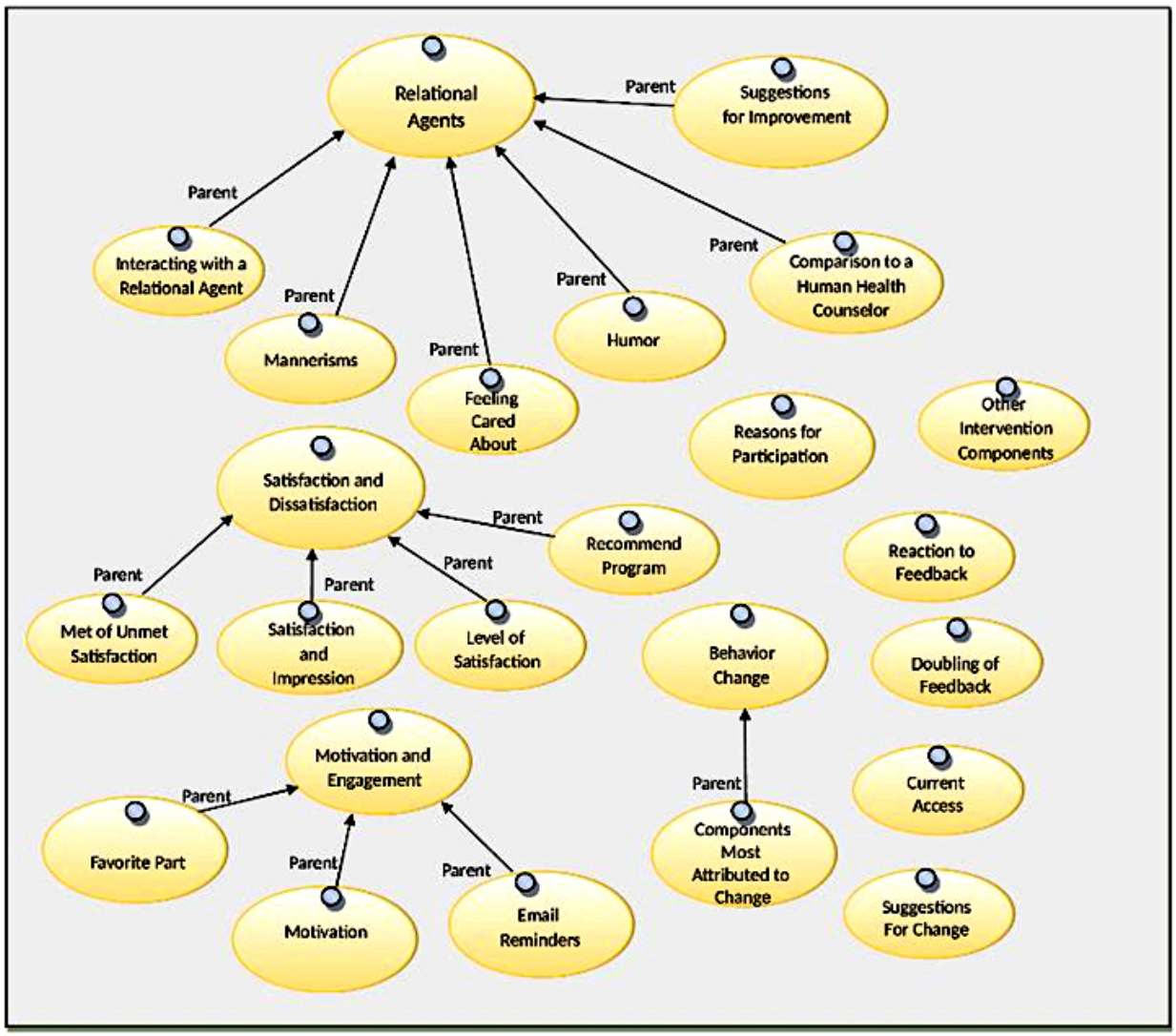
All interviews were audio-recorded and were transcribed. Each transcribed interview was reviewed along with the original audio file to ensure an accurate transcription. Transcribed interviews contained participants' ID number and were stored separately from demographic information. A preliminary coding analytic model was developed based on the interview guide over several meetings with the authors of this paper and was used to organize the data, using overarching categories, as well as different subcategories (see Figure 1).

The final coding was completed after reviewing the data and identifying emerging categories. Manifest content analysis was used to assess elements (and frequency of elements) that were present and countable in the data, such as particular words or wording [31,32]. Coding approaches consisted of a single word, phrases, complete sentences, and paragraphs in the larger sections of the interviews. Larger sections within the interviews were coded to provide context or clarification for use of single words or phrases. The NVivo 10 (QSR International) qualitative software was used for analyses [33]. Satisfaction was assessed using a scale of 1 to 10, with 1 representing least satisfied and 10 representing most satisfied. An analysis of variance (ANOVA) test was performed using Statistical Package for the Social Sciences (SPSS; IBM Corp) [34] and assessed potential gender differences for levels of satisfaction with the interventions.

Methodological Rigor

Trustworthiness is a central component of qualitative research and consists of several strategies that ensure rigor and credibility of findings [31,32]. The strategies utilized to address trustworthiness in this study were prolonged engagement, member checking, reflexive journaling, double-coding, and triangulation [31,32]. For prolonged engagement, the first author conducted all of the interviews and was involved in data collection over four and a half months.

Figure 1. Analytic model.



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The transcription of the interviews, as well as code development were completed, respectively, over 2 and 4 months. For member checking, the first author assessesed the accuracy of information by probing for additional information when necessary to enhance clarification. During the interview, the first author encouraged participants to share their true opinions or sentiments regarding their experirences with the intervention and suggestions for improving future and similar interventions. For reflexive journaling, the first author documented ideas and strategies in the development of codes, response categories, and subcategories. For dependability audit, the first author consulted with a qualitaitive expert, the third author, throughout the analytic process, giving special attention to all decisions made from this study's inception to analyses and ultimate interpretation of results. For double coding, the third author randomly selected 20% of the interviews and coded them independently [31]. High consistency (100%) was noted between coders. Lastly, triangulation of quantitative and qualitative data was used to furrther assess participants' experiences, as well as their levels of satisfaction with the interventions.

Response Categories

The results of this study were determined by analyzing verbatim responses of participants. Responses were organized into 10 primary categories, assessing participants' experiences with different components of the interventions. The categories were as follows: (1) reasons for participation, (2) motivation and engagement with the intervention, (3) satisfaction or dissatisfaction with the intervention, (4) RAs, (5) other intervention components, (6) behavior change, (7) the component(s) of intervention most attributed to change, (8) reaction to tailored feedback, (9) current access to the intervention, and (10) suggestions for change.

Results

Organization of Results

The number of participants who endorsed a category of responses is provided. Response exemplars are provided for most categories or subcategories along with the race and gender of the participant(s) (black male=BM, black female=BF, white male=WM, and white female=WF) and ID numbers.

Participants

A total of 34 of 216 individuals who completed the RA interventions and/or 12- to 24-month follow-ups completed the semistructured interview. Participants were predominately white (31/34, 91%). For gender, there were 18 men (53%, 18/34) and 16 women (47%, 16/34). Participants were aged between age 20 and -75 years (mean=52.4, standard deviation=14.4). Nearly half (16/34, 47%) reported being married. Most of the participants were in the preparation stage (23/34, 68%) for exercise and in the precontemplation stage (26/34, 77%) for sun protection.

Reasons for Participation

Responses fell into three primary categories: (1) interest in health improvement (13/34, 38%). One response example of this is *I needed to have a healthier lifestyle...* (656345, WF); (2) helping with research (11/34, 32%). One of the participants in this category noted, *I just figured I could provide some assistance with what they were doing maybe it might be able to help me in the future* (653768, WF); and (3) interest or curiosity about the program (6/34, 18%). A response exemplar for this category was *I just wanted to see what kind of program it was* (640486, WM).

Motivation and Engagement

The questions used to explore motivation, engagement, and the specific components that promoted these behaviors were as follows:

1. What motivated you to keep using the program?
2. What was your favorite part of the program?
3. As a part of this program, you also received email reminders to access the program if you did not log on for a while. Did this help with keeping you on track?

Responses for question 1 resulted in eight categories of responses, with nearly half of the participants (16/34, 47%) recalling a desire to be healthy as their motivation. Other motivating factors reported were: accessibility of the program (3/34, 9%), interaction with the RA (2/34, 6%), email reminders (1/34, 3%), and completing the surveys (1/34, 3%).

For question 2, 13 of 34 participants (38%) noted the RA was their favorite part of the program. Two participants noted the following:

> *It [the RA] was so much easier and interactive.* [652687, BF]
>
> *...the fact that it pushed me to actually get up and move.* [652207, WF]

Twelve of the 34 participants (35%) did not recall having a favorite part of the program. Six of these participants (6/34, 18%) reported enjoying *all parts* of the program and/or found all the components to be equally helpful. Other participants repeated the same responses provided for reasons for participation (eg, helping with research).

For question 3, most participants recalled that the email reminders helped them to remain on track with the program (23/34, 68%). Fourteen participants (14/4, 41%) reportedly accessed the program *the same day or right after* receiving the email. Others mentioned accessing the program after 2 to 3 days (8/34, 24%). One of those participants mentioned the email reminder also served as a motivator to maintain regular exercise and sun protection behaviors, as indicated in the following quote:

> *It was great to have that reminder every couple of days to help me to think oh yeah, I've got to check my exercise...or how much exercise yesterday or how much today, or to put on sunscreen.* [651780, WF]

Satisfaction or Dissatisfaction With the Intervention

Similar to the motivation and engagement category, satisfaction (and dissatisfaction) with the program were explored using several questions:

1. Would you say that the program met your expectations?

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2. Describe your overall satisfaction or impression with the program?
3. On a scale of 1 to 10 where 10 is the most satisfied and 1 is the least satisfied, how would you rate your level of satisfaction with the program?
4. If a family member or friend were in a similar situation, would you recommend they participate in this program?

Additionally, for question 1, participants were asked to provide examples of how or reasons why the program met (or did not meet) their expectations. For question 1, 30 participants (30/34, 88%) reported that the program met their expectations. Two exemplars of responses are as follows:

> *...being informed about the dangers and using sunscreen and [information about] different types of exercise.* [626637, WF]
>
> *...[It] served as a reminder to exercise and protect my skin when I go outside.* [615633, WM]

For question 2, 31 participants (31/34, 31%) reported a positive impression with the program. Some exemplars of responses were as follows:

> *[I had] an amazing experience.* [563466, WM]
>
> *...it was very well thought out.* [651780, WF]
>
> *...it was well done.* [652687, BF]

Levels of satisfaction, based on a scale of 1 to 10, ranged from 7 to 10 (32/34, 94%). For question 4, 32 participants (32/34, 94%) mentioned recommending the program to either a family member or friend. Most of the participants explained that the program would help others learn the importance of exercise and sun protection, as well as serve as a motivator or a partner to help them maintain these behaviors overtime.

Relational Agents

Seven questions were used to assess participants' interaction with RA, as well as the physical attributes of the RA .

Interacting With a Relational Agent

For question 1, participants were asked, "what was it like for you to interact with a relational agent?" Most of the participants (32/34, 94%) described a positive interaction, and six of those descriptions were: *user-friendly* (587027, MW), *entertaining* (615633, WM), *interactive* (652440, WM), *easy and effortless* (652207, WF), *informative* (626033, WF), and that *[the RA]...made me feel better about myself* (651438; WM). Moreover, one participant described the RA as a *virtual pal* (627122, WF).

Two participants reportedly disliked the RA or their interactions with the RA (2/34, 6%). One participant mentioned that he would have preferred the *...interaction with a human being* (655948, WM). They were asked about their reasons for preferring a human being; they provided no additional information and reiterated that it was their preference.

Mannerisms

Participants were asked whether they felt the mannerisms of the RA were similar to those of a human being. (Did you feel her mannerisms, eg, facial features or hand gestures, were similar to those of a human being?). A total of 30 participants recalled the RA's mannerisms were similar to those of a human being (30/34, 88%). The following response exemplars described 3 participants' assessments of the RA's mannerisms:

> *...he was enthusiastic, I guess in an upbeat way, very friendly.* [587027, WM]
>
> *I thought so. The way she moved her hands—that always seemed perfectly normal. I thought that the voice was cheery and professional.* [651780, WF]
>
> *Yes, definitely they were. The gestures were definitely believable.* [652687, BF]

Humor

Participants were asked whether they found the jokes that the RA shared with them throughout the course of the intervention to be humorous (During the program, the virtual health coach, or the RA shared many jokes with you. I was wondering if you found them to be humorous) . Eleven participants (11/34, 32%) recalled that the jokes were humorous, 8 participants (8/34, 24%) recalled that *some of the jokes* were humorous, and 13 participants (13/34, 38%) could not recall whether or not the jokes were humorous.

Comparison With Human Health Counselor

When comparing the RA with a human health counselor (how would you compare him or her with a human health counselor, eg, a personal trainer and/or a nurse?), 15 participants (15/34, 44%) mentioned the RA was *informative* and motivated them to maintain regular exercise and sun protection behaviors. Of that sample, 3 participants mentioned preferring the RA to a human health counselor or a personal trainer, as illustrated in the following quotes:

> *It [the RA] was less judgmental and less intimidating.* [651780, WF]
>
> *She reminds you enough to get the point across without being overbearing.* [563466, WM]
>
> *I have probably listened to her more that I would have an actual person.* [653244, WF]

In contrast, 12 participants (12/34, 35%) reported that their interaction with the RA was *limited* and explained that responses to their questions were at times *too general* or that certain responses became *repetitive* over the course of the intervention. A total of 7 participants (7/34, 21%) rejected the assumption that the RA could be compared with a human health counselor and thus, a real person, as indicated in the following quotes:

> *I can't really make that comparison.* [654855, WM]
>
> *...it is not human.* [657225, WM]

Feeling Cared About

Participants were asked whether they felt the RA cared about them (Throughout your interaction with the RA, did you feel that she [or he] really cared about you?). In the first four interviews, the participants felt that the word *care* or *caring* is a human characteristic that cannot be attributed to either the RA and/or their interaction with the RA. This question was revised after these interviews. For the remaining interviews, participants

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were asked, "Throughout your interaction with the RA, did you feel that she (or he) really cared about your exercise and sun protection behaviors?" Most of the participants reportedly felt the RA cared about their engagement and maintenance of both exercise and sun protection (28/34, 82%). Some of the participants reported the following reasons:

> *If I am not mistaken, he addressed me by name.* [615633, WM]
>
> *It's like having virtual pal online and being able to converse with them, and the virtual pal...care[s] how you are doing and that kind of thing.* [651689, WF]
>
> *Just the way she talked and the way she presented herself in the telling the benefits of sun protection and exercise.* [656345, WF]

Interaction With the Relational Agent Over Time

Participants were asked whether their interaction with the RA changed throughout the intervention. A total of 26 participants (26/34, 77%) recalled their positive feelings toward the RA remained the same throughout the intervention, 6 other participants (6/34, 18%) mentioned their feelings improved over time as they became more familiar with the RA and/or with the routine of the program, and one participant noted the RA became *like a friend*:

> *I mean he obviously became more familiar as I interacted more and more. [I] got more use to what to expect out of it so I think, like, an acquaintance becoming a friend as you sort of interact with them more and more.* [586627, WM]

Suggestions for Improvement

Participants were asked whether they would change anything about the RA. A total of 20 participants (20/34, 59%) mentioned the RA needed no improvements. An exemplar of those responses is as follows:

> *No, I think she did a wonderful job. If I wanted somebody more real or something like that, I am sure you can get a video of a real person doing that. This was better to me.* [563466, WM]

A total of 12 participants (12/34; 35%) provided various suggestions for improvement, including improving the *monotone* voice of the RA to a normal pitch (4/34, 12%) and allowing the user to choose an RA of the opposite gender, similar race, and age groups (3/34, 9%).

Other Intervention Components

Participants were asked whether there were other things they liked about the program. A total of 14 participants (14/34, 41%) liked the information on the health benefits of exercise and sun protection. Other participants mentioned the program and/or the RA served as a constant *motivator* to become and remaining healthy (14/34, 41%). Moreover, 4 other participants (4/34, 12%) recalled that they liked the *ease* of the program. Two of those participants stated the following:

> *...it really was easy to use.* [653244, WM]
>
> *I could go at own pace.* [615633, WM]

Behavior Change

Participants were asked about the ways in which the program helped them change their exercise and sun protection behaviors (How has the program been helpful in changing your exercise and sun protection behaviors?). A total of 11 participants (11/34, 32%) mentioned that the program helped them to engage in regular exercise. Two response exemplars are as follows:

> *The activity part was really helpful. If I can park a little further in the parking lot and walk. I have taken a lot to heart.* [639021, WM]
>
> *It pushed me to actually get up and move.* [652207, WF]

A total of 8 participants (8/34, 24%) noted that the program helped them to engage and maintain sun regular protection behaviors. Two exemplars of responses are as follows:

> *Before I started doing that I really didn't use sunscreen at all. I started using sunscreen...more than I thought I would ever use.* [653244, WF]
>
> *I started using sunscreen. I actually use [SPF] 70 proof. I use hats more than I did before. I've stayed in the shade...and put more umbrellas in our backyard so we have shading that we need.* [656345, WF]

A total of 7 participants (7/34, 21%) reported a change in both exercise and sun protection. Two exemplars of responses are as follows:

> *It served as a reminder to exercise and protect my skin before going outside.* [615633, WM]
>
> *...[I apply] sunscreen and other protective things. I exercise.* [656345, WF]

Four other participants (4/34, 12%) stated the program served as reinforcement for continuing with their own routines for exercise. Because eligible participants were not currently exercising regularly at baseline, it is possible they were referring to exercise they engaged in irregularly, or to a routine they had engaged in at some time before enrolling in the study. Two participants (2/34, 6%) reported being *more aware* about the importance of sun protection behaviors as preventions against skin cancer. Lastly, two other participants (2/34, 6%) stated their participation in the program did not lead to change in either exercise or sun protection behaviors. They provided no additional information for the lack of behavior change.

Components Most Attributed to Change or Awareness

On the basis of participants' responses to the behavior change category, they were asked about the component(s) of the intervention they attributed most to their behavior change (n=26), becoming *more aware* of the benefits of sun protection and reducing cancer risk (n=2), or that served as a reinforcement for their own exercise routines (n=4; Was it the virtual health coach, which was the RA; the reports; the workbook; or the tracking charts?). A total of 22 participants (22/26, 85%) attributed their behavior change primarily to the RA, and 10 participants (10/26, 38%) noted that the combination *of all* aforementioned components was equally helpful in changing their exercise and/or sun protection behaviors.

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Reaction to Tailored Feedback

Participants were asked if the tailored feedback they received throughout the intervention helped to change their exercise and sun protection behaviors (As a part of the program, you received some feedback about ways to increase engagement regular PA and sun protection. For instance, you may have heard pr read that support from others is extremely helpful to meet your healthy lifestyle goals. As a result, you may have begun working out with a friend to help achieve your goals) . A total of 29 participants (29/34, 85%) reported that the feedback helped them to engage in and maintain regular exercise and sun protection behaviors; 3 participants (3/34, 9%) reported that some of the feedback messages for exercise were irrelevant for their lifestyles. Two response exemplars are as follows:

> *It kind did not apply to me because I had an exercise regimen and with my schedule, it's hard to connect with somebody.* [586372, BM]
>
> *I live in a village of 196 people, and we've got 63 acres in back of us. No, I can't ask someone to [go] out [and walk] with me.* [651005BM]

Doubting of Feedback

All participants were asked whether they ever doubted any of the feedback or statements that were given to them. All 34 participants (100%) responded "no" to this question. A response exemplar is as follows:

> *No. From having done my own research prior to this, research on sun exposure and exercise and things like that, I found that everything that you guys said was very believable.* [563466, WM]

Current Access

Participants were asked whether they would have preferred current or continued access to the program. A total of 18 participants (18/34, 53%) reported "yes" to current access. Of that sample, 6 participants mentioned the program would continue to serve as a motivator or as a *good prod* (n=2) for maintaining regular exercise and sun protection behaviors or serve as a reference for *reviews* or suggestions for exercise and sun protection (n=4). Two exemplars of responses are as follows:

> *I guess it would be again, a good prod cause sometimes I kind of forget about doing things I wanted to do and get bogged down in different priorities.* [586372, BM]
>
> *Yes...just having motivation...you get on there and you can go through the saver tools of answering the questions about how much you are exercising, and making sure that you have sunscreen on and wearing the proper gear.* [651780, WF]

Conversely, 12 participants said that they did not want access to the program. Most of those participants stated they enjoyed the program and learned a lot from it; however, they felt that continuing access would not lead to any additional impact on their behaviors. Four other participants were reportedly *unsure* to whether they would like current access to the program.

Suggestions for Improvement

Participants were asked to report their suggestions for improving the overall program (I was wondering if there is anything that you like us to do differently? Are there some things you would have liked to see more or less of ?). A total of 6 participants (6/34, 18%) mentioned that they would not make any changes to the program; 22 participants (22/34, 65%) repeated the same responses they provided in the Suggestions for Change subcategory of the RA category. Three of the 6 participants who provided suggestions for improvement shared the following:

> *Perhaps at some point through the program have a meeting with an actual [human] health agent over the phone.* [587027, WM]
>
> *If you could actually put the program on your iPhone as well, or you could do it on the go.* [651780, WF]
>
> *...an option to shorten your time on there. I guess...sort of shut it off in the middle of whatever you were doing so you later finish it.* [652440, MW]

Quantitative Assessments of Satisfaction

Potential gender differences in level of satisfaction were examined using an ANOVA test. Results that men and women did not significantly differ in levels of satisfaction: $F_{1,33}$=0.399, P=.51; η_p^2 =.002.

Discussion

Principal Findings

This study explored the experience of 34 individuals who completed two RA interventions for exercise and sun protection, using primarily a qualitative approach. The primary purpose of this study was to explore participants' reaction to and interaction with the RA and determine the importance of this component in promoting exercise and sun protection behaviors in this sample. Moreover, this study investigated participants' experience with all components of the program, as well as their reasons for participating in an exercise and sun a protection intervention. Reasons for participation have shown to be associated with motivation and engagement overtime. Furthermore, individuals' expectations of a program for exercise and sun protection and their proximity to their actual experience subsequently influenced their evaluation.

Participants' reasons for participation, which included health improvement, coincided with factors for motivation and sustained engagement in the program. Approximately, 13 participants (13/34, 38%) noted the RA as their "favorite," and 6 participants (6/34, 18%) reportedly liked and or enjoyed all parts of the program, including the RA. A number of participants did not express having a favorite part of the program. The wording of this question, "what was your favorite part of the program," assumes that every participant had a favorite part of the program. However, it is unclear whether an alternative question such as "did you have a favorite part of the program?" would have produced different results.

The personalized email reminder from the RA helped most participants (23/34, 68%) access the program regularly and for

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some participants served as a reminder and motivator to exercise and protecting their skin from the sun if they had not been doing so regularly in the last few days. These findings indicate that periodic reminders are an important component to promote consistent engagement in health intervention, as well as helping individuals to think about their exercise and sun protection behaviors.

A total of 30 participants (30/34, 88%) reported being satisfied with the program. Satisfaction, in general, was noted as an outcome of met expectations and positive impression with the program. Most participants described the program as "informative," "motivational," and "accessible." Levels of satisfaction ranged between 7 and 10. Most participants (26/34, 77%) reported behavior change in exercise and/or sun protection. Stage of change for exercise and sun protection did not appear to be associated with participants' experiences and/or their evaluations of the interventions. The RA was the intervention component that attributed most to behavior change. Thus, the RA was shown to be an important platform for disseminating health intervention, increasing behavior change and thus, a valuable tool for health promotion research.

Regarding behavior change, participants were asked "how has the program been helpful in changing your exercise and sun protection behaviors?" This wording assumes that all participants adopted exercise and sun protection behaviors as a result of their participation in Project RAISE. Some participants may have felt compelled to an untruthful report of their behavior change. However, socially desirable responses are less likely when the interview is conducted over the telephone, and the topic is noncontroversial [35,36]. The interviewer also emphasized to participants the importance of reporting their true experience with and/or sentiments about the program to help improve future and similar interventions to minimize incorrect reporting.

Participants' responses to feedback and or recommendations for engagement in exercise and sun protection indicate that they found them, overall, to be credible and/or effective. However, 3 participants mentioned that some of the recommendations for exercise were irrelevant to their lifestyles, which could be attributed to the wording of this question. As part of this question, participants were given the example of tailored feedback for exercise they may have received during the program: "For instance, you may have heard or read that support from others is extremely helpful to meet your healthy lifestyle goals. As a result, you may have begun working out with a friend to help achieve your goals. Did you find the suggestions helpful?" It is possible their responses were based solely on the singular message for exercise. This question is somewhat leading and may have influenced their responses. In hindsight, this question should have served only as a potential probe to participants who had difficulty answering or remembering messages or feedback for exercise. Additionally, two separate questions should have been used to assess tailored feedback messages or exercise and sun protection.

A little over 50% of participants wanted continued access to the intervention materials beyond the 12-month period. It may be helpful if future studies include a website on information or suggestions for exercise for 6 months after the intervention. However, this option might be costly and thus impractical for most health programs. Another option is to allow participants to save or print information, including feedback and recommendations, throughout the intervention.

A few participants made suggestions for improving future and similar programs. These included (1) disseminating the program to mobile phone, (2) allowing users to stop anytime during a session and to continue from that section later, and (3) using shorter surveys. A mobile phone–delivered RA intervention would increase dissemination by enabling participants to access the program anywhere and at their convenience. The ability for participants to stop at a section of a session and continue from there a later time would provide participants with more flexibility to complete the program. Moreover, the use of shorter surveys might prevent participants from feeling overburdened. However, the shortening of surveys could impact their psychometrics, hinder data collection, and thus, tailoring.

Strengths and Limitations

This study has several strengths. To our knowledge, this is the first study to conduct an in-depth assessment of participants' experiences with RA interventions. Moreover, this study assessed the role of the RA in increasing participation engagement, as well as potential behavior change. This study also demonstrated the role of a primarily qualitative approach in developing a greater level of understanding of participants' experiences with RA interventions for exercise and sun protection. However, several limitations should be noted. First, the interview was conducted a year after participants completed the 12-month intervention. This may have impacted some participants' ability to recall experiences of certain components (eg, jokes shared by RA) and their evaluation. While the RA intervention was distinctive and individuals may be more likely to remember it compared with a standard or non-RA intervention, the completion of interviews soon after the 12-month program could have provided more details on participants' experiences. Second, the sample consisted of individuals who completed the 12-month intervention. Thus, the study results may not be representative of most participants' experiences with the intervention. It is likely that individuals who were dissatisfied with the intervention simply disregarded our invitation to complete the interview. Moreover, it is possible that nonresponders had personal or professional priorities during that period that prevented them from participating in this study. Third, there are inherent limitations of the qualitative analyses used in this study. Content analysis is subjective and can be influenced by researchers' biases. The subjectivity of content analysis can lead to incorrect interpretation of data, as it is influenced by a researcher's skills and idiosyncrasies. This study used numerous strategies recommended to ensure the credibility of data collection, analyses, and interpretations.

Lastly, the sample size of black participants was too small to conduct an in-depth assessment of this group's experience with the intervention. Thus, it is unclear whether black participants would have reported similarly positive experiences with the RAs in comparison with their white counterparts. Moreover, the small sample size for this group prevented the assessment

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of gender in black participants' experiences with the RAs. Future studies should assess the experience of individuals of different racial and ethnic groups with these interventions. Moreover, a large sample of men and women is needed to explore potential gender differences in experiences with these interventions.

Finding Implications and Conclusion

This study makes substantial contributions to the understanding of participants' experiences with RA interventions and the importance of this complementary component in increasing participant engagement and promoting behavior change. Participants viewed the RA as interactive, supportive, and motivational, which were found to be central factors in their behavior change for exercise and sun protection. These findings suggest that the RA could potentially promote engagement in other health behaviors. Moreover, because these RA interventions are easy to use and participants can access them at their own convenience, participation burden is less compared with traditional clinical trials that require numerous face-to-face sessions and over a long period. Moreover, RA interventions require less clinical staff and no lab space to implement and thus, might be a more cost-effective approach to promoting health behavior change. Future studies should conduct cost analysis of RA interventions compared with standard behavioral health interventions.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Project RAISE relational agents.

[PDF File (Adobe PDF File), 271KB - jmir_v20i2e48_app1.pdf]

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Abbreviations

BF: black female
BM: black male
RAISE: Relational Agent Intervention for Sun Protection and Exercise
RA: relational agent
TTM: transtheoretical model
WF: white female
WM: white male

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Original Paper

Effectiveness of a Web-Based Self-Help Program for Suicidal Thinking in an Australian Community Sample: Randomized Controlled Trial

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Abstract

Background: Treatment for suicidality can be delivered online, but evidence for its effectiveness is needed.

Objective: The goal of our study was to examine the effectiveness of an online self-help intervention for suicidal thinking compared to an attention-matched control program.

Methods: A 2-arm randomized controlled trial was conducted with assessment at postintervention, 6, and, 12 months. Through media and community advertizing, 418 suicidal adults were recruited to an online portal and were delivered the intervention program (Living with Deadly Thoughts) or a control program (Living Well). The primary outcome was severity of suicidal thinking, assessed using the Columbia Suicide Severity Rating Scale.

Results: Intention-to-treat analyses showed significant reductions in the severity of suicidal thinking at postintervention, 6, and 12 months. However, no overall group differences were found.

Conclusions: Living with Deadly Thoughts was of no greater effectiveness than the control group. Further investigation into the conditions under which this program may be beneficial is now needed. Limitations of this trial include it being underpowered given the effect size ultimately observed, a high attrition rate, and the inability of determining suicide deaths or of verifying self-reported suicide attempts.

Trial Registration: Australian New Zealand Clinical Trials Registry ACTRN12613000410752; https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=364016 (Archived by WebCite at http://www.webcitation.org/6vK5FvQXy); Universal Trial Number U1111-1141-6595

(J Med Internet Res 2018;20(2):e15) doi:10.2196/jmir.8595

KEYWORDS

psychosocial interventions; randomized controlled trial; suicide

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Introduction

Suicidal thinking is common and often precedes suicidal plans and attempts [1,2]. Effective treatments exist for suicidal thinking [3,4], but many individuals do not seek help due to factors such as low suicide literacy (ie, having little knowledge about suicidality), lack of perceived need, preference to manage the problem alone, stigma, shame, beliefs about receiving professional help, fear of hospitalization, structural factors (eg, time and finances), and having previously experienced negative encounters with health care professionals [5-9]. Providing anonymous self-help online may address these barriers to help-seeking. The internet provides an avenue to reach people with suicidal thinking and offers the potential to prevent escalation to suicidal behavior or suicide itself. While there is good evidence that Web-based programs are effective for a variety of mental health problems [10,11], suicidality is often an exclusion criteria in these trials and interventions [12].

A Dutch trial of a self-guided online intervention for suicidal thinking reported significant reductions in suicidal thoughts relative to the waitlist control condition that included access to a website with psychoeducational material about suicide [13,14]. These results require replication and extension. In the Dutch trial, respondents with a high depression and/or suicidality score were excluded, participants could not maintain anonymity as they had to provide their own and their general practitioner contact details, and follow-up was limited to 3 months. This trial evaluated an English language version of the Dutch self-help intervention, used a more broadly recruited community-based sample, did not exclude those with severe depressive symptoms, permitted anonymity, followed up over 12 months, and compared the intervention to an attention-matched control program to ensure an equal amount of material was presented to each group. It was hypothesized that, compared to controls, participants randomized to the active intervention would experience reduced severity of suicidal thinking at postintervention and 6- and 12-month follow-up. Improvements on secondary outcomes (suicidal ideation, suicidal behavior, reasons for living, perceived burdensomeness, thwarted belongingness, acquired capability, depression, hopelessness, anxiety, panic, rumination, alcohol use, insomnia, physical health, mental health, and physical functioning) were also expected. We sought to identify any potential moderating effects of sex, age, depression severity, history of attempted suicide, chronicity of suicide risk, and the effect of adherence on outcomes.

Methods

Trial Design

The study was a 2-arm randomized controlled trial delivered entirely online consisting of a treatment condition, Living with Deadly Thoughts (LwDT), and an attention-matched control condition, Living Well. There were 4 measurement occasions: baseline, postintervention (6 weeks after baseline) and 6- and 12-month follow-up. Full details on the study methodology can be found in the trial protocol [15]. The trial is reported in accordance with the CONSORT-EHEALTH checklist (see Multimedia Appendix 1).

Participants

Participants were recruited between November 2013 and December 2015 through online media forums including websites, social networking websites, and advertizing on search engines. A link to a welcome screen included an invitation to provide consent and complete the online screening procedure.

Eligibility criteria were as follows: aged 18 to 65 years, valid email address, access to a reliable internet connection, located in Australia, fluent in English, no history of a diagnosed psychotic disorder, currently experiencing suicidal thoughts, and no suicide attempts in the past month. These were assessed using single, self-report questions. Unlike the original trial [13], no restrictions were placed on the severity of suicidal thinking or depression.

Respondents who did not meet inclusion criteria were redirected to a "thank you" page listing referral information. Respondents who were excluded based on a recent suicide attempt were also provided with the opportunity to submit their phone number to receive a phone call from the Suicide Call Back Service (SCBS), a 24/7, Australia-wide, not-for-profit service that provides telephone counseling (www.suicidecallbackservice.org.au). Participants were informed that the study was not intended to replace treatment as usual and were encouraged to seek or continue other treatment.

Interventions

Active Condition: Living With Deadly Thoughts

LwDT is an adapted but closely aligned translation of the Dutch Web-based program *Leven onder Controle* (literally "Living under Control"). The content is drawn from principles of cognitive behavior therapy [16] and dialectical behavior therapy [17], and the program's goal is to reduce the severity of suicidal thinking.

The program consists of 6 online modules. Participants are instructed to complete 1 module per week and to spend 30 minutes per day using the program. Each module contains 4 components: (1) theory, (2) a weekly assignment, (3) 2 to 3 exercises, and (4) optional exercises to help consolidate relevant information and skills. The modules become available in a fixed sequence, 4 days after the start of the previous module, regardless of completion, and remain available throughout the intervention period. Access to referral information via a "get help now" link is available on every Web page. A safety procedure included monitoring and intervention (if required) by the SCBS (see Safety Procedures).

Attention Control Condition: Living Well

The attention control condition was matched to the active program in length, style, and availability. It involved a 6-week modular online learning course containing lifestyle information on (1) nutrition, (2) a healthy home environment, (3) a healthy weight, (4) a healthy heart, (5) healthy skin, and (6) a healthy mouth. Participants in the control condition received the safety

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protocol procedure, including monitoring and intervention (if required) by the SCBS (see Safety Procedures).

Primary Outcome Measure: Severity of Suicidal Thinking

The primary outcome was severity of suicidal thinking, assessed using the Intensity of Suicidal Ideation subscale of the Columbia Suicide Severity Rating Scale (C-SSRS) [18]. This subscale comprises 5 items, each rated for frequency, duration, controllability, deterrents, and reasons for ideation.

Secondary Outcome Measures

Secondary outcome measures included presence of ideation and behavior, measured by the Suicidal Ideation and Suicidal Behavior subscales of the C-SSRS, respectively; reasons for living, using the Brief Reasons for Living Scale [19]; perceived burdensomeness and thwarted belongingness, assessed by the Interpersonal Needs Questionnaire [20]; acquired capability, measured by Acquired Capability for Suicide Scale [20]; depression, measured by Centre for Epidemiological Studies Depression Scale [21]; hopelessness, assessed by the Burns Hopelessness Scale (D Burns, personal communication); anxiety, measured by the 7-item Generalized Anxiety Disorder scale [22]; panic, using the Panic Syndrome subscale of the Brief Patient Health Questionnaire [23]; rumination, assessed by the Ruminative Response Scale [24]; alcohol consumption, using the Alcohol Use Disorders Identification Test–Consumption [25]; and insomnia, assessed by the Insomnia Severity Index [26]. Health-related quality of life was measured using the Short Form–12 [27], and health and disability were measured by the World Health Organization Disability Assessment Schedule [28]. The Suicidal Ideation Attributes Scale (SIDAS) [29] was included to validate its psychometric features.

Standard demographic information including sex, age, relationship status, education, and employment status were collected together with self-reported lifetime suicide attempts and adherence to program by website usage.

Safety Procedures

Given the vulnerable, at-risk population that this study targeted, safety procedures were designed in collaboration with the SCBS with the goal of protecting and assisting participants while enabling them to maintain anonymity within the trial and considering ethics and clinical obligations. The ability to remain autonomous in the decision to make contact with services as much as possible was also important, as this is consistent with the concept of self-help and patient empowerment.

The safety procedures required eligible participants to make contact with the SCBS during enrollment to obtain a unique identification code, so that codes rather than names could be used in all subsequent communication between the research team and SCBS. On each measurement occasion, the first 3 items of the intensity of suicidal ideation section of the C-SSRS were used to detect high risk. Scores above a specified cutoff (a score of 5 on any of these items) alerted the participant to contact the SCBS. Not doing this within 2 days triggered a reminder email to the participant, as well as a message to the SCBS asking them to contact the participant (if contact information was available, otherwise no further action was taken). The provision of contact information to the research team or to SCBS was a voluntary option at enrollment for the trial.

Conversations between participants and SCBS staff (counselors, social workers, and psychologists) were conducted according to SCBS protocols without input from the research team.

Sample Size

Power to detect change in suicidal thoughts on the C-SSRS was based on an effect size of 0.3 (Cohen *d*), as found in the original trial [13]. To detect this effect size with 80% power and alpha=.05, assuming *r*=.5 between the baseline and postintervention measures and allowing for up to 30% attrition (again informed by the previous trial), 285 participants per arm would be required to yield at least 200 completers. Therefore, the aim was to recruit 570 participants into the trial.

Randomization and Sequence Generation

Randomization to the active or control condition occurred on a 1:1 ratio using a block design (4 participants per block), stratified by sex and severity of suicidal thinking (high severity was defined as endorsing yes on the fifth item of the Suicidal Ideation subscale of the C-SSRS, which assesses active suicidal ideation, defined as having a specific plan and intent). The randomization procedure was incorporated into the website and was fully automated.

Blinding

No research personnel were involved in the delivery of the interventions. Participants were not informed whether their assigned condition would receive the active or control program. However, it is likely that participants were able to discern their allocation based on the nature of the intervention they received, which increases risk of detection bias. All outcome measures were self-report and completed via an online portal. All research personnel (except those involved with the day-to-day management of the trial), remained blind to intervention allocation.

Procedure

Ethical approval was obtained from the human research ethics committees of the University of New South Wales (HC13117) and the Australian National University (2012/471). The trial was registered at Australia New Zealand Clinical Trials (ACTRN12613000410752) and has a Universal Trial Number (U1111-1141-6595).

Following the screening process, eligible participants received instructions specifying that participation required making contact with the SCBS to obtain a unique identification code. Respondents provided consent, a valid email address, a name/nickname, and a telephone number (nonmandatory). Participants were then invited to complete baseline measures after which they were randomized.

Six weeks after randomization (after completing the program), participants were invited to complete the postintervention questionnaire. Follow-up assessments took place at 6- and

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12-month follow-up. Participants who stopped using the program but who did not formally withdraw continued to be emailed follow-up questionnaires. Participants in the control group were given access to LwDT after the 12-month follow-up assessment.

Statistical Analysis

Primary analyses were performed on an intention-to-treat basis. All outcomes were tested using planned contrasts of mean change scores from pre- to postintervention via a mixed-model repeated measures (MMRM) analytic approach. An unstructured variance-covariance matrix was used to model within-individual dependencies. MMRM analysis uses all available data and yields estimates of effect under restricted maximum likelihood. The test of the efficacy of the intervention was based on the interaction between intervention condition and time. Supplementary analyses on the primary outcome were conducted for individuals who completed more than half of the program, as defined by completion of 4 or more of the available 6 modules. Using the whole sample, moderation of the effectiveness of the intervention by sex, age, baseline depression severity, history of suicide attempts (nil vs at least one), and chronicity of suicidal thinking (total number of months spent thinking about suicide) was examined. Moderation was tested using an identical MMRM approach with the addition of the moderating variable of interest as a factor into the model with 2- and 3-way interactions with group and time [30]. All analyses were performed using SPSS version 24 (IBM Corp).

Results

Participant Characteristics

Participant flow is shown in Figure 1. The registration Web page received 12,474 visits during recruitment. Almost three-quarters (8829/12,474, 70.78%) of these visits were by respondents who failed to complete the screening questionnaire. Two-thirds (2394/3645, 65.68%) of those who completed screening were eligible to participate. Of these, 41.56% (995/2394) consented to participate but fewer than half (446/995, 44.8%) contacted the SCBS to obtain an identification code. Almost all (418/446, 93.7%) of those who obtained an identification code completed the baseline assessments and were randomized.

Sample characteristics are provided in Table 1. At baseline, the majority of participants were female (323/418, 77.3%), lived in a metropolitan area (253/418, 60.5%), and had completed secondary-school level education (316/418, 75.6%). A considerable proportion were married or in a de facto relationship (160/418, 38.3%). Mean age of the total sample was 40.6 (SD 11.9) years and the majority were employed (248/418, 59.3%). There were no differences at baseline between the 2 conditions in demographic characteristics (all *P* values were greater than .05).

On average, the severity of suicidal thinking fell in the very high range, with one-third of the sample reporting multiple past suicide attempts. Symptoms of psychopathology were elevated, including depression, hopelessness, anxiety, panic, and sleep disturbance. Compared to normative samples, health-related quality of life was lower and impairment was higher. There were no group differences on baseline clinical variables, with the exception of the intensity of suicidal thinking, which was higher in the intervention group relative to the control group, t_{416}=2.71, *P*=.007.

Attrition

Attrition was 45.9% (192/418) at postintervention, 65.3% (273/418) at 6 months, and 66.3% (277/418) at 12-month follow-up (see Figure 1). Chi-square tests showed that individuals who dropped out were similarly distributed across the control and intervention groups (postintervention, χ^2_1=0.33, *P*=.57; 6 months, χ^2_1=0.33, *P*=.56; 12 months, χ^2_1=0.14, *P*=.71). Baseline characteristics of those who dropped out indicated that they were more depressed, $F_{1,416}$=8.42, *P*=.004; more anxious, $F_{1,416}$=6.53, *P*=.01; reported greater levels of thwarted belongingness, $F_{1,416}$=6.98, *P*=.009; increased frequency of suicidal behaviors, $F_{1,416}$=6.42, *P*=.01; and higher levels of disability, $F_{1,416}$=6.39, *P*=.01.

In terms of adherence to the program, there were no significant between-group differences in the number of modules completed, χ^2_6=9.26, *P*=.16. In the active intervention group, 8.2% (17/207) participants did not start the intervention (ie, did not access the first module), 91.8% (190/207) accessed at least 2 modules, 44.4% (92/207) accessed at least 3 modules, and 34.8% (72/207) accessed 4 or more modules. There were no significant between-group differences in baseline characteristics (all *P* values greater than .05), nor were there significant between-group differences in care received in a hospital setting, χ^2_2=4.19, *P*=.12, or from a general practitioner, χ^2_2=5.10, *P*=.08.

Safety Procedures

Participants who scored above the cutoff on the C-SSRS at any time during the study were telephoned by the suicide crisis help-line. More participants in the intervention condition (59/207) were called compared to those in the control condition (37/211), χ^2_1=7.10, *P*=.008. Differences between groups in number of alerts per participant did not entirely explain overrepresentation of participants with alerts in the intervention group: 10 intervention versus 4 control participants had 3 or more alerts (Fisher exact test, *P*=.109). The breakdown of number of alerts per group is provided in Table 2.

Based on self-report data from the C-SSRS Suicidal Behavior subscale, 23 participants made a suicide attempt during the course of the study, with no differences between groups, χ^2_1=.03, *P*=.87 (11 vs 12 attempts, respectively, for control and LwDT).

Intervention Effects on Primary Outcome: Severity of Suicidal Thinking

There was no overall group difference between the LwDT group and the control group on the primary outcome, severity of suicidal thinking at postintervention, $t_{245.51}$=−1.20 (95% CI −1.84 to −0.44), *P*=.23; 6 months, $t_{172.57}$=−0.88 (95% CI −2.17

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to −0.84), *P*=.38; and 12 months, $t_{163.89}$=−3.58 (95% CI −1.75 to −1.22), *P*=.72.

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Figure 1. Participant flow diagram.

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Table 1. Sample characteristics of participants in the intervention (Living with Deadly Thoughts) and control (Living Well) groups.

Characteristic	Intervention (n=207)	Control (n=211)	*P* value
Gender (female), n (%)	160 (77.3)	163 (77.3)	.37
Age, years, mean (SD)	39.53 (11.94)	41.73 (11.86)	.06
Educational history (completed secondary school), n (%)	158 (76.3)	158 (74.9)	.42
Marital status (married or de facto), n (%)	87 (42.0)	73 (34.6)	.27
Employment (employed), n (%)	121 (58.5)	127 (60.2)	.47
Area of residence, n (%)			
Metropolitan	127 (61.4)	126 (59.7)	.95
Regional, rural, or remote	79 (38.2)	84 (39.8)	.63
Lifetime history of suicide attempts, n (%)			
Never	90 (43.5)	101 (47.9)	.37
Once	46 (22.2)	43 (20.4)	.65
More than once	71 (34.3)	67 (31.8)	.58
Adherence to program, n (%)			
Accessed at least 4 modules	71 (34.3)	88 (41.7)	.14

Table 2. Alerts per group.

Number of alerts	Intervention (n=207)	Control (n=211)
1	34	25
2	15	8
3	7	1
4	2	2
5	1	1

However, both groups showed significant reductions in the severity of suicidal thinking relative to baseline at postintervention, $t_{244.85}$=−4.55, *P*<.001 (95% CI −2.64 to −1.05), *d*=0.56; 6-month follow-up, $t_{171.78}$=−5.46, *P*<.001 (95% CI −3.9 to −1.83), *d*=0.72; and 12-month follow-up, $t_{163.93}$=−6.72, *P*<.001 (95% CI −4.55 to −2.48), *d*=0.77.

Participants who completed at least 4 of the 6 modules in the LwDT condition were compared to those who completed at least 4 modules of the control program. Analyses indicated that completers of the LwDT program experienced a reduction in severity of suicidal thinking relative to completers of the control program at posttest, $t_{150.45}$=−2.16, *P*=.033 (95% CI –2.95 to –0.12), *d*= 0.60, but not at 6-month, $t_{117.62}$=−1.40, *P*=.17, or 12-month follow-up, $t_{108.02}$=.57, *P*=.57.

Moderation of Intervention Effects on Severity of Suicidal Thinking

Moderation of the effectiveness of the intervention by sex, age, baseline depressive symptoms, history of attempted suicide, and chronicity of suicidal thinking was investigated by examining 3-way interactions between group, time, condition, and the moderating variable of interest. Severity of suicidal thinking was not moderated by sex, $F_{3,178.36}$=1.56, *P*=.20; age, $F_{3,177.43}$=0.43, *P*=.73; baseline depression symptoms, $F_{3,192.9}$=0.52, *P*=.70; or history of previous attempts, $F_{3,182.21}$=0.31, *P*=.82. However, a moderation effect on the primary outcome was detected for chronicity of suicidal thinking, $F_{3,187.37}$=3.13, *P*=.03, with evidence that the LwDT program was more effective at reducing the severity of suicidal thinking in participants who had spent less time (fewer months) thinking about suicide.

Intervention Effects on Secondary Outcomes

The LwDT program, compared with the LW program, had no significant effect on secondary outcomes except for anxiety (see Multimedia Appendix 2), which showed a greater decrease at 12 months ($t_{185.55}$=−2.04, *P*=.04). This effect was not significant at posttest (*P*=.65) or 6 months (*P*=.17).

Across both groups (LwDT and Living Well) there was a significant reduction at all time points in the following: suicidal ideation (as measured by the C-SSRS and by the SIDAS), suicidal behavior, burdensomeness, depression, hopelessness, anxiety, panic, physical health, mental health, and physical functioning. There were also significant decreases in both groups for thwarted belongingness at 6- and 12-month follow-up, rumination at 6- and 12-month follow-up, and sleep difficulties at posttest and 12-month follow-up. Test statistics for these within-group comparisons are available from the authors upon request.

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Variables that did not significantly improve over time were acquired capability for suicide, reasons for living, and alcohol use, although a group difference emerged at 12-month follow-up, with those in the intervention group having lower alcohol use scores than those in the control group, $t_{145.59}$=–2.152, P=.03.

Discussion

Principal Findings

Regardless of intervention allocation, participants' level of suicidal thinking reduced over time, with no difference between the groups at postintervention or 6- or 12-month follow-up. Also, there was no evidence of between-group differences on most of the secondary variables.

These findings are discrepant from the original study of LwDT, where a significant difference was found for the intervention compared to a waitlist control group in suicidal thoughts and worry [13]. Several differences between these studies may account for this. First, the sample in the current trial was more severe than those in the original trial, both in terms of suicidality and depression. If the same criteria had been used in the original trial, 50% of those entering this trial would have been excluded. The findings from the moderation analysis might be interpreted to suggest that the intervention is indeed more suitable for those with less chronic suicidal thinking, as these participants had better outcomes. Severe levels of suicidality and depression are associated with poor motivation and impaired cognitive functioning, including poor concentration and attention [31]. However, baseline level of depression did not impact the effectiveness of the intervention, although the possibility remains that suicidal severity could interfere with program completion. It should also be noted here that the Dutch trial found more pronounced effects for severe suicidality [13,32], which contradicts the current findings. Another possibility relates to help-negation, which is the decreased propensity to engage in help-seeking behaviors as a consequence of more severe levels of suicidal ideation. Individuals who dropped out of the study after baseline had more severe levels of depression, anxiety, and suicidal behaviors, a finding that indicates that severe symptoms may interfere with completion of the program and that LwDT may be better suited to individuals with moderate symptom levels and less severe suicidality.

A second difference is that the original study involved a waitlist control condition, while the present trial had an attention-control condition. A number of features of the control intervention, including the fortnightly monitoring during the active phase, risk-triggered alerts, proactive follow-ups (if required) by the SCBS, and delivery of helpful lifestyle materials may have contributed to the reduction in suicidality, in addition to an expected standard placebo effect. The proactive nature of the intervention in the control group may have contributed to the improvement over time, obscuring any addition impact of the LwDT intervention. The monitoring of suicide ideation itself combined with the intervention by the call back service provides a safety protocol procedure that is known to have an effect [33].

A key procedural aim of this study was to provide LwDT without requiring participants to register with their doctors. Lack of anonymity poses an obstacle to help-seeking for many individuals [34]. Although the involvement of SCBS provided a solution to the issue of anonymity, it unfortunately created another challenge. Some participants attempted to call and, as is the case with many crisis services, were placed on hold and unable to register for the trial immediately. Some participants provided anecdotal reports of attempting to get through several times before giving up. Others indicated that they did not wish to contact SCBS for a range of reasons, including previous negative experiences with crisis support helpline services. Of the participants who provided consent, 55% did not go on to register with SCBS and were therefore unable to take part in the trial. LwDT, if delivered under real-world conditions outside the context of a research trial, would not require compulsory contact with a crisis support service such as SCBS. In the current context, it is a limitation that created a barrier to participation and may impact the generalizability of results.

A related issue was attrition and the role that general practitioners may have played in the original trial. In this study, attrition was 46% at postintervention, which is at the higher end of rates of attrition of online interventions [35,36]. However, these rates refer to depression and anxiety online treatment programs and not programs specifically for suicidality. For online treatments, predictors of dropout include severity and chronicity [35]. Although speculative, it is likely that the severely suicidal nature of the sample in this trial may have contributed to the relatively high level of dropout. The dropout rate in this study was also higher than that in the original trial (11%), which most likely arose as a product of 2 factors: the monitoring role played by the participants' regular doctor and the exclusion of severely suicidal and depressed participants. Some online programs that are completed in combination with professional support report lower rates of attrition [37].

The difference in number of alerts in this trial between the groups was also notable, with significantly more alerts triggered in the intervention group. This difference was not observed in the Dutch trial. Reasons for this difference are speculative but may be due to an imbalance of high-need people between the groups (as intensity of suicidal ideation was higher at baseline in the intervention group). Alternatively, the high alert rate may indicate that the intervention has an effect on help-seeking from a telephone helpline—something that is actively encouraged in the LwDT program. As registration with a helpline was mandatory for this trial, this may have lowered the threshold for calling, a factor that did not apply in the Dutch trial.

Limitations

The current trial had a number of other limitations. First, the target sample size for the trial was not met due to time constraints. The study was therefore underpowered and, given the high attrition rate, any smaller differences would not have been detected. Determination of any deaths by suicide was not possible within the context of the trial, given the lack of access to official records and anonymity of the participants. While this trial was not powered to detect group-level differences in attempted suicides or suicide deaths, future trials in this field

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recruiting larger numbers of participants would do well to incorporate an analysis of patient records to assess deaths by suicide over an extended period. Further, the incidence of suicide attempts could not be verified given the reliance on self-report rather than hospital and medical records.

Conclusion

The results of this study indicate that completing an online intervention is associated with reduced suicidal thinking and psychological symptoms over time, but this may be due to the exposure to a structured program, monitoring, and safety procedures. Further assessment with a waitlist control group would be required to confirm any advantage of the structured program above that of the safety procedures, and such a trial is unlikely to receive ethical approval.

This study has several clinical and research implications. Overall, there was no evidence that the LwDT program is harmful and, looking to the original Dutch trial, may be beneficial to those who have a less chronic history of suicidal thinking. This is consistent with clinical guidelines for the use of low-intensity interventions (ie, National Institute for Health and Care Excellence guidelines) for individuals who have low to moderate symptom levels. However, with the Dutch trial indicating more pronounced effects for people with a history of suicide attempt and this trial showing less effectiveness for those with a longer history of suicidal thinking, future research should investigate what target group might benefit most from online self-help, what adjustments might need to be made to the program to accommodate for various degrees of suicidality, and how the delivery of the program might improve outcomes at both ends of the spectrum. For example, incorporation in a stepped care model or tailoring of the program to individual needs might increase effectiveness across levels of severity.

Furthermore, the results that were achieved are of interest because they suggest that interventions are associated with a drop in symptoms. Research in support of crisis lines is also built on this type of outcome study and used to support their effectiveness. Also notable, with respect to helplines, is that even though it would make sense to implement programs such as LwDT in organizations that provide crisis support, less than half of eligible respondents enrolled with the SCBS, indicating that this could also be a deterrent. This should be taken into account when preparing such programs for use outside of a research context. Finally, the type of high-quality trial methodology—a randomized controlled trial—such as ours may not be the best methodology to observe outcomes, given the constraints outlined above.

We have shown that the provision of a self -help program via the internet is feasible but that further research is needed to better understand the types of interventions, both online and offline, that could assist people experiencing suicide ideation and the most useful settings in which to situate these interventions.

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Authors' Contributions

HC and BAJvS designed the study and oversaw trial implementation, data collection, and interpretation. BAJvS and AJFMK conducted the original study in the Netherlands on which the current trial was based. BAJvS, HC , PJP, AM, AJFMK, and JAG obtained study funding. AWS and DS managed the trial. AWS conducted statistical analyses that were overseen by the trial statisticians, PJP and AM. FS provided clinical support on the trial. AWS and HC wrote the manuscript. All authors have read and provided revisions of the final manuscript.

Conflicts of Interest

BAJvS and AJFMK are authors of the Dutch Web-based program described in this manuscript. BAJvS and AJFMK are also authors of and receive royalties from an adapted paper version of the self-help program published under the title Piekeren Over Zelfdoding [38]. BAJvS, AJFMK, and HC are authors of the English translation of the Web-based program described in this manuscript.

Multimedia Appendix 1

CONSORT - EHEALTH checklist (V 1.6.1).

[PDF File (Adobe PDF File), 253KB - jmir_v20i2e15_app1.pdf]

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Multimedia Appendix 2

Estimated marginal means from mixed-model repeated measures for primary and secondary outcomes at each time point for the intervention condition.

[PDF File (Adobe PDF File), 39KB - jmir_v20i2e15_app2.pdf]

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Abbreviations

C-SSRS: Columbia Suicide Severity Rating Scale
LwDT: Living with Deadly Thoughts
MMRM: mixed-model repeated measures
NHMRC: National Health and Medical Research Council
SCBS: Suicide Call Back Service
SIDAS: Suicidal Ideation Attributes Scale

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Original Paper

Digital Health Interventions for Adults With Type 2 Diabetes: Qualitative Study of Patient Perspectives on Diabetes Self-Management Education and Support

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Abstract

Background: The prevalence of type 2 diabetes is increasing globally, and health services in many countries are struggling with the morbidity, mortality, and costs associated with the complications of this long-term condition. Diabetes self-management education (DSME) and behavioral support can reduce the risks of developing diabetes-related complications and improve glycemic control. However, their uptake is low. Digital health interventions (DHI) can provide sustained support and may overcome challenges associated with attending diabetes self-management sessions. They have the potential for delivery at multiple locations at convenient times, anonymity, and presentation of content in attractive and tailored formats. This study investigates the needs and wants of patients with type 2 diabetes to inform the development of digital self-management education and support.

Objective: The objective of this study was to explore patient perspectives on unmet needs for self-management and support and the role of DHI in adults living with type 2 diabetes.

Methods: This study used a qualitative approach based on data generated from 4 focus groups with 20 patients.

Results: The data generated by the focus groups illustrated the significant burden that the diagnosis of diabetes places on many patients and the negative impacts on their emotional well-being, work, social life, and physical health. Although patients' experiences of the health care services varied, there was agreement that even the best services were unable to meet all users' needs to support the emotional regulation, psychological adjustment, and behavioral changes needed for successful self-management.

Conclusions: By focusing on medical management and information provision, existing health care services and education programs may not be adequately meeting all the needs of patients with type 2 diabetes. DHIs have the potential to improve access to DSME and behavioral support and extend the range of content offered by health services to fit with a wider range of patient needs. Features that could help DHIs address some of the unmet needs described by participants in this study included placing

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an emphasis on emotional and role management, being available at all times, having up-to-date evidence-based guidance for patients, and providing access to peer-generated and professional advice.

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KEYWORDS

diabetes mellitus, type 2; self-management; patient education; eHealth; mHealth; qualitative research

Introduction

The Potential for Digital Health Interventions for Self-Management Education in Type 2 Diabetes

The prevalence of type 2 diabetes is increasing globally, and health services in many countries are struggling with the morbidity, mortality, and costs associated with the complications of this long-term condition [1]. Diabetes self-management education (DSME) is important as it can reduce the risks of developing diabetes-related complications and improve glycemic control, at least in the short term [2-4]. However, uptake of DSME and behavioral support is low: in England, less than 10% of newly diagnosed people with type 2 diabetes have been recorded as attending structured education [5], and in the United States, less than half of the patients have been found to receive DSME [6]. Barriers to attending DSME include inconvenience, fear of stigma, and a lack of knowledge about the potential benefits [7]. Education and behavioral support requirements by patients extend beyond initial DSME, and there is often a need for ongoing diabetes self-management support beyond educational courses in the light of patients' evolving needs [8]. Digital health interventions (DHI) can provide sustained support and may overcome challenges associated with attending DSME. They have the potential for delivery at multiple locations at convenient times, anonymity, and presentation of content in attractive and tailored formats [9].

Examples of features used in existing interventions to improve the user experience include making fonts consistent, using logos and pictures, using bold to emphasize key points and improve design, repeatedly emphasizing the basic structure of the site and the program, including a screencast video to demonstrate the site, removing unhelpful jargon and terminology, managing expectations about the site in general, and personalizing the "source" by providing details about the development team [10]. User-expressed needs about the detail and degree of tailoring of information provision varies considerably, and it may not be possible to have a consensus on a format that satisfies all users [11].

Potential Problems With Digital Health Interventions

Challenges with DHIs include low levels of uptake in the target population with high levels of attrition and reduced user engagement over time [12]. The literature suggests there are two main approaches to improving uptake and maintaining ongoing engagement: (1) maximizing acceptability and usability of the intervention itself so patients *want* to use it [13,14] and (2) providing a degree of human support or facilitation so that patients are able to use it [15]. User engagement with interventions can be influenced by user perceptions [14] and intervention design [13]. User perceptions have both cognitive and affective elements [16]. Proposed cognitive drivers for user engagement include efficiency (ease of finding what users are looking for), effectiveness (impact of use), and trustworthiness. Important affective elements have been identified as enjoyment and interest [17]. Enjoyment can be defined as a general positive disposition and liking of media content [18], whereas interest motivates learning about something new and complex [19]. Users need to be interested to initially visit the website and then need to enjoy using the intervention to stay engaged [20]. With regard to understanding attrition, revisiting a website is associated with higher levels of education, being older, and a positive affective user experience [21]. Effective interventions therefore need to be interesting, enjoyable, and useful for patients. Qualitative research that explores the patient perspective can be a key tool to inform the development of such interventions.

Study Design

This study describes qualitative research that was conducted with patients to identify user requirements before the development of a new Web-based self-management intervention for adults with type 2 diabetes called HeLP-Diabetes [22]. HeLP-Diabetes was developed as part of a 5-year National Institute for Health Research (NIHR) Programme Grant for Applied Research and provides comprehensive self-management support that includes health information, behavior change support, emotional support, self-monitoring tools, and access to online peer support. It can be used by adults with type 2 diabetes who are able to understand written English at any stage of their diabetes journey, and has been shown to be effective in improving diabetes control [23].

User requirements were conceptualized as "needs" and "wants," where "needs" were features that were expected to achieve therapeutic benefit [24,25], whereas "wants" were features that users (patients) desired in an intervention and that were likely to make them want to return to the program.

The theoretical basis for understanding the *needs* of people living with type 2 diabetes was based on Corbin and Strauss's model of the work of living with chronic illness [26]. Their study has informed much of the subsequent literature on self-management [27]. Corbin and Strauss described three types of work when living with a chronic illness: illness work, everyday life work, and biographical work. These tasks have also been described as medical management, emotional management, and role management [28]. Illness-related work consists of the tasks of managing treatment regimens, preventing and managing crises, symptom management, and diagnosis-related work. Everyday work describes the mundane work of everyday living and includes the sentimental work of managing emotions and relationships. Biographical work

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describes the work done in extracting meaning from life experiences and creating personal socially constituted identities as patients, parents, spouses, partners, professionals, or friends. Being diagnosed with a chronic illness can have a significantly disruptive impact on a person's biographical narrative [29,30].

As mentioned previously, support or facilitation in using DHI can help increase use and potential impact of such interventions. Most of the data on the effects of providing human support or facilitation for DHI come from mental health, where studies on Internet cognitive behavioral therapy demonstrate that including therapist support significantly improves engagement with Internet cognitive behavioral therapy programs and their effectiveness [15,31]. In these studies, therapist input has been limited to encouraging engagement with the program, rather than providing therapy. However, human support, and in particular, health professional support, is an expensive and scarce resource, so it is important to determine how much human input is required and who should provide it.

This study was undertaken to determine patient needs and wants for a DHI to support self-management in patients living with type 2 diabetes.

Methods

Ethical Approval

The study was reviewed by the North West London Research and Ethics Committee (REC reference 10/H0722/86).

Recruitment

English-speaking adults in England with type 2 diabetes were recruited for this study. Printed leaflets and posters were distributed to general practitioner (GP) surgeries and local diabetes support groups across London. An advertisement was placed in the *Diabetes Balance* magazine of Diabetes UK. Online recruitment included an advert on the Diabetes UK website, a local council website, ethnic minority forums, and other diabetes forums. Respondents were sent an information sheet and consent form and were invited to complete a questionnaire that was used to recruit a maximum variation sample. Factors that the literature suggested were likely to influence wants and needs included demographic factors (eg, age, gender, ethnicity, and first language), clinical factors (eg, duration of diabetes, current treatment, presence or absence of diabetes-related complications, and previous experience of self-management programs), and factors related to health and computer literacy (such as educational attainment, previous experience with computers, and access to the Internet) [32-35]. Participants were purposively sampled to vary across these characteristics.

Data Collection

Four focus groups with 3 to 6 participants were held in a community center in London. Focus groups were chosen as they encourage interactions between participants and allow ideas to be generated, reflected on, and debated by participants [36,37]. They were facilitated by two or three researchers from the team (CD, KP, EM, and FS), audio-recorded, and transcribed verbatim. Previous reviews of patient information materials and websites provided the basis for the structure of the focus groups [38,39]. At the start of the focus group, participants were shown 3 examples of existing websites that support diabetes self-management and asked to explore them. These had been selected by the research team to demonstrate the range of interventions and component parts available. They varied in terms of content, complexity, tone, navigation, and presence of interactive features such as forums, Ask the Expert, or self-monitoring tools. The websites were selected based on a number of criteria: up-to-date, accredited by national diabetes organizations (eg, American Diabetes Association or Diabetes UK), and written in English. The topic guide was piloted in an interview by one researcher (CD) to ensure it stimulated discussion across the target areas.

The 4 focus groups were held in 2 community centers. The facilities had computer access and rooms suitable for small group discussions. A venue outside health care settings was chosen to put participants at ease and to minimize the impact of the power differentials that might be created in such settings from participants taking on the role of a patient.

Each focus group was run by 2 to 3 researchers and lasted up to 4 hours in total. The first 15 min was allocated to welcoming participants and introductions, followed by up to 90 min exploring the 3 websites. This was followed by a 30-min break and then 90 min of group discussion. Having more than one researcher was helpful as they took a more observational role to monitor the interactions between facilitator and participant and could pick up on undue prompting or dominance from the main facilitator [40]. Having nonmedical cofacilitators helped monitor for dynamics that would limit the data generated from the focus groups if the facilitator took on the role of the "expert" and inhibited participant discussions [40]. Discussions were semistructured with a list of topics to be covered (not necessarily in a defined order) during the session.

Data collection continued until no new data emerged regarding content and design or patient-defined wants and needs for self-management.

Data Analysis

Analysis was conducted by a multidisciplinary team. Transcripts were independently read by five authors (CD, KP, JR, EM, and FS), and emerging themes were discussed at a multidisciplinary meeting. As described previously, the underlying sociological theory guiding the analysis of patient needs was Corbin and Strauss's study on living with a chronic illness. The main constructs of the model were used to sensitize and encourage a holistic perspective that explored the impact of type 2 diabetes mellitus on people's day-to-day activities, relationships, and emotions (everyday life work); the burden of having to take medicines or make lifestyle changes for the medical management of the condition (illness work); and the disruption or changes to the roles that patients played within their families and at work (biographical work). This model was not used to define a priori codes or categories, but was used as a sensitizing tool to organize codes generated using inductive thematic analysis. Two authors (EM and KP) coded the transcripts and mapped themes onto the Corbin and Strauss's model. The mapping was then discussed and agreed upon in a meeting

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between the 5 authors (CD, JR, FS, KP, and EM). The resulting structure was used to determine patient needs and wants for a DHI. None of the themes developed inductively fell out with the Corbin and Strauss's model.

Illustrative extracts of the data are presented in the Results, with identification by focus group number and participant number together with age, gender, ethnicity, duration of diabetes, and computer experience.

Atlas Ti (version 6.2, Scientific Software Development, Berlin, Germany) was used to manage the transcripts and coding and to facilitate the final data analysis.

Results

Participant Characteristics

The demographics of the 20 participants who took part in the pilot interview and 4 focus groups are summarized in Table 1.

Just over half the participants were male with a mean age of nearly 57 years. Almost half were retired and over half had degree-level qualifications. Moreover, 70% (14/20) of participants were white; the remaining participants described their ethnicity as black, Asian, or other. Time since diagnosis ranged from 3 months to 36 years. An overwhelming majority of participants had home Internet access, and most had used the Internet to look up information about diabetes. In addition, 60% (12/20) of participants had been on a diabetes self-management course, but most had never used a computer-based self-management program.

The data mapped easily onto the Corbin and Strauss's model, with the resultant themes and subthemes summarized in Table 2.

Participant-Defined Health Needs

Challenges With Role Management

Many participants described a significant and constant burden that they experienced as a result of the diagnosis. Some participants felt a sense of loss at diagnosis, and the identity constructed around being a patient with type 2 diabetes was quite negative and associated with poor health, stigma, and shame:

> *Facilitator: you've described it [diagnosis of diabetes] being like bereavement, and a lot of people say that, because you are, in a sense; you're grieving for the loss of your...?*
>
> *PT5: Liberty. Freedom.*
>
> *Facilitator: Is that what it is? Right.*
>
> *PT10: Health.*
>
> *PT5: Yes.*
>
> *PT5:Well, it's more to do with the mortality business, isn't it? Without wanting to sound grim, but...* [PT5: male, 55 years old, white British, 5 years since diagnosis; PT10: male, 70 years old, white British, 6 months since diagnosis; focus group 1]

Participants reported a perception that other people blamed them for their illness, and that the relationship between lifestyle and type 2 diabetes led to stigmatization of people who developed diabetes:

> *Usually people say, oh, you must have had a bad lifestyle, something or whatever, which may be true sometimes, but it's not the only reason, so...* [PT19: female, 64 years old, white British, 36 years since diagnosis; focus group 3]

Many of the participants described how the demands of an illness that required them to take medication and eat regularly made it impossible for them to carry on with the work they had previously been doing:

> *You know, and again, they took me off shifts, because I couldn't remember if I'd taken my pills one week, you know? One week, I'm working early and next week, I'm working late, and then I'm working nights, and I used to go, I can't remember if I've taken them or not. My manager said, that's no use, is it?* [PT17: male, 54 years old, white British, 8 years since diagnosis; focus group 3]

Managing the Emotional Burden of Diabetes

Participants reported experiencing strong negative emotions, which they found difficult to manage. Participants frequently reported experiencing depression, anger, frustration, and guilt.

> *Low, angry, frustrated. Everything. Because, you know, sometimes you're frustrated because the doctor hasn't told you what you want to hear. Or you're angry with the world, and you take it out on your children, your partners, everybody. And then you've got the depression that takes you down, because you're just thinking one thing after another.* [PT11: Female, 51 years old, black (Caribbean), 10 years since diagnosis; focus group 2]

The impact of dietary changes on participants' social and family lives was also experienced as a difficultly. Some participants found it too hard to keep to their planned diet when out with friends or family, and would simply try to manage the consequences, whereas others would try to adhere to the changes they had instituted, but reported negative reactions from their families:

> *Because we're talking about food; I mean, I go to my family, and when I say I can't eat that food, they usually think that's disrespecting them, so you've got all that as well to deal with.* [PT11: Female, 51 years old, black (Caribbean), 10 years since diagnosis; focus group 2]

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Table 1. Demographics of participants.

Characteristic	Value
Gender, n (%)	
Male	12 (60)
Female	8 (40)
Age in years, mean (range)	56.8 (36-77)
Employment status, n (%)	
Employed	5 (25)
Not working but looking for work	2 (10)
Retired	8 (40)
Retired (semi)	1 (5)
Not working and not looking for work	2 (10)
Other—full time student	1 (5)
Other—volunteer	1 (5)
Education, n (%)	
School leaver	4 (20)
A Level	5 (25)
Degree	11 (55)
Ethnicity	
White British	14 (70)
Black (African, Caribbean, and other)	4 (20)
Asian (Indian)	1 (5)
Other (Iranian)	1 (5)
Duration of diabetes, n (%)	
<1 year	2 (10)
1-5 years	7 (35)
6-10 years	5 (25)
>10 years	6 (30)
Diabetes management, n (%)	
Diet only	3 (15)
Diet + tablets	10 (50)
Diet + tablets + liraglutide injection	1 (5)
On insulin	6 (30)
Home Internet access, n (%)	
Yes	19 (95)
No	1 (5)
Attended diabetes education, n (%)	
Yes	12 (60)
No	8 (40)
Used the Internet to look up diabetes-related information, n (%)	
Yes	17 (85)
No	3 (15)
Used a computer self-management intervention before, n (%)	
No	16 (80)

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Characteristic	Value
Yes	2 (10)
Yes (own spreadsheets)	2 (10)

Medical Management: Problems With Existing Health Services

Although some participants were very appreciative of the care they had received from the health service, this was not a universal experience, with many participants reporting difficulties with access to health care professionals, lack of interest or expertise in staff, and an increasing sense of a "tick box" culture, where problems were recorded but not addressed. Even participants who were positive about their care reported unease about taking up time in consultations:

> *I've been very fortunate with my practice in [location] because they've given me a huge amount of support actually in terms of information gathering. But I understand that you've only got to be a couple of miles down the road and you get nothing at all. And even if you ask the questions, the doctors feel that you're taking up their time, and in fact that's true of all doctors, I appreciate that.* [PT10: male, 70 years old, white British, 6 months since diagnosis; focus group 1]

> *I'm asked that, once a year, that question, do you feel depressed? Yes. Next question. It's not like, what are you going to do about it? And when I see the nurse, every six months, she just says, are you exercising? And she ticks a little box if I say yes or no. And that's it.* [PT6: male, 55 years old, black (African), 10 years since diagnosis; focus group 1]

Participants had experience of poor quality information that was difficult to understand and not relevant to their personal needs. They were clear that they wanted to have access to detailed information in case it was needed, but controlling the flow of information was very important to avoid "information overload." Patients wanted access to in-depth information when it was relevant to them. An example of this included information about abnormal test results or dietary advice that took into account personal circumstances. Some participants struggled with complex information, for example, understanding nutritional content and guidance about recommended daily allowances:

> *...but sometimes it's a question of having too much information and you can't take it all on board and you can't make all the changes overnight. [PT20: female, 41 years old, white British, 5 years since diagnosis; pilot interview] And where are the tools that help me to understand it? You know, I'm looking at carbs and sugar, and it's all very confusing and highly complicated.* [PT16: male, 58 years old, white British, 4 months since diagnosis; focus group 4]

Participants emphasized the need for self-management to be integrated with health care professional management and thought it would be beneficial to have access to their electronic medical records (EMR). They thought it would be important to correct misinformation and have the correct information to share with their multiple different health care providers, such as opticians, podiatrists, dentists, and emergency doctors. However, participants were keen to have control over their information, and to decide what to share with whom:

> *I think it might be useful to correct things, if you find anything that's been recorded incorrectly, that at the moment, you've got no idea if there's anything…anything's wrong or not.* [PT16: male, 58 years old, white British, 4 months since diagnosis; focus group 4]

> *I'm a great believer in being able to access your own records, and also having...the worst thing is, when you go along to A&E, and they say to you...they might turn around to you and say, oh when were you diagnosed? You know, and you have to start from...the whole story from the beginning.* [PT7: female, 65 years old, white British, 3 years since diagnosis; focus group 4]

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Table 2. Mapping of patient needs onto Corbin and Strauss's model of living with a chronic illness. GP: general practitioner. DSME: diabetes self-management education. EMR: electronic medical record.

Level 1 and Level 2	Level 3
Life work and emotional management	
Negative emotions associated with living with type 2 diabetes	Burn-out
	Denial
	Indifference
	Depression
	Anger
	Frustration
	Self-blame
	Guilt
	Shame
Triggers for negative emotions	Food
	Seeking medical help
	Lack of understanding from family members
	Intrusive comments from family members
Strategies for keeping a positive outlook	Maintaining optimism
	Accept limits on control
	Treat depression
Sources of support	Caring family members
	Peers
Illness work and medical management	
Barriers posed by the health care system	"Tick-box" consultations
	Conflicting advice
	Professionals not keeping up to date
	Difficulty getting appointments with GP
	Difficult accessing DSME
	Poor quality information (too much, too little, too complicated, not relevant)
Enablement by the health care system	Supportive doctors and nurses
	Taking time to explain results
	Timely access to DSME
Low priority of illness work	Lack of time
Features patients want from access to EMR	Access to blood results
	Access to a medical summary
	Transparency and being able to correct errors
	Control data sharing
Biographical work and role management	
Negative self-image	Feeing bereaved of loss of health
	Deserving punishment
	Feeling like a criminal
	Stigma of diagnosis
Changes in parent role	Dependence on children

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Level 1 and Level 2	Level 3
Changes in working roles	Lack of support for making adaptations to work roles
	Impact of changing needs of patient role on working role

What Participants Wanted From a Digital Health Intervention: Content and Design Features

Participants were clear that digital interventions should address all aspects of living with diabetes, including diet, physical activity, taking medicines, working with health care professionals, managing difficult emotions, and handling interactions at work, social occasions, and with friends and family. Of those, food and nutrition therapy were of most interest. Participants were also interested in hearing about alternative medicine and the opinions of peers.

They wanted information about diabetes, including how it is caused and how it affects the body; available treatments, including goals of treatment, pros and cons of each treatment, and potential side effects; and access to a suite of resources. They wanted the program to be a "one-stop shop," which they could turn to at times of need. There were clear tensions between wanting and needing information on the one hand and, on the other, not wanting to be overwhelmed with "bad news." They stated it was vital that the information was presented in a positive fashion, with an emphasis on what can be done to prevent complications, acknowledging that diabetes can be hard to control and avoiding "victim blaming" when things do go wrong:

> *I suppose I'd want something that was a bit, kind of, an A to Z of one's life.* [PT20: female, 41 years old, white British, 5 years since diagnosis; pilot interview]

> *So that's the big problem, it seems to me. The mainstream medical opinion seems to be all doom and gloom...If you just put that diabetes is such and such but can be controlled or managed or whatever word you want to use, through very simple means, I think that's a huge relief to people.* [PT10: male, 70 years old, white British, 6 months since diagnosis; focus group 1]

> *I think you've always got to look at the positive side of your illness. But yes, you're always going to have a negative side, and sometimes you've got to have a funny side...* [PT8: female, 46 years old, white British, 16 years since diagnosis; focus group 1]

Textboxes 1 and 2 summarize participants' views on the content and design features they wanted to see in a DHI supporting self-management in type 2 diabetes.

Health Professional Facilitation and Other Elements That Might Engage Users

Participants wanted self-management support programs to be integrated into their general medical care, rather than stand-alone. They wanted to work with their health professionals to obtain good health outcomes. Participants were therefore strongly in favor of their health care professionals helping users register on a DHI, showing people how to use it, and discussing their use of the program in diabetes-related consultations, but they were skeptical as to whether this would be possible:

> *I think it would be a good thing but I can't see many people doing it. I know obviously they, to even ring your GP surgery normally to make an appointment can be very tiresome for a lot of people. You can't get through.* [PT8: female, 46 years old, white British, 16 years since diagnosis; focus group 1]

Participants suggested the following potential features that might encourage users to access a DHI on an ongoing basis: regularly adding new content; articles about latest research findings; regular emails; the use of video, forums, and interactive tools; and the ability to use administrative functions such as booking appointments with health care professionals.

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Textbox 1. Summary of the range of content desired by participants in this study.

Medical information

- Medication
- Side effects
- Hypoglycemia
- News and research

Dietary advice

- Controlling blood glucose
- Weight loss
- Controlling cholesterol
- Understanding food
- Recipe ideas

Physical activity

- Benefits of exercise
- Advice about weight loss
- Self-monitoring tools
- Easy-to-do physical activities
- Resources for group activities

Alternative medicine

- Relaxation therapy and stress reduction
- Complementary therapies

Peer support

- Advice from peers
- Emotional support
- Social comparisons
- Role models
- Not much enthusiasm for social media

Pregnancy

Safe conception and what to do if pregnant

Practical advice

- Travel
- Insurance
- Financial advice, for example, benefits

Information about health services

- Services that patients should have access to
- Local support groups
- Telephone support lines

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Textbox 2. Design features desired by participants in this study.

Design and navigation

- Easy to use
- Clear, concise, and consistent
- Minimize scrolling
- Use videos
- Pages can be printed in black and white
- Have interactive features like quizzes
- Provide self-monitoring tools
- Act as a central hub for all diabetes-related queries with links to other resources

Language and tone

- Accessible
- Use medical terminology where needed, but provide definitions and explanations
- Be encouraging and supportive
- Not shy away from difficult truths
- Have a sense of humor

Trust

- Thorough proofreading
- No advertising
- Working links to and from good websites
- Use trusted brands

Avoid irritants

- Poor design
- Not relevant or localized
- Out of date
- Boring or static

Keeping users engaged

- Regularly adding new content
- Articles about latest research findings
- Regular emails
- Use of video and interactive tools
- Booking appointments

Discussion

Principal Findings

The participants in this study described a range of unmet needs for supporting their self-management efforts and identified a number of potential ways that DHI could help them. The features of DHIs desired by participants included specific content relating to diabetes (eg, hypoglycemia, medication side-effects, weight loss, and physical activity) and emphasized the strong desire of participants for reliable and accessible dietary advice. Patients in the United Kingdom have good access to primary care doctor and nursing support with structured templates to help standardize diabetes care. However, where patient self-management needs extend beyond the remit of these structures that often focus on using medication to optimize glycemic control, it can be difficult to get support.

A DHI could help overcome some of the barriers to self-management currently posed by limitations of existing health care systems. An evidence-based, well-written, up-to-date DHI could be available 24/7, and could improve access to high-quality information, DSME, and behavioral support where patients are not able to access face-to-face services that provide tailored information and help with behavior changes such as increasing physical activity, dietary change, and weight loss.

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Access for patients to their electronic medical record via the DHI was seen as a potential benefit that could engage patients, especially if access to these systems allowed administrative functions such as booking medical appointments. Technology-based prompts have been shown to have positive effects on engagement with other DHIs [10], and participants in this study reported that regular emails would be an acceptable strategy for increasing intervention use.

The DHI developed as a result of these data, HeLP-Diabetes, was effective in improving diabetes control for users. We believe a key reason for this was the careful attention paid during the development phase to users' wants and needs, and we commend this approach to others. The data generated during the focus groups were underpinned by a strong sense of the burden that the diagnosis of diabetes placed on participants, which had negative impacts on their emotional well-being, work, social life, and physical health. This finding fitted with our overall theoretical framework, based on the Corbin and Strauss's model, and underlined the importance of ensuring that the self-management program addressed the three key tasks of medical, emotional, and role management. Although participants' experiences of the health care services varied, participants reported difficulties getting the information and patient-centered care they needed to support self-management when consultations with health professionals were too time-pressured or protocol-driven to accommodate individual patient needs.

The strengths of this study included the use of focus groups and semistructured topic guides, which allowed participants to raise their own concerns and determine the direction and content of the discussions. The use of a sociological model [17] encouraged a holistic approach to the data that provided a broader perspective on self-management than usual bio-medical definitions of DSME.

Limitations

The main limitation was that, although we were successful in recruiting a sample that was diverse in terms of ethnicity, duration and treatment of diabetes, and gender, the participants who volunteered for the study were relatively well-educated and computer-literate and the sample may have over-represented patients who were motivated and actively engaged in self-management. People with lower health literacy and from other cultures may have different needs that were not explored in this study. The majority of participants had also not had any previous experience of using a computer-based self-management program. The risks of using a naïve population are that interventions might not be optimized for the needs of potential users who are most comfortable using Web-based tools and suggestions for intervention development would not be grounded in a detailed understanding of existing interventions. However, the advantage of using a "naïve" population is potentially better generalizability with the needs and preferences representing the general population rather than early adopters who might be more technically savvy. The exponential growth of the Internet and mobile phone use illustrates how useful and user-friendly technology can have a mass-market impact; thus, exploring the needs of a study population that represents a more generalizable population beyond early adopters would be important in maximizing the potential benefits of such an intervention. Well-designed DHIs for diabetes have been shown to engage and benefit users with a wide range of health literacy, and findings can be generalizable to a wide range of users [41].

Comparison With Prior Work

There were many areas where a DHI could help address the unmet needs described above. There have been a number of systematic reviews of DHIs in type 2 diabetes, including narrative syntheses, meta-analyses, and meta-ethnographies [9,42-44]. The interventions described in these reviews have tended to focus on improving the medical management of type 2 diabetes through information provision and behavior change support [45-49]. However, for participants in this study, the "work" of emotional and role management was more important for them than most aspects of medical management other than food and diet. Previous studies have highlighted inconvenience and poor motivation as reasons for poor engagement with DSME and DHI for diabetes [7,49]. This study suggests that another important aspect might be a potential mismatch between the content and emphasis of existing DSME interventions and patient-defined needs and priorities for diabetes self-management. Increasing the focus on emotional management for such interventions also has clinical importance as cross-sectional and prospective evidence suggests that changes in diabetes-related distress correlate with changes in glycemic control, possibly through changes in adherence with medication, whereas depressive symptoms are correlated with self-management behavior [50,51].

Conclusions

By focusing on medical management and information provision, existing health care services and education programs may not be adequately meeting the needs of patients with type 2 diabetes. DHIs have the potential to help improve access to DSME and extend the range of content offered by health services to meet a wider range of patient needs. The features of a DHI that could address the unmet needs described by participants in this study included an emphasis on emotional and role management, being available 24/7, having up-to-date evidence-based guidance for patients, and providing access to peer-generated and professional advice. The findings of this study have been used in the development of an effective DHI for adults with type 2 diabetes, called HeLP-Diabetes, which has been evaluated in a randomized controlled trial and implementation study and has been shown to be acceptable to a wide range of users [23].

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Number RP-PG-0609-10135). The views expressed are those of the authors and not necessarily those of the National Health Service, the NIHR, or the Department of Health.

Conflicts of Interest

EM is the managing director of HeLP Digital, a not-for-profit Community Interest Company that disseminates digital health interventions to the NHS. She has not, and will not, receive any remuneration for this work.KP has worked with HeLP Digital, a not-for-profit Community Interest Company that disseminates digital health interventions to the NHS. He has not, and will not, receive any remuneration for this work.

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Abbreviations

DHI: digital health intervention
DSME: diabetes self-management education
GP: general practitioner
NIHR: National Institute for Health Research

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Original Paper

A Web-Based, Social Networking Beginners' Running Intervention for Adults Aged 18 to 50 Years Delivered via a Facebook Group: Randomized Controlled Trial

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Abstract

Background: Online social networks continue to grow in popularity, with 1.7 billion users worldwide accessing Facebook each month. The use of social networking sites such as Facebook for the delivery of health behavior programs is relatively new.

Objective: The primary aim of this study was to determine the effectiveness of a Web-based beginners' running program for adults aged 18 to 50 years, delivered via a Facebook group, in increasing physical activity (PA) and cardiorespiratory fitness.

Methods: A total of 89 adults with a mean age of 35.2 years (SD 10.9) were recruited online and via print media. Participants were randomly allocated to receive the UniSA Run Free program, an 8-week Web-based beginners' running intervention, delivered via a closed Facebook group (n=41) that included daily interactive posts (information with links, motivational quotes, opinion polls, or questions) and details of the running sessions; or to the control group who received a hard copy of the running program (n=48). Assessments were completed online at baseline, 2 months, and 5 months. The primary outcome measures were self-reported weekly moderate to vigorous physical activity (MVPA) and objectively measured cardiorespiratory fitness. Secondary outcomes were social support, exercise attitudes, and self-efficacy. Analyses were undertaken using random effects mixed modeling. Compliance with the running program and engagement with the Facebook group were analyzed descriptively.

Results: Both groups significantly increased MVPA across the study period (P=.004); however, this was significantly higher in the Facebook group (P=.04). The Facebook group increased their MVPA from baseline by 140 min/week versus 91 min for the control at 2 months. MVPA remained elevated for the Facebook group (from baseline) by 129 min/week versus a 50 min/week decrease for the control at 5 months. Both groups had significant increases in social support scores at 2 months (P=.02); however, there were no group by time differences (P=.16). There were no significant changes in the other outcomes. A process evaluation revealed relatively high levels of engagement with the Facebook group during the 8-week intervention (eg, mean number of interactions 35 [SD 41]).

Conclusions: An 8-week beginners' running program delivered through Facebook produced sizable and sustained changes in weekly MVPA and received strong engagement and positive feedback from participants. Future research investigating this intervention approach is warranted in other populations and health behaviors.

Trial Registration: Australian New Zealand Clinical Trials Registry ACTRN12616001500448; https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=371607&isReview=true (Archived by WebCite at http://www.webcitation.org/6xSAuz4NW)

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KEYWORDS

social network; health behavior; program evaluation; Internet; physical activity

Introduction

Physical inactivity is among the leading risk factors for mortality and has been linked to an increased risk of chronic diseases such as type 2 diabetes, cardiovascular disease, and certain cancers including breast and colon cancer [1]. Worldwide, physical inactivity is estimated to cost global health care systems USD 53.8 billion dollars [2].

The Australian Government Department of Health [3] recommends that adults aged between 18 and 64 years engage in 150 to 300 weekly minutes of moderate physical activity (PA; eg, brisk walking), or 75 to 150 weekly minutes of vigorous PA (eg, jogging or singles tennis), or the equivalent combination of moderate to vigorous physical activity (MVPA).

Jogging or running affords many practical benefits: it is inexpensive, it requires little to no equipment, it is time efficient, and can easily be incorporated into daily routine [4]. Regular running has been linked to positive physical and psychological outcomes such as improving cardiovascular fitness, maintaining or improving blood pressure, and preventing or managing mental illnesses such as depression [5]. In addition, vigorous PA (eg, running or jogging) is reported to have greater cardioprotective benefits than moderate activity (eg, walking) [6].

Previous research has explored running as a means of increasing physical and emotional well-being [7,8]. The delivery of jogging interventions vary, with some programs using one or a combination of face-to-face, group-based, Internet- or print-based delivery methods [7,8]. Online social networking is a unique delivery method that has yet to be explored for jogging interventions.

Online social networks such as Facebook are incredibly popular, accounting for a quarter of all time spent online [9,10]. Globally, Facebook is the most popular online social networking site, with 2 billion active users each month and 15 million monthly Australian users [11]. Facebook's popularity and its ability to impart social influence offers promise for the delivery of low-cost, mass-scale health behavior interventions.

Two systematic reviews examining the use of online social networks in behavior change interventions found modest evidence of effectiveness [12,13]. Many studies to date have used Facebook as a component of a more complex intervention and offered a range of additional intervention materials and resources [13], for example, an online discussion page [14], a self-monitoring website [15], pedometers [16-18], accelerometers [19], or cook books [20]. This makes it difficult to disentangle the effectiveness of the online social networking component from other intervention components.

Studies specifically looking at the use of online social networks for PA interventions have reported mixed results. Facebook apps have shown promising results for the delivery of health interventions in terms of efficacy and engagement [17,21] but require considerable expertise and funding to develop.

Cavallo and Valle [15,18] explored the use of Facebook groups, a pre-existing Facebook feature, for PA intervention delivery. In both studies, the Facebook group was a component of the intervention, with participants also having access to a separate online website. Comparison groups received alternative interventions (website only [15] and Facebook self-help group [18]). The primary outcomes were social support for PA [15] and self-reported PA [15,18]—no significant groups by time differences were reported.

To the best of our knowledge, no studies have explored the use of a Facebook group as the sole means of delivering a PA intervention. Given Facebook's popularity and the simplicity and cost-effectiveness of using pre-existing Facebook features such as Facebook groups, further research is required to evaluate the effectiveness of this intervention delivery method.

The primary objective of this study was to determine the effectiveness of an 8-week beginners' running program (*UniSA Run Free*) delivered entirely via a Facebook group in increasing PA and cardiorespiratory fitness in adults aged 18 to 50 years. The secondary objectives were as follows: (1) to determine the effectiveness of this program in improving PA attitudes, self-efficacy, and social support; (2) to determine engagement and feasibility of the program; and (3) to examine whether changes in MVPA are related to demographics, baseline characteristics, and engagement.

Methods

Overview

This parallel randomized controlled trial (RCT), allocation ratio 1:1, was approved by the University of South Australia Human Research Ethics Committee (protocol number: 0000033766). Data collection took place in Australia from January 2016 to August 2016. Data analysis occurred from August 2016 to November 2016. Participants provided informed consent online before commencing the study. The study was designed and is reported following the Consolidated Standards of Reporting Trials guidelines [22] and is registered with the Australian and New Zealand Clinical Trials Registry, protocol number: ACTRN12616001500448.

Recruitment and Randomization

Participants were recruited through a variety of advertising methods including online (via Facebook advertising) and via print media. Participants were eligible to take part in the study if they met the following criteria: (1) aged between 18 and 50 years, (2) Australian residents, (3) current Facebook users, (4) able to read and understand English, and (5) not participating in a regular running program. Individuals were excluded if they had a medical condition that would prevent them from participating in a running program and if they were pregnant or planning to become pregnant within the next 5 months.

Interested participants were directed to the UniSA Run Free Facebook page that provided study information and invited

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potential participants to register their interest by privately texting their contact details. An online survey was used to confirm eligibility (participants were asked questions related to the eligibility criteria), collect written informed consent, and perform baseline assessments. Participants were formally enrolled once they completed baseline surveys. Upon enrollment, they were randomly allocated (by the primary researcher, JL) to the intervention (UniSA Run Free program) or control condition (self-directed running program) using a computer-generated random number sequence with allocation concealment (opaque envelopes were used for allocation concealment).

Details regarding the honorarium for this study were provided in the participant information sheet and consent form. All participants who enrolled in the study and who completed all three assessments were placed in a prize draw for an Aus $200 gift voucher.

Interventions

UniSA Run Free (Intervention Condition)

UniSA Run Free is an 8-week beginners' running program delivered via a closed Facebook group. This program is based on social cognitive theory (SCT), which encompasses key constructs underpinning the UniSA Run Free Facebook group content and the outcome measures selected for this study [23,24].

SCT emphasizes the interaction of three factors that may affect or be affected by each other, referred to as *reciprocal determinism* [23,24]. These include:

1. Environmental factors—a Facebook group was chosen for the intervention delivery as it provides a social environment to promote peer encouragement, sharing, and support.
2. Personal factors—this program was targeted at *beginner runners* (people with similar skill levels; those participating in a regular running program were excluded).
3. Behavioral factors—the program was graded to allow for incremental gains in running skills and fitness (behavioral change).

An additional key construct of SCT is self-efficacy, which refers to a persons' self-confidence to carry out the behavior [23,24]. Self-efficacy was promoted through short-term (session goals) and long-term goals (running 30 consecutive minutes by the end of the program) and Facebook posts (see Figure 1) offering information and motivational material.

The running program consisted of three interval training sessions per week; each session included a warm up, main activity, and cool down (see Figure 2). The program was created by health professionals at the University of South Australia (CM and JK) in collaboration with fitness experts, to ensure it progressed in a safe and achievable manner for novice runners. The end goal of the program was for the participants to run continuously for 30 min. The UniSA Run Free program was delivered entirely via a closed Facebook group (only participants randomized to the intervention group could access this). The running sessions were posted onto the Facebook group weekly. In addition, participants were posted an A4 fridge magnet (see Figure 2) outlining the running program in its entirety so that they could tick sessions off as they were completed.

Each day (for the duration of the 8-week program), the group facilitator (JL) posted a message to the closed Facebook group. These posts were informative and encouraged social interaction including asking participants to post photos, providing information with links, motivational quotes, opinion polls, and posts prompting participants to answer questions and interact with others (see Figure 1).The type of post and the content was varied to maximize participants' engagement and interest. Participants were encouraged to interact with the facilitator's posts and contribute their own posts to the group. The facilitator ensured that her responses to participants' posts were consistent (ie, liking posts).

Self-Directed Running Program (Control Condition)

Participants randomized to the control condition were given a self-directed running program only to follow (individually) and did not have access to the Facebook group. The running program, which was provided in its entirety, was posted to participants in the form of an A4 sized fridge magnet (see Figure 2) and included the same running program structure as for the UniSA Run Free group, with participants encouraged to tick off sessions as they were completed.

Participants in the intervention and control conditions commenced the running program in February 2016.

Experiment Procedure

There were three assessment time points: baseline, 2 months (coinciding with the last week of the running program), and 5 months (3 months post program). All assessments were self-administered and completed remotely (online). Blinding of participants was not possible because of the nature of the intervention. Blinding of assessors was not applicable, as assessments were self-administered.

Outcome Measures

The primary outcomes were self-reported MVPA and cardiorespiratory fitness, and secondary outcomes were self-efficacy, exercise attitudes, and social support. A process evaluation was also undertaken to investigate engagement and feasibility of the UniSA Run Free Facebook program.

Self-Reported Moderate to Vigorous Physical Activity

Self-reported total weekly MVPA was measured via the Active Australia Survey (AAS) [25]. The AAS has been widely used and validated with an Australian population and is comprised of eight questions that measure the frequency and amount of time spent in MVPA within the past 7 days [25]. As per AAS protocol, MVPA was determined by calculating walking time + other moderate activity time + 2 x vigorous activity, with each individual item truncated at a maximum of 840 min per week and total PA truncated at a maximum of 1680 min, to reduce over-reporting [25]. The AAS has been shown to have moderate reliability (rho=.56-.64) and moderate validity compared with pedometry and accelerometry (rho=.43 and rho=.52, respectively) [25,26].

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Figure 1. Examples of the UniSA Run Free Facebook group posts.



Cardiorespiratory Fitness

Cardiorespiratory fitness was measured via the YMCA step test [27]. Laboratory-based testing is considered to be the gold standard for measuring cardiorespiratory fitness; however, this requires sophisticated equipment, is time-consuming, and expensive. Submaximal tests such as the YMCA step test have been designed to be self-administered in free-living conditions (as per this study) and have been found to be a valid (r=.61, compared with laboratory VO_2 max testing [25]) means of estimating cardiorespiratory fitness [28].

This YMCA step test requires participants to step up and down continuously on a 30-cm step for 3 min and at completion, measure their heart rate (total beats in a 60-sec period). To ensure that participants followed the correct procedure, a YouTube clip guiding participants through the YMCA step test was specifically created for the purpose of this study [29], and participants were provided with instructions for measuring radial artery heart rate.

Secondary Outcomes

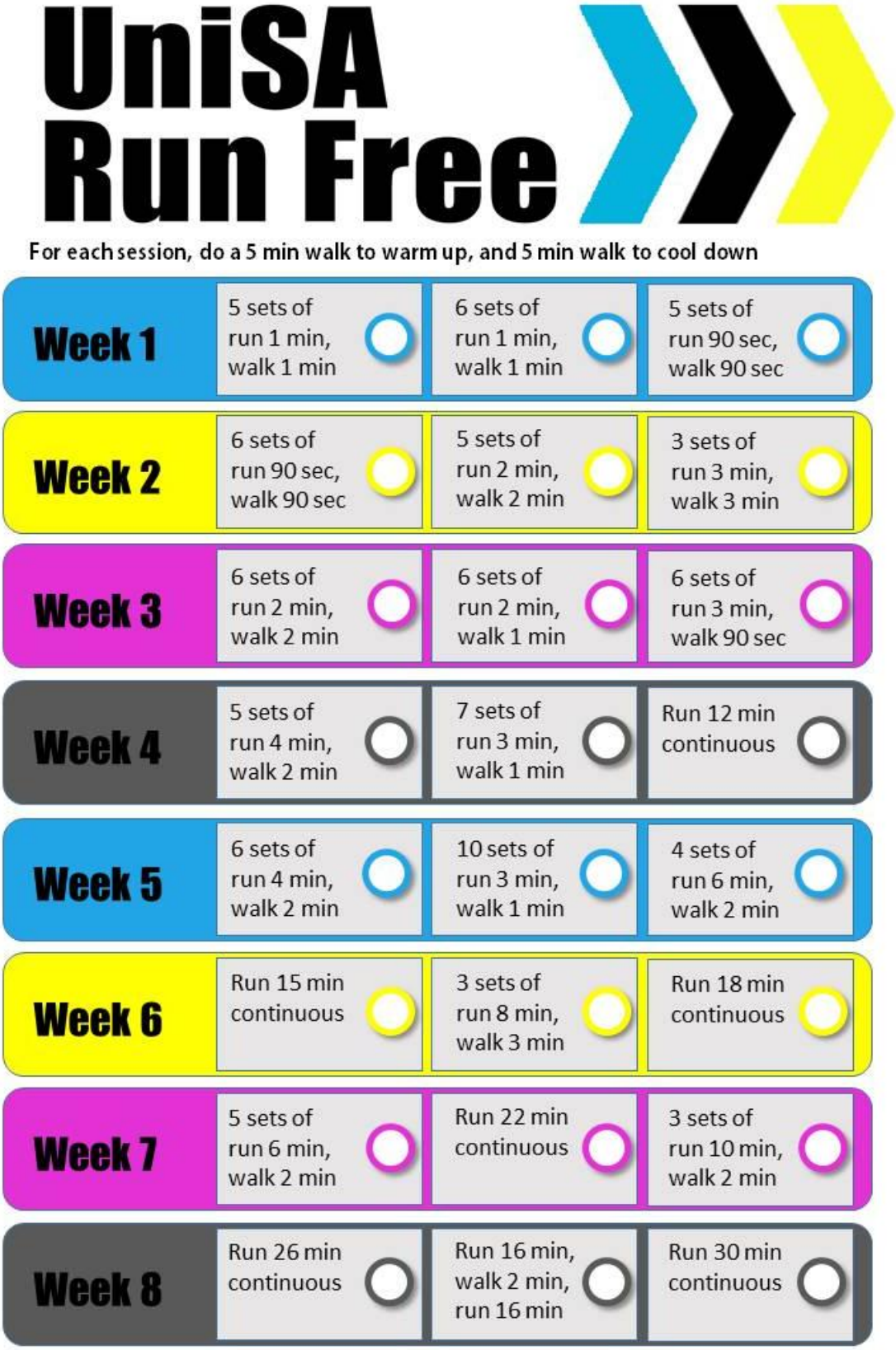
SCT was used to guide the intervention design; therefore, the secondary outcomes were selected to measure these constructs (self-efficacy, attitudes, and social support). The Self-Efficacy Barriers to Exercise Measure comprises of 13 statements asking participants to rank how confident they felt in continuing to exercise when certain issues occurred [30]. The internal consistency of this measure is 0.93 [30]. As per standard procedure, the Self-Efficacy Barriers to Exercise Measure was scored by adding the ratings for each response and dividing the sum by 13 [31].

The Exercise Attitude Questionnaire-18 consists of 18 statements, where participants rank their attitude to exercise on a 5-point Likert scale [32]. Internal consistency of this instrument is 0.74 and test-retest reliability intraclass correlation coefficient=0.90 [32]. As per guidelines, all negative statement scores were reversed and all results calculated based on the mean score, giving a score ranging from 0 to 100 [33].

The social support and exercise survey was used to evaluate the amount of social support participants received in regards to their PA [34]. It includes 13 questions where participants rank their experiences on a 5-point Likert scale (none to very often). Internal consistency of the combined family and friends score is 0.79 [34]. The scale is scored by calculating the sum of all items [34].

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Figure 2. Running program A4 size fridge magnet.



The following baseline demographic characteristics were also collected: age (years), weight (kg), height (cm), and highest level of education (high school, technical and further education certificate or diploma, or a university degree or higher).The self-reported height and weight information was used to calculate participants' body mass index (BMI). BMI was categorized into the following: underweight (<18.5 kg/m^2), normal (18.5 to <25.0 kg/m^2), overweight (25.0 to <30.0 kg/m^2), and obese (≥30.0 kg/m^2) [35].

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Process Evaluation

Process evaluation occurred concurrently with the RCT and assessed engagement with and feasibility of the UniSA Run Free program. Participants' compliance with the running program was determined by participants indicating in the 2-month survey the number of running sessions completed. From this, the percentage of completed running sessions was calculated. Intervention participants' engagement with the Facebook group was measured in two ways: (1) the Facebook group page was audited to determine the number of interactions (posts, comments, likes, poll votes, and photos uploaded) per participant and (2) in the 2-month survey, participants were asked to self-report the number of visits to the group page (to capture occasions where the page was viewed without interactions). Additionally, the feedback survey contained seven items regarding the perceived usefulness, relevance, and motivation benefit of the Facebook group.

Statistical Analysis

Participants' baseline characteristics were analyzed descriptively. Changes in primary and secondary outcomes from baseline to the 2- and 5-month assessments were analyzed using random effects mixed modeling. Analyses were conducted using generalized linear mixed models (GLMMs) in Statistical Package for the Social Sciences (SPSS) version 21 (IBM Corp), with the individual entered as a random effect and group, time, and group x time interaction entered as fixed effects. Data analysis was completed on an intention-to-treat basis, where all participants randomized at the commencement of the trial were retained for analysis regardless of compliance [36]. The GLMM function is able to handle missing data; therefore data imputation was not needed. Effect size differences between groups at 2 and 5 months were calculated using Cohen *d* [37].

Compliance and engagement with the UniSA Run Free program were described descriptively. A subgroup analysis using GLMM was undertaken within the UniSA Run Free group to determine if change in MVPA was related to key sociodemographic characteristics (age and sex), baseline characteristics (BMI, fitness, and MVPA), as well as compliance with the running program and engagement with the Facebook group (ie, liking or commenting on the facilitators posts). For these analyses, the predictor variables were dichotomized into high and low categories based on the median splits. Specifically, compliance was categorized into high (≥70% of running sessions completed) and low (<70%), fitness categorized into high (<100 beats per minute, BPM) and low (≥100 BPM), engagement into high (≥15 interactions) and low (<15 interactions), BMI into high (≥25 kg/m^2) and low (<25 kg/m^2), and age into older (≥35 years) and younger (<35 years). Baseline PA was dichotomized on the basis of meeting the PA guidelines (≥150 weekly minutes) and failing to meet guidelines (<150 weekly minutes).

A priori sample size calculations suggested that a sample of 114 participants would be sufficient to detect a moderate effect size (*d*=0.4), assuming a two-group design with three repeated measures, 80% power, and an alpha of .05. Because the study was conducted in the context of a student research project, there were time constraints on participant recruitment. A total of 89 participants were recruited with post-hoc power analyses, suggesting that this sample had 64% power to detect effect size differences of *d*=0.4.

Results

Participants

A total of 210 potential participants registered their interest in the study; however, only 89 met the participant criteria and completed baseline assessment and were therefore formally enrolled. Of these 89 participants, 41 (46%) were randomized to the intervention group and 48 (53%) to the control group (based on the computer generated number sequence). Three-quarters (78% [69/89]) completed the 2-month assessments, whereas two-thirds (65% [58/89]) completed the 5-month assessments.

Twelve participants formally withdrew from the study for various reasons, as listed in Figure 3.

Participants' demographic and baseline characteristics are given in Table 1. Of the 89 participants, 71 (80%) were female, and the mean age was 35.2 years (SD 10.9). Overall, 37 participants (42% [37/89]) were within the normal BMI range [35], 28 were overweight (32% [28/89]), and 23 were obese (26 [23/89]). A total of 65 participants (73% [65/89]) were currently undertaking or had completed a university degree or higher. Participants reported getting a mean of 318 min (SD 278) of MVPA per week.

Primary and Secondary Outcomes

The results for the primary and secondary outcome measures are shown in Table 2.

Self-Reported Moderate to Vigorous Physical Activity

There was a significant increase over time in MVPA in both the intervention and control groups (time effect *P*=.004). However, the increase was considerably larger in the intervention group (group x time effect of *P*=.04). From baseline to 2 months, the UniSA Run Free group increased their weekly MVPA by a mean of 140 min per week (SE 50 min), whereas the control group increased by 91 min (SE 47 min), equating to a between group effect size difference of *d*=1.01 in favor of the intervention group. At 5 months, the intervention groups' MVPA remained elevated by a mean of 129 min per week (SE 49 min) compared with baseline, whereas the control groups' MVPA fell to 50 min (SE 49 min) below baseline values. This equated to a between group effect size difference of *d*=3.65.

Cardiorespiratory Fitness

There was a nonsignificant trend for both groups to improve their cardiorespiratory fitness, denoted by a suggested decrease in mean BPM over time (time effect *P*=.12). However, there were no group by time differences (*P*=.76).

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Figure 3. Participant flow through the study.

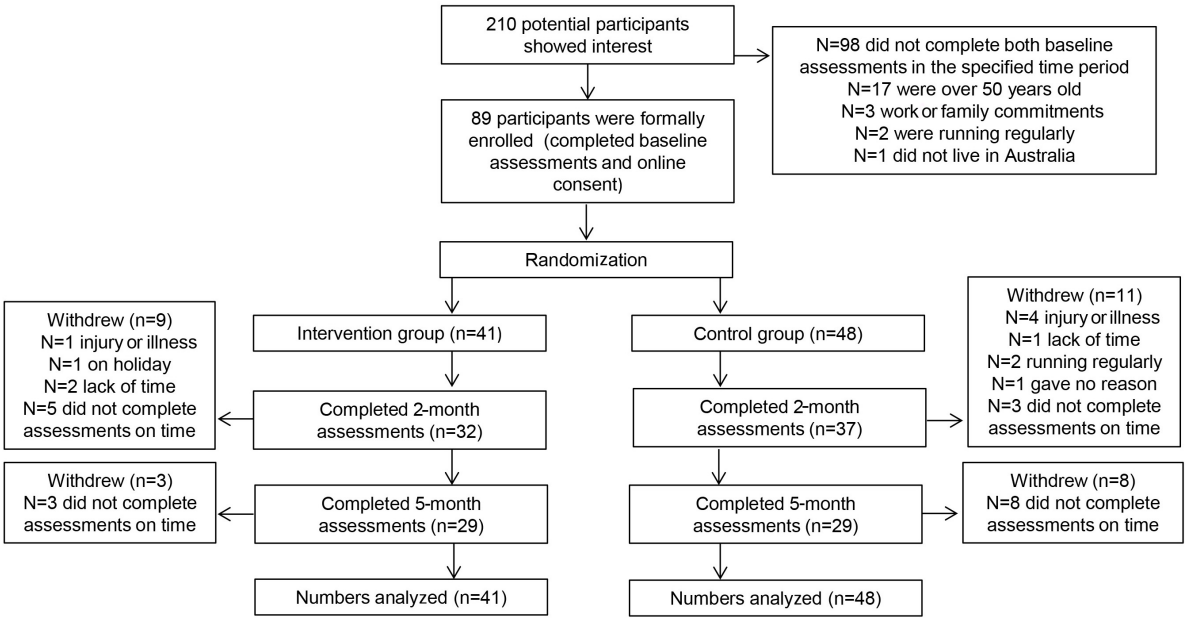


Table 1. Descriptive characteristics of the study sample at baseline (n=89). Arrows (↑ or ↓) indicate the desirable direction for each of the outcome measures.

Baseline characteristics	Control (n=48)	Intervention (n=41)
Age in years, mean (SD)	35.1 (10.9)	35.3 (11.2)
Gender, n (%)		
Male	14 (29)	4 (10)
Female	34 (71)	37 (90)
Highest level of Education, n (%)		
High school	6 (13)	2 (5)
Diploma or technical and further education certificate	13 (27)	3 (7)
University degree or higher	29 (60)	36 (88)
Fitness, mean (SD) ↓	103 (26)	105 (27)
BMI[a], mean (SD) ↓	26.7 (4.5)	27.6 (5.6)
Self-reported MVPA[b](min/week), mean (SD) ↑	360 (301)	269 (242)
Self-efficacy[c], mean (SD) ↑	42.6 (21.2)	44.9 (23.6)
Exercise attitude, mean (SD) ↑	62.5 (12.2)	62.99 (10.3)
Social support[d], mean (SD) ↑	25.4 (9.7)	23.07 (8.8)

[a]BMI: body mass index.

[b]MVPA: moderate-to-vigorous physical activity.

[c]Self-Efficacy of Barriers to Exercise Measure.

[d]Social support and exercise survey.

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Table 2. Outcome measures at baseline, 2-month follow-up, and 5-month follow-up. Arrows (↑ or ↓) indicate the desirable direction for each of the outcome measures.

Outcome measures	Assessment period, mean (SE)			Treatment effect, effect size (95% CI)		Group-by-time interaction, *F* (*P*)
	Baseline	2 months	5 months	Baseline compared with 2 months	Baseline compared with 5 months	
Self-reported MVPA[a](min/week) ↑						
Intervention	269.0 (47.5)	409.5 (52.0)	398.3 (52.8)	1.01 (.56-1.45)	3.65 (2.94-4.30)	3.39 (.04[b])
Control	359.6 (43.9)	450.8 (48.3)	309.8 (52.1)			
Fitness (BPM[c]) ↓						
Intervention	105.1 (4.2)	100.4 (4.6)	99.6 (4.7)	.08 (−.34 to .50)	−.08 (−.50 to .33)	.27 (.76)
Control	103.2 (3.9)	96.4 (4.3)	100.2 (4.7)			
Self-efficacy[d] ↑						
Intervention	44.9 (3.3)	41.6 (3.7)	44.6 (3.9)	−.20 (−.62 to .22)	.00 (−.42 to .42)	.56 (.58)
Control	42.6 (3.1)	44.3 (3.4)	42.2 (3.8)			
Exercise attitude[e] ↑						
Intervention	63.0 (1.7)	64.4 (1.8)	63.4 (1.9)	−.05 (−.47 to .36)	−.14 (−.56 to .28)	.24 (.79)
Control	62.5 (1.5)	64.4 (1.6)	64.6 (1.8)			
Social support[f] ↑						
Intervention	23.1 (1.5)	27.4 (1.6)	24.0 (1.6)	.41 (−.01 to .83)	.15 (−.27 to .57)	1.87 (.16)
Control	25.4 (1.4)	26.1 (1.5)	24.9 (1.6)			

[a]MVPA: moderate-to-vigorous physical activity.

[b]Indicates statistical significance (*P*<.5).

[c]BPM: beats per minute.

[d]Self-Efficacy of Barriers to Exercise Measure.

[e]Exercise attitude questionnaire.

[f]Social support and exercise survey.

Secondary Outcomes

There were no group by time differences for any of the secondary outcomes (self-efficacy, exercise attitudes, or social support). Both groups significantly improved their social support across the intervention period (time effect *P*=.02), which appeared slightly larger in the intervention group; however, this was not statistically significant (group x time *P*=.16).

Process Evaluation

The process evaluation was completed for n=41 intervention participants and n=48 control participants. The mean number of running sessions reported as completed by the intervention participants was 17.3 (72% [SD 7.2]), whereas the corresponding number for the control group was 14.4 (60% [SD 8.1]) out of a maximum possible 24 sessions.

Six (19%) intervention participants reported visiting the Facebook group at least daily. All remaining participants reported visiting the group between one and six times per week (n=34; 78%), whereas one participant (3%) reported never visiting it.

Engagement with the Facebook group was measured by the total number of interactions per participant in response to posts made by the UniSA Run Free facilitator and those made by other participants over the 8-week program. The mean total number of interactions with the Facebook group was 34.7 (SD 40.7; median 15 [interquartile range 62.3]; range 0-158).This engagement data was positively skewed as eleven out of 41 participants had more than 50 interactions with the Facebook group.

During the 2-month survey, participants in the intervention group were asked to provide feedback on the UniSA Run Free program. Feedback was generally positive, with 63 per cent agreeing that the Facebook group helped them complete the running program. The feedback received about the posts made by UniSA Run Free facilitator was positive, with 75 per cent agreeing that the posts were supportive, and most participants agreed that the posts were relevant (66%) and motivating (66%). In relation to participant-initiated posts, most agreed that the posts were supportive (69%), relevant (59%), and motivating (59%).

Subgroup Analysis

Subgroup analyses was undertaken to determine whether, within the intervention group, changes in MVPA were related to age, sex, highest level of education, percentage of running sessions completed, baseline BMI or fitness, engagement with the Facebook group, and baseline PA. Results showed that

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participants with high overall program compliance increased their MVPA significantly more than the participants with a low compliance (<70%; *P*=.03). In addition, participants who failed to meet PA guidelines at baseline (<150 weekly minutes) increased their MVPA significantly more (*P*=.04). Changes in MVPA appeared unrelated to age (*P*=.90), sex (*P*=.07), education (*P*=.95), baseline BMI (*P*=.89), and baseline cardiorespiratory fitness (*P*=.94).

Adverse Effects

Throughout the 8-week intervention, 5 participants reported adverse events in the form of musculoskeletal lower limb injuries (intervention group n=2 and control group n=3). Three of these participants reported an exacerbation of a pre-existing condition, one participant sustained a knee injury from participating in another activity (nonstudy related), and the remaining participant sustained a new knee injury during a running session. All adverse effects were reported to the University of South Australia Human Ethics Committee.

Discussion

Principal Findings

The key findings of this study was that a beginners' running program delivered via a Facebook group produced sizable and sustained changes in weekly MVPA compared with the same running program delivered in a self-administered format. Both groups reported a significant improvement in social support for PA, and there was a trend for both groups to improve their cardiorespiratory fitness, though this did not reach statistical significance. The running program delivered via Facebook achieved strong engagement, high compliance, and favorable feedback from participants.

Although some previous studies utilizing Facebook groups to deliver PA interventions have reported significant improvements in MVPA over time, to the best of our knowledge, no significant group by time effects have been noted [15,18]. The positive group by time effects for MVPA for this study may be related to a number of factors. First, the Facebook group was used to deliver all of the intervention materials; rather than being a component of a more complex intervention. Second, facilitator posts that varied in content and style were provided daily to encourage participant engagement. Third, the type of posts made, that is, posts containing questions, photos, and humor were guided by previous research, suggesting these post types are associated with higher engagement [38,39].

There was a nonsignificant trend for both groups to improve their fitness across the study period (time effect *P*=.12). Given that the study was underpowered and at risk of type 2 errors, the trend may in fact represent true improvement in fitness. Conversely, it is possible that an 8-week program was not long enough to see significant changes in this outcome. Wenger and Bell [40] suggest that it takes 10 to 11 weeks to improve cardiorespiratory fitness. The YMCA step test was selected, as it is easy for participants to self-administer, relatively safe (being a submaximal test), and can be completed with minimal special equipment. However, it is acknowledged that this is less reliable than laboratory-based cardiorespiratory fitness tests [41].

Relative to other online social networking interventions, participant engagement in UniSA Run Free was high; as indicated by a mean number of 35 (SD 41) total Facebook interactions, 19% of participants visiting the Facebook group daily, and 78% visiting between 1 and 6 times per week. In comparison, Wójcicki and colleagues [42] who investigated the feasibility of an 8-week Facebook group–delivered PA intervention in adolescents, reported low levels of group engagement, with only 27% of participants interacting with the Facebook group. Similarly, Napolitano and colleagues [20] reported only 24% of participants interacting with the Facebook group during an 8-week weight loss intervention. These differences in engagement may be because of the Facebook group being implemented differently in this study. Most other studies have used a Facebook group as a supplement to other intervention materials. In contrast, in our study, the Facebook group was central to the intervention and included all key intervention materials.

Retention rates for this study were also reasonably high at 78% at 2 months and 65% at 5 months. Similarly, high retention rates have been noted in previous Facebook-delivered PA interventions, ranging from 77% [43] to 96% [20]. The high retention rates for this delivery method may be related to its *real life* design, whereby participants can complete the intervention and assessments at home with minimal contact from research personnel, making it less intrusive and easier to fit around daily routines.

Strengths and Limitations

This study had a number of methodological strengths. First, it was a parallel RCT, including intention-to-treat analysis, which is the gold standard in clinical trial design. Second, the comparison group were provided with an alternative intervention (hard copy of the running program), which allowed comparison of the two intervention delivery methods (hard copy vs Facebook group delivery) [44].

High levels of engagement and retention were also strengths and provide evidence of the feasibility of a Facebook group for intervention delivery. Furthermore, this delivery method enabled the intervention to be available to participants living all across Australia, thus, further demonstrating that online social networks have minimal geographic boundaries. Finally, results of the subgroup analyses found that the intervention was more effective in participants who failed to meet the minimum PA guidelines at baseline (150 min per week), indicating that this intervention was successful in assisting those most at risk of physical inactivity.

Key limitations of this study should also be addressed. Due to time restrictions with recruitment, this study was underpowered. Future work is needed to determine the effectiveness of this intervention with a larger sample, particularly for cardiovascular fitness and social support, which showed trends for improvement. Higher baseline MVPA of the control group (90.6 min/week higher than the intervention group) must also be acknowledged because of potential ceiling effect.

For practicality, all outcome measures were self-reported or self-administered. Self-reported measures are typically more

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prone to social desirability bias [45], and the self-administered nature of the step test reduces the ability to standardize test conditions and accuracy of heart rate measurement. In addition, determining participants' social networking use (ie, frequency) at baseline would be beneficial as this may influence engagement and health behavior outcomes.

Finally, the somewhat homogenous nature of this sample (female and highly educated), which is typical of volunteer research studies, is also acknowledged [46,47]. This, along with the high baseline MVPA levels (for both groups), warrants caution in generalizing results. Further research is required to investigate the effectiveness of this intervention with other population subgroups (eg, teenagers and individuals over 50 years).

Conclusions

Previous research has found modest evidence supporting Facebook groups as a delivery method for PA interventions. Many previous studies have offered additional intervention materials and resources, making it difficult to disentangle the effectiveness of the online social networking component. Therefore, this study addressed the effectiveness of an 8-week beginners' running program delivered entirely through a Facebook group in improving PA and cardiorespiratory fitness. Significant improvements were found in both groups at 2 months in MVPA; this increase was considerably larger in the intervention group (P=.04). Engagement with the Facebook group was relatively high compared with other online interventions. Further research is warranted to investigate the effectiveness of this delivery method in other health-related behaviors and with other population groups. The ease of use, low cost, and accessibility of a Facebook group make it a promising method for delivering socially supportive health and behavioral programs on a mass scale.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

CONSORT - EHEALTH checklist (V 1.6.1).

[PDF File (Adobe PDF File), 2MB - jmir_v20i2e67_app1.pdf]

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Abbreviations

AAS: Active Australia Survey
BMI: body mass index
BPM: beats per minute
GLMM: generalized linear mixed model
MVPA: moderate to vigorous physical activity
PA: physical activity
RCT: randomized controlled trial
SCT: social cognitive theory

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Original Paper

A Novel Approach for Fully Automated, Personalized Health Coaching for Adults with Prediabetes: Pilot Clinical Trial

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Abstract

Background: Prediabetes is a high-risk state for the future development of type 2 diabetes, which may be prevented through physical activity (PA), adherence to a healthy diet, and weight loss. Mobile health (mHealth) technology is a practical and cost-effective method of delivering diabetes prevention programs in a real-world setting. Sweetch (Sweetch Health, Ltd) is a fully automated, personalized mHealth platform designed to promote adherence to PA and weight reduction in people with prediabetes.

Objective: The objective of this pilot study was to calibrate the Sweetch app and determine the feasibility, acceptability, safety, and effectiveness of the Sweetch app in combination with a digital body weight scale (DBWS) in adults with prediabetes.

Methods: This was a 3-month prospective, single-arm, observational study of adults with a diagnosis of prediabetes and body mass index (BMI) between 24 kg/m^2 and 40 kg/m^2. Feasibility was assessed by study retention. Acceptability of the mobile platform and DBWS were evaluated using validated questionnaires. Effectiveness measures included change in PA, weight, BMI, glycated hemoglobin (HbA_{1c}), and fasting blood glucose from baseline to 3-month visit. The significance of changes in outcome measures was evaluated using paired *t* test or Wilcoxon matched pairs test.

Results: The study retention rate was 47 out of 55 (86%) participants. There was a high degree of acceptability of the Sweetch app, with a median (interquartile range [IQR]) score of 78% (73%-80%) out of 100% on the validated System Usability Scale. Satisfaction regarding the DBWS was also high, with median (IQR) score of 93% (83%-100%). PA increased by 2.8 metabolic equivalent of task (MET)–hours per week (SD 6.8; *P*=.02), with mean weight loss of 1.6 kg (SD 2.5; *P*<.001) from baseline. The median change in A_{1c} was −0.1% (IQR −0.2% to 0.1%; *P*=.04), with no significant change in fasting blood glucose (−1 mg/dL; *P*=.59). There were no adverse events reported.

Conclusions: The Sweetch mobile intervention program is a safe and effective method of increasing PA and reducing weight and HbA_{1c} in adults with prediabetes. If sustained over a longer period, this intervention would be expected to reduce diabetes risk in this population.

Trial Registration: ClincialTrials.gov NCT02896010; https://clinicaltrials.gov/ct2/show/NCT02896010 (Archived by WebCite at http://www.webcitation.org/6xJYxrgse)

(J Med Internet Res 2018;20(2):e72) doi:10.2196/jmir.9723

KEYWORDS

mobile health; prediabetes; HbA 1c; weight loss; blood glucose

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Introduction

Scope of the Problem

Prediabetes, a high-risk state for future type 2 diabetes, is a global epidemic with increasing prevalence in both developing and developed countries [1]. Among adults, the prevalence of prediabetes in the United States, the United Kingdom, China, and India is 33.9%, 35.3%, 35.7%, and 10.3%, respectively [2-5]. Considering that the complications associated with type 2 diabetes begin at the prediabetes stage [6] and that more than half of individuals with prediabetes will eventually develop diabetes [7], efforts are urgently needed to intervene on this high-risk population. Regular physical activity (PA; 150 min per week), weight loss, and healthy diet are highly effective strategies for preventing or delaying the onset of type 2 diabetes [8-10]; however, randomized controlled trials (RCTs) of these interventions have required intensive one-on-one or group lifestyle coaching, which raises questions about the feasibility and scalability of implementing these interventions outside of research settings. For example, the landmark Diabetes Prevention Program (DPP), which consisted of a 16-session individual curriculum over 6 months in addition to supervised group exercise sessions, had estimated direct costs of approximately US $1400 per person annually (of which more than half of the cost was for staffing) [10,11].

Mobile health (mHealth) technologies potentially represent an ideal method to deliver diabetes prevention interventions on a large scale given the ability to reach sizable numbers of patients at substantially lower costs than human-based interventions. Various digitally supported interventions have been used for diabetes prevention and weight loss, including email, voice calls, SMS text messaging (short message service, SMS), Web-based applications, mobile apps, activity monitors, and telemedicine [12]. In fact, the Centers for Disease Control and Prevention (CDC) has recently started to recognize virtual programs as valid DPPs [13]. Most of these programs, which have shown promise in diabetes prevention, have required either in-person training [14] or have a major component of human coaching [15,16], which limits scalability and long-term adherence, as interventions that rely on human coaching require substantial human resources and professional training, as well as sustained time commitment on the part of participants.

Study Intervention

Sweetch is a fully automated, personalized, artificial intelligence-based mHealth platform (Sweetch Health, Ltd) designed to promote adherence to PA, weight reduction, and diet guidelines for people with prediabetes. To sustain healthy life habits, Sweetch uses artificial intelligence (machine learning) to automatically translate various raw mobile phone data streams into insights about the user's life habits. Completely free of human involvement, Sweetch presents personalized, contextual, just-in-time, just-in-place recommendations with the goal of guiding the user toward achieving his or her desired activity and weight reduction goals.

The Sweetch mobile platform is designed to initially address adherence to the PA component of diabetes prevention strategies, and as participants comply with the PA goal, a weight reduction goal is subsequently introduced. Evidence suggests that PA alone, independent of weight loss or adherence to dietary recommendations, is an effective diabetes prevention strategy. Large RCTs have shown that diabetes risk is (1) reduced substantially for participants who meet exercise goals even if failing to meet weight loss or diet goals [17], (2) is comparable in participants who meet exercise goals and those who meet both diet and exercise goals [8], and (3) that leisure time PA (LTPA) is associated with resolution of the metabolic syndrome [18]. A large systematic review of 300,000 participants revealed a 30% lower relative risk of type 2 diabetes in those with regular PA (defined as walking for 150 min per week at a brisk pace) compared with almost no walking, an association that persisted even after adjustment for body mass index (BMI) [19].

Study Objectives

The objective of this pilot study was to determine the feasibility, acceptability, safety, and effectiveness of the Sweetch app in combination with a digital body weight scale (DBWS) in adults with prediabetes. As the Sweetch app is fully automated, a major objective of the pilot study was to calibrate the system (ie, explore which recommendation types work best and in what context). We hypothesized that the Sweetch intervention would result in clinically meaningful improvements in LTPA and body weight and potentially improvements in glycemic control over the follow-up period.

Methods

Study Design

This was a 3-month single arm, prospective, observational study conducted at two clinical sites within the Johns Hopkins Clinical Research Network: Johns Hopkins Hospital, a tertiary care academic medical center in Baltimore, Maryland, and a community internal medicine practice within the Reading Health System in Reading, Pennsylvania conducted from October 10, 2016 to November 17, 2017. The study was approved by the institutional review boards (IRBs) of both institutions, and written informed consent was obtained from all participants. The clinical trial was registered on ClinicalTrials.gov (NCT02896010).

Initially, the study was designed as an RCT with two arms, in which participants were assigned to receive either the Sweetch app alone or the Sweetch app in combination with a DBWS. Early on in the trial, it became clear that inclusion of the DBWS was necessary for the purpose of app calibration, as this allowed real-time correlation of weight data with PA measures; therefore, the design was revised to a single-arm observational study in which all subsequently enrolled participants were assigned to receive the Sweetch app and a DBWS. At the time of IRB approval of this change in the study design (February 7, 2017), 14 participants had received the app alone and were continued in the study according to their initial treatment assignment.

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Textbox 1. Eligibility criteria for participants in the study.

Eligibility criteria

- Carried a diagnosis of prediabetes (at least one of the following diagnostic criteria: impaired fasting glucose confirmed by a fasting glucose 100-125 mg/dL, impaired glucose tolerance confirmed by a 2-hour glucose of 140-199 mg/dL following a 75-gram oral glucose tolerance test, or glycated hemoglobin [HbA_{1c}] 5.7% to 6.4%)
- Had a body mass index (BMI) between 24 to 40 kg/m^2 or 22 to 40 kg/m^2 for Asian individuals
- Were English speaking
- Had a mobile phone (Android or Apple 5S and above)

Textbox 2. Exclusion criteria for participants in the study.

Exclusion criteria

- Any medical condition that prevented adoption of moderate intensity physical activity (defined as inability to walk at a 15-20 minute mile pace)
- Body weight >400 lb (as this weight exceeded the upper limit of the digital body weight scale)
- Any diagnostic criterion for diabetes mellitus
- Use of any glucose-lowering medication or weight-loss medication within the previous 3 months
- Current use of systemic glucocorticoids
- Use of antipsychotic medications
- Elevated liver enzymes (3 times upper limit of normal)
- Conditions that can result in spurious A_{1c} readings (eg, anemia or hemoglobinopathy)
- Severe mental illness or learning disability
- Current participation in another clinical trial

Participants

Participants were recruited via various methods including clinician referral, chart review, on-site advertisements, flyers or posters, and social media advertisements. Textboxes 1 and 2 show the inclusion and exclusion criteria for participants in the study.

These exclusion criteria were selected because of the potential confounding effect they could have on glycemic control during the study. Participants who met the above criteria were subsequently screened by laboratory testing (if lab results were not available within 14 days before screening) and vital signs to confirm eligibility. An enrollment target of 50 participants was selected based on convention, as enrollment numbers of 50 to 100 participants are typical in pilot studies of exercise or weight loss interventions.

Study Procedures

Participants who met the eligibility criteria were invited to return for a baseline visit within 14 days, at which time the Sweetch app was downloaded on the participant's mobile phone, and the participant was registered within the app. If the participant was assigned to receive the DBWS, it was provided and synchronized to the Sweetch app.

Following this baseline visit, the participant returned to the clinic in 90 days (window of 76-120 days) for the final visit, at which time repeat laboratory tests (A_{1c} and fasting glucose) and vital signs were collected, and usability or satisfaction questionnaires were administered. Participants who developed any of the exclusion criteria after enrollment, logged out of the app, or removed the app from their mobile phone for a period of at least 14 consecutive days were dropped from the study, as data could not be collected from those participants. As it was not known a priori whether this intervention would be effective for reducing risk in adults with diabetes, from an ethical standpoint, all participants were referred to a local registered dietician (RD), who was also a certified diabetes educator (CDE), to receive lifestyle counseling at the baseline visit. In addition, a 1-page brochure related to diabetes prevention was provided.

Demographic information, past medical history, and medications were collected from participants at the baseline visit. A 5-item mobile phone usage and attitudes survey, adapted from the mobile phone domain of the Media and Technology Usage and Attitudes Scale [20], was administered at baseline (Multimedia Appendix 1). To assess the participant's willingness to increase PA, a 4-item Physical Activity States of Change Questionnaire [21] was administered electronically upon participant's registration within the app. Responses to this questionnaire are scored as previously described to classify the participant's baseline PA stage of change category (precontemplation, contemplation, preparation, decision or action, and maintenance).

Biometric measures including blood pressure, height, weight, and waist circumference were measured at the baseline and final visits. Although most participants received a DBWS, only clinic-based weight measurements were used as outcome

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measures. Waist circumference was measured using a flexible measuring tape according to the technique recommended by the American Society for Nutrition [22]. Blood pressure was measured in accordance with recommendations by the American Heart Association [23]. A_{1c} and glucose measurements were obtained via a central laboratory serum specimen. Fasting glucose measurements were obtained after participant reported a minimum of 8 hours fast.

Description of Sweetch Mobile Platform

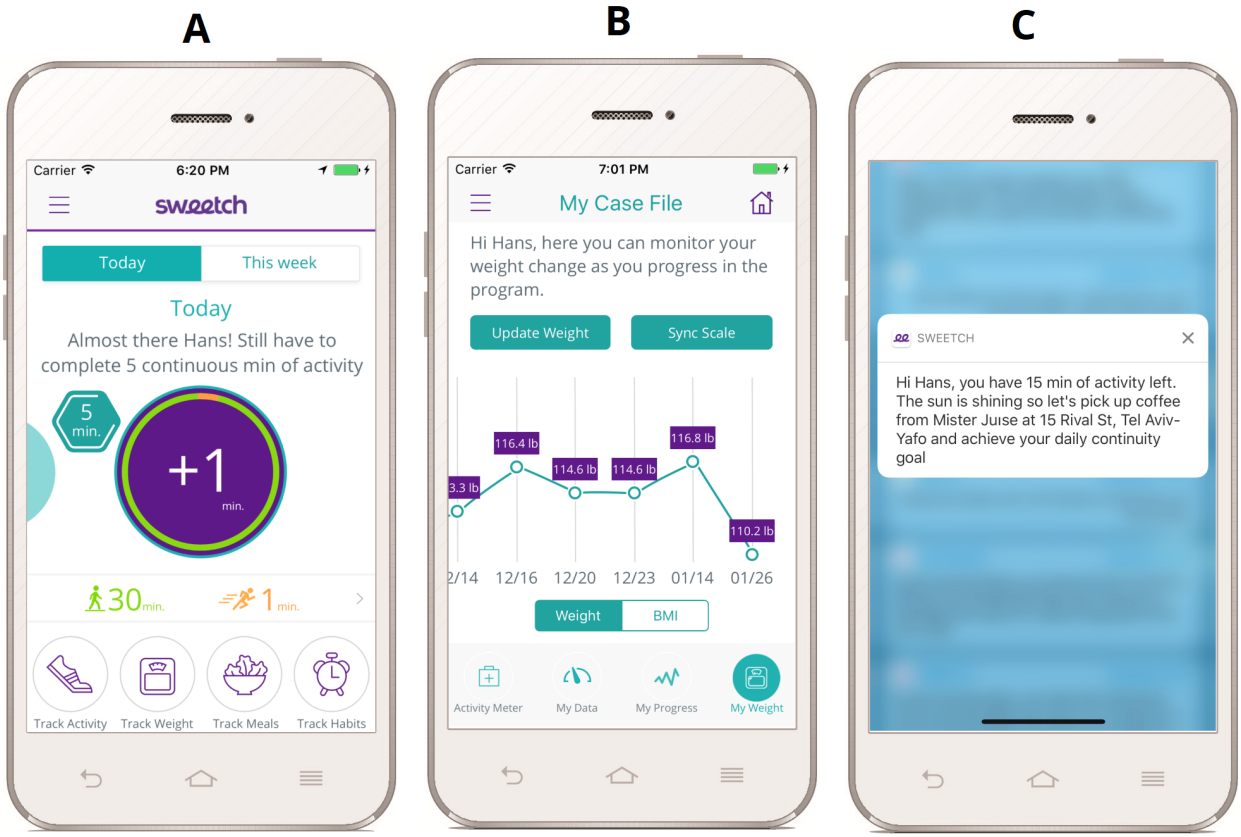
Sweetch is a personal digital intervention program that seeks to help individuals lose weight and become more active with the goal of reducing their long-term risk of diabetes and other conditions associated with the metabolic syndrome. Sweetch's core philosophy is that each individual has his or her own life habits, motivations, and pace of behavioral-change progress; therefore, generic recommendations to walk 10,000 steps or for 30 min a day and eat less carbohydrates may not produce sustainable and meaningful behavioral change for all individuals, especially in the long run. Sweetch uses machine learning to automatically translate raw data streams originating from the patient's mobile phone and DBWS into insights about the individual's life habit—schedule, activity patterns, driving and walking routes, surroundings, and more. Then, using advanced algorithms, Sweetch presents the user with personalized, contextual, just-in-time, just-in-place, recommendations that guide him or her toward achieving recommended activity, weight reduction, and diet goals in a way that fits the user's real-world life habits. Sweetch's technology learns what types of message result in better compliance for the specific user at a specific context (ie, day of week, time, location, effect of consecutive messages of different types, etc).

The Sweetch app translates behavioral change theory [24] into practice by the following means:

- breaking down the target of 150 min of PA per week into small segments throughout the day, making the goals more achievable. These small segments are personalized to each user on an on-going basis.
- providing direct feedback and encouragement when goals are met.
- shaping behavior by identifying and immediately reinforcing the target behavior.
- pointing out opportunities in the user's daily routine for increased LTPA. Notifications constitute "teachable moments" that could result in sustained behavioral change.

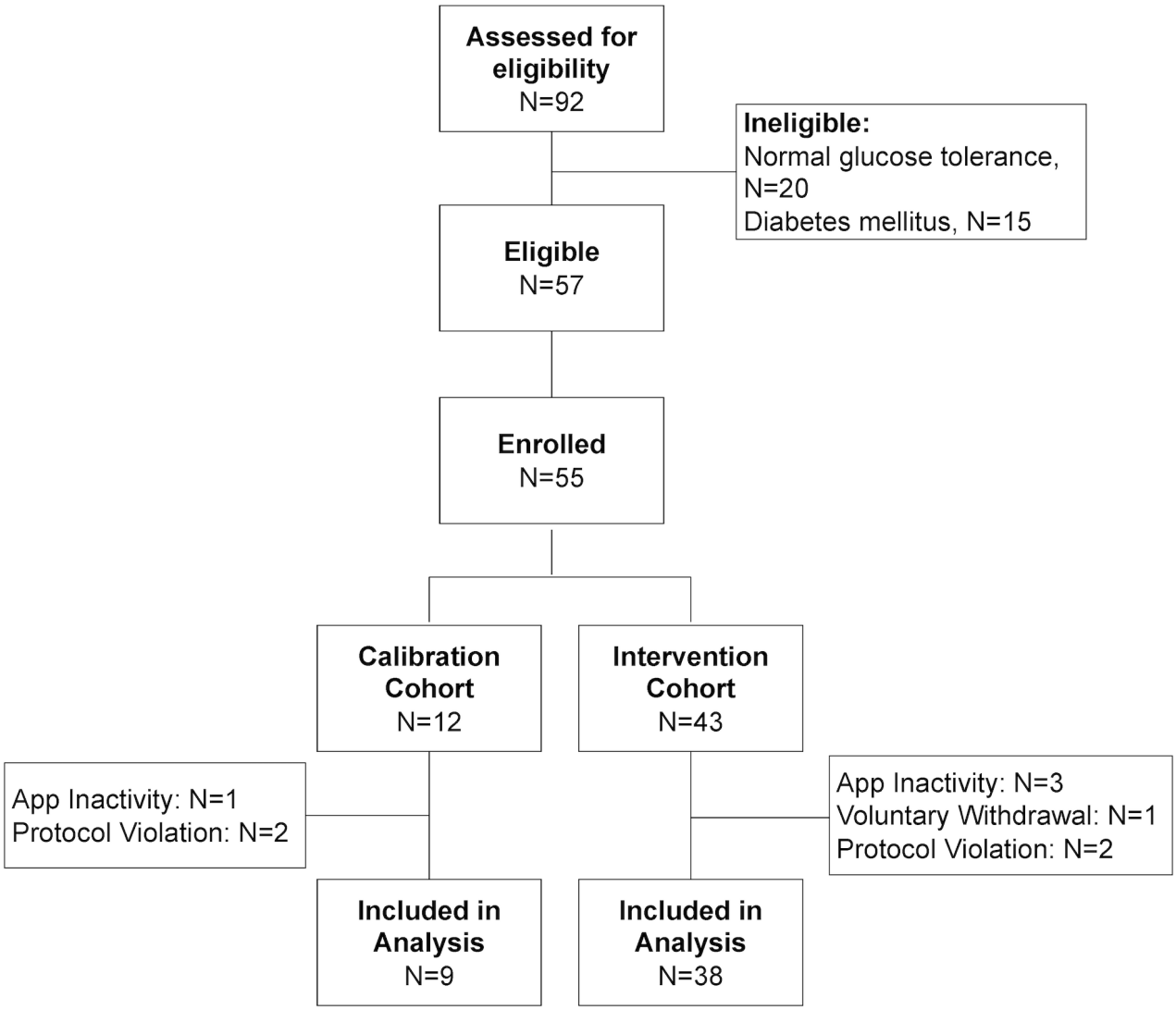
This approach aims for gradual progress, high level of personalization, and long-term adherence. The Sweetch app enables the participant to track activity progress on a daily and weekly view in the app, presenting remaining activity that needs to be completed (Figure 1). Weight change and goals are summarized graphically over time. Personalized push notifications are adapted based on actual life habits and sent to users, providing an actionable recommendation.

Figure 1. Features of Sweetch app. A. Activity Tracking on daily and weekly view, presenting remaining activity to be completed. B. Weight changes summarized graphically. C. Personalized push notification adapted based on actual life habits.



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Figure 2. Study enrollment flowchart.



The novelty of the Sweetch mobile platform is that it optimizes, in real time and using fully automated algorithms, the messages each user gets so to achieve best possible compliance. Similarly, the personalized goals are continuously adapted based on the user's real-world behavior to best fit the user's real-life capabilities. The Sweetch app uses a passive assessment approach to provide tailored recommendations with minimal or no engagement on the part of the user. A few examples of Sweetch's tailored recommendations include (1) notifying the user to do activity only when the user's calendar indicates available time, (2) recommending specific activity based on the user's surrounding locations (park, coffee shops, etc) as reflected by the user's real-time location, (3) sending weight notifications only when the user is at home, and (4) varying notification elements (positive, social, etc) in different sequences based on the user's real-world reaction to different timing and types of messages.

Digital Body Weight Scale

The Sweetch app communicates with a commercially available Bluetooth-enabled digital scale with a body composition analyzer (Shenzhen Unique, Ltd; Model No. CF369). The DBWS syncs weight data to the Sweetch app using Bluetooth technology (BLE 4.0) and supports communication from Android and iPhone operating system (iOS, Apple Inc) mobile phones.

Calibration and Intervention Cohorts

This pilot study consisted of two cohorts: a calibration cohort and an intervention cohort (Figure 2). The earliest participants enrolled in the study were entered in a calibration cohort. Raw mobile phone data and weight measurements obtained from the DBWS were correlated with the clinic-based outcomes from the initial participants (weight change and change in glycemic measures) to continually adjust metrics of relevant PA that corresponded to the greatest improvements in body weight and glycemic measures. In addition, several refinements were made in the app during the calibration period, including the incorporation of the participant's calendar data (indicating available time for PA), enhancing the sensitivity of the PA tracking, taking into consideration varying definitions of continuous activity as indicators of effective activity, and increasing app availability during different operating system modes (eg, suspended and terminated). An enhanced version

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was developed based on outcomes and usability or satisfaction responses of participants in the calibration cohort. In the analysis, any participant who received this enhanced version for 50% or more of their time in the trial was considered part of the intervention cohort.

Outcome Measures

This pilot study evaluated measures of feasibility, acceptability, effectiveness, and safety. Feasibility was assessed by retention, defined as the proportion of enrolled participants who completed and adhered to the study protocol. Acceptability was evaluated at the final visit using a 10-item questionnaire with Likert scale responses regarding the Sweetch app, a six-item questionnaire regarding the DBWS, and a two-item questionnaire comparing the perceived benefit of the app with the DBWS on attainment of weight loss and PA goals. The app questionnaire was adapted from the validated System Usability Scale (SUS), a quick and reliable tool to evaluate a wide variety of technological products, including mobile devices [25]. The responses to the app questionnaire were rescored from 0 to 100, and a median score above 68 was deemed a priori to indicate above average user acceptability. The six-item questionnaire for the DBWS was developed specifically for this study. Responses were rescored from 30 to 100, and a median score of 68 and above was considered acceptable. The two-item questionnaire had four categorical responses comparing the app with DBWS on attainment of weight loss and activity goals. Satisfaction scores are reported for all participants who completed the study per protocol.

Effectiveness measures included changes in PA, weight, BMI, A_{1c}, fasting glucose, and blood pressure. PA was evaluated using metabolic equivalent of task (MET)–hours, which was the same metric used in the DPP. MET-hours were calculated as the product of the duration and type of PA, weighted by an estimate of the metabolic equivalent of that activity, and summed per week, with the result expressed as the average MET-hours per week. Unlike the DPP, which used self-reported data on PA, calculations of MET-hours were based entirely on data captured automatically by the participant's mobile phone (details provided in Multimedia Appendix 2). Effectiveness measures are reported for the intervention cohort only.

As the Sweetch app aims to increase LTPA and reduce weight gradually, the intervention was not expected to pose any serious risk of adverse events (AEs) for participants. Participants were instructed to call the research coordinator by phone or email in the event of an AE, in which case the principle investigator would contact the participant for details and adjudicate whether the event was related or unrelated to the intervention. At the final visit, participants were asked about any new medical problems or hospitalizations experienced during the study, whether they believed these to be related to the intervention, and the reasons why.

Statistical Analysis

As this was a pilot study, formal sample size calculations were not performed. Participant data were statistically analyzed using Stata statistical software: release 13 (StataCorp LP). Summary statistics describing the baseline demographic characteristics, PA stage of change, and mobile phone usage attitudes score are provided in Table 1, with results reported for all enrolled participants and separately for the calibration and intervention cohorts. Normality of continuous variables was assessed using the Shapiro Wilk test. For normally distributed and nonnormally distributed continuous variables, respectively, mean (standard deviations) and median with interquartile range (IQR) are reported. Counts and frequencies are reported for categorical variables.

To estimate the statistical differences between the pre- and postintervention measurements in the intervention cohort, paired *t* test and Wilcoxon matched pairs (signed-rank) test were used for normally distributed and nonnormally distributed continuous variables, respectively (Table 2). A two-tailed *P* value <.05 was considered statistically significant. Change in PA (MET-hours per week) was calculated by subtracting the participant's mean MET-hours per week of the last 2 full weeks on study from the mean MET-hours per week of the first full 2 weeks on study (weeks 2 and 3). For all other continuous outcome measures, the change from baseline was calculated by subtracting the value of the baseline visit from the final visit. For normally distributed variables (PA, weight, BMI, and waist circumference), the mean and SDs are reported for the baseline visit and final visit, and statistical significance in the mean of the paired differences (change from baseline) was evaluated using the paired *t* test. For nonnormally distributed variables (A_{1c}, fasting glucose, systolic blood pressure, and diastolic blood pressure), the median and IQR are reported for the baseline and final visits, and statistical significance in the median of the paired differences (change from baseline) was evaluated using the Wilcoxon matched pairs test. Percentage weight change was calculated by subtracting the weight at the final visit from the weight of the baseline visit, dividing by the weight of the baseline visit and multiplying by 100%. Summary responses to the app SUS (Figure 3) and DBWS SUS (Figure 4) are reported for study completers (in both calibration and intervention cohorts) as proportions of responses within each Likert category for each item in the questionnaire. The total score for these usability scales were calculated as described above and reported as medians with IQR.

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Table 1. Baseline characteristics of study participants. Data reported for means (standard deviation) or median (interquartile range [IQR]).

Characteristics	Enrolled (N=55)	Calibration cohort (N=9)	Intervention cohort (N=38)
Gender, n (%)			
Male	22 (40)	4 (44)	14 (37)
Female	33 (60)	5 (56)	24 (63)
Age (years), mean (SD)	55.0 (10.6)	57.6 (0.9)	57.2 (−9.1)
Weight, kg, mean (SD)	92.47 (17.7)	92.1 (22.9)	92.6 (17.2)
BMI[a] (kg/m^2), n (%)			
25-30	5 (9)	2 (22)	2 (5)
30-35	14 (26)	3 (33)	10 (26)
35-40	36 (65)	4 (45)	26 (69)
Waist circumference, cm, median (IQR)	106.7 (97.8-15.0)	100.3 (87.6-104.1)	108.2 (100.0-116.8)
A_{1c}, %, median (IQR)	6.0 (5.7-6.2)	5.7 (5.7-6.0)	6.0 (5.7-6.2)
Fasting glucose, mg/dL, median (IQR)	102 (97-109)	98 (94-109)	105 (98-111)
Race, n (%)			
Black	14 (25)	5 (56)	7 (18)
White	39 (71)	4 (44)	31 (82)
Other	2 (4)	0 (0)	0 (0)
Education attainment, n (%)			
Less than high school	2 (4)	0 (0)	2 (5)
High school graduate	8 (14)	0 (0)	7 (18)
Some college	13 (24)	1 (11)	10 (26)
Associates degree	1 (2)	0 (0)	1 (3)
Bachelor’s degree	19 (34)	7 (78)	9 (24)
Advanced degree	12 (22)	1 (11)	9 (24)
Employment status, n (%)			
Part time (<40 hours)	14 (26)	2 (22)	10 (26)
Full time (>40 hours)	27 (49)	3 (33)	21 (55)
Unemployed	3 (5)	3 (33)	1 (3)
Retired	10 (18)	2 (22)	6 (15)
Disabled	1 (2)	1 (11)	0 (0)
Comorbidities, n (%)			
Hypertension	26 (47)	4 (44)	19 (50)
Hyperlipidemia	18 (33)	4 (44)	2 (5)
Hypertriglyceridemia	2 (4)	0 (0)	12 (32)
Mobile phone usage attitudes score[b], median (IQR)	88 (80-100)	88 (80-100)	87 (80-100)
Physical activity stage of change, n (%)			
Precontemplation	0 (0)	0 (0)	0 (0)
Contemplation	30 (54)	7 (78)	19 (50)
Preparation	8 (15)	1 (11)	7 (20)
Decision or action	8 (15)	1 (11)	5 (10)
Maintenance	9 (16)	0 (0)	7 (20)

[a]BMI: body mass index.

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[b]Survey questions in Multimedia Appendix 1.

Table 2. Secondary outcomes in intervention cohort (N=38). Data reported are means (standard deviation) or median (interquartile range [IQR]).

Outcome	Baseline	Final visit	Change from baseline	*P* value[a]
Physical activity, MET[b]-hours/week[c], mean (SD)	14.6 (6.2)	17.4 (8.1)	2.8 (6.8)	.02
Weight, kg, mean (SD)	90.3 (17.2)	88.7 (17.2)	−1.6 (2.5)	<.001
Percentage weight change, mean (SD)	—	—	−1.9 (2.8)	—
BMI[d], kg/m^2, mean (SD)	32.6 (4.5)	31.9 (4.6)	−0.6 (0.8)	<.001
Waist circumference, cm, mean (SD)	109.0 (12.0)	107.6 (12.0)	−1.4 (2.9)	<.01
A_{1c}, %, median (IQR)	6.00 (5.70-6.20)	5.85 (5.70-6.10)	−0.10 (−0.20 to 0.10)	.04
Fasting glucose, mg/dL, median (IQR)	106 (98-111)	102 (97-109)	−1 (−3 to 0)	.59
Systolic blood pressure, mm Hg, median (IQR)	131 (119-143)	129 (118-139)	1 (−10 to 7)	.56
Diastolic blood pressure, mm Hg, median (IQR)	77.5 (71-84)	75 (67-83)	−4 (−7 to 4)	.21

[a]Evaluated using paired *t* test for physical activity, weight, BMI, and waist circumference and Wilcoxon matched pairs (signed-rank) for A_{1c}, fasting glucose, systolic blood pressure, and diastolic blood pressure.

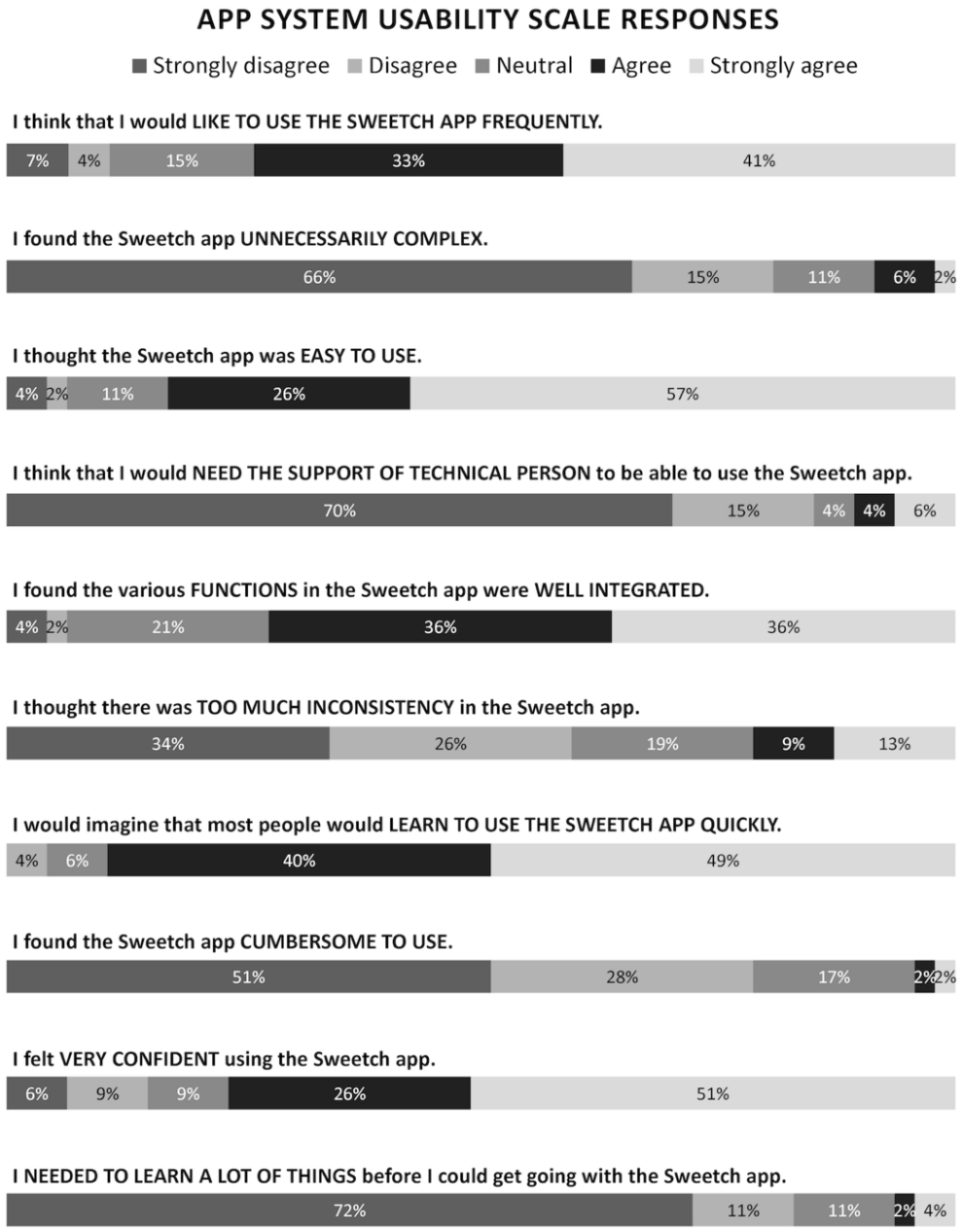
[b]MET: metabolic equivalent of task.

[c]One observation missing from physical activity data because of inaccurate height entry into app by participant, resulting in inaccurate calculations of METs.

[d]BMI: body mass index.

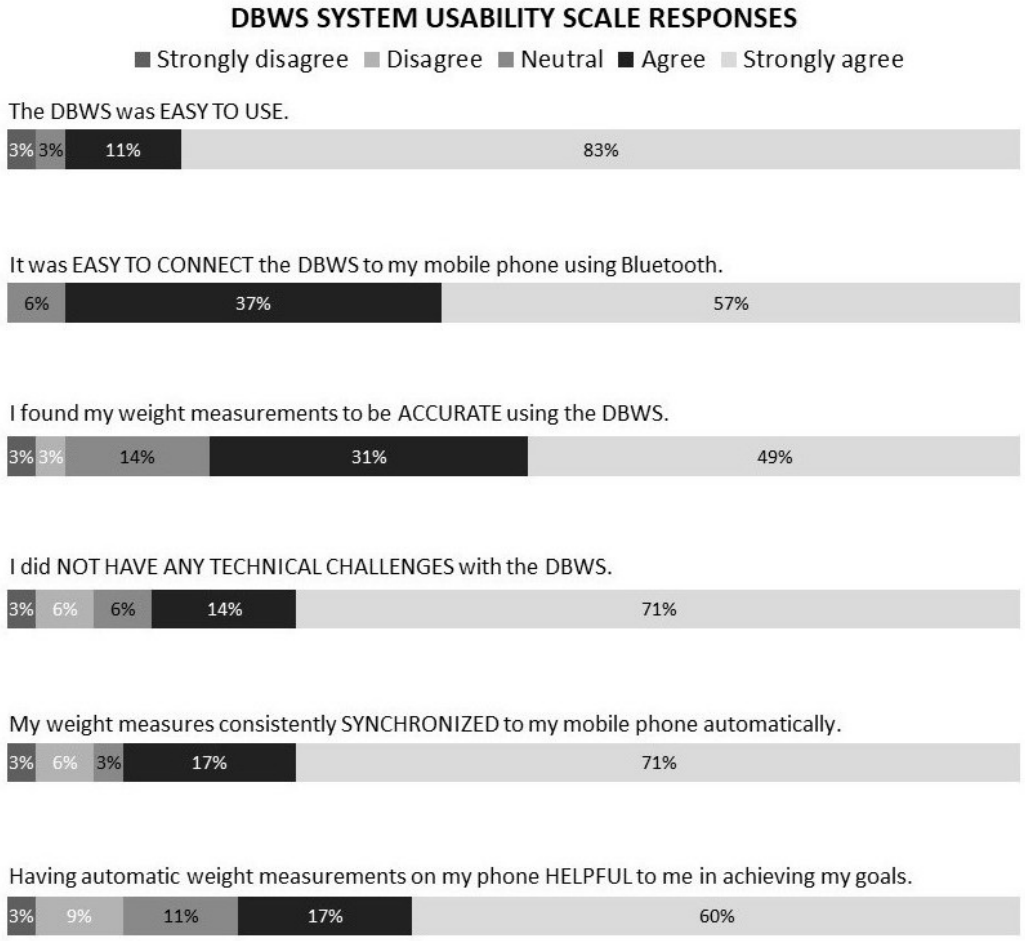
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Figure 3. Sweetch app usability and satisfaction results of participants who completed study per protocol (in both calibration and intervention cohorts, N=47).



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Figure 4. Digital body weight scale (DBWS) usability and satisfaction results of participants who completed study per protocol (in both calibration and intervention cohorts, N=35).



Results

Study Population

Of participants who met the inclusion criteria by prescreening, 92 were assessed for eligibility by laboratory testing (Figure 2). After excluding 35 participants who had either normal glucose tolerance or diabetes mellitus, 57 participants were eligible for the study, of whom 55 (96%) enrolled. Of the 55 enrolled participants, 12 (22%) and 43 (78%) were in the calibration and intervention cohorts, respectively. Of the 12 participants in the calibration cohort, 9 (75%) completed the study according to protocol. One participant was dropped because he was logged out of the app for a period longer than 14 days, and 2 were dropped because of protocol violations (one participant failed to return for final visit, and another's final visit was outside the study window). In the intervention cohort, 38 out of the 43 (88%) participants completed the study. Reasons for dropping out in this cohort included 3 participants that logged out or removed the app, one who voluntarily dropped out, and one protocol violation (torn knee meniscus that limited ambulation; notably, this participant did not attribute the knee injury to increased PA). Among the 55 enrolled participants, 14 (25%) received the Sweetch app alone, and 41 (75%) received the app + DBWS. Among the 47 participants who completed the study per protocol and were included in the analysis, 4 of 9 (44%) in the calibration cohort received both the app + DBWS and 31 of 38 (82%) in the intervention cohort received both the app + DBWS. Thus, 35 of the 47 (74%) study completers received both the app + DBWS.

The baseline characteristics of the study participants are shown in Table 1, summarized for all enrolled participants and separately for the calibration and intervention cohorts. Overall, participants were predominately female (60%), white (71%), middle aged (mean age 55.0 years [SD 10.6]), and obese (91% had BMI ≥30 kg/m^2) adults with prediabetes. The median (IQR) baseline A_{1c} was 6.0% (5.7%-6.2%), and fasting glucose was 102 mg/dL (97-109). The diagnosis of prediabetes was established on the basis of impaired fasting glucose alone for 13/55 (24%), elevated A_{1c} alone for 21/55 (38%), and both criteria for 21/55 (38%) of enrolled participants. There was a high prevalence of cardiovascular risk factors overall, with 47% of participants having hypertension and 33% having hyperlipidemia. The majority (82%) of participants had at least some college education, and 75% were employed at least part time. The median score on the mobile phone usage and attitudes baseline survey was 88%, indicating that the participants had a high level of proclivity with basic mobile phone technology. Regarding PA stage of change, the majority of participants were in the contemplative stage (54%), defined as intending to become physically active in the next 6 months [21].

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Feasibility and Acceptability

With respect to feasibility measures, there was relatively high retention in the study, with 47 of 55 (86%) participants completing the study according to protocol. The median (IQR) time between the baseline and follow-up visits for study completers was 91 (90-98) days. Only one participant voluntarily withdrew from the study out of lack of interest. Despite referral to a dual-certified RD and CDE at the baseline visit, only 2 of 55 (4%) participants actually attended a visit for lifestyle counseling.

The Sweetch mobile platform had a high degree of acceptability by the participants. The median (IQR) score for the Sweetch app SUS measure was 78% (73%-80%), with a score above 68% indicating above average acceptability. The summary responses to the raw items used to calculate the app SUS measure are shown in Figure 3. The majority of participants agreed or strongly agreed that they would like to use the Sweetch app frequently (74%), found the app easy to use (83%), found the functions of the app well integrated (72%), felt that most people could learn to use the app very quickly (89%), and felt confident using the app (77%). Similarly, a majority of participants strongly disagreed or disagreed that the app was unnecessarily complex (81%), would need the support of a technical person (85%), had too much inconsistency (60%), found the app cumbersome to use (79%), and that they needed to learn a lot of things before being able to use the app (83%).

There was also high satisfaction with the DBWS with a median (IQR) usability score of 93% (83%-100%). The summary responses for the DBWS SUS measure are shown in Figure 4. The majority of participants strongly agreed or agreed that the DBWS was easy to use (94%) and connect to the mobile phone using Bluetooth (94%), found the weight measurements to be accurate (80%), did not have any technical challenges with the DBWS (85%), weight measures consistently synchronized to the mobile phone automatically (88%), and having automatic weight measurements on the mobile phone was helpful to achieving goals (77%). Comparing the perceived relative value of the app and DBWS in achieving their PA goal, 48% of participants found the app and DBWS equally effective, 46% found the app more effective than the DBWS, and 6% found the DBWS more helpful than the app. As a tool for weight loss, 72% found the app and DBWS equally effective, 14% found the app more helpful than then DBWS, 11% found the DBWS more helpful than the app, and 3% found neither to be helpful.

Effectiveness and Safety

With respect to the effectiveness measures (Table 2), there was a significant increase in PA from baseline with a mean change of 2.8 MET-hours per week (SD 6.8; P=.02). Weight reduction of 1.6 kg (SD 2.5; P<.001) was observed, corresponding to weight change of approximately 2%. BMI declined by 0.6 kg/m^2 (SD 0.8; P<.001), and waist circumference was reduced by 1.4 cm (SD 2.9; P<.01). There was a statistically significant and clinically meaningful reduction in A_{1c} in the intervention cohort, with median (IQR) A_{1c} change from baseline of −0.1% (−0.2% to 0.1%; P=.04). There was no significant change in the fasting glucose from baseline, with median (IQR) change of −1 mg/dL (−3 to 0; P=.59). There was no significant change in blood pressure with median (IQR) change of 1 mm Hg (−10 to −7; P=.56) and −4 mm Hg (−7 to 4; P=.21) in systolic and diastolic blood pressure, respectively. There were no AEs reported in this study. One participant had a knee injury (torn meniscus) approximately 30 days into the study, but this was unrelated to the Sweetch intervention.

Discussion

Principal Findings

This pilot study demonstrated that the Sweetch mobile platform in combination with a DBWS was effective at increasing PA and reducing weight and A_{1c} and had a high degree of acceptability. From a feasibility standpoint, there was a high rate of participant retention. Usability and satisfaction scores for the app and DBWS were uniformly high. As expected, given the nature of this intervention, there were no AEs.

The findings of this study suggest a potential role of fully automated mobile-based interventions for diabetes prevention. Participants achieved significant increases in PA, with a 2.8 MET-hour increase per week per participant. By comparison, the change in PA achieved at 3 and 6 months in the DPP study, which is considered the goal standard for diabetes prevention programs, was extrapolated to be 1.7 and 3.6 MET-hours per week, respectively. Participants lost an average of 1.6 kg, corresponding to approximately 2% weight loss at 3 months. The DPP showed that for each 1 kg weight loss in the lifestyle arm, there was a 16% reduction in diabetes risk, adjusted for changes in diet and activity [17]. The degree of weight loss achieved in this study was slightly less than the weight loss trend at the 3-month time point in the DPP; however, to sustain behavioral change, the Sweetch intervention sought to gradually expose participants to different diabetes prevention goals, starting with PA. As participants complied with the PA goal, a weight goal was subsequently introduced. Given the study interval of 3 months, the weight loss goal was introduced to participants later in the trial; hence, the smaller reduction in weight compared with the DPP. In this study, weight loss corresponded to a BMI reduction of 0.6 kg/m^2; a large prospective cohort study showed that BMI reductions of at least 0.5 kg/m^2 are associated with 12% reduction in the relative risk of incident diabetes over the long term [26].

With respect to glycemic measures, participants in the intervention cohort achieved A_{1c} reductions of 0.1% (P=.04), with no significant change in fasting glucose. The discordance between these glycemic measures may be explained by the fact that (1) A_{1c} is a more stable estimate of glycemic exposure than fasting glucose, (2) an intervention that increases PA may disproportionately improve postprandial hyperglycemia over fasting hyperglycemia because of improvements in muscle insulin sensitivity, and (3) unlike fasting glucose, A_{1c} results are not influenced by recent carbohydrate exposure and/or participant adherence to an 8-hour fast. Inferring from the results of the lifestyle arm in the DPP, an A_{1c} reduction of 0.1% is considered a clinically meaningful surrogate for diabetes risk: at 3 and 6 months, the change in A_{1c} from baseline in the DPP

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were −0.05% and −0.1%, respectively [10]. Thus, the A_{1c} change realized at the 3-month time point in this study exceeded the change at 3 months that was extrapolated from the lifestyle arm of the DPP. It is important to note that in this study, all participants were referred for lifestyle education with a CDE and RD, but only 2 of 55 (4%) participants actually attended a visit for lifestyle counseling; therefore, it is likely that the findings can be attributed almost entirely to the Sweetch intervention. Although there was no significant change in blood pressure, this was not the main objective of this study.

Significance of Findings

This study adds to a growing body of evidence supporting the use of mHealth technology for improving PA levels, weight loss, and diabetes prevention [12]. A mobile phone or Web-based DPP (Alive-PD) that included tailored goal setting, weekly tracking, human-based phone coaching, and twice-weekly DPP curriculum achieved reductions of 0.26% and 3.3 kg weight loss at 6 months [27]. Another intervention that included in-person DPP curriculum sessions and a mobile app for self-monitoring of weight, activity, and diet resulted in 6.2 kg weight loss at 5 months but failed to demonstrate any significant change in glycemic measures [14]. A hybrid program combining human coaching and digital tools, Noom Coach (Noom, Inc, New York), demonstrated significant weight loss but did not report glycemic data [15]. Nonetheless, given the significant effect on weight reduction seen with this intervention, the CDC included Noom in their recently established DPP recognition registry [28]. Omada Health (San Francisco), another solution that combines human coaching and digital tools, also demonstrated significant weight loss, but no change in A_{1c} was observed at 3 months [29]. On the other hand, the intervention demonstrated significant A_{1c} reductions of 0.37% at 12 months (P=.001).

The fact that our study demonstrated both weight and A_{1c} reductions at only 3 months suggests that long-term effects will be comparable, if not superior, to existing interventions. Most importantly, Sweetch's machine learning technology enables fully automated intervention; hence, supporting larger-scale deployment with greater cost-effectiveness potential when compared with human-based diabetes prevention solutions. A future long-term study with the Sweetch mobile platform is planned to confirm the durability of these findings and to satisfy CDC recognition criteria for a DPP.

Study Strengths and Limitations

There were several strengths to this study. PA measures were tracked, rather than self-reported, which increases the validity of this measure as compared with the DPP that relied on participant self-report of PA. Our study used the DPP study as a comparison, as this study is considered the gold standard for diabetes prevention. Unlike a similar study that used home A_{1c} test kits and thus received A_{1c} data on only 53% of participants at study follow-up [30], we had complete ascertainment of A_{1c} levels on study completers. That said, one of the lessons learned from this study is that point-of-care A_{1c} screening would be more efficient for recruitment and would enhance the implementation of this intervention in a real-world clinical setting where patients identified as having prediabetes could receive the intervention immediately without the need for fasting and a return visit. With respect to the app itself, another lesson learned from this study is that adding a component focused on nutrition in addition to weight loss and PA goals may be required to achieve maximal weight loss and greater improvements in glycemic measures.

Limitations of this study were the single-arm design with a self-selected sample of participants who may be more motivated to change their lifestyle than the average patient with prediabetes. Although the focus of this intervention was weight loss and PA, participants did receive nutrition information (brochure) at the baseline visit, which may have affected the intervention. Our patient demographic consisted predominately of white females, which is not uncommon in behavioral weight loss studies. Although the study enrolled overweight and obese adults, the study population consisted of predominantly obese individuals who may have led a more sedentary lifestyle than their overweight counterparts. A further study with a larger sample size will allow inferences to be made about the generalizability of these findings to overweight prediabetic patients. Finally, although the aim of the app is diabetes prevention, given the size and duration of this study, we were limited to using surrogate measures (ie, PA, weight change, and A_{1c}) to draw inferences about diabetes risk, rather than measuring diabetes incidence.

Conclusions

The Sweetch mobile platform was well received by participants and was effective at increasing PA and reducing body weight and A_{1c} over 3 months without any adverse effects. The study results are promising, but future studies will be required to confirm the sustainability of these findings over a longer follow-up period.

Acknowledgments

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Authors' Contributions

EE analyzed the data and wrote the manuscript. AY recruited participants and wrote the manuscript. BK and AD recruited participants for the study and wrote the manuscript. NM designed the study, recruited participants, independently conducted the data analysis, and wrote the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Mobile phone usage and attitudes baseline survey.

[PDF File (Adobe PDF File), 32KB - jmir_v20i2e72_app1.pdf]

Multimedia Appendix 2

Calculation of MET-hours per week per participant.

[PDF File (Adobe PDF File), 45KB - jmir_v20i2e72_app2.pdf]

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Abbreviations

AE: adverse event
BMI: body mass index
CDC: Centers for Disease Control and Prevention
CDE: certified diabetes educator
DBWS: digital body weight scale
DPP: Diabetes Prevention Program
IQR: interquartile range
IRB: institutional review board
LTPA: leisure time physical activity

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MET: metabolic equivalent of task
mHealth: mobile health
PA: physical activity
RCT: randomized controlled trial
RD: registered dietician
SUS: System Usability Scale

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Original Paper

Implementation of Digital Awareness Strategies to Engage Patients and Providers in a Lung Cancer Screening Program: Retrospective Study

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Abstract

Background: Lung cancer is the leading cause of cancer-related deaths in the United States. Despite mandated insurance coverage for eligible patients, lung cancer screening rates remain low. Digital platforms, including social media, provide a potentially valuable tool to enhance health promotion and patient engagement related to lung cancer screening (LCS).

Objective: The aim was to assess the effectiveness of LCS digital awareness campaigns on utilization of low-dose computed tomography (LDCT) and visits to institutional online educational content.

Methods: A pay-per-click campaign utilizing Google and Facebook targeted adults aged 55 years and older and caregivers aged 18 years and older (eg, spouses, adult children) with LCS content during a 20-week intervention period from May to September 2016. A concurrent pay-per-click campaign using LinkedIn and Twitter targeted health care providers with LCS content. Geographic target radius was within 60 miles of an academic medical center. Social media data included aggregate demographics and click-through rates (CTRs). Primary outcome measures were visits to institutional Web pages and scheduled LDCT exams. Study period was 20 weeks before, during, and after the digital awareness campaigns.

Results: Weekly visits to the institutional LCS Web pages were significantly higher during the digital awareness campaigns compared to the 20-week period prior to implementation (mean 823.9, SD 905.8 vs mean 51, SD 22.3, P=.001). The patient digital awareness campaign surpassed industry standard CTRs on Google (5.85%, 1108/18,955 vs 1.8%) and Facebook (2.59%, 47,750/1,846,070 vs 0.8%). The provider digital awareness campaign surpassed industry standard CTR on LinkedIn (1.1%, 630/57,079 vs 0.3%) but not Twitter (0.19%, 1139/587,133 vs 0.25%). Mean scheduled LDCT exam volumes per week before, during, and after the digital awareness campaigns were 17.4 (SD 7.5), 20.4 (SD 5.4), and 26.2 (SD 6.4), respectively, with the difference between the mean number of scheduled exams after the digital awareness campaigns and the number of exams scheduled before and after the digital awareness campaigns being statistically significant (P<.001).

Conclusions: Implementation of the LCS digital awareness campaigns was associated with increased visits to institutional educational Web pages and scheduled LDCT exams. Digital platforms are an important tool to enhance health promotion activities and engagement with patients and providers.

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KEYWORDS

lung neoplasms; diagnostic imaging; social media; patient participation; search engine

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Introduction

Lung cancer is the leading cause of cancer-related deaths in the United States, with more than 157,000 deaths per year [1]. The National Lung Cancer Screening Trial found that lung cancer screening (LCS) with low-dose computed tomography (LDCT) resulted in a decrease in lung cancer mortality by 20% when screening high-risk patients [2]. As a result, the US Preventive Services Task Force issued a Grade B recommendation for annual screening of high-risk adults age 55 to 80 years for lung cancer, with LDCT being the only recommended screening test [3].

Section 2713 of the Affordable Care Act mandates that private insurance companies cover screening examinations with A or B recommendations from the US Preventive Services Task Force [4]. Additionally, the Centers for Medicare and Medicaid Services issued a coverage directive in February 2015 that LCS counseling and shared decision-making visits are covered services along with LDCT screening for eligible beneficiaries [5]. However, despite mandated coverage of LDCT for eligible patients by public and private payors, reported screening rates of eligible patients have remained under 4% as of 2015 [6].

There are many potential reasons for relatively low rates of LCS among eligible patients [7]. Patients and providers may not be aware of the availability and importance of this relatively new screening test [8,9]. Additional potential contributors to low LCS rates include cost concerns, radiation dose concerns, physician and/or patient ambivalence about the mortality benefits of screening, social stigma associated with smoking and lung cancer among patients, lack of physician knowledge about screening eligibility, and uncertainty regarding insurance coverage and reimbursement [10-13].

The Internet and digital platforms, including social media, provide unique tools for health care organizations and providers to engage in public health and health promotion initiatives [14]. The Internet has become a dominant source of health information: 72% of adult Internet users go online for health information, with the majority of searches initiated through search engines [15]. Studies have also demonstrated the value of social media in emergency preparedness, epidemiology, health education, and patient engagement [16-20]. However, social media has the potential to negatively impact health behaviors [14]. Nevertheless, the power of social media as a tool to foster engagement between health care providers and patients appears to be growing [14].

Shared decision making using one or more decision aids is required for coverage by the Centers for Medicare and Medicaid Services and strongly emphasized in clinical practice. Thus, education and outreach to both patients and providers are critical to improving screening rates among eligible patients. To that end, social media and search engine outreach present a unique opportunity to promote awareness of a screening examination that provides a clear mortality benefit.

The purpose of this study was to determine if a patient- and provider-focused LCS digital awareness campaign was associated with (1) utilization of LDCT and (2) engagement with online educational content on LCS and LDCT.

Methods

This single-institution, retrospective study was exempt from the Institutional Review Board. A 20-week pay-per-click campaign was developed to target two specific populations within a 60-mile radius of a large quaternary medical center and two affiliated off-campus imaging sites: (1) patients and caregivers and (2) health care providers. Primary outcome was visits to institutional LCS Web pages. Secondary outcome was utilization of LDCT at the academic medical center. Utilization is defined as exams that were scheduled within the precampaign, campaign, and postcampaign 20-week periods and subsequently completed.

Patient Awareness Campaign

Facebook (Menlo Park, CA, USA) and Google (Mountainview, CA, USA) were selected as the digital platforms for the patient awareness campaign due to their prevalent use among adult Internet users. Information about LCS for patients and caregivers, including eligibility, insurance coverage and the benefit of early detection, appeared on Facebook and Google search from May 12 to September 30, 2016. Using the options that these platforms make available to directly reach specific groups of people, the patient awareness campaign hypertargeted the following: current and former smokers aged 55 years and older, females aged 55 years and older, patients and employees of the academic medical center (individuals 18 years and older), and caregivers (ie, individuals aged 18 years and older).

Content on Facebook took several different forms including rotating sets of images (ie, carousels), two unique 30-second videos on the risks of smoking and screening eligibility, an animated graphics interchange format (GIF) depicting a growing lung nodule, and a static display of images including computed tomography (CT) technologists and CT scanners (Figure 1).

Content on Google search was primarily text and grouped by categories including signs and symptoms, smoking and lung cancer, and LCS eligibility. Content appeared when users in the specified geographic location searched designated keywords. Messages included “Don’t wait for symptoms,” “Lung screening saves lives,” and “Learn about screening eligibility.” Some content also addressed LDCT’s lower dose of radiation and stressed that treatment may be more effective with early detection.

All patient awareness content included links to one of two institutional Web pages: (1) general information about LCS and LDCT and (2) frequently asked questions (FAQ) tailored specifically for patients [21,22].

Provider Awareness Campaign

LinkedIn (Mountainview, CA, USA) and Twitter (San Francisco, CA, USA) were selected to deliver provider-focused content from June 21 to September 30, 2016. The following health care provider characteristics were hypertargeted: primary care specialties (eg, family medicine, internal medicine) and

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licensed providers (eg, MD, NP, PA) who may see patients independently as a part of their practice.

Content on LinkedIn focused on LCS mortality benefit and eligibility criteria by referencing high-risk patients and identifying specific requirements for eligibility such as number of pack-years smoked (Figure 2). Content also addressed the value of a CT scan compared to a standard chest radiograph. In addition, providers were prompted to consider LCS counseling during a shared decision-making visit with high-risk patients.

Content on Twitter targeted a broad group of health care professionals and patient advocacy organizations, highlighting which patients may be eligible for LDCT without copay and the mortality benefit of LCS with LDCT. In some cases, content posed a question (eg, "Do you know someone who might be eligible?") or featured an animated GIF depicting a growing lung nodule. Targeted keywords included "smoking cessation," "lung cancer social media," and "lung health" (Figure 3).

All provider-focused content included links to one of two institutional Web pages: (1) general information about LCS and LDCT and (2) FAQ tailored specifically for physicians [21,23].

Figure 1. Patient-focused lung cancer screening content on Facebook included carousels, videos, graphics interchange formats, and static images.

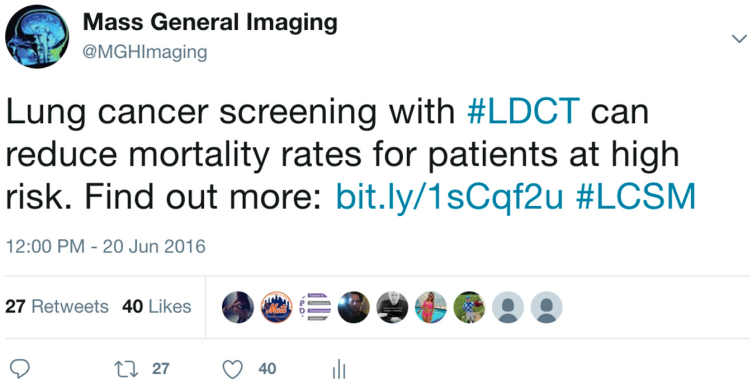


Figure 2. Provider-focused lung cancer screening content on LinkedIn focused on eligibility and mortality benefit.



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Figure 3. Provider-focused lung cancer screening content on Twitter focused on eligibility and mortality benefit.



Data Collection

All digital platforms provided aggregate data on users' geographic location (eg, by state, by municipality). Additionally, Twitter and Facebook provided aggregate data on age and gender, and LinkedIn provided aggregate data on job title (ie, provider type). Metrics were collected including "impressions" (ie, the number of times content was served on a platform) and "clicks" (ie, the number of times users clicked anywhere on the content). All platforms also provided information on click-through rates (CTRs) (ie, clicks/impressions).

Visits to institutional LCS Web pages as a result of the campaign were measured using Google Analytics Universal version and included the number and date of page views (ie, total number of pages viewed; includes repeated views of a single page) and "sessions" (ie, a period of time during which a user is actively engaged in a website; can include multiple page views). Data on LDCT examinations were obtained from the electronic medical record (Epic Hyperspace 2015 IU RA1836 Version 82.2.16, Verona, WI, USA), including the date the examinations were scheduled and performed.

Statistical Analysis

The number of total scheduled exams per week was calculated for each week during the precampaign, campaign, and postcampaign 20-week periods. The mean number of visits to the patient FAQ Web page, physician FAQ Web page, and the general LCS information Web page before, during, and after the digital awareness campaigns were computed. Results are reported separately for each of the three Web pages.

Similarly, the mean number of exams scheduled before, during, and after the campaign were also calculated. Scheduled exams included in the analysis were subsequently performed. A one-way analysis of variance (ANOVA) was conducted to determine any statistically significant differences between the means of the assessed variable before, during, and after the digital awareness campaigns. Pairwise subgroup analysis was performed using a two-sided *t* test to assess for statistically significant differences between the mean number of scheduled exams at any two campaign periods. Bonferroni-adjusted *P* values were used to correct for multiple comparisons. In the subgroup analysis, a *P* value less than .016 was considered to be statistically significant to account for the three assessed subgroups (Bonferroni correction). Otherwise, a *P* value less than .05 was considered statistically significant in all other analyses. Statistical analyses were performed with Stata 14 (College Station, TX, USA).

Results

Patient Awareness Campaign

Facebook generated 1,846,070 impressions with a CTR of 2.59% (47,750/1,846,070), which was higher than the reported health care industry average of 0.8% [24]. The highest CTR was among individuals aged 18 to 24 years (3.21%, 13,238/411,200). Facebook metrics by gender and age are presented in Table 1. Google search generated 18,955 impressions, with a CTR of 5.85% (1108/18,955) compared to a health and medical industry average of 1.8% [25]. Highest CTRs resulted from content that referenced signs of lung cancer (17.09%, 335/1960) and the benefits of early detection (10.4%, 22/211).

Provider Awareness Campaign

LinkedIn generated 57,079 impressions with a CTR of 1.10% (630/57,079) compared to an overall industry average of 0.3% [26]. The 630 clicks came from physicians (10.2%, 64/630), registered nurses (9.5%, 60/630), nurse practitioners (5.7%, 36/630), nurses (2.4%, 15/630), physician assistants (2.2%, 14/630), clinical specialists (2.1%, 13/630), and other job title categories (67.9%, 428/630). Content with the highest CTR contained statistics about patients most at risk of lung cancer and the mortality benefit of LDCT. Twitter generated 587,133 impressions with a CTR of 0.19% (1139/587,133) compared to an overall industry average of 0.25% (oral communication, H Justin, sales manager, Twitter, June 2016).

Table 2 presents campaign performance per platform as defined by (1) comparison with industry standard CTRs and (2) resulting online sessions that included institutional Web pages on LCS.

Visits to Institutional Web Pages

Visits to institutional Web pages on LCS are presented in Table 3. The mean weekly visits for the institutional LCS general Web page before, during, and after the campaign were 51.0 (SD 22.3), 823.9 (SD 905.8), and 438.8 (SD 1094.5), respectively (*P*=.03). The mean weekly visits to the institutional patient FAQ webpage before, during, and after the campaign were 11.5 (SD 6.9), 535.3

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(SD 484.9), and 131.2 (SD 283.7), respectively (P<.001). The mean weekly visits to the institutional provider FAQ webpage before, during, and after the campaign were 5.2 (SD 2.6), 90.8 (SD 92.7), and 28.6 (SD 45.5), respectively (P<.001).

Low-Dose Computed Tomography Utilization

During the 20 weeks before the study period, 349 LDCT exams were scheduled, resulting in a mean 17.4 (SD 7.5) exams per week. During the 20-week study period, 415 LDCT exams were scheduled, resulting in a mean 20.4 (SD 5.4) exams per week. During the 20 weeks after the study period, 483 exams were scheduled, resulting in a mean 26.2 (SD 6.4) exams per week (Figure 4). All these exams were subsequently performed. ANOVA analysis revealed statistically significant differences between the means of the total number of weekly exams scheduled before, during, and after the digital awareness campaigns (P<.001). Pairwise subgroup analysis revealed statistically significant differences between the mean number of scheduled exams during and after the digital awareness campaigns and before and after the digital awareness campaigns (P<.001).

Table 1. Facebook metrics by gender and age.

Demographic	Impressions, n	Reach, n	Clicks, n	CTR, %	Sessions, n
Age					
18-24	411,200	192,388	13,238	3.21	2658
25-54	557,542	273,412	12,879	2.30	6304
≥55	876,419	266,931	21,632	2.46	3264
Gender					
Male	797,492	319,848	23,042	2.89	3021
Female	1,028,935	406,128	24,320	2.36	4487

Table 2. Campaign performance by digital platform. CTR: click-through rate.

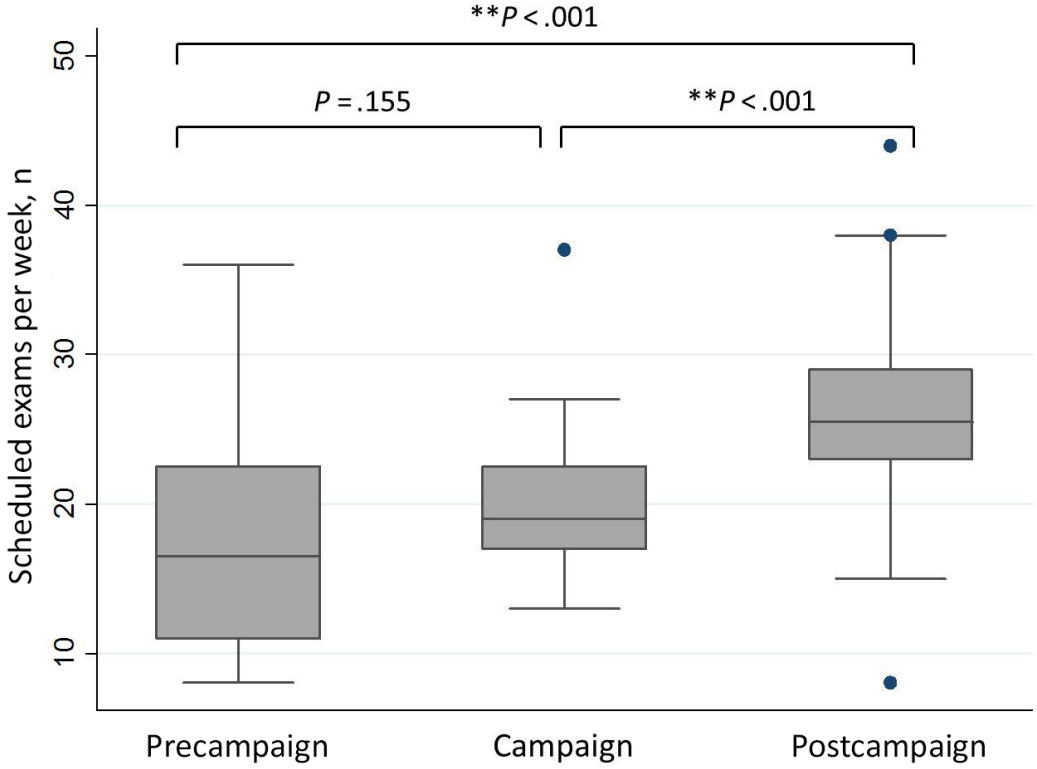
Campaign	Impressions, n	Clicks, n	Campaign CTR, %	Industry standard CTR, %	Sessions, n
Provider awareness					
Twitter	587,133	1139	0.19	0.25	927
LinkedIn	57,079	630	1.10	0.3	595
Patient awareness					
Facebook	1,846,070	47,750	2.59	0.8	13,341
Google	18,955	1108	5.85	1.8	1522

Table 3. Mean weekly visits to institutional Web pages. FAQ: frequently asked questions; LCS: lung cancer screening.

Institutional Web page	Precampaign, mean (SD)	Campaign, mean (SD)	Postcampaign, mean (SD)	P
General LCS information	51.0 (22.3)	823.9 (905.8)	438.8 (1094.5)	.03
Physician FAQ	5.2 (2.6)	90.8 (92.7)	28.6 (45.5)	<.001
Patient FAQ	11.5 (6.9)	535.4 (484.9)	131.2 (283.7)	<.001

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Figure 4. The differences between the mean number of weekly scheduled exams before, during, and after the campaigns. The boxes represent the upper and lower quartiles of the dataset, the whiskers extend to the highest and lowest observations in the dataset that are one and a half times the interquartile range, and the dots represent the outliers observed in the dataset.



Discussion

This single-institution study found that simultaneous digital awareness campaigns focused on both patients and providers were associated with an increase in visits to institutional Web pages on LCS and scheduled LDCTs. This study has several important implications, particularly for stakeholders in health promotion and population health management.

The digital awareness campaigns were associated with a significant increase in visits to institutional Web pages on LCS. This finding suggests the possibility that the campaign was successful in providing patients and providers with information on LCS and LDCT. Patient education, in particular for high-risk patients, is a fundamental component of the shared decision-making process for LCS [27]. Social media and search engine platforms provide an important vehicle to connect with potential patients who may not be integrated into the health care delivery system.

Secondly, the patient-focused digital awareness campaign surpassed reported health care industry standards for CTRs. There are several potential explanations for this finding. First, interest in LCS-related content may be higher than general industry standards for health care-related topics due to the increased interest in lung cancer when compared to the broader landscape of health care information disseminated on social media platforms. Alternatively, hypertargeting of the patient demographic groups may have contributed to the higher-than-industry-standard CTRs observed in this study. Interestingly, the highest CTRs observed were among individuals aged 18 to 24 years. This finding may be related to higher rates of social media utilization among younger individuals. However, in development of social media outreach efforts, identifying caregivers and family members that may have an influence over health care decisions has been shown to be an important aspect in patient engagement [28]. In the case of LCS, integrating younger individuals into discussions about their loved ones' screening decision may also influence their own smoking behavior.

Within the provider-focused digital awareness campaign, LinkedIn surpassed industry standards for CTRs, whereas Twitter did not. At first glance, this finding may appear surprising, given that LinkedIn is primarily used for networking between professionals. However, social networking sites for professionals may have more robust targeting algorithms to reach providers, given the greater specificity in the job titles of their users. This may allow for enhanced ability to provide content to individuals who are more likely to be interested in LCS. Therefore, institutions that are considering provider education campaigns should consider utilization of such sites. Academic institutions may not be leveraging these sites fully, which may represent untapped potential to connect with health care providers within and outside of the organization [29].

Lastly, the number of scheduled LDCTs was significantly higher during and after the digital awareness campaigns when compared to the precampaign study period. Although this observational study does not allow for causality to be inferred, the findings suggest that digital awareness campaigns have the potential to not only provide education, but also influence behavior. Previous research has demonstrated that social media may be more cost-effective and have a broader reach than

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traditional media in recruiting patients eligible for LCS into research studies [30].

Future research may benefit from surveying patients undergoing LDCT to ascertain which outreach efforts may have influenced their decision to pursue LCS.

There are several limitations to this retrospective observational study. Importantly, the observational nature precludes determination that the digital awareness campaigns had a causal relationship with LDCT utilization. Although paid placements on social and search platforms clearly drove traffic to institutional Web pages, CTRs may have been above industry standards as a reflection of content branded to an academic medical center with significant brand equity in the targeted geographic area.

Additionally, the study did not control for other institutional, local, or national initiatives related to LCS, which may have influenced outcome measures. In particular, institutional initiatives during the 20 weeks after the digital awareness campaigns promoted the LCS general Web page as part of Lung Cancer Awareness Month activities, likely accounting for its relatively high mean daily visits during this period. Also, the number of shared decision-making visits was not readily accessible, which may be an additional proxy for the potential impact of education influencing patient and/or provider behavior. Further, the time required for obtaining a shared decision-making visit with a clinical provider could contribute to lead time bias in LDCT utilization.

Finally, demographic data from the digital platforms were provided in aggregate, which limits assessment of patient and provider demographics. Similarly, statistical significance of differences between the digital awareness campaign metrics and industry standards cannot be determined. Demographic data, including race, ethnicity, and socioeconomic status, of patients who received a LDCT before, during, or after the 20-week study period were not analyzed as part of this study.

Concurrent patient- and provider-focused digital awareness campaigns on LCS were associated with increased visits to online educational content and increases in the number of LDCT examinations. Digital platforms appear to be an important tool in health promotion and educational initiatives related to LCS with the potential to impact care-seeking behavior.

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Conflicts of Interest

None declared.

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Abbreviations

CT: computed tomography
CTR: click-through rate
FAQ: frequently asked questions

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GIF: graphics interchange format
LCS: lung cancer screening
LDCT: low-dose computed tomography

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Review

Users, Uses, and Effects of Social Media in Dietetic Practice: Scoping Review of the Quantitative and Qualitative Evidence

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Abstract

Background: Social media platforms are increasingly used by registered dietitians (RDs) to improve knowledge translation and exchange in nutrition. However, a thorough understanding of social media in dietetic practice is lacking.

Objective: The objective of this study was to map and summarize the evidence about the users, uses, and effects of social media in dietetic practice to identify gaps in the literature and inform future research by using a scoping review methodology.

Methods: Stages for conducting the scoping review included the following: (1) identifying the research question; (2) identifying relevant studies through a comprehensive multidatabase and gray literature search strategy; (3) selecting eligible studies; (4) charting the data; and (5) collating, summarizing, and reporting results for dissemination. Finally, knowledge users (RDs working for dietetic professional associations and public health organizations) were involved in each review stage to generate practical findings.

Results: Of the 47 included studies, 34 were intervention studies, 4 were descriptive studies, 2 were content analysis studies, and 7 were expert opinion papers in dietetic practice. Discussion forums were the most frequent social media platform evaluated (n=19), followed by blogs (n=13) and social networking sites (n=10). Most studies targeted overweight and obese or healthy users, with adult populations being most studied. Social media platforms were used to deliver content as part of larger multiple component interventions for weight management. Among intervention studies using a control group with no exposition to social media, we identified positive, neutral, and mixed effects of social media for outcomes related to users' health behaviors and status (eg, dietary intakes and body weight), participation rates, and professional knowledge. Factors associated with the characteristics of the specific social media, such as ease of use, a design for quick access to desired information, and concurrent reminders of use, were perceived as the main facilitators to the use of social media in dietetic practice, followed to a lesser extent by interactions with an RD and social support from fellow users. Barriers to social media use were mostly related to complicated access to the site and time issues.

Conclusions: Research on social media in dietetic practice is at its infancy, but it is growing fast. So far, this field of research has targeted few social media platforms, most of which were assessed in multiple-component interventions for weight management among overweight or obese adults. Trials isolating the effects and mechanisms of action of specific social media platforms are needed to draw conclusions regarding the effectiveness of those tools to support dietetic practice. Future studies should address barriers and facilitators related to the use of social media written by RDs and should explore how to make these tools useful for RDs to reach health consumers to improve health through diet.

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KEYWORDS

social media; diet; review

Introduction

With the increasing worldwide prevalence of obesity [1] and its related comorbidities [2,3], effective and low-cost approaches that can improve health behaviors, such as those related to diet, are needed to improve health and well-being in populations. The advent of Web 2.0 [4] has triggered a revolution in the way patients access health information for their health management [5,6] and provide opportunities for population-wide promotion of healthy behaviors. Social media is a broad example of Web 2.0 and refers to Internet-based platforms devoted to blogging, social networking, collaborative writing projects, content communities, and virtual social worlds [7].

Social media platforms are novel avenues with high reach potential of dissemination that can be used by health care professionals to improve knowledge translation of evidence-based health information to health consumers and patients. The growing use of social media by patients and health professionals has been widely advocated in the scientific literature [8-10]. A survey of 195 registered dietitians (RDs) and dietetic students conducted by the Dietitian Connection network in Australia found that almost all (97%) of RDs use social media, Facebook being the platform of predilection followed by Instagram, illustrating that visual imagery has significantly gained in popularity among RDs for showcasing food and recipes [11]. Furthermore, social media represents valuable additions to traditional face-to-face clinical encounters to deliver behavioral interventions [12] notably to support long-term and sustained dietary behavior change efforts for chronic disease management and prevention [13].

Social media can be used for numerous purposes in dietetic practice, including public health. Social media has been used to broaden the scope of nutrition education program by using different social media platforms (Facebook, Twitter, and Pinterest) to disseminate actionable messages [14,15]. Social media also provides a promising way to deliver dietary behavior change interventions [16-18].

Dietetic professional associations have recognized the role of social media RDs' professional practice [19] and feature a repertoire of their members who are active on social media such as Twitter [20] and blogs [21,22]. However, much remains unknown in the scientific literature about social media in dietetic practice and whether they can help health consumers make informed decisions to improve health through diet.

To fill this gap in knowledge, we aimed to answer the following research question: What evidence is provided about the users, uses, and effects of social media in dietetic practice? The specific research questions were as follows:

1. Who is using social media in dietetic practice?
2. What are the purposes of social media in dietetic practice?
3. What are the effects of interventions using social media in dietetic practice on food- and nutrition-related outcomes?
4. What are the barriers and facilitators that could influence the use of social media in dietetic practice?
5. What are the research gaps in this literature to inform future research?

Methods

Knowledge Synthesis Methodology

Our research objectives were addressed using the scoping review methodology, which is a type of knowledge synthesis that aims to map rapidly the key concepts underpinning a research area and the main sources and types of evidence available [23]. We formulated our protocol [24] using the methodology proposed by Arksey and O'Malley [23] and taking into account recommendations by Levac et al [25]. All steps were iterative to ensure full understanding of the content and extent of the literature. A summary of our 6-stage methodology follows.

Stage 1: Identifying the Research Question

Studies were included if they reported primary questions focused on the users, uses, or effects of social media on food- and nutrition-related outcomes. On the basis of Kaplan and Heanleins's classification scheme [7], we defined *social media* as "a group of Internet-based applications that build on the ideological and technological foundations of Web 2.0, and that allow the creation and exchange of user-generated content," including the following platforms: collaborative projects (eg, wikis), blogs and microblogs (eg, Twitter), content communities (eg, Pinterest), social networking sites (eg, Facebook), and virtual social worlds (eg, Second Life; Linden Lab, San Francisco, California). Discussion forums were also included as they incorporate content that is publicly available and created by end users, and were judged to fall within the social media spectrum. We defined *social media in dietetic practice* as any social media platforms written by RDs for nutrition- and food-related purposes. Involvement of RDs with social media (eg, writing blog postings on positive messages to promote dietary behavior change or moderating a Facebook-based peer support group in a weight loss intervention) had to be specified in the study methods, or this information had to be obtained upon correspondence the authors. Studies were eligible regardless of their experimental design, users, and the degree of involvement of RDs with social media. We excluded studies in which the social media platform was not clearly described, studies on other eHealth technologies (eg, mobile apps), editorials, and publications not written in English or French.

Stage 2: Identifying Studies and the Gray Literature

With the collaboration of a medical information specialist, we developed a search strategy to identify all relevant sources of information on social media in dietetic practice. Using specific keywords related to social media, Web 2.0, and nutrition, we conducted a systematic search, using November 15, 2016, as a cutoff date, in the following scientific databases: MEDLINE, EMBASE, PsycINFO, the Cochrane Library, Web of Science, ABI/INFORM Global, and ProQuest Dissertations & Theses.

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All databases were searched with a publication date range limit of 2000 or later, corresponding to the advent of social software and Web 2.0 applications [26]. The Medline search strategy is presented in Multimedia Appendix 1. This search strategy was thereafter modified to account for specificities of the other scientific databases.

We conducted additional searches by scanning the reference lists of included studies, exploring the literature with the search engine "Google scholar," and searching for gray literature using the most widely used Internet search engines "Google," "Bing," and "Yahoo." For each of these search engines, we used a more specific search string query. As performed by Archambault et al [27], we analyzed the first 100 results of each search engine, which displayed results by relative importance of website pages using a link analysis algorithm [28].

Stage 3: Selecting Studies and the Gray Literature

Two review authors (AL and A-AD) independently assessed the eligibility of publications identified by the search strategies using titles and abstracts. Then, the same 2 reviewers retrieved full-text copies of publications that were judged potentially relevant to the review to validate inclusion. Disagreements were resolved through discussion and with a third review author (SD) when consensus was not reached. Authors were contacted to obtain further details when papers contained insufficient information to make a decision about eligibility.

Stage 4: Charting the Data

A data-charting template was developed to extract the following common features from all studies: authors' names, year of publication, title, journal, status of publication (eg, published, in press, or gray literature), country, experimental design, aim of the study, number of users, sociodemographic characteristics of users, type of social media studied, uses of social media, nutrition- and food-related outcomes studied, description of the effects of social media on outcomes studied, and description of barriers and facilitators that could affect the use of social media. The template was a priori tested with 10 included studies to validate extensiveness and clarity among the reviewers. The review authors independently extracted the data from all included studies and resolved any discrepancies in judgment by discussion and consensus, or with the third review author (SD) when necessary.

Stage 5: Collating, Summarizing, and Reporting Results

As suggested by Levac et al [25], our analysis involved textual descriptions and data tables to map and summarize extracted data. To structure the presentation of results, we classified studies according to their research objectives: intervention studies (eg, studies investigating the effects of social media), descriptive studies (eg, studies describing who uses social media and for what purposes), content analysis studies (eg, studies in which information of social media content is analyzed), or expert opinion papers (eg, studies discussing ethical and professional use of social media by RDs).

A descriptive numerical summary of the study characteristics extracted was then conducted. Our classification for purposes of social media use was inspired by Coulter and Ellins's classification scheme for patient-oriented interventions [29,30] with the addition of relevant dietetic, professional [31], and interactive technology [32] outcomes. Studies globally assessed multiple food- and nutrition-related outcomes and/or evaluated those outcomes at different times (eg, 16 weeks, 6 months, 12 months). Consequently, we retrieved all effects of social media on food- and nutrition-related outcomes as they were reported by authors in studies where intervention groups exposed to single or multiple social media platforms were compared with a control group with no social media access.

Finally, we performed a qualitative thematic analysis to identify potential barriers and facilitators related to the use of social media by users. The qualitative analysis was performed with the NVivo software, version 10 (QSR International, Cambridge, MA, 2012), and consisted of interpreting textual data subjectively by classifying and coding the information into categories that best reflected outputs we had identified [33]. The description of barriers and facilitators was guided by the validated taxonomy developed by Gagnon et al [31]. The review authors independently read each study and identified sentences or paragraphs in the text relevant to these categories and aggregated them into main themes to facilitate the synthesis. The review authors resolved any coding discrepancies through discussion and consensus.

Stage 6: Consulting Knowledge Users

At each critical stage of the review process, we either held a teleconference meeting or exchanged emails with two RD representatives working, respectively, in public health nutrition and in a national dietetic professional association to explain our methodology and progression of our work and to gather their feedback and generate relevant results for dietetic practice.

Results

Description of Included Studies

After excluding duplicates, we identified 23,609 potentially relevant publications from electronic databases and gray literature searches. From these, we excluded 22,815 publications after examining the titles and abstracts, and we retrieved 756 full texts of potentially relevant publications for detailed evaluation. During this screening process, we retrieved 19 additional publications from reference lists of included studies and other sources (the *Journal of the Academy of Nutrition and Dietetics* and authors' contacts), for a total of 775 full-text publications assessed for eligibility. From these, 590 publications were excluded as at least one of our inclusion criteria was not met, and 121 publications were classified as awaiting classification due to our inability to locate full text or due to missing details despite attempts to contact study authors. A total of 64 publications (describing 47 unique studies) fulfilled our eligibility criteria and were included in this scoping review [16,18,19,34-94] (Figure 1).

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Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram for the scoping review process.

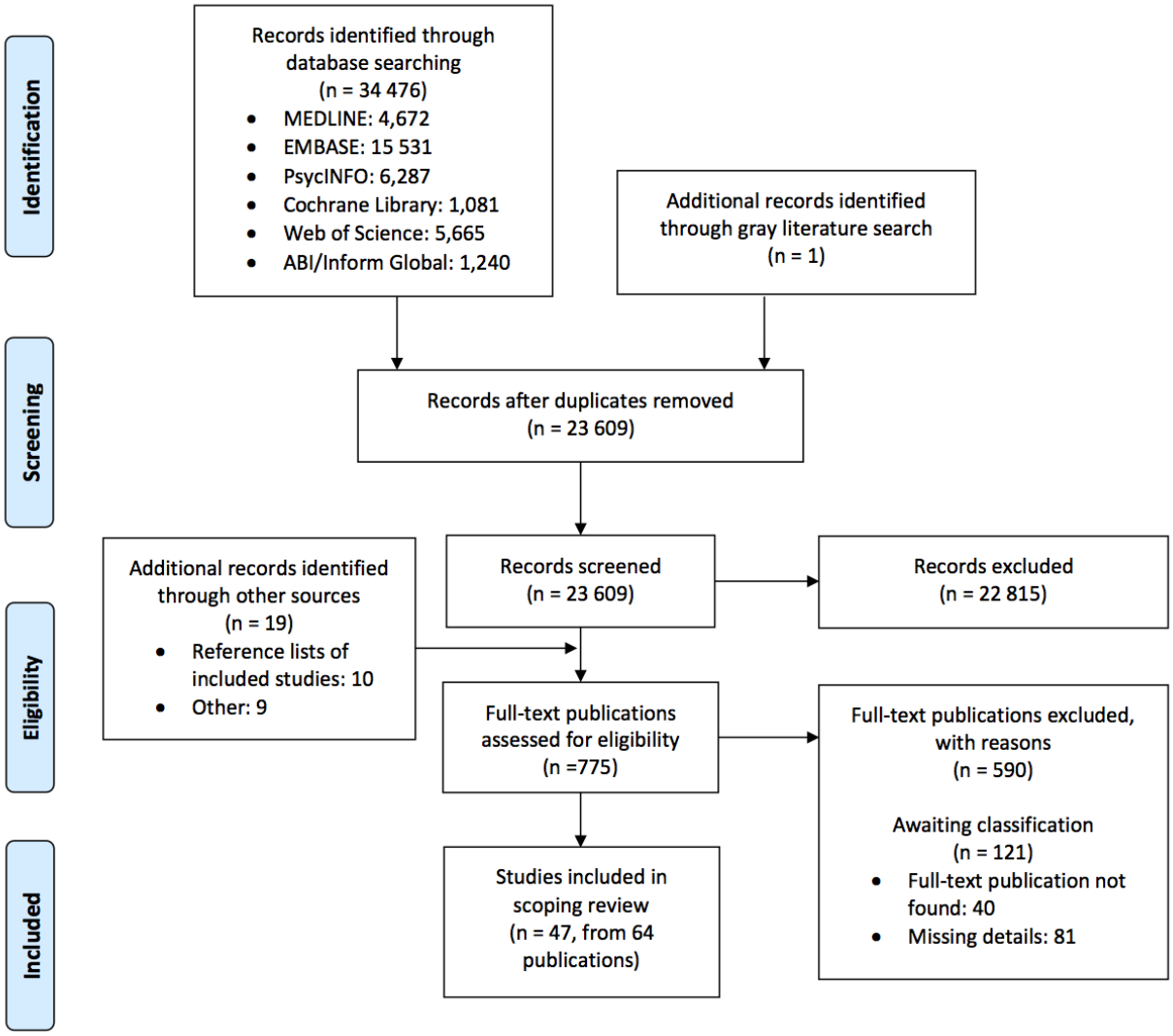
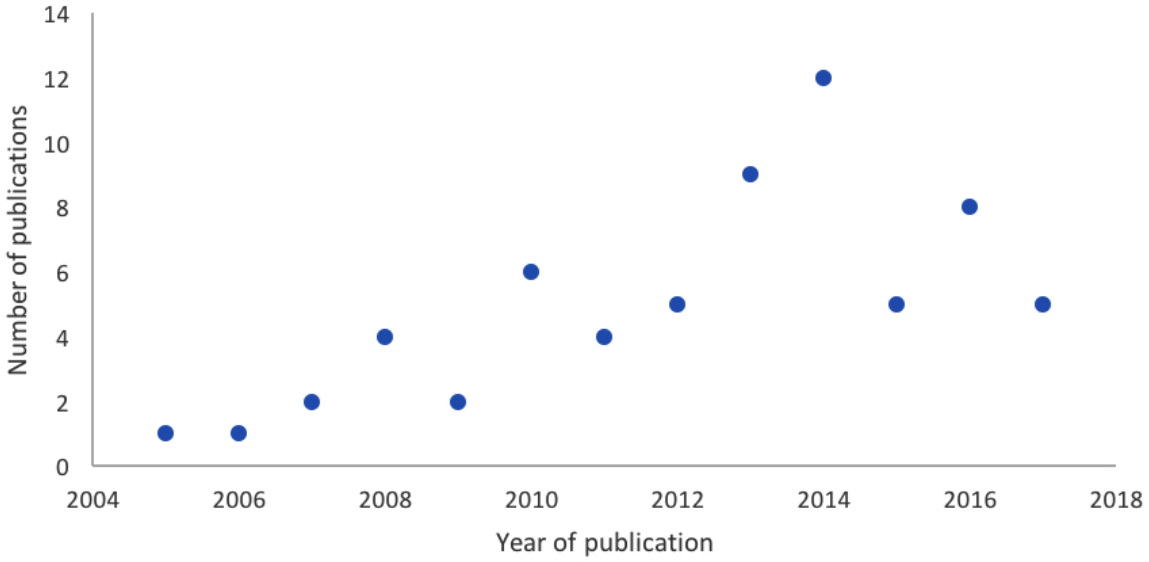


Table 1. Distribution of included studies by country (N=47).

Country	Number of studies, n (%)	Studies
United States	26 (55)	[19,34,36,41,47,48,52-54,58,72-84,87,88,93]
Australia	6 (13)	[37,40,44,55,56,92]
Canada	5 (11)	[18,38,49,50,61]
Austria	2 (4)	[59,60]
Belgium	1 (2)	[43]
Germany	1 (2)	[63]
Ireland	1 (2)	[64]
Italy	1 (2)	[39]
Korea	1 (2)	[42]
United Kingdom	1 (2)	[66]
United States and Norway	1 (2)	[35]
New Zealand	1 (2)	[86]

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Figure 2. Distribution of included publications by years of publication (n=64).



The characteristics of included studies are summarized in Multimedia Appendix 2. Studies were categorized as intervention studies (n=34; eg, quasi-experimental or randomized control trials where intervention content was delivered through one or more social media platforms), descriptive studies (n=4; eg, qualitative studies reporting the design of social media or describing perceptions and preferences of social media users), content analysis studies (n=2; eg, studies analyzing the specific content of social media), or expert opinion papers (n=7; eg, Position Papers for Ethics in Practice published in the *Journal of the Academy of Nutrition and Dietetics*). Most publications reported primary research results (42/64; 66%). Of the publications, 10 were study protocols (10/64; 16%), 3 were conference abstracts (5%), and 2 were dissertations/theses (4%). Most studies were conducted in the United States, Australia, and Canada (Table 1).

Most studies were published from 2013 onward, with the highest number of publications occurring in 2014, 2013, and 2016 (Figure 2).

Users of Social Media in Dietetic Practice

The majority of intervention studies targeted adult populations (26/34, 76%) [18,41-44,48,50,52,54-56,58-60,66,72,75,77,79,82-84,87,88,92,93]. Among them, specific populations of users were adult women [18,50,66,84,88], young adults aged 18-35 years [55,56,72], pregnant adult women [79,92], and collegiate athletes [58]. RDs were the main users of social media in 2 intervention studies [47,78]. Remaining intervention studies targeted health care professionals (ie, those who expressed interest in enrolling in an online continuing nutrition education course [80] or professionals working in the fields of speech pathology, nursing, medical oncology, and pharmacy [40]), adolescents (2/34, 6%) [63,64], nuclear families with children aged 10-17 years (1/34, 3%) [37], and preschool-aged children and their parents (1/34, 3%) [76]. In descriptive studies, users of social media in dietetic practice were all adult populations [35,38,39,86], with some studies specifically targeting adult women [38] and RDs and patients [39]. RDs were the main users of social media in all expert opinion papers [19,34,36,53,73,74,81].

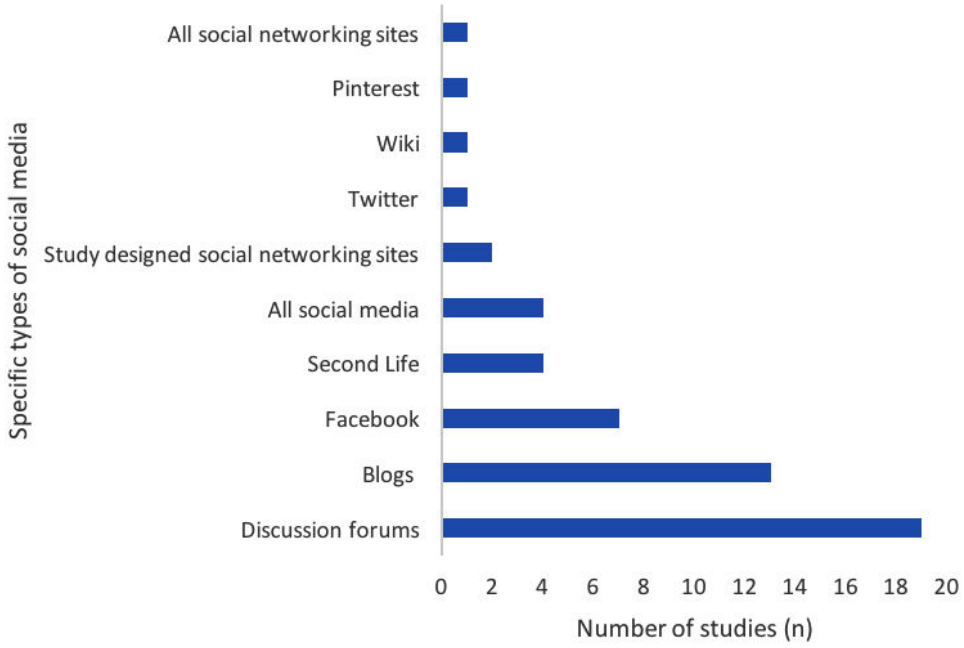
Intervention studies covered a limited range of health conditions, with most users of social media being overweight and obese (15/34, 44%) [41,44,52,54-56,59,60,72,75,82-84,88,92] or obese (3/34, 9%) [63,87,93]. In total, 8 intervention studies targeted healthy users (8/34, 24%) [18,43,50,58,66,76,79,80]. Other health conditions included patients with type 1 diabetes [64] (1/34, 3%), patients with type 2 diabetes [77] (1/34, 3%), patients with polycystic ovary syndrome (1/34, 3%) [84], and patients with metabolic syndrome (1/34, 3%) [42]. The principal health conditions of social media users were not described in 5 intervention studies [37,40,47,48,78]. Among descriptive studies, users of social media in dietetic practice were patients with type 1 or type 2 diabetes [35], healthy [38], or overweight and obese [86]. One descriptive study did not describe the health condition of social media users [39].

Uses of Social Media in Dietetic Practice

Figure 3 illustrates the frequency of social media platforms evaluated in included studies. In this figure, *All social networking sites* refers to social networking sites that could be used for dietetic professional networking, such as LinkedIn and Facebook, as described by Graham 2009 [53], and *All social media* refers to all social media platforms (ie, blogs/microblogs, discussion forms, social networking sites, collaborative projects, content communities, and virtual worlds). In Figure 3, percentages do not add up to 100 due to the possibility of multiple social media platforms per study: the SMART study [51,72] included a social networking site (Facebook) and a blog; the study described in Baghaei 2011 [37] included a study designed social networking site entitled SOcial Families, a blog, and a discussion forum; and the study described in Hales (2014) [54] and Turner-McGrievy (2014) [84] included a social networking site (Facebook) and a microblog (Twitter).

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Figure 3. Frequency of social media tools evaluated in included studies (n=47).



Discussion forums were the most frequent social media platforms evaluated, followed by blogs and the social networking site Facebook. In the majority of intervention studies (27/34, 79%) [37,41-43,44,48,52,54,55,56,58-60,63,66,72,75-77,79,80,83, 84,87,88,92,93], the social media platform was part of a multicomponent intervention including other modes of delivery such as emails, websites, phone calls, text messaging, or face-to-face meetings. We identified 7 single-component intervention studies. Those studies, evaluated the effects of a blog for healthy eating behavior change among adult women [18,50], a closed Facebook group for diabetes management among adolescents with type 1 diabetes [64], a discussion forum for the delivery of online journal clubs among RDs [78], the virtual world Second Life for weight management among overweight or obese adults [82] and as a training tool for RDs to perform the subjective global assessment [47], and a wiki to disseminate evidence-based practice guidelines for the nutritional management of patients with head and neck cancer [40].

The main overarching research themes of included studies are displayed in Table 2. Among intervention studies, blogs or microblogs, discussion forums, social networking sites (eg, Facebook), and virtual social worlds (eg, Second Life) were specific social media platforms used to promote healthy eating, physical activity, or lifestyle behavior change. Descriptive studies focused mostly on users' perceptions regarding the use of blogs to improve their dietary behaviors [38] and support self-monitoring for diabetes management [35] and users' design preferences for a weight management program that included a blog [86]. Content analysis studies provided overviews of food blogs. Ethical and professional use of social media platforms by RDs was the main use of social media discussed in all expert opinion papers.

The specific contexts of use of social media in intervention studies are displayed in Table 3. Among intervention studies, social media platforms were most commonly evaluated in the contexts of weight management and diet, such as healthy eating promotion among French-Canadian women [18,50] and collegiate athletes living in the United States [58], or the promotion of the Mediterranean diet among adult Scottish women [66].

Effects of Interventions Using Social Media in Dietetic Practice on Food- and Nutrition-Related Outcomes

Multimedia Appendix 3 presents the outcomes assessed in intervention studies using social media comparing single or multiple intervention groups with a control group with no social media access. Those studies evaluated blogs [18,55,58], discussion forums [44,48,56,66,75,78-80], a combination of Facebook and a blog [72] or a microblog (Twitter) [54], and a virtual social world (Second Life) [82]. Globally, study authors reported intervention effects on outcomes related to users' health behaviors and status (eg, dietary intakes, body weight, and clinical indicators), compliance, participation and retention rates, and professional knowledge and self-efficacy.

Those effects were mostly neutral, but some authors reported positive or mixed effects (Multimedia Appendix 3). One study [46] reported a negative effect, with levels of eating restraint significantly higher in the intervention groups (exposed to a multicomponent behavior change intervention that included a discussion forum) compared with the control group after a 12-week Web-based weight loss intervention.

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Table 2. Distribution of included studies according to main uses of social media (N=47).

Main use and types of social media[a,b]	Number of studies	Studies
Intervention studies		
Promoting behavior change		
Blogs or microblogs	8	[18,37,50,54,55,58,72,76]
Discussion forums	15	[37,42-44,48,52,56,59,60,63,66,75,79,87,88]
Social networking sites	8	[37,41,54,64,72,84,92,93]
Virtual worlds	3	[77,82,83]
Professional dietetic education		
Collaborative projects	1	[40]
Discussion forums	2	[78,80]
Virtual worlds	1	[47]
Descriptive studies		
Promoting behavior change		
Blogs or microblogs	3	[35,38,86]
Social networking sites	1	[39]
Content analysis studies		
Overview of social media content		
Blogs or microblogs	2	[49,61]
Expert opinion papers		
Professional dietetic practice		
All social media	4	[19,34,36,74]
All social networking sites	1	[53]
Content communities	1	[73]
Discussion forums	1	[81]

[a]All social networking sites" refers to social networking sites that could be used for dietetic professional networking, such as LinkedIn and Facebook, as described by Graham 2009 [53]; "all social media" refers to all social media platforms (ie, blogs/microblogs, discussion forms, social networking sites, collaborative projects, content communities, and virtual worlds).

[b]There was a possibility of multiple social media platforms per study: the Social Mobile Approaches to Reduce weighT (SMART) study. SMART study [51,72] included a social networking site (Facebook) and a blog; the study described in Baghaei 2011 [37] included a study designed social networking site entitled SOcial Families, a blog, and a discussion forum; and the study described in Hales (2014) [54] and Turner-McGrievy (2014) [84] included a social networking site (Facebook) and a microblog (Twitter).

Regarding positive effects, groups exposed to intervention content delivered through a social media platform (a blog, the virtual world Second Life, Facebook, or a discussion forum) had higher compliance [18,54], participation [18], and retention rates [18]; had significant improvements in vegetables [18] and fruit intakes [18,82]; were more satisfied with the intervention materials [66]; and had a higher increase in professional knowledge, skills, and self-efficacy in using an ecological approach to prevent childhood obesity among community-based nutrition and health professionals [80] compared with control groups with no social media exposure. In studies where interventions included a social media platform (a blog or a discussion forum) for peer support, positive effects were described for general nutrition knowledge [58], vegetables [55], fruits [82] and ultraprocessed food [55] intakes, body weight [44,55], cholesterol and blood pressure levels [44], and retention rates [44] among intervention groups compared with controls.

Only one single-component study isolated and reported the specific effects of one social media. In this study [78], no statistically significant difference between a face-to-face group and a group of RDs participating in a Web-based journal club delivered through a discussion forum was found on users' perceptions regarding the journal club environment (in terms of ability to meet the journal club objectives), the process of learning (in terms of critical appraisal skills), and the potential to apply knowledge to practice, and on users' mean scores for the knowledge questions related to the study discussed in the journal club.

However, it was reported that RDs participating in the online journal club using a discussion forum had more positive perceptions of the journal club environment in terms of logistics for timing and opportunities for critical appraisal and of the process of learning in terms of discussion participation compared with the face-to-face control group.

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Table 3. Distribution of included studies according to specific contexts of use of social media in intervention studies (N=34).

Contexts of use of social media	Number of studies	Studies
Weight management		
Weight loss	12	[41,44,52,54,56,59,60,72,84,87,88,93]
Weight loss and weight management	2	[82,83]
Prevention of weight gain	3	[55,63,75]
Prevention of pediatric obesity	1	[76]
Prevention of excessive gestational weight gain	2	[79,92]
Healthy diet	4	[18,50,58,66]
Continuing professional education	3	[47,78,80]
Diabetes management	2	[64,77]
Healthy lifestyle	2	[37,48]
Cancer management	1	[40]
Cardiovascular disease prevention	1	[43]
Metabolic syndrome prevention	1	[42]

In studies using multiple intervention components, social media such as blog features [37,55,58], Facebook Fan Page [41], and discussion forums [48,56] were seldom accessed or used by study participants during the course of interventions to assist behavior change. On the other hand, an interesting finding reported by Patrick et al [72] was that "...Facebook emerged as the primary modality through which dynamic content was delivered at the group level" in the Social Mobile Approaches to Reduce weighT study.

In total, 6 multiple component intervention studies reported process measures relating to social media usage. Among those, Baghaei et al [37] found that increased engagement of families in lifestyle behavior change through social networking was associated with a decrease in users' perception that health was determined by external factors, such as chance. Gold et al [52] observed that the use of the discussion board feature was negatively correlated with weight change from baseline to 6 months among some intervention participants, but no association between the use of the discussion forum and weight change was observed during weight maintenance phase (6-12 months) of the study. In the Webber et al study [88], the number of publications submitted to the discussion forum was positively associated with weight loss. Hales et al [54] and Turner-McGrievy et al [84] both observed that engagement with Facebook (assessed by the number of views, likes, comments, and participant-initiated posts) was significantly associated with weight loss at 6 months. Finally, Karpinski 2012 [58] found a weak positive correlation between the number of blog postings (type of postings not described) and dietary behavior scores, but no association with self-efficacy scores among study participants.

Barriers and Facilitators That Could Affect the Use of Social Media in Dietetic Practice by Users

Facilitators

A total of 5 studies [35,38,41,61,78] identified factors facilitating blog, discussion forum, or Facebook adoption by users (Table 4). Using Gagnon et al taxonomy [31], facilitators were mostly related to users' perceptions of the characteristics of the specific social media, such as *design and technical concerns* (eg, reminders of new posts via email), the *characteristics of the innovation* (eg, ease of use with quick access to desired information), and the *validity of the resources* (ie, appropriateness for the users and completeness of the information available) and, to a lesser extent, to *factors associated with social media users*. For example, the possibility to ask questions to the RD was a perceived facilitator for the use of healthy eating blogs written by RDs [38], and the presence of moderators' post was cited as a facilitator to using Facebook in a weight management intervention [41]. Social support experienced with fellow social media users was an important facilitator for the use of healthy eating blogs by RDs [38], and for the participation of users in food-blogging communities, as several bloggers speaking of "the 'comfort,' 'encouragement," and 'supportive' nature of the food-blogging community..." [61].

Barriers

A total of 6 studies [35,38,41,61,68,78] identified barriers to blog, discussion forum, or Facebook adoption by users. Globally, barriers were related to users' perceptions of the characteristics of the specific social media such as *the characteristics of the innovation* (eg, lack of usefulness of the social media for routine use or complicated access due to login identification) and *environmental issues* (eg, "the intimidation of online environment" in the context of online journal clubs [78], computer issues [38], and limited access to the Internet [41,78]). To a lesser extent, barriers were related to individual factors such as lack of time. For example, "being busy with life, going on vacation, and engaging in other family commitments" were barriers to participation in food-blogging communities [61]. Lack of time was also cited as a barrier to using Facebook, with participants mentioning they "had hectic lives and work schedules that interfered with intervention participation and behavior change" [41].

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Table 4. Barriers and facilitators related to the use of social media in dietetic practice.

Factors (Gagnon et al taxonomy [31])[a]	Number of studies in which the factor was mentioned as a facilitator	Number of studies in which the factor was mentioned as a barrier
Factors related to the specific social media		
Design and technical concerns		
Reminders[b]	3 [38,41,78]	1 [38]
Visual appearance[b]	1 [38]	1 [38]
Writing style[b]	1 [38]	1 [38]
Accessibility[b]	1 [38]	
Characteristics of the innovation		
Relative advantage (usefulness)		1 [35]
Ease of use/complexity		
General ease of use/complexity of the social media platform[b]		1 [38]
Rapid/lengthy access to the social media platform[b]	1 [38]	2 [66,78]
Popularity of the social media site or of the author[b]	1 [38]	
Legal issues		
Conflict of interest, promotion of commercial products[b]		1 [38]
Validity of the resources		
Scientific quality of the information resources		1 [38]
Content available (completeness)	1 [38]	1 [38]
Appropriate for the users (relevance)	1 [38]	
Environmental issues		
General online environment[b]		1 [78]
Computer issues[b]		1 [38]
Access to the Internet/limited access to the Internet[b]		2 [41,78]
Individual factors or health care professional characteristics (knowledge and attitude)		
Lack of time[b]		3 [38,41,61]
Human environment		
Factors associated with social media users		
Social media users/registered dietitian interaction	3 [35,38,41]	
Other factors associated with social media users		
Identification of other social media users[b]	1 [41]	
Social media users should log in at the same time[b]	1 [78]	
Requirement to respond to other social media users' posts[b]	1 [78]	
Social support from other users[b]	2 [38,61]	

[a]The following modifications were made to the Gagnon et al taxonomy [31] to fit the context of social media in dietetic practice: the term "Information and Communication Technologies (ICT)" was replaced with "social media," the term "patients" was replaced with "social media users," and the term "health professional" was replaced with "registered dietitian."

[b]These new factors did not exist in the Gagnon et al taxonomy [31].

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Discussion

Principal Findings

Using a scoping review methodology, we aimed to systematically map the literature available on social media in dietetic practice and to identify knowledge gaps. We found that this literature is relatively young but that it is growing fast. Most of the research results in this field have been published from 2013 onward. We retrieved 10 study protocols; therefore, new evidence can be expected in the near future. So far, research targeting social media written by RDs for diet and food-related purposes consisted mostly of experimental (eg, randomized controlled trials) and quasi-experimental studies in the context of weight management (ie, weight loss, prevention of weight gain, and prevention of unhealthy gestational weight gain) among overweight or obese adult users.

Although we can sense a growing interest among dietetic professional associations to promote an ethical and professional use of social media by RDs to improve knowledge translation in nutrition (7 expert opinion papers were published in the *Journal of the Academy of Nutrition and Dietetics*), we were intrigued to find only 4 intervention studies targeting RDs as social media users. Those studies were conducted in limited contexts of social media use (ie, continuing professional education and knowledge translation of evidence-based practice guidelines). There is also limited evidence of RDs' perspectives regarding the barriers and facilitators to the use of social media. From the perspective of lay users, the interaction with an RD through social media was mentioned as an essential facilitator to their behavior change process. However, we have yet to understand what constitutes quality exchanges between users and RDs through social media, how much bidirectional interaction is needed between users and RDs to provide clinically significant changes in dietary behaviors and outcomes, and what are RDs' perspectives in those communications. Globally, research aiming at identifying adoption factors of social media in dietetic practice has only focused on healthy eating blogs, discussion forums, and Facebook. More research is needed on barriers and facilitators related to the use of other social media platforms such as collaborative projects (eg, wikis), virtual social worlds, and content communities (eg, Pinterest, YouTube), and how to make these tools useful for RDs to reach patients and health consumers.

So far, research on social media in dietetic practice has globally aimed to address, with only a few exceptions, one main question: *Are social media effective tools to promote dietary, physical activity, or lifestyle-related behavior change?* However, more work will be needed to provide a clear answer to this question. In general, neutral effects of the use of social media in dietetic practice on outcomes such as users' health behaviors and status (eg, dietary intakes, body weight, and clinical indicators), compliance, participation and retention rates, and professional knowledge and self-efficacy have been reported in the literature. In concordance with a scoping review of social media use among patients and caregivers [95], these findings were mostly drawn from complex interventions where social media platforms were one component among various others, such as emails, interactive websites, and face-to-face consultations, for peer and counselor support in healthy behavior change. Few types of social media platforms have been evaluated or compared. Most intervention studies evaluated discussion forums, which are the oldest forms of social media and have the lowest scores in respect to social presence and media richness, as they are text-based and hence only allow for simple exchanges [7]. We found no study conducted uniquely with social media platforms such as Instagram, which has emerged as a popular tool to share food-related pictures [96] and convey social media norms regarding healthy eating [97,98], or Twitter, which has been recognized as a useful channel for the sharing and dissemination of health information [99,100]. Therefore, although best practices for the evaluation of the effectiveness of social media remains a debated question among behavioral research scientists [101], more research is needed to draw clear conclusions regarding the effectiveness of social media in dietetic practice and their mechanisms of action to support cost-effective and clinically significant behavior change.

This scoping review highlights a number of important knowledge gaps in the literature. As common difficulties in Web-based interventions include low actual reach, declined usage of online tools, and high attrition rates [102], there is a need for collaborative research and participatory action research to sustain a meaningful engagement of knowledge users. We have found only 4 studies addressing users' salient beliefs and perceptions to design evidence-informed social media platforms for healthy behavior change. Many RDs working fields and dietetic-related outcomes have not yet been portrayed in the social media scientific literature. For example, the use of social media in the fields of child-feeding behaviors, food skills self-efficacy and acquisition, and the dissemination and implementation of social media-based nutrition interventions are yet to be investigated. As opposed to other fields in health care, such as medicine [103-105] and online health communities [106] for which content analyses of social media tools have been previously published, we only identified 2 content analysis studies of social media written by RDs and both focused on food blogs. Further comparative content analysis of social media written by RDs compared with layperson would help deepen our understanding of the quality and extent of nutrition information disseminated through social media. In addition, despite the unprecedented growth in the popularity of social media worldwide [107], recent studies have highlighted social inequalities in health, notably older and less educated individuals who represent an important percentage of the population who uses the Internet for health purposes [108,109]. Most of the evidence regarding the effectiveness and the use of social media in dietetic practice is based on adult populations living in developed countries such as the United States, Australia, and Canada, thus limiting the generalization of the results to other populations. Finally, women were the target population in most of the studies included in this review. It is now well recognized that women and men differ in their dietary intakes, eating behaviors, and meal preparation and cooking skills [110-113], and previous studies have identified gender differences on specific social media platforms usage (ie, women are more likely than men to use Pinterest, Facebook, and Instagram [114] and health forums [115]). Thus, there is a need for more research

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on gender-sensitive dietary interventions delivered through social media.

Limitations

This scoping review was subject to some limitations that must be acknowledged. First, as performed in previous scoping reviews of social media use in health care settings [95,116], we categorized studies according to Kaplan and Haenlein's social media definition [7], and we thought it was important to also include discussion forums as they represent the earliest form of user-generated content online. This methodological consideration orients the conclusions that can be drawn from this review. Second, despite an exhaustive search in relevant scientific databases and the reference lists of the identified studies as well as the gray literature, we cannot exclude the possibility that we missed some studies. Third, we included only studies written in English or French for time and budget constraints. Finally, given the fast-growing adoption of social media by health care professionals [9,10], we anticipate that the social media in dietetic practice literature will expand exponentially; this scoping review is limited to peer-reviewed studies or gray literature published before November 2016 (with the addition of one study [94]).

Conclusions

Research on social media in dietetic practice is at its infancy, but it is growing fast. So far, this field of research has targeted limited social media platforms (ie, discussion forums, blogs, and Facebook), which were mostly evaluated in multiple-component interventions for weight management among overweight or obese adults. Trials isolating the effects and mechanisms of action of specific social media platforms are needed to draw clear conclusions regarding the effectiveness of those tools to support cost-effective and clinically significant behavior change. More work is also needed on barriers and facilitators underlying the use of social media written by RDs, and how to make these tools useful for RDs to reach patients and health consumers with diverse sociodemographic characteristics to improve dietary behaviors and help reduce social inequalities in health.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Medline search term strategy and number of results (November 2016).

[PDF File (Adobe PDF File), 30KB - jmir_v20i2e55_app1.pdf]

Multimedia Appendix 2

Characteristics of included studies.

[PDF File (Adobe PDF File), 112KB - jmir_v20i2e55_app2.pdf]

Multimedia Appendix 3

Types of outcomes assessed in intervention studies using social media comparing single or multiple intervention groups with a control group with no social media access (N=14 studies).

[PDF File (Adobe PDF File), 59KB - jmir_v20i2e55_app3.pdf]

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Abbreviations

RD: registered dietitian
SMART: Social Mobile Approaches to Reduce weighT

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Original Paper

The Effect of Doctor-Consumer Interaction on Social Media on Consumers' Health Behaviors: Cross-Sectional Study

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Abstract

Background: Both doctors and consumers have engaged in using social media for health purposes. Social media has changed traditional one-to-one communication between doctors and patients to many-to-many communication between doctors and consumers. However, little is known about the effect of doctor-consumer interaction on consumers' health behaviors.

Objective: The aim of this study was to investigate how doctor-consumer interaction in social media affects consumers' health behaviors.

Methods: On the basis of professional-client interaction theory and social cognitive theory, we propose that doctor-consumer interaction can be divided into instrumental interaction and affective interaction. These two types of interactions influence consumers' health behaviors through declarative knowledge (DK), self-efficacy (SE), and outcome expectancy (OE). To validate our proposed research model, we employed the survey method and developed corresponding measurement instruments for constructs in our research model. A total of 352 valid answers were collected, and partial least square was performed to analyze the data.

Results: Instrumental doctor-consumer interaction was found to influence consumers' DK (t_{294}=5.763, P<.001), SE (t_{294}=4.891, P<.001), and OE (t_{294}=7.554, P<.001) significantly, whereas affective doctor-consumer interaction also impacted consumers' DK (t_{294}=4.025, P<.001), SE (t_{294}=4.775, P<.001), and OE (t_{294}=4.855, P<.001). Meanwhile, consumers' DK (t_{294}=3.838, P<.001), SE (t_{294}=3.824, P<.001), and OE (t_{294}=2.985, P<.01) all significantly affected consumers' health behaviors. Our mediation analysis showed that consumers' DK, SE, and OE partially mediated the effect of instrumental interaction on health behaviors, whereas the three mediators fully mediated the effect of affective interaction on health behaviors.

Conclusions: Compared with many intentional intervention programs, doctor-consumer interaction can be treated as a natural cost-effective intervention to promote consumers' health behaviors. Meanwhile, both instrumental and affective interaction should be highlighted for the best interaction results. DK, SE, and OE are working mechanisms of doctor-consumer interaction.

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KEYWORDS

physician patient relationships; health behavior; social media; social theory; psychological theory; medical informatics

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Introduction

Background

Social media is penetrating people's daily life and influencing their health-related activities. Consumers, patients and nonpatients included, are interacting with health professionals or with each other on social media more often than ever before. In the United States, 81% of adults have social media profiles [1]. In China, the most populous country in the world, the number of social media consumers is estimated to reach 679.19 million by 2021 [2]. A US-based study indicates that nearly one-third of consumers' health-related activities are conducted through social media and almost two-third of consumers search for information regarding a specific doctor or a health professional using social media [3]. Moreover, almost half of consumers claim that information from social media affects their health-related decisions, and more than half of them trust doctors' Web-based posts or blogs [4]. Currently, more than 60% of doctors use various forms of social media for personal or professional reasons, and this percentage has been increasing in recent years [5]. Both consumers and doctors have engaged in using social media to disseminate health-related information, and therefore, social media could be an important medium for interactions between doctors and consumers.

Social media are Internet-based applications that build on Web 2.0 techniques to allow the creation and exchange of user-generated content. These applications can replace the traditional one-to-one communication with the many-to-many communication paradigm between patients and doctors [6]. However, doctors' behaviors on social media may be different from those in the offline context. It may be challenging to apply principles of medical practice for doctors in the social media setting because social media may make them feel less restrained [7]. Besides, social media empowers consumers by providing them with not only the opportunities to interact with many doctors at the same time but also the access to know other consumers with similar interests or experiences [8]. Moreover, the content of interaction may be different in a social media setting. As doctors cannot provide medical diagnosis or treatment using social media directly, the health problems discussed during the interaction may not be acute and serious, consumers may feel less anxious, and therefore, doctors' affective behaviors may not be as important as they are in the offline context. Hence, the new communication approach, behaviors, and content affect the relationship between consumers and health professionals, which may influence consumers' health outcomes and well-being [9].

Despite the fact that individuals' health outcomes of using social media, including health-related emotions, physical conditions, and beliefs, have been well studied, social media's impact on health behaviors is less understood [10]. Improving health behaviors, such as ceasing smoking, increasing physical activity, keeping a healthy diet, and avoiding overconsumption of alcohol, can substantially lower the risk of dying prematurely [11]. Health behaviors have been found to be correlated with many chronic noninfectious diseases such as diabetes [12], hypertension [13], stroke [14], Alzheimer disease [15], and even cancer [16]. Moreover, unhealthy lifestyle leads to poor health status, obesity [17], depression, anxiety [18], and even poor academic performance [19]. Improving health behaviors at the population level also helps promote health equity in the society [20]. Given the significant impact of health behaviors, policy makers in different countries have taken actions to promote health behaviors. For example, the US Department of Health and Human Services has introduced Healthy People 2020 to promote health behaviors [21]. In the meantime, the State Council of China has set promoting healthy lifestyle among Chinese people as one of the major goals of the Healthy China 2030 Program [22]. Therefore, developing effective interventions to improve health behaviors is very meaningful and contributive. With regard to health behaviors in the social media context, prior literature has shown that several interventions based on social media are effective in changing patients' behaviors and promoting their health status [23-25]. Nevertheless, the effect of interaction between doctors and consumers on social media on consumers' health behaviors has not been studied. Thus, our research question is as follows:

> How does doctor-consumer interaction on social media influence consumers' health behaviors?

Overall, we hypothesize that doctor-consumer interaction influences consumers' health behaviors significantly through some potential pathways. Compared with health promotion interventions using traditional approaches, doctor-consumer interaction on social media could be a low-cost health promotion intervention [26]. Therefore, it is worth evaluating the effect of doctor-consumer interaction and identifying the mechanisms of how it works. To address this question, we ground our research on professional-client interaction theory to conceptualize doctor-consumer interaction in the social media context and social cognitive theory to explore the working mechanisms of doctor-consumer interaction.

Theoretical Foundation

In this study, we integrate professional-client interaction theory and social cognitive theory to help us understand the effect of doctor-consumer interaction on health literacy. Professional-client interaction theory is mainly used to comprehend doctor-consumer interaction because the subtypes of interaction can be used to describe doctor-consumer interaction, whereas social cognitive theory is used to explore the working mechanisms of doctor-consumer interaction in this study because the interaction can be treated as a learning process.

Professional-client interaction theory claims that physicians' behaviors toward patients in physician-patient interaction could be classified as instrumental behaviors and affective behaviors [27]. Instrumental behavior is about the content of physicians' behaviors that focuses on the solution of a health problem, whereas affective behavior is about the mode of physicians' behaviors that requires physicians to treat patients as a person rather than a case [28]. We argue that the categorization of physicians' behaviors toward patients in professional-client interaction can be extended to the social media context as doctors can still solve consumers' health problems and provide emotional support on social media. To contextualize the

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professional-client interaction in the social media context, we divide doctor-consumer interaction into instrumental interaction and affective interaction [29]. On the basis of instrumental behavior, we define instrumental interaction as a doctor-consumer interaction that focuses on the solution of consumers' health concern. Toward affective interaction, we define it as the interaction that cares about consumers' emotions in line with affective behaviors. The effect of instrumental and affective interaction is reasoned and hypothesized in the following sections.

Social cognitive theory, originally labeled as social learning theory, assumes that one learns by observing models' behaviors and performs their behaviors in the social context [30]. Meanwhile, the maintenance of learned behaviors over time depends on self-regulation and reinforcement. Learned behaviors are results of the dynamic reciprocal interaction among personal, behavioral, and environmental determinants. Furthermore, learned behaviors continue to interact with personal and environmental determinants in the reinforcement process, where beneficial behaviors are repeated and others are avoided. The determinants of learned behaviors can be categorized into 5 categories: outcome expectancy (OE), observational learning, environmental factors, self-regulation, and moral disengagement [31]. Besides, among environmental factors, incentive motivation and facilitation are the 2 main factors [32]. Incentive motivation is a reward or punishment from the environment, whereas facilitation is a resource or tool for facilitating behaviors. In our study, through interacting with doctors on social media, consumers' health behaviors can be developed in the interaction process because doctors can be the role model or the information source of healthy lifestyle behaviors. Therefore, doctor-consumer interaction can be treated as a learning process and be understood by social cognitive theory. The determinants of learned behaviors in social cognitive theory could be referred to explore the determinants of health behaviors.

Research Model and Hypotheses

According to professional-client theory, we divide doctor-consumer interaction into instrumental interaction and affective interaction. Meanwhile, according to social cognitive theory, we propose that the 2 types of interaction influence consumers' health behaviors through declarative knowledge (DK), self-efficacy (SE), and OE. The specific hypothetic relationships are depicted in Figure 1.

Declarative Knowledge, Self-Efficacy, Outcome Expectancy, and Health Behaviors

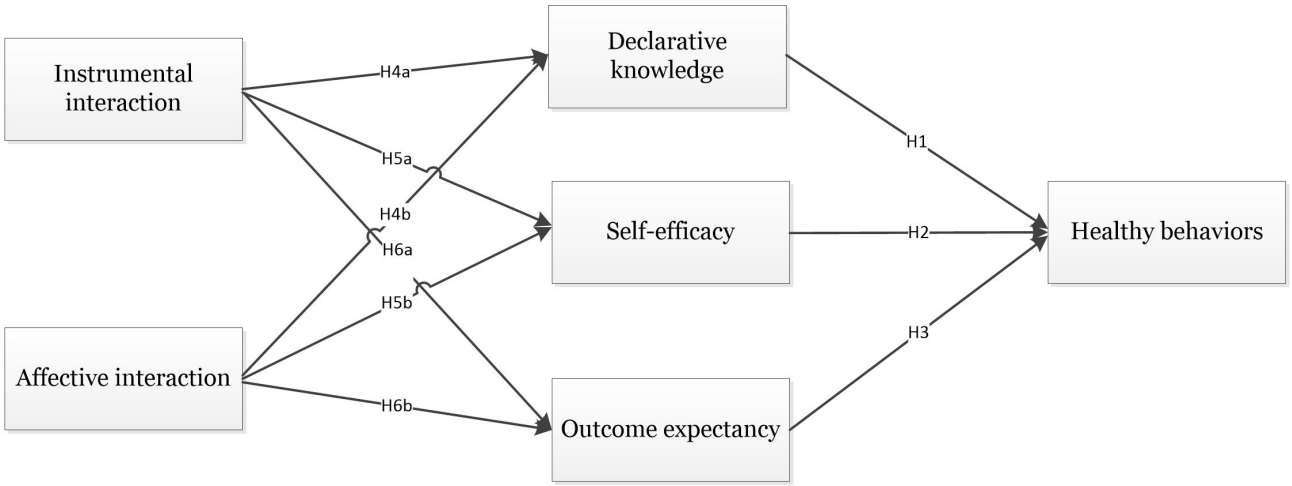
According to the content of knowledge, knowledge can be classified as declarative knowledge and procedural knowledge [33]. DK is about facts and things that concern the static properties of objects, persons, or events, whereas procedural knowledge is about dynamic skillful actions. For example, information about attributes, facts, and situations is declarative knowledge, whereas procedures for actions or experience are usually referred to as procedural knowledge. Therefore, DK is easy to be communicated and described by verb, whereas procedural knowledge should be acquired in practice. Because consumers only can learn the procedural knowledge when they practice it, DK is more feasible and suitable in our context. Because DK can help people access to the meaning of health behaviors [34], the meaning of health behaviors influences people's attitudes and their behaviors. Therefore, we can hypothesize the following:

> H1: DK positively influences consumers' health behaviors.

SE is people's judgment of their capability to perform a specific behavior or task [30]. It has 3 dimensions: magnitude, strength, and generalizability. Magnitude of SE refers to the degree of difficulty to which people believe they can attain a certain kind of behavior, whereas strength of SE is confidence about the judgment. Generalizability reflects the degree to which the judgment can be generalized to different situations. In our context, SE can be consumers' judgment to master the cognitive and social skills to improve or maintain their health status. As SE can affect people's level of effort and persistence on a specific behavior according to the dimensions of SE [35], high SE may lead people to put in more effort to do the behaviors and insist on them longer. Hence, we can hypothesize the following:

> H2: SE positively influences consumers' health behaviors.

Figure 1. Research model.



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OE refers to the belief that the expected outcomes are resulted in given behaviors [36]. Three forms of OE exist, including physical form, social form, and self-evaluation form. Physical outcomes include positive and negative effects of behaviors, while the given behaviors may also receive social approval and disapproval. Self-evaluation toward the given behaviors may also be positive or negative [37]. Consumers' behaviors are regulated by these different forms according to given behaviors' consequences. In our study, OE is about whether consumers' interaction with doctors on social media can solve their health concerns or problems. Since people are generally rational, their self-interest behaviors can be regulated by the outcomes of behaviors [38]. Positive outcomes may stimulate people to implement the corresponding behaviors. Therefore, we can hypothesize the following:

H3: OE positively influences consumers' health behaviors.

Doctor-Consumer Interaction and Declarative Knowledge

In doctor-consumer interaction, consumers not only have opportunities to ask more questions to doctors but also have access to health information from other sources. Therefore, the doctor-consumer interaction makes consumers acquire health information that can be processed and authenticated to form health knowledge [39]. Given that consumers who interact with doctors on social media can use only Web-based digital tools including texts, pictures, or videos, they cannot make use of the health information on social media directly. Therefore, doctor-consumer interaction can increase consumers' DK. With regard to 2 types of doctor-consumer interaction, consumers can receive information about their health problems directly in instrumental interaction and get information about dealing with their anxiety in affective interaction [40]. Thus, we can hypothesize the following:

H4a: Instrumental interaction between consumers and doctors on social media positively influences consumers' DK.

H4b: Affective interaction between consumers and doctors on social media positively influences consumers' DK.

Doctor-Consumer Interaction and Self-Efficacy

Four information cues have been proposed to influence the formation of SE: enactive mastery, vicarious experience, verbal persuasion, and emotional arousal [41]. Enactive mastery is people's performance attainment, whereas vicarious experience is from behavioral models. Verbal persuasion is to make people believe their capability of doing some tasks, whereas emotional arousal is the psychological state that arouses people's capability. In doctor-consumer interaction, doctors can be the behavioral models who give vicarious experience to consumers and may persuade consumers to develop health behaviors. In our study, toward the relationship between doctor-consumer interaction and SE, vicarious experience and verb persuasion can be the mediating processes. Thus, we can hypothesize the following:

H5a: Instrumental interaction between consumers and doctors on social media positively influences consumers' SE.

H5b: Affective interaction between consumers and doctors on social media positively influences consumers' SE.

Doctor-Consumer Interaction and Outcome Expectancy

Consumers' OE can also be affected by vicarious experience [42]. Positive learned experience conveys the possible reward of doing specific behaviors and strengthens one's expectation of positive outcome. In our study, as doctors can be health models and provide support to consumers during the interaction with them, the possibilities of solving consumers' health problems and performing healthy lifestyle behaviors are increased [43]. Meanwhile, interacting with doctors on social media enforces the social ties between consumers and doctors and helps consumers acquire different kinds of social support from doctors. Thus, we can hypothesize the following:

H6a: Instrumental interaction between consumers and doctors on social media positively influences consumers' OE.

H6b: Affective interaction between consumers and doctors on social media positively influences consumers' OE.

Methods

Data Collection

Data were collected in China, which has the largest social media market in the world. The Web-based survey was conducted using Zhubajie, which is the biggest crowdsourcing platform in China. Survey announcement was posted in Zhubajie, and registered service providers were invited to fill the questionnaires. In the announcement, we set several requirements to judge whether the answers were qualified. The requirements included using social media, having experiences of interacting with doctors on social media, and filling the questionnaire sincerely, etc. Service providers whose answers met our requirements received a token of appreciation, whereas providers who failed our requirements did not receive the token. Participants also provided informed consent before they filled the questionnaires. After 2 weeks, we obtained a total of 435 responses from Chinese social media consumers who had experienced interactions with doctors on social media.

Because we used Web-based data, several actions were taken to ensure the validity of dataset [44]. To identify the applicable respondents, we set screening questions to check whether the respondents were consumers who interacted with doctors on social media, such as whether participants followed doctors on social media, whether they replied to doctors' posts on social media, and whether they forwarded doctors' posts on social media. To avoid responses from experienced survey takers or ones with less attention, we discarded 39 cases that took less than 5 min and checked the cases with missing values or similar values for all questions. To address cheating issues, we did not use the data from respondents who had not correctly responded

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to the set reverse-coded questions. Thus, we were left with 352 complete and valid responses. In this sample, most of the respondents were in the age group of 25-30 years, were females, possessed a college degree, and were familiar with using social media. This is reasonably consistent with the report of China Internet Network Information Center on demographics of Chinese social media consumers [45]. The specific demographic information of our final sample is summarized in Table 1.

Measurement Instrument

To validate our research model, we used the survey method in this study. The survey instrument was developed by adapting previously validated scales to the context of our study. Items for affective and instrumental interaction were adapted from Ben-Sira who had studied relevant variables [28]. Items for DK and health behaviors were adapted from the Activity Question Scale, Nutrition Knowledge Scale, and Health Lifestyle Behavior Scale [46]. Items for SE were adapted from the General Self-Efficacy Scale [47] and those for OE were from the Anderson et al study, which had covered OE in other context [48]. A total of 42 items that contain screening questions and demographic questions were presented in the questionnaire. All items were measured on a 5-point Likert scale with anchors ranging from strongly disagree to strongly agree.

As the survey instrument was originally developed in English, we used the back translation method to translate it into Chinese. The English instrument was first translated into Chinese by one of the bilingual authors, TW, whose native language was Chinese. Next, another bilingual author, DZ, back translated the Chinese version into English. The 2 authors then compared the 2 English versions to check for inconsistency, if any. A pretest was conducted on the developed survey instrument by interviewing 8 experts in the area of information systems, medical informatics, and health management and 17 users of social media. We further revised the questionnaire based on the comments and suggestions received. The survey instrument is presented in Multimedia Appendix 1.

Statistical Analysis

This study employed structural equation modeling using partial least square (PLS) analysis. As the second-generation multivariate causal analysis method, PLS can be applied to complex structural equation models and is less restrictive on sample size than other methods [49,50]. Meanwhile, PLS is suitable for exploratory studies as it aims at theory building rather than theory testing. The analysis was conducted by using SmartPLS 2.0.3M of SmartPLS GmbH in Germany [51].

We analyzed the reliability and validity of measurement instruments using confirmatory factor analysis. As shown in Table 2, all Cronbach alpha and composite reliabilities are above 0.6, thus demonstrating reliability for all constructs [52]. The value of average variance extracted (AVE) of each construct is above 0.5 and items' loadings are above 0.7, thus demonstrating good convergent validity [52]. On the basis of the results shown in Table 3, the square roots of the AVEs are all greater than the interconstruct correlations, thus demonstrating discriminant validity [53]. Hence, we conclude that the quality of the measurement model is adequate for testing hypothesized relationships.

Table 1. Demographic information.

Characteristics	n (%)
Age in years	
<25	122 (34.7)
25-30	150 (42.6)
>30	80 (22.7)
Gender	
Male	153 (43.5)
Female	199 (56.5)
Education	
High school	35 (9.9)
College	304 (86.4)
Master's degree and above	13 (3.7)
Duration of using social media within a day	
<1 hour/day	164 (46.6)
1-3 hours/day	128 (36.4)
>3 hours/day	60 (17)
Experiences of using social media	
<1 year	29 (8.2)
1-5 years	201 (57.1)
More than 5 years	122 (34.7)

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We also examined the possibility of common method bias in our study. First, we looked into the correlational coefficients among variables in Table 3 and found that none of the pairs had a very high correlation (r>.90) [53]. Second, we conducted Harman single-factor test using principle component analysis in SPSS 18.0 of International Business Machines Corporation in United Stated. Ten factors were extracted and the first factor in the unrotated solution explained 31%, which is less than 50% [54]. Third, we employed the marker variable technique to test common method bias [55]. We used perceived organizational support as the marker variable. The average correlation among perceived organizational support and those of the principle constructs is r=.198. Therefore, common method bias may not be an issue in our study.

Table 2. Construct reliability and convergent validity.

Construct and items	Factor loadings	Composite reliability	Average variance extracted	Cronbach alpha
Instrumental interaction (INI)				
INI1	0.8021	0.8125	0.5912	.6547
INI2	0.7388			
INI3	0.7644			
Affective interaction (AI)				
AI1	0.7639	0.8051	0.5793	.6369
AI2	0.7704			
AI3	0.7489			
Declarative knowledge (DK)				
DK1	0.7566	0.8564	0.5444	.7912
DK2	0.769			
DK3	0.7582			
DK4	0.7022			
DK5	0.7002			
Self-efficacy (SE)				
SE1	0.7798	0.8876	0.6124	.8419
SE2	0.7624			
SE3	0.7873			
SE4	0.7869			
SE5	0.796			
Outcome expectancy (OE)				
OE1	0.7635	0.8342	0.6239	.6983
OE2	0.8345			
OE3	0.7697			
Health behaviors (HB)				
HB1	0.8094	0.9021	0.5688	.8737
HB2	0.7335			
HB3	0.7244			
HB4	0.7611			
HB5	0.731			
HB6	0.7916			
HB7	0.7232			

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Table 3. Discriminant validity. The square roots of average variance extracted (AVEs) are in italics.

Constructs	Instrumental interaction	Affective interaction	Declarative knowledge	Self-efficacy	Outcome expectancy	Health behaviors
Instrumental interaction	*0.7681*					
Affective interaction	0.558	*0.7611*				
Declarative knowledge	0.4757	0.4346	*0.7378*			
Self-efficacy	0.4204	0.4217	0.2574	*0.7826*		
Outcome expectancy	0.5193	0.4653	0.5408	0.3536	*0.7899*	
Health behaviors	0.4463	0.403	0.3924	0.39	0.3597	*0.7542*

Results

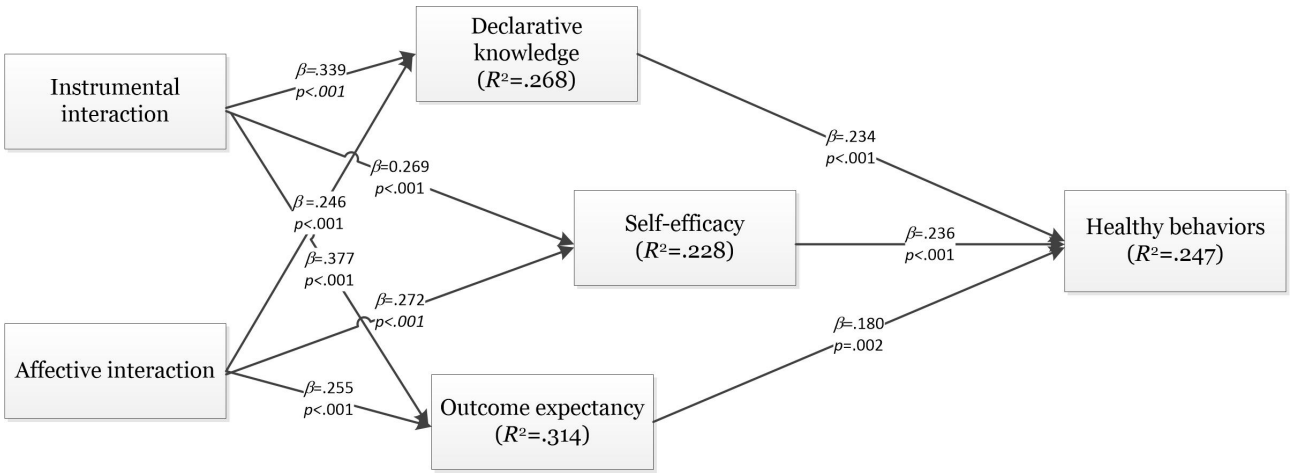
Analysis Results of Hypothesized Model

PLS with bootstrapping procedure was used to test the hypothesized model. Estimates derived from the PLS analysis were used to test the research hypotheses. The results of the analysis are summarized in Figure 2. The results revealed that DK, SE, and OE significantly influenced consumers' health behaviors. The significant effect of these 3 constructs demonstrated the explanatory power of social exchange theory. Therefore, H1, H2, and H3 were all supported. With regard to the impact of the interaction between doctors and consumers, the results showed that both types of doctor-consumer interactions significantly affected consumers' DK, SE, and OE. These results manifested that the interaction between doctors and consumers on social media could increase consumers' DK of health, enforce their SE of doing healthy lifestyle behaviors, and lead to positive OE of doing healthy lifestyle behaviors. Therefore, H4a, H4b, H5a, H5b, H6a, and H6b were all supported.

Mediation Analysis of Declarative Knowledge, Self-Efficacy, and Outcome Expectancy

To test the mediation role of DK, SE, and OE, we adopted the bootstrapping technique [56,57]. Compared with traditional methods such as the Baron and Kenny [58] method and the Sobel [59] method, the bootstrapping method can test the indirect effect of independent variables on dependent variables directly and does not require the normal distribution of mediation effect [60]. In this study, the 95% confidence interval of the indirect effects was obtained with 5000 bootstrap resamples. By using the SmartPLS 2.0 M3 [51], we summarize the mediation analysis results in Table 4. According to the results, the indirect effects of instrumental interaction and affective interaction on health behaviors were significant. Therefore, DK, SE, and OE significantly mediated the relationship between doctor-consumer interaction and health interaction. Meanwhile, based on the significance of direct effect, the effect of instrumental interaction on health behaviors was partially mediated by that of DK, SE, and OE, whereas the relationship between affective interaction and health behaviors was fully mediated by that of DK, SE, and OE.

Figure 2. Analysis results of structural model.



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Table 4. Mediation analysis using bootstrapping method.

Independent variable	Mediating variable	Dependent variable	Indirect effect			Direct effect			Mediation proportion
			2.5% CI	97.5% CI	Effect value	2.5% CI	97.5% CI	Effect value	
INI[a]	DK[b]	HB[c]	0.0275	0.1311	0.0793	0.0744	0.3096	0.1920	Partial mediation
INI	SE[d]	HB	0.0186	0.1084	0.0635	0.0744	0.3096	0.1920	Partial mediation
INI	OE[e]	HB	0.0159	0.1198	0.0679	0.0744	0.3096	0.1920	Partial mediation
AI[f]	DK	HB	0.0180	0.0972	0.0576	−0.0050	0.2437	0.1220	Full mediation
AI	SE	HB	0.0181	0.1103	0.0642	−0.0050	0.2437	0.1220	Full mediation
AI	OE	HB	0.0057	0.0861	0.0459	−0.0050	0.2437	0.1220	Full mediation

[a]INI: instrumental interaction.

[b]DK: declarative knowledge.

[c]HB: health behaviors.

[d]SE: self-efficacy.

[e]OE: outcome expectancy.

[f]AI: affective interaction.

Discussion

Principal Findings

In this paper, we studied the effect of doctor-consumer interaction on social media on consumers' health behaviors empirically. On the basis of professional-client interaction theory, we divided doctor-consumer interaction into instrumental interaction and affective interaction and conceptualized them in the social media context. In the meantime, depending on social cognitive theory, we proposed 3 variables that mediate the relationship between doctor-consumer interaction on social media and consumers' health behaviors: DK, SE, and OE. To test our hypotheses, we established a research model by integrating the above theories and developing corresponding measurement instruments. By using the survey method, we collected data from consumers who had the experience of interacting with doctors in China. By analyzing the data, we found that all our hypothetical relationships were supported. Therefore, we can conclude that interacting with doctors on social media can improve consumers' health behaviors.

Furthermore, we also looked into the mediation effect of the 3 proposed mediators. By using the advanced bootstrapping method, we discovered that the effect of instrumental interaction on health behaviors was partially mediated by DK, SE, and OE, whereas the effect of affective interaction on health behaviors was fully mediated by the above mediators. Therefore, the 3 mediators are adequate to explain the process from instrumental interaction to health behaviors, whereas more potential mediators are needed to be explored for the effect of affective interaction on health behaviors.

Implications

This study brings a few interesting contributions to theory and practice. From the theoretical perspective, we extend professional-client interaction theory into the social media context by conceptualizing doctor-consumer interaction in social media and dividing it into instrumental and affective interaction. Our empirical study confirms the effectiveness of this extension. Meanwhile, the 2 types of interaction provide a deep insight into understanding the role of doctor-consumer interaction.

Second, we integrate professional-client interaction theory and social cognitive theory in this study. Professional-client interaction theory helps us understand doctor-consumer interaction in the social media context, whereas social cognitive theory points out the underlying working mechanisms of the effect of doctor-consumer interaction. By integrating these 2 theories, we describe a full map of the role of doctor-consumer interaction.

Third, we propose and test 3 working mechanisms of doctor-consumer interaction. DK, SE, and OE are proposed as the working mechanisms based on social cognitive theory. Compared with previous literature, we first consider the role of DK in health behaviors and test all the 3 factors in the social media context. Especially, our mediation analysis uncovered that these 3 mediators fully mediated the effect of affective interaction and partially mediated the effect of instrumental interaction.

From a practical perspective, this study suggests that doctor-consumer interaction can be considered as a natural intervention to change consumers' health behaviors and then their health status. Therefore, compared with traditional offline health education and promotion activities, health care providers and health educators could pay attention to doctors' activities on social media. Doctor-consumer interaction guidelines should be developed. Meanwhile, consumers should be encouraged to interact with doctors on social media.

Second, both instrumental and affective interaction could be considered in doctor-consumer interaction on social media. Compared with interaction in the offline context, the role of affective interaction should be highlighted in the social media context. For example, besides providing professional suggestions to consumers, doctors should show their interests on consumers' health problems and give them enough chances to express their anxiety and confusion.

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Finally, the proposed working mechanisms can help evaluate the effectiveness of doctor-consumer interaction. Health care providers and health educators can even refer our measurement scales to check the effects of their interaction with consumers on social media.

Limitations and Future Work

The results of this study should be interpreted in the light of its limitations. First of all, we have indeed identified several working mechanisms of doctor-consumer interaction; however, our mediation analysis indicates that more working mechanisms await exploration, especially for the instrumental effect. Future studies can consider other mediators and other theoretical perspectives to improve the validity of our research model. Moreover, interaction among consumers about health problems may also influence consumers' attitude toward health behaviors. Future studies can include both doctor-consumer interaction and consumer-consumer interaction.

Second, the generalizability may be restricted as our sample is restricted to Chinese consumers rather than people from other countries. In China, the two most popular social media platforms are WeChat and Weibo [45], but in other countries, other social media platforms such as Facebook or Twitter are more dominant. Differences between WeChat or Weibo and social media platforms in other countries exist. For example, Twitter is a global microblogging service provider and keeps itself simple, whereas Weibo focuses on China and adds many features in its platform [61]. These differences may make consumers in these 2 platforms behave differently. Future studies may conduct cross-country comparisons to better generalize the results of this study.

Third, our study is a cross-sectional one in which constructs were measured at the same point of time. However, as consumer behavior and social media are both dynamic, the results may change with the passage of time. Therefore, the cross-sectional design may not reflect the dynamics of social media usage. Meanwhile, the time sequence of independent variables, mediators, and dependent variables could not be revealed in a cross-sectional survey. A longitudinal study that collects the data of different variables at different times may help address this issue.

Finally, although the explained variance of health behaviors in our structural model is acceptable, some unexplained variance remains and other relevant factors should be explored. In this study, we applied the social cognitive theory and only considered the personal factors including DK, SE, and OE to explain health behaviors; other situational and environmental factors should be included in future studies. Moreover, other theories such as the health belief model could be applied to understand health behaviors [62].

Conclusions

This paper contributes to the literature on doctor-patient communication by investigating doctor-consumer interaction on social media. Our study demonstrated the important role of doctor-consumer interaction on social media for consumers' health behaviors. This result not only implies that social media could be feasible channels to promote consumers' health behaviors but also reveals that doctors could consider engaging in using social media to interact with consumers for health purposes. The significant mediating role of DK, SE, and OE consists of the working mechanisms of doctor-consumer interaction on social media. Theoretical and practical implications for leveraging social media to promote health behaviors are provided.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Measurement instruments.

[PDF File (Adobe PDF File), 34KB - jmir_v20i2e73_app1.pdf]

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Abbreviations

AI: affective interaction
AVE: average variance extracted
DK: declarative knowledge
HB: health behaviors
INI: instrumental interaction
OE: outcome expectancy
SE: self-efficacy

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Original Paper

Attitudes Toward e-Mental Health Services in a Community Sample of Adults: Online Survey

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Abstract

Background: Despite evidence that e-mental health services are effective, consumer preferences still appear to be in favor of face-to-face services. However, the theory of planned behavior (TPB) suggests that cognitive *intentions* are more proximal to behavior and thus may have a more direct influence on service use. Investigating individual characteristics that influence both preferences and intentions to use e-mental health services is important for better understanding factors that might impede or facilitate the use of these services.

Objective: This study explores predictors of preferences and intentions to access e-mental health services relative to face-to-face services. Five domains were investigated (demographics, technology factors, personality, psychopathology, and beliefs), identified from previous studies and informed by the Internet interventions model. We expected that more participants would report intentions to use e-mental health services relative to reported preferences for this type of support and that these 5 domains would be significantly associated with both intentions and preferences toward online services.

Methods: A mixed sample of 308 community members and university students was recruited through social media and the host institution in Australia. Ages ranged between 17 and 68 years, and 82.5% (254/308) were female. Respondents completed an online survey. Chi-square analysis and *t* tests were used to explore group differences, and logistic regression models were employed to explore factors predicting preferences and intentions.

Results: Most respondents (85.7%, 264/308) preferred face-to-face services over e-mental health services. Relative to preferences, a larger proportion of respondents (39.6%, 122/308) endorsed intentions to use e-mental health services if experiencing mental health difficulties in the future. In terms of the 5 predictor domains, 95% CIs of odds ratios (OR) derived from bootstrapped standard errors suggested that prior experience with online services significantly predicted intentions to use self-help (95% CI 2.08-16.24) and therapist-assisted (95% CI 1.71-11.90) online services in future. Being older predicted increased intentions to use therapist-assisted online services in future (95% CI 1.01-1.06), as did more confidence using computers and the Internet (95% CI 1.06-2.69). Technology confidence was also found to predict greater preference for online services versus face-to-face options (95% CI 1.24-4.82), whereas higher doctor-related locus of control, or LOC (95% CI 0.76-0.95), and extraversion (95% CI 0.88-1.00) were predictive of lower likelihood of preferring online services relative to face-to-face services.

Conclusions: Despite generally low reported preferences toward e-mental health services, intentions to access these services are higher, raising the question of how to best encourage translation of intentions into behavior (ie, actual use of programs). Strategies designed to ease people into new Internet-based mental health programs (to enhance confidence and familiarity) may be important for increasing the likelihood that they will return to such programs later.

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KEYWORDS

eHealth; mHealth; consumer preference; attitude

Introduction

Background

Mental illness presents a significant social and economic burden worldwide, contributing to approximately 13% of the total global burden of disease [1]. Estimated 12-month prevalence rates indicate that as many as one in five adults are likely to currently experience a mental illness, many of whom will not access mental health services or receive treatment [1,2]. Access to mental health care is often limited not only by the well-documented barriers of socioeconomic disadvantage and stigma but also by issues of accessibility, including geographical constraints and cost of services [3].

In an attempt to reduce such barriers to treatment, a number of national and global initiatives have been developed. For instance, the Australian Government has prioritized investment in the development and dissemination of e-mental health services as an alternative for those unable or unwilling to access traditional avenues of support [4]. A number of European nations are also currently working on a joint framework for mental health policy, with a key focus on the implementation of eHealth services in the treatment and prevention of mental illness [5]. A variety of services fall under the term e-mental health, including mental and behavioral health promotion, prevention, treatment and management-oriented interventions that are delivered via the Internet or other electronic technologies, with or without human support [6]. A number of meta-analyses have now shown these services to be comparable to face-to-face options in their effectiveness in treating mental illness [7-9].

Although effective, uptake of e-mental health services remains low [10,11]. For example, in a systematic review of computerized cognitive behavioral therapy (cCBT), Waller and Gilbody [12] reported that only 38% of those recruited into cCBT intervention trials began treatment (median rate), and individuals in cCBT treatments were almost twice as likely to drop out of the intervention as those in active control conditions. Low participation and retention rates have also been observed in other e-mental health service investigations [10]. Furthermore, face-to-face services tend to be viewed more favorably than e-mental health services, with the former rated as more helpful and trustworthy, capable of eliciting better engagement, and viewed more favorably regarding future use [10]. Low preference rates for online services (over face-to-face) are commonly reported, with findings ranging from 1.2% [13] to 29.6% [14] in some studies, whereas face-to-face services tend to have comparably higher rates of preference, ranging from 32.0% [15] to 96.4% [16]. These issues (negative perceptions, poor uptake, and retention rates) are of concern for those investing resources into e-mental health services and highlight the need for a better understanding of the factors that contribute to the use of these services.

The theory of planned behavior (TPB) [17] proposes that behavior can be predicted by intentions, which in turn are partly determined by one's attitudes toward that behavior. In other words, cognitive intentions theoretically have a more direct influence on behavior than attitudes or preferences, which may be more distal. In a study of young adults, Horgan and Sweeney [14] found that although most participants (79.4%) held a preference for face-to-face support and less than a third (30.8%) had previously used the Internet for mental health information, the majority (68.0%) of the sample indicated they would use the Internet for assistance if required, supporting the notion that preferences and intentions may be related but distinct constructs. Thus, the TPB would argue that greater knowledge of the factors that influence both preferences and intentions toward e-mental health services is important for better understanding the factors that impede or facilitate the use of these services.

The Internet interventions model [18] provides a unifying framework intended to guide the development and improve the understanding of behavior change within online interventions. The model posits that 9 components should be considered for effective development and evaluation of Internet-based treatments, including user characteristics, the environment, support, website characteristics, website use, mechanisms of change, behavior change, symptom improvement, and treatment maintenance. Although the focus of the model is on factors that may influence behavior change and outcomes throughout use of these interventions, it also conceptualizes factors that may contribute to a person's *use* of Internet interventions; thus, in line with TPB [17], we can infer that these factors may also play a role in shaping intentions and preferences toward e-mental health services. In this study, dual consideration of both the TPB and Internet interventions models provides a framework for identifying and examining potential factors that may influence preferences and intentions toward e-mental health services.

Under *user characteristics*, the Internet interventions model [18] identifies both fixed and modifiable factors that may influence use of, and outcomes from, Internet interventions, including (1) the disease (eg, psychopathology, disease severity, and target problem); (2) demographics (eg, age, gender, and socioeconomic status); (3) traits (eg, personality, temperament, and intelligence); (4) cognitive factors (eg, decision making and developmental stage); (5) beliefs and attitudes (eg, perceived benefits and barriers to treatment); (6) physiological factors (eg, motor functioning); and (7) skills (computer abilities and mindedness). However, the role of such individual characteristics in influencing prospective attitudes toward the use of e-mental health services has not yet been thoroughly tested.

There is little empirical evidence regarding characteristics that influence individuals' views toward e-mental health services, and the research that does exist is inconsistent [14,19,20-23]. For example, Klein and Cook [20] found that less than 25% of

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respondents reported a preference for e-mental health services (with or without professional support). These "e-preferers" were more likely to report intentions to use these services in the future and had lower scores on the personality traits of extraversion, agreeableness, emotional stability, and openness to experience. Conversely, Tsan and Day [23] found no relationship between emotional stability (neuroticism) and attitudes toward online help-seeking behavior. Mixed findings are also apparent regarding the influence of attitudes toward technology, prior use of mental health services, and demographic variables (eg, age, gender, education, relationship status, country of birth, and location of residence) on attitudes toward e-mental health services [20,24-26].

We note that some of the inconsistencies may reflect differences across studies in how e-mental health services are defined. For example, there are distinct differences between online services that involve therapist assistance compared with self-help programs without therapist support [10,27], although the former can vary substantially in terms of the amount and type of contact provided. Thus, further investigation into preferences and intentions toward different e-mental health services is warranted. Obtaining a better understanding of individual characteristics that contribute toward these cognitive factors can provide insight useful for triaging or screening patients within routine care settings. Furthermore, such research may assist program developers to create more targeted strategies or tailoring of programs to improve uptake of these services.

Aims of This Study

This study aimed to explore differences in individual characteristics across both intentions to access and preferences for e-mental health services relative to face-to-face services. For this study, we define e-mental health services as computer-based interventions where the primary content delivery mechanism is through the technology platform (ie, online treatment programs), with or without additional therapist feedback or support. Thus, although important, we exclude telehealth-type services where technology is used to facilitate traditional face-to-face counseling approaches over distance (eg, online counseling using videoconferencing software).

On the basis of the research to date, we expected that participants would prefer face-to-face services over e-mental health services, although we anticipated a higher number of participants to report an intention to use e-mental health services in the future. Considering recent findings that tailored support is strongly preferred over generic programs [19], we also expected that more participants would indicate a greater likelihood of using therapist-assisted e-mental health services in future compared with self-help options.

We also aimed to investigate individual characteristics that might predict attitudes toward accessing e-mental health support (ie, preferences and intentions). We identified 5 general factors that broadly fit within the Internet interventions framework [18] and that have been explored previously with mixed or unclear findings [20,25,26,28,29]. These included the following: (1) *demographics* (ie, age, geographical location, and gender); (2) technology factors including *skills and use* (ie, confidence using computers and the Internet generally, and previous use of e-mental health services); (3) *personality traits* (ie, level of extroversion, neuroticism, or conscientiousness); (4) the *disease* (ie, levels of psychopathology); and (5) *beliefs* regarding influences on mental health outcomes (ie, locus of control, LOC). We expected each of these domains to have a unique influence on both preferences and intentions to use e-mental health services, but given there are mixed findings within the literature, we had no clear a priori hypotheses regarding the direction of effects. In this way, this study was exploratory in nature.

Methods

Participants and Procedure

Participants included 308 community members and university students aged between 17 and 68 years (mean 34.26; standard deviation, SD 11.23), who were mostly female (82.5%, 254/308). About half (52.3%, 161/308) lived in regional or remote areas, with the remainder (47.4%, 146/308) residing in major cities (not specified , *n*=1). Most participants reported experiencing either at least one current (51.3%, 158/308) or previous (85.7%, 264/308) mental health concern. These percentages appeared to be above the national average based on previous Australian mental health surveys [30,31], although we did not differentiate between clinical and nonclinical levels of difficulty.

Ethical clearance was obtained from the host institution's Human Research Ethics Committee (HREC number: H13REA216) before data collection. Recruitment of a community sample from the Australian general public was conducted through promotion on social media and advertisements at the institution's website. Interested participants were given a Web link for additional information about the study. Participants were required to provide consent via this link and were subsequently directed to the anonymous online battery of questionnaires. As an incentive for participation, community participants were offered the opportunity to enter a draw to win one of three AUD $50 gift vouchers, by submitting their email address separately. Alternatively, undergraduate psychology students enrolled at the host institution were given the option of receiving course credit for an approved undergraduate unit or entering the voucher draw.

Measures

Demographics

Participants were asked to provide their age, gender, and postcode. Individual postcodes were recoded into the Australian Standard Geographical Classification Remoteness Area index categories (RA1, major city; RA2, inner regional; RA3, outer regional; RA4, remote; RA5, very remote) [32], which were then categorized into major city (RA1) or outside major City (RA2-5) for analyses.

Technology Factors

Confidence With Technology

A single-item measure was used to determine participants' level of confidence in using computers and the Internet in general on a 5-point scale (1= *very confident* to 5= *really not confident*).

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Previous Online Help-Seeking Behaviors

A dichotomous (either *yes* or *no*) response item for previous e-mental health service use was created to identify whether or not participants had ever sought help via a therapist-assisted or self-help Internet-based treatment program.

Individual Characteristics

Locus of Control

The 18-item Multidimensional Health Locus of Control-Form C (MHLC-C) scale [33] was used to assess the degree to which participants attributed their mental health to themselves or to external forces using a 6-point scale (1= *strongly disagree* to 6= *strongly agree)*. The MHLC-C comprises 4 LOC subscales: (1) internal (6 items, eg , *If my condition worsens, it is my own behavior which determines how soon I will feel better again*); (2) external chance (6 items, eg, *As to my condition, what will be will be*); (3) external doctor (3 items, eg, *If I see my doctor regularly, I am less likely to have problems with my condition*); and (4) external others (3 items, eg, *Other people play a big role in whether my condition improves, stays the same, or gets worse*). Previous studies have reported satisfactory reliability for the MHLC-C, with Cronbach alphas in the range of .70-.87 for all subscales [33]. This study observed internal consistencies of alpha=.70 (internal), alpha=.84 (chance), alpha=.68 (doctor), and alpha=.49 (others). As the external (others) subscale had poor reliability in our sample, it was excluded from further analysis.

Psychopathology

The 21-item Depression Anxiety Stress Scale [34,35] was used to measure participants' mental health state over the previous week. The measure comprises three 7-item subscales measuring depression, anxiety, and stress symptoms on a 4-point scale (0= *did not apply to me at all* to 3= *applied to me very much or most of the time*). Previous literature has established adequate internal consistency ranging from .82 to .93 in nonclinical samples [35]. In our study, internal consistency was good (depression: alpha=.92; anxiety: alpha=.85; stress: alpha=.86).

Personality

Three subscales from the NEO Five Factor Personality Inventory (NEO-FFI) were used to measure participants' level of extroversion, neuroticism, and conscientiousness [36]. Together, these subscales comprised 36 items of the full 60-item questionnaire, with 12 items measuring each trait. Responses were recorded on a 5-point scale (1= *strongly disagree or is definitely false* to 5= *strongly agree or is definitely true*). Total subscale scores were calculated by adding items together (with reverse scoring where required), such that higher scores indicate a stronger presence of that trait. Previous research supports the external validity of the NEO-FFI as a measure of adult personality and demonstrates satisfactory internal consistencies for each scale [36,37]. This study demonstrated adequate reliability with Cronbach alphas of .82 (extraversion), .88 (neuroticism), and .88 (conscientiousness).

Outcome Variables

Service Preference

A single item asked participants to indicate overall, which type of mental health service they would prefer to use if they experienced mental health difficulties in the future: (1) traditional face-to-face mental health assistance (defined as face-to-face therapy with a general practitioner, psychologist, psychiatrist, or counselor); (2) Internet-based mental health assistance with therapist support (eg, support via email, instant messaging, or using video-conferencing); or (3) Internet-based mental health assistance without therapist support. Service preference was converted into a dichotomous variable by combining responses 2 (therapist-supported) and 3 (self-help) into a general Internet-based mental health support category.

Intention to Use e-Mental Health Services

Participants were asked about their intended help-seeking behavior should they experience a mental health difficulty in the future. Intention to use a therapist-assisted Internet-based treatment program or a self-help Internet-based treatment program without therapist assistance was measured using an author-developed 5-point scale (1= *extremely likely* to 5= *extremely unlikely*). Responses were later dichotomized (as *yes* or *no*) for analyses; ratings of 1 (*extremely likely*) or 2 (*somewhat likely*) were categorized as "yes," whereas all other responses (*neither likely or unlikely*, *somewhat unlikely*, or *extremely unlikely*) were categorized as "no".

Statistical Analysis

Analyses were conducted using IBM SPSS Statistics version 22 and R version 3.4.0 [38]. Preliminary exploration of relationships in the data was conducted using zero-order correlations (Spearman rank) for all dependent and independent variables. Descriptive statistics for proportions of participants endorsing preferences and intentions for e-mental health services were explored and compared across demographic characteristics (age, gender, and rural/regional status) using *t* and chi-square tests.

Predictors of preferences and intentions toward online services were examined through logistic regression (LR) analyses. Given the exploratory nature of the study and the large number of predictors included, our 5 predictor groupings (demographics, technology factors, LOC, psychopathology, and personality factors) were first tested individually through a series of LR models for each of the 3 dependent variables (service preference, intentions to use therapist-assisted e-mental health services, and intentions to use self-help e-mental health services). Significant demographic variables from the first LR model were carried through into each subsequent model as covariates to examine the influence of psychological and technological factors after removing variation attributable to demographic differences.

We then examined a final model for each dependent variable, incorporating all significant individual predictors from prior LR groupings (based on evaluation of 95% CI) to evaluate their relative contribution in the context of other predictive domains. Variance inflation factors were reviewed for all individual and combined models to check for multicollinearity, with no issues identified. Minimum sample size recommendations generally

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suggest at least 10-20 events per predictor for LRs [39,40], with events defined as the proportion of cases in the least frequent of the two outcome categories. As some dichotomous response categories were endorsed by relatively few respondents, to account for potential problems arising from too many predictors in the final combined models (eg, biased estimates), we used nonparametric bootstrapping techniques to estimate bias-corrected confidence intervals (CIs), in line with suggestions by Vittinghoff and McCulloch [40]. Parameter estimates and bias-corrected CIs were obtained for these models using 10,000 resamples of the data.

For all final combined models, analyses were run both with and without the bootstrapping method to check if there were any substantive differences in terms of which predictor variables were significant or nonsignificant. No differences were evident, and thus the results from bootstrapping analyses are presented.

Results

Preliminary Analyses

The most common mental health concerns reported by participants were stress (40.9%, 126/308), anxiety (28.9%, 89/308), and depression (22.7%, 70/308). Most participants reported being either confident (28.9%, 89/308) or very confident (65.9%, 203/308) using computers and the Internet. There were no demographic differences between those who were confident/very confident and those who were not. Only a small proportion of participants had previously sought help through e-mental health services (6.8%, 21/308).

Spearman rank correlations between all variables are shown in Table 1. Among the 3 dependent variables, service preference had a low correlation with intention to use both self-help and therapist-assisted online services (both r_s<.26), whereas both intention ratings were moderately correlated with each other (r_s=.52). All zero-order correlations of independent variables with intentions and preference were low (r_s<.30), although some were significant.

Regarding demographic variables, participant age was associated with the most other variables, suggesting that younger participants were more likely to report less desirable characteristics (eg, psychopathology: r_s=−.12 to −.21; neuroticism: r_s=−.17, and chance LOC: r_s=−.26), but were also more confident with computers and the Internet (r_s=−.23). Older participants tended to score higher on conscientiousness (r_s=.16) and internal LOC (r_s=.17).

Proportion of Respondents Preferring and Intending to Use e-Mental Health Services

Consistent with our hypotheses, the majority of respondents (85.7%, 264/308) indicated a preference for traditional face-to-face support. A total of 10.7% (33/308) respondents preferred therapist-supported online interventions and only 3.6% (11/308) preferred self-directed online support. As outlined above, the latter two categories were combined into a single e-mental health preference category (14.3%, 44/308). Using this dichotomized variable, there were no significant differences in age, t_{306}=0.58, P=.57, or gender, χ^2_1=0.1, P=.76, between those who preferred face-to-face and those who preferred Internet-based services. Service preference was significantly different across geographic locations (metropolitan vs. nonmetropolitan), χ^2_1=5.3, P=.02, with a greater proportion of metropolitan participants (19.2%, 28/146) compared with nonmetropolitan participants (9.9%, 16/161) preferring Internet-based services.

With regard to intentions, 25.0% (77/308) of participants indicated they would be “likely” or “very likely” to use self-help e-mental health services in the future if experiencing mental health difficulties. There were no differences in age, t_{306}=1.31, P=.19; gender, χ^2_1=−0.8, P=.39; or location, χ^2_1=0.2, P=.67, between participants who reported intentions to use these services and those who did not. A larger proportion of participants reported intentions to use therapist-assisted e-mental health services in the future (33.8%, 104/308). These respondents were slightly older (mean 36.64, SD 10.77) than those who did not intend to use these services (mean 33.04, SD 11.28), t_{306}=−2.69, P=.007. There were no significant differences in gender, χ^2_1=0.2, P=.70, or location, χ^2_1=0.1, P=.73. Single-group chi-square analysis indicated that the proportion of respondents responding they would use therapist-assisted services was significantly greater than the proportion likely to use self-help services, χ^2_1=12.6, P<.001. There was some overlap between these two categories, with 39.6% (122/308) endorsing future use of self-help and/or therapist-assisted services if needed.

Of the 308 survey respondents, 96.4% (297/308) indicated they would be "likely" or "very likely" to use either e-mental health or face-to-face services if experiencing mental health problems in future. Examining these responses, the proportion stating they would be likely to *use* online services (self-help and/or therapist-assisted; 39.6%, 122/308) was significantly greater than the relative proportion reporting a *preference* for online services (14.3%, 44/308), χ^2_1=177.5, P<.001. Follow-up cross-tabulation of these two response variables showed that for those preferring traditional face-to-face support approaches, more than a third (34.1%, 90/264) still indicated they would be likely to use online services in future. For those that preferred online services, most (76%, 32/44) indicated they would also be likely to use them.

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Table 1. Spearman rank correlations for variables used in logistic regression analyses. SH: self-help online (intention to use). TH: therapist-supported online (intention to use). DASS-21: Depression Anxiety Stress Scale-21.

Predictors	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1. Service preference	1																
2. SH	.26[a]	1															
3. TH	.20[a]	.52[a]	1														
4. Gender	.02	.05	.02	1													
5. Age	.05	.09	.16[a]	−.02	1												
6. Location	−.13[b]	.02	.02	.13[b]	.12[b]	1											
7. Online confidence	.11	.11	.10	−.01	−.23[a]	−.12[b]	1										
8. Prior use	.15[a]	.20[a]	.22[a]	−.05	.01	−.05	.01	1									
9. LOC (I)[c]	−.06	−.06	−.02	−.09	.17[a]	−.08	−.04	−.04	1								
10. LOC (C)[d]	.06	.04	−.08	−.08	−.26[a]	−.07	−.07	.08	−.10	1							
11. LOC (D)[i]	−.21[a]	−.11	−.01	−05	−.02	.08	.03	−.01	.06	−.06	1						
12. DASS-21 depression	.15[a]	.03	−.08	−.14[b]	−.15[a]	−.11	−.07	.11[b]	.12[b]	.31[a]	−.06	1					
13. DASS-21 anxiety	−.03	.00	−.07	−.04	−.21[a]	−.01	−.11	.09	.04	.30[a]	.03	.64[a]	1				
14. DASS-21 stress	.08	.05	−.05	.06	−.12[b]	−.05	−.05	.14[b]	.06	.24[a]	−.09	.70[a]	.67[a]	1			
15. Neuroticism	.15[a]	.03	−.10	.03	−.17[a]	−.04	−.10	.09	.04	.27[a]	−.03	.71[a]	.61[a]	.66[a]	1		
16. Extraversion	−.18[a]	−.01	.01	.06	−.01	.07	.14[b]	−.08	−.12[b]	−.21[a]	.13[b]	−.44[a]	−.28[a]	−.31[a]	−.42[a]	1	
17. Conscientiousness	−.10	.08	.04	.12[b]	.16[a]	−.01	.05	−.07	−.06	−.16[a]	.05	−.36[a]	−.17[a]	−.09	−.32[a]	.34[a]	1

[a]Significant at the $P<.01$ level.

[b]Significant at the $P<.05$ level.

[c]LOC (I): locus of control—internal.

[d]LOC (C): locus of control—chance.

[e]LOC (D): locus of control—doctor.

Predictors of Service Preferences

We first report results of the initial LR analyses for the 5 variable groupings (see Table 2), followed by the combined model where significant predictors were retained (see Table 3).

For demographic variables, the overall model was nonsignificant, $\chi^2_3=6.6$, $P=.09$, Cox and Snell R^2 (R^2_{CS})=.02, Nagelkerke R^2 (R^2_N)=.04. However, location (ie, major city vs outside major city) was a significant individual predictor of service preference, $P=.02$. This discrepancy may be due to a masking effect from the inclusion of multiple nonsignificant predictors in the model. As earlier chi-square comparison of service preference across location was also significant, we decided to retain location as a covariate within subsequent models to control for potential confounding effects when exploring other individual factors.

For technology factors, the model was significant, $\chi^2_3=14.0$, $P=.003$, $R^2_{CS}=.05$, $R^2_N=.08$. Controlling for location, previous use of online mental health services significantly predicted service preference ($P=.02$), with the likelihood of preferring e-mental health services estimated as three times greater for those who had used these services in the past. Online confidence was nonsignificant based on P value, but was significant based on its CIs, odds ratio (OR) 1.85 (95% CI 1.01-3.89), $P=.07$. We note here that by default, R computes P values using a Wald test, whereas 95% CIs are computed using the likelihood ratio test. At large sample sizes, these tests are asymptotically equivalent; however, the likelihood ratio test is generally considered to perform better in smaller samples as the Wald test becomes too conservative [39,41]. As such, we retained both technology predictors for further analysis in the combined model.

Three LOC subscales (*doctor*, *chance*, and *internal*) were entered together into a third LR model along with the location covariate. The overall model was significant, $\chi^2_4=18.8$, $P=.001$, $R^2_{CS}=.06$, $R^2_N=.11$. Of the 3 LOC subscales, doctor LOC was a significant predictor of service preference ($P=.001$), indicating that for every one-unit increase in the doctor-related external LOC (ie, potential for change is attributed to the influence of doctors), participants were 16% less likely to prefer Internet-based mental health services. Chance and internal LOC subscales were not significant independent predictors.

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Table 2. Logistic regression analyses for preference for online services over face-to-face, intentions to use therapist-assisted e-mental health services, and intentions to use self-help e-mental health services.

Predictors	Preference (online vs face-to-face)			Intention: online therapist-assisted services[a]			Intention: online self-help services		
	B[b]	SE	OR[c] (95% CI)	*B*	SE	OR (95% CI)	*B*	SE	OR (95% CI)
Demographic variables[d] (n=307)									
Gender: female	0.31	0.45	1.36 (0.59-3.56)	0.18	0.33	1.19 (0.63-2.32)	0.34	0.37	1.4 (0.7-3.03)
Age[e]	0.14	0.15	1.01 (0.99-1.04)	0.03[f]	0.01	1.03 (1.01-1.05)	0.02	0.01	1.02 (0.99-1.04)
Location: major city[a]	0.84[g]	0.35	2.31 (1.19-4.63)	0.01	0.25	1.01 (0.62-1.65)	−0.04	0.27	0.96 (0.57-1.64)
Technology variables (n=308)									
Online confidence	0.61	0.34	1.85 (1.01-3.89)	0.51[g]	0.22	1.67 (1.1-2.64)	0.46	0.24	1.59 (1.01-2.65)
Previous use: yes	1.16[g]	0.51	3.2 (1.13-8.42)	1.73[e]	0.51	5.67 (2.2-16.51)	1.50[f]	0.47	4.5 (1.82-11.54)
Locus of control[h] (n=301)									
Internal	−0.04	0.04	0.97 (0.9-1.04)	−0.02	0.03	0.98 (0.93-1.03)	−0.02	0.03	0.98 (0.93-1.03)
Chance	0.03	0.03	1.03 (0.97-1.09)	−0.02	0.02	0.98 (0.93-1.02)	0.01	0.02	1.01 (0.96-1.06)
Doctor	−0.17[f]	0.05	0.84 (0.76-0.93)	0.00	0.04	1 (0.93-1.08)	−0.08	0.04	0.93 (0.85-1)
Psychopathology[h] (n=308)									
Depression	0.14[g]	0.06	1.15 (1.03-1.3)	−0.03	0.05	0.97 (0.88-1.06)	−0.04	0.05	0.96 (0.88-1.06)
Anxiety	−0.14[g]	0.07	0.87 (0.75-0.99)	−0.01	0.05	0.99 (0.89-1.09)	0.03	0.05	1.03 (0.93-1.15)
Stress	0.03	0.06	1.03 (0.91-1.15)	0.01	0.05	1.01 (0.92-1.1)	0.03	0.05	1.03 (0.93-1.13)
Personality[h] (n=308)									
Extraversion	−0.05[g]	0.03	0.95 (0.9-1)	−0.01	0.02	0.99 (0.95-1.03)	0.00	0.02	1 (0.96-1.04)
Neuroticism	0.02	0.02	1.02 (0.98-1.07)	−0.02	0.02	0.98 (0.95-1.01)	0.02	0.02	1.02 (0.98-1.05)
Conscientiousness	−0.02	0.02	0.98 (0.94-1.03)	0.00	0.02	1 (0.97-1.04)	0.03	0.02	1.03 (0.99-1.07)

[a]Retained as covariate in all subsequent *preference* models.

[b]B: coefficient.

[c]OR: odds ratio.

[d]Overall model fit not significant at the *P*<.05 level for dependent variables *preference*, *therapist-assisted intentions*, and *self-help intentions*.

[e]Retained as covariate in all subsequent *therapist-assisted intentions* models.

[f]Significant at the *P*<.01 level.

[g]Significant at the *P*<.05 level.

[h]Overall model fit not significant at the *P*<.05 level for dependent variables *therapist-assisted intentions* and *self-help intentions*.

For psychopathology, the overall model was significant, χ^2_4=13.9, *P*=.008, R^2_{CS}=.04, R^2_N=.08. Both depression (*P*=.02) and anxiety (*P*=.04) were significant individual predictors of service preference. For every one-unit increase in depression scores, participants were 15% more likely to prefer Internet-based mental health services; conversely, for every one-unit increase in anxiety scores, participants were 13% less likely to report a preference for Internet-based services. Stress was not significant in this model.

The overall model for personality factors including neuroticism, extraversion, and conscientiousness from the NEO-FFI was significant, χ^2_4=17.6, *P*=.002, R^2_{CS}=.06, R^2_N=.10. Of the three personality factors, extraversion was the only significant predictor of service preference (*P*=.04); for every one-unit increase in extraversion, there was a 5% lower likelihood of preferring Internet-based mental health services.

Combined Model

As outlined above, the following variables were entered together into a single LR to examine their combined and relative contribution toward service preference: location, online confidence, previous use of online services, external LOC (doctor), depression, anxiety, and extraversion. The model fit was significant, χ^2_7=38.9, *P*<.001, R^2_{CS}=.12, R^2_N=.22. Bootstrapped coefficients and bias-corrected CIs are shown in Table 3.

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Table 3. Logistic regression analyses for combined variables predicting service preference, intention to use therapist-assisted e-mental health services, and intention to use self-help e-mental health services.

Predictor	*B* (coefficient)	Standard error	Odds ratio (95% CI)[a]
Service preference (n=300)			
Location: major city	0.48	0.39	1.62 (0.76-3.41)
Online confidence	0.96[b]	0.37	2.62 (1.24-4.82)
Previous use: yes	0.97	0.88	2.63 (0.60-9.23)
LOC doctor[c]	−0.17[b]	0.88	0.84 (0.76-0.95)
Depression	0.12	0.07	1.12 (0.98-1.28)
Anxiety	−0.15	0.09	0.86 (0.74-1.04)
Extraversion	−0.07[b]	0.03	0.93 (0.88-1.00)
Therapist-assisted online services (n=308)			
Age	0.04[b]	0.01	1.04 (1.01-1.06)
Previous use: yes	1.83[b]	0.77	6.22 (2.08-16.24)
Online confidence	0.54[b]	0.24	1.71 (1.06-2.69)
Self-help online services (n=308)			
Previous use: yes	1.54[b]	0.50	4.65 (1.71-11.90)
Online confidence	0.50	0.26	1.64 (0.97-2.68)

[a]Nonparametric bootstrapping was used to compute coefficients and bias-corrected CIs.

[b]Significant coefficient (*B*) based on 95% CI for exp(*B*) (ie, odds ratio).

[c]LOC: locus of control.

Significant predictors in the full model were external LOC (doctor), extraversion, and confidence with computers and the Internet. As participants scored higher on extraversion or LOC was more strongly oriented toward their doctor, they became significantly less likely to endorse a preference for online services. Conversely, preference for online services became significantly more likely as online confidence increased.

Predictors of Intention to Access Therapist-Assisted e-Mental Health Services

As with preferences, the overall LR model for demographic variables predicting intentions to use therapist-assisted e-mental health services in future was nonsignificant, χ^2_3=7.6, *P*=.056, R^2_{CS}=.02, R^2_N=.03. However, given that participant age was a significant individual predictor (*P*=.007), and earlier *t* tests showed significant age differences between those that did and did not intend to use therapist-assisted services, we retained it as a covariate for subsequent models.

Models involving LOC (χ^2_4=6.7, *P*=.16, R^2_{CS}=.02, R^2_N=.03), psychopathology (χ^2_4=8.6, *P*=.07, R^2_{CS}=.03, R^2_N=.04), and personality (χ^2_4=8.9, *P*=.06, R^2_{CS}=.03, R^2_N=.04) were not significant. However, the model for technology factors, with age included as covariate, was significant, χ^2_3=26.8, *P*<.001, R^2_{CS}=.08, R^2_N=.12. Online confidence (*P*=.02) and prior use (*P*<.001) were both significant individual predictors, indicating a greater likelihood of intending to use therapist-assisted e-mental health services as these increased.

Combined Model

Bootstrapped estimates were computed for the model containing age, online confidence, and prior use. Results are shown in Table 3. Age remained a significant predictor of intentions, as did prior use of online services and online confidence. Participants were over six times more likely to report they intended to use therapist-assisted online mental health services in future if they had used similar services previously, and 71% more likely to report intention to use these services for each unit increase in confidence.

Predictors of Intention to Access Self-Help e-Mental Health Services

For the prediction of intentions to use self-help online interventions, the LR models containing demographics (χ^2_3=2.7, *P*=.44, R^2_{CS}=.01, R^2_N=.01), LOC (χ^2_3=4.6, *P*=.21, R^2_{CS}=.02, R^2_N=.02), psychopathology (χ^2_3=1.1, *P*=.79, R^2_{CS}<.01, R^2_N=.01), and personality (χ^2_3=3.3, *P*=.35, R^2_{CS}=.01, R^2_N=.02) were not significant. Parameter estimates are shown in Table 2. There were no significant individual predictors from each of these models at the *P*<.05 level.

For technology factors, the overall model was significant, χ^2_2=14.7, *P*=.001, R^2_{CS}=.05, R^2_N=.07. Previous use of online mental health services was a significant predictor (*P*=.001), indicating that the likelihood of reporting an intention to use self-help e-mental health services in future was more than four times higher for those with prior experience using similar online

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services. Confidence with computers and the Internet was not significant based on estimated *P* value; however, CIs indicated that retaining these factors in the combined model could be valuable, OR 1.59 (95% CI 1.01-2.65), *P*=.06.

Combined Model

A model containing previous online service use and technology confidence was estimated using bootstrapping, with estimates shown in Table 3. CIs for online confidence no longer indicated significance, whereas previous use of online services remained a significant predictor.

Discussion

Principal Findings

This study examined attitudes towards e-mental health services in a community and student sample of adults, with a focus on both individual preferences and intentions regarding the use of these services in future. Most participants in our sample endorsed a preference for face-to-face treatment over Internet-based options with or without support, with similar proportions as identified in prior research [14]. One-quarter (self-help) to one-third (therapist-assisted) of the overall sample indicated they would use online services in future if experiencing mental health difficulties, and this rate was stable (35.3%) when examining only participants who reported a preference for face-to-face services, which represented the majority of our sample.

Overall, our findings supported our first set of hypotheses, specifically, that preferences for e-mental health services appear to be somewhat distinct from participants' views regarding the likelihood that they would use these services, with individuals reporting greater intentions to use them than what is reflected in their reported preferences. These findings are also largely in line with results from recent studies with adults and students regarding attitudes toward e-mental health services, where findings indicate that intention to use online services ranges between 22% and 70.8% [14,19,20,42]. The highest rates in previous studies were with student populations or where the reason for help-seeking was a diagnosed mental health condition. In community samples, and where the reason for help-seeking was less severe difficulties (eg, mental health concerns), rates more closely reflect those reported in our study.

We further examined predictors of preferences and intentions toward online services across a broad range of domains, drawing on constructs from the Internet interventions model [18], including demographic, personality, psychopathology, attributional, and technological factors. We found only partial support for these individual characteristics as predictors of preference and intentions toward the prospective use of online treatment services. Living outside of a major city was associated with a lower preference for online services, as was less confidence with computers and the Internet, and not having used online services in the past. The fact that those facing more geographical restrictions were also more likely to prefer face-to-face services is noteworthy, as advances in e-mental health services are intended to improve access to services for those with geographical restrictions [43]. There is some evidence from previous literature that those in geographically remote areas tend to also have less access to technology, and thus may have lower levels of computer confidence [44-46]. This is reflected in our combined preferences model, where online confidence remained significant but location and previous use did not. This likely indicates some shared variance between the 3 variables in predicting preferences, with confidence having the stronger effect. Thus, increasing the availability of e-mental health services alone may not actually circumvent barriers associated with regional access, especially if those living in these areas lack the skills or confidence to try them.

Other variables associated with the likelihood of preferring face-to-face services were doctor-related LOC, anxiety, depression, and extraversion, with only doctor LOC and extraversion significant in the combined model, predicting a lower likelihood of preferring e-mental health services. Doctor LOC reflects a tendency to attribute health outcomes externally to the influence of health professionals. Findings are mixed in the broader literature regarding the impact of external versus internal LOC on treatment preferences, although those with a more external LOC may do better with interventions that provide greater structure or contact [47]. If e-mental health services are viewed as more unstructured than face-to-face therapy, this could be a deterrent for some people who prefer more directive approaches. We found, however, that after controlling for other factors such as technology confidence, doctor LOC predicted support preferences only, with no bearing on reported intentions to use services. These findings are encouraging, as they suggest that despite some stable individual characteristics being associated with a person's support preferences, changeable factors such as increasing access, familiarity, and providing education around e-mental health programs are likely to have a greater impact on intentions and subsequent use of online services, even when these options are less preferred.

When examining psychopathology, we found no relation to intentions to use e-mental health services. In the individual models for psychopathology, there was some evidence that individuals with higher levels of depression were more likely to prefer online supports, whereas those with higher levels of anxiety were more likely to prefer face-to-face options, although these were no longer significant in the combined model when controlling for other factors. Further research within a clinical sample may be warranted to see whether these findings are generalizable, an issue we discuss further below.

Age, prior use, and online confidence were significantly associated with intention to use online therapist-assisted services in future if experiencing mental health difficulties. It has been found that younger people are less likely to seek help for mental health problems in general, although they are increasingly turning to self-help Internet-based options [48]. Our findings suggest that younger participants may hold similar negative views regarding therapist-supported online services to those they hold around face-to-face services (eg, concerns about stigma, wanting to rely on self), leading to lower intentions to use therapist-supported online services in future. Self-directed services, however, did not show this effect, and may present a viable target for improving e-mental health service use among younger people.

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For intention to use self-help online services, prior use and online confidence were significant individual predictors, although only prior use was significant in the combined model. Conservatively speaking, ORs suggested individuals were at least around twice as likely to endorse the use of online services in future if they have prior experience with similar services. We note there were large CIs for these estimates, likely a result of the small proportion of our sample reporting prior use of e-mental health services (6.8%, 21/308). Nonetheless, the fact that prior use was consistently important throughout our study, and related to both preferences and intentions, suggests it is an important target for intervention strategies moving forward. It may be useful, for example, to target people who have already used e-mental health services (early responders) and who are again seeking help for mental health difficulties, or to provide notifications of program updates or new releases to users who have previously tried an online intervention but dropped out. Additionally, easing people in through low barrier, low-intensity services that are easy to engage with may increase the chances of engagement with more comprehensive offerings in future should the need arise.

Limitations

Although the Internet interventions model [18] described earlier was used as a broad framework within this study for identifying individual user characteristics that may predict preferences and attitudes toward Internet interventions, it is important to contextualize these findings. First, the Internet interventions model aims to provide a framework for understanding use and outcomes of Internet interventions, in other words, how online treatments lead to change and how their efficacy can be maximized. Respondents in our study did not partake in any online treatments, and thus data are limited to attitudes and intentions only. As exemplified by the TPB framework [17], behaviors (eg, engagement with online treatment) can be viewed as distinct from how someone views online treatment. Although there has been some prior work demonstrating a relationship between individual characteristics and willingness to participate in online treatments [49], whether these same characteristics equally predict later effective engagement is not clear. This same limitation applies to this study. Longitudinal monitoring of how well predictors of attitudes and intentions toward online treatments translate into the subsequent uptake of services appears to be an opportunity for further exploration.

Second, our study was intentionally broad in terms of assessing intentions toward online treatment for general mental health difficulties and was conducted with a community sample where not all participants were experiencing current mental health difficulties or were actively seeking treatment. Individual characteristics proposed within the Internet interventions [18] model—for example, elevated levels of depression or anxiety (ie, the severity of the problem)—may be more predictive of attitudes toward targeted online treatment programs that hold relevance for someone experiencing a specific mental health difficulty. As such, assessing attitudes and intentions toward online treatment within a clinical sample of respondents may yield different findings regarding the influence of psychopathology.

Third, reliance on a forced choice for the preference construct means that we were unable to determine the strength of the preference toward either service type and does not allow us to directly compare preferences to intentions. Future research should examine the strength of preferences and intentions using similar rating scales to enable more direct comparison. Other limitations include the representativeness of the sample, which consisted mostly of females, confident computer users, and people who endorsed a higher than average number of mental health concerns, and so the generalizability of results may be limited. Finally, some elements of the Internet interventions model (eg, cognitive and physiological factors; [18]) were not incorporated in our study, and we were unable to assess external LOC pertaining to others due to poor reliability of the subscale in our sample.

Conclusions

In summary, we found low rates of preference for online services compared with face-to-face treatments, and this was more evident for those living outside of major cities, where these services are intended to improve reach. Despite low preferences, intentions to access these services remain promising, raising the question of how to best encourage translation of intentions into behavior (ie, actual use of services). The importance of being confident with computers and the Internet suggests that preferences may undergo a natural shift toward e-mental health services over time, as access to technology continues to increase in regional areas and as young people continue to grow up as digital natives. However, encouraging early use of brief online programs may also be an effective strategy that could enhance uptake of future e-mental health programs. Integrating programs into nonthreatening contexts (eg, schools, primary care) may be one way to provide people with a taste of these options and increase the chances they will try them later. Health care professionals may play a role here, through promoting evidence-based online treatment programs, encouraging patients to try online services following discharge from face-to-face care, or providing in-person demonstrations or brief trial-runs of online programs in clinics or waiting rooms, to both normalize and demystify these services. This study adds to the emerging literature on consumer attitudes toward e-mental health services through examining preferences and intentions; however, more directed research around how these translate into use of e-mental health services is needed.

Acknowledgments

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Conflicts of Interest

None declared.

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Abbreviations

cCBT: computerized cognitive behavioral therapy
LOC: locus of control
LR: logistic regression
MHLC-C: multidimensional health locus of control—form C
NEO-FFI: NEO five-factor personality inventory
OR: odds ratio
TPB: theory of planned behavior

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Original Paper

Help-Seeking on Facebook Versus More Traditional Sources of Help: Cross-Sectional Survey of Military Veterans

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Abstract

Background: The media has devoted significant attention to anecdotes of individuals who post messages on Facebook prior to suicide. However, it is unclear to what extent social media is perceived as a source of help or how it compares to other sources of potential support for mental health problems.

Objective: This study aimed to evaluate the degree to which military veterans with depression use social media for help-seeking in comparison to other more traditional sources of help.

Methods: Cross-sectional self-report survey of 270 adult military veterans with probable major depression. Help-seeking intentions were measured with a modified General Help-Seeking Questionnaire. Facebook users and nonusers were compared via *t* tests, Chi-square, and mixed effects regression models. Associations between types of help-seeking were examined using mixed effects models.

Results: The majority of participants were users of social media, primarily Facebook (n=162). Mean overall help-seeking intentions were similar between Facebook users and nonusers, even after adjustment for potential confounders. Facebook users were very unlikely to turn to Facebook as a venue for support when experiencing either emotional problems or suicidal thoughts. Compared to help-seeking intentions for Facebook, help-seeking intentions for formal (eg, psychologists), informal (eg, friends), or phone helpline sources of support were significantly higher. Results did not substantially change when examining users of other social media, women, or younger adults.

Conclusions: In its current form, the social media platform Facebook is not seen as a venue to seek help for emotional problems or suicidality among veterans with major depression in the United States.

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KEYWORDS

social media; social networking sites; internet; Facebook; service use; utilization; treatment-seeking

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Introduction

Social media has become an integral part of people's daily lives, including military veterans. As of 2016, there were 1.89 billion active users on Facebook [1], with 76% logging on daily and spending 50 minutes on average on the site [2,3]. All told, an estimated 1 out of every 7 minutes spent online is spent on Facebook [4]. In 2014, Facebook reported that 4 million of its users were US active duty members or military veterans [5], and a 2012 online survey on personal technology use among military service members found that more than three-quarters of them used social networking sites, predominantly Facebook [6].

Facebook is most commonly used for purposes such as entertainment, communicating with friends and family, and keeping up with news and current events, with 31% to 47% of users citing such reasons [7]. However, there are also ways Facebook appears to be used that may be relevant to obtaining emotional support or help for mental health concerns. For instance, 30% of Facebook users cite learning about ways to help others as a reason for their Facebook use, and 23% note receiving support from network members as another reason [7]. Among veterans, US Department of Veteran Affairs (VA) patients appear to use social media to find others with similar health problems at about the same rate as nonveterans [8].

Social media may be a valuable venue for help-seeking for several reasons. It is a highly accessible resource, and use of internet-based sources of help for health issues is common [9]. Researchers have been interested in the potential to use social media to reach, recruit, identify, engage, support, or treat individuals at risk for mental health problems [10-15]. Individuals coping with mental illness are active on social media [16], and Facebook is used as a place to share feelings [17] and mobilize social support [18], particularly advice and practical help [19]. Occasionally, it is even used as a forum to disclose suicidal thoughts [20]. Facebook, for its part, has collaborated with suicide prevention organizations to develop tools to identify and intervene on behalf of individuals who appear to be at risk for self-harm or suicide [21].

The importance of novel approaches to enhance help-seeking is accentuated by the fact that rates of help-seeking are generally low in proportion to the number of people suffering from psychiatric problems such as depression [22] and even recent suicidal ideation [23]. A similar pattern is seen among military service members and veterans, who are also thought to underuse mental health services or be underserved [24-26]. The need to address this gap between suffering and help-seeking is likely to grow given evidence of rising suicide rates and the list-topping proportion of the global burden of disease attributable to mental illnesses [27,28]. However, it is unclear to what extent social media actually serves as an existing source of help-seeking, particularly for mental health problems and particularly beyond the adolescent and young adult population [29,30].

Thus, the aim of this study was to evaluate the degree to which veterans with depression use social media for help-seeking in comparison to other more traditional sources of help.

Methods

Recruitment

We drew participants from a larger study of 301 primary care patients at a VA hospital and its satellite clinics who had symptoms of major depression and reported having at least one close relationship. Patients were excluded if they had severe hearing impairment or recently active major psychiatric comorbidities (bipolar disorder, psychosis, or neurocognitive disorder). Due to the low percentage of women veterans, we oversampled women to increase diversity of our sample. Potentially eligible veterans were first screened for depression via a phone-administered 8-item Patient Health Questionnaire (PHQ-8) followed by an in-person visit if eligible and interested. Those eligible for inclusion in this study were the 270 individuals who had a PHQ-8 score ≥9, who were then administered a set of survey items about social media use. Meta-analyses have found that a cutoff score of 9 on the PHQ-9 is one of the optimal choices for diagnosing major depression in primary care settings [31]; the identical cutpoint should be used on the PHQ-8 due to its high level of correlation with PHQ-9 score [32].

Measures

Help-Seeking

We administered the General Help-Seeking Questionnaire (GHSQ), an adaptable self-report measure that assesses intention to seek help if experiencing an emotional problem or suicidal thoughts. Multiple possible sources of help are presented, and response options for each range from 1=extremely unlikely to 7=extremely likely. Because original items were developed in Australia, we slightly modified them for an American context and added Facebook as another potential source of help. Participants were asked about help-seeking on Facebook generally, without specifying particular areas or functions within Facebook (eg, support groups or interest pages). We sorted sources into 4 categories: (1) Facebook help-seeking; (2) informal help-seeking, which is drawn from members of one's social network such as friends and family; (3) phone helpline help-seeking, which cited the Veteran's Crisis Line as an example; and (4) formal help-seeking, which included a mental health professional or primary care provider. For categories with multiple items, we averaged participant responses to each source. The GHSQ has strong reliability and validity [33], particularly when used in multi-item form as we did [34].

Social Media Use

We used a series of survey items adapted from questions used by the Pew Research Center [35,36] to assess social media use. First, we assessed whether veterans were social media users ("Do you ever use the internet or a mobile app to use Twitter, Instagram, Pinterest, Tumblr, or Facebook?"). Next, we assessed frequency of use of the same social media platforms. Finally, we assessed frequency of active social media use (sharing, posting, or commenting) because prior research has indicated that social media use is often characterized by passive consumption of information (eg, scrolling through news feeds), a behavior linked to worsened emotional well-being [37].

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Covariates

We assessed additional sociodemographic and clinical characteristics including age, gender, minority status, education level, rurality of residence, stability of housing, financial hardship, history of suicide attempt, alcohol misuse, posttraumatic stress disorder symptoms, depression symptoms, and offline social contact. See Multimedia Appendix 1 for additional details.

Statistical Analysis

We first examined missingness of data; all survey items had less than 2% missing data. We used mean imputation for missing responses to GHSQ items that were part of informal or formal help-seeking. We summarized key variables using descriptive statistics. We analyzed sociodemographic and clinical characteristics of participants who were Facebook users and nonusers using 2-sample *t* tests and Pearson Chi-square tests. To compare help-seeking intentions from different GHSQ source categories, we used multilevel mixed-effects linear regressions. We performed subgroup analyses to determine whether the pattern of help-seeking intentions differed when the sample was restricted to various groups of participants, including frequent Facebook users (defined as visiting at least daily), active Facebook users (defined as sharing, posting, or commenting on Facebook at least daily), and users of social media platforms other than Facebook. Analyses were performed using Stata versions 14.2 and 15.0 (StataCorp LLC), and 2-sided statistical significance was defined as $P<.05$.

Results

Descriptive Data

In terms of help-seeking intentions, 58.1% (157/270) endorsed having at least 1 source they intended to use (GHSQ score of 5 or more) if experiencing an emotional problem. If having suicidal thoughts, 55.6% (150/270) endorsed having at least 1 help-seeking source.

Of our 270 participants, 162 (60.0%) were Facebook users, 106 (39.3%) used Facebook at least daily, and 65 (24.1%) used Facebook actively (as opposed to passively) at least daily. Use of any social media platform other than Facebook was uncommon (49/270, 18.1%), with use of individual platforms (eg, Twitter) even more rare. Compared to nonusers, Facebook users were younger and used other social media and more likely to be women, live in urban areas, and be at risk for misusing alcohol; they were less likely to have a history of a suicide attempt (Table 1). However, mean help-seeking intentions for each source of help did not differ significantly between Facebook users and nonusers. This was true for both help-seeking for emotional problems and suicidal thoughts. Results also remained consistent after adjustment for potential confounders (age, gender, urbanicity, alcohol use, use of social media sites other than Facebook, and history of suicide attempt). All remaining results are based on data from only participants who were Facebook users.

A total of 58.6% (95/162) of Facebook users endorsed having at least 1 help-seeking source for emotional problems; for suicidal thoughts, 50.6% (82/162) intended to use at least 1 source of help. The mean help-seeking intention for emotional problems via Facebook was 1.67 (95% CI 1.46 to 1.87) on a scale ranging from 1=extremely unlikely to 7=extremely likely. Help-seeking intention for suicidal thoughts via Facebook was similarly low (mean 1.41, 95% CI 1.25 to 1.58). Figures 1 and 2 illustrate the preponderance of participants who were extremely unlikely to seek help from Facebook as opposed to a more even distribution of likelihood to seek help from other sources.

Comparisons of Help-Seeking Intentions by Source of Help

As shown in Figure 3, comparisons of help-seeking intentions through Facebook versus other potential means of help (formal, informal, or phone helpline) revealed highly significant differences, with veterans being less likely to seek help from Facebook than from any other source. This was true for help-seeking for both emotional problems and suicidal thoughts. For example, the mean level of help-seeking intentions via a phone helpline was significantly higher for both emotional problems (2.89; 95% CI 2.61 to 3.17, $P<.001$) and suicidal thoughts (3.33; 95% CI 3.00 to 3.66, $P<.001$) compared to Facebook. In addition, the mean level of help-seeking intentions was highest for formal sources for both emotional problems (4.42; 95% CI 4.20 to 4.65, $P<.001$) and suicidal thoughts (4.16; 95% CI 3.88 to 4.44, $P<.001$). Detailed data on comparisons of different help-seeking sources is contained in Multimedia Appendix 1.

Help-Seeking Intentions Among Subgroups of Facebook Users

Results were mostly similar when we restricted analyses to participants who were frequent Facebook users (106/162) and active Facebook users (65/162) (see figures in Multimedia Appendix 1). Active Facebook users did show a small but significant 0.53-point increase (95% CI 0.12 to 0.94, $P=.01$) in intention to seek help from Facebook for emotional problems and a 0.33-point increase (95% CI 0.01 to 0.66, $P=.047$) in intention to seek help from Facebook for suicidal thoughts, compared to nonactive Facebook users. Among Facebook users who also used other forms of social media (42/162), help-seeking intentions via Facebook were not significantly different from those who exclusively used Facebook, either for emotional problems (1.90 vs 1.59; 95% CI –0.15 to 0.78, $P=.18$) or suicidal thoughts (1.58 vs 1.36; 95% CI –0.15 to 0.59, $P=.25$).

In examination of demographic groups of interest, results were again consistent with the overall sample. Among women (28/162), help-seeking intentions via Facebook were not significantly different from men for emotional problems. Finally, among participants younger than age 40 years (37/162), help-seeking intentions via Facebook were not significantly different from participants age 40 years and over, either for emotional problems or suicidal thoughts.

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Table 1. Characteristics of participants with active depressive symptoms.

Characteristic	Facebook users (n=162)	Facebook nonusers (n=108)	*P* value
Age, years, mean (SD)	52 (14)	61 (13)	<.001
Under 40, n (%)	37 (22.8)	11 (10.2)	
40-49, n (%)	29 (17.9)	8 (7.4)	
50-59, n (%)	40 (24.7)	20 (18.5)	
60 or over, n (%)	56 (34.6)	69 (63.9)	
Male, n (%)	134 (82.7)	99 (91.7)	.04
Racial or ethnic minority, n (%)	37 (22.8)	26 (24.1)	.81
Education, n (%)			.55
High school or less	20 (12.3)	20 (18.5)	
Some college	59 (36.4)	39 (36.1)	
Two-year degree	43 (26.5)	25 (23.1)	
Four-year degree or more	40 (24.7)	24 (22.2)	
Rural residence, n (%)	22 (13.6)	25 (23.1)	.04
Stable housing, n (%)	149 (91.2)	98 (90.7)	.72
Financial hardship, n (%)	44 (27.2)	28 (25.9)	.97
History of suicide attempt, n (%)	19 (11.7)	29 (26.9)	.001
Alcohol misuse[a], n (%)	65 (40.1)	27 (25.0)	.01
PTSD symptoms[b], n (%)	108 (66.6)	67 (62.0)	.44
PHQ-9 score[c], n (%)	15 (9.3)	15 (13.9)	.77
Use social media besides Facebook[d], n (%)	42 (25.9)	7 (6..5)	<.001
Offline social contact[e], n (%)			.57
Every few months or less	15 (9.3)	7 (6.5)	
Once or twice a month	35 (21.6)	18 (16.7)	
Weekly to a few times a week	79 (48.8)	57 (52.8)	
Daily or more	33 (20.4)	26 (24.1)	

[a]Alcohol misuse was operationalized as an Alcohol Use Disorders Identification Test score ≥4 in men (≥3 in women).

[b]Posttraumatic stress disorder was operationalized as a Primary Care Posttraumatic Stress Disorder Checklist score ≥3.

[c]Nine-item Patient Health Questionnaire score represents severity of symptoms of major depression.

[d]Participants were asked whether they ever use Instagram, Pinterest, Tumblr, or Twitter.

[e]Average frequency of in-person social contact with up to 3 individuals nominated as close relations.

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Figure 1. Frequency of help-seeking intentions if experiencing an emotional problem across 4 potential sources of support among Facebook users (n=162).

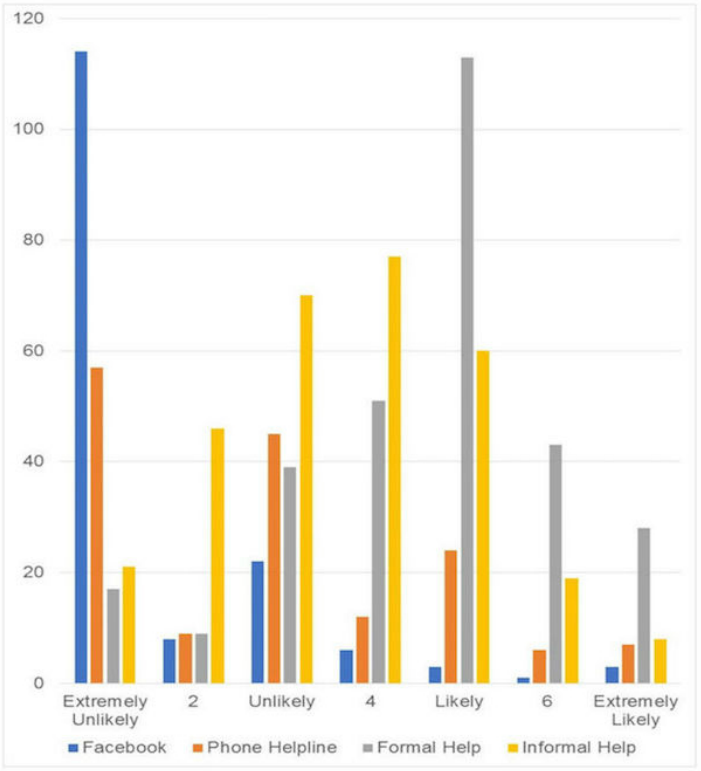
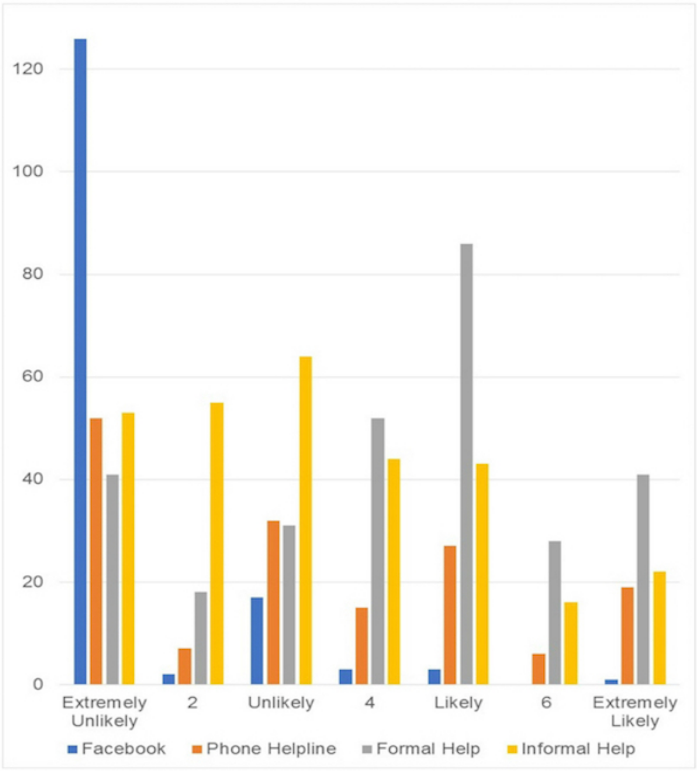
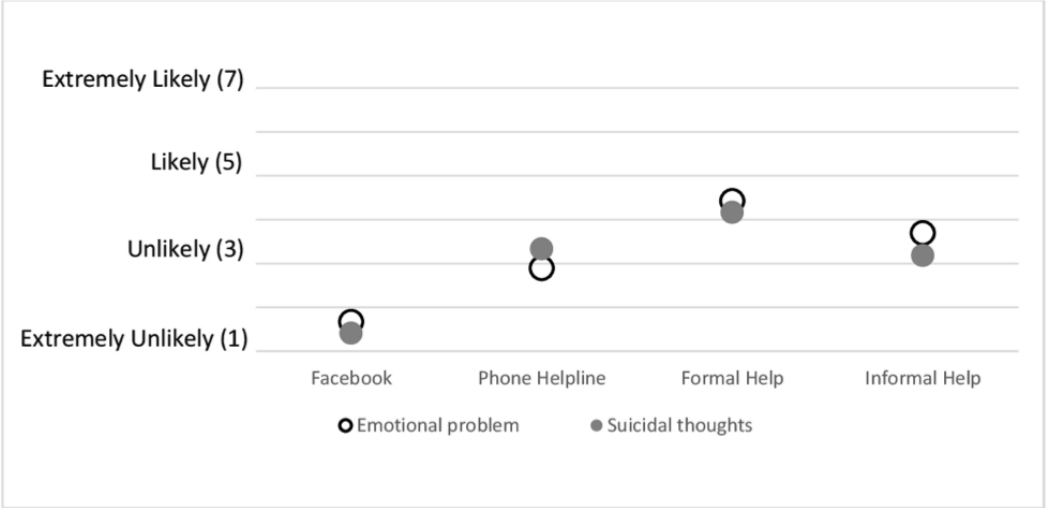


Figure 2. Frequency of help-seeking intentions if experiencing suicidal thoughts across 4 potential sources of support among Facebook users (n=162).



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Figure 3. Help-seeking intentions for 4 potential sources of support among participants who use Facebook (n=162).



We identified a small subgroup (9/162) of participants who indicated intention to seek help for emotional problems or suicidal thoughts from Facebook (GHSQ score of 5 or more). These individuals had somewhat higher levels of help-seeking intentions more generally. Their mean help-seeking intentions using formal, informal, and phone sources for either emotional problems or suicidal thoughts was 4.83, which was 1.29 points (95% CI 0.45 to 2.13, *P*=.003) higher than other Facebook users.

Discussion

Principal Findings

The primary finding from this study is that social media appears to be a very undesirable venue for mental health help-seeking for VA patients with probable major depression. This finding remained true even among the most frequent users of Facebook and among individuals who used Facebook in an active way (which is more associated with positive mental health than passive use) [38]. Findings were also consistent whether the reason for help-seeking was a more mild emotional concern or something much more severe (suicidal thoughts).

The lack of interest in Facebook for help-seeking is all the more striking when compared to higher levels of interest in offline sources of help. The majority of our military veterans endorsed at least one venue they were likely to use for help-seeking. Mean help-seeking intentions for formal help and phone helplines in our sample were higher than in a prior study of Iraq/Afghanistan-era military veterans [39] and similar to prior studies involving Australian college students [40].

This study does not reveal why individuals do not intend to seek help from Facebook. However, we suspect several possible reasons for the large discrepancy in the likelihood of informal help-seeking via Facebook versus offline sources. First, many "Facebook friends" are not "real friends," or at least not close ones. Prior empirical work has shown that only a small segment of Facebook friends are actually close, personal social connections [41]. It is this small group that is most likely to influence behavior in the real world [41]. Second, it may be stigmatizing to self-disclose mental health problems on Facebook. People have a strong tendency to present a positive self-image on Facebook [42], and stigma is a major barrier to help-seeking that occurs disproportionately among military veterans [43]. Third, interactions on Facebook are likely perceived as being more impersonal and lacking a human touch. So-called "broadcast communication," which includes posts such as status updates that are sent out widely to Facebook friends [44], predominates on Facebook and perhaps contributes to such a perception. Fourth, participants may not have perceived Facebook as a trustworthy platform in which to openly discuss mental health matters. Concerns about privacy might stifle mental health help-seeking, and some research has suggested trust in social media is low in the United States and acts as a predictor of whether one engages in self-disclosure of health issues online [45]. There are areas within Facebook that are less susceptible to concerns related to impersonal communication and anonymity. For example, closed support groups, including ones tailored to veterans, would likely be more socially acceptable forums within Facebook for help-seeking or exchange of social support [46]. Last, because many of the most common reasons for using Facebook are unrelated to health concerns, it may be that, for military veterans, Facebook simply does not come to mind as a help-seeking tool.

In addition, help-seeking intentions via Facebook may be more favorable in individuals younger than our sample population, such as millennials who have grown up with Web 2.0 and social media [47]. Prior research has even shown that adolescents may disclose more personal information on social media than in person [48]. It is also encouraging that when individuals do self-disclose negative emotions on Facebook, they often receive objective social support, even more so if the person is depressed [49]. Researchers are also developing tools to help detect risk for suicide based on content of social media posts, which could in theory lead to ways to reach out to individuals online even if they do not actively seek out help themselves [50].

Limitations

The primary limitation of this study is the lack of measurement of actual help-seeking or treatment utilization, given that research has found stated intentions of help-seeking may not

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translate into actual help-seeking behaviors [51]. Likewise, we were unable to capture whether veterans ever posted on Facebook in the act of help-seeking. Although emotional problems and even suicidality were relatively common in our sample, results must be interpreted cautiously as our survey queried intentions to seek help in a hypothetical scenario. Additionally, survey order effects could have influenced results such that individuals underreported Facebook help-seeking intentions. Because the item on Facebook help-seeking intentions was placed after items on other sources of help such as friends and family, respondents may have perceived Facebook as being mutually exclusive from these options. Finally, results are not likely generalizable to other populations not well represented in our sample of military veterans, including veterans who lack any social supports, women, or youth.

Conclusions

Our results should not be interpreted as negating the relevance of tools, such as one recently rolled out by Facebook [28], to assist individuals actively experiencing suicidal ideation. Rather, we believe our results frame the utility of such tools as being best suited to the select few who both experience suicidality and are comfortable using Facebook in a crisis. Overall, this study suggests Facebook in its current form is by no means perceived as a go-to source for mental health help-seeking among veterans with depression. Instead, more traditional sources of support appear to be the most viable venues for help-seeking in this population.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Sociodemographic and clinical variables examined.

[PDF File (Adobe PDF File), 30KB - jmir_v20i2e62_app1.pdf]

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Abbreviations

GHSQ: General Help-Seeking Questionnaire
PHQ-8: Patient Health Questionnaire
PTSD: Posttraumatic stress disorder
VA: US Department of Veterans Affairs

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Review

Telehealth Interventions Delivering Home-based Support Group Videoconferencing: Systematic Review

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Abstract

Background: Group therapy and education and support sessions are used within health care across a range of disciplines such as chronic disease self-management and psychotherapy interventions. However, there are barriers that constrain group attendance, such as mobility, time, and distance. Using videoconferencing may overcome known barriers and improve the accessibility of group-based interventions.

Objective: The aim of this study was to review the literature to determine the feasibility, acceptability, effectiveness, and implementation of health professional–led group videoconferencing to provide education or social support or both, into the home setting.

Methods: Electronic databases were searched using predefined search terms for primary interventions for patient education and/or social support. The quality of studies was assessed using the Mixed Methods Appraisal Tool. We developed an analysis framework using hierarchical terms feasibility, acceptability, effectiveness, and implementation, which were informed by subheadings.

Results: Of the 1634 records identified, 17 were included in this review. Home-based groups by videoconferencing are feasible even for those with limited digital literacy. Overall acceptability was high with access from the home highly valued and little concern of privacy issues. Some participants reported preferring face-to-face groups. Good information technology (IT) support and training is required for facilitators and participants. Communication can be adapted for the Web environment and would be enhanced by clear communication strategies and protocols. A range of improved outcomes were reported but because of the heterogeneity of studies, comparison of these across studies was not possible. There was a trend for improvement in mental health outcomes. Benefits highlighted in the qualitative data included engaging with others with similar problems; improved accessibility to groups; and development of health knowledge, insights, and skills. Videoconference groups were able to replicate group processes such as bonding and cohesiveness. Similar outcomes were reported for those comparing face-to-face groups and videoconference groups.

Conclusions: Groups delivered by videoconference are feasible and potentially can improve the accessibility of group interventions. This may be particularly useful for those who live in rural areas, have limited mobility, are socially isolated, or fear meeting new people. Outcomes are similar to in-person groups, but future research on facilitation process in videoconferencing-mediated groups and large-scale studies are required to develop the evidence base.

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(J Med Internet Res 2018;20(2):e25) doi:10.2196/jmir.8090

KEYWORDS

videoconferencing; telemedicine; patient education as topic; social support; review

Introduction

Group work is commonly used within health care across a range of disciplines such as chronic disease self-management (CDSM) and to provide psychotherapy, education, and group support. Groups are beneficial as they provide opportunities to meet others with similar health issues or in similar circumstances, learn from peers, develop self-awareness, give and receive feedback, and recognize that others share comparable challenges that can lead to more success with self-management [1]. Within the field of psychotherapy, group treatment provides crucial therapeutic elements such as universality, group cohesiveness, and interpersonal learning, all of which promote positive individual outcomes [2].

However, there are a number of barriers for participants to attending groups. Reasons for nonparticipation include mobility-reducing physical health issues, time constraints, distance, insufficient funds, lack of respite care if caring for someone else, and transportation [3]. From an organizational perspective, groups enable scarce resources to be used effectively. For instance, diabetes education often uses group settings to reduce the pressure on health staff resources given the increasing numbers of people diagnosed with diabetes [4]. Using home-based videoconferencing may be one opportunity to reduce these known barriers and improve the accessibility of group-based interventions.

Web-based groups, commonly called online groups, are used for health professional and peer-led health education and social support [5-7] and in behavior change interventions [8,9]. Online support groups can be asynchronous or synchronous, providing a range of therapeutic benefits that are similar to face-to-face support groups [10,11], and online education and behavior change interventions have reported improvements in health outcomes [9,12]. However, a systematic review on the effectiveness of online health behavior change interventions concluded that although most studies report improvements, effect sizes range widely and were generally small in magnitude [8].

Most online groups have been text-based, using discussion boards; few have used videoconferencing. Although videoconferencing has been used in a range of medical disciplines, it is still not widely adopted, and the research focus to date has been on using videoconferencing for individual patient consultations [13]. Those studies that have used group videoconferencing have employed differing configurations and technology such as all participants located at either one site or several participating sites (often a community health center) and the facilitator or facilitators located at another site [14-17]. Other formats for group videoconferencing interventions include mixing face-to-face meetings and group videoconferences [18], enabling participants to hear each other but not see each other [19], and using virtual environments for groups [20].

There have been concerns regarding the effectiveness of videoconferencing groups, which may have deterred uptake of this technology. A key outcome for using groups in health care is the social support that can be fostered by members. Some have argued that social interaction may be lacking in Internet-based programs [21], and the convenience of increased access has the potential to reduce engagement within videoconferencing groups. Compared with in-person participation, videoconferencing groups may feel artificial, disconnection with others, and engender privacy concerns [22].

Few studies have used videoconferencing to deliver group-based education [23]. It has been more widely used in psychological interventions. A review containing two studies concluded that conducting group therapy by videoconferencing is as feasible and effective as an in-person group and that technology increased access to services but did not forgo the change mechanisms in group therapy [24]. However, no previous reviews have identified factors affecting implementation and outcomes of group-based education by videoconferencing. The aim of this study was to undertake a systematic review of the literature to determine the feasibility, acceptability, effectiveness, and implementation of health professional-led group videoconferencing to provide education and/or social support into the home setting.

Methods

Literature Search

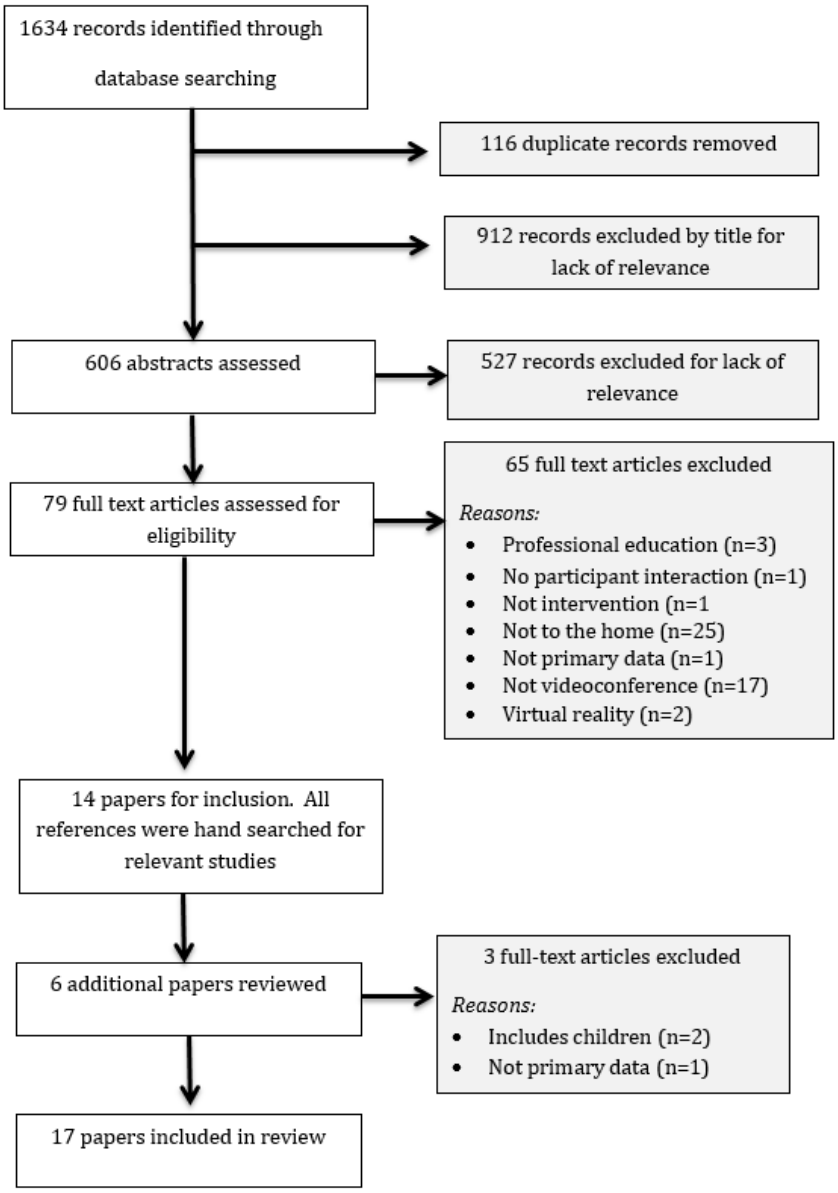
Publications were collected from January 2000 to March 2016 on videoconferencing group education and/or social support into the home between health professionals and groups of patients or consumers. The following electronic databases were searched: Academic Search, CINAHL with full-text, Health Source Consumer, Health Source Nursing, MEDLINE, Psychology and Behavioural Sciences Collection, PsycINFO, SocioIndex, PubMed, InfoRMIT, ProQuest, and Google Scholar. Databases included literature that was peer-reviewed and gray literature. Table 1 provides the search terms that were tailored according to the database. Search terms were identified from initial literature scoping and not restricted to the title only.

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Table 1. Search terms. The symbol * denotes truncation in the search. MeSH: Medical Subject Headings.

Step in search strategy	Search term
1	Telemedicine [MeSH] OR telecare OR telemonitoring OR telehomecare OR internet-based care/programs OR virtual OR web-based OR multi-site OR multisite
2	Videoconferencing [MeSH term] OR real-time OR synchronous
3	Health literacy [MeSH term] OR chronic disease self-management OR self-care [MeSH term] OR patient education as topic [Mesh term] OR health education [MeSH term] OR educat* OR train* OR social support [MeSH term] OR therap* OR life style [MeSH term] OR peer support OR peer educat* OR telerehabilitation [Mesh term]
4	Feasibility Studies [Mesh term] OR feasibil* OR Patient Satisfaction [MeSH term] OR accept* OR Program Evaluation [MeSH term] OR effective*
5	Adults
6	Limits: English Language; abstract; publication date January 2000 to March 2016
7	1 and 2 and 5 and 6
8	1 and 2 and 3 and 5 and 6
9	1 and 2 and 3 and 4 and 5 and 6

Figure 1. Study selection flow diagram.



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Study Selection

Included studies were interventions that collected primary data directly from participants, which documented the use of group videoconferencing for patient education or social or mental health support into participants' homes. Intervention studies that were delivered by family practice, local primary care organizations, generalist community health services (including home nursing, counseling, allied health, and health education) and tertiary settings to the community to adults aged 18 years or older were included. Excluded studies were those that provided group education to youth or children, students, health professionals, were part of a virtual reality game, or did not enable participants to see and/or hear others in the group. No restrictions were imposed on the quality of the literature because initial assessment suggested there was a limited number of interventions conducted using group videoconferencing. In particular, studies that have delivered group videoconferencing into the home as opposed to a community health care setting are less common.

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) [25] flowchart representing the study selection process is shown in Figure 1. Potential eligible studies were identified by author AB scanning all 1634 titles. Authors AB and LP independently conducted an abstract review of the 606 remaining studies followed by a full-text review of 79 studies for final inclusion. Hand reference searching of the 14 remaining studies identified 6 additional studies for full-text review, of which 3 were excluded. Where there was uncertainty about potential eligibility, the third author SN read the paper, enabling a decision to be made. In total, 17 studies were included in the review. Table 2 provides results of database searches.

Table 2. Quality assessment of studies.

Author, year	Strength of evidence	Main features
Adamski, 2009 [31]	Low	Mixed-methods comparison study, method of qualitative data gathering is unclear, analysis unclear, no detail on quantitative data for comparison or intervention group
Austrom, 2015 [32]	Low	Mixed-methods prospective cohort pilot study, no control group, small numbers (n=4), no details on analysis for qualitative data, integration of data limited
Banbury, 2014 [33]	High	Qualitative study using three evaluation methods, satisfactory numbers (n=52), method of analysis reported
Burkow, 2013 [34]	High	Qualitative study using interviews, sample selection unclear, analysis clear, intervention well described
Burkow, 2015 [35]	High	Mixed-methods prospective cohort study, no control group, small sample size (n=10), qualitative data from interviews, findings well integrated
Damianakis, 2016 [36]	High	Qualitative study using archived recordings of videoconference meetings, content analysis and criteria well reported, three authors independently coding
Ehlers, 2015 [37]	Low	Mixed-methods randomized controlled study using two comparison groups, recruitment and randomization unclear, small numbers (n=30), qualitative data from interviews, field notes and journal, three researchers independently coding, limited integration
Khatri, 2014 [38]	High	Mixed-methods cohort prospective pilot study, small numbers (n=18), two comparison groups, qualitative data from transcripts of group meetings, two researchers independently coding, data well integrated
Lundberg, 2014 [39]	Low	Qualitative case study, interviews, field notes, and website data; methods of meetings unclear; analysis unclear
Marziali, 2006a and 2006b [40,41]	Low	Mixed-methods randomized controlled study, randomization unclear, outcome data for <80% of participants, qualitative data from archived video sessions, analysis clear
Marziali, 2009 [42]	High	Qualitative study, archived videoconference recordings and interviews, analysis clear, small size (n=18)
Marziali, 2011 [43]	High	Mixed-methods comparison study; qualitative data archived from videoconference meetings, chat sessions, and interviews; size satisfactory (n=91); two independent coders; good integration of data
Nyström, 2006 and 2008 [44,45]	High	Qualitative study, diary notes, and interviews; researcher as observer but not considered in findings
Tsaousides, 2014 [46]	Low	Mixed-methods cohort nonrandomized prospective study, no control group, small number (n=7), outcome data for >80% of measures, bias sample
Wild, 2015 [47]	High	Quantitative randomized controlled study, satisfactory numbers (n=117), clear randomization

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Table 3. Analysis framework definitions.

Overarching theme	Definition
Feasibility	Feasibility tests the viability of the study to see whether the study can be performed [49]. For this study, it focuses on the installation and testing of equipment [52]. It includes factors relating to the videoconferencing system, equipment, and its usability for participants and facilitators. It encompasses understanding what technology factors hindered or helped with connecting groups of people and enabling facilitation and discussion
Acceptability	Acceptability relates to the extent to which the intervention is suitable, satisfying, or attractive to the participants [53]. Issues influencing acceptability included feelings of intrusiveness and invasion of privacy; whether improved exposure was beneficial, such as connecting with new people in similar circumstances; participants and facilitators ability to adapt their communication for the videoconferencing environment; attendance and dropout rates; and length of intervention
Effectiveness	Effectiveness concerns the interventions effect on participants' health status and/or health outcomes [51,54]. Effectiveness incorporates data on whether the intervention changed something in the person, either an attribute, or their circumstances. It includes whether the intervention enabled a successful group process demonstrating cohesion and universality. In addition, whether participants felt or received empathy toward others and changes to levels of social support, social isolation, or loneliness were extracted
Implementation	Implementation is the extent the intervention can be successfully and reliably delivered to participants as it is intended [38,51,53]. In particular, studies that sought to evaluate whether an existing face-to-face intervention could be reliably replicated using group videoconferencing were included. Data were extracted for the online group process only

Quality Assessments of Included Studies

Quality assessment of identified studies was completed using the Mixed Methods Appraisal Tool (MMAT) [26] as 7 of the 14 included studies had used mixed-methods study designs. The MMAT has met validity and reliability standards [27], is suited to a public health context, and has been used in a number of systematic reviews that comprise studies with nonrandomized controlled trial papers [28-30]. Quality assessment was conducted independently by AB and LP, with differences of opinions discussed with SN.

Analysis Framework

The outcome terms of feasibility, acceptability, and effectiveness were often used in the included studies, but there were no consistent definitions. Telehealth literature was reviewed first to define the concepts of these terms (Table 3). The additional overarching theme of implementation was also included to capture data regarding validity and reliability of delivering face-to-face programs in the videoconferencing context. Subheadings informing the overarching themes were inductively derived from the identified studies. These concepts were then used as the framework for data extraction (Figure 1). The framework utilizes similar concepts identified by Hebert [48], where system quality, user satisfaction, and individual impact conceptualize the structure-process-outcome of telehealth variables. Our overarching concepts are present in other models that are designed to guide planning and evaluation of telehealth interventions [49-51]. However, in our framework, we have narrowed our focus of feasibility to capture data only relating to technology factors and acceptability to comprise only of patient satisfaction subjective data, enabling greater clarity between the two concepts.

Data Extraction and Synthesis

Using the analysis framework, data were extracted from the eligible studies into an Excel (Microsoft) spreadsheet. For mixed-methods studies, qualitative and quantitative data were extracted simultaneously. Following data extraction, the studies were split into two groups comprising high- and low-level quality assessments. Content analysis compared subheading level data of the two groups with confirming and contrasting results noted. Using two groups to compare results is intended to provide greater validity for quantitative data and trustworthiness for qualitative data [55].

A narrative synthesis of data was undertaken to summarize the findings from individual studies descriptively and focused on aggregative synthesis, bringing together evidence and looking for generalizable lessons [56]. This narrative synthesis reports descriptive themes on successful and unsuccessful factors for delivering group videoconferences into the home, regardless of the topic or subject of the group work.

Results

Study Selection

We identified 1634 studies from the selected databases (see Table 4).

Figure 2 provides a summary of the study selection method. Two studies were reported in four papers, and in accordance with MMAT guidelines, only one MMAT was completed for each of those studies [40,41,44,45]. Multimedia Appendix 1 provides details of the level of evidence and key factors influencing the decision-making process. There were 9 high-quality studies and 6 of low quality. A common feature of low-quality studies was the use of mixed-methods with small sample sizes and limited detail on the method of integration of quantitative and qualitative data [31,32,37,40,46].

General Study Characteristics

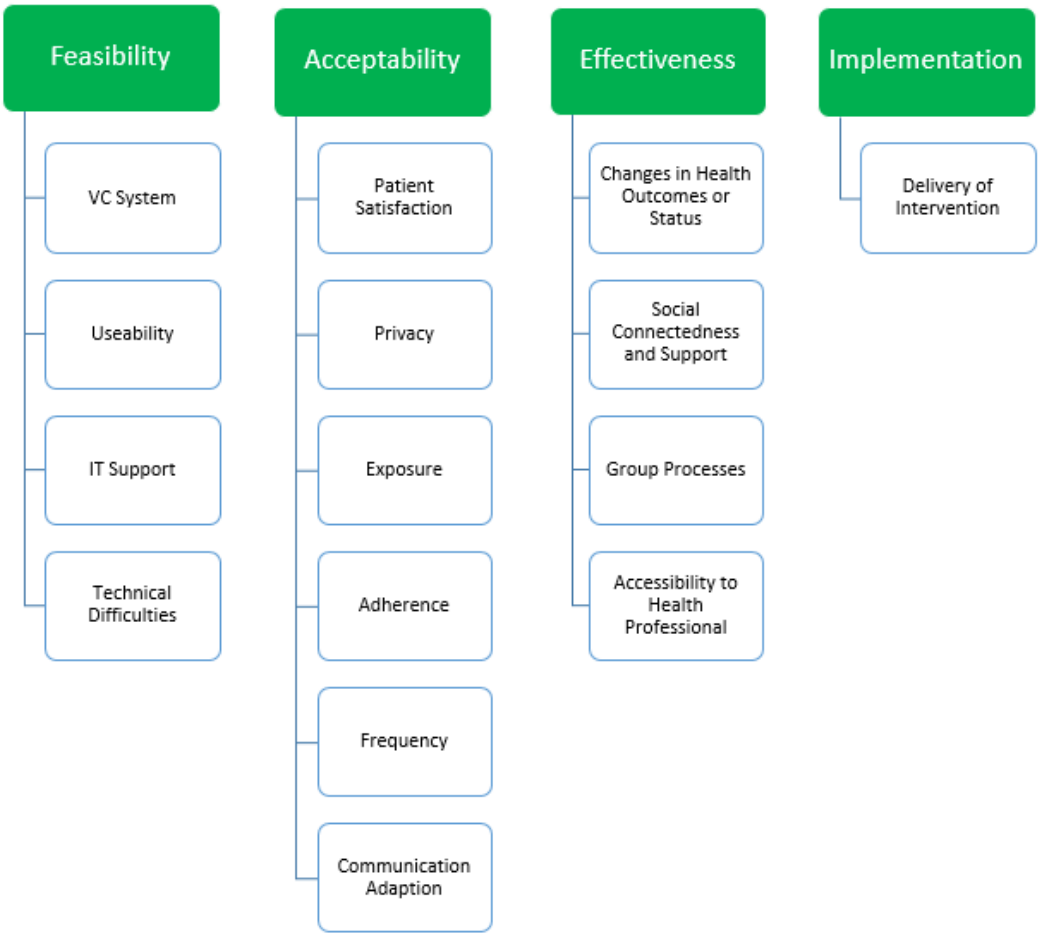
Table 5 provides a summary of the included studies. There were 17 publications: five were from Canada [36,38,40-43], four from the United States [31,32,37,46], two from Sweden [39,44,45], two from Norway [34,35], and one each from Australia [33] and Germany [47]. They included 14 observational studies and three randomized control trials [37,40,47]. Sample sizes ranged from 4 to 117. Of the included studies, 9 were mixed, 6 were qualitative, and 1 used quantitative methods.

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Table 4. Number of studies retrieved from databases.

Database	Number of studies retrieved
PubMed	951
Academic Search, CINAHL with full text, Health Source Consumer, Health Source Nursing, MEDLINE, Psychology and Behavioural Sciences Collection, PsycINFO, SocioIndex	246
InfoRMIT	45
ProQuest-narrow and refined terms	45
Google Scholar	344
Reference searching	3

Figure 2. Analysis framework. VC: videoconferencing; IT: information technology.



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Table 5. General study characteristics of included studies.

Author, year, country	Aim of study	Type of group; group lead	Methodology	Full[a] or part[b]	Level of evidence
Adamski, 2009, United States [31]	Support to caregivers of persons with dementia	Psychoeducational; Unspecified	Mixed	Full	Low
Austrom, 2015, United States [32]	Support to caregivers of persons with dementia	Psychoeducational;Psychologist	Mixed	Full	Low
Banbury, 2014, Australia [33]	Health literacy and chronic disease education	Educational; Health Promotion Specialist	Qualitative	Full	High
Burkow, 2013, Norway [34]	Pulmonary rehabilitation and diabetes education	Educational and exercise; Multidisciplinary	Qualitative	Part	High
Burkow, 2015, Norway [35]	Pulmonary rehabilitation	Educational and exercise; Multidisciplinary	Mixed	Full	High
Damianakis, 2016, Canada [36]	Support to caregivers of survivors of traumatic brain injury	Psychoeducational; Social worker	Qualitative	Part	High
Ehlers, 2015, United States [37]	Book club to improve physical activity behaviors	Educational; Health Promotion Specialist	Mixed	Part	Low
Khatri, 2014, Canada [38]	Cognitive behavioral therapy	Psychoeducational; Nurse	Mixed	Part	High
Lundberg, 2014, Sweden [39]	Support for caregivers of persons with dementia or stroke survivor	Educational; Nurse and social worker	Qualitative	Part	Low
Marziali, 2006a and 2006b, Canada [40,41]	Support for caregivers with neurodegenerative disease	Psychoeducational; Social worker and nurse	Mixed	Part	Low
Marziali, 2009, Canada [42]	Healthy lifestyles program for persons with chronic disease	Educational; Not specified	Qualitative	Part	High
Marziali, 2011, Canada [43]	Support caregivers of persons with dementia	Psychoeducational; Nurses and social workers	Mixed	Part	High
Nyström, 2006 and 2008, Sweden [44,45]	Support for new parents	Facilitated support; Child Health Nurse	Qualitative	Full	High
Tsaousides, 2014, United States [46]	Cognitive behavioral therapy treatment for emotion regulation for persons with traumatic brain injury	Psychoeducational; Psychotherapist	Mixed	Full	Low
Wild, 2015, Germany [47]	Weight loss education for persons following bariatric surgery	Psychoeducational; Psychotherapist	Quantitative	Part	High

[a]Intervention only comprised videoconference groups.

[b]Intervention comprised other elements such as online education.

Intervention Characteristics

Multimedia Appendix 2 provides intervention characteristics of the studies. A total of 467 participants contributed to the 15 studies. Six studies targeted caregivers [31,32,36,39,40,41,43], the most predominant target group within the review. Others targeted people with chronic disease [33-35,38,42], obesity [47], traumatic brain injury [46], new parents [44,45], and those not reaching public health healthy lifestyle guidelines [37]. Eight studies reported participants' age or average age as above 50 years, and of these, 5 participants had an average age of above 65 years, many of whom were inexperienced computer users.

The services provided by group videoconferencing were: psychoeducational [31,32,36,38,40,41,43,46,47], where the intervention included a psychological intervention or psychological-based support; therapeutic support group [44,45], where groups of people facing similar issues were brought together—these emphasize emotional support and shared experiences as participants can direct the topic and format of the group discussions, and they may also contain an educational element; and an educational support group [33-35,37,39,42] in which the groups received education and took part in facilitated discussion on specific conditions or diseases.

In 7 studies, videoconference group meetings were the only component of the intervention, whereas for the other 10 studies, the videoconference group meetings were one of multiple components. These other components included: access to information on an intervention-specific website (6); text-based discussion forums (5); email link to other participants (4); face-to-face group meetings (4); link for one-to-one health consultations with a health professional (2); link for one-to-one videoconferencing social meeting (1); and an electronic health diary for wireless transmission or manual entry of sensor data (1). In 2 studies, weekly videoconference group exercise sessions took place.

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There was a range of health professionals providing group facilitation, including a specialist, psychologists, psychotherapists, social workers, nutritionists, nurses, and health promotion specialists.

Outcome measures varied between studies. Data relating to the health status and/or health outcomes were collected using both validated and nonvalidated measures. Validated measures were defined as those for which the authors provided an academic reference and the psychometric properties, such as the Short Form Health Survey-36 [57]. Nonvalidated measures were those developed for the specific purposes of the study [58]. The heterogeneous nature of the studies and the limited number of quantitative studies meant that a meta-analysis of quantitative data was inappropriate [59]. Five studies measured perceived health and health-related quality of life (HRQoL) [32,35,40,43,47], 5 depression [32,38,40,43,47], 3 social support [37,40,43], 2 caregiver self-efficacy [32,43], and 1 study measured caregiver burden [32]. Other studies explored the following factors: physical activity, general self-worth, physical self-worth, physical activity self-efficacy, physical activity self-regulation, physical activity benefits or barriers [37], activities of daily living [40], neuroticism [43], weight and eating behavior [47], emotional regulation and problem solving [46], health service use [43], and technology usability [35].

All studies included results on feasibility, acceptability, and effectiveness, and some reported issues connected with implementation [33,36-38,40-44,47].

Feasibility

Videoconferencing Systems

Multimedia Appendix 2 provides details of the number of participants connected to the groups at one time and Multimedia Appendix 3 describes key findings of the studies. The majority of studies used desktop computers [32,39,41-45], 2 used tablet computers [33,37], and 2 used computers connected to users' televisions [34,35]. Six studies used intervention-specific websites with videoconferencing group links embedded within them [36,38,40-45]. Three studies used the same website [36,40,41,43], one of which was an updated version [42], and 2 studies used the same videoconferencing system [34,35].

Devices and additional equipment such as webcams and headsets were generally supplied, although in 2 studies the inclusion criteria specified participants having access to a computer and broadband [45,46]. In another study, they used participants' computers and Internet access but provided refurbished equipment for those who needed it [43]. Reported connection speeds were 200 to 400 kbps [32,34] and high-speed broadband [33].

Usability

Participants were not always experienced in videoconferencing or computer use. Overall, inexperience did not appear to be a major problem as the majority of studies reported that, over time, participants found the technology easy to use [32-35,40-42,46] and found videoconferencing enjoyable [42,44-46]. One study, in which a third of participants had a degree, reported that poor digital literacy may have contributed to low participation rates [37]; suggesting that education level is not necessarily associated with digital literacy. Other studies noted technology was not a barrier, with participants persisting in overcoming technical difficulties [32,42,43].

Information Technology Problems

Various levels of technical problems were encountered; 8 of the 15 studies reported few difficulties [31,32,34-36,38,44-46], whereas 7 reported a number of problems [33,37,39,42,43,45,47], 2 of which required substantial work hours to overcome [39,47]. The most common problem reported was audio difficulties, which included delays, dropouts, and background noise [33,37,38,44,45], followed by problems in downloading software [38,42,43].

Visual problems were reported less frequently but included poor lighting in participants' homes [33] and too small a picture to clearly see body language [44,45]. External factors such as location, type of dwelling, and speed of connection also effected videoconferencing quality [33]. However, 3 studies reported that technical difficulties declined during the course of the intervention [33,38,46].

Training and Support

Training was provided to participants either face-to-face [34,35,40,43], with verbal and written instructions [41,46], or an emailed tutorial [37].

Most studies received information technology (IT) support during the videoconference group meetings either by IT specialists or facilitators that were able to troubleshoot problems. IT support was offered using a range of mechanisms including remotely accessing participants' devices [32,33], talking participants through problems by telephone or online [31-36,38,39,44], information manuals [34,35,41,42], home visits (either at the start of the program during installation [43] or during the program [32-34]), and emailed tutorial [37]. For those studies that incurred several problems, participants felt frustrated and in one study needed reassuring that they were not at fault for the technical glitches [38]. Good technical support was considered an important element for an intervention, which could ease participants' anxiety [31].

Brief training for group facilitators was reported in 2 studies [34,35]. Technical difficulties were frustrating for facilitators [38,39], and one study reported a challenging online environment where the facilitator could only see one participant in the active window and was unable to see other members facial expressions or body language [41].

There were no consistent differences in feasibility reported between studies of high quality and those of low quality.

Acceptability

Patient Satisfaction

Overall, patient satisfaction with group videoconferencing was high. All but one study [37] reported that participants had found meeting in a videoconference group either satisfactory or a positive or very positive experience. Factors that contributed to this included being able to see and hear other group members, meeting new people in similar circumstances, sharing

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experiences, and being part of a group that provided social support. A few participants would have preferred to have met face-to-face rather than by videoconferencing, with one group citing, as their reasons for this preference, low social presence [37].

Adherence and Frequency

Overall, attendance at the videoconferencing groups was high, with few dropouts. Attendance rates ranged from 66% to 93.8%, with 6 studies reporting groups with rates of >80% [32,35,36,46,47]. Reasons for participants dropping out or nonattendance included technical problems, not liking to talk about their health, too busy, and illness. Three studies asked participants to complete homework, which included watching educational videos before the next session, completing health diaries, and practicing new skills [34,35,46]. Adherence rates were very good, with homework completed 93% of the time [46] and all participants viewing educational videos and completing health diaries [34,35].

The duration of group videoconferencing meetings ranged from 45 min to 105 min, typically lasting for 1 hour. The majority of videoconferencing groups met weekly. In some studies, participants wanted to meet for longer [34,35,46], more frequently [32,35], or expressed disappointment when the videoconferencing group finished [33]. In 2 studies, individual sessions were provided for discussion on personal issues that would not suitable for the group setting; however, the need to ask questions varied depending upon disease stability [34,35].

Videoconferencing groups were compared with other interventions including face-to-face [31,37,38], text-based chat forum [43], and usual/standard care [47]. Two studies reported similar or higher levels of participation compared with the alternative intervention [31,43]. One study found that attendance rates and participation by the videoconferencing group were lower compared with the face-to-face group [37] and that while on the videoconference, some participants were talking and doing other things such as making dinner and watching TV. Three studies provided 10 to 12 weeks of health professional facilitation, after which groups met on a self-help basis where a group member assumed the facilitation role [41-43]. For the self-help groups, one study reported attendance rates dropping from 70% when the groups were health professionally led to 50% for member-led groups [43]. Another group expressed the wish to continue as a self-help group but felt that without a leader this would be difficult [32].

Privacy and Exposure

Issues of privacy and seeing into each other's homes were not reported as a problem in any studies. In one study, there needed to be prior agreement for someone else to be present in the room while the videoconferencing group was taking place, and the guest was required to be visible [35]. In addition, to closely guard privacy, the camera cover could be closed when not in use.

Conversely, viewing the participant's home environment could increase tailored education and support. In a study of dementia caregivers, the facilitator and participants were able to see that a dementia patient was trying to leave the house repeatedly, which prompted the facilitator to provide safety education and information on local dementia safety services [32]. Another study, which provided support to family caregivers of survivors with traumatic brain injury, had additional family members join the support group intermittently. They were accepted by other participants as part of the group members' on-going and evolving needs [36].

An unexpected challenge was the difficulty in obtaining participants' consent forms, which were by mail. The researchers speculated that this was related to privacy issues of being able to see into participants' home environment. The organization had specified on the consent forms that if they suspected any type of elder abuse, they were required to investigate the matter [31].

There were no clear differences in the reported outcomes for acceptability between studies of high and low quality.

Communication Adaption

Over time, the vast majority of participants became familiar with the technology and adapted their communication accordingly [33,36,42,46]. Overall, only a few participants felt uncomfortable using videoconferencing to communicate with others. Difficulties arose when several people talked at the same time and then stopped on hearing others and then after a pause started talking at the same time again [34]. It was acknowledged that structure and protocols are needed to optimize group communication [35]. Clear communication guidelines and protocols contributed to avoiding talking over each other. In 2 studies, this was reiterated at each session as well as highlighting the importance of confidentiality, active listening, and speaking slowly and clearly [33,47].

Effectiveness

The effectiveness of interventions was considered in terms of changes in health outcomes, including improved health knowledge, insight, and skills; social connectedness and whether face-to-face group processes were replicated; engagement between participants; and increased access to a health professional.

Changes in Health Outcomes

Skills for development included cognitive behavioral therapy strategies [38], insight and coping strategies [40,43], ability to navigate the health care system [36], emotional regulation [46], disease-specific knowledge and skills [32,34,35], and health literacy [33].

The heterogeneity of the studies led to a wide range of assessment tools to report health status and health outcomes. For comparative studies, changes in pre- and postintervention results were similar for face-to-face groups [31,38] and usual care [47] but significantly better than a text-based forum [43].

In pre-post treatment scores, there was a significant change in HRQoL (P=.04) [35] but no significant differences in emotional regulation, problem solving [46], or physical activity and associated factors [37]. Of note is the trend of videoconferencing groups improving aspects of mental health and self-efficacy [32,38,43,47]. One high-quality study of participants with

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clinically significant depression at baseline reported that videoconferencing groups had significantly better HRQoL (P=.03) and lower depression score (P=.02) compared with the control group of usual care 1 year after surgery [47].

Health knowledge, insight, and skills were developed through didactic teaching methods, discussion, sharing experiences, asking and listening to questions, self-reflection, and books (available on an e-reader). Information that was available on websites was accessed at the beginning of the intervention but much less so as the intervention continued [37,39].

Social Connectedness and Support

Engaging with others who were experiencing similar problems was highly valued and enabled empathic connections to develop. High-quality studies consistently reported positive outcomes of engagement. Videoconferencing groups helped reduced feelings of anxiety, isolation, and loneliness [36,39,42,44] and provided emotional and social support [32-35]; however, some participants took a while before they felt at ease with others, which may have been related to the online environment [46]. Two studies combined face-to-face meetings with online meetings [34,39]; one study reported that, for those who could not attend the face-to-face meeting, engagement with others during the intervention was not compromised [34]. Only one study reported that the videoconferencing environment limited participants' connection with each other [37]. Videoconferencing groups were considered superior in comparison with a text-based forum, with few people contributing to the forum and threaded discussions going off-topic [43].

Group Processes

Bonding and cohesiveness were reported in all high-quality studies and in one low-quality study [40,41]. Higher levels of cohesiveness were demonstrated in groups with more stable memberships compared with groups whose membership altered because of changes in participants' availability [33]. Gender differences were noted in a study comprising one group of men and one of women, with the men's discussions being more problem-focused and the women's being more emotion-focused [44,45]. Qualitative studies reported discussion themes that illustrated participants' ability to discuss sensitive and personal issues and to give and receive empathetic support [33,36,42,44,45].

Accessibility of Groups

Accessing a group from home was considered beneficial in all studies except one, whose participants would have preferred to have met face-to-face [37]. The ability to meet from one's home was viewed positively and helped overcome a number of barriers that, for some participants, would have prohibited their attendance at a face-to-face group. Barriers included illness, transportation difficulties, not being able to leave the person they were caring for, and/or living rurally or in an area where there was no face-to-face alternative. Additionally, some participants reported feeling more relaxed and open by being at home and valued the convenience [33,34,36,42-46].

Implementation

Treatment reliability and validity was assessed in four psychoeducational studies [36,38,41,43]. They aimed to demonstrate that technology-supported groups met the same standards and outcomes as face-to-face groups. The face-to-face group format and process was replicated in videoconferencing groups in 3 studies [36,38,41], and treatment protocol was adhered to in videoconferencing format in 2 of the studies [38,43]. Validity was demonstrated through the analysis of discussion themes such as cohesiveness, empathic support, problem solving, or issues in disease-specific caregiver literature and was consistent with the face-to-face groups [36,38,40-42]. Results were reported as similar to face-to-face groups [38,43,47]. In 2 studies, facilitators reported that implementing the intervention by videoconferencing was initially challenging, but over time, techniques were mastered, and the operation became more automatic [38,41]. Difficulty in retrieving online assessments and evaluation forms were reported [31,37].

Details on pre-program procedures overall were lacking but included participants being required to be ready up to 15 min before the start of the meeting, which could be used for informal chat time [33], enabling a socialization opportunity [34]; the importance of punctuality [47] and pre-program face-to-face meetings are not necessary [35].

Discussion

Principal Findings

We reviewed evidence of feasibility, acceptability, effectiveness, and implementation of health professional-led group videoconferencing to provide education and/or social support into the home setting. Fifteen studies met our inclusion criteria. Overall, evidence indicated that group videoconferencing into the home was feasible and acceptable, but it was harder to draw firm conclusions on the effectiveness of such interventions.

The routine and widespread use of home-based videoconferencing groups for health support applicability has as yet not been widely researched. Therefore, intervention studies identified to inform this systematic review were mostly pilot in nature and contained small sample sizes and generally were nonrandomized study types. The identified studies were considerably divergent in regards to the interventions, comparison groups, and outcome measures used. A wide range of health outcome measures were employed; however, their usefulness is debatable as sample sizes were commonly small, and therefore, studies may have been underpowered, with the quantitative data providing no new information. Overall, qualitative data provided a deeper understanding of equipment usability, IT support, privacy and exposure issues, group dynamics, and perceived benefits.

Feasibility

Videoconferencing systems were most commonly used with desktop computers, which most studies provided for the participants. Mobile health (mHealth) devices such as tablet computers and mobile phones were infrequently used, despite their ability to provide access to videoconferencing with few technical skills. For those with limited experience in using

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technology, mHealth and apps can provide simplified access by overcoming difficulties such as downloading software and using a mouse. As ownership of mobile devices and access to the Internet grows, it is feasible that health programs can be developed so that participants can "bring your own devices," as has been implemented in the education sector [60,61]. Using consumers own devices would lower program costs; however, further work in understanding issues of interoperability, security, and acceptability is warranted to investigate the use of personal devices for health care.

Good IT support was a vital component in the feasibility of delivering the interventions. The majority of studies reported few technical problems, and for those that did report difficulties, audio lag was the most common issue. IT support was mostly available during the videoconferencing groups by IT personnel or in a few studies by the facilitator, with a range of strategies used, including remote access to devices and verbal instructions. IT support is a key resource consideration for organizations proposing to use group videoconferencing interventions with clients. It is central to successful implementation for both facilitators and clients and should be adequately costed into program budgets.

The review includes studies implemented from 2006 to 2015. During this time, there has been a rapid and dramatic improvement in technology. However, later studies did not report fewer technical difficulties compared with earlier ones, but interestingly, as interventions progressed, IT problems declined. It is unclear whether this was because of participants' technology skills improving or whether the technical problems were fixed by IT support. Geographical location and the IT systems utilized may account for technical difficulties. There were fewer technical problems reported by studies from the United States, which may pertain to more developed Internet operations and IT systems. Although IT glitches could lead to frustration, it appears that participants were persistent in overcoming difficulties, as the benefits of being part of a group and meeting others outweighed the technical difficulties.

Acceptability

Acceptance of meeting by videoconferencing was high. Overall, participants found the experience of using videoconferencing groups positive, with few participants preferring to have met face-to-face. Some participants expressed they would have liked the programs to be more frequent or last for longer. Adherence to the programs was high, which may indicate publication bias for successful interventions. The majority of the studies targeted interventions for people aged 50 years and older, indicating, contrary to some opinions [62], technology can be used in the care of older people who may have poorer digital literacy. Inexperience in computer use did not appear to be a barrier for participants, with many studies reporting the technology was easy to use. In some populations, videoconferencing is becoming ubiquitous and a natural means of communicating. Therefore, it is not unreasonable to conclude that, in time, the use of group videoconferencing will become mainstream.

Previously, privacy issues have been cited as a barrier for telehealth implementation [62,63]. In our review, no studies reported participants concern about others seeing into their homes [64,65]. Few studies discussed the impact of interventions taking place in the home and the lack of control practitioners have in this environment. Prior consideration of delivering interventions into shared living spaces is necessary, in particular, the inclusion or exclusion of other residents. The benefits of viewing participants in their environment was highlighted, enabling education to be tailored to participants' needs. Other studies have reported the importance of health education, taking into account the context of people's lives [66]. Videoconferencing may provide educators with an additional understanding of contextual issues for clients, which may lead to a more patient-centered health intervention.

Few studies provided details on whether specific communication strategies were adapted to facilitate videoconferencing groups. Social presence is the extent to which a technology used to facilitate a meeting can provide a social or personable feeling to the interaction [67]. Although videoconferencing allows for a higher social presence than other computer-mediated communications such as discussion boards, it has a lower social presence compared with face-to-face meetings [68,69]. Clear communication guidelines and strategies appeared to have helped overcome some technical difficulties and aid effectiveness of the interventions [70]. However, descriptions on facilitator skills necessary for the challenging videoconferencing environment were rarely discussed. How facilitators may have changed their communication method and style would further help develop an understanding of best practice for telehealth group videoconferencing interventions. A review of videoconferencing for CDSM noted differences in attitudes between participants and health professionals, with clients more accepting of the technology [71]. These differences may be because of a more complex intervention environment for facilitators.

There is an indication that groups via videoconferencing may provide a new avenue to either kick-start new self- help groups or sustain existing groups. Although details were scant on the effectiveness or uptake, there were interventions that developed groups that were designed to continue meeting after an agreed amount of time of health professional facilitation [40,43]. Member-led self-help groups may provide a new model for cost-effective social support groups, given that, after initial set-up, there is no cost to the health service provider.

Effectiveness

Compared with other modes of delivery, videoconferencing groups were significantly better than a text-based forum and similar to face-to-face groups and usual care. Increases in health knowledge and skills were achieved across a range of topics including mental health issues, health system use, and lifestyle behaviors. Home-based videoconferencing groups overcame known barriers for attending face-to-face groups, such as transportation, travel distance, lack of time, inconvenience [72,73], and not being able to leave the care beneficiary. However, it should be noted, as outlined earlier, there are other drawbacks such as consideration of other residents and interruptions that hinder using videoconferencing in the home environment.

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A consistent finding was the perception that groups enabled engagement and social support, which was highly rated by participants. Lack of social support, social isolation, and loneliness are known risk factors for ill health and hospitalization [74,75]. Using new technology to help develop social support networks and overcome social isolation and loneliness in real-time is an emerging area [33]. Videoconferencing groups could be used to develop new and relatively low-cost interventions, particularly with at-risk groups such as those living in rural areas, with limited mobility and older people.

Identifying which groups of people are most likely to benefit from telehealth interventions is an important factor in improving the evidence base for telehealth [76]. Telehealth interventions may not be suited for all populations, and it is important to understand which groups would be best targeted, or are most responsive to, the use of group videoconferencing, to ensure that resources are used efficiently. Due to the heterogeneous nature of the studies, it is not possible to draw any firm conclusion as to whether there are specific subgroups that are particularly suited for group videoconferencing.

However, similar to studies with videoconferencing group participants located in health care centers [17,77], there is a clear trend for improving mental health outcomes such as depression, self-efficacy, stress and anxiety, and overcoming a fear of meeting new people. Furthermore, videoconferencing groups can provide sustained mental health outcomes, as demonstrated by Wild [78], with their follow-up study reporting significantly lower depression and higher self-efficacy approximately 2 years following their group videoconferencing intervention. It is possible that being in the home environment is less stressful than meeting people in-person and that meeting by videoconferencing provides a greater feeling of anonymity [79] and security and the ability to leave the group more easily.

Implementation

Studies that implemented existing psychoeducational interventions reported good reliability and validity and were as effective as face-to-face interventions. In addition, many studies reported the ability to replicate group processes such as bonding, cohesiveness, and empathy.

We did not specifically consider cost-effectiveness in this review but of note is the potential savings that videoconferencing groups may provide. In one study, providing rehabilitation to home-based groups decreased costs by 50% compared with face-to-face outpatient rehabilitation [35]. Cost-effectiveness has been reported for face-to-face group–based approaches for CDSM programs [80], and there may be even greater cost savings if groups are delivered by videoconferencing. Cost savings to the health provider can be made by educating a number of people simultaneously, more efficient use of clinical time, and it may even reduce the numbers of nonattendance [81]. For patients, particularly those in rural areas, videoconferencing improves access to health professionals and removes time-consuming and expensive travel costs. As people age, their use of health care services increases, and therefore, an understanding of whether group videoconferencing would be acceptable and cost-effective in providing interventions to older populations who are high users of health services would be valuable. The cost-effectiveness of group videoconferencing compared with usual care may encourage uptake and is suggested as an area for further research.

Limitations

Comparability of study findings was limited by the heterogeneity of the interventions, participants, and assessed outcomes. Sample sizes were small, which was a limitation for those studies reporting quantitative data. However, the number of studies in the field was so limited that all relevant studies to identify commonalties and consistent themes were reviewed. In addition, identifying the limitations of videoconferencing-only interventions was not possible as studies that included other elements such as face-to-face meetings or text-based discussion forums did not report separate findings.

The range of different tools used to measure the same health outcome, such as depression, meant it was not possible to compare the effectiveness of studies. Adoption of consistent tools for telehealth interventions would enable outcomes to be compared and further advance the evidence base. Telehealth is an emerging field, and new tools are likely to be developed specifically for this use. Indeed, the new Whole Systems Demonstrator Users Technology Acceptability Questionnaire measures a range of user beliefs and identifies who are more likely to refuse telehealth [82]. This tool was developed since this systematic review and may provide researchers with a consistent tool that is suitable for a range of telehealth programs.

Limiting study eligibility to health intervention videoconferencing groups delivered to the home rather than to another setting may have produced bias. During the search strategy, 25 studies were identified that delivered videoconferencing groups into health care settings. The decision to limit the search to those delivered into the home was to explore the implications for participants and facilitators in delivering home-based groups.

Conclusions

Group videoconferences into the home are feasible but need good IT support. The benefits of being able to take part in a group from home often outweigh the frustration of IT problems. At present, interventions that have used mHealth are limited. However, it is not unreasonable to expect these to increase because of the ubiquitousness of mHealth devices. Similarly, the rapid advancement of technology suggests that technical difficulties will decrease, and there will be more interventions which experience few technical problems.

The acceptability of group videoconferencing was high in different age-related and content-related groups. Exposure into people's homes was not a concern; in fact, it can help target interventions to be more context specific. Further work is required to identify which subgroups would benefit the most from this type of intervention, as well as understanding how to modify communication for group videoconferencing.

Group videoconferencing is effective in overcoming many barriers for accessing face-to-face groups. Evidence suggests that group processes can be replicated in the online environment.

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The effectiveness of interventions varied, although there was a trend to improvement for participants with mental health problems. Further research to identify which populations and the learning content most likely to benefit from group videoconferencing should be undertaken.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Quality assessment of studies reviewed.

[PDF File (Adobe PDF File), 51KB - jmir_v20i2e25_app1.pdf]

Multimedia Appendix 2

Intervention characteristics of included studies.

[PDF File (Adobe PDF File), 41KB - jmir_v20i2e25_app2.pdf]

Multimedia Appendix 3

Outcome measures and reported findings of included studies.

[PDF File (Adobe PDF File), 58KB - jmir_v20i2e25_app3.pdf]

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Abbreviations

CDSM: chronic disease self-management
HRQoL: health related quality of life
IT: information technology
mHealth: mobile health
MMAT: Mixed Methods Appraisal Tool

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Original Paper

Effect of Recruitment Methods on Response Rate in a Web-Based Study for Primary Care Physicians: Factorial Randomized Controlled Trial

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Abstract

Background: Low participation rates are one of the most serious disadvantages of Web-based studies. It is necessary to develop effective strategies to improve participation rates to obtain sufficient data.

Objective: The objective of this trial was to investigate the effect of emphasizing the incentive in the subject line of the invitation email and the day of the week of sending the invitation email on the participation rate in a Web-based trial.

Methods: We conducted a 2×2 factorial design randomized controlled trial. We contacted 2000 primary care physicians from members of the Japan Primary Care Association in January 2017 and randomly allocated them to 1 of 4 combinations of 2 subject lines (presence or absence of an emphasis on a lottery for an Amazon gift card worth 3000 yen or approximately US $30) and 2 delivery days (sending the invitation email on Tuesday or Friday). The primary outcome was the response rate defined as the number of participants answering the first page of the questionnaire divided by the number of invitation emails delivered. All outcomes were collected between January 17, 2017, and February 8, 2017.

Results: We analyzed data from 1943 out of 2000 participants after excluding those whose email addresses were invalid. The overall response rate was 6.3% (123/1943). There was no significant difference in the response rates between the 2 groups regarding incentive in the subject line: the risk ratio was 1.12 (95% CI 0.80 to 1.58) and the risk difference was 0.7% (95% CI –1.5% to 2.9%). Similarly, there was no significant difference in the response rates between the 2 groups regarding sending the email on Tuesday or Friday: the risk ratio was 0.98 (95% CI 0.70 to 1.38) and the risk difference was –0.1% (95% CI –2.3% to 2.1%).

Conclusions: Neither emphasizing the incentive in the subject line of the invitation email nor varying the day of the week the invitation email was sent led to a meaningful increase in response rates in a Web-based trial with primary care physicians.

Trial Registration: University Hospital Medical Information Network Clinical Trials Registry UMIN000025317; https://upload.umin.ac.jp/cgi-open-bin/ctr_e/ctr_view.cgi?recptno=R000029121 (Archived by WebCite at http://www.webcitation.org/6wOo1jl9t)

(J Med Internet Res 2018;20(2):e28) doi:10.2196/jmir.8561

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KEYWORDS

Web-based surveys; electronic mail; incentives; surveys and questionnaires; survey methods; questionnaire design; data collection; physicians; general practitioners

Introduction

One of the most serious drawbacks of Web-based studies is their considerably smaller participation rates compared to paper-based studies [1,2], even though Web-based studies are widely used to explore clinicians' knowledge, perspectives, and clinical practice [3-5]. In a meta-analysis examining participation rates of studies targeting clinicians, the mean participation rate had decreased over the years [1]. Furthermore, participation rates of 20% or less are not uncommon in Web-based studies especially for physicians [1]. These low participation rates may impair the precision of estimates due to reduced sample size and call into question representativeness of the subject group, leading to selection bias. Thus, researchers planning Web-based studies need to develop effective strategies to improve participation rates to obtain sufficient data.

Previous studies have investigated factors related to participation rates in Web-based studies. Incentives, contact timing, content of subject line and message of invitation emails, length of questionnaire, survey webpage design, and individualization among others were proposed as factors that may improve participation rates of Web-based studies [6-8]. Among these, incentives, contact timing, and content of invitation emails were considered the most useful because they require no special system. In studies targeting clinicians, incentives were considered to increase participation rates, and monetary incentives were reported to be more effective than nonmonetary incentives and no incentive [6,9-11]. However, whether emphasizing incentives in the subject line of an invitation email increases participation rates remains unclear. Two studies have reported that participation rates of Web-based studies have decreased by emphasizing incentives in the subject line among college students or general population adults [12,13]. Alternatively, Janke et al [14] reported that an invitation email emphasizing a monetary incentive in the subject line significantly improved response rate (10.4% vs 5.6%, *P*=.03) among college students. We do not yet know whether clinicians show similar patterns. To our knowledge, the effect of emphasizing incentives in the subject line of invitation emails for clinicians has not been studied.

As for contact timing, previous studies have reported conflicting findings regarding the effect of the day of the week of sending postal mail invitations on study participation rates among general practitioners [15]. One study found that the weekend was more effective than weekdays for postal mailing [16], but 2 others did not [17,18]. The effect of the day of sending invitations by email has not been examined to date, whereas this has been done with postal mail [15].

The objective of this trial was to investigate the effect of emphasizing the incentive in the subject line of the invitation email and the day of the week of sending the invitation email on the participation rate in a Web-based trial.

Methods

Design

We conducted a 2×2 factorial design randomized controlled trial (RCT) to test 2 recruitment strategies for the invitation email in a Web-based trial with participants who were members of the Japan Primary Care Association (JPCA).

Procedures

This study was a substudy regarding the recruitment process embedded in another randomized controlled study (Do Overstated Conclusions Trick Our Readers? The DOCTOR study [UMIN000025317]), which investigated whether overstated conclusions in abstracts of clinical research papers can bias primary care doctors' impressions of the results. The DOCTOR study was conducted between January 17, 2017, and February 8, 2017. In the DOCTOR study, participants were asked to complete a 2-page online questionnaire about evidence-based medicine. The questionnaire had 9 and 4 items, respectively, on the first and second pages. A completeness check was automatically conducted after the questionnaire was submitted and respondents were asked to complete the mandatory items if they were blank. The first researcher (RS) developed all the Web systems for the DOCTOR study. Details of the methods and results of the DOCTOR study are reported elsewhere [19].

To maximize the number of respondents in the DOCTOR study, we recruited the participants in 2 phases. In the first phase, we randomly sampled 2000 primary care physicians from 7040 potential participants and sent the invitation email to investigate the most effective subject line (emphasizing an incentive of a chance to win an Amazon gift card worth 3000 Japanese yen [US $30]; Amazon gift cards were to be provided to 20 respondents through a lottery) on different days of the week (Tuesday vs Friday). In the second phase, we invited remaining potential participants using the most effective method confirmed in the first phase. We hereby report the results from the first phase. The English version of the invitation email is included in the supplementary appendix reported elsewhere [19].

Interventions

We tested the 2 interventions related to the invitation email. One intervention involved mentioning the chance to receive an Amazon gift card in the subject line ("[Get Amazon gift card] Survey on EBM for 5 minutes") or not ("[Funded by the association] Survey on EBM for 5 minutes"). The other intervention involved sending the invitation email at 6:00 PM on either Tuesday, January 17, 2017, or Friday, January 20, 2017.

Participants

The eligibility criteria for participation were as follows: being a member of the JPCA, which is the largest association of primary care doctors in Japan; having more than 2 years of

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clinical practice experience; and having a registered email address with the JPCA. Eligible participants of the DOCTOR study were 7040 primary care doctors out of the 10,851 members of the JPCA in January 2017 when the DOCTOR study was conducted.

To limit participants to members of the JPCA, we did not announce the DOCTOR study on websites or social networking services with open access. The recruitment process was conducted only through emails from the secretariat of the JPCA, which invited doctors to voluntarily participate in the study.

Randomization and Blinding

We randomly assigned a sample of 2000 primary care physicians who were randomly selected from the eligible JPCA members to 4 groups (500 participants in each group): (1) those who received the invitation email with a subject line emphasizing the incentive on Tuesday, (2) those who received the invitation email with a subject line emphasizing the incentive on Friday, (3) those who received the invitation email with a subject line not emphasizing the incentive on Tuesday, and (4) those who received the invitation email with a subject line not emphasizing the incentive on Friday.

The invitation emails were sent by the secretariat of the JPCA according to the allocation table prepared by RS using a computer-generated random sequence. Potential participants were not informed that the invitation emails were sent in 4 different ways. Outcomes such as response, completion, and access to the DOCTOR study website were automatically recorded.

Outcomes and Data Collection

The primary outcome was the response rate defined as the number of participants completing the first page divided by the number of invitation emails delivered. The formula was equivalent to Response Rate 2, defined by the American Association for Public Opinion Research [20], which was used in a previous study investigating strategies to improve response rates for a Web-based clinician study [21].

Secondary outcomes were the completion rate and access rate to the DOCTOR study website. The completion rate was defined as the number of respondents who completed all the pages on the DOCTOR study website divided by the number of invitation emails delivered. The access rate was the number of participants accessing the DOCTOR study website divided by the number of invitation emails delivered.

The data were collected between January 17, 2017, and February 8, 2017. The response rate and completion rate were recorded by a Web application developed by RS for the DOCTOR study. The access rate was recorded using Google Analytics (Google). The allocation of each participant was tracked using a URL link unique to each allocation embedded in the invitation email. We used an IP address and a cookie to avoid double-counting the same user if any of them accessed or responded more than once. No bug fixes, downtime, or content changes were necessary during the period of the DOCTOR study.

Sample Size

We included 2000 of the potential participants of the DOCTOR study in this factorial RCT to apply the most effective invitation email strategy to the remaining potential participants. With a sample size of 2000, we calculated the power to be 0.81 at an alpha level of .05 to detect the significant absolute risk difference of 3% against an assumed control response rate of 4% based on results of previous surveys targeting JPCA members.

Data Analysis

Statistical analyses were performed using R version 3.3.1 (The R Foundation). To compare the response rates, completion rates, and access rates between groups, we reported both risk ratios and risk differences with 95% confidence intervals using the chi-squared test. We also compared demographics of respondents between the intervention groups. We used the chi-squared test for dichotomous variables and Student *t* test for continuous variables. We set the threshold of statistical significance at $P \leq .05$. All analyses were conducted according to the intention-to-treat principle.

Ethics and Informed Consent

The DOCTOR study was approved by the Institutional Review Board (IRB) of Kyoto University Graduate School of Medicine. We did not include the present factorial RCT in the DOCTOR study when applying for an ethics review by the IRB because the aims of the study were not directly related to health care. The Board of Directors of the JPCA approved this factorial RCT in the recruitment processes of the DOCTOR study. The participants of the DOCTOR study provided their consent on the website.

To avoid the risk of personal information leak, we did not obtain identifiable personal information from participants other than winners of the incentive lottery. In addition, identifiable personal information of the winners was stored separately from the research data.

Trial Registration

The DOCTOR study was registered prospectively at University Hospital Medical Information Network Clinical Trials Registry [UMIN000025317].

Results

Participant Flow

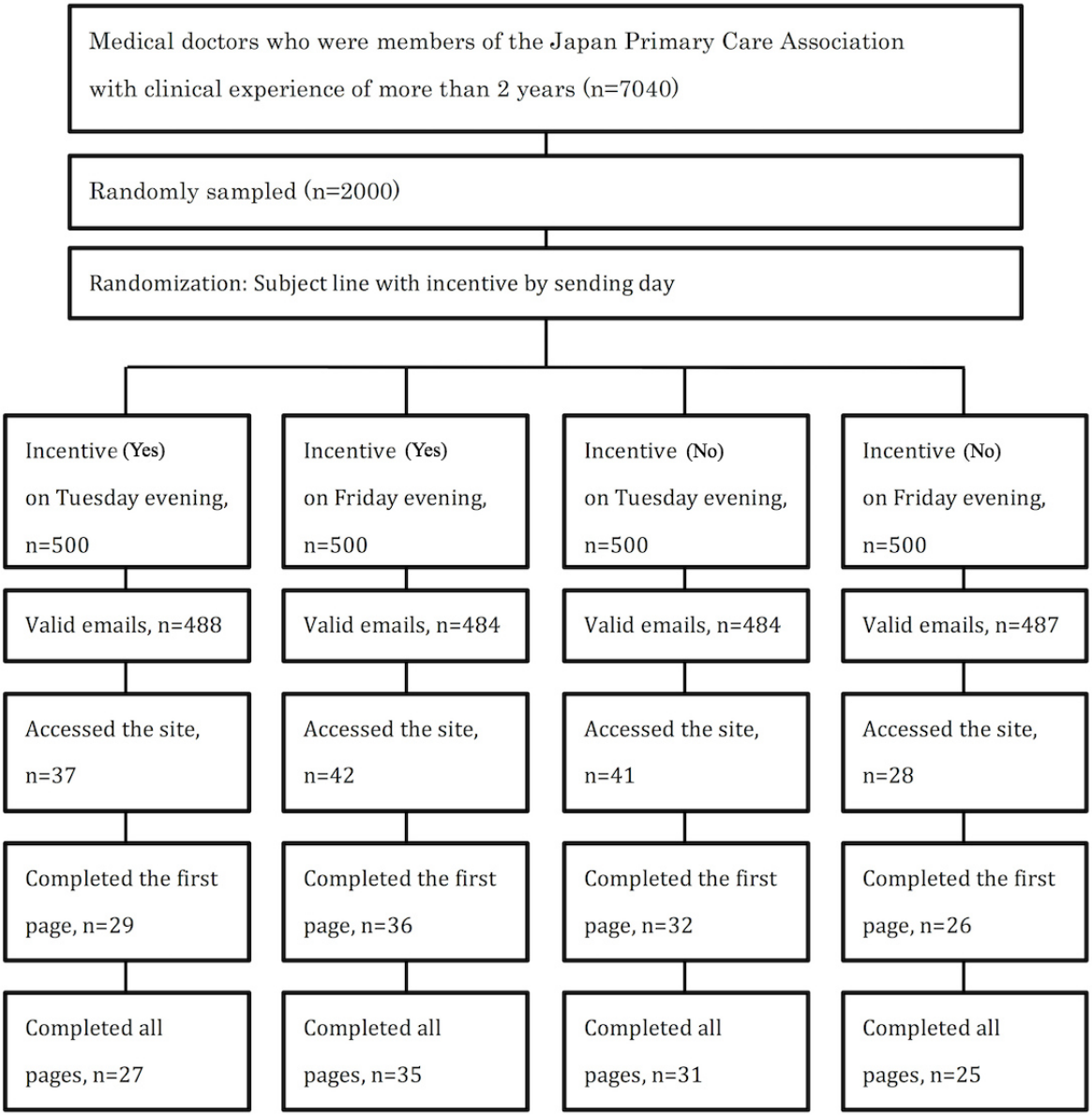
Figure 1 shows the participant flow. Out of 2000 invitation emails, 57 were undeliverable; therefore, we analyzed data from the remaining 1943 participants for all outcomes. Of 1943 primary care doctors, 148 (7.61%) accessed the study site, 123 (6.33%) responded, and 118 (6.07%) completed the questionnaire.

Characteristics of Respondents

Table 1 shows the characteristics of the 123 respondents. We did not find statistically significant differences in the characteristics among the 4 groups except for primary workplace at the nominal *P* value of .01 without adjusting for multiple comparisons.

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Figure 1. Flow diagram of participants.



Access, Response, and Completion Rate on a Two-Level Factorial Basis

Access, response, and completion rates in each randomized group (Tuesday or Friday × incentive in the subject line or not) are reported with 95% confidence intervals in Table 2. We found no statistically significant difference in all the outcomes among the 4 groups. The interaction effects on all the outcomes between the 2 factors were not statistically significant. In the following sections, we therefore report the effect of the 2 interventions separately.

Effect of Subject Line of the Invitation Email Emphasizing Amazon Gift Card Incentive

Table 3 summarizes the rates of access, response, and completion. The response rates, which were the primary outcome of this study, were 6.7% (65/972) in the intervention group and 6.0% (58/971) in the control group, respectively. There was no significant difference in the response rate between the 2 groups: the risk ratio was 1.12 (95% CI 0.80 to 1.58) and the risk difference was 0.7% (95% CI –1.5% to 2.9%). Similarly, the completion rate and access rate were almost the same in the 2 groups (see Table 3).

Effect of the Day of the Week of Sending the Invitation Email

Table 4 shows all outcomes regarding the day of the week of sending the invitation email. The response rate was 6.3% (61/972) on Tuesday evening and 6.4% (62/971) on Friday evening.

No significant difference was demonstrated between the Tuesday group and Friday group: the risk ratio was 0.98 (95% CI 0.70 to 1.38) and the risk difference was –0.1% (95% CI –2.3% to 2.1%).

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Table 1. Characteristics of respondents (n=123).

Characteristic	Tuesday		Friday		*P* value
	Incentive in the subject line	No incentive in the subject line	Incentive in the subject line	No incentive in the subject line	
Gender, male, n (%)	29 (86.2)	32 (93.8)	36 (91.7)	26 (92.3)	.76
Years of practice, mean (SD)	18.8 (9.8)	18.7 (9.8)	18.8 (9.9)	16.0 (8.7)	.63
Workplace, n (%)					.01
University hospitals	3 (10.3)	6 (18.8)	5 (13.9)	5 (19.2)	
Hospitals (public and private)	17 (58.6)	17 (53.1)	15 (41.7)	13 (50.0)	
Clinics		3 (9.4)	16 (44.4)	8 (30.8)	
Academic research institutes	0 (0.0)	4 (12.5)	0 (0.0)	0 (0.0)	
Others	0 (0.0)	2 (6.2)	0 (0.0)	0 (0.0)	
Degree/certification, n (%)[a]					
PhD	8 (27.6)	5 (15.6)	14 (38.9)	8 (30.8)	.20
Primary care	21 (72.4)	23 (71.9)	20 (55.6)	13 (50.0)	.18
Family medicine	4 (13.8)	5 (15.6)	7 (19.4)	10 (38.5)	.10
Other certification	18 (62.1)	23 (71.9)	19 (52.8)	13 (50.0)	.29

[a]Duplicate responses allowed.

Table 2. Access, response, and completion rate in 4 randomized groups (Tuesday or Friday × incentive in the subject line or not).

Characteristic	Tuesday, n (%; 95% CI)		Friday, n (%; 95% CI)	
	Incentive in the subject line (n=488)	No incentive in the subject line (n=484)	Incentive in the subject line (n=484)	No incentive in the subject line (n=487)
Access	37 (7.6; 5.4 to 10.3)	41 (8.5; 6.1 to 11.3)	42 (8.7; 6.3 to 11.5)	28 (5.7; 3.9 to 8.2)
Response	29 (5.9; 4.0 to 8.4)	32 (6.6; 4.6 to 9.2)	36 (7.4; 5.3 to 10.1)	26 (5.3; 3.5 to 7.7)
Completion	27 (5.5; 3.7 to 7.9)	31 (6.4; 4.4 to 9.0)	35 (7.2; 5.1 to 9.9)	25 (5.1; 3.3 to 7.5)

Table 3. Effect of emphasizing the incentive in the subject line on study participation.

Characteristic	Incentive in the subject line, n (%; 95% CI)		Risk difference, % (95% CI)
	Yes (n=972)	No (n=971)	
Access	79 (8.1; 6.5 to 10.0)	69 (7.10; 5.6 to 8.9)	1.0 (–1.3 to 3.4)
Response	65 (6.7; 5.2 to 8.4)	58 (6.0; 4.6 to 7.7)	0.7 (–1.5 to 2.9)
Completion	62 (6.4; 4.9 to 8.1	56 (5.8; 4.4 to 7.4)	0.6 (–1.5 to 2.7)

Table 4. Effect of sending day of the invitation email on study participation.

Characteristic	Tuesday (n=972), n (%; 95% CI)	Friday (n=971), n (%; 95% CI)	Risk difference, % (95% CI)
Access	78 (8.0; 6.4 to 9.9)	70 (7.2; 5.7 to 9.0)	0.8 (–1.5 to 3.2)
Response	61 (6.3; 4.8 to 8.0)	62 (6.4; 4.9 to 8.1)	–0.1(–2.3 to 2.1)
Completion	58 (6.0; 4.6 to 7.6)	60 (6.2; 4.7 to 7.9)	–0.2 (–2.3 to 1.9)

Discussion

Principal Findings

This study was the first to investigate the effect of emphasizing the incentive in the subject line of the invitation email and the day of the week of sending the invitation email on physicians' participation in a Web-based study. The cumulative response rate was 6.3% (123/1943). We found that emphasizing the incentive in the subject line of the invitation email did not significantly improve outcomes such as the response rate, completion rate, or access rate. Likewise, sending the invitation email on Tuesday or Friday did not affect the outcomes.

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Previous studies reported conflicting results related to the effect of emphasizing incentives in the subject line on response rates [12-14]. In studies that found a significant effect of the subject line on the response rate of Web-based studies, the magnitude of the effect was about 1.1 to 1.2 in the risk ratio [8,13]. Thus, one possible explanation is that our study was underpowered due to the very low control response rate. There is, however, less practical meaning in the risk ratio of 1.1 in the situation of the expected response rate of 4%, such as in this study. Our sample size was large enough to detect the practically meaningful difference in the risk ratio of 1.6 to 1.7. The second possible reason is that the incentive mentioned in the subject line was not attractive enough to motivate primary physicians to respond to the invitation. Our subject line mentioned a drawing for a US $30 Amazon gift card, which might be less attractive than incentives paid in cash or by check which can be used anywhere. Furthermore, lottery incentives were reported to be less effective than fixed incentives [22]. The third possible reason is the effect of the control subject line mentioning the support from the JPCA. The authority effect might have reduced the between-group difference in outcomes with regard to the subject line.

Regarding the day of the week of sending the invitation email, our results were consistent with those of previous studies concerning postal invitation. Sending the invitation email on Tuesday evening or Friday evening did not affect the study participation of the primary care doctors in the Web-based study. Pit et al [15] synthesized the results of 3 studies and reported no significant difference in doctors' participation in paper-based studies based on the day of the week on which the postal mails were sent or received. Our results suggest that the day of the week an invitation email is sent does not increase doctors' participation in Web-based studies, similar to postal mail invitations for paper-based studies.

The 2 interventions about invitation emails failed to trigger primary care physicians' response. The cumulative response rate of 6.3% is low, but it is not uncommon in Web-based studies for physicians [1]. Our results suggest that using additional media such as postal mail, telephone, or social media may be needed to attain a large enough response rate [23,24].

Strengths and Limitations

There are several limitations to this study. One is its generalizability. All the participants were primary care physicians in Japan; therefore, it is unclear whether our findings can be applied to those in other countries. Furthermore, primary care physicians, who were the target population of this study, are known to respond to surveys less than physicians in other specialties [25]. Our results, therefore, may not be generalizable to physicians in other specialties. There were additional limitations related to the interventions. In terms of subject lines, we showed that mentioning a lottery for an Amazon gift card (US $30) as an incentive was not effective. However, we could not clarify the effect of subject lines emphasizing larger monetary incentives paid in cash or by check than ours, as $30 may not have been considered attractive enough by Japanese physicians. As for the effect of the sending day, we only compared Tuesday to Friday; therefore, the effect of other days of the week remains unclear.

However, there are also several strengths to this study. This is the first study to investigate the effect of 2 invitation email strategies targeting physicians. As participation rates in Web-based surveys for physicians are decreasing by year, our findings would provide important information when designing Web-based surveys, especially for primary care physicians. In addition, we used a rigorous RCT design, which avoided the risk of bias as much as possible. Furthermore, our sample size was large enough to detect a practically meaningful difference between the groups.

Conclusion

Neither emphasizing a monetary incentive in the subject line of the invitation email nor varying the sending day of the invitation email increased the response rate in a Web-based physician study. Further studies are needed to find an effective invitational strategy using multimodal media beside email to improve response rates of physicians in Web-based studies.

Acknowledgments

We appreciate the help of Morito Kise in planning the study and the staff of the secretariat of the JPCA for assisting in the process of sending the invitation emails. The DOCTOR study was funded by the JPCA. The JPCA also supported this research by sending the invitation emails to members.

Conflicts of Interest

RS has received personal fees from Kagakuhyoronsha Co, Ltd; Medical Review Co, Ltd; and Otsuka Pharmaceutical Co, Ltd, outside the submitted work. KS has received a grant from the JPCA. TAF has received lecture fees from Eli Lilly, Janssen, Meiji, Mitsubishi-Tanabe, MSD, and Pfizer. He has received royalties from Igaku-Shoin and Nihon Bunka Kagaku-sha publishers. He has received research support from Mitsubishi-Tanabe and Mochida. AMS, TA, YT, and MK report no competing interests.

Multimedia Appendix 1

CONSORT - EHEALTH checklist (V 1.6.1).

[PDF File (Adobe PDF File), 3MB - jmir_v20i2e28_app1.pdf]

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Abbreviations

DOCTOR: Do Overstated Conclusions Trick Our Readers?
IRB: institutional review board
JPCA: Japan Primary Care Association
RCT: randomized controlled trial

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Original Paper

Web-Based Alcohol, Smoking, and Substance Involvement Screening Test Results for the General Spanish Population: Cross-Sectional Study

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Abstract

Background: Information technology in health sciences could be a screening tool of great potential and has been shown to be effective in identifying single-drug users at risk. Although there are many published tests for single-drug screening, there is a gap for concomitant drug use screening in general population. The ASSIST (Alcohol, Smoking and Substance Involvement Screening Test) website was launched on February 2015 in Madrid, Spain, as a tool to identify those at risk.

Objective: The aim of this study was to describe the use of a tool and to analyze profiles of drug users, their consumption patterns, and associated factors.

Methods: Government- and press-released launching of a Spanish-validated ASSIST test from the World Health Organization (WHO) was used for voluntary Web-based screening of people with drug-related problems. The tests completed in the first 6 months were analyzed .

Results: A total of 1657 visitors of the 15,867 visits (1657/15,867, 10.44%) completed the whole Web-based screening over a 6-month period. The users had an average age of 37.4 years, and 78.87% (1307/1657) screened positive for at least one of the 9 drugs tested. The drugs with higher prevalence were tobacco (840/1657, 50.69%), alcohol (437/1657, 26.37%), cannabis (361/1657, 21.79%), and sedatives or hypnotics (192/1657, 11.59%). Polyconsumption or concomitant drug use was stated by 31.80% (527/1657) of the users. Male respondents had a higher risk of having alcohol problems (odds ratio, OR 1.55, 95% CI 1.18-2.04; *P*=.002) and double the risk for cannabis problems (OR 2.07, 95% CI 1.46-2.92; *P*<.001). Growing age increased by 3 times the risk of developing alcohol problems for people aged between 45 and 65 years (OR 3.01, 95% CI 1.89-4.79; *P*<.001).

Conclusions: A Web-based screening test could be useful to detect people at risk. The drug-related problem rates detected by the study are consistent with the current literature. This tool could be useful for users, who use information technology on a daily basis, not seeking medical attention.

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KEYWORDS

screening; substance-related disorders; Web-based systems; primary health care; ASSIST

Introduction

The consumption of drugs and addiction are common problems throughout the world and a foreseeable cause of death [1]. In 2014, almost 250 million people between the ages of 15 and 64 years had consumed an illegal substance at least once. The number of adults addicted to a drug, in the world reached 29 million, according to the United Nations Office of Drugs and Crime [2].

The magnitude of this problem is quantified in Spain by the EDADES (Encuesta De Alcohol y Drogas en ESpaña)[3] survey, carried out twice a year by means of a home-based, door-to-door questionnaire addressed to a large part of the Spanish population. Its purpose is to determine the pattern of drug consumption among the Spanish population, engaging approximately 20,000 people.

The screening of problems related to the consumption of drugs such as alcohol and tobacco from a health perspective is a grade B evidence recommendation (meaning the Agency recommends the service to offer or to provide the service) both in the United States (United States Preventive Services Task Force) [4] as well as in Spain (Programa de Actividades Preventivas y Promoción de la Salud en Atención Primaria) [5]. However, the evidence accumulated to date for the simultaneous screening of several most common substances found in primary care or the general population remains scarce [6].

Tools have therefore been designed for screening subjects with addiction to substances, however, these are limited in detecting at-risk people who do not meet substance-related disorder criteria [7-10]. In 1997, the World Health Organization (WHO) developed ASSIST (Alcohol, Smoking and Substance Involvement Screening Test) to detect and manage substance-related problems in primary and general medical care settings; the Spanish version of this tool has been adapted and validated [11-13].

The need for other different evaluation means and medical advice to deal with these problems has been highlighted by the users [14]. Computerized versus in-person-based ASSIST interventions have already proven effectiveness in reducing drug consumption in English-speaking samples but not in Spanish samples [15]. Tools that use the internet as an efficient communications channel could be an alternative in dealing with this type of problem, as 78.7% of Spanish families have an internet connection and 64.3% of the population uses it on a daily basis. The current trend is for the internet to be used from handheld mobile devices such as mobile phone [16] instead of personal computers. The advantages of this means for screening include accessibility, 24-hour availability, ease of transfer to users who speak the same language, and the low cost of updating the tools without the need for a major reinvestment in resources. [17].

Screening based on internet platforms and portals has already proved to be useful in other areas, such as mental health [18-20], in relation to high-risk sexual conduct [21], and addictions to alcohol and smoking [22-24]. Some of these have been translated and validated into Spanish. To our knowledge, no Web-based version of this test in Spanish has ever been used for screening [17,25].

ASSIST is designed to detect people at risk of the most common substances used by the general population or in primary care settings. The administration of the ASSIST, by virtue of being a paper-and-pencil assessment requires a great amount of time to be administered in-person in case of subjects complaining about several drugs. Self-administration of the Web-based test could reduce the time required to get the screening done [26].

As part of the Ministry of Health's National Anti-Drug Abuse Plan, the ASSIST website [27] was launched in Madrid on February 2015 as a Web-based self-screening tool for all kinds of substances and brief self-applied intervention for the Spanish-speaking general public, based on the guidelines of the WHO's ASSIST test [28,29].

First, the main objective of this study was to describe the user type for the tool, as well as the drug consumption patterns 6 months after it has been launched. Second, factors associated with the severity of substance use as well as polyconsumption were analyzed.

Methods

Design: Cross-Sectional Study

Recruitment Methods

To enable access, coverage, and anonymity, it was decided that the screening would take place on a website. The subjects screened from February 24, 2015 to August 24, 2015 (first 6 months) were included in the analysis. It was an open survey, since access was possible as many times as considered necessary without registering. To control duplicate reporting, a multicomponent checkup was developed ahead with cookies used for identification purposes, and a second checkup was applied during analysis. From a promotion and population scope perspective, no initial contact was made with the potential participants on the internet. The tool was publicly launched in the Government Delegation's National Anti-Drug Abuse Agency on February 24, 2015 and promoted by press releases and coverage during the presentation [28,29] without using any other Web-based or printed commercial or publicity campaign. Website was fully dedicated to the screening. A banner in the Agency home page website was placed for the first 3 months. The press release took place on several official websites, platforms, and Spanish medical websites [30-33].

Study Population

Eligibility Criteria

Subjects who claimed to be older than 18 years when accessing the website, who answered all the ASSIST test questions at one time, and whom we identified as coming from a sole device

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with a sole identifier (internet protocol, IP) were included, although no IP check was done before the analysis. A screen-printed research informed consent was claimed, which had to be read and validated to ensure acknowledgment before entering the test. No incentives (monetary, prizes, or others) were offered.

Web Design and Survey Administration

The entire website [27] is a voluntary Web-based self-screening tool in Spanish that is anonymous and free of charge for the evaluation of drug consumption by subjects older than 18 years (Multimedia Appendix 1). The website was an e-survey itself and was developed in conjunction with a group of IT professionals experienced in health sciences. The site was designed to be displayed both on mobile and desktop viewports. The study does not include the collection of health information with identifiers since it was a blind survey. However, on access to the platform, users were notified that personal data will not be required and that the website will never replace the judgment of a health professional. Users granted consent by clicking that pop-up message. The previous pop-up message plus the 3 initial questions (age, weight, and gender) limited access to automated robots. Users later separately accessed each ASSIST question for each drug. No randomization of ASSIST questionnaires was done to comply with original validated version. All the questions were presented for each drug on 3 different screens (Multimedia Appendix 2). The screening tool performed an automated form validation to ensure that all questions were answered.

After completing the test, the users received a report with a summary of the test results, a comparison with the EDADES [3] survey data, personalized according to the same age range, as well as the digital equivalent of the recommendation and drug-related risk cards for each drug under the Spanish version of ASSIST published by the WHO [12]. This document was available for downloading or printing. Furthermore, if the pattern indicated that intervention was recommended, a space was offered to consult a map of addiction treatment centers available in Spain, according to post codes (Multimedia Appendix 3).

Measuring Instruments

Variables

The main result variable was the score obtained from the answers to the self-administered ASSIST test for each of the screened drugs. ASSIST is a brief questionnaire used to identify risky drug use developed by the WHO and adapted and validated in Spanish. The questionnaire consists of 8 questions on recent and lifelong consumption of 9 substances (tobacco, alcohol, cannabis, cocaine, amphetamines or other stimulants, sleeping pills, hallucinogenic drugs, inhalants, and others). Several domains of the questions are considered (time of use, recent use, desire to consume, health issues, social issues, legal issues, difficulty to stop consuming, etc). According to the WHO, from 0 to 3 points means no intervention is recommended as the risk of a condition related to the substance is low; from 4 to 26 points (11-26 for alcohol), brief intervention is recommended; and for scores of 27 points and above, intensive treatment is recommended. The analysis then classifies the risks into 3 levels (low, moderate, and serious). Other social and demographic variables are recorded such as gender, age, and weight.

Sources of Data

Users reported weight, gender, and age anonymously. Self-reported anthropometric data have already proven to be a valid method of collecting these data [34]. The time between clicks was used to estimate the duration of the survey collected automatically. The answers to the ASSIST test questions and the demographic data and resulting scores were stored encrypted.

Google Analytics was used to compare sociodemographic characteristics reported by the users to their Google accounts' available information. This tool is normally used by Web designers and search-engine-optimization experts to improved usability [35,36], and it gives you the estimated age, gender, locations and preferences of the users accessing your website by executing a JavaScript code when anyone enters the website. Users navigating with an open email account or certain type of Web browsers are giving this demographic information straightaway to this tool according to Google's privacy terms. This third-party's policy includes availability of this information to every website designer. The information presented by Google is summarized in central trend and spread measurements. This type of tool has been used in the analysis of similar eHealth environments for guided internet interventions [37] and also uses the website standards established by the Web Analytics Association [38]. Anonymized IP check was done to detect duplicate database entries and last one was kept for analysis.

Statistical Analysis

The descriptive analysis of the variables was conducted using the central trend and spread measures, if they followed normal distribution and, for asymmetric distributions, medians and interquartile ranges (IQR) were used. In the bivariate analysis, the group averages were compared with the Student *t*-test or the Mann-Whitney *U* test, if the distributions were not normal. In the bivariate analysis of categorical variables, the chi-squared test was used. Uncompleted questionnaires (1.2%) were not analyzed, and atypical timestamp questionnaires (3.4%) were considered faked users and not taken into account for the analysis. Variables with a significant association ($P<.05$) were considered for entry into the logistic regression model. Multiple logistic regression models were performed to determine crude odds ratios, 95% CI, and their corresponding *P* values for each drug. Model fit was assessed using the Hosmer-Lemeshow goodness-of-fit statistic where the model was determined a good fit if the *P* value was not significant.

Stata v14.0 software was used for the log file statistical analysis with *unique* extended commands to identify unique cases (M Hills), *geocode_ip* (S Correia) and *dc* or *Data Check* (JM Domènech) to verify the integrity of the database with unique identifiers. IP, type of device, type of Web explorer, time spent, and demographic data referred were combined to detect unique users.

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Results

Participants

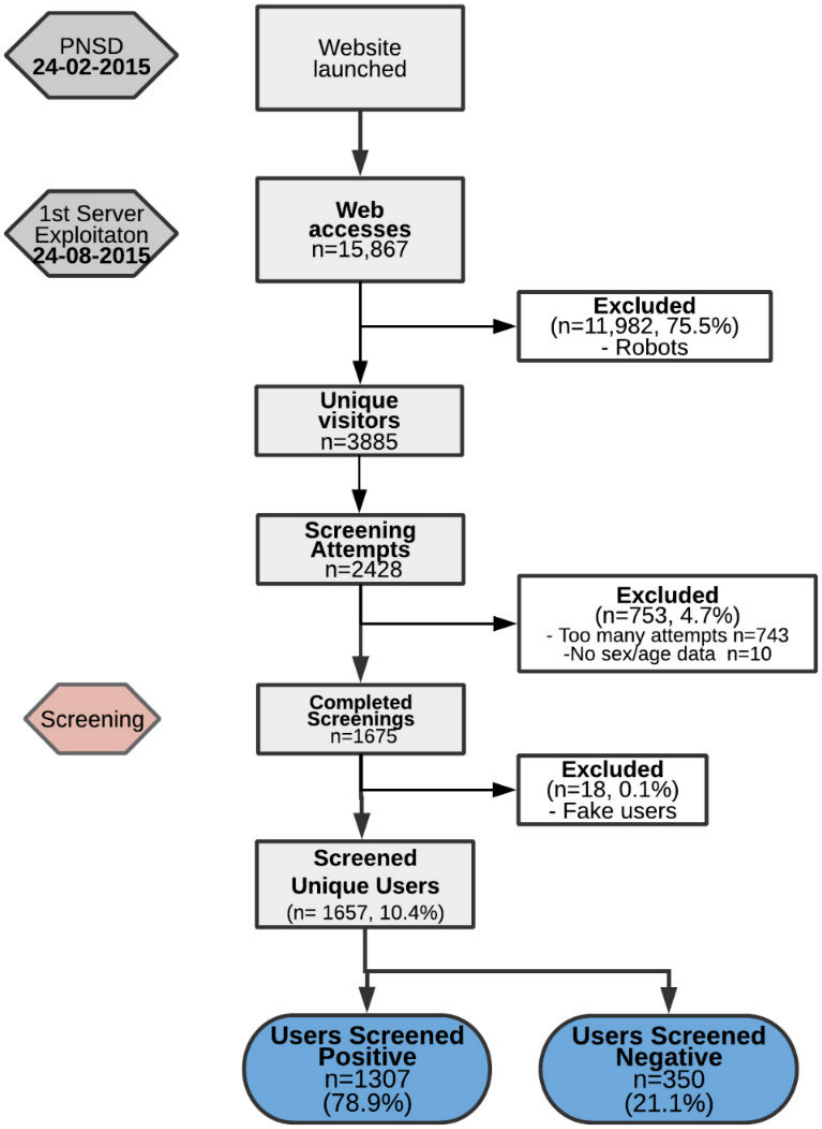
From February 24, 2015 to August 24, 2015, the website received a total of 15,867 visits. Figure 1 shows that total unique site visitor as determined by Analytics were 3885, and the test view rate was 2428 (62.50%). A total of 1657 (10.44%) were users who finally completed screening. Participation rate was 1675 of 2242 (74.71%) with a final completion rate of 68.24% (1657/2428).

A total of 76.9% of the access sessions during the period studied took place in the first month after the website was presented, with 3 activity peaks (February 25, launching day, March 4, and March 10, 2015) first one likely related to press release.

A total of 83.1% of the users were from Spain, 2.3% from Mexico, and 2.2% from Argentina. In Spain, the majority of 35.7% of users were from Madrid, followed by Barcelona (8.2%), Bilbao (3.7%), and Valencia (3.5%, see Figure 2).

Users were mainly from 3 internet sources: 40.2% direct traffic (manual access to the website), 33.2% were redirected from another website related to press release, and 20.3% came from a search engine. A total of 6.4% came from social networks. A multilevel regression model was carried out to analyze the possible influence of location clustering in developing any drug risk showing no significant differences (intraclass correlation coefficient, ICC=.01, 95% CI 0.001-0.11).

Figure 1. Flow diagram of participants. PNSD: Plan Nacional Sobre Drogas.



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Figure 2. Map of website number of accesses in Spain. The size of the bubble shows the total number of users screened at those locations.

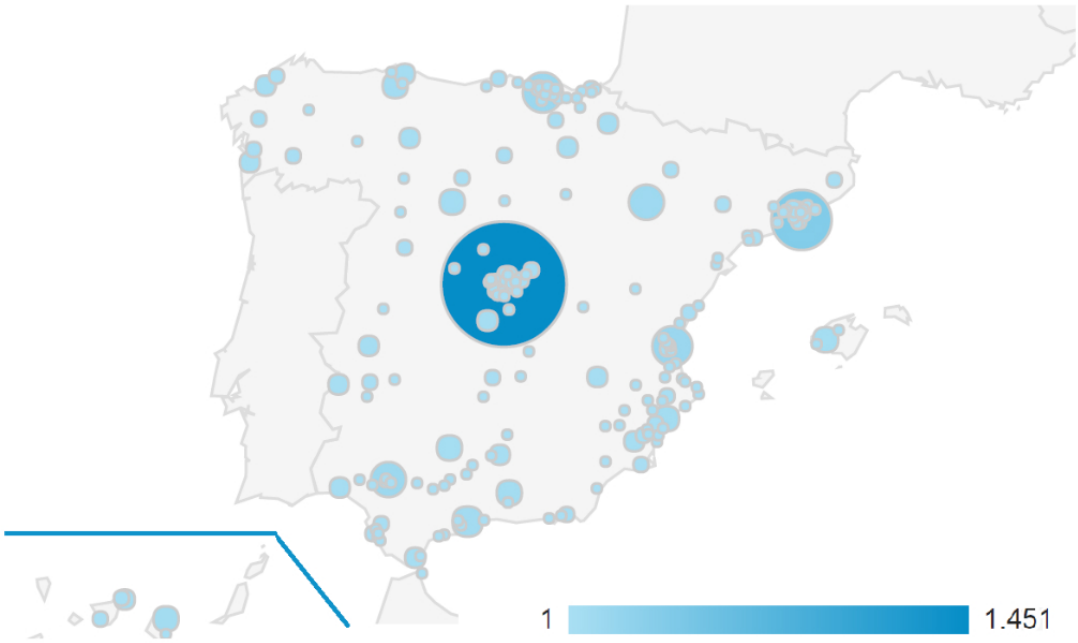


Table 1. Demographic characteristics referred to by visitors completing the Alcohol, Smoking and Substance Involvement Screening Test (ASSIST).

Characteristics	Total population (n=1657)	Patients screened positive (n=1307)	Patients screened negative (n=350)	*P* value
Gender, men, n (%)	990 (59.74)	812 (62.12)	178 (50.9)	<.001
Age in years (mean, SD)	37.5 (12.9)	37.7 (13.1)	36.9 (12.2)	.30
Weight (median, IQR[a])	70.9 (60.0-81.0)	71 (22)	71 (20)	.45[b]
Number of drugs reported (median, IQR)	3 (2-4)	2 (1-3)	3 (2-5)	<.001[b]
Duration of screening, minutes (median, IQR)	3 (2-4)	3 (2-4)	2 (1.3-3.0)	<.001[b]
Month in which screening took place, n (%)				
February	526 (32.74)	417 (25.17)	109 (6.8)	
March	897 (54.13)	700 (43.51)	17 (12.2)	
April	118 (7.12)	94 (5.79)	24 (1.5)	
May	40 (2.41)	28 (1.68)	12 (0.8)	
June	11 (0.66)	8 (0.45)	3 (0.2)	
July	10 (0.61)	8 (0.45)	2 (0.1)	
August	8 (0.51)	6 (0.41)	2 (0.1)	
Type of device, n (%)				
Personal computer	1055 (63.66)	810 (48.89)	245 (14.8)	.006
Phone/tablet	602 (36.31)	497 (30.00)	105 (6.3)	.006
Referral websites, n (%)				
Direct access	743 (44.84)	586 (35.44)	157 (9.4)	.03
Google search	288 (17.38)	228 (13.78)	60 (3.6)	.03
Drug information websites, nonprofit	133 (8.03)	110 (6.53)	23 (1.5)	.03
Government websites	103 (6.21)	82 (5.01)	21 (1.2)	.03
Social media	51 (3.07)	41 (2.47)	10 (0.6)	.03

[a]IQR: interquartile range.

[b]Mann-Whitney *U* test.

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Table 2. Distribution of risk patterns according to the drug and gender. Statistically significant values are in italics.

Drug risks	Total (n=1657), n (%)	Men (n=990), n (%)	Women (n=667), n (%)	*P* value
Tobacco				.41
Not stated	0 (0.00)	0 (0.0)	0 (0.0)	
Low	817 (49.30)	485 (29.3)	332 (20.0)	
Moderate	764 (46.10)	454 (27.4)	310 (18.7)	
Serious	76 (4.58)	51 (3.1)	25 (1.5)	
Alcohol				*. 001*
Not stated	200 (12.07)	118 (7.1)	82 (5.0)	
Low	1020 (61.55)	580 (35)	440 (26.6)	
Moderate	326 (19.67)	209 (12.6)	117 (7.1)	
Serious	111 (6.69)	83 (5.0)	28 (1.7)	
Cannabis				*<.001*
Not stated	761 (45.92)	417 (25.1)	344 (20.8)	
Low	535 (32.28)	310 (18.7)	225 (13.6)	
Moderate	274 (16.53)	198 (12)	76 (4.5)	
Serious	87 (5.25)	65 (3.9)	22 (1.2)	
Cocaine				*<.001*
Not stated	1166 (70.36)	632 (38.1)	534 (32.3)	
Low	408 (24.62)	300 (18.1)	108 (6.5)	
Moderate	65 (3.92)	47 (2.8)	18 (1.1)	
Serious	18 (1.08)	11 (0.7)	7 (0.4)	
Stimulants				[a]
Not stated	1316 (79.42)	747 (45.1)	569 (34.3)	
Low	316 (19.07)	225 (13.6)	91 (5.5)	
Moderate	18 (1.08)	14 (0.8)	4 (0.2)	
Serious	7 (0.42)	4 (0.2)	3 (0.2)	
Inhalants				[a]
Not stated	1574 (94.99)	932 (56.3)	642 (38.7)	
Low	78 (4.71)	53 (3.2)	25 (1.5)	
Moderate	5 (0.30)	5 (0.3)	0 (0.0)	
Serious	—	—	—	
Sedatives/Hypnotics				*.01*
Not stated	1190 (71.82)	741 (44.7)	449 (27.1)	
Low	275 (16.60)	145 (8.7)	130 (7.9)	
Moderate	162 (9.78)	88 (5.3)	74 (4.5)	
Serious	30 (1.81)	16 (1)	14 (0.8)	
Hallucinogenic drugs				[a]
Not stated	1423 (85.88)	820 (49.5)	603 (36.4)	
Low	233 (14.06)	169 (10.2)	64 (3.9)	
Moderate	1 (0.06)	1 (0.1)	0 (0.0)	
Serious	—	—	—	
Opium				*.019*

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Drug risks	Total (n=1657), n (%)	Men (n=990), n (%)	Women (n=667), n (%)	*P* value
Not stated	1552 (93.66)	918 (55.4)	634 (38.3)	
Low	91 (5.49)	65 (3.9)	26 (1.6)	
Moderate	11 (0.66)	7 (0.5)	4 (0.2)	
Serious	3 (0.18)	0 (0)	3 (0.2)	

[a]n<5=less than 5 cases.

Consumption Patterns

The average age of the subjects was 37.4 years (standard deviation, SD 12.9) and 59.9% of cases stated to be male. Users could test themselves for drug-related risks and no risks could be showed. Of all the users screened, 21.1% did not have any moderate to high substance-related risks (as opposed to 78.9% with a moderate or high risk in relation to at least 1 substance). The average time spent taking the test was 3 min (IQR: 2-4), with a statistically significant higher time spent for those who screened positive on the test for at least 1 drug. The number of drugs reported was higher for the group who screened positive compared with the group who showed no moderate to high drug-related risks (*P*<.001); see Table 1.

The most highly consumed drug by men as well as women was tobacco, which all the self-surveyed subjects stated to smoke at some point, followed by alcohol (87.9%) and cannabis (54.1%). We found moderate or serious substance-related risk for tobacco (50.7%), alcohol (26.4%), cannabis (21.8%), and sedatives or hypnotics (11.6%) as the 4 most frequent.

In the subgroup analysis, significant differences were observed based on gender: men had moderate to high risks for alcohol disorders in 17.6% of cases compared with women in 8.8% (*P*=.001) of cases; in the consumption of cannabis, men had 15.9% cases compared with women in 5.9% (*P*<.001) cases, and in the consumption of cocaine, men had 3.5% of cases compared with women in 1.5% (*P*<.001) cases (see Table 2). Male respondents had 1.55 times risk of having alcohol problems (odds ratio, OR 1.55, 95% CI 1.18-2.04; *P*=.002) and had double the risk for cannabis problems (OR 2.07, 95% CI 1.46-2.92; *P*<.001); see Table 3.

In the subgroup analysis of age categories, users who screened positive for moderate to high substance-related risks were distributed into groups up to 44 years of age. The highest number of users with drug-related risks was in the 35- to 44-year-old category: tobacco (12.3% moderate, 1.6% serious), alcohol (5.3% moderate; 1.9% serious), cocaine (1.6% moderate), and sedatives/hypnotics (2.6% moderate). The cannabis-related risks were concentrated in the 2 youngest age groups (18-24 and 25-34 years) with 5.7% of all subjects consuming the drug. Growing age increased 3 times risk of developing alcohol problems for people between 45 and 65 years (OR=3.01, 95% CI 1.89-4.79; *P*<.001). In contrast, increasing age protects against developing cannabis-related problems (OR=0.30, 95% CI 0.17-0.56; *P*<.001); see Table 3.

With regard to polyconsumption or the consumption of different drugs throughout the same period of time, a moderate or serious risk was observed in 31.6% of the subjects. Number of substances and sex distribution are shown in Table 4. Male respondents, compared with female respondents, were more likely to develop polyconsumption (OR=1.92, 95% CI 1.5-2.47; *P*<.001) . Those user screening by mobile devices had higher risk of developing problems even when adjusting for potential confounder such as age (OR=1.41, 95% CI 1.1-1.8, *P*=.006) . Age showed no significant differences regarding poly-consumption.

Table 5 shows the combinations of the most common moderate or serious drugs-related risks for 2 drugs and the percentage of polyconsumers of each pattern. The most frequent combinations found were tobacco and cannabis (31.3%), tobacco and alcohol (16.2%), and tobacco and sedatives (8.4%). There was also a group of subjects with a serious risk for each such as tobacco and cannabis serious (10.4%) and tobacco and alcohol serious (7.2%).

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Table 3. Factors associated with moderate to high risky drug use estimates in general people screened at the website. Statistically significant values are in italics.

Sociodemographic factors	Tobacco (n=840)		Alcohol (n=437)		Cannabis (n=361)	
	OR (95% CI)	*P* value	OR (95% CI)	*P* value	OR (95% CI)	*P* value
Sex						
Female	1.00 (Ref)		1.00 (Ref)		1.00 (Ref)	
Male	1.21 (0.96-1.51)	.10	1.55 (1.18-2.04)	*.002*	2.07 (1.46-2.92)	*<.001*
Age group (years)						
18-24	1.00 (Ref)		1.00 (Ref)		1.00 (Ref)	
25-34	0.74 (0.53-1.03)	.08	1.39 (0.89-2.15)	.15	0.56 (0.38-0.84)	*.005*
35-44	0.81 (0.58-1.15)	.24	1.83 (1.18-2.84)	*.007*	0.34 (0.20-0.53)	*<.001*
45-54	0.83 (0.57-1.21)	.34	3.01 (1.89-4.79)	*<.001*	0.30 (0.17-0.56)	*<.001*
55-64	0.92 (0.59-1.43)	.70	3.08 (1.79-5.31)	*<.001*	0.14 (0.05-0.45)	*.001*
>65	0.84 (0.43-1.64)	.60	3.73 (1.69-8.21)	*.001*	—	
Accessing device						
Personal computer/mac	1.00 (Ref)		1.00 (Ref)		1.00 (Ref)	
Mobile phone/tablet	1.47 (1.16-1.86)	*.001*	0.80 (0.61-1.07)	.14	1.48 (1.06-2.06)	*.021*
Website referral source						
None	1.00 (Ref)		1.00 (Ref)		1.00 (Ref)	
Official press releases	0.98 (0.64-1.50)	.91	0.96 (0.57-1.63)	.89	1.48 (0.60-1.34)	.20
Google searches	1.08 (0.82-1.41)	.58	1.06 (0.76-1.47)	.74	0.90 (0.60-1.34)	.6
Drug information websites	1.81 (1.20-2.72)	*.005*	1.62 (1.02-2.56)	*.039*	0.47 (0.27-0.84)	*.011*
Social media referrals	1.27 (0.71-2.26)	.42	1.38 (0.71-2.71)	.35	0.84 (0.60-1.34)	.68
Time spent in the test	1.47 (1.16-1.86)	*.001*	1.08 (1.04-1.12)	*<.001*	1.08 (1.02-1.14)	*.006*

Table 4. Gender differences and number of substance-related risks at screening.

Number of substances at risk	Total (n=1657, n (%)	Men (n=990), n (%)	Women (n=657), n (%)	*P* value
No substance	350 (21.12)	178 (17.9)	172 (25.8)	
1 substance	780 (47.07)	452 (45.7)	328 (49.2)	*.026*
2 substances	431 (26.01)	295 (29.8)	136 (20.4)	*<.001*
3 substances	77 (4.64)	55 (5.6)	22 (3.3)	*.001*
4 substances	13 (0.78)	7 (0.7)	6 (0.9)	*.83*
5 or more substances	6 (0.36)	3 (0.3)	3 (0.5)	[a]

[a]n<5=less than 5 cases.

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Table 5. Qualitative description of polyconsumers of 2 substances (n=431).

Drugs patterns	Tobacco n (%)		Alcohol n (%)		Cannabis n (%)		Cocaine n (%)		Amphetamine n (%)		Inhalants n (%)		Sedatives n (%)		Opium n (%)	
	Mod[a]	Ser[b]	Mod	Ser	Mod	Ser	Mod	Ser	Mod	Ser	Mod	Ser	Mod	Ser	Mod	Ser
Tobacco																
Mod																
Ser																
Alcohol																
Mod	70 (16.2)	—														
Ser	31 (7.2)	5 (1.2)	`													
Cannabis																
Mod	135 (31.3)	8 (1.9)	8 (1.9)	1 (0.2)												
Ser	45 (10.4)	8 (1.9)	—	—												
Cocaine																
Mod	13 (3.0)	2 (0.5)	7 (1.6)	1 (0.2)	3 (0.7)	1 (0.2)										
Ser	1 (0.2)	1 (0.2)	—	—	1 (0.2)	1 (0.2)										
Amphetamine																
Mod	2 (0.5)	—	2 (0.5)	—	2 (0.5)	—	1 (0.2)	—								
Ser	2 (0.5)	—	—	—	—	—	—	1 (0.2)								
Inhalants																
Mod	2 (0.5)	—	—	—	1 (0.2)	—	—	—	—	—						
Ser	—	—	—	—	—	—	—	—	—	—						
Sedatives																
Mod	36 (8.4)	3 (0.7)	15 (3.5)	5 (1.2)	1 (0.2)	1 (0.2)	1 (0.2)	—	—	—	—	—				
Ser	3 (0.7)	2 (0.5)	2 (0.5)	3 (0.7)	—	—	—	—	—	—	—	—				
Opium																
Mod	2 (0.5)	—	—	—	—	—	—	—	—	—	—	—	1 (0.2)	—		
Ser	—	—	—	—	—	—	—	—	—	—	—	—	—	—		

[a]Mod: moderate.

[b]Ser: serious.

[c]Hallucinogenic drugs were not included, as there were no positive screening results of polyconsumption (2 or more).

Discussion

Principal Findings

In the first 6 months after the Web-based self-screening for drug consumption website was launched, a total of 15,867 users were recorded, of which 1657 (10.4%) completed the screening. The average age obtained was 37.4 years and 78.9% showed moderate or serious drug-related risks. The most highly consumed drugs stated were tobacco (50.7%), alcohol (26.4%), cannabis (21.8%), and sedatives (11.6%) with men taking more alcohol, cannabis, or cocaine; and young people (aged 18-35 years) using more cannabis. Polyconsumption was observed in 31.6% of the cases.

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In terms of the number of users, our website showed data similar to others in the existing literature [17]. Nevertheless, it is true that other single-drug platforms, such as those for only alcohol screening, have achieved a greater scope with larger samples after targeted marketing campaigns also on the internet, as well as by mailings and massive letter box drops of pamphlets [23,24].

Our website user map (see Figure 2) shows that the geographic distribution of users with drug problems are similar to that found in the literature [3], the most common cities still being Madrid and coastal cities (Barcelona, Valencia, and Bilbao). This could be explained either because big cities have higher drug use rates [3] or just because they are major cities and we are getting more respondents from these cities. However, after adjusting in a multilevel regression model, cluster had no influence on developing drug problems.

Users surfing the Web using Google services are giving their demographic characteristics and interest information for analysis according to the Google privacy terms. A total of 52.1% of users could be analyzed, and differences were observed in relation to age and gender. In the data provided by the users, there were 59.9% men, as opposed to 41.2% in the Google sample, and 7.1% of users stated in the test that they were younger (18-24) than when compared with the data obtained with Google. This could be due to the 50% of incomplete information from the Google remaining sample, or if representation is assumed, due to the fact that some people did the test for others.

Drug-use patterns partially differ with respect to consumption prevalence in Spain according to the EDADES [3], in which hypnotics-sedatives were higher than cannabis in the 15- to 64-year-old population and, in our sample, cannabis was still the third highest consumed drug. The characteristics of both samples could explain this difference, given that the upper age ranges are more highly represented in the EDADES study, as opposed to our sample and, in addition, because these are drugs that are initially consumed at middle age. Furthermore, both tests differ since the EDADES questionnaire addresses mostly consumption rates but does not address other type of drug-related risks for nondependent people.

In terms of polyconsumption, there are also differences: the definition used in the EDADES survey refers to the combined consumption of substances in the same period [3]. The ASSIST test questions say, “at some time” and “in the last three months,” therefore, to a certain extent, it already partly includes that information. Moreover, the ASSIST offers an estimation of the clinical and social risks related to substance use. Therefore, as far as terminology is concerned, our polyconsumption is the combination of moderate and serious risk estimates relating to any of 2 or more substances detected. This is clinically relevant as the users are at a greater risk and may need more intense treatment.

Applicability of the Results

This is the first drug-related risks screening website related to all common drugs, using a scale that has been internationally validated by the WHO (ASSIST), adapted to Spanish for Web-based screening.

The results also show a target group for potential intervention relating to the tobacco-cannabis polyconsumption pattern, due to the high percentage detected in certain age groups (18-34 years).

One of the major advantages of this type of tool would be the possibility of reaching populations that would otherwise delay resorting to the health system and also offering primary care doctors and other health care professionals a valid tool for handling the risks related to the consumption of substances before it becomes an established medical condition.

The potential impact of applying overall prevention measurements (screening as secondary prevention), instead of those addressed to specific populations is a public health issue that is currently being debated. The screening in itself would be pointless if counteraction was not offered. There is already evidence of decreasing mortality rates in favor of global intervention after screening general population samples by models designed for cardiovascular disease, as opposed to screening specific population alone [39]. Drug-related interventions such as brief interventions using ASSIST Web-based tools have already proven effectiveness in the English samples compared with in-person brief interventions [15].

Limitations

One of the main limitations would be the ability to identify sole users and therefore to eliminate duplicating or overestimating the results. Several users could have access from the same device and even from the same network to complete the test, without being able to make a distinction between them. Therefore, the server data were exploited, limited by the anonymized IP address, compared with the data from the device used for access and the time (day and time) that the test was taken and, together with the aforementioned demographic data, an algorithm was established to identify single and valid users. When the users could not be differentiated, an attempt was made to eliminate “testing users” from the analysis to identify erroneous situations such as the screening of many drugs in a short period of time, several attempts by the same user, etc. For users making several attempts, the last answer was accepted as valid.

Another limitation that can be assumed is related to the scope of publication. Users accessed the website mainly because they had heard about it or were redirected by a different website; 1 of every 5 did so after browsing with Google. Given that the environment was created under a research framework publicized by a public body (National Anti-Drug Abuse Plan), access and users came from locations where there was publicity resulting from the presentation. Future studies would benefit by including a broader population to improve external validity.

Another difficulty encountered was the restriction of the screening age to 18 years and older. At the time we developed the website, validation for the adolescent population had not been published. In 2015, Gryczynksi et al [40] validated this tool for adolescents in primary health care, meaning that it could therefore be extrapolated to our general population. Its adaptation to our environment would be simple, as it requires

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minimal programming changes to allow access to younger users (12-17 years) according to the aforementioned validation.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Home page.

[PNG File, 102KB - jmir_v20i2e57_app1.PNG]

Multimedia Appendix 2

Drug screening page.

[PNG File, 119KB - jmir_v20i2e57_app2.PNG]

Multimedia Appendix 3

Drug risks evaluation webpage.

[PNG File, 99KB - jmir_v20i2e57_app3.PNG]

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Abbreviations

ASSIST: Alcohol, Smoking and Substance Involvement Screening Test
IP: internet protocol
OR: odds ratio
PNSD: Plan Nacional Sobre Drogas
WHO: World Health Organization

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Original Paper

Ecuadorian Cancer Patients' Preference for Information and Communication Technologies: Cross-Sectional Study

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Abstract

Background: The instantaneous spread of information, low costs, and broad availability of information and communication technologies (ICTs) make them an attractive platform for managing care, patient communication, and medical interventions in cancer treatment. There is little information available in Latin America about the level of usage of ICTs for and by cancer patients. Our study attempts to fill this gap.

Objective: The aim of this study was to assess the level of ICT use and patterns of preferences among cancer patients.

Methods: We conducted an anonymous cross-sectional survey study in 500 Ecuadorian cancer patients. This questionnaire consisted of 22 items about demographic and clinical data, together with the preferences of people who use ICTs. Chi-square, crude, and adjusted logistic regressions were performed.

Results: Of the total, 43.2% (216/500) of participants reported that they had access to the Internet, and 25.4% (127/500) reported that they neither owned a cell phone nor did they have access to the Internet. The Internet constituted the highest usage rate as a source of information about malignant diseases (74.3%, 162/218) regardless of age (P<.001). With regard to the preferences on how patients would like to use ICTs to receive information about diseases, WhatsApp (66.5%, 145/218) and short message service (SMS) text messaging (61.0%, 133/218) were widely reported as interesting communication channels. Similarly, WhatsApp (72.0%, 157/218) followed by SMS (63.8%, 139/218) were reported as the preferred ICTs through which patients would like to ask physicians about diseases. Adjusted regression analysis showed that patients aged between 40 and 64 years were more likely to be interested in receiving information through SMS (odds ratio, OR 5.09, 95% CI 1.92-13.32), as well as for asking questions to physicians through this same media (OR 9.78, CI 3.45-27.67) than the oldest group.

Conclusions: WhatsApp, SMS, and email are effective and widely used ICTs that can promote communication between cancer patients and physicians. According to age range, new ICTs such as Facebook are still emerging. Future studies should investigate how to develop and promote ICT-based resources more effectively to engage the outcomes of cancer patients. The widespread use of ICTs narrows the gap between cancer patients with restricted socioeconomic conditions and those with wealth and easily available technological means, thereby opening up new possibilities in low-income countries.

(J Med Internet Res 2018;20(2):e50) doi:10.2196/jmir.8485

KEYWORDS

social media; telemedicine; cancer; Web 2.0; mHealth

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Introduction

Background

A rapid increase in the use of information and communication technologies (ICTs) in recent decades is an enormous contributing factor in the development of a number of novel clinical and public health intervention strategies at every level, such as primary prevention, screening, early diagnosis, treatment, survivorship, and end-of-life care [1,2].

ICTs are broadly defined as technologies used to communicate, manipulate, and store data by electronic means [3]. These include email, short message service (SMS) text messaging, video chat, Web-based social media, as well as all the different computing devices that perform a wide range of communication and information functions [3].

ICTs might be beneficial for cancer patients in several ways. Web-based communities with low survival rates can provide emotional support, whereas those with high survival rates offer a more informational support [4]. For those looking for social support, blogs have proven to be helpful, especially on patients who become isolated because of physical deterioration or treatment requirements [5]. As a matter of fact, disclosing negative emotions or insights has proved to provide health benefits by reducing cancer concerns at follow-up, as reported in breast cancer patients [6]. Similar results could be expected to be found in other malignancies. On the other hand, for those looking for a more informational support, communities might offer advice on what to expect and what to do, or offer recommendations in common problems addressing test results, term definitions, treatment, time courses, side effects, and more [7].

There has been an increase in the number of publications about public health uses of social networking sites in the past 5 years [8]. This fair amount of studies regarding the impact and utility of ICTs emphasizes the importance and potential uses that the ICTs provide to the patient-physician relationship.

Objectives

The objectives of this study were to assess the frequency of use of ICTs and to examine patterns of preferences among patients with any kind of cancer diagnosis. This study analyzes in cancer patients whether there is an existing association between ICTs' use frequency and interest in receiving information and asking physicians about the disease through them. To our knowledge, there are no data about the use of ICTs in cancer patients for health-related purposes in Ecuador or Latin American countries. Understanding the role of ICTs in the context of a cancer patient could assist in the development of new personalized apps, promote the relationship between the patient and health care providers, and if used correctly, perhaps improve outcomes in the management of cancer treatment.

Methods

Study Design

We conducted an anonymous cross-sectional survey study in which 500 cancer patients rated themselves using questions about their level of ICT usage. Eligible outpatients from either public or private practices in SOLCA Hospital, a cancer center of reference in Ecuador, were surveyed using a Spanish version of the Michigan questionnaire (MQ), which was modified to be used by cancer patients. The survey included 22 items and collected information about demographics, use of cell phones, the interest of patients in using ICTs to receive information about cancer, and the interest of patients in using ICTs to communicate with health care providers about cancer.

Eligibility was restricted to patients aged 18 years and older who had been diagnosed with cancer. Patients younger than 18 years were not included because of a hospital policy restricting participation of minors, unless the parent or legal guardian signs a consent, and it is further revised and approved by a hospital official. We excluded patients with psychiatric diseases, language impairment, or those who found it difficult to visualize the survey.

Sample Size

We used the Web-based Open Source Epidemiologic Statistics for Public Health (OpenEpi) to calculate the sample size for a descriptive study. Setting a population size of 1 million, an anticipated frequency of 50%, confidence interval of 95% and a design effect of 1.0, the calculated sample size was 384. We included 500 patients to increase power and overcome type-II error in anticipation to missing data.

Procedure

We used a modified version of MQ, a self-administered survey that was hand-filled by the patient [9]. MQ was originally designed to determine the use of electronic media in asthma patients. We adopted a rigorous method to translate it into Spanish [10]. An expert panel of oncologists checked the adapted version. They also considered additional potential questionnaire items to include all necessary questions (Textbox 1). This questionnaire assesses the frequency of use of ICTs by patients and their preferences for receiving disease-related information.

We collected demographic information about each patient, including age, gender, education, and race/ethnicity, as well as information about duration of disease since diagnosis and the use of cancer medication. Furthermore, patients were asked whether they had access to the Internet and cell phone. Patients were also asked whether they had a smartphone.

Participants were then asked to quantify their use of each technology (SMS text messaging, Facebook, Twitter, email, LinkedIn, YouTube, Skype, WhatsApp, and the Internet) using a scale of daily, at least once a week, at least once a month, less than once a month, or never. They were also asked which ICTs (Internet, Facebook, Twitter, YouTube, email, and WhatsApp) they use to obtain information by themselves about cancer. Of note, the term Internet represents the networking communications systems used by the patient for the health-related purposes we analyze. The use of the Internet might be from any type of hardware that uses any Web-based platform, excluding Facebook, Twitter, YouTube, email, and WhatsApp; for instance, a Web browser, any social media not included in the categories, etc.

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Textbox 1. Modifications and added questions suggested for the questionnaire.

Modifications

- Question #6 of the Michigan Questionnaire addressing asthma treatment has been replaced by another addressing cancer treatment.
- Question #7 of the Michigan Questionnaire addressing ICT use frequency has been modified to include YouTube, LinkedIn, Skype, WhatsApp, and Instagram. On the other hand, MySpace was removed as a category.
- Question #9 of the Michigan Questionnaire addressing ICT use to get information about asthma has been modified to include YouTube, WhatsApp, Instagram, and others. MySpace was removed as a category.
- Questions #10 and #11 of the Michigan Questionnaire addressing interest in using ICTs to receive information and ask doctors about asthma, respectively, have been modified to include LinkedIn, WhatsApp, and others. MySpace was removed as a category.
- The disease of interest of the Michigan Questionnaire (asthma) has been replaced by cancer on questions 6, 9, 10, 11, 12, and 13.

Added Questions

- Included questions addressing patient's occupation, education level, primary cancer location, present/absent metastasis, cellular and smartphone ownership, and access to Internet.

Participants were also asked to quantify their interest in receiving information about factors that could affect cancer control through ICTs. The level of interest was quantified as high, somewhat, low, or no interest. Using the same scale, participants were asked to quantify their interest in asking questions to their doctors or other health care providers using each of the ICT forms (SMS text messaging, Facebook, Twitter, LinkedIn, email, and WhatsApp). Free-text entries were solicited to determine what information participants would like to receive the most via these technologies, the reasons they might not be interested in using such technologies for communication, and any other comments about the use of these methods for cancer patients.

We incorporated WhatsApp as a new category into some questions in the survey. This category was included because we considered it highly relevant because of its penetration in Latin America, which according to the Global Web Index reaches 66% of the population, being the highest proportion reported among all continents [11]. This ICT is not included in the original questionnaire.

Before answering our questionnaire, patients were informed of the purpose of the study and their role in it. During the survey, patients completed their questionnaires either by themselves or with the help of a previously trained person (eg, physician, nurse, or intern). In total, we administered 673 surveys to cancer patients. However, 153 patients did not want to participate and left the survey in blank. After reaching 500 completed surveys, no more surveys were delivered. The response rate was 74.29%.

Ethical Considerations

This study was approved by the Ethics Committee of the Hospital Luis Vernaza, Ecuador. We obtained informed consent before participation in the survey. We guaranteed that the identity of the patient would not be revealed.

Statistical Analysis

For each ICT type, the frequency-of-use responses were dichotomized into categories of *at least once a week* and *less than once a week*. Age, gender, education level, years since the cancer diagnosis, and metastasis were used as independent variables on each analysis. Age groups were categorized into young adults (18-39 years), old adults (40-64 years), and elderly (≥65 years). Gender was either male or female. Education level was categorized into none or primary school, secondary school, and undergraduate or postgraduate. The time since cancer diagnosis was categorized as <3 years and ≥3 years. Metastasis was dichotomized into *yes* and *no*.

We performed a chi-square test to assess the association among Internet access or owning a cell phone or smartphone and age, gender, education level, and years since diagnosis. We employed the same test to determine the association between the same independent variables and the frequency of use of each ICT type (SMS text messaging, Facebook, Twitter, YouTube, email, the Internet, LinkedIn, Skype, and WhatsApp). We used the same analysis to determine whether there was an association between these independent variables and the use of each ICT to obtain information.

We performed similar analyses on the association between the independent variables described and the degree of interest (dichotomized into *high or some interest* and *little or no interest*) in receiving information through each ICT type and having high or some interest in communicating (asking physician) through each media type.

We undertook adjusted regression analyses between the complete set of independent variables and use (*at least once a week* and *less than once a week*) and interest in receiving information and communicating through each ICT. Analysis was adjusted for age, gender, education level, years since diagnosis, and metastasis. Reference categories were as follows: ≥65 years, male, no education/primary school, ≥3 years since diagnosis, and *yes* regarding the positive diagnosis for metastasis. Finally, we performed separated nonadjusted analysis between frequency of use of an ICT and interest in receiving information and communicating with physician through that same ICT.

All data were analyzed using the SPSS, version 24.0 software (SPSS Inc., Chicago, IL, USA). We performed Fisher exact test where necessary. A *P* value of less than .05 was considered statistically significant.

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Results

From 500 patients, 389 (77.8%, 389/500) were female, and 170 (34.0%, 170/500) had a high school degree (Table 1). The average age was 57.5 years (standard deviation, SD 14.9), with an average time of being diagnosed with cancer of 2.9 years (Table 2). The most common type of malignancy was breast cancer, which was found in 196 patients (39.2%, 196/500; Figure 1).

Internet Access, Owning a Cell Phone or Smartphone

Of the total number of participants, 216 (43.2%, 216/500) reported having access to the Internet. A total of 371 participants reported they owned a mobile phone (74.2%, 371/500), of which 42.9% (159/371) were smartphones (Table 3). Also, 127 participants reported of neither owning a cell phone nor having access to the Internet (25.4%, 127/500).

Use of ICTs At Least Once a Week

Interestingly, WhatsApp presented the highest rate of ICT usage at least once a week (76.2%, 166/218), followed by Facebook (67.4%, 147/218), SMS text messaging (63.8%, 139/218), and the Internet (60.1%, 131/218; Table 3). SMS text messaging, Facebook, and Instagram were the most used ICTs by patients aged under 40 years (P=.002; Table 3). WhatsApp presented the highest rate of usage at every educational level (P=.01; Multimedia Appendix 1). Patients who had cancer for 3 years or more reported higher usage rates of WhatsApp (95%, 37/39), email (51%, 20/39), and Twitter (23%, 9/39; P=.05) than patients with fewer than 3 years of the disease (Multimedia Appendix 2).

Use of ICTs for Seeking Cancer Information

Internet presented the highest usage rate as a source of information about cancer (74.3%, 162/218; Table 3, Figure 2). Other sources were YouTube (24.3%, 53/218), WhatsApp (22.5%, 49/218), and Facebook (21.1%, 46/218). Internet was the most used ICT for all age groups (P<.001; Table 3). WhatsApp was the most often referred-to form of ICT at every educational level (P=.001; Multimedia Appendix 1). In general, patients with 3 years or more of the disease used every ICT to look for information to a greater extent than did patients with fewer than 3 years of the disease (P=.04) (Multimedia Appendix 2).

Table 1. Demographic information of surveyed population (N=500).

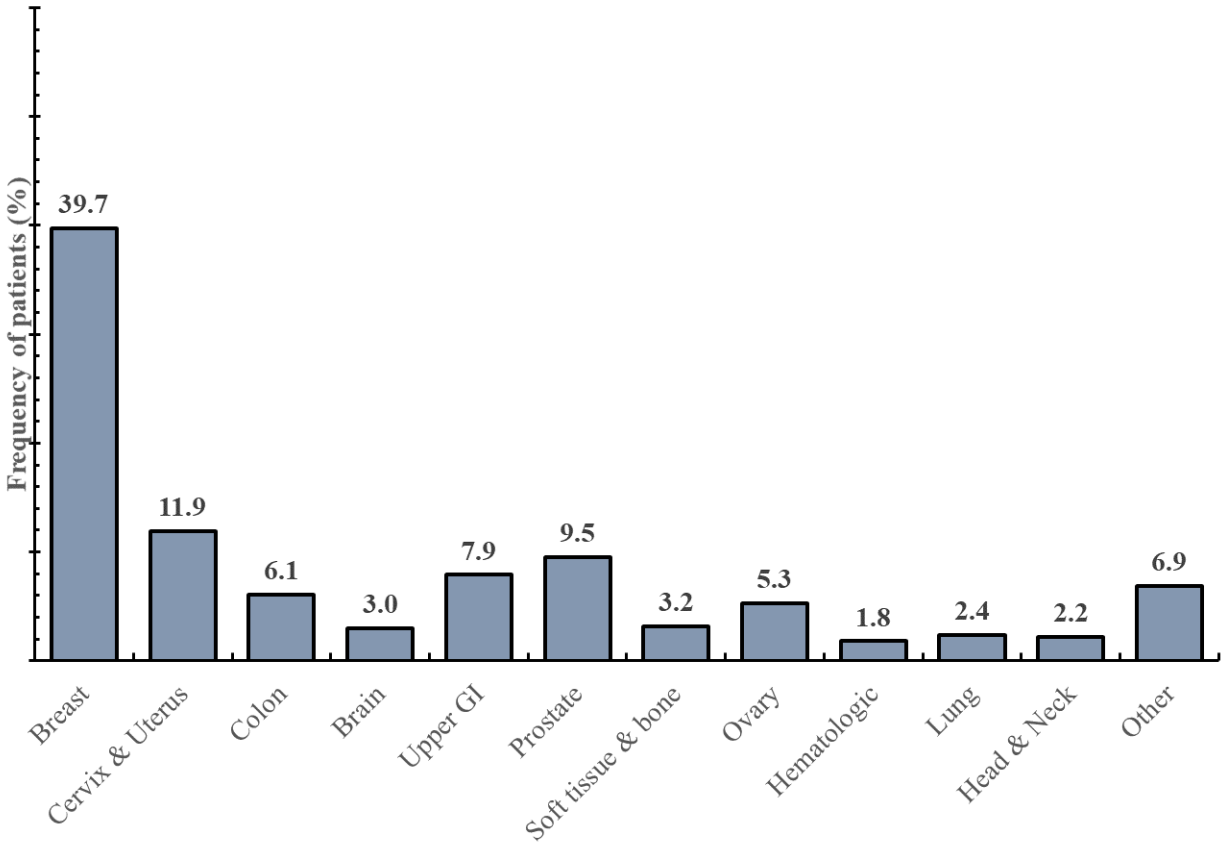
Characteristics	Patients, n (%)
Age in years	
18-39	62 (12.4)
40-64	258 (51.6)
≥65	180 (36.0)
Gender	
Male	111 (22.2)
Female	389 (77.8)
Education level	
No education/Primary school	205 (41.0)
Secondary school	170 (34.0)
Undergraduate/Postgraduate	125 (25.0)
Years with cancer	
<3	386 (77.8)
≥3	110 (22.2)

Table 2. Mean age and years since diagnosis of surveyed population.

Characteristics	Mean (SD)
Age in years	57.5 (14.9)
18-39	30.8 (6.8)
40-64	53.3 (7.0)
≥65	72.7 (5.7)
Years with cancer	2.9 (5.6)
<3	0.9 (0.6)
≥3	9.0 (9.0)

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Figure 1. Types of malignancies in surveyed population.



High- or Medium-Level Interest in Receiving Disease Information Using ICTs

WhatsApp (66.5%, 145/218) and SMS text messaging (61.0%, 133/218) were widely reported as the most effective means of communication for receiving information, followed by Facebook (39.4%, 86/218), and email (38.1%, 83/218; Table 3). Across ages, WhatsApp was reported by most patients aged under 40 years (97%, 31/32) and older than 65 years (75%, 33/44), whereas SMS text messaging presented the highest interest rate in patients who were aged between 40 and 64 years (69.7%, 99/142; *P*<.001; Table 3). Meanwhile, all education levels were mostly interested in receiving information by WhatsApp (*P*<.001), followed by Facebook for those with secondary school degree or lower (*P*=.03; Multimedia Appendix 1). Individuals in both categories of years with cancer preferred WhatsApp for receiving information (*P*=.03; Multimedia Appendix 2).

High- or Medium-Level Interest in Asking Physician's Information Using ICTs

WhatsApp presented the highest interest rate for asking physicians information about the disease (72.0%, 157/218), followed by SMS text messaging (63.8%, 139/218), email (39.9%, 87/218), and Facebook (33.5%, 73/218; Table 3). Analysis by age reveals that the youngest and oldest groups prefer WhatsApp (97% and 80%, respectively; 31/32 and 35/44, respectively), whereas the middle group has the greatest affinity for SMS text messaging (71.8%, 102/142; *P*<.001; Table 3). In addition, both genders presented the highest interest rate for SMS text messaging (78%, 40/51 males and 59.3% (99/167), females; *P*=.01; Multimedia Appendix 3). When we turn to the results by educational level, the three categories showed the highest interest for WhatsApp (Multimedia Appendix 1).

Logistic Regression Analysis

Patients aged under 65 years were associated with a higher chance of being interested in receiving information about cancer through Facebook when compared with those aged 65 years and older (reference category). In contrast to the reference, the odds of being interested in receiving information by SMS text messaging was higher in patients aged between 40 and 64 years (odds ratio, OR 5.09; Table 4).

With respect to the odds of interest in asking physicians for information by ICTs, SMS text messaging was the highest in patients who were aged between 40 and 64 years (OR 9.78), while Facebook was the most rated for the youngest group (OR 16.11; Table 4).

On the other hand, analysis by gender reveals that females were associated with less chances of being highly interested in receiving information through SMS text messaging (OR 0.22), email (OR 0.26), and WhatsApp (OR 0.27) than males (reference category), as well as less likely to be interested in communicating with physicians through SMS text messaging (OR 0.16) than the reference (Table 4).

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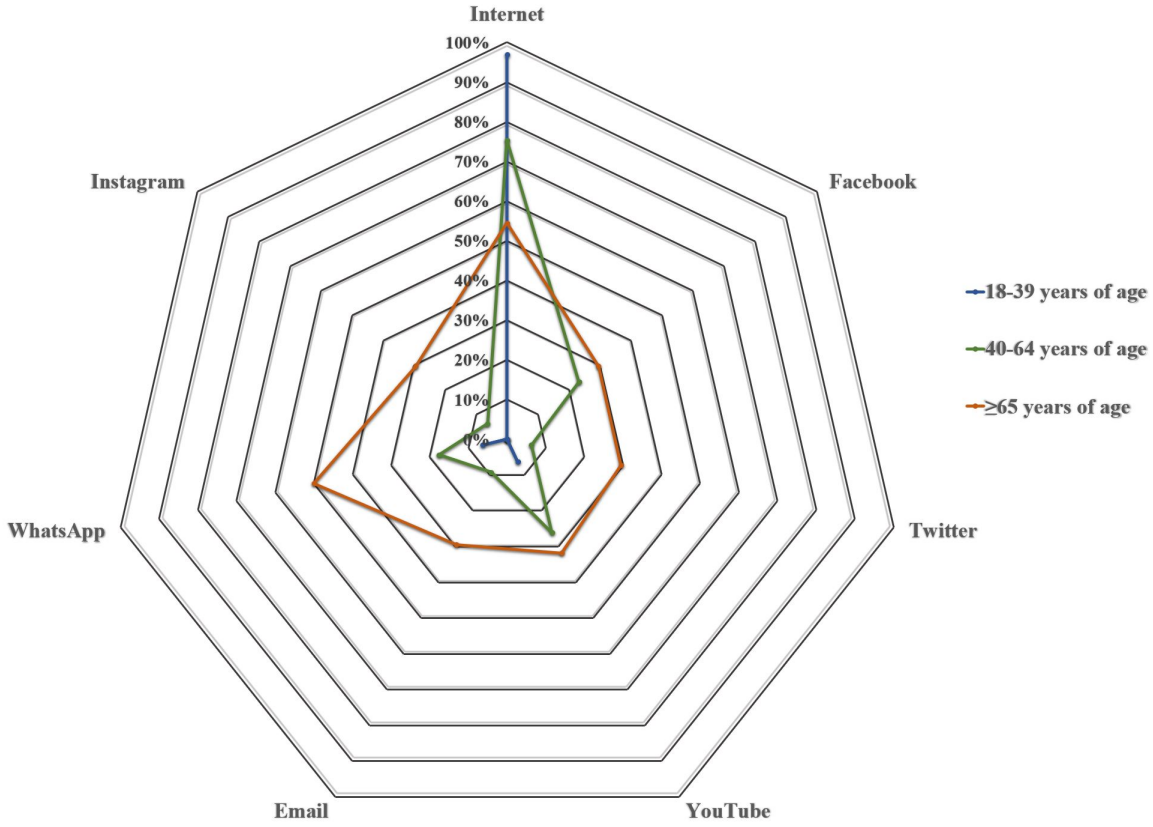
Table 3. Use of information and communication technology (ICT) types to obtain information, interest in receiving information, and interest in asking a physician through ICT types about a disease, by age. All data are presented as percentages. Differences in values between the three age groups are significant at .05 significance level (N=500).

Questionnaire parameter	Age group in years, n (%)			*P* value	Total, n (%)
	18-39, n=62	40-64, n=258	≥65, n=180		
Internet access	32 (51.6)	141 (54.7)	43 (23.9)	<.001	216 (43.2)
Phone owned					
Cell phone	52 (83.9)	202 (78.9)	117 (65.0)	<.001	371 (74.2)
Smartphone	31 (96.9)	93 (66.9)	35 (89.7)	<.001	159 (75.7)
Use of ICT type (at least once a week)					
SMS text messaging	18 (56.2)	103 (72.5)	18 (40.9)	<.001	139 (63.8)
Facebook	29 (90.6)	95 (66.9)	23 (52.3)	.002	147 (67.4)
Twitter	6(18.8)	9 (6.3)	4 (9.1)	.08[a]	19 (8.7)
YouTube	14 (43.8)	48 (33.8)	13 (29.6)	.42	75 (34.4)
Email	11 (34.4)	62 (43.7)	11 (25.0)	.07	84 (38.5)
Internet	21 (65.6)	82 (57.8)	28 (63.6)	.61	131 (60.1)
LinkedIn	0 (0.00)	6 (4.23)	0 (0.0)	.37[a]	6 (2.8)
Skype	0 (0.00)	7 (4.93)	0 (0.0)	.20[a]	7 (3.2)
WhatsApp	28 (87.5)	103 (72.54)	35 (79.6)	.16	166 (76.2)
Instagram	13 (40.6)	13 (9.2)	9 (20.5)	<.001	35 (16.1)
Uses of ICTs to obtain information about a disease					
Internet	31 (96.9)	107 (75.4)	24 (54.5)	<.001	162 (74.3)
Facebook	0 (0.0)	33 (23.2)	13 (29.5)	.004	46 (21.1)
Twitter	0 (0.0)	9 (6.3)	13 (29.5)	<.001[a]	22 (10.1)
YouTube	2 (6.3)	37 (26.1)	14 (31.8)	.02	53 (24.3)
Email	0 (0.0)	13 (9.2)	13 (29.5)	<.001	26 (11.9)
WhatsApp	2 (6.3)	25 (17.6)	22 (50.0)	<.001	49 (22.5)
Instagram	0 (0.0)	9 (6.3)	13 (29.5)	<.001[a]	22 (10.1)
Interest in receiving information through ICT type (high/some interest)					
SMS text messaging	18 (56.3)	99 (69.7)	16 (36.4)	<.001	133 (61.0)
Facebook	20 (62.5)	57 (40.1)	9 (20.5)	<.001	96 (39.4)
Twitter	9 (18.8)	6 (6.3)	9 (13.6)	.05[a]	21(9.6)
LinkedIn	3 (9.4)	9 (6.3)	4 (9.1)	.58[a]	16 (7.3)
Email	11 (34.4)	54 (38.0)	18 (40.9)	.84	83 (38.1)
WhatsApp	31 (96.9)	81 (57.0)	33 (75.0)	<.001	145 (66.5)
Interest in asking physician through ICT type (high/some interest)					
SMS text messaging	21 (65.6)	102 (71.8)	16 (36.4)	<.001	139 (63.8)
Facebook	20 (62.5)	46 (32.4)	7 (15.9)	<.001	73 (33.5)
Twitter	3 (9.4)	9 (6.3)	6 (13.6)	.25[a]	18 (8.3)
LinkedIn	0 (0.0)	0 (0.0)	4 (9.1)	.002[a]	4 (1.8)
Email	13 (40.6)	54 (38.0)	20 (45.5)	.67	87 (39.9)
WhatsApp	31 (96.9)	91 (64.1)	35 (79.5)	<.001	157 (72.0)

[a]Fisher exact test performed.

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Figure 2. Preferences in using information and communication technologies to obtain information about disease by age groups.



Furthermore, regression analysis by education level demonstrates that the highest degree category is not only less likely to be interested in receiving information about the disease through WhatsApp (OR 0.20) than the lowest degree category (reference category) but also are less likely to be interested in communicating with physicians through SMS text messaging (OR 0.34) and WhatsApp (OR 0.18) than the reference.

Moreover, when considering years with disease for the analysis, individuals with cancer for less than 3 years are more likely to use WhatsApp (OR 3.24) for putting questions to physicians about their disease when compared with patients with 3 years or more with cancer (reference category; Table 4).

In addition, patients with no metastasis are more likely to be interested in asking physicians about their disease through email (OR 2.24) than those with metastasis (reference category). However, they were also less likely than the reference for other outcomes.

Finally, individuals using SMS text messaging, email, and WhatsApp at least once a week were associated with more chances of receiving and asking information through these media than individuals using them for less than once a week (reference category; Table 4).

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Table 4. Characteristics of frequent users of selected electronic media type (≥1 time/week) showing high/some interest in receiving information and asking physicians about cancer. Regression analysis was adjusted for variables such as age, gender, education level, years with cancer and metastasis. Regression analysis using weekly information and communication technology (ICT) types was performed separately (nonadjusted).

Variable	Interest in receiving information through ICT type, OR (95% CI)	Interest in asking physicians through ICT type, OR (95% CI)
SMS text messaging (n=218)		
Age in years [a]		
18-39	1.81 (0.56-5.84)	3.37 (0.99-11.46)[b]
40-64	5.09 (1.95-13.32)[b]	9.78 (3.45-27.67)[b]
Gender [c]		
Female	0.22 (0.09-0.52)[b]	0.16 (0.06-0.43)[b]
Education level [d]		
Undergraduate/Postgraduate	0.95 (0.39-2.34)	0.34 (0.13-0.93)[b]
Metastasis [e]		
No metastasis	0.39 (0.18-0.82)[b]	0.58 (0.27-1.23)
Weekly SMS use[f,g]	10.27 (5.40-19.54)[b]	10.98 (5.73-21.05)[b]
Facebook (n=218)		
Age in years		
18-39	11.53 (3.13-42.46)[b]	16.11 (4.06-63.86)[b]
40-64	4.27 (1.49-12.21)[b]	4.42 (1.43-13.65)[b]
Metastasis		
No metastasis	0.35 (0.17-0.72)[b]	0.44 (0.22-0.90)[b]
Email (n=218)		
Age in years		
40-64	0.53 (0.20-1.41)	0.29 (0.12-0.71)[b]
Gender		
Female	0.26 (0.12-0.55)[b]	0.74 (0.37-1.50)
Metastasis		
No metastasis	1.94 (0.96-3.92)	2.24 (1.13-4.42)[b]
Weekly email use	3.17 (1.79-5.63)[b]	3.537 (1.993-6.29)[b]
WhatsApp (n=218)		
Age in years		
40-64	0.30 (0.09-1.05)	0.16 (0.03-0.82)[b]
Gender		
Female	0.27 (0.11-0.66)[b]	1.08 (0.46-2.57)
Education level		
Undergraduate/Postgraduate	0.20 (0.07-0.60)[b]	0.18 (0.05-0.64)[b]
Years with cancer [h]		
<3 years with cancer	0.28 (0.11-0.75)[b]	>3.24 (1.28-8.17)[b]
Weekly SMS use	96.63 (27.87-335.078)[b]	12.69 (6.14-26.24)[b]

[a]Reference age category is ≥65 years.

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[b].05 significance level

[c]Reference gender category is male.

[d]Reference educational-level category is No education/Primary school.

[e]Reference metastasis category is *presence of metastasis*.

[f]SMS: short message service.

[g]Reference ICT use category is *less than once a week*.

[h]Reference *years with cancer* category is ≥3 years.

Discussion

Principal Findings

This study analyzed the preferences of ICTs among cancer patients when used for health-related purposes. Existing associations between ICTs use frequency and interest in receiving information and communicating with physicians has been highlighted.

For instance, WhatsApp was the best rated ICT for both purposes, followed by SMS text messaging. Females and high-education degree patients were less likely to be interested in using these ICTs for such purposes. Also, adult patients were more likely to be interested in using Facebook for the purposes described than the elderly. To add, the Internet (Web browsing) was the most used ICT to look for information about cancer, regardless of age.

Internet Access, Cell Phone, and Smartphone Possession

Research indicates that oncologic patients tend to use the Internet to find information about their disease and receive social support [12]. It has been previously reported by Keinki et al that 59% of cancer patients use the Internet and 7.5% use it as a primary source of health information [13]. A recent publication determined that 43.4% of all Latin-American households were connected to the Internet in 2015 [14]. Our data fit the former distribution as 43.2% of our sample has access to Internet. However, there are populations with no or little access to the Internet as well as without or limited skills to use it effectively [15]. These issues limit their access to health information.

Certainly, the proliferation of ICT users with mobile devices provides an opportunity for easy access to medical information [16]. Recently, a publication found that improving health media strategy can be effective for achieving health equity in any given society [17]. One quarter of our participants reported neither owning a cell phone nor having access to Internet. This group misses out on the opportunity to have any kind of health intervention through ICTs.

Moreover, the use of smartphones has grown in Latin America [18]. Coughlin and coinvestigators showed the potential for research-tested smartphone apps to provide a low-cost and effective strategy for preventing breast cancer in women [1]. In our study, approximately one-third of patients have a smartphone. Thus, the possession of a smartphone is proven to be less attractive for applying interventions in low-income countries because of poor adoption for this technology.

Receiving Information and Communicating With Physicians

Our results suggest that SMS text messaging for people aged 40 to 64 years is a useful tool for communicating (both for receiving and asking for information) with cancer patients. Patients aged 40 to 64 years have a 5 times greater chance of being interested in receiving information by SMS text messaging and almost a 10 times greater chance of asking physicians about their disease, and SMS text messaging is the most highly rated of all other media within this age group.

There are several practical reasons for using SMS text messaging. It costs less than voice messaging, and it can reach people whose phones are switched off. Furthermore, SMS text messaging is silent, which means that messages can be sent and received in places where it may be impractical to hold a conversation [19].

WhatsApp is a cross-platform instant messaging app that allows smartphone users to exchange text, image, video, and audio messages. In Latin America, around two-thirds of Internet users are *Whatsapping* compared with North Americans, who barely use the app [11].This platform was the most extensively used by our cancer patients. The same reasons that justify SMS text messaging usage theoretically apply for WhatsApp use. Furthermore, several Wi-Fi access points in different places throughout the city may facilitate WhatsApp usage. WhatsApp should be the main focus between all ICTs to facilitate medical advice and support.

Currently, in Latin America some mobile operators offer different plans that include unlimited WhatsApp and Facebook services. This is presumably the reason why Latin America has a higher Internet penetration rate when compared with other regions [20].

It is known that older adults are often portrayed as less avid users of ICTs. However, we found that older patients also use WhatsApp for receiving information and for asking their physician about cancer. This goes along with a recent publication in which WhatsApp was declared to be the most frequently used app with an average of 26.4 accesses per day. WhatsApp is a very relevant app, as it is always associated to a flat rate bill, has no limitations, and is cheaper than phone calls or SMS text messages [21].

The results of this study suggest that WhatsApp is a useful tool for communicating (both for receiving and asking for information) with cancer patients. WhatsApp showed the highest level of interest in receiving information and asking physicians across all categories of age, education level, and years with cancer. Therefore, the development of adequate text messages for SMS and WhatsApp to support and inform cancer patients

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is the next challenge. It is key to determine which is the most adequate messaging service to encourage the diffusion of health information.

In general, WhatsApp and SMS text messaging were reliable communication channels for all ages. In young people and patients with fewer than 3 years of cancer, Facebook was especially remarkable. It is known that cancer campaigns come equipped with several photos and have produced the most significant engagement rate, suggesting that visual content may be more effective in facilitating engagement in public health social and digital media campaigns [22]. The rapid diffusion, low costs, and broad availability of social media make it an attractive platform for managing care, communication, and interventions in cancer.

Moreover, this study showed that approximately 75% of patients use the Internet as a source of information about their disease. The Internet is a common venue for disseminating and accessing health information [23].

In addition, by attempting to reduce risks toward cancer and disseminating evidence-based information about cancerous diseases in combination with a minimal cost, YouTube has shown to be the ideal media form [24,25]. YouTube is used by 24.3% of our patients to obtain information about cancer. However, it must be remembered that not all videos in chronic diseases are uploaded by credible authoritative sources [26].

On the other hand, it has been reported that elderly people with cancer are not familiar with YouTube [27]. Older people have reported that they tend to restrict heavy media consumption when using their mobile data plan to control their budget, providing this as a reason not to use YouTube [21]. In contrast with these data, our study found that almost one-third of our patients older than 65 years used YouTube to obtain information about cancer, and when compared with the other age groups, it presented the highest rate of use out of all ICT forms. Thus, our results encourage the continued use of this kind of communication channel in this age group. In the future, it is necessary to understand why the elderly cancer patients have an interest in using YouTube to look for information about cancer.

Limitations

Even though ICTs may provide several benefits for the patient and health communication, there are some limitations that might actually be deleterious for health care [28]. For example, the quality of the content and reliability of health information is sometimes questionable [29,30]. In some instances, authors are unknown [29]. Also, in the scenario of a patient-physician communication through email, confidential information and medical records might be vulnerable to security breaches [31]. Patients may accidentally share personal information through social media or provide incorrect advice, which can be harmful for other patients [32].

Our study has some limitations. First, it was not conducted in all Latin American countries and the preferred use of ICTs in other countries in the same region might differ. Second, almost 80% of the respondents were female; therefore, our findings are not simply extendable to males. In addition, approximately 40% of our patients were diagnosed with breast cancer and almost 12% with cervix and uterus malignancies; thus, the results cannot be extrapolated to other types of cancer. Moreover, the simple fact of applying a survey as the measure instrument may produce unreliable results because of variability on interpretation of the respondent, lack of awareness of what the survey is asking, the emotional status of the patient in the hospital setting, and missing data. Furthermore, our survey has not been validated. However, one strength of this study is that it covered a good sample size (N=500) of cancer patients. The sample also included participants of different age, sex, and educational level. To the best of our knowledge, our study is the first to explore the utility of WhatsApp in cancer patients, and our results provide evidence that this media is quite reliable. Also, ours is one of the first studies performed on the Latin American population concerning ICT usage in this disease. Future research is needed to confirm our findings and assess the real use of ICT tools.

Randomized trials will of course be necessary to determine the efficacy and cost-effectiveness of all new ICT tools in promoting cancer control for patients and support among these individuals, as well as providing a source of information about their disease and encouraging self-management. We also need to examine the benefit for cancer patients. However, the widespread use of ICTs opens up new possibilities for the relationship between physicians and patients.

Conclusions

A variety of ICT forms are revolutionizing health care and becoming mainstream tools to assist patients in self-monitoring and decision making. In this study, we have determined that WhatsApp presented the highest rate of interest for receiving information and communicating with physicians, followed by SMS text messaging. The Internet represents the most significant source of information regardless of age, although patients need to be cautious as the content provided may be unreliable and deleterious for disease management. Depending on age, new ICTs such as Facebook and Twitter are still emerging. Recognizing patterns of preferences can be useful to target specific patient profiles better through ICTs. Future studies should investigate how to develop and promote ICT-based resources more effectively to engage the outcomes of cancer patients. The widespread use of ICTs opens new possibilities for cancer patients in developing countries. Furthermore, robust research is required to establish whether social media improves health communication practices in both short and long term.

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Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Use, obtain information, interest receiving information, and interest in asking a physician through ICT types by education level.

[PDF File (Adobe PDF File), 39KB - jmir_v20i2e50_app1.pdf]

Multimedia Appendix 2

Use, obtain information, interest receiving information, and interest in asking a physician through ICT types by years with cancer.

[PDF File (Adobe PDF File), 36KB - jmir_v20i2e50_app2.pdf]

Multimedia Appendix 3

Use, obtain information, interest receiving information, and interest in asking a physician through ICT types by gender.

[PDF File (Adobe PDF File), 35KB - jmir_v20i2e50_app3.pdf]

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Abbreviations

ICTs: information and communication technologies
MQ: Michigan questionnaire
SMS: short message service

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Review

Clinical Validity, Understandability, and Actionability of Online Cardiovascular Disease Risk Calculators: Systematic Review

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Abstract

Background: Online health information is particularly important for cardiovascular disease (CVD) prevention, where lifestyle changes are recommended until risk becomes high enough to warrant pharmacological intervention. Online information is abundant, but the quality is often poor and many people do not have adequate health literacy to access, understand, and use it effectively.

Objective: This project aimed to review and evaluate the suitability of online CVD risk calculators for use by low health literate consumers in terms of clinical validity, understandability, and actionability.

Methods: This systematic review of public websites from August to November 2016 used evaluation of clinical validity based on a high-risk patient profile and assessment of understandability and actionability using Patient Education Material Evaluation Tool for Print Materials.

Results: A total of 67 unique webpages and 73 unique CVD risk calculators were identified. The same high-risk patient profile produced widely variable CVD risk estimates, ranging from as little as 3% to as high as a 43% risk of a CVD event over the next 10 years. One-quarter (25%) of risk calculators did not specify what model these estimates were based on. The most common clinical model was Framingham (44%), and most calculators (77%) provided a 10-year CVD risk estimate. The calculators scored moderately on understandability (mean score 64%) and poorly on actionability (mean score 19%). The absolute percentage risk was stated in most (but not all) calculators (79%), and only 18% included graphical formats consistent with recommended risk communication guidelines.

Conclusions: There is a plethora of online CVD risk calculators available, but they are not readily understandable and their actionability is poor. Entering the same clinical information produces widely varying results with little explanation. Developers need to address actionability as well as clinical validity and understandability to improve usefulness to consumers with low health literacy.

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KEYWORDS

cardiovascular disease; risk assessment; risk communication; risk formats

Introduction

Online health information may be the first step toward seeking professional medical advice, so the quality of this information is important: is it clinically valid, does it communicate risk effectively, is it understandable to the user, and what actions does it prompt? Unfortunately, the majority of users may not have the necessary skills to effectively evaluate these issues.

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Health literacy is the ability to access, understand, and make use of health information and services [1], and a large proportion of the general population has inadequate skills [2] (poor health literacy skills in Australia: 59% [3], Europe: 47% [4], Canada: 60% [5]). Low health literacy is associated with less trust in online health information, decreased ability to evaluate that information, and worse health outcomes for cardiovascular disease (CVD) and other chronic conditions requiring self-management [2,6,7]. The issue of eHealth literacy is a related but separate barrier to using health information online—not only do users need to understand and act on the information, but they need the basic skills to find reliable websites in the first place [8]. Less educated, low income, and older individuals may be particularly disadvantaged by inaccessible and poorly explained online health information [2,6,9]. While there is no consensus on how best to evaluate health websites, the majority of studies have concluded that the quality is low [10]. EHealth interventions are increasingly common but have largely neglected the issue of health literacy, which may contribute to their low use [7,8,11].

CVD is the leading cause of mortality and morbidity worldwide, but its incidence can be reduced through risk factor modification via lifestyle change and/or medication [12-15]. This makes it a highly relevant issue for eHealth, as it affects a large proportion of the population and may be prevented through individual behavior change before medical intervention is necessary. Many eHealth interventions target lifestyle with the ultimate aim of preventing CVD [11], but how do individuals know when to access professional medical assistance? The decision to prescribe medication should be based on the likelihood of avoiding a heart attack or stroke, which depends on the baseline absolute CVD risk for an individual [16]. CVD prevention guidelines often use algorithms based on large cohort studies to estimate the risk of a CVD event, usually over 5 or 10 years [12,13]. For example, by identifying 1000 patients with an absolute CVD risk of >21% and lowering their blood pressure, 38 heart attacks and/or strokes would be prevented over 5 years [17,18]. On the other hand, identifying 1000 patients with an absolute CVD risk <11% and treating their blood pressure would prevent only 14 CVD events over 5 years [17,18]. Both groups would however, be exposed to the potential side effects, costs, and inconvenience of antihypertensive medication in order to achieve these reductions in CVD event rates [18]. To estimate the absolute risk of a CVD event, numerous tools exist using different parameters and models [19]. The commonly used Framingham model is based on age, sex, smoking, diabetes, cholesterol, and blood pressure [20]. More recent models used in UK and US guidelines include ethnicity and socioeconomic indicators [13,15]. These risk calculators are available to the public online, but little is known about their quality.

Previous research indicates that online CVD risk calculators can be easily misunderstood. Users may enter their risk factors incorrectly, the provision of multiple risk formats can be confusing if not explicitly explained, and the risk calculators themselves may make assumptions about missing data that lead to less accurate results [21,22]. Users may also question the credibility of the calculator's results if their prior expectations are not met [23]. On the other hand, an engaging interactive format can increase the emotional response to the risk result and potentially motivate action more than a standard verbal description of risk by a doctor [24,25].

This study aimed to systematically review publicly available online risk calculators for CVD and evaluate them on criteria relevant to health literacy (clinical validity, risk communication, understandability, and actionability).

Methods

Procedures

The general approach for this study was to follow a systematic review process using 2 independent searchers (SH, RS) who qualitatively described each risk calculator and evaluated them quantitatively based on the validated Patient Education Material Evaluation Tool for Print Materials (PEMAT-P) scale. For the search and evaluation, we used a third rater (MF) to resolve discrepancies and reach consensus in accordance with section 7.6 of the Cochrane Handbook for Systematic Review of Interventions [26]. The qualitative descriptions of the risk calculator were used to develop a framework for quantitative data extraction (risk model, risk result, and presence/absence of risk communication formats), after which an individual researcher (MF) conducted the basic data extraction. This process was discussed and refined with the lead researcher (CB) on a fortnightly basis, with additional advice from a general practitioner/academic researcher (LT).

Ethical Approval

Since there were no participants in this study and the data was based on publicly available websites, an ethics application was not required.

Inclusion and Exclusion Criteria

Online risk calculators were considered if they met the following inclusion criteria: (1) assessed risk of future CVD in individuals without a previous CVD event, (2) were available without the need for registration or payment, and (3) were interactive. Calculators were not considered if they were downloadable files such as an Excel (Microsoft Corp) spreadsheet or PDF, addressed absolute risk of future cardiovascular events in people with atrial fibrillation, or did not provide a risk result for the end user.

Search Strategy

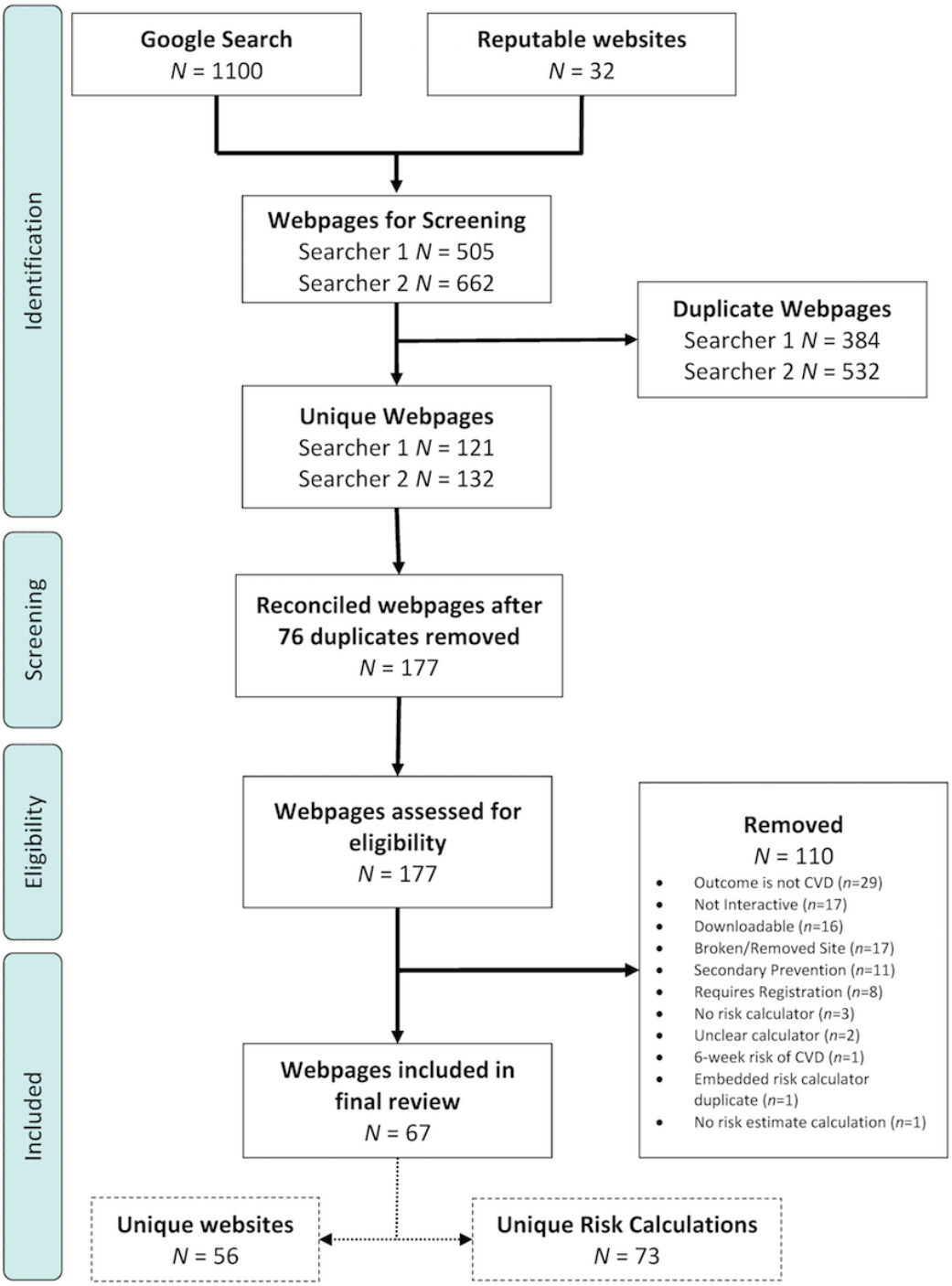
There were 2 main search strategies for identifying Web addresses that contained the CVD risk calculators. The first strategy was to access predetermined reputable websites including 6 national heart foundation websites (Australian National Vascular Disease Prevention Alliance, the National Heart Foundation of New Zealand, the Joint British Societies, the UK National Health Service, the American Heart Association, and the American College of Cardiology) and a not-for-profit source [27], and the second strategy used Google Australia with English-language terms. The 2 independent searchers (RS, SH) were instructed to reset their cache in their Web browsers before each Google search to minimize the effect of Google search optimization. The 2 search term themes were "CVD/medication" and "risk." The lead researchers (CB, LT)

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and the 2 independent searchers agreed upon 11 specific terms for CVD/medication (CVD, heart disease, stroke, heart attack, hypertension, hypercholesterolemia, hypercholesterolaemia, aspirin, blood pressure medication, cholesterol medication, and statin) and 2 specific terms for risk (risk calculator and risk assessment). A single CVD/medication and a single risk term were combined for a single search resulting in 22 unique Google searches. The first 50 results were considered (not including Web advertisements), providing a pool of 1100 results to be title scanned. The search results were limited to the first 50 after method piloting showed no additional websites would have been included up to 100 results. Searchers only recorded the Web addresses if they were to be assessed for eligibility. Duplicates were considered either as identical Web addresses, Web addresses that linked to the same risk calculator, or where a risk calculator from one webpage was embedded in another.

The searchers (SH, RS) conducted this search as part of a Master of Public Health degree capstone unit from August to November 2016. In March 2017, an independent member of the team (MF) reconciled these search results based on the record of screened Web addresses provided by the original searchers (see Figure 1) by using Excel and removing duplicate Web addresses. The 2 independent searchers then rated risk calculators with the PEMAT-P providing 2 PEMAT-P ratings for 1 risk calculation.

Figure 1. Search strategy and results (updated with higher res image).



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Evaluation and Data Extraction

The 2 searchers (SH, RS) developed the framework for basic data extraction by qualitatively describing the content of the risk calculator results for the high-risk profile. From this, a standard form was developed (CB, MF) to numerically record basic descriptive data for each calculator: risk model used, how the risk was presented (eg, relative risk, absolute risk, life expectancy, graphical formats) and recommended actions for the high-risk profile (eg, take medication, change lifestyle, see general practitioner). The third rater (MF) then extracted the data numerically, with any uncertainties discussed with the lead researcher (CB) to reach consensus.

The 2 searchers (SH, RS) also rated the content of each risk calculator using a validated tool, the PEMAT-P [27]. Searchers were instructed to first read the PEMAT-P user manual before proceeding with rating and spoke fortnightly with a supervising researcher (CB) to discuss/explain any items that were not immediately clear (eg, examples of an active voice). PEMAT-P provides 2 submeasures that are particularly relevant to health literacy: understandability, which is a measure of how well a health consumer is able to process and explain the key message of the material, where higher percentages indicate better understandability, and actionability, which is a measure of how well a health consumer is able to identify what to do based on the information presented, where higher percentages indicate better actionability. For the 2 independent searchers, the correlation between understandability scores was 0.57 and the correlation between actionability scores was 0.71. Discrepant item scores between the first 2 raters were resolved by a third rater (MF, after discussion with CB) to finalize the PEMAT-P score for each risk calculator. These decisions were double-checked with the original searchers, who agreed with the final approach.

A predefined high-risk cardiovascular profile for a hypothetical patient was used to assess the clinical validity of each calculator. This was a 65-year-old male smoker with systolic/diastolic blood pressure of 130/80 mm Hg, total/high-density lipoprotein cholesterol ratio of 6, and body mass index of 26 kg/m^2. Where risk calculators had additional factors, the question was left blank (if possible) or an answer was given that either indicated the middle of the range or provided no additional risk on top of the risk profile (eg, a low-risk ethnicity, no history of CVD or taking medication). The 2 independent raters (SH, RS) created descriptive lists of the different clinical risk models, risk formats, and recommended actions for each calculator based on the high-risk profile. The third rater (MF) then used this framework to code the full dataset after discussion with CB, using the same high-risk profile.

Results

Search Results

This search yielded 67 unique webpages (see Figure 1). A list of the included Web addresses and their ID numbers can be found in Multimedia Appendix 1 (Table A). One website would sometimes host multiple risk calculators for different CVD events (eg, specifically for stroke or myocardial infarction). In total, these 67 webpages were found within 56 websites. Three calculators were able to calculate multiple absolute risks of future CVD events based on different models (ID2, ID4, ID10). These calculators were counted only once in the search strategy but are duplicated for the purposes of data extraction as different models of future CVD risk use different risk factors. Risk factor profiles are based on model-specific results. For example, ID2 is able to calculate risks based on 3 different models, therefore has been counted as 3 unique calculators. From the included 67 webpages, there are a total of 73 unique risk calculators.

Risk Calculator Characteristics

The descriptive characteristics of the calculators are provided in Table 1.

The calculators used a variety of published risk models but the most common were those used in clinical practice guidelines: Framingham (44%), American College of Cardiology/American Heart Association (ACC/AHA) (10%), QRISK2 (5%), Reynolds (4%), and Assessing cardiovascular risk using the Scottish Intercollegiate Guidelines Network (ASSIGN) (3%). One-quarter did not specify the underlying model (25%). The outcomes included CVD/coronary heart disease (CHD), angina, heart attack/myocardial infarction, stroke, heart failure, kidney disease, diabetes, and CVD/CHD death. Most calculators used a 10-year time frame (77%) but some used 5-year (7%), 30-year (3%), or lifetime (7%) risk, and one allowed different estimates for the range of 1 to 10 years (1%). Many risk calculators did not state specific outcomes beyond mentioning CVD risk, and some did not state the time frame.

The absolute percentage risk was stated in most but not all calculators (79%). Other risk formats included categorical risk with 2 to 4 groups ranging from low to high (32%), a verbal description of the frequency such as 8 in 100 (18%), heart age (10%), life expectancy (3%), and relative risk (3%). In 34 risk calculators (47%) only 1 risk format was presented, and in 39 (53%) risk calculators 2 to 5 risk formats were presented. The risk profile outlined previously yielded highly variable results depending on the model and outcomes used, with an absolute risk ranging from 3% to 43% over 10 years, a heart age of 68 to 86 years, a life expectancy of 79 to 84 years, and a relative risk of 1.8 to 2.1 compared to a healthy person's risk. Visual aids included icon arrays or pictographs (18%), bar or line graphs (16%), and charts showing risk level (10%).

For the PEMAT-P evaluation, the calculators scored moderately on understandability and poorly on actionability. The average understandability score was 64% (SD 20%) which ranged from 30% to 100%, and the average actionability score was 19% (SD 26%) which ranged from 0 to 100%. Screenshots from very high-scoring examples for understandability (ID14) and actionability (ID66) are shown in Figures 2 and 3, respectively. Reliability was variable for the individual PEMAT-P items, with Cohen kappa scores ranging from –0.05 to .65 and agreement ranging from 42% to 99%. These discrepancies were resolved by using a third rater and team discussion to reach consensus on each decision. The PEMAT-P scores for individual risk calculators and reliability by PEMAT-P item are provided in Multimedia Appendix 1 (Tables B and C).

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Table 1. Characteristics of final calculators (n=73).

Characteristic	Count, n (%)
Risk model	
Framingham	32 (44)
Not stated	18 (25)
ACC/AHA[a]	7 (10)
QRISK2	4 (5)
Reynolds Risk Score	3 (4)
ASSIGN[b]	2 (3)
ARIC[c] Study	1 (1)
BNF[d]	1 (1)
Health Professional Follow-Up Study and Nurses' Health Study	1 (1)
MESA[e]	1 (1)
Pocock et al (2001)	1 (1)
QStroke	1 (1)
Strong Heart Study	1 (1)
Risk format	
Absolute risk	58 (79)
Categorical risk	23 (32)
Frequency	13 (18)
Heart age	7 (10)
Life expectancy	2 (3)
Relative risk	2 (3)
Icon array/pictograph	13 (18)
Graphs	12 (16)
Charts	7 (10)
Recommended actions	
Stop smoking	21 (29)
Lower cholesterol/take cholesterol medication	21 (29)
Lower blood pressure/take blood pressure medication	14 (19)
Improve diet	10 (14)
Increase physical activity	9 (12)
Seek doctor's advice	9 (12)
Take aspirin	6 (8)
Address body mass index	3 (4)

[a]ACC/AHA: American College of Cardiology/American Heart Association.

[b]ASSIGN: Assessing cardiovascular risk using the Scottish Intercollegiate Guidelines Network.

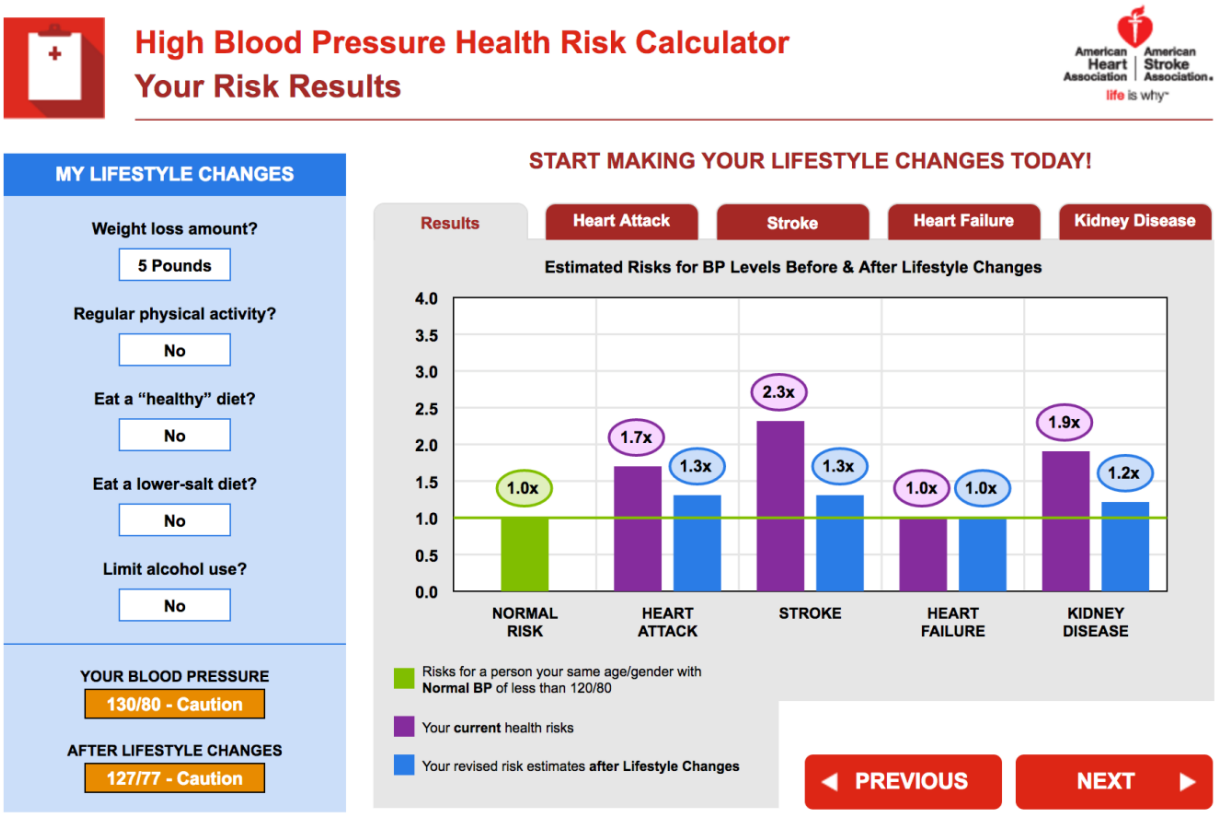
[c]ARIC: Atherosclerosis Risk in Communities.

[d]BNF: British National Formulary.

[e]MESA: Multi-Ethnic Study of Atherosclerosis.

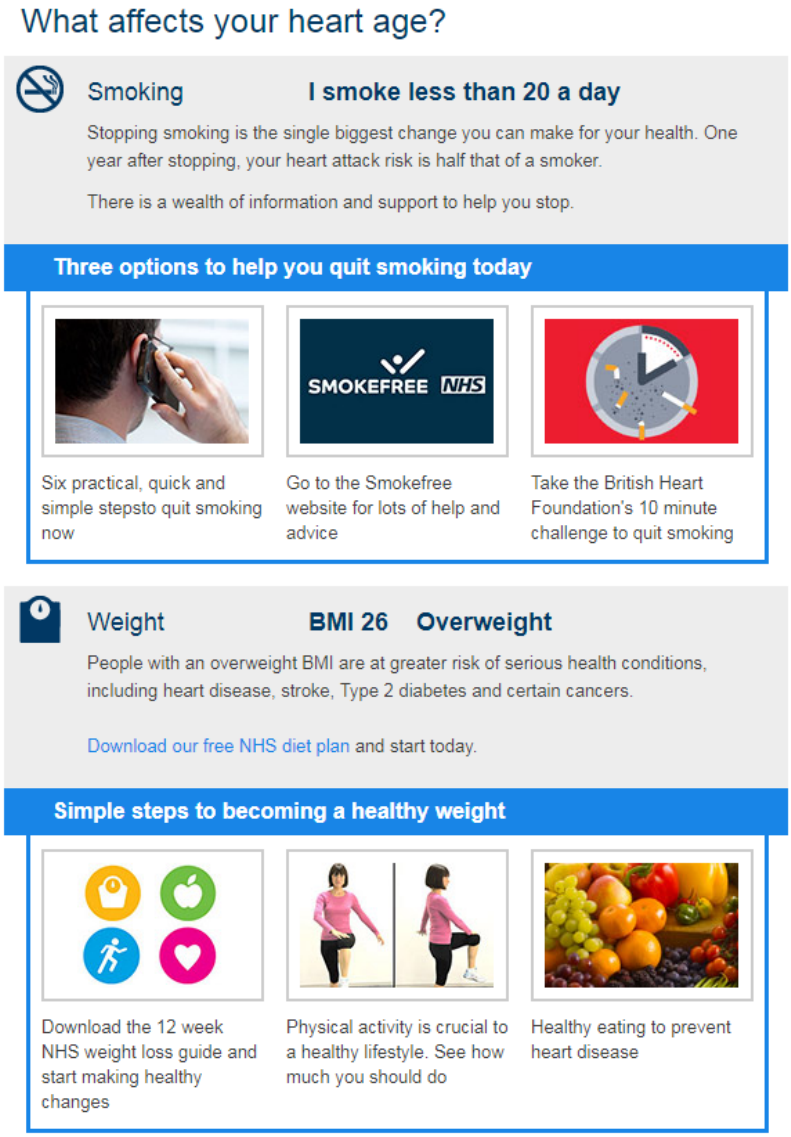
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Figure 2. An example of a risk calculator with a high understandability Patient Education Material Evaluation Tool for Print Materials score.



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Figure 3. An example of a risk calculator with a high actionability Patient Education Material Evaluation Tool for Print Materials score.



Discussion

Principal Findings

This review found 73 unique CVD risk calculators available to the public online that use a wide variety of risk models, risk communication formats, understandability, and actionability. Of particular concern is the variation in CVD risk estimates based on entering the same hypothetical high-risk patient data with little explanation for why this would occur: ranging from as little as 3% to as high as a 43% risk of a CVD event over the next 10 years. One-quarter (25%) of the risk calculators did not specify the underlying model, study, calculations, or assumptions, so it not possible to assess their validity or the reasons for variation. The remaining three-quarters (75%) did specify enough information to determine the underlying algorithm, where differences in the study population (eg, US-based Framingham versus UK-based QRISK), included risk factors (eg, whether less directly predictive factors like body mass index were included as well as strong clinical indicators like cholesterol), and CVD outcomes (eg, mortality only, nonfatal heart attack and stroke, angina) explain the discrepant risk results for the same profile. In the academic literature, there are over 17 validated CVD risk models [19], and both the United Kingdom and United States have moved on from the original 10-year Framingham model in their current clinical guidelines [13,15]. In contrast, Framingham is still the dominant model online, but there were no publicly available 5-year risk calculators that scored very highly on both understandability and actionability. This means that countries like Australia that use a 5-year Framingham model could benefit from additional development using highly rated features of 10-year calculators (Figures 2 and 3). Patients with low health literacy searching for their own CVD risk information are most likely to encounter 10-year models that do not correspond to local clinical guidelines.

In terms of risk communication, absolute risk should ideally be presented in a variety of formats to cater to different needs and learning styles [28]. While absolute risk, verbal explanations of risk categories, and graphical presentations were all present in our sample of risk calculators, just over half used a combination of different presentation formats for the same numerical information. At minimum, all calculators should

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present the absolute risk in numerical form, but over 20% did not meet this minimum standard. Icon arrays displaying risk in terms of CVD event frequencies were only used in 18% of risk calculators, despite much attention in the risk communication literature and recommendations to use these formats in international patient decision aid standards [28].

The PEMAT-P evaluation was chosen for its unique focus on reducing health literacy demand through both understandability and actionability [29]. It does not yet have an agreed threshold for acceptable levels, but comparison to recent studies of information for related conditions suggests that understandability was moderate and actionability was poor overall (present study: 64% and 19%; online heart failure websites: 56% and 35%; printed lifestyle information for chronic kidney disease: 52% and 37% for understandability and actionability, respectively) [30,31]. To improve actionability, clinical guidelines recommend both lifestyle and medication for the selected high-risk patient profile [12], but even the most strongly recommended action of quitting smoking was only mentioned by 29% of calculators, and there was more focus on statins than blood pressure–lowering medication even though both risk factors were elevated compared to ideal levels. Presenting clear, jargon-free information on all the available options as well as referring the user to a doctor to discuss high-risk results is recommended to better meet the needs of low health literacy users.

The findings of this study are comparable to broader literature on the quality of online health information; a review showing 70% of studies evaluating 5941 websites concluded that higher quality is needed [10]. For a recent example, the US Department of Health and Human Services' Office of Disease Prevention and Health Promotion evaluated the quality of the 100 top-ranked health-related websites and found that only 58% met at least 3 out of 6 reliability criteria, while 42% followed at least 10 out of 19 usability principles [32]. This was part of an effort to set national objectives to improve the quality of eHealth by 2020, to which health literacy criteria could perhaps be added in future.

Strengths and Limitations

The strengths of this study include a systematic review and evaluation process with multiple independent searchers/raters. The main limitation is the replicability of conducting a systematic search using online search engines like Google. The dynamic nature of the Web with constant variation in website content and metadata means that no search is perfectly replicable even though the cache was cleared between search terms. However, the methods used are likely to have captured the most common and popular search results, since many duplicates were removed between the 2 searchers. It is likely that additional calculators existed at the time of the search and could potentially have been found by a different searcher, search engine, or geographical location, but this study provides a comprehensive list of accessible calculators at the time of searching.

The variable reliability of the PEMAT-P items was slightly lower than previous research [33], but could possibly be improved by recoding the low-scoring items or through further training of the coders, although the PEMAT-P developers intended it for use by nonexperts [29]. Lower PEMAT-P reliability could also be due to the risk calculators not fitting PEMAT definitions for printable materials. Reevaluation was not possible in this study due to the changing nature of the interactive risk calculator websites but could be considered for future research using PEMAT-P with static materials. The data extraction for basic descriptive content (risk model and risk result formats) was conducted by an individual researcher in this study, so reliability could not be assessed, although this is not generally reported in systematic review data extraction [26].

Implications

The plethora of calculators and wide variation in results from the same input have the potential to confuse and harm the general public if appropriate medical advice is not sought. Actionability scores are poor on average, and minimum risk communication standards are not being met. Future research evaluating the suitability of online risk calculators for low health literacy users would benefit from a revised version of the PEMAT-P designed specifically for interactive online formats. Existing items relevant to health literacy may need to be clarified, including (1) better definition for the presence/absence of a table, since website content is often built around a table format, (2) instructions for dealing with interactive graphs based on buttons, (3) a definition of short material for webpages, (4) how to address subtle visual aids such as color, size, or positioning which are more heterogeneous in interactive online formats, and (5) how to best address actionability items with general health advice versus personalized advice based on the risk result. In addition, concepts from eHealth evaluation tools could be incorporated, including (1) ease of navigation through the calculator; (2) presence/absence of distractions in the webpage (eg, advertisements, pop-ups); and (3) ability to save, print, or email the results and recommended actions. Finally, additional information is needed to enable clinicians and consumers to determine whether health risk calculators give a reliable estimate, including the model or algorithm used (eg, study name/reference, outcomes measured, and time frame), what population the calculation has been validated in (eg, age, sex, and ethnicity), an explanation of how this relates to current clinical guidelines, and when the evidence for the calculation was last updated.

Conclusion

Online CVD risk calculators produce highly variable results for the same person with little explanation for why this would occur. Differences in the models used, risk factors included, risk communication formats presented, and actions specified explain part of this variation, but one-quarter of risk calculators did not specify any underlying assumptions. Health professionals should be aware of the reasons for conflicting results that patients might encounter, and developers need to address actionability as well as clinical validity and understandability to improve usefulness to the majority of the population with low health literacy. Country-specific calculators that match national clinical guidelines and build on examples with high understandability and actionability scores would benefit both health professionals and consumers.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Risk calculator archive and Patient Education Material Evaluation Tool for Print Materials scores.

[PDF File (Adobe PDF File), 64KB - jmir_v20i2e29_app1.pdf]

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Abbreviations

ACC: American College of Cardiology
AHA: American Heart Association
ARIC: Atherosclerosis Risk in Communities
ASSIGN: Assessing cardiovascular risk using the Scottish Intercollegiate Guidelines Network
BNF: British National Formulary
CHD: coronary heart disease

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CVD: cardiovascular disease
MESA: Multi-Ethnic Study of Atherosclerosis
PEMAT-P: Patient Education Material Evaluation Tool for Print Materials

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Original Paper

Health Information Obtained From the Internet and Changes in Medical Decision Making: Questionnaire Development and Cross-Sectional Survey

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Abstract

Background: The increasing utilization of the internet has provided a better opportunity for people to search online for health information, which was not easily available to them in the past. Studies reported that searching on the internet for health information may potentially influence an individual's decision making to change her health-seeking behaviors.

Objective: The objectives of this study were to (1) develop and validate 2 questionnaires to estimate the strategies of problem-solving in medicine and utilization of online health information, (2) determine the association between searching online for health information and utilization of online health information, and (3) determine the association between online medical help-seeking and utilization of online health information.

Methods: The Problem Solving in Medicine and Online Health Information Utilization questionnaires were developed and implemented in this study. We conducted confirmatory factor analysis to examine the structure of the factor loadings and intercorrelations for all the items and dimensions. We employed Pearson correlation coefficients for examining the correlations between each dimension of the Problem Solving in Medicine questionnaire and each dimension of the Online Health Information Utilization questionnaire. Furthermore, we conducted structure equation modeling for examining the possible linkage between each of the 6 dimensions of the Problem Solving in Medicine questionnaire and each of the 3 dimensions of the Online Health Information Utilization questionnaire.

Results: A total of 457 patients participated in this study. Pearson correlation coefficients ranged from .12 to .41, all with statistical significance, implying that each dimension of the Problem Solving in Medicine questionnaire was significantly associated with each dimension of the Online Health Information Utilization questionnaire. Patients with the strategy of online health information search for solving medical problems positively predicted changes in medical decision making (P=.01), consulting with others (P<.001), and promoting self-efficacy on deliberating the online health information (P<.001) based on the online health information they obtained.

Conclusions: Present health care professionals have a responsibility to acknowledge that patients' medical decision making may be changed based on additional online health information. Health care professionals should assist patients' medical decision making by initiating as much dialogue with patients as possible, providing credible and convincing health information to patients, and guiding patients where to look for accurate, comprehensive, and understandable online health information. By doing so, patients will avoid becoming overwhelmed with extraneous and often conflicting health information. Educational interventions to promote health information seekers' ability to identify, locate, obtain, read, understand, evaluate, and effectively use online health information are highly encouraged.

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KEYWORDS

internet; help-seeking behavior; literacy; decision making

Introduction

Just several decades ago, people relied solely on traditional media to obtain health information, for example, reading newspaper and magazines, listening to radio, watching television, and seeking physicians' advices. With the rapid advance of modern media technology, access to the internet has been dramatically growing. The increasing utilization of the internet has provided a better opportunity for people to search for health information online, which was not easily available to them in the past, regardless of its credibility, accuracy, and reliability.

According to a report published by the Taiwan Network Information Center in 2016, 18.81 million (89.39%) of people aged 12 years and older in Taiwan used the internet [1]. In addition, 14.48 (76.98%) and 15.41 (81.92%) million of them were mobile internet users and wireless internet users, respectively [2]. Not only Taiwan has its own search engines [3] in its written language—Traditional Chinese—but several popular global search engines, for example, Yahoo [4] and Google [5], also have a Traditional Chinese version [6,7]. People in Taiwan are free to use the internet without any censorship and control from Taiwan's Government. Among those internet users, a certain number of them search online for health information. In the United States, based on a report published by the Pew Research Center, 87% of the total population used the internet, and the offline population has gradually declined from 48% of the total population in 2000 to 13% of the total population in 2016 [8]. According to a telephone survey conducted in 2010 by the Pew internet Project and California Health Care Foundation, approximately 80% of internet users in the United States searched online for health information. Among those internet users, 66% searched for health information about a disease or a medical problem, 56% searched for a medical treatment or a procedure, and 44% searched for information related to health care professionals [9]. Along with the advance of internet technology, searching online for health information is becoming more and more popular among patients and the general population.

Nevertheless, the credibility, accuracy, and reliability of health information on the internet are of great concern. Taking extracorporeal membrane oxygenation, a life-supporting treatment, as an example, a group of researchers reported that health information found on the internet, as indicated by the survival rate of extracorporeal membrane oxygenation users, was distorted as compared with that reported in the literature, and was much more distorted than health information found in the traditional media, for example, the newspaper [10]. This distorted online health information may potentially influence health information seekers' attitude toward a disease, a medical treatment, or a procedure.

Whether health information reported on the internet is associated with the change of health-seeking behaviors has also been studied. Hsieh et al conducted a questionnaire study based on a random sample collected in Taiwan to examine the association between an individual's internet usage and her ambulatory care utilization. They found that an individual with more frequent use of the internet was more likely to utilize more medical care as indicated by ambulatory care visits [11]. Furthermore, significant social events, particularly highlighted on the internet and traditional media, were very likely to encourage the use of life-supporting treatments [12]. Those studies implied that searching on the internet for health information may potentially influence an individual's decision making to change her health-seeking behaviors.

Although distorted health information on the internet and its association with health-seeking behaviors have been studied, whether health information obtained online influences the medical decision making of the health information seekers is, to the best of our knowledge, under-researched. The objectives of this study were: (1) to develop and validate 2 questionnaires to estimate the strategies of problem solving in medicine and the online health information utilization; (2) to determine the association between searching online for health information and online health information utilization, and (3) to determine the association between online medical help-seeking and online health information utilization.

Methods

Settings and Participants

Participants of this study were recruited purposefully by inquiring with people in the waiting area of the outpatient clinic in a university-affiliated community teaching hospital located at Northern Taiwan from September 7, 2015, to December 31, 2015. The university-affiliated community teaching hospital has 31 acute care beds, with a total of approximately 1000 outpatient clinic visits per day on average. After the patients agreed to participate in this study, the paper-and-pencil format of the Problem Solving in Medicine (PSM) and Online Health Information Utilization (OHIU) questionnaires were handed to them, and then collected after they completed.

Hypotheses

On the basis of the objectives, this study was set out to test the following 5 hypotheses:

- Hypothesis 1: Patients who prefer to search online health information for solving medical problems are more likely to change medical decisions based on the obtained information.
- Hypothesis 2: Patients who prefer to search online health information for solving medical problems are more likely to consult other people for further discussions based on the obtained information.

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- Hypothesis 3: Patients who prefer to search online health information for solving medical problems are more likely to have high self-efficacy on deliberating the online health information.
- Hypothesis 4: Patients with the strategy of online formal medical help-seeking for solving medical problems predict how they handle online health information.
- Hypothesis 5: Patients with the strategy of online informal medical help-seeking for solving medical problems predict how they handle online health information.

Instruments

To assess the association between patients' strategies of problem solving in medicine and their online medical information utilization, 2 questionnaires were implemented in this study.

The PSM questionnaire was developed based on the online academic help-seeking questionnaire [13]. It consists of 3 dimensions—information searching, formal query, and informal query—which attempt to examine students' online academic help-seeking when they access academic information on the internet. The three-dimensional structure was utilized for the development of the PSM questionnaire and was specially designed for solving medical problems in this study.

To construct a valid and reliable questionnaire, more dimensions were added, including items designed specifically for the participants. In total, 2 faculty members specializing in education and 1 senior attending physician working in a university-affiliated community hospital validated the items for 2 rounds. In the first round, the 3 dimensions in paper-and-pencil format were reviewed, and the "nononline version" framework for each dimension was suggested. In the second round, some revisions for the wording of the questionnaire items were suggested during a group discussion.

A total of 27 items were included in the PSM questionnaire, and these items belonged to the following 6 dimensions: nononline health information search (NHIS), online health information search (OHIS); nononline formal medical help-seeking (NFMH), online formal medical help-seeking (OFMH), nononline informal medical help-seeking (NIMH), and online informal medical help-seeking (OIMH). Each dimension of the questionnaire contained a total of 4 to 5 items. The PSM questionnaire used a Likert scale ranging from 1 to 5, indicating a participant's agreement with each item from *strongly disagree* to *strongly agree*, respectively. The details of the 6 dimensions are as follows (see Multimedia Appendix 1):

1. NHIS: assessing the extent to which participants seek related nononline health information to solve their medical problems (eg, searching medical textbooks, magazines, or newspapers).
   Sample item: "When I have a medical problem, I will search for relevant knowledge from professional medical books."
2. OHIS: assessing the extent to which participants seek related online health information to solve their medical problems (eg, searching the internet via search engines).
   Sample item: "When I have a medical problem, I will search for solutions using internet search engines (eg, Google, Yahoo)."
3. NFMH: assessing the extent to which participants query medical experts about solving medical issues (eg, consulting the physician in the hospital directly). Sample item: "When I don't know how to solve a medical problem, I will call a doctor, a medical expert, or other health care professionals for help."
4. OFMH: assessing the extent to which participants query medical experts through the internet about solving medical issues (eg, consulting the physician by email or through the Web). Sample item: "When I can't solve a medical problem, I will email a doctor, a medical expert, or a health care professional to seek medical helps."
5. NIMH: assessing the extent to which participants seek medical helps from their family members or experienced people (eg, querying family members about previous medical problem-solving experiences). Sample item: "When I have a medical problem, I will seek helps from a drugstore."
6. OIMH: assessing the extent to which participants seek medical helps from unknown experts on the internet (eg, posting medical help requests on Web forums). Sample item: "When I have a medical problem, I will post a message on relevant Web forums requesting help from other forum users."

The second questionnaire, the OHIU questionnaire, was specifically developed for the participants in this study. The dimensions and items of the OHIU questionnaire were developed based on face-to-face interviews with 16 patients (8 males and 8 females, with an average age of 45 years), who were recruited at a university-affiliated community hospital. The researchers invited the patients who claimed they had experiences of and showed interest in searching online for health information to participate in a face-to-face interview. A semistructured interview about his/her OHIU was conducted based on the following interview questions: (1) why did you search for online health information? (2) what was your attitude toward the online health information you obtained? and (3) what did you do after searching for the online health information?

The 2 faculty members and the senior attending physician who helped validate the PSM questionnaire also validated the dimensions and items of the OHIU questionnaire. The OHIU finally included 3 dimensions: "changing decisions" (CD), "consulting others" (CO), and "promoting self-efficacy" (PS). Each dimension has a total of 4 items. The OHIU questionnaire used a Likert scale ranging from 1 to 5, indicating a participant's agreement to each item from *strongly disagree* to *strongly agree*, respectively. The details of the 3 dimensions are as follows (Multimedia Appendix 2):

1. CD: assessing the extent to which participants change medical decisions based on the online health information they obtained. Sample item: "After searching for online health information, I will change my views to align with the information I obtained."
2. CO: assessing the extent to which participants consult other people based on the online health information they obtained.

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Sample item: "Online health information is an important reference for me when making medical decisions."

3. PS: assessing the extent to which participants promote self-efficacy in deliberating the online health information based on the online health information they obtained. Sample item: "I am confident that I can evaluate the accuracy of online health information for making medical decisions."

Data Analysis

We conducted confirmatory factor analysis (CFA) to test the hypotheses about the structure of the factor loadings and intercorrelations for all the items and dimensions of the PSM and OHIU questionnaires. To ensure the convergent validity of this proposed measurement model, 3 rules were followed: (1) all of the items in the CFA standardized factor loadings should be higher than .60; (2) the values of the composite reliability should exceed .80; and (3) the average variance extracted should exceed .50 [14-17]. The items that did not fulfill the 3 rules were excluded from further analysis.

For examining the correlations between each dimension of the PSM questionnaire and each dimension of the OHIU questionnaire, we employed Pearson correlation coefficients.

Furthermore, we conducted structure equation modeling for examining the possible linkage between each of the 6 dimensions of the PSM questionnaire and each of the 3 dimensions of the OHIU questionnaire. We examined model fit using squared multiple correlation (R^2).

All the statistical analyses were conducted using IBM SPSS AMOS 20. A *P* value of less than .05 was regarded as statistically significant. This study was approved by the Hospital Committee. All procedures performed in studies involving human participants were in accordance with the ethical standards of conducting a questionnaire study. Informed consent was obtained from all individual participants included in the study.

Results

Participants

A total of 457 patients (258 females and 199 males) participated in this study. The age of the participating patients ranged from 14 to 79 years, with a mean of 44.77 (SD 11.87) years. Of the 457 participants, 1.1% (5/457) had an educational level of elementary school or lower, 3.5% (16/457) had a level of junior high school, 20.4% (93/457) had a level of senior high school, 60.4% (276/457) had college or university degrees, and 14% (64/457) had graduate degrees or above. Moreover, 76.2% (348/457) of the patients indicated that their weekly time for internet usage was approximately 10 hours. Most of the patients (99.1%, 453/457) reported that they searched online for health information from *occasionally* to *always*.

Structure of Measurement

It has been suggested that the measurement model for each dimension in the structural model is estimated first in the process of examining the structural model, and then the final whole structural model is tested [18]. Regarding examining the measurement model, a single CFA with all the dimensions and its items of the PSM and OHIU questionnaires included in one model was conducted to clarify the model structure, validity, and reliability of both questionnaires. Multimedia Appendix 3 shows the CFA results.

A total of 31 items, 21 for the PSM questionnaire and 10 for the OHIU questionnaire, were kept in the final measurement model. All of the standardized factor loadings for this measurement model were close to or above .60 (between .56 and .96) and statistically significant (*t* statistics ranged from 11.33 to 22.90), supporting the sufficient factors in this model. All of the composite reliability coefficients exceeded .80 (between .81 and .91). All of the average variance extracted values exceeded .50 (between .55 and .77). Cronbach alpha values ranged from .79 to .90. The above validity values showed an adequate representation of convergent and construct validity for this proposed model. With respect to the goodness-of-fit indices of this model for the 2 questionnaires, the following data were obtained: Chi-square=1280.3, degree of freedom=398, the ratio of Chi-square to degrees of freedom=3.22, the standardized root mean square residual=0.065, the root mean square error of approximation=0.070, the goodness-of-fit index=0.84, the adjusted goodness-of-fit index=0.80, the incremental fit index=0.90, and the comparative fit index=0.90. The results of the analysis showed perfect or acceptable fitness values that supported the acceptable model fit for both questionnaires in this model.

The Relationships Between the Problem Solving in Medicine and Online Health Information Utilization Questionnaires

We conducted Pearson correlation coefficients to examine the relationships between the 6 dimensions of the PSM questionnaire and the 3 dimensions of the OHIU questionnaire (Table 1; Multimedia Appendix 4). We found that the linear relationships between each of the 6 dimensions in the PSM questionnaire and each of the 3 dimensions in the OHIU questionnaire, although they only ranged from weak (r=.12) to moderate (r=.41), were significantly different from 0—no linear relationship (P<.05). The results implied that each dimension of the PSM questionnaire was significantly associated with each dimension of the OHIU questionnaire. That is, all of the proposed hypotheses were positively supported based on Pearson correlation coefficients.

Test of the Structural Model

Based on the correlation results, a structural equation model was further conducted to analyze the structural path relationships among patients' strategies of problem solving in medicine and online health information utilization. Figure 1 shows the structural relationships by means of path coefficients among the dimensions of the 2 questionnaires. The standardized and statistical significant path coefficients were indicated by *P* values. In addition, the path with no statistical significance in this model is omitted. The results indicated that the test of the structural model showed a good or acceptable model fit (Chi-square=1380.05, degree of freedom=399, the ratio of Chi-square to degrees of freedom=3.46, the standardized root mean square residual=0.077, the root mean square error of

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approximation=0.073, the goodness-of-fit index=0.83, the adjusted goodness-of-fit index=0.79, the incremental fit index=0.88, and the comparative fit index=0.88). These indices revealed that this structural model sufficiently explained the collected data.

Table 1. The correlations among the dimensions of the Problem Solving in Medicine and Online Health Information Utilization questionnaires (Pearson correlation coefficient and *P* value).

Problem Solving in Medicine questionnaire	Online Health Information Utilization questionnaire					
	NHIS[a]	OHIS[b]	NFMH[c]	OFMH[d]	NIMH[e]	OIMH[f]
Changing decisions	.20 (*P*<.001)	.40 (*P*<.001)	.18 (*P*<.001)	.23 (*P*<.001)	.23 (*P*<.001)	.25 (*P*<.001)
Consulting others	.18 (*P*<.001)	.41 (*P*<.001)	.33 (*P*<.001)	.25 (*P*<.001)	.14 (*P*=.004)	.24 (*P*<.001)
Promoting self-efficacy	.25 (*P*<.001)	.41 (*P*<.001)	.24 (*P*<.001)	.28 (*P*<.001)	.12 (*P*=.008)	.25 (*P*<.001)

[a]NHIS: nononline health information search.

[b]OHIS: online health information search.

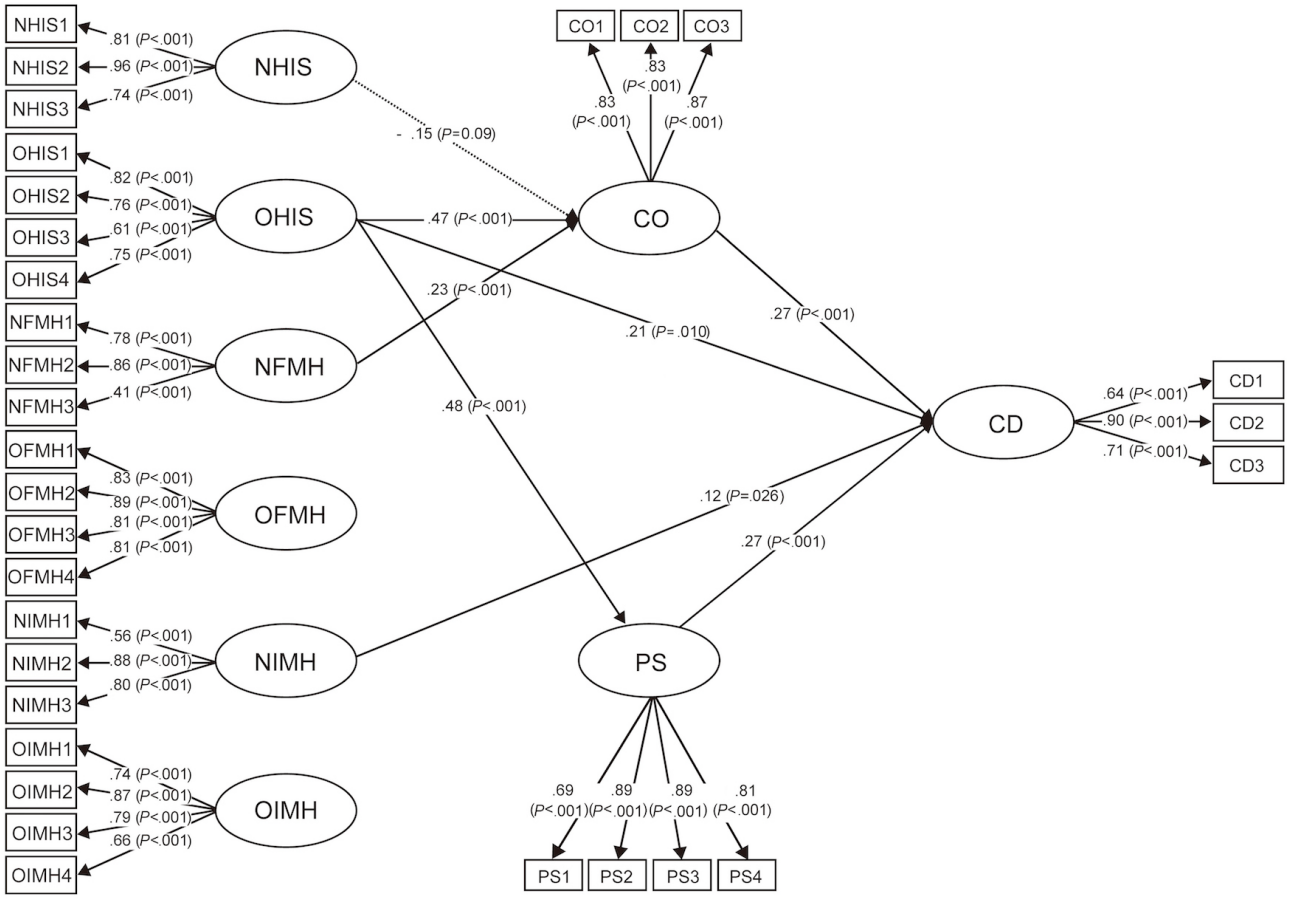
[c]NFMH: nononline formal medical help-seeking.

[d]OFMH: online formal medical help-seeking.

[e]NIMH: nononline informal medical help-seeking.

[f]OIMH: online informal medical help-seeking.

Figure 1. The structural equation model of the relationships between patients' responses to Problem Solving in Medicine and Online Health Information Utilization questionnaires. CD: changing decisions; CO: consulting others; NFMH: nononline formal medical help-seeking; NHIS: nononline health information search; NIMH: nononline informal medical help-seeking; OFMH: online formal medical help-seeking; OHIS: online health information search; OIMH: online informal medical help-seeking; PS: promoting self-efficacy.



As shown in Figure 1, patients with the strategy of OHIS for solving medical problems positively predicted CD (Hypothesis 1; path coefficient=.21; *P*=.01), CO (Hypothesis 2; path coefficient=.47; *P*<.001), and PS on deliberating the online health information (Hypothesis 3; path coefficient=.48; *P*<.001) based on the online health information they had obtained. In comparison, patients' strategy of OFMH when encountering medical problems was not significantly associated with any dimensions of their OHIU (Hypothesis 4), and OIMH was not

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significantly associated with any dimensions of their OHIU (Hypothesis 5).

The squared multiple correlations (R^2) of the 3 dependent variables (CD, CO, and PS) ranged from .29 to .38 (CD: .38; CO: .31; PS: .29), implying that each of the dependent variables was explained by its predictors at a range from 29% (PS) to 31% (CO). In addition, all of the independent variables in this study (6 dimensions in the problem solving in medicine questionnaire; PS and CO in the online health information utilizationquestionnaire) explained 38% of the total variance in participants' change of medical decision making (CD).

Discussion

Principal Findings

Our study found that patients' strategies of problem solving in medicine were associated with their online health information utilization. In particular, patients who engaged in online health information search for solving medical problems were significantly and positively associated with changing their medical decisions. Therefore, the more online health information patients searched for solving their medical problems, the more likely their medical decision was changed based on the online health information they had gathered.

Patients using the strategy of nononline formal medical help-seeking when encountering medical problems were significantly associated with consultation with others about the online health information they obtained. Furthermore, those using the strategy of nononline informal medical help-seeking were significantly associated with changing medical decisions based on the online health information. In comparison, patients with the strategy of nononline health information searches, for example, searching medical textbooks, medical magazines, and newspapers/TV news, were significantly and negatively associated with consulting others based on the online health information they had gathered.

Online Health Information and Decision Making

As Lagan and colleagues reported based on a -based study, 83% of the pregnant women changed their decisions based on the online health information they had searched for and obtained [19]. Bert and colleagues also found that pregnant women were more likely to change their lifestyles if the searched online health information included the lifestyle topics of nutrition, physical activities, and alcohol consumption during pregnancy [20]. Our study results showing the association between online health information searches and medical decision changes were echoed by several other studies conducted using different study designs.

On the basis of the Porter Novelli Health Styles database, Dutta-Bergman examined online health information seekers' health attitude, health cognitions, and health behaviors. Dutta-Bergman reported that individuals searching for health information on the internet were more likely to have better health information orientation, health-oriented beliefs, and healthy activities than those who did not [21]. Certainly, such individuals undoubtedly may easily change their decisions if they consider that their current health-related conditions are not consistent with the information they have obtained from the internet.

Our study results also highlighted that the credibility of online health information plays a very important role in medical decision making. Although most health information seekers are usually skeptical of trusting health information reported on the internet, they may not pay attention to how they select the online health information. For example, a qualitative study concluded that, although online health information seekers recognized the online health information from governments, organizations, and educational institutions as credible, they usually selected the health information from the first page of the search results by looking for keywords or short descriptions using search engines such as Google and Yahoo [22]. However, the adjusted odds that a patient changed her decision after searching for the online health information from health care institutions increased by 79% as compared with the adjusted odds after searching for the online health information not from health care institutions [20]. These results imply that both the online health information providers and the online health information seekers certainly play a major role in evidence-based medical decision making.

Online health information providers may benefit evidence-based medical decision making by providing online health information seekers with valid, accurate, and credible health information. However, health information reported in the media is commonly distorted [23,24], and the distortion of health information on the internet is still commonplace [10,12]. Given that online health information seekers recognize online health information from governments, organizations, and educational institutions as more credible than that from other websites [22], it is suggested that governments, professional organizations, educational institutions, and any other recognized online health information providers take responsibility for providing valid, accurate, and credible online health information.

On the other hand, online health information seekers not only receive the health information on the internet but also synthesize, disseminate, and exchange that information [25]. Therefore, online health information seekers' ability to identify, locate, obtain, read, understand, evaluate, and effectively use online health information (health literacy, information literacy, and media literacy) is of great importance to make evidence-based medical decisions. Any educational interventions that may promote online health information seekers' ability to receive, synthesize, disseminate, and exchange online health information are highly encouraged.

Although searching online for health information predicted change of medical decision making in this study, only 38% of the total variance for the dependent variable, CD, was accounted for in this model, leaving 62% unexplained. Other potential variables to explain the variance of change of medical decision making can be further investigated in the future studies.

Online Health Information Management

In addition to changing medical decisions, online health information seekers, when solving medical problems, may also use online health information to supplement their consultations

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with others, for example, physicians, family members, and experts. One reason that a large proportion (94%) of pregnant women searched online for health information was to verify the health information already given by health care professionals [19]. Similar findings concluding that patients use online health information to validate health information gathered from health care professionals were also reported by a qualitative study based on 13 asynchronous online focus groups from 5 countries [26]. Our study showed that patients with the strategy of searching online for health information when solving medical problems tended to validate the online health information by consulting with others. Accordingly, the validation of information is bidirectional by either validating health information from health care professionals by searching the internet or validating health information on the internet by consulting with other people.

We also reported that patients using the strategy of online health information search in the face of medical problems were associated with having high self-efficacy on: (1) searching for valid, accurate, and credible health information; (2) using the health information; and (3) making correct judgments. Our study result was similar to that reported by Bert and colleagues, pointing out that pregnant women had more confidence in health information after they had verified the information through internet searches [20], and also supported by Pang and colleagues' report, suggesting that people will look for different sources to validate and evaluate health information [27].

Nononline Medical Help-Seeking

Patients with the strategy of nononline formal medical help-seeking when encountering medical problems tended to consider online health information as a supplement to their further consultation with others. Studies have shown that the patients with greater intention to seek medical help from professional resources, for example, physicians, are more likely to have higher levels of health literacy [28], and patients seeking online formal medical help are more likely to have higher levels of eHealth literacy [29]. Suka and colleagues also reported that health literacy was positively associated with help-seeking intentions, and a majority of the study participants chose to seek help at any time from formal resources [30]. Given that our study patients, preferring to seek help from formal sources, might have better health literacy, consulting with others for further verifying the online health information should be expected.

In comparison, those with the strategy of nononline informal medical help-seeking—for example, seeking help from pharmacist, family members, and friends with experiences, and by praying to god for advice—were more likely to change their medical decisions based on the online health information they obtained. Kleinman and colleagues proposed that family members, friends, other community leaders, and folk healers have played and still play an important role on how people perceive and solve medical problems [31]. Griffiths and colleagues reported that informal help from friends and family members has advantages, such as social, emotional, informational, and companionship support, as well as disadvantages, namely, stigma and inappropriate support due to friends' or family members' lack of related knowledge [32]. Changing medical decisions following the suggestions given by those with insufficient knowledge can be unhelpful or even toxic. Therefore, providing educational interventions for promoting nononline informal medical help-seekers' ability to obtain, read, understand, evaluate, and use health information is highly suggested.

Nononline Health Information Search

This study also found that nononline health information search, for example, searching medical textbooks, medical magazines, and newspapers/TV news, was significantly and negatively associated with consulting with others based on the online health information. With the increasing and prevalent use of the internet as a tool for medical help-seeking, those who still prefer to seek medical help through nononline ways may have negative attitude toward trusting online health information, and thus are less likely to consult with others based on the online health information they have already recognized as doubtful. The negative attitude toward online health information is reflected on the statistically insignificant associations between the strategy of nononline health information search and changing medical decisions and between the strategy of nononline health information search and having high self-efficacy on searching for valid and credible health information, using the health information, and making correct judgments.

Although NHIS was positively associated with CO (r=.18, P<.001) in Pearson correlation coefficients, NHIS became a negative predictor in the structural equation model. This negative suppression effect may occur when both the independent variables positively and highly correlate to each other, with a positive zero-order correlation to the dependent variable [33,34]. A previous study suggested to delete one of the two independent variables or to combine the two independent variables into a single variable [35].

In this study, we found that NHIS and OHIS were positively and highly associated with each other (r=.47, P<.001). However, we did not delete either NHIS or OHIS, nor did we combine the two independent variables into a single variable because the two independent variables were of great importance and also the focuses in this study. As a result, the negative suppression effect occurred, and NHIS became a negative predictor of CO.

Strengths and Limitations

Few studies have been conducted for examining the associations between the strategies of problems solving in medicine and online health information utilization, with a particular focus on the association between online health information search and changing medical decisions. Moreover, the large number of patients recruited for this study strengthens the extrapolation of the study results. Nevertheless, some limitations are inevitable in this study.

The first limitation is attributable to the sampling method used in this study. The participants were purposefully recruited in the outpatient clinics of a university-affiliated community hospital located at Northern Taiwan. The generalizability of the results of a study conducted by purposeful sampling in a single center rather than different settings might be of concern. In

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addition, participants were recruited from the waiting area of the outpatient clinics. They might be more likely to select nononline formal medical health-seeking as their strategies and their health condition might be worse than that of the general population. Both of these issues might further limit the generalizability of the study results.

Considerable factors, such as age, gender, and educational level, surround medical decision making. However, some of those factors surrounding medical decision making were not controlled in this study. For example, severity of illness may influence a patient's medical decision making, but it was not collected and controlled in this study.

This was an attitudinal study conducted using valid and reliable questionnaires to measure the relationships between the strategies of problems solving in medicine and online health information utilization. However, this was not a field study in which the influence of online health information search on changing medical decisions can be directly observed and measured. Whether an association identified in a questionnaire study reflects exactly the same association in a field study is not guaranteed.

As some of the participants were outpatient clinic patients, they might have chronic diseases and have relatively higher health literacy regarding their chronic problems. Their perceptions of the online health information may be different from new patients. However, we did not adjust for their chronic diseases status.

Conclusions

With the growing use of the internet and the dramatic proliferation of health information on the internet, the findings from this study suggest that the influence that online health information has on online health information seekers' medical decision making is visible. Therefore, the credibility of online health information plays a very important role on medical decision making. Present health care professionals have a responsibility to acknowledge that, regardless of the credibility of online health information, patients' medical decision making may be changed following the health information reported on the internet. Health care professionals should assist patients' medical decision making by initiating as much dialogue with patients as possible, providing credible and convincing health information to patients, and guiding patients where to look for accurate, comprehensive, and understandable online health information. By doing so, patients will avoid becoming overwhelmed with extraneous and often conflicting health information. Educational interventions to promote health information seekers' ability to identify, locate, obtain, read, understand, evaluate, and effectively use online health information are highly encouraged.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

The Problem Solving in Medicine questionnaire.

[PDF File (Adobe PDF File), 33KB - jmir_v20i2e47_app1.pdf]

Multimedia Appendix 2

The Online Health Information Utilization questionnaire.

[PDF File (Adobe PDF File), 27KB - jmir_v20i2e47_app2.pdf]

Multimedia Appendix 3

The confirmatory factor analysis for the Problem Solving in Medicine and Online Health Information Utilization questionnaires (N=457).

[PDF File (Adobe PDF File), 50KB - jmir_v20i2e47_app3.pdf]

Multimedia Appendix 4

The scatter plot of each of the 6 dimensions in the Problem Solving in Medicine questionnaire and each of the 3 dimensions in the Online Health Information Utilization questionnaire.

[PDF File (Adobe PDF File), 191KB - jmir_v20i2e47_app4.pdf]

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Abbreviations

CD: changing decisions
CFA: confirmatory factor analysis
CO: consulting others
NFMH: nononline formal medical help-seeking
NHIS: nononline health information search
NIMH: nononline informal medical help-seeking
OFMH: online formal medical help-seeking
OHIS: online health information search
OHIU: Online Health Information Utilization questionnaire
OIMH: online informal medical help-seeking
PS: promoting self-efficacy
PSM: Problem Solving in Medicine questionnaire

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Original Paper

Type 2 Diabetes Education and Support in a Virtual Environment: A Secondary Analysis of Synchronously Exchanged Social Interaction and Support

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Abstract

Background: Virtual environments (VEs) facilitate interaction and support among individuals with chronic illness, yet the characteristics of these VE interactions remain unknown.

Objective: The objective of this study was to describe social interaction and support among individuals with type 2 diabetes (T2D) who interacted in a VE.

Methods: Data included VE-mediated synchronous conversations and text-chat and asynchronous emails and discussion board posts from a study that facilitated interaction among individuals with T2D and diabetes educators (N=24) in 2 types of sessions: education and support.

Results: VE interactions consisted of communication techniques (how individuals interact in the VE), expressions of self-management (T2D-related topics), depth (personalization of topics), and breadth (number of topics discussed). Individuals exchanged support more often in the education (723/1170, 61.79%) than in the support (406/1170, 34.70%) sessions or outside session time (41/1170, 3.50%). Of all support exchanges, 535/1170 (45.73%) were informational, 377/1170 (32.22%) were emotional, 217/1170 (18.55%) were appraisal, and 41/1170 (3.50%) were instrumental. When comparing session types, education sessions predominately provided informational support (357/723, 49.4%), and the support sessions predominately provided emotional (159/406, 39.2%) and informational (159/406, 39.2%) support.

Conclusions: VE-mediated interactions resemble those in face-to-face environments, as individuals in VEs engage in bidirectional exchanges with others to obtain self-management education and support. Similar to face-to-face environments, individuals in the VE revealed personal information, sought information, and exchanged support during the moderated education sessions and unstructured support sessions. With this versatility, VEs are able to contribute substantially to support for those with diabetes and, very likely, other chronic diseases.

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KEYWORDS

type 2 diabetes; social interaction; self-management; virtual reality; social support

Introduction

Virtual environments (VEs) are one way to provide education and support to individuals with chronic illness. These 3D computer-generated replications of real-world settings foster interaction among individuals who interact as avatars (eg, computer-generated representations of humans) [1,2]. A VE imitates real-world interactions because an individual experiences *presence* (eg, feeling one is in the VE) and *copresence* (eg, feeling others are in the VE) [1,3]. These feelings of presence and copresence may accurately replicate real-world group interactions among individuals [4,5], because these interactions are bidirectional and serve to transmit knowledge and support [1,6].

Social Support and Type 2 Diabetes Self-Management

A community of like individuals fosters the continued exchange of information and support, which may help an individual with chronic illness to not feel alone while engaging in chronic illness self-management [7-12]. Individuals with type 2 diabetes (T2D) complete the majority of self-management outside of a health care setting [13] and struggle to adopt healthy behaviors [14-16]. The frequency and amount of T2D self-management behaviors may cause an individual to feel overwhelmed, which may lead to further feelings of frustration and general inattention to these self-management behaviors [17,18]. Notably, individuals with T2D benefit from frequent and sustained interactions with providers and peers (eg, others with T2D) because they obtain critical self-management education and support [19-21]. Yet, frequent interaction with providers and peers in face-to-face environments may not be feasible because of temporal, financial, and geographical limitations [18,22-24].

Synchronous Virtual Environments Facilitate Social Interaction and Support

One way to provide personalized, frequent interaction and support is via T2D-specific VEs that assist individuals in health care decision making [10-12,25]. Research indicates that these VEs facilitated the interaction among providers and peers and replicated locations that an individual with T2D would typically encounter while engaging in self-management [10-12,25]. However, these studies provided little information on how these VE-mediated interactions among peers and providers compared with face-to-face interactions. Therefore, an understanding of *how individuals interact* in a disease-specific VE and *what these individuals discuss* can improve how researchers design consumer health informatics interventions aimed at improving self-management. Additionally, an examination of *how the VE mediates the interaction* is needed to understand the extent to which VEs, and similar types of consumer health informatics media, can supplement traditional face-to-face encounters with providers and peers who support chronic illness self-management. Thus, the purpose of this study was to describe social interaction and support among individuals with T2D who interacted via a VE to obtain T2D-specific education and support.

Methods

We briefly describe the research approach below; a detailed protocol has been described elsewhere [26]. The Duke University Institutional Review Board (Pro00022132) approved this secondary analysis. We did not collect any new data or recontact the participants.

Guiding Framework

A guiding framework based upon social penetration theory [27] and strong/weak tie theory [28,29] guided the description of social interaction and support in a T2D-specific VE. The guiding framework (Figure 1) [26] includes the concepts *social interaction*, *social support*, *self-management*, and *health outcomes*; this paper addresses the concepts of interaction and support.

Parent Study and Sample

Data for this secondary analysis came from the Second Life Impacts Diabetes Education & Self-Management (SLIDES) (1R21-LM010727-01) study. Information on the SLIDES study site, sample, measures, and outcomes is published elsewhere [12,30]. The SLIDES study provided 2 weekly T2D education sessions and 1 weekly support session via a VE hosted on Second Life for adults with T2D [12,30]. The total sample for this analysis (N=24) included study participants (n=20) and investigators and diabetes educators (n=4). The study participant demographics were as follows: women (19/20, 95%), male (1/20, 5%); mean age of 54 years; white (13/20, 65%) , black (7/20, 35%); married (11/20, 55%); with an annual income of US $50,000 or greater (14/20, 70%); with a bachelor's degree or higher (13/20, 65%); and all of them were regular users of the Internet [12,30]. The SLIDES site was password protected, and participants chose anonymous screen names.

Qualitative Data

Qualitative data included transcribed real-time conversations, emails, discussion board postings, and text-chat transcripts among participants and between participants and diabetes educators within the VE over each participant's 6-month study enrollment. Most data included synchronous conversations that occurred when participants and diabetes educators interacted and talked with each other as avatars while in the VE. Figure 2 depicts a synchronous support session in the restaurant, and Figure 3 depicts a synchronous education session in the community center. Participants did not use the text-chat or discussion boards frequently to engage with other participants or the diabetes educators. We imported transcribed conversations into Atlas.ti version 7.5.17 (Atlas.ti GmBH, Berlin, Germany) for analysis.

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Figure 1. Guiding framework for this secondary analysis. T2D: type 2 diabetes; BMI: body mass index; HbA_{1c}: glycated hemoglobin. This figure was originally published in Lewinski AA et al [26].

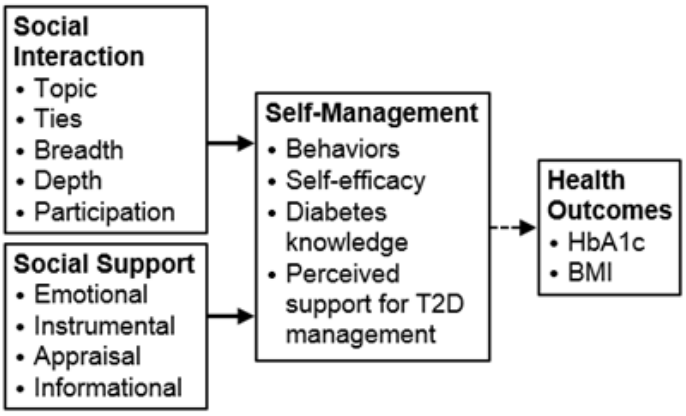


Figure 2. Synchronous support session in the restaurant in the virtual environment. The avatars of the individuals living with type 2 diabetes and the diabetes educator are sitting at the restaurant table and discussing healthy food options.



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Figure 3. Synchronous education session in the community center in the virtual environment. The diabetes educator's avatar is standing and leading the class, the avatars of the individuals living with type 2 diabetes are sitting in the chairs, and the session PowerPoint slides are visible on the large screens on the right and left.



Analysis

We used content analysis to describe social interaction and support among participants who engaged in a T2D-specific VE [31,32]. We modified the first- and second-level coding procedures as previously explained [26] to describe *how individuals interacted* (eg, verbal techniques), *what was said* (eg, topic), and *how the VE mediated this interaction* [33].

A coding team comprising 3 authors (AAL, RAA, and CMJ) developed codes based on the guiding framework. The coding team met biweekly and discussed and reviewed all codes and emerging themes until they reached a consensus. In these meetings, the coding team ensured that all codes were richly defined, the codebook included appropriate exemplar quotations, and the codes were consistently applied to these data [33-35]. Interrater reliability may invalidate research with unstructured qualitative data [35]; therefore, the coding team coded these conversational data by consensus to ensure reliability and validity of the codes and coded segments [33-35]. The first author (AAL) independently coded a segment of data, and then the second (RAA) and last (CMJ) authors independently reviewed the first author's coding. When the coding team disagreed, the original coding would remain if the rationale for the coding was clearly articulated and included an audit trail, even if the other coders had additional interpretations. The coding team revised coding only when the secondary coders deemed the rationale for the coding as not credible. In those cases, the coding team worked to reach an agreement about the appropriate code and revised prior coding as appropriate using the new rationale. The coding team resolved disagreements through extensive discussion, which ensured the reliability and validity of the interpretation of these data [33-35]. This process was repeated for all first- and second-level codes. In total, the second and last authors each independently reviewed 25% of the first author's coding.

Results

In the following sections, we describe how participants interacted in the VE and the support participants exchanged in the VE, with examples of some of the essential features identified and listed in the tables. In the findings, unless otherwise specified, the term *participant* refers to both an individual with T2D and a diabetes educator.

Social Interaction: How Participants Interacted in the Virtual Environment

VE-mediated interactions consist of the following: (1) communication techniques (how participants interact in real-time communication in a VE); (2) expressions of self-management (the content of participants' self-management discussions); (3) depth of conversation (intensity of information shared); and (4) breadth of conversation (the number of topics discussed among participants in a conversation).

Characteristic #1: Communication Techniques

Participants used 4 types of communication techniques when they interacted and conversed with other participants. These include indicators of listening, being in the VE, attributes of bidirectional information exchange, and connecting actions. Table 1 details these types and provides a definition of the interaction behaviors (ie, participant actions during an interaction) and exemplar quotes or instances.

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Table 1. Communication techniques.

Interaction behaviors and definition	Exemplar quote or instance
Indicators of listening—verbal utterances that indicate that someone was present and listening	
Double-checking (clarification of a term, idea, or statement)	A participant stated how she felt at certain glycemic values. The diabetes educator (DE) clarified the values and her actions.
Following conversation (indication a person is listening to the conversation)	"Uh huh."
	"Mmmhmm."
Reflecting back (instances in which a person talking reflects back something someone else has stated)	When the DE heard some participants do not consume alcohol, she stated, "Ok, well that's good. I'm glad to hear that."
Repeating phrase (repeating a phrase when asked to repeat the phrase)	Participants repeated questions or comments to obtain information.
Responsiveness (instances of positive feedback during interactions)	During a lecture, the DE asked, "I heard a squeak. Somebody say something?"
Nonresponsiveness (dismissing a question or comment in an interaction)	Instances included when a participant's question or comment was not acknowledged.
Being busy (statements of how a participant is busy with life events)	"I had a real important meeting. I had to go to."
	A time mix-up occurred and prevented an activity.
Interrupting another (interrupting a conversation or talking over someone)	Instances when the speaker's sentence is cut off by another individual's verbal utterance.
Inappropriate comment (offensive words)	"Dorks."
	"Nerds."
Being in the virtual environment (VE)—indications that participants felt they were in the VE and they were not alone	
Feeling presence (the influence of the VE on interaction)	"Wait a minute. Where am I [avatar] taking off to?"
	"These [items in the grocery store]? Oh I'm pointing on my screen [with my hands], how handy is that?"
Feeling VE copresence (indications a participant is in the VE with others)	"I'm getting tired of standing behind this podium because I never do this in the real world anyway."
Practicing self-management skills (practicing self-management skills in the VE)	"Here we have a simple label. For this particular food, can anybody read what the serving size is?"
Stating location (statements of what is occurring in the VE)	"Everybody's outside right now. Come on outside. We're out near the [location]."
Attributes of bidirectional information exchange—statements used to exchange information	
Posing	
Seeking information (asking a question for more information)	Participants asked questions about self-management topics covered in the education and support sessions.
Responding	
Giving a reminder (reminding an individual about something)	"Remember we said one piece of bread equals one starch serving."
Giving information (giving content about type 2 diabetes (T2D) self-management)	When participants provided information on T2D self-management during sessions.
Answering a question (the act of responding)	"In reply to your question last week..."
	"Let me answer your question."
Correcting someone or oneself (correcting someone about T2D self-management)	"Nope. That's not right."
	"No, because fat is not a starch."
Adjacency pair (question-and-answer pair)	Instances in which there was a direct and immediate response.
Connecting actions—statements and actions taken by individuals when associating with others	
Personality attributes	
Being engaged (an interest or opinion about T2D self-management)	A participant asked, "Will the topic be the same for the other session if I end up going during the day?"

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Interaction behaviors and definition	Exemplar quote or instance
Being encouraging (encouragement for self-management behaviors)	"Wow! That's good."
	"Great job!"
Being enthusiastic (excitement)	"Oh good!" or "Great!"
Being friendly (wishing someone well or being nice to a person)	"I hope you are doing well."
	"Don't worry, you are doing fine."
Being incredulous (laughing or having an awkward response)	During a session, participants stated that they did not drink alcohol. The DE responded with "Really!"
Being polite (polite phrases)	"Thank you" or "Please."
Collaborating (working together to solve a problem)	"Let's look at this meal together and see if we can make it more diabetes friendly."
Commiserating (admitting that problems happen to everyone, and people are not alone)	In response to a participant trying to drink more water, a DE said, "Yeah. It definitely is an adjustment. It takes a lot to get used to it."
Expressing concern (concern about someone)	"You sound terrible tonight! How are you feeling?"
Expressing empathy (showing empathy for another participant)	"Oh, I'm sorry about that."
Expressing gratitude (expression of thanks for an effort during the session)	"Thank you for participating tonight."
Helpfulness (instances of helpful actions)	A participant repeated what someone said in response to a third participant stating "I couldn't hear her clearly."
Signs of copresence	
Calling by name[a] (addressing someone by their avatar name)	"Hi [name]."
	"Good question [name]."
Commenting on appearance (comments on avatar's appearance)	"Do you have another new outfit on?"
	"What a lovely shirt you have on."
Greeting (saying a variation of hello or good-bye)	"Hello" or "Good bye."
	"Hi! How are you?"
Introducing oneself (stating their name and role)	"My name is [name] and I have had diabetes for [years]."
Noticing others (noticing if another participant is present or absent)	"And [name] was talking, and she stopped with [name] when we started to walk over."
Moderating the conversation	
Checking-in (seeing if anyone has any questions)	"Before we go any further, do you have any questions from last week's session?"
Connecting outside the VE (interactions outside the VE)	"Call me in the office tomorrow."
	"Let's talk at your next appointment."
Facilitating interaction (connecting participants together)	"What are the most challenging issues for you in terms of diabetes nutrition?"
Referring to shared history (discussing a shared history or knowledge between themselves)	"How did everything go at the doctor this week?"
	"We talked about this in the first class that the reason why…"
Sticking to time schedule (stating that someone is on a time schedule)	"It's about 5 after, so I'll get started."
	"I don't want to keep you if you need to go."

[a]Name refers to screen name.

Indicators of Listening

Indicators of listening promoted or inhibited subsequent interactions among individuals because of how these behaviors influenced the exchange of information and support. For example, participants exhibited *responsiveness*, a behavior that promoted interaction, when they responded to questions or engaged with others. Conversely, there were instances of *nonresponsiveness*, a behavior that inhibited interaction. For example, the diabetes educator exhibited *nonresponsiveness* when they were speaking, and a participant interrupted with a question to which the educator did not respond. However, *nonresponsiveness* may have occurred due to inherent features of the VE, such as the lack of nonverbal cues (eg, one cannot

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visually see when another participant opens their mouth to speak) or problems with technological equipment (eg, broken headsets).

Being in the Virtual Environment

Participants indicated feelings of being in the VE when they used the embedded components (eg, grocery items) of the VE to interact with other participants as avatars. These embedded components (eg, restaurant menus) facilitated interaction because they stimulated conversation and extended the interaction among participants. During the interactions, the position of another participant's avatar during the exchange of information and support also mattered. For example, the behavior *stating location* promoted interaction because it enabled participants to colocate others in the VE. Participants used statements such as "She's standing right behind you" or "I'm standing right next to you" when they colocated each other in the VE. The position of a participant's avatar served as a proxy for their inclusion in the interaction, and in turn, the subsequent discussion offered participants the opportunity to share and obtain self-management information and support.

Attributes of Bidirectional Information Exchange

Participants used several interaction behaviors when they exchanged information. The behaviors *posing* (ie, asking a question) and *responding* captured the bidirectional nature of an interaction. Prompt responses promoted further interaction, because the participant who asked the question immediately received relevant information. In several instances, participant responses segued into new topics, introduced new T2D content, or summarized the topics reviewed in the session.

Connecting Actions

Participants used connecting actions in the VE that resembled interaction behaviors in face-to-face environments. The 3 types of *connecting actions* are as follows: (1) personality attributes—the participant's personal characteristics that became evident during interactions; (2) signs of copresence— techniques that alerted others to one's presence in the VE; and (3) moderating the conversation— actions of the diabetes educators during the sessions. Participants were helpful when they included others in the conversation, called each other by avatar name, or provided information about self-management. Importantly, the diabetes educators looked to see which participants signed into the VE at the beginning of each session and monitored the presence of participants during the session.

Characteristic #2: Expressions of Self-Management Behaviors

We identified 2 types of expressions of self-management behaviors in a social interaction: (1) challenging aspects of T2D and (2) self-managing in the real world. Each is described with examples of some of the essential behaviors that were identified in Table 2.

Challenging Aspects of T2D

Participants stated limitations and problems, mistakes, and psychosocial aspects, which increased the self-management effort required. However, when participants stated their limitations during the sessions, they also sought information on ways to ameliorate the problem (eg, trying water aerobics instead of weight-bearing exercises). Participants revealed a myriad of challenges in unprompted statements; these admissions of difficulty with self-management evolved from discussions during the sessions.

Self-Managing in the Real World

Participants discussed coping (eg, problem solving), their self-management intentions and objectives (eg, self-management choices), and the external influencers (eg, how others influenced their self-management) in sessions. During discussions, participants shared real-world practices as to how they identified successful self-management strategies. For example, one participant stated she felt overwhelmed with her T2D diagnosis and other comorbidities. In response, several other participants shared how they coped with feeling overwhelmed. Participants shared positive changes in their health status, explained how they met a self-management goal, or described a plan to meet a self-management objective during the sessions.

Characteristic #3: Depth

We operationalized the concept *depth* as the degree of personalized information shared in a social interaction in the VE. The levels of depth occur on a continuum, where level 1 indicated little to no personalization of information shared by the participant, and level 4 indicated that the participant shared highly personal information and acknowledged weaknesses related to T2D self-management [27,36,37]. Table 3 provides the definitions of each level of depth.

Participants revealed personal information when they asked topic-relevant questions during a session or when they gave information or support to another participant. Participants also revealed difficulties with certain self-management behaviors and referred to past instances to highlight mistakes and problem solving. The majority of the diabetes educators' personalized statements related to the topic being discussed by the participants, and these statements were used to stress a point or provide reassurance. Notably, when one participant shared personal information, another participant followed up with his or her own experiences providing support and information. Participants answered personal questions when they discussed their struggles with T2D self-management; participants did this to help others or obtain support for themselves.

Characteristic #4: Breadth

The conversations in these data concerned topics related to T2D self-management (eg, nutrition, foot care) and overall health. Most discussions aligned with the weekly focus of the education sessions. These findings indicated that there was no significant variance in subjects outside of T2D-related topics.

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Table 2. Description of expressions of self-management.

Interaction behaviors and definition	Exemplar quote or instance
Challenging aspects of living with type 2 diabetes (T2D)—statements of challenges in T2D self-management	
Stating limitations and problems	
Stating limitations (a stated financial, temporal, physical, or geographic limitation)	"I rarely go out to eat because it is just too much effort for me. It would be nice to leave my apartment, get out of the house, and drive to the drive-in. My daughter told me that Wendy's has salads. Just to get out of the house and not so home-bound all the time."
Lacking health knowledge (lack of T2D knowledge)	In the virtual environment (VE) grocery store, a participant stated: "Well, I looked at the regular yogurt versus the Greek yogurt 'cause I eat light yogurt, and I was surprised at how much sodium it had in it. It's not a lot as far as the number, but I thought it wouldn't have any sodium in it."
Stating problems (a problem related to self-management)	A participant's daughter buys the participant unhealthy foods or foods the participant does not like.
Admitting difficulty (difficulty applying concepts related to self-management)	"I'm having a hard time drinking my water."
	After receiving a compliment on her weight loss, a participant stated, "It's great though, very tough, but it can be done."
Mistakes	
Making self-management mistake (admitting to a mistake when doing self-management)	"When I first started, I was told to wash my hands. I was diagnosed in [date] and you get sloppy over the years. I had not washed my hands or anything like that. Then I had another [apple] as a snack so when it came supper you can imagine what was on my finger. I had this 379 for suppertime sugar [the individual's blood glucose reading on her glucometer prior to eating supper was 379 which was much higher for her than normal]."
Psychosocial aspects	
Frustration (expressing frustration about self-management)	"That was a new experience for me. That they [insurance company] can change the meter that you use. I didn't like that."
Feeling isolated (feelings of social isolation due to physical limitations or living with T2D)	"I'm the only one in my family with diabetes. Nobody has ever been around anyone with diabetes before in our family. My grandmother had it but she passed on and so they don't understand what I am going through and what they need to do to help me."
Self-managing in the real world—statements related to enacting T2D self-management	
Coping	
Satisficing (choosing a self-management option that is the best choice within the available options)	When discussing a T2D-friendly menu item, a participant stated she goes to fast-food places because she has limited mobility and they have drive-thrus. She described how she worked with her dietitian to identify healthy items at the fast-food restaurants.
Problem solving (a behavior one engages in to accommodate a physical, financial, temporal, or geographical barrier to engage in T2D self-management)	T2D and depression: "I laugh a lot. I don't have to tell you I laugh. I laugh a lot every day and it's really healing to you. It is. Makes you feel better."
	"I went to [restaurant], and my friend has an app that can tell you the ingredients. I was completely surprised at what I thought was a relatively good choice of this 1/2 salad and something else. [That experience] helped me realize I need to look ahead."
Self-management intentions and objectives	
Stating self-management behavior or making a self-management choice (a statement of how a person completes a T2D self-management behavior)	"I use a lot of herbs and spices, and I'm trying to cut back on using a lot of salt."
	"My husband brought me some sugar-free candy for [holiday] last year and I said why did you bring me sugar-free candy? He said because that is what you need! And I said okay, thank you. But I really don't eat candy. I'm gonna avoid candy tomorrow [holiday]. I don't want any candy."

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Interaction behaviors and definition	Exemplar quote or instance
Demonstrating knowledge (when a participant is knowledgeable about T2D self-management	When looking at items in the restaurant, a participant stated, "...it is the sodium that is not bad, but you are getting a whole meal plus of carbohydrates!"
	Saying, "A smaller serving size of the cereal" when modifying a meal in a session.
Self-efficacy for self-management (when a participant states he or she can do something related to T2D self-management)	"I've been real good [about preventing eye complications]. I'm going to get my surgery done and I am going to be okay. I am not going to give up."
	Dealing with an unhelpful family member, a participant stated, "I just tell him to get off my back. That I'm doing the best I can."
External influencers	
Referring to family or friends (mentioning friends and family while in the VE)	"Yeah, I was diagnosed with diabetes this year. This is new to me but I have a brother who had diabetes and he passed away in [date] from diabetes-related circumstances and situations. So this runs in the family. My mother had diabetes, and so it's in the family."
External social environment (social instances and T2D self-management)	"I was reading a magazine while waiting to get my tires rotated. They had a brown rice diet from [University]. I just want to know, what you [diabetes educator] thought about that."

Table 3. Description of depth. Definition based upon social penetration theory and related literature.

Attribute and definition	Exemplar quotes
Level 1: Making small talk (no personal health information revealed)	"I was out last week, out of town and I didn't have Internet access."
	"I had a new grandbaby arrive."
Level 2: Opening up (hinted at personal issues and shared observations about others)	"What if you have other limitations? Like if you are on a walker or something like that? Man, some of those exercises are not going to very well work for you."
Level 3: Informing (shared objective facts about type 2 diabetes)	"Okay, 'cause when I saw you a month ago, it was 6.2 [the participant's hemoglobin A_{1c} value], and I wondered what if I didn't have diabetes?"
Level 4: Disclosing (highest amount of personalization, revealed weaknesses)	"I had major surgery about a year and a half ago that brought my life to a standstill. I am pretty much, well I am homebound except, my big social life is when I go to the doctor's office."

Social Support: The Support Participants Exchanged in the Virtual Environment

Participants exchanged support in the VE in the twice-weekly education and weekly support sessions. A total of 1170 support exchanges occurred in the education (723/1170, 61.79%) and support (406/1170, 34.70%) sessions, or outside of session times (eg, before or after each session; 41/1170, 3.50%). The 4 types of support were not exchanged in equal measure, as informational (535/1170, 45.73%) was the most exchanged, followed by emotional (377/1170, 32.22%) support. Few instances of appraisal (217/1170, 18.55%) and even fewer instances of instrumental (41/1170, 3.50%) support were noted in these data.

Emotional Support

Emotional support includes feelings of empathy, trust, and caring. Diabetes educators and participants exchanged 3 types of emotional support in real-time conversation: (1) physical health (88/377, 23.3%) or empathy for the physical challenges and symptoms of T2D; (2) psychosocial (189/377, 50.1%) or empathy for psychosocial aspects (eg, loneliness, depression, frustration) when one lives with T2D; and (3) motivational (100/377, 26.5%) or empathy and encouragement for engaging in T2D self-management behaviors.

Emotional support interactions centered on integrating T2D self-management into one's daily life. Participants elicited and provided emotional support when they discussed the physical challenges (eg, hypoglycemic events), the psychosocial issues (eg, loneliness), and restrictions (eg, unable to eat certain foods) encountered when living with T2D. The statements that elicited emotional support included participant responses to questions during the education lectures, participant responses to direct questions from a diabetes educator or participant, participant comments during a discussion, or a participant-initiated statement. Supportive comments included short phrases such as "Oh no," and "Mmmhmm," or longer phrases such as "Well, that is good news" and "I knew I wasn't the only one!" Typically, these phrases occurred simultaneously while the participant (the support elicitor) revealed personal information or immediately after the participant concluded his or her statement.

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Informational Support

Diabetes educators and participants frequently exchanged informational support, or T2D-specific information, in the VE. In total, we noted 10 types of informational support. There were 8 types of informational support that correlated with the predetermined session topics: nutrition and food (149/535, 27.9%), preventing complications and problem solving (85/535, 15.9%), monitoring (55/535, 10.3%), medications (insulin; 36/535, 6.7%), medications (not insulin; 35/535, 6.5%), psychosocial aspects and coping (29/535, 5.4%), pathophysiology (28/535, 5.2%), and exercise (24/535, 4.4%). Additionally, we noted that participants exchanged 2 types of informational support that related to the SLIDES study (81/535, 15.1%) and on miscellaneous topics (13/535, 2.4%; eg, information on local places).

Participant-initiated questions and comments stimulated the conversation and subsequent sharing of information by the diabetes educators or the other participants. Informational support was elicited through questions or concerns raised during the discussion. These elicitation behaviors enabled the diabetes educators and the other participants to respond with informational support. For example, participants posed questions such as "What about sugar-free sodas?," "What is [drug]?," or made statements such as sharing one's personal exercise routine. These instances resulted in informational support in the form of suggestions such as quick and easy breakfast choices, ideas for healthy beverages, and how to incorporate more water into one's diet. We noted few instances in which the diabetes educators or individuals delivered information and/or support via corrective feedback to address misinformation about T2D self-management knowledge and behaviors. Overall, the informational support cleared up misunderstandings and enabled each participant who initiated an exchange to ask questions until the topic was clear.

Appraisal Support

Appraisal support, or affirmational statements regarding information seeking and engagement in T2D self-management, was exchanged by everyone in the VE. The 2 types of appraisal support are (1) support for information seeking (32/217, 14.7%) or an affirmational reply after a participant asked a question or provided a comment, and (2) support for self-management behaviors (185/217, 85.3%) or an affirmational reply following a participant's statement about a specific T2D self-management behavior. Diabetes educators affirmed the participant's information-seeking behaviors when they positively responded (eg, "That is an excellent question") during classes or when the participants shared personal information. Diabetes educators and participants congratulated and praised other participants when they discussed how they overcame a challenge, engaged in a preventative behavior, or shared positive news about themselves. For example, when a participant stated how much money she spent on her eye problems, someone stated "Yeah, that is important, stay on top of your eye problems," which reaffirmed the participant's self-management behaviors.

Instrumental Support

Instrumental support, or the exchange of tangible goods related to T2D self-management, was the least exchanged type of support in the VE. Instrumental support exchanges occurred when participants exchanged website links and information (31/41, 76%), information on specific self-management tools (7/41, 17%), and recipes (3/41, 7%). Participants provided instrumental support following a discussion in an education or support session (eg, links to understand a T2D symptom) or in response to a question (eg, questions for meal ideas).

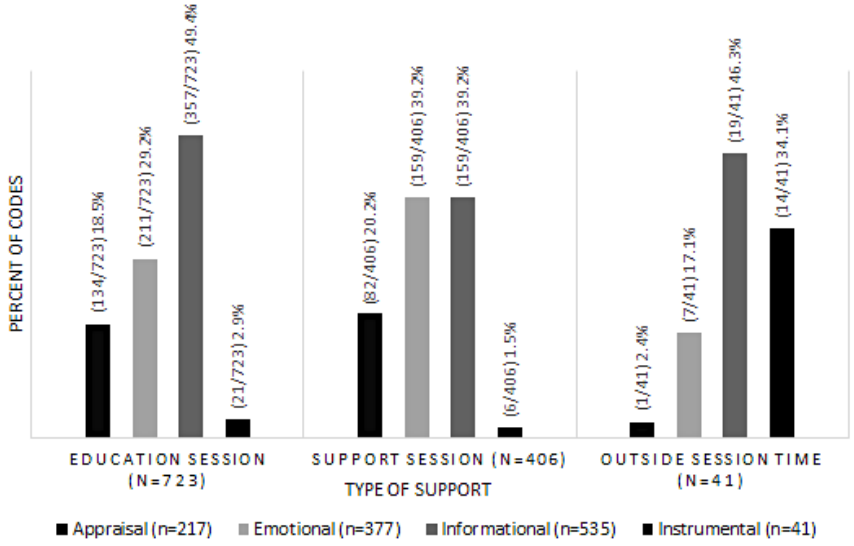
Contributions of Virtual Environment–Facilitated Education and Support Sessions

We disaggregated the 4 types of social support by education and support session to determine when the social support was exchanged (see Figure 4).

The education sessions provided predominately informational support (49.4%, 357 of the 723 exchanges). One way the diabetes educators provided informational support was during the lectures on prespecified content; lectures included PowerPoint slides, learning activities, and questions to facilitate discussion. The general support sessions provided predominately emotional (39.2%, 159 of the 406 exchanges) and informational (39.2%, 159 of the 406 exchanges) support. One way the participants provided emotional support was through the sharing of their own self-management experiences in response to questions from the diabetes educator or other participants. Overall, the discussion during the sessions enabled participants and diabetes educators to converse about current self-management behaviors and challenges.

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Figure 4. Frequency of each type of social support as exchanged in the education and social support sessions, or outside of session time (eg, before or after each session).



Discussion

Principal Findings

We described how participants interacted and exchanged support in a VE. Specifically, we showed that individuals with T2D discussed personal information (ie, ties, depth, participation), that there was not great variation in topics in a moderated conversation (ie, breadth), and also described the content of a supportive interaction in the VE. Together, these data indicate that VE–mediated interactions are similar to interactions in face-to-face environments. Individuals interacted in similar ways to interactions in a face-to-face support group when they shared personal information to obtain education and support for their own T2D self-management behaviors.

Interaction in a Virtual Environment

VE interactions are multidimensional because the VE mediates the communication techniques (eg, indicators of listening) individuals use when talking among themselves to form relationships with each other. Similar to face-to-face interactions, individuals in the SLIDES study used techniques such as greeting, responding to questions, and noticing others to indicate their engagement in the bidirectional interaction. These communication techniques resemble the cues present in a face-to-face interaction that facilitates the exchange of information, in addition to the individual's emotions and feelings [38-43].

Appearance is equally important in the VE as in face-to-face environments. Avatars that look like, and behave like, real humans influence feelings that one is in the VE with others; this increased awareness and acknowledgment of others in the VE may help the development of a community in which repeated interactions occur [1,3,44]. The individuals in our study looked for the avatars of other individuals and made statements such as "I'm standing behind you," and "I'm over here" when individuals wanted to see each other. These statements indicated participants felt *presence* and *copresence* in the VE. Our results provide insight into, and further describe, the finding that avatars serve as a proxy for others in the VE [45].

Individuals entered into the VE as weak ties to others, to obtain T2D-specific information and personalized support from diabetes educators and other individuals with T2D. Weak ties do not require a large amount of investment, the tie can be formed rapidly, and the tie brings in novel information to a group of individuals [28,29,46]. Examples of weak ties in the VE occurred when individuals shared information during the education and support sessions and provided personalized information when they responded to other individuals' or educator's questions, or provided a comment about their self-management experience. Overall, the findings are parallel to, but not equivalent to, Granovetter's strong/weak tie theory [28,29]. Just as the weak ties outside a tight-knit group can provide useful information to the group, our findings show that useful information is also exchanged among a group of people with whom the individual has ties of varying strength.

The repeated interactions (ie, over time, sharing personal information) among individuals in the VE may have facilitated the progression of weak ties into strong ties. Similar to face-to-face interactions [47,48], the individuals in our study discussed varying amounts of personal information with each other in response to questions and comments. Over time, we observed that individuals referenced previously discussed personal information when they responded or engaged with another individual; this may be a sign that time, and depth of conversation, contributes to tie formation among individuals. In contrast, an individual who did not regularly attend sessions, share personal information, or verbally participate did not build relationships with other individuals in the VE that facilitated the transition from a weak to a strong tie.

A strong tie exists between individuals when there is increased frequency, duration, and closeness of contact, and a direct link between 2 individuals [28,29,46]. Frequent and positive interaction with providers (eg, diabetes educators), or a strong tie connection, positively influences health behaviors and health

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outcomes for individuals with T2D [49]. In the VE, the diabetes educators interacted with participants during the sessions; we noted that these interactions were bidirectional as both the diabetes educator and the participant provided personal information about themselves. This style of interaction is similar to what occurs in face-to-face support groups, where diabetes educators serve as facilitators by connecting others, exchanging information, managing group dynamics, and prompting problem solving [50]. These actions created a relaxed learning environment, which resulted in a safe space in the VE where an individual could disclose his or her personal challenges and obtain personal support [49,50].

Individuals who interact online may do so because the Internet enables dialogue between peers and providers about sensitive information while remaining anonymous [51-53]. Although the diabetes educators in the SLIDES study used their real names, the study individuals each had an anonymous screen name and customized their avatar to their personal preference [12]. These features may have helped individuals to share personal information [10,54,55] and potentially more information than in a face-to-face interaction [56].

Support in a Virtual Environment

Similar to a face-to-face interaction, the VE enabled individuals to promptly elicit support and provide supportive responses; these timely exchanges may have resulted in increased feelings of support and the desire to reciprocate the support received [57,58]. However, the VE facilitated routine, positive, interactions with peers and providers from the comfort of one's own home. The interactions with peers who are successful and unsuccessful in T2D self-management enable individuals to problem-solve and identify ways to address their own challenges [8,47,59]. These exchanges prompted further discussion and opportunities to create supportive relationships among a diverse group of peers [47,60], which further substantiates the SLIDES study result that showed a statistically significant increase in social support from the beginning to the end of the study [12]. Overall, our results are similar to face-to-face interactions in which individuals discuss T2D failures and successes to exchange support [47,48,61].

Limitations

This research has several limitations. Due to the small size of the sample (N=24) and only 1 male participant, these findings should be interpreted with caution. We did not analyze each individual's participation over time in the VE, as this type of analysis is beyond the scope of this descriptive study. As participants entered into the SLIDES study at various time points, the most accurate way to assess tie development, tie strength, and amount/type of support each participant exchanged would be to analyze each participant's interactions with the other participants. Future research should use a case study approach to analyze interaction and support at an individual level to determine how interaction, tie development and strength, and support differ by participant (eg, gender, participation). Despite these limitations, the findings are valuable because of the insight provided on social interaction and support in a VE.

Conclusions

In this descriptive study, we analyzed conversations among adults who interacted in a VE. We described *how individuals interacted*, *what these individuals discussed*, and *how the VE mediated the interaction*. Our data indicate that the realistic VE, in conjunction with the ability to synchronously interact with others, may have accurately replicated face-to-face interactions. VEs, a type of consumer health information technology media, may provide individuals a full range of interaction that includes informational, emotional, and appraisal support. With this versatility, VEs are able to contribute substantially to the support for those with T2D and very likely other chronic illnesses.

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Conflicts of Interest

None declared.

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Abbreviations

DE: diabetes educator
SLIDES: Second Life Impacts Diabetes Education & Self-Management
T2D: type 2 diabetes
VE: virtual environment

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Original Paper

Patterns in Patient Access and Utilization of Online Medical Records: Analysis of MyChart

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Abstract

Background: Electronic patient portals provide a new method for sharing personal medical information with individual patients.

Objective: Our aim was to review utilization patterns of the largest online patient portal in Canada's largest city.

Methods: We conducted a 4-year time-trend analysis of aggregated anonymous utilization data of the MyChart patient portal at Sunnybrook Health Sciences Centre in Ontario, Canada, from January 1, 2012, through December 31, 2015. Prespecified analyses examined trends related to day (weekend vs weekday), season (July vs January), year (2012 vs 2015), and an extreme adverse weather event (ice storm of December 20-26, 2013). Primary endpoints included three measures of patient portal activity: registrations, logins, and pageviews.

Results: We identified 32,325 patients who registered for a MyChart account during the study interval. Time-trend analysis showed no sign of attenuating registrations over time. Logins were frequent, averaged 734 total per day, and showed an increasing trend over time. Pageviews mirrored logins, averaged about 3029 total per day, and equated to about 5 pageviews during the average login. The most popular pageviews were clinical notes, followed by laboratory results and medical imaging reports. All measures of patient activity were lower on weekends compared to weekdays (P<.001) yet showed no significant changes related to seasons or extreme weather. No major security breach, malware attack, or software failure occurred during the study.

Conclusions: Online patient portals can provide a popular and reliable system for distributing personal medical information to active patients and may merit consideration for hospitals.

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KEYWORDS

electronic health records; personal health information; patient portals; shared decision making; doctor patient relationship

Introduction

Online patient portals are an innovation for communicating medical information to patients in a reliable, detailed, quick, convenient, and secure manner. The information typically includes blood test results, medical imaging reports, and medical consultation notes. Through portals, patients can track their own information to promote self-management, review past trends, refresh fallible memory, digest overwhelming material, and share records with other health care professionals at separate institutions [1,2]. A patient who becomes sick while vacationing, for example, can use an online patient portal to retrieve their usual creatinine level, prior echocardiogram, or current medication list to help inform care for an emergency occurring in a foreign land [3,4]. In theory, these patient portals might also decrease health care costs by avoiding duplications of services [5].

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The literature provides a mixed picture of whether patient portals improve medical outcomes. One study of diabetic patients randomized to an enhanced program including an online patient portal found a significant improvement in glycemic control measured as HbA1c after one year (7.3% vs 8.1%, *P*=.003) [6]. This finding replicated in some studies and failed to replicate in other studies [7,8]. Further research on patients with breast cancer, human immunodeficiency virus (HIV) infection, renal insufficiency, or heart failure have shown increases in patient satisfaction but equivocal changes in clinical outcomes [9]. The latest systematic reviews find no consistent objective benefit attributable to online patient portals and conclude that more research is needed [10-12]. The overall modest results in medicine differ substantially from banking or other commercial industries that profit greatly from online customer access [13].

The absence of rigorous evidence has undermined the enthusiasm toward online patient portals for hospitals and health care systems [14]. Most projects are in their infancy and motivated by general regulations based on theoretic predictions. Furthermore, most predictions lack real-world data about utilization, reliability, and popularity. Developers also tend to be skilled in information technology yet lacking in medical experience. In this paper, we review the performance of the largest online patient portal in Canada's largest city (Toronto). The intent is to provide baseline data, trends, and patterns of utilization for others planning to create or to evaluate a new online patient portal. We do not examine technical points on software development, and we focus on relatively mature years of operation after completing initial pilot testing.

Methods

Study Setting

Sunnybrook Health Sciences Centre is a major academic hospital in Toronto, Canada. Toronto is a city of 6 million individuals and the fourth largest urban area in North America. In a typical year during the study, Sunnybrook had over 600 acute care beds, 35,000 admissions, 60,000 emergency cases, 500,000 outpatient visits, 16,000 surgical operations, and 4000 newborn deliveries (total exceeding 600,000 patients annually) [15,16]. Sunnybrook is one of five general hospitals affiliated with the University of Toronto, funded under the universal health insurance of the Ontario government, staffed by more than 10,000 health care professionals including volunteers, and run with a budget of Can $1 billion annually [17]. For perspective, the Ontario region had a population of 14 million individuals, 155 hospitals distributed over 238 sites, and 213 acute care emergency departments [18,19].

MyChart System

The patient portal (named MyChart, not to be mistaken with Epic MyChart) was developed by Sunnybrook in 2005, had an early launch in 2006, became widely available in 2007, and later expanded to 10 other institutions [20,21]. The core functions provided patients read-only access to blood test results, imaging reports, and physician notes. Additional features later developed included access to clinic schedules, pathology reports, microbiology data, electrocardiogram results, and patient diaries. The MyChart system did not support secure messaging, patient annotation, prescription renewals, or targeted education (presumably, patients obtain such services through other channels). A MyChart account is available at no cost to patients, does not require a clinician's consent, can be accessed by the Internet, and has a standard interface (Multimedia Appendix 1).

Past Publications of Sunnybrook MyChart System

The Sunnybrook MyChart system has been subjected to early analyses and small studies. The median user was a middle-aged woman who lived within 100 km of the hospital [22]. Individual patient demographic profiles varied substantially and spanned a wide range of diagnoses. Most patients were ambulatory, had at least one chronic medical disease, and expressed a particular interest in accessing their laboratory test results [23]. Patients had originally learned of Sunnybrook MyChart from word-of-mouth, brochures, or posters in high-traffic areas of the hospital and subsequently taught themselves how to use it without a formal Sunnybrook training program [24]. About half shared their personal access identifier and password with at least one family member. Some Sunnybrook physicians did not immediately embrace the initiative for this patient portal.

Sample Selection

We identified the most recent 4 consecutive calendar years of utilization data for the Sunnybrook MyChart system encompassing all complete years of system information (January 1, 2012, to December 31, 2015). This selection interval excluded the initial years of system development, early testing, and major upgrades that preceded widespread launch (April 1, 2007, to December 31, 2011). The analyses focused on aggregate traffic details to respect medical privacy and removed identifiable information to preserve patient confidentiality. This analytic strategy also included patterns where an individual patient might have shared their account details with family or other trusted delegates. The study protocol was approved by the Research Ethics Board of the Sunnybrook Research Institute including a waiver for patient consent on the condition that the study examined only aggregated anonymous utilization data.

MyChart Registration, Login, and Pageviews

Individual patients obtained a MyChart account by submitting a simplified application with personal identification for authentication (denoted as a MyChart registration). The onsite contact office for handling submissions was located adjacent to the hospital cafeteria and delivered as an on-demand service with no appointment. MyChart registration provided patients a temporary password, instructions for website navigation, and access to an unlimited number of website visits (denoted as a MyChart login). In turn, each MyChart login allowed an unlimited number of connections to individual features (denoted as a MyChart pageview). A MyChart pageview could contain differing amounts of information; for example, a single pageview of laboratory results could encompass dozens of individual test results.

Aggregated MyChart Traffic Information

The MyChart system routinely tracked activity as part of system monitoring, quality assurance, and ongoing maintenance. These aggregated data were automatically indexed to time and

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available in an aggregated manner grouped as consecutive days with no exclusions and no missing data. By design, the aggregated data were stripped of individual patient identifiers and expunged of actual detailed demographic or medical information. The purpose was to maintain full patient privacy and data security yet still provide health service research data necessary for evaluating comprehensive patterns of utilization (denoted as MyChart traffic information). MyChart traffic information is not traceable to individual patients, does not reveal individual medical characteristics, and does not breach doctor-patient confidentiality.

Statistical Analysis

The primary analysis used time-trend analysis to describe MyChart traffic information over the study interval. Separate analyses were conducted for each of the primary measures of MyChart activity, specifically, registrations, logins, and pageviews. Secondary analyses examined specific priority pageviews of blood test results, medical imaging reports, and medical consultation notes. We conducted comparative analyses to also examine daily trends (contrasting weekends of Saturdays and Sundays), seasonal trends (focusing on January and July), annual trends (highlighting the first and final year of observation), and resiliency to unforeseen shocks (evaluating the 7-day Toronto ice storm of December 20-26, 2013) [25,26]. The unit-of-analysis throughout was the individual day to avoid small cell sizes and allow adequate statistical power.

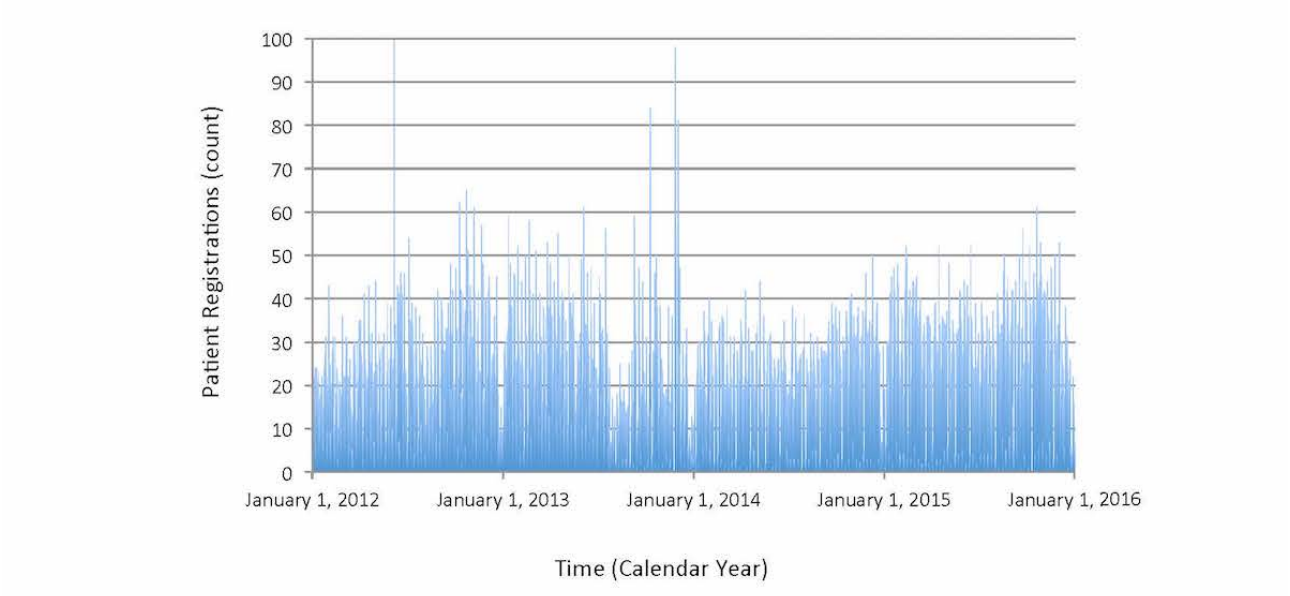
Results

A total of 32,325 patients received a MyChart registration during the 4-year study interval (total of 8081 patients annually). This equaled 22 registrations during the average day, 825 registrations during the most active day, and 0 registrations during the least active day (Figure 1). On average, fewer registrations occurred on weekends than weekdays (6 vs 29, $P<.001$), the month of July was similar to January (20 vs 22, $P=.374$), and the first year was similar to the final year (24 vs 24, $P=.825$). The Toronto ice storm led to an equivocal 61% reduction in registrations compared to the same dates in other years (4 vs 11, $P=.089$). Time trends showed a complicated profile, possibly related to fluctuating interest or promotion campaigns, with no significant sign of attenuating enrollment over time (Figure 1).

MyChart logins were frequent and increased substantially during the study interval (see Table 1). This equaled 734 logins during the average day, 1687 logins during the most active day, and 87 logins during the least active day (Figure 2). On average, weekends were less active than weekdays (385 vs 873, $P<.001$), the month of July was slightly more active than January (735 vs 660, $P=.045$), and the first year was substantially less active than the final year (486 vs 1013, $P<.001$). The Toronto ice storm led to an equivocal reduction in logins (367 vs 564, $P=.89$). Time trends showed a generally increasing profile, with a single unexplained anomaly on June 5, 2012.

MyChart pageviews tended to mirror MyChart logins with a relatively stable ratio equal to about 5 pageviews for the average login. This equaled 3029 pageviews during the average day, 7823 pageviews during the most active day, and 48 pageviews during the least active day (Figure 3). On average, weekends were less active than weekdays (1714 vs 3554, $P<.001$), the month of July was marginally more active than January (2987 vs 2768, $P=.133$), and the first year was substantially less active than the final year (2197 vs 4254, $P<.001$). The Toronto ice storm led to a 55% reduction in pageviews (1065 vs 2380, $P=.010$). Time trends showed a generally increasing profile with no major anomalies. The ratio of pageviews to logins was remarkably consistent (Figure 4).

Figure 1. Time trend of MyChart registrations (x axis=time in consecutive days spanning 4 total years, y axis=total number of patient registrations occurring on corresponding day). Main findings show high variability with no major increasing or decreasing trend over time; slight regular reduction in late December also evident for each year.



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Table 1. Summary of access to online patient portal by year.

Activity	2012, n	2013, n	2014, n	2015, n
Registrations	8909	7891	6837	8688
Logins	177,793	251,885	272,494	369,764
Pageviews	804,042	978,302	1,090,545	1,552,544

Figure 2. Time trend of MyChart logins (x axis=time in consecutive days spanning 4 total years, y axis=total number of patient logins occurring on corresponding day). Main findings show daily average of about 1000 with substantial increasing trend over time and slight reductions in late December also evident for each year. Anomalous spike on June 5, 2012, visible and unexplained, and no anomaly visible on June 6, 2012.

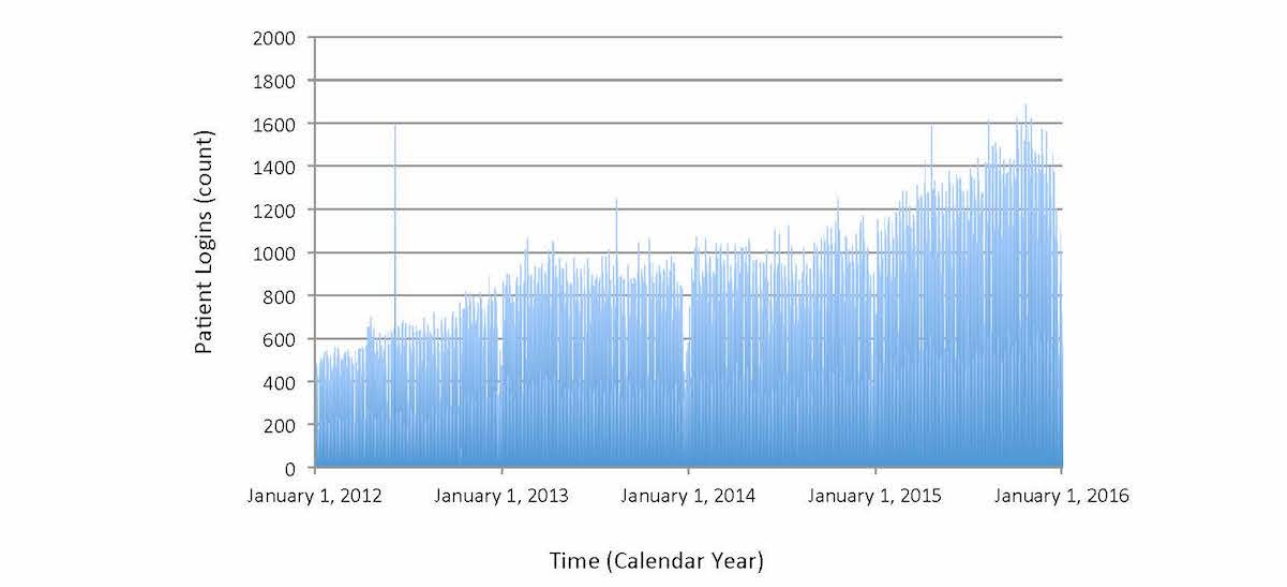
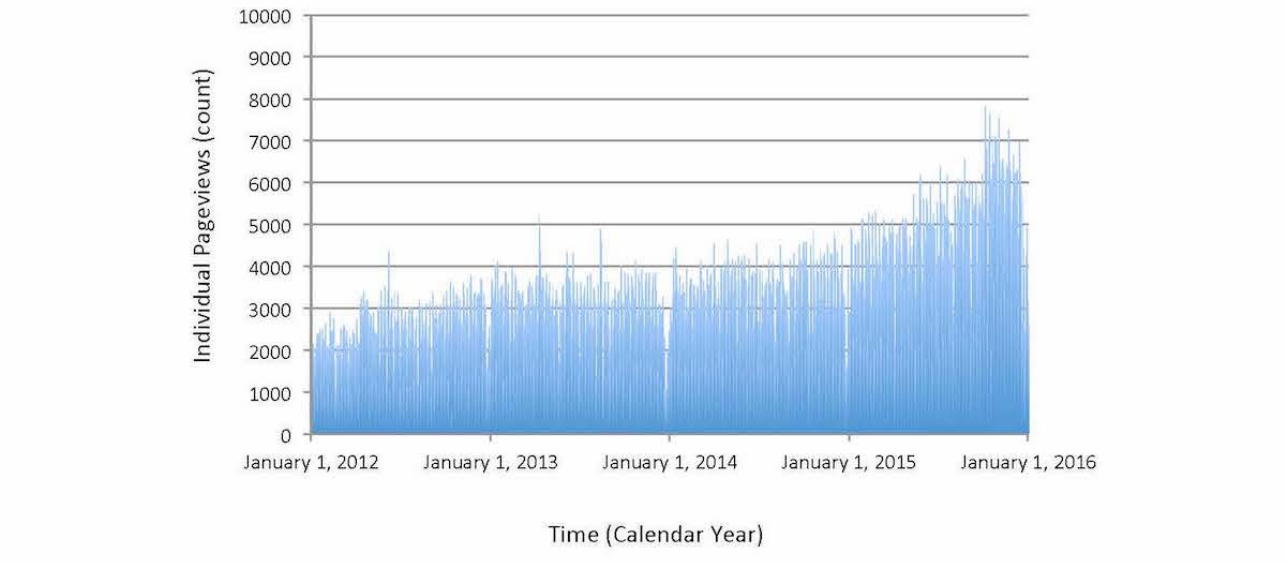
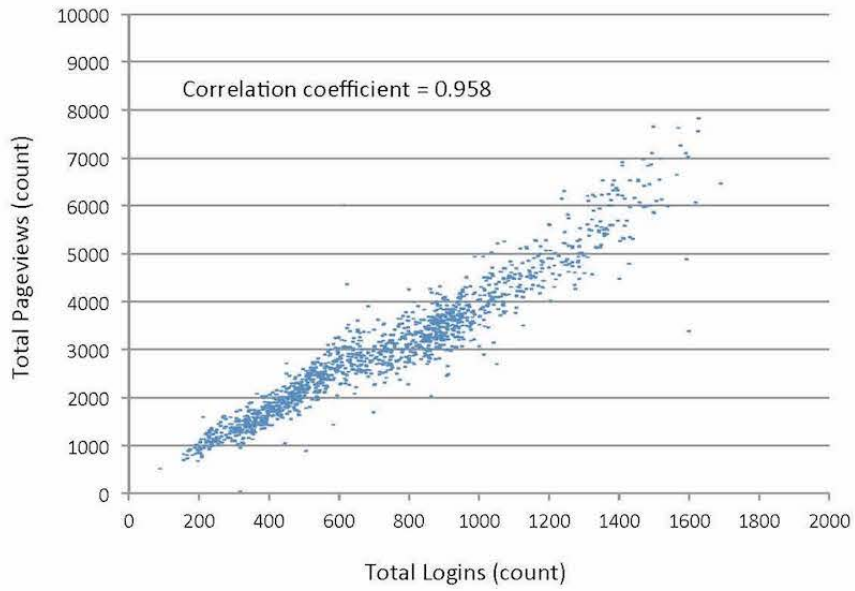


Figure 3. Time trend of MyChart pageviews (x axis=time in consecutive days spanning 4 total years, y axis=total number of pageviews occurring on corresponding day). Main findings show daily average of about 5000 with substantial increasing trend over time and slight reductions in late December also evident for each year. Anomalous spikes on Jun. 6, 2012, Apr. 10, 2013, Aug. 13, 2013, and Oct. 14, 2015, visible and unexplained.



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Figure 4. Scatterplot correlating logins and pageviews (x axis=total number of logins occurring on consecutive days over 4 total years, y axis=total number of pageviews occurring on corresponding day). Main findings show tight correlation that equals about 4-5 pageviews per login; slight anomalies also evident as outlier points that remain unexplained.



Specific MyChart features varied substantially in activity. The most frequent pageviews were clinical notes averaging about 28% of total pageviews. The next most popular pageviews were laboratory results (26%), medical imaging reports (17%), and appointment schedules (12%). In contrast, pathology notes (6%), electrocardiogram reports (4%), and microbiology findings (3%) received relatively few pageviews, perhaps due to their selected specialized nature (number of eligible relevant patients unknown). The lowest extreme was patient diaries (1%) , which received few pageviews despite being one of the few features that allowed patients self-input and self-expression. Time-trend analysis of specific pageviews showed no major anomalies during the study interval.

The distinctly low numbers of pageviews for patient diaries were subjected to further exploratory analyses as a possible indirect marker of patient engagement and self-management. The overall pattern equaled 17 diary pageviews during the average day, 1032 during the most active day (June 6, 2012), and 0 during the least active day. On average, weekends were less active than weekdays (10 vs 19, $P<.001$), July similar to January (15 vs 16, $P=.149$), and the first year similar to the final year (21 vs 17, $P=.241$). The Toronto ice storm led to no significant difference in diary pageviews (7 vs 11, $P=.146$). Together, the contrasts suggested that high volumes of MyChart activity were not matched by high volumes of this marker of patient engagement.

Discussion

Principal Findings

We studied the online patient portal at one large hospital to assess aggregated utilization over 4 years. We found that new registrations were uneven and amounted to about 1% of total patients treated at the hospital (8081/600,000). Despite the low uptake, total utilization grew substantially and exceeded 1000 logins daily in the final year. Utilization declined on weekends yet remained reliable despite an unforeseen extreme ice storm. Patients averaged 5 pageviews per login, showed relatively high interest in viewing clinical notes, and had relatively little interest in maintaining a diary [27,28]. Together, these data suggest that online patient portals can provide a popular and reliable system for distributing medical information to a self-selected subgroup of patients.

Limitations

An important limitation of our study is the absence of detailed data linking patient characteristics, diagnoses, treatments, and medical outcomes: this limitation was necessary for the ethics safeguards to analyze patient activity without patient consent. Our study also did not distinguish how much utilization occurred from one patient with multiple logins versus multiple patients with one login each. The digital data, furthermore, do not track a patient's experience to test how a recent medical encounter changes subsequent online portal utilization or further nuances that examine which pageviews tend to be viewed first and for how long. The ultimate positive benefits of online patient portals for increasing patient satisfaction, knowledge, motivation, equity, and health outcomes are all topics that remain for future research.

A second limitation relates to generalizability because the Sunnybrook system is not the epitome of patient portals. The user interface can be awkward for some patients with cognitive impairment or those unfamiliar with medical data [29]. The system lacks some functions relevant to ongoing patient care such as secure messaging and prescription medication renewals. The system also has few of the connections necessary for networking between hospitals or physicians outside the region. The background software provides no customization based on an individual's past search history or tailoring to a patient's unique profile. All patient portals involve design compromises

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between functionality, simplicity, reliability, and security [30-34] and are likely to evolve further in future years.

Another limitation of our study is the absence of data on possible adverse effects of communicating large amounts of personal health information to individual patients. One worry is that patients lack formal medical training, misinterpret innocuous items, and can be upset about inconsequential anomalies [35,36]. A related concern is that some patients may obsess about minutiae, repeatedly refresh for updated data, or attempt to embarrass health care providers in a deliberate strategy of one-upmanship [37]. The direct viewing of physician notes also allows patients to detect undiplomatic language, spelling mistakes, and other awkward professional lapses [38]. Ultimately, these medical portals empower patients and thereby shift the balance of power around a clinical encounter.

A related limitation is the lack of data on physician behavior since health care providers are aware of patient portals and may adjust their documentation accordingly. One reaction is to stifle candid collegial dialogue due to concerns about later misinterpretation by the patient [39,40]. Another reaction involves unnecessary clutter or auto-text inserted as a medico-legal defensive strategy [41,42]. A further reaction is for health care providers or families to focus excess attention on online data and neglect the patient's symptoms, physical findings, or other changes found at the bedside, not online [43,44]. A comprehensive online patient portal, moreover, could be counterproductive for a patient diagnosed with a personality disorder who can immediately access a physician's notes.

Future Directions

The Sunnybrook online patient portal has strengths that justify future research. The system provides a flexible platform for patients to help integrate clinical services, enhance self-management, and potentially improve health outcomes. Patients can easily share their medical information with family members or community physicians for broader system integration [45]. Patients can also use the system to incorporate tracking tools for personal health status (eg, ambulatory blood pressure monitors) [46]. Patients have frequent opportunities to comment on their experiences through user surveys and, in turn, developers are integrated with the larger health care team to facilitate system advances [47]. All these benefits might increase further with ongoing system expansion. The sustained high rates of utilization found in this study therefore suggest potentially sufficient sample size and statistical power necessary for planning future research.

Conclusions

The utilization of online patient portals observed in this study indicates the technology is popular for a small subgroup of patients who register [48,49]. If each pageview were assumed equal in value to a 50¢ payphone call, for example, the net utilization in this study would be worth Can $1 million annually. If uptake could increase to 20% of total patients and patterns persisted, furthermore, the net utilization might be worth Can $25 million annually (Can $10 billion if extrapolated to all of Canada). Regardless of assumed uptake, this study also implies such value can accrue for years without a major security breach or software failure. As the Internet continues to transform society and individuals grow increasingly comfortable online, more patients may demand information technology solutions to help access personal health data [50,51]. Other hospitals, therefore, might consider an online patient portal for future years.

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Authors' Contributions

DAR had full access to all the data in the study, takes responsibility for the integrity of the data, is accountable for the accuracy of the analysis, and wrote the first draft of the manuscript. NCK was responsible for literature review, statistical analyses, and manuscript revisions.

Conflicts of Interest

The Sunnybrook Health Sciences Centre was involved in the review and approval of the manuscript.

Multimedia Appendix 1

Screenshots of MyChart online patient portal from user perspective.

[JPG File, 280KB - jmir_v20i2e43_app1.jpg]

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Original Paper

Cognitive Style and Mobile E-Learning in Emergent Otorhinolaryngology-Head and Neck Surgery Disorders for Millennial Undergraduate Medical Students: Randomized Controlled Trial

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Abstract

Background: Electronic learning (e-learning) through mobile technology represents a novel way to teach emergent otorhinolaryngology-head and neck surgery (ORL-HNS) disorders to undergraduate medical students. Whether a cognitive style of education combined with learning modules can impact learning outcomes and satisfaction in millennial medical students is unknown.

Objective: The aim of this study was to assess the impact of cognitive styles and learning modules using mobile e-learning on knowledge gain, competence gain, and satisfaction for emergent ORL-HNS disorders.

Methods: This randomized controlled trial included 60 undergraduate medical students who were novices in ORL-HNS at an academic teaching hospital. The cognitive style of the participants was assessed using the group embedded figures test. The students were randomly assigned (1:1) to a novel interactive multimedia (IM) group and conventional Microsoft PowerPoint show (PPS) group matched by age, sex, and cognitive style. The content for the gamified IM module was derived from and corresponded to the textbook-based learning material of the PPS module (video lectures). The participants were unblinded and used fully automated courseware containing the IM or PPS module on a 7-inch tablet for 100 min. Knowledge and competence were assessed using multiple-choice questions and multimedia situation tests, respectively. Each participant also rated their global satisfaction.

Results: All of the participants (median age 23 years, range 22-26 years; 36 males and 24 females) received the intended intervention after randomization. Overall, the participants had significant gains in knowledge (median 50%, interquartile range

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[IQR]=17%-80%, *P*<.001) and competence (median 13%, IQR=0%-33%, *P*=.006). There were no significant differences in knowledge gain (40%, IQR=13%-76% vs 60%, IQR=20%-100%, *P*=.42) and competence gain (0%, IQR= −21% to 38% vs 25%, IQR=0%-33%, *P*=.16) between the IM and PPS groups. However, the IM group had a higher satisfaction score (8, IQR=6-9 vs 6, IQR=4-7, *P*=.01) compared with the PPS group. Using Friedman's two-way nonparametric analysis of variance, cognitive styles (field-independent, field-intermediate, or field-dependent classification) and learning modules (IM or PPS) had significant effects on both knowledge gain (both adjusted *P*<.001) and satisfaction (both adjusted *P*<.001).

Conclusions: Mobile e-learning is an effective modality to improve knowledge of emergent ORL-HNS in millennial undergraduate medical students. Our findings suggest the necessity of developing various modules for undergraduate medical students with different cognitive styles.

Trial Registration: Clinicaltrials.gov NCT02971735; https://clinicaltrials.gov/ct2/show/NCT02971735 (Archived by WebCite at http://www.webcitation.org/6waoOpCEV)

(J Med Internet Res 2018;20(2):e56) doi:10.2196/jmir.8987

KEYWORDS

cognitive style; e-learning; mobile technology; randomized controlled trial

Introduction

e-Learning Can Provide an Opportunity for Active Self-Directed Learning

The large investment involved in undergraduate medical education (UME) for students and society has led medical schools worldwide to seek strategies and methods to improve their students' progress [1-3]. The cost of medical school tuition continues to increase annually [4], and medical students face substantial financial stress in the United States and Taiwan [5]. A reduction in medical training time has been shown to reduce medical school tuition fees [6]. Innovative curricula, quality of teaching, and primary care education are three major issues in UME [4,7], and novel UME should empower undergraduate medical students to use different learning strategies and learn outside the classroom by promoting self-directed learning [8]. For instance, electronic learning (e-learning) can provide an opportunity for active self-directed learning and the dissemination of knowledge in an interactive fashion [9].

Cognitive Style Is Underresearched in the Context of Medical Education

Certain learning characteristics have been positively correlated with academic success; for instance, strong motivation and enjoying studying have been identified as positive predictors during the undergraduate year of medical school [10]. However, it has also been suggested that the predictive power of learning strategies such as cognitive style is underresearched in the context of medical education [11]. At least some undergraduate medical student–initiated learning situations have been reported to be consistent with their individual cognitive and instructional preferences [12]. The Group Embedded Figure Test (GEFT) was first applied to assess cognitive style and instructional materials for medical students in 1981 [13]. Field-independent (FI) learners have been shown to prefer and have better performance in problem-based learning and computer-assisted learning [14], and the preinstructional determination of cognitive style may help to select suitable instructional materials for these students while providing other instructional tools for field-dependent (FD) learners. However, when teaching millennials (also known as digital natives) who are paradoxically motivated by self-interest, the current understanding of these students may be inaccurate because of the considerable diversity in background, personality, and learning preference [15,16]. Therefore, educational reforms such as competency-based medical education have been implemented to better suit the current millennial generation of undergraduate medical students [17].

Mobile Technology in e-Learning Has Gained Popularity

Mobile technology has gained popularity in recent years as a means of immediate interactive multimedia (IM) communication and to access the Internet. Embedded e-learning in a smartphone or tablet can affect the educational environment. In this context, it has been termed "mobile technology in e-learning (M-TEL)," and it has been reported to represent the next natural frontier in the evolution of e-learning [18]. Almost all e-learning today can be accessed from mobile devices, including medical education [19], patient education [20], and the development of mobile medical educators [21]. However, clinical teachers looking to use M-TEL therefore need to ensure that it will meet both the needs of their millennial learners and the requirements of the program.

Students Need to Spend More of Their Time Outside the Classroom to Learn Otorhinolaryngology-Head and Neck Surgery

Reducing training time can limit the number of topics taught in an UME curriculum, including otorhinolaryngology-head and neck surgery (ORL-HNS). However, at least 20% of primary care complaints are related to ORL-HNS, and a substantial downstream effect on managing ORL-HNS problems has been reported in family medical practice [22]. In Taiwan, a reduction of approximate 20% in classroom lectures in 6-year medical programs was implemented in 2013. Therefore, the students need to be encouraged to spend more of their time outside the classroom to learn. In our pilot study [23], we found that M-TEL using IM modules could be an effective and satisfactory way to learn about emergent ORL-HNS disorders. In this study, we hypothesized that FI learners would prefer M-TEL technology compared with FD learners, and that they would have a better performance with a novel IM module (cases) compared with a

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conventional Microsoft PowerPoint show (PPS) module (controls). The control group also received identical instructional materials using the same mobile device.

Methods

Study Design

We conducted this prospective study from August 1, 2015 to July 31, 2017 at a university (Department of ORL-HNS, Faculty of Medicine, Chang Gung University, Taoyuan, Taiwan). This study included two parts: (1) pilot system-design study, and (2) validation study. This study was approved by the institutional review board of Chang Gung Medical Foundation (No: 105-5290C), and all procedures were conducted in compliance with the Declaration of Helsinki 1975. The participants were informed about the aims of the study, and written informed consent was obtained from all participants. The study proposal was registered at ClinicalTrials.gov (NCT02971735).

Setting

In the pilot system-design study [23], we established the instructional materials, including essential knowledge and competence of the 10 most common emergent ORL-HNS disorders using the analysis, design, development, implementation, and evaluation models [24] to design effective instruction for e-learning (Figure 1). All of the materials were developed according to the results of needs assessment in a focus group of undergraduate students and revised using a two-round modified Delphi method to develop the instructional content and assess the relative importance of each item. Storyboards and courseware of the IM and PPS modules were developed using the same user interface (Figure 2).

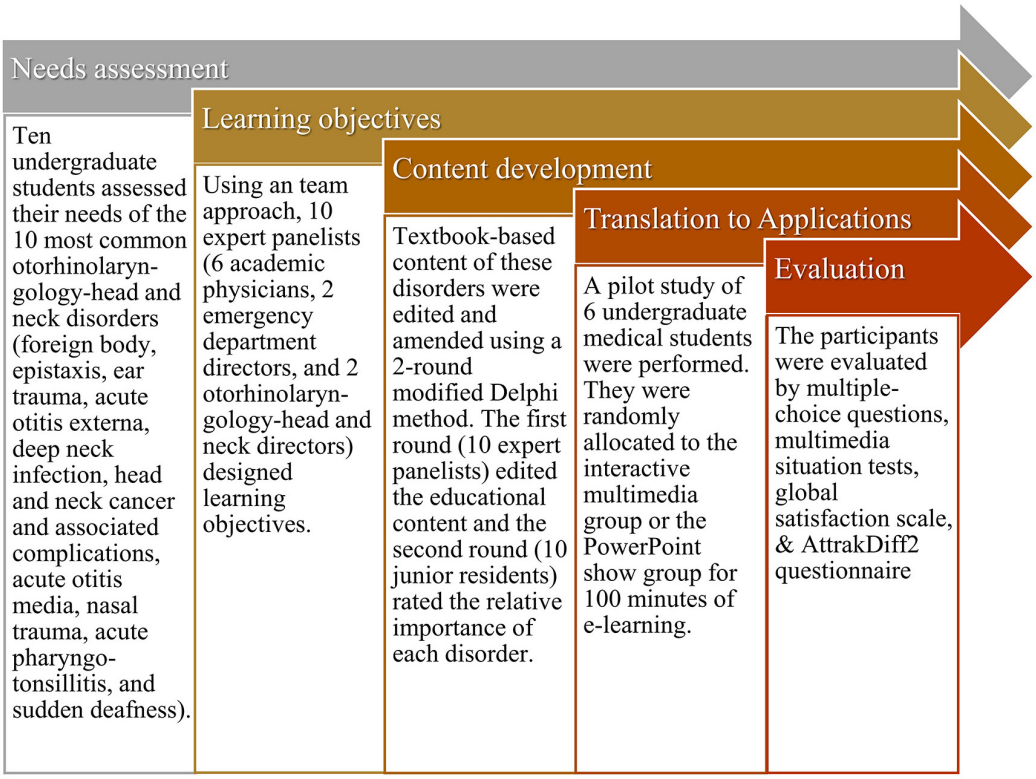
The Novel IM Module

Using the IM module, the learners could operate a leading character to search for and interact with other nonplayer characters to procure instructional materials, to review acquired instructional slides (maximal 80), and to win five small game-based quizzes (Figure 3). The instructional slides were briefly explained using scrolling text. The content for the novel IM module was derived from and corresponded to the textbook-based learning material of the conventional PPS module. Game-based quizzes with different contexts from the multiple-choice questions (MCQs) and multimedia situational tests (MSTs) provided small repetitive summaries of the emergent ORL-HNS disorders. The learners could use a learning map to assess their progress in each section or a bar chart to assess their progress overall.

The Conventional PPS Module

In the PPS module, the learners chose and watched 10 visual-auditory text-image videos of emergent ORL-HNS disorders (a total of 80 min) by themselves. Video lectures were created by recording Microsoft PowerPoint presentations with audio narrations, timings, and ink gestures using Camtasia Studio software version 8 (TechSmith, Okemos, MI, USA). The learners were free to watch the videos at any time, and they could also rewind and fast-forward the videos as needed (Figure 4).

Figure 1. Analysis, design, development, implementation, and evaluation (ADDIE) model for designing effective instruction of mobile technology in electronic learning (e-learning).



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During the course, all of the participants arbitrarily reviewed 80 slides by themselves. The instructional content of the two learning modules was confirmed to be correlated and equivalent by 2 investigators from the study team (r=.91, P<.001, Spearman correlation test) using the Software Evaluation Checklist [25]. This checklist uses seven criteria (curriculum connections, age/grade appreciates, investment justification, lay-out, support materials, instructional content, and graphics/multimedia) with two (yes, no) Likert-type scales (a total of 28 questions). Qualitative feedback from the participants was obtained through feedback forms in the pilot study [23]. Major bug fixes were performed before the validation study.

The validation study was a prospective, parallel-controlled, randomized clinical trial assessing the impact of cognitive styles and learning modules using M-TEL on knowledge gain, competence gain, satisfaction, and learning experience.

Selection of Participants

A total of 60 consecutive volunteers were recruited from a teaching clinic for the validation study from November 23, 2016 to July 5, 2017. All of the volunteers had at least a basic level of computer literacy, and they were shown the practical aspects of using tablets and apps. The inclusion criteria were as follows: (1) age >20 years; and (2) undergraduate medical students (clerkship). The exclusion criteria were: (1) previous ORL-HNS training; and (2) declining to participate.

Figure 2. Start of the apps. Learners read the adventure story and objectives (story symbol), played four instructional domains (red arrow symbol), reviewed instructional materials (book symbol), assessed learning progress (bar chart symbol), and got the helps (hint symbol) on the start screen.



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Figure 3. Screenshots of the interactive multimedia module. Learners arbitrarily operated a leading character to run, jump, and interact with other nonplayer characters (up) to procure instructional materials (middle). After a small session, learners need to complete small game-based quizzes (low).

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Methods of Measurement

There were four different face-to-face assessments. The cognitive style of the participants was assessed using the 25-item GEFT after enrollment [26]. The GEFT has a relatively high Spearman-Brown reliability coefficient of 0.82 [27]. On the basis of the number of correct answers given by the participants, the GEFT scores ranged from 0 (the most FD) to 18 (the most FI). We stratified the students into two subgroups: "classical FD" (GEFT score ≤12) and "classical FI" (GEFT score >12) [26].

Pretests including a 15-min 10-question standard MCQs to evaluate the students' existing knowledge (range 0-100) and a 15-min 5-question MSTs to assess their existing competence (range 0-100) with regard to "emergent ORL-HNS disorders" were given to the students. Each textbook-based MCQ was designed to be answered within 90 seconds and was preselected according to the results of item analysis. The MSTs presented the learners with written descriptions of five scenarios with or without images/videos and asked them to select the appropriate responses from 5 MCQs for one emergent ORL-HNS disorder using the methodology described in a previous publication of key features approach [28]. The MST was developed to assess clinical reasoning competence [23]. After a 100-min learning course, the participants were again requested to answer a different set of MCQs and MSTs posttest. These assessments were comparable with respect to psychometric properties [26]. Two members of staff confirmed that these questions could be sufficiently answered after reviewing the instructional content of the M-TEL.

The students were then asked to complete a global satisfaction score (GSS) (range 0-10) questionnaire.

Randomization and Blinding

Blinding to the purpose of the study during recruitment was maintained to minimize preparation bias. After the participants had provided consent and completed the GEFT and pretests, we randomly assigned them (1:1) to the IM group and PPS group (Figure 5). A balanced design with regard to cognitive style, sex, and age was assured by the randomization procedure. Computer-generated lists of random numbers were created using the Random Number Generator in IBM SPSS software version 23 (IBM, Armonk, NY, USA) for the allocation of the students, who were stratified by center with a 1:1 allocation using a fixed block size of 6 in both parallel subgroups. The allocation sequence was concealed before implementation of the M-TEL module, and the module adhered to our computer-generated randomization protocol.

Intervention

After randomization, the participants were unblinded and used fully automated courseware containing IM or PPS module on a 7-inch tablet in an ordinary office environment for 100 min. Before using the courseware, the functionality of the tablet was explained to the participants. The IM group participated in a parkour course to find and read the instructional materials and played small quiz games that were different from the MCQ and MST questions. The students in the PPS group used an app to read and listen to instructional materials in 10 linear-designed sessions. After completing the brief sessions, the IM and PPS learners could review simple slides of the instructional materials.

Outcome Measures

The primary outcome measure was the percentage change in MCQ score (ie, "knowledge gain") after the M-TEL. Other outcomes were the percentage changes in MST (ie, "competence gain") and GSS.

Sample Size

A priori sample size was estimated using primary outcome effects (percentage change in MCQ score) based on a pilot study (IM module: 43% [SD 18%]; PPS module: 35% [SD 21%]). A two-tailed Wilcoxon signed-rank test to calculate the sample size of 26 in each group (normal parent distribution; calculated effect size: 0.41; type I error: 0.05; power: 80%). Assuming a 10% dropout rate to fulfill the criteria of intention-to-treat analysis, we needed at least 29 participants in each group. Accordingly, we decided to enroll a total of 60 students to show the difference in percentage change in MCQ score.

Statistical Analysis

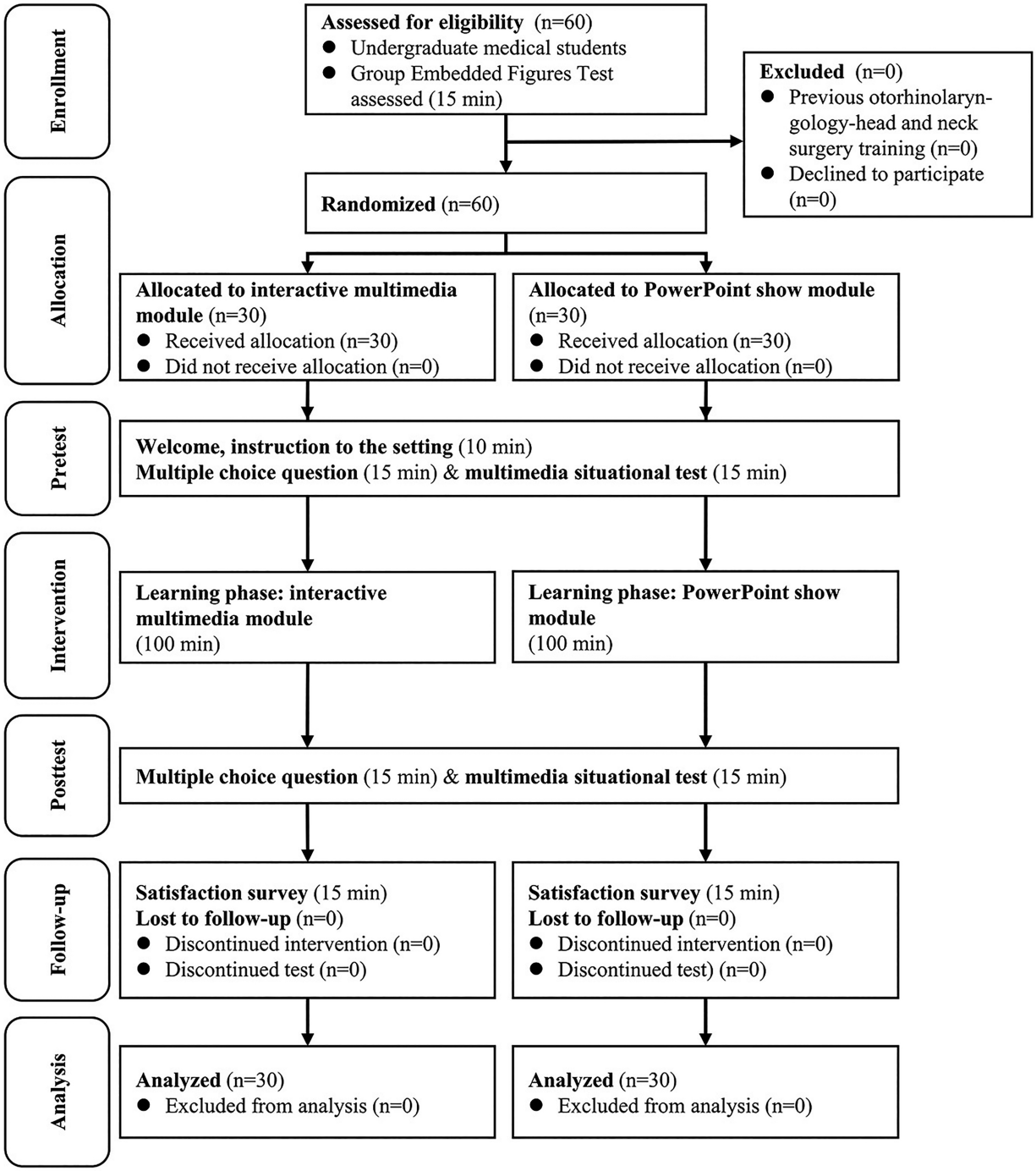
Because the primary outcome measure (percentage change in MCQ score) was not normally distributed according to the D'Agostino-Pearson omnibus normality test, percentage changes ([after value-before value]/[before value] × 100) in MCQ, MST, and GSS; and AttrakDiff2 scores were compared between groups using the Wilcoxon signed-rank test, Mann-Whitney *U* test, or Kruskal-Wallis test as appropriate. Categorical variables were analyzed using Fisher exact test, and the Spearman correlation test was used to analyze the relationship between variables of interest. Friedman test (two-way nonparametric analysis of variance) was used to compare the effect of multiple levels of two factors [29]. All tests were two-tailed, and statistical significance was established at $P<.05$. Statistical analyses were performed using G*Power 3.1.9.2 software (Heinrich-Heine University, Dusseldorf, Germany), Statistical Package for the Social Sciences for Windows version 23.0 (SPSS Inc., Chicago, IL, USA), and GraphPad Prism for Windows version 7.0 (GraphPad Software Inc., San Diego, CA, USA).

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Figure 4. Screenshots of the PowerPoint Show module. Learners watched 10 visual-auditory text-image videos of emergent otorhinolaryngology-head and neck surgery (ORL-HNS) disorders. The instructional slides of this module were identical to those of the interactive multimedia module and arranged linearly.

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Figure 5. The Consolidated Standards of Reporting Trials flow diagram.



Results

Study Participants

A total of 60 undergraduate medical students were screened, all of whom (median age 23 years, range 22-26 years; 36 males, 60% and 24 females , 40%) were randomized 1:1 to the IM group or PPS group as shown in the Consolidated Standards of Reporting Trials flow diagram (Figure 3; Multimedia Appendix 1 [30]). Table 1 summarizes the variables of interest for the overall study cohort. There were no significant differences in age, sex, cognitive style, MCQ, or MST scores between the two groups at baseline. All of the participants (100%, 60/60) received the intended intervention after randomization, and there was no deviation from the study protocol.

Primary and Secondary Outcomes

Overall, all of the participants showed significant improvements in MCQ score (P<.001) and MST score (P=.006) after 100 min of e-learning (Table 1). The median percentage changes in MCQ and MST scores were 50% (interquartile range 17%-80%, P<.001) and 13% (interquartile range 0%-33%, P=.006), respectively. The M-TEL positively impacted the GSS (P<.001). The PPS group had significant improvements in knowledge (P<.001) and competence (P=.001), whereas the IM group had a significant improvement in knowledge (P<.001) but not in

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competence (*P*=.53). There were no significant differences in the percentage changes in the MCQ or MST score between the two groups (*P*=.42 and *P*=.16, respectively). Notably, the IM group had a significantly higher GSS compared with the PPS group (*P*=.01).

Differences in Outcomes Between the Classical Field-Dependent and Field-Independent Learners

Using the original definition of FD and FI defined by Witkin [29], 5 (8%) participants had the classical FD cognitive style and 55 (92%) had the classical FI cognitive style. Table 2 summarizes comparisons of the variables of interest between the classical FD and FI learners. There were no significant differences in age, sex, M-TEL module, or MCQ or MST scores between the classical FD and FI groups at baseline. After 100 min of M-TEL, increases in MCQ and MST scores in the classical FD learners did not reach statistical significance (*P*=.14 and *P*=.85, respectively), whereas they were significantly increased in the classical FI learners (*P*<.001 and *P*=.003, respectively). However, the percentage changes in MCQ and MST scores were not significantly different between the classical FD and FI groups (*P*=.90 and *P*=.68, respectively). Even though the differences were not statistically significant, the classical FD learners had a lower GSS than the classical FI learners.

Table 1. Demographics, cognitive style, learning outcomes, satisfaction, and experience.

Variables	Overall, N=60	Interactive multimedia group, N=30	PowerPoint show group, N=30	*P* value[a]
Demographics				
Age in years, median (IQR[b])	23 (23-24)	23 (23-24)	23 (23-24)	.21
Male sex, n (%)	36 (60)	20 (67)	16 (53)	.43
Cognitive style				
Group embedded figures test score, median (IQR)	17 (15-18)	18 (15-18)	17 (16-18)	.78
Field-dependence, n (%)	5 (8)	3 (10)	2 (7)	>.99
Learning outcomes				
Multiple-choice questions-before, median (IQR)	40 (40-50)[c]	40 (40-60)[c]	45 (30-50)[c]	.47
Multiple-choice questions-after, median (IQR)	70 (60-80)[c]	70 (58-70)[c]	70 (60-80)[c]	.72
Percentage change in multiple-choice questions, median (IQR)	50 (17-80)[d]	40 (13-76)[d]	60 (20-100)[d]	.42
Multimedia situational test-before, median (IQR)	80 (60-80)[c]	80 (60-80)	80 (60-80)[c]	.84
Multimedia situational test-after, median (IQR)	80 (80-100)[c]	80 (60-80)	80 (80-100)[c]	.003
Percentage change in multimedia situational test, median (IQR)	13 (0-33)[d]	0 (−21 to 38)	25 (0-33)[d]	.16
Learning satisfaction				
Global satisfaction score, median (IQR)	7 (5-9)[d]	8 (6-9)[d]	6 (4-7)	.01

[a]Mann-Whiney *U* test (continuous variables) or Fisher exact test (categorical variables)

[b]IQR: interquartile range.

[c]*P*<.05, before versus after, Wilcoxon signed-rank test (two-tailed).

[d]*P*<.05, compared with a neutral value ("0" for multiple-choice questions and multimedia situational test, or "5" for "global satisfaction score"), Wilcoxon signed-rank test (two-tailed).

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Table 2. Comparisons of demographics, learning model, outcomes, satisfaction, and experience between classical cognitive styles.

Variables	Classical field-dependent, N=5	Classical field-independent, N=55	*P* value[a]
Demographics			
Age in years, median (IQR[b])	23 (22-24)	23 (23-24)	.45
Male sex, n (%)	2 (40)	34 (62)	.38
Group embedded figures test score, median (IQR)	9 (4-12)	18 (17-18)	<.001
Learning model			
Interactive multimedia, n (%)	3 (60)	28 (51)	>.99
Learning outcomes			
Multiple-choice questions-before, median (IQR)	40 (25-60)	40 (40-50)[c]	.53
Multiple-choice questions-after, median (IQR)	60 (50-80)	70 (60-80)[c]	.70
Percentage change in multiple-choice question, median (IQR)	67 (−7 to 200)	50 (17-80)[d]	.90
Multimedia situational test-before, median (IQR)	80 (50-100)	80 (60-80)[c]	.63
Multimedia situational test-after, median (IQR)	80 (70-90)	80 (80-100)[c]	.92
Percentage change in multimedia situational test, median (IQR)	0 (−30 to 92)	25 (0-33)[d]	.68
Learning satisfaction			
Global satisfaction score, median (IQR)	6 (4-7)	7 (5-9)[d]	.25

[a]Mann-Whiney *U* test (continuous variables) or Fisher exact test (categorical variables).

[b]IQR: interquartile range.

[c]*P*<.05, before versus after, Wilcoxon signed-rank test (two-tailed).

[d]*P*<.05, compared with a neutral value ("0" for multiple-choice question and multimedia situational test, or "5" for "global satisfaction score"), Wilcoxon signed-rank test (two-tailed).

Post Hoc Analysis

In this study, most of the participants were categorized as classical FI learners, and we were unable to determine which FI learners were more suitable for M-TEL using classical classification [26]. El-Banna proposed that a field-intermediate (FINT) category exists between FD and FI categories [31]. Accordingly, we adopted this modified classification of cognitive style (FD: <mean GEFT score − standard deviation [SD] × 0.25; FINT: ≥mean GEFT score − SD × 0.25 and ≤mean GEFT score + SD × 0.25; FI: >mean GEFT score + SD × 0.25); thereby resulting in three modified categories : FD: <16, n=15 (25%); FINT: ≥16 and ≤17, n=17 (28%0; FI: >17, n=28 (47%). Table 3 illustrates comparisons of these modified FD, FINT, and FI groups using modern classification. There were no significant differences in age, sex, M-TEL module, or MCQ or MST scores among the modified FD, FINT, and FI groups at baseline. Modified FI was independent of the M-TEL module and learning outcomes (all *P*>.05). Increases in MCQ and MST were significant in all three of these cognitive style groups. Although the differences in knowledge and competence gains were not statistically significant among the modified cognitive styles, the FINT group had a significantly higher satisfaction with M-TEL than the modified FD group regardless of which M-TEL module they used. The modified FINT learners had a significantly positive attitude toward M-TEL in terms of GSS, whereas the modified FD learners had the lowest GSS. Furthermore, the FINT learners using the IM module had a significantly higher GSS than those using the PPS module (*P*=.005). The modified FI learners had a positive attitude toward M-TEL in terms of GSS, and a significantly higher GSS when using the IM module compared with the PPS module (*P*=.02). We further compared the effect of modified cognitive style and M-TEL module on outcomes using Friedman test (Table 4). Both modified cognitive style and M-TEL module had significant effects on percentage changes in MCQ score and GSS. The M-TEL module had significant effects on MST score, whereas modified cognitive style did not have any significant effect.

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Table 3. Comparisons of demographics, learning models, outcomes, satisfaction, and experience among modified cognitive styles.

Variables	Modified field-dependent, N=15	Modified field-intermediate, N=17	Modified field-independent, N=28	*P* value[a]
Demographics				
Age in years, median (IQR[b])	23 (22-24)	23 (23-24)	23 (23-24)	.74
Male sex, n (%)	8 (53)	12 (71)	16 (57)	.56
Cognitive style				
Group embedded figures test score, median (IQR)	14 (12-15)	17 (17-17)	18	<.001
Learning module				
Interactive multimedia, n (%)	8 (53)	7 (41)	15 (54)	.69
Learning outcomes				
Multiple-choice questions-before, median (IQR)	50 (30-60)[c]	40 (40-50)[c]	40 (40-50)[c]	.47
Multiple-choice questions-after, median (IQR)	70 (60-80)[c]	70 (65-80)[c]	70 (53-70)[c]	.48
Percentage change in multiple-choice question, median (IQR)	40 (17-100)[d]	75 (33-100)[d]	45 (15-75)[d]	.34
Multimedia situational test-before, median (IQR)	80 (60-80)[c]	80 (60-80)[c]	70 (60-80)[c]	.74
Multimedia situational test-after, median (IQR)	80 (80-80)[c]	80 (70-100)[c]	80 (63-95)[c]	.83
Percentage change in multimedia situational test, median (IQR)	25 (0-33)[d]	25 (0-29)[d]	0.0 (0-37)[d]	.82
Learning satisfaction				
Global satisfaction score, median (IQR)	6 (3-7)	8 (7-10)[d]	7 (5-8)[d]	.02

[a]Mann-Whiney *U* test (continuous variables) or Fisher exact test (categorical variables).

[b]IQR: interquartile range.

[c]*P*<.05, before versus after, Wilcoxon signed-rank test (two-tailed).

[d]*P*<.05, compared with a neutral value ("0" for multiple-choice question and multimedia situational test, or "5" for "global satisfaction score"), Wilcoxon signed-rank test (two-tailed).

Table 4. Comparisons of the effect of modified cognitive style and module of mobile technology in electronic learning on outcomes.

Outcomes[a]	Test statistics	Standard error	Standard test statistics	*P* value	Adjusted *P* value
Percentage change in multiple-choice question					
Modified cognitive style–learning module	−0.53	0.18	−2.92	.003	.01
Modified cognitive style–percentage change	0.71	0.18	−3.88	<.001	<.001
Learning module–percentage change	−1.24	0.18	−6.80	<.001	<.001
Percentage change in multimedia situational test					
Modified cognitive style–learning module	−0.57	0.18	−3.10	.002	.006
Modified cognitive style–percentage change	0.11	0.18	0.59	.55	>.99
Learning module–percentage change	−0.46	0.18	2.51	.012	.04
Global satisfaction score			–		
Modified cognitive style–learning module	−0.52	0.18	−2.83	.005	.01
Modified cognitive style–global satisfaction score	−1.19	0.18	−6.53	<.001	<.001
Learning module–global satisfaction score	−1.71	0.18	−9.36	<.001	<.001

[a]Friedman's two way analysis of variance test.

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Discussion

Principal Findings

The main findings of this study are that M-TEL outside the classroom can help undergraduate medical students to strengthen their knowledge and competence of emergent ORL-HNS disorders, and to provide an enjoyable learning experience overall. In addition, our findings suggest that millennials can significantly gain knowledge rather than reinforce competence using an IM module. Despite the similar efficacy of both modules, the students preferred the IM module to the PPS module because of it being more efficient and enjoyable to use. Although the classical classification of cognitive style [26] did not seem to be associated with learning preference or outcomes, the modified FINT learners had the highest knowledge gain and satisfaction with M-TEL (especially the IM module) compared with the modified FD and FI learners [32]. With further controlling for the modified cognitive style, the PPS module enhanced competence compared with the IM module.

Limitations

There are several limitations to this randomized controlled trial. First, this study was quasi-experimental because of the lack of probability sampling. Even though we selected individuals based on their availability to the investigators, the sample size was representative of the target population (>50% were classmates). Second, the study used different posttest questions to measure learning outcomes, and the interaction between taking a pretest and the intervention itself may threaten the external validity. A design which does not use a pretest would have been preferable [33]. Third, we did not survey learning preferences, cognitive load, or self-direction in this short-term study. These factors have been reported to effect learning outcomes in modern medical curricula [16,34], and they should be closely monitored when students use this type of M-TEL app.

Comparison With Prior Work

As mentioned above, both the IM and PPS modules used the same textbook-based learning material. However, the IM module applied game-design elements and game principles in nongame contexts (gamification) [35]. The gamification of medical education is a rapidly growing field [32,36], and it has been shown to have the potential to improve knowledge [37], and increase motivation and engagement [38]. Our results demonstrate that M-TEL for medical education can facilitate the learning of complex topics with promising results in terms of gains in knowledge, competence, and satisfaction compared with other forms of e-learning [39-41]. However, the learners using the gamified IM model still struggled with performance in MSTs. Therefore, M-TEL may not be an approach that is suitable for all.

Teaching and learning processes are thought to be affected by various cognitive variables. If medical students receive training, which has been designed according to their individual needs, they may develop a sense of competence and positive self-perception [42]. Previous studies have shown that FI learners have higher levels of achievement and better problem-solving ability [43,44]. In this study, relatively few of our undergraduate medical students were classical FD learners, they did not seem to significantly gain knowledge or competence after the 100-min M-TEL module, and they were neutrally satisfied with this learning method. This may be due to the small sample size or suboptimal classification of cognitive style. Therefore, we applied the modified classification of cognitive style that has been used for gifted students [45] and classified our participants accordingly. Using this modified classification, we found that all of the participants significantly gained knowledge and competence after the M-TEL course regardless of cognitive style. In this short-term M-TEL course, the FINT learners had the significantly highest knowledge gain and satisfaction regardless of which M-TEL module they used compared with the modified FD and FI learners, who needed a more specific design of instructional material. For example, the FD learners needed an easy-to-use and follow style of M-TEL, whereas the FI learners wanted a more vigorous style of M-TEL, including engaging quiz games [23].

Medical teachers in Taiwan have traditionally assumed that medical students can automatically adapt to the instructional modality and material by themselves to learn a topic, regardless of whether or not they are effective. Although we previously postulated that both learning module and cognitive style could affect competence gain for UME, we found the undergraduate medical students using the PPS learning module had significantly higher improvements in competence, whereas there was no change in competence in the IM learners. Even though the IM module was more attractive and satisfactory than the PPS module, more integrated formats of instructional material were needed to reduce extraneous cognitive load to facilitate problem-solving performance [44]. Bertini et al [46] concluded that FI learners can effectively transfer tasks when they must be transferred to a novel situation and that they can identify the important aspects of ambiguous or disorganized information. However, in this study, modified cognitive styles did not significantly affect the MST outcomes whereas the learning module did (using Friedman test). Even though most of our participants had the FI cognitive style making them better suited to game-based tasks, but insensitive to situational cues, and the minority had the FD cognitive style resulting in divided attention and increased cognitive load in game-based processing, all of them had a similar posttest MST performance. Nevertheless, the high overall baseline MST score suggests that the study participants were previously equipped with an understanding of the clinical reasoning process [47] and that this helped them to predict the features of clinical situations, to determine the appropriate course of action, and to choose correct solutions in the MST. Even though they were novices in ORL-HNS, the high baseline scores created a buffer to achieve a significant increase in MST performance.

Since learners can start and stop M-TEL at any time or place of their choosing [48], this learning modality may be superior to traditional classroom lectures with regard to self-directed effort management and organized study, and allow them to achieve deep understanding by repeatedly reviewing the instructional materials. Because learning preference and satisfaction allow students to learn outside the classroom, cognitive style should be taken into consideration to design

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curricula to suit the style of the individual undergraduate medical student, thereby enhancing the effectiveness of M-TEL [49].

Conclusions

M-TEL using conventional PPS and novel IM modules seems to be an effective method to teach emergent ORL-HNS disorders to undergraduate medical students. The PPS module represented a formal, serious learning modality, whereas the IM module represented a satisfactory, enjoyable way for the millennial students to learn. Cognitive style and M-TEL module significantly affected knowledge gain and satisfaction, and the modified FINT learners had the highest gains in knowledge and satisfaction when using the IM module. These findings support the development of M-TEL, including various learning modules for undergraduate medical students with different cognitive styles.

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Authors' Contributions

LAL, YPC, SLW, CKC, and HYL participated in the conception and design of this work. LAL, YPC, CJK, LJH, WNL, TJF, and HYL collected data. LAL, YPC, CGH, JTF, SLW, CKC, and HYL analyzed and interpreted data. LAL, YPC, SLW, CJK, LJH, WNL, TJF, and HYL carried out the development of the project software. All authors participated in the writing of the manuscript and take public responsibility for it. LAL, YPC, CGH, JTF, SLW, CKC, and HYL revised it critically for important intellectual content. All authors reviewed the final version of the manuscript and approve it for publication. All authors attested to the validity and legitimacy of the data in the manuscript and agree to be named as authors of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

CONSORT-EHEALTH checklist V 1.6.1.

[PDF File (Adobe PDF File), 701KB - jmir_v20i2e56_app1.pdf]

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Abbreviations

FD: field-dependent
FI: field-independent
FINT: field-intermediate
GEFT: group embedded figure test
GSS: global satisfaction score
IM: interactive multimedia
IQR: interquartile range
MCQ: multiple-choice questions
MST: multimedia situational test
M-TEL: mobile technology in e-learning
ORL-HNS: otorhinolaryngology-head and neck surgery
PPS: PowerPoint show
UME: undergraduate medical education

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Original Paper

Impact of a Student-Driven, Virtual Patient Application on Objective Structured Clinical Examination Performance: Observational Study

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Abstract

Background: Peer-assisted learning (PAL) refers to a learning activity whereby students of similar academic level teach and learn from one another. *Groupe de perfectionnement des habiletés cliniques* (Clinical Skills Improvement Group), a student organization at Université Laval, Canada, propelled PAL into the digital era by creating a collaborative virtual patient platform. Medical interviews can be completed in pairs (a student-patient and a student-doctor) through an interactive Web-based application, which generates a score (weighted for key questions) and automated feedback.

Objectives: The aim of the study was to measure the pedagogical impact of the application on the score at medical interview stations at the summative preclerkship Objective Structured Clinical Examination (OSCE).

Methods: We measured the use of the application (cases completed, mean score) in the 2 months preceding the OSCE. We also accessed the results of medical interview stations at the preclerkship summative OSCE. We analyzed whether using the application was associated with higher scores and/or better passing grades (≥60%) at the OSCE. Finally, we produced an online form where students could comment on their appreciation of the application.

Results: Of the 206 students completing the preclerkship summative OSCE, 170 (82.5%) were registered users on the application, completing a total of 3133 cases (18 by active user in average, 7 minutes by case in average). The appreciation questionnaire was answered online by 45 students who mentioned appreciating the intuitive, easy-to-use, and interactive design, the diversity of cases, and the automated feedback. Using the application was associated with reduced reported stress, improved scores (P=.04), and improved passing rates (P=.11) at the preclerkship summative OSCE.

Conclusions: This study suggests that PAL can go far beyond small-group teaching, showing students' potential to create helpful pedagogical tools for their peers.

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KEYWORDS

peer-assisted learning; virtual patient; medical education; undergraduate

Introduction

Peer-assisted learning (PAL), whereby students of similar academic level teach and learn from one another during a structured activity, is becoming increasingly popular in medical schools worldwide [1]. PAL benefits both the student-teachers, who develop communication skills and consolidate their knowledge, and student-learners, who benefit from a safe learning environment and cognitive congruence with teachers who better understand their learner's perspective [2,3]. An area where PAL is particularly beneficial is the practice of medical interview and physical examination, for which autonomous

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study is insufficient and active learning with peers is essential [4,5]. One way by which students practice their interview and examination with peers is by presenting fictional cases to each other in the context of a mock Objective Structured Clinical Examination (OSCE) [6,7] or simply in a study group.

Thanks to advances in technology, the use of virtual patients (VPs) has a growing place in medical curricula worldwide [8,9]. VPs are a specific type of computer program that simulates real-life clinical scenarios for the purpose of medical education and assessment [8]. Although VP sharing initiatives like the Canadian Healthcare Education Commons– *Collaboration pour l'éducation en santé au Canada* Virtual Patient Working Group of the Association of Faculties of Medicine of Canada [10] exist, VPs are currently expensive to produce on a large scale (8). Medical students, born in the technological era, represent an undervalued resource to foster VP development through PAL.

As an attempt to bring PAL into the technological era, the *Groupe de perfectionnement des habiletés cliniques* (GPHC; translation: Clinical Skills Improvement Group) at Université Laval, Canada, created a collaborative VP platform containing over 220 peer-reviewed clinical cases. Cases were made available through an interactive Web-based application that allows students to practice their medical interview, receive automated feedback, and track their progression within their personalized profile. When launched in March 2016, the GPHC VP application was very well-received and used by most students for the OSCE study period. In this manuscript, we describe the development of the VP application and present a validation study on its impact on students' performance at the final preclerkship OSCE. We hypothesized that using the application would increase the likelihood of having a passing score at the OSCE and that the extent to which it is used (number of cases) would correlate positively with OSCE final score.

Methods

Development of a Web-Based Virtual Patient Application

The GPHC is a PAL organization formed by preclerkship medical students at Université Laval. Founded in 2010, the GPHC helps peers improve their clinical reasoning and physical examination skills by organizing PAL workshops and mock OSCEs. In addition to workshops, the GPHC collaborates with faculty members to develop pedagogical material, including the *Petit Guide des Habiletés Cliniques* (translation: Pocket Guide to the Physical Examination) and the *Petit Guide de l'Entrevue Médicale* (translation: Pocket Guide to the Medical Interview), summarizing the key aspects of the medical interview and physical examination to help students preparing for their OSCE. To complement these books, the GPHC sought to create a digital platform that facilitates the practice of the medical interview.

With the financial support from Université Laval medical students' investment funds, the GPHC hired 2 students in software engineering to develop a Web-based VP platform. In parallel, the GPHC launched a large-scale case writing campaign, through which over 100 medical students helped create 230 clinical scenarios. Students had to cite the references used to create their clinical scenario. Each case underwent a 2-level peer-review process—first from the student-author of the corresponding chapter of the pocket guide to the medical interview and then from a member of GPHC's executive committee. We collaborated with software engineers to produce an interactive Web-based application interface that would adapt to every device (computers, phones, tablets) and provide a score, automated feedback, and graphs to measure progression. At present, the application is used at Université Laval, Université de Montréal, McGill University, and Ottawa University, with 1150 active users.

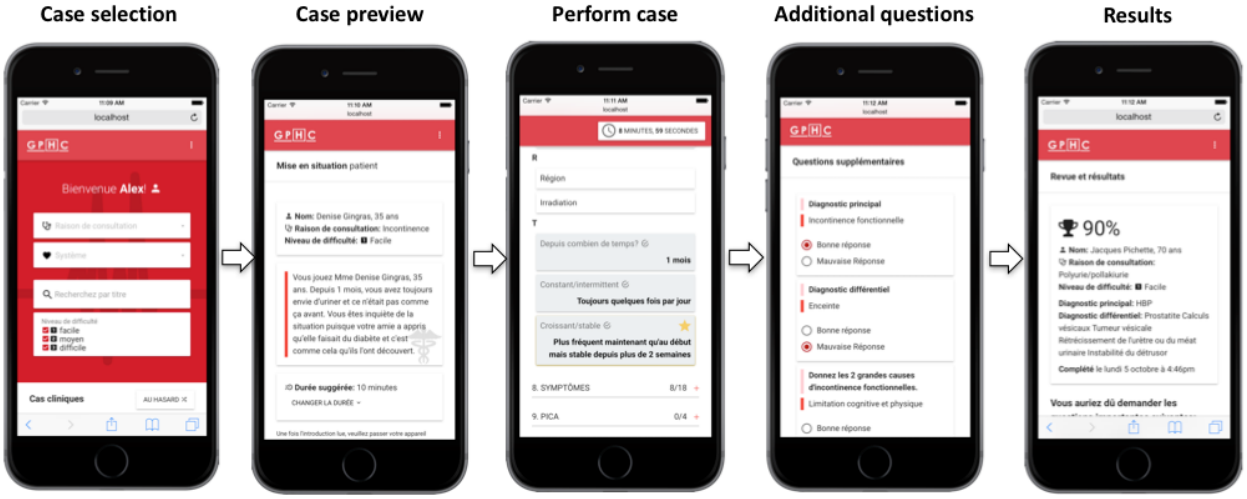
The application is designed to be used in pairs—by a student-patient and a student-doctor—in the following sequence (see Figure 1 for a summary): students first select 1 of the 230 cases based on a difficulty level (easy, moderate, hard), system (cardiology, pneumology, etc), or complaint (cough, nausea, fever, etc); for additional challenge, a random mode is available. Students can then set the time allocated to complete the case. Once a case is chosen, a case summary is presented to the student-patient, who can also preview the full questionnaire to analyze how the case is structured. In all clinical scenarios, questions are ordered in the prototypical, structured manner that is taught in classrooms. Then, a case statement is formulated to the student-doctor: "M. Gagnon, 56 years old, presents for diarrhea. Proceed to the questionnaire to determine the most likely cause of his symptoms."

When the student-patient starts the simulation, the timer starts ticking and the student-doctor has a limited time to ask questions (can be set at 6, 8, 10, or 12 minutes). When questions are asked, the patient clicks on the question on the application and the answer appears. The application records each question asked. When time is over, the student-doctor is asked additional questions: "What is the most likely diagnosis?" "Can you name 3 probable alternate diagnoses?" and 2 additional questions (usually on management or physiopathology). The application then generates a score based on the questions asked, weighted for key questions.

In each scenario, 10 questions are rated as most important by the case-writer and reviewers, either because they give a good lead on the differential diagnosis or because they are essential to eliminate an imminent dangerous condition. Some aspects of communication, concerning, for instance, the patient's agenda (concerns, ideas, and expectations), were included as key questions in some cases. The total score is based on the following: 50% for key questions (5% each), 15% for primary diagnosis, 15% if differential diagnosis was adequate, and 20% for other nonkey relevant questions (eg, allergies, habitus, review of systems), with a 5% bonus for 2 additional questions. This score calculation was chosen to reflect clinical reasoning over reciting a list of undifferentiated questions. The application also generates an automated feedback, summarizing which key questions were asked or forgotten, reinforcing the student's ability to execute a medical interview.

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Figure 1. Interface of the Web-based application.



After the case is finished, students are asked to rate their appreciation of the case and formulate comments (eg, flag errors, recommend other alternate diagnoses for the list) so that case quality is improved over time by revision from GPHC's executive committee. Scores and feedback for every completed case are kept in a personalized profile where students can track their progression (score to each case, cumulative average), compare to other users (percentile for each case, each system, and overall), and consult previously completed cases. Finally, frequent users are offered the opportunity to give back to their peers by writing new cases, which undergo peer review before being added to the case list.

Validation Study Design

Université Laval's preclerkship medical program can be completed in 2, 2.5, or 3 years. At the end of the curriculum, students must pass a summative OSCE to continue toward their clerkships. On May 22, 2016, 206 students underwent their preclerkship summative OSCE. Of these students, 170 (82.5%) were registered users on GPHC's application. We compiled every case (duration >3 minutes) performed by the students during the 2 months preceding the OSCE (3133 cases total; 18 per student on average). Students were informed that data collected in the application could be used for research purposes. We divided cases into 5 periods: period 1 (week preceding the OSCE, May 15 to May 21), period 2 (the preceding week, May 8 to May 14), period 3 (the preceding week, May 1 to May 7), period 4 (the preceding week, April 24 to April 30), and period 5 (the 3 preceding months, January 1 to April 23).

We calculated the number of cases of >3 minutes completed by each student in each period as well as their average score in each period. With the approval of the medical program and ethics review board, we accessed the results of the summative OSCE stations. We calculated a mean of the medical interview stations. Finally, we produced an online appreciation form asking students to rate statements on a 5-point Likert-type scale (from 1=strongly disagree to 5=strongly agree) and comment about what they like about the application. We analyzed answers to open questions using inductive thematic analysis [11]. Primary outcomes were student's OSCE score and likelihood of passing preclerkship OSCE. Secondary outcomes were correlation between application use and OSCE score, increase in application scores over time, and thematic analysis of the online appreciation form. The research protocol was accepted by Université Laval ethics review board (*Comité d'éthique de la recherche avec des êtres humains de l'Université Laval*).

Statistical Analyses

All statistical analyses were performed in SAS 9.3 (SAS Institute Inc). Significance level was set at $P<.05$. We dichotomized the score at final preclerkship OSCE between the student who passed the medical interview section of the OSCE (score ≥60%) and failed it (score <60%). We also dichotomized students based on their use of the application (≥10 versus <10 completed cases). The cutoff of 10 cases was selected after initial analysis of the data to allow for balanced group size. We used logistic regressions to measure whether completing ≥10 cases on the application increased a student's likelihood of the passing preclerkship OSCE. We used a 1-sided Student *t* test to determine whether students who completed ≥10 cases had higher scores than those who completed <10 cases. We also used linear regressions to measure the association between use of the application (total number of cases completed) and the mean score on the application and the final preclerkship OSCE. We calculated a 95% confidence interval of R^2 determination coefficient.

Results

For the 206 students who underwent their preclerkship summative OSCE, 182 (88.3%) passed the medical interview section and 24 (11.7%) failed. During the study period, 3133 cases were completed by the 170 users (18.4 per student on average). Most cases (2224/3133, 70.99%) were performed in the 2 weeks preceding the summative OSCE (see Table 1). Average scores steadily improved from 69.8% in period 4 (April 24 to April 30) to 80.5% in period 1 (May 15 to May 21, summative OSCE being on May 22). A slight decrease was observed between period 5 (74.1%) and 4 (69.8%).

Frequent users of the application (≥10 cases completed) had significantly higher scores (66.9% SD 5.5) on the OSCE medical interview sections than those who completed <10 cases (65.5%

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SD 5.6, *P*=.04). They also trended toward a higher likelihood of having a passing grade in the medical interview sections (90.3%) than those who completed <10 cases (86.3%, *P*=.11, not significant). Total number of cases completed had a low correlation with the OSCE medical interview score (R^2=.02, 95% CI –0.01 to 0.284; see Figure 2).

The appreciation questionnaire was answered online by 45 students (see Table 2). Students who answered the questionnaire were for the most part frequent users of the application (91% with >10 completed cases, 62% with >20 cases). The questions reaching the greatest consensus were "I prefer to use only the pedagogical material provided by professors because I do not trust the quality of material produced by peers" (median 2) and "I feel that practicing with GPHC's application has helped me to better structure my anamnesis" (median 5). In their comments, convergent themes revealed by inductive thematic analysis were the intuitive, easy-to-use, and interactive design, the diversity of cases, and the automated feedback (see Textbox 1).

Table 1. Use of the application throughout the study period.

Period	Dates	Cases completed, n	Active users, n	Cases by active users, mean (SD)	Average score, mean
5	January 1 to April 23	79	17	4.9 (7.3)	74.1
4	April 24 to April 30	109	26	4.4 (3.2)	69.8
3	May 1 to May 7	729	91	8.1 (6.4)	75.2
2	May 8 to May 14	962	125	7.8 (6.1)	76.0
1	May 15 to May 21	1254	130	9.7 (7.6)	80.5
Total	January 1st to May 21	3133	170	18.5 (17.2)	79.7

Figure 2. Relationship between number of completed cases on the application and the Objective Structured Clinical Examination score (OSCE).

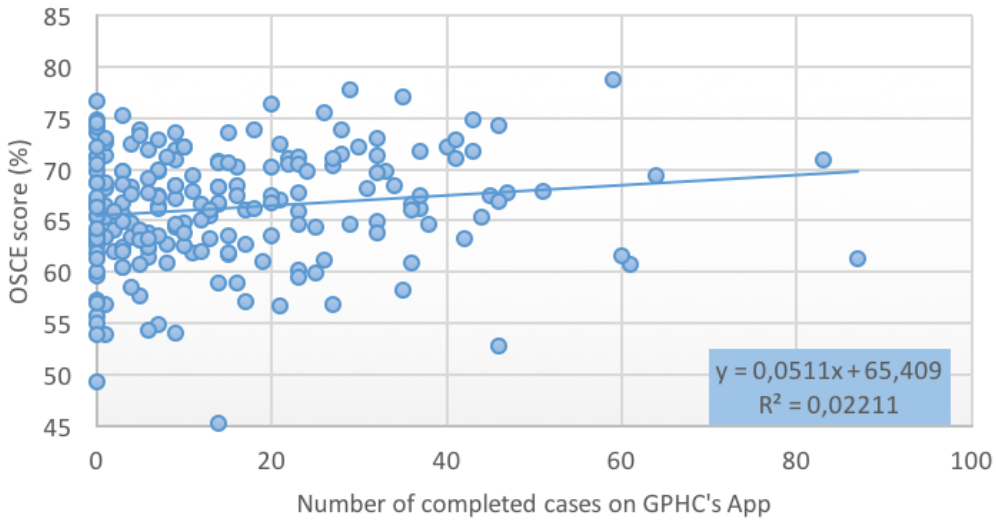


Table 2. Results of the appreciation questionnaire.

Statement	Median[a]
I prefer to use only the pedagogical material provided by professors because I do not trust the quality of material produced by peers.	2
I prefer practicing the clinical examination by actively performing cases in the application to autonomous study in books.	5
I feel that practicing with the GPHC[b]application has helped me to better structure my anamnesis.	5
I feel that practicing with GPHC's application has helped me to improve my clinical reasoning.	5
Practicing with GPHC's application has improved my confidence regarding the summative OSCE[c].	5
Practicing with GPHC's application has reduced my stress level related to the summative OSCE.	4

[a]Score represent a 5-point Likert-type scale, from 1=strongly disagree to 5=strongly agree.

[a]GPHC: *Groupe de perfectionnement des habiletés cliniques.*

[a]OSCE: Objective Structured Clinical Examination.

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Textbox 1. Comment sample from the appreciation questionnaire.

Increase efficiency

- "The large bank of peer-reviewed clinical cases saves us the time we would take to write cases, that we can use more efficiently by doing more cases on the app!"
- "The app allows us to do more cases without having to write them ourselves, which increases the efficiency of our study."
- "Interactive, lots of cases easily available, simple to use, I love it!"

Easy to use

- "The app allowed me to practice my OSCE with relatives who do not have a medical background."
- "It is interactive, and we can even practice with people who do not study medicine!"

Get out of our comfort zone

- "The diversity of the cases helps us identify our weaknesses and exposes us to cases we would not write inside our study group."
- "The random mode allows us to get out of our comfort zone and be prepared for a wide variety of cases."

Weaknesses

- "...however, some cases still contain errors. Hopefully the feedback function will allow you to improve them over time."

Discussion

Principal Findings

As a student-led PAL organization, we developed a collaborative VP platform to improve medical interview skills among preclerkship medical students. The Web-based interactive application was used by 82.5% (170/206) of students in their preparation for the summative preclerkship OSCE, who appreciated the intuitive, easy-to-use, and interactive design, the diversity of cases, and the automated feedback. Students who used the application reported reduced stress levels related to the preclerkship summative OSCE. We conclude that students can successfully create learning tools that potentially improve their peers' performance at summative evaluations.

This initiative represents a unique contribution to the eLearning field. We believe that most current VP platforms are ill-suited to many aspects of the development of history-taking, examination, communication, and procedural skills of novice learners [12]. They usually consist of single-user clinical scenarios where the student has to interrogate the patient (computer) by selecting questions, physical examination maneuvers, and laboratory tests to perform and ultimately commit to a diagnosis and/or management plan. By displaying a list of questions and maneuvers, they prevent students from thinking of questions themselves, artificially relieving them from practicing an important part of the clinical examination. Indeed, one of the main difficulties novices face during clinical examination is cognitive overload, whereby they devote so much cognitive capacity to determining which questions to ask (or maneuvers to execute) that they have insufficient cognitive resources to simultaneously interpret findings in light of their differential diagnosis [13].

Our VP application, designed to be used in groups of 2 students (a student-patient and a student-doctor), places users in a much more realistic clinical environment, where they have to simultaneously determine which questions to ask and interpret answers. Another benefit of our student-run VP platform is its low cost. From a medical program perspective, developing a VP is currently costly, as 85% cost more than $10,000 per case and 37% cost more than $50,000 per case [14]. For a total cost of Can $23,000 (US $18,700) (plus $3,000 per year for system maintenance), the GPHC application is an autonomous collaborative platform containing over 220 VP scenarios.

Our VP application also represents a novel and important advance in the field of PAL. To our knowledge, this is the first peer-led VP platform in which students can create, revise, and use clinical scenarios. Most PAL initiatives reported to this date consist of small-group workshops and/or mock OSCE exams [1,3,6,7]. Using technology to foster collaboration, our application allows clinical cases created in a given study group to be used by all their colleagues and even future generations of students. The pedagogical material is self-improving through the contribution of users, who are asked to comment on existing cases (flagging errors, rating case quality) and submit new cases. Peer review of cases is performed by committee members of the PAL organization (GPHC). The result is a high-quality, self-improving VP platform helping students actively practice their medical interview and clinical reasoning.

Limitations

Our study has limitations. First, motivation level represents a potential bias, as it influences both the use of the application and the use of traditional pedagogical tools (hence the OSCE score). Since we could not control for motivation level, we cannot exclude that the use of the application represents a sign of motivation and good studentship rather than a cause of good test results. Second, the effect of application use on OSCE scores, although significant at some statistical tests, remains modest. It was predicted from the start that application use would only marginally explain OSCE scores, as a variety of other factors are involved in test scores. Third, the fact that most students who answered the appreciation questionnaire were frequent users of the application may have led to an

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overestimation of positive answers. Likewise, reasons why nonusers have favored other study tools could not be evaluated. Nevertheless, the fact that the majority of students (83%) adopted the application as a significant study tool (18 cases per user on average) despite it being totally optional remains in our opinion the study's most compelling result. Since they typically have a busy schedule and a wide variety of study tools at their disposition, medical students are very critical of the tools to which they will devote study time; their confidence in our student-led VP platform hence reflects its helpful complementarity with faculty-provided material.

Conclusion

GPHC's Web-based application is a student-run, collaborative VP platform. To our knowledge, it is the first digital PAL initiative of its kind. The application is highly appreciated among students, and its use was associated with increased scores at the summative preclerkship OSCE.

Conflicts of Interest

None declared.

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Abbreviations

GPHC: Groupe de perfectionnement des habiletés cliniques
OSCE: Objective Structured Clinical Examination
PAL: peer-assisted learning
VP: virtual patient

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Review

Peer-Based Social Media Features in Behavior Change Interventions: Systematic Review

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Abstract

Background: Incorporating social media features into digital behavior change interventions (DBCIs) has the potential to contribute positively to their success. However, the lack of clear design principles to describe and guide the use of these features in behavioral interventions limits cross-study comparisons of their uses and effects.

Objective: The aim of this study was to provide a systematic review of DBCIs targeting modifiable behavioral risk factors that have included social media features as part of their intervention infrastructure. A taxonomy of social media features is presented to inform the development, description, and evaluation of behavioral interventions.

Methods: Search terms were used in 8 databases to identify DBCIs that incorporated social media features and targeted tobacco smoking, diet and nutrition, physical activities, or alcohol consumption. The screening and review process was performed by 2 independent researchers.

Results: A total of 5264 articles were screened, and 143 articles describing a total of 134 studies were retained for full review. The majority of studies (70%) reported positive outcomes, followed by 28% finding no effects with regard to their respective objectives and hypothesis, and 2% of the studies found that their interventions had negative outcomes. Few studies reported on the association between the inclusion of social media features and intervention effect. A taxonomy of social media features used in behavioral interventions has been presented with 36 social media features organized under 7 high-level categories. The taxonomy has been used to guide the analysis of this review.

Conclusions: Although social media features are commonly included in DBCIs, there is an acute lack of information with respect to their effect on outcomes and a lack of clear guidance to inform the selection process based on the features' suitability for the different behaviors. The proposed taxonomy along with the set of recommendations included in this review will support future research aimed at isolating and reporting the effects of social media features on DBCIs, cross-study comparisons, and evaluations.

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KEYWORDS

systematic review; social media; behavior control; health behavior; behavioral medicine; eHealth

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Introduction

Supporting positive change in health behavior is a widely explored and active area of research commonly referred to as behavior change intervention (BCI) [1]. With advances in information and communication technologies (ICTs), researchers have developed digital behavior change interventions (DBCIs) [2], in which digital platforms such as the Web are used to deliver interventions targeting individuals whose physical locations may be different from that of the intervention provider, thus expanding the reach of the intervention. Along with this, DBCI presents other benefits such as reducing the financial and human resources usually required as input at such scale and enabling participants to engage with the interventions at times of their own choosing.

Social Media in Digital Behavior Change Interventions

Using technologies such as the Web and sensor-rich phones potentially brings a tremendous leap toward large-scale BCIs. However, although many interventions focus on working at the individual participant level, an enormous amount of information that individuals share naturally with one another along with the accompanying peer support exchanged are left untapped. The use of social media features may provide new mechanisms to better understand individuals' context and behaviors. These Web-based features enable users of an intervention to communicate or share data in virtual communities. A few examples of social media features are as follows: user profiles, groups, polls, online forums, etc. The features can help enhance the overall effectiveness of DBCIs by encouraging social interactions within interventions, promoting social support, and facilitating the adoption of social norm approaches. Social media features have been shown to be beneficial within intervention as identified in previous research in terms of increased motivation level and engagement with the interventions, for example [3-5].

A recent systematic review, which examined the use of online social networks (OSNs) in health BCIs, identified 10 research studies matching their set of criteria [6]. The use of social media features in DBCIs is an area of research that requires further examination. Two reviews exist that applied different search criteria, which did not seek to capture the full range of social media features included within DBCIs, including online forums, chat rooms, blogs, etc, which are not always defined within OSNs [7,8]. Systematic reviews with regard to the use of social media features in DBCIs that have been published tend to target only 1 [9,10] or 2 [11] out of the 4 behavioral risk factors published by the World Health Organization (WHO) as leading risk factors for global disease burden, which included tobacco smoking, alcohol use, physical inactivity, and diet [12]. This makes it hard to facilitate comparison across behaviors.

Systematic Review of Social Media Inclusion

This review systematically identifies and analyzes peer-reviewed publications of DBCIs that include social media features or OSNs and target tobacco smoking, diet and nutrition, physical activities, or alcohol consumption. This creates an opportunity to have a better understanding about their effectiveness and how this differs for the various targeted behaviors. Although a taxonomy for the reporting of BCIs that focuses on standardizing definitions of techniques included in them was published [13], a corresponding taxonomy would be beneficial for social media features. Specifically, this paper presents the construction of a taxonomy of social media features, which will help in analysis and also provide guidance for selecting and including these features in interventions targeting specific risk factors. The behavioral outcomes in terms of users' engagement and perceptions with regard to the inclusion of social media features are presented and analyzed. The impact and effectiveness of each of these features are also reported. A set of recommendations based on this review's findings has been included to help researchers who are planning to include social media features in their behavioral interventions.

Methods

Identification of Studies

Information sources included literature searches that were conducted in the following health-related and multidisciplinary databases to ensure both the technical and behavioral aspects of interventions could be captured: Web of Science, Scopus, Engineering village, Medline, ERIC, CINAHL, PsycINFO, ProQuest, and Cochrane. Combined variants of relevant terms from the social media and DBCI domains were used to build a search query (eg, common social media terms such as *Facebook* and *forum* combined with terms such as *online* and *Web* and target behaviors such as *diet* and *smoking*). After refinements by 2 independent researchers, the finalized search query (see Multimedia Appendix 1) was used to conduct the searches. The search was conducted on November 30, 2015, with a time range between the year 2000 and the search date.

Screening Process

The search results were downloaded, combined, and sorted for an initial filtering to remove duplicates. Then, 2 independent reviewers went through separate but identical copies of the result-set of unique entries to flag the nonrelevant ones based on our inclusion and exclusion criteria by going through their titles and abstracts. Differences were then resolved through consultation. The same reviewers conducted a subsequent eligibility screening of the remaining full-text articles.

To be included in the review, studies had to be (1) in the form of published and peer-reviewed full-text articles from conferences and journal papers and (2) targeting at least one of the following modifiable behavioral risk factors published by the WHO: "Tobacco use, physical inactivity, unhealthy diet and the harmful use of alcohol" [12].

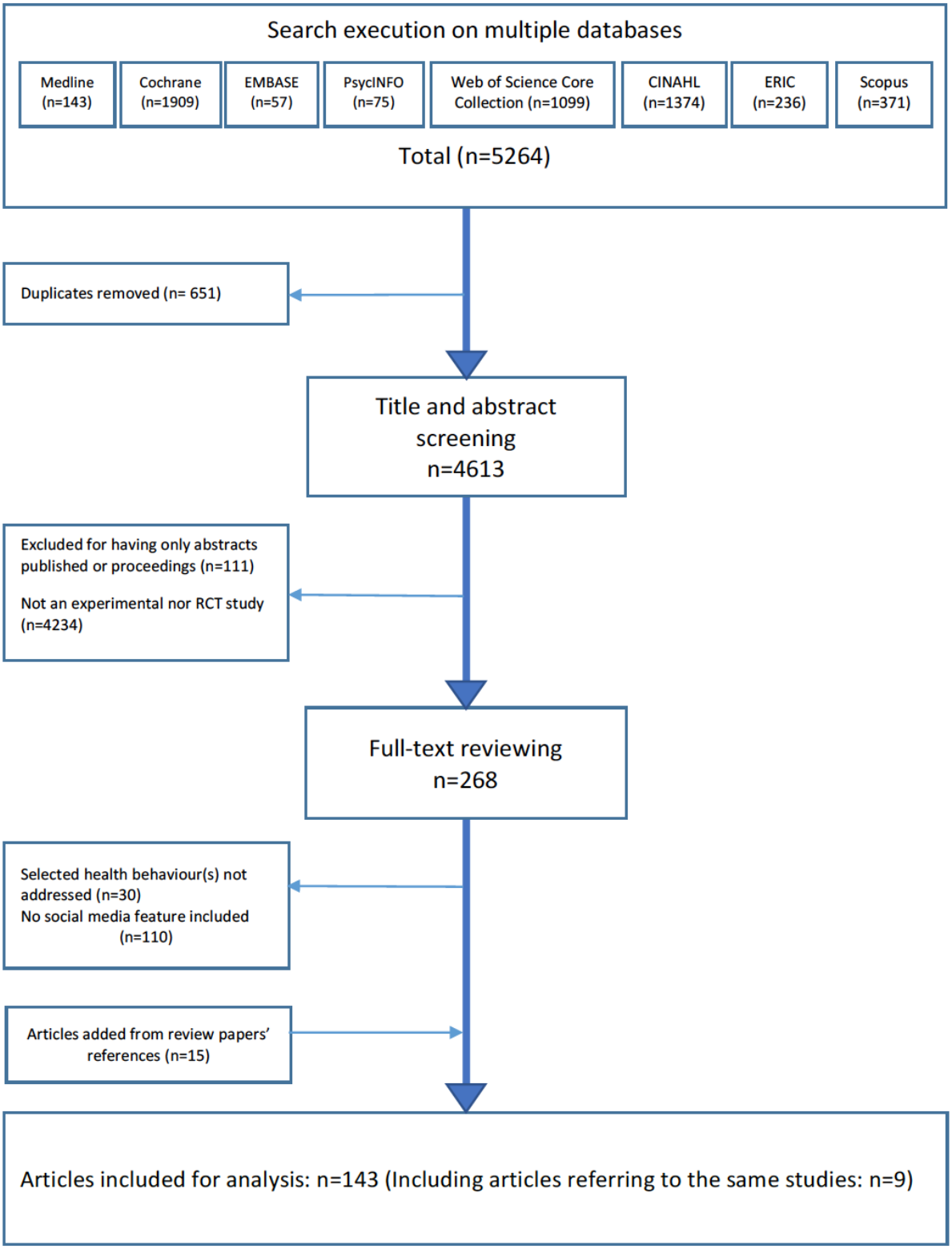
No restrictions were placed on sample population used; participants from all age groups (including minors), gender, and health status were eligible for inclusion. Review papers for behavioral interventions that included references to studies matching our selection criteria were manually searched to identify studies that might have been missed in our initial search.

A total of 143 publications were retained for data extraction and analysis as presented in Figure 1 according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. Out of these, 8 studies were reported

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through more than 1 publication (7 studies with 2 publications each and 1 study with 3 publications). Therefore, 134 studies were analyzed. Among these studies, 74 adopted a randomized controlled trials (RCT) design, with the remaining favoring a mostly experimental approach. However, they all provided valuable insights of social media features in their evaluation and were, therefore, included.

Figure 1. Flow diagram of the studies' inclusion process.



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Data Extraction and Analysis

A data extraction table was used to record key details for each study being reviewed (see Multimedia Appendix 2). Two reviewers were involved in this process. The first one performed the actual extraction, whereas the second reviewer verified the extracted data. The outcome of each of the studies was classified as positive, neutral, or negative. This classification was done by comparing the objective(s) and hypothesis stated for the studies with their reported results and findings. For studies that adopted an RCT design, when their intervention arm(s) were more effective than their control arm(s) by either or both the extent of change in behavior and the number of participants successfully adopting healthier behaviors, they were considered as having a positive outcome. In cases where no significant difference was reported between the intervention and control arms, the studies were considered as having a neutral outcome. Finally, for studies in which the control arm(s) were more effective in improving participants' behavior than the intervention arm(s), the outcome was classified as negative. However, in the last situation, the reason(s) behind the control group outperforming the intervention arm would require further investigation, which is out of the scope of this review. Similarly, the same methods were adopted for studies with experimental or prepost designs by comparing the initial objective(s) and hypothesis with the studies' findings.

The data table was analyzed for patterns of social media features' inclusion in the different interventions to determine whether there was any correlation with the studies' outcomes. The data were also used to inform the development of the taxonomy of social media features.

Results

Study Characteristics

A breakdown of the 134 studies reviewed, categorized by their targeted behaviors, is shown in Table 1. The majority of the studies targeted physical activity, either as a single behavior or in combination with other behaviors such as diet and nutrition. Alcohol consumption was addressed by the fewest number of studies.

Taxonomy of Social Media Features

An initial prereview literature search was undertaken to identify potential social media features for incorporation in the search query for the review. The data extraction process for the publications reviewed led to the identification of an initial list of 29 social media features, with 70.1% (94/134) of the studies using more than 1 of these features. An initial set of hierarchical categories was then proposed and compared with one of the closest and related taxonomy published, which was by Michie et al [13]. This was undertaken by the main researcher and was reviewed by an independent researcher. Out of the 16 groups of techniques in Michie et al's taxonomy, 6 of them were found to be relevant to social media features used in behavioral interventions, namely, goals and planning, feedback and monitoring, social support, comparison of behavior, reward and threat, and finally, identity. However, because of the fact that some social media features tended to be in multiple groups of techniques, a new hierarchical categorization better adapted for these features was proposed. This has been reviewed by 2 independent researchers to reach the final version presented in this paper. It is important to note that this taxonomy does not include an exhaustive list of social media features, but instead focused on those that are included in the 134 studies in this review. The list of social media features has been adapted to match the proposed taxonomy, which required in some cases the merging of 2 or more features (eg, blog and testimonial, and experience sharing) or the splitting of specific features into multiple ones (social challenge, contest, or competition). The final version of the taxonomy is presented in Figure 2.

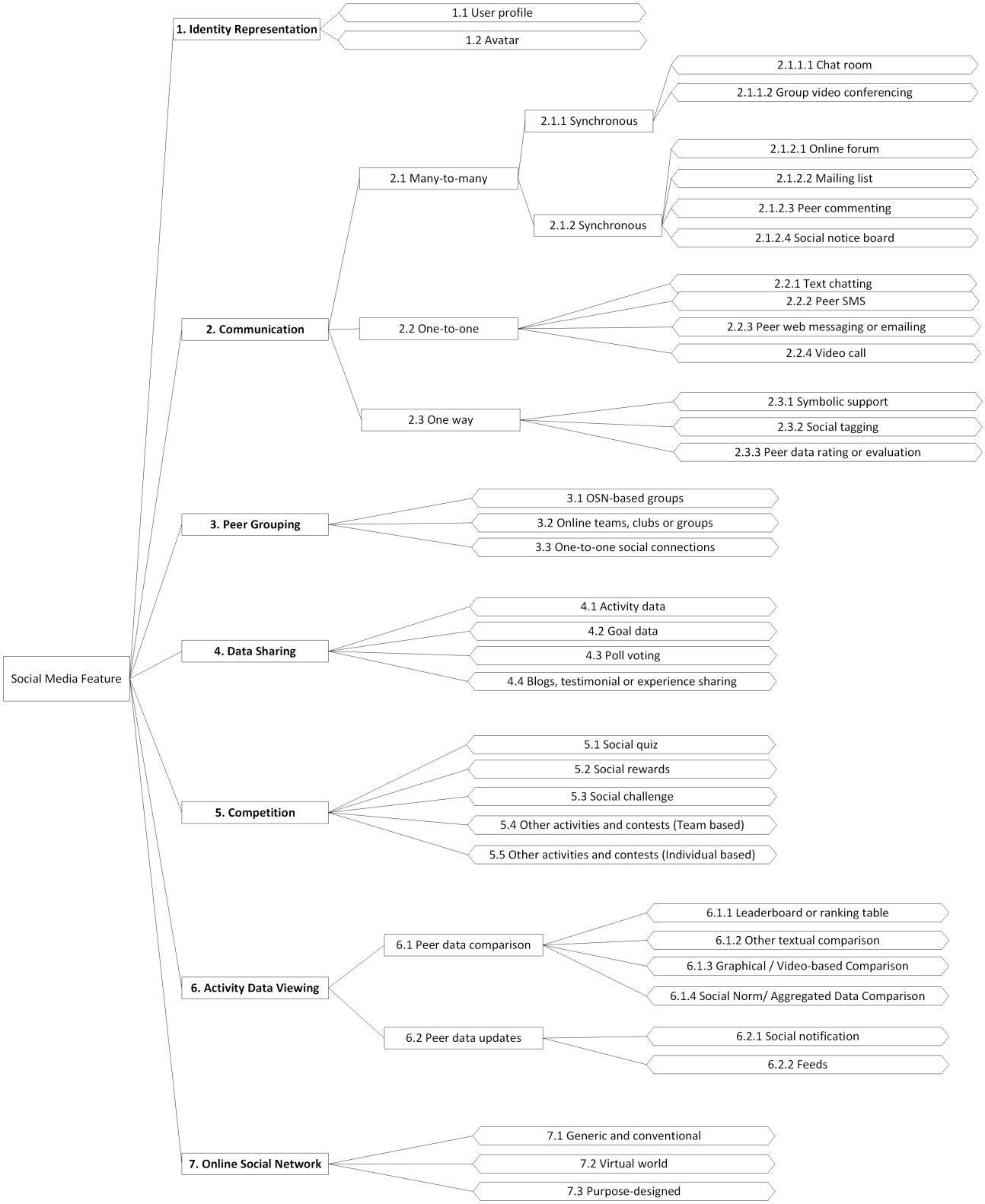
Seven main categories of social media features have been identified, which are described in Table 2. A brief description of each social media feature in the taxonomy is provided in Multimedia Appendix 3.

Table 1. Breakdown of number of studies by addressed behaviors.

Addressed behaviors	n (%)
Alcohol consumption	5 (3.7)
Diet and nutrition	7 (5.2)
Diet and nutrition + physical activity	11 (8.2)
Diet and nutrition + physical activity + alcohol consumption	1 (0.7)
Physical activity	38 (28.4)
Physical activity + smoking cessation	1 (0.7)
Smoking cessation	25 (18.7)
Weight loss or weight maintenance + diet and nutrition	3 (2.2)
Weight loss or weight maintenance + diet and nutrition + physical activity	43 (32.1)
Total number of studies analyzed	134 (100.0)

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Figure 2. Taxonomy of social media features.



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Table 2. Categories of social media features.

Number	Category	Description
1	Identity representation	Used to provide information about an individual and his or her activities to peers and are usually customizable by the participant. This is usually either in the form of user profiles or avatars
2	Communication	Enable intervention participants to communicate with one another and could be further categorized as many to many (eg, chat rooms), one to one (eg, peer emailing), and one way (eg, thumbs up or likes)
3	Peer grouping	Grouping of participants based on characteristics such as age, geographical locations, or part of the same intervention arm, while ensuring that they are aware about others in their group and with the possibility to have some form of direct or indirect communication. Groups can consist of a minimum of 2 participants or[a] OSN-based and non-OSN–based groups with more than 2 individuals
4	Data sharing	Enable participants of an intervention to share data about their activity, goals, or experience to either or both other participants and nonparticipants
5	Competition	Designed to introduce a competitive aspect in interventions through the use of features that enable participants to feel motivated while competing against one another (eg, social quiz)
6	Activity data viewing	Provide access to activity data of peers to participants through either regular updates (feeds and notifications) on a timely basis or enable them to compare their own data with that of their peers (eg, leaderboards)
7	Online social network (OSN)	The use of an Internet-based platform for enabling social interaction among intervention participants. OSNs can be subcategorized as either Generic and Conventional type (Facebook, mySpace, Twitter), Virtual World (SecondLife), or Purpose Designed (Yahoo Diet Diary, iWell, QuitNet, other intervention-specific proprietary OSNs). OSNs although being considered as a social media feature, usually act as a container for multiple other social media features

[a]OSN: online social network.

An important aspect to bear in mind when working with this taxonomy is that the different categories and their subcategories are not mutually exclusive and social media features are classified according to their most predominant properties. An example of an overlap between data sharing and peer data updates, where both are about the sharing of data, is that, for the latter, a user would receive updates about other peers without the peers actively involved in the sharing process (shared in an automated fashion), whereas, for the former, the peers would be actively sharing specific data with specific individuals or groups and could possibly have more fine-grained control over the sharing process.

Social Media Features' Inclusion

Communication-based features were the most prevalent and were included in a majority of studies, as shown in Table 3. Features from the competition, OSN, and identity representation categories were the least prevalent. The other high-level categories were peer grouping, activity data viewing, and data sharing. The inclusion of social media features from the different categories does not appear to differ by specific behaviors targeted. The only anomaly with this trend was for alcohol consumption. Studies with combinations of multiple behaviors were considered for each behavior individually.

The inclusion of specific social media features in studies targeting the different behaviors is presented in Multimedia Appendix 4.

When considering which addressed behaviors had the highest inclusion rate for each social media feature, physical activity and smoking cessation each had 11 highest inclusion rate instances, followed by dieting or nutrition and alcohol consumption with 5 instances each, and finally, 3 instances for weight loss or maintenance. The set of social media features that were the most included ones remained unchanged across all the behaviors considered in this review, except for alcohol consumption. These were online forums, social connections, and user profiles.

Social media features under the communication category remained the most popularly included across all the 5 behaviors considered in this review. Most of the studies included at least one social media feature based on communication, and with a consistent inclusion rate, 6 out of 10 studies in this review have made use of online forums as part of their interventions.

Features from the identity representation category and peer grouping category were more prevalent in interventions that addressed smoking cessation compared with other behaviors, with none of the interventions that targeted alcohol consumption using any of the features from this category.

Physical-activity related interventions were the most likely to include social media features from the competition category through social rewards. However, the highest inclusion rate from this category was below 12%. Although none of the interventions that addressed alcohol consumption included competition-based features, 2 smoking cessation interventions used features from this category, which included social quiz or activities and contests (individual-based) features.

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Table 3. Studies that included social media features from the different categories.

SMF[a] categories	Studies' references
Communication	[3,5,14-141]
Peer grouping	[3,5,7,8,14,15,19,26,29-32,34,35,38,46,49,50,55,57,58,60,66,67,69,73,76,80,82,83,85,87,89,91,92,97,104-106,110,112,113,118,121,124,126,127,129,130,133,139-147]
Data sharing	[3,14,19,26,31,32,34,38,41-43,46,49,54-57,59,60,72,73,76,80,81,85,92,97,103-106,110,112,118-120,126,127,133,138,146,148-150]
Competition	[3,5,7,8,15,19,38,39,42,46,49,50,54,57,67,87,91,98,104,109,112,118,133,142,151,152]
Activity data viewing	[3,5,7,8,14,19,26,27,29-32,34,38,39,46,49,50,54,55,57,58,60,66,67,73,76,80-83,85,87,91,92,97,103-105,126,127,129,130,133,142-145,147-149,151,152]
Online social network	[3,5,14,15,19,26,29-32,35,46,49,55,57,58,60,67,69,76,80,83,85,91,92,97,104,105,114,118,126,129,130,133,138,140,141,143-145]
Identity representation	[3,5,14,15,19,26,29-32,35,38,40,46,49,50,54-58,60,67,76,80,82,83,85,91,92,97,98,104,105,126,129,130,134,140,141]

[a]SMF: social media features.

Table 4. Interventions reported outcomes while including social media features from the different categories.

Study outcome	Communication, n (%)	Peer grouping, n (%)	Data sharing, n (%)	Competition, n (%)	Activity data viewing, n (%)	Online social network, n (%)	Identity representation, n (%)
Studies with positive outcome	88 (71.0)	47 (84)	40 (93)	20 (77)	40 (80)	31 (84)	34 (87)
Studies with neutral outcome	33 (26.6)	9 (16)	2 (5)	6 (23)	10 (20)	6 (16)	5 (13)
Studies with negative outcome	3 (2.4)	0 (0)	1 (2)	0 (0)	0 (0)	0 (0)	0 (0)

For the peer data comparison subcategory of activity data viewing, interventions addressing physical activity were the most likely to include these features compared with other behaviors, with only 1 study in alcohol consumption and another from smoking cessation including a feature from this category.

OSNs of generic and conventional types were most popular in studies addressing weight loss or weight maintenance, followed closely by diet and nutrition and physical activity interventions. On the other hand, virtual worlds were included the most in interventions addressing smoking cessation. Although there was not much difference in the inclusion rate for purpose-designed OSNs for the 4 behaviors, studies that targeted smoking cessation used them the most.

Social Media Features and Behavioral Outcomes

The majority of studies were classified as having positive outcomes (94/134, 70%), followed by neutral outcomes (37/134, 28%) and negative outcomes (3/134, 2%). Table 4 presents an analysis of the prevalence of social features by study outcome.

The majority of studies that included social media features reported positive outcomes, with the lowest percentage being 71% for the communication category and the highest at 93% for data sharing. Out of the 134 studies reviewed, only 4 studies reported negative outcomes. This trend persisted consistently across all the 5 behaviors considered, as shown in Table 5.

Studies that included social media features from the data sharing category were more likely to report positive outcomes for all the behaviors considered as compared with features from other categories. For example, one intervention that addressed physical activity, diet and nutrition, and weight loss or weight maintenance enabled participants to use blogs to share their personal experience [26]. In line with this, testimonial sharing was included in several studies addressing smoking cessation [14,31,32,55], which encouraged participants to share their own experience with others. Most of these studies also enabled the sharing of quit-smoking goals among one another. Although in most studies, data sharing through the variety of features under this category was initiated by participants, at least one study [34] addressing physical activity provided a functionality for participants to request others to share their data, which in this case was step counts. Haines-Saah et al [58], who used an OSN-based private group (peer-grouping category) for enabling participants to post photos (Data sharing category), reported gender bias in terms of engagement, whereby female participants tended to share more pictures and remained engaged for a longer period of time.

This was followed by identity representation and OSNs, both of which had significant overlaps due to the fact that OSNs were often used as a container for other social media features, with identity representation consisting of a user profile and avatar often being included. The most prevalent OSNs were QuitNet for studies addressing smoking cessation and Facebook for other behaviors. Studies that included features from the communication category reported higher levels of neutral and negative outcomes across the different behaviors compared with the other categories. Except for features from the communication category, studies addressing smoking cessation all reported positive outcomes (100%) for the other categories.

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Table 5. Studies addressing different behaviors that reported positive, neutral, or negative outcomes.

Studies and their reported outcomes	Communication, n (%)	Peer grouping, n (%)	Data sharing, n (%)	Competition, n (%)	Activity data viewing, n (%)	Online social network, n (%)	Identity Representation, n (%)
Physical activity							
Positive	57 (66)	31 (79)	[a] *24 (89)*	17 (74)	28 (76)	19 (76)	22 (81)
Neutral	26 (30)	8 (21)	2 (7)	6 (26)	9 (24)	6 (24)	5 (19)
Negative	3 (3)	0 (0)	1 (4)	0 (0)	0 (0)	0 (0)	0 (0)
Diet and nutrition							
Positive	44 (71)	19 (83)	*17 (94)*	7 (70)	15 (75)	17 (89)	16 (89)
Neutral	16 (26)	4 (17)	1 (6)	3 (30)	5 (25)	2 (11)	2 (11)
Negative	2 (3)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Smoking cessation							
Positive	21 (81)	*12 (100)*	*11 (100)*	*2 (100)*	*7 (100)*	*8 (100)*	*9 (100)*
Neutral	5 (19)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Negative	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Alcohol consumption							
Positive	4 (80)	*1 (100)*	*1 (100)*	*0 (0)*	*1 (100)*	0 (0)	0 (0)
Neutral	1 (20)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Negative	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Weight loss or weight maintenance							
Positive	33 (73)	12 (80)	*11 (92)*	5 (83)	9 (82)	11 (85)	10 (83)
Neutral	10 (22)	3 (20)	1 (8)	1 (17)	2 (18)	2 (15)	2 (17)
Negative	2 (4)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)

[a]Cells with the highest positive values have been indicated in italics.

Reported Impact of Social Media Features

Of the studies reviewed, 72.4% (97/134) published additional information about social media features that were included within their interventions either or both in their results and discussions sections. However, despite the high percentage, the type and amount of information provided about the social media features varied widely from one study to another, ranging from usage data (eg, frequency a feature was used, number of participants using it), impact-related information (eg, whether the feature had an effect on usage or behavioral outcomes), and participants' perceptions (eg, usefulness, satisfaction, helpfulness, and social support derived). Similarly, the level of details varied from one descriptive sentence (eg, the studies by Block et al and Sternfeld et al [21,22]) to a full paragraph of text providing each social media feature's statistical data and accompanying description (eg, the intervention by Napolitano et al [105]).

None of the studies that explicitly reported on the social media features described any negative impact on the outcome of the interventions. Indeed, 69.1% of the studies described the outcome of these features in positive terms and reported a range of effects attributed to their usage, such as higher levels of engagement with the interventions, increased perception of usefulness and satisfaction, as well as improvements in addressed behaviors attributed directly to the use of social media features. The remaining studies (n=30) reported either or both low usage (<50% of participants using a social media feature) and neutral outcomes.

Usage

The inclusion of social media features has been reported to be associated with increased user engagement in behavioral interventions.

Communication

Asynchronous features from the communication category (eg, online forums) were reported to support increases in usage and engagement [52,79,109,117,119,120], whereas studies that included synchronous features (eg, online video and chat rooms) for meetings [16,41,62-65] mostly reported no effect or reduced engagement when compared with controls (face-to-face). Interestingly, it was reported that female participants tended to engage in online group discussions more than their male counterparts [69]. Online forums have also been found to encourage usage over longer periods [109].

Peer Grouping and Data Sharing

Engagement was also found to be gender-biased in an OSN-based private group where participants could post photos, with females sharing more pictures and remaining engaged for

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longer periods of time [58]. Social connections were found to contribute toward motivating participants to engage more with the interventions [3,7,50,146]. Similar findings were also reported for peer-led support, leading to an increase in the frequency of participants visiting an intervention's website [108].

Along with peer grouping–based features, interventions commonly included data sharing features [50,58,60]. The inclusion of polls was found to promote engagement the most as compared with other types of textual or graphical data [60], whereas the ability to create social connections to share each other's activity data [50] or the use of an OSN-based private group to share photos [58] also produced high levels of engagement among their participants.

Competition and Activity Data Viewing

Competitive elements such as social challenges in interventions addressing physical activity were also found to promote engagement [7]. Linked with the competitiveness, the use of Leader Boards or Ranking tables from the Activity Data Viewing category caused participants who were interested with their ranking to access the intervention's application more often [152]. Similarly, the inclusion of graphical-based comparisons [50] led to increases in user engagement.

Online Social Networks

It was reported that participants spent more time using an intervention that included an OSN platform [94]. Indeed, higher levels of engagements from participants were observed when OSNs were included along with their accompanying social media features [26,92]. However, this had no effect on attrition or retention rates [26,60].

Participants' Perceptions: Social Support, Helpfulness, Satisfaction, and Motivation

Social media features are usually associated with enhanced social support and motivation perceived by participants.

Most of these studies included features from the communication category such as online forums and chat rooms. Although some of those that included online forums reported positive perceptions of social support among participants [40,72,98], there was also the possibility of no change [114] and even a demotivating effect based on content quality shared by participants [84,114]. Forums were often found to be useful or helpful by a majority of participants [15,27,40,51], although in some studies this dropped to below 50% of participants [42,93,95]. The lower percentages were attributed to a "lack of critical mass" in the number of participants engaging actively in the forums to change others' perception positively [93] or could be based on participants' preferring personal email counseling compared with peer-to-peer support from online forums [86]. It was reported that participants actively sought social support from peers through chat rooms and derived positive perception of social support [68,98], but this perception was lower as compared with in-person group meetings [65]. Other features that were associated with positively enhancing participants' perception were group video chatting [41], mailing list [68], peer commenting [66], peer emailing [98], peer SMS text messages (short message service, SMS) [106,113,127], text chatting (one-to-one) [83], and symbolic support [66].

Peer grouping features were also found to help improve social support perceptions. Participants with access to these features had higher levels of social support coping [38,72,87,106,113]. However, this could also be attributed to participants feeling pressured in meeting goals or enjoying recognition and encouragements from peers [34,38,104]. Similar to content quality affecting motivation, social connections could have a demotivating factor in cases where the social support originates from better-performing peers [73].

Data sharing and peer data viewing had positive effects on perception of social support and motivation, especially when peers provide feedback [34,56,72,87,104,106,146]. However, data sharing was not always attributed with enhanced social support, with reported mixed effects when support originated from nonparticipants (external supporters) and their inability in constructing motivating messages [127] or possible concerns from participants about the usefulness to peers for the data being shared [42,149]. A positive correlation between the level of social support and the activeness of participants in data-sharing activities for an intervention addressing diet and nutrition was reported [66].

The inclusion of competition-based features in interventions was more likely to have a positive effect on participants' perception of social support motivation levels in an intervention that addressed physical activity as at least one of its behaviors addressed [50,98], but this was not always the case [104]. Although rarely used in addiction-related behaviors, a feature from the Competition category, in the form of a quit-smoking contest in an intervention addressing Smoking Cessation, was perceived as "somewhat valuable" and had a low usage rate (35.3%) [104].

The only study among the reviewed articles to report on the impact on social support associated with the inclusion of *OSN* in behavioral interventions found no change in social support perception [114]. However, OSNs were among the most-reported features for perceived usefulness [15,26,58,60,67]. Although at least two interventions [15,26] used purpose-designed OSNs, Facebook was used as the OSN in the other interventions [58,60,67]. This perception of usefulness could likely be also linked to the prevalent popularity of Facebook as a generic OSN platform among individual users. Another interesting finding was the increased credibility perception among participants when a virtual world–type OSN with a recreated classroom along with an instructor avatar was used in an intervention addressing diet and nutrition and physical activity [35].

Behavioral Outcome

A total of 29 studies reported on the effectiveness of some of the social media features included in their interventions in contributing to change participants' behaviors (see Multimedia Appendix 5). These features were from 5 of high-level categories in our taxonomy, namely, identity representation, communication, peer grouping, activity data viewing, and OSN.

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Communication-based social media features included in behavioral interventions were among the most reported for their effectiveness in modifying behaviors. Interactions among participants through asynchronous features such as forums were reported to have led to behavior change in at least four studies [75,79,108,135,136] that addressed a combination of physical activity, diet and nutrition, and weight loss. However, in at least one study, this change was minimal and only found among female participants [75]. Forums were among the most reported in studies addressing smoking cessation with regard to its effect in changing participants' behavior positively [31,32], although in at least one case no effect was found [117]. Chat rooms, enabling synchronous communication among participants were also reported to effectively modify behavior in some studies. Among interventions that addressed physical activity, diet and nutrition, and weight loss or weight maintenance, chat rooms were found to be effective in 2 interventions [76,135,136], whereas no effects were observed in others [62-64]. Smoking Cessation interventions could also benefit from their effectiveness, as it has been reported that participants with access to chat rooms were more likely to report abstaining from smoking [141]. One-to-one communication-based features have been reported to increase abstinence rates [14,55], increase physical activity, and lead to weight loss [57].

The use of peer grouping–based features was found to result in a number of positive outcomes, such as weight loss among studies addressing weight loss or weight maintenance, diet and nutrition, and physical activity [5,8,76,118,129], increase in activity levels for studies that addressed only physical activity [50,73,81,82], and also increase in the likeliness of quitting smoking in smoking cessation interventions [31,38,55].

Activity data viewing was also reported to have a positive impact on behavior change among studies addressing physical activity. Social interactions through games and allowing viewing of peers' performance [46,133] led to increases in physical activity levels.

OSNs used as part of behavioral interventions were also associated with positive behavior change, especially for weight loss [57,76,118,143-145], although this was not always the case [26]. All these studies addressed multiple behaviors, namely, physical activity, diet and nutrition, and weight loss or weight maintenance. Improvements in dietary awareness were also attributed to the use of OSNs [85]. OSNs that included user profiles were also found to encourage participants to smoke less and cause an increase in intentions to quit [140,141].

Discussion

Principal Findings

This review found that the majority of studies targeted either physical activity or a combination of behaviors that included physical activity (eg, physical activity, diet and nutrition, and weight loss or weight maintenance). The use of a specific social media feature in interventions addressing such combinations could be potentially risky in certain circumstances, such as a specific social media feature being found to highly encourage an individual to improve a particular behavioral aspect when that behavior is targeted as a single one, but in an intervention combining a second behavior, its effectiveness might be nullified or even create an opposite outcome. This review has not analyzed this aspect in more detail. However, it would be desirable to investigate these effects further.

Physical activity and smoking cessation interventions had the highest prevalence of social media features. Among these features, however, some were consistently more popularly included than others across all the different behaviors considered. Most of the behavioral interventions that included social media features reported positive (>70%) outcomes with respect to their set of objectives and hypothesis. Interventions that included social media features from the data sharing category had the highest positive outcome percentages (>88.9%). The main effects identified to be associated with the inclusion of social media features in behavioral interventions were about usage or engagement of participants; enhanced perception of social support, helpfulness, satisfaction, and motivation; and lastly, behavioral outcome.

It is possible that social media features were found to be more prevalent in physical activity interventions because features that draw on social behavior change techniques are more relevant to this behavior. This is in line with and adds to the findings of McCully et al's [153] survey that reported an increasing viability for using the Internet as a platform for delivering behavioral interventions on large scales. However, it should be pointed out that in most of the reviewed studies, their outcomes were not always explicitly attributed to the impact of the social media features that were included as was also reported in Chang et al's review [9].

The studies reviewed used nonstandard ways of reporting on the social media features by using different names to refer to the same feature and with varying levels of details. For example, online forums were also referred to as messaging board, bulletin board, discussion forum, discussion board, etc. In terms of description, these forums were sometimes moderated by intervention counselors, but not all studies described whether these features were moderated or the extent that counselors were involved in the group discussions. Some studies made use of generic online social networking sites such as Facebook and QuitNet, whereby a large number social features were available to the intervention participants without the researchers necessarily describing them; these features were however included in our analysis. These issues closely relate to the justifications put forward by Michie et al [13] that led to the proposal of a taxonomy for the reporting of BCIs. Without detailed and standardized description, it is not possible to draw comparisons across different studies on the use and impact of social media features. The taxonomy of social media features proposed from this review can support future research by informing more standardized and detailed descriptions that will facilitate cross-study comparison.

Our review identified that similar social media features (eg, online forums) were associated with positive outcomes across different behaviors. This suggests that although mostly prevalent in physical activity interventions, social media features might be relevant for a variety of health issues. However, this could

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also be the result of intervention designers including these features without enough consideration about their suitability and effectiveness on users for the different types of behaviors addressed and could, instead, be more focused on maximizing functionalities in their interventions. Therefore, there is a strong justification to empirically test the suitability and impact of including social media features in behavioral interventions.

Three main areas were identified with regard to the effects of social media features on users, namely, usage, participants' perception, and behavioral outcome. These effects may be attributed to the social influence element of these features reported in previous research [3,4] that found a positive impact in sustaining behavior change. A number of studies reported that the inclusion of social media features increased user engagement in behavioral interventions, and in at least one study, higher levels of sustained user engagement through interaction with multiple social media features was reported [49]. However, when compared with face-to-face alternatives, social media features were found to produce lower levels of engagement. Among the studies that reported the perceived usefulness or helpfulness, or sense of enjoyment and satisfaction of participants when using social media features included in interventions, more than half referred to features from the communication category, more specifically, online forums. Interestingly, in most cases, participants with access to these features felt pressured, motivated, or felt both to achieve goals, contrary to the findings of Dennison et al [154] that reported some degree of reluctance and feeling of embarrassment when participants' data were shared among peers. However, social support originating from better-performing peers [73] or in the form of poor support content quality from peers [84,114] did have a demotivating effect in a few studies reviewed. Although often assumed by researchers that social media features could result in lowering of attrition rate, this effect was minimal, with only one study [109] reporting an increase in likeliness for participants to complete an intervention, whereas 2 other studies reported finding no such effect [26,60]. In terms of social media features affecting behavioral outcome, our analysis found that the most effective features were communication-based, and more specifically, asynchronous ones (eg, online forums). Indeed, features from this subcategory of communication are known to provide more direct social support either from peers or trained professionals interacting with users on a one-to-one or one-to-many basis. This in turn can have an impact on behavioral outcomes [155,156].

The low level of focus on privacy based on the limited amount of information provided by the studies reviewed regarding this aspect associated with the sharing and peer viewing of participants' data is an area that requires further attention. Although privacy might not have been an issue where the intervention's data were accessible only to their respective users and their therapists, social media features unlock the potential of data being shared among peers. Another potential challenge of including social media features was the associated cost for moderating shared data, but this was explicitly mentioned by only 1 study [125], which reported that moderation of the online discussion groups (online forums) was the most significant cost of their study.

Limitations and Strengths of the Review

Among the reviewed studies, there was a lack of information reported on the social media features included and their impact on whether the behaviors addressed were affected directly or indirectly by them. This was in line with Michie et al [13], who found that BCIs with poor descriptions in their research protocols and study reports made them challenging to evaluate their effectiveness and to replicate.

This review included studies from the year 2000 as social media really started gaining popularity from around then. Although it is a fact that there have been a lot of new technologies and changes in the field of ICT, including social media, most basic concepts are still being used, although often adapted to match the current level of technology. Therefore, the social media features included in those studies are still relevant. Accordingly, diligent care must be taken when interpreting this review's findings in the current context. For example, results from the use of social media in recent years would be different from that of the previous decade because of the ways that they are used through different types of devices and interfaces. With our taxonomy, however, future extensions will be possible and help researchers to analyze and compare the evolvement of social media features in behavioral interventions.

This work has adopted a systematic approach for reviewing behavioral interventions, which included social media features across a wide range of behaviors, which has the potential to be used as a foundation for future research in the area. Along with the review, a taxonomy for categorizing social media features has also been presented. The taxonomy does not consist of an exhaustive list of social media features but rather focuses on those that were included in the reviewed studies.

Future Work

As this is the first attempt at producing a taxonomy for social media features included in behavioral interventions, it is expected that continued refinement will be carried out for standardizing the names and descriptions of the different categories and features in concert with researchers from both Social Science and Computer Science. More research needs to be carried out to find ways for isolating the effects of social media features on intervention users, as this review has found that many studies do not report on these aspects clearly. The complete dataset of studies reviewed consisting of their different attributes such as social media features used, sample size, and behavior(s) addressed has been included in Multimedia Appendix 2.

Recommendations

This review has found that although social media features are being widely included in behavioral interventions, little research-based evidence of their effectiveness in modifying behaviors exist. There appears to be tendency to use these features based on convenience and popularity rather than their suitability for specific behaviors. We are, therefore, proposing a set of recommendations aimed at researchers and intervention designers to help evaluate and maximize the effectiveness of social media features on behavioral intervention participants.

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First, develop and use a uniform and well-defined labeling scheme for social media features with the help of the taxonomy presented in this review. This will greatly facilitate future research work attempting to identify social media features included in behavioral interventions for comparison and reviewing.

Second, better design of studies capable of isolating, describing, and evaluating the impact of including social media features on participants and on the interventions' overall outcomes, both qualitatively and quantitatively, while ensuring the following aspects are covered: impact of social media features included in behavioral interventions on usage, perception of social support, helpfulness and satisfaction, attrition, and credibility. As reported in this review, the positive or negative impact for the different studies included was quite subjective, and therefore, they could only be cross-evaluated superficially. Should future studies publish sufficient quantitative data as part of their results, effects size could then be used as a selection criteria for systematic reviews.

Third, conduct more research focused on user's experience of social media features and factors such as privacy and cost in their use to understand how they can best be implemented. A user-centered design approach aimed at ensuring that any concerns from the users' point of view are taken on board from an early stage could be considered. As a result, this could potentially increase users' engagement with the social media features.

Conclusions

It was found that a majority of studies in this review reported positive outcomes with respect to their objectives and hypothesis. A new taxonomy of social media features used in behavioral interventions has been developed that will support researchers and intervention designers in comparing social media features and guiding their future inclusion in behavioral interventions with better consistency. Social media features were reported to increase usage; enhance perceived levels of social support, motivation, and feeling of satisfaction; and also having a direct effect in behavioral outcome. The main concerns identified with respect to the inclusion of social media features in behavioral interventions were, first, an underreported methodical selection process based on their suitability for specific behaviors and other contextual elements. Another issue uncovered was the nonstandardized way to identify and describe social media features and their effects on intervention users. Moreover, little information has been published with respect to the privacy and cost issues associated with social media features' inclusion in behavioral interventions. Therefore, more research on these aspects has been recommended.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Search query construction.

[PDF File (Adobe PDF File), 17KB - jmir_v20i2e20_app1.pdf]

Multimedia Appendix 2

Data table extracted from studies reviewed.

[XLSX File (Microsoft Excel File), 178KB - jmir_v20i2e20_app2.xlsx]

Multimedia Appendix 3

Social media features' description.

[PDF File (Adobe PDF File), 39KB - jmir_v20i2e20_app3.pdf]

Multimedia Appendix 4

Inclusion of specific social media features by behavior.

[PDF File (Adobe PDF File), 84KB - jmir_v20i2e20_app4.pdf]

Multimedia Appendix 5

Social media features leading to behavioral change.

[PDF File (Adobe PDF File), 179KB - jmir_v20i2e20_app5.pdf]

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Abbreviations

BCI: behavior change intervention
DBCIs: digital behavior change interventions
ICTs: information and communication technologies
OSN: online social network
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RCTs: randomized controlled trials
SMS: short message service
WHO: World Health Organization

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Original Paper

Web-Based Just-in-Time Information and Feedback on Antibiotic Use for Village Doctors in Rural Anhui, China: Randomized Controlled Trial

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Abstract

Background: Excessive use of antibiotics is very common worldwide, especially in rural China; various measures that have been used in curbing the problem have shown only marginal effects.

Objective: The objective of this study was to test an innovative intervention that provided just-in-time information and feedback (JITIF) to village doctors on care of common infectious diseases.

Methods: The information component of JITIF consisted of a set of theory or evidence-based ingredients, including operation guideline, public commitment, and takeaway information, whereas the feedback component tells each participating doctor about his or her performance scores and percentages of antibiotic prescriptions. These ingredients were incorporated together in a synergetic way via a Web-based aid. Evaluation of JITIF adopted a randomized controlled trial design involving 24 village clinics randomized into equal control and intervention arms. Measures used included changes between baseline and endpoint (1 year after baseline) in terms of: percentages of patients with symptomatic respiratory or gastrointestinal tract infections (RTIs or GTIs) being prescribed antibiotics, delivery of essential service procedures, and patients' beliefs and knowledge about antibiotics and infection prevention. Two researchers worked as a group in collecting the data at each site clinic. One performed nonparticipative observation of the service process, while the other performed structured exit interviews about patients' beliefs and knowledge. Data analysis comprised mainly of: (1) descriptive estimations of beliefs or knowledge, practice of indicative procedures, and use of antibiotics at baseline and endpoint for intervention and control groups and (2) chi-square tests for the differences between these groups.

Results: A total of 1048 patients completed the evaluation, including 532 at baseline (intervention=269, control=263) and 516 at endpoint (intervention=262, control=254). Patients diagnosed with RTIs and GTIs accounted for 76.5% (407/532) and 23.5% (125/352), respectively, at baseline and 80.8% (417/532) and 19.2% (99/532) at endpoint. JITIF resulted in substantial improvement in delivery of essential service procedures (2.6%-24.8% at baseline on both arms and at endpoint on the control arm vs 88.5%-95.0% at endpoint on the intervention arm, $P<.001$), beliefs favoring rational antibiotics use (11.5%-39.8% at baseline on both arms and at endpoint on the control arm vs 19.8%-62.6% at endpoint on the intervention arm, $P<.001$) and knowledge about side effects of antibiotics (35.7% on the control arm vs 73.7% on the intervention arm, $P<.001$), measures for managing or preventing RTIs (39.1% vs 66.7%, $P=.02$), and measures for managing or preventing GTIs (46.8% vs 69.2%, $P<.001$). It also reduced antibiotics prescription (from 88.8%-62.3%, $P<.001$), and this decrease was consistent for RTIs (87.1% vs 64.3%, $P<.001$) and GTIs (94.7% vs 52.4%, $P<.001$).

Conclusions: JITIF is effective in controlling antibiotics prescription at least in the short term and may provide a low-cost and sustainable solution to the widespread excessive use of antibiotics in rural China.

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KEYWORDS

internet; drug resistance, bacterial; primary health care; randomized controlled trial; China

Introduction

Background

Antibiotics resistance (ABR) has become an urgent and worldwide public health problem. According to an independent review commissioned by UK Prime Minister David Cameron, around 700,000 people died in 2014 due to antimicrobial resistance and will reach 10 million lives a year by 2050, and a cumulative US $100 trillion of economic output are at risk due to drug-resistant infections if we do not find proactive solutions now [1]. Primary care ranks top priority for curbing the problem since it incurs the majority of prescribed antibiotics [2]. Over 80% of all antibiotics are prescribed in primary care, and there is a wide variation both within and between countries in antibiotic prescribing rates that cannot be explained by differences in the epidemiology of infections [3-5]. The situation of ABR in China, especially rural areas, is among the most serious in the world. A cross-sectional study of 40 counties in rural western China reported that 48.43% of all service episodes at village clinics used at least one kind of antibiotic [6]. Another study conducted in Shandong province revealed that the antibiotics were used for 59.01% of all the patients at village clinics [7].

A variety of measures have been used in improving antibiotics use (ABU) at primary settings. These include education of doctors and patients, structural changes, commitment letters, guidelines, prescription formularies, negative disease lists, shared decision-making (SDM), and others [8-11]. Most of these approaches have showed marginal to moderate effects in various countries. ABR has also gained high recognition in China. Starting from 2009, the then Ministry of Health had launched a nationwide Special Antimicrobial Use Rectification Program. It consisted of a package of interventions, for example, introduction of stewardships, establishment of microbiological laboratories in county or higher-level hospitals, implementation of periodic ABU audits, and capping overall proportion of antibiotic prescriptions, etc. China's new health reforms also include various systemic changes aimed at curbing excessive ABU, for example, differential lists of antibiotics for different level of health care providers and zero profit from antibiotics prescriptions [12,13]. Although these efforts have been associated with reductions in antibiotic prescribing at county or higher-level public hospitals, there are indications that antibiotic use at primary care settings remains very high [14]. This is especially true in resource-poor rural areas where more than 60% of the nation's vast population resides [15].

Objectives

In response to the above challenges and others, this study aimed at developing and evaluating an innovative intervention, which provides the village doctors with just-in-time information and feedback (JITIF). Guided by proven theories and best practices, JITIF incorporates a number of cost-effective and sustainable approaches in a synergetic way in leveraging accountable ABU within routine primary care in rural China. Being designed as a potential package to be routinely used at rural primary care settings, JITIF covers all kinds of infections categorized as respiratory tract infections (RTIs), gastrointestinal tract infections (GTIs), urinary tract infections (UTIs), skin infections (SIs), and eye and dental infections (EDIs). Given that the prevalence of different infections varies greatly, we decided to test and promote JITIF in two stages. The first stage aims at testing its efficacy through a relatively small-scale randomized controlled trial focusing only on the two most common kinds of infections (ie, RTIs and GTIs), whereas the second leverages the experiences and findings from the first into a larger and more comprehensive trial covering all the aforementioned infections. This paper documents the main ingredients and mechanisms of the intervention package and preliminary findings about its efficacy from the first stage study.

Methods

Ingredients of Just-in-Time Information and Feedback

As indicated by its title, the intervention comprises two components: information and feedback. The information component consisted of a set of theory and evidence-based ingredients, including operation guidelines, public commitment, and takeaway information. The operation guidelines divided routine care of symptomatic infection patients into 5 pragmatic steps (patient categorization, disease diagnosis, SDM, drug prescription, and patient education) and provided standard operation procedures (SOPs) for each of them.

The public commitment asked each of the participating village doctors in the intervention group to sign a letter of commitment and made the signed letter public by posting it on the walls of his or her clinic and printing it on the back of the patient takeaway information leaflet. The letter was first drafted by a researcher and then revised by all the intervention group doctors via a consensus session scheduled at the end of the project orientation training workshop. The finalized letter (see Multimedia Appendix 1) conveyed a clear message that the doctor who had signed the letter was strongly committed to use antibiotics accountably.

The takeaway information (see Multimedia Appendix 2) was divided into two parts and printed on the front and back pages, respectively, on an A4-sized paper for patients to take home. The front page was patient specific and contained mainly: (1) the name of the patient and date of the service encounter; (2) main symptoms, related history (if applicable), and clinical diagnosis of the current infection; (3) whether antibiotics were used and why (including benefits and side effects of ABU); (4) (if applicable) name, dosage, duration, and administration mode of the antibiotics used; (5) (if applicable) agreed plan for symptom relief; (6) (if applicable) agreed plan for backup antibiotics treatment; and (7) suggested activities for preventing

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the same infection in the future. The back page, however, was mostly the same to all the patients. It contained the commitment letter and a signature of the attending doctor.

The feedback component of JITIF told each participating doctor about his or her performance scores (PSs) and percentages of prescribed ABU. The PSs for any individual doctor were based on the records of his or her management of symptomatic infection patients in the past 3 months and were rated by a panel of experts on care of infectious diseases according to a preset checklist. The percentages of prescribed ABU were also based on the same records and for the same time period but calculated automatically by the Web-based support system. Any PS (or percentage of ABU) for a given doctor was presented in red, yellow, and green, respectively, if it fell below (or above), within, and above (or below) the interquartile range of the same PS (or percentage of ABU) for all the participating doctors assessed in the same time period.

Implementation of Just-in-Time Information and Feedback

JITIF strived to deliver the abovementioned feedback and information at a time when the recipients were most ready to accept or act upon it. In reaching this end, it used a Web-based aid (WBA) consisting of 5 consecutive pages, each facilitated one of the 5 steps of routine service for infection patients mentioned above. A typical WBA page (see Multimedia Appendix 3) consisted of 2 main columns (the right and the left column). The right column presented SOP for the doctor to follow and is hereafter referred to as the SOP column. The left column was further divided into top and bottom parts used to display relevant performance and references, respectively, and thus referred to as performance and reference column, respectively.

Page 1 (see Multimedia Appendix 3) was used to categorize the patient. Its SOP column presented: (1) 5 structured or open questions followed by input boxes, radio buttons, or dropdown lists designed to remind and facilitate the attending doctor in enquiring and recording the patient's name, gender, identification number, and address; (2) 1 open question asking about the patient's main health problems, followed by a list of tick boxes designed to help the doctor in rapidly grouping the patient into specific categories, that is, RTIs, GTIs, UTIs, SIs, EDIs, and noninfectious diseases; (3) 1 structured question asking about whether it was the first visit for the current infection or not. These categorizations lead to different sets of content and SOPs to be addressed in the subsequent pages. The performance column of Page 1 displayed the overall PSs in total and by different type of infections (eg, RTIs, GTIs, UTIs) for the current doctor and his or her peers, whereas the reference column of Page 1 showed the bulleted points of the doctor's public commitment.

Page 2 dealt with disease diagnosis. Its content varied depending on the category ticked in the previous page. Taking the example of RTIs, the SOP column of Page 2 proposed 3 substeps (SOP_{2-1} to SOP_{2-3}). SOP_{2-1} examined common symptoms and signs of RTIs, with particular attention being paid on symptoms and symptom features helpful in distinguishing viral versus bacterial infections. SOP_{2-2} inquired previous formal and informal care for the current illness, especially ABU. SOP_{2-3} reached a clinical diagnosis of RTIs, for example, influenza, sore throat, and common cold. The performance column of Page 2 presented the doctor's PSs in total and in terms of data completeness and/or accuracy for each of the 3 substeps included in the SOP column, whereas the reference column of Page 2 presented bulleted tips on soliciting information about RTI-related symptoms or signs, history, and distinguishing specific RTIs.

Page 3 leveraged SDM. It stressed adequate discussion between the attending doctor and attendee patient before prescribing any antibiotics. Its SOP column comprised 4 substeps. SOP_{3-1} predicted pathogen and occurrence and trajectory of patient's symptoms. SOP_{3-2} asked the patient's worries about the infection and expectations from the visit. SOP_{3-3} enumerated potential treatment options, including vacuum treatment (letting the patient go without prescribing any medicine), symptom relief treatment (carefully selected nonantibiotic alternative measures, for example, traditional food and physical therapies), backup antibiotic treatment and antibiotic treatment, and discussed benefits and side effects of each of them. SOP_{3-4} helped the patient in choosing one of the treatment options discussed. The performance column of Page 3 presented the doctor's PS on this whole stage and on each of the 4 substeps mentioned above, whereas the reference column of Page 3 presented bulleted indications for using and not using antibiotics for the current type of infection (eg, RTIs, GTIs, and UTIs) and tips on practicing SDM.

Page 4 facilitated prescription if the treatment options chosen during the previous SDM contained antibiotic and/or nonantibiotic medications. Its SOP column provided prescription formularies, and its performance column provided percentage of antibiotic prescriptions by the attending doctor, as compared with that by his or her peers, for patients with different common infections, whereas its reference column provided bulleted rules for choosing medicines for the specific infection under concern (eg, common cold, influenza).

Page 5 promoted patient education. Its SOP column proposed 3 substeps. The content of $SOP5_{5-1}$ depended again on the treatment options chosen during the previous SDM. For options with antibiotic and nonantibiotic medications, it educated use of the medicines prescribed. For vacuum treatment, it proposed carefully selected alternative measures. For backup antibiotic treatment, it informed the patient when and on what indications he or she should come back to the doctor again. SOP_{5-2} counseled regarding the prevention of secondary infection to the patient's relatives and future reinfection for the patient himself or herself. $SOP5_{5-3}$ developed and printed a tailored takeaway information sheet for the patient. The performance column of Page 5 showed PSs on this whole stage and on each of the 3 activities, whereas the reference column of Page 5 showed bulleted tips on counseling use of medications, backup treatment, and infection prevention.

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Evaluation of Just-in-Time Information and Feedback

Evaluation of JITIF adopted a randomized controlled trial design. The study settings included 12 intervention and 12 control villages in Anhui, a province located in east central China with a population of 68.6 million, of whom 57% live in rural areas. Per capita GDP and income in Anhui rank in the midrange (14 out of 31) among all provinces in China, and the social, cultural, and economic background in Anhui is representative of over 80% of the population in the nation. The study sites were determined via a 3-step clustered randomization. Step 1 divided all the 55 rural counties in Anhui province into north (17 counties), middle (16), and south (22). Step 2 randomly selected: (1) 4 counties from each of the regions, (2) 1 township from each of the selected counties, and (3) 2 administrative villages from each of the selected townships. Step 3 randomly assigned the 2 villages within each township into intervention and control arms. All the 24 village clinics in the selected villages agreed to participate. The 12 clinics on the intervention arm completed a baseline (from August 20 to September 30, 2015) and an endpoint (from August 22 to September 30, 2016) evaluation and implemented JITIF right after the baseline evaluation and throughout the whole study period, whereas the 12 clinics on the control arm completed only the baseline and endpoint evaluation. The study was not registered since randomization was applied only to clinics and not to patients.

Measures used in evaluating JITIF included changes between baseline and endpoint and between control and intervention groups in terms of: (1) percentages of patients with symptomatic RTIs or GTIs being prescribed with oral, intravenous, and injection antibiotics; (2) delivery of essential service procedures, including checking body signs, measuring temperature, performing auscultation, discussing nonantibiotic therapies, educating drug administration, counseling infection prevention, etc; and (3) patients' knowledge about side effects of antibiotics and infection management and prevention. To enable examining compatibility between baseline versus endpoint and intervention versus control groups, the evaluation also collected data about patients' age, sex, education, and clinical diagnosis.

Collection of the above data adopted nonparticipative observation using a structured form and face-to-face interview using a structured questionnaire. The observation form (see Multimedia Appendix 4) was designed to solicit data about delivery of service procedures, clinical diagnosis by the doctor, and prescribed antibiotics from patient-doctor encounters happened at village clinics, whereas the structured questionnaire was designed to collect data on knowledge about infection, antibiotics, and infection prevention from the same patients observed. One researcher and one graduate student on health services worked as a group in performing the observation and interview at a clinic, respectively. The observation covered the whole process of eligible patient-doctor encounters, while the interview happened just before the patient had finished his or her consultation and was about to leave the clinic. A total of 4 groups participated in the data collection, each responsible for 3 interventions and 3 control clinics. None of these field data collectors had any relationship that may bias the data collection. Both the baseline and endpoint data collection at each clinic lasted for 1 week. Within the week, all eligible patients were invited to the clinic to participate. The eligibility criteria were men and women who: (1) were 18 years and older; (2) came to the clinic for symptomatic RTI or GTI as the primary health problem; and (3) were willing to participate and able to respond (eg, without mental problems).

The study took a combination of measures in ensuring data quality. These included: (1) training of field observers and interviewers on potential biases and measures avoiding them; (2) clarification of study purpose stressing that both positive and negative findings are of equal interest; and (3) feedback of rating-rerating discrepancies. Here, the feedback consisted of the following: (1) all the patient-doctor encounters were, after informed consent, audio-recorded; (2) a data quality supervisor randomly selected one case of the audio recordings from each of the site clinics every day, concealed all the labeling information, except a unique reference number of the recordings and then sent them to a third researcher; (3) the third researcher rated all applicable essential service procedures according to the audio recordings and using the same rating form as that used by the field observers and then sent the ratings back to the data quality supervisor; (4) the data quality supervisor calculated the differences between the ratings for the encounters with the same reference number but by different generators (one of the field observer and the third independent researcher); and (5) the data quality supervisor sent a short report about the average and observer-specific differences to each of the field observers every day during the data collection period.

Data Analysis

The completed observation forms and questionnaires were double-entered into a database using EPI DATA (The EpiData Association. Version 3.1) and then analyzed using SPSS (IBM Corporation. Version 11) and Microsoft Excel (Microsoft Corporation. Version 2013). The data analysis consisted mainly of: (1) distribution of respondents and RTIs or GTIs by sociodemographics; (2) estimations of knowledge, delivery of indicative procedures, and use of antibiotics at baseline and endpoint and for intervention and control groups; and (3) chi-square power tests for differences in these estimations between different groups. For additional information about methods, please refer to Multimedia Appendix 5.

Human Subject Protection

This study involved recruitment, intervention, and assessment of patients and village doctors. So it adhered to rigorous human subject protection principles and procedures. The study protocol had been reviewed and approved by the Biomedical Ethics Committee of Anhui Medical University before study commencement. Participation of villagers and village doctors was voluntary. Written informed consent was sought from all participants.

Results

Patient and Doctor Participants

As shown in Figure 1, the study recruited 24 village clinics. These clinics had 65 village doctors (2-4 each). These doctors consisted of 23 females and 42 males. They were aged between

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32 and 68 years and had been a village doctor for 7 to 58 years. All of them participated in the study without withdrawal. No statistically significant differences were found between the control and intervention group doctors in terms of gender composition and years of age and practice. The overall and item-specific rating-rerating discrepancies of the essential service procedures also did not show any statistically significant differences between the two arms.

Table 1 summarizes characteristics of the participating patients, and Figure 1 shows the flowchart of participant selection and follow-up. A total of 1048 patients completed the observation and interview, including 532 patients at baseline (intervention=269 out of 284, control= 263 out of 274) and 516 patients at endpoint (intervention=262 out of 272, control=254 out of 265). The number of females was more than twice that of males (718 vs 330). The majority of participants had lower than high school education. There was no statistically significant difference in the patients' age, gender, and education between baseline and follow-up and between control and intervention group (P=.42 to .999). Patients diagnosed (by the participating village doctor) with RTIs and GTIs accounted for 76.5% (407/532) and 23.5% (125/532), respectively, at baseline and 80.8% (417/532) and 19.2% (99/532) at endpoint.

Changes in Service Delivery

Table 2 compares essential procedures delivered by the participating doctors between baseline and endpoint and between intervention and control. Before application of JITIF, the proportion of patients who had received the listed service procedures was very low, ranging from 2.6% (for counseling symptoms relief) to 24.8% (for checking body signs). About 1 year's implementation of JITIF resulted in substantial improvement in all these procedures, practiced over 88.5% for all the RTI and GTI patients on the intervention arm. The control versus intervention differences at endpoint were all statistically significant (P<.001), whereas no statistically significant difference was observed between patients on the two arms at the baseline. Although marginal increases were observed in the majority of the procedures from baseline to endpoint within the control group (eg, from 13.7% to 15.7% for performing auscultation; from 10.6% to 11.8% for telling diagnosis; and from 4.6% to 6.7% for discussing treatment alternatives), these changes were not significant (P=.51 to .98).

Table 1. Sociodemographic characteristics and symptomatic infections.

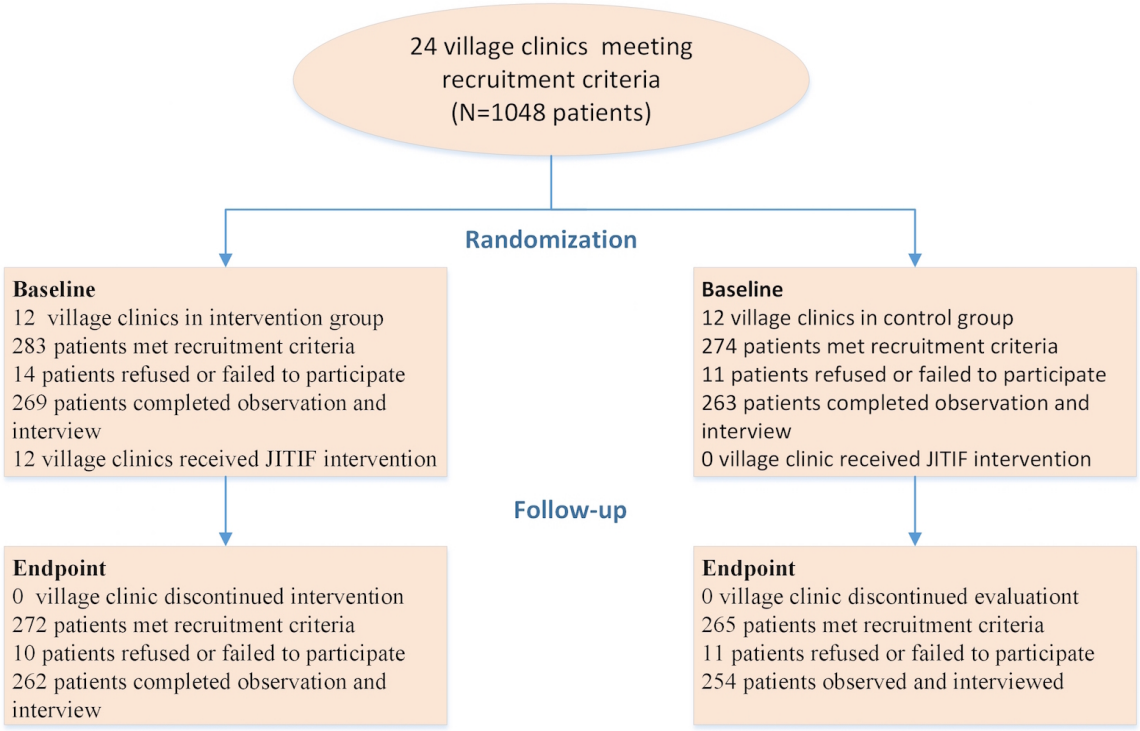
Participant group	Baseline			Endpoint			Overall *P* value
	Control (n=263), n (%)	Intervention (n=269), n (%)	*P* value	Control (n=254), n (%)	Intervention (n=262), n (%)	*P* value	
Age			.90			.81	.97
≤30	52 (19.8)	53 (19.7)		50 (19.7)	54 (20.6)		
31-40	51 (19.4)	58 (21.6)		49 (19.3)	57 (21.8)		
41-50	53 (20.2)	59 (21.9)		51 (20.1)	55 (21.0)		
51-60	52 (19.8)	47 (17.5)		49 (19.3)	50 (19.1)		
≥61	55 (20.8)	52 (19.3)		55 (21.6)	46 (17.6)		
Gender			.65			.42	.63
Male	86 (32.7)	83 (30.9)		75 (29.5)	86 (32.8)		
Female	177(67.3)	186 (69.1)		179 (70.5)	176 (67.2)		
Education			.94			.73	.999
Illiteracy	63 (24.0)	60 (22.3)		67 (26.4)	58 (22.1)		
Primary school	72 (27.4)	71 (26.4)		61 (24.0)	68 (26.0)		
Middle school	85 (32.3)	92 (34.2)		85 (33.5)	91 (34.7)		
High school	43 (16.3)	46 (17.1)		41 (16.1)	45(17.2)		
Clinically diagnosed infections			.81			.70	.37
RTIs[a]	200 (76.0)	207 (77.0)		207 (81.5)	210 (80.2)		
GTIs[b]	63 (24.0)	62 (23.0)		47 (18.5)	52 (19.8)		

[a]RTIs: respiratory tract infections.

[b]GTIs: gastrointestinal tract infections.

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Figure 1. Flowchart of participant selection and follow-up.



Changes in Patients' Beliefs and Knowledge

Table 3 presents changes in beliefs and knowledge about infections and antibiotics among the patients. At baseline, most of the patients held no-objection even favoring (Yes or Not clear) views toward using antibiotics for common symptoms of RTIs or GTIs. Majority of them thought that antibiotics should generally be used for common cold (71.9% and 71.4% among the control and intervention groups at baseline, respectively), sore throat (84.8% and 85.1%), fever (70.0% and 69.9%), rhinorrhea (71.1% and 71.4%), indigestion (33.5% and 36.5%), acute gastroenteritis (87.8% and 88.5%), and diarrhea (63.1% and 63.9%). These percentages reduced by 6.0% (for beliefs in antibiotics use for sore throat) to 22.8% (for beliefs in antibiotics use for indigestion) as compared between control versus intervention, and almost all of the changes were statistically significant (P<.05) except that for sore throat (P=.08). The patients' knowledge was also quite unfavorable at baseline. Those who were able to tell at least 1 specific side effect and measure for managing or preventing RTIs or GTIs accounted for less than 35.8%, 42.5%, and 46.8%, respectively, at baseline. These all witnessed significant increases at endpoint on the intervention arm, being 73.7%, 66.7%, and 69.2%, respectively.

Changes in Antibiotics Prescription

Table 4 shows antibiotics prescription for patients between baseline and endpoint and between control and intervention groups. Put together, the proportion of symptomatic RTI or GTI patients who had been prescribed with antibiotics decreased from 88.0% at baseline to 62.3% at endpoint on the intervention arm (P<.001) but showed little change during the same period on the control arm, being 91.7% versus 89.7%, respectively (P=.48). This decrease was consistent for RTIs (from 87.1% to 64.3%, P<.001) and GTIs (from 94.7% to 52.4%, P<.001). By comparison, the reduction in oral antibiotics was substantially greater than that in intravenous antibiotics being from 60.5% to 42.3% versus from 62.5% to 12.8% for RTI and GTI patients.

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Table 2. Practices of essential service procedures at baseline and endpoint.

Procedure	Baseline			Endpoint			Overall *P* value
	Control, n (%)	Intervention, n (%)	*P* value	Control, n (%)	Intervention, n (%)	*P* value	
Asking history of previous treatment for the current illness							
Yes	52 (19.8)	54 (20.1)	.93	52 (20.5)	237 (90.5)	<.001	<.001
No	211 (80.2)	215 (79.9)		202 (79.5)	25 (9.5)		
Checking body signs (eg, swallow tonsils for RTIs or dehydration for GTIs)							
Yes	65 (24.7)	59 (21.9)	.45	63 (24.8)	236 (90.1)	<.001	<.001
No	198 (75.3)	210 (78.1)		191 (75.2)	26 (9.9)		
Measuring temperature							
Yes	62 (23.6)	57 (21.2)	.51	61 (24.0)	238 (90.8)	<.001	<.001
No	201 (76.4)	212 (78.8)		193 (76.0)	24 (9.2)		
Performing auscultation of the chest for RTIs[a] or the abdomen for GTIs[b]							
Yes	36 (13.7)	37 (13.8)	.98	40 (15.7)	232 (88.5)	<.001	<.001
No	227 (86.3)	232 (86.2)		214 (84.3)	30 (12.2)		
Telling diagnosis and disease trajectory							
Yes	28 (10.6)	27 (10.0)	.82	30 (11.8)	242 (92.4)	<.001	<.001
No	235 (89.4)	242 (90.0)		224 (88.2)	20 (7.6)		
Explaining potential causes of the illness							
Yes	17 (6.5)	15 (5.6)	.67	17 (6.7)	242 (92.4)	<.001	<.001
No	246 (93.5)	254 (94.4)		237 (93.3)	20 (7.6)		
Discussing treatment alternatives							
Yes	12 (4.6)	16 (5.9)	.47	17 (6.7)	247 (94.3)	<.001	<.001
No	251 (95.4)	253 (94.1)		237 (93.3)	15 (5.7)		
Educating drug intake if applicable							
Yes	32 (12.2)	31 (11.5)	.82	32 (12.6)	249 (95.0)	<.001	<.001
No	231 (87.8)	238 (88.5)		222 (87.4)	13 (5.0)		
Counseling symptoms relief							
Yes	8 (3.0)	7 (2.6)	.76	7 (2.8)	248 (94.7)	<.001	<.001
No	255 (97.0)	262 (97.4)		247 (97.2)	14 (5.3)		
Counseling infection prevention							
Yes	9 (3.4)	8 (3.0)	.77	8 (3.1)	241 (92.0)	<.001	<.001
No	254 (96.6)	261 (97.0)		246 (96.9)	21 (8.0)		

[a]RTIs: respiratory tract infections.

[b]GTIs: gastrointestinal tract infections.

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Table 3. Changes in patients' beliefs and knowledge about antibiotics and infections.

Questionnaire item	Baseline			Endpoint			Overall *P* value
	Control, n (%)	Intervention, n (%)	*P* value	Control, n (%)	Intervention, n (%)	*P* value	
Do you think antibiotics should generally be used for common cold?							
Yes or Not clear	189 (71.9)	192 (71.4)	.90	182 (71.7)	156 (59.5)	.004	.004
No	74 (27.2)	77 (28.6)		72 (28.3)	106 (40.5)		
Do you think antibiotics should be generally used for sore throat?							
Yes or Not clear	223 (84.8)	229 (85.1)	.91	213 (83.9)	204 (77.9)	.08	.03
No	40 (15.2)	40 (14.9)		41 (16.1)	58 (22.1)		
Do you think antibiotics should generally be used for fever?							
Yes or Not clear	184 (70.0)	188 (69.9)	.96	171 (67.3)	148 (56.5)	.01	.001
No	79 (30.0)	81 (30.1)		83 (32.7)	114 (43.5)		
Do you think antibiotics should generally be used for rhinorrhea?							
Yes or Not clear	187 (71.1)	192 (71.4)	.95	181 (71.3)	157 (59.9)	.01	.005
No	76 (28.9)	77 (28.6)		73 (28.7)	105 (40.1)		
Do you think antibiotics should generally be used for indigestion?							
Yes or Not clear	175 (66.5)	172 (63.9)	.53	153 (60.2)	98 (37.4)	<.001	<.001
No	88 (33.5)	97 (36.1)		101 (39.8)	164 (62.6)		
Do you think antibiotics should generally be used for acute gastroenteritis?							
Yes or Not clear	231 (87.8)	238 (88.5)	.82	221 (87.0)	210 (80.2)	.04	.008
No	32 (12.2)	31 (11.5)		33 (13.0)	52 (19.8)		
Do you think antibiotics should generally be used for diarrhea?							
Yes or Not clear	166 (63.1)	172 (63.9)	.84	158 (62.2)	130 (49.6)	.004	.001
No	97 (36.9)	97 (36.1)		96 (37.8)	132 (50.4)		
Can you name any specific side effects of antibiotics use?							
Yes	92 (35.0)	96 (35.7)	.87	91 (35.8)	193 (73.7)	.001	<.001
No or Not clear	171 (65.0)	173 (64.3)		163 (64.2)	69 (26.3)		
Can you name any specific measures for preventing or managing RTIs[a] ?							
Yes	80 (40.0)	81 (39.1)	.86	88 (42.5)	140 (66.7)	<.001	<.001
No or Not clear	119 (60.0)	126 (60.9)		119 (57.5)	70 (33.3)		
Can you name any specific measures for preventing or managing GTIs[b] ?							
Yes	30 (47.6)	29 (46.8)	.93	22 (46.8)	36 (69.2)	.02	.02
No or Not clear	33 (52.4)	33 (53.2)		25 (53.2)	16 (30.8)		

[a]RTIs: respiratory tract infections.

[b]GTIs: gastrointestinal tract infections.

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Table 4. Antibiotics prescription by baseline, endpoint, control, and intervention groups.

Antibiotics prescription	Baseline			Endpoint			Overall *P* value
	Control, n (%)	Intervention, n (%)	*P* value	Control, n (%)	Intervention, n (%)	*P* value	
Antibiotics prescriptions for RTIs[a]							
Oral	97 (66.0)	122 (65.6)	.94	92 (60.5)	85 (42.3)	.001	<.001
Intravenous	89 (53.0)	95 (54.0)	.89	85 (51.2)	71 (38.4)	.02	.003
Any	159 (90.3)	176 (87.1)	.33	156 (89.7)	135 (64.3)	<.001	<.001
Antibiotics prescriptions for GTIs[b]							
Oral	34 (68.0)	32 (64.0)	.67	25 (62.5)	6 (12.8)	<.001	<.001
Intravenous	30 (60.0)	34 (58.6)	.88	21 (60.0)	16 (36.4)	.04	.03
Any	50 (96.2)	54 (94.7)	.72	36 (90.0)	22 (52.4)	<.001	<.001
Antibiotics prescriptions for RTIs and/or GTIs							
Oral	131 (66.5)	154 (65.3)	.79	117 (60.9)	91 (36.7)	<.001	<.001
Intravenous	119 (54.6)	129 (55.1)	.91	106 (52.7)	87 (38.0)	.002	<.001
Any	209 (91.7)	230 (88.8)	.29	192 (89.7)	157 (62.3)	<.001	<.001

[a]RTIs: respiratory tract infections.

[b]GTIs: gastrointestinal tract infections.

Discussion

Principal Findings

As mentioned earlier in the Introduction, many studies have been performed to determine the effectiveness of different types of interventions in promoting a more rational use of antibiotics at primary care settings, and multifaceted interventions have generally been more successful, especially if they employ SDM, involve peers, and benefit the practice as a whole [16]. Examples of such interventions include the Treat Antibiotics Responsibly, Guidance and Education Tool [17], the Stemming the Tide of Antibiotic Resistance [4], and the Nudging Guideline-Concordant Antibiotic Prescribing program [18]. These programs resulted in the reduction in inappropriate antibiotic prescribing by less than 20%. This study documented moderate to substantial changes, as a result of JITIF, in terms of: (1) prescribed antibiotics for RTI or GTI patients; (2) practice of essential clinical procedures; and (3) patients' beliefs in and knowledge about antibiotics and infections. These changes are consistent with each other, and all point to an encouraging implication that the intervention is effective, at least in the short term. Most notably, the reduction in antibiotics use was about 10% greater than that of previous programs. This may be attributed partly to higher antibiotics prescription at baseline among our population.

Perhaps, the primary reason underlying the efficacy of this study may be that JITIF incorporates a number of theory- or evidence-based approaches in a synergetic way. The public commitment, for example, originated from an alternative behavior model holds that: (1) people place a high value on consistency and follow through with their public commitment to avoid disapproval by their peers and (2) publicly committing to a behavior prompts people to later justify that behavior and identify the behavior with their self-image, which may enhance personal dedication to performing that behavior [18,19]. Unlike other passive methods to improve quality of medical care such as financial incentives, public commitment features low cost and high sustainability. The inclusion of SDM was based on research findings that good level of SDM occurs only about 10% of the time [20] and that perceived pressure from patients has often been mentioned as a major reason for excessive antibiotics prescribing [21]. With options being clearly communicated to the patient and the patient's preferences and expectations being explicitly sought, SDM should reduce irrational demand and expectations among the patients and correct misperceptions of patients' needs among the doctors. As for the provision of service references, performance feedback, and Web-based SOPs, they were designed in accordance with planned behavior theory [22,23]. The theory states that attitude toward behavior, subjective norms, and perceived behavioral control, together shape an individual's behavioral intentions and practices. On the basis of authorized guidelines, the service references list positive behaviors for the doctors to practice (attitude), and the performance feedback tells the doctor that the majority of his or her peers are practicing to the references (subjective norm), while the Web-based SOPs provide easy ways in implementing positive behaviors and thus enhance the doctor's sense of behavioral control.

The study also revealed useful information for better understanding routine health care for patients with symptomatic RTIs or GTIs at primary care settings in rural Anhui, China. Each of the procedures observed in this study (Table 2) has important implications for service quality. Researches showed that over one-third of the patients with symptomatic RTIs or GTIs had used self-obtained antibiotics before seeking help from village clinics [24]. So, there are reasons for village doctors

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to enquire and take into account prior treatment in planning current therapies for their patients. Similarly, checking body signs, measuring temperature, and performing auscultation helps doctors in reaching better understanding of the patients' conditions and in gaining their trust and loyalty [25,26], whereas telling diagnosis and disease cause and trajectory reassures recovery within a short period (eg, 1-2 weeks) and reduces worries and, thus, demands for excessive treatment among the patients [27]. As for the remaining procedures, discussing treatment alternatives forms the key part of SDM which is, as mentioned above, beneficial in a number of ways; educating drug intake and symptom relief alleviates suffering and increases treatment compliance [28], whereas counseling infection reduces secondary infection (to family members) and reinfection of the patient himself or herself in the future [29]. However, these procedures were seldom practiced as evidenced by our observations at baseline on both the arms and at endpoint on the control arm (in less than 25% of the cases). Fortunately, JITIF seemed to work very well in leveraging delivery of these procedures. In short, the study indicates that: (1) the current care for patients with infections at rural primary care settings in China falls short in terms of most of the essential procedures, and thus there is a clear need to reverse the situation and (2) JITIF may be an easily applicable and effective approach in reaching this end.

Strengths and Limitations

This study has both strength and weakness. Its strength originates from: (1) a packaged intervention consisting of cost-effective and sustainable approaches incorporated in a synergetic way and (2) an efficacy evaluation using a randomized controlled trial design that involved both baseline versus endpoint and control versus intervention comparisons. Perhaps, the biggest concern of the study may be observation-induced interferences on the practice behaviors. When being observed, the doctors may be more compliant to authorized guidelines [30]. To minimize such influences, the observation on the control and intervention arms used the same observers and identical protocol. However, doctors on the intervention arm were given detailed references, SOPs, and feedback, and thus they knew much better about what they were expected to do than those in the control group. Even so, the study findings suggest that JITIF may prove to be an effective intervention under closely observed or monitored conditions, and we are planning to leverage this study into a larger-scale randomized controlled trial that uses continuous artificial intelligence–based audio recording of the service encounters between village doctors and patients with infection symptoms. Another drawback of the study relates to nonblinded data collection, especially, rating of essential service procedures. The field data collectors may have given, due to various reasons, more positive ratings to intervention than the control groups since they knew the grouping, though the combination of the data quality control measures may have helped in keeping to a minimum. A third shortcoming concerns the use of antibiotics prescription as the primary measure in assessing JITIF efficacy. Given the prevalent use of antibiotics (as high as over 86% for symptomatic RTI or GTI patients), there are reasons to believe that JITIF helped in reducing excessive antibiotics prescription and thus is beneficial. However, less prescribed antibiotics may not necessarily mean better outcomes for all the patients [31]. And there is still a need of a further outcome-oriented evaluation, for example, linking JITIF with recovery from RTIs or GTIs and direct and indirect costs due to the infections. In addition, although our preliminary evaluation indicates that JITIF is quite effective as a whole, it is hard to tell what each of the individual ingredients of the package had contributed.

In conclusion, excessive use of antibiotics was very prevalent, and most essential service procedures for patients with symptomatic infections were not commonly practiced at primary care settings in rural Anhui, China. JITIF was effective in reducing antibiotic use and improving service procedures.

Acknowledgments

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Authors' Contributions

XS conceived this project, facilitated the protocol and instrument development, and drafted this manuscript. ML and RF led field data collection. J Chai programmed the website. J Cheng supervised field data collection. MX, MD, and TJ analyzed the data. DW provided expertise for the overall design of the study and finalized the manuscript.

Conflicts of Interest

None declared.

Notice of editorial concern: This randomized study was not registered, in violation of ICMJE rules for prospective registration of randomized trials, explained by authors as being due to randomization only occurring to clinics, not patients, and a lack of English material necessary for the registration (research plan, tools, ethical review, and other materials are available in Chinese only). While the editor did not accept these as valid reasons for not registering the trial, he granted an exception because the risk of bias appears low. However, readers are advised to carefully assess the validity of any potential explicit or implicit claims related to primary outcomes or effectiveness.

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Multimedia Appendix 1

Commitment letter.

[PDF File (Adobe PDF File), 26KB - jmir_v20i2e53_app1.pdf]

Multimedia Appendix 2

Sample patient takeaway information.

[PDF File (Adobe PDF File), 46KB - jmir_v20i2e53_app2.pdf]

Multimedia Appendix 3

Sample screenshot of Web-based aid.

[PPTX File, 183KB - jmir_v20i2e53_app3.pptx]

Multimedia Appendix 4

Checklist for observation of essential service procedures.

[PDF File (Adobe PDF File), 48KB - jmir_v20i2e53_app4.pdf]

Multimedia Appendix 5

Additional information on web-based aid for just-in-time information and feedback (JITIF-WBA).

[PDF File (Adobe PDF File), 44KB - jmir_v20i2e53_app5.pdf]

Multimedia Appendix 6

CONSORT E-HEALTH checklist (V 1.6.1).

[PDF File (Adobe PDF File), 887KB - jmir_v20i2e53_app6.pdf]

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Abbreviations

ABR: antibiotic resistance
ABU: antibiotic use

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EDI: eye and dental infection
GTI: gastrointestinal tract infection
JITIF: just-in-time information and feedback
PS: performance score
RTI: respiratory tract infection
SDM: shared decision-making
SI: skin infection
SOP: standard operation procedure
UTI: urinary tract infection
WBA: Web-based aid

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Original Paper

How Knowledge Is Constructed and Exchanged in Virtual Communities of Physicians: Qualitative Study of Mindlines Online

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Abstract

Background: As a response to the criticisms evidence-based practice currently faces, groups of health care researchers and guideline makers have started to call for the appraisal and inclusion of different kinds of knowledge in guideline production (other than randomized controlled trials [RCTs]) to better link with the informal knowledge used in clinical practice. In an ethnographic study, Gabbay and Le May showed that clinicians in everyday practice situations do not explicitly or consciously use guidelines. Instead, they use *mindlines*: collectively shared, mostly tacit knowledge that is shaped by many sources, including accumulated personal experiences, education (formal and informal), guidance, and the narratives about patients that are shared among colleagues. In this study on informal knowledge, we consider virtual networks of clinicians as representative of the mindlines in the wider medical community, as holders of knowledge, as well as catalysts of knowing.

Objective: The aim of this study was to explore how informal knowledge and its creation in communities of clinicians can be characterized as opposed to the more structured knowledge produced in guideline development.

Methods: This study included a qualitative study of postings on three large virtual networks for physicians in the United Kingdom, the Netherlands, and Norway, taking the topic of statins as a case study and covering more than 1400 posts. Data were analyzed thematically with reference to theories of collaborative knowledge construction and communities of practice.

Results: The dataset showed very few postings referring to, or seeking to adhere to, explicit guidance and recommendations. Participants presented many instances of individual case narratives that highlighted quantitative test results and clinical examination findings. There was an emphasis on outliers and the material, regulatory, and practical constraints on knowledge use by clinicians. Participants conveyed not-so-explicit knowledge as tacit and practical knowledge and used a prevailing style of pragmatic reasoning focusing on what was likely to work in a particular case. Throughout the discussions, a collective conceptualization of statins was generated and reinforced in many contexts through stories, jokes, and imagery.

Conclusions: Informal knowledge and knowing in clinical communities entail an inherently collective dynamic practice that includes explicit and nonexplicit components. It can be characterized as knowledge-in-context in practice, with a strong focus on casuistry. Validity of knowledge appears not to be based on criteria of consensus, coherence, or correspondence but on a more polyphonic understanding of truth. We contend that our findings give enough ground for further research on how exploring mindlines of clinicians online could help improve guideline development processes.

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KEYWORDS

knowledge management; translational medical research; guidelines as topic; evidence-based medicine; evidence-based practice

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Introduction

Knowledge in Health Care, Guidelines, and Evidence-Based Medicine

The processes we use for generating, validating, and disseminating medical knowledge through clinical guidelines face growing criticism. Although many tools have been developed and implemented to support the appraisal of evidence from high-quality research studies (notably randomized controlled trials, RCTs), it is rarely, if ever, possible to fully assess and incorporate the range of evidence relevant to all the problems facing clinicians and patients in everyday practice. Knowledge from (for instance) "outbreak investigations, laboratory research, mathematical modeling, qualitative research, or quality improvement processes and clinical audit" are underrepresented in clinical guidance [1]. Furthermore, a guideline, however comprehensive, cannot address the level of granularity needed to manage the unique needs of an individual patient [2].

The mismatch between the knowledge captured in guidelines and the knowledge actually needed for clinical practice does not appear to have been anticipated by the pioneers of evidence-based medicine (EBM). They argued that clinical expertise and patient preferences should be "integrated" with best research evidence [3]. Contrary to how some critics depicted EBM , "best" evidence was not considered to be synonymous with a simple and restrictive hierarchy of evidence, as some clinical questions are best addressed using study designs other than RCTs or because there are some questions for RCT evidence that is impossible to obtain or unavailable [4]. Despite this early call for a pluralist approach to evidence in guideline development, standards and checklists for assessing the quality of guidelines (notably the *Grading* of *Recommendations* Assessment, Development and Evaluation recommendations [5]) can sometimes depict an overly hierarchical approach, inadvertently privileging RCTs even when these are not appropriate and making it difficult to give appropriate weight to knowledge from non-RCT study designs.

Critics have described a number of problems with the guideline development process [6-9]. For instance, EBM's hierarchy of evidence would promote a reductionist approach because it privileges a single epistemological position. Current guidelines may be characterized by a near-absence of heuristics [10], relying instead on complex and impracticable decision trees. There appears to be a critical mismatch between population-derived evidence and the needs of the individual patient. Shared decision-making tools and processes seem underdeveloped, making it difficult to have democratic dialogue with patients when applying guidelines in real time. Vested interests sometimes exert a distorting influence, leading to overinvestigation, overdiagnosis, and overtreatment. And single-condition guidelines appear inherently incapable of dealing effectively with multimorbidity.

Movements of scientists have recently emerged that seek to reform EBM, health care research, and guideline development [1,6,11-13] to deal with these challenges. Most notably, the Guidelines International Network has set up the AID working group [14], whose members include staff from the National Institute for Health and Care Excellence (NICE), National Healthcare Group (NHG, guideline developer for general practitioners [GPs] in the Netherlands), and comparable organizations, to identify "methods and promising initiatives for appraising and including a wider range of knowledge sources in guidelines."

In this discussion, it is important to note that EBM and evidence-based health care (EBHC) have helped to develop numerous methods for the development and management of formal, explicit knowledge such as the structured population-intervention-comparison-outcome approach to formulating research questions, evidence hierarchies, search tools and strategies, techniques for statistical summation of trial results (meta-analysis), and so on. However, EBM scholars have largely neglected to investigate and describe how tacit, embodied, and practical knowledge is constructed in *informal* settings. This question—how is knowledge actually developed and shared in informal communities of clinicians?—formed the focus of the empirical study reported here. We're studying GPs reflections-on-practice and knowledge-for-practice. This is one step removed from actual practice, but important in its own right.

Mindlines

The concept of *mindlines* offers an important theoretical perspective on this question. Ethnographic research by Gabbay and Le May [15-17] demonstrated that clinicians rarely used explicit evidence from guidelines directly. Instead, they drew heavily on socially shared knowledge (which was predominantly tacit) and embodied patterns of behavior, which these authors called "mindlines."

As a relatively new concept in the field of knowledge management, the definition of mindlines remains somewhat fuzzy. Although the term *mindlines* stuck as a suitable antonym of *guidelines*, the authors who originally coined the term are the first to admit that they are not very content with the term "lines." This somewhat echoes Tim Ingold's observation that "the straight line has become an icon of modernity. It offers reason, certainty, authority, a sense of direction. Too often in the twentieth century, however, reason has been shown to work in profoundly irrational ways, certainties have bred fractious conflict, authority has been revealed as the mask of intolerance and oppression, and directions have been confounded in a maze of dead ends [18]."

In their book [15], Gabbay and Le May write that mindlines should not be seen as a measurable, closed system but instead quote a GP who finds that it is "[...] more like diffuse, often bending sets of influences which vary on different days in their impact depending on what else is going on and which sometimes go in different directions." The authors have recently presented mindlines as processes, not entities per se [19].

Many researchers have interpreted the concept in different ways, as shown in our review on the concept of mindlines 10 years after its conception [20]. This may partly be because the notion of mindlines fuses a raft of theories into one single concept of knowledge, knowledge creation, and knowledge diffusion.

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Notwithstanding the residual uncertainty and disagreement about the meaning of the term, however, we think the concept of mindlines is helpful in any effort to describe and understand knowledge and knowledge processes on informal networks of clinicians.

First, mindlines convey the idea of knowledge as both individual and collective. This links theoretically and empirically with the literature on communities of practice [21-23]. This concept emphasizes not only a common topic of interest but also a common (and often emotionally laden) group identity that is shaped and reinforced through group interaction. For example, in an early article on communities of practice, Jean Lave [21] exhorts those who study knowledge and its acquisition to:

> *...consider learning not as a process of socially shared cognition that results in the end in the internalization of knowledge by individuals, but as a process of becoming a member of a sustained community of practice. Developing an identity as a member of a community and becoming knowledgeably skilful are part of the same process, with the former motivating, shaping, and giving meaning to the latter, which it subsumes.*

Second, mindlines represent both explicit and not-so-explicit knowledge. Tacit knowledge [24,25] and practical knowledge [26] form an important aspect of mindlines. They are more complex than simple cognitive shortcuts, heuristics, or rules of thumb [16]. Gabbay and Le May also refer to the socialization, externalization, combination, and internationalization processes of tacit knowledge creation [27] to explain how mindlines form.

Third, mindlines can be characterized as a form of "knowledge-in context-in practice" [17]. They consist and are shaped by many influences, including personal experience, training, interactions with colleagues, patients and industry representatives, as well as local circumstances and contextual constraints. It pushes the discussion away from barriers to knowledge translation [28] and toward a focus on the dynamic trade-offs that practitioners have to make [29].

Fourth, storytelling and casuistry are important cornerstones of the idea of mindlines. This reflects theories of narratives shared among clinicians in face-to-face interactions [30,31] and casuistry [32].

Fifth, Gabbay and Le May stress the importance of making sure mindlines "are based on the research evidence wherever possible" [16], yet mindlines appear to lack a consistent theory of validity of knowledge. This noticeable lacuna calls for further research.

By exploring the idea of mindlines theoretically and empirically in guideline development organizations and the wider community of clinicians, we hope to find innovative ways to appraise and incorporate a wider range of evidence into guidelines and also explore how guidelines are interpreted and applied in real time. In this way, we hope help to ensure that guidelines are better able to interface with the mindlines that emerge informally among communities of clinicians and the implementation of evidence-based decision making in everyday practice.

Virtual Networks as Artifacts

New technologies (specifically, social networks, online bulletin boards, and email lists) offer new possibilities for collaborative knowledge creation that are not built into the traditional EBM framework.

We sought to explore these possibilities by examining virtual networks of physicians as part of a larger research project that aims to inform closer links between the development and use of clinical guidelines and the mindlines that emerge informally among communities of clinicians. The empirical work reported in this paper focuses on three virtual social networks of physicians in different countries. Our objectives were to describe the form and nature of knowledge, and the practices involved in knowing, of these practitioner communities; identify how mindlines develop in such communities; and explore how a broader set of knowledge sources influence (or why they fail to influence) the clinical community.

Gabbay and Le May's theoretical work on mindlines was derived from an extensive review of the philosophy of knowledge [15], as well as extensive ethnographic research comprising direct observation of clinical practice and face-to-face discussions (eg, among local peers in practice meetings). Our own empirical work, undertaken at a time when clinicians' peer interactions increasingly occur virtually, asynchronously and in large online communities [33-35], sought to complement the original approach taken by Gabbay and Le May.

As informal communities of exchange between GPs, Web-based networks are not unique. Informal communities of doctors in hospitals are explored extensively, for instance, in the study by Haldar et al [36]. But Web-based communities have some specific characteristics that make them particularly interesting in our context.

First, the dialogue is not limited in time and space (eg, not limited to a particular medical institution where doctors meet). Second, the access is less regulated than many other comparable arenas. There is some kind of selection (you must be a doctor, you must have sufficient electronical skills, etc), but the selection is less formal and less strict than in many other settings where doctors interact and exchange knowledge. Third, as private communities of clinicians, they provide an environment to freely discuss topics without the presence of patients or representatives of the pharmaceutical industry. Fourth, there is no formal censorship of the dialogue. The most important censorship is the *governmentality* or self-regulation of the group (eg, members don't want to ask "stupid" questions). Fifth, they offer an efficient way of researching collective knowledge involving thousands of GPs from hundreds of sites and practices.

Sixth, it has been shown that more formal online communities, including social media, have the potential to empower health care professionals and patients to apply knowledge by involving them in the intermediation and development of that knowledge [37,38]. Some virtual communities are already successfully used to create and share new knowledge using a strict structured format of questions and replies. For example, the network sermo.com that originated in the United States and claims to

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have 600,000 clinicians participating, lets its members post and answer multiple choice questions, with some additional features such as adding new answers to those questions to choose from and masking other member's answers for a few weeks [39].

This ethnographic study of online professional communities is aimed to reveal how informal collective knowledge can be built and shared. Although practice is not studied directly (hence, it is not possible to document how tacit, embodied knowledge influences specific instances of clinical practice), this methodology reveals for the first time how "mindlines" may develop dynamically through multiple contributions to topic-based threads.

We take virtual networks to be "knowledge artifacts," not so much as carriers of objective knowledge, but as in the words of Cabitza et al "collaboratively created [inscribed artifacts], maintained and used to support knowledge-oriented social processes (among which knowledge creation and exploitation, collaborative problem solving and decision making) within or across communities of practice" [40,41]. As such, virtual networks and mindlines share the inherent duality of knowledge artifacts as holders or as catalysts of knowledge at the same time.

Methods

Design

The study was set up as a digital ethnography of the interactions in virtual social network groups of physicians looking at how knowledge is formed and shaped in the online environment.

Digital ethnography takes many forms including virtual ethnography, Internet ethnography, sensory ethnography, and hypermedia ethnography, each with a slight difference in application and epistemic assumptions, but akin in their use of digital technologies [42]. These technologies, such as online questionnaires, digital video, social networking websites, and blogs, offer social scientists a multitude of new tools to do research with [43].

Digital ethnography can examine the same concepts that researchers in the humanities find useful in any kind of ethnographic research: experiences (affective, sensory, and embodied), practices (what people do), personal relationships, social worlds (as a theory of communities), things (and how they are made meaningful), localities, and events; albeit somewhat differently [44]. For instance, whereas conventional ethnography can explore the influence of physical environments on human experiences and action, digital ethnography can do the same for the digital environment.

Pink et al state five core principles of digital ethnography: there is more than one way to engage with the digital, for example, broadband, smartphones, and games (multiplicity); digital media are part of other, nondigital relationships and activities (nondigital-centricness); it is a flexible research design that can be fitted to the specific research question and context (openness); it continuously asks itself how it produces knowledge in a digital world (reflexivity); and it engages in alternative forms of communicating "beyond the standard written production of academic scholarship," such as ongoing collaboration and dialogue with the research participants (unorthodoxy) [44].

Networks

We had access to three social networks that provided contrasting but comparable datasets: a Facebook group of UK-based clinicians called "Tiko's GP Group (TGG)," a virtual network set up by the professional GP societies in the Netherlands called "HAWeb," and a network of physicians in Norway called "Eyr." All networks have a dedicated administrator or administrative team moderating membership and online activities. TGG and HAWeb networks are closed; they can be accessed only after specific approval of a group administrator who confirms that the participant is a clinician (TGG) or a member of a medical society (HAWeb). Eyr is not closed but accessible for anyone after registering; however, in practice, almost all members are medical doctors.

The four authors of this paper are a Dutch GP who practices in both the United Kingdom and the Netherlands, a UK GP (TG), a Norwegian social scientist (EE), and a Norwegian nurse (KH). We were helped by research assistant Kristiane M Hansson (KMH).

Data Collection

SW had already become a member of TGG and HAWeb. He had helped to develop HAWeb for the Dutch GP associations NHG and Landelijke Huisartsen Vereniging, LHV in the Netherlands after seeing and signing up for similar network groups online. In the United Kingdom, he heard from young colleagues about TGG on Facebook and signed up to get GP relevant updates and news. SW and KMH signed up for Eyr specifically for this research project. We contacted the administrator of each network to explain the project and ask for consent. We did not participate in any group discussions except the one to highlight the nature of the research and give participants the opportunity for feedback.

On the basis of the large number of posts on these virtual networks and to allow comparison across networks, we chose to restrict the focus of our study to postings relating to raised levels of cholesterol (detected by a blood test and viewed as a risk factor for cardiovascular disease) and statins (cholesterol lowering drugs such as simvastatin, atorvastatin, and related molecules). For years, statins have had a prominent position in debates in medical communities across many countries. Questions asked about statins include which subgroups of people with raised cholesterol levels will gain a significant benefit from taking a statin [45] and how to deal with patients who cannot tolerate statins—for example, because of the common side effect of muscle aches [46]. However, the prevailing debate in the medical literature concerns the interpretation of evidence on whether the benefits and harms of statin therapy have been over- or underestimated [47-49]. Some scholars argue that almost everyone should take a statin as it may prolong their life, and side effects are rare; others for whom side effects are much commoner than the results of RCTs suggest and people with minimally raised cholesterol and no other risk factors would be better to avoid these drugs. As this debate is heated and still

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ongoing, statins form a rich and interesting subject to explore mindlines online.

To obtain ethical approval for online research, we sought consent from the social network administrators first and then presented the research plan in an online discussion post in the networks, asking members for approval and feedback. This research was approved for each network in each country separately: by Ethics of Research Committee, QMERC at the Queen Mary University London in the United Kingdom under reference number 2014/82, by Norwegian Centre of Research Data, NSD at the University of Oslo in Norway under reference number 48032, and by Research Ethics Committee, REC at the Radboud University Nijmegen Medical Centre in the Netherlands under reference number 2016-2680. To maintain anonymity of participants, quotes in this publication have been translated from Dutch and Norwegian or paraphrased from English posts to avoid connecting them to members using the virtual networks' native search engines.

Using the native search engines in these networks, we looked for online posts from 2013 to 2015 that contained (parts of) the following words: statins or statin, cholesterol, cholesterol-lowering treatment, cholesterol-lowering drugs, hypercholesterolemia, familial hypercholesterolemia, HMG-CoA reductase inhibitors, and their Norwegian and Dutch equivalents.

Data Analysis

As our analysis was focused on the generation and application of mindlines in online conversations between doctors, we needed an analytical approach that reached beyond mere thematic descriptions. We therefore used an iterative part thematic descriptive and part interpretative approach [50] to analyze and synthesize the data with mindlines as a reference model. First, we were interested in themes and topics related to the participants' use of knowledge and knowledge sources such as references to guidelines, research-based evidence, personal experiences, reported patient experiences with statins, and so on. Second, we wanted to capture the participants' "acts of knowing" in terms of the logics underpinning their reasoning and the interactions in the online communities. We were interested not only in *what* sources they built their arguments on but *how* they built and exchanged their arguments. How did the participants construct their arguments? What characterized their "styles of reasoning" [51,52]? How did they address and invite each other into discussions? How were patient problems articulated? and what sorts of responses were given by whom?

The empirical data from online discussions were subject to preliminary analysis by each researcher independently with the aim of identifying and classifying both the aforementioned aspects of the knowledge creation in the conversations. Second, we discussed our findings as a group and compared and weighed our different descriptions against each other and against Gabbay and Le May's description of mindlines [16]. A draft of the descriptive research results was fed back to the online communities for review and to request input for topics for discussion. Finally, in an interpretive synthesis process, the topics discussed by the online communities, key findings, and limitations of the study were drawn out through reflection and discussion among team members.

Results

Three Virtual Networks

Each network agreed to grant access to the research team. The TGG group of UK GPs consisted of approximately 2900 members. The HAweb group consisted of more than 30,000 members, and Eyr had 2300 to 2400 members. The activity (rate of posts) of members varied hugely both within and between networks. We found the TGG group in the United Kingdom to be by far the most active of the three. On the topic of cholesterol and statins, there were more than 1300 posts over 2 years. Most members did not contribute; all discussions were started by 64 individual members, and all posts were written by about 150 individual members. These posts varied considerably in length. Most were informal and very short, consisting of a word, an exclamation, or a link, though there were interspersed with longer postings that included segments of patient narrative or presentation of an argument. Most discussions had responses, with some threads extending beyond 30 posts. In Eyr and HAweb, there were fewer than 100 posts in 35 discussions over the same time frame. These posts tended to be longer and more formal and attracted none or a small number of responses.

TGG group was not only accessible via a browser but also via the Facebook app on a mobile phone, which made it easily accessible and integrated with other activities and friends on Facebook. Eyr and HAWeb are more dedicated services without a mobile phone app. A member had to log in first to see discussion, but would get further updates and could reply via email directly once they had engaged in one.

Many of the GPs who did post on TGG appeared to be relatively young and inexperienced (judging by their profile pictures and postings such as worrying that they may have posed a "silly question" and saying that they were doing locum work). The members on Eyr and HAWeb appeared to be more senior, as their postings featured concerns about issues relevant for practice owners or revealed extensive previous experiences relating to the issue at hand.

All networks had administrators and a protocol on rules and what kinds of postings are permitted, but in practice, moderation appeared to be very limited on these networks. No clear signs of interventions by an administrator were found on any of the threads studied (though we did not find any breaches of protocol either).

The Shape and Nature of Knowledge Online

Guidelines Mentioned Only Rarely

As Gabbay and Le May's also observed, we found few occasions where GPs referred to evidence and guidance on the TGG group. In a sample of over 1300 posts, there were just 45 links from members to online content elsewhere, 17 posts containing the word guidance, 50 with the word guideline(s), 25 with the word evidence, and 29 references to NICE (the national guideline developing organization in the United Kingdom). Of 37 links to other websites; four were to NICE, three to GP-Update (provider of specialist courses and online learning for GPs), and

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four to GP Notebook (a database of clinical medicine topics for GPs with a search facility). In 46 of the 76 discussion threads, the words NICE, evidence, study, guidance, or guideline were not mentioned in any post. On Eyr, members' references to guidance or guidelines were similarly sparse, but linking to other papers and sources of information occurred more frequently: 47 times in 26 discussions. On HAWeb, there were few links to other websites, but referencing to guidelines happened in 18 out of the 56 posts over 9 discussions.

The higher proportion of posts that referred to guidelines on HAWeb and Eyr appeared to be related to the more formal nature of the posts. Many of these specific references were presented to the community as useful to solve the problem at hand and could be posted without any further commentary. Other links were posted to draw attention to medical news in the media: to the debate on the usefulness of statins in lowering cardiovascular risk, the influence of vested interests on guidelines, or how statins were discussed in new journal articles.

Strikingly, in many cases on TGG and Eyr, members did not state which guidelines or evidence they were referring to. Rather, a *nominal* perspective toward guidelines was taken ("guidelines" referred to in name only, and in a generic sense):

> *As the guidelines state—those suspected of familial hypercholesterolaemia should be referred to a specialist for most likely high-dose statins.* [Post on TGG]

> *I keep getting into patients in nursing homes in the age group 90+ with 80 mg statins in addition to 15 other medications. Separately certainly correct according to guidelines (written by people who are sponsored by industry).* [Post on Eyr]

On HAWeb, this was not the case, as GPs used the term "standard," which is the specific name for guidelines produced by NHG (hence, from a GP-funded agency). In the Netherlands, there is almost no competing guidance for GPs, which probably explains why these GPs talked about " *the* guideline" rather than "guidelines in general."

Case-Based Reasoning

The concept of mindlines envisages knowledge being constructed collaboratively by sharing cases about patients and their situations. In the TGG group, there was a strong tendency to start a discussion or post a question based on a clinical case. In 44 out of the 76 discussion threads, initiators started off with describing a patient they had recently encountered. Statins were not necessarily the main topic on which they sought peer advice, but were mentioned as part of explaining the clinical situation. Group moderators and the GPs themselves made great efforts to protect patient confidentiality. In all cases, personal details were anonymized and adjusted to make reidentification impossible.

There were some references to actual cases in Norwegian Eyr too, but none in the Dutch network. It is not clear what explains these differences, but it may be coincidental and related to the small number of posts about statins and cholesterol, as on other topics in HAWeb members do present patient cases. An alternative explanation is that the prevailing debates among epidemiologists have taken place predominantly in the United Kingdom and attracted extensive coverage in the medical and lay press there; some exchanges have been acrimonious and linked to allegations of conflicts of interest and the threat of legal action against the *British Medical Journal*. Dutch GPs, in contrast, were exposed over the same time frame to a much more consistent message from a single, uncontested national guideline.

A Focus on "What" Rather Than "Why"

Where clinical cases were shared in the online group, they were mostly presented in a short, clipped, telegraphic style of writing. Elaborate narratives taking a more holistic view of the patient's context, preferences, or social relationships were uncommon. Rather, clinical findings and test results were used to describe patients and frame the problem:

> *Presenting a woman 51 years. BMI around 28. Little exercise. Former smoker but stopped 5 years ago. Before this 20 pack years. BP average 140/100. Total cholesterol 6.8, LDL 4.1. Other normal. No familial risk of cardiovascular disease.* [Post on Eyr]

The above quote is typical of the style in which a patient was presented "objectively" to peers in the virtual network. There is a strong emphasis on quantitative biomarkers and on aspects of lifestyle such as smoking and exercise that have been identified in research studies (and the guidelines that draw on them) as risk factors for cardiovascular outcomes. In this way, the account is strikingly parsimonious, omitting aspects of the narrative that are not directly related to cardiovascular risk factors. There is no detail, for example, about how she articulates *why* she is not exercising (or what could be done about it), what made her stop smoking, her life story, family circumstances, or the way she reasons about her own health and lifestyle. Perhaps the reason for this is that the virtual forum is being used to help *interpret* the guidelines on a case-by-case basis; although other factors (such as patient preference and circumstances) will also inform the clinical decision, this is not the aspect of practice for which the posting GP is seeking input from others.

Emphasis on Outliers

Another finding when considering the presented clinical cases was that these posts were most frequently about unusual situations and outliers. For instance, out of the 44 clinical cases in the TGG group, 16 covered a case of familial hypercholesterolemia, a condition affecting only 0.2% of the UK population [53]. On these networks, it appears that what becomes explicit, what gets discussed, and forms the basis of learning does not reflect the bread-and-butter knowledge of clinical practice but uses unusual cases to extend and challenge that knowledge (see Discussion).

Material, Regulatory, and Practical Constraints on Knowledge Use

In all three networks, members frequently referred to regulations, directives, systems, and financial restrictions in which decisions were situated. They discussed knowledge in relation to their role in the welfare state, the perceived influence of industry, and important socioeconomic and ethical considerations. Recommendations on statins often conflicted

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with economic reality—for instance, in this post on problems relating to funding and quality indicators for statins:

> *Module 2013 states at indicator 11B: preferred means simvastatin alone. So no pravastatin, as is preferred in accordance with the revised standard CVRM 2012 simvastatin. But now we had run into the problem that in practice many patients in the past had side-effects of simvastatin and quit. With provide an inexpensive alternative—restarting pravastatin—you score worse on the new indicator 11B in 2013.* [Post on HAWeb]

Here, a GP laments that the indicator 11B recommends that he prescribe simvastatin to lower cholesterol as advised by the national guidelines on cardiovascular risk management. But if he wants to offer patients who have side effects a better alternative in the form of another cholesterol lowering drug (pravastatin), his "quality score" (according a prescription module from a health insurance company for the GP practice to gain the status of a "plus practice") goes down. This illustrates how knowledge, and decisions based on that knowledge, are embedded in the local context in practice—and also how they are influenced by the "action at a distance" of well-intentioned national policies to improve prescribing quality but which are insensitive to the granularity of individual cases. In this case, a financial remuneration system competes with knowledge from guidelines and also goes against a solution that would seem more beneficial to the particular patient being considered in the here and now.

Not-So-Explicit Knowledge

The concept of mindlines entails that much of the knowledge shared is tacit, inexplicit, and more than can be told [25]. Though the very nature of tacit knowledge makes several authors suggest that this is inherently uncodifiable [54], others note that tacit knowledge can be surfaced and measured, albeit indirectly [24]. If defined as the knowledge subconsciously needed to perform things that are the focus of our attention [55], tacit knowledge can be surfaced through storytelling, modeling, shared practice, and other social interaction. On the basis of this latter understanding, there is a degree of shared knowledge assumed in most posts in our dataset. GPs would causally use concise reasoning in short sentences, which the poster knew did not need to be articulated explicitly. For example, one GP presented a case as follows:

> *Need LDL before thinking familial HC, def do TFT and Dm check, poss NAFLD given results, think what you done correct, I would just wait re clinic refer before getting results back in case TFT/DM show cause.* [Post on TGG]

This goes beyond jargon as an economic means of using language. The phrase "Poss NAFLD given results" assumes not merely that list members will know that NAFLD is an abbreviation of "nonalcoholic fatty liver disease," but also that everyone in this community knows that this diagnosis is relevant to the discussion and a reasonable conjecture given the blood test results.

To give a more subtle example, members of our virtual networks mentioned statins and their use frequently in posts and discussions on unrelated topics. Throughout these posts, the role of statins is not immediately evident, as the comments on statins are tangential or incidental to the topic being discussed. Members appeared to embed their knowledge about statins across multiple posts in a nonlinear, intuitive way. For example, in this posting, in a thread about research on gastric bypass (a surgical treatment for obesity), a participant first declares that he is skeptical about the procedure; depicts much of the research on it to be poor quality, conducted by those with vested interests, and heavily influenced by publication bias; and relates some stories of colleagues' patients who underwent gastric bypass. He then brings in statins as an example of a therapy that is likely to have very limited impact on a problem whose underlying cause lies elsewhere:

> *I am skeptical about this kind of research, especially as long as they are conducted at private clinics and gastro surgical departments. that promote this. It's possible I told this story before, but I take my chance to tell it again. I worked on one of the largest hospitals in the laparoscopic pediatric surgery. A colleague was tasked with the making prospective study of laparoscopic vs. conventional appendectomy. The results proved to be so discouraging that all "material" was thrown in the shredder. Unfortunately, the pharmaceutical industry keeps this going. I find it reassuring that X writes that we know too little about long term effects of such operations and that the Knowledge Centre needs to look into this. Recently received input from a few colleagues about bypass surgery. One patient weighing 125 kg before surgery, and now weighs 170 plus. My point is that we need to add significantly more "weight" to preventive health. It is quite pointless to repair, be with it statins, ACB, operations and other means.* [Post on Eyr]

Here, the reference to statins could be explained by members of the community as fitting in an argument of alternative interventions to reduce cardiovascular risk, but this remains subtle and implicit. The poster—probably rightly—assumes that his colleagues will understand the context in which he is referring to statins. And thus, the poster makes a small contribution to a wider "mindline" on the limited efficacy of statins in the face of multiple risk factors and social determinants.

Another example of tacit knowledge transmission was the use of images and figures. Pictures of parts (a tongue, an eye, and some skin) of unrecognizable, consenting patients were posted in four discussions in our dataset, accompanied with a brief wording, along with tangential mention of the use of statins. Most of these involved diagnosing dermatological cases that are highly dependent on pattern recognition. For example, one person posted a picture of an unusual rash, and (in a thread where several others had offered guesses as to the diagnosis) another GP suggested that this may be a vasculitic rash related to an adverse drug reaction, saying he had seen a very similar rash in such circumstances before. Although the other posters

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in this thread were attempting to elucidate the diagnosis rationally from particular features of the rash, this poster was relying on intuitive knowledge that he was unable to (and/or did not find it necessary to) articulate in words.

Another important way tacit knowledge was shared in these online forums was through GPs' postings on what they would do, without citing any formal sources of evidence or explaining their reasoning. On the TGG group, such practical knowledge exchange was common. For example:

> *Personally, I would choose to reduce alcohol and assess to solve or aid in reducing alcohol while give her a referral for 2 year test.* [Post on TGG]

Similarly, GPs often suggested what might or might not work, with either no justification or a justification (as in the example below) in which some of the rationale was implicit rather than explicit. In the case below, the poster is arguing that the relatively rare (and usually mild) side effect of depression on statins could become life-threatening in patients with a history of severe depression:

> *I would not even use statins, without having much harder risk factors than the currently loaded policy. As a psychiatrist, I treated a few patients which were so depressed that they needed hospitalization, shortly after starting with statins. And rhabdomyolysis by individual interactions and other unforeseen circumstances, is simply not to be trifled with.* [Post on Eyr]

At the same time, these statements often reveal not just how patients should be treated, but also personal experience and internalized preferences of the members themselves. For example, in a discussion on a case where patient has a very high cholesterol level, but (taking other risk factors such as weight and blood pressure into account) a moderate risk of cardiovascular events, members discuss what would be the appropriate thing to do. In commenting on his own post, the initiator of the discussion wrote:

> *If it was me, I'd want a statin. I think that's what my gut says.* [Post on TGG]

In this example, the member is expressing his professional disagreement with imposed policy, referring to how he would feel if he were the patient. In some discussions, members even disclosed their own or their family members' conditions and how they dealt with them, what medication they would take, and how they experienced the services they used (as patients). For example, in one thread, a member presented the case of a patient with raised levels of cholesterol and a positive family history of high cholesterol, in which she states that this is her husband. She is concerned that his GP only discussed the matter via telephone and wonders whether it would have been appropriate for her husband to go to a specialist lipid clinic. This posting, and the responses to it, illustrate how clinicians' professional knowledge could not be easily separated from their personal experience of illness and risk. Rather than distant abstract explicit facts, clinical knowledge is embodied and concrete, directly affecting these clinicians themselves.

Collective Reinforcement of Knowledge

The online communities served as a collegial fellowship of professional peers where the expected format is for one person to ask for advice and others to share their experiences and reflections. The discussants do not provide final answers, instead, they ask additional questions and give comments, suggestions, or theories that should be subject to further experiments and testing. Each answer is not inherently right or wrong, but the multitude of answers provides a broader sense of what is going on and the options for taking action. This is the means by which a knowledge base gets constructed to support a decision toward multiple actions appropriate for the situation at hand:

> *A: 17 year old pt has total cholesterol of 7.9 and LDL 5.6. no other risk factors. no family history of heart disease or high lipids, What would you do?*
>
> *B: Why was it done then!!*
>
> *B: Diet, weight.*
>
> *C: Send the blood result to the one that ordered it for them to deal with. She/He should know why they requested it!*
>
> *D: familial hypercholesterolemia...send to lipid clinic and family too.*
>
> *E: Bounce straight back to the one who ordered it. They can decide to repeat it instead of basing a lifetime of advice on 1 possibly accidental outcome. Never do a test if (a) you don't want to know the result and/or (b) will not be able to interpret. Unless you are about to go on vacation or quit that job.* [Post on TGG]

As a basic part of the concept of mindlines, the knowledge about statins is collectively reinforced through all kinds of social interactions and situations. In most case, the purpose remains largely clinical, but members also wrote about statins and lipids outside the context of clinical practice (eg, in relation to the allegedly unethical behavior of pharmaceutical companies in promoting overdiagnosis and overtreatment). Medical knowledge about statins was embedded in a wider array of stories, jokes, and noteworthy events. For instance, in a TGG group discussion about a cardiologist who advised to replace margarine with butter, a member states that he likes butter for many reasons and posts a picture from an unappetizing cartoon figure ripping his shirt open, revealing his torso, with the words "grease me up woman!"

Identity and Social Support

As in other topic threads, knowledge about statins was built and shared in postings that also served to support social cohesion and interaction or describe an atmosphere. For instance, a member started a discussion to express her joy at seeing other members of this virtual group at a face-to-face event. A member, who apparently was not at the face-to-face event, asked:

> *So, what was the buzz? Was it statins versus stilettos or vests versus venlafaxine? Xxx.* [Post on TGG]

Other members added to this discussion (talking about cardigans, the need for more gossip, and that they should meet up again

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face-to-face). GPs showed great affection for the group; throughout the TGG network there were many postings that they enjoyed the interactions and the contact with peers. For instance, one discussion thread began with a member ventilating about an afternoon surgery in which there had been many complex cases. Participants expressed their support in several ways, and then one participant interjected with the following:

> *Been a regular here for such a long time...I love this group.* [Post on TGG]

Such socioemotional contributions appeared very important, especially when members were posting about the stressful and challenging aspects of their job. In addition, these kinds of posts show an understanding of knowledge as relational on many levels: as indivisibly linked to the speaker, intrinsically interwoven with other concepts, as a mean to connect with others, and to form and sustain a community.

Discussion

Characterizing Online Knowledge and Knowledge Processes

The three virtual networks in this study support knowledge processes in an unstructured, self-organizing way. They are not about translation in a direct sense but intermediation [56]: "the messy engagement of multiple players with diverse sources of knowledge" where a limited set of rules and nudges are imposed by administrators and software. As concrete software tools, these networks can be understood as knowledge artifacts "holding" mindlines but at the same time as "collaboratively created artifacts for knowing" to support the development and sharing of mindlines [40]. This blurred duality of "knowledge" and "knowledge development and processing" encapsulated in one single concept is also key to understand what mindlines contribute to the debate on EBHC. It reminds clinicians, researchers, and guideline developers to stop thinking of knowledge as a simple package, ready to be "implemented" in every day clinical practice. This may be old news in other research fields and traditions (most notably in the social sciences), but not in health care where the often-unquestioned love for "facts" from RCTs require stronger rebuttal. We would contend that our findings inspired by the concept of mindlines provide good arguments to move beyond current evidence-based practice.

First, our findings support the idea of knowledge and knowing as a social practice of a group, consistent with literature on communities of practice and organizational learning (eg, [57,58]). Members of the networks have a shared interest and purpose (providing health care), they interact and learn together (asking questions, contributing to discussions, showing affection, and behaving like a fellowship of colleagues), and they share a repertoire of routines to solve the problems they face (ways of presenting a case, the use of jargon, and critiquing research evidence).

Second, our findings show that on these networks, both explicit and not-so-explicit knowledge is present. Nonexplicit, tacit, and practical knowledge is present on virtual networks, but in different shapes. It can be seen in jargon, images, stories, and "I would do"–statements.

Third, online knowledge on these networks adhered to the concept of mindlines in that it could be characterized as "knowledge-in context-in practice" [17]. In the example of the prescription module, we see how prescription of GPs is accessible to distant others who are monitoring and rewarding or punishing the GPs in ways that put pressure on clinical practice. Such as the Foucauldian panopticon, knowledge and knowledge processes form and are embedded in power relations [59]. By explaining the problems they faced when implementing recommendations, posters offered other members useful insights into the regulations, quality frameworks, and payments schemes in what Larry May has coined a "web of commitments" [60]. For instance, a GP's duty is not merely to apply the guideline to a single patient appropriately, but also to maximize health gains from a limited public fund and/or acknowledge the patient's limited means to pay for the treatment. This could be interpreted as contextual reality (social, financial, legal, and so on) "pushing back" [61] on clinical knowledge and recommendations, complicating them, but also reducing their abstractness and operationalizing the knowledge, making it practical and relevant for the task at hand, right there, right then.

Fourth, storytelling and casuistry are evident in our online datasets. The stories shared tended to be case-oriented, focusing on unusual, rare, or extreme events. This is not a peculiar characteristic of the online environment. On the contrary, it has been well described and analyzed in a philosophical paper addressing the paradox of using extremely rare cases to teach students about more common conditions ("when you hear hoof beats, don't think zebras" [62]). However, it perhaps illustrates that the virtual network is being used in particular to *extend* clinical knowledge.

We observed a more *telegraphic* format online than the classic narratives shared among clinicians in face-to-face interactions [30,31].

The cases largely lacked the "biographic and social context of the illness experience" [63] present in everyday clinical practice. A hybrid kind of case-based inductive inference occurred: casuistry [32] and pathology-based at the same time, with the main focus on test results and other quasi-quantitative facts about the individual patient (such as whether and how much they smoked). Notwithstanding that this approach may be partly because of the topic (cholesterol as a blood test–based risk factor), the format and style of discussion contrasts markedly with the discussions among GPs in a bygone era in Balint groups, where the central focus of case presentations was the patient's subjective narrative and the unfolding of the interpersonal GP-patient relationship in an overtly psychodynamic framing [64].

Validity

Mindlines lack of a theory of validity of knowledge, but based on our findings, we would suggest that validity in online communities appears to be about what works as kind of pragmatic reasoning. If we assess the popularity of some of these networks, we assume that users find much value in them.

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But the knowledge on these networks almost never clearly comes to a conclusion or single recommendation based on a criterion of correspondence (to reality) or coherence (fitting into a web of beliefs). Rather, their value seems to lie in their ability to support a practical decision in the here and now.

The clinicians in these networks tend to say what they would do or suggest what (in their view) might work. The personal commitment to these suggestions is stressed: "personally..." or "I would say..." In making these suggestions and asking additional questions, it appears they do not mind exploring issues of uncertainty. Indeed, by attending to these uncertainties, they seem to gain a kind of knowledge that is useful for them. Uncertainty itself "is not a regrettable and unavoidable aspect of decision making but a productive component of clinical reasoning" [65].

This relates to Weick's concept of "collective sensemaking" that is embedded in the theory on mindlines. Through discussion, we make things comprehensible in the best way we can collectively, because an ultimate truth or reality remains uncertain [66]. As the ultimate truth cannot be known, discussants are "scratching around" to make the world as understandable as they can, and only they can judge whether these understandings are useful [66]. As Wittgenstein observed, some problems are readily solved by the addition of data; others (especially those for which a simple answer is impossible) are solved by a *deepening of understanding* [67].

By saying what they would do personally, members appear to adhere to a criterion for valid knowledge similar to pragmatic theories of truth as defined by James: "Ideas...become true just in so far as they help us to get into satisfactory relations with other parts of our experience" [68]. But not fully, as our results show that many views do not come with a clear function and can be contradictory, disjointed, on a tangent, or unclearly related.

An alternative way to look at validity in online virtual networks with a lack of final conclusions would be to use Michail Bakhtins' concept of polyphonic or unified truth [69]. Bakthin was an early twentieth century Russian philosopher and literary analyst who posed that truth is not construed from one dominant perspective but from the interaction between multiple perspectives from many participants, each with their own validity. He refers to an author of a story who does not present his authoritative truth but lets his or her characters voice many (even contradictory) views that together form the narrative's "polyphonic" reality. Truth is better conceptualized not as a single thought or post but as the sum total of interactions of posted perspectives, including areas of dissonance and disagreement. This is more than just the summation of those posts; it is an emergent property.

Bakhtin also helps to cope with another problem of mindlines as presented on these online networks. Most network members don't contribute any posts, only a minority of members do. In how far do the posts represent the *true* mindlines of the collective? This problem is not just limited to mindlines or online networks but to all notions of collective knowledge. In Bakhtin's view on truth, what is not shared degenerates. Ideas can only thrive and become truthful if they engage in dialogic relationships with other ideas.

Limitations and Further Research

Although the field of Internet research should not be seen as a new Kuhnian paradigm—an entirely new kind of social science—it is a novel addition to and challenger of older methods to study social relations [70]. As Christine Hine wrote, "Internet research has arguably been a valuable reflexive opportunity for the traditional disciplines that have fed its development" [71]. Reflecting on the novel principles of digital ethnography as suggested by Pink et al [44], this study has several limitations and elicits areas for further research.

Regarding multiplicity, we studied the three networks that each represent different ways in which clinicians can engage with the digital communities: an email-based network, a professional network, and a commercial network. Further research could be helpful to understand these matters better.

As to nondigital-centricness, we have not yet examined how these virtual communities fit into the nondigital lives of their members. Other research would be necessary to do this. However, this study aimed to characterize informal medical knowledge in the medical community to enable further research in how this knowledge relates to guidelines, not how it correlates with actions in medical practice. Further research would be helpful to explore how knowledge of groups in virtual networks relates to informal knowledge of groups of clinicians in other social spaces.

About openness, we experienced an informative interaction especially with the administrators and the members on the TGG group early on in the research. The person collecting the data (SW) was known to the community as a researcher in EBHC as such, but this is unlikely to have led to any significant distortions in the content of the discussion as he did not participate actively in the discussions held. These contributions of the administrators and members greatly helped to shape the study to its current form. However, the HAWeb and Eyr communities were less responsive, possibly because of their lower activity. In our further research, we would aim to find additional means to increase interactivity with members to shape the research.

With regard to reflexivity, we acknowledge the importance to be critical of how the outcomes of this research were produced. Limitations of this study are the narrow scope of the topic and the limited number of virtual networks. Furthermore, the defined time frame may not reflect how the activity (number of posts and people) on the networks changed over time. This makes it impossible to state confidently that the findings reflect online discussions generally rather than discussions on a particular topic. As such, the findings are preliminary. A broader set of topics or other virtual networks may have revealed additional characteristics of knowledge on virtual networks. Further research could aim to pick a contrasting clinical topic such as mental health, and we would welcome other research studies to look into communities of clinicians to describe knowledge processes.

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Concerning the principle unorthodoxy, we aim to continue the dialogue with the research participants, also regarding this and future publications on this topic.

Conclusions

Our findings would be consistent with a definition of web-based clinical knowledge, knowledge creation, and knowledge translation in one single concept as mindlines, seeing them as instruments produced by clinicians to base their decisions on; a lubricant for explicit and tacit knowing shared among social groups and reinforcing norms of good practice in a fluid, dynamic, and constantly evolving way.

The far less structured interactions on the virtual social networks in this research represent a broad understanding of knowledge associated with many important knowledge theories that may be of use for the guideline community. Our findings show that not all networks will provide deep, rich knowledge. But it offers sufficient support to anticipate that analyzing certain virtual social networks as part of guideline update processes could help to better frame and synchronize recommendations with the mindlines of clinicians. It could highlight new topics for guidance updates, find what guidance needs to be formulated better, and evaluate uptake of recommendations. Conversely, this further research should inform whether it is possible—and if so how—to make the links between guidance and clinical practice closer, potentially by using online networks.

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Conflicts of Interest

SW is a member of the three online groups that were studied and helped to set up HAWeb in the past. He has no financial interest in either of these networks. SW is also a member of a clinical update committee at NICE and a volunteering member of the Guidelines International Network AID working group. All other authors declare no competing interests.

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Abbreviations

EBHC: evidence-based health care
EBM: evidence-based medicine
GP: general practitioner
NAFLD: Nonalcoholic fatty liver disease
NHG: Nederlands Huisarts Genootschap (Dutch College of General Practitioners)
NICE: National Institute for Health and Care Excellence
RCT: randomized controlled trial
TGG: Tiko's GP Group

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Original Paper

Perceived Threat and Internet Use Predict Intentions to Get Bowel Cancer Screening (Colonoscopy): Longitudinal Questionnaire Study

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Abstract

Background: Many people use the Internet for health-related information search, which is known to help regulate their emotional state. However, not much is known yet about how Web-based information search together with negative emotional states (ie, threat of cancer diagnosis) relate to preventive medical treatment decisions (ie, colonoscopy intentions).

Objective: The aim of this study was to investigate how frequency of health-related Internet use together with perceived threat of a possible (bowel) cancer diagnosis influences intentions to get a colonoscopy. Previous research has shown that people who experience threat preferentially process positive information in an attempt to downregulate the aversive emotional state. The Internet can facilitate this regulatory strategy through allowing self-directed, unrestricted, and thus biased information search. In the context of threat regarding a possible bowel cancer diagnosis, feelings of threat can still be effectively reduced through cancer screening (ie, colonoscopy). We, therefore, predict that in that particular context, feelings of threat should be related to stronger colonoscopy intentions, and that this relationship should be enhanced for people who use the Internet often.

Methods: A longitudinal questionnaire study was conducted among healthy participants who were approaching or just entering the bowel cancer risk group (aged 45-55 years). Perceived threat of a possible (bowel) cancer diagnosis, frequency of health-related Internet use, and intentions to have a colonoscopy were assessed at 2 time points (6-month time lag between the 2 measurement points T1 and T2). Multiple regression analyses were conducted to test whether threat and Internet use at T1 together predicted colonoscopy intentions at T2.

Results: In line with our predictions, we found that the threat of a possible (bowel) cancer diagnosis interacted with the frequency of Internet use (both T1) to predict colonoscopy intentions (T2; B=.23, standard error [SE]=0.09, P=.01). For people who used the Internet relatively often (+1 SD), the positive relationship between threat and colonoscopy intentions was significantly stronger (B=.56, SE=0.15, P<.001) compared with participants who used the Internet less often (−1 SD; B=.17, SE=0.09, P=.07). This relationship was unique to Web-based (vs other types of) information search and independent of risk factors (eg, body mass index [BMI] and smoking).

Conclusions: The results of this study suggest that health-related Internet use can facilitate emotion-regulatory processes. People who feel threatened by a possible (bowel) cancer diagnosis reported stronger colonoscopy intentions, especially when they used the Internet often. We propose that this is because people who experience threat are more likely to search for and process information that allows them to downregulate their aversive emotional state. In the present case of (bowel) cancer prevention, the most effective way to reduce threat is to get screened.

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KEYWORDS

emotion; Internet; colonoscopy; cancer screening

Introduction

Motivation to Undergo a Colonoscopy

Colonoscopy is a highly diagnostic tool for early bowel cancer detection and secondary prevention [1,2]. Health professionals, therefore, strongly encourage people at risk (eg, aged >50 years) to get screened. Despite the clear benefits, many people are still reluctant to have a colonoscopy [3]. Therefore, it is very important to understand the factors that motivate or discourage people to undergo a colonoscopy.

Until now, research on the predictors of colonoscopy attendance has focused predominantly on sociodemographic factors [4,5]. Recently, it has been suggested, however, that affective or emotional factors also play a key role in patients' decision making [6]. This is—among other things—because negative emotional states have a significant and biasing influence on information processing and behavior [7]. Given that "cancer" is associated with negative emotions such as threat [8], colonoscopy attendance should also be affected by the threat associated with the illness.

Such emotion-based processing biases assert a particularly strong influence when information processing is self-directed and not guided by feedback or other means, as in case of Internet searches for health information [9]. Given that a large number of people are nowadays using the Internet to gather health-related information (72% of US Internet users [10]), it is important to understand the impact of Internet use on medical decision making. However, the effect of Internet use on medical decisions in highly affect-laden domains such as cancer prevention (ie, colonoscopy attendance) has so far mostly been neglected. In this study, we, therefore, investigated the joint influence of cancer-related threat and frequency of Internet use on people's intentions to have a colonoscopy.

Emotion Regulation on the Internet

When people use the Internet for health information search, they do not only pick up practical information (eg, what to do when having a cold) but they also regulate their emotional states (eg, finding comfort and relief by browsing through health-related forums [11]). Such emotion regulation in the context of Internet use is particularly likely in the health context because negative emotions such as threat are very common there. Patients can feel threatened by their diagnosis and its consequences for their everyday life, and healthy people can also feel threatened by the possibility of being diagnosed in the future. Regarding cancer, people report strong negative associations and emotions independent of whether they are diagnosed [8]. Those negative emotions can have a profound influence on how people perceive and process health-related information. Specifically, according to the principle of counter-regulation [12], people preferably search and process positive information when they feel threatened because positive information can help downregulate their negative emotional state. Particularly relevant to the current context, previous research on health-related Internet searches showed in the support of the counter-regulation principle that under threat, people search, process, and remember more positive information [13,14]. This positivity bias could be conceptually replicated in a longitudinal study among chronically ill patients. Here, the severity of patients' disease (as a proxy of threat) predicted more positive perceptions of their own health 7 months later. Importantly, this relationship got stronger the more frequently patients used the Internet for health-related information searches, but not for those who used other sources [9]. This suggests that frequent Internet use augmented patients' positivity bias, presumably because the Internet allowed them to (repeatedly) select positive information.

The positivity bias observed in the above studies suggests that people who feel threatened engage in emotion-focused coping to relieve their negative affective state [15]. Emotion-focused coping is a common and adaptive form of emotion regulation in situations in which control is low and people cannot do much about the emotion-eliciting situation—for instance, in case of a chronic illness as in the study summarized above [9]. However, emotion-focused coping is not always adaptive. A positivity bias could also make people underestimate the severity of their medical condition, which in turn can lead to suboptimal medical choices. Especially in situations in which people can still take preventive measures, such as colonoscopy, to reduce the risk of further developing a certain disease, emotion-focused coping and the implied positivity bias ("I am sure I am not affected anyway") could have detrimental consequences. In fact, in those preventive health situations, people should be more likely to engage in problem-focused coping because this coping strategy is the more adaptive form of emotion regulation in situations in which people feel that there is a chance of restoring the lack of control (eg, being in a risk group but not yet affected). Accordingly, research has shown that in more controllable situations, people tend to directly address and change the emotion-eliciting situation rather than merely trying to feel better about it [15-17].

When feeling threatened by the possibility of receiving a cancer diagnosis, individuals should, therefore, look for ways to effectively reduce their threat. Given that a colonoscopy can help to regain certainty, and in the worst case receive a treatment at an early stage, it represents an effective means to reduce threat. Accordingly, people fearing bowel cancer should be particularly likely to get screened. Using the Internet to search for information regarding bowel cancer should further strengthen this link because numerous sites clearly communicate the high diagnosticity of colonoscopy and encourage making use of its benefits. Moreover, because the Internet allows self-directed and repeated information searches, people who use the Internet relatively often for health-related purposes and who strive to reduce their threat are more likely to engage with this positive and encouraging information. In that case, people's regulatory needs (to reduce threat) are optimally supported by the self-directed and autonomous nature of Internet search. In contrast, exposure to offline information about colonoscopy

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(eg, through general practitioner, friends and brochures) should not have the same supportive effect on people's intentions as offline information does not allow for a similar degree of self-directedness, autonomy, and the resulting selectivity [9].

However, to date, it is not yet clear how people's feelings of threat regarding a possible cancer diagnosis are related to problem-focused coping strategies, such as increased intentions to have a colonoscopy, and whether Internet use has the predicted augmenting effect. Finding out more about the factors which make or keep people from going to cancer screenings is of pivotal importance, because cancer screening is a very effective tool for early cancer detection and, in the case of colonoscopy, there is not much risk attached to the screening itself [1]. Nevertheless, many people find a colonoscopy invasive and unpleasant, and those negative affective attitudes have previously been shown to be negatively related to people's intentions to undergo a colonoscopy, as well as to their actual screening behavior [18,19]. Importantly, previous studies have either focused on global affective associations (eg, relaxed, tense, and happy [19]) or negative emotions regarding the procedure itself (eg, fear of pain or discomfort [18]). As argued above, we predict, however, that threat associated with a cancer diagnosis should be an independent and positive predictor of intentions to undergo a colonoscopy because it may motivate specific and more adaptive emotion-regulation strategies (ie, problem-focused coping).

This study investigates the role of perceived threat (of being diagnosed with bowel cancer) and people's frequency of health-related Internet use on their intentions to have a colonoscopy. To test this, we recruit healthy participants aged between 45 and 55 years (no current cancer diagnosis or chronic disease), because in this age group, people should start to consider getting a colonoscopy in the near future. We predict that higher threat levels together with frequent health-related Internet use should enhance people's intentions to get a colonoscopy. This positive relationship between threat and intentions should be less pronounced for people who use the Internet less often for health-related purposes.

To provide some background information for the main findings, we also plan to conduct the following additional analyses. First, we test whether our model holds when controlling for variables that have been shown to influence colonoscopy intentions in previous studies (ie, demographic factors [4,5] and threat of screening [18]). Second, we conduct exploratory analyses addressing further questions: does Internet use—as argued above—help to cope with the perceived threat of a diagnosis? To this end, we test whether Internet use predicts a reduction of perceived threat of a diagnosis over time. Does—in line with our argument—only Internet use moderate the impact of perceived threat of a diagnosis on colonoscopy intentions, or do the same effects occur for offline information search? And finally, how does the perceived threat of a diagnosis and its interaction with Internet use relate to risk factors of bowel cancer [20]?

Methods

Overview and Study Design

This study employed a longitudinal design with 2 measurement points (T1 and T2), which were approximately 6 months apart. We recruited a convenience sample of participants between the age of 45 and 55 years because people in this age group will face the decision whether or not to get a colonoscopy in the near future. Recruitment and measurement were done via a Web-based questionnaire, which ensured that our sample was at least somewhat familiar with using the Internet in a personal health context. Our main predictor variables (threat of cancer diagnosis and frequency of Internet use) as well as our outcome variable (colonoscopy intentions) were assessed with multiple-item self-report measures.

Participants

Participants were recruited via different Web-based platforms for a study related to psychology, health, and cancer prevention. The study was conducted in German language and described as a survey on cancer screening, and targeted a group of participants aged between 45 and 55 years. Participation was voluntary and the only exclusion criteria were a (current or past) cancer diagnosis or a diagnosis of a chronic disease (eg, diabetes). Completing the survey at both measurement points was rewarded with a voucher worth €10. This study was approved by the ethical committee of the Faculty of Medicine at the University of Tübingen, Germany.

Main Questionnaire

Upon following an link, participants were guided to an introduction page, which included information about the study (duration, reward, purpose of the study, ethical approval, and anonymity of data handling). Once participants had read the information, they could give informed consent by ticking a box. To ensure complete anonymity of the data handling process, participants provided their email address, which was stored separately and could neither be accessed by the researchers nor later be matched to their personal data. The system administration then sent an email with the link to the survey, which was administered via the Web-based survey program Qualtrics. In addition, 6 months later, another email with the link to the second survey was sent automatically and independent of whether participants had completed the first measurement. All email addresses were deleted after data collection had ended. To receive the voucher, participants had to re-enter their email address at the end of the questionnaire in the second measurement point, which was again stored separately from the questionnaire data.

The questionnaire was pretested by healthy participants. To increase user friendliness, a process bar was displayed throughout the survey, and the number of items presented per page was adjusted in such a way that scrolling was mostly unnecessary. After answering (and if necessary correcting) all questions presented on one page, participants clicked on a "next" button. Participants were not able to return to already completed pages.

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At the beginning of both measurements, participants generated a unique code, which would later allow matching their data without violating their anonymity. After receiving an overview of the questionnaire, participants reported their age, gender, and highest level of education. The main part of the survey contained the measurement of the key variables (see below) but also several additional measures. (This study was conducted in collaboration with another laboratory, and the additional measures were included to test their hypotheses. To increase transparency, the list with additional measures can be found in Multimedia Appendix 1.) As T1 contained more items than T2, T1 took on average 31 min and 55 s (SD 11.58, n=150) and T2 took 20 min and 5 s (SD 8.57, n=150) to complete.

Measures

Threat of Diagnosis

Our main predictor was participants' perceived level of threat regarding a possible cancer diagnosis. In addition, we assessed participants' perceived level of threat regarding the screening itself (ie, colonoscopy) [18], to be able to distinguish between the 2 different types of threat. Both types of threat were measured with respect to the following: (1) cancer in general and (2) bowel cancer in particular. There were in total 15 items measuring threat (diagnosis and screening) of general cancer and 15 items measuring threat (diagnosis and screening) of bowel cancer. All threat items were modeled after Peacock and Wong's [21] stress appraisal measure, and contained estimates of stress, threat, anxiety, outcome negativity, and helplessness. Threat regarding (bowel) cancer diagnosis was assessed with items such as "I am afraid of being diagnosed with (bowel) cancer." Threat regarding a (bowel) cancer screening was assessed with items such as "Undergoing cancer screening (a colonoscopy) would be a threatening situation for me." Responses were given on 5-point Likert scales (1=*not at all applicable* and 5=*very applicable*). Factor analyses confirmed the 2 subtypes (threat diagnosis vs screening) for both general and bowel cancer (general cancer: $eigenvalue_{T1}$ 2.73 vs 6.17, $eigenvalue_{T2}$ 2.40 vs 5.93; bowel cancer: $eigenvalue_{T1}$ 3.50 vs 5.17, $eigenvalue_{T2}$ 2.82 vs 5.13). One nonfitting item was dropped. High intercorrelations (r_{150}>.8) between general and bowel cancer items suggested that they should be treated as one construct (additional analyses showed that the main model presented below holds when only looking at threat regarding bowel cancer). This resulted in the following two final variables: our main predictor variable threat of cancer diagnosis (6+6 items; $alpha_{T1}$=.87, $alpha_{T2}$=.85) and the additional variable threat of cancer screening (8+8 items; $alpha_{T1}$=.95, $alpha_{T2}$=.95).

Internet Use

The second predictor of interest was health-related Internet use and was assessed with 2 self-report items (for a similar procedure see [9]). One item asked about the frequency of general health-related Internet use on a 7-point scale ("How often do you use the Internet for health-related purposes?"; 1=*several times a day*, 2=*once a day*, 3=*2-5 times a week*, 4=*once a week*, 5=*1-2 times a month*, 6=*2-6 times a year*, and 7=*rarely or never*), and about the frequency of Internet use regarding information on cancer prevention on a 5-point Likert scale ("Have you used the Internet to gather information on cancer prevention?"; 1=*never* and 5=*a lot*). We pooled those 2 items (reverse-coded and converted the 7-point scale into a 5-point scale) to arrive at a general Internet use variable ($r_{150,T1}$=.63, P<.001; $r_{150,T2}$=.41, P<.001).

Colonoscopy Intentions

Participants' intentions to get a colonoscopy were measured by the following 2 questions (assessed on 5-point Likert scales): (1) whether they would participate when asked by the doctor (1=*I would not participate* and 5=*I would participate*), and (2) whether they would actively ask for it (1=*definitely* and 5=*under no circumstances*). Both items were averaged (after reverse-coding the second item) to form the main outcome variable ($r_{150,T1}$=.22, P=.01; $r_{150,T2}$=.44, P<.001).

Additional Variables

We assessed the following 7 risk factors for bowel cancer based on the clinical literature [20]: family member with a bowel cancer diagnosis ("Are there are instances of bowel cancer known in your family" *yes* vs *no)*, current diagnosis of bowel disease ("Are you currently diagnosed with a bowel disease?"; *yes* vs *no*), smoking ("Are you smoking?"; *yes* vs *no*), quality of diet ("How would you evaluate your diet?"; 1=*poor* and 5=*balanced*), quality of lifestyle ("How would you evaluate your lifestyle?" 1=*poor* and 5=*balanced*), physical activity ("How many minutes per week do you exercise?"; 1=*less than 30 min*, 2=*more than 30 but less than 60 min*, 3=*more than 60 but less than 90 min*, 4=*more than 90 but less than 120 min*, 5=*more than 120 but less than 150 min*, and 6=*more than 150 min*), and body mass index (BMI; weight [kg]/height [m]×height [m]).

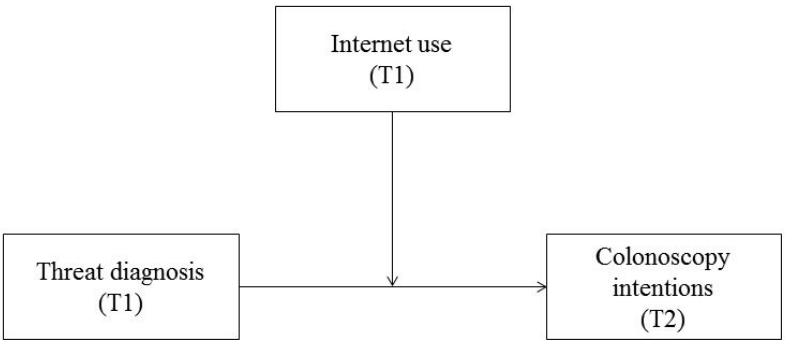
We also estimated the degree to which participants use other sources than the Internet to get information on health-related issues ("Which other sources of information do you use, and how often?"). Responses were given on 5-point Likert scales (1=*rarely* and 5=*very regularly*) for the following options: general practitioner, therapist, family or friends or acquaintances, books, television or radio, newspaper or magazine, and public events or lectures. Those were combined to a single average score reflecting the use of alternative information sources ($alpha_{T1}$=.72, $alpha_{T2}$=.61).

Data Analysis

To test the main hypothesis that people's colonoscopy intentions are predicted by an interaction of their perceived threat of a diagnosis and their Internet use (Figure 1), a multiple regression analysis was conducted. Colonoscopy intention (T2) was regressed on threat of diagnosis, Internet use (both T1), and their interaction, as well as colonoscopy intentions at T1 (autocorrelation). All predictor variables were mean-centered; the outcome variable was left in its original metric. Before carrying out the respective regression analyses, we computed the correlations among the predictor variables to check for multicollinearity.

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Figure 1. The main model tested in our analyses.



In the second step, we tested separately whether the predicted interaction between perceived threat of a diagnosis and Internet use explains colonoscopy intentions above and beyond the known predictors: (1) sociodemographic variables [4,5] and (2) threat of screening [18]. Therefore, we conducted two additional multiple regressions in which these known predictors (both assessed at T1) and perceived threat of diagnosis (T1), Internet use (T1), and their interaction were entered as predictors (and the autocorrelation) of colonoscopy intentions (T2).

Moreover, we conducted exploratory analyses to test the additional research questions mentioned above. First, to test whether Internet use contributes to coping with the perceived threat of a diagnosis, we regressed perceived threat of the diagnosis at T2 on Internet use at T1, perceived threat of diagnosis at T1, and their interaction. Second, we also tested whether offline information search moderated the effect of perceived threat of diagnosis on colonoscopy intentions just as Web-based information search. Here, we conducted a multiple regression predicting colonoscopy intentions (T2) by offline information search (T1), perceived threat of a diagnosis (T1), and the interaction between the last two factors (and the autocorrelation). Finally, to test the role of actual risk factors, we computed their correlation with perceived threat of a diagnosis in bivariate correlations. Moreover, to find out whether perceived threat asserts an effect beyond the actual risk factors, we entered the risk factors as additional predictors into the regression conducted to test the main prediction. All tests were conducted with Statistical Package for the Social Sciences (SPSS) version 22 (IBM Corp).

Results

Sample Description and Dropout Analysis

Of the 368 participants who started the questionnaire at T1, 250 participants completed it (ie, answered all mandatory questions: 250/368, 67.9%). Following our a priori exclusion criteria, we excluded 14 participants who were diagnosed with cancer and 5 people who indicated to be diagnosed with a chronic disease (diabetes; n_{new}=231). We additionally excluded 33 participants who spent less than 10 or more than 60 min on the survey because their responses were likely unreliable (mean time of completion of the final sample was 31 min and 55 s; n_{new}=198). From those 198 datasets, 150 could be matched with a completed and reliable questionnaire at T2 (150/198, 75.8%): dropout rate of 24.2% (48/198) from T1 to T2 (see Figure 2).

Participants who dropped out did not differ from the final sample with respect to gender ($\chi^2_{1,n=198}$=1.10, *P*=.29) but were slightly older (mean=49.73 years, SD 3.27) than the final sample (mean=48.44 years, SD 2.93; t_{196}=2.58, *P*=.01, *d*=0.43).

Participants who were included in the final sample (vs dropout) reported slightly lower threat levels with regards to a possible cancer diagnosis (mean=3.36 years, SD 0.59 vs mean=3.67 years, SD 0.81; $t_{63.61}$=2.46, *P*=.02, *d*=0.48) and used the Internet more often for health-related purposes (mean=3.40 years, SD 0.84 vs mean=3.02 years, SD 1.08; $t_{62.80}$=−2.23, *P*=.03, *d*=0.42). Despite the differences between the subsamples, we remain confident that our final sample is suitable for analysis because the differences we found are rather small and such differences are mostly problematic in contexts of intervention testing (eg, randomized controlled trials), but much less so in longitudinal questionnaire studies such as this study.

The final sample consisted of 150 participants (60.7% female; mean=48.44 years, SD 2.93, min=45 years, max=55 years). Participants' highest obtained level of education was relatively high, with the majority of people (102/150, 68.0%) holding a certificate of secondary education after 10 years of schooling. A total of 21 participants (14.0%) were holding at least a high school degree (ie, 12 years of schooling), and 27 participants (18.0%) held a university (polytechnic) degree (see Table 1 for an overview of sample characteristics).

Of all participants, the minority reported incidents of bowel cancer in their family (14/150, 9.3%). Moreover, only a few participants had already gotten a colonoscopy (T1: 12/150, 8.0%; T2: 14/150, 9.3%). Excluding participants who had already undergone colonoscopy from the sample did not significantly alter the results reported below.

Test of Predictions

In the main regression model, we predicted people's colonoscopy intentions (at T2) with their perceived threat of a cancer diagnosis (at T1) and their Internet use (at T1; see Figure 1). Participants' colonoscopy intentions at T1 were also included in the model (autocorrelation). Multicollinearity checks revealed that our main predictor threat of diagnosis was uncorrelated with Internet use (for intercorrelations, see Table 2).

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Figure 2. Generating the final sample.

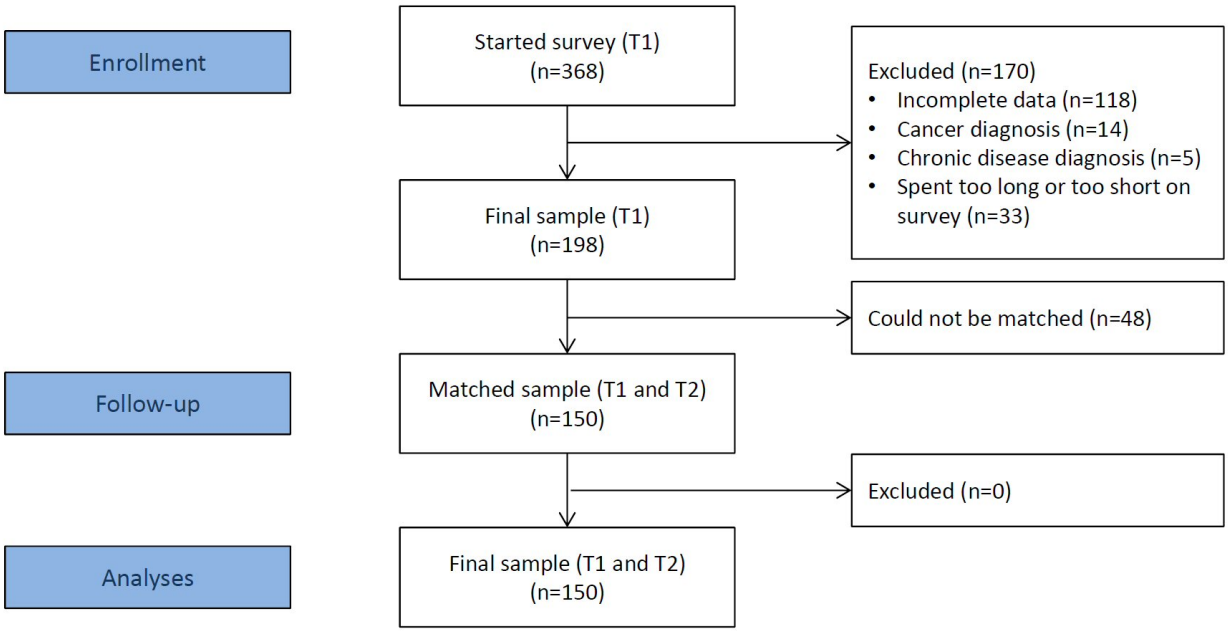


Table 1. Sample characteristics of the final sample (N=150) at T1.

Characteristic	Value
Age in years, mean (SD)	48.44 (2.93)
Gender, n (%)	
Female	91 (60.7)
Male	59 (39.3)
Education (finished), n (%)	
Secondary education	102 (68)
High school	21 (14.0)
University degree	27 (18.0)
Family cancer history, n (%)	14 (9.3)
Bowel disease diagnosis, n (%)	5 (3.3)
Smoking, n (%)	8 (5.3)
Body mass index, mean (SD)	22.90 (3.01)
Quality of diet, mean (SD)	2.25 (0.79)
Quality of lifestyle, mean (SD)	2.31 (1.00)
Physical activity, mean (SD)	3.54 (1.20)

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Table 2. Pearson correlations between measures used in the regression analysis (N=150) and descriptive.

Measure	Threat diagnosis (T1)	Internet use (T1)	Colonoscopy intentions (T1)	Mean (SD)
Threat diagnosis (T1)	-	-	-	3.36 (0.59)
Internet use (T1)	−.13	-	-	3.40 (0.84)
Colonoscopy intentions (T1)	.13	−.11	-	3.37 (0.78)
Colonoscopy intentions (T2)	.26[a]	−.15[b]	.55[c]	3.44 (0.78)

[a]*P*<.01.

[b]*P*<.10.

[c]*P*<.001.

The regression model testing the main hypothesis was significant (adj. R^2=.36, standard error [SE]=0.63, $F_{4,145}$=21.48, *P*<.001; see Table 3). Threat of diagnosis was related to stronger colonoscopy intentions (*B*=.37, SE=.10, *P*<.001), whereas Internet use in and of itself was unrelated (*B*=−.10, SE=0.06, *P*=.11).

Most importantly, the predicted interaction reached significance (*B*=.23, SE=.09, *P*=.01). In line with our prediction, simple slope analyses showed that for participants with relatively high Internet use (+1 SD), threat of cancer positively predicted intentions to participate in colonoscopy (*B*=.56, SE=.15, *P*<.001), whereas this relation was marginal for participants with low Internet use (−1 SD; *B*=.17, SE=.09, *P*=.07; see Figure 3).

In the second regression analysis, we again tested the main model but also controlled for main effects of major sociodemographic factors such as age, gender, and education level. None of the factors were significant predictors in the model, and including them did not influence the original predicted interaction between threat and Internet use (Table 3).

In the third regression analysis, we extended the main model with the main effect of threat of screening (T1) because previous research had identified the threat of screening as a predictor of screening intentions [18]. Replicating previous findings, threat of screening predicted reduced intentions to have a colonoscopy (*B*=−.21, SE=0.08, *P*=.01; Table 3). The original predicted interaction between threat of diagnosis and Internet use remained marginally significant (*B*=.17, SE=0.09, *P*=.07). Simple slope analyses showed a similar pattern as in the main model for participants with high Internet use (+1 SD), threat of diagnosis was positively related to intentions (*B*=.48, SE=0.15, *P*=.002). This was also, but much less so, the case for participants who use the Internet less often (−1 SD, *B*=.19, SE=0.09, *P*=.04).

Exploratory Analyses

Internet Use and Coping

In the introduction, we argued that Internet use can augment coping processes that aim at reducing negative emotions such as threat. In an exploratory analysis, we tested whether threat of diagnosis at T1 together with Internet use at T1 predicted threat of diagnosis at T2. The respective regression model was significant (adj. R^2=.69, SE=.31, $F_{3,146}$=111.70, *P*<.001). Besides a significant autocorrelation between the two threat measures (*B*=.75, SE=0.05, *P*<.001), we also obtained a main effect of Internet use (*B*=−.14, SE=0.03, *P*<.001), which suggested that the more people used the Internet at T1 for health-related purposes, the lower their threat levels at T2. Hence, using the Internet appears to be an efficient means of coping with threat related to bowel cancer.

Source of Information

In the next analysis, we tested whether the moderating role of Internet use is unique to Internet use, or whether searching alternative offline sources (eg, magazines, television, and friends) for health-related information has a similar effect. To test this, we replaced the predictor Internet use with the measure of participants' use of alternative sources. Besides the autocorrelation, the only significant predictor was threat of diagnosis (*B*=.29, SE=0.10, *P*=.004). There was neither a main effect of alternative information use (*P*=.40) nor an interaction with threat (*P*=.22). This suggests that the effects are assumed specific to Internet use.

Risk Factors

In the final set of analyses, we tested whether it is the "right" (ie, at risk) people that feel threatened. From the 7 risk factors, 3 were significantly correlated to participants' level of threat at T1: smoking (smokers felt more threatened by diagnosis; r_{150}=.25, *P*=.002), having a family member who has had bowel cancer (participants with a cancer diagnosis in the family felt more threatened; r_{150}=.20, *P*=.01), and BMI (the higher the BMI, the stronger the threat; r_{150}=.20, *P*=.02).

Adding all 7 risk factors as additional predictors to the main regression model shows that none of the risk factors were themselves related to colonoscopy intentions (all *P* s>.05). Moreover, controlling for those factors did not alter the interaction between threat of diagnosis and Internet use (*B*=.23, SE=0.10, *P*=.02). These results indicate that participants' threat of cancer partly relies on risk factors, but people's emotions and not these risk factors contribute to the intention to participate in cancer screening.

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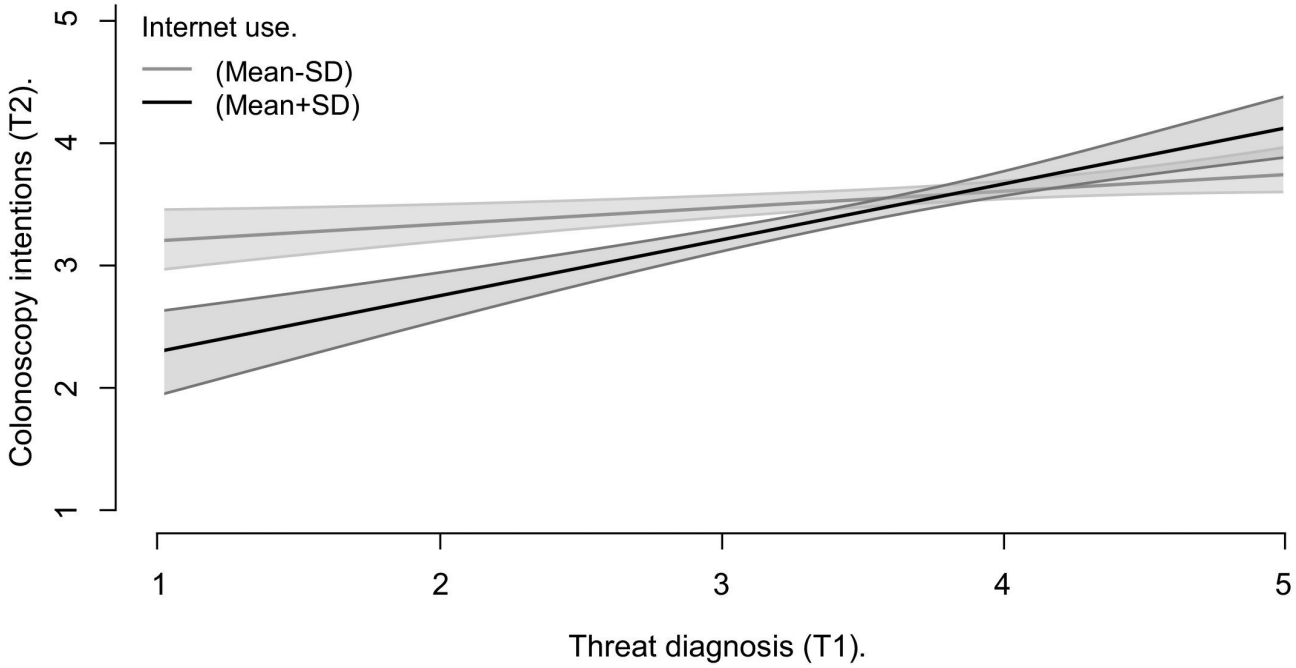
Table 3. Parameter estimates from different regression analyses predicting colonoscopy intentions (T2).

Model and predictors	*B*	Standard error	*t*	*F*	Degrees of freedom	Adjusted R^2
Main model				21.48[a]	4,145	.36
Threat diagnosis (T1)	.37	.10	3.61[a]			
Internet use (T1)	−.10	.06	−1.63			
Threat×Internet use	.23	.09	2.57[b]			
Colonoscopy intentions (T1)	.52	.07	7.75[a]			
Second model				12.60[a]	7,142	.35
Threat diagnosis (T1)	.34	.11	3.12[c]			
Internet use (T1)	−.10	.07	−1.39			
Threat×Internet use	.23	.09	2.55[b]			
Colonoscopy intentions (T1)	.51	.07	7.44[a]			
Demographic variables (T1)						
Age	.01	.02	0.43			
Gender	−.14	.11	−1.25			
Education	.04	.04	0.86			
Third model				19.19[a]	5,144	.38
Threat diagnosis (T1)	.34	.10	3.37[c]			
Internet use (T1)	.01	.08	0.17			
Threat×Internet use	.17	.09	1.84[d]			
Colonoscopy intentions (T1)	.42	.08	5.42[b]			
Threat screening (T1)	−.21	.08	−2.58[b]			

[a]*P*<.001.
[b]*P*<.05.
[c]*P*<.01.
[d]*P*=.07.

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Figure 3. The relationship between threat of diagnosis (T1) and colonoscopy intentions (T2) as a function of participants' frequency of Internet use (T1; at +1 SD and −1 SD). Shaded areas represent the ±1 standard error margin.



Discussion

Principal Findings

The goal of this longitudinal study was to investigate the role of perceived threat of cancer and people's frequency of health-related Internet use on their intentions to have a colonoscopy. In support of our predictions, we found that higher levels of threat together with frequent health-related Internet use increased people's intentions to have a colonoscopy 6 months later. Importantly, this relationship was independent of demographic factors (ie, gender, age, and level of education) and factors associated with the risk of developing bowel cancer (eg, BMI and smoking). It was also unique to Web-based (other types of) information search. Our findings are, therefore, in line with (1) the coping literature suggesting that in situations in which control over negative emotions such as threat and uncertainty is still possible (eg, cancer prevention through colonoscopy), people are more likely to engage in adaptive problem-focused coping [15]; (2) previous research showing that frequent health-related Internet use can augment such coping processes [9]; and (3) the recent appeal that emotional factors are key predictors of medical decision making and should therefore be investigated more thoroughly [6].

We propose that our findings can best be explained within the coping literature, according to which negative emotions such as threat and uncertainty motivate people to engage in behavior that reduces this aversive emotional state. In situations in which control can be restored, such as in the context of cancer prevention (eg, colonoscopy), people should be most likely to engage in problem-focused coping and search for ways to effectively reduce their threat. Given the high diagnosticity of colonoscopy and the possibility of early detection and intervention, it represents a suitable means to regain certainty and reduce threat. For people who use the Internet often for health-related information search, the benefits of colonoscopy should become even more salient. That is because most information about colonoscopy on the Web univocally emphasizes its benefits and encourages people in the risk group (eg, from 50 years onwards) to get screened, and because the Internet allows people to align their search behavior with their current emotional needs (ie, reduce threat). Our main findings, as well as our exploratory finding that enhanced Internet use reduced feelings of threat 6 months later, suggest that with its combination of encouraging content and self-directed search behavior, the Internet provides an optimal context for (problem-focused) coping to take place.

Although we did—in line with our expectations—not find parallel effects for offline and Web-based information search, similar effects can certainly also occur offline. The counter-regulation resulting in selective information processing [12-14] underlying the reported effect is not limited to a specific type of information source. It becomes more likely, however, when multiple sources provide the basis for selective information processing. Thus, when an individual discusses with many people whether or not to get screened, we may obtain similar results, given the majority of information is encouraging. As the Internet offers a large amount of easily accessible, predominantly encouraging information, it would be much more difficult to collect the same amount and type of information offline. Therefore, we deem the reported effects to be more likely to result from Web-based rather than from offline information search.

The finding that the perceived threat of diagnosis is related to (self-reported) risk factors suggests that the perceived threat is not irrational. However, given that the interaction between threat and Internet use predicts colonoscopy intentions beyond the risk factors, the current findings emphasize the notion that emotions play an important role in medical decision making [6]. However, research investigating emotional predictors of colonoscopy intentions and attendance is still scarce. Moreover,

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the few existing studies reported predominantly negative effects [18,19]. For example, threat regarding the colonoscopy screening itself had been associated with reduced intentions to get screened. In this study, we did not only replicate this previous finding but we also extended it by showing that threat regarding a possible cancer diagnosis has the opposite positive effect on colonoscopy intentions—especially when people used the Internet often for health-related questions. This study, therefore, contributes to a more nuanced understanding of the different ways in which negative emotions can impact medical decision making.

Limitations and Future Directions

One limitation of this study is that we measured intentions rather than real colonoscopy attendance. That was partly because of the choice of our sample (aged 45 to 55 years), which was just entering the phase in which preventive cancer screening gains importance. Accordingly, only a small number of participants had actually had colonoscopy at T2 (14/150, 9.3%). Nevertheless, studying intentions still offers valuable insights because intentions are direct antecedents of behavior. More specifically, intentions capture the commitment and motivational inclination toward a specific behavior, and several studies suggest that they are indeed reliable predictors of the implied behavior [22,23]. Future research in an older sample is, however, needed to test whether emotional factors together with Internet use have a similar effect on actual screening behavior.

Another point of discussion concerns the question of what information people are actually searching for and processing when browsing the Internet for health-related purposes. In this study, we only assessed the frequency of their search behavior, but not the actual content. Measuring real search behavior would have been difficult to realize given this study's longitudinal questionnaire design. To reliably measure Web-based information search, additional studies with higher experimental control would be required. Such studies already exist in the context of threat, Internet search, and emotion-focused coping (eg, people search, process, and remember more positive information in a state of threat [13,14]), but similar studies extending those findings to the domain of problem-focused coping are still lacking.

Nevertheless, our exploratory finding that Internet use at T1 reduced feelings of threat at T2 sheds some light on the intraindividual dynamics underlying our main finding. This finding suggests that people processed information that helped regulate their negative emotions. This interpretation seems likely considering that most of the available information on the Web stresses the benefits and high diagnosticty of the screening method. An important question for future research is, however, whether a similar effect could be obtained for medical decisions, which are not as beneficially portrayed on the Internet (eg, prostate cancer screening). In such cases, threatened people who use the Internet more frequently for health-related information search may get even more uncertain about a specific (preventive) medical intervention, which in turn could lower their intentions. It is, therefore, important to emphasize that for now, the current findings should be interpreted in the specific context of bowel cancer screening (ie, colonoscopy).

Finally, our Web-based sampling procedure may have biased the pattern of our results because we oversampled Internet users. Although many people are using the Internet for health-related purposes [10], especially older people (who are at risk) tend to use the Internet less. Although this suggests that the sample is biased regarding these demographic factors, it does not question the generalizability of the current findings because they focused specifically on Internet users. Another aspect of our sampling procedure should also be considered. As the study was explicitly announced as study on cancer prevention, the sample may mainly consist of people who were already interested in this topic. Although it seems difficult to predict how this affected the results, further research should aim at replicating the current findings with a more representative sample.

Implications

In this study, we demonstrated that negative emotions such as feelings of threat can have a significant influence on screening intentions. Our study, therefore, extends previous work by showing that negative emotions do not only keep people from getting screened [18,19] but they can also motivate people to get screened, provided they activate problem-focused coping strategies. This is important information for general practitioners or anyone concerned with increasing colonoscopy attendance rates. Although it may be beneficial to reduce people's threat regarding the screening procedure itself [18], our findings suggest that reducing or ignoring people's threat regarding a possible cancer diagnosis may lower its potential to instigate problem-focused coping strategies. Instead, it may be more effective to take people's feelings of threat seriously, and respond to them by stressing that a colonoscopy can help reduce uncertainty because of its high diagnosticity and possibility for early cancer treatment. This implication seems warranted, independent of whether information is communicated via the Web or offline.

Our findings also highlight the important role of Internet use in the health context. It seems that frequent health-related Internet use augmented people's coping efforts and screening intentions. This is an important finding because Internet use in the health context has often been associated with negative aspects, such as low quality of information and inaccurate self-diagnoses [24]. This study, however, shows that Internet use in the health context can also be beneficial because it strengthened cancer screening intentions among those who feel most threatened by a possible diagnosis. As mentioned above, this finding should be interpreted in the specific context of colonoscopy, as we do not know yet how information on the Web about less positively portrayed medical interventions may interact with people's emotional states and their coping strategies.

Interestingly, for those who reported low levels of threat, frequent Internet use was related to weaker intentions. This could either be because those people are less likely to search for information concerning bowel cancer screening in the first place, or because they simply do not engage with it in the same emotionally oriented way people with stronger feelings of threat would do. This would imply that health information on the Web may be most (or only) effective when it matches people's emotional and regulatory needs. In other words, emotional states

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such as threat can act as a catalyst amplifying the message of Web-based health information. Although this had positive consequences in the present context of cancer prevention, the same mechanism may also be responsible for less positive phenomena such as cyberchondria [25]. Here, Internet use amplifies people's anxiety regarding a possible diagnosis so that they become increasingly convinced that they are sick. It is important to note, however, that cyberchondria is an example of maladaptive coping, whereas in this study, we were mainly interested in adaptive coping. That the Internet can contribute to both is an important conclusion because cyberchondria and other negative effects often dominate the public debate.

Conclusions

This longitudinal study showed that people's emotional states interact with their health-related Internet use in predicting screening intentions. More specifically, we found that colonoscopy intentions were highest among people who reported strong feelings of threat regarding a (bowel) cancer diagnosis and who use the Internet often for health-related information search. We propose that this is because information on the Web about colonoscopy is predominantly positive, highlighting the diagnosticity of the screening method, and because people who experience threat are likely to preferentially and repeatedly process that specific type of information [13], as it can help reduce their aversive state of threat. Internet search in the health domain may therefore represent one way through which emotion regulation can be facilitated.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

List of additional scales administered as part of this study.

[PDF File (Adobe PDF File), 70KB - jmir_v20i2e46_app1.pdf]

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Abbreviations

BMI: body mass index
SPSS: Statistical Package for the Social Sciences
SE: standard error
T1: first measurement point
T2: second measurement point

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Original Paper

A Multidimensional Tool Based on the eHealth Literacy Framework: Development and Initial Validity Testing of the eHealth Literacy Questionnaire (eHLQ)

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Abstract

Background: For people to be able to access, understand, and benefit from the increasing digitalization of health services, it is critical that services are provided in a way that meets the user's needs, resources, and competence.

Objective: The objective of the study was to develop a questionnaire that captures the 7-dimensional eHealth Literacy Framework (eHLF).

Methods: Draft items were created in parallel in English and Danish. The items were generated from 450 statements collected during the conceptual development of eHLF. In all, 57 items (7 to 9 items per scale) were generated and adjusted after cognitive testing. Items were tested in 475 people recruited from settings in which the scale was intended to be used (community and health care settings) and including people with a range of chronic conditions. Measurement properties were assessed using approaches from item response theory (IRT) and classical test theory (CTT) such as confirmatory factor analysis (CFA) and reliability using composite scale reliability (CSR); potential bias due to age and sex was evaluated using differential item functioning (DIF).

Results: CFA confirmed the presence of the 7 a priori dimensions of eHLF. Following item analysis, a 35-item 7-scale questionnaire was constructed, covering (1) using technology to process health information (5 items, CSR=.84), (2) understanding of health concepts and language (5 items, CSR=.75), (3) ability to actively engage with digital services (5 items, CSR=.86), (4) feel safe and in control (5 items, CSR=.87), (5) motivated to engage with digital services (5 items, CSR=.84), (6) access to digital services that work (6 items, CSR=.77), and (7) digital services that suit individual needs (4 items, CSR=.85). A 7-factor CFA model, using small-variance priors for cross-loadings and residual correlations, had a satisfactory fit (posterior productive *P* value: .27, 95% CI for the difference between the observed and replicated chi-square values: −63.7 to 133.8). The CFA showed that all items loaded strongly on their respective factors. The IRT analysis showed that no items were found to have disordered thresholds. For most scales, discriminant validity was acceptable; however, 2 pairs of dimensions were highly correlated; dimensions 1 and 5 (r=.95), and dimensions 6 and 7 (r=.96). All dimensions were retained because of strong content differentiation and potential causal relationships between these dimensions. There is no evidence of DIF.

Conclusions: The eHealth Literacy Questionnaire (eHLQ) is a multidimensional tool based on a well-defined a priori eHLF framework with robust properties. It has satisfactory evidence of construct validity and reliable measurement across a broad range

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of concepts (using both CTT and IRT traditions) in various groups. It is designed to be used to understand and evaluate people's interaction with digital health services.

(J Med Internet Res 2018;20(2):e36) doi:10.2196/jmir.8371

KEYWORDS

eHealth; health literacy; computer literacy; questionnaire design

Introduction

Modern health promotion and health care with increasing digitalization of information and services have become increasingly challenging for both community members and providers [1,2]. Community members can be delivered a panoply of messages from many media and may have access to information from a rapidly growing World Wide Web of information and service providers [3].

For people to be able to effectively and equitably access health services, it is critical that such services are provided in a way that generates appropriate actions and that the recipient benefits in the intended way. If people have a range of health literacy limitations, that is, limitations across "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" [4], they are at risk of having reduced access to care, poor self-management skills, increased hospitalization, and decreased life span [5].

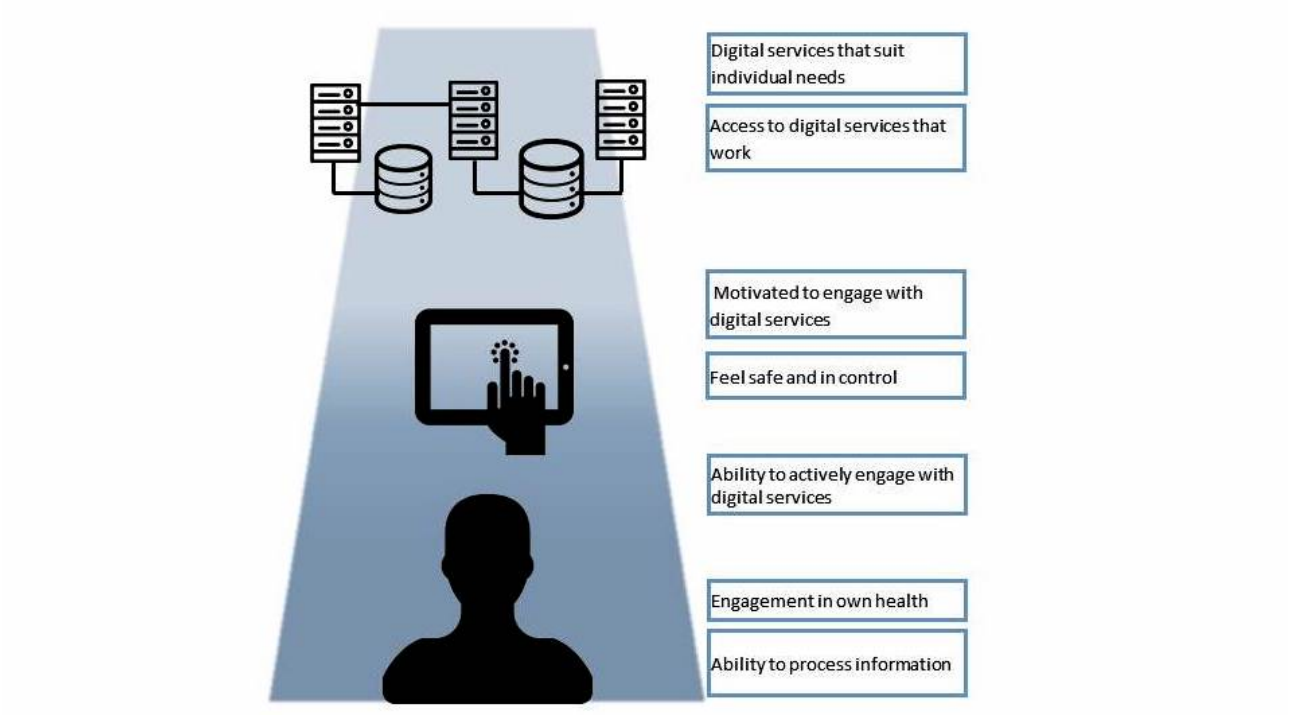
With the increasing digitalization of health care through electronic services, including health portals and health records, which are accessed by people from their homes, a new level of complexity has been added to the ways health care systems and the community have to interact.

The increased complexity demands a range of digital competencies among users, and this then calls for new ways to describe and evaluate users' digital capabilities and experiences in this rapidly changing health context.

Consequently, the concept of eHealth literacy (or digital health literacy) has emerged. Norman and Skinner (2006) described it as "the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem" [6]. Norman and Skinner's concept has since been updated by others to include elements related to users' cognitive skills [7,8] and dimensions such as communication, cultural elements, and social elements [9]. Despite increasing interest in this eHealth literacy concept, limited evidence exists regarding whether addressing people's eHealth literacy improves health outcomes [10]. This may be due to either a lack of appropriate instruments to measure eHealth literacy or, until now, low adoption of technology when providing health care [10,11].

In 2015, we identified a new concept for eHealth literacy: a model based on systematic and inductive methods that sought to identify the full range of elements relevant to individuals attempting to understand and use eHealth technologies and digital services [12].

Figure 1. The eHealth literacy framework (eHLF).



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This model, the eHealth Literacy Framework (eHLF), consists of 7 dimensions that describe the attributes of the users (information and knowledge about their health); the intersection between users and the technologies (their feeling of being safe and in control and their motivation); and users experience of systems (they work and are accessible, and suits users' needs). The eHLF provides a comprehensive map of the individual technology user's health literacy that covers his or her knowledge and skills, the system, and how the individual interacts with the system (see Figure 1).

The eHLF was specifically designed to inform the development of a conceptually and psychometrically sound questionnaire measure of eHealth literacy. The aim of this study was to create and test items and scales that capture the 7 eHLF dimensions using the validity-driven approach [13].

Methods

Initial Development

Development of the eHLQ followed the validity-driven approach [13] that has been used to develop several widely used and highly robust questionnaires [14-16]. The objective of the eHLQ development was to create an instrument that captures the 7 hypothesized dimensions of eHLF. Items were based on 450 statements obtained from Norgaard et al's (2015) conceptual development of eHLF [12]. These statements had been collected during 8 concept mapping sessions, which included participation of patients (recruited from patient organizations and primary care clinics), computer scientists, academics, and health professionals [12]. Items for the questionnaire were simultaneously written in Danish and English as recommended by Eremenco (2005) [17] to avoid words or phrases that may be difficult to translate into other languages. To provide a rich range of candidate items for the construction of each scale, up to 9 items were drafted for each of the 7 eHLF dimensions. The statements were written to relate to a 4-point set of response options: strongly disagree, disagree, agree, and strongly agree, assigned a value of 1 to 4, respectively. Items were also written to represent a range of difficulty that were broadly guided by Bloom's taxonomy (ie, related to knowledge and remembering, understanding, applying, analyzing, and evaluating) [18] so that the full range of the construct could be covered. The items were extensively discussed in Australian, Danish, and other contexts by the multidisciplinary team whose members have extensive experience in writing questionnaire items and applying them across cultures.

Danish draft items were tested in 7 cognitive interviews to check whether respondents understood the items as intended [19]. The cognitive testing involved initial administration of items using paper and pen format with careful observation of each respondent. The interviewer then reviewed items with the respondent and asked specific questions about items the respondent had hesitated on or appeared to have found difficult in answering. Respondents were asked "What were you thinking about when you were answering that question?" This process elicited the cognitive process behind the answers. A prompt was used if needed: "Why did you select that response option?" The items were adjusted based on the inputs with a particular focus on how the informants understood terms or concepts in relation to providers of health care and technologies.

Recruitment of Participants

Respondents were recruited from a wide range of sociodemographic settings to broadly represent the targets for the application of the questionnaire in the future. Individuals were included if they were above age 18 years and able to read or understand Danish. Potential respondents were randomly approached by trained interviewers in a variety of locations in the broader community, such as in libraries, private sector workplaces, a hospital, nursing homes, health centers, and an outpatient clinic. To ensure inclusion of people who may have low literacy, potential respondents were given the option of completing the questionnaire themselves or to have it read aloud in an interview. If respondents did not have time to finish the questionnaire, they were encouraged to complete it at home and were provided with a reply-paid envelope. They also had the option of completing a Web-based questionnaire.

Demographic data including age, sex, educational background, self-reported health condition, and presence of chronic conditions were also collected to evaluate whether the resulting scales were invariant to these exogenous factors and thus provided unbiased estimates of mean differences across these groups.

The administration of the questionnaires also included the administration of a validation version of the eHealth literacy assessment toolkit, which is reported elsewhere (personal communication, Karnoe 2017). Respondents did not receive any payment for filling out the questionnaire.

Item Analysis and Selection

The first step in the analysis for the items was to examine item characteristics. It was intended that each scale would have the smallest number of items necessary to capture the meaning of the construct in the most efficient manner while ensuring adequate coverage of the construct. Each item and each set of items forming a scale, as well as associations between and across items and scales, were tested using psychometric procedures afforded by the conventions of both classical test theory [20] and item response theory (IRT) [21].

Statistical Analysis

Descriptive statistics were generated for each item to determine missing values, floor and ceiling effects, interitem correlations, correlation with scale score, scale reliability (composite reliability, Cronbach alpha, person separation index), estimated item location, and *P* value for item fit tests. Given that hypothesized constructs were specified a priori within the eHLF [12], confirmatory factor analysis (CFA) was used.

Results from each of these analyses were used to assist with decisions about optimizing the number of items in each scale. Of central importance to the item deletion retention strategy was ensuring that the retained items properly represented the intended a priori construct from the eHLF. Items that performed poorly on the above criteria were earmarked for deletion. We also sought to generate scales that had a minimum reliability of .8 but where items had no excessively high interscale

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correlations, violations of local independence, or high correlated residuals. Where the content of items had substantial overlap, and tended to perform well on a range of indicators, the item selection strategy then included criteria to improve the diversity of item locations, that is, selection of a range of items within a scale that range across all difficulty levels of the construct that the scale measures.

CFA was conducted with Mplus versions 7.4 and 8 (Muthén & Muthén, Los Angeles, CA, USA) using Bayesian Structural Equation Modeling (BSEM) [22,23]. BSEM is a specific application of Bayesian statistical analysis to factor analysis and structural equation modeling. In a conventional CFA usage, for example, maximum likelihood analysis, model parameters that represent possible cross-loadings and correlations between item residuals are typically set to be exactly zero. When these restrictions are placed on CFA models used to confirm, a multifactor structure poor model fit often results, and a large number of stepwise modifications (estimation of parameters originally constrained to zero) can be required to achieve a reasonably fitting result. This approach may not, however, necessarily lead to a single solution depending on the sequence of choices of modifications made along the way, and there is frequently a strong upward bias in the estimation of interfactor correlations, leading to erroneous conclusions about scale discriminant validity. By using small-variance priors, BSEM allows models to be fitted that have the flexibility to estimate small variations from these strictly zero constraints. For the final BSEM analysis, after a little systematic experimentation (Multimedia Appendix 1), the variance of the Bayesian priors for the cross-loadings was set at 0.01 such that there was a 95% probability that the cross-loadings would be within the range ±.20. Similarly, the variance for the residual correlations was set to give a 95% probability that the correlations were within the range of ±.2 [22].

The approach to model fit in BSEM differs from that in conventional CFA. The conventional CFA fit indices (eg, chi-square, comparative fit index, and root mean square error of approximation) are not used. Rather, fit in BSEM is assessed using a procedure called “posterior predictive checking” that results in a “posterior predictive *P* value” (PPP value). In a very well-fitting model, the PPP value is expected to be close to .5, whereas a value of <.05 (or <.10 or <.01 if less or greater stringency is applied) is typically regarded as indicating unsatisfactory fit. A PPP value of >.05 was chosen as the threshold for satisfactory fit in this study. Additionally, a fit statistic derived from the Bayesian model-fitting process is calculated with 95% CIs. A pattern of symmetrical upper and lower CIs centered around zero indicates excellent fit, whereas a lower 95% CI that is positive suggests that the fit is not satisfactory [22-24].

The IRT model-based evaluation of item fit used a unidimensional IRT model—the generalized partial credit model (GPCM) [25]. For each scale, we compared the observed item scores with the scores expected under the model using an implementation in SAS statistical software version 9.4 (SAS Institute, Cary, NC, USA) [26]. This provides a graphical test of item fit where the item’s mean score is plotted against the group’s scale mean and evaluated against values.

For each item, the estimated item discrimination parameter (the IRT-equivalent of a factor loading) and the estimated item location (computed as the average of the item thresholds) were reported.

Differential item functioning (DIF) is a statistical characteristic of an item indicating the extent to which the item can be said to measure the same construct across subpopulations [27]. We tested DIF using logistic regression techniques [28-30] addressing the elevated risk of type I error due to the larger number of tests performed and by the Benjamini and Hochberg procedure [31] controlling the false discovery rate results.

Ethical Considerations

According to Danish law, when survey-based studies are undertaken in accordance with the Helsinki Declaration, specific approval by an ethics committee and written informed consent are not required. Potential respondents were provided with information about the survey and its purpose, including that participation was voluntary. The completion of the survey by participants was then considered to be implied consent.

Results

Item Construction and Refinement

Between 7 and 9 draft items per scale were generated (58 items in total). Cognitive testing was undertaken with 7 individuals (4 women), aged between 16 and 74 years from different cultural backgrounds and with varying educational levels. The interviews found that almost all items were understood as intended; 1 item was removed due to unclear text, whereas only some small refinements were made to other items to improve clarity and simplicity. The refinements mainly related to getting the clearest possible Danish words related to the core concept of technology, digital tools, or electronic tools. The term “digital” was preferred across demographic groups. Moreover, the best Danish term to express “health” and “health conditions” was tested, and the term “health” was found to work the best. The final number of items for going to the field was 57.

Item Number Reduction and Scale Construction

The refined items were randomized and administered to 475 individuals—100 outpatients who all filled in a paper version. Out of the 375 people in the community a total of 328 filled in the paper version and 47 filled in the digital version.

The hypothesized 7-factor BSEM model for the initial 57 items showed a satisfactory fit to the data (PPP value .79, 95% CI for the difference between the observed and replicated chi-square values −239.75 to 99.85). A total of 10 items had low (<.5) standardized factor loadings; however, 3 items showed evidence of factorial complexity having cross-loadings >.25. There were also 15 pairs of items with residual correlations >.30. Of these item pairs, 12 correlated residuals were between items that were associated with different target factors, suggesting that, from an IRT perspective, the assumption of local independence of the hypothesized scales was largely satisfied.

After inspection of the results of the initial BSEM analysis and the parallel IRT analyses, items that performed poorly or were clearly redundant to others (ie, had highly similar content and

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measurement properties) across analyses were iteratively removed, resulting in 35 items in 7 scales comprising 4, 5, or 6 items in each (see Multimedia Appendix 2).

A final BSEM model (Multimedia Appendix 1) was then fitted to the data for these items. Model fit was satisfactory (PPP value .27, 95% CI for the difference between the observed and replicated chi-square values −63.7 to 133.8). With 4 exceptions, all factor loadings were >.50 (see Multimedia Appendix 3). All loadings <.5 were >.4.

There were no statistically significant cross-loadings, and there were 8 residual correlations ≥.3. All but one of these larger residual correlations was negative with 4 associated with scale (1) using technology to process health information. The only positive residual correlation ≥.3 was between 2 contiguous items, former 44 and 45. They were, therefore, separated and ended up in the final version as item numbers 26 and 35. There were no within-scale positive residual correlations ≥.3.

The fit of the GPCM to the data was excellent in all of the dimensions (Multimedia Appendix 4).

Estimates of composite scale reliability are also shown in Multimedia Appendix 3 (95% CIs in parentheses, and, for comparison, Cronbach alpha) for the final 7 scales. All 7 scales had acceptable composite reliability (>.7), and 5 scales have a reliability above .8; however, scales 2 and 6 had somewhat lower reliability than intended (.75 and .77, respectively).

Interfactor correlations ranged from .31 (factors 3 and 4) to .97 (factors 6 and 7) with the next highest being .96 (factors 1 and 5), suggesting satisfactory discrimination between the majority of the scales with the exception of the following: (6) access to digital services that work; (7) digital services that suit individual needs; (1) using technology to process health information; and (5) motivated to engage with digital services (Table 1).

The DIF analysis showed no evidence of influence of age or sex on the item scores. The item locations, item discriminations, and factor loadings are shown in Multimedia Appendix 3. As expected, the order of factor loadings and the order of the item discriminations are very similar. The spread in the item locations indicate that, for each scale, the items represent a range of difficulty, indicating that the full range of the construct is covered. The analyses generated scales that were well targeted to the respondent sample (Table 1) and showed good distributional properties (Table 2).

An analysis of the construct representation, that is, the completeness of the match between the intended construct (first column in Multimedia Appendix 2) and the content of the resulting scales (second column, Multimedia Appendix 3) indicated strong concordance between the intended and generated constructs for 5 of the 7 constructs. For construct 1, ability to process information, the specific elements of fundamental reading, writing, and cognitive ability were missing; however, they were represented through higher-order functions such as application and use of such skills. This scale was renamed as (1) using technology to process health information. For construct 2, engagement in own health, the surviving items focused more on whether the respondents perceived that they had adequate knowledge and understanding of their health in general terms. The intended construct of eHLF had a broader focus on awareness and engagement in and utilization of information and knowledge about health.

Table 1. Interfactor correlation between the eHealth Literacy Questionnaire scales.

Factor name	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6
Factor 2. Understanding of health concepts and language	0.69					
Factor 3. Ability to actively engage with digital services	0.90	0.61				
Factor 4. Feel safe and in control	0.36	0.49	0.31			
Factor 5. Motivated to engage with digital services	0.95	0.61	0.83	0.47		
Factor 6. Access to digital services that work	0.77	0.57	0.73	0.69	0.83	
Factor 7. Digital services that suit individual needs	0.78	0.45	0.74	0.58	0.84	0.96

Table 2. eHealth Literacy Questionnaire scales and descriptive statistics.

No	Scale	n (%) (N=475)	Mean (SD)	Median (IQR[a])
1	Using technology to process health information	462 (97.3)	2.55 (0.66)	2.60 (2.20-3.00)
2	Understanding of health concepts and language	466 (98.1)	2.97 (0.55)	3.00 (2.60-3.40)
3	Ability to actively engage with digital services	465 (97.9)	2.81 (0.69)	2.80 (2.40-3.20)
4	Feel safe and in control	466 (98.1)	2.61 (0.66)	2.60 (2.20-3.00)
5	Motivated to engage with digital services	466 (98.1)	2.55 (0.65)	2.60 (2.00-3.00)
6	Access to digital services that work	466 (98.1)	2.52 (0.55)	2.50 (2.17-2.83)
7	Digital services that suit individual needs	457 (96.2)	2.42 (0.62)	2.33 (2.00-3.00)

[a]IQR: interquartile range.

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The construct included, potentially, a very wide range of elements around physiological functions, risk factors, and elements of the health care system. This disparate range of elements would require an inventory to capture in complete breadth of the construct; however, the eHLQ items generated and surviving the item reduction phase, captured a somewhat higher order assessment of the respondent's understanding and engagement in health information, which is more suitable for a psychometric scale, rather than an inventory. The scale was renamed as (2) understanding of health concepts and language.

Discussion

Principal Findings

We sought to develop and test a new measure of eHealth literacy using both classical and modern psychometric approaches to questionnaire development. Using a robust conceptual model, developed through extensive local and international community consultation [12] and through a validity-driven approach [12,13], 7 new psychometrically robust scales to comprehensively measure the broad concept of eHealth literacy were developed. Construction and validity testing in a broad range of target groups generated clear evidence of construct validity, discriminant validity, and scale reliability. This initial validity testing indicates that the eHLQ is likely to be valuable for the characterization and understanding of digital health literacy.

This research introduced some highly rigorous and innovative elements to questionnaire development and validation. First, the data to generate the eHLF model were obtained using concept mapping in 2 cultures (Danish and English) and through an international e-consultation. Concept mapping has been found to be a highly robust technique for developing conceptual models and for questionnaire development [32]. Additionally, when the items were written, they were simultaneously constructed in Danish and English. With this step, we sought to uncover and remove idiomatic expressions in either language so that when it is translated to further languages, only concrete concepts are presented for translation with fidelity and to support international equivalence of the constructs. We also employed extensive and rigorous application of the two, often opposing, traditions of psychometric analysis: CTT and IRT. The items surviving the scrutiny of these procedures, as well as from rigorous qualitative methods, have satisfactory psychometric properties in all the scales.

The eHLQ is now ready for application, and for further testing, in a wide range of settings and purposes; these include the following:

- Evaluation of interventions. The eHLQ will provide insight into users' perceptions and experiences when using digital health solutions. As with previous tools developed using the same methods as the eHLQ [14,15], we expect that, with further testing, it will be a robust patient-reported outcome measure and sensitive to change.
- Implementation and adoption of digital health services. We also expect the scales to provide insights into why digital health services implementations work or fail (ie, understanding intermediate or process outcomes). Given that the scales cover individual user attributes, attributes of the system, and the interaction between the two, the eHLQ is expected to uncover mechanisms that determine adoption outcomes.
- Community and population surveys. The eHLQ is expected to be useful for local, regional, and populations surveys. This information will inform policy makers, program managers, and service providers about the profile of needs and strengths of individuals across the population and demographic subgroups.

The eHLQ also offers an opportunity to stratify users for inclusion in design processes [33] to explore the reactions of these groups to new digital solutions or, more generally, to document the strengths and weaknesses among user subgroups. Information about subgroups with respect to their eHLQ profile (of strengths and weaknesses) and other characteristics may be used to design interventions or inform designers through creation of archetypes or personas as described the in Ophelia (OPtimising HEalth LIteracy and Access) process developed for service redesign and development of person-centered services [34,35].

A further important element of scale construction was the consideration of within-construct concept representation and item difficulty. The items we drafted sought to cover the full range of issues within a construct and to achieve a spread of item difficulties from items being easy to answer to items being hard to score highly. The statistical analyses demonstrate that these demanding targets were broadly achieved. Some subconcepts identified in the concept mapping, and detailed in the eHLF, did not survive the item development and testing process, and therefore, some scales are not as broad as initially intended. The requirement for being faithful to the codesign outcomes (the eHLF), broad item difficulties, and meeting the requirements of the 2 psychometric traditions has generated a tool that robustly captures the concept of eHealth literacy, but with some minor subcomponents underrepresented. If researchers and developers wish to capture the omitted subelements (basic functional health literacy or broader issues around knowledge and engagement), other tools should be used to supplement the eHLQ, such as the eHealth literacy assessment toolkit (personal communication, Karnoe 2017), or the digital health literacy instrument (DHLI) by van der Vaart [36].

We found that there are 2 particularly high interfactor correlations between factors 1 and 5 (r=.95) and factors 6 and 7 (r=.96). The eHLF contains 7 dimensions, all of which we sought to include in the final eHLQ model. Content analysis, the careful deliberations while developing items, and the original views of patient and professional groups indicated that each of the original constructs were different. The high correlations may be a result of them being located along the same causal path. When considering the content of these sales, we expect that different interventions will result in different patterns of change in the pairs of related scales. This should be carefully monitored over time and across different settings.

The psychometric and construct representation demands we placed on the eHLQ construction process were further compounded by the need for the eHLQ to be a relatively short

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questionnaire. Importantly, all of the scales have acceptable reliability, despite having only 4 to 6 items. Given that the eHLQ is intended for application among people with low literacy and they may be ill, it is critical that the smallest possible number of items be included. Every scale had satisfactory loadings on its intended items, with negligible cross-loadings on other items. Although we had hoped all scales would have a reliability .8, this was not quite achieved for 2 scales (≥.75 for both). Importantly, this level of reliability is acceptable for research and evaluation purposes.

Future concurrent validity and other validity tests, including predictive validity tests, will be valuable. For the most part, we have found that the concept mapping, and subsequent qualitative studies, ensures that the validity of the data the questionnaire generates is robust. The eHEALS [37] appears to be the best current measure of some elements of eHealth literacy, and it will be valuable for future researchers to compare the tools.

Moreover, future research should include further quantitative and qualitative work to develop interpretation and use arguments [38] to generate comprehensive validity testing of the eHLQ across a wide range of contexts to support current and future users understand the data generated by the eHLQ.

The eHLQ provides a wider range of dimensions of eHealth literacy than previous tools. It covers not only an individual's competences, as in the Lily model [6] and the van der Vaart DHLI model [36], but also an individual's experiences and interactions with technologies and services. It provides a much richer understanding of the whole of the system through providing perspectives of individuals, the system, and the interaction between the two.

Recent study by van der Vaart [36] specifically expanded the digital health field by creating 7 areas that mainly focus on individual competencies. These are operational skills, navigation skills, information searching, evaluating reliability, determining relevance, adding self-generated content, and protecting privacy.

The introduction of the eHLQ's scales covering user interaction and the user's experience of engaging with the system is an important innovation for the rapidly growing digital health field. The eHLQ has the potential to provide insight into the maturity of a country's digital services. With mature digital health services, we expect that individuals find the system more responsive to their needs, and thus can engage more fully in support of achieving health and equity. This is akin to the new health concept of health literacy responsiveness [39]. We expect that in a digitally mature society, the scales covering the system and the interaction will reflect stronger: (6) access to digital services that work and (7) digital services that suit individual needs. In settings with developing systems, where there are few digital services or limited or piecemeal coverage and access, the scores on these scales are expected to reflect major challenges for individuals.

It is important to note that eHealth literacy, like the concept of health literacy, is both a reflection of the individual's knowledge and the skills he or she may employ in the cultural, social, and institutional context in which they are engaging in; therefore, it is critical to assess these domains simultaneously [9,12,40]. As we see wide-scale improvements in digital health services, we would expect to see the user interaction scales improve—that is, (4) feel safe and in control and (5) motivated to engage with digital services.

The eHLQ has already generated substantial interest in the field. It is currently being translated into Chinese, Norwegian, and Czech, and a German-speaking country initiative is under way. The English version is also undergoing validity testing. The conceptual model and the range of intended applications fit well with a wide range of current policy initiatives. These include the World Health Organisation (WHO) People Centred Health Services Framework [1] and the WHO Shanghai Declaration, which places health literacy as one of the three key elements to support the achievement of the sustainable development goals by 2030 [41]. To reach these ambitious goals, eHealth literacy responsive systems need to be implemented on a wide scale to leave no one behind. The eHLQ is currently in the field and is available with the authors.

Conclusions

The eHLQ is a psychometrically robust multidimensional instrument with 7 scales that comprehensively cover all 7 dimensions of the eHLF. The eHLQ and the eHLF's conceptual underpinnings are likely to be a useful set of tools to support researchers, developers, designers, and governments to develop, implement, and evaluate effective digital health interventions.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Fit statistics and summary model parameters for six Bayesian structural equation models with varying prior variances for cross-loadings and correlated residuals–model 3 chosen as a satisfactory solution.

[PDF File (Adobe PDF File), 245KB - jmir_v20i2e36_app1.pdf]

Multimedia Appendix 2

The 7 constructs of the eHealth Literacy Framework and derived scales of the eHealth Literacy Questionnaire.

[PDF File (Adobe PDF File), 178KB - jmir_v20i2e36_app2.pdf]

Multimedia Appendix 3

The estimated item locations, item discriminations, and factor loadings.

[PDF File (Adobe PDF File), 213KB - jmir_v20i2e36_app3.pdf]

Multimedia Appendix 4

Illustration of the fit of items applying item response theory and the generalized partial credit model. The observed items scores are compared with the scores expected under the model.

[PDF File (Adobe PDF File), 679KB - jmir_v20i2e36_app4.pdf]

Multimedia Appendix 5

eHLQ Licence Agreement.

[PDF File (Adobe PDF File), 141KB - jmir_v20i2e36_app5.pdf]

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Abbreviations

BSEM: Bayesian Structural Equation Modeling
CFA: confirmatory factor analysis
CSR: composite scale reliability
CTT: classical test theory
DHLI: digital health literacy instrument
DIF: differential item functioning
eHLF: eHealth Literacy Framework
eHLQ: eHealth Literacy Questionnaire
GPCM: generalized partial credit model
IRT: item response theory
Ophelia: OPtimising HEalth LIteracy and Access
PPP: posterior predictive *P* value

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Proposal

Integration of eHealth Tools in the Process of Workplace Health Promotion: Proposal for Design and Implementation

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Abstract

Background: Electronic health (eHealth) and mobile health (mHealth) tools can support and improve the whole process of workplace health promotion (WHP) projects. However, several challenges and opportunities have to be considered while integrating these tools in WHP projects. Currently, a large number of eHealth tools are developed for changing health behavior, but these tools can support the whole WHP process, including group administration, information flow, assessment, intervention development process, or evaluation.

Objective: To support a successful implementation of eHealth tools in the whole WHP processes, we introduce a concept of WHP (life cycle model of WHP) with 7 steps and present critical and success factors for the implementation of eHealth tools in each step.

Methods: We developed a life cycle model of WHP based on the World Health Organization (WHO) model of healthy workplace continual improvement process. We suggest adaptations to the WHO model to demonstrate the large number of possibilities to implement eHealth tools in WHP as well as possible critical points in the implementation process.

Results: eHealth tools can enhance the efficiency of WHP in each of the 7 steps of the presented life cycle model of WHP. Specifically, eHealth tools can support by offering easier administration, providing an information and communication platform, supporting assessments, presenting and discussing assessment results in a dashboard, and offering interventions to change individual health behavior. Important success factors include the possibility to give automatic feedback about health parameters, create incentive systems, or bring together a large number of health experts in one place. Critical factors such as data security, anonymity, or lack of management involvement have to be addressed carefully to prevent nonparticipation and dropouts.

Conclusions: Using eHealth tools can support WHP, but clear regulations for the usage and implementation of these tools at the workplace are needed to secure quality and reach sustainable results.

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KEYWORDS

eHealth; health promotion; mHealth; occupational health; workplace

Introduction

Workplace Health Promotion

Workplace health promotion (WHP) projects in organizations are one of the key solutions for improving health in organizations [1]. WHP projects include the whole package of analyzing the current structures and procedures in the organization, developing interventions for individuals to support them to change their own health behavior, and developing interventions for the organization to change critical working conditions. Electronic health (eHealth) and mobile health (mHealth) tools could be used to support and to improve the whole process of WHP projects. On the other hand, there is much uncertainty about the role of eHealth and mHealth tools in organizations, especially when it comes to health-relevant

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data assessed within a WHP process. Therefore, there are several points to be considered about the challenges and opportunities, which lie in this approach.

eHealth refers to the use of technology (mostly including the Internet) in health-related services, whereas mHealth includes mobile and wireless technologies (eg, mobile phone apps, wearable devices) in health programs [2]. mHealth can be seen as a specific part of eHealth; therefore, we use the term eHealth as an umbrella term for using electronic or mobile devices for health services.

eHealth tools can raise interest, motivation, and participation in WHP projects [3,4]. Especially the point of participation is one of the major issues in today's WHP projects, as the majority of participants in WHP projects consist of a selected group of people with healthier lifestyles [5]. eHealth tools can support raising participation quotes of employees in WHP projects, as they are able to help employees overcome such barriers [6]. Indeed, studies have reported that eHealth tools seem to be more attractive for unhealthier employees, as they provide the possibility to stay anonymous [7,8].

Another issue in WHP is ineffective planning of the WHP process and the tendency to develop interventions that try to reach the broadest range of employees ("one-fits-all-principle"). This might be an obstacle for employees to participate in WHP projects, as a broad content of WHP interventions might not sufficiently meet the demands of the specific target group. Tailored WHP projects specifically developed for each organization have shown to raise participation quotes in WHP projects [9]. Especially tailored feedback is an important motivator for the employees' participation in WHP programs [8]. This is where eHealth tools can bring considerable added value as these tools can be easily programmed to meet the demands of the individual user (eg, by giving instant, tailored feedback).

Currently, a large number of eHealth tools are available in all areas of health promotion—including applications for sports, weight reduction, and healthy nutrition [10] as well as applications addressing psychological factors (eg, to reduce stress or burnout, enhance recovery and coping strategies, or learn new competencies and skills) [11]. Current eHealth tools focus strongly on changing individual attitudes and behavior, but rarely focus on the improvement of the working environment such as analyzing and changing working conditions (an exception is presented by Koldijk et al [11]). Supporting the whole WHP process (including the analysis of the current state, intervention development process, intervention implementation, and further activities) is even less addressed in the currently developed eHealth tools. Therefore, solutions in the field of eHealth for WHP should focus more strongly on targeting the whole WHP process, especially on improving the working environment.

In addition, the usage of eHealth tools should be regulated similar to any other psychotherapeutic or medical intervention [12]. Therefore, eHealth tools in WHP should fulfill certain quality criteria to be trusted and accepted by an organization and its employees. Quality criteria mainly concern functionality, aesthetics, and security of eHealth tools [13,14], but can also target feedback systems or communication of results [12,15].

Combining eHealth tools and the current WHP processes can add sustainability by enhancing motivation and interest, as noted. The necessity to find rules for the successful implementation and having a guideline to avoid some pitfalls, on the other hand, emerged during different studies where the authors were asked to evaluate and support projects in WHP. The possibilities of combining eHealth tools and WHP were discussed in these projects with health experts from different fields (psychologists, physicians, nutritionists, kinesiologists, and other experts). These steps led to small pilot projects, in which eHealth tools were applied to the working context. The discussions and pilot projects provided a good basis for the further development of a WHP process model that allows integrating eHealth tools on different levels.

In this paper, we introduce a concept of WHP that supports the design and integration of eHealth tools in each step of the WHP process and present success factors and possible obstacles for the implementation. The presented concept is based on several models, especially the "WHO model of healthy workplace continual improvement process" [16], the models and criteria of the European Network for Workplace Health Promotion [17,18], the criteria of the International Labour Organization [19], and specifications such as the DIN SPEC 91020 [20]. We suggest adaptations to these models to allow a smooth integration of eHealth tools in the WHP process. Furthermore, we provide recommendations in the form of guidelines on how to implement eHealth tools for WHP in the practical field.

Policies and Strategies for Workplace Health Promotion

WHP can be defined as "the combined efforts of employers, employees and society to improve the health and well-being of people at work" [20]. The Luxembourg Declaration on Workplace Health Promotion [21]—which is generally used as a framework for planning and executing WHP projects—has established guidelines that have to be fulfilled for successful WHP projects:

> *a) All staff have to be involved (participation), b) WHP has to be integrated in all important decisions and in all areas of organisations (integration), c) all measures and programs have to be oriented to a problem-solving cycle: needs analysis, setting priorities, planning, implementation, continuous control and evaluation (project management), and d) WHP includes individual-directed and environmental-directed measures from various fields. It combines the strategy of risk reduction with the strategy of the development of protection factors and health potentials (comprehensiveness).*

Especially the last point of these guidelines about combining individual-focused and organization-focused strategies is not always considered in the practical field. The individual-focused approach includes aspects such as coping and time-management skills [22], or fitness activities and lifestyle guidance [23]. In the organization-focused approach, the work environment and

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the modification of the work conditions and work structures are addressed [23,24]. Interventions in the organization-focused approach include clarifying job designs [24], changing working hours, reducing shift work and unpredictable working hours, encouraging flexible work arrangements [22,24,25], and introducing supportive leadership styles and a supportive and comfortable social climate [23].

In the majority of WHP projects, individual-focused interventions are conducted and the organization-focused method is less addressed [26]. However, pursuing the organization-focused approach is more sustainable and can have a much broader impact on the employees' health than only focusing on reducing individual risk factors [27].

A Comprehensive Perspective on Workplace Health Promotion

We present a WHP process with 7 steps that can assist organizations in conducting successful WHP projects. We suggest adaptations to these models to allow a smooth integration of eHealth tools in the WHP process. Categorizing the process in steps is important, as every step can contain facilitating and hindering factors that need to be addressed [28]. Furthermore, planning WHP projects in individual steps can support the responsible persons in organizing and deploying the needed resources for each step [29] and support a successful implementation of eHealth tools in the WHP process. To discover the possibilities and benefits of including eHealth tools in WHP, we need to understand the aim of each step and we need to identify critical factors that might prevent reaching these aims successfully.

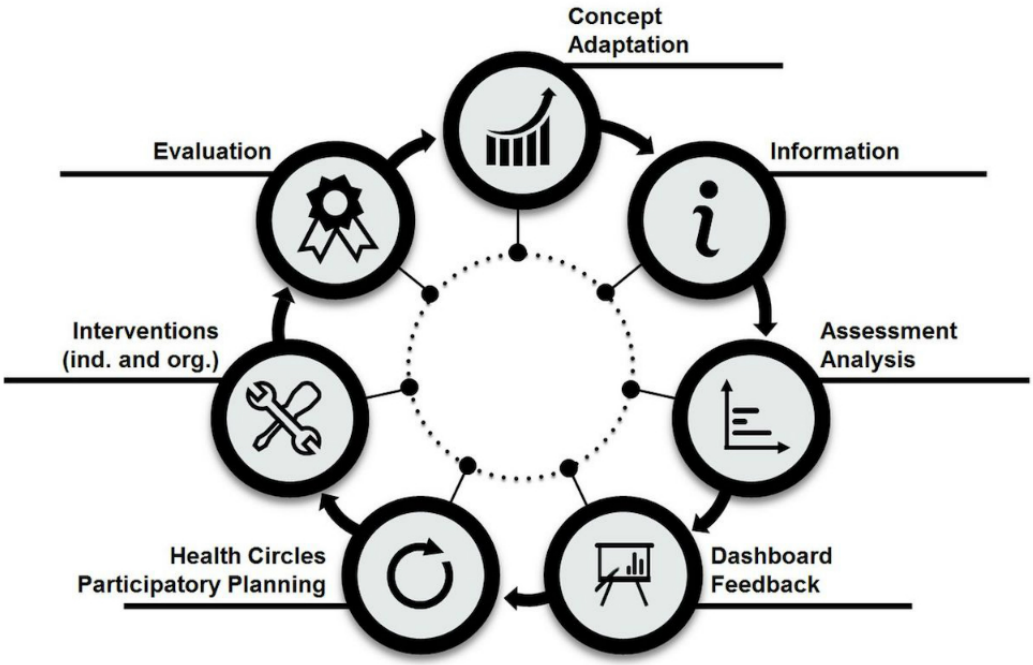
The most holistic WHP process has been established by the World Health Organization (WHO) [16]. In their "WHO model of healthy workplace continual improvement process," 8 steps are defined in a circle, indicating that WHP is an ongoing process that develops and improves over time. The WHO model shares similarities with other models [30-32] that present steps to successfully conduct employee surveys to assess job demands and job resources. In these models, the first step always comprises the conceptual design of the WHP process, which is indirectly included in the WHO model in the steps "mobilize" and "assemble." Another step includes the analysis as well as the presentation and interpretation of the analysis results, which is included in the WHO model under the steps "assess" and "prioritize." However, assessment and presentation of the assessment results should be distinguished, as the presentation of the assessment results usually comprises discussions with the management [32]. These discussions further lead to the development of an intervention implementation plan [31]. Therefore, especially when using eHealth tools, the presentation step should be treated separately to the actual assessment to implement the right tools for the right process step and, at last, to achieve the best possible outcome.

Implementation of eHealth Tools in Workplace Health Promotion

Life Cycle Model of Workplace Health Promotion

The proposed "life cycle model of Workplace Health Promotion" (Figure 1) is based on the WHO model and other models and focuses on the support of the integration of eHealth tools (Figure 1): (1) Concept/Adaptation, (2) Information, (3) Assessment/ Analysis, (4) Dashboard Feedback, (5) Health Circles/ Participatory Planning, (6) Interventions (individual/ organization), and (7) Evaluation. We first present the adapted model applicable for WHP in general and then present the important issues for the integration of eHealth tools in that process. Implementing eHealth tools can be a great advantage in every step. The content of each step as well as the advantages and possible implementation procedures for eHealth tools are described in the next chapters.

Figure 1. Life cycle model of workplace health promotion.



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Concept/Adaptation

The first step includes planning the WHP project (duration and content of the project, needed resources and experts) and setting the main objectives. It is also important to discuss if the project should be conducted identically in all locations and departments or if some departments or locations get a slightly different concept. These decisions can be made by the senior management or by other persons with decision authority [29]. However, for the success of the WHP project, these discussions should involve all relevant stakeholders (eg, management, human resources department, company physicians, safety specialists, work and organizational psychologists, work council, employee representatives). These key stakeholders should demonstrate their commitment to the WHP project by assembling a steering group [30,33] or a "healthy workplace team" [16]. Typically, this is the first time where key questions regarding anonymity of data, responsibilities, or data security are discussed [30]. This discussion is a core point, as critical aspects can influence all other steps and preclude the success of the whole project. Regarding eHealth tools, a plan for the correct implementation of these tools should be discussed in the steering group as well [34].

A great advantage of eHealth tools in this first step could lie in providing the opportunity to keep in contact with all relevant stakeholders. These tools can support the cooperation between the steering group and other experts involved in the WHP process by providing a platform for communication. This platform can be further used to set and track the objectives of the WHP project, to manage the information flow to the employees, to monitor the assessment of the current state of the organization and the interventions (date, duration, location, content), and to manage intervention groups (participation rates, satisfaction). Monitoring satisfaction ratings and participation rates can provide a good overview of the overall acceptability of the WHP program, and they should be assessed during the whole WHP process [35]. However, it is also important that the steering group and experts meet face-to-face as much as possible for clearer communication and discussions [15].

Information

An important factor for success is establishing a clear information flow between the management, key stakeholders, steering group, and employees. All persons have to be informed about the project and its concept and objectives. Information should be given in a top-down process; this means the information flow should follow the hierarchical structure of the company. As this information flow is very important to "take fears" and gain the trust of the employees, this step is typically a separate step in models of WHP (see also [16]). All employees have to be informed about the whole WHP process and its different steps. This transparency ensures that the WHP project does not raise false expectations on the part of the employees that could later lead to disappointment or negative appraisal [36]. One major issue in this step concerns fears about exposure or surveillance. Employees have to be guaranteed anonymity and strict data protection. In addition, it must be clear that the participation is voluntary.

Especially mHealth tools can reach a large number of people, as they are not restricted to a certain location [37]. By offering different channels of communication (eg, text messages, audio and video files), users can be reached in every setting and situation [38]. The overall accessibility of health programs is especially suitable for programs targeting mental health, as persons with mental health problems can avoid exposure in an open group when using eHealth tools [6,39]. Having all information in one tool that is accessible at any time and in any location could help raising awareness and motivation for the activities planned in the WHP process. In addition, information should be given about the added values and benefits of using eHealth tools in WHP as well as information about how to use these tools and data security issues [37]. These tools should be introduced to the employees as nondirective as possible (eg, by letting the employees themselves decide if and how to use the tools) to avoid possible resistance [40].

Such an information board for the employees could also include the possibility to interact with health experts or the steering committee. Having social contact with other participants in the WHP program enhances participation rates and raises the effectiveness of eHealth tools [41]. Platforms for social contact could also include communication between the employees and health experts to share or discuss health issues [42].

Assessment/Analysis

The next step is to analyze the current state of the organization in accordance with the objectives set in the first step. Usually, surveys in the form of questionnaires or interactive workshops are used as analysis tools [31]. Next to a so-called needs assessment, where the employees are asked about their wishes regarding health promotion activities, other physical and psychological factors are assessed as well (eg, health status of employees, job satisfaction, motivation, and commitment) [16]. Other resources such as key data on sickness absences or fluctuation as well as data from previous WHP projects can be valuable additions to the data obtained in surveys or workshops. Furthermore, it is important to analyze aspects of the workplace and the organization (eg, policy, rules, regulations, available resources) to be able to successfully integrate health promotion activities within the workplace environment [33].

eHealth tools can be used to assess, store, and analyze questionnaires and psychophysiological data [43]. In WHP projects, the assessment is usually very comprehensive, consisting of many questionnaires. Therefore, Web-based tools should be used instead of mobile tools, as filling questionnaires on the Web is more feasible than on mobile devices [44]. By supporting the assessment with Web tools, it becomes easier to manage data and results, as all data are immediately stored at one place and can be accessed from different locations [45]. In addition to Web tools, the mobile phone can be used to conduct short surveys or tests [46]. The assessment tool could also support in combining different data sources (eg, questionnaire data, interview data, behavioral analyses, psychophysiological data, or corporate key figures of the company). A combination of different data sources can also prevent demotivation when it comes to data collection, as collecting a lot of questionnaire

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data might be perceived as an additional burden for the employee [37].

Dashboard Feedback

The interpretation of the results has to be done including experts in the field of health promotion (eg, safety officer, company physician, work and organizational psychologist). Similar to the third step, information flow, informing all persons about the analysis results must be done in a top-down process, starting with the top management and cascading down to the middle management, lower management, and employees [31]. First, the results are discussed internally in the steering group and top management. In this phase, the group interprets the results and defines certain areas of focus or task assignments [31]. Going further in the top-down process, the assessment results should be communicated in an easy language so that they are easily understood and accepted by the employees [47].

eHealth tools can support transferring the assessment results into feedback pages automatically. These feedback pages summarize the collected data and ideally present them in a clear and concise way with simple graphical representations [48]. This easy-to-read recap of the process can be called "dashboard" and can be used as a first rough indicator in addition to the more detailed analysis of the assessment. It is important that the information will be presented in ways that are meaningful, accurate, and easily understood [12]. This can be a challenge for eHealth tools, as the information gained from the data has to be presented in the best quality and tailored to the company and the user [49]. The main results in the dashboard can be unlocked for the whole company and all employees or only for specified groups or persons. However, it seems to be a good approach to provide the feedback pages to all employees to ensure further participation in the next step of intervention planning [30]. eHealth tools can especially support in a comprehensive presentation of the results. However, the interpretation of the results should be done by health experts as well as separately and outside these tools to avoid misinterpretations.

Health Circles/Participatory Planning

After presenting and discussing the analysis results, a health plan has to be established and specific interventions have to be developed to promote health at the workplace [16]. In this step, employees should be involved in the decision-making process to raise the employees' acceptance toward the developed interventions and increase participation rates of employees [28]. A good approach is the building of "health circles," which are discussion groups within the organization to develop options for improving health at the workplace [50,51]. The developed interventions can address improving health either directly by offering sports activities or health-related workshops, or indirectly by changing potentially harmful work conditions (which is stated in the Luxembourg Declaration [21] as individual-focused and organization-focused measures).

With the support of eHealth tools, the organization of health circles can be improved by adding calendar options or inviting interested employees to the health circles with messages. In addition, the whole execution of the health circles can be supported by providing information about the assessment results in a dashboard and thus having access to the results at any time. The developed interventions as well as information about further steps in the process can be entered into the eHealth tool, and this information can be provided to the whole company and all employees or to specified groups or persons.

Interventions (Individual/Organization)

In this step, the developed interventions from the health circles are implemented. Interventions should be developed with attention to health-beneficial effects, but also with special attention to organizational frameworks and individual preferences that allow high participation rates in the developed interventions. Interventions should be easy to implement and to attend (geographically and chronologically) and should be perceived as interesting and meaningful to enhance participation [52].

This is the step where the majority of the eHealth tools are currently developed. These tools can strongly support interventions, especially individual-focused interventions (eg, monitoring physical and mental health or nutrition intake, activity tracking). eHealth tools provide the possibility to combine monitoring devices (eg, tracking belts, smart watches) and WHP programs to track physical exercises or weight loss [8,53]. With these devices, psychophysiological data (eg, heart rate or heart rate variability for stress assessment) could also be assessed, and in a next step, it could be combined with self-reported questionnaire data [54]. Including instant, individual feedback developed by experts gives users additional information about their health progress and helps them to understand the meaning of the collected data [53]. Offering individualized feedback about the employees' personal health status and health progress along with information about programs to improve health are important motivators for the employees' participation in the WHP programs [8,9,44,55,56]. This is where eHealth tools can bring considerable added value, as these tools can be easily programmed to give instant, tailored feedback for each user. Getting feedback is part of a self-monitoring and goal-setting process that can raise the motivation for changing behavior [44].

However, it is very important that the feedback is programmed together with the knowledge and skills of experts in the field, as feedback about health parameters can contain critical information that might lead to misinterpretations [57]. This is especially the case if the feedback shows a critical health result, which might raise the participants' fears about serious health issues [58]. In the case of stress feedback, getting critical feedback could also cause more stress [54]. Therefore, automatic feedback ideally should be given together with possibilities to talk with a health expert. Instant or delayed feedback can also be seen as incentives and can raise the motivation to participate in an intervention. Hence, the effects of a WHP project can be attributed to the sustainable participation in interventions, especially if eHealth tools are implemented [59].

With regard to organization-focused interventions, the possibilities of eHealth tools have not been used to their full potential yet. Improving the environmental conditions at the workplace (eg, the organizational structures, social climate, or

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management) can strongly support health at the workplace in a sustainable way [26]. However, organization-focused interventions are often difficult to carry out and to organize [60]. The implementation of organization-focused interventions has to be managed as clearly and structured as possible to achieve the most successful outcome [61]. eHealth tools can support the organization in organizing and evaluating organization-focused interventions by providing management dashboards where the process and responsibilities are managed.

Evaluation

The step of evaluation comprises evaluating the implementation process and the implementation outcomes. To conduct an evaluation, the organization can go through steps 1-6 again, starting with the first step "Concept/Adaptation." According to WHO [16], an evaluation should be done at least every 3-5 years. Aims of the evaluation can comprise whether the participation rates are satisfactory or whether the implemented interventions have been effective [32]. The effectiveness of an intervention can be analyzed by evaluating the proximate (short-term) outcomes (eg, improvement of individual skills), intermediate (medium-term) outcomes (eg, changes in demands and resources, social processes, leadership behavior), and distal (long-term) outcomes (eg, improvement of individual health or organizational performance), which are all important outcomes in the intervention context [62].

eHealth tools can support the whole evaluation process. The evaluation should be focused on summative (after implementation) as well as formative evaluation (throughout the whole life cycle of WHP) and can also include the evaluation of the software development cycle of the eHealth tool [63]. An advantage of eHealth tools that is often stated is that they are cheaper than "traditional" health programs (eg, [64]). Therefore, it is suggested to evaluate the cost-effectiveness of the intervention in addition to the effectiveness of the intervention [65]. An evaluation can be also done regarding the acceptance and usability of an eHealth tool, which optimally results in a continuous improvement process [49]. A tool that is perceived as useful and easy-to-use can raise the usage of the tool [42]; therefore, these aspects should be evaluated regularly.

Organizational Requirements

Implementation Requirements

eHealth tools offer many possibilities and benefits, but open questions for the implementation of these tools still remain. The most commonly reported barriers (but also facilitators) of WHP projects were found in the characteristics of the organization, for example, lack of resources, no fit between intervention and organizational culture, or lack of managerial support [66]. The organizational characteristics should be investigated very carefully to ensure the success of a WHP project. This is especially the case if WHP projects are supported with eHealth tools. The complexity of the working environment could influence the way employees use eHealth tools, and thus, the work setting must be analyzed carefully before implementing these tools [67].

In the best case, the eHealth tools are fully integrated in the organizational structure and working routines [68]. Failing to integrate eHealth tools as a part of the organization's everyday life can be a barrier that prevents employees from using these tools at the workplace [37]. A framework for the integration of eHealth tools has to consider at least the part of the employees, the targeted user group, and the organization that provides the environment for the usage of the tools.

Regarding the employees, the organization has to provide opportunities to use the eHealth tools at work, such as providing the tools (eg, access to computers and mobile phones), providing training and technical support, and providing possibilities to use the tools during work time [37,69]. Furthermore, organizations need to develop clear guidelines for their employees on how to use the eHealth tools at the workplace. Clear guidelines ensure a safe usage of these tools within the organization's environment [70]. Guidelines can encompass recommendations regarding data security (eg, protection against unauthorized access or data transmission protection) or sharing information on social platforms (eg, recommendations on how to share health-relevant content safely) [53,70].

The organization benefits from having guidelines for the integration of eHealth tools. Table 1 presents organizational guidelines in each step of the implementation of eHealth tools in a WHP process. The guidelines are based on the proposed "life cycle model of Workplace Health Promotion" and can support the management and the steering group in responding to critical issues and can prevent an unsuccessful implementation of eHealth tools in WHP. The guidelines do not include the legal requirements for defining and implementing WHP in the countries or general guidelines to implement WHP that are not specifically related to eHealth tools. In Table 1, the most relevant references and an explanation or example are included for each action.

Security is of great importance for the successful integration of eHealth tools. Individuals have to be informed about the storage and usage of their individual data [12]. Privacy violations are possible from the technical point of view (eg, via hacking, outdated or nonexistent encryption methods, or legal interceptions) [12] or from the psychological view (eg, fears about data management and data reporting [71]). Even when reporting aggregated data (eg, arithmetical means of groups), attention should be paid that these data cannot be traced back to a specific person in the organization. This part can be tricky, as organizations want to have insight about the health status of their organization and thus of their employees. On the other hand, individual health data have to be protected strictly.

eHealth tools for WHP only can be successful if the employees trust the data management behind the tool. Particularly, the health domain is a very sensitive domain where violations of anonymity and privacy are experienced as harmful [81]. Invasions of privacy at the workplace undermine the trust in the tool and in the organization, which might lead to an unsuccessful WHP project.

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Table 1. Guidelines for the organization for a safe usage of eHealth tools in workplace health promotion (WHP). Note: It is suggested to discuss all actions in the step "Concept/Adaptation" and find solutions before the WHP process starts.

Step, discussions and actions	Scientific base	Examples or explanation
Concept/adaptation		
Privacy regulations of the employees' health data	[71]	Privacy regulations of the employees' health data have been discussed and suggestions have been included in the implementation concept. eHealth tools should be created in a way that prevent the steering group from seeing individual data
Data security of the eHealth tool	[53,70]	Discussions with technical experts about protection against unauthorized access or data transmission protection
Inclusion of all relevant persons in the WHP[a] process	[38]	Next to the "traditional steering group," technical experts or eHealth developers are included in the process as well
Access to the WHP activities independent of Web and/or app access	[69]	Employees who do not have mobile phones should have access to the information (eg, via general accessible computers or by proving them with devices)
Goals, added value, and benefits of the eHealth tool	[37]	Discuss in which steps of the process eHealth tools can give optimal support and where the traditional approach (without eHealth tools) is better suited
Nondirective approach for using eHealth tools	[40]	Letting the employees themselves decide if and how to use the eHealth tools to avoid possible resistance
Benefits, incentives	[72,73]	Incentives can help to enhance the signing up of the participants and help to keep the dropout rate at a low level
Regulations about the usage of eHealth tools at the workplace	[37,69]	Provide opportunities to use the eHealth tools at work (eg, access to computers, mobile phones, and/or activity tracker), provide training and technical support
Quality of the eHealth tools	[13,74]	eHealth tools that are used and integrated are chosen with regard to quality criteria in this area (eg, Mobile App Rating Scale, MARS [12] or enlight quality assessment and checklist [74])
Information		
Information about privacy regulations and anonymity	[75]	Address all doubts, fears, and comments about privacy regulations and anonymity in the information process. Provide platforms where employees could voice their concerns and answer them adequately
Usage for eHealth tools is on an opt-in base	[21]	The usage of any eHealth tools is free, employees can opt-in and are not obliged to use any tool
Procedures to integrate the existing eHealth tools	[76]	Find solutions how to integrate the eHealth tools that are already used by the employees
Definition of responsibilities in the process	[77]	A responsible person or a group is defined and introduced which serves as an expert(s) for the eHealth tool, and administers the process and is the "driver" for the process
Assessment/analysis		
Execution and presentation of the assessment	[44]	It is suggested to use computers for more comprehensive assessments. If presenting on mobile devices, the questionnaires have to be adapted to fit the mobile phone screens
Combination with other data sources	[76]	Combine questionnaire data with behavioral or psychophysiological data (eg, with the help of activity tracker) or with corporate key figures from the company
Data storage	[78]	Discuss the storage of data (eg, data have to be stored separately from e-mail addresses or other data that could be used to identify individuals)
Dashboard feedback		
Content of the information provided on the dashboard	[31]	Discuss possibilities to personalize the dashboard content to the company's needs
Detail of the information provided on the dashboard	[31]	Specify a minimum number of entries for presenting results and subgroup analyses (eg, a minimum of 5 persons for a subgroup analysis) to avoid inference to a single person

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Step, discussions and actions	Scientific base	Examples or explanation
Regulations on how to share feedback information	[53,70]	Specify guidelines on how to share information on social platforms or other forums/platforms
Inclusion of all relevant health experts	[57]	Health experts (eg, physicians, psychologists, sports experts, nutritionists) have been included in the interpretation of the results to avoid misinterpretations, and in the development of interventions
Health circles/participatory planning		
Participation of employees in the selection of activities	[30]	All employees have been given the possibility to participate in the decision-making process to raise the employees' acceptance toward the developed interventions and increase participation rates of employees
Support of planning and organizing health circles	[79]	It includes "audience response systems" for discussions that allow employees to stay anonymous and see dashboard results immediately for a more fruitful discussion
Interventions (individual/organization)		
Procedures for giving automated, individual feedback	[57]	The way of giving ethical, correct individual feedback to the employees is discussed and defined with health experts
Procedures in case of critical results	[59]	A support line has been established in case employees need professional support after receiving a critical feedback
Inclusion of organization-focused interventions	[21,26,61]	eHealth tools can support by providing management dashboards where the process and responsibilities are managed
Evaluation		
Evaluation of the eHealth tool	[49,68]	A continuous improvement process is started where the evaluation results regarding the acceptance and usability of eHealth tool are addressed
Evaluation of efficiency	[80]	Clear rationales and algorithms are found to monitor goals and effects with the support of eHealth tools

eHealth tools as well as processes regarding the implementation into the WHP process should be created together by developers, health experts, and WHP specialists to create an environment that is transparent, trustworthy, and safe for the employees. Including a multidisciplinary team (including all types of designers, stakeholders, supervisors, and end-users) already in an early phase of the development of the eHealth tool is a success factor for the further usage of these tools [38,68]. The tool should be designed in a way that it is easy to access and use [52]. In addition to including experts in the development phase, it is important to include relevant people in the implementation phase as well as in the evaluation phase of eHealth tools [82].

The Important Role of Managers and Workplace Health Promotion Experts

WHP includes an interdisciplinary approach that combines different areas of expertise (eg, medicine, psychology, nutrition, safety) to achieve the most successful outcome [18,83]. Including all relevant people in the implementation process as well as including them during the whole WHP project can be a success factor for eHealth tools in WHP. Especially when using eHealth tools for individual-focused interventions (eg, tracking sports activities, monitoring nutrition intakes, or assessing health data), communicating with experts in the field of health promotion could motivate the participants to proceed with the intervention [44]. Using an unguided tool without human involvement could lead to nonparticipation, as important information and advices are not fully provided. Including social support in the form of peer mentors can be additionally included in the process to increase participation. Peer mentors can give advice or support healthy behavior with small incentives [84]. Including an incentive system to increase participation in eHealth programs could be a success factor for increasing participation as well [59,72].

At the workplace and especially for WHP, managers are important key factors that could influence the success of eHealth tools at work. A lack of support from the management is a major risk factor for the success of WHP projects [66]. Managers (in the top, middle, as well as in the lower management) are promoters of a healthy organizational climate and important key factors for successful and sustainable WHP activities [85,86]. In WHP projects, managers are able to positively influence employee health by supporting health promotion programs and policies and forwarding these policies to lower levels of management in a top-down process [87,88]. In addition, managers are responsible to provide resources for planning, implementing, and evaluating the WHP projects [89].

WHP programs have to be supported by the top management to demonstrate visibility and raise commitment of the developed WHP interventions [90]. In the WHP projects where managers do not actively promote the WHP programs, participants lose interest and are more likely to drop out [52]. Additionally, managers should provide all necessary resources to establish optimal conditions for the WHP projects [69]. To enhance the

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engagement of managers—and in the long run, the engagement of employees—the eHealth tools should be based on a scientific theory proving evidence of its benefits for the organization and its employees [37,91]. With a scientific theory behind, the mechanisms of change can be better assessed and evaluated [2].

The management is an important factor for the organization and implementation of WHP strategies, but is also a specific target group for WHP programs. eHealth tools can provide an added value for managers by supporting them in the field of leadership assistance and development [48].

Conclusions

Integrating eHealth tools in WHP can be successful if they are integrated in all steps of the WHP process. They can enhance the efficiency of WHP projects with easier administration and management of the WHP process, providing an information and communication platform for all employees, and supporting the assessment of the current state of the organization. The clearest benefits lie in developing interventions for changing individual health behavior, as eHealth tools allow programming immediate, personal feedback that can be a strong reinforcement for behavior change. In addition to individual-focused interventions, organization-focused interventions can be supported by establishing electronic management dashboards that can be accessed everywhere at any time.

We presented guidelines that can help scientists and practitioners in successfully implementing eHealth tools in organizations. Some pilot studies were conducted in the practical field and provided first insights into where an eHealth tool can support the steering group and the employees during a WHP project.

The life cycle model of WHP can provide assistance for a successful implementation of eHealth tools in the WHP process. Ideally, a model like this can integrate the needs and obligations for psychosocial risk management [92], as the steps are very similar in the process (see also [19]). The assessment of psychosocial risks at the workplace is similar to WHP as both procedures aim to enhance health at the workplace. eHealth tools can support psychosocial risk management in the same way as the WHP processes.

Very clearly, the usage of these eHealth tools needs regulation and quality criteria as there are still many open questions such as data privacy and data security. At the moment, there is much uncertainty about the role of eHealth tools in organizations, especially when it comes to health-relevant data assessed within a WHP process. Good and clear directions for the usage and implementation of these tools are needed to secure quality and reach sustainable results. The developed guidelines for organizations can be the first step in supporting organizations to successfully implement eHealth tools in the WHP process.

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Conflicts of Interest

None declared.

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Abbreviations

eHealth: electronic health
mHealth: mobile health
WHO: World Health Organization
WHP: workplace health promotion

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Original Paper

Reported Theory Use by Digital Interventions for Hazardous and Harmful Alcohol Consumption, and Association With Effectiveness: Meta-Regression

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Abstract

Background: Applying theory to the design and evaluation of interventions is likely to increase effectiveness and improve the evidence base from which future interventions are developed, though few interventions report this.

Objective: The aim of this paper was to assess how digital interventions to reduce hazardous and harmful alcohol consumption report the use of theory in their development and evaluation, and whether reporting of theory use is associated with intervention effectiveness.

Methods: Randomized controlled trials were extracted from a Cochrane review on digital interventions for reducing hazardous and harmful alcohol consumption. Reporting of theory use within these digital interventions was investigated using the theory coding scheme (TCS). Reported theory use was analyzed by frequency counts and descriptive statistics. Associations were analyzed with meta-regression models.

Results: Of 41 trials involving 42 comparisons, half did not mention theory (50% [21/42]), and only 38% (16/42) used theory to select or develop the intervention techniques. Significant heterogeneity existed between studies in the effect of interventions on alcohol reduction (I^2=77.6%, P<.001). No significant associations were detected between reporting of theory use and intervention effectiveness in unadjusted models, though the meta-regression was underpowered to detect modest associations.

Conclusions: Digital interventions offer a unique opportunity to refine and develop new dynamic, temporally sensitive theories, yet none of the studies reported refining or developing theory. Clearer selection, application, and reporting of theory use is needed to accurately assess how useful theory is in this field and to advance the field of behavior change theories.

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KEYWORDS

alcohol drinking; behavior, addictive; regression analysis; meta-analysis; randomized controlled trial; Internet

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Introduction

Excessive alcohol consumption is a major avoidable risk factor for the global burden of disease and injury [1]. An estimated 4.9% of the world's adult population suffers from alcohol use disorders [2], with alcohol causing an estimated 3.8% of all deaths and 4.6% of disability-adjusted life years [1]. Alcohol-related costs amount to more than 1% of the gross national product in high- and middle-income countries [1]. Digital behavior change interventions are products or services to promote behavior change delivered via computer technology, which includes smartphone apps, websites, computer programs, wearable devices, and telecommunications [3]. Digital behavior change interventions have a potentially broader reach than face-to-face brief interventions and have been identified as cost-effective [4]. Reviews of digital interventions to reduce hazardous and harmful alcohol consumption have found that they can be more effective than controls [4-14]. However, there is substantial heterogeneity between the effectiveness of different interventions that is currently unexplained [5,8,9,11,12].

Behavior change theories "explain why, when and how a behaviour does or does not occur, and the important sources of influence to be targeted in order to alter the behaviour" [15]. A good theory should have a "parsimonious, coherent explanation of phenomena" [15] that is comprehensible, internally consistent, generates testable predictions, and is not contradicted by observations [16]. Theories often lack specificity and so fail to generate hypotheses that can be tested in the real world [17]. These testable predictions can and should be used as a basis to refine and improve theories [18] or to retire theories that do not explain or predict intervention outcomes [16]. Using a good behavior change theory in intervention development and evaluation has many potential benefits [19]. Theories can inform researchers about which variables might be most influential in mediating the target behavior, thereby providing a systematic method for selecting [20] and refining appropriate intervention techniques [21]. Using a theoretical framework for data collection means that evidence of effectiveness can be accumulated across different contexts, populations, and behaviors [19], and the process of adapting and refining interventions is more efficient [20]. Theory-based interventions can reveal what makes an intervention effective by enabling empirical tests of theoretical propositions. These can, in turn, provide a basis for refining theory [18], and future theory-based interventions are likely to be improved [22]. This illustrates the concept of a virtuous spiral between theory and intervention development whereby theory can inform intervention development, and interventions can test and refine the underlying theory [3]. These benefits suggest that systematic use of a high quality behavior change theory in intervention development may result in a more effective intervention [19,23-25] and be able to inform future interventions [22].

The extent to which theory is used may explain some of the substantial heterogeneity found between the effectiveness of different digital alcohol reduction interventions. Mixed evidence exists with both positive [21,26-30] and negative associations [31,32] being found between theory use and the effectiveness of behavior change interventions. There are a number of factors that may contribute to this pattern of results. The value of theory is dependent on using a high quality and appropriate theory that is relevant to the behavior [15]. Furthermore, the way theory has been used and reported is generally inadequate; many studies do not report theory use in intervention development or evaluation [23,30,33-36]. If interventions are described as having a theoretical basis, this description is often unclear or not extensive [24,29]. For example, a review of physical activity and dietary interventions found that only half reported using theory and, of those, only a small proportion systematically applied theory [29].

The theory coding scheme (TCS) is a tool used to describe the theoretical basis of interventions [19]. The tool was specifically developed to inform evidence syntheses and has been widely used in meta-analyses to assess the potential association between theory and intervention effectiveness [14,25,29]. The TCS has 19 items—each with satisfactory interrater reliabilities—that can be grouped into six categories of theory use: reference to underpinning theory, targeting of relevant theoretical constructs, using theory to select recipients or tailor interventions, measurement of constructs, testing of theory, mediation effects, and refining theory [19]. Composite scores can provide an estimate of the extent of reported theory use, which also facilitates the assessment of whether an association exists between the extent of theory use and intervention effectiveness [29].

The association between theory use in computer-delivered interventions and alcohol-related outcomes in the general population has been assessed using meta-regression [14]. This review found no association between the extent of theory use in intervention development and effectiveness but did find that the use of a particular theory—the social norms approach [37]—was associated with improved outcomes [14]. This paper will investigate whether these findings generalize to populations of hazardous and harmful drinkers. This population is of particular interest because they experience more economic, health, and social costs compared with low-risk drinkers [38]. There is also a need for replication of studies, including meta-analyses, to confirm initial findings and build a strong evidence base [39,40].

This paper reports a theoretical analysis of interventions that we planned as part of a Cochrane review of the effectiveness of digital interventions for reducing hazardous and harmful alcohol consumption in community-dwelling populations (systematic review registration number: CRD42015022135) [41,42].

This paper will address the following research questions:

1. How is theory use reported in the development and evaluation of digital interventions for reducing hazardous and harmful alcohol consumption?
    a. Which items and categories of theory use are used most frequently?
    b. What is the extent of reported theory use (mean total theory use score)?

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2. Is there an association between intervention effectiveness and items, categories, and extent of theory use?

Methods

Search Strategy and Study Selection

Studies for inclusion in the systematic review were identified through a broad search of databases (eg, MEDLINE, Cochrane Library, CINAHL, PsycINFO, and Clinicaltrials.gov) and relevant websites (eg, International Alcohol Information Database, Beacon 2.0, and Drug and Alcohol Findings). The reference lists of all included studies and relevant reviews were checked. The search combined terms for hazardous or harmful alcohol consumption (eg, alcohol, drinking, alcohol use, and risks) with terms for computer-assisted therapy or digital interventions (eg, Internet, computers, and smartphone). Full details of the search strategy are reported in the protocol in the Cochrane Library [41].

Inclusion Criteria

Studies were randomized controlled trials with the outcome measure of quantity of alcohol consumed (in grams per week), which could be reported in standard drinks, alcohol units, or similar. Participants were community-dwelling individuals who could have been recruited in a range of settings (eg, primary health care, social care, educational, and workplace) and were under no obligation to complete the intervention (eg, mandated college students). Participants were screened and identified as hazardous or harmful drinkers typically via completing short online questionnaires such as the Alcohol Use Disorders Identification Test (AUDIT) or quantity-frequency measures. The intervention had to target alcohol consumption or alcohol-related problems in the drinker and be delivered primarily through a digital device. A comparator condition must have been included (eg, no intervention, usual care, feedback or general health advice, or health information via printed leaflets or booklets). Full details of the inclusion criteria are in the protocol [41].

Review Procedure

The review procedure consisted of two phases to identify relevant studies using the inclusion criteria detailed above. Initially, studies were reviewed independently by two researchers based on their title and abstract, using Endnote to ensure consistency. A conservative approach was taken so that studies were included if their relevance to the review was uncertain. In the second phase, the full research paper of any studies identified as potentially eligible were reviewed independently by two researchers. Any discrepancies were resolved by discussion and by consulting a third researcher if necessary. The inclusion criteria were amended to reflect any clarifications that occurred during the discussion of discrepancies.

Data Extraction

A standardized data extraction form was developed and piloted, which two researchers used to independently carry out data extraction of all included studies. Data were extracted about the following: details of the intervention (eg, setting, duration, size, and characteristics of sample) and baseline and follow-up data for the primary outcome measure of the main Cochrane review (grams of alcohol consumed per week).

A theoretical analysis of the studies was conducted using the TCS [19]. Coding extended to any development, feasibility, or protocol papers that were referenced in the included studies and may have reported supplementary information about the intervention. Two researchers independently coded a sample of 5 studies using the TCS. Differences were resolved through discussion, and a third researcher was consulted if agreement was not reached; notes on the coding guidelines were made accordingly. Four further rounds of testing were performed until the interrater reliability (IRR) reached a substantial level of agreement (prevalence-adjusted bias-adjusted kappa, PABAK statistic greater or equal to .70 [43]). The PABAK statistic was .84 across the five rounds of IRR checking, which reflects a substantial level of agreement. After this level of agreement was achieved, the remaining studies were coded by one researcher.

The TCS was amended for use in this systematic review; two items ("quality of measures" and "randomization of participants to condition") were excluded because they related to methodological issues rather than informing whether or how theory was used in an intervention. The amended TCS had 17 items (three of which had subitems); see Table 1 for a list of these items and their descriptions. Each study was dummy coded for the TCS items as present (1) or absent (0). If any theory was mentioned (item 1), then the relevant name was documented, regardless of whether empirical support for the theory existed. If a protocol or other paper was referenced as describing the intervention, then that paper was also coded for those items relating to intervention development (items 1-11). Composite scores were calculated for the six categories of theory use (see Table 2 for a description of these categories) and a total theory use score [19]. The total theory use score was a sum of all 17 items, three of which had subitems, which resulted in a maximum possible score of 22. For the composite scores, any item detailing "all" (items 7 and 8) that was coded as present was also coded as present for the equivalent item detailing "at least one" (items 10 and 11) so that the composite scores were representative (as in [25]).

Analysis

Frequency counts and descriptive statistics were used to describe the theoretical basis to digital interventions for alcohol reduction. The range and frequency of theories used were tabulated.

The meta-regressions were conducted in Stata (StataCorp; version 14). Effect sizes were based on a random effects model, as the intervention effects were likely to have residual heterogeneity not modeled by the covariates. The effectiveness of the intervention was measured using the primary outcome measure of difference in grams of alcohol consumed per week between the digital intervention and control arms at the longest follow-up time point. The weighted mean difference method was used to estimate pooled effect sizes and 95% CIs. Previous simulation studies have found that for accurate estimates in meta-regression, at least 40 studies are required [44] and that

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more than 200 studies are required for 80% power to detect modest associations [45].

A series of unadjusted random effects meta-regression analyses were conducted to examine the association between the TCS covariates (individual theory items, included by at least 10% (5/42) of studies; the categories of theory use; and total theory use) with intervention effectiveness and the percentage of the between-study heterogeneity (adjusted R^2) explained by each predictor. The regression coefficient (B) represented the mean of the unstandardized effects between trials that differentially included each TCS covariate. A negative coefficient for a covariate indicated that the studies reporting that theory item, or with higher composite scores for the categories of theory use and total theory use, were associated with a larger reduction in consumption than studies that did not.

To investigate the independent associations, an adjusted meta-regression analysis was conducted, including all of the variables that had a meaningful association with intervention effectiveness in the unadjusted models. A meaningful association was defined as B>23, based on the lower boundary of a 95% CI for the effect found in a systematic review of brief alcohol interventions [46].

In the event of a nonsignificant result, a Bayes factor was calculated to establish the relative likelihood of the null versus the experimental hypothesis given the data obtained. The experimental hypothesis was that the TCS covariate was associated with intervention effectiveness, and the null hypothesis was that there was no association. The Bayes factors were calculated with the alternative, directional hypotheses conservatively represented in each case by a one-tailed, nonuniform distribution using the online calculator associated with Dienes [47,48]. The standard error was specified as the expected effect size (ie, 23), which means plausible values have been effectively represented between 0 and twice the effect size, with smaller values more likely. Bayes factors allow the distinction between two interpretations of a null result: there is evidence for the null-hypothesis or that the data are insensitive in distinguishing an effect. Bayes factors vary from 0 to ∞: values of 3 to 10 indicate moderate evidence for the experimental hypothesis over the null, whereas values greater than 10 indicate strong evidence; values of 0.10 to 0.33 indicate moderate evidence for the null over the alternative, whereas values less than 0.10 indicate strong evidence; and values between 0.33 and 3 indicate that the data are insensitive in distinguishing an effect [49].

Results

Study Selection

Studies were selected for this meta-regression if they were included in the primary meta-analysis of the Cochrane review [42]. A total of 5928 records were identified through database searching and through other sources, with 3165 records remaining after duplicates were removed. Records were then screened by their title and abstract (with 2477 excluded) before the full text was screened (633 excluded; see Figure 1 for reasons for exclusion). Forty-one trials compared a digital intervention (one contained two digital arms) with a control (these included assessment only, waiting list control groups, and provision of standard health-related information) and reported appropriate information for inclusion in the primary meta-analysis. This resulted in 42 digital intervention arms. Multimedia Appendix 1 reports the references to studies included in this meta-regression.

Study Characteristics

The 42 digital intervention arms included 19241 participants (9631 randomized to a digital intervention and 9610 randomized to a control condition). The longest period of follow-up ranged from 1 month (n=8) to 12 months (n=7). Interventions were Web-based in 34 studies, comprised a stand-alone computer program in 6 studies, and a smartphone app in 1 study. A total of 24 studies focused on students or younger adults (<25 years), whereas the others recruited adults of any age. Use of the intervention was restricted to a specific location (eg, primary care clinic or psychology lab) in 10 studies, and 30 trials allowed participants to use the intervention at the location of their choice. The majority of the studies (n=23) took place in North America, 9 took place in continental Europe, 4 in Scandinavia, 2 in the United Kingdom, 2 in New Zealand, and 1 in Australia.

How Is Theory Use Reported in Digital Interventions?

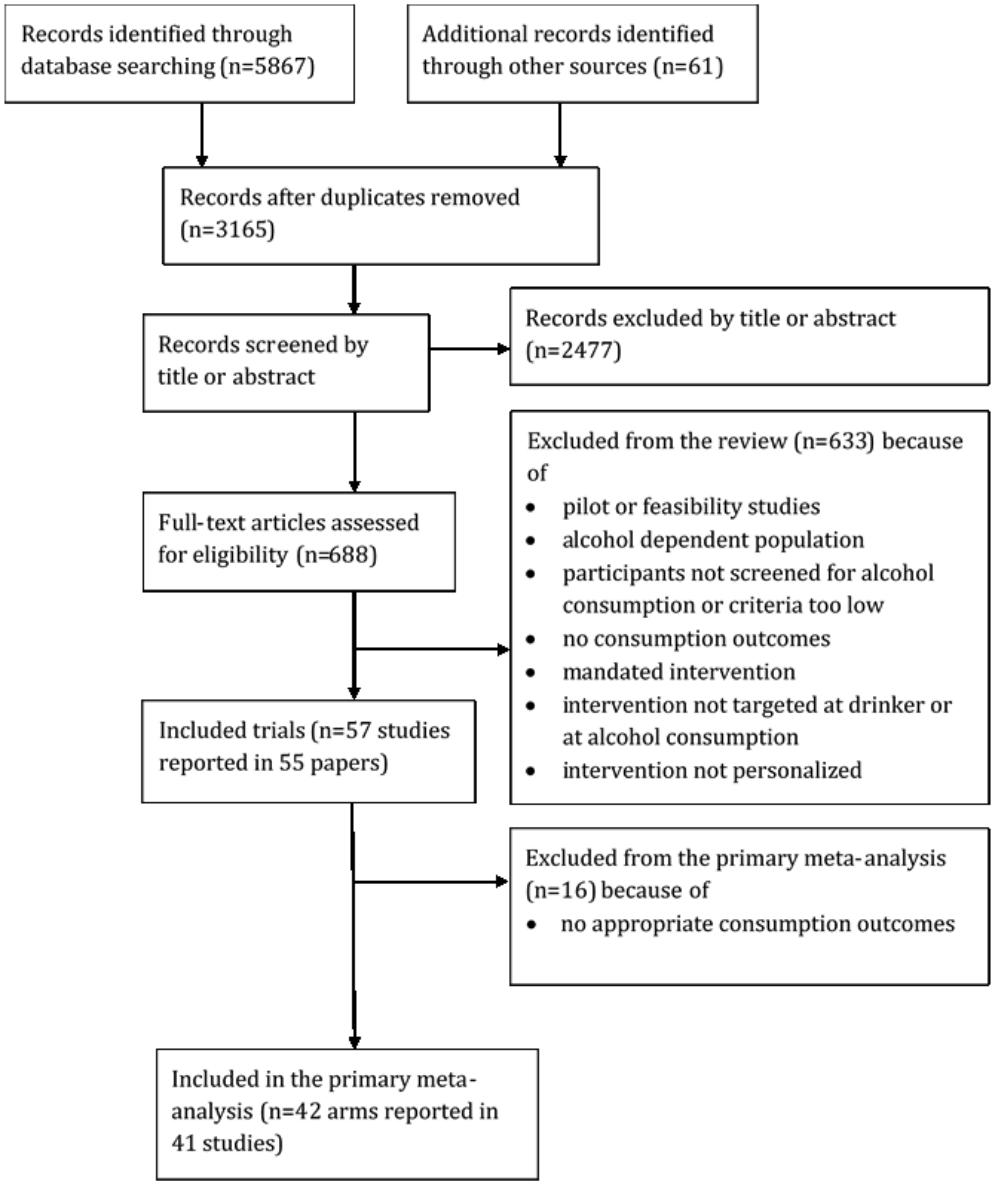
Table 1 reports the frequency of reporting in studies for the TCS items, and Table 2 reports the composite scores for the six categories of theory use and the total use of theory. The most frequently reported theory items were as follows: “theory or model mentioned” (50% [21/42]), “targeted constructs mentioned as a predictor of behavior” (40% [17/42]), and “theory or theoretical predictors used to select or develop intervention techniques” (38% [16/42]). No intervention reported refining theory, either by adding or removing theoretical constructs or by specifying that the interrelationships between theoretical constructs should be changed. The mean total theory use score was 4.4 (SD 5.43) out of a possible 22, which indicates that typically studies are not extensively reporting theory use in intervention development and evaluation. Multimedia Appendix 2 reports the 18 different theories or models mentioned and by which studies. The most frequently mentioned were motivational interviewing theory (38% [8/21]), transtheoretical model (29% [6/21]), and social norms theory (29% [6/21]).

Association Between Reporting of Theory Use and Intervention Effectiveness

The primary meta-analysis in the Cochrane review found that participants randomized to a digital intervention drank 22.8 (95% CI 15.4-30.3) grams of alcohol per week less than controls [42], the equivalent of about 3 standard UK units of alcohol or 1.7 standard drinks in the United States. There was a significant proportion of the residual variation attributable to between study heterogeneity (I^2=77.6%, P<.001; see Figure 2), which could potentially be explained by study-level covariates.

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Figure 1. Flowchart showing identification of included trials (reproduced from the main Cochrane review).



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Table 1. Number of studies in which items on the theory coding scheme are present.

Theory coding scheme item (item number)	Item description [19]	Studies where item coded as present, n (%)
Theory or model of behavior mentioned (I1)	Models or theories that specify relations among variables to explain or predict behavior are mentioned even if the intervention is not based on this theory	21 (50)
Targeted construct mentioned as predictor of behavior (I2)	"Targeted" construct refers to a psychological construct that the study intervention is hypothesized to change	17 (40)
Intervention based on single theory (I3)	The intervention is based on a single theory (rather than a combination of theories or theory and predictors)	9 (21)
Theory or predictors used to select recipients for the intervention (I4)[a]	Participants were screened or selected based on achieving a particular score or level on a theory-relevant construct or predictor	0 (0)
Theory or predictors used to select or develop intervention techniques (I5)	The intervention is explicitly based on a theory or predictor or combination of theories and predictors	16 (38)
Theory or predictors used to tailor intervention techniques to recipients (I6)[a]	The intervention differs for different subgroups that vary on a psychological construct or predictor at baseline	3 (7)
All intervention techniques are explicitly linked to at least one theory-relevant construct or predictor (I7)	Each intervention technique is explicitly linked to at least one theory-relevant construct or predictor	6 (14)
At least one, but not all, of the intervention techniques are explicitly linked to at least one theory-relevant construct or predictor (I8)	At least one, but not all, of the intervention techniques are explicitly linked to at least one theory-relevant construct or predictor	11 (26)
Group of techniques are linked to a group of constructs or predictors (I9)[a]	A cluster of techniques is linked to a cluster of constructs or predictors	2 (5)
All theory-relevant constructs or predictors are explicitly linked to at least one intervention technique (I10)	Every theoretical construct within a state theory, or every stated predictor, is linked to at least one intervention technique	7 (17)
At least one, but not all, of the theory-relevant constructs or predictors are explicitly linked to at least one intervention technique (I11)	At least one, but not all, of the theoretical constructs within a stated theory or at least one, but not all, of the stated predictors (see I5) are linked to at least one intervention technique	10 (24)
Theory-relevant constructs are measured: post intervention (I12a)	At least one construct of theory (or predictor) mentioned in relation to the intervention is measured post intervention	12 (29)
Theory-relevant constructs are measured: post and pre intervention (I12b)	At least one construct of theory (or predictor) mentioned in relation to the intervention is measured pre and post intervention	10 (24)
Changes in measured theory-relevant constructs or predictors (I13)	The intervention leads to significant change in at least one theory-relevant construct or predictor (vs control group) in favor of the intervention	8 (19)
Mediational analysis of constructs or predictors (I14):		
Mediator predicts the dependent variable (I14a)	Mediator predicts dependent variable, or change in mediator leads to change in dependent variable	6 (14)
Mediator predicts dependent variable, controlling for the independent variable (I14b)[a]	Mediator predicts dependent variable when controlling for independent variable	3 (7)
Intervention does not predict the dependent variable when controlling the independent variable (I14c)	Intervention does not predict dependent variable when controlling for mediator	4 (10)
Mediated effect is statistically significant (I14d)	Mediated effect is statistically significant	6 (14)
Results discussed in relation to theory (I15)	Results are discussed in terms of the theoretical basis of the intervention	12 (29)
Appropriate support for theory (I16)	Support for the theory is based on appropriate mediation, or refutation of the theory is based on obtaining appropriate null effects (ie, changing behavior without changing the theory-relevant constructs)	7 (17)
Results used to refine theory: adding or removing constructs to the theory (I17a)[a]	Authors attempt to refine the theory upon which the intervention was based by adding or removing constructs to the theory	0 (0)

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Theory coding scheme item (item number)	Item description [19]	Studies where item coded as present, n (%)
Results used to refine theory: specifying that the interrelationships between the theoretical constructs should be changed (I17b)[a]	Authors attempt to refine the theory upon which the intervention was based by specifying that the interrelationships between the theoretical constructs should be changed and spelling out which relationships should be changed	0 (0)

[a]Present in <10% of studies, so not included in the meta-regression analyses.

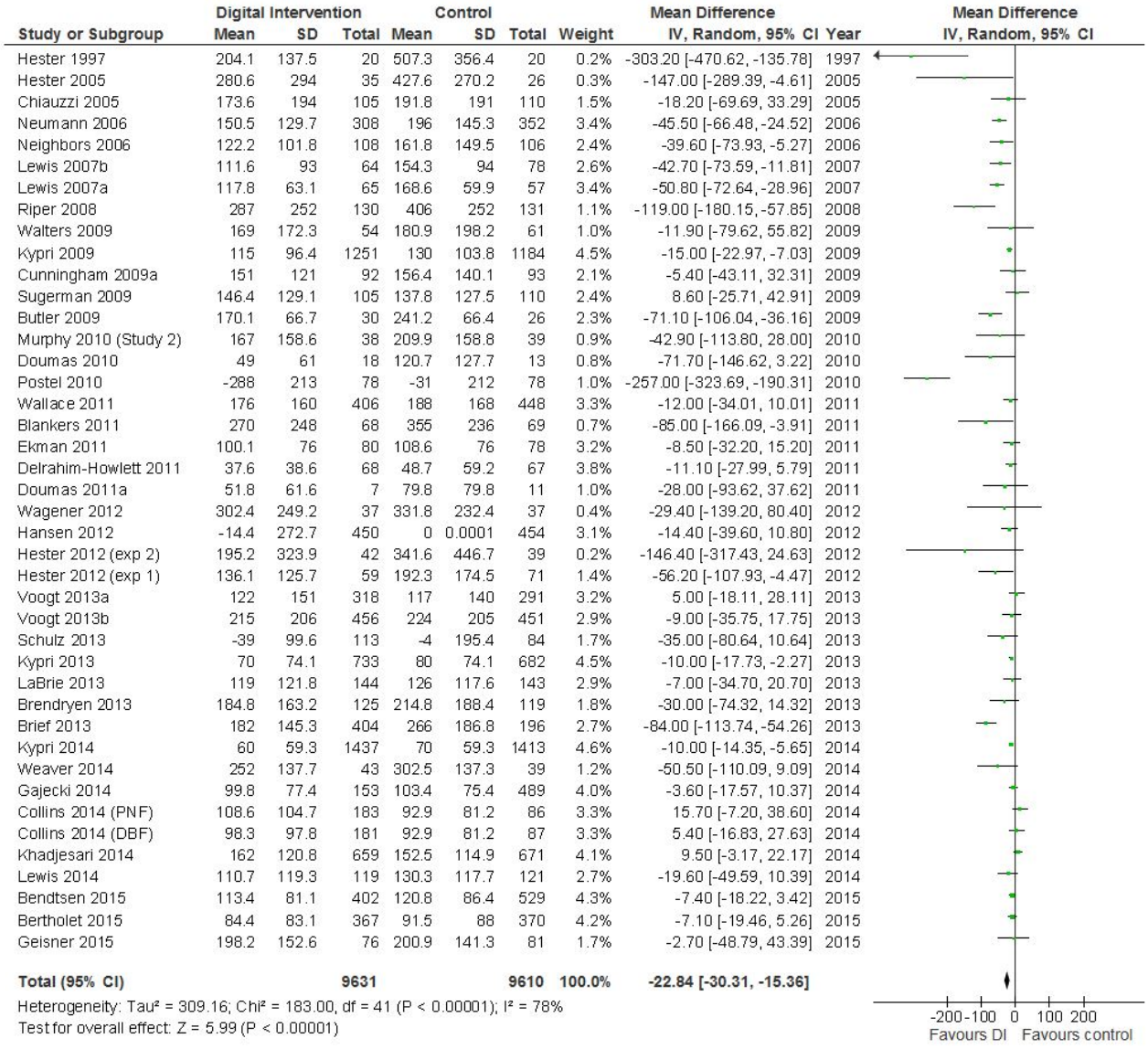
Table 2. Descriptive statistics for categories of theory use.

Theory coding scheme categories (category number)	Category description (what the items in each category assess) [19]	Items included	Maximum score	Mean (SD)	Studies scoring ≥1, N
Reference to underpinning theory (C1)	Stated or suggested, rather than demonstrated theoretical base	1, 2, 3	3	1.1 (1.23)	20
Targeting of relevant theoretical constructs (C2)	Whether evidence was provided that a targeted theoretical construct predicted behavior, whether theory or predictors were explicitly used for designing the intervention, and the extent to which the intervention targets particular theory-relevant constructs	2, 5, 6, 7, 8, 9, 10, 11	8	2.0 (2.43)	17
Using theory to select recipients or tailor interventions (C3)	Whether theory was used to select participants likely to benefit from the intervention, or to tailor the intervention to the needs of a particular individual	4, 6	2	0.1 (0.26)	2
Measurement of constructs (C4)	Whether the relevant theory-based constructs or predictors have been measured	12a, 12b	2	0.5 (0.86)	11
Testing of theory: mediation effects (C5)	Whether theoretical constructs are measured, whether the intervention changes the theoretical constructs, and whether these changes explain the effect	12a, 12b, 13, 14a, 14b, 14c, 14d, 15, 16	9	1.6 (2.83)	14
Refining theory (C6)[a]	Whether the results of evaluating theory-based interventions are used to refine theory	17a, 17b	2	—	—
Total use of theory	—	All items	22	4.4 (5.43)	20

[a]No score >0 for any studies, so not included in the meta-regression analyses.

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Figure 2. Digital intervention versus control-quantity of drinking (g/week), based on longest follow-up (reproduced from the main Cochrane review).



Unadjusted Associations Between Reporting of Theory Use and Intervention Effectiveness

The unadjusted associations between reported theory use and intervention effectiveness are reported in Table 3. The TCS items, category scores, and total use of theory were entered as covariates in the analyses. Seven TCS covariates were not included in these analyses as they were either present in <10% of studies (items 4, 6, 9, 14b, 17a, and 17b) or had a composite score of 0 (category 6). The results indicated that the TCS covariates explained little of the heterogeneity, and no significant associations with intervention effectiveness were detected.

The Bayes factors derived from the reported theory use are reported in Table 3 and indicated that the majority of these data were insensitive to detect an effect. The TCS item of "Changes in measured theory-relevant constructs or predictor" had a Bayes factor greater than 3 (BF=3.50), which indicates moderate evidence for an association with intervention effectiveness. Seven TCS covariates had a Bayes factor of less than 0.33, indicating moderate evidence for no association between the item and intervention effectiveness ("targeted construct mentioned as predictor of behavior" BF=0.22; "theory or predictors used to select or develop intervention techniques" BF=0.27; "at least one, but not all, of the intervention techniques are explicitly linked to at least one theory-relevant construct or predictor" BF=0.23; "at least one, but not all, of the theory-relevant constructs or predictors are explicitly linked to at least one intervention technique" BF=0.30; "reference to underpinning theory" BF=0.12; "testing of theory: mediation effects" BF=0.24; and "total use of theory" BF=0.05). One TCS covariate had a Bayes factor of less than 0.10, indicating strong evidence for no association between the item and intervention effectiveness ("targeting of relevant theoretical constructs" BF=0.06).

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Table 3. Unadjusted meta-regression analyses for the individual theory coding items, six categories of theory use, and use of theory scores.

Theory coding scheme covariates (item or category number)	B (SE)	*P* value	95% CI	Adjusted R^2 (%)	I^2 (%)	Bayes factor
Theory or model of behavior mentioned (I1)	9.73 (14.63)	.51	−19.84 to 39.31	−4.90	78.09	0.36
Targeted construct mentioned as predictor of behavior (I2)	24.17 (14.09)	.09	−4.30 to 52.64	2.27	78.13	0.22
Intervention based on single theory (I3)	12.92 (17.60)	.47	−22.64 to 48.49	−4.44	78.08	0.40
Theory or predictors used to select or develop intervention techniques (I5)	18.25 (14.57)	.22	−11.20 to 47.69	−3.43	78.15	0.27
All intervention techniques are explicitly linked to at least one theory-relevant construct or predictor (I7)	−3.73 (19.91)	.85	−43.98 to 36.51	−4.86	76.50	0.73
At least one, but not all, of the intervention techniques are explicitly linked to at least one theory-relevant construct or predictor (I8)	26.39 (15.34)	.09	−4.60 to 57.39	10.54	77.49	0.23
All theory-relevant constructs or predictors are explicitly linked to at least one intervention technique (I10)	8.53 (19.81)	.67	−31.60 to 48.46	−5.82	78.14	0.51
At least one, but not all, of the theory-relevant constructs or predictors are explicitly linked to at least one intervention technique (I11)	18.79 (15.99)	.25	−13.54 to 51.11	−3.45	78.15	0.30
Theory-relevant constructs are measured: post intervention (I12a)	−14.67 (15.81)	.36	−46.62 to 17.28	1.42	76.37	1.18
Theory-relevant constructs are measured: post and pre intervention (I12b)	−13.78 (16.88)	.42	−47.90 to 20.33	−1.67	76.94	1.09
Changes in measured theory-relevant constructs or predictor (I13)	−33.04 (17.48)	.07	−68.37 to 2.28	16.92	74.82	3.50
Mediational analysis of constructs or predictors: mediator predicts the dependent variable (I14a)	−7.77 (20.24)	.70	−48.68 to 33.15	−3.13	76.43	0.84
Mediational analysis of constructs or predictors: intervention does not predict the dependent variable when controlling the independent variable (I14c)	−21.88 (24.11)	.37	−70.61 to 26.86	4.48	75.41	1.29
Mediational analysis of constructs or predictors: mediated effect is statistically significant (I14d)	−7.77 (20.24)	.70	−48.68 to 33.14	−3.13	76.43	0.84
Results discussed in relation to theory (I15)	1.59 (16.08)	.92	−30.91 to 34.08	−6.81	77.35	0.54
Appropriate support for theory (I16)	−8.73 (19.43)	.66	−48.01 to 30.55	−2.11	76.33	0.87
Reference to underpinning theory (C1)	7.19 (5.89)	.23	−4.72 to 19.10	−1.55	78.08	0.12
Targeting of relevant theoretical constructs (C2)	3.94 (2.97)	.19	−2.06 to 9.93	−4.08	78.12	0.06
Using theory to select recipients or tailor interventions (C3)	13.30 (27.27)	.63	−41.81 to 68.42	−7.21	77.67	0.60
Measurement of constructs (C4)	−7.58 (8.41)	.37	−24.58 to 9.42	0.19	76.61	0.79
Testing of theory: mediation effects (C5)	−2.09 (2.53)	.41	−7.20 to 3.02	2.29	75.71	0.24
Total use of theory	0.39 (1.37)	.78	−2.38 to 3.15	−7.46	77.58	0.05

Table 4. Adjusted meta-regression analysis for the covariates with a meaningful association with effect size in unadjusted models.

Theory coding scheme covariates (item number)	B (SE)	*P* value	95% CI	Variance inflation factor	Bayes factor
Targeted construct mentioned as predictor of behavior (I2)	50.82 (21.00)	.02	8.31-93.34	2.98	0.24
At least one, but not all, of the intervention techniques are explicitly linked to at least one theory-relevant construct or predictor (I8)	−12.19 (20.71)	.56	−54.12 to 29.74	2.37	0.98
Changes in measured theory-relevant constructs or predictor (I13)	−61.41 (19.42)	.003	−100.71 to −22.10	1.45	23.71

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Adjusted Associations Between Reporting of Theory Use and Intervention Effectiveness

An adjusted model was conducted entering the covariates that had a modest (albeit nonsignificant) association with effect size (B>23) in the unadjusted models (item 2, item 8, and item 13) and are reported in Table 4. The adjusted model had little effect on the degree of heterogeneity identified in the primary meta-analysis (I^2=74.3% and adjusted R^2=32.93%). The adjusted model produced two significant associations between TCS covariate and intervention effectiveness (item 2: "targeted construct mentioned as predictor of behavior" [B=50.82, 95% CI 8.31-93.34, *P*=.02] and item 13: "changes in measured theory-relevant constructs or predictor" [B=−61.41, 95% CI −100.71 to −22.10, *P*=.003]). However, these are difficult to interpret in the absence of any significant associations in the unadjusted models and that the pattern of results is not robust to standardized effect sizes or slight changes to the inclusion of studies.

Discussion

Principal Findings

There is limited reporting of theory use in the development or evaluation of digital interventions to reduce hazardous and harmful alcohol consumption. Half of the studies in this review did not make any reference to theory, and only a third of studies reported using theory to develop the intervention. No study reported using their results to refine the theory.

No significant associations were detected in the unadjusted models between the reporting of theory use and intervention effectiveness, though the meta-regression had limited power to detect modest associations [45], and any associations were likely to be small given the substantial heterogeneity in this literature. The data underlying the majority of null findings were found to be insensitive to distinguish an effect by calculating Bayes factors; however, there was moderate or strong evidence that eight TCS covariates are not associated with intervention effectiveness in this context. Insofar that a researcher believed smaller effect sizes were important, then it is likely these data would be judged as insensitive rather than supporting the null hypothesis. Despite failing to find evidence of a significant association, there was moderate evidence from the Bayes factor calculation that the item "changes in measured theory-relevant constructs or predictor" is associated with intervention effectiveness, which warrants further investigation. The adjusted model included three TCS covariates from the unadjusted models, and two of these had significant associations, though these results are difficult to interpret in the absence of significant results in the unadjusted models and that the pattern of results is not robust to standardized effect sizes.

Comparison With Prior Work

The findings from this study differ from another recent review of studies assessing the association between theory use and effectiveness of computer-delivered alcohol interventions in the general population rather than our population of those with excessive or problematic drinking [14]. This difference is probably because of the different sample of studies included in each review: this review searched more databases though excluded a greater number of studies (eg, if follow-up was less than 1 month or participants were not screened and so not necessarily a hazardous or harmful drinker). This resulted in both reviews including unique studies as well as some common to both reviews. Another potential reason for the difference in findings is the way in which the TCS was used. In this review, all of the items relating to the reporting of theory use in intervention development and evaluation were used (excluding two relating to methodological issues), whereas in the Black et al review [14], only items relating to intervention development and participant selection (the first 11 items) were used.

Limitations

Our results should be treated cautiously as the majority of null findings were insensitive to distinguish an effect, and the meta-regression was underpowered, which is a function of the available literature and methodology. However, it is important to have a starting point for collating evidence, and this meta-analysis can be updated as new literature emerges. It is estimated that more than 200 studies are required for 80% power to detect modest associations [45]. Once this level of power is reached, then additional analyses investigating associations between type of theory and intervention effectiveness may be insightful. A limitation of meta-regressions is that study characteristics can be highly correlated, which causes issues with multicollinearity [50]. However, in the adjusted model, the variance inflation factor statistics were less than three for each covariate, indicating that multicollinearity was not a major issue.

The composite scores calculated were crude measures that gave all items in the TCS equal weight, so were not necessarily the most accurate representation. However, the methodology used was the best tool currently available for assessing the reporting of theory use and quantifying its extent.

A limitation of the available literature was that only the *reporting* of theory use could be coded. This makes our findings difficult to interpret, as a lack of reporting of theory use in the published study does not necessarily equate to a lack of use of theory. Therefore, any inconsistent reporting of theory use between studies could have led to misclassification of studies, which cannot be accounted for. Future research could assess whether authors of the published studies code their studies using the TCS differently and whether this is associated with intervention effectiveness. This highlights the need for improvement in the way in which theory use is currently reported. The TCS can also be used as a checklist for researchers to use when reporting how theory was used, which would clarify whether theory had not been used or not been reported, and could be included as supplementary material alongside the trial evaluation paper. As the literature grows, a future meta-analysis including a larger number of studies should assess whether study characteristics moderate associations between theory use and intervention effectiveness.

Future Research

A large number of behavior change theories exist [15], but only a relatively small number were used. The transtheoretical model

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was one of the most frequently used, despite lacking empirical support [51]. An absence of studies using their results to refine theories and, therefore, contribute to theory development was identified. Current behavior change theories are mainly based on limited static measures. Future research could study whether the development of digital interventions is better suited to dynamic, temporally sensitive theories [52]. The evaluation of digital interventions could help to develop this type of theory: the underpinning technology can often collect comprehensive data reflecting an individual's behavior over time and in different settings and contexts [52-54].

Conclusions

In sum, a lack of evidence was found that the reporting of theory use was associated with the substantial heterogeneity in effect between digital interventions for alcohol reduction. Limitations render the data and literature insensitive to answer the more general and important question of whether systematic use of a good and appropriate theory improves intervention effectiveness. Digital interventions provide an excellent opportunity to improve our understanding of behavior and, therefore, to develop dynamic, temporally sensitive behavior change theories [52-54]. However, no existing studies reported using their results to refine theory. This paper highlights the need for clearer selection, application, and reporting of theory use in the development and evaluation of digital behavior change interventions.

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Conflicts of Interest

CG, DC, JB, and SM are currently working on the development and evaluation of an app to reduce excessive alcohol consumption—they have registered the trial though not yet published results. EB and JB have received unrestricted research grants from Pfizer relating to smoking cessation. EK, FB, and CM are authors on a related Cochrane review [46]. EK is a senior scientist in the NIHR School of Primary Care Research and is an investigator on an on-going SIPS Junior trial (NIHR program grant number NIHR RP-PG-0609-10162), which will have an app component in one arm of the trial. MH, FdV, and JR have no interests to declare.

Multimedia Appendix 1

References to studies included in meta-regression (reproduced from the main Cochrane review).

[PDF File (Adobe PDF File), 31KB - jmir_v20i2e69_app1.pdf]

Multimedia Appendix 2

Matrix of which theories mentioned (item 1) for each study (n=21).

[PDF File (Adobe PDF File), 55KB - jmir_v20i2e69_app2.pdf]

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Abbreviations

AUDIT: Alcohol Use Disorders Identification Test
BF: Bayes factor
IRR: interrater reliability
PABAK: prevalence-adjusted bias-adjusted kappa
TCS: theory coding scheme

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Original Paper

Patient-Reported Measures for Person-Centered Coordinated Care: A Comparative Domain Map and Web-Based Compendium for Supporting Policy Development and Implementation

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Abstract

Background: Patient-reported measure (PRM) questionnaires were originally used in research to measure outcomes of intervention studies. They have now evolved into a diverse family of tools measuring a range of constructs including quality of life and experiences of care. Current health and social care policy increasingly advocates their use for embedding the patient voice into service redesign through new models of care such as person-centered coordinated care (P3C). If chosen carefully and used efficiently, these tools can help improve care delivery through a variety of novel ways, including system-level feedback for health care management and commissioning. Support and guidance on how to use these tools would be critical to achieve these goals.

Objective: The objective of this study was to develop evidence-based guidance and support for the use of P3C-PRMs in health and social care policy through identification of PRMs that can be used to enhance the development of P3C, mapping P3C-PRMs against an existing model of domains of P3C, and integration and organization of the information in a user-friendly Web-based database.

Methods: A pragmatic approach was used for the systematic identification of candidate P3C-PRMs, which aimed at balancing comprehensiveness and feasibility. This utilized a number of resources, including existing compendiums, peer-reviewed and gray literature (using a flexible search strategy), and stakeholder engagement (which included guidance for relevant clinical areas). A subset of those candidate measures (meeting prespecified eligibility criteria) was then mapped against a theoretical model of P3C, facilitating classification of the construct being measured and the subsequent generation of shortlists for generic P3C measures, specific aspects of P3C (eg, communication or decision making), and condition-specific measures (eg, diabetes, cancer) in priority areas, as highlighted by stakeholders.

Results: In total, 328 P3C-PRMs were identified, which were used to populate a freely available Web-based database. Of these, 63 P3C-PRMs met the eligibility criteria for shortlisting and were classified according to their measurement constructs and mapped against the theoretical P3C model. We identified tools with the best coverage of P3C, thereby providing evidence of their content validity as outcome measures for new models of care. Transitions and medications were 2 areas currently poorly covered by existing measures. All the information is currently available at a user-friendly web-based portal (p3c.org.uk), which

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includes all relevant information on each measure, such as the constructs targeted and links to relevant literature, in addition to shortlists according to relevant constructs.

Conclusions: A detailed compendium of P3C-PRMs has been developed using a pragmatic systematic approach supported by stakeholder engagement. Our user-friendly suite of tools is designed to act as a portal to the world of PRMs for P3C, and have utility for a broad audience, including (but not limited to) health care commissioners, managers, and researchers.

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KEYWORDS

patient reported outcome measures; quality of life

Introduction

Person-Centered Coordinated Care

Person-centered coordinated care (P3C) is at the nexus of 2 constructs: person-centered care [1] and care coordination [2]. It is a complex intervention with defined philosophical principles based on the individual's right to self-determination [3-5] and collaborative approaches to care planning with patients [6]. Although it is perceived to be at the center of many new models of care in the United Kingdom, few (if any) services have a comprehensive understanding of what it is and how to implement it [7]. It can be defined as: "Care and support that is guided by and organised effectively around the needs and preferences of individuals."

Five core domains of P3C have been previously identified: (1) information and communication, (2) care planning, (3) transitions, (4) patient-defined goals or outcomes, and (5) shared decision-making, as well as a number of further subdomains and component activities that are required for implementation [8]. It is a model that shares many similarities with the independent conclusions of others [9-11].

Patient-Reported Measures

Patient-reported measures (PRMs) are questionnaires that probe individual patient perspectives on a range of health and health-related experiences and outcomes. A full list of PRMs covered by this study (including names and abbreviated names) is included in Multimedia Appendices 1 and 2.

Patient-Reported Measures as Research Tools for Establishing Person-Centered Coordinated Care

The initial development of PRMs was largely driven by research [12], where patient-reported outcome measures (PROMs) were used to measure patient-reported symptoms, health status, functional status quality of life (QoL), or health-related quality of life in studies aiming at quantifying burden of disease on the impact of specific interventions. They are now also deployed in a variety of novel contexts, including clinical practice, quality improvement initiatives, and system-level feedback for health care management and commissioning [13]. This reflects an increasing emphasis from policy makers to utilize such measures for providing information about "how patients feel" [14] about the services they use and the interventions they are provided with.

Patient-reported experience measures (PREMs) are (in contrast to PROMs) tools for measuring patients' experiences of care. Such measures have diversified into a large family of tools often covering core aspects of P3C, such as patient-practitioner communication, shared decision-making, and patient activation. We, thus, define a further category PRMs as *P3C-PRMS*, where aspects of P3C may be measured by experiences, processes, or health-related status.

Studies have established that person-centered approaches can reduce health care costs or lower use of health care services [15-17], with over half of P3C studies utilizing some form of PRM for evaluation [5,18-22]. Such findings have led to the increasing support for approaches such as self-management and patient activation in chronic conditions [23-25], which is one of the underpinning principles of chronic disease management in the United Kingdom and a continuing policy aim [26]. Such trends in policy and academic landscape are reflected internationally [27-29], including the US model of patient-centered medical homes [30].

Patient-Reported Measures as Clinical Tools for Person-Centered Coordinated Care

More recently, PRMs (particularly PROMs) have become integrated into some areas of clinical practice [31]. In particular, oncology [32-34] and psychiatry [35,36] (with the advantages of a single clinical environment) have pioneered the use of PRMs for formalized feedback in routine clinical settings. A consistent finding is that PRMs can improve communication between the patient and the practitioner [32,33,37,38] and can result in a better quality and experience of care (particularly on processes) [34,37,39-44]. One systematic review reported that routine use of PROMs had an impact on the process of care in 65% of studies [44,45] and an impact on outcomes of care in 47% of studies [44,45].

Patient-Reported Measures as System-Level Feedback for New Models of Care

PRMs are increasingly being utilized for system-level feedback for health care management, system auditing, and commissioning processes. This has largely been driven by the need for new service delivery models to cope with the demands of an ageing population with multiple long-term conditions (MLTCs), which has been called "the greatest challenge facing health systems around the world today" [21]. Patients with MLTCs may require an individualized approach to the delivery of health care as standard single disease guidelines and pathways appear ill-suited to improving relevant outcomes for this group [46-48]. PRMs provide a mechanism to systematically measure experiences and outcomes, which may be well aligned with the specific needs of these patients.

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Such challenges are recognized by the policy landscape, which increasingly emphasizes person-centered approaches, often envisaged to be implemented in a systematic manner via the use of PRMs. For instance, in the United Kingdom, *Equity and Excellence: Liberating the NHS* [14] emphasized quality and patient involvement in decision making, committing to increase the use of PROMs. In 2014, the NHS (National Health Service) "five year forward view" highlighted how new models of care would become "more tailored to the individual," and how "personalised care will only happen when statutory services recognise that patients' own life goals are what count; that services need to support families, carers and communities; that promoting well-being and independence need to be the key outcomes of care; and that patients, their families and carers are often 'experts by experience'."

Such policy shifts have mirrored developments in the United States, where as early as 2001, the Institute of Medicine published its globally influential work *A New Health System for the 21st Century*, where one aim was a patient-centered system to drive forward improvements in health care quality [27]. More recently, Accountable Care Organizations (ACOs) [28,29] have been compared with the five-year forward view, and feedback of patient experience has been defined as one of the fundamental building blocks of high-performing primary care [49].

However, the use of PRMs for system-level aggregation is relatively new and faces novel challenges, with large-scale national surveys often being implemented to address the needs of policymakers— for example, particularly targeting accountability and transparency [50]. However, it has been argued that there is a "chasm" between the views of senior managers and clinicians at the front line [51]. Schemes have been criticized for survey length, being too generic and not focused at those who could most benefit from improvements in care, infrequent sampling frequency, slow feedback, and failure to use results to improve care [52], in addition to methodological problems and the difficulty of effectively using the data to actually improve care [52-55]. For example, the NHS Friends and Family Test (a single, global question of patient experience, essentially: "Would you recommend this service to friends and family?") has been criticized as unsuitable as a comparator across organizations or as a basis for incentive payments [53]. The incentivization of PROMs for depression under the Quality and Outcomes Framework (a United Kingdom-based payment and performance management scheme for general practice) was quickly withdrawn after widespread criticism [55,56]. Other schemes—such as mandatory PROs for surgical procedures—have at least established that PRMs can be routinely collected and provide meaningful data [57-62].

At present, there is very little evidence that these tools can drive improvements in quality of care when used at a system level [34,63,64]. Despite the lack of evidence, health care is on a policy-driven trajectory that is placing an increasing emphasis on the use of PRM for system-level feedback. For instance, in the United Kingdom, this has been reflected in a number of national initiatives, where PRMs have been used as system-level monitoring tools in schemes such as the Vanguards and Better Care Funds (BCFs), often targeting patient groups such as older adults or those with long-term conditions (LTCs). However, many of these schemes are at early or pilot stages, and there is frequently a lack of agreement about what core outcome measures might be appropriate for new models of care. The use of these tools in novel contexts will require signposting, guidance, and clarity to a new range of stakeholders. This should include information on not only what existing measures are available but also associated information such as what they measure, references, the contexts in which they have been used, and the degree of psychometric validation.

The research reported in this paper was performed to address some of these shortcomings. We performed the following activities: (1) we constructed a user-friendly Web-based guidance portal (or "compendium") of PRMS (p3c.org.uk); (2) next, for a targeted subset of these measures, we developed a "domain map" of measures that can be used to implement and measure P3C; (3) from this, we generated "short-lists" of measures according to specific categories; and (4) finally, we constructed an item-list from the mapped measures. Our user-friendly suite of tools is designed to act as a portal to the world of PRMs for P3C, and have utility for a broad audience, including (but not limited to) health care commissioners, managers, and researchers, thus allowing various stakeholders to rapidly identify measures that cover target domains of P3C.

Methods

An overview of our identification, selection, and shortlisting process is presented in Figure 1 and explained in detail below.

Identification of Relevant Measures

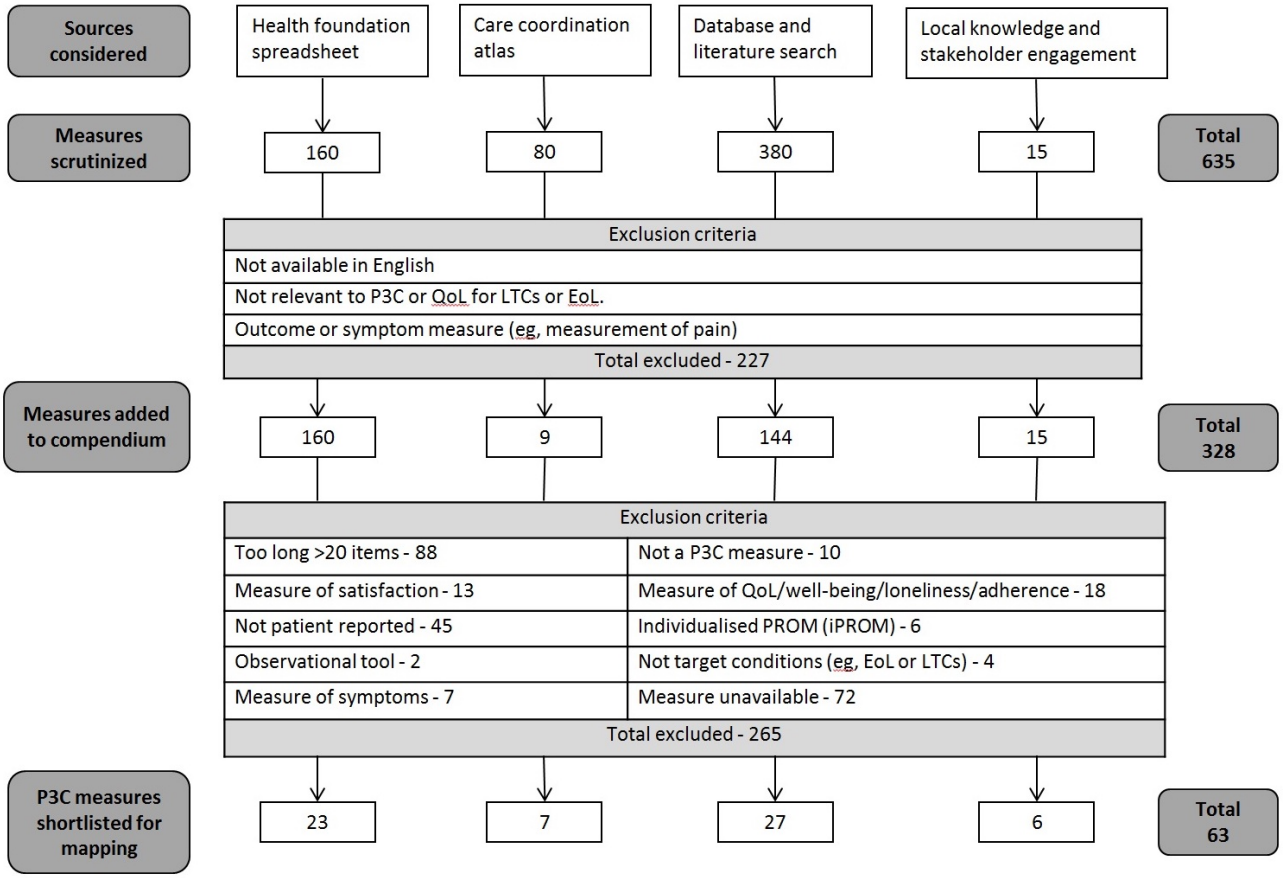
We considered 2 broad categories of measures for inclusion into the Web-based compendium. These were PRMs targeting P3C (P3C-PRMs) and QoL measures.

QoL measures were deemed a desirable addition to the dataset for the target audience of the compendium as QoL is often a target outcome of P3C interventions, many of the contexts in which P3C measures are used (eg, evaluation of P3C interventions) often also measure QoL [65], some studies have established correlations between person-centeredness and QoL [66], and policy guidance for person-centered interventions often includes QoL measures [67]. Furthermore, in the context of chronic illness where curative outcomes are not possible, there is an ethical imperative for health and social interventions to either maintain or improve people's QoL.

As shown in Figure 1, the initial data source was the existing spreadsheet published in The Health Foundation's document *Helping Measure Person-Centered Care* [65]. The subsequent sources represent new measures that were discovered *in addition* to The Health Foundation's comprehensive scan. See Multimedia Appendix 1 for full list of data sources and shortlisting criteria.

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Figure 1. Overview of the identification, selection, and shortlisting process. P3C: Person-centered coordinated care; QoL: quality of life; LTC: long-term condition; EoL: end of life.



Due to the complexity and fragmentary nature of the existing data sources, complementary strategies were required and several data sources were interrogated to identify a broad list of candidate measures (see Figure 1). These sources were subjected to an initial "first screen," and included if they were available in the English language and if they measured the construct of interest (P3C or QoL) for LTCs or end of life (EoL) (eg, first set of exclusion criteria in Figure 1). We rejected all non-native English measures, and our work makes the pragmatic assumption that all English-language instruments (eg, United States, United Kingdom, etc) are comparable (however, the compendium does retain information concerning country-of-origin). Measures that were health outcome or symptom measures (eg, measurement of pain) were also rejected. We examined the following sources.

Existing Compendiums and Lists of Measures

A recent study identified that there are more than 200 named and validated tools available for person-centered care alone [65], with a large number of tools that have only been validated in a single study. The Health Foundation's evidence review, "helping measure person-centered care," provided details of the most commonly researched person-centered measurement tools for person-centered care (see [65]). Given the availability of this resource, we initiated our search for P3C-PRMs with existing compendiums. Our initial list was seeded with 160 measures from The Health Foundation's list and 80 measures from the Care Coordination Atlas [68] (see Figure 1).

Literature Search

In contrast to P3C-PRMs (which often represent recent constructs developed under new models of care and are therefore often represented by a single, recent publication), many QoL measures (eg, EuroQoL-5D and short-form health survey) have often been subjected to rigorous validation in a large number of publications and subsequently subjected to head-to-head comparisons in a number of systematic reviews. We therefore used a review-of-reviews approach to identify QoL measures for the compendium (although these QoL measures were not included in the mapping procedure; see the section on short-listing of measures for mapping). These literature screens also identified several additional P3C-PRMs, and those that passed our screening criteria were added to our candidate list for domain mapping.

We limited our literature database search to Pubmed. Two groups of search terms were utilized—the first for QoL measures, and the second for P3C-related measures (Textbox 1). Due to the volume of literature, group 1 search term was limited to reviews over the last 2 years (as of March 2016). The search yielded 311 papers for review. Next, group 1 and group 2 search terms were combined for all papers (ie, not limited to reviews) for the last 2 years (as of March 2016). This produced 461 papers for review.

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Textbox 1. Search terms used in the Pubmed database.

Group 1 search terms (terms for measures): (PROM OR "Patient Reported Outcome" OR PREM OR "Patient Reported Experience" OR PCOM OR "Patient Centered Outcome Measure" OR "Patient Centered Outcome Measures")

Group 2 search terms (terms for P3C); an expanded list from [10]: ("Patient Centered" OR "Person Centered" OR "Patient Centered" OR "Person Centered" OR "Patient Co-Ordinated" OR "Patient coordinated" OR "Integrated care" OR "Shared decision" OR "Self Management" OR "Family centered" OR "Family centered" OR "Patient engagement" OR "Patient empowerment" OR "Patient activation" OR "Care Planning" OR "Goal Setting" OR "Client centered" OR "Client centered" OR "Family centered" OR "Family centered" OR "Patient centric" OR "Patient centered" OR "Patient centered")

We supplemented these literature searches with existing literature resources and databases that specifically comprise comparison of various PRMs:

1. "Consensus-based Standards for the selection of health Measurement Instruments" (COSMIN online database of references [69] (435 articles)
2. Papers that referenced "Terwee criteria" for measurement properties [70] (422 articles)
3. Papers that referenced EMPRO (evaluating measures of patient-reported outcomes), a tool for the standardized assessment of PROMs [71] (18 articles)
4. The Oxford PROMs group systematic reviews of PROMs for LTCs [72] (15 articles)

In total, 830 articles were screened from the literature searches, of which 130 were clearly identified (from the abstract) as covering measures with a relevant construct (eg, English-language QoL or P3C measures for LTCs and EoL). From these relevant articles, 380 measures were identified, of which 144 new measures fulfilled our inclusion criteria and were added to the compendium (236 rejected) (Figure 1).

Stakeholder Engagement

With the rapid, ongoing development of new models of care, we utilized local knowledge and relevant stakeholder engagement to identify further measures. A total of 15 further measures were identified in this manner.

Overall, a total of 328 relevant P3C-PRMs and QoL measures were identified from the above sources and added to the compendium). Please refer to Figure 1 for an overview of the data sources and shortlisting process and the spreadsheet in Multimedia Appendix 1 for full details of data sources and the shortlisting process. It should be noted that our website has additional measures beyond those included in this publication, for example, as it is not a static resource and also includes some measures represented with multiple versions.

Short List of Person-Centered Coordinated Care-Patient-Reported Measure for Domain Map: Inclusion and Exclusion Criteria

After identification of P3C-PRMs and QoL measures with which to populate our compendium, we created a "map" of how items from the P3C-PRMs mapped to components of our model for P3C. We targeted measures that were concise and suitable for people with LTCs, MLTCs and for those at EoL.

As a first step, we applied a second set of inclusion and exclusion criteria to the identified PRMs in our compendium to produce a short list of P3C-PRMs. Our goal was to produce a list of P3C-PRMs that were succinct, did not measure patient satisfaction, and were suitable for use with people with LTCs or EoL. Our exclusion criteria to identify measures for the mapping exercise were as follows:

- *Short measures—less than 20 items (with some pragmatic exceptions):* We preferred short measures, as these are necessary to attain satisfactory response rates and reduce responder burden (especially with our specified target population of MLTCs and EoL), but also to ensure utility for routine health-service use.
- *Instruments were not measures of patient satisfaction*: Patient satisfaction is a widely criticized construct that is known to produce biased responses [73].
- *Patient-reported measures*: Measures that are patient-reported logically adhere to principles of patient-centered care. Furthermore, evidence also suggests that PRMs are more successful at predicting outcomes than either observations or physicians-reported measures [74,75]. However, in certain contexts (dementia; EoL), proxy measures (ie, measures completed by family member or professional) are unavoidable, and were therefore retained for shortlisting in these contexts.
- *Instruments were not measures of QoL, well-being, loneliness, or adherence:* Although our Web-based compendium does include QoL measures, these are not designed to measure aspects of P3C and cannot therefore be included in our mapping exercise.
- *Instruments were not individualized PROMs:* Individualized PROMs [76] such as the Person Generated Index [77] allow patients to modify the content or scoring system, prioritizing the symptoms to address [78]. Such patient empowerment is particularly salient to complex scenarios such as MLTCs [79]. However, this flexibility means that they cannot be mapped against domains of P3C.
- *Instruments were of utility for our disease-specific criteria (eg, LTC, EoL):* If instruments were specific to a condition that was not an LTC, they were excluded.
- *Measures were available to map*: Although we made best efforts to obtain copies of all target measures (eg, via references, Web searches and contacting authors), for many target measures, we could not obtain a copy of the measure, and they could not therefore be mapped.

Table 1 below describes the exclusion criteria used for the shortlisting process for P3C-PRMs. In total, 63 P3C-PRMs fulfilled our inclusion criteria and were shortlisted for the process of mapping (Figure 1; see Multimedia Appendix 1 for details).

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Table 1. Exclusion criteria and number of measures rejected from mapping procedure. Patient-reported measures included in compendium (N=328) underwent second set of inclusion and exclusion criteria.

Exclusion criteria	Number excluded (n=265)
Too long; generally >20 items	88
Measure unavailable	72
Not patient reported	45
Measure of QoL[a], well-being, loneliness, or adherence	18
Measure of satisfaction	13
Not a P3C[b] measure	10
Measure of symptoms	7
Individualized patient-reported outcome measures[c]	6
Not target conditions (eg, EoL[d] or LTCs[e])	4
Observational tool	2

[a]QoL: quality of life.

[b]P3C: person-centered coordinated care

[c]Although "individualized patient-reported outcome measures" are inherently person-centered, domains are specified by patient and therefore cannot be mapped to the P3C model.

[d]EoL: end of life.

[e]LTCs: long-term conditions

Domain Mapping of Measures for Person-Centered Coordinated Care

The selection criteria identified 63 candidate measures for P3C. Although standardized systems designed for head-to-head evaluation of instruments (such as EMPRO and COSMIN [69]) do exist, such methods are not appropriate in this context because (1) a wide diversity of instruments measure a range of overlapping constructs and (2) many instruments are only supported by a single validation paper.

As the aim of this work is to provide guidance to support the measurement and development of P3C through the use of PRMs, we instead assessed the shortlisted measures against a framework based on our model of P3C. This allowed us to construct a map of the questionnaires, allowing us to rapidly identify how various measures corresponded to components or constructs of person-centered approaches.

Our model of P3C was developed from our previous work including literature scoping and stakeholder engagement and contains all relevant domains of P3C [8]. It corresponds closely to well-accepted definitions of person-centered care such as the House of Care [11] and the National Voices "I" statements [9]. The model utilized in this paper includes the following primary domains (in addition to secondary domains; see Multimedia Appendix 2 for a full list of domains):

1. My goals and outcomes
2. Care planning
3. Transitions
4. Decision making
5. Information and Communication
6. Medication

Two researches (HW and JH) independently assigned each item on the questionnaire to domains that were derived from our model of P3C. Any inconsistencies in assignment between the 2 researchers were cross-checked and synchronized.

The final domain (medication) was not present within our previous model of P3C. However, it was represented with reasonable frequency across the items within the instruments that we mapped, and was therefore included as an additional domain for the purposes of this work. Mapping data for all instruments are provided in Multimedia Appendix 2.

Results

Domain Mapping of Person-Centered Coordinated Care Measures

In total, 855 items from the 63 shortlisted measures were mapped against our domain model of P3C. Multimedia Appendix 4 presents a summary of this domain mapping procedure, providing the number of items on each measure that map to specific domains of P3C. Multimedia Appendix 2 contains a full table of every item that maps to a domains or subdomain of P3C. The results are also graphically summarized in Figure 2.

Figure 2 and Multimedia Appendix 4 reveal that although Information and Communication (56.6%, 484/855) and Goals and Outcomes (31.69%, 271/855) are well covered by existing instruments, Care Planning (20.7%, 177/855) and Decision Making (17.2%, 147/855) are not as comprehensively covered. Only 17 items (2.0%, 17/855) were categorized as dealing with Transitions/Continuity of Care. However, transitions and care continuity have been recognized as a frequently problematic area of care coordination [9]. Future research and development of new (and existing) measures should be directed at addressing

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this limitation of existing instruments. Similarly, Medication (which has not been traditionally considered a domain of P3C) was only included in 35 items (4.1%, 35/855), with polypharmacy having been highlighted as a particular issue in the management of MLTCs [80].

Multimedia Appendix 4 displays the number of items that correspond to each domain (n) and the percentage (of the total) of items that map to this domain. These percentages are useful to identify the overall "balance" of a measure, that is, how heavily it corresponds to single or multiple domains.

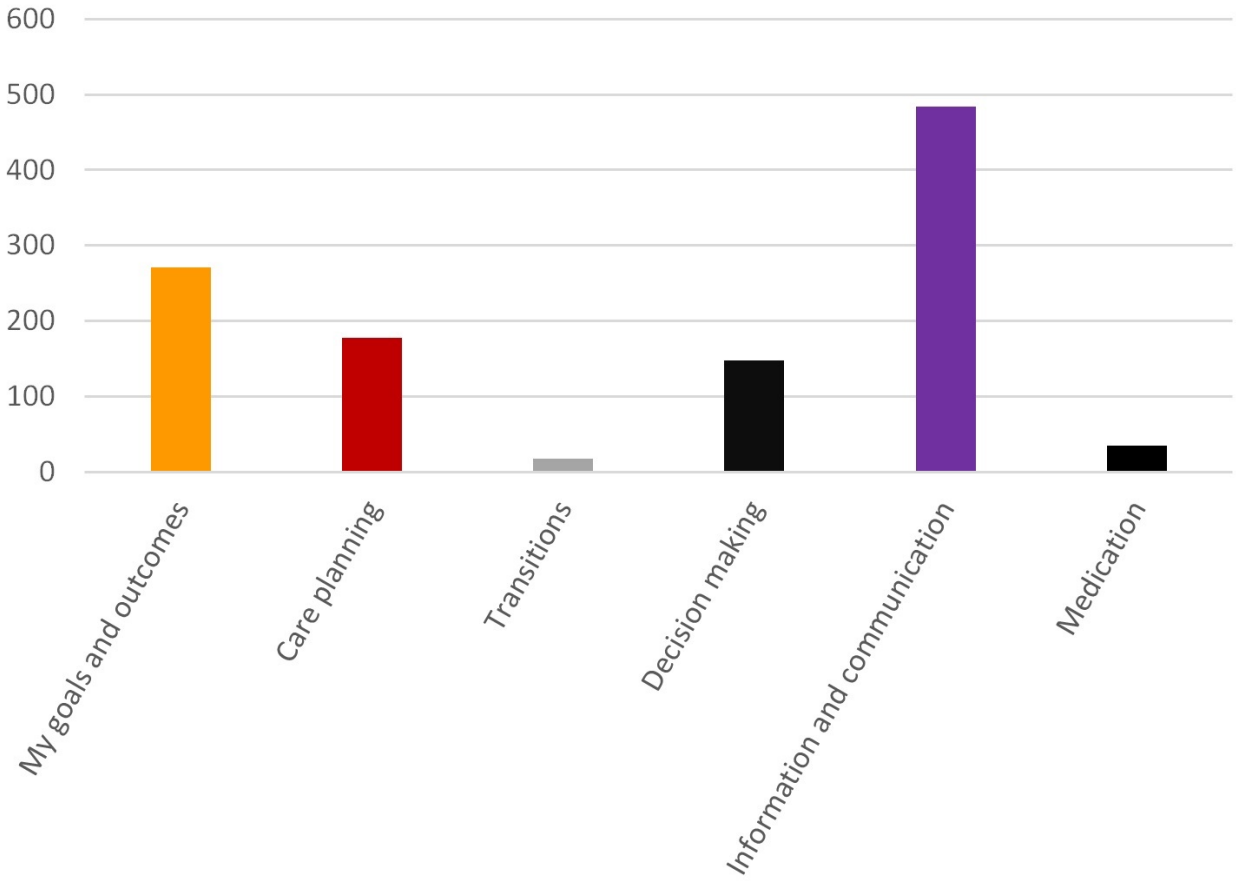
Pragmatic Shortlists

We also created shortlists of PRMs for P3C and QoL (available on our website p3c.org.uk/shortlist) to simplify, categorize, and signpost to the key entries in our dataset. These shortlists were developed via engagement with key stakeholders (NHS England, patients, commissioners, and professionals), where we defined 2 categories of shortlists: (1) according to domains of P3C, including measures that have good coverage of all domains, and (2) disease/age-specific categories (diabetes, cancer, psychiatry, stroke, heart failure, Parkinson's, older people, dementia, and EoL).

These disease-specific categories include both the relevant measures of P3C for the specified condition and the measures of QoL that have been well-validated for the specified condition (see Methods section for the rationale for including QoL measures). The shortlisting of measures proceeded on the following principle: for QoL measures, there are generally a small number of well-used and validated measures (eg, EuroQoL-5D and short-form health survey), which are frequently included in systematic reviews. Therefore, these measures were selected on the basis of systematically reviewed psychometric properties (see references on website for details).

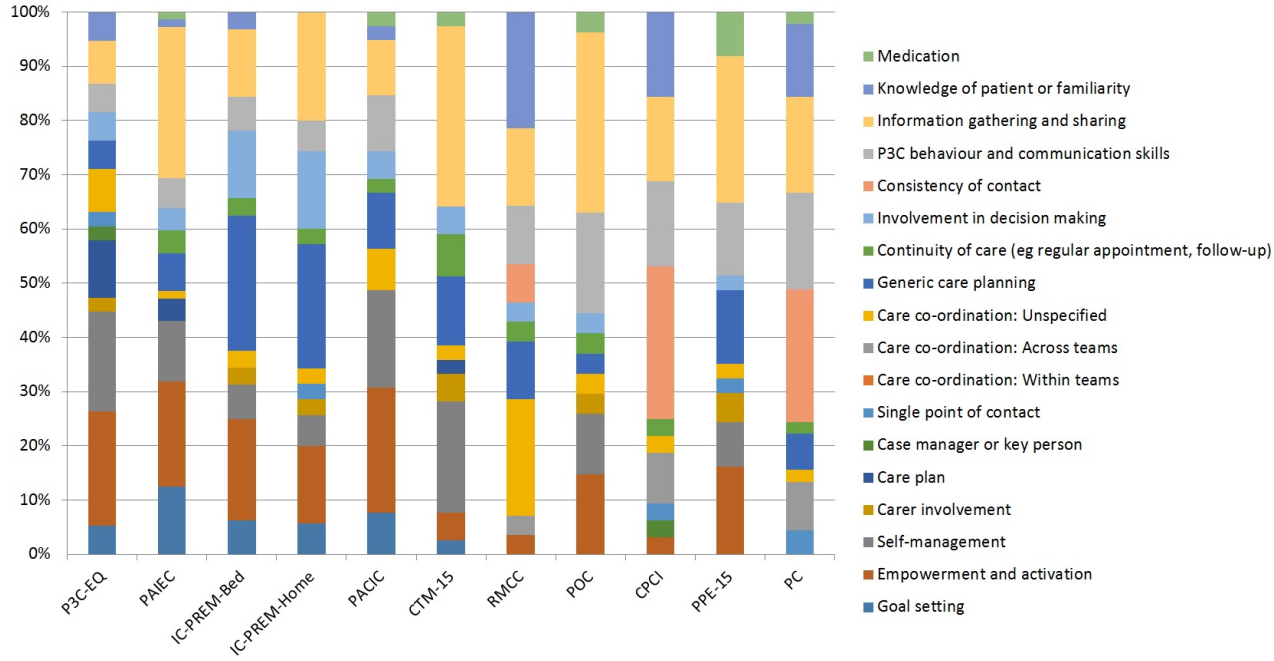
However, for measures of P3C, these were often newly developed or infrequently included within systematic reviews. Comparisons between the various measures are usually inappropriate due to the heterogeneous nature of the tools, and there is insufficient evidence to recommend one survey tool over another [65]. Thus, we instead shortlisted based on a range of pragmatic criteria. We utilized our domain map to identify measures that covered each of the 6 domains of P3C. We also preferred measures that had reasonable psychometric properties, had been codesigned with patients, and had been developed according to recent constructs of P3C. Finally, we also took into account the context (hospital, primary care, nursing home or rehabilitation); whether patients, staff, or both are the target; the preferred length or number of survey items; and whether the focus is on the broad concept of P3C or a narrower subcomponent (such as communication or shared decision-making) [65]. These criteria allowed us to assign measures according to domains of P3C: generic measure; measures for goals and outcomes; care planning; transitions; decision making; and information and communication.

Figure 2. Number of items from all instruments mapping to specific domains of person-centered coordinated care (P3C). The x-axis is the total number of items (over all 63 mapped instruments) that map to a domain of P3C (y-axis).



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Figure 3. Example domain map for 11 measures with broad domain coverage of person-centered coordinated care (P3C) (mapping to ten or more different subdomains of P3C), in order from the best coverage (on the left) to less broad coverage (on the right). P3C-EQ: person-centered coordinated experience questionnaire; PAIEC: patient assessment of integrated elderly care; IC-PREM-Bed: integrated care patient-reported measure, bed-based version; IC-PREM-Home: integrated care patient-reported measure, home-based version; PACIC: patient assessment of care for chronic conditions; CTM-15: care transitions measure, 15 item version; RMCC: relational and management continuity of care; POC: perceptions of care; CPCI: components of Primary Care Index; PPE-15: Picker Patient Experience Questionnaire; PC: patient perception of continuity instrument.



Measures With Broad Coverage of All Person-Centered Coordinated Care Domains

To identify measures with broad coverage of P3C, we identified the number of different subdomains of P3C that each measure mapped to (see Multimedia Appendix 2 and Multimedia Appendix 4 for details). In total, 11 measures mapped to at least 10 different subdomains of P3C of a possible 18, according to the criteria used in this publication (see Figure 3 and Multimedia Appendix 2 for full details). These were as follows: (1) the Person-Centered Coordinated Care Experience Questionnaire (P3C-EQ; 11 items; covers 13 subdomains of P3C), a recently developed measure designed to provide extensive coverage of the domains of P3C [81]; (2) the Patient Assessment of Integrated Elderly Care (PAIEC; 21 items; covers 12 subdomains of P3C), a recently modified version of the Patient Assessment of Care for Chronic Conditions (PACIC) specifically designed for older populations [82]; and (3) and (4) IC-PREM-Home and IC-PREM-Bed (both 15 items; covers 11 subdomains of P3C) are a pair of PREMs that have been designed specifically to evaluate the delivery of person-centered care for older people in intermediate care services [83]; (5) the Patient Assessment of Care for Chronic Conditions (PACIC; 20 items; covers 11 subdomains of P3C), a well-established tool for measuring patient experience of chronic illness care that is applicable in many settings [16]; (6) the Care Transition Measure (CTM-15; 15 items; covers 11 subdomains of P3C), cited as being the most widely used measure of care transition quality [84]; (7) the Relational and Management Continuity of Care (RMCC; 25 items; 10 subdomains of P3C) [85]; (8) Perceptions of care (POC; 21 items; 10 subdomains of P3C); (9) Components of Primary Care Index (CPCI; 20 items; 10 domains of P3C) [86]; (10) the Picker Patient Experience Questionnaire (PPE-15; 15 items; 10 subdomains of P3C), originally designed for use in inpatient care settings [87]; (11) and the Patient Perception of Continuity Instrument (PC; 23 items; 10 subdomains of P3C).

List of Person-Centered Coordinated Care Items and Questions

Our mapping exercise also facilitated the construction of database of specific questions (items) for P3C. This allows the user to search according to a domain (or subdomain) of P3C, and return all relevant items, including associated information such as originating instrument; type of scale; response options; and links to the measure and relevant page on the p3c.org.uk website. The item database can be interrogated via a spreadsheet contained in Multimedia Appendix 3. It is intended as a tool of particular utility in the identification of measures that correspond to specific domains, in addition to having utility in the generation of new measures.

Web-Based Database of Measures for Person-Centered Coordinated Care

We utilized our assembled database of measures to compile a free Web-based repository of measures for P3C, which includes both P3C-PRMs and QoL measures. All our data have been made publicly available, and include many more measures in addition to the list previously published by The Health Foundation [65]. Although the database of measures used for this paper (Multimedia Appendix 1) represents a static snapshot of measures (as of June 2016), the Web-based database is a flexible, extensible, and updated product, and includes a large number of instruments (333 at time of publication), many of

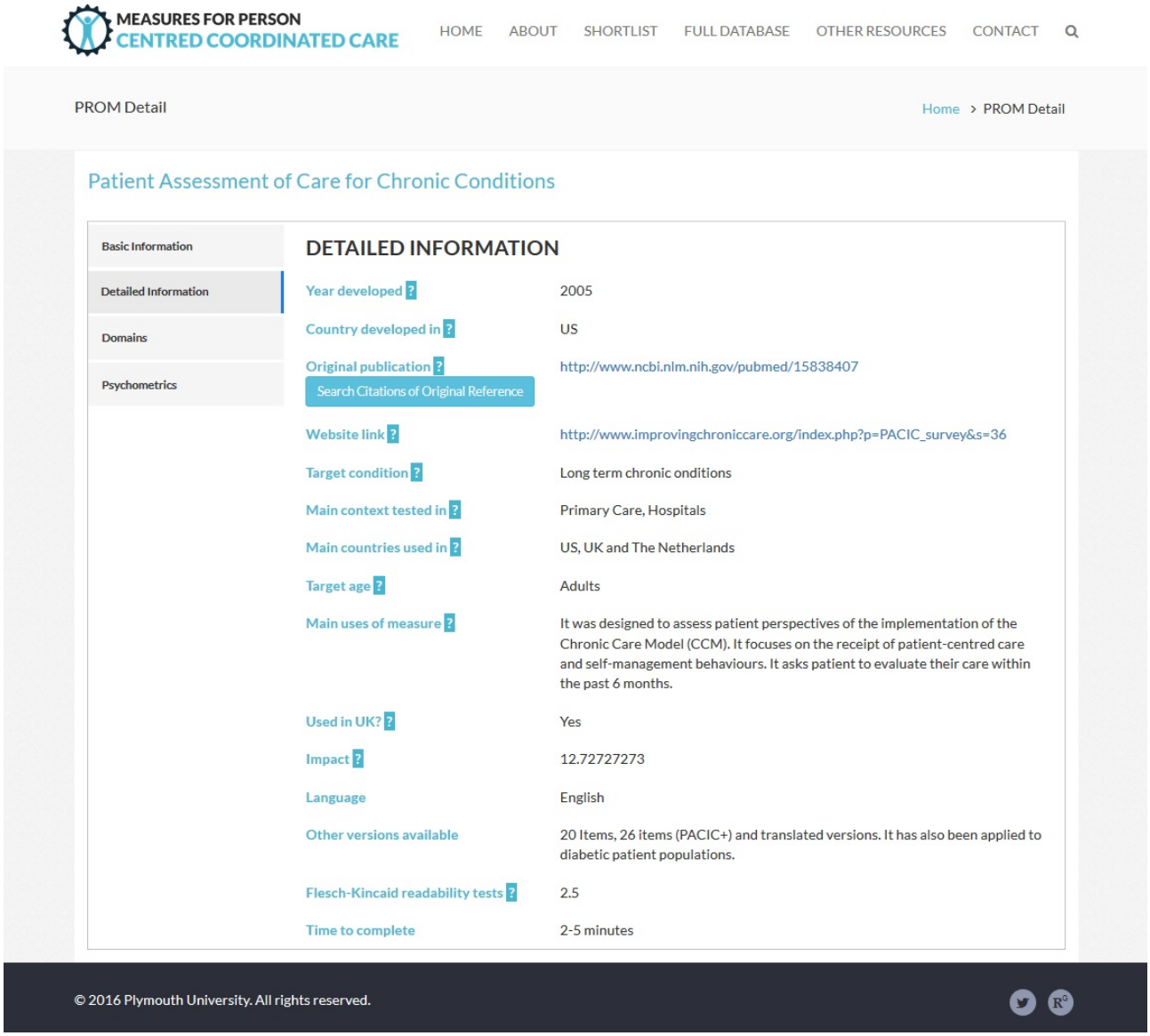
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which are not included in this paper (including multiple versions of instruments when these are available). In addition, it includes a wealth of supporting information (see Figures 4 and 5 for an example entry from the website). The supporting information includes the following details:

1. Basic information (name; abbreviated name; description; type of measure; respondent; licensing information and link; and link to the questionnaire).
2. Detailed information (year developed; country developed; link to original validation paper; a search tool for automated literature searches; and target conditions and age). It is worth noting that our database includes measures that originate from various international contexts (provided in the detailed information), and that validation or adaptation of measures may be required before they are deployed in novel contexts.
3. Domains of P3C or QoL that the instrument covers.
4. Psychometrics—either a description of psychometric properties or (where available) a graphical indication of the results of systematic review of the psychometric properties of the instrument.

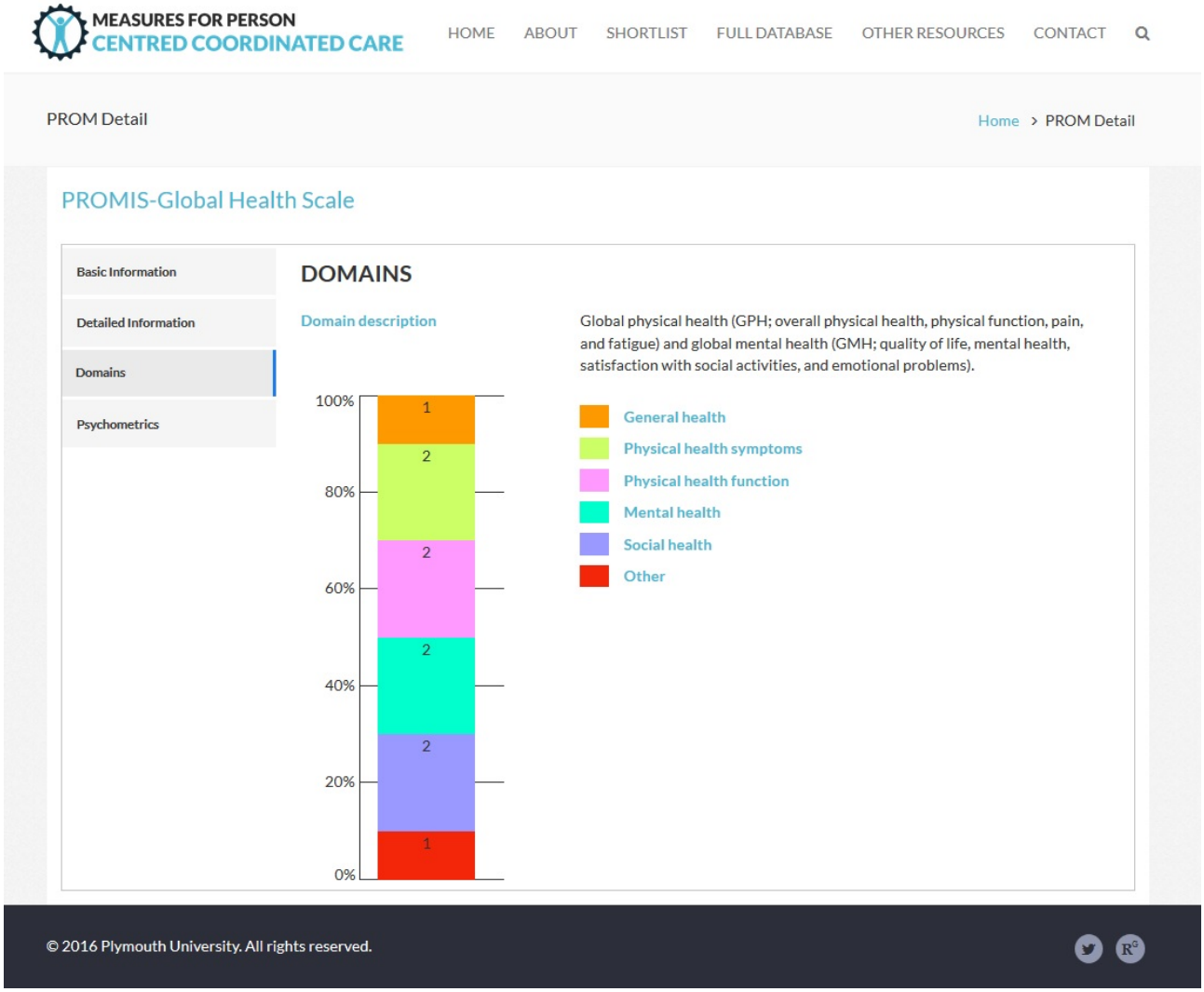
Because the full database was drawn from a wide diversity of sources, the Web-based database is uneven in the level of detail about PRMs. Generally, those that are well-validated measures have more complete information available.

Figure 4. Example entry from website.



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Figure 5. Example entry from website, showing domain mapping information.



Discussion

Principal Findings

PRMs are evolving into an increasingly diverse suite of tools that are now being utilized within a diversity of novel contexts, where it has recently been argued that “providers need more support and guidance” [88]. In response to such calls, the primary output of this work was a systematic characterization of PRMs with utility in the evaluation and delivery of P3C, including an Web-based portal of measures; a domain “map” of 63 shortlisted measures for P3C care, allowing for rapid identification of measures that cover target domains; generation of “short-lists” of measures according to specific categories; and the construction of an item-list from the mapped measures.

For such PRMs to be used to drive improvements in health or health care services, the logic of the intervention should be well understood, it should be codesigned with all relevant parties, and mechanisms of feedback should be appropriately designed to drive the desired change (while also avoiding undesired effects such as “tunnel vision”) [88]. In the area of person-centered care, such arguments may be particularly pertinent, where practitioners often mistakenly believe they are delivering person-centered care when they are not [89]. In this regard, our tools are accompanied by a detailed guidance document, which support the use of metrics to drive improvements [8]. This provides a detailed definition of P3C and guidance for implementation and development using quality improvement strategies with embedded metrics. It demonstrates how principles of person-centered care can be translated into actions through 4 core practice routines [3]: (1) establish the partnership by eliciting the a narrative, (2) agree and formulate a plan based on shared decision-making, (3) safeguard the plan in a document, and (4) coordinate the plan.

Linking process and outcomes of P3C to the 4 core practice routines described above provides a way in which to measure and support ongoing development of P3C by using measures that probe these areas. The compendium and comparative mapping work makes this linking possible. Furthermore, understanding the processes and outcomes in relation to these core practices will allow for the development of training and improvement strategies tailored to this framework, thus allowing practitioners to develop their understanding of P3C and focus on improving particular aspects of their practice. Each practice routine is important for this outcome, and this could be measured from the perspective of the patient using a number of generic tools (eg, person-centered coordinated experience questionnaire [P3CEQ], patient assessment of integrated elderly care [PAIEC],

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Patient Assessment of Care for Chronic Conditions [PACIC], Care Transitions Measure [CTM-15], etc) or instruments for a specific task (eg, instruments for shared decision-making such as CollaboRATE and SURE (Sure of myself, Understand information, Risk-benefit ratio, Encouragement).

Conclusions

Our tools are designed to help address a number of the above issues and have utility for a range of stakeholders. In particular, the Web-based database and pragmatic shortlists are designed to be a user-friendly front end that simplifies and signposts to a vast and complex literature. These tools act as a portal for health care professionals that may not have academic knowledge of PRMs (eg, health care managers and commissioners). Our tools enable rapid identification of suitable PRMs (eg, for a specific disease or concept), and thereby can help avoid the unnecessary development of new measures when suitable tools already exist. Furthermore, the website is an extensible, ongoing product and includes further measures and information beyond the context of this publication. Used along with our detailed guidance for commissioners [8], collectively these tools support the implementation and development of P3C. Furthermore, the tools are also designed to be of utility to researchers, with the Web-based database including features such as automated literature searches.

The domain map (Multimedia Appendix 2) establishes content validity for a number of instruments designed under new models of care (eg, P3C-EQ, IC-PREM-Bed, IC-PREM-Home and CTM-15), revealing that they do indeed cover more domains of P3C than other measures (as defined by our model, which is closely related to others) [9,11]. In fact, our recently developed measure, the P3C-EQ [81], has a broader coverage of aspects of P3C than any other measure we identified. Furthermore, the mapping exercise highlights potential shortfalls in the coverage of measures (especially transitions and care continuity). PRMs for holistic measurement for P3C are a relatively new concept, and the item map thus highlights how the future development and adaptation of measures could proceed (ie, *transitions and medication* and *polypharmacy* are currently underrepresented). Finally, the item database itself is a useful resource to aid in this ongoing development of improved measures.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Full list of data sources and shortlisting process.

[XLSX File (Microsoft Excel File), 333KB - jmir_v20i2e54_app1.xlsx]

Multimedia Appendix 2

Full mapping details.

[XLSX File (Microsoft Excel File), 47KB - jmir_v20i2e54_app2.xlsx]

Multimedia Appendix 3

Item list/database.

[XLSX File (Microsoft Excel File), 657KB - jmir_v20i2e54_app3.xlsx]

Multimedia Appendix 4

Results of mapping exercise for 63 person-centered coordinated care patient-reported measures.

[PDF File (Adobe PDF File), 262KB - jmir_v20i2e54_app4.pdf]

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Abbreviations

COSMIN: consensus-based standards for the selection of health measurement instruments
CTM-15: care transitions measure, 15-item version
EMPRO: evaluating measures of patient-reported outcomes
EoL: end of life
LTC: long-term condition
MLTCs: multiple long-term conditions
P3C: person-centered coordinated care
P3C-EQ: person-centered coordinated experience questionnaire
P3C-PRM: person-centered coordinated care patient-reported measure
PACIC: patient assessment of care for chronic conditions

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PAIEC: patient assessment of integrated elderly care
PREM: patient-reported experience measure
PRM: patient-reported measure (an umbrella term we utilize for all measures)
PROM: patient-reported outcome measure
QoL: quality of life

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Original Paper

Using Robots at Home to Support Patients With Chronic Obstructive Pulmonary Disease: Pilot Randomized Controlled Trial

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Abstract

Background: Socially assistive robots are being developed for patients to help manage chronic health conditions such as chronic obstructive pulmonary disease (COPD). Adherence to medication and availability of rehabilitation are suboptimal in this patient group, which increases the risk of hospitalization.

Objective: This pilot study aimed to investigate the effectiveness of a robot delivering telehealth care to increase adherence to medication and home rehabilitation, improve quality of life, and reduce hospital readmission compared with a standard care control group.

Methods: At discharge from hospital for a COPD admission, 60 patients were randomized to receive a robot at home for 4 months or to a control group. Number of hospitalization days for respiratory admissions over the 4-month study period was the primary outcome. Medication adherence, frequency of rehabilitation exercise, and quality of life were also assessed. Implementation interviews as well as benefit-cost analysis were conducted.

Results: Intention-to-treat and per protocol analyses showed no significant differences in the number of respiratory-related hospitalizations between groups. The intervention group was more adherent to their long-acting inhalers (mean number of prescribed puffs taken per day=48.5%) than the control group (mean 29.5%, P=.03, d=0.68) assessed via electronic recording. Self-reported adherence was also higher in the intervention group after controlling for covariates (P=.04). The intervention group increased their rehabilitation exercise frequency compared with the control group (mean difference −4.53, 95% CI −7.16 to −1.92). There were no significant differences in quality of life. Of the 25 patients who had the robot, 19 had favorable attitudes.

Conclusions: This pilot study suggests that a homecare robot can improve adherence to medication and increase exercise. Further research is needed with a larger sample size to further investigate effects on hospitalizations after improvements are made to the robots. The robots could be especially useful for patients struggling with adherence.

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Trial Registration: Australian New Zealand Clinical Trials Registry ACTRN12615000259549; http://www.anzctr.org.au (Archived by WebCite at http://www.webcitation.org/6whIjptLS)

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KEYWORDS

robotics; chronic obstructive pulmonary disease; hospitalization; medication adherence; telehealth; rehabilitation exercise

Introduction

Background

Chronic obstructive pulmonary disease (COPD) is a progressive respiratory disease that primarily involves airflow obstruction. The worldwide prevalence of COPD is around 10% in men and 6% in women, and it is projected to be the third leading cause of death by 2020 [1]. As the disease progresses, the frequency and severity of exacerbations increase. On average, patients are thought to experience around 3 exacerbations per year, with approximately 50% of these going unreported and untreated.

Treatment for COPD primarily involves medication and behavioral changes such as smoking cessation and exercise. Pulmonary rehabilitation (consisting of exercise, education, and support) can improve patient outcomes and reduce hospital admissions and health care costs [1]. Patients with moderate, severe, and very severe COPD benefit more from rehabilitation than patients with mild forms of the disease, and home-based programs are as effective as hospital-based programs [2]. Despite its benefits, the availability and uptake of rehabilitation programs are low [3,4].

There are several risk factors for COPD-related hospital admissions, including nonadherence to medication [5]. Medication adherence in COPD patients is around 50% and has been linked with better education, higher satisfaction with the patient-provider relationship, and less depression [6]. Hospital admissions for COPD exacerbations are expensive, with the average cost per admission in New Zealand (NZ) being around NZ $4800 [7]. More research is needed to work out ways to improve adherence and make home-based rehabilitation available for people with moderate to severe COPD.

Technological innovations, such as telephone-based interventions, are being increasingly used to help patients with chronic conditions manage their condition. However, there is little evidence for the effectiveness of many telehealth interventions. Although a review of 9 small studies of varying quality found that home telephone support and telemonitoring could reduce the rate of hospitalization and emergency department visits in COPD patients and increase patient satisfaction and quality of life, the review recommended larger higher-quality trials to be conducted [8]. A meta-analysis of 80 systematic reviews of telehealth care (3 of which were with COPD) found that mortality for COPD patients was not affected but hospitalizations were reduced and quality of life was increased; however, this review also recommended larger high-quality studies to be performed [9]. A large study of Home Telehealth tested with veterans in the United States reduced bed days of care by 25% and hospital admissions by 19%, but this was not a randomized trial [10]. Larger and more recent randomized trials have found that telehealth has no effects on hospitalizations or health-related quality of life in COPD patients compared with standard care, and more research is needed to identify subgroups who are most likely to benefit and into mechanisms behind any effects [11,12].

A new and emerging form of technology for delivering remote care is the socially assistive robot. Assistive robots are generally acceptable to people, and there is some evidence that they can improve loneliness and quality of life [13-16] and reduce costs in rural medical practice [17,18]. Due to their social presence, robots may engage people more with health interventions than other telehealth configurations. There is preliminary evidence that people have increased adherence to instructions from a robot than from a computer delivering health instructions [19,20]. However, there are no long-term randomized controlled trials investigating whether robots can improve adherence to medication and reduce hospitalizations in patient groups.

Aims

The aims of this pilot study were to provide data on the feasibility, clinical effectiveness, and cost-effectiveness of a robot delivering telehealth care to patients with COPD. The study was not powered to show effects. Older patients, people from rural areas, and Māori and Pacific peoples were targeted for recruitment in this study, because risk of readmission is higher for these groups [7]. This paper presents the primary outcome—that is, hospitalization—along with a cost-effectiveness analysis and the secondary outcomes of medication adherence and quality of life. The hypotheses were that the robot would reduce days of hospitalization, increase adherence, increase exercise, and improve quality of life compared with a control group.

Methods

Trial Design

A parallel randomized controlled trial was conducted. Patients were randomized using a 1:1 allocation ratio and stratified based on ethnicity and gender. The statistician (AP) generated the random number sequence using a randomization program and kept this in a separate location to the research team. The physiotherapists (NJ and VLO) recruited participants in hospital, and after collection of the baseline questionnaires, emailed the statistician with the gender and ethnicity of the participant to find out his/her group allocation. Participants were randomized to either receive a robot in their homes for 4 months in addition to standard care or to receive standard care alone. The physiotherapists informed each participant of their group allocation. Participants could not be blinded to group allocation.

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Ethics, Consent, and Permissions

Approval was obtained from the New Zealand Health and Disability Ethics Committees (Ref 14/NTA/229) and from Counties Manukau District Health Board Research Review Committee. Written informed consent was obtained from all participants.

Participants

Participants were recruited face to face from Middlemore Hospital (Counties Manukau District Health Board) at the time of discharge. Inclusion criteria were as follows: confirmed diagnosis of COPD, COPD-related admission, previous admission in past year, gets out of the house less than 4 times per week, living alone or with spouse who is also largely housebound, geographic rural location, poor social support, and aged between 16 and 90 years. All patients recruited into the study had preexisting lung function tests available in their medical record. All participants had a forced expiratory volume in 1 second (FEV_1)/forced vital capacity (FVC) ratio of <0.7, and 37% were classified as severe (30%<FEV_1<50% predicted) and 50% as very severe (FEV_1<30% predicted).

Exclusion criteria included elevated levels of NT-pro BNP (N-terminal pro b-type natriuretic peptide) and Troponin T, CURB-65 score>2 (CURB, *C* onfusion, blood *U* rea nitrogen>19 mg/dL, *R* espiration rate >30, *B* lood pressure<90 systolic blood pressure or <60 diastolic blood pressure, age >65) [21], on long-term oxygen therapy at time of admission (all of which predict an increased risk of dying within 30 days), incurable cancer, residence in rest home, and working. The study originally planned a 6-month intervention period and for recruitment to occur at 2 locations, but the period was shortened to 4 months and recruitment occurred at only one location because of logistical difficulties and a limited funding period. After consent was obtained, participants completed baseline questionnaires in hospital. The trial protocol can be accessed by emailing the corresponding author.

Intervention

The iRobi robot (Yujin Robot Limited, Korea) has previously been used for health care in retirement and rural settings in New Zealand [18,22]. For this trial, it was programmed to deliver COPD management consisting of several components guided by a clinical pathway. The overall program was designed to monitor health and prompt medical contact if health was deteriorating.

The detailed functions were as follows: (1) measure pulse oximetry, forced expiration volume, heart rate, and symptoms, mental state, and functional status using the Clinical COPD Questionnaire (CCQ) on a weekly basis [23]; (2) remind patients when to take medication and inhalers and record their adherence several times a day; (3) remind patients to do their rehabilitation exercises and display videos of a patient performing these at least twice weekly; (4) provide education about COPD via video modules and pop-up messages; (5) allow participants to use an *I am feeling unwell* function on demand; and (6) show trends over time of health status and adherence on its screen to the patient. The robot was integrated with Wi-Fi–linked Smartinhalers (Adherium, New Zealand) to monitor inhaler use. The data were sent to a secure Web server that managed all robot and patient data and logged all activities, with alerts if the measurements were out of range or patients were not adherent.

When the *I am feeling unwell* button was pressed, the robot asked whether or not the situation was an emergency. If yes, then the robot advised the participant to dial 111 (emergency services). If no, then the robot asked whether their current health concern was related to their COPD. If yes, then the robot initiated assessment of pulse oximetry, forced expiration volume, heart rate, and CCQ and sent the study physiotherapist an SMS text message (short message service [SMS]) alert. Otherwise, the robot advised the participant to contact their general practitioner. Patients were advised that if the *I am feeling unwell* assessment was completed outside work hours, then the physiotherapist would call the participant on the next working day. Patients were informed that they should carry on with the usual ways that they dealt with health problems outside work hours because the robot server was only monitored 5 days a week from 9 AM to 5 PM. The alert function was also triggered if any parameters were outside the normal range, if medications were missed more than 3 consecutive times (either on Smartinhaler data or robot server), or if exercise was missed more than 3 consecutive times.

Two part-time physiotherapists were employed to monitor data via a Web browser and were asked to carry a cell phone to answer calls or respond to alerts. They checked the server every working day. If the physiotherapists detected an adherence or health-related issue, they phoned the patient to discuss concerns and passed on relevant information to respiratory physicians if necessary. If patients were not using the robots, they were encouraged to do so in the phone-call. Blood tests for biomarkers were arranged in some cases and treatment was adjusted where indicated. Patients were encouraged to see their general practitioner rather than the hospital team. The modules were designed by the multidisciplinary team (robotic engineers, psychologist, nurse, general practitioner, medical student, respiratory physician, and physiotherapists). Although patients were not involved in the design of the modules, our team has previous experience in designing such modules for other health conditions, and we did test the robot with a few patients before the study began to gather feedback and check its usability. The programmed scenarios included handling of out-of-range health data, emergency conditions, and input errors.

The physiotherapists delivered the robots and Smartinhalers to the homes of the participants in the robot group approximately 1 week after discharge. During the interim week, the engineers set up each robot with the associated Smartinhalers and Internet connection devices for each individual. The physiotherapists introduced the purpose of the robot as helping the patients to comanage their condition with the medical care team. They explained that patients should use the robot every day and explained what the robot did, why, and when, and demonstrated all the functions. They also explained that the Smartinhalers tracked the patient's inhaler use, and thus, the physiotherapists could monitor if the participants were using the inhalers enough or too much. Patients were given a written manual with instructions on how to use the robot and Smartinhalers. Internet

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connectivity for the robot was set up by the researchers, and Internet costs were covered by the study.

Control Group

The control group received standard care (usual care from the general practitioner, hospital inpatient and outpatient services, and rehabilitation program). This included referral for rehabilitation and contact with respiratory physiotherapists and other clinicians as needed. Follow-up care was determined by the medical team under whom the patients were admitted and was not influenced by the study. Care often included being followed up by their general practitioner and receiving a respiratory specialist clinic appointment within the 4-month period from discharge. The control group received Smartinhalers to record their adherence, delivered by the physiotherapists to their homes approximately 1 week after discharge.

Sample Size

It is important to note that this was a pilot trial. However, we calculated a sample size using G power with power set at .90, alpha of .05, and a large effect size d=1.15, based on previous research on COPD case management [24]. To find a similar effect size, the required sample size would be 16 patients per group, but 30 patients per group were recruited to allow for inclusion of potential confounding factors in analyses and potential study dropout.

Primary Outcome

The number of days of hospitalization over the study period for respiratory-related reasons was assessed from hospital records.

Secondary Outcomes

Adherence to medication was assessed using Adherium Smartinhalers, which electronically recorded inhaler use over the duration of the study from the website portal. Adherence was calculated as a percentage of taken prescribed doses over the 4-month period. Adherence was also measured using the 6-item Medication Adherence Report Scale [25] at baseline and follow-up. Adherence to respiratory exercise was assessed by asking patients how many times they performed their respiratory exercises over the past week at baseline and at follow-up.

Quality of life (consisting of symptoms, functional status, and mental state) was assessed using the CCQ at baseline and follow-up [23]. Hospitalization costs for each participant over the 4-month study period were obtained from hospital records for benefit-cost analyses. Questionnaires at baseline and follow-up were paper based (not Web based) and delivered in person. The follow-up questionnaires were administered at the participant's home for both groups 4 months after recruitment. There were no changes to trial outcomes after the trial commenced.

Benefit-Cost Analysis

A benefit-cost analysis was performed by comparing the respiratory-related hospitalization costs per group balanced by the costs of the intervention. It did not include general practitioner costs.

Process Implementation Interviews

At the end of the study, process implementation interviews were conducted with participants in the intervention group in their homes.

Data Analysis

Analysis was performed using SPSS (International Business Machines Corporation, United States of America) by a researcher blind to group allocation. Negative binomial logistical regression was conducted to compare the total number of respiratory hospitalizations and days spent in hospital per group. The analysis was repeated when including comorbidities and previous hospital admissions as covariates because these were considerably different between groups at baseline. Intention-to-treat (ITT) and per protocol (PP) analyses are presented for the hospitalization data. The definition of the PP analysis was to include only those patients who received and completed their allocated treatment. Therefore, the 2 people who died and 3 who withdrew before the end of the study period were excluded from the robot group for the PP analysis. Two people who died in the control group and 1 who withdrew were also excluded from the PP analysis. People who received a robot and did not use it much were still included in the PP analysis. Due to the presence of an extreme outlier (46 days in hospital), the hospitalization data were analyzed using bootstrapping. Adherence and CCQ data were analyzed as ITT. The Smartinhaler data were not normally distributed, thus Mann-Whitney U tests were performed between groups. For self-reported adherence and CCQ, change scores from baseline to follow-up were calculated, and analyses of covariance were performed controlling for baseline scores and then repeated when also controlling for comorbidities and previous hospitalizations. Spearman correlations were conducted within the intervention group to explore whether the frequency of robot use was associated with medication adherence, rehabilitation exercise, and hospitalizations. The interviews were transcribed and analyzed using an inductive qualitative approach whereby a researcher read the interview transcripts and identified the key themes. Each transcript was then coded for the themes, and themes were checked by another author.

Results

Recruitment was conducted between August 1, 2015 and February 20, 2016 and follow-up between December 1, 2015 and July 1, 2016. Figure 1 shows the participant flow diagram. Sixty patients were randomized, 30 to each group. Robots were delivered to 27 participants in the intervention group (2 dropped out and 1 died before receiving the robots). Twenty-nine were included in the ITT analysis (there was no hospitalization data for the patient who died, but data were available for the dropouts). The PP analysis included 25 in the intervention group because 2 patients withdrew before receiving a robot, 1 withdrew during the study, 1 died before getting the robot, and 1 died during the study period. Twenty-seven were included in the PP control group as 2 died during the study and 1 withdrew. The trial ended when all follow-up data had been collected. There were no unintended effects or harms due to the robots.

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Figure 1. Consolidated Standards of Reporting Trials (CONSORT) flow diagram.

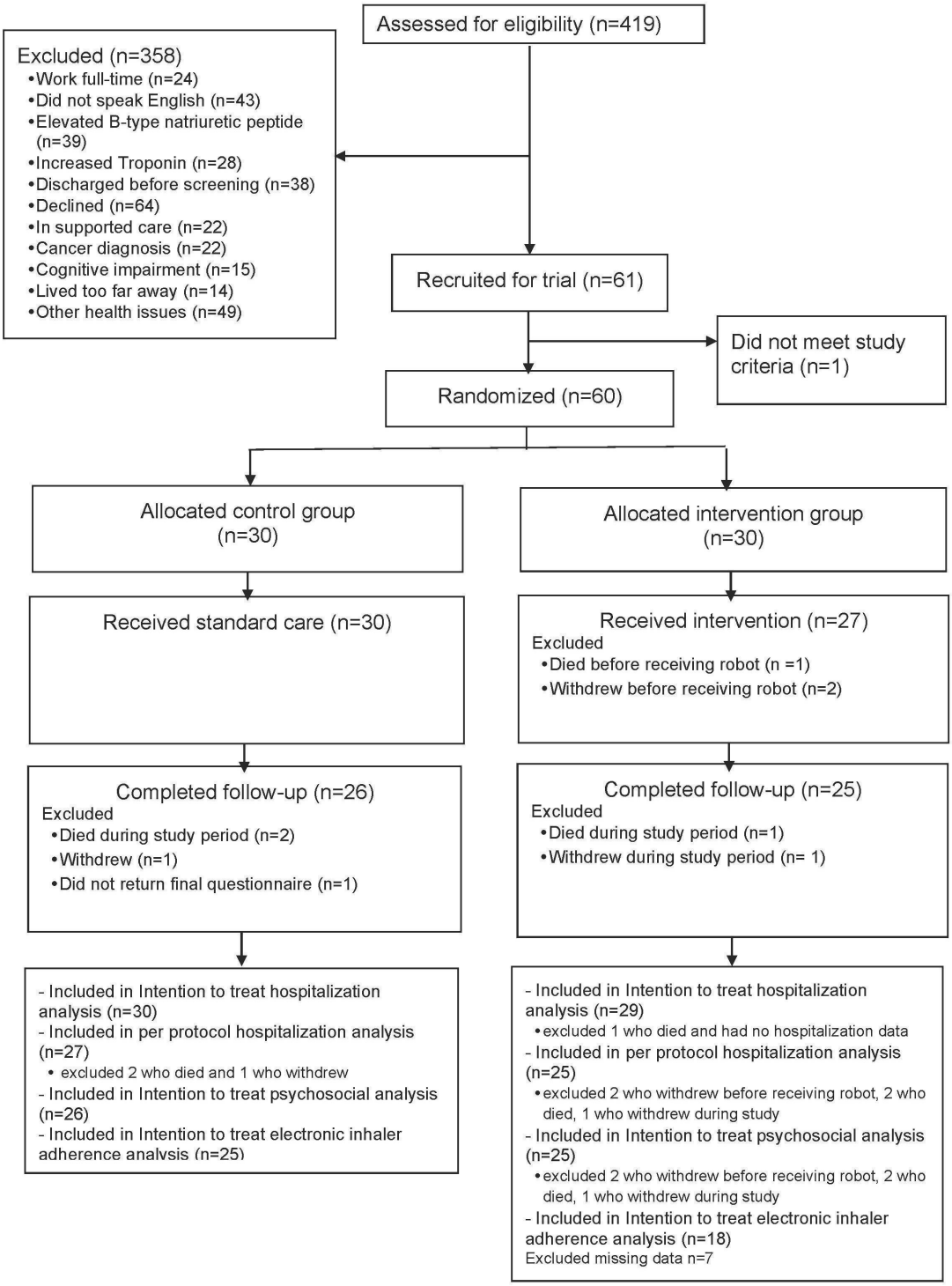


Table 1 shows baseline demographic and clinical characteristics. All the participants had at least one other comorbid health problem as assessed by the Charlson Comorbidity Index (mean 2.77 [SD 1.61]), and the intervention group had a trend for more comorbidities. Over the previous 12 months, the average number of hospital admissions for any reason was 1.93 (SD 2.09). On average, patients were admitted for 5.81 days (SD 8.71) over the previous year. Again, there was a trend for patients in the intervention group to have had more days in hospital over the past 12 months than the control group. Of the total number of admissions, the average number due to a respiratory condition was 1.07 (SD 1.69), with an average length of stay of 3.65 days (SD 6.03). Table 1 also shows the medications that patients were on during the study, baseline scores for adherence, and CCQ.

Primary Outcome

Table 2 shows the total number of respiratory admissions per group and the total number of days spent in hospital for each group in the ITT analysis and the PP analysis. The negative binomial regressions were not significant but were in the intended direction for both the ITT and the PP analyses. When

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covariates were included in the model, there were still no significant differences between groups, and sensitivity analyses were not significant.

Secondary Outcomes

ITT analysis showed participants in the intervention group had significantly better adherence to inhaled corticosteroids, long-acting beta agonists, and a combination of these as measured by electronic inhalers (mean 48.5% [SD 34.07]) compared with the control group (mean 29.5% [SD 32.44]; U=139.50, z=−2.12, P=.03, d=0.68). When controlling for comorbidities and previous hospital admissions, the results were similar but became nonsignificant (intervention adjusted mean 49.4%, SE=8.23; control adjusted mean 28.9%, SE=6.92; $F_{1,39}$=3.44, P=.07, partial η^2=0.08; mean difference −20.49, 95% CI −42.84 to 1.84). There was a greater increase in self-reported adherence in the intervention group during the study than in the control group, as shown in Table 3, and this was significant when controlling for covariates.

There were no significant differences between groups in the CCQ using ITT analysis, as indicated in Table 3, although the results were in the intended direction.

There was a significant difference between groups in the self-reported change in the frequency of performing rehabilitation exercises (estimated marginal means control −2.00, intervention 2.54, $F_{1,51}$=12.13, P=.001, partial η^2=.20, mean difference −4.53, 95% CI −7.16 to −1.92), with the intervention group showing increased frequency of rehabilitation exercises compared with the control group in an ITT analysis.

Benefit-Cost Analysis

Patient cost data (both direct and total costs for respiratory-related admissions) were extracted from hospital records over the 4-month study period and compared between groups as both ITT and PP (Table 4). Primary care costs were not considered. Multimedia Appendix 1 shows the estimated benefit-cost analysis over 5 years, with the robot showing a net benefit when examining the ITT total cost group comparison. The robot costs reflect the study robot configuration, and in a more commercial product, the robot configuration is likely to be more integrated and less expensive, and thus the long-term benefit-cost may be improved on the analysis shown.

Process Implementation Interviews

Twenty-five participants from the intervention group were interviewed when the robot was collected. Of those who were not interviewed, 3 patients did not receive the robot at all because of death or because they withdrew from the study before it began, 1 patient died during the study period, and 1 declined to be interviewed.

Nineteen participants thought the robot was useful and had positive comments. Participants liked the robot for a number of reasons, and 4 main themes emerged from their answers (see Table 5). First, all of the participants commented that the robot helped remind them to take their medication (19 participants). A number of participants enjoyed doing the exercises with the robot (12/19 participants). Participants commented that their family and friends were interested in the robot, particularly young children who enjoyed visiting to see the participant as well as the robot. They commented that the robot raised awareness for the family about when the participant should be taking medication and about their illness (14/19 participants). Finally, participants enjoyed having the robot because they felt it had a personality and was good company (15/19 participants). As a consequence, many participants had given their robot a name over the time they had it.

Six participants did not enjoy having the robot. Three of these participants returned the robot before the 4-month period was complete. The negative attitudes toward the robot are presented as themes in Table 5. Participants commented that they did not find the robot useful because they were very good at managing their medication and exercise on their own (5/6 participants), they were unnerved by having the robot in their home (3/6 participants), or they did not like having to manage the robot and could not be bothered with it (all 6 participants). There was a trend for people who disliked the robot to have higher adherence at baseline. This is in line with participants' comments that they did not find the robot useful because they were already good at managing medication.

Robot Use

Figure 2 shows the robot being used by a participant with a physiotherapist demonstrating the pulse oximeter function. The function that was used the most was the medication function. Over the 4-month period, it was used on average 464 times per patient (range 41-1509 times). This indicates that, on average, the medication function was used 3 to 4 times a day, which is what would be expected because most patients took medications several times throughout the day. The number of times people used the medication function was significantly associated with better medication adherence measured electronically (Spearman correlation, r_s=.82, P<.001) but not with hospitalizations (r_s=.26, P=.16).

Patients used the exercise function for an average of 84 times over the 4-month period (range 3-221). They used the measurement function for an average of 51 times (range 9-95) and the entertainment function for an average of 29 times (range 1-165). Patients used the education function for an average of 8 times (range 0-77).

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Table 1. Demographic variables and baseline measures for the control and intervention groups.

Variable	Control (N=30)	Intervention (N=30)	*P* value
Gender—Females, n (%)[a]	18 (60)	19 (63)	.50
Age in years, mean (SD)	69.10 (9.85)	70.57 (10.34)	.58
Ethnicity, n (%) [a]	–	–	.56
NZ[b] European	16 (52)	15 (50)	–
Māori	10 (33)	8 (27)	–
Pacific Island	1 (3)	4 (13)	–
Other	3 (10)	3 (10)	–
BMI[c], mean (SD)	27.41 (8.38)	29.16 (8.83)	.46
Smoking status, n (%) [a]	–	–	.51
Current smoker	8 (28)	6 (24)	–
Ex-smoker	21 (72)	19 (76)	–
Disease severity at discharge			
FEV_1[d] percent predicted, mean (SD)	30.27 (12.59)	33.80 (13.61)	.30
FEV_1 severity, n (%) [a]	–	–	.54
Moderate	3 (10)	5 (17)	–
Severe	10 (33)	12 (40)	–
Very severe	17 (57)	13 (43)	–
SpO_2[e], mean (SD)	92.41 (5.28)	93.96 (3.31)	.21
Comorbidities (CCI[f] total score; mean, [SD])[h]	2.47 (1.76)	3.07 (1.41)	.05
No. of hospital admissions in previous 12 months, mean (SD)[g]	1.47 (1.55)	2.40 (2.46)	.16
No. of days of hospital admissions in past year, mean (SD)[g]	3.83 (5.31)	7.80 (10.87)	.22
No. of hospital respiratory admissions in past year, mean (SD)[g]	0.90 (1.30)	1.23 (2.01)	.67
No. of days of respiratory admissions past year, mean (SD)[g]	2.63 (3.00)	4.67 (7.57)	.49
CCQ[h] Functional at discharge, mean (SD)	3.75 (1.36)	3.48 (1.19)	.41
CCQ Symptoms at discharge, mean (SD)	3.84 (1.23)	3.60 (1.03)	.41
CCQ Mental at discharge, mean (SD)	3.53 (1.54)	3.88 (1.59)	.96
CCQ Total at discharge, mean (SD)	24.01 (7.12)	23.56 (6.82)	.80
Adherence MARS 5[i] at discharge[g], mean (SD)	22.30 (3.76)	21.43 (4.15)	.22
Medication prescribed during study, n (%)			
SABA[j]	23 (77)	26 (87)	.48
SAMA[k]	2 (7)	4 (13)	.41
SABA/SAMA combination	2 (7)	1 (3)	.53
LAMA[l]	22 (73)	24 (80	.71
LABA[m]	24 (80)	23 (77)	.96
ICS[n]	4 (13)	4 (13)	.15
ICS/LABA combination	22 (73)	22 (73)	.84
Prednisone	17 (57)	18 (60)	.91
Antibiotic	23 (77)	20 (67)	.30

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Variable	Control (N=30)	Intervention (N=30)	*P* value
Medication assessed for adherence, n (%)			
SABA[o]	21 (95)	25 (100)	.47
SABA/SAMA combination[o]	1 (5)	0 (0)	.47
ICS[p]	2 (8)	1 (5)	.75
LABA[p]	1 (4)	0 (0)	.39
ICS/LABA combination[p]	23 (88)	18 (95)	.46

[a]chi-squared test.
[b]NZ: New Zealand.
[c]BMI: body mass index.
[d]FEV_1: forced expiratory volume in 1 second.
[e]SpO_2: pulse oximeter oxygen saturation.
[f]CCI: Charlson Comorbidity Index.
[g]nonparametric test.
[h]CCQ: Clinical COPD Questionnaire.
[i]MARS 5: Medication Adherence Report Scale
[j]SABA: short-acting beta agonists.
[k]SAMA: short-acting muscarinic antagonist.
[l]LAMA: long-acting muscarinic antagonist.
[m]LABA: long-acting beta agonists.
[n]ICS: inhaled steroids.
[o]Control: N=22, Intervention: N=25.
[p]Control: N=26, Intervention: N=19.

Table 2. The total number of respiratory admissions per group and the total number of days spent in hospital for each group in the intention to treat (ITT) analysis and the per protocol (PP) analysis, with and without controlling for past year admissions and comorbidities.

Outcome type	Control, (ITT: N=30; PP: N=27)	Intervention, (ITT: N=29; PP: N=25)	Beta	Wald chi-square statistic	95% Wald CI	*P* value
Intention to treat						
Total number of hospitalizations for respiratory problems (ITT), N	15	15	.000	0.000	−0.84 to 0.84	>.99
Controlling for comorbidities and previous hospitalizations			.129	0.075	−0.80 to 1.06	.79
Total number of days in hospital for respiratory problems (ITT), N	65	50	.040	0.017	−0.57 to 0.65	.90
Controlling for comorbidities and previous hospitalizations			.453	1.33	−0.32 to 1.22	.25
Per protocol						
Total number of hospitalizations for respiratory problems (PP), N	15	14	−.008	0.000	−0.92 to 0.90	.99
Controlling for comorbidities and previous hospitalizations			−.112	−0.044	−1.16 to 1.94	.83
Total number of days in hospital for respiratory problems (PP), N	67	55	−.120	0.132	−0.53 to 0.77	.72
Controlling for comorbidities and previous hospitalizations			.370	0.796	−0.44 to 1.18	.37

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Table 3. Intention-to-treat analyses of difference in secondary outcomes between groups, with and without controlling for covariates.

Outcome	Baseline, mean (SD)		Four months later, mean (SD)		Change score, adjusted mean (SE)		Mean difference (95% CI)	*P* value	Partial eta squared
	Control, n=29	Intervention, n=29	Control, n=27	Intervention, n=25	Control, n=26	Intervention, n=25			
Adherence	22.16 (3.76)	21.44 (3.72)	22.27 (4.12)	23.08 (2.63)	0.12 (0.55)	1.63 (0.56)	1.51 (−3.10 to 0.08)	.06	.07
Additional controls[b]	–	–	–	–	–	–	−1.69 (−3.32 to −0.060	.04	.09
CCQ [a] Functional	3.74 (1.34)	3.41 (1.18)	2.92 (1.22)	2.32 (1.04)	−0.73 (0.21)	−1.21 (0.21)	0.48 (−0.12 to 1.07)	.11	.05
Additional controls	–	–	–	–	–	–	0.455 (−0.17 to 1.08)	.15	.04
CCQ Symptoms	3.84 (1.20)	3.61 (1.07)	3.08 (1.21)	2.76 (1.01)	−0.61 (0.21)	−.91 (0.22)	0.30 (−0.32 to 0.92)	.33	.02
Additional controls	–	–	–	–	–	–	0.314 (0.33 to 0.96)	.33	.02
CCQ Mental	3.58 (1.50)	3.78 (1.62)	2.33 (1.38)	2.16 (1.43)	−1.25 (0.26)	−1.50 (0.27)	0.26 (0.50 to 1.02)	.50	.01
Additional controls	–	–	–	–	–	–	0.338 (−0.46 to 1.14)	.34	.02
CCQ Total	24.07 (6.90)	23.36 (7.16)	18.17 (6.96)	16.29 (6.30)	−5.46 (1.26)	−7.13 (1.29)	1.67 (−1.95 to 5.29)	.36	.02
Additional controls	–	–	–	–	–	–	1.82 (−2.04 to 5.68)	.35	.02

[a]CCQ: Clinical COPD Questionnaire.

[b]Controlling for comorbidities and previous hospitalizations.

Table 4. Differences in hospitalization costs between groups over the trial period using bootstrapped *t* tests and analysis of covariance with covariates.

Description of cost types	Control, (ITT[a]: N=30; PP[b]: N=27)	Intervention, (ITT: N=29; PP: N=25)	Mean difference (95% CI)	*P* value	Effect size
Direct costs ITT in NZ [c] $, mean (SD)	2293 (5368)	1140 (2725)	1152 (−760 to 3356)	.32	*d*=0.27
Controlling for comorbidities and previous hospitalizations	–	–	1173 (−1123 to 3471)	.31	0.02[d]
Total costs ITT in NZ $, mean (SD)	3178 (7455)	1599 (3841)	1579 (−1292 to 4451)	.34	*d*=0.27
Controlling for comorbidities and previous hospitalizations	–	–	1613 (−1587 to 4813)	.32	0.02[d]
Direct costs PP in NZ $, mean (SD)	1659 (3633)	1086 (2748)	573 (−1127 to 2436)	.53	*d*=0.18
Controlling for comorbidities and previous hospitalizations	–	–	497 (−823 to 1929)	.58	0.01[d]
Total costs PP in NZ $, mean (SD)	2302 (5079)	1514 (3858)	789 (−1851 to 3192)	.53	*d*=0.17
Controlling for comorbidities and previous hospitalizations	–	–	686 (−1082 to 2842)	.59	0.01[d]

[a]ITT: intention to treat.

[b]PP: per protocol.

[c]NZ: New Zealand.

[d]Effect size is partial eta squared.

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Table 5. Positive and negative comments about iRobi from the process implementation interviews.

Comments	Quote
Positive	
Medication reminders	"It made such a difference to my life. I felt that it helped me regain independence and I was breathing better. I was using the preventer regularly and taking my medication." [Participant 3]
	"It was very helpful at the times I forgot my medication." [Participant 10]
	"I could rely on it to remind me about my medications, otherwise I would forget." [Participant 30]
	"Really useful. In the past my ex would text me to tell me to take my medication but the robot was better. I have always been bad at remembering." [Participant 43]
Exercise reminders	"It made me aware of when to do my exercises, which was good." [Participant 5]
	"The reminders about the exercises were good, the robot would tell me to do it and my grandson would come and get me to say the robot needed me." [Participant 31]
Family and friends	"If the family are too shy to ask me then they can look on the robot. The robot is not just for me." [Participant 45]
	"I had a 90 year old friend come over to look at it and she loved it. She wanted one herself." [Participant 29]
	"Everyone was interested in it when they came over!" [Participant 33]
Acted like a companion	"I named the robot after my great grandson because I miss him now that he is overseas. It made it like he is here with me." [Participant 32]
	"Bob (name of the robot) was like one of us. I would pat it on the head and he would respond. I often found myself having conversations with him." [Participant 38]
	"I will have no friend at home anymore! I liked having it in the house because it talked randomly and I would always touch it as I walked by." [Participant 58]
Negative	
Not useful	"Not useful. It didn't do anything for me. I have been doing the same thing for years anyway." [Participant 25]
	"I didn't need it. With this illness you never forget to take medication because otherwise you can't breathe." [Participant 16]
Disliked the robot in home	"I felt like I was being policed because people were monitoring how much I was using my inhaler and I felt guilty or like I was being judged. It was an intrusion." [Participant 14]
	"I felt like my privacy was invaded and I couldn't go anywhere. I was worried about leaving it at home in case something went wrong or it was stolen." [Participant 27]
	"The robot would follow me around with its head. I hope that there was not a camera in it." [Participant 49]
Found the robot annoying or hard to use	"It drove me batty. It always wanted me to do something." [Participant 49]
	"I couldn't read it half the time. I started off doing everything but I had problems going from screen to screen. It got very frustrating. It would tell me to take medications I had already taken." [Participant 25]

Technical Issues

Patients in both groups were given the phone number of the physiotherapists to call if there were any issues with the robots and/or Smartinhalers. Patients rang the physiotherapists when they experienced technical issues during the study, including network connection issues, touch screen failures, and hard disk failures on the robot, and the Smartinhalers not charging or connecting correctly. Another issue concerned the pulse oxygen devices, which occasionally became unplugged or had driver issues. In the case of hardware failure, the robot had to be taken away for repair and was replaced with another robot. Technical problems occurred with 50% of the robots delivered.

The time logs kept by the physiotherapists indicated they spent 62 hours in total for troubleshooting technical issues. Calls were mostly from patients in the robot group, as very few patients from the control group contacted the physiotherapists about the Smartinhalers, even if they experienced problems. Most issues could be fixed over the phone, but in a few instances the physiotherapists and/or engineers had to visit the participant's house. In all cases, the effects of technical failures were negative on patients' attitudes toward the robots. The physiotherapists spent another 49 hours on patient contact for medical issues that they identified through monitoring (all in the intervention group).

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Figure 2. iRobi robot being used by a patient with a physiotherapist showing the functions.



Discussion

Principal Findings

This pilot study indicates the feasibility and possible effects of giving a robot to COPD patients at home to help manage their condition. The primary outcome was number of days in hospital, which was not significantly different. This is consistent with recent large-scale studies on telehealth for COPD showing no reductions in hospitalizations [11,12]. The study extends research into the delivery of such care to a robot platform. While the robot did not significantly reduce hospitalizations, many patients appeared to appreciate the robot's capacity to offer companionship, which may offer benefits over other kinds of platforms such as computers or iPads, although this needs to be further investigated.

The intervention improved adherence to both medication and rehabilitation exercise. Electronic recording showed that adherence to long-acting inhalers was significantly higher in the intervention group. This is backed up by the self-report data showing higher overall medication adherence in the intervention group, which was significantly better than the control group after controlling for past hospitalizations and comorbidities. More frequent use of the medication reminder function on the robot was associated with higher adherence, which suggests the robot was helpful in this regard for at least some patients. Self-reported adherence to rehabilitation exercises significantly increased in the intervention group compared with the control group. It is possible that the social aspects and embodiment of the robot combined with the increased availability of the exercise instructions and the reminders to together create behavior change.

A reduced length of stay might reflect that patients with robots were more comfortable being discharged because of the robot's presence in the home and the fact that they were being more closely monitored by the physiotherapists. The physiotherapists intervened when they noticed adherence was suboptimal. An illustrative example was when a physiotherapist noticed that the Smartinhaler reliever was used over 30 times in a few minutes, the physiotherapist rang the patient and consulted with

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a respiratory clinician. The result was a change in medication for the patient and improved management.

About 75% of the sample responded to the robot positively and commented that it helped with medication, education, and companionship. However, 25% of participants did not find the robot useful, and some patients returned it. The patients who did not find it useful tended to have higher adherence at baseline. This suggests that patients should be screened and only offered a robot if they have poor adherence, because this group is the most likely to experience benefits. It also suggests the need to introduce the robot and its functions to the patient when they are an inpatient so that they can make a more informed decision about whether to accept treatment. Anxious patients may find additional benefits from the social presence of the robot, and this is an area for future research.

The robot was programmed to take weekly measurements in the hope of identifying downward trends (which would potentially require a change in management) without placing undue burden on the patient. However, daily measurements are likely better for this purpose. The measurements did serve as a baseline for comparison if patients who contacted us were concerned about a possible exacerbation or deteriorating health.

Limitations

This study was limited by a small sample, deaths, and dropout, which means the study was underpowered. Our original sample size calculation was optimistic, and a more realistic analysis could have been achieved if it was based on length of hospital stay in COPD patients in the region. The average length of stay in NZ for COPD admissions in 2012 was 4.37 days, and this has been declining over time [7]. For Middlemore hospital over the course of this study, the average length of stay was 4.2 days. The results suggest the intervention had small effects, if any, on hospitalizations, and thus a large sample (similar to recent telehealth trials) would be required to find effects if no changes were made to the robot or protocol in a future study. An additional limitation was that, at baseline, there was a trend that the intervention group had more previous hospitalization days and comorbidities, which could have affected the results. The nonblinding of participants was another limitation, which is common for eHealth trials. The benefit-cost analysis should be viewed with caution because the hospitalization costs were not significantly different between groups—it is provided as an indication only.

The study was conducted in South Auckland, where there is a large population of Māori, Pacific Islanders, and immigrants, and many patients have low socioeconomic status. About a third of the patients were living in rural areas. While these are key groups to target because they tend to have poorer health outcomes, the results may not generalize to all regions. Running the study for a longer period may help indicate whether increased adherence to medication and exercise recommendations could translate into improved quality of life and/or a reduction in hospitalizations.

Future Work

A number of technical issues would need to be improved before the robot could be implemented on a larger scale, including reliability of the robots and the Internet network. An information technology support company would have to be involved to provide technical support. As a result of this pilot study, the team has now created a software mode to enable the robot to function offline if the network fails intermittently. The software team is working on linking the medication management software with a national electronic prescription database so that medications can be downloaded after the normal entry by pharmacies. In the future, the robot software will need to be integrated with primary care and other Web-based health platforms. Robot studies are expensive, as currently robots must be purchased, programmed, and supported for the purpose of the study. In addition, achieving software reliability is challenging for a study as there is little time for iterative improvement and for establishing a mature software version.

A larger study with more power to detect effects is recommended after improvements to the technology and the trial design are made. It may be useful to screen patients to give the robot only to those who are low in adherence and/or health literacy or who have high levels of anxiety or who are living by themselves. Further work is needed to investigate whether the robot has advantages over a computer tablet providing similar services in this population. The team could possibly program the robot for other long-term conditions such as diabetes and rheumatoid arthritis if given sufficient development time.

The majority of COPD patients admitted to hospital are managed in general medical wards and by a team not involved in their long-term care. Our experience suggests that physiotherapists and respiratory nurse specialists involved in long-term care (eg, pulmonary rehabilitation, outpatient care, outreach or integrated care programs) are ideal people to implement telehealth programs using robots. Many patients recruited into this study appeared to be on suboptimal bronchodilator therapy with insufficient numbers on long-acting muscarinic antagonists (LAMAs) in particular. In NZ, access to LAMAs is through special authority application, and patients can only be prescribed LAMAs if their FEV_1 is <60% predicted. Spirometry was infrequently recorded on patients during their admission, and <50% of general practitioners in NZ have spirometers. This nonadherence to international guidelines might be one reason as to why NZ has the fourth highest admission rates for COPD in the world.

Ideally, patients would be introduced to the robot while in hospital to gauge whether they like the concept and can adapt to the measurement requirements. They would also benefit from a formal review by a respiratory physician before discharge. Some thought also needs to be given as to how to achieve a 24-hour monitoring of the Web server's patient information 7 days a week. This would potentially require a national or regional solution that includes a 24/7 monitoring system such as an extension of the New Zealand Healthline, with instant links back to the health care team members when patients are becoming unstable. A similar solution for diabetes and asthma management could be set up, which would reduce costs and pay for infrastructural development.

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Conclusions

A robot may be useful for COPD patients who are struggling with medication adherence and rehabilitation exercises to improve adherence, although hospitalizations may not be reduced. We recommend improvements to the robot, changes to the way it is incorporated into the health care system, and a larger study comparing robots with other forms of technology, before stronger conclusions can be made.

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Authors' Contributions

EB made substantial contributions to conception and design, acquisition of funding, data analysis and interpretation and was the major contributor in writing the manuscript. JG made substantial contributions to conception and design, acquisition of funding, data interpretation, and revising the manuscript. NJ and VLO were involved in data collection and revising the manuscript. HSA made substantial contributions to conception and design of the robot software and was involved in revising the manuscript. HR was involved in data analysis and was a major contributor in writing the manuscript. KP was involved in design of the robot functions. NK was involved in conceptualization and design, acquisition of funding, and revising the manuscript. PR conducted the benefit-cost analysis, and AP helped with statistical advice and analysis. BM made substantial contributions to conception and design, acquisition of funding, data interpretation, and revising the manuscript. All authors read and approved the final manuscript.

Conflicts of Interest

EB, BM, HSA, NK, and KP received funding from Yujin Robot Ltd for unrelated projects on transportation and aged care robots. The remaining authors declare that they have no competing interests.

Multimedia Appendix 1

Benefit-cost analysis based on intention to treat analysis of mean total costs per patient in each group.

[PDF File (Adobe PDF File), 33KB - jmir_v20i2e45_app1.pdf]

Multimedia Appendix 2

CONSORT‐EHEALTH checklist (V.1.6.1).

[PDF File (Adobe PDF File), 651KB - jmir_v20i2e45_app2.pdf]

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Abbreviations

BMI: body mass index
CCI: Charlson Comorbidity Index
CCQ: Clinical Chronic Obstructive Pulmonary Disease Questionnaire
COPD: chronic obstructive pulmonary disease
CURB-65: Confusion, bUn>19mg/dL, RR>30, BP<90 SBP or <60 DBP, Age>65
FEV1: forced expiratory volume in 1 second
ICS: inhaled corticosteroids
ITT: intention to treat
LABA: long-acting beta agonists
LAMA: long-acting muscarinic antagonist
NT-pro BNP: N-terminal pro b-type natriuretic peptide

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NZ: New Zealand
PP: per protocol
SABA: short-acting beta agonists
SAMA: short-acting muscarinic antagonist
SMS: short message service
SpO_2: peripheral capillary oxygen saturation

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Original Paper

Open Availability of Patient Medical Photographs in Google Images Search Results: Cross-Sectional Study of Transgender Research

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Abstract

Background: This paper focuses on the collision of three factors: a growing emphasis on sharing research through open access publication, an increasing awareness of big data and its potential uses, and an engaged public interested in the privacy and confidentiality of their personal health information. One conceptual space where this collision is brought into sharp relief is with the open availability of patient medical photographs from peer-reviewed journal articles in the search results of online image databases such as Google Images.

Objective: The aim of this study was to assess the availability of patient medical photographs from published journal articles in Google Images search results and the factors impacting this availability.

Methods: We conducted a cross-sectional study using data from an evidence map of research with transgender, gender non-binary, and other gender diverse (trans) participants. For the original evidence map, a comprehensive search of 15 academic databases was developed in collaboration with a health sciences librarian. Initial search results produced 25,230 references after duplicates were removed. Eligibility criteria were established to include empirical research of any design that included trans participants or their personal information and that was published in English in peer-reviewed journals. We identified all articles published between 2008 and 2015 with medical photographs of trans participants. For each reference, images were individually numbered in order to track the total number of medical photographs. We used odds ratios (OR) to assess the association between availability of the clinical photograph on Google Images and the following factors: whether the article was openly available online (open access, Researchgate.net, or Academia.edu), whether the article included genital images, if the photographs were published in color, and whether the photographs were located on the journal article landing page.

Results: We identified 94 articles with medical photographs of trans participants, including a total of 605 photographs. Of the 94 publications, 35 (37%) included at least one medical photograph that was found on Google Images. The ability to locate the article freely online contributes to the availability of at least one image from the article on Google Images (OR 2.99, 95% CI 1.20-7.45).

Conclusions: This is the first study to document the existence of medical photographs from peer-reviewed journals appearing in Google Images search results. Almost all of the images we searched for included sensitive photographs of patient genitals, chests, or breasts. Given that it is unlikely that patients consented to sharing their personal health information in these ways, this constitutes a risk to patient privacy. Based on the impact of current practices, revisions to informed consent policies and guidelines are required.

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(J Med Internet Res 2018;20(2):e70) doi:10.2196/jmir.8787

KEYWORDS

informed consent; photography; open access publishing; confidentiality; image repositories; big data; publication ethics; transgender persons

Introduction

This paper focuses on the collision of three factors: a growing emphasis on sharing research through open access publication, an increasing awareness of big data and its potential uses, and an engaged public interested in the privacy and confidentiality of their personal health information. One conceptual space where this collision is brought into sharp relief is the open availability of patient medical photographs from peer-reviewed journals in the search results of online image databases such as Google Images.

Researchers, funders, policy makers, and the public promote the importance of open access research publications [1]. In some instances, this perspective is communicated through public access mandates established by research institutions, funders, or governments [2]. Open access publications allow us to share information more widely with relevant stakeholders including the public, policy makers, and clinicians. Increased access to research supports the principles of accountability, replicability, transparency, and equity. Such access has the potential to reduce research waste and has been promoted as a core component of the Responsible Research and Innovation framework [3].

While open access publishing is increasingly being embraced, big data and access to massive online databases are expanding. Google Images was launched in 2001, and in its first year included 250 million images [4]. It is estimated that it now has over 1 trillion indexed images [5]. Google obtains its images from crawling websites [6] and indexing those images within its searchable database [7]. Given the way Google Images works, it is not surprising that photographs from peer-reviewed publications are available online. Physicians and their patients may not realize that sensitive medical photographs published in closed and open access publications are now also freely available within these image databases.

Clinical photographs form part of the patient medical record [8]. Some have argued that patients also own or at least co-own their medical images [9]. As such, it is important to attend to the ethical aspects of capturing, storing, transferring, and using these images [10]. Current guidelines underline the need for prior written consent from patients before taking clinical photographs, using them for teaching or research purposes, or publishing them in peer-reviewed journals, books, or pharmaceutical publications [11]. Similarly, some journals, including the *BMJ*, call for written consent from patients (and photographers) before publication (ie, Uses of Images policy) [12]. Within this context, clinicians are expected to balance the importance of medical photography for education, research, and clinical care, with the ethical principle of patient autonomy, including informed consent and confidentiality [9], and respect for patients.

Until recently, medical photography consent forms did not contain any reference to electronic publishing or social media (eg, [13]). With growing awareness of the potential for materials published electronically, clinicians are recommending enhanced attention to informed consent and greater specificity in consent forms [14]. New publications focusing on informed consent to use images highlight the ways information can be shared electronically and that photographs cannot later be removed if the patient removes consent [15]. Aside from general warnings, we were not able to locate examples of medical photography consent forms that include permission to publish clinical photographs on Google Images or that warn of this specific risk.

In many countries, transgender, gender non-binary, and other gender diverse (trans) people are required to work with clinicians in order to access medical transition. These mandatory interactions can create complex dynamics between patients and health care providers, including challenges related to voluntary and informed consent in the contexts of clinical research and medical photography. While the privacy and confidentiality of medical photographs are important for all patients, privacy breaches carry an increased possibility of harm for trans people. This risk exists because trans people experience heightened rates of discrimination, harassment, and violence [16,17], particularly those who are visibly gender non-binary or whose trans identities become known to individuals in their lives who may not have been previously aware of this information [18].

In this study, we identified a sample of peer-reviewed publications that included clinical photographs of trans people and searched for the publications and their associated photographs on Google Images. The objective of this study was to assess the availability of patient clinical photographs from published journal articles in Google Images search results and the factors impacting this availability. We hypothesized that if journal articles were openly available online, either through open access or article repositories, that the likelihood of finding the accompanying photographs in Google Images search results would be increased. The results of this study will inform privacy and informed consent guidelines in relation to the publication of medical photographs in peer-reviewed journals, including recommendations for clinicians and publishers.

Methods

The sample for this cross-sectional study was identified from an evidence map of peer-reviewed empirical research including transgender, gender non-binary, and other gender diverse (trans) people. In order to develop the original dataset, a comprehensive search strategy was developed in collaboration with a health sciences librarian and included 220 trans-related search terms and 15 academic databases from the fields of health, education, social science, business, and the humanities. Further details about study identification and inclusion and exclusion criteria

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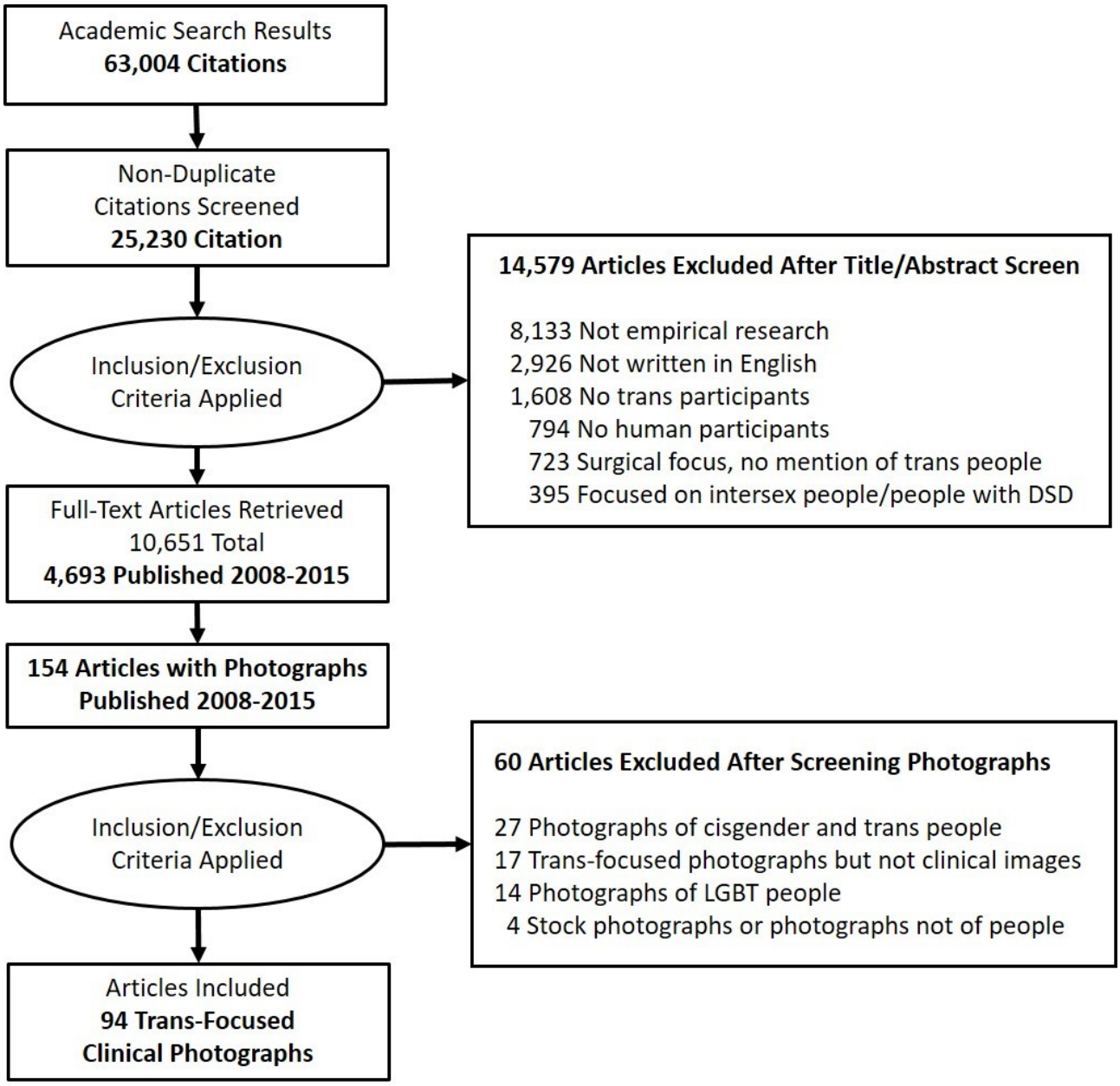
are found in the study protocol paper [19]. A sample search strategy is included in Multimedia Appendix 1.

The inclusion criteria were designed to identify empirical research published in English in peer-reviewed journals that included trans participants. As noted in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram in Figure 1, the initial search produced 25,230 references after duplicates were removed and 10,651 met the initial screening criteria; 4693 of these articles were published between 2008 and 2015. After screening on full text, 154 references published between 2008 and 2015 were identified that included photographs. We identified 94 articles with medical photographs of trans participants (see Multimedia Appendix 2 for a full list of this sample). For each reference, images were individually numbered in order to track a total of 605 medical photographs. We excluded 60 references for the following reasons: (1) the article included images of both cisgender and transgender people (27 references), (2) the article was trans-focused but the photographs were not clinical (17 references), (3) the article included images of lesbian, gay, bisexual, or transgender (LGBT) people (14 references), and (4) the article included only stock images or photographs that were not of people (4 references).

Google Images Search

For each publication, the first author (ZM) searched for the reference in Google Images using the full title of the article in quotation marks. This approach was selected after piloting several different strategies including searching for the full title without quotation marks, searching for the last name of the first author and the first few words of the title, or the last name of the first author and keywords in the title. The aim was to find an approach that was consistent, feasible, and that could be easily replicated. Searching for the title in quotation marks produced the most focused results, typically including 2-4 pages of images.

Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram.



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The Tor Browser is "a proxy that masks the location information and browsing history of the user, allowing for anonymous use of the Internet" (p. 18) [20]. This browser was used to conduct searches in order to minimize the influence of Google Analytics. For each individual search, a new identity was established within the Tor Browser and the Internet Protocol (IP) address for the last location in the Tor circuit was documented. Results for each search were saved in PDF. Any images identified from the search were compared to the photographs in the original article. For each image that was a match, we saved an electronic copy of the photograph. In addition, we clicked the hyperlink to "Visit Webpage" in order to determine the original source of the photograph. Results from the source webpage were also saved as PDFs.

One of the reasons for saving the searches as PDFs is that the results of Google Images searches are not static and potentially they will change over time. For this reason, it was important to have clear documentation of search results and images that were located as part of the search. Details of each search were saved in an Microsoft Excel spreadsheet including the last name of the study's first author, image identification number, URL for the image, URL for the source webpage, IP address from the Tor Browser, search date, and details about whether the image was found or not. All searches were conducted between May 21 and June 23, 2017.

Online Availability Search

As part of the data collection process, we were also interested in knowing whether the publication was available through open access and if this might influence whether the photographs were located on Google Images. A strategy for checking whether references were available through open access was developed with the team's health sciences librarian. One reviewer coded 10% of the trans-focused studies. A second reviewer verified the data extracted. Based on this information, we took two steps to check for open access using Google Scholar, PubMed, Researchgate.net, and Academia.edu. We searched the title of the article in quotation marks using Google Scholar. If the article was listed, we clicked through to either the paywall [21] or to the PDF.

Because some articles are available through the National Library of Medicine but are not available through Google Scholar (eg, *Journal of American Public Health Association*), we also searched for all references in PubMed. In addition, we searched for each reference on Researchgate.net and on Academia.edu, two social networking sites where researchers can share preprints and PDFs of academic publications. While Google Scholar often includes information about whether a PDF is available on Researchgate.net or Academia.edu, this is not always the case.

Dataset Demographics

In order to characterize the data at the level of individual photographs, we identified the following information for each photograph: (1) body location: face, chest, genitals, skin graft site, other, (2) population: trans women (including male-to-female transsexuals and people on the trans feminine spectrum), trans men (including female-to-male transsexuals and people on the trans masculine spectrum), and other, (3) timing: presurgery or pretreatment (including preoperative), during surgery or treatment, postsurgery or posttreatment (including immediately postoperative), specimen, autopsy, and other, (4) anonymization: anonymized, not anonymized, or not applicable, and (5) whether the image was in color or black and white. Images that were not photographs (such as X-rays and magnetic resonance images) were not included in this sample. Although such images may constitute personal health information, they are often considered separate from photographs. For clarity, we maintained a focus on medical photographs.

Patient Involvement

This study sits within a larger project focused on the development of an evidence map documenting research with trans individuals and communities. As part of the process of constructing evidence maps, it is recommended that researchers clarify concepts and engage key stakeholders in considering the potential scope of the review [22]. Accordingly, individual consultations were held with members of trans and cisgender communities to discuss terminology, search scope, and potential uses of study results. In addition, people from sexual and gender diverse communities were hired as research assistants on the project when possible. This specific project on the inclusion of medical photographs of trans patients in online image repository search results did not involve consultation with patients or trans community members. There will be an emphasis on patient and community involvement during the dissemination phase, including presentations at relevant trans health conferences and community events.

Results

Google Images Availability

In total, 37% (35/94) of articles included at least one photograph that was found on Google Images. When we searched the photographs individually, 20.3% (123/605) of clinical photographs in the articles were found on Google Images.

Online Availability

Over a third (38% [36/94]) of the references were available through open access on the journal website, through the journal publishers, or through PubMed. In addition, we checked for availability of articles on other websites including Researchgate.net, Academic.edu, and institutional repositories. Over half of the references (59% [55/94]) were available through at least one of these channels, meaning that article content was freely accessible.

Dataset Demographics

The average publication included 6 photographs, with a range of 1-29 images. In total, 605 photographs were included in the sample. The information presented in this section relates to analysis at the level of individual photographs. Photographs most commonly included genitals (48.4% [293/605]), chest or breasts (21.7% [131/605]), skin donor site (primarily forearm or leg) (10.1% [61/605]), and face (8.1% [49/605]) (see Figure 2).

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According to descriptions provided, 63.8% (386/605) of the individual photographs were of trans men or female-to-male trans people, 35.2% (213/605) were of trans women or male-to-female trans people, and 1% (6/605) could not be easily categorized. In terms of timing, 22.0% (133/605) of images were taken before treatment or surgery, 32.0% (194/605) of images were taken during surgery, and 37.4% (226/605) were taken postsurgery or after treatment. In addition, 3.1% (19/605) of images were of specimens, and 3.3% (20/605) were autopsy photographs. The majority (80.0% [484/605]) of the images were printed in color, and a fifth (20.0% [121/605]) in black and white.

Nearly 10% (58/605) of the images included identifiable elements including faces, full-body autopsy images, or potentially recognizable tattoos. Authors made anonymization attempts in almost a quarter of these photographs (24% [14/58]). This included placing small black boxes [23,24] or black bars [25] over the person's eyes. In one case, the authors taped a large piece of paper over the image covering the person's nose, eyes, and forehead [26]. For three-quarters (74% [43/58]) of the photographs with identifiable elements, there were no attempts at anonymization.

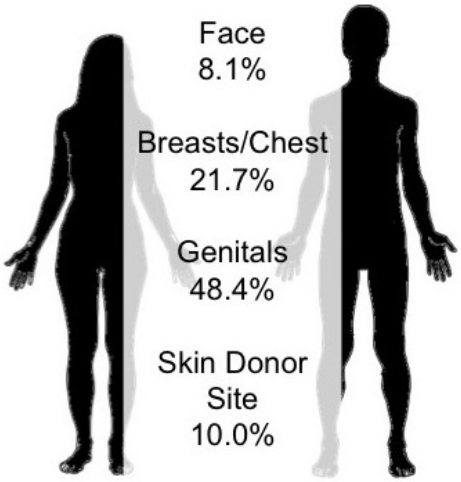
Documenting Informed Consent

We reviewed all 94 papers to verify if any mention was made of informed consent. Seven papers described obtaining written informed consent for publication of medical images from trans patients. For example, Aminsharifi et al [27] made the following statement, "Written informed consent was obtained from the patient for the publication of this case and accompanying images. A copy of the written consent is available for review by the Editor-in-Chief of this journal on request" (p. 268). We did not write to individual authors to confirm whether they obtained informed consent to publish clinical photographs and whether the consent form included explicit mention of electronic publishing or social media.

Factors Affecting Google Images Availability

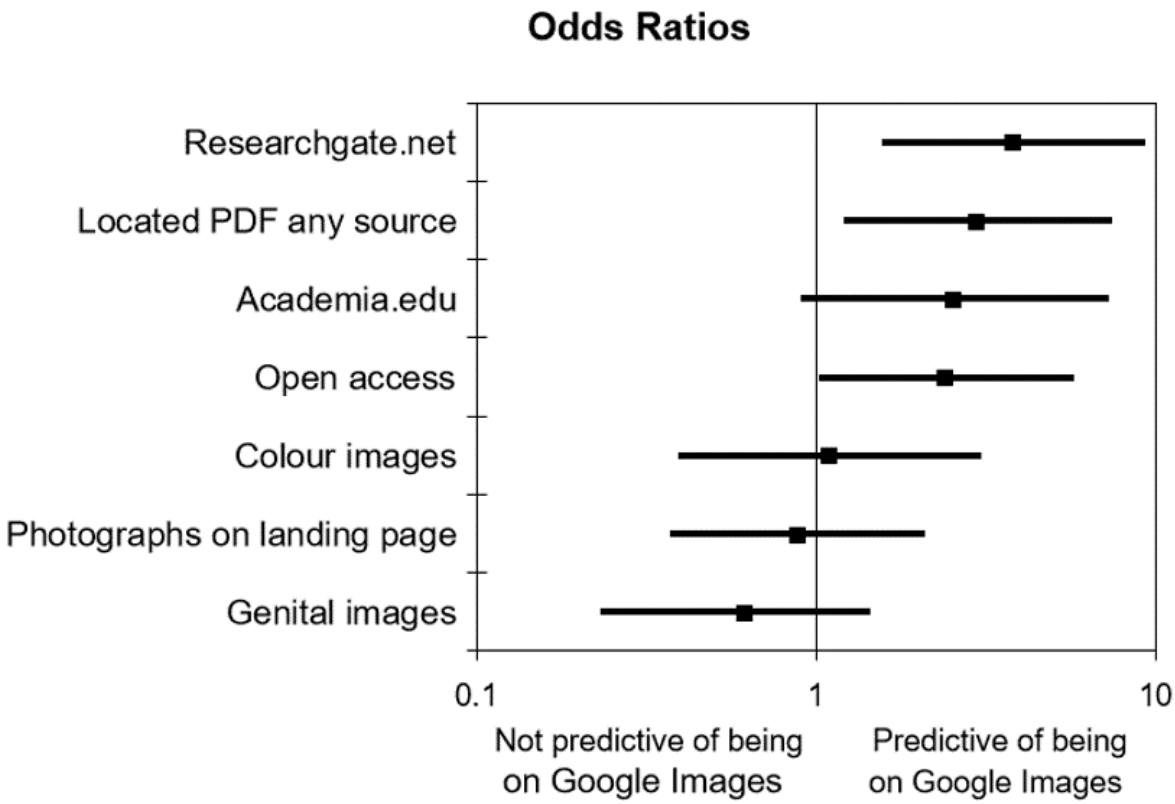
In order to understand what factors might be contributing to the number of clinical photographs available on Google Images, we calculated the odds ratios (OR) of availability on Google Images across specific factors that we expected might play a role based on the belief that Google may be filtering images of genitals from their search results. We also felt that article availability on Web-based platforms could influence whether photographs were included in Google Images search results. In addition, because of the ways Google crawls websites, we thought that if photographs were visible from the original landing page [28], then they might be more likely to appear in search results. As noted in Figure 3, the ability to locate a PDF of the article online through open access, Researchgate.net, or Academia.edu is one factor that contributes to the availability of at least one image from the article on Google Images (OR 2.99, 95% CI 1.20-7.45). This means that if the article is freely available online, there is 2.99 times the likelihood of finding an image from that article on Google Images. The odds ratio was also calculated for the following factors: color photographs (OR 1.09, 95% CI 0.39-3.07), photographs visible on journal landing page (OR 0.88, 95% CI 0.37-2.10), and pre- or postsurgery images of genitals (OR 0.62, 95% CI 0.23-1.44).

Figure 2. Characteristics of medical photographs.



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Figure 3. Odds ratios indicating likelihood of clinical photographs being included in Google Images search results.



Discussion

Principal Findings

In this cross-sectional study, we sought to determine what percentage of medical images from trans-focused peer-reviewed journal articles published between 2008 and 2015 was available on Google Images. Thirty-five articles out of 94 (37%) included at least one photograph that was found on Google Images, and the likelihood was almost three times higher for articles that were openly available through open access or other Web-based platforms. In total, 20.3% (123/605) of clinical photographs were found on Google Images. Given that it is unlikely that patients consented to sharing their personal health information in these ways, this constitutes a risk to patient privacy. For research studies, this likely also poses a problem in relation to research ethics guidelines.

Strengths and Limitations

To our knowledge, this is the first study to document the existence of medical photographs from peer-reviewed journals appearing in Google Images search results. One of its strengths is the systematic, documented approach to searches across a range of platforms including Google Scholar, PubMed, Researchgate.net, and Academia.edu.

At this time, there are no other studies with which to compare our results. This study included published clinical studies focused specifically on trans people. Given the emphasis on medical transition and gender affirming surgeries, it is likely that these publications include a higher number of genital, chest, or breast photographs than a random sample related to the overall population.

There are also other potential image databases we could have searched. In developing our search strategy, we tried several alternatives. However, it is important to note that some image search engines filter out results that are not family- or child-friendly. With the number of sensitive photographs in our dataset, it was important to select a search engine with the potential to clearly adjust these settings: Google Images provided this option (although it is unclear how many of the images may have been filtered out because they include pictures of genitals or breasts).

One of the challenges has been to understand the best way to search for images. After piloting several strategies, we focused on searching for the title of the article in quotation marks. This approach was more specific and led to a smaller number of search results than other search options. As technology develops, it will be possible to compare multiple search strategies and to search directly by image without using text. Google Image currently has this option, but we did not have the image files at the beginning of our searches in order to pursue this strategy.

Another difficulty is that the results of searches on Google Images are not static. This means that over time the results will shift, and medical photographs found during this search may not appear in the future. Similarly, images that were not found as part of this study could appear in future searches. Another challenge with this search is that sometimes images from one article in the dataset would appear in the results of a search for a different article. It seems that sometimes this was because of

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overlapping authors on the research teams, but at other times this appeared to be linked to the keywords (eg, phalloplasty or vaginoplasty). We did not include this information in our results, but this is an area for future attention.

When considering these challenges, it is important to keep the larger purpose of this study in mind. We were interested in determining what percentage of medical photographs from a sample of peer-reviewed journal articles were available on Google Images. While the specific results related to each photograph and article matter, the more important finding is the overall number of images we were able to find on Google Images and the implications for patients, clinicians, policy makers, and publishers.

It should also be noted that this sample was drawn from trans-focused publications. We have not yet tested whether the results would be similar for a general sample of clinical publications. However, given the methods used we have no reason to believe that the findings would be different. We plan to test this hypothesis in future studies.

Implications for Patients, Clinicians, Policy Makers, and Publishers

In over a third of the articles in this dataset, at least one medical photograph was located on Google Images. Almost all of the images we searched for included graphic photographs of patient genitals, chests, or breasts. Many of the pictures were taken during surgery or included pre- and postsurgical images. A number included patient faces or other identifying features with no attempts at anonymization. Some photographs included full-body images of people who are deceased, at times displayed in ways that did not preserve human dignity.

For trans people, the ability to control access to information about their lives as people who are transgender, transsexual, or gender non-binary has concrete ramifications linked to disclosure. This includes decisions about personal health information including medical photographs. Trans people experience heightened rates of discrimination, harassment, and violence [16,17], particularly those who are visibly gender non-binary or whose trans identities become known to individuals in their lives who may not have been previously aware of this information [18]. There are a limited number of surgeons and other medical specialists who provide care to trans patients. Typically, within a state or geographic region there may be only one or two providers who specialize in performing specific types of gender affirming surgeries. In Canada for example, there is only one clinic in the country where vaginoplasties and phalloplasties are conducted. These circumstances contribute to heightened privacy and confidentiality concerns for trans patients. The limited number of surgeons means that patients can be identified more easily based on the combined information provided in medical photographs alongside descriptive case reports. While there may be value in the use of medical photographs for education, clinical care, and research, there are serious ethical issues to consider in relation to the visibility of medical images in public search results: these concerns are enhanced for trans individuals.

There are multiple intervention points to address this situation. The first strategy is to inform patients as part of the written informed consent process that their medical photograph(s) could appear in online image databases, including the search results from Google Images. In addition to current guidelines indicating that patients should be shown a copy of any photographs that will be published as part of case reports or other medical publications, they need to be aware of the potential for their photograph to become more widely available on the Internet. Current research with patients in the field of dermatology suggests that patients are more open to having their images shared between medical practitioners than via websites [29].

As part of informing patients, institutional policies for medical photography and guidelines for clinicians will also need to reflect the risk of medical photographs appearing openly online. Similarly, journal guidelines for the use of medical images should address these possibilities and any steps being taken to mediate these risks.

A second strategy is to determine how online image databases are accessing medical photographs from peer-reviewed publications. While this may be facilitated by open access publishing, there are articles that are not available through open access or other online websites where the photographs still appear in Google Images search results. In June 2017, Google changed its policies to state that it will remove “confidential, personal medical records of private people” from its search results [30]. While it is currently unclear whether this will affect photographs published in peer-reviewed journals, it would be helpful to have additional information about this shift in practice and whether other search engines will institute equivalent policies.

Another option is for journal publishers to take a different approach to the ways medical photographs are shared online. For example, some publishers have medical photographs available as PowerPoint files but accessible only behind their paywall. As part of the chain of stakeholders sharing patient medical information, publishers also have a responsibility to consider the implications of patient photographs being shared through massive searchable image repositories such as Google Images.

Conclusions

The drive towards unrestricted open access suggests that the boundaries of the public domain between academic journals and search engines such as Google Images will become more porous. The public, the technology sector, and other stakeholders including clinicians, researchers, and policy makers all have stakes in the ways information travels across platforms. As Open Science [31] is increasingly emphasized, the need for critical perspectives is paramount [32]. Clinicians, researchers, and policy makers must respect patient autonomy, including attention to patient confidentiality, privacy, and informed consent. Medical photographs form part of the patient record and as such are subject to guidelines concerning the privacy of patient health information, regardless of the type of image and whether or not the patient is recognizable. In terms of copyright, these images may also be owned or co-owned by patients themselves. As part of research studies, medical photographs

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constitute part of the confidential data contributed by participants. Based on the impact of current practices, revisions to informed consent policies and guidelines are required. It is recommended that informed consent documents reflect the potential for medical photographs published in peer-reviewed journals to appear in image repositories such as Google Images search results. These new informed consent policies should be developed in collaboration with patients, with particular attention to images that may be published in online peer-reviewed publications or other online formats. In addition to the need for informed consent documents that detail all potential uses of medical photographs, it is recommended that journal publishers move to protect patient privacy by investigating technical options that would block the capture of medical images from their websites. Finally, the appearance of medical photographs in Google Images or other online search results after publication is also related to the technology and practices that online search engines use to capture images and create their image database, which are largely out of the control of manuscript authors and journal publishers. To address the root cause of this issue, search engines' relevant policy and practice guidance should be revised.

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Authors' Contributions

ZM conceptualized this study, conducted data collection and analysis, and wrote the initial draft of the manuscript. He is the guarantor for this research. CK and FB are cosupervisors of this project. They provided consultation at all stages of review development. SA and VW provided guidance concerning statistical analysis. All coauthors contributed revisions to the manuscript, and read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Sample PubMed search strategy for original evidence map.

[PDF File (Adobe PDF File), 89KB - jmir_v20i2e70_app1.pdf]

Multimedia Appendix 2

Full list of clinical studies with medical photographs.

[PDF File (Adobe PDF File), 172KB - jmir_v20i2e70_app2.pdf]

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Abbreviations

IP: Internet protocol
LGBT: lesbian, gay, bisexual, or transgender
OR: odds ratio
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
Trans: transgender, gender non-binary, and other gender diverse people

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Original Paper

Pharmacy Customers' Experiences With Electronic Prescriptions: Cross-Sectional Survey on Nationwide Implementation in Finland

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Abstract

Background: One of the forerunners in electronic health, Finland has introduced electronic prescriptions (ePrescriptions) nationwide by law. This has led to significant changes for pharmacy customers. Despite the worldwide ambition to develop ePrescription services, there are few reports of nationally adopted systems and particularly on the experiences of pharmacy customers.

Objective: The aim of this study was to investigate Finnish pharmacy customers' (1) experiences with purchasing medicines with ePrescriptions; (2) experiences with renewing ePrescriptions and acting on behalf of someone else at the pharmacy; (3) ways in which customers keep up to date with their ePrescriptions; and (4) overall satisfaction with ePrescriptions.

Methods: Questionnaires were distributed to 2913 pharmacy customers aged ≥18 years purchasing prescription medicines for themselves with an ePrescription in 18 community pharmacies across Finland in autumn 2015. Customers' experiences were explored with 10 structured questions. The data were stored in SPSS for Windows and subjected to descriptive analysis, chi-square, Fisher exact, Kolmogorov-Smirnov, the Mann-Whitney U, and Kruskal-Wallis tests.

Results: Completed questionnaires were returned by 1288 customers, a response rate of 44.19% (1288/2913). The majority of the respondents did not encounter any problems during pharmacy visits (1161/1278, 90.85%) and were informed about the current status of their ePrescriptions after their medication was dispensed (1013/1276, 79.44%). Over half of the respondents had usually received a patient instruction sheet from their physician (752/1255, 59.92%), and nearly all of them regarded its content as clear (711/724, 98.2%). Half of the respondents had renewed their ePrescriptions through the pharmacy (645/1281, 50.35%), and one-third of them had acted on behalf of someone else with ePrescriptions (432/1280, 33.75%). Problems were rarely encountered in the renewal process (49/628, 7.8%) or when acting on behalf of another person (25/418, 6.0%) at the pharmacy. The most common way of keeping up to date with ePrescriptions was to ask at the pharmacy (631/1278, 49.37%). The vast majority of the respondents were satisfied with ePrescriptions as a whole (1221/1274, 95.84%).

Conclusions: Finnish pharmacy customers are satisfied with the recently implemented nationwide ePrescription system. They seldom have any difficulties purchasing medicines, renewing their ePrescriptions, or acting on behalf of someone else at the pharmacy. Customers usually keep up to date with their ePrescriptions by asking at the pharmacy. However, some customers are unaware of the practices or have difficulty keeping up to date with the status of their ePrescriptions. The provision of relevant information and assistance by health care professionals is therefore required to promote customers' adoption of the ePrescription system.

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KEYWORDS

electronic prescribing; pharmacies; patient satisfaction; surveys and questionnaires

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Introduction

Introduction of ePrescriptions

Electronic health (eHealth), including electronic health records, electronic identification, online portals, and mobile health apps, has rapidly become common not only among health care providers but also patients and consumers. eHealth is about efficient and high-quality services, empowerment of patients, as well as enhanced information exchange and communication between health care professionals and patients [1]. As part of eHealth strategies, the implementation of electronic prescriptions (ePrescriptions) has been assessed as a pharmaceutical policy reform in many countries [2-4]. For example, in 2017, the Government of Canada invested Can $300 million over 5 years to enhance eHealth activities, including expanding ePrescribing and patients' access to their electronic health records [5]. The implementation of ePrescriptions primarily aims not just to improve medication safety but also to enhance the prescribing, dispensing, and purchasing of medicines [2,6]. The definition of ePrescription, however, varies between electronic transfer of a prescription from a prescriber to a particular pharmacy and a nationwide system where prescriptions are issued, transferred, stored, dispensed, and renewed via an information network [2,4,6]. This latter system has so far been introduced in a few countries including Sweden, Estonia, Denmark, the Netherlands, and Finland.

Once introduced, health care policy reforms should be rigorously evaluated by comparing their actual impacts with those anticipated before implementation [7,8]. The evaluation should encompass the effects from different viewpoints. The implementation of ePrescriptions has been widely studied from the perspective of health care professionals. Studies have concerned topics such as the benefits and problems of ePrescriptions [9-11], facilitators and barriers to their implementation [12], and their impact on workflow and medication safety [11,13-15]. However, experiences from nationwide ePrescription systems have been reported in only a few studies [7,9,14-17].

Patients' Perceptions of ePrescriptions

Despite researchers' wide interest in the implementation of ePrescriptions, the literature on the experiences of patients—one of the main user groups—is limited. The aim of ePrescriptions is to offer enhanced health care for patients. They enable the electronic storing of prescriptions and, as a consequence, streamline the purchasing of medicines at the pharmacy or even online [17]. Furthermore, electronic storing of medical records has provided patients with access to their personal records via Web-based services, and this has given them a more active role in the management of their medications [18-20]. It is therefore important to study whether patients have sufficient understanding of the system, whether they know how to use the services, and whether the services operate properly [21].

Patients' perceptions of ePrescriptions have been studied in the United States [22-26] and Sweden [17]. Studies conducted in Australia [27] and Scotland [28] have reported patients' attitudes toward ePrescriptions before the implementation. However, the study settings have mainly been local and the samples rather small, involving patients from 1 clinic [23,24,27] or 1 state [25,26]. According to the literature, patients' attitudes toward ePrescriptions are positive [17,22,23,27,28] partly as a result of their experiences with ePrescription services [17,22]. An ePrescription has commonly been defined as a prescription that a prescriber electronically issues and sends to a certain pharmacy [22-27]. To the authors' knowledge, patients' attitudes toward a nationwide ePrescription system have only been studied in Sweden [17]. However, there is little published information on how the nationwide system works in practice from the patient's perspective and how patients keep up to date with their ePrescriptions.

This study is part of a research project studying health care professionals' and patients' experiences with the recently implemented nationwide ePrescription system in Finland. The project aims to investigate whether the system has achieved the objectives predefined by law. The objective of this study was to investigate Finnish pharmacy customers' experiences with ePrescriptions. The specific aims were to explore the following:

- experiences of purchasing medicines with ePrescriptions
- experiences of renewing ePrescriptions and acting on behalf of someone else at the pharmacy
- how customers keep up to date with their ePrescriptions
- how satisfied they are with the ePrescription system as a whole

Methods

Study Context

Introduction of ePrescriptions in Finland

In Finland, the nationwide introduction of ePrescriptions by law began in 2012, and Finnish pharmacies started to dispense ePrescriptions in the same year [29]. The issuing of ePrescriptions was made obligatory in public health care in 2013 and in private health care in 2015. At the beginning of 2017, all health care providers were obliged to introduce the ePrescription system, and nowadays, conventional prescriptions (eg, paper, telephone) are only permitted in exceptional situations such as blackouts. The use of ePrescriptions aims to improve patient and medication safety as well as facilitate and streamline the prescribing and dispensing of medicines. In 2015, when the survey reported in this paper was conducted, over 90% of nearly 56 million prescriptions dispensed in Finnish pharmacies were electronic [30,31].

The ePrescription System From the Patient's Perspective

In Finland, ePrescriptions are issued, transferred, stored, and dispensed electronically [29]. Once issued, ePrescriptions are stored in a centralized database (the Prescription Centre) from which they can be retrieved and dispensed in any Finnish pharmacy. The patient can choose the most convenient pharmacy at the time of purchasing the medicine. Patients can view their ePrescriptions and other personal medical records in a Web service called My Kanta [19,32].

A patient who is present when an ePrescription is issued is entitled to receive a patient instruction sheet from the physician. The document includes a summary of the ePrescription: the

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brand or generic name of the medicine prescribed, dosage instructions, prescriber, place and date of prescribing, quantity or duration of therapy, and the expiry date of the prescription. However, the patient can decline to receive a patient instruction sheet.

At the pharmacy, a patient gets his or her medicines dispensed by showing a patient instruction sheet, a personal health insurance card, or other valid ID [33]. The Act on Electronic Prescriptions 61/2007 requires the pharmacist to give the patient the latest information about the amount of medication still to be dispensed. The information is also printed out onto the dispensing label to be attached to the medicine package.

The patient can ask for a renewal of an ePrescription at a health care unit or at a pharmacy from where the renewal request is sent electronically to a health care unit [33]. Patients can ask someone else to act on their behalf at the pharmacy. The person purchasing another's medicine with an ePrescription is required to present the patient's insurance card or a patient instruction sheet. Signed consent is needed when a patient authorizes another person to ask for a renewal of an ePrescription, requests a printed summary of his or her ePrescriptions, or asks the pharmacist, physician, or nurse to delete his or her ePrescription.

Validity of Prescriptions

In Finland, a prescription is valid for 2 years from the date of issue, the exceptions being prescriptions for central nervous system agents with abuse potential or narcotic agents, which are valid for 12 months. Prescription validity was extended from 12 months to 24 months in January 2017; so, at the time of this study, ePrescriptions were valid for 1 year. A prescription can be prescribed for a specific period (*1-year dosage*) or for an amount (*400 tablets*). Nevertheless, patients can be reimbursed for the maximum of 3 months' dosage dispensed at the pharmacy at a time. Consequently, a reimbursable purchase for 3 months' medication can be repeated 4 times during the validity period of 1 year.

The Survey

A questionnaire survey was conducted among pharmacy customers aged ≥18 years who were purchasing medicines for themselves with ePrescriptions in autumn 2015. Questionnaires were handed out by 18 different-sized pharmacies across Finland. The number of questionnaires delivered to each pharmacy varied between 30 and 200, and was adjusted according to the number of prescriptions dispensed daily at the pharmacy. We provided pharmaceutical staff with instructions on the distribution of questionnaires. Pharmacists informed customers about the study after dispensing their medication and offered them the questionnaire together with a franked envelope for their responses. They were not required to keep a list of customers who declined to participate. The questionnaires were handed out as long as there were forms left, but for a maximum of 2 weeks. After the study period, pharmacies reported the number of questionnaires left to compute the response rate. Altogether, 2915 questionnaires were distributed. Reminders could not be sent as we were unaware of the customers' addresses.

The Questionnaire

The 4-page form contained 26 questions (Multimedia Appendix 1). The main themes of the questions were as follows: (1) customers' experiences with purchasing medicines with ePrescriptions, (2) experiences with and opinions on the My Kanta service, (3) opinions on the benefits and problems with ePrescriptions, and (4) information sources and information needs related to ePrescriptions. The questionnaire was designed on the basis of the mandated objectives of ePrescriptions [29], the anticipated impacts of ePrescriptions [34], and some previous studies [17,35]. The questionnaire was pilot tested in a local pharmacy in spring 2015. The pilot customers were interviewed at the pharmacy after filling in the questionnaires to check that they had understood the questions. Minor modifications were made based on the pilot test. However, modifying the questions reported in this paper was not necessary.

This paper reports results from 10 questions related to respondents' experiences with purchasing medicines with ePrescriptions, renewing ePrescriptions through the pharmacy, acting on behalf of another person, and their overall satisfaction with ePrescriptions (Questions 2-10 and 21 in Multimedia Appendix 1). Two questions were defined with the phrase "this time at the pharmacy," the aim being to gain cross-sectional data about technical problems or ambiguities in ePrescriptions during the dispensing process and how pharmacists comply with the instruction to inform customers about their ePrescription details. All the questions were structured. Some questions had space for respondents to expand on their answer, and some were multiple choice questions. The question asking how satisfied the respondent is with ePrescriptions as a whole was answered on a 6-point Likert-type rating scale, where 1 represented not at all satisfied and 6 very satisfied.

Structured questions yielded background information on the respondents' gender, area of residence, education, and regularity of prescription medicine use (Questions 22 and 24-26 in Multimedia Appendix 1). The respondent's year of birth was obtained by means of an open-ended question (Question 23 in Multimedia Appendix 1). Furthermore, to explore the extent of respondents' experiences, a structured question asked respondents to estimate how many times they had purchased medicines with ePrescriptions within the last 6 months (Question 1 in Multimedia Appendix 1).

Statistical Methods

Data from the questionnaires were entered into the Statistical Package for Social Scientists software (version 23.0 SPSS Inc, Chicago, IL, USA). A descriptive approach (frequencies, means) was used in the analysis. In the analyses, the respondent's age was placed into 1 of the 4 groups (18-34, 35-59, 60-74, and 75 years or older). Categorical data from questions concerning respondents' experiences with ePrescriptions, renewals at the pharmacy, acting on behalf of someone else, and checking the status of ePrescription were compared with background variables using either the Pearson chi-square test or two-sided Fisher exact test. After Kolmogorov-Smirnov normality test, statistical significance of differences between means in independent groups was assessed using the Mann-Whitney *U* or Kruskal-Wallis

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tests for the satisfaction with ePrescriptions. Statistical significance was determined as $P<.05$.

Ethical Statement

The study setting and research process complied with local and national ethical instructions for research [36]. This study required no ethical approval.

Results

Study Population

In total, 2915 questionnaires were handed out to pharmacy customers and 1290 were returned to the authors. Two forms, however, were excluded as the respondents were aged less than 18 years. Consequently, the study sample was 2913, giving a response rate of 44.21% (N=1288).

Background information on the study population is presented in Table 1.

Table 1. Characteristics of the study respondents (N=1288).

Characteristic	n (%)
Gender (n=1287 [a])	
Female	965 (74.98)
Male	322 (25.02)
Age in years (n=1167 [a])	
18-34	137 (11.74)
35-59	379 (32.48)
60-74	476 (40.79)
≥75	175 (15.00)
Education (n=1263 [a])	
Basic education (comprehensive school)	274 (21.69)
Vocational degree	459 (36.34)
Secondary school graduate	152 (12.03)
Lower-level university degree	203 (16.07)
Higher-level university degree	175 (13.86)
Current use of prescription medicines (n=1272 [a])	
Temporarily	117 (9.20)
Regularly	715 (56.21)
Both regularly and temporarily	440 (34.59)
Area of residence (n=1276 [a])	
Southern Finland	301 (23.59)
Southwestern Finland	208 (16.30)
Western and Central Finland	205 (16.07)
Eastern Finland	183 (14.34)
Northern Finland	256 (20.06)
Lapland	123 (9.64)
Medicine purchases with an ePrescription within the last six months (N=1283 [a])	
First time during the study	37 (2.88)
2-5 times	688 (53.62)
6-10 times	335 (26.11)
Over 10 times	223 (17.38)

[a]Some of the respondents did not report their gender, age, education, usage of prescription medicines, area of residence, or how many times they had purchased medicines with an ePrescriptions within the last 6 months.

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The majority of the respondents were female and the mean age was 59 years (range 18-93, median 62). All 6 geographical areas of Finland were represented among the study population. Most of the respondents had gained experience with purchasing medicines with ePrescriptions several times within the previous 6 months.

Experiences With the Patient Instruction Sheet

Over half (752/1255, 59.92%) of the respondents had usually received a patient information sheet concerning the prescribed medicine from the physician (Table 2). Over one-third of the respondents (503/1255, 40.08%) reported not receiving the information sheet: for 23.75% (298/1255), the physician did not offer it, whereas 5.58% (70/1255) reported they had declined to receive it. The rest (135/1255, 10.76%) did not know what a patient information sheet is. Those who had usually received the sheet generally regarded its content as clear (711/724, 98.2%). However, respondents in the age group 75 years and older were likely to state that the content was unclear (P=.04).

Experiences With Purchasing Medicines With ePrescriptions

The majority (1161/1278, 90.85%) of the respondents reported not encountering any problems with their ePrescriptions at the pharmacy (Table 2). Almost one-tenth (117/1278), however, experienced some inconvenience or a problem during the visit.

From the total of 162 reported problems, the most common were that the ePrescription had expired without the respondent's knowledge (59/117, 50.4%), the ePrescription had no medication remaining and the respondent was unaware of this (40/117, 34.2%), and the physician had not sent the ePrescription as promised (22/117, 18.8%). Those aged 75 years and older and respondents using prescription medicines both regularly and temporarily were more likely to experience problems (P=.005 and P=.04, respectively) compared with others (Table 2).

Most of the respondents (1013/1276, 79.29%) were told how much medication was remaining on their ePrescription after the purchase (Table 2). Older pharmacy customers were more likely to be informed about the number of batches remaining than working age customers (P<.001). Furthermore, significant differences were observed between respondents' education level (P=.02) and the regularity of prescription medicine use (P<.001). Those with higher levels of education and those using prescription medicines only temporarily were unlikely to be informed compared with respondents with only basic education or using prescription medicines regularly.

Experiences With ePrescription Renewals and Acting on Behalf of Someone Else

Approximately half of the respondents (645/1281, 50.35%) had renewed their ePrescriptions through the pharmacy (Table 2). Significant differences were observed between genders (P=.033), age groups (P<.001), education (P<.001), regularity of prescription medicine use (P<.001), and area of residence (P<.001). Those who had made the renewal request at the pharmacy rarely encountered any problems during the process (579/628, 92.2%). However, 49 respondents (7.8%) reported inconveniences such as long waiting times, medication running out before the renewal, technical problems, no notification that a renewal had been authorized or that the ePrescription had not been renewed despite the customer's request.

One-third of the respondents (432/1280, 33.75%) had acted on behalf of someone else with an ePrescription at the pharmacy. The majority of those who had acted on behalf of others were satisfied with the service (393/418, 94.1%), whereas 25 respondents (6%) reported problems such as being unaware of the required signed consent or a parent's inability to access a minor's up-to-date ePrescription details in the My Kanta service.

Experiences With Keeping Up to Date With ePrescriptions

The respondents generally kept up to date with their ePrescription status (eg, amount of medication remaining or expiry date of a prescription) by asking at the pharmacy (631/1278, 49.37%), reading the label affixed to the medication package (574/1278, 44.91%), or using the My Kanta Web service (491/1278, 38.42%); see Table 3.

Asking at the pharmacy and reading the dispensing label were the most common methods among the oldest age group (P=.01 and P<.001, respectively). In contrast, the oldest pharmacy customers were less likely to use My Kanta than younger respondents (P<.001).

Reading the dispensing label was also common among women (P=.008), respondents using prescription medicines regularly (P<.001), and respondents with only basic education (P<.001). The My Kanta service was used regularly by respondents with education higher than comprehensive school (P<.001) and by those using prescription medicines both regularly and temporarily (P=.03).

Overall Satisfaction With ePrescriptions

The general attitude toward ePrescriptions was positive among the respondents. On the 6-point Likert scale, 95.84% (1221/1274) of all respondents rated their overall satisfaction as 4 to 6 (Table 4). The mean for the level of satisfaction was 5.35. Overall satisfaction differed significantly between age groups (P=.049), respondents' education (P<.001), and regularity of prescription medicine use (P=.03). The oldest respondents, respondents with only basic education, and respondents using prescription medicines regularly were likely to be very satisfied with ePrescriptions.

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Table 2. Respondents' experiences with ePrescriptions.

Characteristic	Has usually received a patient instruction sheet from a physician	Perceives the content of the patient instruction sheet as clear[a]	Did not encounter any problems with his or her ePrescription(s) at the pharmacy	Was told about the amount of medication still to be dispensed under the ePrescription(s) at the pharmacy	Has renewed ePrescription(s) through the pharmacy
All, n (%)	752 (59.92)	711 (98.20)	1161 (90.85)	1013 (79.39)	645 (50.35)
Gender	*P*=.42	*P*=.74	*P*=.47	*P*=.10	*P*=.03
Female, n (%)	571 (60.6)	542 (98.0)	867 (90.5)	751 (78.3)	466 (48.6)
Male, n (%)	181 (58.0)	169 (98.8)	293 (91.8)	261 (82.6)	178 (55.5)
Age in years	*P*=.545	*P*=.039	*P*=.005	*P*<.001	*P*<.001
18-34, n (%)	77 (56.2)	71 (97)	127 (92.7)	96 (70.1)	30 (21.9)
35-59, n (%)	224 (59.3)	215 (99.1)	354 (93.7)	274 (73.3)	144 (38.2)
60-74, n (%)	283 (61.8)	271 (98.9)	425 (90.0)	397 (84.5)	282 (59.6)
≥75, n (%)	96 (56.8)	86 (95)	146 (84.4)	150 (85.7)	132 (75.9)
Education	*P*=.73	*P*=.06	*P*=.20	*P*=.02	*P*<.001
Basic education, n (%)	151 (59.5)	144 (99.3)	238 (87.5)	229 (85.1)	182 (67.4)
Vocational degree, n (%)	277 (61.4)	265 (99.3)	415 (91.0)	365 (80.2)	251 (54.9)
Secondary school graduate, n (%)	94 (62.7)	90 (99)	142 (93.4)	117 (77.0)	56 (36.8)
Lower-level university degree, n (%)	117 (57.9)	106 (95.5)	182 (91.0)	147 (72.8)	73 (36.1)
Higher-level university degree, n (%)	98 (56.6)	94 (96.9)	163 (93.1)	133 (76.9)	65 (37.1)
Current use of prescription medicines	*P*=.16	*P*=.13	*P*=.04	*P*<.001	*P*<.001
Temporarily, n (%)	69 (59.0)	68 (100)	111 (94.9)	74 (64.3)	30 (25.6)
Regularly, n (%)	399 (57.9)	377 (99.0)	650 (91.9)	570 (80.6)	376 (52.7)
Both regularly and temporarily, n (%)	278 (63.6)	261 (97.0)	387 (88.4)	354 (80.8)	228 (52.3)
Area of residence	*P*=.07	*P*=.56	*P*=.17	*P*=.29	*P*<.001
Southern Finland, n (%)	174 (59.6)	161 (97.0)	275 (91.7)	232 (77.6)	110 (36.8)
Southwestern Finland, n (%)	132 (64.1)	122 (98.4)	193 (92.8)	153 (74.3)	94 (45.4)
Western and Central Finland, n (%)	135 (67.5)	129 (98.5)	183 (91.0)	164 (80.8)	107 (52.7)
Eastern Finland, n (%)	100 (56.2)	94 (96.9)	162 (89.5)	145 (79.7)	115 (63.2)
Northern Finland, n (%)	136 (54.6)	131 (99.2)	223 (87.5)	208 (82.2)	130 (51.0)
Lapland, n (%)	70 (58.3)	69 (100)	115 (95.0)	101 (82.8)	80 (65.0)

[a]Respondents who had usually received a patient information sheet answered the question.

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Table 3. How respondents (N=1278) check the status of their ePrescriptions (eg, amount of medication remaining or expiry date of a prescription). A respondent may have chosen several alternatives.

Characteristic	Ask at the pharmacy	Read the label affixed to the medication package	Use the My Kanta service	Keep track of it themselves	Read the patient instruction sheet	Do not check it at all	Use another method[a]
All, n (%)	631 (49.37)	574 (44.91)	491 (38.42)	109 (8.53)	72 (5.63)	65 (5.09)	25 (1.96)
Gender	*P*=.13	*P*=.008	*P*=.42	*P*=.32	*P*=.40	*P*> .99	*P*=.13
Female, n (%)	485 (50.3)	451 (46.7)	362 (37.5)	86 (8.9)	57 (5.9)	48 (5.0)	22 (2.3)
Male, n (%)	146 (45.3)	123 (38.2)	129 (40.1)	23 (7.1)	15 (4.7)	16 (5.0)	3 (0.9)
Age in years	*P*=.01	*P*<.001	*P*<.001	*P*=.97	*P*=.02	*P*=.002	*P*=.40
18-34, n (%)	75 (54.7)	50 (36.5)	65 (47.4)	11 (8.0)	10 (7.3)	13 (9.5)	5 (3.6)
35-59, n (%)	187 (49.3)	140 (36.9)	180 (47.5)	29 (7.7)	23 (6.1)	26 (6.9)	6 (1.6)
60-74, n (%)	208 (43.7)	245 (51.5)	183 (38.4)	40 (8.4)	15 (3.2)	15 (3.2)	10 (2.1)
≥75, n (%)	98 (56.0)	98 (56.0)	26 (14.9)	13 (7.4)	15 (8.6)	4 (2.3)	2 (1.1)
Education	*P*=.24	*P*<.001	*P*<.001	*P*=.047	*P*=.04	*P*<.001	*P*=.31
Basic education, n (%)	130 (47.4)	147 (53.6)	68 (24.8)	20 (7.3)	8 (2.9)	10 (3.6)	5 (1.8)
Vocational degree, n (%)	221 (48.1)	221 (48.1)	187 (40.7)	34 (7.4)	22 (4.8)	17 (3.7)	7 (1.5)
Secondary school graduate, n (%)	81 (53.3)	67 (44.1)	62 (40.8)	23 (15.1)	11 (7.2)	3 (2.0)	1 (0.7)
Lower-level university degree, n (%)	110 (54.2)	69 (34.0)	94 (46.3)	17 (8.4)	14 (6.9)	14 (6.9)	6 (3.0)
Higher-level university degree, n (%)	77 (44.0)	56 (32.0)	72 (41.1)	15 (8.6)	16 (9.1)	21 (12.0)	6 (3.4)
Current use of prescription medicines	*P*=.07	*P*<.001	*P*=.03	*P*=.74	*P*<.001	*P*<.001	*P*=.18
Temporarily, n (%)	51 (43.6)	34 (29.1)	40 (34.2)	12 (10.3)	12 (10.3)	22 (18.8)	2 (1.7)
Regularly, n (%)	337 (47.1)	317 (44.3)	257 (35.9)	58 (8.1)	23 (3.2)	31 (4.3)	10 (1.4)
Both regularly and temporarily, n (%)	234 (53.2)	217 (49.3)	191 (43.4)	37 (8.4)	37 (8.4)	11 (2.5)	13 (3.0)
Area of residence	*P*=.20	*P*=.69	*P*=.97	*P*=.10	*P*=.07	*P*=.72	*P*=.26
Southern Finland, n (%)	142 (47.2)	130 (43.2)	118 (39.2)	23 (7.6)	18 (6.0)	16 (5.3)	9 (3.0)
Southwestern Finland, n (%)	93 (44.7)	91 (43.8)	80 (38.5)	24 (11.5)	20 (9.6)	12 (5.8)	3 (1.4)
Western and Central Finland, n (%)	92 (44.9)	100 (48.8)	75 (36.6)	17 (8.3)	12 (5.9)	10 (4.9)	4 (2.0)
Eastern Finland, n (%)	101 (55.2)	86 (47.0)	69 (37.7)	11 (6.0)	6 (3.3)	7 (3.8)	4 (2.2)
Northern Finland, n (%)	133 (52.0)	107 (41.8)	103 (40.2)	28 (10.9)	9 (3.5)	10 (3.9)	1 (.4)
Lapland, n (%)	63 (51.2)	53 (43.1)	45 (36.6)	5 (4.1)	7 (5.7)	9 (5.0)	3 (2.4)

[a]Freely worded answers included “ask the physician about it,” “use a Web portal of a private health center,” and “monitor the consumption of the medication.”

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Table 4. Respondents' (N=1274) overall satisfaction with ePrescriptions on a 6-point Likert scale, from 1 being "not at all satisfied" to 6 being "very satisfied."

Characteristic	1, n (%)	2, n (%)	3, n (%)	4, n (%)	5, n (%)	6, n (%)	*P* value
All	13 (1.0)	12 (0.9)	28 (2.2)	89 (7.0)	447 (35.1)	685 (53.8)	
Gender							.55
Female	10 (1.0)	5 (1.6)	2 (0.6)	24 (7.6)	107 (34.0)	174 (55.2)	
Male	3 (1.0)	7 (0.7)	26 (2.7)	65 (6.8)	339 (35.4)	511 (53.3)	
Age in years							.049
18-34	0 (0.0)	1 (0.7)	4 (2.9)	8 (5.9)	60 (44.1)	63 (46.3)	
35-59	2 (0.5)	3 (0.8)	4 (1.1)	23 (6.1)	157 (41.8)	187 (49.7)	
60-74	4 (0.8)	4 (0.8)	11 (2.3)	41 (8.7)	138 (29.2)	275 (58.1)	
≥75	6 (3.6)	3 (1.8)	4 (2.4)	5 (3.0)	45 (26.6)	106 (62.7)	
Education							<.001
Basic education	6 (2.2)	1 (0.4)	6 (2.2)	14 (5.2)	63 (23.5)	178 (66.4)	
Vocational degree	4 (0.9)	7 (1.5)	10 (2.2)	36 (7.9)	154 (33.8)	244 (53.6)	
Secondary school graduate	1 (0.7)	0 (0)	5 (3.3)	15 (10.0)	60 (40.0)	69 (46.0)	
Lower-level university degree	1 (0.5)	2 (1.0)	4 (2.0)	4 (2.0)	86 (42.6)	105 (52.0)	
Higher-level university degree	1 (0.6)	1 (0.6)	2 (1.1)	18 (10.3)	79 (45.1)	74 (42.3)	
Current use of prescription medicines							.03
Temporarily	0 (0)	1 (0.9)	3 (2.6)	11 (9.4)	47 (40.2)	55 (47.0)	
Regularly	8 (1.1)	3 (0.4)	11 (1.6)	43 (6.3)	240 (34.0)	400 (56.7)	
Both regularly and temporarily	5 (1.1)	7 (1.6)	11 (2.5)	35 (8.0)	156 (35.8)	222 (50.9)	
Area of residence							.73
Southern Finland	4 (1.3)	4 (1.3)	7 (2.3)	26 (8.7)	95 (31.9)	162 (54.4)	
Southwestern Finland	0 (0)	1 (0.5)	5 (2.4)	16 (7.7)	86 (41.5)	99 (47.8)	
Western and Central Finland	2 (1.0)	3 (1.5)	6 (3.0)	10 (5.0)	69 (34.5)	110 (55.0)	
Eastern Finland	2 (1.1)	1 (0.5)	2 (1.1)	10 (5.5)	67 (36.8)	100 (54.9)	
Northern Finland	2 (0.8)	2 (0.8)	7 (2.8)	14 (5.5)	88 (34.8)	140 (55.3)	
Lapland	2 (1.6)	1 (0.8)	1 (0.8)	12 (9.8)	41 (33.6)	65 (53.3)	

Discussion

Principal Findings and Comparison With Prior Work

This study found that Finnish pharmacy customers are highly satisfied with ePrescriptions as a whole. They rarely encounter any problems in purchasing medicines with ePrescriptions, in acting on behalf of someone else, or in renewing ePrescriptions at the pharmacy. The most common way of keeping up to date with their ePrescriptions is to ask at the pharmacy. The results are in line both with the literature [17,23,26] and with our earlier studies [19,37].

Finnish pharmacy customers are very satisfied with the nationwide ePrescription system, even more than the Swedes [17] or pharmacists and physicians in Finland [14,15]. In our earlier study, pharmacy customers reported benefits more often than problems in ePrescriptions [37]. Overall, the most common benefits of using ePrescriptions highlighted by medicine users are the ease of purchasing prescription medicines and the electronic storing of prescriptions [17,22,23,37].

Despite its several benefits, Finnish health care professionals have criticized the ePrescription system as slow and rigid [14,15]. Although the new system has streamlined the dispensing process as a whole, many community pharmacists reported facing errors or ambiguities in ePrescriptions requiring clarification during the dispensing process every week or even daily [15]. However, the results of this study indicate that pharmacy customers are not conscious of the rigidity of data systems or defects in ePrescriptions.

Many problems customers encountered during the pharmacy visit were related to their lack of awareness of the current status of their ePrescriptions such as the expiry date and to insufficient information received about the services. The consequences of these problems remain unknown, but they may have caused a gap in the customer's medication or at least a new visit to the pharmacy. Customers' difficulty keeping up to date with their ePrescribed medications has also been reported in our earlier

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studies among Finnish pharmacy staff and pharmacy customers [37,38] as well as in studies conducted in the United States [22-24,39]. In Finland, the difficulty occurs particularly among older persons and medicine users without a computer, the Internet, or electronic IDs, which are required to log into the My Kanta service [37,38]. According to this study, most of the respondents check the status of their ePrescriptions by asking at the pharmacy, whereas the My Kanta service was used more rarely. In addition to inaccessibility, one reason why the Web service is relatively little used could be that customers are unaware of it [19]. Medicine users' familiarity with the Web service should be enhanced as eHealth services aim to improve patient empowerment. However, there will still be patients refusing or being unable to use new technologies. Future studies should examine which existing or new methods they prefer to receive information about their ePrescriptions.

Another finding suggesting pharmacy customers need assistance or additional information on ePrescription practices was that several respondents were unfamiliar with the patient instruction sheet. According to the Finnish Act on Electronic Prescriptions, the health care units involved are required to provide information about ePrescriptions and related services for patients before they receive an ePrescription for the first time [29]. However, laypeople probably need to be given information several times before they can adopt the new technology, which implies that the obligation to provide information should be extended from prescribers to dispensers. The information needs to be consistent and offered not only on the first occasion but repeatedly to new users of the ePrescription service. The health care professionals involved must also be properly trained in the new services in advance.

Some of the problems reported in renewing ePrescriptions and acting on behalf of someone else at the pharmacy may now be outdated because the system has undergone a few improvements since the survey was conducted. For one thing, patients have since been able to use the My Kanta service to send renewal requests by themselves. A phone number can be added to the request for a text message stating when a renewal has been authorized. Not only is the process convenient and streamlined but the electronic renewal of prescriptions via Web-based portals may also improve patients' medication adherence and the results of medication therapies [20,40,41]. Second, guardians are now entitled to view the ePrescriptions and other health records of their dependents less than 10 years in My Kanta. In the future, it would be sensible to allow patients to consent to another person acting on their behalf via the My Kanta service. The paperless system would ease the workload on pharmacies and health care units, which are required to archive consents for 12 years after they have expired. In addition, an electronic consent would be easier for the patient to cancel or change. To promote the use of My Kanta, a mobile app could be one of the future developments.

Strengths and Limitations

The findings of this study are based on a fully operational ePrescription system that had been in nationwide use for a few years during the survey. Most of the respondents had purchased medicines with an ePrescription several times before the study. The method used prevented us from sending out reminders but was suitable for reaching the target population, that is, persons with experiences of ePrescriptions. The response rate of 44% is comparable with that of other studies conducted with similar methods [42,43]. As the questionnaires were randomly distributed by pharmacists, we had no background information on the customers asked to participate in the study. Comparable statistics on Finnish pharmacy customers' characteristics are not available. However, the respondents' use of prescription medicines (regularly, temporarily, or both) as well as age and gender distributions were similar to those of an earlier study surveying Finnish pharmacy customers' experiences with generic substitution conducted with a similar method [42]. Consequently, we believe our study population well represents those customers purchasing their prescription medicines at Finnish community pharmacies.

This study explored Finnish pharmacy customers' first experiences with the recently implemented ePrescriptions in 2015. The nationwide system has been further developed ever since. To evaluate patients' adaptation to the ePrescription system more rigorously, their experiences, overall satisfaction, and ways of keeping up to date with their ePrescriptions should be continuously explored as the system matures. On the other hand, while the digital divide constantly narrows, future studies should investigate whether the new digital generation has different perspectives and ideas on how to make the ePrescription system more customer friendly.

Conclusions

Overall, Finnish pharmacy customers are highly satisfied with ePrescriptions and rarely have any problems with them. The problems encountered are often related to customers' unawareness of the practices and difficulty keeping up to date with the status of their ePrescriptions. Despite the national Web service for viewing ePrescriptions, customers' most common way of keeping up to date with their ePrescriptions is to ask at the pharmacy. In conclusion, pharmacy customers need clear information and assistance from health care professionals in advance and during implementation of a nationwide ePrescription system.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

The Questionnaire.

[PDF File (Adobe PDF File), 199KB - jmir_v20i2e68_app1.pdf]

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Abbreviations

eHealth: electronic health
ePrescriptions: electronic prescriptions

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