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Contents

Viewpoints

Original Papers

Viewpoint

Swarm-Based Medicine

Paul Martin Putora[1], MA, MD, PhD; Jan Oldenburg[2], MD, PhD

[1]Department of Radiation Oncology, Kantonsspital St Gallen, St Gallen, Switzerland

[2]National Resource Center for Late Effects, Department of Oncology, Norwegian Radium Hospital and Oslo University, Oslo, Norway

Corresponding Author:
Paul Martin Putora, MA, MD, PhD
Department of Radiation Oncology
Kantonsspital St Gallen
Rorschacherstr 95
St Gallen, 9007
Switzerland
Phone: 41 714942268
Fax: 41 714942893
Email: paul.putora@kssg.ch

Abstract

Occasionally, medical decisions have to be taken in the absence of evidence-based guidelines. Other sources can be drawn upon to fill in the gaps, including experience and intuition. Authorities or experts, with their knowledge and experience, may provide further input—known as “eminence-based medicine”. Due to the Internet and digital media, interactions among physicians now take place at a higher rate than ever before. With the rising number of interconnected individuals and their communication capabilities, the medical community is obtaining the properties of a swarm. The way individual physicians act depends on other physicians; medical societies act based on their members. Swarm behavior might facilitate the generation and distribution of knowledge as an unconscious process. As such, “swarm-based medicine” may add a further source of information to the classical approaches of evidence- and eminence-based medicine. How to integrate swarm-based medicine into practice is left to the individual physician, but even this decision will be influenced by the swarm.

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KEYWORDS

swarm; evidence; eminence; guidelines; recommendations

Introduction

Medicine has become so complex that it is impossible for an individual to fully master even his or her own subspecialty. Physicians need to source information effectively in order to treat their patients according to current state-of-the-art approaches.

With the increasing complexity of medicine, the term “evidence-based medicine” has arisen. This reflects a scientific and arguably objective view of the matter. The highest level of evidence is obtained from randomized trials proving or disproving hypotheses. Generally, evidence-based medicine aims to be universal and is taught as the highest standard in medical schools. When adhering to evidence-based medicine, the responsibility for decisions is transferred from the individual to evidence, which might add to its popularity.

There are many concerns about the limitations of evidence-based medicine, but there are two obvious ones. First, evidence-based medicine is based on available data. However, relevant data is not available for all relevant issues. Also, trials with a negative outcome are underrepresented in medical literature, rendering the evidence base biased and the view of reality skewed [1].

The second obvious flaw is perfectly demonstrated by the parachute study. In this, the authors argue that there is no Level I evidence to support the practice of using parachutes when falling from high altitudes; only common sense and “case reports” suggest this [2]. Thus, the existing data does not pass the stringent standards of evidence-based medicine. In other words, we are and will not be able to make every decision based on available evidence.

The other extreme, to put it bluntly, is “eminence-based medicine”. In this approach, decisions are taken by experts, who unfortunately are sometimes wrong. This form of decision making is predominantly based on clinical experience and a subjective interpretation of the matter. The obvious advantage is that a wider field of decision making can be covered, since

the domain is not limited to available evidence. At the same time, errors of individuals may negatively influence decisions. There is no objective control over the process and the drawbacks are obvious.

Swarm-Based Medicine

The ongoing expansion of information technology is accompanied by a no less remarkable increase in communication supporting medical decision making. With the help of current tools, we are able to communicate faster, on multiple levels, independent of location. With the help of information technology, the medical community is becoming a dynamic, communicating collective with the features of a swarm.

The medical community, with its exponentially growing interactions, is gradually gaining attributes of swarms with inherent intelligence defined as the collective behavior of decentralized, self-organized systems, natural or artificial [3]. A new innovation or change in practice is communicated from members of the swarm such as physicians, hospitals, and medical societies, informally and immediately, rendering the swarm able to follow improved procedures.

Although there is no formalized *typical* procedure of a community, attempts are being made to identify common approaches (eg, with patterns of care studies). They provide valuable feedback on what is happening and help us recognize trends [4].

The National Comprehensive Cancer Network (NCCN) has implemented NCCN Trends, which is a survey-based data and analysis tool. This is being used to gather information from over 200,000 clinicians in order to assess how cancer care is being delivered as well as assess the understanding and acceptance of emerging treatments [5]. This is just one of many projects that are trying to gather insight into knowledge beyond evidence. Most often their focus is not on individuals leading the way, but on the swarm as a whole.

The understanding of the swarm delivering health care is important for several reasons. It means that individuals within the health care system, though basically the same, do not perform identical actions and the effect of health care on the population is determined by the swarm's behavior rather than by solitary outliers.

Trials may be coordinated among multiple nations; information from conferences as well as its critical appraisal by experts are available online. Medical societies as well as individuals interact with social media. Physicians usually incorporate input from evidence and eminence. Medical literature as well as practical tips and tricks from colleagues during a coffee break are both essential. As innovative IT methods are increasingly utilized in registries (eg, cancer registries) and faster tools for patterns of care studies are being implemented, the old "coffee break tips" are enhanced by information from the community—from the swarm.

Although not a conscious process, the pure mass of the "normal" serves as quality assurance, as a reference of what is typical as well as a form of benchmarking against which to compare one's own views. In comparison to randomized trials, the community practice patterns—the decisions of the swarm—undergo everyday scrutiny and have to perform out in the *wild*.

In the classical swarm model as introduced by Reynolds, the swarm consists of "boids" [6], which are agents that follow simple rules and are not aware of the product of swarm intelligence. Swarm-based models have been implemented on a lower level in medicine (eg, the Ant Colony Optimization algorithm in radiotherapy planning); however, their application on a social level is more complex [7]. By conscious interaction, agents executing treatment decisions face information on the swarm's behavior. It has been demonstrated that this knowledge does not obstruct crowd wisdom [8].

One example of the balancing of crowd intelligence and eminence-based medicine might be the process of electronic voting (eVote), during the European Consensus Conference on Diagnosis and Treatment of Germ-Cell Cancer, on areas without sufficient evidence for decision-making [9]. The "swarm" of 60 germ cell cancer experts, mostly from Europe but also from the United States and Canada, had the opportunity to eVote on 48 areas of considerable controversy, caused by lack of evidence.

Intriguingly, the most unanimous eVotes were achieved after distinguished experts had argued in favor of a particular approach. However, participants did not follow recommendations that, during lively discussions, were perceived as unconvincing or unreasonable. "Vox Populi", or crowd wisdom, and swarm behavior probably follow similar principles and might be greatly facilitated by modern digital communication.

The availability of information is essential in the creation of guidelines. An interesting comparison of guidelines from 13 countries on lower back pain revealed many similarities [10]. The authors observed that the differences were few and probably less than might be expected for different healthcare systems and cultures, likely due in part to guideline committees usually being aware of the content of other guidelines and being motivated to produce similar recommendations. In some instances, the guidelines were national adaptations of European guidelines. Similarly, several investigations, such as the European Initiative on Quality Management in Lung Cancer Care [11], have found many similarities among guidelines on lung cancer care, although the quality of them varied significantly. As these guidelines were based on available literature and previously presented guidelines, this led to a large overlap of cited sources.

Impact of Swarm-Based Medicine

Humans, armed with Internet technology, exercise crowd intelligence in various spheres of social interaction ranging from predicting elections to company management [12]. Internet-based interaction may result in different outcomes, such as improved response capability and decision-making quality.

The direct comparison of swarm-based medicine with evidence- or eminence-based is interesting, but these concepts should be perceived as complementing each other and working independently of each other. Optimal decision making depends

on a balance of personal knowledge and swarm intelligence, taking into account the quality of each, with their weight in decisions being adapted accordingly [13]. The possibility of balancing controversial standpoints and achieving acceptable conclusions for the majority of participants has been an important task of scientific and medical conferences since the Age of Enlightenment in the 17th and 18th centuries. Our swarm continues with this interconnecting synchronization at an unprecedented speed and is, thanks to eVotes, Internet forums, and the like, more reactive than ever. Faster changes in our direction of movement, like a school of fish, are becoming possible. Information spreads from one individual to another. It is unconscious, but with our own *dance* we influence the rest of the *beehive*.

Within an environment, individual behavior determines the behavior of the collective and vice versa. Internet technology has dramatically changed the environment we behave in. Traditionally, medical information was provided to patients as well as to physicians by experts. This intermediation was characterized by an expert standing between sources of information and the user. Currently, and probably even more so in the future, Web 2.0 and appropriate algorithms enable users to rely on the guidance or behavior of their peers in selecting and consuming information. This is one of many processes facilitated by medicine 2.0 and is described as "apomediation" [14]. Apomediation, whether implicit or explicit, increases the influence of individuals on others. For an individual to adapt its behavior within a swarm, other individuals need to be perceived and their actions reacted upon. Through apomediation, more individuals take part in the swarm.

Our patients are better informed; second opinions can be sought via the Internet within hours. Our individual behavior is influenced by online resources as well as digital communication with our colleagues. This change in individual behavior influences the way we find, understand, and adopt guidelines. Societies representing larger groups within the swarms use this technology to create recommendations. This process is influenced by individuals and previous actions of the community; these then in return influence individual behavior. Information technology has a major impact on the lifecycle of guidelines and recommendations. There is no entry and exit point for IT in this regard. With increasing influence on individual behavior, its influence on collective behavior increases, influencing the other direction to the same extent.

Dynamic changes in movement of the swarm and within the swarm may lead to individuals leaving the herd. These may influence the herd to move in the direction of the outliers. At the same time, an individual leaving a flock or swarm is exposed. Physicians as well as clinical centers expose themselves when they leave the group for the sake of innovation. Negative results and failure might lead to legal exposure should treatments fail.

The perception of swarm behavior itself changes the way we approach guidelines. When several guidelines are published, being aware of them as a result of interaction increases our awareness for bias. Major deviations from other recommendations warrant scrutiny. The perception of swarm behavior and embracing the knowledge of the swarm may lead to an optimized use of resources. Information that has already been obtained may be incorporated directly by agents, enabling them to build on this and establish new knowledge—as social learning agents [15,16].

Conclusion

Swarm behavior might facilitate the generation and distribution of knowledge. Swarm behavior may also be detrimental. Some innovations may be hindered as they might be perceived as outliers. However, this negative effect may also be partially counteracted by a conscious perception of the swarm aspect of our behavior.

The amount of collected data is increasing exponentially and data mining and recommender systems are improving in parallel. These new tools will provide us with information on our collective behavior, which was not accessible until now. As with many valuable sources, it will be interesting to see how they will be approached by academia and industry.

This information does not need be produced; it lies before us and all we need to do is become aware of it. How to integrate swarm-based medicine into practice is left to the individual physician, but even this decision will be influenced by the swarm.

Conflicts of Interest

None declared.

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Original Paper

Exploring Patients' Views of a Cognitive Behavioral Therapy-Based Website for the Self-Management of Irritable Bowel Syndrome Symptoms

Sarah Tonkin-Crine[1], BSc, MSc; Felicity L Bishop[2], MA, MSc, PhD; Matthew Ellis[2], BSc, MSc; Rona Moss-Morris[3], BSc, MHSc, PhD; Hazel Everitt[1], MBChB, BSc, MSc, PhD

[1]Primary Care and Population Sciences, Faculty of Medicine, University of Southampton, Southampton, United Kingdom

[2]Academic Unit of Psychology, Faculty of Social and Human Sciences, University of Southampton, Southampton, United Kingdom

[3]Psychology Department, Institute of Psychiatry, King's College London, London, United Kingdom

Corresponding Author:
Sarah Tonkin-Crine, BSc, MSc
Primary Care and Population Sciences
Faculty of Medicine
University of Southampton
Aldermoor Health Centre
Aldermoor Close
Southampton, SO16 5ST
United Kingdom
Phone: 44 2380 240180
Fax: 44 2380 701125
Email: sktc1o07@soton.ac.uk

Abstract

Background: Cognitive behavioral therapy (CBT) has been shown to have positive effects on the management of irritable bowel syndrome (IBS) symptoms. A factorial pilot randomized placebo-controlled trial (called MIBS) tested the potential effectiveness of a self-management CBT-based website alongside two medications: methylcellulose and mebeverine, and a placebo. The results showed no significant differences in quality of life or symptom severity measures, but enablement and participant's global assessment of relief was higher in the website groups.

Objective: To conduct a qualitative study nested within this trial, in order to explore patients' views and experiences of using the CBT-based website to facilitate self-management of IBS.

Methods: Semistructured interviews were carried out with patients who had used the website with one session of nurse support (n=16) or the website alone (n=15) while participating in the MIBS trial. An inductive thematic analysis was conducted.

Results: We identified three types of engagement with the CBT-based website. One group of participants, mostly in the website-only condition, had limited or no engagement with the website. One group engaged with the content and advice on practical lifestyle changes. The final group of participants engaged with the content and advice on psychological aspects related to IBS. Similarities and differences between these three groups are explored.

Conclusions: Teaching self-management techniques through a Web intervention was received positively by most of the participants. Concepts linked to cognitive aspects of CBT appeared to be harder for participants to engage with. Participants who received nurse support rated the cognitive aspects more positively, suggesting that some therapy support alongside the website should be considered. However, the Web format was preferred by some who favored anonymity as well as those who appreciated the accessibility and ease of use of this type of management. Suggestions on how to encourage engagement with Web interventions are discussed.

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KEYWORDS

irritable bowel syndrome; cognitive behaviour therapy; Internet; primary care; qualitative research

Introduction

The prevalence of irritable bowel syndrome (IBS) is estimated to be 12% in northern European countries [1] with British organizations estimating that 10-22% of the UK population are affected [2]. NICE (National Institute for Health and Care Excellence) guidelines recommend that, in primary care, IBS patients be offered diet and lifestyle advice, pharmacological therapy, and psychological therapy [3]. Common medications offered to patients to help manage IBS are antispasmodics (eg, mebeverine) and bulking agents (eg, fybogel and methylcellulose). However, there is limited evidence about the effects of these medications [4]. Cognitive behavioral therapy (CBT), also identified in the NICE guidance, has shown to be helpful for patients with IBS; however, access to CBT is limited and the therapy can be expensive due to the costs of therapist training and the therapist time taken to deliver the CBT [3,5-7].

To improve accessibility to psychological therapies and reduce costs, research has investigated CBT Internet programs that help patients manage a wide variety of health conditions [8,9]. Reviews of this work indicate that Internet-based programs can be effective and suggest that Internet-based therapy can provide complementary and additional help for patients alongside existing health care [10].

Recent studies have started to investigate the effectiveness of Internet-delivered cognitive behavioral programs for patients with IBS [11-14]. Program content has included stress management and relaxation techniques [11], and mindfulness and exposure exercises [12], in addition to explaining the biopsychosocial model of IBS to participants. Studies have shown that Internet programs are effective at reducing experienced IBS symptoms and improving quality of life, compared to control conditions, that is, either a waiting list control [11] or a waiting list with access to an online discussion forum to try to control for nonspecific effects [12]. An additional follow-up indicated that patients could experience long-term beneficial effects on symptoms after participating in Internet programs [15], and a second study identified that CBT-based programs using exposure exercises may be a better option than programs that provide more general methods for reducing stress/symptoms [13]. However, a subsequent study investigating Internet-based CBT for IBS in a clinical population where patients were consecutively sampled as opposed to self-referral, reported smaller treatment effects than previous studies [14].

As part of the MIBS (Management of IBS) pilot trial, a Web-based CBT self-management program (named Regul8) was developed to help patients with IBS manage their symptoms [16,17]. This work followed the development of a paper-based CBT manual, which in conjunction with 3 hours of therapy time, was shown to be effective in reducing IBS symptom severity and impact [7]. The MIBS trial was designed to assess the effectiveness for IBS of the CBT-based self-management website and two commonly prescribed medications (mebeverine and methylcellulose) against placebo [17]. The results of the trial found no significant differences in IBS quality of life or symptom severity score between participants who received the website or medication at follow-up. However, enablement [18] and global assessment of relief [19] were significantly improved in participants who had received the website at 12 weeks compared to groups who had not received the website [17].

While research has suggested that Internet programs are effective at improving patients' reported IBS symptoms, less is known about patients' views and experiences of using such programs. Previous qualitative work has explored patients' views of Internet-delivered CBT self-management programs to help management of depression [20-22]. These studies indicated that people may react differently to Internet interventions, some being able to work through programs alone, with others needing more encouragement and support to increase their motivation [20,21]. Being able to identify with the information provided and apply it to their own lives is also thought to be important for participants [20]. Last, the anonymity afforded by Internet-based programs may be attractive to participants who experience or anticipate stigma in face-to-face programs [20,22].

Inductive qualitative methods can help to explore an area where there is little existing knowledge. To date, there have been no reported qualitative investigations of people's experiences of using an Internet-delivered CBT program for IBS. Following the MIBS pilot randomized control trial (RCT), we explored participants' views of taking part in the trial, their experiences of using the Regul8 website, and their experiences of the trial medication. Our aim was to explore whether an Internet-delivered CBT program is acceptable to patients with IBS and, if so, to identify how it could be improved for use in future trials. While this study was carried out prior to having knowledge of the final trial results, the findings are presented with consideration to these.

Methods

The MIBS Trial and Website

This qualitative study was nested within the pilot MIBS RCT, which was designed to assess the potential effectiveness of two types of management strategies for symptoms of IBS [17]. The trial contained 9 participant groups (total N=135) in a 3x3 factorial design with variants of medication and the Web-based self-management program as the factors. Participants were asked to take 7 capsules a day for 6 weeks and either received one of two commonly used medications for IBS: mebeverine or methylcellulose, or a placebo. Participants were additionally randomized to three self-management groups: one group had access to the Regul8 website and a 30-45 minute telephone support session with a nurse to encourage engagement with the CBT program (n=46), a second group had access to the website only (n=45), and the third group had no website access (n=45).

The Regul8 website was designed to be interactive, and participants were provided with tasks to do within each session: these included recording symptoms and comparing them with stress and eating patterns, using goal-setting sheets for lifestyle change, and keeping thought records to identify and challenge unhelpful thoughts. Participants were able to use the Web program to keep track of goals or symptoms so that all their information was stored in one place and participants could

discuss progress with these goals during the telephone support sessions where available. These interactive tasks allowed participants to focus on those parts of the program they felt were most relevant to them and to personalize the program, as a therapist may do. For example, participants may choose to have more goals related to changing their diet rather than using relaxation techniques. The website was split into 8 sessions that participants were required to complete over 6 weeks. The content of each session is described in Multimedia Appendix 1, and a webpage is shown in Figure 1. (MIBS pages are shown in Multimedia Appendix 2). More information on the program is available in the published protocol [16]. Separate "think aloud" [23] qualitative work was carried out during development of the website to inform the content and design in order for it to be understandable and user friendly for patients.

Recruitment

All participants for this qualitative study were selected from the group of 91 who had taken part in the MIBS trial and who had had access to the Regul8 website (Figure 2). Participants were first contacted by email, and this was followed up by a phone call if there was no response within a week. Participants were called up to 3 times, at weekly intervals, if there was no response. Participants were purposively sampled to obtain participants of both genders, with a range of ages and with experience of using the website with and without nurse support. Participants were invited in the reverse order that they took part in the trial so that participants who had used the website most recently were contacted first. This was to recruit participants who had taken part in the trial most recently, with the assumption that these participants would better remember the content of the website and how they used it. Participants were interviewed when they had completed all aspects of the trial or when they were close to finishing the trial.

Figure 1. A MIBS webpage that gives participants an example of how thoughts, behaviors, emotions, and symptoms can interact.

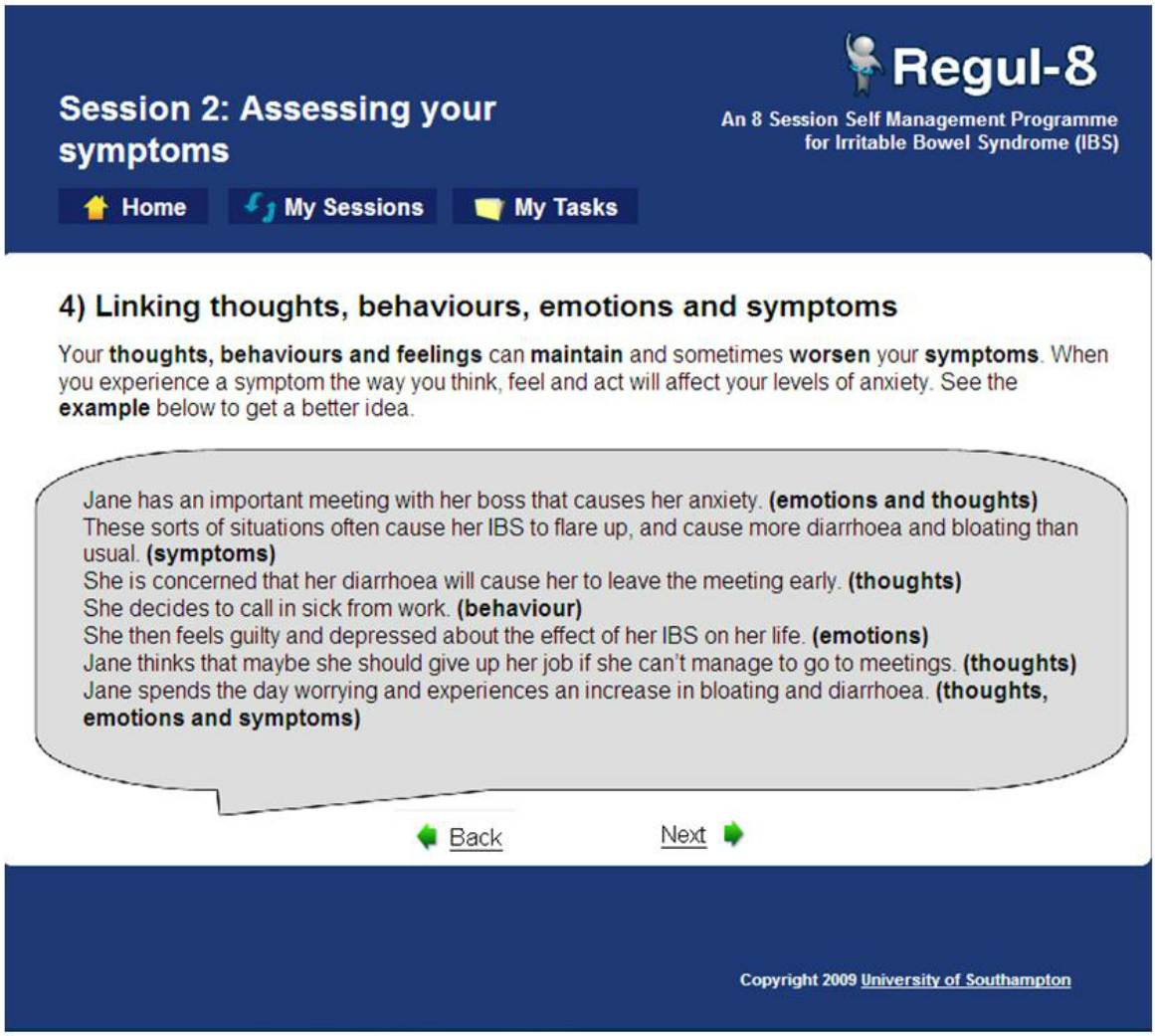
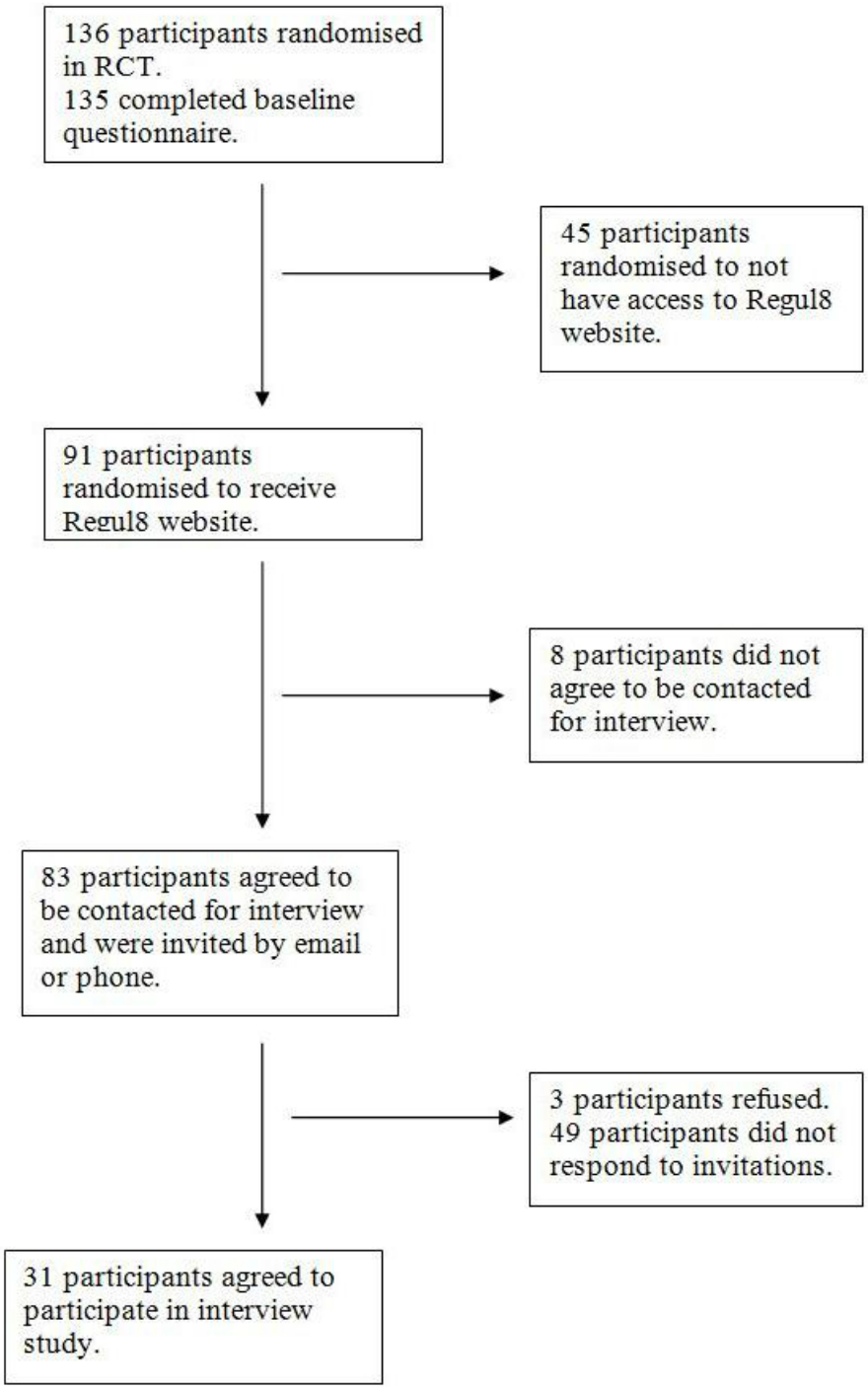


Figure 2. Flowchart showing how participants were identified from the original trial group.



Procedure

Telephone interviews were carried out by 2 researchers, STC and ME, between August 2010 and June 2011. Both interviewers were independent from the MIBS team and had had no involvement in the development of the website or management of the trial. Participants were made aware of this at the start of each interview to encourage interviewers to speak freely and honestly about their experiences of the MIBS trial. Questions focused on participants' experience of taking part in the trial and their views and experiences of using the website and taking any type of medication for their symptoms. Questions related to the website asked about patients' initial expectations of receiving a website as a management strategy for IBS, their feelings about receiving a website, what they liked and disliked about the website, and what they felt changed while working through the website. Questions were open-ended to allow participants to discuss anything they felt was relevant. All interviews were digitally recorded and transcribed verbatim. All identifiable information was deleted from transcripts. Interviews continued until researchers were satisfied that data had indicated saturation (no new themes identified in the data within the last few interviews) and when all participants who had volunteered to take part had been interviewed.

Qualitative Analysis

Techniques from thematic analysis were used to analyze the data [24]. Thematic analysis was chosen to allow the researchers to take an inductive approach to analysis, ensuring that emerging themes were grounded in the original data and to help reduce the influence of the researchers' existing knowledge and preconceptions. Transcripts were read and re-read to aid familiarity. One researcher, STC, coded the first ten transcripts, line-by-line, to develop initial codes. Initial codes were applied to subsequent transcripts and were refined and expanded. Codes were then compared for similarities and differences and grouped to form initial themes. NVivo 8 was used to facilitate coding. Initial themes were checked and approved by FB and HE. Themes were then compared across later transcripts, and new codes emerging from these were compared with earlier transcripts using a constant comparative technique [25]. Once all transcripts had been included in the analysis, code labels and titles of themes were checked and revised where appropriate with ongoing checks by FB and HE to ensure validity. Four themes were identified: (1) IBS is unpredictable and uncontrollable, (2) Perceptions of medication as a treatment for IBS, (3) Website format is acceptable, and (4) Engagement with the Regul8 website. This paper focuses on the fourth theme, Engagement with the Regul8 website. Within this theme, researchers identified three different ways that participants engaged with the Regul8 website. Three groups of participants were defined (by STC). Transcripts were examined independently by STC, HE, and FB to assess how transcripts fitted with these groups, and group definitions were then discussed and refined. A thematic map was developed to show the relationship between themes and the groups identified [24]. All transcripts were assigned to the final groups independently by the 3 researchers. Disagreements between assignments to the groups were identified and discussed, and transcripts were assigned when a consensus was reached.

Results

Participant Characteristics

Thirty-one participants were interviewed. Interviews lasted between 7 and 49 minutes, with a mean of 19 minutes. Those interviewed had a mean age of 51 years (SD 8.61), with ages ranging from 34-60 years; 60 was the maximum age to be eligible for inclusion in the MIBS trial.

The only significant differences between MIBS Regul8 participants who were interviewed and those that were not were gender and completion of 4 or more Web sessions (Table 1). As a group, interviewees completed one and a half more website sessions on average; however, this difference between groups was not statistically significant. Both groups had similar baseline symptom severity scores and quality of life scores. In both groups, participants were split equally between receiving the nurse support session or not.

Findings

Website Format Is Acceptable

All participants reported that the website was well designed, easy to understand, and written in simple, nonspecialist language, for example, explaining it as "simple, concise and clear" (P2). However, all participants reported that the website took time to complete, and several mentioned that a user had to be self-motivated to work through the material:

> *I found it time consuming, you know, to log in, and I'm not one of those on the computer all day. I found it a bit time consuming and sometimes I must admit I thought I can't be bothered to do this today and I didn't but as I said, things had started to improve quite early on with the early part of the sessions.* [P13]

Engagement With the Regul8 Website

Overview

Analysis revealed three types of engagement with the Regul8 website that emerged from participants' discussions: (1) limited or no engagement, (2) engagement with content on how practical lifestyle changes may affect IBS, and (3) engagement with content on how emotions and thoughts may affect IBS (as well as practical lifestyle changes). Figure 3 summarizes these three types. Characteristics of each group appear in Table 2. Only 28 out of the 31 interviewees are represented in these groups since 3 participants (P26, P27, and P31) did not give enough detail on their use of the Regul8 website during their interviews.

Table 1. Characteristics of 31 participants who took part in interviews compared to the 60 participants who received access to the Regul8 website in the main trial.

Characteristics		31 participants interviewed	60 participants who refused or who did not take part in interviews	Significant differences between the two groups ($P<.005$)
Demographics				
Gender, n (%)				$P<.000$
	Male	15 (49)	13 (22)	
	Female	16 (51)	47 (78)	
Age, years				Not significant
	Mean average	51	43	
	SD	8.6	9.4	
	Range	34-61	22-60	
Ethnicity, n (%)				Not significant
	White British	28 (91)	55 (95)	
	White other	2 (6)	3 (3)	
	Indian	0 (0)	1 (1)	
	Unknown	1 (3)	1 (1)	
Baseline measures				
IBS symptom severity score [a] (0-500)				Not significant
	Mean average	241.6	237.6	
	Range	85-461	75-470	
IBS quality of life score [b] (0-100)				Not significant
	Mean average	59.6	65.2	
	Range	18.38-88.97	20.59-96.32	
Website group and compliance				
Type of website access, n (%)				Not significant
	Website with nurse support	16 (51)	30 (50)	
	Website only	15 (49)	30 (50)	
Compliance with website				Not significant
	Mean average sessions completed	5.2 out of 8	3.7 out of 8	
Completed 4 or more website sessions, n (%)				$P<.001$
	Yes (compliant)	21 (71)	30 (50)	
	No (non-compliant)	9 (29)	30 (50)	

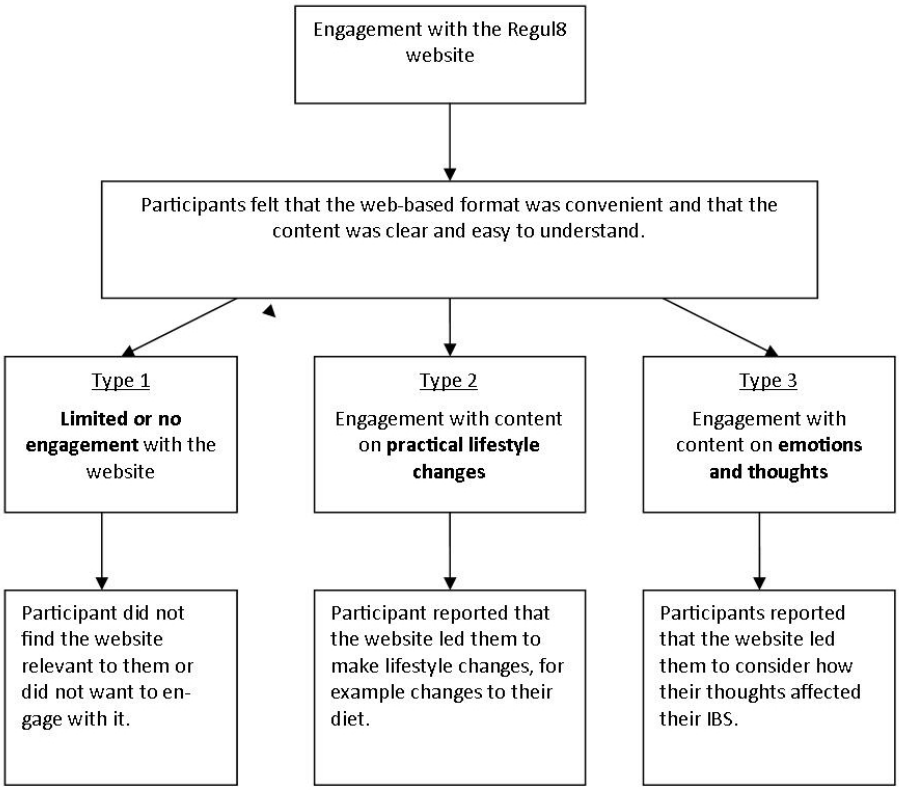
[a]IBS symptom severity score indicates self-reported severity of symptoms by participants at baseline; higher scores represent more severe symptoms.

[b]IBS quality of life score indicates self-reported quality of life by participants at baseline; higher scores represent better quality of life.

Table 2. Participant characteristics for each of the three types of engagement identified.

Type	Number	Participant characteristics
Limited or no engagement with website	10	6 /10 compliant with the website. Completed on average 4.4 sessions out of 8. 2/10 participants received nurse telephone support
Engagement with content on practical lifestyle changes	6	4/6 compliant with the website. Completed on average 5.1 sessions out of 8. 4/6 received nurse telephone support
Engagement with content on emotions and thoughts	12	11/12 compliant with the website. Completed on average 6.4 out of 8. 8/12 received nurse telephone support.

Figure 3. Thematic map identifying the 3 types of patient engagement with the Regul8 website.



Limited or No Engagement With the Regul8 Website

Ten participants reported either that they did not use the website at all or that they did not find it relevant and did not see it as a way to help them manage their IBS. Despite this, most participants in this group were recorded as completing 4 or more website sessions and therefore being compliant. As participants were able to click through website pages and select different sessions easily, it is possible that these participants browsed the majority of pages and were therefore recorded as having viewed the material, however, either did not absorb the information or decided it was irrelevant to them.

We identified three common obstacles that appeared to deter participants from engaging with the website. The first was an ongoing search for a "wonder drug". Participants who were searching for a "magic pill" to "cure" their IBS resisted the idea that they might be able to (or would even want to) manage their illness through changing their thoughts and/or behaviors. They were hoping for a treatment that would enable them to "by and large lead a normal life" (P25) without disrupting their daily lives or taking time away from preferred or prioritized activities such as work and leisure. For example, in this extract one participant explains his desire for a medical treatment:

> *I don't think I have much time, I think if I had time and I did some of the sort of more relaxation techniques at the time that the website was talking about them, then that would help, but to do some of these techniques I feel I need that, you know, almost one-on-one, you know, I think things like yoga could almost help it but I couldn't just pick up a book and*

> *learn yoga, you know, it's that kind of training I would love to do but um, time unfortunately doesn't permit it and so I sort of put up with the symptoms, which is why I hoped it would be a wonder drug.* [P5]

Consequences of prioritizing a medical solution to IBS included seeing the website as unimportant within the trial and not seeing the website as a form of management in its own right. Indeed, 2 participants reported having made a conscious choice to abandon the website because they had stopped taking the trial medications.

Participants' preconceptions about the impersonal nature of websites constituted a second obstacle to engagement. Some participants saw websites as a means to provide factual information and were expecting the website to provide extensive, authoritative, and new facts about IBS and its management. They were disappointed that the website did not meet their expectations: "it wasn't extensive information, it was quite limited, I think I expected more" (P1). As described above, the website was interactive and did not merely provide information but required participants to self-assess, write down their own goals, or keep a written record of any unhelpful thoughts. This was difficult for some participants who believed that websites are unsuitable for interventions that require exploration of one's personal thoughts and feelings about IBS. Regardless of their views on the legitimacy of a psychological approach to IBS in general, these participants did not feel that a website was the appropriate means of delivering such an intervention:

> *I just found the whole sort of process a little bit, um as I say a little bit sort of condescending, you know, to how a website, on an impersonal device like a computer, trying to give me a sort of counselling approach to managing the symptoms. [Interviewer: yes, yeah] so you know it was sort of, it was very impersonal [Interviewer: mm hmm] didn't, didn't gel with me at all.*" [P5]

Interestingly the majority of the participants who felt this way were in the group who did not receive the nurse telephone session to support their progress with the website (see Table 2).

The third obstacle to engagement related to poor perceived fit between the website and the individual and can be summarized by the phrase, "the website is not right for me". Sometimes this centered on the psychological elements of the website, and obstacles to engaging with psychological content are discussed in detail below. Poor perceived fit was also related to perceived symptom severity and existing levels of knowledge. When they felt the website was not right for them, participants politely suggested other groups for whom it might be more suitable, including patients with more or less severe symptoms (with participants usually recommending the website for people who had different symptoms from themselves) or newly diagnosed patients who were assumed not to have an understanding of IBS and self-management techniques:

> *Well the trial wasn't too bad, the website was ok, I think I would have put more effort into it if, like I say, I was having the issues with serious symptoms at the time but like I said I wasn't really, so [there is] less motivation to work your way through the pages of the website.* [P4]

Despite not engaging with the interactive parts of the website, some participants nevertheless found it reassuring to have their existing beliefs about IBS confirmed and took comfort from feeling that they were not alone in their experiences of IBS. The latter might be a particularly valuable feature of websites for conditions such as IBS that patients often find difficult to discuss in everyday life:

> *I thought [the website] might have some suggestions as to things you could do to help relieve it. Which was sort of implicit there somewhere, so that was quite good. I think it was probably reassuring in a way…that obviously the symptoms I'd had were very common and were similar to other people...'cause I hadn't really talked to anyone else about it.* [P9]

Engagement With Content on Practical Lifestyle Changes

Six participants reported that the website had been helpful and had given them information and advice on making practical changes to their lifestyle:

> *I found [the website] actually really useful, the exercises…I have kind of tried to change slightly, and one of the bizarre things that was actually suggested, eat porridge…that made a big difference to settling my stomach down...there were some little things like that, that you went "oh I didn't even realize", never thought about it, so actually those things really helped.* [P22]

The changes participants reported were most often related to their diet but also included an increase in exercise, focusing on improving their sleep patterns, and practicing relaxation techniques. Sometimes participants reported that they had made significant changes that they felt were going to influence their IBS a great deal:

> *The exercise [section was useful]. I'm a child minder so I am sort of running around all day, but...it's not sort of exercise, it's not, you know, if I'm walking I'm walking with one of the kids so it's not a walk that increases my heart rate... but you know we've been going up the park and that more and, you know, sort of running around the park more for more exercise. So [the website] was good.* [P8]

Other participants reported that the website had led them to make to smaller changes, which usually involved monitoring their behavior, but that had given them more of an insight into their IBS:

> *I looked at the action plans [on the website] and all it was really for me was just putting it in black and white, what I needed to do, which in some ways, it made you think a bit more, maybe took yourself out of the situation and made you think about things… more of an insight into what was going on, "Oh right, yeah, so that's why that's happened." The one thing it did make me do was look at my diet more and made me associate different reactions and triggers for my IBS.* [P11]

As well as engaging with the content of the website, participants also commented on how they favored the interactive format of the Web-based program, which encouraged them to keep records of their thoughts and behaviors, and the nurse telephone support session, when available, and how these helped them to engage with the information.

> *[The nurse] made me feel perhaps better and realize that things perhaps had helped at the time that I hadn't realized if you get what I mean? But that was not to do with the drugs, it was more with the [website] advice that was given, I found that more helpful.* [P12]

Engagement With Content on Psychological Aspects

Twelve participants spoke about how the website had led them to consider how their thoughts and emotions could affect their IBS:

> *[The website sessions] made you stop and think, "am I that kind of person that's being described there?"…it's all psychosomatic and I'm making it up in my head and I realized that it wasn't necessarily that, because you have a physical symptom but then unfortunately because of the nature of IBS you'd…and the type of person you may be, the boom or bust person, that then unfortunately you may think "Oh my God, this is something wrong with me seriously" and then make the symptoms worse. Um, so I think having that actually on the Internet site it made me stop and reflect, and sometimes I think stop me from running ahead of myself.* [P10]

Several of the participants who had engaged with the psychological aspects mentioned how they had joined the trial because they were very eager to find something to help their IBS. Participants mentioned joining "out of desperation" because they had previously been "through hell" as a result of their IBS and because they felt they were "living on medication". One participant specifically stated that she had joined the trial because of the "cognitive therapy" that was offered as part of the website.

All twelve participants reported that the website had helped to clarify how their thoughts and emotions may be connected to their symptoms. Some mentioned that the website had helped them identify how their emotions were connected to specific behaviors that they had subsequently tried to change:

> *I do find that if I'm stressed, het up or worried then I'm very, very likely to have an attack. I'm not, I don't consciously think, "I'm going to have an attack now"...but whereas I got to the stage where I wouldn't leave the house without making sure the medication was in my handbag and plenty of it...while I was doing the trial I never thought like that at all. I never, in fact, half the time I'd go out, and that was one of the things I had to do...was go out, try and put myself in a situation where I wouldn't normally have gone without checking first I'd got it all, and put myself in those situations.* [P7]

Others talked about how the website had helped them understand the connection between their mind and body and how they were more comfortable considering how their thoughts and emotions may affect them:

> *I mean it's not a disease, it's an illness, you know it's more than one thing and a lot of it is in the head and I think that makes you think about it, and um, think about your behavior and actions, and the consequences and your emotions and all that so yeah, I think that [the website] is very good.* [P24]

Approximately half of the participants, who had engaged with the psychological content of the website, also engaged with the advice on practical lifestyle changes.

As for group 2, this group also liked the nurse telephone support when it was available to them:

> *I think I got more out of it by having even the interim call with [nurse], during it, because um, the website can't cater for everything without it being over-complex and pages and pages of options.* [P2]

Interestingly some felt that the website was a particularly good format for discussing a sensitive subject that some people may not want to talk about face-to-face:

> *[The website] explained [IBS] and it forced you to be quite open and honest probably more so than you would be in face to face conversation um, especially, um…you know it's not the most pleasant of topics to discuss.* [P2]

We explored differences between participants who had engaged with the content on the psychological aspects of IBS and those who had not engaged with it. The majority of participants who did not engage with the psychological components of the website had only limited engagement with the website overall and seemed to miss out on the information on the influence of thoughts and emotions on IBS symptoms because of their lack of interaction with the website.

There were participants, however, who reported specific reasons for why they did not engage with the psychological content. These included participants who saw IBS as a physical and not psychological illness, participants who did not want to think about their IBS or any associated thoughts, those who did not understand how CBT and the tasks provided could help them, and those who felt negative thoughts were not relevant to them:

> *While I can accept that IBS might be brought on by stress which could be a symptom of what's going on in your head, I couldn't tie up that sort of logical, you know, write things down and try and feel better and that will make your symptoms better, I couldn't make that link, I could see it was there but I just couldn't do it and trying to do it just made me very frustrated.* [P5]

Discussion

Principal Findings

Participant feedback indicated that patients taking part in the MIBS trial engaged with the CBT self-management website to different extents that may help to explain the quantitative results of the MIBS trial [17]. While the majority of participants indicated that the website had been helpful to them and, as a result, that they had made subsequent changes to their lifestyle, a minority of those interviewed did not appear to gain any benefit from the website, either through improved symptoms, quality of life, or understanding their IBS better. Our analysis highlighted a variety of factors that may have shaped engagement with the website.

It was clear that medication was the only form of management that was seen as acceptable or potential efficacious by some interviewees. The trial design, investigating the Regul8 website alongside medication, meant that recruitment ran the risk of obtaining participants who were interested in only one type of intervention. Participants who had joined purely to try the medication may have had very little motivation to explore the website as a potential source of help. This is always a potential issue for recruitment to factorial trials and should be considered when providing trial information to potential participants and when providing trial materials once patients have been recruited.

Other participants who did not engage with the website reported that they found it too impersonal. This has been found in previous research that indicates that face-to-face delivery of psychological treatments is accepted by the majority but phone and Internet delivery is seen as less acceptable in comparison [26]. Of those interviewed, participants who had not received the nurse telephone support session generally reported being less engaged with the website. Input from a health care professional may have helped participants to relate the website information to their own lives, to understand the connection between their thoughts and symptoms, and to see the relevance of carrying out the tasks on the website. Previous studies have indicated that support given by a clinician or counsellor is associated with greater engagement with Web-based interventions, and interaction with health care professionals can significantly predict adherence to Web interventions [27-29]. Discussions with a professional may also have provided recognition and reassurance to participants who had previously had less constructive interactions with medical professionals. The level of support in this trial was minimal with one nurse telephone session of 30-45 minutes. This was much less support than offered within other trials of Web-based support for IBS that provided weekly feedback to participants [11,12]. It was encouraging to see that this support, while minimal, still had an impact on what participants reported as useful, with many saying that they valued this element of the program because it helped them to understand and follow the webpages.

Last, some participants reported not engaging with the website or with some specific website sections because they did not find it relevant to themselves. Some felt that the website was aimed at people who had less knowledge about IBS than themselves. The introduction section of the website, which gave lots of background knowledge on IBS, was a compulsory section that all participants were required to work through. Being presented with knowledge that was already very familiar may have decreased participants' motivation to work through the remainder of the modules with some assuming that the website offered nothing new for them. Although the Regul8 website included tailoring by symptoms, some participants still felt that the website was aimed at people with different symptoms than themselves, either more or less serious. These assumptions could be addressed by changing the content of webpages, to emphasize the relevance to all patients or by increasing the ability of patients to skip information they already know. Participants who do not engage with certain sections of a Web intervention, for example the CBT aspects, may need further support and could benefit from one-on-one discussions with health care professionals as detailed above. It is important in this instance, however, to recognize that participants reported making changes to their lives and feeling benefits from following the website advice even though they had not engaged with the CBT aspects (eg, improved symptoms from changing their diet, using relaxation techniques to reduce anxiety related to IBS symptoms). This highlights the idea that engagement with CBT is not necessary in order to see positive effects on reported symptom control.

Overall, this study provided an insight into the views and experiences of patients with IBS symptoms in using a Web-based self-management program. Both the qualitative results presented here and the quantitative results of the trial [17] highlighted how the Regul8 website and design of the MIBS trial could be improved upon. The trial design can be improved by evaluating the Web intervention independently from any type of medication, which will prevent participants joining for access to medication only. This will also prevent any patient expectations that website content should mention medication. The delivery of the Regul8 website was acceptable to patients; however, the content could be improved by presenting optional units for patients with more information or allowing patients to skip sections, emphasizing that the website content is for everyone regardless of symptom severity, time since diagnosis, or prior knowledge, and by explaining that CBT techniques are useful for anyone regardless of whether an individual currently feels stressed or anxious. These lessons might also be applicable to trials of Web-based CBT in other chronic illnesses. A future larger RCT of the Regul8 website will further investigate the effectiveness of the website with telephone support on IBS symptoms and quality of life.

Limitations

Patients taking part in the MIBS trial and these interviews were a self-selected group of volunteers and likely represented a population who were highly motivated to find a way to manage their IBS symptoms. This could result in participants being more positive about the management types available in the trial than the average IBS patient. It could also mean that patients were more motivated to use the website and therefore may have found it easier to work through.

Interviews are always likely to capture socially desirable responses. This was especially likely in these interviews as

interviewees knew that interviews were being carried out in order to evaluate the trial and the website. Interviewers presented themselves as independent researchers, and we were encouraged to see that many participants seemed at ease when offering any negative feedback about the trial and/or website where relevant. This indicated that participants felt comfortable speaking openly and honestly about their experiences.

Due to the availability of independent interviewers, some interviews were carried out several months after participants had taken part in the study. As a result, some participants were unable to remember some aspects of the trial in order to comment on them in detail. Three interviews were not included in the analysis above because participants were not able to provide enough information on the Regul8 website. It was promising to see other participants' experiences of the trial were, most often, positive and memorable and that they reported maintaining the changes they had made as a result of the website some months after completing the trial.

The qualitative results of this study were able to identify participants who reported that they had not used the website. This was despite quantitative results indicating that the same participants had been "compliant" with the website and had completed at least 4 of the 8 sessions. This discrepancy highlighted how quantitative measures gave a limited insight into participants' use of the website and indicated that additional measures that recorded time spent on webpages and interaction with Web activities may provide more detailed information about Web use.

Conclusions

Most patients reported gaining benefits, in the form of improved symptoms, greater quality of life, and/or greater understanding of IBS from following a CBT-based online self-management program either alone or with minimal nurse telephone support. Different levels of engagement with the website were seen across participants. For some, the website was helpful only for promoting lifestyle behavior change, while others also found benefit in following cognitive aspects such as challenging negative thoughts associated with IBS symptoms. Some participants may need extra support with the latter, and nurse or therapist input may help address patients' preconceived ideas about the relevance of CBT or cognitions and emotions to their condition. Overall the Regul8 website offered an interactive self-management program that was well received by the majority of patients who found it relevant for their condition, and findings suggest further ways to improve the content of the intervention to encourage greater engagement.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Summary of the Regul8 Web-based self-management sessions.

[PDF File (Adobe PDF File), 28KB - jmir_v15i9e190_app1.pdf]

Multimedia Appendix 2

A series of MIBS webpages showing how the website was tailored and personalized to individual needs.

[PDF File (Adobe PDF File), 370KB - jmir_v15i9e190_app2.pdf]

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Abbreviations

CBT: cognitive behavioral therapy
IBS: irritable bowel syndrome
MIBS: management of IBS
NHS: National Health Service
NICE: National Institute of Health and Care Excellence
NIHR: National Institute of Health Research
RCT: randomized controlled trial

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Original Paper

Effects of a Web-Based Patient Activation Intervention to Overcome Clinical Inertia on Blood Pressure Control: Cluster Randomized Controlled Trial

Jeffrey Thiboutot[1], MD; Christopher N Sciamanna[2], MD, MPH; Bonita Falkner[3], MD; Donna K Kephart[2], MHA; Heather L Stuckey[2], DEd; Alan M Adelman[2], MD, MS; William J Curry[2], MD; Erik B Lehman[2], MS

[1]Mount Sinai School of Medicine, New York, NY, United States

[2]Pennsylvania State University College of Medicine, MS Hershey Medical Center, Hershey, PA, United States

[3]Jefferson Medical College, Thomas Jefferson University, Philadelphia, PA, United States

Corresponding Author:
Christopher N Sciamanna, MD, MPH
Pennsylvania State University College of Medicine
MS Hershey Medical Center
Division of General Internal Medicine, H034
500 University Drive
Hershey, PA, 17033
United States
Phone: 1 717 531 4601
Fax: 1 717 531 0146
Email: cns10@psu.edu

Abstract

Background: Only approximately half of patients with hypertension have their blood pressure controlled, due in large part to the tendency of primary care providers (PCPs) not to intensify treatment when blood pressure values are elevated.

Objective: This study tested the effect of an intervention designed to help patients ask questions at the point of care to encourage PCPs to appropriately intensify blood pressure treatment.

Methods: PCPs and their patients with hypertension (N=500) were recruited by letter and randomized into 2 study groups: (1) intervention condition in which patients used a fully automated website each month to receive tailored messages suggesting questions to ask their PCP to improve blood pressure control, and (2) control condition in which a similar tool suggested questions to ask about preventive services (eg, cancer screening). The Web-based tool was designed to be used during each of the 12 study months and before scheduled visits with PCPs. The primary outcome was the percentage of patients in both conditions with controlled blood pressure.

Results: Of 500 enrolled patients (intervention condition: n=282; control condition: n=218), 418 (83.6%) completed the 12-month follow-up visit. At baseline, 289 (61.5%) of participants had controlled blood pressure. Most (411/500, 82.2%) participants used the intervention during at least 6 of 12 months and 222 (62.5%) reported asking questions directly from the Web-based tool. There were no group differences in asking about medication intensification and there were no differences in blood pressure control after 12 months between the intervention condition (201/282, 71.3%) and control condition (143/218, 65.6%; *P*=.27) groups. More intervention condition participants discussed having a creatinine test (92, 52.6% vs 49, 35.5%; *P*=.02) and urine protein test (81, 44.8% vs 21, 14.6%; *P*<.001), but no group differences were observed in the rate of testing. The control condition participants reported more frequent discussions about tetanus and pneumonia vaccines and reported more tetanus (30, 13.8% vs 15, 5.3%; *P*=.02) and pneumonia (25, 11.5% vs 16, 5.7%; *P*=.02) vaccinations after 12 months.

Conclusions: The use of an interactive website designed to overcome clinical inertia for hypertension care did not lead to improvements in blood pressure control. Participant adherence to the intervention was high. The control intervention led to positive changes in the use of preventive services (eg, tetanus immunization) and the intervention condition led to more discussions of hypertension-relevant tests (eg, serum creatinine and urine protein). By providing patients with individually tailored questions to ask during PCP visits, this study demonstrated that participants were likely to discuss the questions with PCPs. These discussions did not, however, lead to improvements in blood pressure control.

Trial Registration: ClinicalTrials.gov NCT00377208; http://clinicaltrials.gov/ct2/show/NCT00377208 (Archived by WebCite at http://www.webcitation.org/6IqWiPLon).

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KEYWORDS

hypertension; Internet; tailored-feedback; Web-based

Introduction

Hypertension is one of the most common chronic illnesses in the United States, affecting more than 1 in 4 adults [1]. Hypertension is strongly associated with increased risk of cardiovascular disease, which is estimated to have caused 599,413 deaths in the United States in 2009, or 24.6% of all deaths [2]. Clinical trials have shown that blood pressure control reduces the risk of stroke, myocardial infarction, and heart failure [3]. Despite the known benefits of blood pressure control, in 2008, the National Health and Nutrition Examination Survey (NHANES) observed that only approximately 50% of those diagnosed with hypertension had their blood pressure controlled [1].

Given the contribution of hypertension to cardiovascular disease and the relatively high rates of uncontrolled blood pressure, many intervention methods have been developed and tested. Team-based care, for example, in which the patient's primary care provider works with other professionals, such as nurses, pharmacists, dietitians, social workers, and community health workers, has consistently been observed to improve blood pressure control [4,5]. The Guide to Community Preventive Services from the Centers for Disease Control and Prevention (CDC) recently concluded that team-based care increased the percentage of patients with controlled blood pressure by 12.0% (interquartile range [IQR] 3.0-19.5, 31 studies) [4]. Despite these recommendations, as fee-for-service care remains the dominant reimbursement model for health care in the United States, disseminating team-based care is challenging without understanding how it could be paid for [6,7].

Engaging patients in their own care, known as *patient activation*, has been increasingly described as a strategy to improve self-management of chronic diseases such as hypertension [8]. One important way for patients to be involved in their care is to ask questions during physician visits. Kravitz and colleagues [9] observed that standardized patients who were instructed to ask specific questions to receive a treatment of depression were more than twice as likely to receive a prescription for an antidepressant medication as those who were instructed to make no request. This is consistent with many studies that report that giving patients reminders to ask providers about tests and treatments they are due to receive, such as vaccines and cancer screenings, increases the likelihood that they receive the recommended care [10,11]. In a meta-analysis, for example, Stone and colleagues [12] observed that giving reminders to patients was consistently effective at increasing adherence with cancer screening guidelines and was more effective than patient education.

We undertook this study to understand whether the same approach could be used with a chronic medical condition such as hypertension. We hypothesized that if patients whose blood pressure was not controlled were reminded to ask specific questions that may lead their provider to intensify their care, that the reminders would increase blood pressure control. The target, therefore, was clinical inertia, or the tendency of providers not to make a change to the plan of care for participants who are not at their treatment target [13-15]. Berlowitz and colleagues [15] observed that patients whose blood pressure was greater than 155/90 mm Hg and whose blood pressure was elevated at a previous visit where the provider made no change, had an intensification made to their blood pressure medications in only 25.6% of visits. Therefore, we hypothesized that the intervention would increase medication intensification among patients whose blood pressure was not at target, which would thereby increase the percentage of patients who achieved standard blood pressure goals. The study was designed as a cluster-randomized trial, common to clinical trials of interventions that are implemented at the level of a larger unit, such as a hospital [16], physician [17], or physician practice [5].

The overall intent of the intervention was to encourage users whose blood pressure was not at goal to ask questions that would lead to medication intensification. We chose to target patients with hypertension that had a history of not being controlled, but did not require all patients at baseline to have uncontrolled hypertension for the following reasons. First, the intervention was designed for a managed care organization (MCO) to make available to the individual patients covered by the MCO. However, MCOs, other than staff-model MCO's (eg, Kaiser Permanente), are typically unaware of which patients have controlled and uncontrolled blood pressure because they lack access to data from the electronic health record. For that reason, we anticipated that MCOs would make such a tool available to patients without regard to blood pressure values, given findings from Egan and others [1] that blood pressure control in the United States is suboptimal. Second, a number of the recommendations from blood pressure guidelines [18] are for regular tests to be done (eg, kidney function) that are not specific to whether or not blood pressure is controlled. Third, blood pressure control varies over time, so that many patients whose blood pressure is controlled at 1 point in time will have uncontrolled blood pressure at a subsequent visit, requiring additional medications.

Methods

Overview

A complete description of the study design and baseline characteristics of participants is published elsewhere [19]. The

protocol and all consent forms were approved by the Institutional Review Board of the Pennsylvania State University College of Medicine. This was a randomized controlled trial (NCT00377208).

Design

Randomization

Physicians were randomized to the intervention condition or control condition and, consistent with a cluster-randomized trial design, all patients recruited from a physician were then assigned to the same condition as their physician. Therefore, all interventions pertained to the cluster to which the physician was assigned. For example, for providers assigned to the intervention condition, all of their patients who were enrolled in this study were assigned to the hypertension intervention. To reduce the chances that staff would treat patients differently, particularly while assessing outcomes, staff were blinded to the condition of the provider. Providers and their patients were randomized to 1 of 2 following conditions.

Intervention Condition

Participants were instructed to answer questions online once each month and before any visits with their hypertension care provider. Questions focused on the care they had recalled receiving (eg, creatinine testing) and the blood pressure from their most recent doctor visit. Based on their responses and prewritten rules, participants received a brief prewritten tailored feedback message. Each tailored feedback message included a question that the patient should consider asking their provider (eg, "What can you do to help me lower my blood pressure?") and a lay summary of the guideline recommendation and the evidence underlying the recommendation. All decision rules and tailored messages were based on the Seventh Report of the Joint National Committee on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure (JNC 7) [18] and were reviewed by a nephrologist (BF).

Control Condition

Participants randomized to this group received Web-based tailored feedback and were prompted to ask questions during primary care provider (PCP) visits regarding preventive services that they were due to receive. All decision rules and tailored messages were based on guidelines from the United States Preventive Services Task Force (USPSTF; eg, tetanus vaccination, screening for colon cancer). The frequency of activities in the control condition was identical to those in the intervention condition.

Measures

The primary outcome measure was blood pressure control. Blood pressure was measured by a standardized protocol [20]. As blood pressure control targets are different for those with diabetes and chronic kidney disease (≤130/≤80 mm Hg) than those without these conditions (≤140/≤90 mm Hg), chart reviews were used to determine the prevalence of each [18]. The hypothesized mediating variable was the change in the number of blood pressure medications, which the intervention was intended to increase. Secondary outcomes included changes in the number of hypertension screening tests (eg, urine protein, serum creatinine), also recommended in JNC 7, as well as changes in doctor-patient communication.

Changes in medications and hypertension-related tests (eg, creatinine) were measured by chart abstraction at 12 months after the baseline study visit. The use of preventive services (eg, tetanus vaccination) was measured via patient self-report. The impact of the intervention on doctor-patient communication was measured by a self-reported survey, completed within 72 hours after the participants' first visits with their hypertension care provider. This exit survey was designed to measure what was discussed during the visit, and provide insight into how the tailored feedback was being used. Similar methods have been studied by 1 of the investigators (CNS) and observed to be accurate for identifying activities that occur during provider visits [21]. All outcome measures were performed similarly for participants in both clusters. For example, participants in the control condition, which focused on preventive services, had their blood pressure measured and their chart reviewed at the same time (eg, 12 months after the baseline study visit) and in the same manner as participants in the intervention condition, which focused on hypertension.

Recruitment and Study Flow

See Figure 1 for the Consolidated Standards of Reporting Trials (CONSORT) diagram of participant flow. Consistent with the cluster-randomized trial design, we first recruited PCPs and then recruited patients to the same condition as their PCP. The PCPs whose practices were located within 40 miles of Penn State Hershey Medical Center (PSHMC) in Central Pennsylvania were recruited. To limit the study to providers engaged primarily in clinical care, recruitment was limited to PCPs who were physicians, board certified in internal medicine or family practice, and who practiced at least 4 half-days each week. To maximize recruitment of minority patients, online census data were used to create a list of zip codes within 40 miles of PSHMC with the highest racial and ethnic minority populations. A list of PCPs within these zip codes was then purchased from a marketing firm (SK&A, A Cegedim Company, Irvine, CA, USA). Recruitment letters were mailed to providers. To minimize the potential for unblinding physicians, which can lead physicians to intervene in other ways, known as *co-intervention* [22], all recruitment letters and discussions with physicians stated that the overall goal of the study was to improve primary and secondary prevention for patients with hypertension. The rationale for this was based on findings by Fontana and colleagues [23], who observed that patients with chronic medical conditions, such as hypertension, are less likely to receive preventive services such as mammography. Study staff members made follow-up phone calls to assess the level of interest of the physicians in having their practice participate in the study. Project staff visited physicians who expressed interest to explain the study more fully and to recruit them into the study.

After getting consent from the PCP, study staff visited the practice to review the charts of patients to identify eligible patients who met the blood pressure and age criteria (Table 1). Patients meeting these criteria were mailed recruitment letters cosigned by their PCP and the study investigator (see

Multimedia Appendix 1). Patients interested in participating were then encouraged to call the toll-free study number. During a screening phone call, the study was explained to the patient and the patient was assessed for the remaining inclusion and exclusion criteria (Table 1).

Eligible participants were scheduled for a baseline visit at their physician's office, where study staff received their consent (see Multimedia Appendix 2), measured their blood pressure, and recorded their current medications. After the baseline visit, participants were considered enrolled and were assigned to the same condition as their PCP. After leaving the baseline visit, participants completed the baseline measures (eg, demographics) on the study website using their personal work or home computer. During the study, scheduled dates of all visits with their PCP were tracked via a question in each monthly survey. After the first visit with their PCP, participants completed an exit survey online to assess what care was provided during the first visit with the PCP (eg, topics discussed, medication changes made; see Multimedia Appendix 3). At the end of the 12-month study, participants completed follow-up self-reported measures on the study website (see Multimedia Appendix 4). At 12 months, participants met for 1 final time with a study staff member in the office of their PCP to measure their blood pressure and record their current medications. There was no cost associated with using the study website.

Figure 1. CONSORT diagram of participant flow.

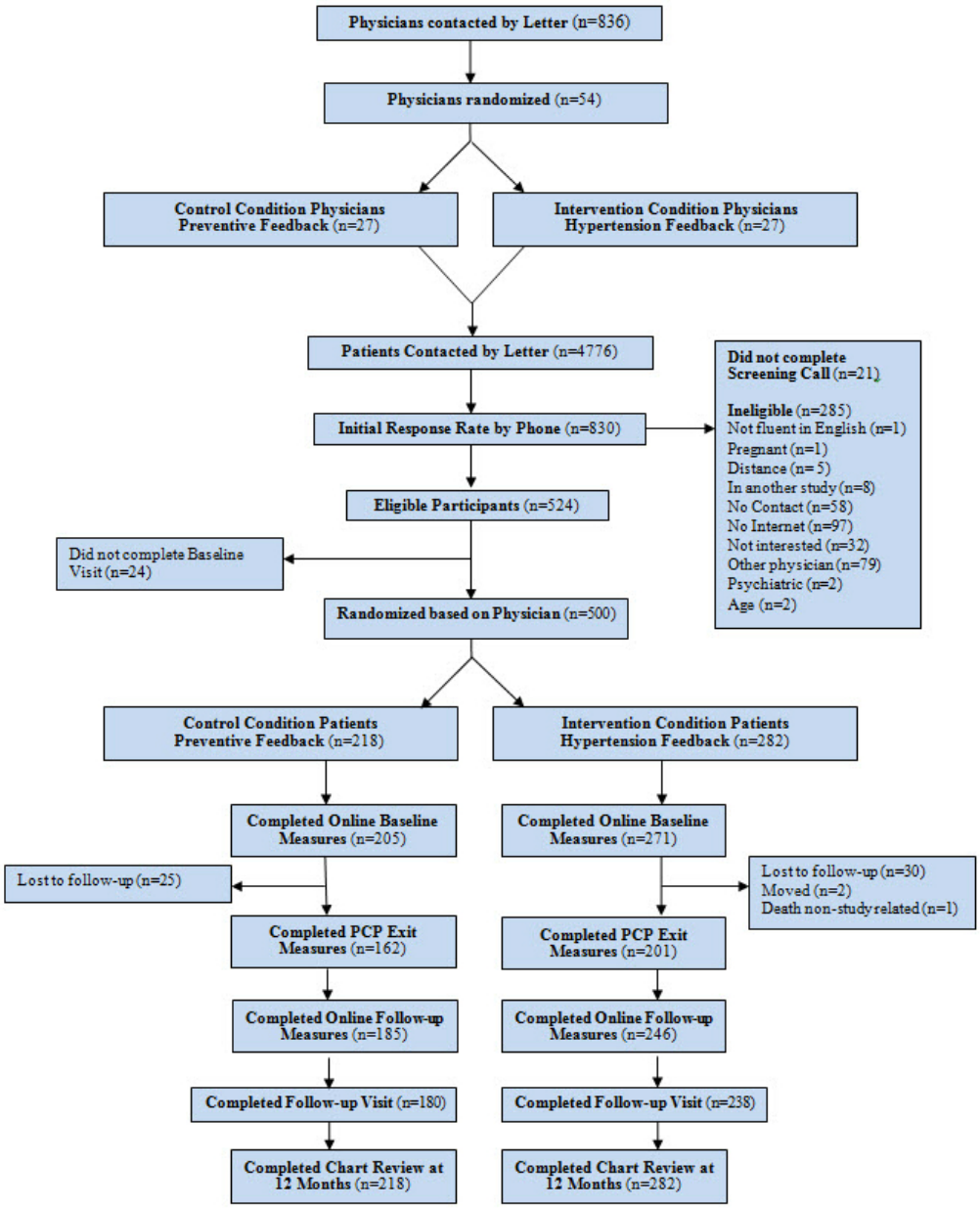


Table 1. Patient inclusion and exclusion criteria.

Criteria	Description
Inclusion	Age ≥21 years
	Fluent in English
	At least 2 high blood pressure readings in the previous 12 months (≥130/≥80 mmHg for patients with diabetes or chronic kidney disease, ≥140/≥90 mmHg without)
	Primary care provider was participating in the study
Exclusion	Receiving care from another physician for hypertension treatment (eg cardiologist)
	Hospitalized for a psychiatric disorder in the past 3 years
	Participating in another clinical research study
	Pregnant or planned to become pregnant in the next 12 months
	Planning on moving out of the area in the next 12 months
	No personal access to the Internet at home or at work
	No personal email account

Randomization

Randomization was done at the level of the PCP. PCPs were enrolled and randomized into 1 of 2 conditions by selecting an envelope containing a document noting the assigned condition (intervention condition or control condition) from a stack of sealed envelopes, the order of which was generated by the study statistician (EL). All patient participants were assigned to the same condition as their PCP, consistent with a cluster-designed randomized trial [5,16,17]. This was done to eliminate contamination because the intervention had the potential to change the care that the PCP may provide to other patients in the practice. To ensure fidelity to the use of the intervention, participants in both conditions were eligible to receive US $5 for each month they used the website, for a potential total of US $60.

Intervention Condition

The intervention condition participants received access to the hypertension module of the Web-based intervention for 12 months, which included: (1) Web-based hypertension feedback based on the individual patient's self-report of health variables (see Figure 2 and Multimedia Appendix 5), decision rules, and tailored feedback based on recommendations from JNC 7 [18], (2) a "pocket chart" that patients could print and take to their doctor visits to help them record their blood pressure that could later be entered into the website, and (3) automated reminders that tracked the dates of upcoming visits with their PCP to remind patients to use the website before physician visits. Participants were expected to use the website at least once each month and received reminder emails if 30 days had elapsed since the last time they used the website.

On the website, patients entered blood pressure values measured at clinical visits and answered questions about their hypertension-related care (eg, date and value of last creatinine blood test). The patient was then provided with onscreen tailored feedback, based on preprogrammed rules adapted from recommendations in JNC 7 [18]. For any situation in which the patient appeared to be in need of a change to their care (eg, blood pressure was higher than JNC 7 goals), the tailored feedback also included a question that the participant should consider asking at the next visit (eg, "Can I lower my blood pressure by drinking less alcohol?"). Participants also received a layperson description of the scientific rationale for the statement, and a link to an external website to provide supporting information for each recommendation (eg, American Heart Association). The feedback was ordered so that the highest priority recommendations appeared closest to the top of the page (see Figure 3 and Multimedia Appendix 6).

The Web-based feedback was based on the hypertension guidelines in JNC 7 [18], which was reviewed for the presence of specific recommendations on hypertension management. Recommendations were ranked based on the strength of the supporting evidence as well as the likelihood of impact from increasing adherence to the recommendation. These recommendations were reviewed by the study's clinical hypertension expert (BF). For example, although JNC 7 recommends checking potassium before initiating medication therapy, its impact on blood pressure control or on the morbidity from hypertension is likely to be limited compared to the impact of adding a medication to lower the blood pressure value [18]. Given the time constraints of PCP visits [24], it was assumed that patients would be able to ask no more than 1 to 2 questions during physician visits and expect that these questions would be appropriately addressed. For this reason, the prioritization of recommendations was done so that the recommendations that were the most widely accepted and most likely to affect blood pressure control appeared closest to the top of the Web page. For example, the tailored messages on the top focused on the target values of systolic and diastolic blood pressure because these are a consistent focus of recommendations from the JNC 7 [18], the National Committee for Quality Assurance (NCQA) [25], and are considered a measure of high quality of care [26].

The intervention was designed to be used before a visit with the physician who provided the patient's hypertension care. For that reason, it was essential to track the dates of these visits so the patients could be reminded to use the intervention before these visits. It was assumed that the intervention would be significantly less effective if used long before or following an

office visit, as the intervention is designed to activate patients to ask specific questions during visits [27]. For that reason, participants in both conditions received monthly email reminders to use the intervention, in large part to track the date of the next hypertension care provider visit so that users could be prompted to use the intervention before these planned visits. Participants in both conditions then received email reminders to use the site starting 10 days before their physician visit and repeated twice if the participant had not used the site before the planned visit. This had a secondary benefit of assuring that the feedback was based on the most recent data (ie recent laboratory or blood pressure values). This approach was effective in a separate study, where more than 90% of patients used the website in the 2 weeks before a physician visit [28].

An important requirement of the intervention was that patients enter data (eg, blood pressure, creatinine values) that they would typically only receive during visits with a health care provider. For that reason, we created a wallet-sized pocket chart to help patients gather this data during office visits. The participant could then later enter these numbers into the website. Participants were encouraged to print the pocket chart and bring it to their doctor visits and ask their physician to record test results, or ask their physician for the test value and record it themselves.

Control Condition

The control condition was identical to the intervention condition, except that the content of the control condition intervention focused exclusively on preventive services rather than hypertension (see Multimedia Appendix 7). The control condition participants received the same components of the intervention as intervention condition participants (eg, Web-based personalized feedback, pocket chart, email reminders), but the website focused on preventive services that were not related to hypertension care (eg, mammography screening, tetanus immunizations) and were recommended by the USPSTF (see Multimedia Appendix 8). The control condition, being an active treatment control condition, was designed to improve preventive care and not hypertension care. For example, it was designed not to provide feedback about increasing physical activity, which can lower blood pressure. This control condition design, similar to that used by other investigators [29,30], was chosen to limit attrition and control for contact time.

Effect Size and Statistical Analysis

The expected effect size was based on a meta-analysis by Stone and colleagues [11] that examined the efficacy of reminders given to patients on rates of adult immunization and cancer screening services. Patient reminders were observed to significantly increase immunizations (odds ratio [OR] 2.5), mammography utilization (OR 2.3), cervical cytology screening (OR 1.7), and colon cancer screening (OR 2.8), effect sizes that were consistent with reviews by other investigators [31-33]. Therefore, the current study was powered to detect an effect size that translates to a more conservative relative risk for blood pressure control of 1.5% to 60% in the intervention condition and 40% in the control condition. Given the cluster design and that practice effects tend to induce positive correlation among patient outcomes, we included in our sample size calculations a conservative intrapractice correlation coefficient (intervention condition) of 0.1. Our power calculations indicated that 12 practices per treatment group (24 total) with at least 200 patients per treatment group (400 total) were needed to detect these differences.

The 2 randomized groups were compared on important demographic and other baseline variables to ensure successful randomization. Student *t* tests and Pearson chi-square tests were used, respectively, to examine between-group differences in continuous and categorical variables. This comparison was done to ensure that randomization created equal groups (Table 2).

Data analysis was focused on the primary hypothesis that a higher percentage of participants in the intervention condition condition, compared to control condition participants, would have controlled blood pressure at 12 months, using intent-to-treat principles [34]. Overall rate of blood pressure control was compared between groups using Pearson chi-square test. The effects of the intervention on continuous blood pressure values were then compared using the Student *t* test. Linear mixed effects modeling was used to control for the potential impact of variables that differed between conditions at baseline (number of blood pressure medications and employment status) [35]. Subgroup analyses were performed to understand the impact of the intervention on individuals whose blood pressure was not controlled at baseline. The data were first analyzed limited to those who followed up at 12 months. Although there are many methods to account for missing data at follow-up, we used the Markov chain Monte Carlo (MCMC) method via the multiple imputation procedure statement (PROC MI) in the SAS statistical analysis software system (SAS Institute, Inc, Cary, NC, USA), as has been used in human immunodeficiency virus clinical trials and in other cluster-randomized trials [36,37]. Most importantly, the point estimates of blood pressure with or without the multiple imputation differed by <1.0%, with neither method yielding results that were near clinical or statistical significance. Because the results were not qualitatively different between these methods, the results are presented using imputed values for all 500 participants randomized at baseline.

Figure 2. Screenshot of intervention condition monthly survey.

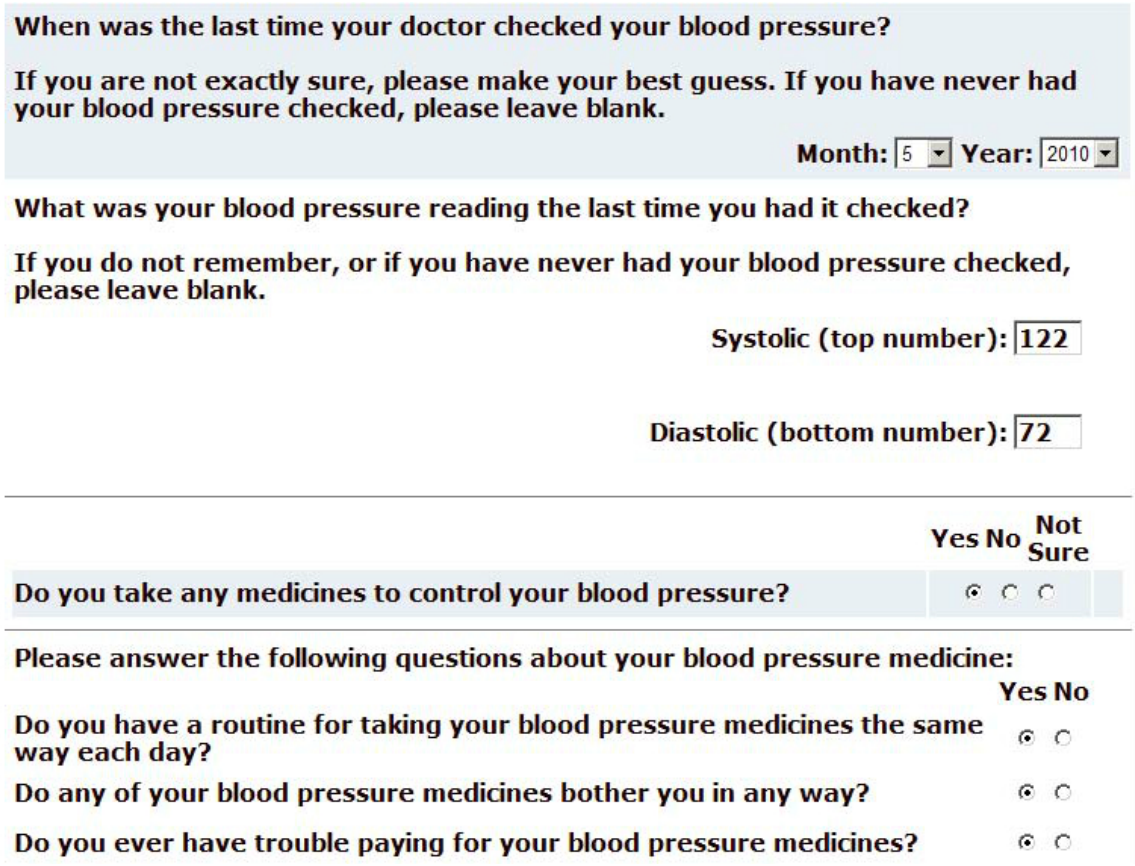
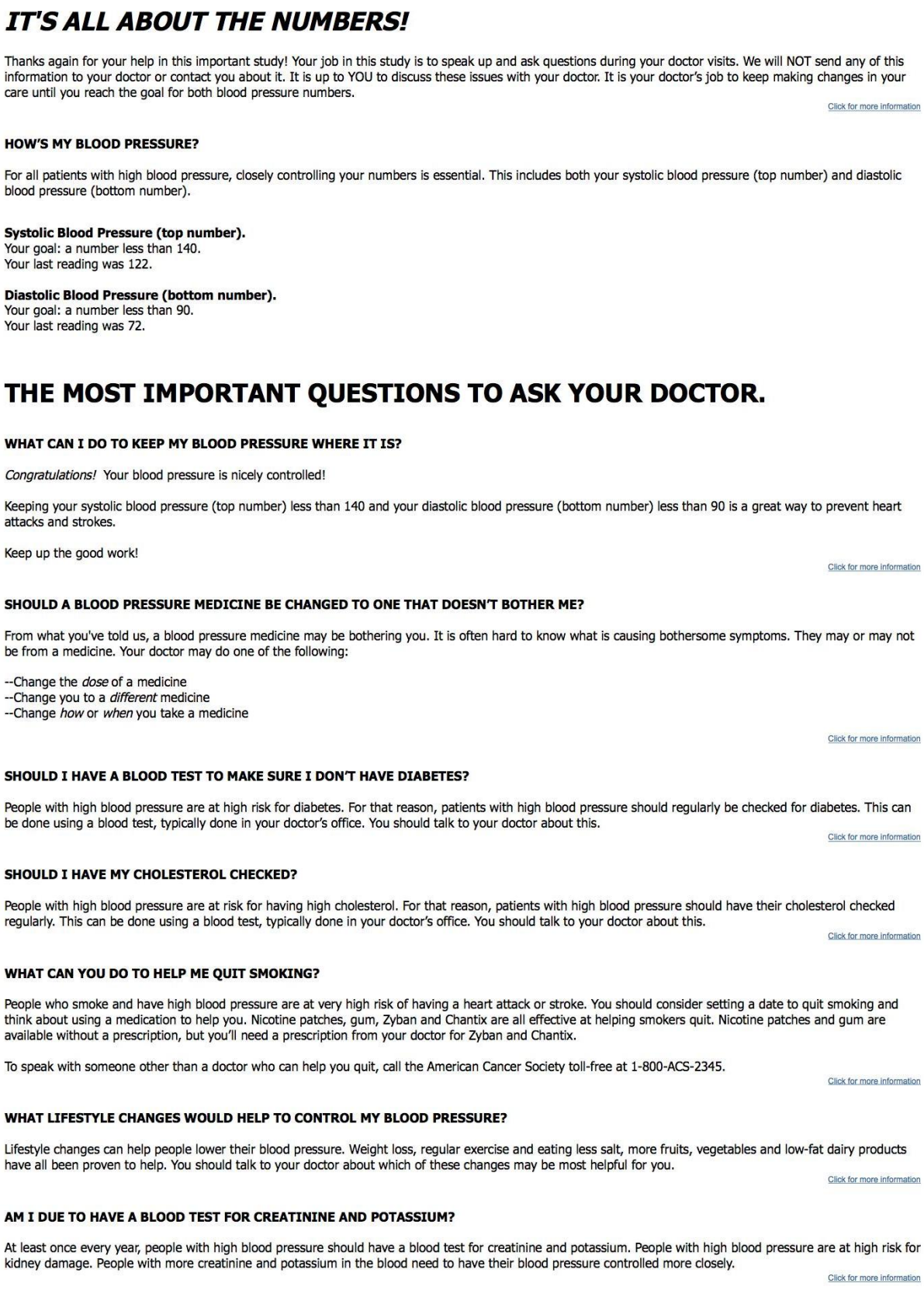


Figure 3. Screenshot of intervention condition feedback from monthly survey.



IT'S ALL ABOUT THE NUMBERS!

Thanks again for your help in this important study! Your job in this study is to speak up and ask questions during your doctor visits. We will NOT send any of this information to your doctor or contact you about it. It is up to YOU to discuss these issues with your doctor. It is your doctor's job to keep making changes in your care until you reach the goal for both blood pressure numbers.

Click for more information

HOW'S MY BLOOD PRESSURE?

For all patients with high blood pressure, closely controlling your numbers is essential. This includes both your systolic blood pressure (top number) and diastolic blood pressure (bottom number).

Systolic Blood Pressure (top number).
Your goal: a number less than 140.
Your last reading was 122.

Diastolic Blood Pressure (bottom number).
Your goal: a number less than 90.
Your last reading was 72.

THE MOST IMPORTANT QUESTIONS TO ASK YOUR DOCTOR.

WHAT CAN I DO TO KEEP MY BLOOD PRESSURE WHERE IT IS?

Congratulations! Your blood pressure is nicely controlled!

Keeping your systolic blood pressure (top number) less than 140 and your diastolic blood pressure (bottom number) less than 90 is a great way to prevent heart attacks and strokes.

Keep up the good work!

Click for more information

SHOULD A BLOOD PRESSURE MEDICINE BE CHANGED TO ONE THAT DOESN'T BOTHER ME?

From what you've told us, a blood pressure medicine may be bothering you. It is often hard to know what is causing bothersome symptoms. They may or may not be from a medicine. Your doctor may do one of the following:

--Change the *dose* of a medicine
--Change you to a *different* medicine
--Change *how* or *when* you take a medicine

Click for more information

SHOULD I HAVE A BLOOD TEST TO MAKE SURE I DON'T HAVE DIABETES?

People with high blood pressure are at high risk for diabetes. For that reason, patients with high blood pressure should regularly be checked for diabetes. This can be done using a blood test, typically done in your doctor's office. You should talk to your doctor about this.

Click for more information

SHOULD I HAVE MY CHOLESTEROL CHECKED?

People with high blood pressure are at risk for having high cholesterol. For that reason, patients with high blood pressure should have their cholesterol checked regularly. This can be done using a blood test, typically done in your doctor's office. You should talk to your doctor about this.

Click for more information

WHAT CAN YOU DO TO HELP ME QUIT SMOKING?

People who smoke and have high blood pressure are at very high risk of having a heart attack or stroke. You should consider setting a date to quit smoking and think about using a medication to help you. Nicotine patches, gum, Zyban and Chantix are all effective at helping smokers quit. Nicotine patches and gum are available without a prescription, but you'll need a prescription from your doctor for Zyban and Chantix.

To speak with someone other than a doctor who can help you quit, call the American Cancer Society toll-free at 1-800-ACS-2345.

Click for more information

WHAT LIFESTYLE CHANGES WOULD HELP TO CONTROL MY BLOOD PRESSURE?

Lifestyle changes can help people lower their blood pressure. Weight loss, regular exercise and eating less salt, more fruits, vegetables and low-fat dairy products have all been proven to help. You should talk to your doctor about which of these changes may be most helpful for you.

Click for more information

AM I DUE TO HAVE A BLOOD TEST FOR CREATININE AND POTASSIUM?

At least once every year, people with high blood pressure should have a blood test for creatinine and potassium. People with high blood pressure are at high risk for kidney damage. People with more creatinine and potassium in the blood need to have their blood pressure controlled more closely.

Click for more information

Table 2. Baseline data comparing characteristics in different conditions.

Characteristic	Total (N=500)	Intervention (n=282)	Control (n=218)	*P* value[a]
Age (years), mean (SD)	60.5 (11.9)	59.6 (12.1)	61.6 (11.4)	.07
Gender (female), n (%)	288 (57.6)	165 (58.5)	123 (56.4)	.64
Race/ethnicity, n (%)				
Non-Hispanic white	375 (75.0)	123 (75.5)	162 (74.3)	.75
Hispanic	13 (2.6)	10 (3.5)	3 (1.4)	.13
Background, n (%)				
Education (college ≥4 years)	202 (42.4)	113 (41.7)	89 (43.4)	.71
Income (≤US $50,000)	221 (49.3)	124 (49.0)	97 (49.7)	.88
Employed for wages	214 (45.0)	140 (51.7)	74 (36.1)	<.001
Health				
Body mass index, mean (SD)	32.4 (7.4)	32.1 (7.3)	32.7 (7.6)	.42
Smoking, n (%)	41 (8.6)	21 (7.8)	20 (9.8)	.44
Diabetes, n (%)	104 (22.0)	61 (22.6)	43 (21.3)	.73
Health (very good/excellent), n (%)	160 (33.6)	88 (32.5)	72 (35.1)	.54
Blood pressure (BP)				
Systolic (mm Hg), mean (SD)	132.6 (15.0)	132.7 (14.9)	132.4 (15.2)	.84
Diastolic (mm Hg), mean (SD)	75.5 (11.0)	75.7 (11.1)	75.2 (10.9)	.62
Systolic controlled, n (%)	303 (64.5)	181 (67.5)	122 (60.4)	.11
Diastolic controlled, n (%)	405 (86.2)	203 (85.8)	175 (86.6)	.80
Overall controlled, n (%)	289 (61.5)	170 (63.4)	119 (58.9)	.32
Number of BP medications, n (%)	1.0 (1.61)	1.0 (1.51)	1.0 (1.73)	.02
Internet use, n (%)				
Internet use for health, ≥once/month	94 (20.9)	52 (20.4)	42 (21.7)	.75
Used Internet before a physician visit	227 (51.1)	140 (54.9)	87 (46.0)	.06

[a]*P* value from 2-sample *t* test for continuous outcomes and Pearson chi-square test for categorical outcomes.

Results

Summary

Five university physicians group clinics associated with Hershey Medical Center and 836 family practices were contacted to enroll in our study. Of the physicians contacted, 54 (6.4%) responded and agreed to participate. Consistent with a cluster-randomized design, randomization was at the level of the provider, and each cluster included the provider and all patients of that single provider who were enrolled in the study. Therefore, all patients recruited were assigned to the condition (intervention condition or control condition) that the provider had been randomly assigned, and all analyses were performed at the level of the cluster, in this case the provider. After a medical record chart review, patients of enrolled physicians with a diagnosis of hypertension (n=4776) were sent recruitment letters inviting them to participate in the study. Of those who were sent a letter, 828 (17.3%) responded and 812 (17%) were able to be contacted and screened for eligibility. Eligible participants (n=528) were scheduled for a baseline visit at which 3 consecutive blood pressures were measured. Of those scheduled, 500 completed the baseline visit and 218 participants were enrolled into the control condition (prevention) and 282 into the intervention condition (hypertension). Following the baseline visit, 476 (95.2%) participants logged onto the website and completed the online baseline measures. From the 476 participants who completed the baseline measures questionnaire, demographic data as well as baseline secondary outcome data were collected (Table 2). Following their first visit with their PCP, 363 (72.6%) participants completed a survey to record what occurred during the visit. After 12 months, 418 (83.6%) returned for their follow-up visit.

Fidelity

As stated previously, the intervention was designed to be used by answering a series of questions and reviewing tailored feedback at least once each month. Of the 500 participants, 411 (82.2%) used the intervention during at least 6 of 12 months, and 174 (34.8%) logged into and used the website each of the 12 months enrolled in the study (Figure 4). Adherence was monitored electronically by number of months in which

participants logged in (Figure 5). There was no significant difference in use of the intervention observed between study groups.

Baseline Characteristics

Table 2 reports the baseline characteristics. There were no significant differences in most variables between study groups, including the demographic variables of age, gender, race, ethnicity, education, and income. Mean systolic blood pressure, for example, was 132.7 mm Hg among intervention condition participants and 132.4 mm Hg among control condition participants (*P*=.84). Similarly, the percentage of participants whose blood pressure was controlled at baseline was similar between groups (170/268, 63.43% in intervention condition; 119/202, 58.9% in control condition; *P*=.32). At baseline, the rates of blood pressure control did not differ between intervention condition and control condition participants or between those enrolled at university-based primary care practices versus community-based primary care practices (data not shown). However, there were significant group differences in 2 variables. More intervention condition participants were employed for wages (140/271, 51.7% vs 74/205, 36.1%; *P*<.001) and control condition participants used a greater number of blood pressure medications (1.73 vs 1.51; *P*=.02) than intervention condition participants. It was also observed that only 1.0% of participants enrolled in the study were uninsured; this is much lower than the Behavioral Risk Factor Surveillance Survey (BRFSS) results from 2007 to 2008 of 15.4% [38].

Primary Outcomes

Table 3 reports blood pressure outcomes at 12 months. The overall rate of participants with controlled blood pressure increased from 312 of 500 (62.4%) at baseline to 344 of 500 (68.8%) at 12 months. No significant difference was observed between study groups with respect to rates of blood pressure control (intervention condition: 201/282, 71.3%; control condition: 143/218 control, 65.6%; *P*=.31). Similar results were observed when blood pressure was examined as a continuous variable and when the results were expressed as continuous changes within groups. For example, the mean systolic blood pressure at 12 months was not significantly different between conditions (intervention condition: mean 128.3, SD 13.5; control condition: mean 128.9, SD 14.4; *P*=.88). Table 3 shows similar results were found for mean systolic and diastolic blood pressures, and systolic and diastolic control rates. Even after adjusting for baseline differences in the number of blood pressure medications and employment status, blood pressure control in the intervention condition condition was no greater than in the control condition condition after 12 months.

Because the goal of the intervention was to intervene on patients with uncontrolled blood pressure, a subgroup analysis was performed that was limited to those participants whose blood pressure was uncontrolled at baseline. Of the 188 participants found to be uncontrolled at baseline, 87 (46.3%) were controlled at 12-month follow-up. However, no significant difference was observed in blood pressure control rates between study groups (intervention condition: 47/103, 45.6%; control condition: 40/85, 47.1%; *P*=.57).

Secondary Outcomes

Table 4 presents the impact of the intervention on doctor–patient communication based on data from the exit survey after the first PCP visit during the study. This survey was designed to measure what was discussed during the visit to understand how the tailored feedback was used. Most participants (222/355, 62.5%) reported asking a question that was suggested by the tailored feedback during the visit with their PCP. As expected, there were significant differences in the topics discussed during visits by intervention condition and control condition participants. For example, more control condition participants than intervention condition participants discussed having a tetanus vaccine (50/141, 35.5% vs 28/166, 16.9%; *P*=.02) and a pneumonia vaccination (39/135, 28.9 vs 23/160, 14.4%; *P*=.01). Similarly, more intervention condition participants than control condition participants discussed having serum creatinine tested (92/175, 52.6% vs 49/138, 35.5%; *P*=.02) and urine protein tested (81/181, 44.8% vs 21/144, 14.6%; *P*<.001).

Table 5 presents changes in medications and changes in preventive services and hypertension screening tests between conditions. Changes in medications and hypertension-related tests (eg, creatinine) were measured by chart abstraction at 12 months, whereas the use of preventive services (eg, tetanus vaccination) was measured via patient self-report. No significant difference was observed in the change in number of blood pressure medications used in each group over the 12-month study (–0.17 intervention, –0.28 control; *P*=.64). For preventive services, significantly more participants in the control condition reported receiving a tetanus vaccination in the past year (30/218, 13.8 vs 15/282, 5.3%; *P*=.02) and pneumonia vaccination in the past year (25/218, 11.5% vs 16/282, 5.7%; *P*=.02). However, no differences were observed in the percentage of participants in the intervention condition and control condition who reported receiving an influenza vaccine or colonoscopy. Hypertension screening tests during the intervention also did not differ between conditions. For example, based on chart abstraction, 211 of 282 (74.8%) intervention condition participants had their creatinine tested versus 156 of 218 (71.6%) of control condition participants (*P*=.56). Similar results were observed for urine protein and serum potassium testing during the 12 study months.

Figure 4. Percentage of participants using the intervention during each of the 12 study months.

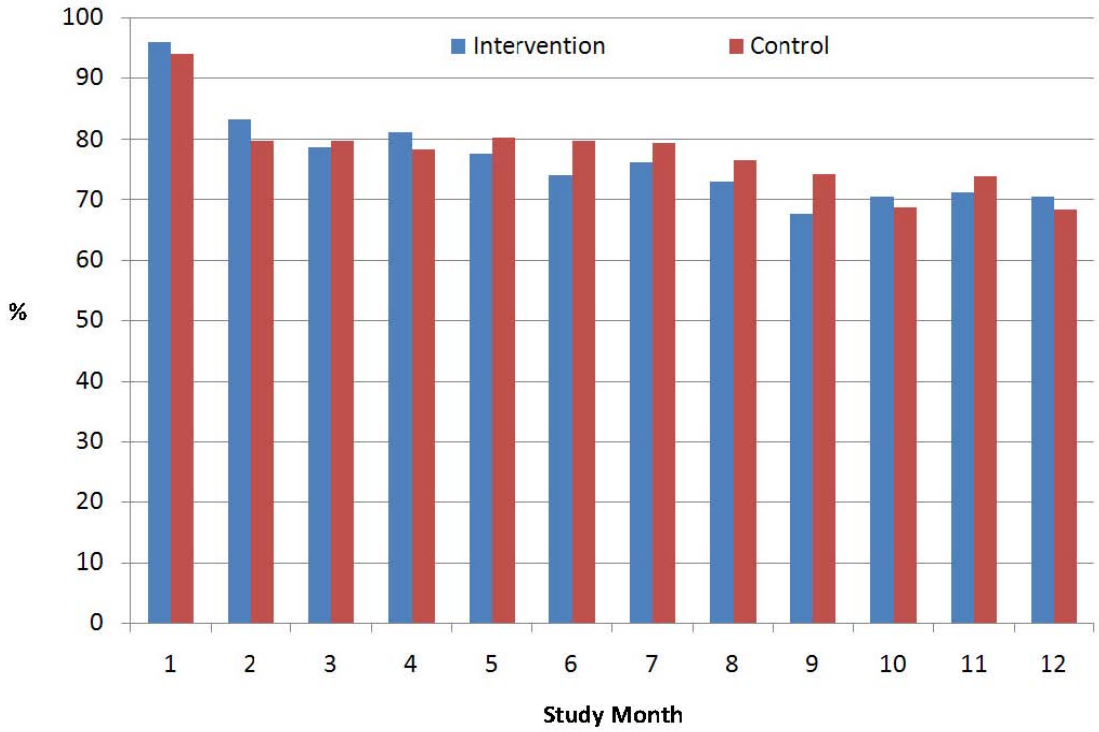


Figure 5. Mean (± standard error) number of log-ins per month in both conditions in each of the 12 study months.

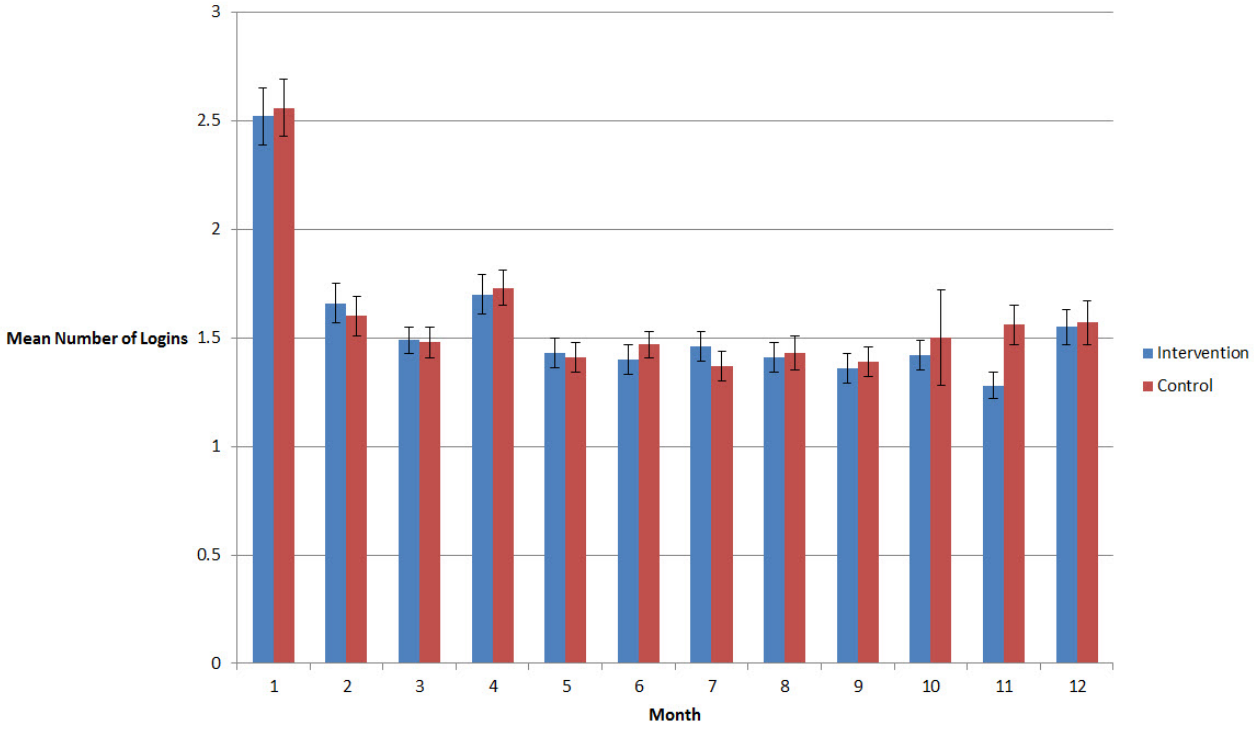


Table 3. Primary blood pressure (BP) outcomes.

Outcome	Total	Intervention	Control	*P* value[a]
All participants (N=500)				
Systolic BP (mm Hg), mean (SD)	128.5 (13.9)	128.3 (13.5)	128.9 (14.4)	.88
Diastolic BP (mm Hg), mean (SD)	74.1 (9.2)	73.8 (8.9)	74.4 (9.6)	.15
Systolic BP controlled, n (%)	372 (74.4)	206 (76.6)	156 (71.6)	.35
Diastolic BP controlled, n (%)	447 (89.4)	254 (90.1)	193 (88.5)	.59
Overall BP controlled, n (%)	344 (68.8)	201 (71.3)	143 (65.6)	.27
Participants uncontrolled at baseline (n=188)				
Systolic BP (mm Hg), mean (SD)	135.4 (13.5)	134.9 (13.3)	136.1 (13.9)	.83
Diastolic BP (mm Hg), mean (SD)	77.0 (10.1)	77.3 (9.5)	76.7 (10.8)	.79
Systolic BP controlled, n (%)	103 (54.8)	58 (56.3)	45 (52.9)	.89
Diastolic BP controlled, n (%)	152 (80.9)	81 (78.6)	71 (83.5)	.51
Overall BP control, n (%)	87 (46.3)	47 (45.6)	40 (47.1)	.57

[a]*P* value from 2-sample *t* test for continuous outcomes and Pearson chi-square test for categorical outcomes.

Table 4. Impact on doctor–patient communication.

Self-reported outcomes	Total n (%)	Intervention condition n (%)	Control condition n (%)	*P* value[a]
General				
Asked any questions from the website	222 (62.5)	125 (63.8)	97 (61.0)	.52
Discussed notes about website at visit	143 (42.3)	76 (39.8)	70 (45.5)	.37
Control				
Discussed having a tetanus shot	78 (25.4)	28 (16.9)	50 (35.5)	<.001
Discussed having a pneumonia shot	62 (21.0)	23 (14.4)	39 (28.9)	.01
Discussed having a flu shot	143 (45.7)	74 (43.3)	69 (48.6)	.94
Discussed having a test for colon cancer	76 (24.9)	38 (22.8)	38 (27.5)	.55
Intervention				
Discussed what your last blood pressure numbers were	309 (87.3)	171 (87.2)	138 (87.3)	.97
Discussed having creatinine tested	141 (45.1)	92 (52.6)	49 (35.5)	.02
Discussed urine test for protein	102 (31.4)	81 (44.8)	21 (14.6)	<.001
Discussed secondary causes of hypertension	20 (7.2)	10 (6.7)	10 (7.8)	.52
Discussed changing to blood pressure medication that works better for you	27 (9.3)	17 (10.7)	10 (7.6)	.47
Discussed more frequent visits until blood pressure controlled	38 (13.7)	24 (16.2)	14 (10.9)	.42
Doctor recommended starting a new blood pressure medication	34 (10.3)	21 (11.7)	13 (8.7)	.62
Doctor recommended increasing dose of a blood pressure medication	31 (9.9)	18 (10.7)	13 (9.0)	.52

[a]*P* value from Pearson chi-square test for categorical outcomes.

Table 5. Secondary outcomes of changes in medications and preventive and hypertension screening tests.

Secondary outcomes	Total (n=500)	Intervention (n=282)	Control (n=218)	*P* value[a]
Medications, mean (SD)				
Total number of medications at baseline	1.61 (1.0)	1.51 (1.0)	1.73 (1.0)	.16
Total number of medications at follow-up	1.39 (1.1)	1.34 (1.1)	1.45 (1.1)	.64
Change in number of medications	–0.22 (0.93)	–0.17 (0.92)	-0.28 (0.93)	.64
Preventive services, n (%)				
Tetanus vaccine within 1 year	45 (9.0)	15 (5.3)	30 (13.8)	.02
Pneumonia vaccine within 1 year	41 (8.2)	16 (5.7)	25 (11.5)	.02
Influenza vaccine within 1 year	280 (56.0)	152 (53.9)	128 (58.7)	.81
Colonoscopy within 1 year	37 (7.4)	22 (7.8)	15 (6.9)	.72
Hypertension screening tests, n (%)				
Serum creatinine tested within 1 year	367 (73.4)	211 (74.8)	156 (71.6)	.56
Urine protein tested within 1 year	144 (28.8)	86 (30.5)	58 (26.6)	.26
Serum potassium tested within 1 year	362 (72.4)	209 (74.1)	153 (70.2)	.31

[a]*P* value from 2-sample *t* test for continuous outcomes and Pearson chi-square test for categorical outcomes.

Discussion

Principal Findings

The present study evaluated the efficacy of an intervention designed to prompt patients to ask questions about their blood pressure control. We hypothesized that by encouraging patients to ask questions with a focus on questions aimed at improving control ("What can you help me do to lower my blood pressure?"), physicians would give patients higher doses of blood pressure medications or additional medications, which would improve blood pressure control more in the intervention condition. The results indicated, however, that the intervention did not improve blood pressure control. Although the intervention led to more discussions of some hypertension-related screening tests (eg, creatinine testing), it did not lead to improvements in blood pressure control. At baseline, 312 of 500 (62.4%) participants had their systolic and diastolic blood pressure controlled as per JNC 7 guidelines [18]. After 12 months of the intervention, those rates were higher, but not significantly different (intervention condition: 201/282, 71.3%; control condition: 143/218, 65.6%; *P*=.27). Similarly, blood pressure improvements were not observed when blood pressure was expressed as a continuous variable or when the analysis was limited to the subgroup of individuals whose blood pressure was uncontrolled at baseline (n=188). However, participants in the control condition group who were prompted to ask questions about preventive services, were more likely to receive a tetanus vaccine (30/218, 13.8% vs 15/282, 5.3%; *P*=.02) and a pneumonia vaccine (25/218, 11.5% vs 16/282, 5.7%; *P*=.02). These findings were consistent with previous studies observing that patient reminders improve preventive service utilization [11].

There are several possible hypotheses to explain why no effect on blood pressure was observed. First, patients may not have been comfortable asking for intensifications to their medication treatment plan because of a concern about questioning the expertise of the provider. Although Kravitz and colleagues [9] observed that prompting standardized patients to ask for a depression treatment increased the chances of receiving treatment, we believe that asking for a drug intensification for hypertension is a very different act. In a clinical encounter for depression, for example, the patient possesses more data than the provider upon which decisions will be made (eg, depressive symptoms). In a clinical encounter for hypertension, this is reversed; the provider typically has more data than the patient (eg, blood pressure values). Because of this difference, encouraging patients to ask questions about their blood pressure control has inherent limitations, making this intervention strategy questionable for this setting. The patient may or may not be aware of their blood pressure at the time of the visit. The blood pressure in the United States is typically measured by a nurse and not a physician, and the nurse may or may not tell the patient the value of their blood pressure. The intervention, however, was designed to prompt patients to become aware of their blood pressure by specifically asking for it. For that reason, two-thirds of participants in the intervention condition entered a blood pressure value. For the other third, however, their lack of awareness of their blood pressure suggests that this method may be of limited use for blood pressure control, unless home blood pressure monitoring is used. Simply put, without knowing the blood pressure, patients would have nothing to ask about. We are currently studying the impact of a similar intervention for asthma (RO1HL088590) which will be more similar to the depression study by Kravitz and colleagues [9] because asthma care is also based on symptoms.

Asking for medication intensification may have been perceived by patients as questioning the judgment of the provider, which may have created a barrier to asking for medication intensifications. This is consistent with the observation, in Table 4, that the intervention led to more conversations about testing

for creatinine and urine protein, but no differences in conversations about intensifying medications. It is possible that, if home monitoring had been used, patients may have been more likely to ask for medication intensifications. This situation would be more akin to depression in which the patient has all of the data, which doctors typically do not ask for. We hypothesize that if a patient entered the visit, as suggested by some investigators [39], with an average of 10 blood pressure values that he/she knew were too high, the results of the study may have been different.

A second possible reason for the lack of effect may be the general lack of awareness of the significance of a blood pressure value that is not at target. Although professionals view a systolic blood pressure of 160 mm Hg very differently from 140 mm Hg, these differences are likely not as meaningful to patients. Wright-Nunes and colleagues [40] observed that, even among patients with chronic kidney disease for whom blood pressure control is critical, only 48% of participants identified the correct blood pressure goal, and those who correctly identified their goal had a mean systolic blood pressure 9.96 mm Hg less than those who could not [40]. If the study had limited participation to those with Stage 2 hypertension (systolic ≥160 mm Hg, diastolic ≥100 mm Hg), for example, both providers and patients may have been more responsive to the interventions, believing that the distance from current control to the goal was further. In addition, the lack of symptoms for hypertension removes a key incentive for asking when it is not controlled. Although patients with symptomatic conditions (eg, asthma, depression, migraine) are prompted to ask for treatment intensifications to feel better, patients with conditions that have few symptoms (eg, hypertension, high cholesterol, type 2 diabetes) lack the symptom trigger to request treatment intensifications.

A third possible reason is that blood pressure varies significantly from measurement to measurement, yet the decision rule that created the tailored message was based on just 1 blood pressure measurement [41]. This may have led providers to be less influenced by a request for intensification or created uncertainty in patients who may have presented a barrier to asking. There are several clinical settings in which an elevated blood pressure may not necessitate a dose adjustment [18]. For example, if a medication dose is increased, it may take up to 4 to 6 weeks to see the full effect on blood pressure, so it would be prudent to wait before making a dose change [18]. Also, if the blood pressure has generally been controlled and the blood pressure is in the mild hypertensive range during 1 visit, it may not be appropriate to intensify treatment at the visit. For this reason, Berlowitz and colleagues [15] defined clinical inertia only in patients whose blood pressure was elevated at a prior visit and at a second visit, with no change being made at the second visit. The treatment algorithm we put in place was not sensitive to trends in the blood pressure over time and whether an elevated blood pressure was a 1-time event, such as a patient is having back pain, which often elevates systolic blood pressure. In those situations, deferring decisions on blood pressure medications to a subsequent visit, using home blood pressure monitoring, or ambulatory blood pressure monitoring would be reasonable clinical decisions. Had the intervention been integrated into an electronic health record (eg, patient portal) to generate trend graphs, or used structured repeated home blood pressure monitoring to better determine the blood pressure trend and average, the results may have been different. However, although Hyman and colleagues [42] encouraged the use of ambulatory blood pressure and electronic pill bottle data to reduce physician uncertainty as a potential barrier to intensification, this additional data did not lead to different differences in blood pressure.

Finally, a fourth possible reason for the lack of effect was the impact of secular trends of blood pressure in the United States. Hypertension control improved significantly between 1988 and 2008, which limited the ability of the study to affect blood pressure control because more patients were controlled than anticipated in our power calculations [1]. Egan and colleagues [1] observed that blood pressure control improved from 27.3% (95% CI 25.6-29.1) in 1988-1994 to 50.1% (95% CI 46.8-53.5; *P*=.006) in 2007-2008. Although the level of control was higher than expected, it is noteworthy that the intervention had no impact on the sizeable minority of patients whose blood pressure was uncontrolled at baseline.

Limitations

This study does have some limitations. First, the patients may not have used the intervention before doctor visits or asked questions during doctor visits and the study did not collect the data to assure that these were done. However, mean use per month (± standard error; as seen in Figure 5) met the goals for the study (≥1/month) and was similar between conditions. We did not have access to time use data, which may have differed between conditions. Because the only activity that participants in each condition were able to do on the site was to read approximately 1 page of tailored text feedback, it is unlikely that this would differ greatly between conditions. Also, each tailored message was accompanied by a link to an external site that provided additional information on the topic (eg, the website for the American Heart Association), and tracking the time spent on those external sites was not technically feasible to our developers at the time this study was conducted. A second design limitation of the study is that we chose not to audio or video record all encounters because of concerns about reactivity. Although Kravitz and colleagues [9] used standardized patients to measure changes in care, the design of the current study was to understand whether typical patients would receive different care as a result of the intervention. Future studies may require audio recording to understand which questions were asked and in what way and more detailed Web tracking to understand which pages were viewed and which links were clicked by participants. In addition, audio recording would be a useful future adjunct to understand the impact of patients proactively asking such questions on what occurs during visits and how doctors treat patients. Recently, for example, Gudzune and colleagues [43] used audio recording to detect that primary care providers demonstrated less emotional rapport with overweight and obese patients, potentially weakening the patient-physician relationship. It is possible that the intervention used in this study may have had a negative impact that would be hard to detect without such audio recording.

Second, a limitation of the study was the management and use of blood pressure values. Patients were encouraged to enter the

most recent blood pressure value onto the website, which then generated tailored feedback based, in part, on that number. However, approximately one-third of participants did not enter a blood pressure value because they were unaware of their blood pressure. Even if the participant had entered a blood pressure value, during the subsequent visit to their provider, that value would likely have been different. This situation may have created confusion and uncertainty for patients, undermining their desire to ask for treatment intensifications. This would not be the case, for example, for tetanus vaccination, which is stable over time. To address this limitation, future studies should consider using home blood pressure monitoring, so that patients are prompted to ask questions based on their average home values. Powers and colleagues [41] observed that the mean of 5 home measurements was more accurate for categorizing blood pressure as being high than a single pressure value measured in the office. Green and colleagues [44], for example, encouraged participants to monitor their blood pressure at home, taught them the goals of the numbers, and also how to use an online patient portal (eg, secure email, refilling medications, viewing their health data), yet this did not significantly increase the percentage of patients whose blood pressure was controlled. However, the study by Green and colleagues did not include a patient activation component as in this study, in which patients were encouraged to ask specific questions in response to specific blood pressure values. Future studies may consider examining the impact of combining both elements (blood pressure monitoring plus patient activation questions) on blood pressure control because both may be necessary to assist patients in overcoming clinical inertia in their care.

A third limitation of the study is that the level of blood pressure control observed at baseline in this study was higher than anticipated. The study was powered to detect a 60% blood pressure control rate in the intervention condition versus 40% in the control condition, yet 61.5% of patients had controlled blood pressure at baseline. Enrolling patients whose blood pressure was controlled or nearly controlled lessened the likelihood that patients would see a message from the program that convinced them that their blood pressure was sufficiently far from the goal to talk to their doctor about changing their medications. If the study had limited participation to those with Stage 2 hypertension (systolic ≥160 mm Hg, diastolic ≥100 mm Hg), for example, both providers and patients may have been more responsive to the interventions, believing that the distance from current control to the goal was further. However, if more of the same type of patients were enrolled, it is unlikely that the results would have been different. Of the 188 patients whose blood pressure was not controlled at baseline, blood pressure control at 12 months was slightly higher in the control condition than the intervention condition, suggesting that inflating the sample size would not have changed the outcomes.

Fourth, as in most clinical trials, ours was in a limited geographic region with patient profiles that do not match the target population in the entire United States. Only 1% of participants in this study were uninsured, for example, compared to 4% of primary care patients nationwide [45]. Also, the study included lower rates of African-Americans and Hispanic adults than in the United States' population. In 2007, according the United States Census Bureau, 15% of adults in the United States were Hispanic or Latino and 63% were non-Hispanic white compared with 2.6% and 75.0% in the present study. Although efforts were made to recruit from communities with higher minority representation, Dauphin County in central Pennsylvania has a markedly lower rate of minority representation than the rest of the nation, making this challenging. We recognize, therefore, that the results may not be generalizable to populations with higher levels of minority representation. In addition, similar to other studies of educational interventions for hypertension [46,47], we excluded patients recently hospitalized for a mental illness because of concerns that this may increase losses to follow-up. However, excluding such individuals is unlikely to affect the external validity of the findings because less than 1% of adults are hospitalized for mental illness each year [48].

A fifth potential limitation is that detailed covariate data were not collected and may have differed between conditions, yet were not adjusted for. Physical activity, alcohol intake, and salt intake each can influence blood pressure [18], yet were not measured. In addition, clinical inertia is greatest when a change was made at the previous visit, yet this was not assessed [15]. Although randomization was used, employment status differed significantly between conditions, so it is possible that other potential confounders differed between conditions as well. We were able to adjust for differences in employment status and number of hypertension medications; thereby, minimizing the impact of differences in these variables on the outcomes, but this would not be possible for unmeasured potential confounders. Given the randomized design, however, the likelihood that these variables differed significantly between conditions is low, given the similarity between conditions on age, gender, race, and other medical conditions (Table 2). For example, body mass index, which is associated with physical activity level [49], was nearly identical between conditions (intervention condition: mean 32.1; control condition mean 32.7; P=.42].

Conclusions

There are several strengths to our study. First, the study used an active treatment control group. Not only did this limit participant attrition and control for contact time, the active treatment control condition provided data to document that the intervention was effective at increasing preventive care, limiting concerns over whether participants had actually used the intervention as it was designed. Second, using the Internet as a communication medium makes what is learned easily disseminated. Although most Web-based studies to date have not shown major health benefits (eg, weight control) [50], some interventions (eg, sleep) have shown benefits [51]. Understanding how best to use this medium, given the low potential per-user cost and wide disseminability, makes studies such as this critical to perform. Although participants in this study were paid and may have checked-in in a perfunctory manner to qualify for the reimbursement because the task being asked was relatively minor (review 1 page of tailored feedback), this would seem unlikely. Also, at the present time, much research is underway to test the impact of gaming elements [52,53] and social elements [54], both of which have the potential to increase engagement without directly compensating

participants. Despite low rates of adherence to Web-based interventions [55,56], we observed high rates of fidelity (>70% of all study months) by asking patients to complete a brief Web-based survey, leading to tailored feedback, each month and before provider visits. This intervention structure, monthly use of an online tool, could be used to potentially impact the care of patients experiencing a range of conditions.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Patient recruitment letter.

[PNG File, 38KB - jmir_v15i9e158_app1.png]

Multimedia Appendix 2

IRB approved informed consent form.

[PDF File (Adobe PDF File), 47KB - jmir_v15i9e158_app2.pdf]

Multimedia Appendix 3

Patient online exit survey.

[PDF File (Adobe PDF File), 373KB - jmir_v15i9e158_app3.pdf]

Multimedia Appendix 4

Patient online follow up measures.

[PDF File (Adobe PDF File), 1MB - jmir_v15i9e158_app4.pdf]

Multimedia Appendix 5

Intervention online monthly survey.

[PDF File (Adobe PDF File), 363KB - jmir_v15i9e158_app5.pdf]

Multimedia Appendix 6

Intervention online feedback.

[PDF File (Adobe PDF File), 1MB - jmir_v15i9e158_app6.pdf]

Multimedia Appendix 7

Preventive online monthly survey.

[PDF File (Adobe PDF File), 611KB - jmir_v15i9e158_app7.pdf]

Multimedia Appendix 8

Preventive online feedback.

[PDF File (Adobe PDF File), 1MB - jmir_v15i9e158_app8.pdf]

Multimedia Appendix 9

CONSORT-EHEALTH checklist V1.6.2 [57].

[PDF File (Adobe PDF File), 997KB - jmir_v15i9e158_app9.pdf]

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Abbreviations

BRFSS: Behavioral Risk Factor Surveillance Survey
CDC: Centers for Disease Control and Prevention
CONSORT: Consolidated Standards of Reporting Trials
JNC 7: Seventh Report of the Joint National Committee on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure
MCMC: Markov chain Monte Carlo
MCO: managed care organization
NCQA: National Committee for Quality Assurance
NHANES: National Health and Nutrition Examination Survey
OR: odds ratio
PCP: primary care provider
PSHMC: Penn State Hershey Medical Center
USPSTF: United States Preventive Services Task Force

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Original Paper

Long-Term Outcomes of Internet-Based Self-Management Support in Adults With Asthma: Randomized Controlled Trial

Johanna L van Gaalen[1], MD; Thijs Beerthuizen[1], MD; Victor van der Meer[1], MD, PhD; Patricia van Reisen[1], MD; Geertje W Redelijkheid[1], MD; Jiska B Snoeck-Stroband[1], MD, PhD; Jacob K Sont[1], PhD; SMASHING Study Group[1]

Leiden University Medical Center, Department of Medical Decision Making, Leiden, Netherlands

Corresponding Author:
Jacob K Sont, PhD
Leiden University Medical Center
Department of Medical Decision Making
Albinusdreef 2, J-10-86
Leiden, 2333 ZA
Netherlands
Phone: 31 715264578
Fax: 31 715266838
Email: j.k.sont@lumc.nl

Abstract

Background: Long-term asthma management falls short of the goals set by international guidelines. The Internet is proposed as an attractive medium to support guided self-management in asthma. Recently, in a multicenter, pragmatic randomized controlled parallel trial with a follow-up period of 1 year, patients were allocated Internet-based self-management (IBSM) support (Internet group [IG]) or usual care (UC) alone. IBSM support was automatically terminated after 12 months of follow-up. In this study, IBSM support has been demonstrated to improve asthma-related quality of life, asthma control, lung function, and the number of symptom-free days as compared to UC. IBSM support was based on known key components for effective self-management and included weekly asthma control monitoring and treatment advice, online and group education, and communication (both online and offline) with a respiratory nurse.

Objective: The objective of the study was to assess the long-term effects of providing patients 1 year of IBSM support as compared to UC alone.

Methods: Two hundred adults with physician-diagnosed asthma (3 or more months of inhaled corticosteroids prescribed in the past year) from 37 general practices and 1 academic outpatient department who previously participated were invited by letter for additional follow-up at 1.5 years after finishing the study. The Asthma Control Questionnaire (ACQ) and the Asthma Quality of Life Questionnaire (AQLQ) were completed by 107 participants (60 UC participants and 47 IG participants). A minimal clinical important difference in both questionnaires is 0.5 on a 7-point scale.

Results: At 30 months after baseline, a sustained and significant difference in terms of asthma-related quality of life of 0.29 (95% CI 0.01-0.57) and asthma control of -0.33 (95% CI -0.61 to -0.05) was found in favor of the IBSM group. No such differences were found for inhaled corticosteroid dosage or for lung function, measured as forced expiratory volume in 1 second.

Conclusions: Improvements in asthma-related quality of life and asthma control were sustained in patients who received IBSM support for 1 year, even up to 1.5 years after terminating support. Future research should be focused on implementation of IBSM on a wider scale within routine asthma care.

Trial Registration: International Standard Randomized Controlled Trial Number (ISRCTN): 79864465; http://www.controlled-trials.com/ISRCTN79864465 (Archived by WebCite at http://www.webcitation.org/6J4VHhPk4).

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KEYWORDS

asthma; quality of life; self-management; long-term; eHealth; Internet; telemedicine

Introduction

Asthma is a common chronic disease with a prevalence of approximately 6% among adults [1]. It is characterized by chronic inflammation and/or structural changes of the airways, which leads to recurrent episodes of wheezing, coughing, difficulty breathing, and/or chest tightness [2,3]. According to clinical guidelines [2,3], treatment strategies for asthma should be aimed at minimization of symptoms, optimization of lung function, and prevention of symptom aggravation with few medication side effects. Even though effective therapies are widely available, many patients do not achieve these treatment goals [1,4]. As a consequence, asthma still imposes a significant burden of disease on the individual patient. A proactive patient-centered approach consisting of education, treatment goals, self-monitoring, and an action plan, accompanied by guidance and regular review by a health care provider, has the potential to improve outcomes in asthma [5], including improved quality of life and a reduced number of hospitalizations and unscheduled doctor visits. In spite of the prominent role within guidelines, adoption of this "guided self-management" is lacking [6]. While many practices do offer patients a routine medical review, only a minority of patients are provided with an action plan by their health care provider [7,8]. Usage of action plans by patients could be enhanced if action plans are part of a patient-professional partnership and when they are tailored to the needs of the individual patient [9].

Provision of Internet technology has been proposed as an appealing medium for asthma management [10-14]. Indeed, in the study by Van der Meer et al [15] in patients with mild to moderate persistent asthma, it was demonstrated that provision of an Internet-based self-management (IBSM) support program for 1 year leads to improved asthma-related quality of life, asthma control, lung function, and the number of symptom-free days as compared to usual care (UC) alone. A post hoc analysis of this study [16] demonstrated that patients with asthma that was not well controlled benefited the most from IBSM support. In addition, this study showed that at 12 months of follow-up, about 60% of the patients were still using the program of their own initiative. However, it is unknown whether the benefits are sustained over a long-term period. We hypothesized that the benefits of providing 1 year of IBSM support are sustained over a long-term period.

In this paper, we aim to assess the long-term effects of providing patients 1 year of IBSM support as compared to UC alone.

Methods

Participants

Two hundred patients who previously participated in a 12-month multicenter, nonblinded, pragmatic randomized controlled parallel trial were invited for additional follow-up 1.5 years after finishing the study. Full details of the study methodology and subjects for the Self-Management of Asthma Supported by Hospitals, ICT, Nurses and General practitioners (SMASHING) study have been published elsewhere [15]. Briefly, patients were recruited from 37 general practices in the Leiden and The Hague area and from the outpatient clinic of the department of Respiratory Medicine of the Leiden University Medical Center (LUMC), the Netherlands. Eligibility criteria were adult age (18-50 years), physician-diagnosed asthma, prescription of inhaled corticosteroids ≥3 months in the previous year, access to Internet at home, and the ability to understand written and oral Dutch instructions. Patients who received a maintenance dose of oral corticosteroids were excluded.

All participants were trained in a group educational session to measure lung function as forced expiratory volume in 1 second (FEV_1) by using a handheld electronic spirometer (PiKo-1, Ferraris Respiratory). After this session, patients were asked to report during a 2-week period FEV_1 (daily), day and night symptom score (daily), and to fill in at least once weekly an Asthma Control Questionnaire (ACQ) [17] on a specifically designed website or by mobile phone text messaging (SMS). The ACQ is a validated 7-item questionnaire for assessment of actual level of asthma control, consisting of 6 questions on asthma symptoms in the previous 7 days and an FEV_1 measurement. Optimal cut-point for "well-controlled" is ≤0.75 and a value of ≥1.50 confirms "uncontrolled" asthma [18]. During these 2 weeks, patients did not receive feedback on their actual level of asthma control.

After the 2-week period, all patients were randomized to either IBSM support adjacent to UC, that is, Internet group (IG), or to UC alone. Strategy allocation of patients on a 1:1 ratio was conducted by JKS using a computer-generated permuted block scheme. Patients were stratified on care provider (general practice vs outpatient clinic) and asthma control at baseline. The SMASHING study was powered to detect a difference in the primary outcome asthma-related quality of life, as measured by the Asthma Quality of Life Questionnaire (AQLQ) score [19] between the two groups. Due to the nature of the intervention and its pragmatic character, researchers were not blinded for group allocation. This study was approved by the ethical committee of the LUMC, the Netherlands, and was conducted in concordance with the principles of the Declaration of Helsinki [20], as amended in Seoul 2008. The trial conformed to the Consolidated Standards of Reporting Trials (CONSORT)-eHealth Checklist (Multimedia Appendix 1) [21].

Internet-Based Self-Management Support Program

The IBSM support program is based on focus groups [22], the Chronic Care model [23], and known key components for effective self-management [5]. The program was aimed at supporting patients in conducting self-management activities and developing a patient-provider partnership in asthma care [3]. Focus groups were conducted to explore barriers for conducting self-management skills and to identify the potential role of an IBSM support tool. In particular, patients with asthma that was not well controlled (ACQ>0.75) were motivated to use novel information and communication technologies for management of their disease. The Chronic Care model is aimed at improving health care outcomes for patients with a chronic disease by means of a proactive patient-professional partnership that addresses both organizational factors (eg, decision support systems) and resources (eg, self-management support). We incorporated modules for electronic monitoring of asthma control and lung function (weekly ACQ and FEV_1), a personal

action plan, communication with a respiratory nurse (RN), and education.

During 12 months of follow-up, IG patients had access to IBSM support (Multimedia Appendix 2); after this period, IBSM support (including access to the website) was automatically terminated. Patients were instructed on how they could log in by using a personal username and password and how to use their personal action plan. The program included reminder options for monitoring activities (ie, ACQ, day and night symptom score, lung function), which were initially sent once weekly by either email or mobile phone SMS text messaging, but during follow-up frequency could be adjusted according to the preferences of the individual patient. Patients received immediate feedback (to maintain, step up or step down in medication, and/or to contact a health care professional) on self-monitoring outcomes according to a treatment algorithm (Figure 1) and a predefined action plan based on 6 medication steps (Table 1).

Five respiratory physicians, two general practitioners with a particular focus on respiratory diseases, and two respiratory epidemiologists participated in the development of this algorithm. Action plans of patients were based on their actual medication at the time of study enrollment. Treatment steps corresponded with (inter) national guidelines [3,24] on asthma management. Briefly, asthma medication can be aimed at (1) decreasing of airway narrowing (ie, beta2-agonists), and/or (2) decreasing airway inflammation (ie, glucocorticosteroids, leukotriene modifiers). A traffic light display (Figure 2) was used to indicate the level of asthma control: green (well-controlled, ACQ≤0.5), yellow (0.5<ACQ<1.0), orange (1.0<ACQ<1.5), and red (uncontrolled, ACQ score≥1.50).

After each medication change, a 4-week evaluation period commenced during which no advice to change treatment was given, except in the case of symptom deterioration. E-messaging, telephone, or Web-based communication allowed patients to interact with the RN. Additionally, the RN supported patients by nurse-initiated communication characterized by a supportive style to give positive feedback on achieved successes (eg, step-down in medication) or to inquire for reasons on not following treatment advice (eg, side effects). The RN reminded patients to fill in research questionnaires at 12 months of follow-up. On average, the RN spent 1-2 hours per week on patient- and nurse-initiated communication for all IG patients.

Education components of IBSM support were provided both online (eg, educational pages, newsfeed) and offline. Offline education consisted of a group education session that dealt with topics related to asthma self-management, usage of the IBSM tool, and designing an action plan based on current medication. Online information was based on information provided by the Lung Foundation Netherlands. Newsfeed content was kept up to date and contained items related to asthma and management of chronic diseases (eg, healthy lifestyle). During the study, neither major content/functionality changes nor bug fixes were required.

Program content was developed by JKS in close collaboration with the departments of Public Health and Primary Care (LUMC), Respiratory Medicine (LUMC, Amsterdam Medical Center), and Haga Teaching Hospital, The Hague. Software was developed by Furore BV, Amsterdam.

Table 1. Medication treatment steps.

Step[a]	Medication
1	As needed rapid-acting beta2-agonist[b]
2	Low-dose inhaled glucocorticosteroids
3a	Low-dose inhaled glucocorticosteroids + long-acting beta2-agonist
3b	Medium-dose inhaled glucocorticosteroids
3c	High-dose inhaled glucocorticosteroids
4a	Medium-dose inhaled glucocorticosteroids + long-acting beta2-agonist
4b	High-dose inhaled glucocorticosteroids + long-acting beta2-agonist
4c	Contact RN or other health care provider: consider addition of leukotriene modifier
5	Contact RN or other health care provider: consider addition of oral glucocorticosteroids

[a]Step numbers correspond with GINA guideline treatment steps [3].

[b]Applies to all treatment steps as this is reliever medication.

Figure 1. Treatment algorithm.

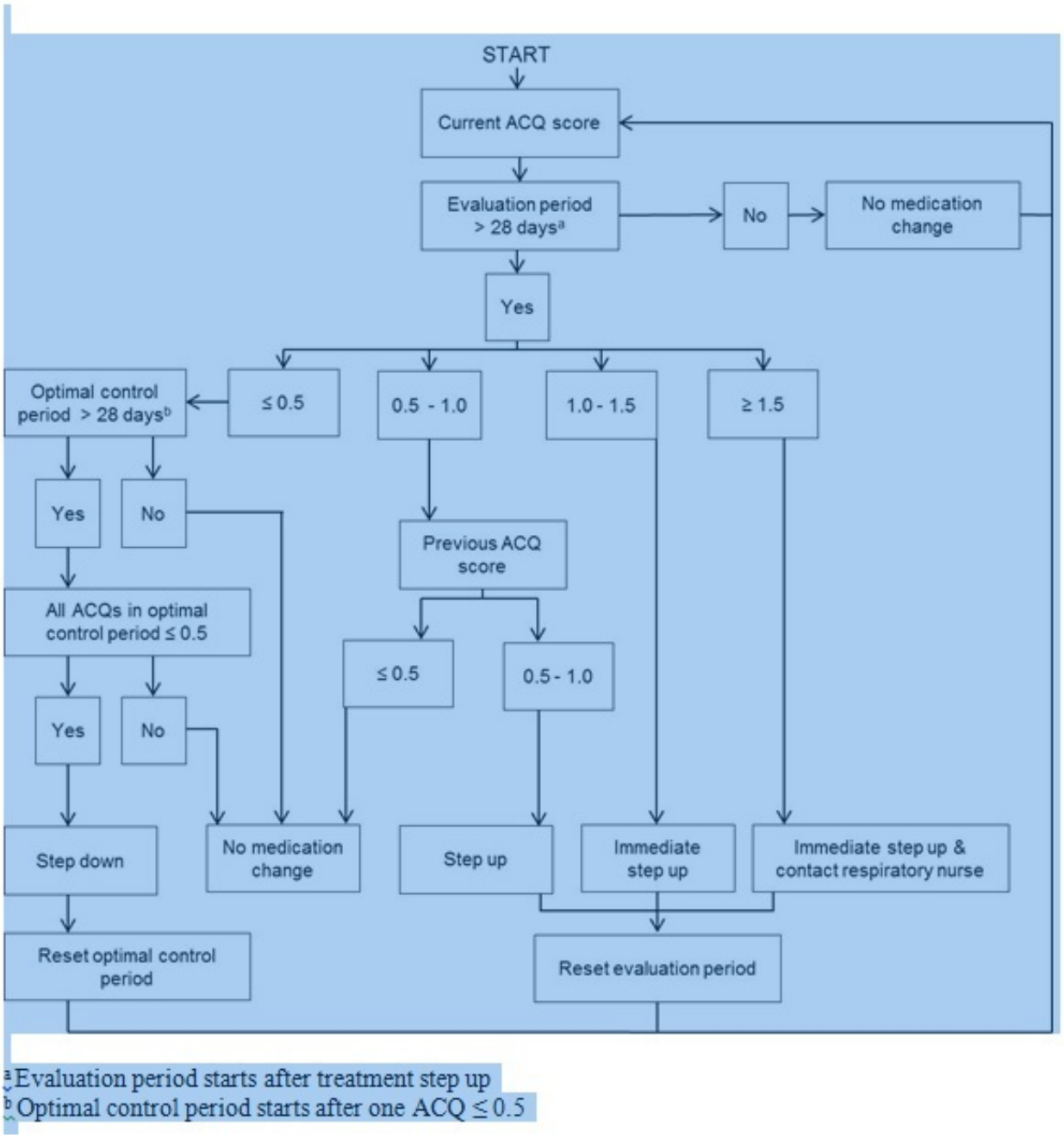
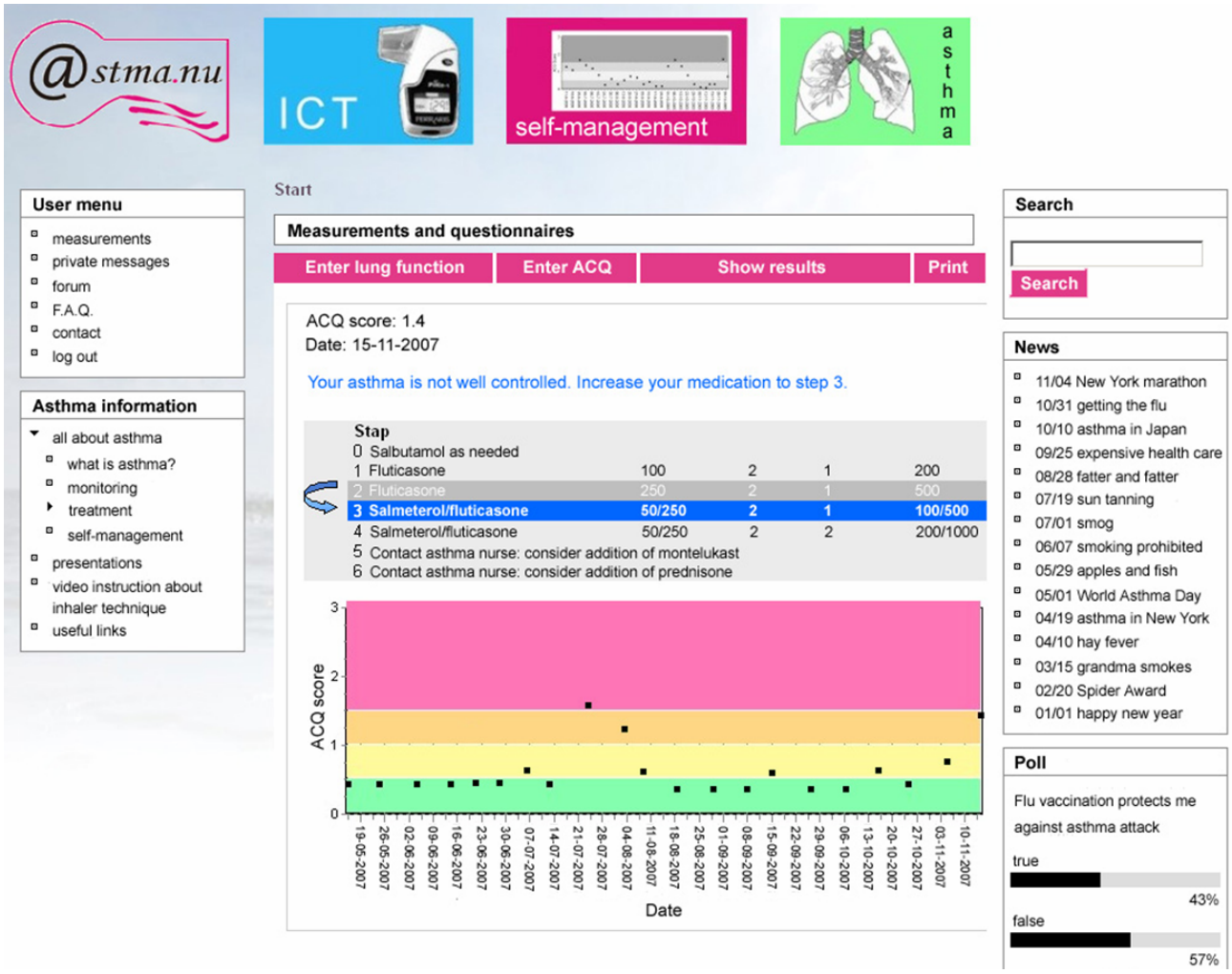


Figure 2. Traffic light display.



Usual Care

Patients allocated to UC received care as usual by their health care provider. According to the Dutch College of General Practitioners [24], each patient should be provided with a (paper-based) action plan and be invited for a medical review at least once a year.

Additional Follow-Up 30 Months After Baseline

Patients who previously participated were invited, by a letter containing information on the follow-up measurements, to attend the LUMC for follow-up measurements at 30 months after baseline (Table 2). Nonresponding patients received a reminder letter within 2-4 weeks and an additional telephone call. All participants gave written informed consent during this visit, prior to obtaining measurements. Patients were asked to report on their daily dose of inhaled corticosteroids (ICS) and to complete 2 paper-based questionnaires, namely an ACQ (including FEV_1) and an AQLQ [19], a validated 21-item questionnaire for assessment of asthma-related quality of life. The minimal clinical important difference for the ACQ is -0.5 and for the AQLQ is 0.5 [25,26]. Both questionnaires have a 7-point scale. Patients were asked to withhold short-acting beta2-agonists for 6-8 hours prior to FEV_1 measurement. Questionnaires were sent in the mail to patients who were unable or unwilling to attend the LUMC, and an additional home visit was scheduled in case of unavailability of a Piko-1 meter. Inhaled corticosteroid doses were reported as fluticasone equivalents.

Statistical Analysis

Differences in characteristics at baseline (null months) were analyzed between participants and nonparticipants of both groups (UC and IG) with unpaired *t* tests. ACQ and AQLQ scores, FEV_1, and daily ICS dose were compared between participants from both groups by applying linear mixed-effect models. ICS doses were reported as fluticasone equivalents. Within- and between-group differences were analyzed with paired and unpaired *t* tests, respectively. Statistical analyses were carried out by intention to treat. For analysis, Stata 9.2 was used. Subgroup analyses were conducted for patients with well-controlled (ACQ≤0.75) and uncontrolled asthma (ACQ>0.75) [17] at baseline.

Table 2. Outcome measures.

Characteristics	IBSM support (IG only)			
	Baseline	3 months	12 months	30 months/additional follow-up
Clinical				
Asthma control (ACQ)	X	X	X	X
Lung function (FEV_1)	X	X	X	X
Daily inhaled corticosteroid	X	X	X	X
Quality of life				
Asthma-related quality of life (AQLQ)	X	X	X	X

Results

Characteristics

In total, 107 out of 200 (54%) invited patients consented to participate for additional follow-up at 1.5 years after finishing the SMASHING study (Figure 3), of whom 60 patients were previously allocated to UC and 47 patients to the IG.

Participants in the IG differed in baseline ACQ scores from nonparticipants (0.93 vs 1.29; *P*=.009). Apart from these differences, no other differences in clinical characteristics at baseline between participants and nonparticipants in each group were identified. Table 2 gives an overview of baseline characteristics of study participants. Baseline characteristics of both groups were similar (Table 3).

Clinical Outcomes

Twelve months after baseline, significant improved outcomes in favor of the IG were demonstrated for asthma-related quality of life (AQLQ) at 0.37 (95% CI 0.14-0.61) and asthma control of -0.57 (95% CI -0.88 to -0.26) as compared with UC. For those who participated at 30 months, a difference in ACQ score between baseline and 12 months was 0.43 (95% CI 0.21-0.66) in favor of the IG. For those who did not participate at 30 months, a difference between baseline and 12 months of 0.34 (95% CI 0.06-0.61) in favor of the IG was detected. However, there was no significant difference in effect (in ACQ score between 0 and 12 months) between participants (0.43) and nonparticipants (0.33) at 30 months.

At 30 months after baseline, a significant and slightly attenuated improvement was shown for both AQLQ (adjusted between-group difference 0.29 [95% CI 0.01-0.57]) and ACQ (adjusted difference of -0.33 [95% CI -0.61 to -0.05]) scores in favor of the IG (Figures 4 and 5). No such differences were demonstrated for ICS dosage and lung function measured as FEV_1 (Figures 6 and 7). Patients with uncontrolled asthma at baseline (ACQ≤0.75) had significant better outcomes at 30 months for AQLQ (adjusted within-group difference of 0.52 [95% CI 0.10-0.95]) and asthma control (adjusted difference -0.44 [95% CI 0.04-0.85]) in favor of the IG.

Table 3. Baseline characteristics.

Characteristics		Internet group n=47	Usual care group n=60
Age, mean (SD)		36 (8.7)	37 (8.0)
Gender, n (%)			
	Male	12 (26)	19 (32)
	Female	35 (74)	41 (68)
Smokers, n (%)		25 (53)	27 (45)
Inhaled corticosteroids (µg/day), mean (SD)		455 (279)	476 (338)
AQLQ score, mean (SD)[a]		5.88 (0.74)	5.84 (0.82)
ACQ score , mean (SD)[b]		0.93 (0.60)	0.97 (0.65)
Prebronchodilator FEV_1, mean (SD)[c]		3.26 (0.80)	3.41 (0.96)
Prebronchodilator FEV_1 (% predicted), mean (SD)[c]		96.8 (20)	95.5 (18)

[a]Score range (worst-best), 1-7; minimal clinical important difference (MCID): 0.5.

[b]Score range (worst-best), 6-0; MCID: 0.5.

[c]Number of available observations in the Internet group is 26 and in the usual care group 37.

Figure 3. Flowchart of study participants.

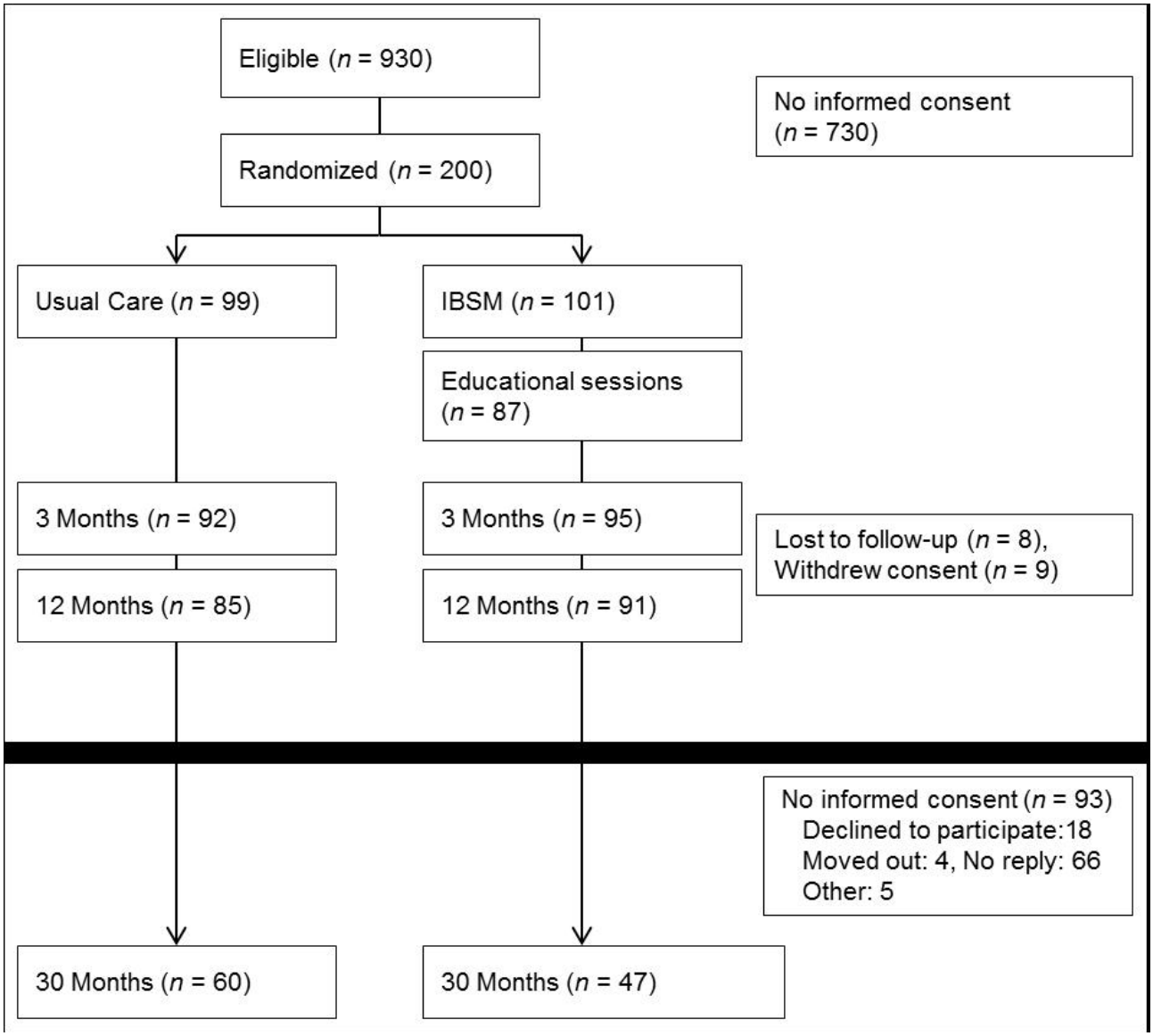


Figure 4. Mean Asthma Quality of Life Questionnaire score for the Internet and Usual care group as measured at 0, 3, 12, and 30 months of follow-up.

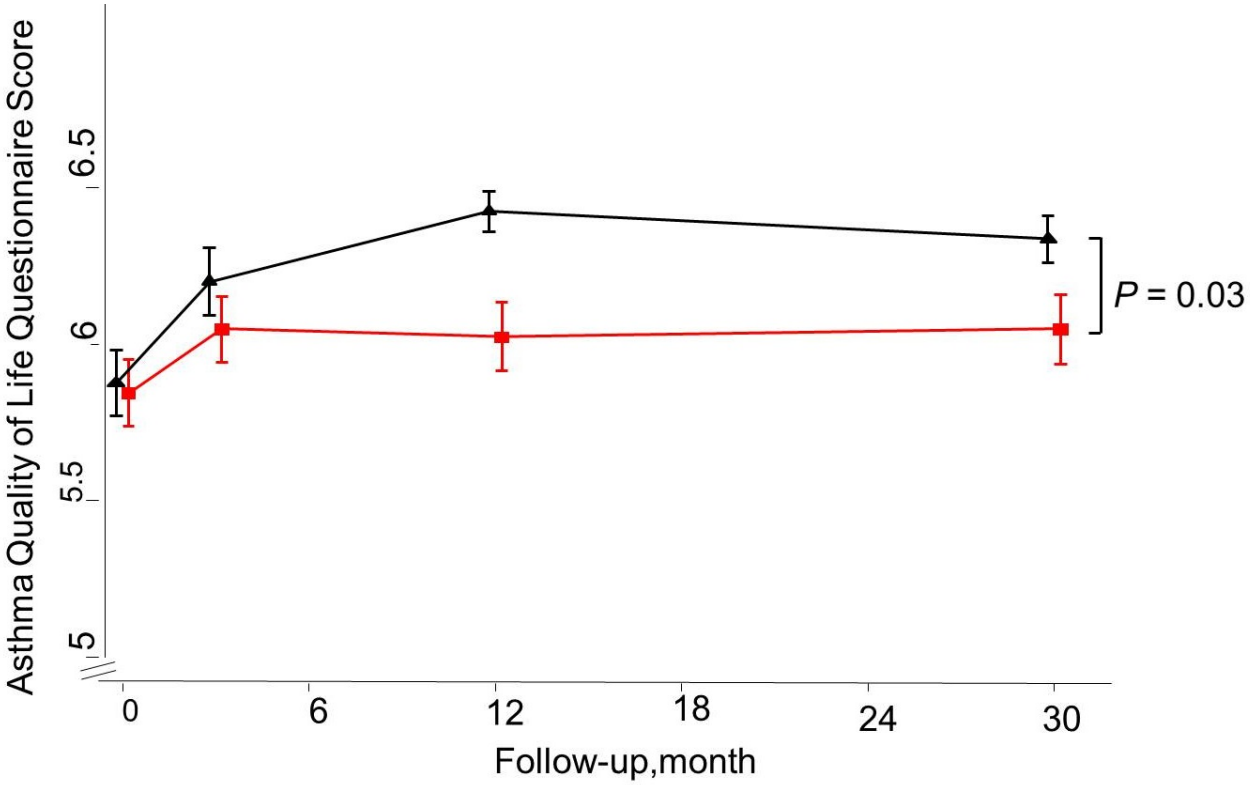


Figure 5. Mean Asthma Control Questionnaire score for the Internet and Usual care group as measured at 0, 3, 12, and 30 months of follow-up.

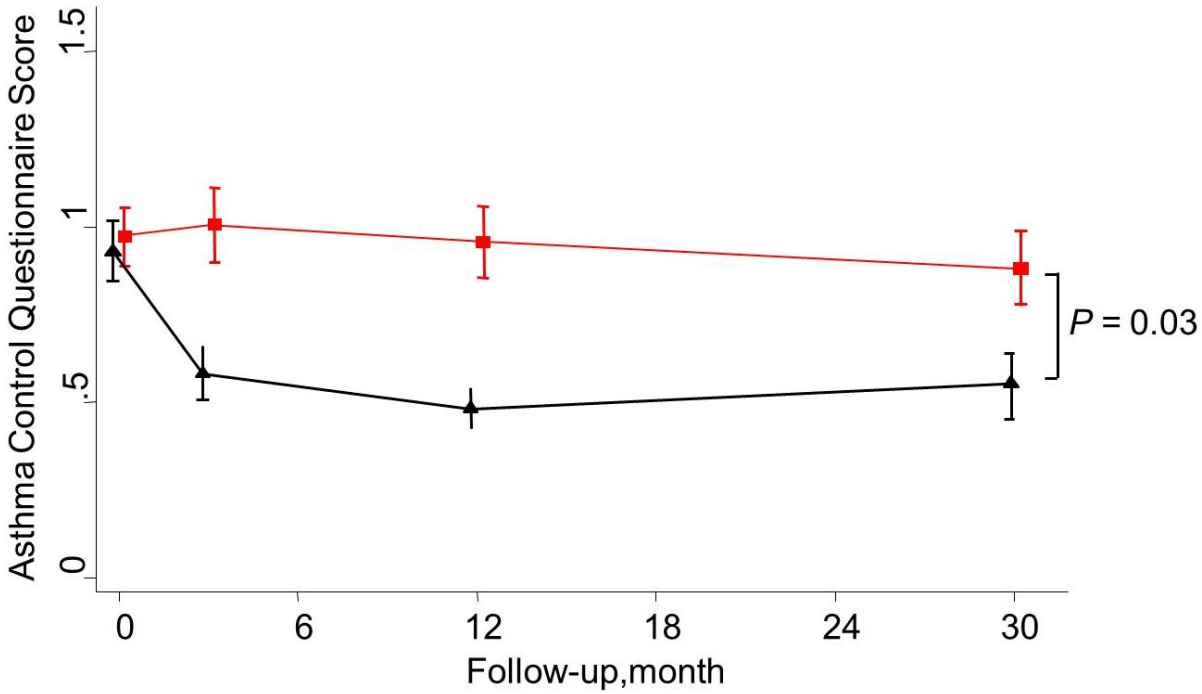


Figure 6. Mean ICS dosage for the Internet and Usual care group as measured at 0, 3, 12, and 30 months of follow-up.

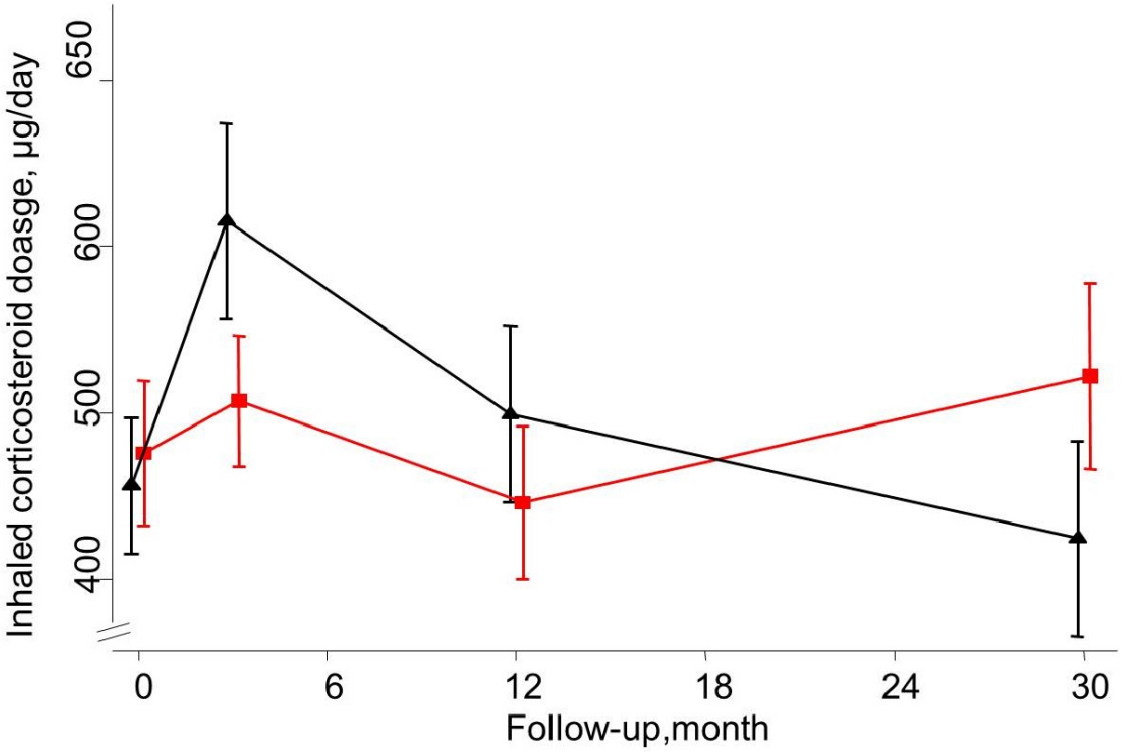
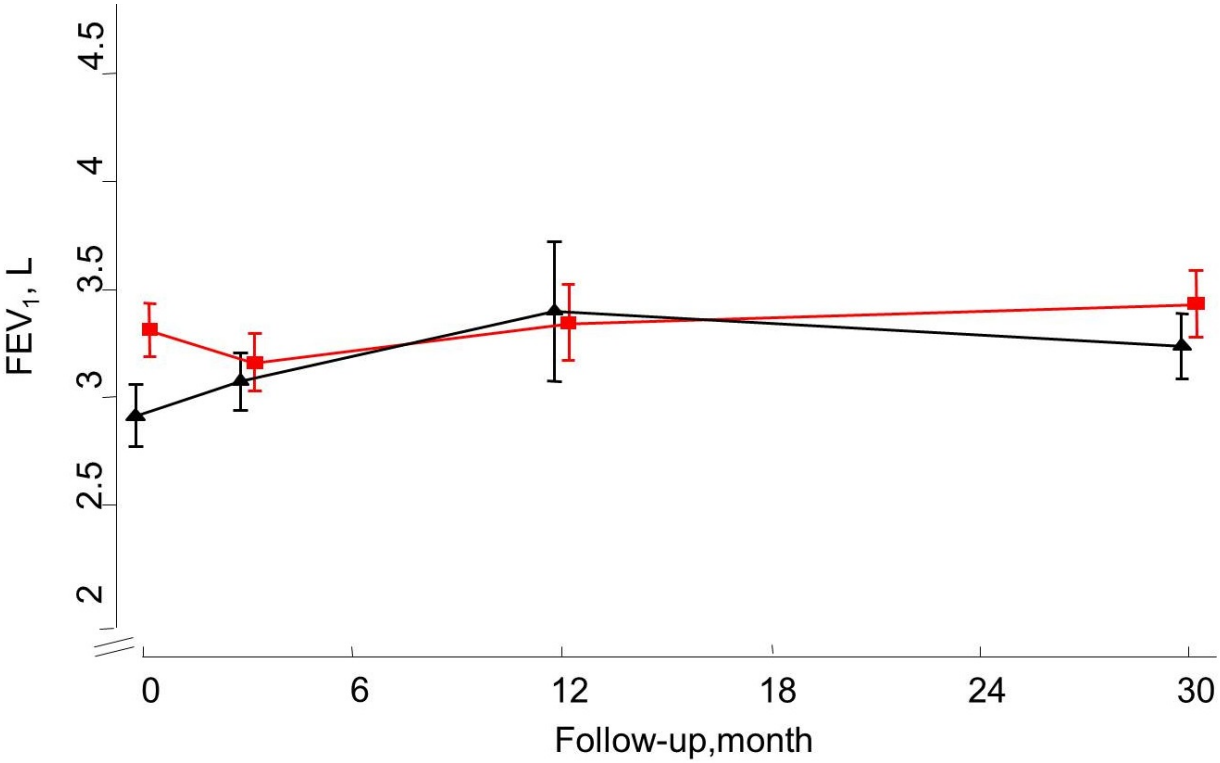


Figure 7. Mean FEV1 for the Internet and Usual care group as measured at 0, 3, 12, and 30 months of follow-up.



Discussion

Principal Findings

This study indicates that provision of IBSM support for 1 year leads to sustained benefits in terms of asthma control and asthma-related quality of life as compared with usual care, even up to 1.5 years after terminating support. IBSM support was additional to usual care and consisted of education, an action plan, self-monitoring, and regular medical review. Therefore, this study illustrates that sustained health improvements in health can be achieved by a structured care approach and self-management support as outlined by the Chronic Care model [23]. To our knowledge, this is the first study on long-term

outcomes of Internet-based comprehensive self-management delivered to patients with asthma in primary care. In the study by Thoonen et al [27], it was demonstrated that guided self-management to patients with asthma in Dutch general practice for 2 years leads to small but sustained benefits in asthma control (except for lung function) and asthma-related quality of life as compared to usual care.

Limitations

The original SMASHING study had several strengths, which have been discussed at length elsewhere [15]. Briefly, the study had a strong randomized controlled design without major baseline differences between patients in both groups and was characterized by a pragmatic attitude [28]. Nevertheless, results of this follow-up measurement need to be interpreted with some caution. First, our response rate was relatively low compared to other long-term outcome studies [29], which might limit the generalizability of our results. Second, even though a sustained effect for both asthma control and asthma-related quality of life in favor of the IG was demonstrated, these differences did not reach the threshold of a clinical important difference (MCID). However, we included patients with well-controlled asthma at baseline. In contrast, the subgroup of patients with uncontrolled asthma at baseline did show a clinical relevant difference in terms of asthma-related quality of life. Patients with worse asthma control have a larger room for improvement and could therefore be more willing to participate in self-management activities [30].

Even though IG patients had better outcomes in terms of asthma control and asthma-related quality of life as compared with UC patients, this difference was not accompanied with a higher ICS dosage for IG patients. Whether this can be attributed to the ability of the individual IG patient to tailor treatment to his or her need remains unclear. Moreover, the propensity to change in-treatment steps could have been reduced as guidance by IBSM support was terminated.

To what extent demonstrated long-term benefits can be attributed to the mode of delivery, beyond incorporating components (education, monitoring, action plan, and regular review) for effective self-management, remains unclear. More specifically, whether the IBSM approach has led to improved self-management skills can only be postulated as we did not collect data on self-management outcomes, such as self-efficacy or compliance. If self-management skills have been improved, this is due to more intensive support in the start-up phase, since at 12 months after baseline only about 60% of the patients were still using the program on their own initiative [16]. This illustrates that patients do not seem to develop dependence on modern technology, a known barrier for both patients and professionals for using modern technology for asthma self-management support [31]. Moreover, it also suggests that intensity of a self-management support program should be tailored to the individual patient; once a patient has met his or her personal objective, the intensity should be adjusted. Recently, Ryan et al [32] compared a comprehensive self-management approach for adults with poorly controlled asthma (ACQ≥1.5) in general practice in which the monitoring module was either paper-based or mobile phone-based. After 6 months follow-up, both patient groups had improved in terms of asthma control and self-efficacy, but no difference was demonstrated between groups. Clearly, this study does illustrate that there is room for improvement in provision of routine asthma care, since in both groups self-management was delivered in concordance with asthma guidelines (consisting of education, self-monitoring, action plan, and guidance by a professional). Nevertheless, this does not imply that modern technology might not be important since it does offer opportunities to enhance adoption of self-management support within routine care.

Conclusions

From a patient perspective, there is an increasing demand to use modern technology in the management of chronic disease. In asthma, this is illustrated by a growing number of available apps for asthma “self-management” [33]. Unfortunately, these apps are characterized not only by their lack of all components for effective self-management but also by a lack of reliable content.

Given the sustained benefits, cost-effectiveness becomes more favorable for IBSM, since major intervention costs, such as equipment and education sessions, apply to the first year, while maintenance costs can be spread over a longer period and could be improved by an increased number of users.

For successful adoption of IBSM within routine care and into a patient’s daily life, several preconditions need to be identified and addressed among stakeholders [34,35]. For instance, IBSM support should address daily routines of patients, for example, frequency of monitoring should be able to be adjusted to the needs of the individual patient. From an organizational point of view, an adequate infrastructure for asthma care (eg, routine consultations) should be available within practices. Moreover, technology should be integrated within the current available digital infrastructure. At a professional level, (Internet-based) self-management support requires a proactive role from the health care provider, which allows for a patient-professional partnership. Finally, from an economic point of view, financial incentives such as adequate reimbursements of lung function meters and consultations by health care insurance companies could be considered. More research is needed on the question of how to embed self-management support by means of modern technology within routine practice.

A comprehensive Internet-based self-management approach leads to sustained benefits in terms of asthma-related quality of life and asthma control, even up to 1.5 years after terminating support, particularly for patients with asthma that was not well controlled at baseline. Future research is needed to gain insight on long-term outcomes, cost-effectiveness, and strategies for integration of self-management support by modern technology in real-life settings.

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Authors' Contributions

VM, MB, and JKS were involved in the design of the study. VM, MB, PR, WR, and TB contributed to data acquisition. VM and MB guided patients in Internet-based self-management support. JG, TB, PR, WR, and JKS contributed to data analysis. JG and JKS drafted the manuscript, which was critically revised by all authors. The manuscript has been read and been approved by all authors.

Conflicts of Interest

None declared.

Multimedia Appendix 1

CONSORT-EHEALTH checklist V1.6.2 [21].

[PDF File (Adobe PDF File), 994KB - jmir_v15i9e188_app1.pdf]

Multimedia Appendix 2

Screenshots of the original SMASHING website: website functionalities and daily symptom/lung function monitoring; weekly symptom monitoring by using the 7-item Asthma Control Questionnaire; and feedback on symptoms and lung function monitoring.

[PPTX File, 2MB - jmir_v15i9e188_app2.pptx]

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Abbreviations

ACQ: asthma control questionnaire
AQLQ: asthma-related quality of life questionnaire
FEV1: forced expiratory volume in one second
GINA: Global Initiative for Asthma
IBSM: Internet-based self-management
ICS: inhaled corticosteroids
IG: Internet group
MCID: minimal clinical important difference
RN: respiratory nurse
SMASHING: Self-Management in Asthma Supported by Hospitals, ICT, Nurses and General practitioners
UC: usual care

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Original Paper

Effects of a Web-Based Tailored Intervention to Reduce Alcohol Consumption in Adults: Randomized Controlled Trial

Daniela N Schulz[1], MSc; Math JJM Candel[2], PhD; Stef PJ Kremers[3], PhD; Dominique A Reinwand[1,4], MSc; Astrid Jander[1], MSc; Hein de Vries[1], PhD

[1]CAPHRI School for Public Health and Primary Care, Department of Health Promotion, Maastricht University, Maastricht, Netherlands
[2]CAPHRI School for Public Health and Primary Care, Department of Methodology and Statistics, Maastricht University, Maastricht, Netherlands
[3]Nutrition and Toxicology Research Institute Maastricht (NUTRIM), Department of Health Promotion, Maastricht University, Maastricht, Netherlands
[4]Jacobs University Bremen gGmbH, Jacobs Center on Lifelong Learning and Institutional Development, Bremen, Germany

Corresponding Author:
Daniela N Schulz, MSc
CAPHRI School for Public Health and Primary Care
Department of Health Promotion
Maastricht University
P Debyeplein 1
Maastricht, 6229 HA
Netherlands
Phone: 31 43 3882832
Fax: 31 43 3671032
Email: dn.schulz@maastrichtuniversity.nl

Abstract

Background: Web-based tailored interventions provide users with information that is adapted to their individual characteristics and needs. Randomized controlled trials assessing the effects of tailored alcohol self-help programs among adults are scarce. Furthermore, it is a challenge to develop programs that can hold respondents' attention in online interventions.

Objective: To assess whether a 3-session, Web-based tailored intervention is effective in reducing alcohol intake in high-risk adult drinkers and to compare 2 computer-tailoring feedback strategies (alternating vs summative) on behavioral change, dropout, and appreciation of the program.

Methods: A single-blind randomized controlled trial was conducted with an experimental group and a control group (N=448) in Germany in 2010-2011. Follow-up took place after 6 months. Drinking behavior, health status, motivational determinants, and demographics were assessed among participants recruited via an online access panel. The experimental group was divided into 2 subgroups. In the alternating condition (n=132), the tailored feedback was split into a series of messages discussing individual topics offered while the respondent was filling out the program. Participants in the summative condition (n=181) received all advice at once after having answered all questions. The actual texts were identical for both conditions. The control group (n=135) only filled in 3 questionnaires. To identify intervention effects, logistic and linear regression analyses were conducted among complete cases (n=197) and after using multiple imputation.

Results: Among the complete cases (response rate: 197/448, 44.0%) who did not comply with the German national guideline for low-risk drinking at baseline, 21.1% of respondents in the experimental group complied after 6 months compared with 5.8% in the control group (effect size=0.42; OR 2.65, 95% CI 1.14-6.16, *P*=.02). The experimental group decreased by 3.9 drinks per week compared to 0.4 drinks per week in the control group, but this did not reach statistical significance (effect size=0.26; beta=−0.12, 95% CI −7.96 to 0.03, *P*=.05). Intention-to-treat analyses also indicated no statistically significant effect. Separate analyses of the 2 experimental subgroups showed no differences in intervention effects. The dropout rate during the first visit to the intervention website was significantly lower in the alternating condition than in the summative condition (OR 0.23, 95% CI 0.08-0.60, *P*=.003). Program appreciation was comparable for the 2 experimental groups.

Conclusions: Complete case analyses revealed that Web-based tailored feedback can be an effective way to reduce alcohol intake among adults. However, this effect was not confirmed when applying multiple imputations. There was no indication that one of the tailoring strategies was more effective in lowering alcohol intake. Nevertheless, the lower attrition rates we found during the first visit suggest that the version of the intervention with alternating questions and advice may be preferred.

Trial Registration: International Standard Randomized Controlled Trial Number (ISRCTN): 91623132; http://www.controlled-trials.com/ISRCTN91623132 (Archived by WebCite at http://www.webcitation.org/6J4QdhXeG).

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KEYWORDS

alcohol intake; adults; eHealth; computer tailoring; Web-based intervention; tailoring methods; effectiveness

Introduction

Although the consumption of alcohol is associated with numerous negative consequences, such as cardiovascular disease, cancer, cirrhosis, neuropsychiatric disorders, traffic accidents, and reduced work productivity [1-3], high alcohol consumption is highly prevalent among adults worldwide [4-6]. Many people with unhealthy drinking patterns are not aware of their alcohol intake or the problems associated with this behavior [7,8]; others are aware, but do not seek care, help, or support [9-11] possibly out of fear, shame, or lack of time. The high prevalence of unhealthy drinkers and the low number of them who seek help underline the need for easily accessible and low-threshold interventions to encourage people to reduce their alcohol intake.

Web-based tailored interventions in which information is adapted to the user's individual characteristics and needs to give them personally appropriate advice [12,13] have proved an effective tool to improve health-related behaviors. Various studies have reported favorable effects on lifestyle behaviors, such as increasing physical activity [14,15], increasing fruit and vegetable consumption and lowering saturated fat intake [16], and giving up smoking [17]. The main advantages of intervention programs providing tailored advice compared to nontailored materials are that they contain less unnecessary information and more attractive and relevant information [18,19], they are cost-effective [20], the tailored messages are more likely to be read, saved, printed out, remembered, and discussed with others [13,21-23], and tailored information is more effective for behavior change than generic messages [12,24,25].

To date, several studies of Web-based tailored alcohol interventions have been published, but randomized controlled trials among the general adult population using tailored self-help programs have been scarce [25-32]. Most previous studies were conducted among young people, especially among university or student populations [33-37]. These samples are not representative of the general population and may, for example, differ in motivation to change, reading level, computer and Internet access, and computer literacy [37]. Earlier studies reported that single-session, individually personalized feedback without therapeutic guidance can be an effective and cost-effective method to reduce alcohol consumption [38]. A recently published study of adult men using a single-session intervention in which respondents had to go to a laboratory to participate in an online 10-minute intervention reported only on short-term effects 1 month after the intervention [26].

Little research has been done to assess what elements work well in tailored interventions. The 5 criteria of Health Behavior Change treatment on the Internet (HBC-I)—advise, assist, assess, provide anticipatory guidance, and arrange follow-up—form essential, but not sufficient, elements that determine whether a program offers potential for behavior change [39]. Other feasible elements appear to be the use of tailoring strategies, such as normative, positive, and ipsative feedback, personal tone, and empathy [40]. Factors explaining the differences in effectiveness of programs include the number of contact/exposure moments, the use of theory, the layout, the communication channel, the length of the questionnaires, the amount of information given, and the depth of tailoring [12,41].

Although Internet-based programs have the potential to reach large numbers of people, various studies have pointed out that the actual use may be limited and that high rates of attrition are common [42-47]. To prevent early dropout and, thus, increase the effectiveness of a program, 2 different strategies could be used to hold respondents' attention in online interventions. In the first strategy, questions and advice are given alternately, so that the respondents are rewarded while they are still filling in the questionnaires and are thereby motivated to continue. Such alternation might also enhance the attractiveness of the program. In the second strategy, advice is given in a more traditional way at the end of the session (ie, after the last question has been completed). This method may lead to postponement of dropout—provided that the questionnaires are not too long—because respondents have to wait until the end of the questionnaire before receiving tailored feedback. Yet, this method may also increase the risk that the participant becomes overwhelmed by the amount of information he or she receives all at once [48].

The objective of our study was twofold. First, we explored the overall effectiveness of a 3-session, Web-based, tailored alcohol intervention for unhealthy drinkers in the general adult population. Second, we compared the dropout rate, effectiveness, and user satisfaction of 2 kinds of feedback strategies (alternating vs summative).

Methods

Participants, Procedure, and Study Design

We conducted a randomized controlled trial (ISRCTN91623132) involving an experimental group and a waiting list control group, with a follow-up measurement after 6 months. The intervention, focusing on unhealthy drinkers in the general population, was conducted online in Germany in June 2010 to January 2011. Adult participants were recruited via an online access panel (ie, a register of a sample who expressed willingness to participate in online surveys and research studies) called respondi AG (place of business: Cologne, Germany). The sample received an email containing a link to either the intervention website

(experimental group) or a Web-based alcohol questionnaire (control group). Randomization was carried out by a computer system. Two reminder messages in the form of emails were sent to individuals of the sample who did not respond to the first invitation. Incentives, in the form of bonus points that respondents could exchange for cash, a gift voucher, or a charitable donation were given to respondents who filled in the questionnaires completely. Informed consent was given during the registration process as a panel member in which the members gave permission to use their data for scientific research.

Inclusion Criteria

The following inclusion criteria were established for this study: being a panel member of respondi; having computer/Internet literacy; having sufficient command of German; being 18 years or older; and having an unhealthy drinking pattern, which was defined as (1) not complying with the guideline recommending no more than 1 glass (women) or 2 glasses (men) of alcohol per day, (2) drinking on more than 5 days per week, (3) having a score higher than 7 on the Alcohol Use Disorders Identification Test (AUDIT) [49], or (4) currently trying to become pregnant, drinking alcohol while pregnant or breastfeeding (in relation to pregnancy), or trying to get one's partner pregnant (for men).

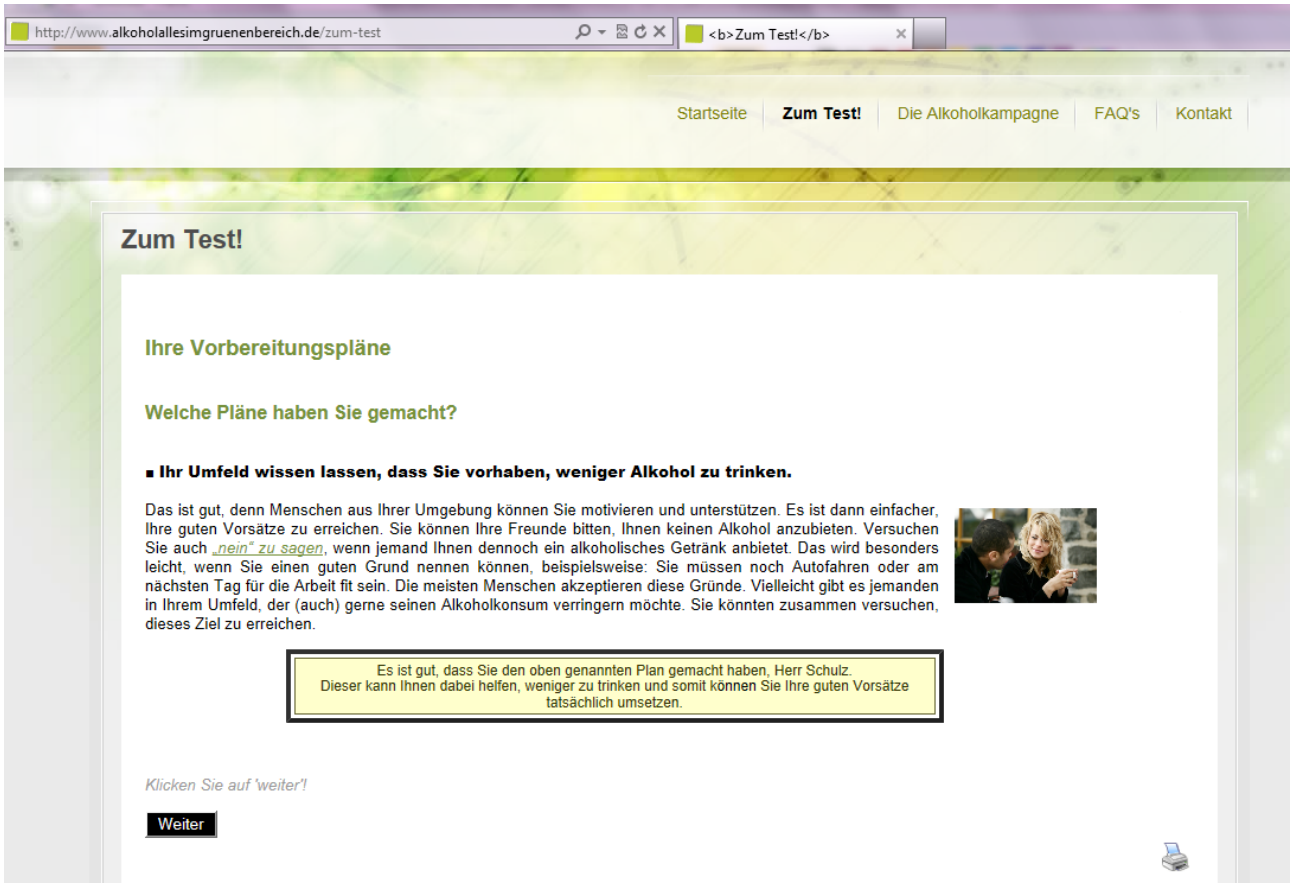
Intervention

The intervention program, called Alcohol-Everything Within the Limits?! (German: "Alkohol-Alles im grünen Bereich?!," see Figure 1), is a Web-based, 3-session, tailored program targeting adult problem drinkers. The main aim of the intervention was to stimulate participants to lower their alcohol intake. The theoretical framework for the development of the intervention was the I-Change model [50]. This psychosocial model was chosen because it combines different models and integrates these in premotivational, motivational, and postmotivational phases, which is optimal for use in computer tailoring to support the process of behavioral change. The I-Change model builds on other psychosocial models, such as the Theory of Planned Behavior [51], Social Cognitive Theory [52], the Health Belief Model [53], and the Transtheoretical Model [54].

The personalized advice, which was presented immediately on the respondent's computer screen, consisted of 5 parts, each focusing on a different psychosocial construct of the model (ie, knowledge, awareness, attitude, social influence, self-efficacy, and action planning). The first part of the program served as a starting point of the drinking behavior change process (premotivational phase) by addressing the concepts of knowledge and awareness: it gave information about the German alcohol guidelines, specifically, not drinking more than 1 (women) or 2 (men) standard drinks (ie, drinks containing 10 grams of alcohol) per day and having at least 2 alcohol-free days a week, and assessed whether respondents were meeting this guideline by using comparative/normative feedback. In addition, respondents' scores were depicted graphically using a traffic light symbol (indicating whether they met, almost met, or did not meet the guidelines). To increase the respondent's level of knowledge, the relation between alcohol and various diseases was explained, and information tailored to the respondent's health status was given about alcohol and pregnancy, and about the possible influence of participants' drinking behavior on their children (if applicable). The second part of the program offered personalized feedback concerning the perceived pros and cons of alcohol drinking as perceived by the respondent, with the goal of creating a positive attitude toward not drinking more than 1 (women) or 2 (men) alcoholic drinks per day. The third part explained the importance of social influence in a tailored message by focusing on the respondent's partner, family, friends, and colleagues. In the fourth part, preparatory action plans were defined to prepare the intended behavioral change. The final part focused on self-efficacy and coping plans by identifying difficult situations and suggesting ways to cope with them. Personalized tips were given on how to deal with the perceived difficult situations to overcome potential barriers (postmotivational phase), and the situations and plans were summarized for individual respondents to help them remember these.

During the feedback moment after 3 months and the follow-up measurement after 6 months, participants of the experimental group again received personalized advice based on their previous scores for the psychosocial constructs. Additionally, ipsative feedback was given about the respondents' alcohol intake by comparing the drinking score at the current visit with that at the last visit or visits. Feedback was given about potential change and all scores were illustrated in a graph to enable the respondent to monitor the total change process at a glance.

Figure 1. Screenshot of the intervention website, showing personal advice regarding preparatory plans.



Conditions

All study groups received identical questionnaires. After completing the third measurement, respondents in the waiting list control group were given the link to the intervention website where they could also receive personalized advice. The experimental condition was divided into 2 subgroups. The intervention website for these 2 subgroups offered the same feedback messages. At all 3 feedback moments (at baseline, after 3 months, and after 6 months), 1 experimental subgroup received questions and personal advice alternately (alternating condition) whereas respondents in the other experimental subgroup were given all personal advice at once after having answered all the questions (summative condition). In other words, in the alternating condition, the feedback message was split into a series of messages discussing individual topics offered while the respondent was still completing the Web-based session, whereas in the summative condition, the entire set of materials/feedback messages was provided at one time at the end of the Web-based session. The actual texts were identical for both conditions. Both subgroups also received a full overview of their advice (equivalent to approximately 7 to 10 A4 pages of text, including pictures and graphics) at the end of a session/measurement, which they could print or save onto their computer. We gave personalized feedback again after 6 months to stimulate participation and to enable us to reassess user satisfaction with the program.

Questionnaires

Drinking Behavior

Weekly alcohol intake was measured by the widely used Dutch 5-item Quantity-Frequency-Variability (QFV) questionnaire [55]. The AUDIT was used to identify problem drinking [49]. Habitual drinking behavior was assessed by the 12-item Self-Report Habit Index (SRHI) questionnaire [56].

Psychosocial Determinants

Knowledge regarding the national alcohol guideline was assessed by 1 question: “What do you think is the standard acceptable alcohol amount per day and per week?” with 14 answering options, such as “Two glasses every day is allowed.” A knowledge test was included in the final measurement for all 3 conditions, consisting of 9 questions, such as “How much alcohol is recommended (ie, permitted without having to worry about unfavorable consequences) during pregnancy?” or “How much alcohol does a standard drink contain?”

Attitude was assessed by 6 pros and 6 cons of alcohol intake, such as “Drinking alcohol...allows me to relax” and “...is bad for my health” (1=totally disagree; 5=totally agree; pros alpha=.83, cons alpha=.71).

Social influence was assessed by dividing this concept into norm, modeling, and support. Norm was assessed using the following item “According to people in my immediate environment, I should definitely drink no more than 1 glass (women) or 2 glasses (men) of alcohol a day (=1)” to “I should definitely drink more than 1 glass (women) or 2 glasses (men)

of alcohol a day (=5)." Modeling was assessed by asking "How many people in your immediate environment drink no more than 1 glass (women) or 2 glasses (men) of alcohol a day?" (1=nobody; 5=everybody). Support was assessed by including the statement "People in my direct environment support me in my efforts to drink no more than 1 glass (women) or 2 glasses (men) of alcohol a day" (1=no, they don't support me at all; 4=yes, they support me very much).

Self-efficacy was assessed by 6 items regarding difficult social, emotional, and routine situations, such as "I'm able to meet the alcohol guideline...when I'm at a party," "...when I feel stressed or nervous," and "...during a meal" (1=no, definitely not; 2=yes, definitely; alpha=.81).

Preparatory plans were assessed by 4 items, such as "I'm planning to take less money with me when I go out, so I can't buy a lot of alcoholic drinks" (1=no, definitely not; 5=yes, definitely; alpha=.77).

Coping plans were assessed by 6 items regarding the various risk situations, such as "I've made a plan to drink no more than 1 glass (women) or 2 glasses (men) of alcohol when I feel stressed or nervous" (1=totally disagree; 5=totally agree, alpha=.96).

Motivational stage of drinking in accordance with the alcohol guideline was assessed by applying the Transtheoretical Model of Behavior Change [54]. We used 1 item: "Do you intend to drink on no more than 5 days per week and no more than 1 glass (women) or 2 glasses (men) of alcohol a day?" (1=no, I don't intend to do so; 2=I never thought about it; 3=I thought about it, but I don't know yet; 4=yes, but not within the next 5 years; yes, 5=within 1-5 years; 6=yes, within 6-12 months, 7=yes, within 3-6 months; 8=yes, within 1-3 months; 9=yes, within a month; 10=yes, and I'm already doing so).

Health Status

Six items were used to assess if respondents suffered from diabetes mellitus, angina pectoris, cancer, or high blood pressure or had suffered a stroke or cardiac infarction. Symptoms of depression were assessed by means of the 10-item Center for Epidemiologic Studies Depression Scale (CES-D10) [57].

Demographic Information

The following demographic variables were assessed: age, gender (1=male; 2=female), educational level (1=low/no education or primary education; 2=medium/secondary education; 3=high/tertiary education), income (euros per month), employment situation (1=paid employment; 2=no paid employment), marital status, pregnancy/breastfeeding status (1=pregnant/breastfeeding and drinking; 2=n/a), number of children living at home, and native country (1=Germany; 2=other country).

Appreciation of the Program

Both experimental subgroups were invited to fill in an evaluation questionnaire to assess the levels of personalization and their appreciation of the intervention. Seven questions were included, such as "The personal advice I received was interesting" (1=no, absolutely not; 5=yes, absolutely).

Primary Objective

The primary objective was to compare the experimental group (ie, the subgroups who received the computer-tailored feedback strategies) with the control group regarding (1) complying with the alcohol guideline (healthy drinking; yes/no) after 6 months, and (2) mean weekly alcohol consumption (in number of standard drinks) at 6 months after baseline.

Secondary Objective

The second objective was to compare the 2 computer-tailored feedback strategies (alternating vs summative) in terms of dropout rates, effects on drinking behavior, and appreciation of the program.

Power Analyses

We estimated the required sample size for both the logistic regression analysis and the linear regression analysis based on the intervention effects of a comparable study by Riper et al [25]. For the logistic regression analysis, a power analysis calculation indicated that a total sample of 180 respondents was needed (after possible attrition) to test for the intervention effect. We calculated the sample size for 2 experimental groups and 1 control group based on a .05 level of significance, a statistical power of 80%, and a 2-sided test. We expected that the compliance with the guideline would be 20% in the intervention groups and 5% in the control group. For the linear regression analysis, a power analysis calculation indicated that a total sample of 254 respondents was needed (after possible attrition) to test for the intervention effect. Again, we calculated the sample size for 2 experimental groups and 1 control group, based on a .05 level of significance, a statistical power of 80%, a 2-sided test, an effect size of 0.30 (when contrasting the 2 intervention groups with the control group), and a correlation of 0.60 between premeasurement and postmeasurement of the outcome variable.

Statistical Analyses

The data were analyzed using SPSS software, version 19 (IBM Corp, Armonk, NY, USA). To check whether the randomization had been successful in terms of demographics and drinking behavior; linear regression analyses were used for continuous variables and chi-square tests for discrete variables. Descriptive statistics were used for the characteristics of the study sample and the dropout rate within the groups. Logistic regression analyses were performed to determine differences in dropout rates between the study conditions.

The 2 experimental groups together were compared to the control group for drinking behavior. First, effect sizes were calculated based on means and odds ratios (Cohen's *d*). Effect sizes below 0.30 were considered small, whereas those between 0.30 and 0.80 were considered medium, and those greater than 0.80 were regarded as large [58]. Second, differences in effect between the groups were explored by means of logistic as well as linear regression analyses. The following baseline variables were entered as independent variables in both types of regression analyses using the backward method: condition, gender, age, educational level, employment status, income, country of birth, marital status, having children, pregnancy, disease, CES-D10, number of alcoholic drinks, AUDIT, SRHI, pros, cons, social

support, social modeling, social norm, self-efficacy, coping plans, and intention. Preparatory plans were not included in the analyses because not every participant was presented with these items. The dependent variables were (1) meeting the guideline (0=no; 1=yes), and (2) the weekly number of alcoholic drinks after 6 months.

Linear regression analyses were used to determine differences in program evaluation between the 2 experimental subgroups. The dependent variables were the separate items regarding appreciation of the program. Those demographic variables that differed between the study groups were included in the analyses as covariates.

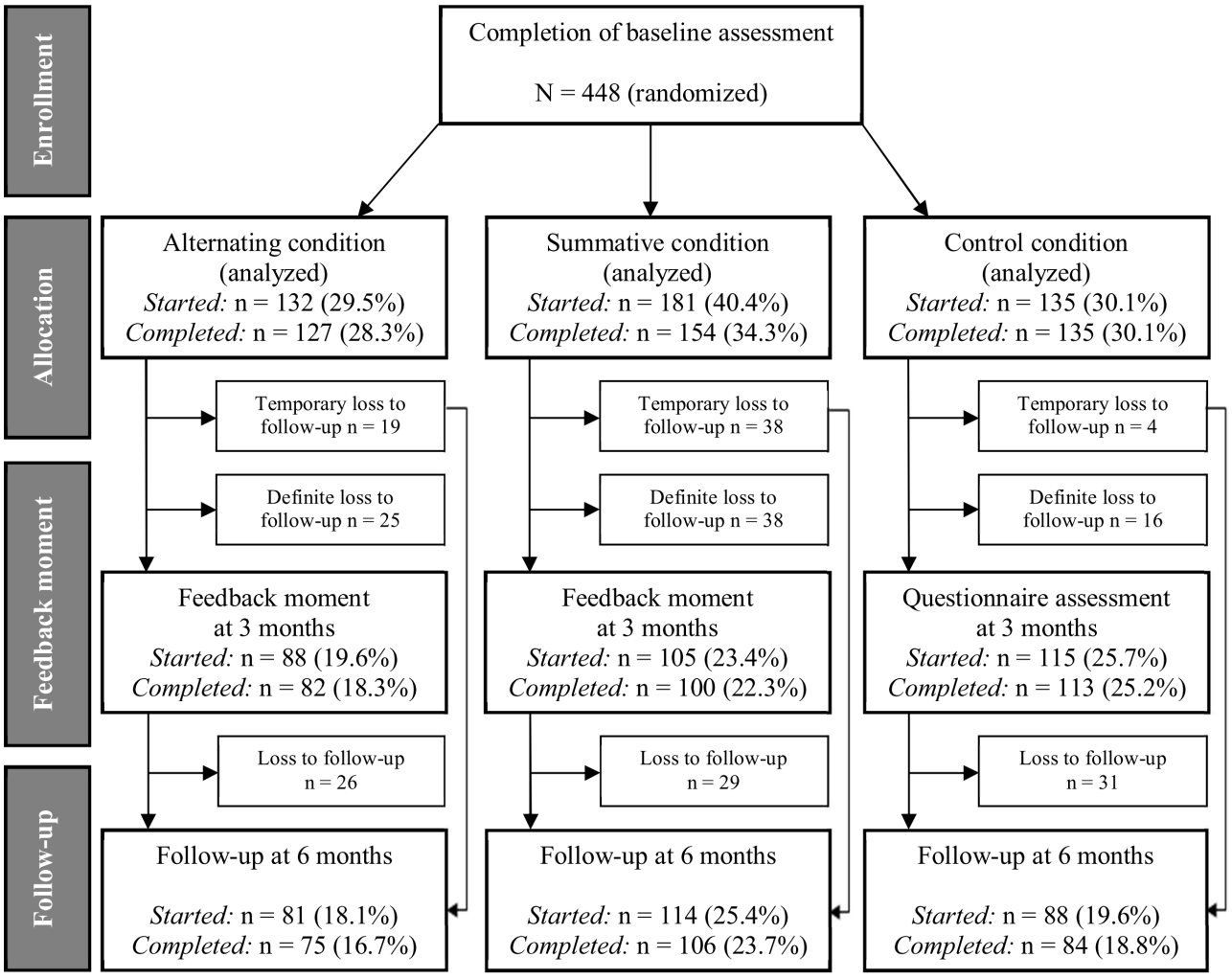
Tests were performed at alpha=.05 for the intervention factor and alpha=.10 for covariates [59]. Analyses were done on data for complete cases only as well as intention-to-treat (ITT) analyses, in which multiple imputation [60] was used to fill in missing values. Missing values were filled using demographics, health status, psychosocial determinants, baseline drinking behavior, drinking behavior after 3 and 6 months, and study condition as predictors. The number of imputations was set at 55. This was done according to the recommendation to create as many imputed datasets as the percentage of cases with missing data [61]. In addition, we also conducted a sensitivity analysis in which the last observation carried forward (LOCF) method was used to fill in missing values.

Results

Participation and Attrition

Figure 2 presents a flowchart for the study participants. A total of 1149 participants logged on to the program; 614 did not meet the inclusion criteria and 87 respondents provided incomplete or missing data, resulting in a total sample size of 448 respondents. At the 3-month feedback moment, loss to follow-up was 31.3% (140/448). The dropout rate differed significantly among the 3 conditions (P=.001): dropout was significantly lower in the control condition compared to the alternating condition (OR 0.40, 95% CI 0.22-0.73, P=.003) and compared to the summative condition (OR 0.35, 95% CI 0.19-0.63, P<.001). Moreover, dropout was lower among men (OR 1.48, 95% CI 0.95-2.32, P=.08) and among respondents with a high educational level compared to those with a low educational level (OR 0.60, 95% CI 0.36-1.00, P=.05) although this did not reach statistical significance. At 6 months, loss to follow-up was 36.8% (165/448) and the dropout rate was distributed equally among the 3 conditions (P=.74); however, there was a significant difference in dropout among respondents with different levels of income (P=.03); the dropout rate was lower in respondents with the highest income compared to those with the lowest income (OR 0.36, 95% CI 0.15-0.83, P=.02).

Figure 2. Flowchart of the study sample.



Differences in Completion-Rate Between the Experimental Subgroups

During the first session, the dropout rate of the intervention was significantly lower in the alternating condition compared to the summative condition. In the alternating condition, 96.2% (127/132) completed the program whereas in the summative condition, 85.1% (154/181) did so (OR 0.23, 95% CI 0.08-0.60, *P*=.003). However, differences regarding attrition were no longer significant after 3 and 6 months. After 3 months, 62.1% (82/132) of those in the alternating condition and 55.2% (100/181) of those in the summative condition returned to the website and filled in the program completely (OR 0.94, 95% CI 0.57-1.54, *P*=.80). At 6-month follow-up, 56.8% (75/132) of those in the alternating condition and 58.6% (106/181) of those in the summative condition returned to the website and filled in the program completely (OR 1.24, 95% CI 0.77-2.01, *P*=.38).

Sample Characteristics

Slightly more men than women were included in the study and the mean age of the respondents was approximately 42 years. The average weekly alcohol intake was almost 13 glasses. The baseline demographic characteristics of the study sample are shown in Table 1. Significant differences at the *P*<.10 level were found for the baseline characteristic of income (χ^2_6=14.70; *P*=.02) and habitual drinking (beta=0.10, 95% CI 0.00-0.18, *P*=.04).

Intervention Effects

The number of respondents who complied with the alcohol guideline rose after 6 months (Figure 3). The percentage of respondents complying with the guideline increased by 21.1% in the experimental group and by 5.8% in the control group. The number of alcoholic drinks per week among the study population also decreased during the intervention period (Figure 3). The experimental group reduced their mean weekly alcohol intake by 3.9 drinks (SD 9.96) compared to 0.4 drinks (SD 19.54) in the control group.

As shown in Table 2, the results of the logistic regression analysis showed that the intervention was effective in achieving a low-risk drinking status according to the guideline among complete cases (OR 2.65; *P*=.02). However, different results were found when using ITT analyses. After applying multiple imputations, no intervention effect was found among the study sample (OR 1.11; *P*=.72). Results of the sensitivity analysis using LOCF can be found in Multimedia Appendix 1.

The linear regression analysis among complete cases (see Table 3) found an effect for the intervention in lowering the weekly number of alcoholic beverages in the experimental group, but this did not reach statistical significance (beta=−0.12, 95% CI −7.96 to 0.03, *P*=.05). After applying multiple imputations, no intervention effect was found (B=−1.15, 95% CI −4.02 to 1.72, *P*=.43).

Differences Between the Two Experimental Subgroups

A comparison between the 2 experimental subgroups (n=128) regarding compliance with the guideline (OR 0.41, 95% CI 0.13-1.36, *P*=.15) and weekly alcohol intake (beta=−0.03, 95% CI −3.14 to 2.11, *P*=.70) showed no differences in effect. Comparable results were found after multiple imputations of missing values. There were neither differences regarding achievement of low-risk drinking status according to the guideline (OR 0.72, 95% CI 0.38-1.37, *P*=.31) nor regarding the weekly number of alcoholic beverages after 6 months (B=−0.11, 95% CI −2.89 to 2.68, *P*=.94) between the 2 experimental subgroups.

Differences in Appreciation of the Program

In general, the intervention was evaluated positively by both experimental subgroups (Table 4). At baseline, respondents of the alternating condition reported that they had read more of the advice compared to respondents of the summative condition; however, this difference did not meet statistical significance (*P*=.07). After 6 months, this difference was not apparent. At the 6-month follow-up measurement, the advice was perceived as more informative among the summative condition compared to the alternating condition, although this did not meet statistical significance (*P*=.08).

Table 1. Demographics, health status, and drinking behavior of the study sample at baseline.

Variable	Total N=448	Alternating condition n=132	Summative condition n=181	Control condition n=135
Age (18-69 years), mean (SD)	41.72 (15.74)	42.23 (15.06)[a]	41.41 (16.16)	41.62 (15.92)
Gender, n (%)				
Male	253 (56.5)	69 (52.3)	104 (57.5)	80 (59.3)
Female	195 (43.5)	63 (47.7)	77 (42.5)	55 (40.7)
Education, n (%)				
Low	177 (42.0)	61 (47.3)	61 (38.9)	55 (40.7)
Medium	101 (24.0)	25 (19.4)	40 (25.5)	36 (26.7)
High	143 (34.0)	43 (33.3)	56 (35.7)	44 (32.6)
Income per month, n (%)				
<€1000	61 (13.6)	11 (8.3)	24 (13.3)	26 (19.3)
€1001-€2000	106 (23.7)	41 (31.1)	30 (16.6)	35(25.9)
€2001-€4000	135 (30.1)	34 (25.8)	55 (30.4)	46 (34.1)
>€4000	43 (9.6)	19 (14.4)	12 (6.6)	12 (8.9)
Not reported	103 (23.0)	27 (20.5)	60 (33.1)	16 (11.9)
Employment situation, n (%)				
Job (paid employment)	269 (65.3)	89 (71.8)	97 (63.4)	83 (61.5)
No job	143 (34.7)	35 (28.2)	56 (36.6)	52 (38.5)
Marital status, n (%)				
Married	170 (40.4)	55 (42.6)	62 (39.5)	53 (39.3)
Living together	67 (14.9)	26 (20.2)	28 (17.8)	13 (9.6)
In relationship, but not living together	51 (12.1)	12 (9.3)	22 (14.0)	17 (12.6)
Single/unmarried	90 (21.4)	22 (17.1)	35 (22.3)	33 (24.4)
Divorced	31 (7.4)	9 (7.0)	6 (3.8)	16 (11.9)
Widowed	12 (2.9)	5(3.9)	4 (2.5)	3 (2.2)
Children, n (%)				
No	226 (50.4)	58 (43.9)	100 (55.2)	68 (50.4)
Yes, but no longer living at home	93 (20.8)	26 (19.7)	33 (18.2)	34 (25.2)
Yes, living at home >18 years	34 (7.6)	14 (10.6)	11 (6.1)	9 (6.7)
Yes, living at home <18 years	95 (21.2)	34 (25.8)	37 (20.4)	24 (17.8)
Native country, n (%)				
Germany	409 (97.1)	126 (97.7)	152 (96.8)	131 (97.0)
Other	12 (2.9)	3 (2.3)	5 (3.2)	4 (3.0)
Symptoms of depression				
CES-D10, mean (SD)[b]	8.20 (5.05)	8.08 (5.46)	8.38 (5.05)	8.11 (4.68)
Score of ≥11, n (%)	120 (28.8)	39 (30.7)	44 (28.6)	37 (27.4)
Diseases, n (%)				
Diabetes mellitus	21 (4.7)	7 (5.2)	9 (5.0)	5 (3.7)
Stroke	8 (1.8)	1 (0.7)	3 (1.7)	4 (3.0)
Cardiac infarction	7 (1.6)	1 (0.7)	3 (1.7)	3 (2.2)

Variable	Total N=448	Alternating condition n=132	Summative condition n=181	Control condition n=135
Angina pectoris	9 (2.0)	2 (1.5)	4 (2.2)	3 (2.2)
Cancer	6 (1.3)	0 (0.0)	4 (2.2)	2 (1.5)
High blood pressure	95 (21.1)	26 (19.3)	41 (22.7)	28 (20.7)
One or more diseases	128 (28.6)	35 (26.5)	55 (30.4)	38 (28.1)
Alcohol				
Nonadherence to guideline, n (%)	221 (51.4)	63 (47.7)	85 (49.7)	73 (54.9)
Weekly alcohol intake (standard units), mean (SD)[c]	12.94 (11.24)	12.53 (10.99)	11.86 (9.70)	14.73 (13.05)
Pregnant/ breastfeeding and drinking, n (%)	31 (6.9)	8 (6.1)	14 (7.7)	9 (6.7)
AUDIT (score ≥8), n (%)	351 (80.0)	102 (77.3)	141 (79.2)	108 (81.2)
Habit (SRHI-12), mean (SD)[d]	2.11 (0.82)	1.98 (0.79)	2.15 (0.79)	2.19 (0.86)

[a]Age range 18-68 years.

[b]Ranges for total, alternating, summative, and control were 0.00-28.00, 0.00-28.00, 0.00-28.00, and 0.00-22.00, respectively.

[c]Ranges for total, alternating, summative, and control were 0.00-86.00, 0.00-70.00, 0.00-66.00, and 0.50-86.00, respectively.

[d]Ranges for total, alternating, summative, and control were 1.00-4.83, 1.00-4.83, 1.00-4.50, and 1.00-4.33, respectively.

Table 2. Results of the logistic regression analysis (backward method) with guideline status (0=not complying; 1=complying) after 6 months as dependent variable among complete cases (CC, n=197) and after applying multiple imputations (MI, n=448).

Variable[a]	Guideline status (CC)			Guideline status (MI)		
	OR	*P*	95% CI	OR	*P*	95% CI
Condition	2.65	.02	1.14, 6.16	1.11	.72	0.63, 1.98
Guideline status	—	—	—	2.91	<.001	1.63, 5.18
Weekly alcohol intake	0.88	<.001	0.84, 0.93	0.96	.04	0.93, 1.00
Habit	0.23	<.001	0.12, 0.42	0.46	<.001	0.31, 0.70
AUDIT	0.40	.07	0.15, 1.09	—	—	—
Age	0.96	.007	0.94, 0.99	—	—	—
Self-efficacy	0.47	.03	0.24, 0.94	0.62	.045	0.39, 0.99
Intention	0.88	.03	0.78, 0.98	—	—	—
R^2	0.52			0.32		

[a]Assessed at baseline.

Table 3. Results of the linear regression analysis (backward method) with the number of alcoholic drinks after 6 months as dependent variable among complete cases (CC, n=197) and after applying multiple imputations (MI, n=448).

Variable[a]	Number of drinks (CC)			Number of drinks (MI)		
	β	*P*	CI	B	*P*	CI
Condition	−0.12	.05	−7.96, 0.03	−1.15	.43	−4.02, 1.72
Weekly alcohol intake	0.49	<.001	0.52, 0.86	0.61	<.001	0.47, 0.75
Habit	0.18	.01	0.77, 60.36	2.65	.01	0.67, 4.64
Native country	0.10	.09	−1.21, 18.11	—	—	—
Social norm	—	—	—	−1.20	.049	−2.39, −0.01
Self-efficacy	0.14	.049	0.01, 6.17	2.08	.06	−0.12, 4.29
R^2	0.33			0.29		

[a]Assessed at baseline.

Figure 3. Differences and effect sizes (ES) regarding compliance with the alcohol guideline among complete cases (n=197) and number of alcoholic drinks per week between the experimental group and the control group at baseline and after 6 months.

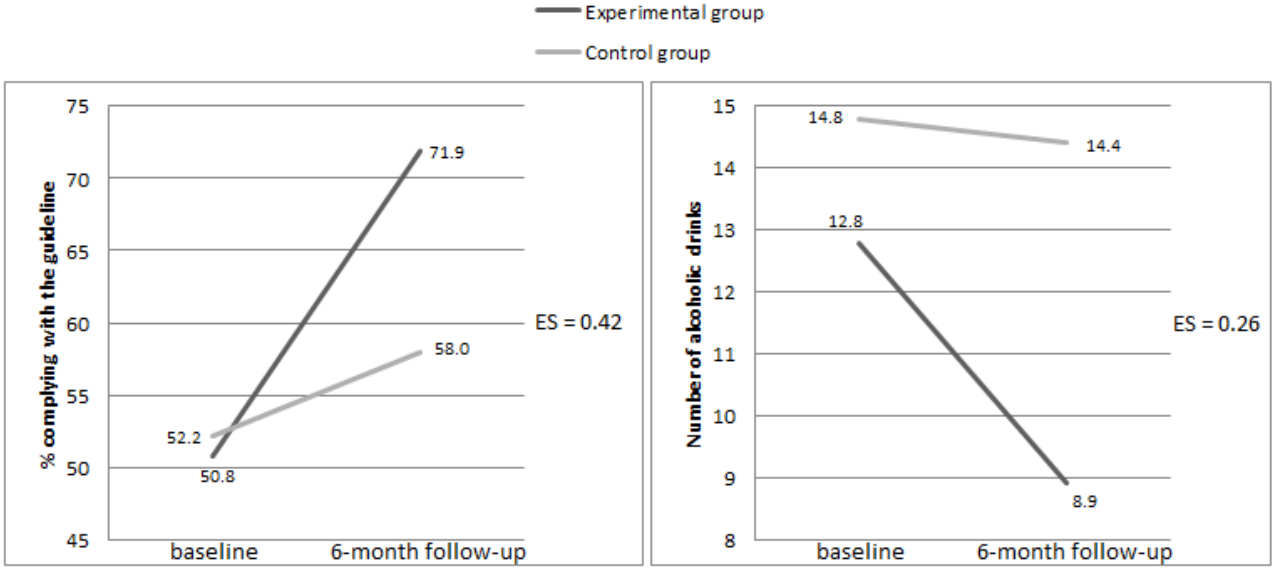


Table 4. Differences between the 2 experimental subgroups (alternating condition: n=59; summative condition: n=72) regarding the evaluation items about appreciation of the program.

Items	Baseline				6-month follow-up			
	Alternating condition	Summative condition	β	*P*	Alternating condition	Summative condition	β	*P*
	Mean (SD)	Mean (SD)			Mean (SD)	Mean (SD)		
Evaluation mark[a]	11.31 (3.22)	11.51 (3.29)	0.03	.72	12.05 (2.99)	12.08 (3.24)	0.01	.95
I have read all pieces of advice[b]	4.34 (0.78)	4.07 (0.89)	−0.16	.07	3.95 (0.92)	3.92 (0.88)	−0.02	.84
The advice was interesting[b]	4.31 (0.90)	4.31 (0.82)	0.00	.99	4.32 (0.88)	4.36 (0.74)	0.01	.89
The advice was credible[b]	4.56 (0.68)	4.40 (0.80)	−0.11	.24	4.46 (0.84)	4.54 (0.69)	0.06	.53
The advice was informative[b]	4.46 (0.90)	4.39 (0.78)	−0.04	.64	4.32 (0.92)	4.57 (0.71)	0.15	.08
The advice was clear[b]	4.53 (0.73)	4.44 (0.73)	−0.06	.53	4.34 (0.86)	4.50 (0.73)	0.13	.14
The advice helps me to drink less alcohol[b]	3.41 (1.19)	3.47 (1.07)	0.03	.74	3.75 (1.09)	3.68 (1.07)	0.01	.93

[a]Scores: 0 (very bad)-15 (excellent).

[b]Scores: 1 (no, absolutely not)-5 (yes, absolutely).

Discussion

Principal Findings

This study used a randomized controlled trial to determine the effectiveness of a Web-based tailored alcohol intervention, and to compare the effects of 2 tailoring strategies in terms of drinking behavior change, dropout rates, and appreciation. The experimental group and the control group both decreased their alcohol consumption, but the effects for our primary outcomes were greater in the experimental group. Complete case analyses as well as ITT analyses were performed. Inconsistent results were found. First of all, only among complete cases intervention effects were identified in terms of meeting the alcohol guidelines. Second, the experimental group reduced their weekly alcohol intake by a greater amount than the control group, although this effect did not reach statistical significance when performing complete case analyses and multiple imputations.

The results of this study partly confirm that Web-based tailored self-help interventions can be an effective tool in decreasing alcohol consumption and encouraging low-risk drinking in adults [25,32]. It is noteworthy that the control group also achieved a small reduction in alcohol intake and an increase in the percentage of respondents adhering to the guideline. This finding is in-line with previous studies, which also found effects in control groups regarding alcohol intake (eg, [26]) as well as regarding other lifestyle behaviors, such as physical activity [62]. Assessment alone can already have significant effects on drinking. The act of completing an assessment questionnaire may have induced the participants in the control group to monitor and reflect on their own behavior, leading to a decrease in consumption [34].

Regarding our secondary goal—comparing an alternating and a summative tailoring strategy—we found no difference between the 2 strategies for changes in alcohol use. These results were the same among complete cases and ITT. Because both experimental subgroups ultimately received the same advice, the timing of the message delivery does not appear to have influenced behavioral impact. The attrition rates of our intervention show that more respondents in the alternating group completed the intervention at baseline. These respondents may have felt rewarded by receiving the advice in-between answering the questions, and this strategy may have made the program more attractive. This was partly confirmed by the program evaluation because the alternating group indicated having read more pieces of the personal advice. At 6-month follow-up, however, the dropout rate no longer differed between the 2 experimental subgroups. The appreciation of the program was also comparable between these 2 groups. Respondents who did not revisit the program after 6 months were those who evaluated the program more negatively at baseline, implying selective dropout.

Strengths and Limitations

Our study was characterized by some strengths. First of all, our intervention program was theory-based. The intervention satisfied the 5 basic criteria (ie, the 5 A's) of the HBC-I [39,63] in addition to providing other essential tailoring elements. The respondents' answers to a number of questionnaires were used to give advice about the risks of heavy drinking and about the need to change their drinking behavior; we assessed various possible predictors of behavioral change, such as attitude, social influence, self-efficacy, and planning; we assisted respondents by giving personal advice on the various psychosocial variables, including support and understanding, as well as personal information regarding relapse prevention (anticipatory guidance); and we arranged follow-up sessions. In previous research, extensive use of theory, including the Theory of Planned Behavior [51], has been associated with considerable effects on health-related behavior [64]. Our program was based on the I-Change model, which consists of the Theory of Planned Behavior constructs supplemented by concepts such as awareness factors and action planning strategies. The latter, in

particular, is associated with increased behavioral effects, as has been demonstrated in general [65,66] as well as specifically for computer-tailored programs [67]. Our intervention program used multiple tailoring by offering 3 feedback moments. A multisession program is likely to be more effective than a single-session program [68-70]. Further research should explore the optimal number of feedback moments as well as the optimal time lag between the different sessions. To our knowledge, this is the first study to compare 2 different tailoring strategies (ie, alternating vs summative) in terms of effectiveness, dropout, and appreciation. Finally, few studies have tested a Web-based tailored alcohol intervention among adults in the general population [71].

Our study was also subject to some limitations. First, our findings were based on self-reports, which may have led to recall bias. Previous research has shown that quantity-frequency measures, such as those we used in this study, are likely to result in greater underestimation than daily diaries [72]. However, because we used the same questions at all measurement moments, this may have not influenced our data indicating changes in behavior, and thus the effectiveness of the intervention. In any case, forgetting seems to be a potent source of underestimation in surveys regarding alcoholic drinks [55]. Second, all respondents were recruited through an online panel and received an incentive for their participation, which might mean that some of them were not motivated to change their drinking behavior and/or that they took part in this study simply to receive the incentive. Third, our study had a moderate-sized sample and a high attrition rate (approximately 41%) as well as missing values on some baseline data (approximately 26%). Based on the power analyses, the number of participants was sufficient for executing logistic regression analyses; however, for the linear regression analysis, our sample size was too small. Therefore, the effect among complete cases might have not reached statistical significance. However, the effect was found in the expected direction. Although our data still yielded statistically significant effects among the complete cases, it may be that a selective group (ie, a very motivated group) completed the intervention program. This implies that we have to interpret the results regarding the intervention effects of this subgroup carefully. However, further support was obtained in a sensitivity analysis employing LOCF. Thus, data analysis with complete cases and LOCF methods showed statistically significant intervention effects in reaching a low-risk drinking status and an effect of the intervention in decreasing the weekly amount of alcohol intake, although without reaching statistical significance. Analyses with multiple imputation methods did not confirm these findings. Although multiple imputation methods are regarded as the most preferred technique to handle missing data [73], our analyses showed remarkable differences in outcomes. Moreover, the use of multiple imputation techniques may result in unreliable estimates when the number of missing values is high [74], as is the case in our study. Consequently, more research is needed to outline the conditions that yield these differences between the approaches. Additionally, when applying multiple imputation, the strategies how this technique is used should be clearly documented because multiple imputation techniques require certain procedures and rules [61,74-75]. At this moment, there seems to be no consensus about the number of imputed datasets needed [61,73-76]. Other shortcomings of multiple imputation are that the results may strongly depend on the imputation model that is created [74,77] and that different multiple imputation programs seem to show different results [73]. Finally, although we had a follow-up measurement 6 months after baseline, the long-term impact of Web-based tailored interventions still remains unclear and requires further research.

Conclusions

Tailored feedback delivered via the Internet can be an effective way to reduce alcohol intake among adults, at least among a subgroup that revisited the program. However, the results of complete case analyses were inconsistent with the findings of ITT analyses when using the multiple imputation technique. Among our Internet panel, there were no indications that an alternating or a summative tailoring strategy works better in reducing alcohol intake by means of eHealth programs. Nevertheless, lower attrition rates during the first visit indicate that the version of the intervention with alternating questions and advice may be preferred.

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Conflicts of Interest

Hein de Vries is scientific director of Vision2Health, a company that licenses evidence-based, innovative, computer-tailored health communication tools. No other authors report any conflicts of interest.

Multimedia Appendix 1

Results of regression analyses after filling missing values with the last observation.

[PDF File (Adobe PDF File), 88KB - jmir_v15i9e206_app1.pdf]

Multimedia Appendix 2

CONSORT-EHEALTH checklist V1.6.2 [78].

[PDF File (Adobe PDF File), 983KB - jmir_v15i9e206_app2.pdf]

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Abbreviations

AUDIT: Alcohol Use Disorders Identification Test
ISRCTN: International Standard Randomized Controlled Trial Number
ITT: intention-to-treat
LOCF: last observation carried forward
QFV: Quantity-Frequency-Variability
SRHI: Self-Report Habit Index

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Original Paper

Using Chat and Text Technologies to Answer Sexual and Reproductive Health Questions: Planned Parenthood Pilot Study

Margaret M Giorgio[1], MPH; Leslie M Kantor[2], MPH; Deborah S Levine[2], MSW, MAT; Whitney Arons[2], MPH, CHES

[1]Department of Nutrition, Public Health, and Food Studies, New York University, New York, NY, United States

[2]Planned Parenthood Federation of America, New York, NY, United States

Corresponding Author:
Margaret M Giorgio, MPH
Department of Nutrition, Public Health, and Food Studies
New York University
411 Lafayette St, 5th Fl
New York, NY, 10003
United States
Phone: 1 617 980 1232
Fax: 1 212 995 4194
Email: mmg362@nyu.edu

Abstract

Background: Teens and young adults in the United States are in need of sexual and reproductive health information, as evidenced by elevated rates of sexually transmitted infections (STIs), pregnancy, and births among this population. In-person sexuality education programs are helpful, but they are unlikely to rapidly accommodate teens and young adults in a moment of crisis. Evidence suggests that technologies such as instant messaging (IM) and text messaging may be effective ways to provide teens and young adults with sexual and reproductive health information. In September 2010, Planned Parenthood Federation of America launched a text and IM program designed to provide immediate answers to urgent sexual and reproductive health questions from a reliable and confidential source and to link young people to sexual and reproductive health services if needed.

Objective: To assess whether this program is successful in reaching the target population, whether user characteristics vary by mode (IM vs text), and whether mode is associated with reaching individuals with high levels of worry or reducing worry postchat.

Methods: Data were collected from prechat and postchat surveys for all IM and text message conversations between September 2010 and August 2011. A bivariate analysis was conducted using chi-square tests for differences in the main covariates by mode of conversation. In the multivariable analysis, logistic regression was used to identify factors that were independently associated with prechat levels of worry and changes in worry postchat.

Results: A total of 32,589 conversations occurred during the program's first year. The odds of feeling very worried prechat were highest for IM users (adjusted odds ratio [AOR] 1.43, 95% CI 1.20-1.72), users 17 years and younger (AOR 1.62, 95% CI 1.50-1.74), Latino/Hispanic users (AOR 1.36, 95% CI 1.27-1.46), and black users (AOR 1.40, 95% CI 1.30-1.50). After controlling for the study covariates, there was no significant difference in the odds of feeling better (less worried) postchat between IM and text message users. Feeling better postchat was associated with being younger (≤17 years: AOR 1.42, 95% CI 1.17-1.72; 18-24 years: AOR 1.20, 95% CI 1.02-1.42), being Latino/Hispanic (AOR 1.31, 95% CI 1.10-1.55), reporting that the service was very helpful (AOR 3.47, 95% CI 3.24-4.32), and asking about emergency contraception (AOR 1.35, 95% CI 1.13-1.61). The odds of feeling better were lowest for users with questions about STIs (AOR 0.61, 95% CI 0.47-0.78).

Conclusions: The results from the process evaluation suggest that the program was able to provide informational support to vulnerable groups, such as teens and racial minorities, in moments of particular worry. Differences between the IM and text message users reveal that each mode appeals to a different population and that both are necessary to reach a diverse audience.

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KEYWORDS

reproductive health; sexual health; public health; text messaging; instant messaging; abortion seekers; sexually transmitted diseases; pregnancy; emergency contraception; Internet

Introduction

There are approximately 43 million people aged 15-24 years in the United States, and their need for sexual and reproductive health information is evidenced by the elevated rates of sexually transmitted infections (STIs), pregnancies, and births among this population [1]. Although teens and young adults represent only 25% of the sexually active population, those aged 15-24 years account for nearly half of all STI diagnoses each year [2]. The pregnancy rate among those aged 15-19 years in the United States continues to be one of the highest in the developed world—more than twice as high as rates in Canada and Sweden [3]. Approximately 82% of pregnancies among those aged 15-19 years are unintended, which accounts for approximately 20% of all unintended pregnancies in the United States annually [4]. However, this rate has declined from previous years. In 2008, the pregnancy rate among those aged 15-19 years in the United States was 67.8 per 1000, which is the lowest it has been in 30 years [5].

Adverse sexual and reproductive health outcomes are not uniformly distributed among racial and ethnic subgroups in the United States. Recent STI surveillance efforts by the Centers for Disease Control and Prevention (CDC) have shown that rates for chlamydia, gonorrhea, and syphilis among those aged 10-24 years are significantly higher for blacks compared to whites [6,7]. In 2010, chlamydia rates were 13 times higher and gonorrhea rates were 37 times higher among black males aged 15-19 years than among white males of the same age group [7]. For males aged between 20-24 years, chlamydia rates were 8 times higher and gonorrhea rates were 23 times higher among blacks than among whites [7]. Similar differences exist by racial and ethnic group. The 2006-2010 results of the National Survey of Family Growth revealed that among females aged 15-19 years, 21% of Latino/Hispanic women reported using no method of contraception during last intercourse as compared with 19% of blacks and 11% of whites [8]. Racial disparities in condom use were also found among males of the same age group, with 31% of sexually active Latino/Hispanic males reporting never using condoms in the past 4 weeks compared to 21% of white and 16% of black males [8]. Pregnancy rates are also higher among black and Latino/Hispanic teens and young adults. In 2008, the highest pregnancy rates among those aged 15-19 years were reported among blacks (117 births per 1000) and Latino/Hispanics (107 births per 1000) compared to a rate of 43 per 1000 for white youth in the same age range [5,9]. This trend remained consistent for women aged 20-24 years; rates per 1000 population were 259 among black women and 245 among Latino/Hispanic women, compared with 63 among whites [6]. In the United States, black and Latino/Hispanic women have also been shown to experience higher rates of unintended pregnancy and abortion than white women do, a trend that persists after controlling for levels of income [10].

The high rates of STIs and unintended pregnancies among teens and young adults in the United States point to an increased need to provide sexual and reproductive health information to this group. Sexuality education programs have traditionally been implemented in schools, health centers, and community settings, yet these venues and methods are lacking in 2 respects. First, not everyone gets sexuality education, and those that do may not receive accurate, effective, or timely sexuality education [11-14]. Second, although in-person sexuality education programs can provide information and support, it is doubtful that they can rapidly accommodate teens and young adults when they are in a moment of crisis. This is especially problematic for time-sensitive issues, such as the window in which emergency contraception is most effective after unprotected sex. In addition, the longer an individual remains in a state of crisis, the higher her levels of anxiety and worry can become. Anxiety has been shown to be a barrier to health-seeking behavior [15,16].

New approaches to sexuality education are needed that can meet the needs of those not receiving adequate sexuality education in schools and communities and may meet needs in a moment of high worry. Technology can play an important role. Two of these types of technologies are instant messaging (IM) and short message service (SMS) text messaging. In 2006, it was estimated that 69 million people in North America used IM [17]. Between 2000 and 2004, researchers estimated an annual growth rate of IM users of approximately 29% [18], with the highest growth occurring among individuals between the ages of 13 and 29 years [19,20]. Text messaging has also become a major communication tool for teens and young adults. Research conducted by the Pew Internet & American Life Project revealed that 95% of those aged 18-29 years and 72% of those aged 12-17 years use the text messaging feature on their phones [21,22]. Among these groups, girls aged 14-17 years are the heaviest users, averaging approximately 100 messages per day [21]. Three-quarters of youth aged 12-17 years own mobile phones. Almost 90% of mobile phone users aged 12-17 years regularly send SMS text messages. Research also shows that those aged 14-17 years typically send or receive approximately 60 SMS text messages per day [23].

Existing evidence suggests that the use of IM and SMS text messaging may be an effective way to provide teens and young adults with sexual and reproductive health information [21,22]. Embarrassment and concerns about confidentiality can act as barriers to teens seeking sexual and reproductive health information from parents, peers, doctors, and/or other adults [24-26]. Teens and young adults may prefer the anonymity that instant and SMS text messaging provide. A recent review of the literature found that SMS text messaging has been used to promote sexual and reproductive health in a variety of ways, including communication between health clinics and patients, partner notification and contact tracing, contraception reminders, and sexuality education [27]. The review noted that some evidence of the effectiveness of this method exists; however, very few of the described studies had been formally evaluated [27]. An internal study conducted for Planned Parenthood Federation of America in 2007 of youth and young adults aged 13-29 years revealed that 32% of the study sample reported that they were likely or very likely to use IM if it was made available on the Planned Parenthood Federation of America website. Further, an email feature on Planned Parenthood Federation of America's teen-targeted website received more than 20,000 questions in 2008. This high volume suggested to Planned Parenthood Federation of America staff that teens desired

anonymity and confidentiality, but also wanted to get personalized answers to their questions. The answers to most of these questions are directly available on the website. However, users' emails indicated a desire to communicate about their unique situations and get what they perceived to be unique answers. Both IM and texting are both vehicles through which users can be anonymous and also get highly personalized responses.

In light of these considerations, Planned Parenthood Federation of America launched a texting and IM program in September 2010 targeted at teens and young adults aged between 15-24 years who have an urgent sexual or reproductive health need. The goals of this program are to (1) give immediate answers to urgent sexual and reproductive health questions from a reliable and confidential source, and (2) link young people to sexual and reproductive health services if needed. The program additionally aims to reach groups experiencing health disparities, particularly black and Latino/Hispanic teens and young adults.

The program is focused on the following topic areas: emergency contraception, pregnancy tests, abortion, and STI testing. These 4 were chosen for a number of reasons. Topics were chosen based on Web analytics on the Planned Parenthood website, which included frequency of searches of these topic areas on the website, searches utilizing search engines (eg, Google, Yahoo) that led visitors to the website, and volume of page views containing this content. Topic areas were also chosen based on an analysis of questions received via the Ask the Expert email feature on the Planned Parenthood website. Further, the language used in the emails indicated high levels of worry that could be an obstacle to seeking help. Providing immediate personal interaction might alleviate this worry and allow the user to take a positive health-seeking action. Lastly, these issues are often time-sensitive and IM and texting allow a direct connection to users right when the information is needed, thereby filling a gap that sexuality education programs and health centers with limited hours are unable to meet.

The program operates as a national sexual and reproductive health hotline that, as of December 2012, operates from 9 am to midnight (ET) Monday to Thursday, 9 am to 10 pm (ET) on Fridays, 9 am to 5 pm (ET) on Saturdays, and from 2 pm to midnight (ET) on Sundays. By clicking the IM function on the Planned Parenthood Federation of America website or by sending a SMS text message, program users interact with live, trained customer service agents. Agents use a bank of more than 900 scripted responses to provide health information, correct misconceptions, and provide contact information for a Planned Parenthood health center when warranted.

To create the bank of standardized responses, likely questions were identified through archives of questions submitted to Ask the Expert on the Planned Parenthood website, Columbia University's Go Ask Alice email feature, Ask Dr Cullins on the Planned Parenthood website, and other frequently asked question (FAQ) documents and archives from Planned Parenthood affiliates. Responses to these questions were then gathered from Planned Parenthood pamphlets, websites, and training materials. Further responses were developed by a team of external health writers with expertise in the topic areas and edited by Planned Parenthood Federation of America staff. In the first months of the program, staff actively reviewed transcripts to identify gaps and improve the existing responses. The program maintains an ongoing system for transcript review and content improvement.

Agents are trained on the substantive topics, the use of scripted responses, and how to respond compassionately and appropriately. Agents provide medical information, but do not provide medical advice or diagnoses. They use scripted messages that contain simple counseling content, but are trained to remain on the script and refer users to health centers for more specific or in-depth counseling. Agent performance is monitored and evaluated by staff with advanced sexual health training to ensure high-quality responses that meet the goals of the program. In addition, agents work in a central location and agents that are more skilled are assigned to the task of monitoring conversations as they are happening and providing guidance as needed.

For the pilot phase of the program, Planned Parenthood Federation of America promoted the service on its traditional and mobile websites, which attract 3 million visitors monthly, as well as on 2 MTV television shows: *16 and Pregnant* and *Teen Mom*.

This paper describes the results from a process evaluation of the first year of the IM and texting program. The process evaluation had 4 main research questions:

1. Was the program successful in reaching the target population, teens and young adults (15-24 years) and black and Latino/Hispanic teens and young adults?
2. Did the program reach the target population when they had high levels of worry?
3. Did user characteristics (sociodemographic, question topic, and level of worry) vary by mode (IM vs texting)?
4. Was IM or texting more likely to reach individuals when they had high levels of worry and to reduce user-reported worry postconversation?

Methods

Data Sources

Data for this process evaluation were collected from September 2010 until August 2011. All SMS text message and IM conversations that occurred during this period were included in the analysis (N=32,589). Data for this analysis came from 3 main sources. The first was a short prechat survey that was offered to all users prior to being connected to an agent. Because of differences between the IM and SMS text service providers, completion of the prechat survey was required for IM users whereas it was offered, but not required, for individuals communicating via texting. The second data source was a postchat survey. Technological limitations of the software program prevented the postchat survey from being offered to all users or from requiring completion by those who were offered it. Lastly, program agents were instructed to fill out a postchat survey for each interaction.

Two service providers, 1 for IM and the other for SMS text messaging, were contracted by Planned Parenthood Federation

of America to provide the technological platforms for the program. Each of these providers maintained databases containing data from the prechat, postchat, and agent surveys. Neither database contained a complete list of all variables and cases. Therefore, the 2 datasets were combined to create the final dataset used for this analysis. This dataset was then cleaned to remove duplicate variables and cases.

Variables

Table 1 contains a list of the variables that were collected through each of the 3 data sources, broken down by conversation mode (IM vs texting). A number of demographic characteristics were assessed, including age, gender, race, and zip code. For age, gender, and race, the participant was offered a precategorized list and asked to choose the 1 category that best described them. For the purposes of this analysis, age categories were collapsed to reflect 3 groups: teens (≤17 years), young adults (18-24 years), and adults (≥25 years). Because of the small number of participants who identified as transgender (n=148), these individuals were not included in the final sample. Although race was assessed through the prechat survey for IM users, texting users were not asked for their race until the postchat survey. The race variable was collapsed into 4 categories: white, black, Latino/Hispanic, and other.

For IM users, question topic was assessed through the agent survey and the prechat survey. To simplify the user experience for texting users, they were not asked to describe their question topic. The respondent or agent was asked to choose from the following list: abortion, STI testing, pregnancy testing, emergency contraception, and other. To construct the question topic variable, the agent-reported question categories were used as the default. In most cases (23,138/32,589, 70.99%), the responses about the question topic area from the program user and agent were in agreement. An informal qualitative analysis of a sample of transcripts from conversations with discordant responses revealed that the agent responses were more reliable than user responses. In addition, the agent-reported topic was the only data available for texting users. In the case of missing data from the agent survey (3585/32,589, 11.00%), IM user responses were used instead.

To assess whether an individual was in a moment of crisis, users were asked to report how worried they felt about their question. Level of worry was assessed twice: first in the prechat survey and again in the postchat survey. Participants were asked to report if they felt very worried, somewhat worried, or not at all worried. A dichotomous variable was created to determine changes in worry level from prechat to postchat, and users were categorized as either less worried, no change, or increased worry. Less worried could mean that someone went from feeling very worried to somewhat worried, from very worried to not at all worried, or from somewhat worried to not at all worried. Similarly, no change could represent an individual who reported any of the 3 levels of worry prechat, as long as they reported the same level of worry postchat. The no change and increased worry response options were combined due to the small number of users (329/32,589, 5.83%) who reported an increased level of worry postchat.

Users were asked in the postchat survey to rate the helpfulness of the service, with response categories of very helpful, somewhat helpful, somewhat unhelpful, and not at all helpful. In the multivariable models, these categories were collapsed to compare individuals who found the program very helpful to all other users.

Statistical Analysis and Multivariable Models

Ethical clearance for this analysis was obtained from the Allendale Investigational Review Board. To investigate the main research questions, descriptive statistics for the final sample were run for all variables. Next, a bivariate analysis was conducted using Pearson chi-square test for significance for differences in the main covariates by mode of conversation. In the multivariable analysis, logistic regression was used to identify factors that were independently associated with prechat levels of worry and changes in worry postchat. Models 1 and 3 present the unadjusted odds for the relationships between conversation type and the 2 worry measures. Models 2 and 4 present the adjusted odds ratios, controlling for the other study covariates.

Table 1. Questions, answer categories, associated variables, and differences by conversation for the study data sources.

Variable domain	Instant messaging	Texting
Prechat survey		
Gender	Your gender?	Please text your age, sex, and zip code
	Women	(open ended)
	Man	
	Transgender	
Age	Your age?	Please text your age, sex, and zip code
	11 and under	(open ended)
	12-14	
	15-17	
	18-24	
	25-30	
	31-50	
	51 or older	
Zip code	Your zip code?	Please text your age, sex, and zip code
	(open ended)	(open ended)
Race	What best describes your race/ethnicity?	(Collected in postchat survey)
	White	
	Black	
	Latino/Hispanic	
	American Indian/Alaska Native	
	Asian/Pacific Islander	
	Biracial/multiracial	
	Other	
Question topic	You may have more than one question, but what is the main thing you want to chat about today?	(Collected in agent survey)
	Abortion	
	STD testing	
	Pregnancy tests	
	Morning-after pill (emergency contraception)	
	Other	
Prechat worry level	How are you feeling right now?	Before we get started, please tell us how you are feeling right now
	Very worried	Very worried
	Somewhat worried	Somewhat worried
	Not at all worried	Not at all worried
Postchat survey		
Postchat worry level	How are you feeling now?	To help us know how well we're doing, please answer three questions. First, how are you feeling now?
	Very worried	Very worried
	Somewhat worried	Somewhat worried
	Not at all worried	Not at all worried
Helpfulness	How helpful were we?	How helpful were we?
	Very helpful	Very helpful

Variable domain	Instant messaging	Texting
	Somewhat helpful	Somewhat helpful
	Somewhat unhelpful	Somewhat unhelpful
	Not at all helpful	Not at all helpful
Race	(Collected in prechat survey)	What best describes your race/ethnicity?
		American Indian
		Asian/Pac Islander
		Black
		Latino/Hispanic
		Multiracial
		White
		Other
Agent survey (same for both IM and texting)		
Appointment offered	For chatter/texter in participating health center area, did you OFFER an appointment?	For chatter/texter in participating health center area, did you OFFER an appointment?
	Yes, no, N/A	Yes, no, N/A
Appointment booked	For chatter/texter in participating health center area, did you BOOK an appointment?	For chatter/texter in participating health center area, did you BOOK an appointment?
	Yes, no, N/A	Yes, no, N/A
Contact info offered	For chatter/texter NOT in participating health center area, did you OFFER local PP contact information?	For chatter/texter NOT in participating health center area, did you OFFER local PP contact information?
	Yes, no, N/A	Yes, no, N/A
Contact info provided	For chatter/texter NOT in participating health center area, did you PROVIDE local PP contact information?	For chatter/texter NOT in participating health center area, did you PROVIDE local PP contact information?
	Yes, no, N/A	Yes, no, N/A
Chatter ask for appointment	For chatter/texter NOT in participating health center area, did the chatter ask explicitly for an appointment?	For chatter/texter NOT in participating health center area, did the chatter ask explicitly for an appointment?
	Yes, no, N/A	Yes, no, N/A
Question topic	What was discussed? Select all that apply.	What was discussed? Select all that apply.
	Abortion	Abortion
	Emergency contraception	Emergency contraception
	Pregnancy testing	Pregnancy testing
	STI testing	STI testing
	Other	Other

Results

Descriptive statistics are displayed in Table 2. There was a total of 32,589 conversations that occurred during the first year of the program, but the n's vary for each variable due to missing data. Users were most commonly white (46.17%, 12,119/26,250), aged 18-24 years (51.20%, 16,485/32,195), and female (89.29%, 28,575/32,002). Although not in the majority, the program reached substantial numbers of Latino/Hispanic and black individuals during the first year. Specifically, the next largest categories were Latino/Hispanic (18.59%, 4881/26,250) and black (16.87%, 4429/26,250) users. The other category accounted for 18.37% (4821/26,250) of the sample and comprised individuals who identified as American Indian/Alaska Native, Asian/Pacific Islander, biracial/multiracial, or other. Almost one-quarter of the users (23.30%, 7500/32,195) were aged 17 years or younger. Questions about abortion were the most prevalent (44.65%, 13,617/30,498). Pregnancy testing and emergency contraception were the next most common topics, both individually representing 17.33% and 17.35% (5284/30,498 and 5292/30,498, respectively) of conversations. The least common topic was STI testing (9.21%, 2810/30,498). Most program users reported at least some level of worry prechat, with 43.22% (13,365/30,921) reporting feeling very worried and 45.43% (13,953/30,921) reporting feeling somewhat worried. Information for a Planned Parenthood health center was provided in just over half (54.57%, 13,318/24,231) of conversations.

The overall response rate for the postchat survey was 17.67% (5759/32,589). Among the users who completed the survey, most found this service to be very helpful (61.91%, 3559/5749). Levels of worry were lower postchat. Only 19.33% (1113/5758) reported feeling very worried after interacting with an agent, as opposed to 51.93% (2990/5758) feeling somewhat worried and 28.74% (1655/5758) feeling not at all worried. The variable that was created to capture changes in level of worry revealed that 37.90% (2140/5647) of users reported feeling less worried immediately after the chat had concluded. Although slightly more than half (56.28%, 3178/5647) reported no change, a small group (5.83%, 329/5647) reported an increase in their level of worry postchat.

Using Pearson chi-square test for significance, statistical differences between texting and IM users were found for most of the major covariates (Table 2). Texting users were more likely than IM users to be male (14.15% vs 10.19%, $P<.001$), Latino/Hispanic (24.65% vs 18.41%, $P<.001$), and aged 17 years or younger (39.02% vs 20.90%, $P<.001$) than individuals using IM. There were also significant differences by question topic areas ($P<.001$). Although 46.61% (13,020/27,933) of IM users asked questions about abortion, it accounted for only 23.27% (597/2565) of questions from texting users. On the other hand, texting users were more likely than IM users to ask about STI testing (16.49% vs 8.55%, $P<.001$) or had questions categorized as other (22.38% vs 10.46%, $P<.001$). Texting users were more likely than IM users to report that the service was very helpful (73.01% vs 60.13%, $P<.001$). No statistically significant differences were found between texting and IM users in the frequency that Planned Parenthood health center information was provided.

Overall, there was a statistically significant difference in which texting users appeared to be slightly less worried than IM users (Table 2). In the prechat survey, IM users were more likely than texting users to report being very worried (43.70% vs 38.79%, $P<.001$), whereas texting users more commonly reported feeling not at all worried compared to IM users (15.52% vs 11.24%, $P<.001$). There is a similar pattern in the postchat survey. Although a comparable proportion of IM and texting users reported feeling very worried, a larger percentage of IM users reported being somewhat worried (53.03% vs 45.14%, $P<.001$). Feeling not at all worried was more common among texting versus IM users (35.16% vs 27.70%, $P<.001$) in the postchat survey. Looking at differences between texting and IM users in the changes in level of worry variable, a larger percentage of texting users reported a higher level of worry postchat (8.25% vs 5.49%, $P<.001$). There was no difference in the percentage of users who reported feeling less worried.

As shown in Table 3, Pearson chi-square test for significance was also used to reveal significant differences in user-reported program helpfulness postchat by question topic ($P<.001$). Among users with questions concerning STIs, only 53.31% (314/589) reported that the program was very helpful. By comparison, 70.48% of users (795/1128) with questions about emergency contraception reported that the chat was very helpful.

Table 4 provides the unadjusted and multivariable estimates of the odds ratios (OR) for the relationship between conversation mode and 2 different measures of worry. Models 1 and 2 use prechat worry (feeling very worried before interacting with a program agent as compared to feeling somewhat worried or not at all worried) as the outcome variable. The unadjusted odds ratio (UOR) reveals that IM users were more likely to report feeling very worried than texting users prechat (UOR 1.22, 95% CI 1.13-1.32). After controlling for the other study covariates, the adjusted odds ratio (AOR) for this relationship increased to 1.43 (95% CI 1.20-1.72). In Model 2, all the coefficients were significant at a $P<.01$ with the exception of gender. The odds of feeling very worried were highest for users aged 17 years and younger (AOR 1.62, 95% CI 1.50-1.74), Latino/Hispanic users (AOR 1.36, 95% CI 1.27-1.46), and black users (AOR 1.40, 95% CI 1.30-1.50). Users with questions about abortion were the most worried, with the odds of feeling very worried prechat being 65% less for users with questions about STI testing, 60% less for users whose questions fell into the other category, 43% less for questions about emergency contraception, and 26% less for questions about pregnancy testing.

Models 3 and 4 use the change in worry variable as the outcome, and the coefficients estimate the odds of feeling better (ie, less worried) postchat compared to reporting the same or increased level of worry. These models only pertain to the 17.67% of the total sample that completed the postchat survey (5759/32,589). The UOR for the relationship between conversation type and postchat worry revealed no significant difference between IM and texting users in the likelihood of feeling better postchat (UOR 0.99, 95% CI 0.84-1.16). After controlling for the other study covariates, this finding remained nonsignificant. However, there were significant relationships between other study covariates and changes in worry level postchat. Compared to the oldest users, individuals in the younger age groups were more likely to report lower levels of worry postchat (≤17 years: AOR 1.42, 95% CI 1.17-1.72; 18-24 years: AOR 1.20, 95% CI 1.02-1.42). Feeling better postchat was associated with users reporting being Latino/Hispanic (AOR 1.31, 95% CI 1.10-1.55) and reporting that the service was very helpful (AOR 3.47, 95% CI 3.24-4.32). Using abortion as a reference, users with questions about emergency contraception were most likely to report feeling less worried postchat (AOR 1.35, 95% CI 1.13-1.61). Conversely, the odds of feeling better were lowest for users with questions about STIs compared to abortion questions (AOR 0.61, 95% CI 0.47-0.78).

Table 2. Characteristics of program users and conversations by mode of conversation, instant messaging (IM), and texting.

Variables	All users (N=32,589)		IM (n=27,939)		Texting (n=4650)		*P* value
Question topic [a]							
Abortion	13,617	44.65	13,020	46.61	597	23.27	<.001
Pregnancy testing	5284	17.33	4761	17.04	523	20.39	
Emergency contraception	5292	17.35	4844	17.34	448	17.47	
STI testing	2810	9.21	2387	8.55	423	16.49	
Other	3495	11.46	2921	10.46	574	22.38	
Gender [b]							
Female	28,575	89.29	24,959	89.81	3616	85.85	<.001
Male	3427	10.71	2831	10.19	596	14.15	
Race [c]							
White	12,119	46.17	11,789	46.30	330	41.93	<.001
Black	4429	16.87	4320	16.97	109	13.85	
Latino/Hispanic	4881	18.59	4687	18.41	194	24.65	
Other	4821	18.37	4667	18.33	154	19.57	
Age (years) [d]							
≤17	7500	23.30	5839	20.90	1661	39.02	<.001
18-24	16,485	51.20	14,361	51.40	2124	49.89	
≥25	8210	25.50	7738	27.70	472	11.09	
Prechat level of worry [e]							
Very worried	13,365	43.22	12,208	43.70	1157	38.79	<.001
Somewhat worried	13,953	45.12	12,590	45.06	1363	45.69	
Not at all worried	3603	11.65	3140	11.24	463	15.52	
Health center information given [f]							
Yes	13,224	54.57	11,993	54.48	1231	55.50	.40
No	11,007	45.43	10,020	45.52	987	44.50	
Postchat questions [g]							
Response rate	5759	17.67	4956	17.74	802	17.25	.42
Postchat level of worry [h]							
Very worried	1113	19.33	955	19.27	158	19.70	<.001
Somewhat worried	2990	51.93	2628	53.03	362	45.14	
Not at all worried	1655	28.74	1373	27.70	282	35.16	
Changes in level of worry [i]							
Less worried	2140	37.90	1876	37.85	264	38.21	.01
No change	3178	56.28	2808	56.66	370	53.55	
More worried	329	5.83	272	5.49	57	8.25	
Helpfulness [j]							
Very helpful	3559	61.91	2980	60.13	579	73.01	<.001
Less than very helpful	2190	38.09	1976	39.23	214	26.99	

[a]All users: n=30,498; IM: n=27,933; texting: n=2565.

[b]All users: n=32,002; IM: n=27,790; texting: n=4212.
[c]All users: n=26,250; IM: n=25,463; texting: n=787.
[d]All users: n=32,195; IM: n=27,938; texting: n=4257.
[e]All users: n=30,921; IM: n=27,938; texting: n=2983.
[f]All users: n=24,231; IM: n=22,013, texting: n=2218.
[g]All users: n=32,589; IM: n=27,939; texting: n=4650.
[h]All users: n=5758; IM: n=4956; texting: n=802.
[i]All users: n=5647; IM: n=4956; texting: n=691.
[j]All users: n=5749; IM: n=4956; texting: n=793.

Table 3. Differences in user-reported program helpfulness postchat by question topic (n=5626).

Helpfulness	Question topic area										
	Abortion (n=2168)		Pregnancy testing (n=1175)		Emergency contraception (n=1128)		STI testing (n=589)		Other (n=566)		*P* value
	n	%	n	%	n	%	n	%	n	%	
Very helpful	1339	61.76	716	60.94	795	70.48	314	53.31	312	55.12	<.001
Less than very helpful	829	38.24	459	39.06	333	29.52	275	46.69	254	44.88	

Table 4. Unadjusted (UOR) and adjusted (AOR) logistic regression estimates of the relationship between conversation mode and worry measures.

Variables	Odds of reporting							
	Very worried prechat[a] (n=25,882)				Reduced worry postchat[b] (n=4359)			
	UOR	95% CI	AOR	95% CI	UOR	95% CI	AOR	95% CI
Conversation mode								
Texting	1.00		1.00		1.00		1.00	
IM	1.22	1.13-1.32	1.43	1.20-1.72	0.99	0.84-1.16	1.22	1.00-1.50
Gender								
Male			1.00				1.00	
Female			1.07	0.98-1.16			1.26	0.99-1.59
Age								
25 and older			1.00				1.00	
18-24			1.13	1.07-1.21			1.20	1.02-1.42
17 and younger			1.62	1.50-1.74			1.42	1.17-1.72
Race								
White			1.00				1.00	
Black			1.40	1.30-1.50			1.12	0.92-1.35
Latino/Hispanic			1.36	1.27-1.46			1.31	1.10-1.55
Other			1.34	1.25-1.44			1.35	1.13-1.61
Conversation topic								
Abortion			1.00				1.00	
STI testing			0.35	0.32-0.39			0.61	0.47-0.78
Pregnancy testing			0.74	0.69-0.80			0.98	0.82-1.17
Emergency contraception			0.60	0.53-0.61			1.35	1.13-1.61
Other			0.40	0.36-0.43			0.97	0.76-1.23
Planned Parenthood contact info given								
No							1.00	
Yes							0.99	0.87-1.13
Helpfulness								
Less than very helpful							1.00	
Very helpful							3.74	3.24-4.32

[a]Coefficients represent the odds of feeling very worried prechat as compared to somewhat/not at all worried.

[b]Coefficients represent the odds of feeling less worried after using the service as compared to reporting the same or increased worry.

Discussion

Principal Findings

The analysis of the first year of data from the IM and texting program revealed that the program was successful in reaching its target audience, with large portions of users being young (≤24 years), black, and Latino/Hispanic. A large percentage of the study population reported feeling very worried when they initiated the conversation. Because this measure was used as a proxy for whether a user was in a moment of crisis, it is reasonable to assume that the program was also successful in reaching individuals during this vulnerable time. In addition, racial minorities (including black, Latino/Hispanic, and all other groups categorized as other) and users 24 years and younger were more likely to feel very worried when they accessed the program. This may suggest that these groups are in greater need of these types of education and information services. Some evidence from the literature supports this. The 2006-2008 results of the National Survey of Family Growth reported that only 47% of females and 38% of males aged 15-19 years had received information about contraception in high school [8], and research has shown lower levels of knowledge about emergency contraception among individuals aged 18 years and younger [28,29]. Several studies have also documented racial disparities

in knowledge levels of sexual and reproductive health issues among US teens and young adults [6,30-32].

Results from the bivariate analysis indicate that the SMS texting service was more likely to be used by younger users and racial minorities than the IM service. This result may simply reflect technology preferences or access of individuals in these groups. This highlights the importance of offering the program through different modes of technology. Although cell phones provide a greater degree of anonymity in the moment, a text conversation, unless deleted, can be reviewed by others who have access to the phone. On the other hand, evidence of a conversation held through IM is gone from the computer once the window is closed, but the computer itself may be in a less private location and the history of visiting the Planned Parenthood website may be accessible to future users of the computer. Because there are continuing advances in technologies with mobile chat, tablets, etc, it is important to consider the implications of these new technologies and their possible impact on program utilization.

The differences that were found between texting and IM users may also be a by-product of the ways that the texting and IM portions of the program were marketed and promoted. The IM portion was only promoted on existing Planned Parenthood Web properties; therefore, it generally reached individuals who were already seeking information online. Recent research has suggested that there are demographic differences in the types of people who seek out health information online [33]. It may be that teens or racial minorities are less likely to search for answers to their sexual and reproductive health questions online, which would cause them to be less likely to be aware of the IM service. Further, the texting service was promoted on the MTV shows *16 and Pregnant* and *Teen Mom*, which appeal to a younger audience. In addition to demographic differences, texting users seemed to be less worried overall than IM users, both before and after the chat session. Again, this may be because of promotion efforts. Because IM users were actively seeking information online, they might already be at a moment of more pressing need. Conversely, individuals who became aware of the texting service while watching MTV may not be as worried when they initially contacted the program. As a result, Planned Parenthood staff may need to reconsider the ways in which the IM portion of the program is marketed and promoted.

Although texting users did appear to be less worried overall, after controlling for the study covariates, there was no difference in the program's effectiveness in reducing levels of worry postchat for texting versus IM users. This is an encouraging result because it indicates that both conversation modes are equally effective in reducing worry immediately after an individual has interacted with the program. However, because there were differences in the demographic profiles of the IM and texting users, it seems that both modes are needed to effectively reach the target population.

The results of this evaluation indicate that the program was more effective in reducing worry levels for the youngest age group (≤17 years) and for Latino/Hispanics. This result echoes the previous point that these groups may be more in need of this service because of inadequate access to sexual and reproductive health information at home or in school.

Whether or not a user felt better (ie, reduced level of worry) differed greatly by the topic area of their question. As compared to individuals with questions about abortion, the program was more effective in reducing worry when users had questions concerning emergency contraception. On the other hand, the odds of feeling better (ie, reducing worry) postchat were lower for individuals asking about STI testing than for abortion. There are several potential explanations for these differences. It could be that the increased odds of feeling better for individuals with questions about emergency contraception is an indication of a poor understanding of it and its uses in the general population. As such, these individuals may have benefited more from the information they received from the program and were subsequently more relieved. The fact that users with questions about STIs were less likely to report a lower level of worry postchat may be a result of the nature of STI questions. Agents are prohibited from making diagnoses during the conversations, but many individuals present with a list of symptoms and want to know what STI they may have. In these cases, agents are limited to providing information for a health center and advising the user that they will have to wait for several days or weeks after they are tested for results. As a result, users with STI-related questions are likely most frustrated with the lack of information regarding a specific diagnosis.

In an effort to test this theory after initial analysis, Pearson chi-square tests were run to determine if there were significant differences in reporting that the chat was very helpful by question topic area (Table 3), which revealed significant differences in user-reported program helpfulness by question topic. As stated previously, among users with questions concerning STIs, just under half reported that the program was very helpful, representing the smallest percentage of all the question categories. This low percentage could support the argument that users with questions about STIs may be more frustrated with the lack of immediate action or new information that resulted from their conversation, thereby making this group less likely to feel less worried postchat. By comparison, approximately 70% of users with questions about emergency contraception reported that the chat was very helpful, representing the largest percentage of all the question categories. Again, this may suggest users with questions about emergency contraception generally have lower levels of knowledge about this topic area than others and, therefore, found the service to be more helpful.

Limitations

This study has several limitations. The IM services attracted far more users than the SMS texting service (IM = 27,939 vs texting = 4650). As discussed previously, this is likely partially because of differences in the way that the text and IM services were advertised. This makes it difficult to assess whether the variations in the characteristics of program users by IM or texting are an artifact of these marketing methods or an indication of underlying preferences of users. Further research is needed to more accurately address this issue. In addition, the overall sample is heavily biased toward IM users.

Technological issues also made it difficult to collect data for this evaluation. Program designers did not want to discourage participating or completing the prechat or postchat survey by presenting lengthy surveys. Therefore, gathered information was limited to basic demographics, program helpfulness, and levels of worry prechat and postchat. The worry variables were meant to capture whether or not an individual was in a moment of crisis. However, this is an imperfect proxy because some individuals could have been very worried about their sexual and reproductive health issues for several weeks. Further, as shown in Table 1, technology difference caused data to not be collected in the same way for IM and texting users. Although the race variable was assessed through the prechat survey for IM users, which they were required to fill out; it was only assessed through the postchat survey for texting users. As a result, missing data for the race variable was much higher for texting than IM users. If this missing data was not random, it may have introduced some bias into the study.

Conclusions

Research has shown that response rates for Internet and text-based surveys are notoriously low [34-36], and the results from this study echo this trend. Response rates for individual question items varied widely from question to question and between the IM and text survey delivery models. In addition, technological limitations of the software program prevented the survey from being offered to all users or from requiring completion by those who were offered it. This problem was most pervasive for the postchat survey. As a result, conclusions about the helpfulness of the program and its effectiveness in reducing worry should be made cautiously. This is especially problematic because one of the main outcome variables for this process evaluation relied on data from this survey. If the individuals who responded to the postchat survey are systematically different from the study sample as a whole, the conclusions drawn from the logistic regression models that investigated changes in postchat worry could be strongly biased. It may be that users who did not find the program helpful or were still very worried about their sexual and reproductive health issue were less likely to respond to the postchat survey.

One of the major goals of the program is to increase access to health services. Program designers hypothesize that providing IM and SMS texting services will help build trust between program users and Planned Parenthood, further encouraging users to seek health services at a Planned Parenthood health center when they are needed. However, funding and technology restrictions did not allow for a more robust follow-up process. Therefore, another limitation of this process evaluation is that it only measures user attitudes immediately after interacting with the program and not behavior change. Further research is needed to systematically measure the impact of the program. This type of evaluation could determine whether individuals who used the program were more likely to utilize health care services or enact positive behavior change than those who did not.

The use of Internet and mobile technology is increasingly becoming an integral part of our everyday interactions and activities. This is especially true among teenagers and young adults. If interventions can be developed that reach young people with information and education that helps reduce worry, encourages the use of needed health services, and motivates changes in health behaviors, these technologies could be an important addition to public health practice.

The results from the process evaluation of the first year of Planned Parenthood Federation of America's IM- and texting-based intervention offer insight into one possibility for the use of Internet and mobile technologies for sexuality education programs. Although the results are unable to describe the program's effectiveness in affecting behavior change, they do suggest that the program was able to provide informational support to traditionally vulnerable groups, such as teens and racial minorities, in moments of particular worry.

The differences found between the IM and texting users reveal that each mode appeals to a different population of users and that both are necessary to reach a larger audience. Future research is needed to rigorously evaluate the impact of the program, including whether it increased knowledge of sexual and reproductive health issues, increased the use of health care services, and promoted safer sexual behaviors among users.

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Conflicts of Interest

None declared.

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Abbreviations

AOR: adjusted odds ratio
FAQ: frequently asked question
IM: instant messaging
SMS: short message service
STI: sexually transmitted infections
UOR: unadjusted odds ratio

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Original Paper

Effects of an Individually Tailored Web-Based Chronic Pain Management Program on Pain Severity, Psychological Health, and Functioning

Dana C Nevedal[1,2], PhD; Chun Wang[3], MS; Lindsay Oberleitner[2], PhD; Steven Schwartz[4], PhD; Amy M Williams[5], MA

[1]VA Connecticut Healthcare System, Department of Clinical Health Psychology, West Haven, CT, United States

[2]Yale University School of Medicine, Department of Psychiatry, New Haven, CT, United States

[3]Wellness & Prevention, Inc., Ann Arbor, MI, United States

[4]Social Wellth, Las Vegas, NV, United States

[5]Wayne State University, Department of Psychology, Detroit, MI, United States

Corresponding Author:
Dana C Nevedal, PhD
VA Connecticut Healthcare System
Department of Clinical Health Psychology
950 Campbell Ave.
West Haven, CT,
United States
Phone: 1 (203) 932 5711 ext 2910
Fax: 1 203 937 4951
Email: dcnevedal@gmail.com

Abstract

Background: It is estimated that 30% of adults in the United States experience daily chronic pain. This results in a significant burden on the health care system, in particular primary care, and on the workplace. Chronic pain management with cognitive-behavioral psychological treatment is effective in reducing pain intensity and interference, health-related quality of life, mood, and return to work. However, the population of individuals with chronic pain far exceeds the population of therapists that can provide this care face-to-face. The use of tailored, Web-based interventions for the management of chronic pain could address limitations to access by virtue of its unlimited scalability.

Objective: To examine the effects of a tailored Web-based chronic pain management program on subjective pain, activity and work interference, quality of life and health, and stress.

Methods: Eligible participants accessed the online pain management program and informed consent via participating employer or health care benefit systems; program participants who completed baseline, 1-, and 6-month assessments were included in the study. Of the 645 participants, the mean age was 56.16 years (SD 12.83), most were female (447/645, 69.3%), and white (505/641, 78.8%). Frequent pain complaints were joint (249/645, 38.6%), back (218/645, 33.8%), and osteoarthritis (174/654, 27.0%). The online pain management program used evidence-based theories of cognitive behavioral intervention, motivational enhancement, and health behavior change to address self-management, coping, medical adherence, social support, comorbidities, and productivity. The program content was individually tailored on several relevant participant variables.

Results: Both pain intensity (mean 5.30, SD 2.46), and unpleasantness (mean 5.43, SD 2.52) decreased significantly from baseline to 1-month (mean 4.16, SD 2.69 and mean 4.24, 2.81, respectively) and 6-month (mean 3.78, SD 2.79 and mean 3.78, SD 2.79, respectively) assessments (P<.001). The magnitude of the 6-month effects were large. Trends for decreases in pain interference (36.8% reported moderate or enormous interference) reached significance at 6 months (28.9%, P<.001). The percentage of the sample reporting fair or poor quality of life decreased significantly from 20.6% at baseline to 16.5% at 6 months (P=.006).

Conclusions: Results suggest that the tailored online chronic pain management program showed promising effects on pain at 1 and 6 months posttreatment and quality of life at 6 months posttreatment in this naturalistic study. Further research is warranted to determine the significance and magnitude of the intervention's effects in a randomized controlled trial.

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KEYWORDS

Web-based; Internet; chronic pain; treatment outcome; pain management; cognitive behavior therapy; psychology

Introduction

Background

Recent estimates indicate that 30% of adults in the United States, or over 93 million people, experience chronic pain each day [1] resulting in significant burden to our health care delivery system [2]. In the United Kingdom, it has been reported that more than 80% of all physician visits were pain-related [3,4]. Chronic pain is also a leading cause of disability and diminished job performance; it is estimated that US businesses lose $61.2 billion per year because of employee pain-related productivity impairment [5]. Treatments for chronic noncancer pain are numerous, often costly, and often associated with a variety of health risks [6-20]. Chronic pain treatments include, but are not limited to, the use of opioid and other analgesic medications [9-11,16,21,22], surgical procedures [19,23], injections [24-26], nerve ablations [15], spinal cord stimulators [20,27], physical and occupational therapies [28], biofeedback [29,30], transcutaneous electrical nerve stimulation (TENS) units [31], psychological interventions [32-41], and comprehensive multidisciplinary pain programs [42-45]. Chronic pain is a complex family of disorders with a wide range of causes and courses (eg, disease, injury), and is frequently maintained or exacerbated by additional psychological, behavioral, social, and environmental factors (eg, stress, depression, sleep dysfunction, physical inactivity, financial stress, legal disability) [14,46-48].

Multiple treatment guidelines exist for chronic pain management [6,8,10,14,18,21-23,27,32,35,43,45,49-53]. Recommended treatments vary by type of pain condition, and many include psychological assessment and interventions as part of a comprehensive treatment strategy [32,35]. Empirical evidence supports the efficacy of a cognitive behavioral approach to chronic pain management on pain intensity and interference, health-related quality of life, mood, and return to work [36,40] delivered face-to-face in individual and group formats [32,54]. Research has shown that offering traditional face-to-face cognitive behavioral therapy (CBT) modules tailored to client needs is an effective approach to chronic pain treatment [34], and allows for a more time-limited and cost-effective approach than treating individual clients using nontailored interventions. However, these delivery formats cannot scale to meet the demand. Many individuals lack local access to cognitive behavioral pain management services delivered by a qualified behavioral medicine specialist [55,56]. Furthermore, among those who have geographic access, cost can be a limiting factor [57], and disparity research has shown that racial and ethnic minorities receive adequate treatment of pain even less often than white patients do [58].

To illustrate the magnitude of this problem, the following thought experiment is provided: It is known that approximately 93 million adults in the United States suffer from chronic pain [1]. In order to provide each person with 8 CBT sessions of 50 minutes for pain management per year, a total of 425,143 behavioral medicine pain management specialists (who carried a heavy caseload of 35 pain patients per week and worked 50 weeks per year) would be needed to provide their care. This is more than 4.5 times the total number of practicing psychologists in the United States [59,60]. Furthermore, if these providers billed at an average rate of just $75 per hour, the total costs associated with this individual face-to-face behavioral pain management care would exceed US $55 billion annually. Clearly, current health care resources, in terms of the number of behavioral medicine specialists and pain management funding dollars, are ill-prepared to meet the demand for chronic pain management.

Evidence for Internet-Based Treatment

Given that nearly 24 million adults are already seeking help for chronic pain online [61,62], Web-based interventions for chronic pain management offer several distinct advantages over more traditional methods of intervention. First, they can inexpensively scale to provide services to large, diverse populations. Next, they are conveniently accessible around-the-clock from any location with a computer and Internet access. This eliminates many barriers for those living in rural areas, those who lack transportation or have mobility problems, those who must follow nonstandard schedules (eg, shift workers), and those whose child- or elder-care responsibilities limit access to care. Third, the technology has advanced sufficiently to allow for a user experience that is deeply tailored and personalized to the individual's unique symptoms, circumstances, needs, issues, barriers to change, etc. Tailored messaging has been effectively used with a variety of health conditions (eg, diabetes, obesity, hypertension, heart disease) and in a variety of contexts (eg, Internet website, interactive voice response, mobile text messages) for both health promotion and condition management [63-68], although application to chronic pain has been rare to date. Tailoring is accomplished most efficiently through online algorithm-based approaches that quickly and accurately assess a large number of factors to produce content tailored at the sentence fragment level and matched to the client's needs and motivations. Fourth, within the context of personalized content, the intervention can be delivered with nearly perfect consistency based on sound psychobehavioral theory and established guidelines. Fifth, the privacy afforded by Web-based interventions may be particularly appealing to individuals who avoid face-to-face psychological interventions because of stigma concerns. Finally, Internet-based treatments can be employed as part of the continuum of care that ranges from stand-alone care to adjunct care for those receiving other therapies, including, but not limited to, pharmacotherapy, physical therapy, or more traditional psychobehavioral interventions. Internet-based interventions may also prove to be cost-effective first-line interventions in stepped-care programs, or useful as booster sessions in the weeks and/or months following traditional face-to-face interventions.

Research has shown that Web-based treatment methods can be beneficial in managing chronic health conditions and promoting health [63,69-73]. A recent meta-analysis quantified the salubrious effects of computer-delivered interventions for health

promotion [71]. Web-based interventions for chronic back pain [69], chronic headaches [74], pediatric pain [75], and pain in older adults [76] have also shown promise. The meta-analytic review by Macea et al [77] concluded that randomized controlled studies of Web-based cognitive behavioral pain management result in small but consistent reductions in subjective pain. However, few of these studies used highly tailored interactive programming [55], and some included telephone or face-to-face components [77]. Given the high prevalence of chronic pain, and pervasive costs in terms of diminished quality of life, elevated health care usage, diminished productivity, combined with the inadequate supply of appropriately trained behavioral health specialists, we believe that there is a clear need to develop and test promising new methods for delivering psychobehavioral interventions for chronic pain conditions in innovative ways via the Internet. These challenges necessitate that new interventions be clinically effective, scalable, accessible, and financially sustainable.

Study Goals

The purpose of this study was to examine the naturalistic outcomes of a Web-based chronic pain management program that is structured around well-established chronic pain behavioral treatment guidelines [6,14,70,78] and tailored to each participant's unique needs. In addition to the overall effectiveness of the program in reducing pain, reductions in interference with daily activities and work, improvement in quality of life and health, and reductions in stress were examined. Furthermore, this study sought to elucidate participant perceptions of program usability and program quality, and whether certain personal characteristics predict maximum benefit of the Web-based chronic pain management program.

Methods

Participants and Procedure

Eligible participants were either employed by 1 of 37 participating US companies or a member of 1 of 18 participating US health care plans. Participating employers and health care plans purchased the Web-based, digital pain management program (HealthMedia Inc. *Care for your Pain* digital health-coaching program) as part of their population health offerings and/or health benefit structure. The programs were offered at no additional cost to eligible individuals.

Prospective participants were recruited by mailings, emails, and posted communications about the digital health-coaching programs, including the pain management program. The invitation to participate was sent by the employer or health care plan to all eligible participants. The invitation contained instructions on how to access the digital health-coaching programs and provided an access code necessary for website sign-up.

As part of the online sign-up process, potential participants were instructed to read a statement of informed consent before taking part in the study. Participants could choose to opt-in to the study after they understood the details of participation, potential benefits and risks, and their rights as a participant. The informed consent and study protocol were reviewed and approved by the Allendale Institutional Review Board. After consent and enrollment, participants were directed to all available digital health-coaching programs. Programs were entirely automated via tailoring algorithms and did not include telephone, email, or face-to-face contact with another person. Some participants received a tailored email message suggesting specific programs on the basis of their self-reported symptoms; others selected programs from a menu of all available programs. All participants who self-selected the pain management program (regardless of method) received this message at the beginning of the program: "Before we get started, let's make sure you're in the right place. This program isn't intended for people suffering from the following: acute pain, cancer pain, pelvic or abdominal pain. If you are experiencing these types of pain, contact your health care provider." Those who continued their entry in this study were invited to complete an online baseline questionnaire that included 58 questions querying demographics, medical and psychological conditions, pain, general well-being, and daily functioning. This information was used to tailor program content and as a baseline measure of self-reported outcomes. Only very brief measures of each construct could be included to attenuate participant burden in this study, which did not compensate participants for the time they spent filling out assessment questionnaires.

All participants who entered the pain management program and completed the 1-month and 6-month follow-up evaluations were included in analyses, and only the first enrollment into the pain program was used for analysis (some participants enrolled in the program multiple times). There were 645 unique participants who provided informed consent and participated in the program between October 10, 2007 and September 15, 2011. Participants did not receive any compensation for participating in this study.

Pain Management Online Program

The Web-based pain management digital coaching program is a commercially available (albeit not direct to consumers) behaviorally oriented program that uses proprietary technology to tailor the end-user experience such that it emulates an interaction with a behavioral pain management expert. The program uses patient self-report data and algorithms developed by expert clinicians to provide differing information and interventions based upon each participant's unique pattern of responses to an interactive consultation that queries the end user regarding type, quality, and location of pain, mood, stress, sleep, current methods of managing pain, level of motivation, and self-efficacy to manage pain, and use/nonuse of prescription pain medications.

The online pain management program integrates evidence-based theories of cognitive behavioral treatment [39,79-85], chronic disease self-management [86], motivational enhancement [87], and theories of health behavior change, including social cognitive theory, theory of reasoned action, theory of planned behavior, and self-determination theory [88-95].

The program provides ongoing feedback, usually 1 to 4 sentences long, between pages of the questionnaire to emulate a live coaching experience. Immediately after completing the baseline questionnaire, participants were provided with a tailored personal action plan and access to online pain management tools

and library. The personal action plan consisted of 18 tailored Web pages. Regardless of the specific content given to a particular user, each user was provided with a welcome page (see Figure 1) and the following content: setting expectations, managing stress, coping with pain, accessing social support, healthy sleep, nutrition, exercise, improving doctor–patient relationships, medication adherence, and chronic disease self-management. The length of the individual pages varied depending on the particular needs of the user (see Figure 2). Appointment and medication reminders and pain, medication, activity, and sleep logs were included among the tools. The library included psychoeducational materials on self-management, coping, stress management, medication adherence, nutrition, exercise, relaxation, pain conditions, cognitions, social support, comorbid concerns (eg, sleep, stress, mood), doctor–patient relationship and communication, and activity impairment at work and home.

Program content was delivered through text, images, videos, and interactive tools. During the study period, participants engaged with the program at-will via unlimited access to the action plan, online tools, and library to self-manage their chronic pain. Participants were invited by email to complete follow-up assessments 1 and 6 months after enrolling in the program. The program architecture and study design is displayed in Figure 3.

Measures

Pain Outcomes

Pain is commonly assessed in multiple domains including subjective pain intensity and unpleasantness ratings, interference with daily life, and ability to manage pain. We assessed each of these domains of pain experience. Pain intensity and unpleasantness over the past week were measured using a standard, well-validated 0-10 numeric rating scale with anchors at 0 (no pain or no unpleasantness) and 10 (extreme pain or extreme unpleasantness) [96,97]. To assess the impact of pain on daily activities, we assessed current interference of pain in everyday life using a single item based on a commonly used measure [98]. Pain interference was rated by participants as none (eg, no pain impact on activities), mild (eg, reduced productivity at work or at home), moderate (eg, frequent absences from work, inability to care for family, or inability to do leisure activities), or enormous (eg, inability to work, inability to care for myself, difficulty sleeping, or difficulty walking).

Current level of motivation and confidence to manage pain were also measured using a 0-10 numeric rating scale with anchors at 0 (not at all motivated or not at all confident) and 10 (very motivated or very confident).

General Functioning Outcomes

Chronic conditions are frequently associated with lower life and health quality ratings. In this study, quality of health was measured using 1 item from the Centers for Disease Control and Prevention Health-Related Quality of Life 4-Item Measure (CDC HRQOL-4) [90]; quality of life was measured using an adapted version of the same item. The items “Would you say that in general your health is...” and “Would you say that in general your quality of life is...” were provided with response options of poor, fair, good, very good, or excellent.

Stress was measured at each time point with a single item: “How much stress do you feel in a typical day?” Responses were provided on a 4-point scale anchored with the following descriptions: none, not much, some, and a lot.

Depression symptoms were measured at baseline using the 10-item Center for Epidemiologic Studies Depression Scale (CES-D), Boston Form [99]. We used the established cutoff value of 4 or more to indicate a positive depression screen [100].

Statistical Analyses

Statistical analyses were conducted using SPSS for Windows version 18.0 (SPSS Inc, Chicago, IL, USA). General linear model repeated measures (for continuous variables) or Cochran Q tests (for binary variables) were used to examine baseline, 1-, and 6-month outcomes. Post hoc pairwise tests were conducted by paired sample *t* tests (for continuous variables) or McNemar tests (for binary variables). Independent sample *t* tests (for continuous variables) or chi-square tests (for categorical variables) were applied to examine the between-group differences on baseline data of (1) participants who improved at 1 or 6 months on pain ratings with participants who did not, and (2) participants who completed the 1- and 6-month evaluation with participants who did not. Any *P* value <.05 was considered statistically significant, unless otherwise noted. Each of the pairwise comparisons was tested at a significance level of .017 (.05/3). Effect sizes were reported, when applicable, using Cohen's *d*, and odds ratio (95% CI).

Figure 1. Welcome page of the Web-based pain management program.

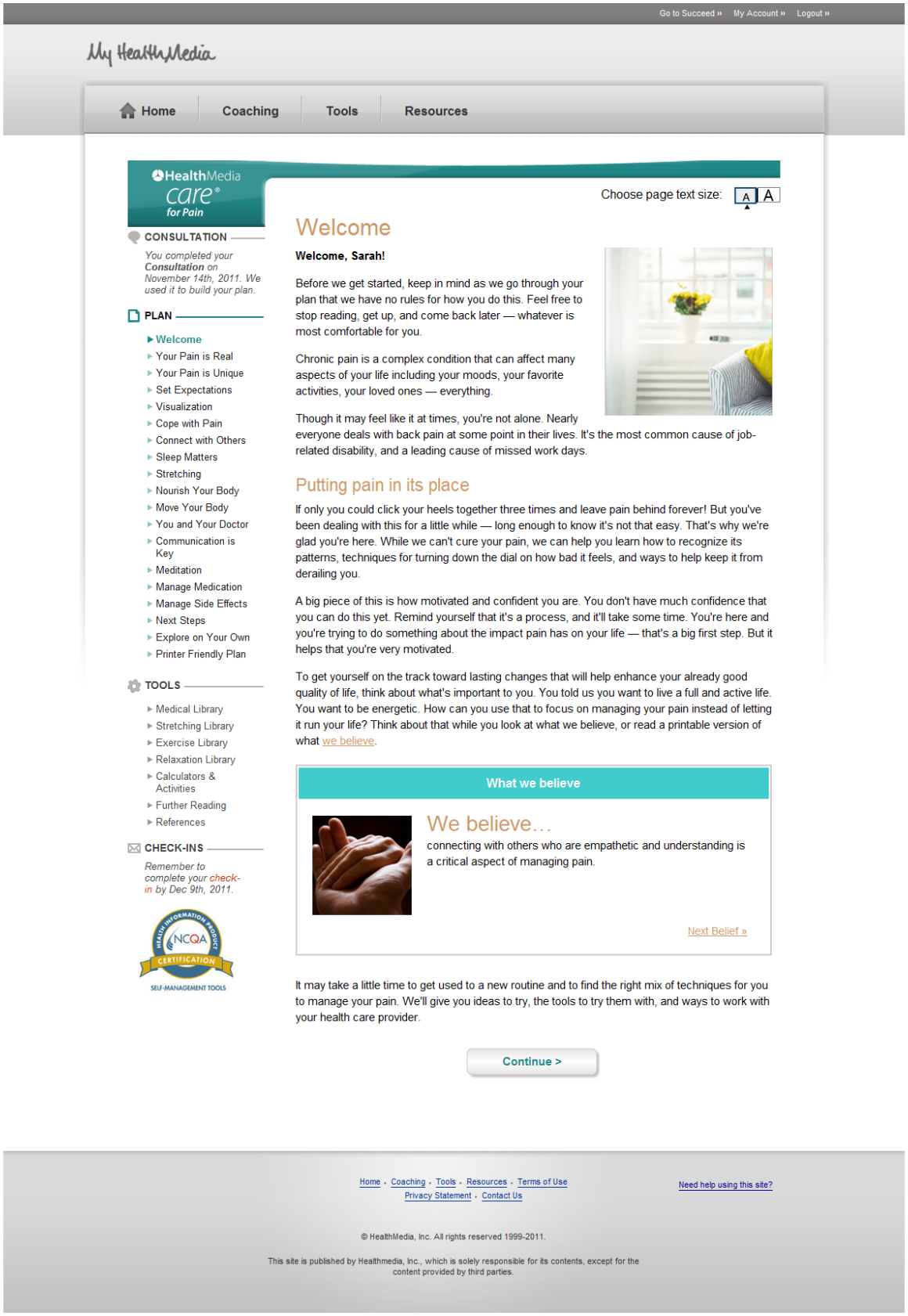
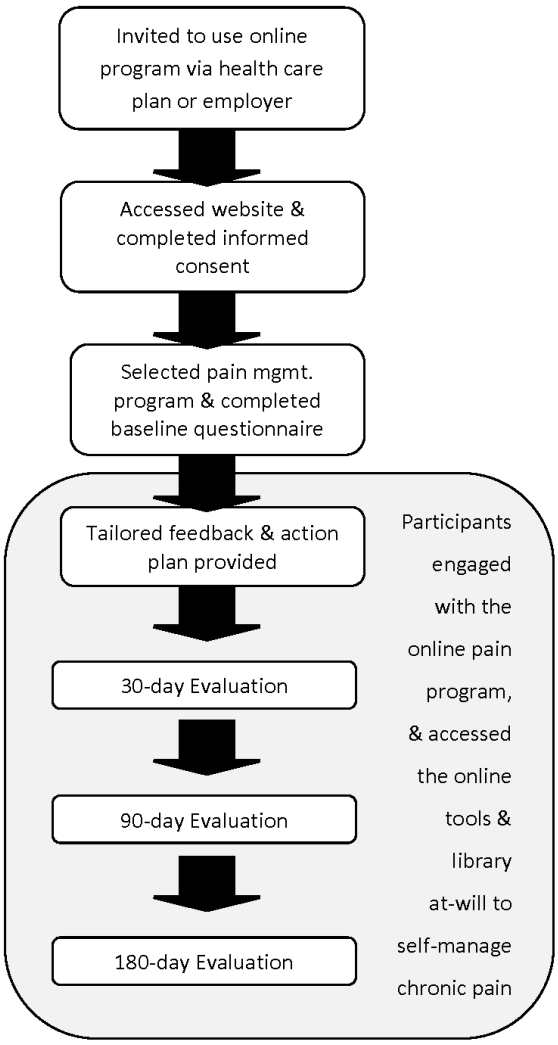


Figure 2. Visualization page of the Web-based pain management program.

Figure 3. Program architecture and study design.



Results

Sample Description

Descriptive characteristics of the sample are provided here to aid in the interpretation of the data (eg, extent of generalizability). Participants resided in 38 of the 50 United States. The average participant age was 56 years (SD 12.83). Data on marital status and education level were not collected in this study. At baseline, participants had an average pain intensity rating of 5.30 out of 10 (SD 2.46), and an average

unpleasantness rating of 5.43 out of 10 (SD 2.52) in which higher numbers reflect greater pain. Participants were motivated to manage their pain (mean 8.58, SD 1.80), and moderately confident that they could manage their pain (mean 6.94, SD 2.50) on the same 0-10 scale (see Table 1).

At study enrollment, 82.6% (285/345) of participants reported taking medication to relieve their pain, and 54.5% (351/644) of participants used medication every day or nearly every day in the past month. At baseline, participants had an average depression score of 2.70 (SD 2.45) out of a possible 10 points on the CES-D Boston Form [79]. Information on self-reported pain treatments and treatment effectiveness is reported in Table 2.

Evaluation Submitter and Nonsubmitter Comparisons

We compared program participants who completed the 1- and 6-month evaluations with participants who did not submit evaluations. Evaluation submitters and nonsubmitters did not differ in baseline demographic characteristics (ie, gender, ethnicity), duration of pain condition, quality of life and quality of health ratings, stress level, depression symptoms, the interference of pain in work and life, level of social support for pain, pain medication adherence, health care provider visits, emergency room visits, hospital admissions, or participation in psychological counseling or therapy for pain. Baseline pain intensity and pain unpleasantness ratings also did not differ between groups.

Some other differences between evaluation submitters and nonsubmitters were identified. Evaluation submitters were, on average, nearly 7 years older than nonsubmitters (mean age 56.2 vs 49.4, P<.001, d=0.53). Evaluation submitters were also less likely to work outside the home (P<.001, OR 0.54, 95% CI 0.45-0.63). Evaluation submitters were more motivated to manage their pain at baseline, (P<.001, d=0.21) and more confident that they could do so (P=.001, d=0.13). Evaluation submitters also rated their overall quality of sleep higher than noncompleters (P<.001, d=0.23). Finally, evaluation submitters were more likely than nonsubmitters to see their primary care physician (P=.02, OR 1.23, 95% CI 1.04-1.46), rheumatologist (P=.01, OR 1.40, 95% CI 1.07-1.82), or physical therapist (P=.02, OR 1.31, 95% CI 1.05-1.63) for pain, but less likely to see a chiropractor (P=.004, OR 0.69, 95% CI 0.53-0.89) for pain management. They were also more likely to take medication daily to relieve pain (P=.02, OR 1.21, 95% CI 1.03-1.41).

Program Usability

Participants indicated their satisfaction with and their perceptions of the usability of the online pain management program. At 1-month postenrollment, 82.6% (523/633) rated the program good or better given choices of poor, fair, good, very good, and excellent. Furthermore, most participants gave the program high usability ratings. Specifically, on a 5-point scale ranging from disagree (=1) to agree (=5), the percentage of participants who rated the program a 3 or better on the following items are as follows: 95.3% (602/632) read the information completely; 96.8% (609/629) found the information easy to read; 88.6% (551/622) found the information to be personally relevant; 93.8% (590/629) found the program easy to use; 90.5% (564/623) found the interactive exercises to be more helpful than simply reading a book or an article online; and 91.5% (558/610) experienced no technical difficulties while using the product.

Pain Outcomes

Participants' pain intensity ratings decreased significantly following the intervention ($F_{2,1272}$ = 142.61, P<.001). The average baseline pain intensity rating was 5.30 (SD 2.46) out of a possible 10. Mean pain intensity decreased to 4.16 (SD 2.69) at 1 month and 3.72 (SD 2.73) at 6 months. Post hoc pairwise tests indicated a significant reduction in pain intensity at 1 month compared with baseline (moderate-sized effect, d=0.69, P<.001), and 6 months compared with 1 month (small-sized effect, d=0.26, P<.001), and 6 months compared with baseline (large-sized effect, d=0.88, P<.001).

Pain unpleasantness ratings also decreased significantly following the intervention ($F_{2,1266}$ = 143.66, P<.001). The average pain unpleasantness ratings were 5.43 (SD 2.52) at baseline, 4.24 at 1 month (SD 2.81), and 3.78 at 6 months (SD 2.79). Post hoc pairwise tests indicated a significant reduction at 1 month compared with baseline (moderate-sized effect, d=0.70, P<.001), 6 months compared with 1 month (small-sized effect, d=0.26, P<.001), and 6 months compared with baseline (large-sized effect, d=0.90, P<.001).

Pain interference was rated by participants as none, mild, moderate, or enormous. At baseline, 36.8% (231/627) of participants reported that they had moderate or enormous degrees of interference in daily life secondary to their pain. The proportion of participants reporting moderate or enormous pain interference decreased significantly following the intervention (1 month: 34.0%, 213/627; 6 months: 28.9%, 181/ 627; $Q_{2,627}$= 21.14, P<.001). Post hoc pairwise tests indicate a significant reduction at 6 months compared to 1 month (P=.004), and 6 months compared to baseline (P<.001).

At baseline, participants reported that they were quite motivated to manage their pain (mean 8.58, SD 1.80). Motivation to manage pain did not change significantly following the intervention (1 month: mean 8.39, SD 2.13; 6 month: mean 8.44, SD 2.18; $F_{2,1234}$ = 2.79, P=.06).

At baseline, participants reported that they were fairly confident that they could manage their pain (mean 6.94, SD 2.50). Confidence in managing pain did not change significantly following the intervention (1 month: mean 7.15, SD 2.60; 6 month: mean 7.11, SD 2.71; $F_{2,1242}$ = 2.26, P=.11).

General Functioning Outcomes

Participants rated their quality of life as corresponding to 1 of the following categories: poor, fair, good, very good, and excellent. One-fifth (20.6%, 129/625) of participants rated their quality of life as poor or fair at baseline. The proportion of participants rating their quality of life as fair or poor decreased following the intervention ($Q_{2,625}$= 8.00, P=.02); 18.1% at 1 month (113/625), and 16.5% (103 /625) at 6 months. Post hoc pairwise tests indicated a significant reduction at 6 months compared with baseline (P=.006).

Quality of health was rated using the same categories as quality of life. At baseline, 19.7% of participants reported their quality of health was fair or poor (123/624). This did not change significantly following the intervention (1 month: 16.8%, 105/624; 6 months: 17.1%, 107/624, $Q_{2,624} = 5.26$, P=.07).

Participants rated their stress by selecting 1 of the following descriptors: none, not much, some, or a lot. At baseline, 18.9% of participants reported a lot of stress (63/334). This proportion decreased nonsignificantly over time (1 month: 16.2%, 54/334; 6 months: 16.8%, 56/334; $Q_{2,334}= 1.84$, P=.40).

Effects of Participation in Additional Online Wellness Programs

We tested to see if participation in additional online wellness programs beyond the pain program resulted in differential program outcomes. None of the group (pain program only: n=256; pain plus additional program or programs: n=389) by time effects were significant (all P>.05).

Treatment Responder Characteristics

Pain intensity and pain unpleasantness were considered primary outcomes in this study. Each participant's pain intensity and pain unpleasantness ratings were summed and divided by 2 to compute an average pain composite at baseline, 1, and 6 months. Because reductions in pain equal to or greater than 30% are generally accepted as clinically meaningful, participants whose average pain composite score at 1 or 6 months was at least 30% less than their average pain composite score at baseline were defined as treatment responders for that time point [101,102]. Those whose average pain composite did not decrease by at least 30% at 1 or 6 months were defined as nonresponders for that time point. Changes in other measures (eg, stress), although important, were not included in the responder analysis because only a subset of participants reported problems in each secondary outcome at baseline. Among those who submitted follow-up evaluations, treatment response rates were 43.7% (270/618) and 52.4% (324/618) at 1 and 6 months, respectively.

Treatment responders and nonresponders did not differ in baseline demographic characteristics (ie, gender, age, ethnicity, and people living in their household), pain duration, motivation to manage pain, type of health care providers treating their pain, pain medication adherence, or level of social support for pain. Characteristics that distinguished treatment responders from nonresponders are reported in Table 3.

Table 1. Baseline sample description (N=645).

Characteristic	%	n	N[a]
Female	69.3	447	645
Age group (years)			645
22-29	2.2	14	
30-39	8.4	54	
40-49	17.2	111	
50-59	33.5	216	
60-69	23.1	149	
70-91	15.7	101	
Race/ethnicity			641
White	78.8	505	
African American	8.4	54	
Hispanic	5.9	38	
Other	6.9	44	
Geographic region of residence			638
Northeast	9.4	60	
South/southeast	17.4	111	
Midwest	23.7	151	
West	49.5	316	
Occupation			632
Professional	18.7	118	
Clerical/admin support	21.7	137	
Not working outside home	31.5	199	
Sales/tech support/service	15.7	99	
Executive/senior manager/administration	5.9	37	
Production/operator/laborer	6.6	42	
Pain duration			253
<6 months	9.1	23	
6 months-1 year	9.9	25	
1-5 years	32.4	82	
5-10 years	20.6	52	
>10 years	28.1	71	
Pain complaints			645
Joint	38.6	249	
Back	33.8	218	
Osteoarthritis	27.0	174	
Migraine	15.8	102	
Neuropathy	15.8	102	
Positive depression screen	33.9	191	

[a]Because of changes to the program questionnaire over time, some items were not asked of all participants (eg, pain duration). The N reported indicates number of participants who responded to the item.

Table 2. Baseline self-reported pain treatments and pain management effectiveness (N=645).

Pain treatment	%	n	N
Pain medication			643
No medication	17.4	112	
Over-the-counter only	29.4	189	
Prescription only	22.4	144	
Prescription and over-the-counter	30.8	198	
Psychological counseling in the past month			623
None	92.3	575	
1-2 times	5.0	31	
3-15 times	2.7	17	
Health care providers treating their pain			645
Primary care doctor	70.1	452	
Orthopedic surgeon	14.1	91	
Rheumatologist	9.6	62	
Neurologist	8.7	56	
Chiropractor	10.1	65	
Physical therapist	14.4	93	
Pain specialist or anesthesiologist	5.1	33	
Other	16.1	104	
Pain treatment effectiveness			625
It takes away little or none of pain	17.3	108	
It takes away some of pain	73.3	458	
It takes away pain completely	9.4	59	

Table 3. Baseline characteristics distinguishing treatment responders from treatment nonresponders at 1 month and 6 months (N=645).

Characteristic	1-Month follow-up[a]			6-Month follow-up[a]		
	OR (95% CI)	Cohen's *d*	*P*	OR (95% CI)	Cohen's *d*	*P*
Pain intensity rating		–0.21	.008		–0.22	.005
Pain unpleasantness rating		–0.25	.002		–0.25	.002
Self-report back pain	0.58 (0.41, 0.82)		.002	0.42 (0.30, 0.59)		<.001
Self-report fibromyalgia	0.44 (0.25, 0.75)		.002	0.46 (0.28, 0.76)		.002
Self-report neuropathy	0.46 (0.29, 0.73)		.001	0.51 (0.33, 0.79)		.002
Self-report obesity	0.55 (0.31, 0.97)		.04	0.34 (0.19, 0.61)		<.001
Back is most painful site	0.56 (0.41, 0.78)		<.001	0.53 (0.38, 0.73)		<.001
Better overall sleep quality		0.25	.008		0.21	.02
Screen positive for depression	0.48 (0.33, 0.69)		<.001	0.47 (0.33, 0.67)		<.001
Pain causes anxiety/irritability/depression		–0.36	<.001		–0.39	<.001
Physical activity restricted by HCP	0.59 (0.41, 0.86)		.006	0.58 (0.40, 0.83)		.003
Interference of pain in work and life		–0.36	<.001		–0.33	<.001
Sick days		–0.33	.001		–0.24	.05
Involved in pain-related litigation	0.60 (0.25, 1.40)		.23	0.34 (0.14, 0.82)		.01
Receiving disability compensation	0.40 (0.16, 1.01)		.05	0.34 (0.14, 0.82)		.01
Believe worsening pain indicates one's condition is worsening	0.49 (0.34, 0.72)		<.001	0.69 (0.48, 0.99)		.04
Believe pain is just a normal part of life/aging		0.31	<.001		0.18	.03
Refuse to let pain stop me from doing what i enjoy	1.44 (1.02, 2.01)		.04	1.11 (0.80, 1.55)		.52
Importance of living a full and active life		0.30	.01		0.26	.03
Importance of working to earn a living		0.17	.16		0.26	.04
Importance of being responsible for my health		0.21	.08		0.24	.04
Importance of limiting health care costs		0.06	.61		0.26	.03
Take prescription medication	0.52 (0.38, 0.72)		<.001	0.58 (0.42, 0.81)		.001
Take prescribed opioid medication	0.36 (0.24, 0.52)		<.001	0.43 (0.30, 0.62)		<.001
Have been taking medication "too long"	0.49 (0.24, 0.99)		.04	0.43 (0.22, 0.86)		.01
Believe medication is not working	0.53 (0.27, 1.07)		.07	0.47 (0.24, 0.91)		.02
Number of doctor visits		–0.25	.001		–0.12	.14
Participate in counseling or psychotherapy		–0.58	.006		0.14	.65

[a]Positive *d* values and OR <1 indicate that treatment responders endorsed the variable more often or scored higher on this variable than nonresponders. Negative *d* values and OR >1 indicate that treatment responders endorsed the variable less often or scored lower on the variable than nonresponders.

Discussion

Principal Findings

In this study, we examined the longitudinal effects of a tailored Web-based chronic pain management program on multiple dimensions of pain experience (ie, intensity, unpleasantness, and interference), motivation to manage pain, confidence in ability to manage pain, quality of life and health, and stress among US adult employees and health care plan members who self-reported chronic pain and completed 1- and 6-month follow-up evaluations. Our main findings suggest that the tailored online chronic pain management program exerts significant beneficial effects on pain intensity, pain unpleasantness, pain interference, and quality of life 6 months after program enrollment. The effects on pain intensity and unpleasantness were notably large in magnitude. Average motivation to manage pain was initially quite high (8.58/10), and did not significantly change during follow-up. Confidence in managing pain did not change significantly over the course of the study, but remained at a consistently moderate level (approximately 6.5/10). The results also suggest that most participants found the program to be user friendly and of good or better quality. Overall, our results indicate that this tailored, online, chronic pain management program is a promising, low-cost, user-friendly intervention with the advantage of virtually unlimited scalability. However, future randomized

controlled studies are necessary to ensure that the promising results of this study were because of the effects of the intervention and not the simple effects of time.

Next, we conducted tests to determine what characteristics distinguished the participants whose pain responded favorably to the intervention from those who did not experience improvement in their pain. First, we found that lower pain intensity and unpleasantness were associated with treatment response, which suggests that the intervention may be most helpful for people experiencing mild to moderate pain. Other characteristics predictive of treatment response include better baseline sleep quality, better emotional functioning, more adaptive cognitions, and a goal-oriented cognitive style. These findings suggest that treatment responders have somewhat better psychological health before treatment. This may indicate that the program works best for people with some psychological resilience. Alternatively, these findings may indicate that the program does not address co-occurring problems of mood, anxiety, stress, emotion regulation, or sleep adequately, leading individuals with these problems to benefit less from treatment. Thus, the effectiveness of the online pain management program might be improved by increasing tailoring and content to address these potential shortcomings. Similarly, treatment responders appeared to be physically healthier (fewer fibromyalgia, spinal, or neuropathic complaints, less obesity and chronic disease, fewer activity limitations), use less medications, and use fewer health services. Overall, this pattern suggests that the Web-based chronic pain management intervention may be most effective for those individuals with mild or moderate chronic pain that have better overall psychological and physical health at the time they initiate the program. Individuals with more numerous comorbidities or certain pain conditions (eg, spinal, neuropathic, or fibromyalgia pain) may require a more intensive, disease-specific, face-to-face intervention to achieve optimal outcomes. Alternatively, Web-based pain management interventions could benefit from program development to tailor the program content more deeply to address the needs of these individuals.

Broader Implications

Ease of access may be especially important for people with chronic pain when pain flares unexpectedly and immediate access to resources that promote adaptive pain coping strategies (eg, relaxation audio clips, imagery, distracting techniques) can provide relief. Additionally, the convenience of using Internet-based pain management from home can lead to greater access to the program tools, reaching individuals with pain that might not otherwise seek out treatment because of disability, physical limitations, lack of transportation, distance, or time [89].

As a result of the easy access to Internet-based pain information, there is a virtually unlimited amount of online information available to individuals experiencing chronic pain. The downside to this is that the sheer amount of available information can be overwhelming, and the validity of this information is often specious. Tailored, online, evidence-based pain management programs identify the unique needs of individual chronic pain clients, match these needs with key information and evidence-based interventions, and deliver them in manageable amounts [37,41,91]. Treatments can be tailored on the varied presentations of chronic pain patients: diagnoses (eg, osteoarthritis, headaches, back pain), personality, motivation to manage pain, comorbid symptoms (eg, depression, insomnia, obesity), preferences of the individual, demographics, and more. As evidence accumulates that tailored online interventions can effectively manage pain and other health conditions, we may find that they are more cost-effective, acceptable, convenient, and sustainable than many traditional clinic-based interventions. Web-based pain management programs may also be cost-effective first-line interventions in stepped-care models of pain management, or targeted toward those healthier patients with less severe manifestations of chronic pain, such as the treatment responders in this study.

Study Strengths

This study has several noteworthy strengths. First, the participant sample was large and diverse with regard to geographic location, occupation, race/ethnicity, and age. This sample offers greater generalizability of results to typical chronic pain sufferers than results derived from undergraduate psychology student convenience samples that are ubiquitous in the psychology literature. Next, the nature of the online pain management program allows us to conclude that the intervention was implemented with nearly perfect consistency. Third, the naturalistic design and longitudinal follow-up support the external validity and generalizability of the study in comparison with tightly controlled laboratory-based studies. Finally, we reported effect sizes and odds ratios to enable the reader to readily assess the clinical significance/magnitude of change associated with our outcomes, and easily compare these with other pain management study results.

Study Limitations

This study also has some limitations that should be made explicit. First, because this was an uncontrolled study, we cannot be certain that the findings were not the result of regression to the mean, or effects of time rather than the intervention itself. Thus, these results should be interpreted as promising evidence, but certainly not conclusive. Second, because participants in this study self-selected the online pain management program, we cannot determine if the pattern of effects we observed generalize to others who would not elect to participate in this program. However, given that pain patients nearly always self-select their own pain management methods from available options (eg, medications, physical therapy, chiropractic manipulation, surgery, rest), this design has ecological validity. Third, limitations in the available data preclude examination of the extent to which participants interacted with the program. Although the program is designed to be self-paced and accessed at-will by the individual, it would have been desirable to test dose–response relationships. Fourth, all the outcomes were based upon brief self-report data and monomethod measurement can be subject to reporting biases (eg, socially desirable responding). Objective measures of pain disability (eg, functional tests) and/or collateral reports of pain behavior would have addressed this problem, but were not logistically possible. Longer, more commonly used outcome measures with

well-established validity evidence would also have improved the quality of this study. However, participant burden was the impetus for selecting very brief measures in this naturalistic study. Because participants were not compensated for the significant time it takes to complete lengthy measures (as is the norm in laboratory-based research) the pragmatic decision was made to design the programs with the very brief measures of outcome.

Future Directions

First and foremost, well-powered randomized controlled trials of tailored Web-based pain management programs are needed to determine time and self-selection effects versus intervention effects on pain and psychosocial outcomes. Future studies should also make use of well-validated measures of pain outcomes [97] and take necessary steps (eg, participant compensation for time) to encourage completion of measures.

Next, future researchers should also measure change in theoretically relevant proximal variables (eg, pain cognitions, use of exercise/relaxation/visualization for pain management) to test mechanisms of the effects of tailored Web-based pain management programs. Once efficacy is established, there will be a need for dismantling studies to examine whether there are differential effects of tailoring program content on certain variables (eg, gender, stage of change, job type) versus others. Finally, empirical evidence showing which variables exert the greatest tailoring effects (vs those with weak or no effects) on outcomes should guide development of future interventions and improvement of those currently in existence.

Conflicts of Interest

Chun Wang is employed as a statistician at Wellness & Prevention, Inc. Dana Nevedal, Lindsay Oberleitner, Steven Schwartz, and Amy Williams are former Wellness & Prevention, Inc behavioral scientists.

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Abbreviations

CBT: cognitive behavioral therapy
TENS: transcutaneous electrical nerve stimulation

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Original Paper

A Field Test of Web-Based Screening for Dry Eye Disease to Enhance Awareness of Eye Problems Among General Internet Users: A Latent Strategy to Promote Health

Motoko Kawashima[1], MD, PhD; Miki Uchino[1,2], MD, PhD; Takashi Kawazoe[3], BSN; Masaaki Kamiyashiki[3], BSN; Kokoro Sano[1], BSN; Kazuo Tsubota[1], MD, PhD

[1]Department of Ophthalomolgy, Keio University School of Medicine, Shinjuku-ku, Japan

[2]Ryogoku Eye Clinic, Sumida-ku, Japan

[3]Carepro Inc, Shibuya-ku, Japan

Corresponding Author:
Motoko Kawashima, MD, PhD
Department of Ophthalomolgy
Keio University School of Medicine
35 Shinanomachi
Shinjuku-ku, 1608582
Japan
Phone: 81 3 3353 1211
Fax: 81 3 5363 3045
Email: motoko326@gmail.com

Abstract

Background: A Web-based self-check system including a brief questionnaire would seem to be a suitable tool for rapid disease screening.

Objective: The purpose of this preliminary study was to test a Web-based self-screening questionnaire for drawing attention to dry eye disease among general Internet users and identifying those with a higher risk of developing the condition.

Methods: A survey website was launched and used to recruit participants from general Internet users. In the first phase, volunteers were asked to complete a Web-based self-screening questionnaire containing 12 questions on dry eye symptoms. The second phase focused on the respondents who reported five or more dry eye symptoms and expressed their intention to seek medical attention. These participants performed the Schirmer test, for evaluating tear production, and completed a paper-based lifestyle questionnaire to provide relevant background data.

Results: Of the 1689 visitors to the website, 980 (58.0%) volunteers completed the Web-based self-screening questionnaire. Among these, 355 (36.2%) respondents reported five or more dry eye symptoms. Then, 99 (27.9%) of the symptomatic participants performed the Schirmer test and completed the paper-based lifestyle questionnaire. Out of these, 32 (32.2%) had abnormal tear production (≤5 mm).

Conclusions: The proposed Web-based self-screening questionnaire seems to be a promising tool for raising awareness of dry eye disease among general Internet users and identifying those with a higher risk of developing the condition, although further research is needed to validate its effectiveness.

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KEYWORDS

dry eye; Schirmer test; tears; Internet; questionnaire; screening; Web; health care

Introduction

Dry eye syndrome (International Classification of Diseases, 10th revision, clinical modification code H04.1) is a highly prevalent chronic ocular-surface disease [1-14]. According to the International Dry Eye Workshop report, it can be defined as a multifactorial disease of the tears and ocular surface that results in symptoms of discomfort, visual disturbance, and tear-film instability with potential damage to the ocular surface [1]. The most common symptoms are dry eye sensation, foreign

body sensation, photophobia, and red eye. These symptoms can be debilitating and cause difficulties in visual functioning and other tasks requiring sustained visual concentration [15-23]. They can also have a negative impact on physical, social, and psychologic health and the overall sense of well-being [15-23].

The increasing prevalence of dry eye disease worldwide is an important public health problem, especially in developed countries with advanced information technology and those with an aging population [1-14]. In Japan, the incidence rates of dry eye disease are almost 22% and are over 10% in female and male computer users, respectively, implying that the country has more than 24 million affected individuals [2]. One reason for the rapid rise in the number of cases of dry eye disease over the last few years is thought to be prolonged visual display terminal (VDT) exposure because of increased computer use. VDT exposure is also becoming common in the general population because of the widespread use of mobile technology and portable information terminals, especially smartphones, among all age groups. The number of Internet users worldwide has doubled in the past 5 years. Japan had approximately 94 million Internet users in 2010, representing 78.2% of the Japanese population [24].

These changes in work and leisure activities have been accompanied by an increase in the number of reported symptoms of several health problems associated with VDT use. Eye problems, constituting a widespread but largely unknown epidemic among computer users, are the most common symptoms [25-30]. Dry eye is a common cause of, or is at least associated with, greater asthenopia symptoms among VDT workers [31-35]. Clinical observations have long suggested that VDT users may be at increased risk of developing dry eye disease [2,15,36], and epidemiologic data evidence the magnitude of the problem [36-38]. In a recent clinical study, the prevalence rate of definite dry eye disease was 8.0% and 18.7% in male and female VDT users, respectively, and that of probable dry eye disease was 52.1% and 57.8%, respectively [3], supporting the view that VDT exposure is a significant risk factor of this condition.

A clinical diagnosis of dry eye disease requires both objective findings from eye examinations and a subjective report of dry eye symptoms. In several studies, a subjective report of the symptoms was the sole criterion for the diagnosis of dry eye disease [2,4-10]; this diagnostic basis was considered appropriate because the condition rarely progresses to the stage of ocular discomfort without symptom presentation [1,20]. However, general Internet and heavy VDT users may be unaware of dry eye disease despite the presence of symptoms. Another problem is that many individuals with dry eye disease do not receive medical intervention [21,22].

In this regard, a Web-based questionnaire targeting VDT users as a high-risk population would be effective. The World Wide Web has enabled the increased use of questionnaires to collect data for various research surveys [39-41]. This tool can be optimized to promote awareness of dry eye disease. However, until now, Web-based self-screening of dry eye disease has not been attempted.

The purpose of this study was to test a Web-based self-screening questionnaire for drawing attention to dry eye disease among general Internet users and identifying those with a higher risk of developing the condition.

Methods

Study Design

Phases

This preliminary study consisted of two phases: the first phase involved a Web-based survey with a self-screening questionnaire on dry eye symptoms, and the second phase involved measurement of tear secretion and a physical survey with a paper-based lifestyle questionnaire. The volunteers were free to participate in either the first phase only or both phases of the study. The study duration was from September 1 to December 29, 2011.

Ethical Statement

The research was conducted in accordance with the ethical principles of the Declaration of Helsinki and was based on a protocol approved by the Institutional Review Board of Ryogoku Eye Clinic. Written informed consent, including approval for the use of information collected during the study, was obtained from the participants through the survey website.

First Phase

Survey Website

In this phase, an informative survey website was first launched. Then, location-specific advertising banners were placed on different websites and search engines by employing Google AdSense to recruit a cross-section of prospective subjects from general Internet users. Because the second phase of the study was to be conducted in Yokohama, Kanagawa Prefecture, volunteers with easy access to Yokohama were preferred. Study information was provided via tweets and posts on Facebook. Every visit to the survey website was recorded. Underage visitors and those receiving medical treatment for any eye problems were excluded. Registration was free, and the volunteers received no compensation for participation.

Web-Based Self-Screening Questionnaire

The applied Web-based self-screening questionnaire was a modified version of the questionnaire used by Toda et al [31], which is generally used for clinical diagnosis of dry eye disease in Japan. The questionnaire consisted of 12 questions regarding dry eye symptoms, and only “yes” or “no” responses via checkboxes were allowed (Figure 1). Respondents with five or more dry eye symptoms were considered to have subjective dry eye symptomatology.

All the respondents were requested to provide an email address voluntarily. Those with subjective dry eye symptomatology were encouraged to participate in further tests and asked about their intention to see a doctor for definitive diagnosis, to assess whether the online self-check system could motivate Internet users to seek medical attention and because they were considered to have a higher risk of dry eye disease.

The following data were also collected: number of visitors to the website, number of respondents to the questionnaire, and descriptive data of the participants (age group, gender, and symptom distribution).

Second Phase

Overview

The second phase of the study was directed at the respondents with subjective dry eye symptomatology, who gave their contact information and consent for the study. The research site was a health center in Yokohama, and only nurses were present.

Schirmer Test

Tear production was measured by using the Schirmer test [42], which is the most common objective diagnostic test for dry eye disease. The participants of this phase performed the test without anesthesia (Schirmer method I) by themselves under the nurses' instructions, as is allowed in Japan. The procedure was approved by the local public health center. The participants with tear production of ≤5 mm were advised to see a doctor (at any clinic of their choice).

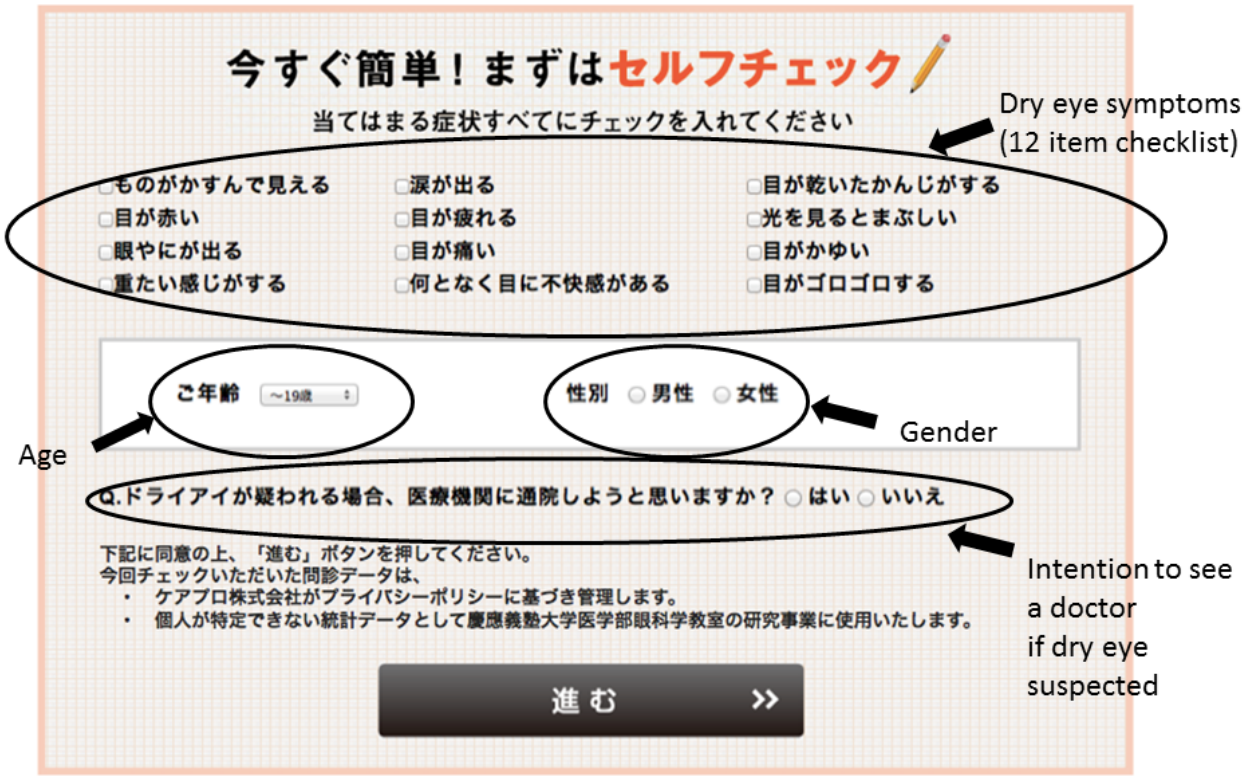
Paper-Based Lifestyle Questionnaire

This questionnaire included items on the durations of VDT and contact lens use, because these are the major factors contributing to dry eye disease [1-3,36]. To collect relevant background data, health-related physical activity was also examined by using the International Physical Activity Questionnaire (IPAQ) [43,44]. Each participant's physical activity level in metabolic equivalent (MET) per week (MET, min/week) was then calculated.

Statistical Analysis

Data were analyzed by using JMP statistical discovery software version 9.0 (SAS Institute). Independent-sample *t* tests were used to determine whether the parametric differences between those with and without an intention to seek a medical opinion for suspected dry eye disease, as well as between those with >5 mm (normal) and ≤5 mm (abnormal) tear production, were significant. $P<.05$ was considered significant.

Figure 1. Web-based self-screening questionnaire.



Results

Characteristics of the First-Phase Participants

Figure 2 depicts the flow diagram of the study. Of the 1689 visitors to the survey website, 980 (58.0%) volunteers, including 440 men (44.9%), 539 women (55.1%), and one person of unidentified gender, completed the Web-based self-screening questionnaire. Their demographic data are summarized in Table 1. Ocular fatigue (61.4%), dry eye sensation (40.7%), and sensitivity to bright light (31.3%) were the major symptoms.

Of the 979 gender-identified respondents, 355 participants had subjective dry eye symptomatology. The symptoms were

significantly more common among women than among men (226 female participants, 63.7%, *P*=.0001, Fisher's exact test). Ninety-two participants (25.9%) did not intend to seek medical attention for the symptoms (Table 2). Men were significantly less inclined to visit a clinic for definitive diagnosis (*P*=.006, Fisher's exact test). Further, significantly fewer participants in their 20s intended to see a doctor (*P*<.001, chi-square test).

Table 1. Characteristics of the 980 first-phase participants.

Characteristic	Category	Total, n (%)
Gender		
	Male	440 (44.9)
	Female	539 (55.1)
	Unidentified	1
Age group, years		
	20–29	446 (45.5)
	30–39	227 (23.2)
	40–49	158 (16.1)
	50–59	73 (7.4)
	>60	76 (7.8)
Dry eye symptom		
	Ocular fatigue	602 (61.4)
	Discharge	296 (30.2)
	Foreign body sensation	227 (23.2)
	Heavy sensation	213 (21.7)
	Dry sensation	399 (40.7)
	Uncomfortable sensation	271 (27.7)
	Excess tearing	166 (16.9)
	Blurred vision	296 (30.2)
	Itching	252 (25.7)
	Sensitivity to bright light	307 (31.3)
	Redness	198 (20.2)
	Pain	189 (19.3)

Table 2. Characteristics of the 979 gender-identified respondents[a].

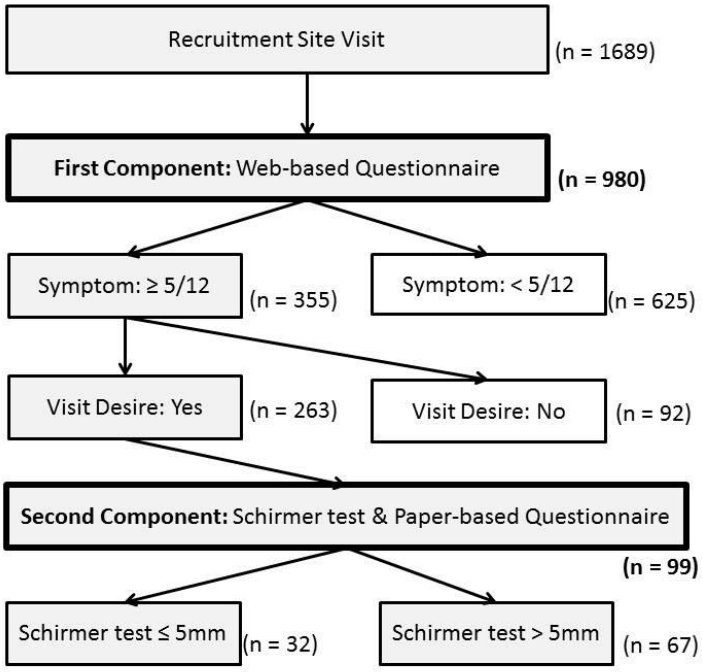
Characteristic	Category	"Yes" response, n (%)	"No" response, n (%)	*P*
Number of dry eye symptoms				
	<5	428 (68.6)	196 (31.4)	.080[b]
	≥5	263 (74.1)	92 (25.9)	
Gender				
	Male	291 (66.1)	149 (33.9)	.006[b]
	Female	400 (74.2)	139 (25.8)	
Age group, years				
	20–29	291 (65.4)	154 (34.6)	.004[c]
	30–39	160 (70.5)	67 (29.5)	
	40–49	120 (75.9)	38 (24.1)	
	50–59	60 (82.2)	13 (17.8)	
	>60	60 (78.9	16 (21.1)	

[a]One of the 980 respondents did not provide information about gender.

[b]Fisher's exact test.

[c]Chi-square test.

Figure 2. Flow diagram of participants.



Characteristics of the Second-Phase Participants

Of the 355 participants with subjective dry eye symptomatology, 99 (27.9%) participants, including 24 men (24%) and 75 women (76%), performed the Schirmer test and answered the paper-based lifestyle questionnaire. Most of these participants were healthy: only 19.2% had a systemic disease. Contact lenses were used by 40.4%, and 10.1% had a smoking history (Table 3).

Thirty-two participants had tear production of ≤5 mm (Table 4). No significant differences were noted in the duration of VDT use (P=.82, Wilcoxon rank-sum test), use of contact lenses (P=.67, Fisher's exact test), duration of contact lens use (P=.98, t test), and smoking history (P=.49, Fisher's exact test) between the >5 mm and ≤5 mm tear production groups. A significant difference was found only in exercise habits: a lower level of physical activity was significantly associated with a lower value in the Schirmer test (P=.02, Wilcoxon rank-sum test).

Table 3. Characteristics of the 99 second-phase participants.

Characteristic	Category	Total, n (%)
Gender		
	Male	24 (24)
	Female	75 (76)
Age group, years		
	20–29	29 (29.3)
	30–39	25 (25.2)
	40–49	14 (14.1)
	50–59	15 (15.2)
	>60	16 (16.2)
Dry eye symptom		
	Ocular fatigue	90 (90.9)
	Discharge	46 (46.5)
	Foreign body sensation	43 (43.4)
	Heavy sensation	52 (52.5)
	Dry sensation	66 (66.7)
	Uncomfortable sensation	66 (66.7)
	Excess tearing	21 (21.2)
	Blurred vision	53 (53.5)
	Itching	40 (41.7)
	Sensitivity to bright light	37 (37.4)
	Redness	38 (38.4)
	Pain	33 (33.3)
Related lifestyle habits		
	Duration of VDT use, mean hours (SD)	5.8 (3.0)
	Contact lens use	40 (40.4)
	Duration of contact lens use, mean hours (SD)	12.6 (3.2)
	Smoking	10 (10.1)
	Systemic disease	19 (19.2)

Table 4. Comparison of the groups with >5 mm (normal) and ≤5 mm (abnormal) tear production.

Characteristic	Category	>5 mm, n (%)	≤5 mm, n (%)	*P*
Gender				
	Male	18 (75.0)	6 (25.0)	.458[a]
	Female	49 (65.3)	26 (34.7)	
Age group, years				
	20–29	25 (86.2)	4 (13.8)	.022[b]
	30–39	18 (72.0)	7 (28.0)	
	40–49	6 (42.9)	8 (57.1)	
	50–59	8 (53.3)	7 (46.7)	
	>60	10 (62.5)	6 (37.5)	
Duration of VDT use, mean hours (SD)		5.9 (2.9)	5.9 (3.2)	.821[c]
Contact lens use		26 (38.8)	14 (43.8)	.667[a]
Duration of contact lens use, mean hours (SD)		12.6 (3.5)	12.6 (2.7)	.978[d]
Smoking		8 (11.2)	2 (6.3)	.493[a]
Systemic disease		10 (14.9)	9 (28.2)	.171[a]

[a]Fisher's exact test.

[b]Chi-square test.

[c]Wilcoxon rank-sum test.

[d]*t* test.

Discussion

Principal Results

In this study, a Web-based self-screening questionnaire was used to draw attention to dry eye disease among general Internet users and identify those at higher risk. Of the 1689 visitors to the survey website, 58.0% (980/1689) completed the first phase of the study, 36.2% (355/980) had five or more dry eye symptoms, 27.9% (99/355) completed the second phase of the study, and 32.3% (32/99) had tear production of ≤5 mm. This self-screening tool therefore identified a few individuals with probable dry eye disease. We speculate that a high number of general Internet users have latent dry eye symptomatology.

Comparison With Previous Research

In the first phase of this study, 63.7% (226/355) of the female participants reported five or more dry eye symptoms, supporting previous conclusions that dry eye disease is more common in women [1-3,5-7,36].

Overall, the participants in phase 2 were generally healthy and health conscious, with a low percentage of smokers and good reported dietary habits (data not shown). A lower level of physical activity was significantly associated with a lower value in the Schirmer test. Notably, 25.9% of the 355 participants who had five or more dry eye symptoms, especially men and people in their 20s, did not intend to see a doctor. The self-screening questionnaire may have slightly improved their health consciousness but was not sufficient to persuade them to seek medical care. Therefore, only some VDT users may be motivated enough to visit a doctor despite having symptoms. Ophthalmologists should promote awareness of dry eye disease more proactively, and the public should be educated about the condition for early detection and intervention.

Limitations and Future Research

First, because the participants were recruited from general Internet users in a limited target area, a considerable part of the high-risk population was excluded. The recruitment method would have also introduced selection bias. Second, the participants with fewer than five dry eye symptoms were excluded from the physical phase of the study. Therefore, parametric differences between these participants and the participants with subjective dry eye symptomatology were not analyzed. Third, the second-phase results were based on the Schirmer test, which measures tear production; therefore, the evaporative aspects of dry eye disease were overlooked. Finally, the Web-based self-screening questionnaire has not yet been validated; the validation process is now underway under the supervision of the Japan Dry Eye Research Society.

Future research should include both biologic measures (break-up time and fluorescein staining) and the Schirmer test to diagnose dry eye disease. In addition, a normal control group and general Internet users in a wider geographic area should be included. Moreover, the self-screening system needs to be improved. As the next research step, the Web-based self-screening questionnaire should be optimized and validated to ensure its

effectiveness in increasing awareness of dry eye disease especially among VDT users.

Conclusion

The proposed Web-based self-screening questionnaire seems to be a promising tool to raise awareness of dry eye disease among general Internet users and identify those with a higher risk of developing the condition. The factors that encourage people with probable dry eye symptomatology to seek medical help are yet to be identified. Further research is required to provide sufficient information on the disease and diagnostic tests, determine symptom severity via a validated self-screening tool, and introduce improved diagnostic measures.

Conflicts of Interest

The survey website and health center used in this study were organized by Carepro Inc. T Kawazoe is the Managing Director of this company, and M Kamiyashiki is an employee.

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Abbreviations

IPAQ: International Physical Activity Questionnaire
MET: metabolic equivalent
VDT: visual display terminal

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Original Paper

Chinese My Trauma Recovery, A Web-Based Intervention for Traumatized Persons in Two Parallel Samples: Randomized Controlled Trial

Zhiyun Wang[1,2], PhD; Jianping Wang[3], PhD, MD; Andreas Maercker[2], PhD, MD

[1]Department of Psychology, School of Philosophy, Wuhan University, Wuhan, China

[2]Department of Psychology, University of Zurich, Zurich, Switzerland

[3]School of Psychology, Beijing Normal University, Beijing, China

Corresponding Author:
Jianping Wang, PhD, MD
School of Psychology
Beijing Normal University
Hou Zhulou 1514
No. 19, XinJieKouWai Street, HaiDian District
Beijing, 100875
China
Phone: 86 10 5880 9004
Fax: 86 10 5880 0519
Email: wjphh@bnu.edu.cn

Abstract

Background: Guided self-help interventions for PTSD (post-traumatic stress disorder) are a promising tool for the dissemination of contemporary psychological treatment.

Objective: This study investigated the efficacy of the Chinese version of the My Trauma Recovery (CMTR) website.

Methods: In an urban context, 90 survivors of different trauma types were recruited via Internet advertisements and allocated to a randomized controlled trial (RCT) with a waiting list control condition. In addition, in a rural context, 93 survivors mainly of the 2008 Sichuan earthquake were recruited in-person for a parallel RCT in which the website intervention was conducted in a counseling center and guided by volunteers. Assessment was completed online on a professional Chinese survey website. The primary outcome measure was the Post-traumatic Diagnostic Scale (PDS); secondary outcome measures were Symptom Checklist 90-Depression (SCL-D), Trauma Coping Self-Efficacy Scale (CSE), Post-traumatic Cognitive Changes (PCC), and Social Functioning Impairment (SFI) questionnaires adopted from the My Trauma Recovery website.

Results: For the urban sample, findings indicated a significant group×time interaction in post-traumatic symptom severity ($F_{1,88}$=7.65, P=.007). CMTR reduced post-traumatic symptoms significantly with high effect size after one month of treatment ($F_{1,45}$=15.13, Cohen's d=0.81, P<.001) and the reduction was sustained over a 3-month follow-up ($F_{1,45}$=17.29, Cohen's d=0.87, P<.001). In the rural sample, the group×time interaction was also significant in post-traumatic symptom severity ($F_{1,91}$=5.35, P=.02). Post-traumatic symptoms decreased significantly after treatment ($F_{1,48}$=43.97, Cohen's d=1.34, P<.001) and during the follow-up period ($F_{1,48}$=24.22, Cohen's d=0.99, P<.001). Additional outcome measures (post-traumatic cognitive changes, depression) indicated a range of positive effects, in particular in the urban sample (group×time interactions: $F_{1,88}$=5.32-8.37, all Ps<.03), contributing to the positive evidence for self-help interventions. Differences in the effects in the two RCTs are exploratorily explained by sociodemographic, motivational, and setting feature differences between the two samples.

Conclusions: These findings give support for the short-term efficacy of CMTR in the two Chinese populations and contribute to the literature that self-help Web-based programs can be used to provide mental health help for traumatized persons.

Trial Registration: Australia New Zealand Clinical Trials Registry (ANZCTR): ACTRN12611000951954; https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?ACTRN=12611000951954 (Archived by WebCite at http://www.webcitation.org/6G7WyNODk).

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KEYWORDS

Web-based; stress disorders; traumatic; randomized controlled trial; self-help

Introduction

Post-traumatic stress disorder (PTSD) is a common mental disorder after trauma. Although suffering from severe distress, many people with PTSD fail to ask for help from mental health professionals, especially in rural areas where people have more difficulties accessing traditional mental health services due to cost, time, geographic constraints, and stigmatization [1-2]. In recent years, the Internet has been adopted as a valuable tool to deliver mental health services to large populations [3-4]. Different Internet-based intervention programs have been developed to help people recover from PTSD [5]. Among them, some provide self-help Web-based interventions for users without support from therapists, like the programs examined by Hirai and Clum [6] and Benight, Ruzek, and Waldrep [7]. Other programs offer interventions for people with PTSD through the Internet with therapists involved to give instructions and feedback to the users, like Interapy [8-9]. These programs have been examined in American and European countries and have shown significant effects in reducing people's traumatic stress-related distress [8,10]. However, few programs have been developed for and tested in Asian populations.

Recently, PTSD has gained much attention from public and mental health professionals in China. Based on the literature, a significant proportion of people suffered from traumatic distress after traumatic events, including earthquakes, floods, and traffic accidents [11-12]. However, few people got help from mental health professionals to deal with their trauma-related problems [13]. A major obstacle to people's mental health help-seeking behavior is the lack of available professionals in China, especially in rural areas [14]. The number of qualified mental health professionals is small, even in large cities like Beijing and Shanghai [15]. Other main factors that hinder Chinese people's mental health help seeking include fear of stigmatization, lack of information on mental illnesses and psychotherapy, confidentiality, etc [15-16]. The Internet thus offers a useful way to improve mental health services for people after trauma in China.

The current study aims to build a Chinese Web-based self-guided intervention program for traumatized persons and to test its effectiveness on Chinese populations. Two modalities of application of the intervention were involved: an unsupported use with preliminary urban clientele and modified use where clients were supported technically during the intervention by volunteers in a rural area. To test the effectiveness of the Chinese My Trauma Recovery (CMTR) program, the current study adopted a randomized controlled pre-, post-, and 3-month follow-up trial design (ACTRN12611000951954) in a two-arm design (urban/unsupported vs rural/supported). It was expected that participants from the two treatment groups would show significant improvement in PTSD symptoms and general mental health compared to the respective waiting list groups. Explorative post hoc analyses compared the effect sizes of the two arms of the study (urban/unsupported vs rural/supported).

Methods

Materials

My Trauma Recovery (MTR) website is a self-help trauma intervention program based on social cognitive theory [17], which consists of six modules of social support, self-talk, relaxation, trauma triggers, unhelpful coping, and professional help [7,18]. It has been translated, as CMTR, by funding via a Swiss-Chinese collaboration between University of Zurich (A Maercker) and Beijing Normal University (J Wang). The translation work was done mainly by the first author, and the second author (and her master's students) and the third author (and his doctoral students) were involved in the back-translation work. CMTR utilizes interactive components, such as pictures, audio segments, video segments, and self-tests, to offer educational information on trauma and provide trauma coping skills practice for its users. All pictures on the CMTR website were new ones with Chinese figures; in addition, a total of 27 audio segments on the website were newly created. Due to the high costs of video, five video segments were kept in English with Chinese subtitles added to these videos. The users are encouraged to take self-tests regularly on CMTR so that they will receive a series of updated charts on their post-traumatic distress, depression symptoms, social support perceptions, and coping self-efficacy levels. An example screenshot of the CMTR website is given in Figure 1.

Figure 1. Example screenshot of the CMTR website.

Participants and Procedure

Overview

Participants were recruited through two main channels from November 2011 to August 2012 and they completed follow-up tests before the end of January 2013. This study was approved by the research ethics board at Beijing Normal University. The urban sample was reached through Internet advertisements and participants were contacted only by email during the research period. The rural sample was recruited in-person via cooperation with a counseling center in Beichuan county in Sichuan province, where a severe earthquake occurred in May 2008; they were supported by volunteers with Internet access and minimally reimbursed for their participation. We expected small effect sizes of 0.2 in the main analyses, with a sample size of 139 [19] (the sample size was limited by funding restrictions). In each sample, the participants were randomly assigned to the treatment or waiting list condition based on a computer-generated randomization list. Assessment had been computer-generated on a professional Chinese survey website (equals a blinded assessment).

The criteria for inclusion were as follows: (1) experienced at least one traumatic event according to the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV) [20] trauma criteria, (2) the latest traumatic event happened 3-60 months prior, and (3) the person reported at least two PTSD symptoms in the trauma screening questionnaire. Respondents were excluded if they had insufficient reading or auditive comprehension competency in the Chinese language, insufficient Internet access time (<360 minutes in 4 weeks), acute psychotic symptoms, or were receiving other mental health intervention.

Urban/Unsupported Sample

Research assistants put advertisements for the research program online via online bulletins, blogs, microblogs, and personal websites. They also distributed flyers with CMTR website information through private contacts at 10 university/hospital counseling centers. The advertisements recruited persons who had experienced traumatic events within the last five years, had suffered from tense distress since then, and had an interest in reducing their distress through a self-help intervention program. As shown in Figure 2, a total of 428 people responded to the advertisements, among which at least 80% were reached via online bulletins, blogs, microblogs, and personal websites. All 428 people were invited via the advertisements to fill in trauma and psychosis screening questionnaires online. Research assistants gave feedback on screening results to people who left contact information and sent a research invitation to those who were eligible for the program. When a person read the participant information and returned a signed consent form by email, he or she was accepted as a participant and his or her sequence number was used as the participant ID. According to a random numbers list, the participants were randomly allocated to one of the two groups.

All participants first completed a baseline test (Time 1) online. Those in the treatment group received a user account to start the one-month intervention on the CMTR website, while those

in the waiting list group had to wait for one month. One month later, both groups completed the post-treatment/waiting test (Time 2). The participants in the waiting list group then started treatment with their user accounts and filled out the post-treatment test (Time 3) one month later. All of the participants finished the follow-up test (Time 4) three months after the completion of the online treatment. The participants were encouraged to use the CMTR website as often as possible at the beginning of the treatment period and they decided themselves when, where, and how often to use the website during the one-month period.

Rural/Supported Sample

To recruit participants, the cooperative counseling center (Zhong Ke Bo Ai, Institute of Psychological Medicine) made research invitation phone calls to known earthquake survivors on their previously collected list. Due to lack of Internet service at home in Beichuan, all participants had to complete tests and receive online treatment in the counseling center's computer room. At the beginning, volunteers gave information about payment for participation. On average, a participant got a total pay of US$58 in kind (eg, rice, cooking oil, pot, etc), if he or she completed the research procedure. All participants were paid progressively more after each visit to the counseling center.

After a face-to-face screening, eligible participants were randomly assigned to the treatment or waiting list group. During the one-month treatment, participants visited the center every 5 days to use CMTR for at least half an hour (5 times). The post-assessment (Time 2) also took place at the center. The participants on the waiting list started the treatment after a one-month delay. Three months after the completion of online treatment, the two groups filled out a follow-up test (Time 4) at the center.

Assistant volunteers were instructed to provide support only with technical problems on the CMTR website. When participants asked for help with their mental problems or website contents, they received a brief reply that CMTR was a self-help program, they could learn to cope with their problems on the website, and they would get further information on mental health help, if needed, after Time 4.

Measures

Trauma and Psychosis Screening Questionnaires

A list of 12 traumatic event types was adopted from the MTR website. Participants chose one or more events that they had experienced recently and reported the date of the latest traumatic event. The 10-item Trauma Screening Questionnaire (TSQ) [21] was used to measure PTSD symptoms among the first 71 respondents in the urban sample and the 7-item Short Screening Scale for DSM-IV PTSD [22] was then substituted for the TSQ. This substitution was done because the 7-item Short Screening Scale has more comprehensive coverage of symptom groups with fewer items.

Five items for psychotic symptoms were taken from the German Diagnostic Interview for Psychiatric Symptoms (DIPS) [23]. The DIPS covers all affective, anxiety, and somatoform disorders based on Diagnostic and Statistical Manual of Mental Disorders, fourth edition, text revision (DSM-IV-TR) [24] and screens for psychosis. It has excellent reliability and validity values [23].

Trauma-Related Distress Questionnaires

Primary Outcome Measure / Post-Traumatic Diagnostic Scale (PDS)

This scale includes 17 PTSD symptom items assessing the frequency of trauma-related symptoms in the past month on a 4-point scale (0=not at all or only one time, 3=five or more times a week/almost always) [25]. Its Chinese version has good psychometric properties in Taiwan samples [26]. The internal consistency of the scale in this study was measured at Cronbach alpha=.92.

Secondary Outcome Measures / Symptom Checklist 90-Depression (SCL-D)

The 13-item depression subscale of SCL [27] was used to measure to what extent participants had been bothered by depressive symptoms in the past month on a 5-point scale, ranging from 0 (not at all) to 4 (extremely). Its Chinese version has been tested in various Chinese samples and shows good psychometric properties [28]. The internal consistency of the scale in this study was Cronbach alpha=.94.

Post-Traumatic Cognitive Changes (PCC)

Five items were adopted from the MTR website to indicate participants' cognitive changes (feeling guilty, worrying about bad things, feeling permanently harmed, and going crazy) after traumatic experiences. Example items are: "I now believe that the world is a very dangerous place", and "I have been permanently harmed (not considering any physical injuries sustained) by the event." A 5-point scale was used ranging from 0 (not at all) to 4 (extremely). The internal consistency of the questionnaire in this study was Cronbach alpha=.84.

Social Functioning Impairment (SFI)

Four questions were adopted from the MTR website to examine participants' functional impairment (ie, not able to complete normal responsibilities, disturbing relationships with family or friends, not able to go out and spend time with friends, not able to do other activities the person would like to be doing) after trauma experiences. Example questions are: "To what extent have your reactions to what has happened reduced your ability to complete your normal responsibilities (eg, job, school, home, childcare duties)?" and "How much have these reactions disturbed your relationships with your family or friends?" Participants answered the questions on a 5-point scale (0=not at all, 4=extremely). The internal consistency of the questionnaire in this study was Cronbach alpha=.88.

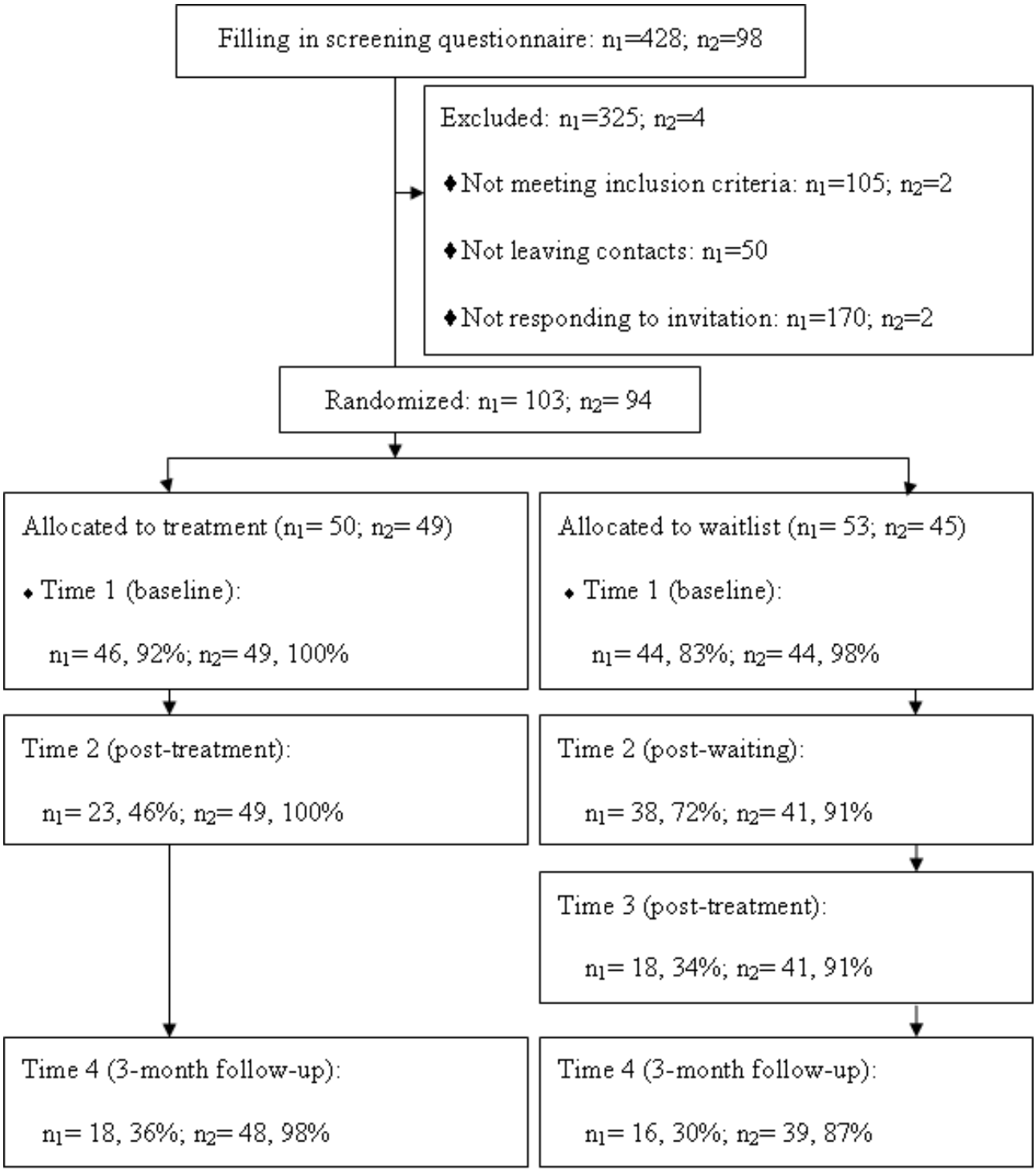
Trauma Coping Self-Efficacy Scale (CSE)

This 10-item scale is a short version of the CSE for Trauma [18]. It measures to what extent participants felt capable of coping with PTSD reactions at different assessment points. A 5-point scale was used ranging from 0 (not at all) to 4 (extremely). The internal consistency of the scale in this study was Cronbach alpha=.83.

Data Analyses

General Linear Model (GLM) was used to examine group×time interactions for all outcome measures from Time 1 to Time 2 within each sample. A series of subsequent ANOVAs (analysis of variance) was then applied. First, within each sample between-group comparisons were made for the two conditions (intervention vs waiting list) at the subsequent points in time (Time 1 to 4, as explained in Figure 2). Second, in each sample we applied within-group comparisons for time effects. Due to the high dropout rates in the urban sample, we decided to apply an intend-to-treat analysis (ITT; last value carried forward). For further analyses on dropouts in the urban sample, see Wang et al [29].

Figure 2. Participant flow in this study. n_1=number of participants in the urban sample; n_2=number of participants in the rural sample.



Results

Demographic Statistics and Traumatic Experiences

Demographic statistics of the 183 participants at Time 1 for each sample are presented in Table 1. Within each sample, the treatment group did not differ from the waiting list group in the five demographic characteristics.

In the urban sample, 51% (46/90) participants reported two or more types of traumatic events. Most frequently reported trauma types were physical assault (29/90, 32%), a sudden and unexpected death of someone close (26/90, 29%), a serious accident at work, home, or during recreational activity (15/90, 17%), and sexual assault (13/90, 14%). Among the 90 participants, 27% (24/90) experienced their latest trauma within 3 months, 60% (54/90) between 3-60 months, and 12% (11/90) longer than 60 months. In the rural sample, 86% (80/93) participants reported two or more types of trauma events. Most common trauma types were natural disasters (92/93, 99%), a sudden and unexpected death of someone close (69/93, 74%), a sudden and violent death of another person (40/93, 43%), and physical assault (40/93, 43%). Concerning the date of the latest trauma, all participants (93/93, 100%) reported 3-60 months prior.

The two samples did not differ on PDS at Time 1 (urban sample: mean 29.43, SD 10.19; rural sample: mean 30.22, SD 8.88; $F_{1,181}$=0.31, P=.58). Using the cut-offs for symptom severity rating of 0 (no rating), 1-10 (mild), 11-20 (moderate), 21-35 (moderate to severe), and 36-51 (severe) [31], 24% (22/90) of participants in the urban sample reported (1-20) mild to moderate, 44% (40/90) reported (21-35) moderate to severe, and 31% (28/90) reported (36-51) extreme symptom severity. The figures were 9% (8/93), 66% (61/93), and 26% (24/93) for the rural sample, respectively.

As shown in Figure 1, 36% (18/50) of participants in the treatment group and 30% (16/53) of participants in the waiting list group completed all measurements in the urban sample. The figures were 98% (48/49) and 87% (39/45) in the rural sample, respectively. Within each sample, the completers did not differ from the non-completers in any of the five demographic characteristics. One-way ANOVAs showed no significant difference between the completers and the non-completers in PDS, PCC, SFI, SCL-D, and CSE within each sample (for the urban sample: $F_{1,88}$=0.08-1.45; all Ps>.23; for the rural sample: $F_{1,91}$=0.18-2.06; all Ps>.15).

Treatment Effects

Summary

Means and standard deviations for all outcome measures at each assessment time are presented in Table 2. In the urban sample, GLM analyses showed significant group-by-time interactions on PDS ($F_{1,88}$=7.65, P=.007), PCC ($F_{1,88}$=5.32, P=.02), and SCL-D ($F_{1,88}$=8.37, P=.005), but not on SFI ($F_{1,88}$=3.33, P=.07) and CSE ($F_{1,88}$=0.03, P=.87). In the rural sample, the group-by-time interaction was significant on PDS ($F_{1,91}$=5.35, P=.02), but not on the other four outcome measures ($F_{1,91}$=0.01-1.12, all Ps>.29).

Between-Group Differences

Based on one-way ANOVAs (Table 2), in each sample, the treatment group did not differ from the waiting list group on all measures at Time 1. After the one-month treatment (Time 2), this group scored significantly lower than the waiting list group on PDS, PCC, SFI, and SCL-D in the urban sample. In the rural sample, the group difference was significant only on PDS at Time 2.

At 3-month follow-up measurement, the ITT analysis revealed no significant between-group difference in either sample. When the two samples were compared, they differed significantly at Time 4 on SFI ($F_{1,181}$=6.97, P=.009) and CSE ($F_{1,181}$=7.19, P=.008), but did not differ significantly on PDS, PCC, and SCL-D ($F_{1,181}$=0.34-1.05; all Ps>.30).

Within-Group Differences

In the urban sample, as presented in Table 3, the treatment group showed significant improvement on PDS, PCC, SFI, and SCL-D from Time 1 to Time 2, and the improvement was sustained during the follow-up period. Within-group evaluations showed no additional improvement or decrease on five measures from Time 3 to Time 4 ($F_{1,45}$=0.02-3.04; all Ps>.08; d=0.03-0.38). During the one-month waiting period, the waiting list group remained stable on five measures. After the completion of delayed treatment, the waiting list group showed nearly significant improvement on PDS (P=.053) and significant decrease on PCC from Time 2 to Time 3. The improvement continued during the follow-up period. Further, within-group comparisons revealed significant decrease on PDS ($F_{1,43}$=10.63, P=.002, d=0.70), PCC ($F_{1,43}$=11.00, P=.002, d=0.71), SFI ($F_{1,43}$=10.04, P=.003, d=0.68), and SCL-D ($F_{1,43}$=10.33, P=.002, d=0.69), but not significant increase on CSE ($F_{1,43}$=3.27, P=.08, d=0.39) from Time 3 to Time 4.

In the rural sample, the treatment group also reported significant improvement on PDS, PCC, SFI, and SCL-D from Time 1 to Time 2. The improvement on SCL-D became, however, non-significant three months later. Further, within-group evaluations showed no change on five measures from Time 3 to Time 4 ($F_{1,48}$=0.01-1.06; all Ps>.30; d=0.01-0.21). For the waiting list group, no change occurred on PDS, PCC, and CSE, but significant decrease appeared on SFI and SCL-D from Time 1 to Time 2. After one-month delayed treatment, the group scored significantly lower on PDS and SCL-D at Time 3 than Time 2. The improvement disappeared, however, at Time 4. Based on further within-group comparison results, the group showed significant increase on SCL-D ($F_{1,43}$=5.20; P=.03; d=0.49) and non-significant change on the other four measures ($F_{1,43}$=0.24-1.72; all Ps>.19; d=0.10-0.28) from Time 3 to Time 4.

Table 1. Demographic characteristics for the urban sample (n=90) and the rural sample (n=93).

		Urban sample n (%)	Rural sample n (%)
Gender			
	Female	67 (74)	76 (82)
	Male	23 (26)	17 (18)
Age			
	18-	6 (7)	
	18-25	40 (44)	1 (1)
	26-40	36 (40)	42 (45)
	41-55	8 (9)	37 (40)
	56-70		13 (14)
Family income per year ($) [a]			
	0-10,000	58 (64)	89 (96)
	10,001-20,000	19 (21)	1 (1)
	20,001+	7 (8)	1 (1)
Marital status			
	Single	64 (71)	5 (5)
	Married	24 (27)	88 (95)
Education			
	Junior middle school/lower	1 (1)	67 (72)
	High middle school	10 (11)	19 (20)
	Bachelor’s degree	62 (69)	7 (8)
	Master’s degree/higher	17 (19)	

[a]According to statistics published on the National Bureau of Statistics of China website on January 18, 2013, the annual per capita net income was about US$1,319 for rural households and about US$4,094 for urban households in 2012 [30].

Table 2. Descriptive statistics, between-group comparisons, and effect sizes (Cohen's *d*) for each sample: intention-to-treat analysis.

			Treatment group mean (SD)	Waiting list group mean (SD)	$F_{1,88}$ (Cohen's *d*)	*P*
Urban sample						
	Time 1					
		PDS[a]	1.74 (0.61)	1.73 (0.59)	0.01 (0.02)	.95
		PCC[b]	2.54 (0.87)	2.78 (0.85)	1.78 (−0.28)	.19
		SFI[c]	2.66 (1.09)	2.79 (0.92)	0.38 (−0.13)	.54
		SCL-D[d]	2.64 (0.79)	2.66 (0.87)	0.01 (−0.02)	.92
		CSE[e]	1.99 (0.73)	1.88 (0.56)	0.67 (0.17)	.42
	Time 2					
		PDS	1.13 (0.73)	1.65 (0.58)	4.29 (−0.44)	.04
		PCC	1.77 (1.09)	2.69 (0.86)	8.50 (−0.61)	.005
		SFI	1.84 (0.96)	2.62 (0.78)	5.08 (−0.48)	.03
		SCL-D	1.71 (0.86)	2.52 (0.91)	4.32 (−0.44)	.04
		CSE	2.25 (0.74)	2.04 (0.72)	0.79 (0.19)	.38
	Time 3					
		PDS		1.33 (0.75)		
		PCC		2.29 (0.99)		
		SFI		2.33(1.19)		
		SCL-D		2.14 (1.03)		
		CSE		2.21 (0.70)		
	Time 4					
		PDS	0.76 (0.78)	0.74 (0.58)	0.18 (0.09)	.67
		PCC	1.39 (1.11)	1.43 (0.87)	0.44 (−0.14)	.51
		SFI	1.60 (1.27)	1.58 (1.08)	0.89 (0.20)	.35
		SCL-D	1.24 (1.01)	1.39 (0.69)	0.27 (−0.11)	.60
		CSE	2.34 (1.15)	2.74 (0.49)	0.41 (−0.14)	.52
Rural sample						
	Time 1					
		PDS	1.77 (0.48)	1.79 (0.57)	0.05 (−0.04)	.83
		PCC	2.53 (0.84)	2.35 (0.88)	1.07 (0.21)	.30
		SFI	2.31 (0.95)	2.49 (0.90)	0.96 (−0.19)	.33
		SCL-D	2.17 (0.77)	2.32 (0.95)	0.63 (−0.17)	.43
		CSE	1.96 (0.54)	1.97 (0.63)	0.01 (−0.02)	.97
	Time 2					
		PDS	1.34 (0.48)	1.62 (0.55)	6.86 (−0.54)	.01
		PCC	2.09 (0.84)	2.11 (0.85)	0.001 (−0.01)	.97
		SFI	1.85 (0.77)	1.88 (0.94)	0.09 (−0.06)	.77
		SCL-D	1.92 (0.66)	2.08 (0.86)	0.96 (−0.20)	.33
		CSE	1.96 (0.39)	1.84 (0.52)	1.60 (0.26)	.21
	Time 3					
		PDS		1.38 (0.56)		

		Treatment group mean (SD)	Waiting list group mean (SD)	$F_{1,88}$ (Cohen's *d*)	*P*
	PCC		1.86 (0.82)		
	SFI		1.70 (0.86)		
	SCL-D		1.68 (0.80)		
	CSE		1.68 (0.58)		
Time 4					
	PDS	1.37 (0.58)	1.54 (0.63)	1.85 (−0.28)	.18
	PCC	2.02 (0.94)	1.96 (1.02)	0.15 (0.08)	.70
	SFI	1.73 (0.90)	1.83 (0.88)	0.21 (−0.10)	.65
	SCL-D	1.97 (0.93)	2.08 (0.96)	0.11 (−0.07)	.74
	CSE	1.96 (0.53)	1.86 (0.72)	1.28 (0.23)	.26

[a]PDS: Post-traumatic Diagnostic Scale

[b]PCC: Post-traumatic Cognitive Changes questionnaire

[c]SFI: Social Functioning Impairment questionnaire

[d]SCL-D: Symptom Checklist 90-Depression scale

[e]CSE: Trauma Coping Self-Efficacy scale

Table 3. Within-groups comparisons and effect sizes (Cohen's *d*) for each sample: intention-to-treat analysis.

		Treatment group		Waiting list group	
		$F_{1,45}$ (Cohen's *d*)	*P*	$F_{1,43}$ (Cohen's *d*)	*P*
Urban sample					
Time 1 vs 2					
	PDS[a]	15.13 (0.81)	<.001	0.77 (0.19)	.39
	PCC[b]	13.86 (0.78)	.001	1.46 (0.26)	.23
	SFI[c]	11.08 (0.69)	.002	2.71 (0.35)	.11
	SCL-D[d]	19.69 (0.93)	<.001	1.91 (0.29)	.17
	CSE[e]	3.36 (−0.38)	.07	1.76 (−0.28)	.19
Time 2 vs 3					
	PDS			3.97 (0.42)	.053
	PCC			6.45 (0.54)	.02
	SFI			0.62 (0.17)	.44
	SCL-D			2.44 (0.33)	.13
	CSE			1.46 (−0.26)	.23
Time 1/2[f] vs 4					
	PDS	17.29 (0.87)	<.001	14.57 (0.81)	<.001
	PCC	13.31 (0.76)	.001	12.69 (0.76)	.001
	SFI	13.80 (0.77)	.001	7.18 (0.57)	.01
	SCL-D	20.61 (0.95)	<.001	14.79 (0.82)	<.001
	CSE	1.34 (−0.24)	.25	6.42 (−0.54)	.02
Rural sample					
Time 1 vs 2					
	PDS	43.97 (1.34)	<.001	3.68 (0.41)	.06
	PCC	13.64 (0.75)	.001	3.38 (0.39)	.07
	SFI	15.42 (0.79)	<.001	13.95 (0.80)	.001
	SCL-D	5.78 (0.49)	.02	5.12 (0.48)	.03
	CSE	0.001(0.01)	.98	1.71 (0.28)	.20
Time 2 vs 3					
	PDS			4.42 (0.45)	.04
	PCC			2.83 (0.36)	.10
	SFI			0.95 (0.21)	.34
	SCL-D			7.27 (0.58)	.01
	CSE			2.56 (0.34)	.12
Time 1/2[f] vs 4					
	PDS	24.22 (0.99)	<.001	1.10 (0.22)	.30
	PCC	16.41 (0.82)	<.001	1.82 (0.29)	.19
	SFI	16.85 (0.83)	<.001	0.41 (0.14)	.52
	SCL-D	2.99 (0.35)	.09	0.17 (0.09)	.68
	CSE	0.002 (−0.01)	.97	0.04 (0.04)	.85

[a]PDS: Post-traumatic Diagnostic Scale

[b]PCC: Post-traumatic Cognitive Changes questionnaire

[c]SFI: Social Functioning Impairment questionnaire

[d]SCL-D: Symptom Checklist 90-Depression scale

[e]CSE: Trauma Coping Self-Efficacy scale

[f]Time 1 vs 4 for treatment groups, Time 2 vs 4 for waiting list groups

Discussion

Principal Findings

This study aims to examine the efficacy of a Chinese self-help intervention program (CMTR) for traumatized persons. Its English version (MTR) had been empirically examined in a US sample of 56 Hurricane Ike survivors and showed effectiveness in reducing participants' worry and depression level [18]. This study tested CMTR to parallel RCTs in one urban/unsupported sample and one rural/supported sample. The former sample consisted of an urban sample. Most of them were younger than 40 years old, single, with a bachelor's or higher degree, and a low to middle family income level [30]. It covers main characteristics of Internet users in China [32]. A parallel sample came from a rural area using the advantage of Web-based interventions for offering mental health services for people far away from urban areas. It also tried to address problems of Internet supply in populations with many elderly and lower-educated people by providing them with IT access and support.

The CMTR program showed significant effectiveness in reducing participants' PTSD symptom severity during the one-month treatment/waiting period in the two samples. The program also produced significant improvement of other mental health outcomes (post-traumatic cognitive changes, functional impairment, and depression) after controlling time effects in the urban/unsupported sample by the applied design. These findings give support for the short-term efficacy of CMTR [18] in the two Chinese populations and contribute to the literature that self-help Web-based programs can be used to provide mental health help for traumatized persons [6,33]. Different from the sample with minimal presence of PTSD symptoms in Steinmetz et al [18], more than two-thirds of the participants in this study reported moderate or severe PTSD symptom severity.

After the two waiting list groups completed one-month delayed treatment, they showed improvement with moderate effect sizes on PTSD symptoms and post-traumatic cognitive changes/depression level—converging with the favorable effect sizes of the main trial. Regarding the group comparison, two findings call for attention. The first is that the waiting list group showed a lower dropout rate than the treatment group at post-treatment/waiting test in the urban sample. Participants' motivation to use the CMTR website may be one potential factor to understand this finding. In the urban sample, all participants took part actively in the program through Internet advertisements and completed the research procedure without any payment. Thus, the participants may have been highly motivated to follow the research instructions before they were able to use the CMTR website, and their high level of motivation may have decreased after using the CMTR website. Based on our data, after the one-month delayed treatment, 18 out of 38 participants (47%) in the waiting list group who used the website completed post-test, which is very similar to the proportion of participants who completed post-test in the treatment group (23/46, 50%).

Previous studies have shown that self-help intervention programs are most efficient for motivated users in the treatment of anxiety disorders [34]. In the current study, we found bigger pre-post intervention differences in the treatment group than in the waiting list group in the urban sample, although the latter may have higher levels of motivation prior to using the treatment program. However, the waiting list group showed significant additional improvement on four outcome measures while the treatment group remained stable on all outcome measures during the three-month follow-up period. Further research is needed to examine the influence of motivation on Web-based intervention efficacy, particularly over the long term.

The second finding is, without any treatment, the waiting list group reported significant decrease on social functioning impairment and depression symptoms after one-month waiting period in the rural sample. They also reported lower level of PTSD symptoms and post-traumatic cognitive changes with moderate effect sizes. Such a placebo effect may be explained by the participants' face-to-face contact with well-known professionals. Because most participants in the rural sample were quite unfamiliar with Internet service, the volunteers at the center helped them to log in to CMTR to use the website. The participants could ask for help from volunteers about Internet service problems at the website, but they did not receive help with the contents on CMTR. For example, these volunteers did not give advice on which content on CMTR to learn first, how much content to finish during one treatment session, or read/explain certain content for the participants. However, such face-to-face contact still influenced the treatment effect of the CMTR program in addition to its impact on the dropout rates in the rural sample.

In the current study, the self-help CMTR website was thus less effective in the rural sample than in the urban sample. Controlling the time (placebo) effect, the treatment group showed significant improvement only on PTSD symptom severity than the waiting list group in the rural sample. After one-month delayed treatment, the waiting list group from rural areas showed further decrease on PTSD and depression symptoms, but the pre-post intervention differences disappeared during three-month follow-up period. The efficacy difference between the two samples may be due to the participants' lower level of motivation in the rural sample. These participants participated in the program in a more passive way (having been recruited and subsequently supported with their Web use by the center) and they received payment for completion of every test. Thus, they may have followed the research instructions because of the reward and were less motivated to use the CMTR website than the participants in the urban sample. Also, the rural sample in this study may have benefited less from the CMTR website

due to their lack of Internet access or knowledge. Based on the feedback from the volunteers, many participants, particularly the elderly, read slowly through the website. It is thus optimistic to expect better treatment efficacy of the CMTR website in non-Internet user populations, when the users would get (minimal) guidance.

In addition, neither sample in this study showed significant improvement in coping self-efficacy. Steinmetz et al [18] argued that the moderate presence of CSE level in their sample may cause the MTR website aspects targeted at increasing CSE to be less relevant to participants' needs. In the current samples, participants also reported moderate to high CSE mean scores at the baseline test. Further studies need to test the efficacy of the CMTR program in enhancing users' coping ability and to explain its effectiveness in reducing users' PTSD symptom severity in cross-cultural comparison.

Limitations

The current study has limitations in sampling and in controlling the contact between research assistants/volunteers and participants. Future studies need to examine the CMTR website in a larger, representative sample. Given that the current study used self-selected samples, the findings cannot be generalized to populations from hospitals or outpatient clinics. Also, it is important to detect if the efficacy of the CMTR website will remain long term in the treatment of PTSD.

Conclusions

The current study provides preliminary support for the short-term treatment efficacy of the CMTR website in two modalities of application. For those traumatized people who have good access to Internet service, the website may be an effective self-help intervention program for their trauma recovery. For those who are in need of treatment but lack Internet knowledge, the CMTR website may be also an effective intervention tool that can be used easily with minimal guidance. However, further research is needed to examine the program's long-term efficacy in large samples and explore the influence of different application modalities (eg, involvement of mental health professionals) on the program's usage (eg, dropout rate, treatment effect).

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Conflicts of Interest

None declared.

Multimedia Appendix 1

CONSORT-EHEALTH checklist V1.6.2 [35].

[PDF File (Adobe PDF File), 985KB - jmir_v15i9e213_app1.pdf]

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Abbreviations

CMTR: Chinese version of My Trauma Recovery program
CSE: Trauma Coping Self-Efficacy Scale
DIPS: German Diagnostic Interview for Psychiatric Symptoms
DSM-IV: Diagnostic and Statistical Manual of Mental Disorders, fourth edition
GLM: General Linear Model
MTR: My Trauma Recovery program
PCC: Post-traumatic Cognitive Changes
PDS: Post-traumatic Diagnostic Scale
PTSD: post-traumatic stress disorder
SCL-D: Symptom Checklist 90-Depression
SFI: Social Functioning Impairment
TSQ: Trauma Screening Questionnaire

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Original Paper

A Pre-Post Study on the Appropriateness and Effectiveness of a Web- and Text Messaging-Based Intervention to Reduce Problem Drinking in Emerging Adults

Severin Haug[1], PhD; Michael P Schaub[1], PhD; Vigeli Venzin[2], MA; Christian Meyer[3], PhD; Ulrich John[3], PhD; Gerhard Gmel[4]

[1]Swiss Research Institute for Public Health and Addiction at Zurich University, Zurich, Switzerland

[2]Cantonal Office for Secondary Education, Zurich, Switzerland

[3]Institute of Social Medicine and Prevention, University Medicine Greifswald, Greifswald, Germany

[4]Addiction Switzerland, Lausanne, Switzerland

Corresponding Author:
Severin Haug, PhD
Swiss Research Institute for Public Health and Addiction at Zurich University
Konradstrasse 32
Zurich, 8031
Switzerland
Phone: 41 44 448 11 74
Fax: 41 44 448 11 70
Email: severin.haug@isgf.uzh.ch

Abstract

Background: Problem drinking, particularly risky single-occasion drinking (RSOD), also called “binge drinking”, is widespread among adolescents and young adults in most Western countries. Few studies have tested the effectiveness of interventions to reduce RSOD in young people with heterogeneous and particularly lower educational background.

Objective: To test the appropriateness and initial effectiveness of a combined, individually tailored Web- and text messaging (SMS)–based intervention program to reduce problem drinking in vocational school students.

Methods: The fully automated program provided: (1) online feedback about an individual’s drinking pattern compared to the drinking norms of an age- and gender-specific reference group, and (2) recurrent individualized SMS messages over a time period of 3 months. Generalized Estimating Equation (GEE) analyses were used to investigate the longitudinal courses of the following outcomes over the study period of 3 months: RSOD, alcohol-related problems, mean number of standard drinks per week, and maximum number of standard drinks on an occasion.

Results: The program was tested in 36 school classes at 7 vocational schools in Switzerland. Regardless of their drinking behavior, 477 vocational school students who owned a mobile phone were invited to participate in the program. Of these, 364 (76.3%) participated in the program. During the intervention period, 23 out of 364 (6.3%) persons unsubscribed from participating in the program. The GEE analyses revealed decreases in the percentage of persons with RSOD from baseline (75.5%, 210/278) to follow-up assessment (67.6%, 188/278, $P<.001$), in the percentage of persons with alcohol-related problems (20.4%, 57/280 to 14.3%, 40/280, $P=.009$), and in the mean number of standard drinks per week: 13.4 (SD 15.3) to 11.3 (SD 14.0), $P=.002$. They also revealed a trend toward a decrease in the mean of the maximum number of drinks consumed on an occasion: 11.3 (SD 10.3) to 10.5 (SD 10.3), $P=.08$.

Conclusions: The results show high acceptance and promising effectiveness of this interventional approach, which could be easily and economically implemented within school classes.

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KEYWORDS

alcohol intervention; problem drinking; young people; text messaging; Internet

Introduction

Alcohol use is a major cause of the disease burden in most countries of the world [1]. In Europe, alcohol is responsible for 12% of male and 2% of female premature death and disability [2]. Problem drinking is associated with multiple social and interpersonal problems [2,3]. Indicators of problem drinking are: (1) a daily average consumption of 30 g or more of pure alcohol for men and 20 g or more for women [4], and (2) risky single-occasion drinking (RSOD) (also called "binge drinking"), defined as drinking 5 or more drinks on one occasion for men and 4 or more drinks for women [5]. The prevalence rates of RSOD are particularly high in adolescence and young adulthood and are higher among men than among women [6].

Studies testing the efficacy of interventions to reduce problem drinking in young people have been conducted predominantly in the United States and have been targeted toward college or university students [7]. Within this target group, individual interventions using motivational interviewing [8] or personalized normative feedback, based on the social norms approach [9], showed promising findings and resulted in lower alcohol consumption and fewer alcohol-related problems [10,11].

Social norm interventions provide information about the actual drinking norm in a reference group. They typically include an individualized drinking profile with the quantity of alcohol consumed in relation to peers, the money spent on alcohol, the calorie intake, and the individual risk patterns of alcohol-related negative consequences. In university and college students, normative feedback interventions delivered using the Web or computer, reduced drinking quantity, drinking frequency, and binge drinking in the short- and medium-term [12].

Computer-tailored interventions based on the social norms approach are also promising for the reduction of problem drinking in populations with lower educational backgrounds. However, it should be noted that the efficacy of tailored messages depends on the individual's ability and motivation to process information. The Elaboration Likelihood Model [13] posits that the degree to which individuals are motivated and able to process a persuasive message (Need for Cognition or NFC) determines the care with which the central merits of a message will be considered and evaluated. Individuals with low NFC pay more attention to the source of the arguments (eg, celebrities, credible authorities, experts), the ease with which they can be processed (eg, presented pictorially versus verbally), and the number of arguments presented, to process information. Although NFC is thought to reflect a cognitive motivation rather than an intellectual ability, it is positively correlated with educational level [14]. Considering individuals' NFCs in the context of health behavior, interventions could be crucial for improving their outcomes [15-17].

Social norm interventions for reducing problem drinking typically consist of a single intervention session in which participants receive tailored Web or printed feedback. Due to their length of up to 7-8 pages of text and graphics, these interventions are primarily matched with persons of higher educational levels and higher NFCs. An approach that might be more effective for individuals with lower educational levels and that might also be more persuasive if persons are processing information on the peripheral route is to provide shorter, more recurrent feedback messages.

Text messaging (short message service, SMS), which is available primarily via mobile phones, provides a suitable technology to deliver short and repeated feedback messages. This service allows a cost-effective instantaneous delivery of short messages directly to individuals at any time and place. In the field of alcohol prevention, SMS particularly allows the delivery of individualized messages at times when young people typically drink alcohol [18]. In Switzerland, as in most other developed countries, nearly all adolescents (98%) between the ages of 12 and 19 own a mobile phone, and SMS is the most commonly used mobile phone application [19].

SMS is increasingly being applied for behavior change interventions, particularly in smoking cessation and diabetes self-management [20,21]. For alcohol treatment, 2 pilot studies based on relatively small sample sizes are available. Suffoletto et al [22] reported fewer heavy drinking days and fewer drinks per drinking day in 15 young adults reporting harmful alcohol use receiving SMSs up to 3 months after emergency treatment. In a study using twice daily supportive text messages (n=26) or a thank you text message (n=28) every 2 weeks for 3 months, co-morbid depressive and alcohol-dependent patients reported lower depression scores and a trend for higher cumulative abstinence duration [23].

Vocational school students are typically characterized by heterogeneous educational levels, including a significant proportion with little or no educational attainment, and high prevalence rates of hazardous drinking [24]. The objectives of the present study were (1) to test the appropriateness of a combined Web- and SMS-based intervention program for the reduction of problem drinking in vocational school students, and (2) to provide an initial test of its effectiveness.

Methods

Setting

In most European countries, vocational schools are post-secondary public schools that are analogous to American community colleges. They are part of the dual educational system that combines apprenticeships in a business context and vocational training in a school context. Vocational schools provide general education and specific skills for a particular profession.

Based on data from the Swiss Federal Statistical Office, approximately half of all adolescents ages 16 to 19 currently attend vocational schools [25], with the highest proportions among adolescents ages 17 (males: 63%, females: 48%) and 18 (males: 63%, females: 49%).

Design and Procedure

A longitudinal pre-post study design was used to test the initial effectiveness of the program. Furthermore, differences in the longitudinal courses of the main outcome criteria between program participants and nonparticipants were explored.

Directors or contact teachers for addiction prevention from all 23 vocational schools in the Swiss canton of Zurich were invited to participate through some of their classes in a study testing the effectiveness of a Web- and text messaging-based program to reduce problem drinking. Of these 23 schools, 7 vocational schools with a total of 36 school classes agreed to participate in the study. All vocational school students in the participating school classes were invited by externally trained staff to participate in an online health survey during a regular school lesson reserved for health education. To decrease reporting bias, the study assistants did not provide further information about the purpose of the study before the screening assessment was completed. The screening assessments were conducted between April 2012 and September 2012. At the time of the assessment, 490 students were present in the school classes, of whom 488 (99.6%) agreed to participate. The online screening included the assessment of demographic data, alcohol consumption, weekly physical activity, smoking status, and ownership of a mobile phone.

The inclusion criterion for program participation was ownership of a mobile phone. A total of 477 of the 488 participants (97.7%) from the screening assessment owned a mobile phone. Subsequently, eligible persons were informed about the aim of the program, assessments, reimbursement, and data protection. Study and program information was provided online and in paper form by the study assistants. Eligible persons were informed that they could unsubscribe from program participation at any time simply by sending an SMS expressing their request to withdraw from the program. Additionally, they were informed that program participants would take part in a draw for 10 vouchers worth €50. Eligible persons could then decide whether to participate in the program or not. After providing informed consent online, all program participants were invited to choose a username and to provide their mobile phone number. Furthermore, additional alcohol-related variables were assessed.

Follow-up assessments after 3 months were conducted in the participating school classes during regular school lessons using paper-and-pencil questionnaires. All vocational school students present in the school classes at the follow-up assessments (also students who were not eligible for participation in the program and nonparticipants) were invited to fill in a questionnaire.

The study protocol was approved by the local Ethics Committee of the Canton of Zurich, Switzerland. The study was executed in compliance with the Declaration of Helsinki.

Intervention

The fully automated program was based on a LAMPP-system (Linux system, Apache server, MySQL-database, PHP-programming language) and included an expert system that generated individually tailored online feedback and text messages. The interventional content was based on effective social norms intervention programs developed primarily for college and university students in the United States and Canada [26,27] that had been modified for the target group of German-speaking adolescents in Switzerland, aged 16-20 with different educational backgrounds.

The program, Alk-Check, automatically generated individually tailored online feedback and SMS messages using data from a comprehensive online assessment. The online assessment tool collected demographic information and information on alcohol consumption, drinking behavior (eg, typical drinking days and times), and alcohol-related problems. Age- and gender-specific norms for alcohol consumption were derived from a previous study [28] that assessed heavy drinking occasions, alcohol volume, and the maximum number of drinks on a single occasion among 973 vocational and secondary school students in the Canton of Zurich, Switzerland.

After completing the online assessment, individually tailored online feedback was provided. The online feedback was tailored according to the individual values on the following 4 baseline variables: gender, age, number of standard drinks in a typical week, and frequency of RSOD occasions in the last 30 days. The feedback included graphical and textual information concerning (1) drinks per week in relation to the age and gender-specific reference group, (2) financial costs of drinking, (3) calories consumed with alcoholic drinks, and (4) number of heavy drinking occasions in relation to the age and gender-specific reference group. The online feedback could be printed and sent by mail to the participants' email accounts.

On the first level, the content and number of text messages were tailored according to baseline drinking patterns. Participants were assigned to one of three risk groups (derived from [4,5]), based on their baseline drinking patterns: (1) "Non-Risk": No RSOD occasion during the last 30 days and <18 (12 for females) standard drinks in a typical week, (2) "Low-Risk": 1 or 2 RSOD occasions during the last 30 days or no RSOD occasions during the last 30 days, and ≥18 (12 for females) standard drinks in a typical week, and (3) "High Risk": >2 RSOD occasions during the last 30 days.

On the second level, the content of the text messages was tailored according to the individual values on the following baseline variables: gender, motivation for reduced alcohol consumption, alcohol-related problems, typical drinking day and time, number of standard drinks in a typical week, and maximum number of drinks on a single occasion during the last 30 days.

Participants from all risk groups received text messages for a period of 12 weeks. Participants of the non-risk group received one weekly text message providing information from the following content categories: (1) drinking and body weight/fitness, (2) resisting peer pressure, (3) pros of sensible drinking, and (4) motivation to maintain sensible drinking.

Participants of the low-risk group received one weekly text message providing information from the following content categories: (1-3), (5) motivation for sensible drinking, (6) alcohol-related problems, (7) maximum number of drinks on a single occasion and related risks, (8) risks of binge drinking, and (9) importance of reducing alcohol consumption. Additionally, they received biweekly text messages sent on the individually indicated typical drinking day and time. The latter messages specifically focused on strategies to reduce alcohol consumption and to motivate them toward sensible drinking practices. Participants of the high-risk group received one

weekly text message providing information from the content categories: (1-3), (5-9), and (10) local outpatient services for alcohol counseling. They also received the additional biweekly text messages sent on the individually indicated typical drinking day and time that focused on strategies to reduce alcohol consumption and to motivate them to adopt sensible drinking practices. Examples of these text messages are shown in Table 1.

Before the study, a prototype of this program was tested and evaluated in 3 focus groups. Within these focus groups, vocational school adolescents aged between 16 and 20 years evaluated the program flow, the layout and content of the online assessment and feedback, and the content of the text messages. The optimizations that resulted from these focus groups were integrated in the final program version.

Measures and Outcome Criteria

The screening assessment included the following demographic variables: gender, age, education, and migration background. Common Swiss levels of educational attainment were assessed: (1) none, (2) secondary school, (3) extended secondary school, and (4) technical or high school. We assessed the country of birth of both parents of the vocational school students to identify a potential migration background. Based on this information, persons were assigned to one of the following categories: (1) persons with neither parent born outside Switzerland, (2) persons with one parent born outside Switzerland, and (3) persons with both parents born outside Switzerland.

Tobacco smoking was assessed using the question, “Do you currently smoke cigarettes or did you smoke in the past?” with the following response options: (1) I smoke cigarettes daily, (2) I smoke cigarettes occasionally, but not daily, (3) I smoked cigarettes in the past, but I do not smoke anymore, and (4) I have never smoked cigarettes or have smoked fewer than 100 cigarettes in my life. Current daily and occasional smokers (categories 1 and 2) were considered smokers. Self-reported moderate to vigorous physical activity was measured by a question derived from the Health Behavior in School Aged Children (HBSC) study [29]: “Outside school: How many hours a week do you exercise or participate in sports that make you sweat or out of breath?”.

The following 3 alcohol-related variables were included in the screening assessment: (1) frequency of RSOD occasions in the last 30 days (“How often did you have 5 [4 for females] or more drinks on one occasion in the last 30 days?” with the response categories “never”, “1-2 times”, “3-4 times”, “5-6 times”, “7-8 times”, “9-10 times”, “11-12 times”, “more than 12 times”); (2) quantity of alcohol consumption, as assessed by a 7-day drinking calendar similar to the Daily Drinking Questionnaire (DDQ) [30], for which participants were asked to think about a typical week in the past month and, for each day, to record the number of standard drinks they typically consumed on that day; and (3) the maximum number of drinks consumed on a single occasion in the last 30 days.

In the program, we also assessed alcohol-related problems and the motivation to reduce their alcohol consumption among participants. Alcohol-related problems were assessed by a questionnaire derived from the European School Survey Project on Alcohol and Other Drugs (ESPAD) [31]. The participants were asked about the number of occasions during the last 3 months when they had experienced problems related to their alcohol use. Ten problems are listed in the questionnaire, which could be grouped into 4 categories: (1) individual problems, (2) relational problems, (3) sexual problems, and (4) delinquency problems. The importance of reducing alcohol consumption was assessed by the question, “How important is it for you to modify your alcohol consumption and to drink less?” with the response categories “very important”, “rather important”, “rather unimportant”, and “very unimportant”.

To obtain the number of program participants who unsubscribed from the program (program attrition), we analyzed the log files of the SMS system in which all incoming and outgoing text messages were recorded.

At follow-up, we also assessed an aspect of the usage of the SMS messages by asking the participants whether they (1) read through the SMS feedback messages thoroughly, (2) took only a short look at the feedback messages, or (3) did not read the feedback messages. Using a yes/no question, we evaluated whether the times when participants received the SMS messages were appropriate. We assessed whether the number of received SMS messages was appropriate or whether the participants would have preferred less or more SMS messages. The program participants also indicated their approval of certain statements concerning different aspects of the SMS messages and the online feedback (comprehensibility, content, degree of tailoring), using the response categories “rather yes” and “rather no”.

Outcome criteria for the test of effectiveness of the intervention were: (1) RSOD in the last 30 days (yes/no), (2) frequent RSOD in the last 30 days (0-2 RSOD occasions vs >2 RSOD occasions), (3) number of standard drinks in a typical week, (4) maximum number of drinks on an occasion in the last 30 days, and (5) alcohol-related problems in the last 3 months (yes/no).

Data Analyses

To test for baseline differences between program participants and nonparticipants, chi-square tests for categorical variables and Mann-Whitney U-tests for continuous or ordinal variables were used. For the attrition analysis (program participants lost to follow-up), we also used chi-square tests for categorical variables and Mann-Whitney U-tests for continuous or ordinal variables.

We used Generalized Estimating Equation (GEE) analyses to investigate the longitudinal course of the outcome criteria over the study period of 3 months. GEE is a repeated-measures regression model that takes into account the correlation of the repeated measures within a person [32]. It is a powerful and versatile procedure for analyzing longitudinal data under minimal assumptions about time dependence and allowed us to use all available longitudinal data, regardless of single missing values at follow-up.

We used logistic GEE models for the binary outcome variables “RSOD” and “alcohol-related problems”, as well as GEE models for the count data of the variables “number of standard drinks in a typical week” and “maximum number of drinks on a single

occasion". Each GEE-model included the examined time variable (baseline vs follow-up assessment) as a predictor and an outcome variable as dependent variable.

Given the clustered nature of the data (students within school classes), we computed robust variance estimators for all GEE analyses. An alpha level of 0.05 (2-tailed) was chosen for all statistical tests in this study. All analyses were performed using the Stata software package, version 10.

Beyond the statistical examination of the longitudinal course of the outcome variables for program participants, we graphically explored the longitudinal course of the outcome variables for non-program participants in contrast to program participants. Due to a lack of statistical power, we did not use statistical tests for this comparison.

Table 1. Sample text messages from different risk groups and content categories.

Risk Group	Content Category	Text Message
Non-Risk	Drinking and body weight/fitness	Hi Peter. Alcohol is rich in calories, slows down the body's burning of fat and increases one's appetite. In short: drinking alcohol regularly makes you overweight in the long term. It's great that you don't drink alcohol at all!
Non-Risk	Resisting peer pressure	Hi Sarah. You are not just a follower who drinks alcohol to fit in. Awesome! This shows strength of character and can even impress others. Only do what you think is right.
Non-Risk	Pros of sensible drinking	Hey. Even with a blood alcohol content of only 0.03% (eg, 1 to 2 beers), you have an increased risk of accidents. Whether by walking, riding your bike or driving your car, without alcohol in the blood you are always safer on the road. Way to go!
Low-Risk	Importance of reducing alcohol consumption	Hi. You would like to drink less alcohol. That's a smart decision for you! If you consume less alcohol, you will feel better and have more energy the next day.
Low-Risk	Alcohol-related problems	Hello Lucy, due to consumption of alcohol, you've had problems with your parents. That's not necessary! Keep in mind that you can avoid these problems by drinking less or no alcohol at all!
High-Risk	Maximum number of drinks on a single occasion and related risks	Hey Mike. You recently had 14 drinks on one occasion. Your blood alcohol concentration was about 0.34% that time. With that amount of alcohol in your blood you can experience unconsciousness, loss of memory, shallow breathing, a reduction of body temperature and loss of reflexes. Watch out!
High-Risk	Strategies to reduce alcohol consumption and to motivate for sensible drinking	Hey. It's good for your body to have soft drinks every now and then! Non-alcoholic drinks provide your body with important minerals and are a good, thirst-quenching alternative. By drinking them you can prevent yourself from getting drunk as quickly.
High-Risk	Local outpatient services for alcohol counseling	Hi Robin. Are you concerned about your own alcohol intake or that of a friend? Talking to someone about it can be really helpful. The website www.alcocheck.ch can offer you support. Write an email to info@alcocheck.ch or call 043 444 77.

Results

Study Participants

Of the 477 persons who owned a mobile phone and were therefore eligible for study participation, 364 (76.3%) registered for program participation. Table 2 presents the demographic, health, and alcohol-related characteristics of program participants and nonparticipants. Program participants differed from nonparticipants with respect to the baseline variables "educational attainment" and "maximum number of drinks on an occasion in the last 30 days". Program participants had a lower level of educational attainment (U=17402.0, P<.001) and had a higher maximum number of drinks on a single occasion (U=17958.5, P=.04).

After 3 months, 367 of the 477 (76.9%) students who were eligible for program participation completed follow-up assessment: program participants 280/364 (76.9%); nonparticipants 87/113 (77.0%). The attrition analysis showed that persons dropping out were significantly more likely to be smokers (χ^2=6.2, P=.01) and to have more frequent RSOD within the last month (U=17297.5, P=.02).

Appropriateness of the Intervention

Program Attrition

During the program, which lasted for 3 months, 23 out of the 364 (6.3%) program participants unsubscribed from participating in the program.

Program Use and Evaluation

Out of the 280 program participants who could be reached for follow-up assessment, we obtained data concerning the program use and evaluation from 234 to 269 persons, depending on the respective variable. These different frequencies are due to missing data, inconsistent data, or variables that were only assessed in some persons depending on their previous answers.

Of the program participants, 254 out of 269 persons (94.4%) with valid data indicated that they regularly received the SMS messages. Of the 249 persons with valid data, 124 (49.8%) indicated that they "read the SMS messages thoroughly"; 111 persons (44.6%) reported that they "took a short look at the feedback messages"; and 14 persons (5.6%) chose the predefined response category, "I did not read the feedback messages".

The time when participants received the SMS messages was rated as appropriate by 75.4% of the program participants (196/260). The number of received SMS messages was rated as appropriate by 57.5% (149/259); 35.5% (92/259) would have preferred fewer; and 6.9% (18/259) would have preferred more SMS messages. Table 3 presents additional evaluations of the tailored online feedback and of the SMS messages by the program participants.

Table 2. Baseline characteristics of program participants and nonparticipants; values are numbers (%), unless stated otherwise.

		Program participants (n=364)	Non-participants (n=113)
Female gender		89 (24.5%)	22 (19.5%)
Age in years, mean (SD)		18.0 (2.4)	17.8 (1.7)
	15-16 years	73 (20.1%)	20 (17.7%)
	17-18 years	194 (53.3%)	64 (56.6%)
	19-20 years	72 (19.8%)	23 (20.4%)
	21 years or older	25 (6.9%)	6 (5.3%)
Immigration background			
	No immigration background	185 (50.8%)	45 (39.8%)
	One parent born outside Switzerland	69 (19.0%)	22 (19.5%)
	Both parents born outside Switzerland	110 (30.2%)	46 (40.7%)
Educational attainment			
	None	18 (4.9%)	3 (2.7%)
	Secondary school	300 (82.4%)	80 (70.8%)
	Extended secondary school	39 (10.7%)	24 (21.2%)
	Technical or high school	7 (1.9%)	6 (5.3%)
Tobacco smoking			
	Never smokers or recent quitters	171 (47.0%)	65 (57.5%)
	Current daily or occasional smokers	193 (53.0%)	48 (42.5%)
Hours of extracurricular moderate to vigorous physical activity per week, M (SD)		4.5 (4.6)	4.8 (3.9)
Frequency of risky single-occasion drinking in the last 30 days			
	Never	85 (23.4%)	36 (31.9%)
	1-2 times	106 (29.1%)	29 (25.7%)
	3-4 times	71 (19.5%)	23 (20.4%)
	5-6 times	48 (13.2%)	5 (4.4%)
	7-8 times	20 (5.5%)	7 (6.2%)
	9-10 times	14 (3.8%)	5 (4.4%)
	11-12 times	6 (1.6%)	1 (0.9%)
	More than 12 times	14 (3.8%)	7 (6.2%)
Number of standard drinks in a typical week, mean (SD)		14.1 (16.1)	11.3 (14.4)
Maximum number of drinks on an occasion in the last 30 days, mean (SD)		11.6 (10.8)	10.0 (11.3)
One or more alcohol-related problems in the last 3 months		80 (22.0%)	
Importance of reducing alcohol consumption			
	Very unimportant	164 (45.1%)	
	Rather unimportant	121 (33.2%)	
	Rather important	48 (13.2%)	
	Very important	31 (8.5%)	

Table 3. Evaluation of online feedback and text messages by program participants; values are numbers (%).

		Rather Yes, n (%)	Rather No, n (%)
The online feedback was…			
	comprehensible (n=265)	250 (94.3)	15 (5.7)
	interesting (n=258)	182 (70.5)	76 (29.5)
	individually tailored for me (n=257)	127 (49.4)	130 (50.6)
The text messages were…			
	comprehensible (n=240)	232 (96.7)	8 (3.3)
	helpful (n=235)	71 (30.2)	164 (69.8)
	individually tailored for me (n=234)	79 (33.8)	155 (66.2)

Program Effectiveness

Risky Single-Occasion Drinking (RSOD)

The GEE analyses revealed a statistically significant decrease in the percentage of persons with at least one RSOD occasion in the last month from the baseline assessment to the follow-up assessment (OR 0.66, 95% CI 0.53-0.83, *P*<.001). Considering only program participants with appropriate follow-up data, the percentage of program participants with at least one RSOD occasion in the last month was 75.5% (210/278) at baseline and 67.6% (188/278) at follow-up (Figure 1).

The GEE analyses also revealed a statistically significant decrease in the percentage of persons with more than two RSOD occasions in the last month from the baseline assessment to the follow-up assessment (OR 0.76, 95% CI 0.61-0.94, *P*=.01). Considering only program participants with follow-up data, the percentage of program participants with more than two RSOD occasions in the last month was 48.2% (134/278) at baseline and 41.0% (114/278) at follow-up (Figure 2).

Number of Standard Drinks in a Typical Week

The GEE analyses revealed a statistically significant decrease in the number of standard drinks in a typical week from the baseline assessment to the follow-up assessment (IRR 0.83, 95% CI 0.74-0.93, *P*=.002). Considering only program participants with follow-up data, the mean number of standard drinks in a typical week was 13.4 (SD 15.3) at baseline and 11.3 (SD 14.0) at follow-up (Figure 3).

Maximum Number of Drinks on an Occasion

An effect close to reaching statistical significance was observed on the decrease in the maximum number of drinks on an occasion in the last 30 days from baseline to follow-up assessment (IRR 0.91, 95% CI 0.83-1.01, *P*=.08). Considering only program participants with follow-up data, the maximum number of drinks on an occasion was 11.3 (SD 10.3) at baseline and 10.5 (SD 10.3) at follow-up (Figure 4).

Alcohol-Related Problems

The GEE analyses revealed a statistically significant decrease in the percentage of persons with one or more alcohol-related problems in the last 3 months from the baseline assessment to the follow-up assessment (OR 0.60, 95% CI 0.41-0.88, *P*=.009). Considering only program participants with follow-up data, the percentage of persons with one or more alcohol-related problems in the last 3 months was 20.4% (57/280) at baseline and 14.3% (40/280) at follow-up.

Figure 1. Percentage of persons with at least one RSOD occasion in the last month (program participants: n=278; nonparticipants: n=86).

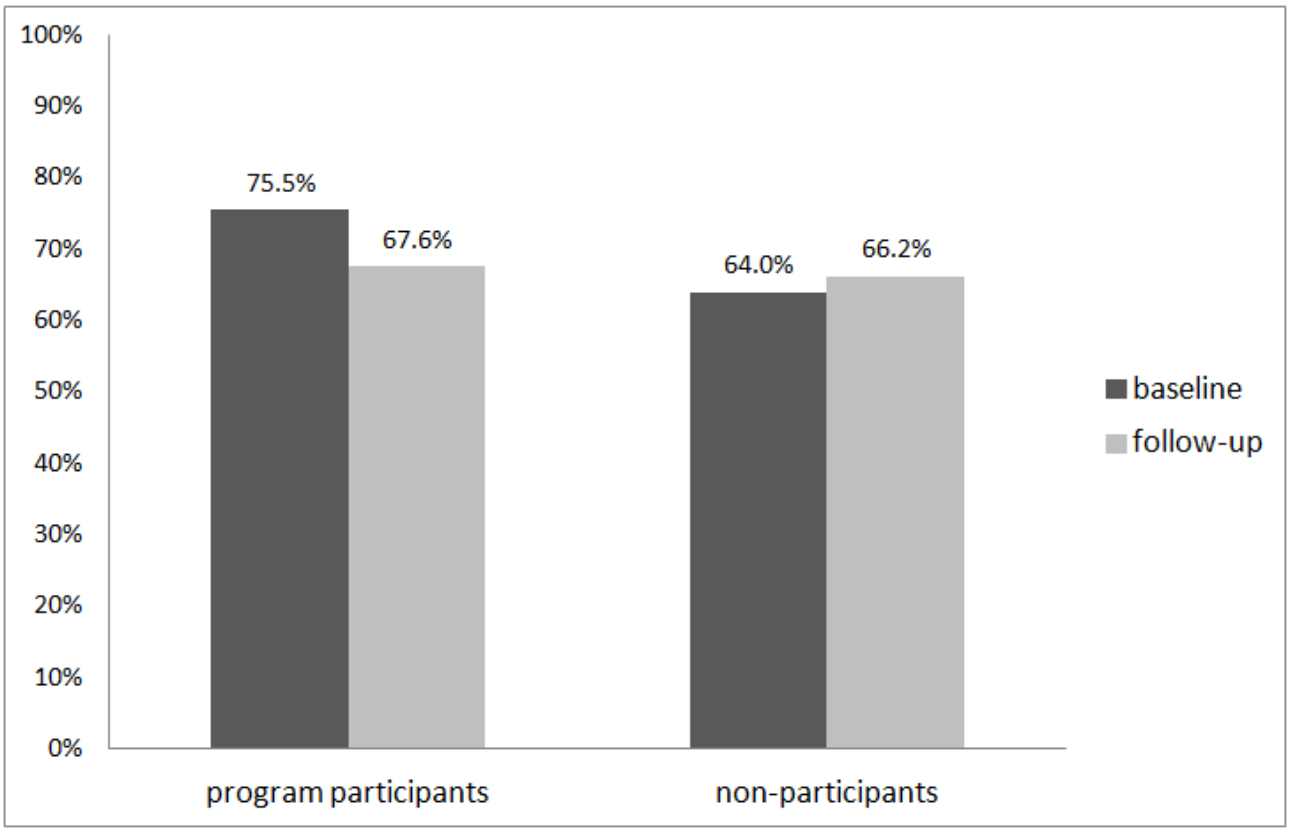


Figure 2. Percentage of persons with more than two RSOD occasions in the last month (program participants: n=278; nonparticipants: n=86).

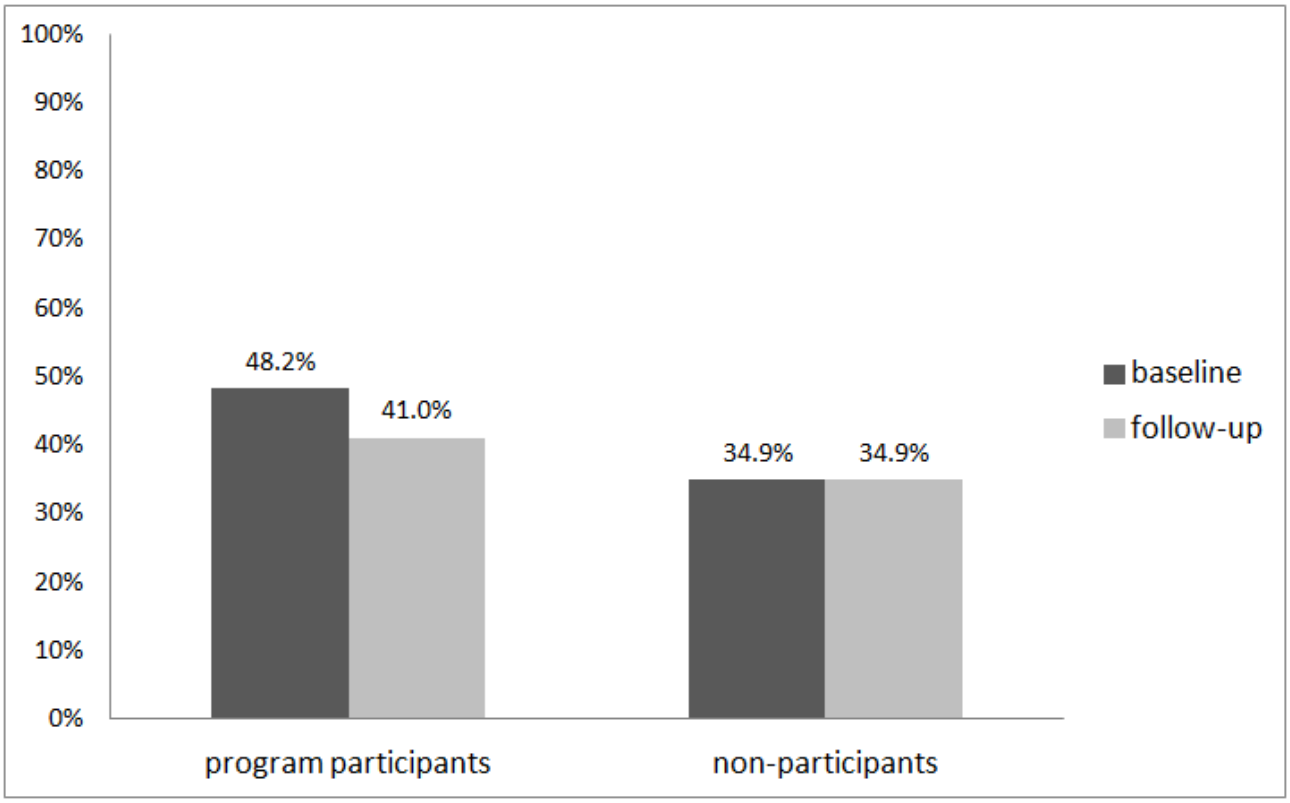


Figure 3. Mean number of standard drinks in a typical week (program participants: n=247; nonparticipants: n=79).

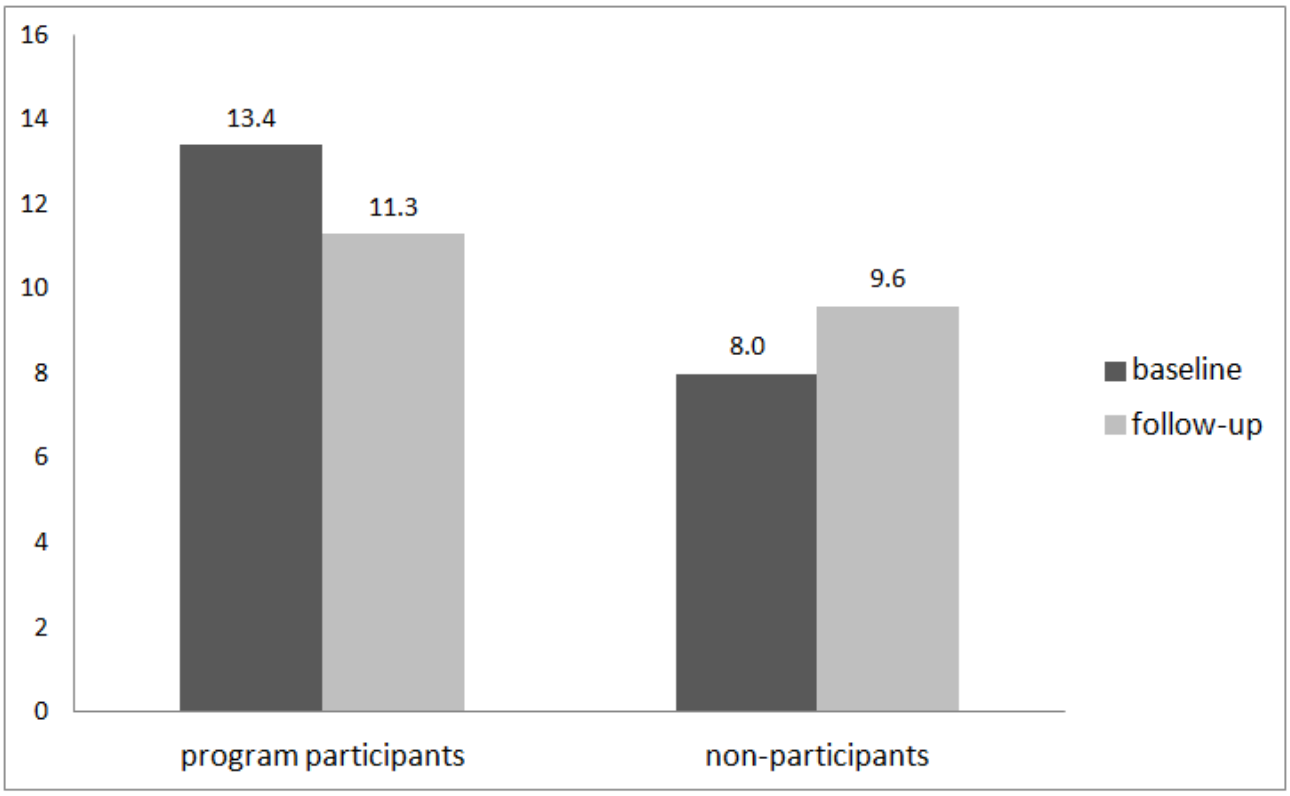
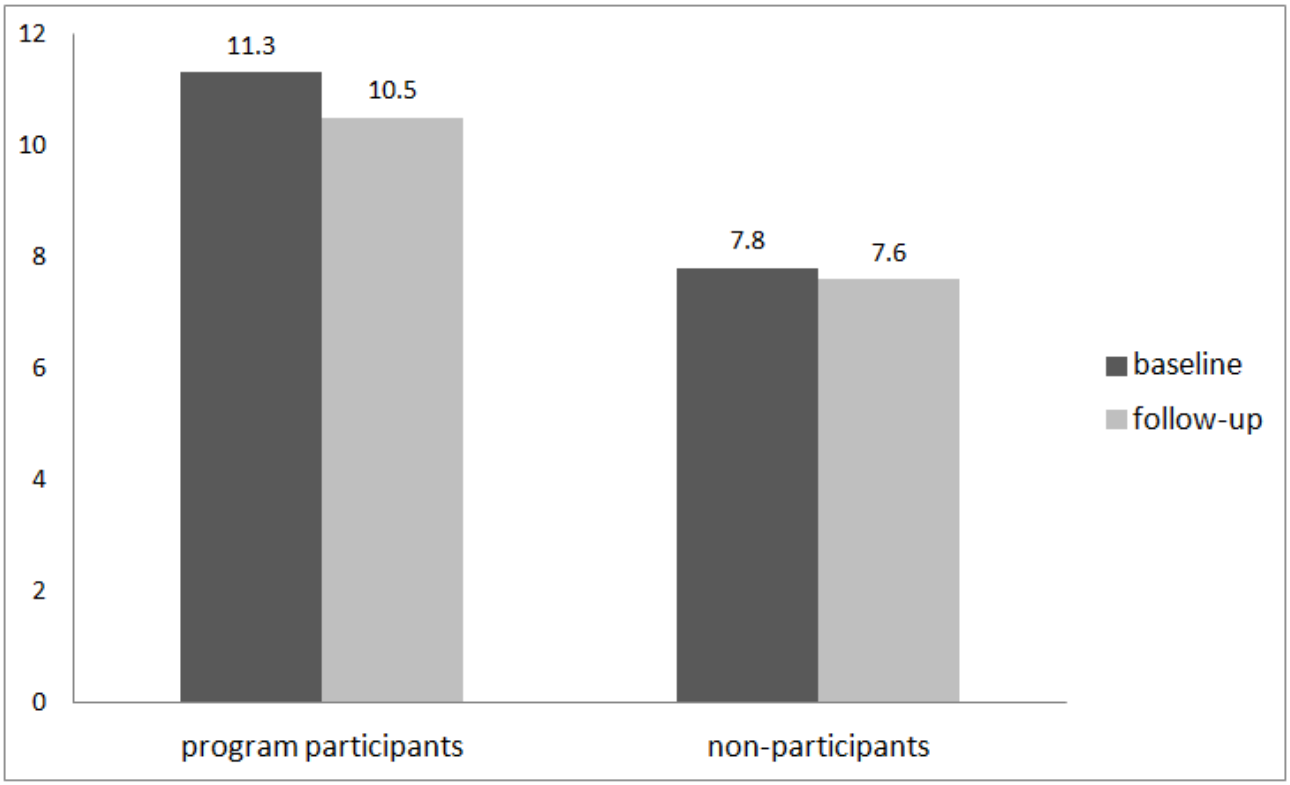


Figure 4. Maximum number of drinks on an occasion (program participants: n=275; nonparticipants: n=83).



Discussion

Principal Findings

The study revealed three main findings: (1) a large percentage of vocational school students could be reached by the program, (2) the acceptance of the program was good, and (3) the program may reduce problematic alcohol consumption in young people with heterogeneous and primarily lower educational levels.

The data of this study and other epidemiological studies [24,33] showed high prevalence rates of problem drinking in vocational

school students compared to population surveys of adolescents and young adults in this age group [34]. Within this high-risk group, the proactive invitation for program participation in combination with the offer of a low-threshold intervention using the Internet and SMS allowed us to reach 3 out of 4 vocational school students (76%) for participation in the program Alk-Check. Taking into account that 4 out of 5 (78%) program participants indicated that a reduction of alcohol consumption was rather unimportant or unimportant for them, this high participation rate is of special relevance. It underlines the importance of proactive recruitment and the attractiveness of the applied communication media for this target group.

Participation in the program was relatively independent of gender, age, and immigration background, but participation rates were higher for persons with lower school educations and for persons with higher alcohol consumption. The latter finding shows that we were able to particularly reach the main target group of the intervention, namely young people with problem drinking.

The overall acceptance of the intervention was good. Nearly all program participants (94%) stayed logged in until the end of the program lasting 3 months. The SMS messages were read by almost all program participants (94%), and both the SMS messages and the online feedback were comprehensible for almost all participants (SMS: 97%, online feedback: 94%). Room for improvement was indicated in particular concerning the tailoring of the SMS messages. While nearly half of the participants (50%) rated the online feedback as individually tailored, only 34% indicated that they perceived the SMS messages as individually tailored.

The results concerning the initial effectiveness of this program derived from a pre-post investigation are promising. The data revealed a statistically significant decrease in the percentage of persons with at least one RSOD occasion in the last month from baseline assessment (76%) to follow-up assessment (68%), as well as a statistically significant decrease in the percentage of persons with more than two RSOD occasions in the last month (from 48% to 41%). Furthermore, we found statistically significant decreases in the percentages of persons with alcohol-related problems and in the mean number of standard drinks per week. These positive changes could not be observed in persons not participating in the program.

Limitations

One limitation of this study is its lack of a control group that was derived on the basis of random assignment. Although participants were included into the study regardless of their drinking behavior, the comparison of baseline characteristics of program participants and nonparticipants indicates toward higher levels of alcohol consumption in program participants. Therefore, beyond the intervention effects, regression to the mean might have influenced the course of alcohol-related variables from baseline to follow-up. However, lack of a control group resulted in a greater proximity to prevention practices and allowed a better estimation of the participation rate in the program.

Conclusions

This is the first study to test a combined Web- and SMS-based intervention program for the reduction of problem drinking and one of the very few studies to test an intervention reducing problem drinking in a school sample. The results of this study show appropriateness and promising effectiveness for this intervention approach of combining singular online feedback to provide comprehensive individualized data about a person's alcohol consumption compared to an age- and gender-specific reference group and repeated individualized SMS messages encouraging sensible drinking. The intervention could be easily and economically implemented within school classes. Based on these initial positive results, testing this interventional approach within a randomized controlled trial would be reasonable.

Acknowledgments

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Authors' Contributions

Single authors (SH, GG) were also involved in the development of the intervention.

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Abbreviations

DDQ: Daily Drinking Questionnaire
ESPAD: European School Survey Project on Alcohol and Other Drugs
GEE: Generalized Estimating Equation
HBSC: Health Behavior in School Aged Children study
NFC: Need for Cognition
RSOD: risky single-occasion drinking
SMS: short message service

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Original Paper

New Media Use by Patients Who Are Homeless: The Potential of mHealth to Build Connectivity

Lori Ann Post[1], PhD; Federico E Vaca[1], MD, MPH; Kelly M Doran[2], MD, MHS; Cali Luco[1], MPA; Matthew Naftilan[1], MS; James Dziura[1], PhD, MPH; Cynthia Brandt[1], MD, MPH; Steven Bernstein[1], MD; Liudvikas Jagminas[1], MD; Gail D'Onofrio[1], MD, MS

[1]Department of Emergency Medicine, Yale School of Medicine, Yale University, New Haven, CT, United States

[2]Department of Emergency Medicine and Department of Population Health, NYU School of Medicine, New York University, New York, NY, United States

Corresponding Author:
Lori Ann Post, PhD
Department of Emergency Medicine
Yale School of Medicine
Yale University
Suite 263
464 Congress Ave
New Haven, CT, 06519
United States
Phone: 1 203 785 4172
Fax: 1 203 785 4580
Email: lori.post@yale.edu

Abstract

Background: Patients experiencing homelessness represent a disproportionate share of emergency department (ED) visits due to poor access to primary care and high levels of unmet health care needs. This is in part due to the difficulty of communicating and following up with patients who are experiencing homelessness.

Objective: To determine the prevalence and types of “new media” use among ED patients who experience homelessness.

Methods: This was a cross-sectional observational study with sequential enrolling of patients from three emergency departments 24/7 for 6 weeks. In total, 5788 ED patients were enrolled, of whom 249 experienced homelessness. Analyses included descriptive statistics, and unadjusted and adjusted odds ratios.

Results: 70.7% (176/249) of patients experiencing homelessness own cell phones compared to 85.90% (4758/5539) of patients in stable housing (*P*=.001) with the former more likely to own Androids, 70% (53/76) versus 43.89% (1064/2424), and the latter more likely to have iPhones, 44.55% (1080/2424) versus 17% (13/76) (*P*=.001). There is no significant difference in new media use, modality, or frequency for both groups; however, there is a difference in contract plan with 50.02% (2380/4758) of stably housed patients having unlimited minutes versus 37.5% (66/176) of homeless patients. 19.78% (941/4758) of patients in stable housing have pay-as-you-go plans versus 33.0% (58/176) of homeless patients (*P*=.001). Patients experiencing homelessness are more likely to want health information on alcohol/substance abuse, mental health, domestic violence, pregnancy and smoking cessation.

Conclusions: This study is unique in its characterization of new media ownership and use among ED patients experiencing homelessness. New media is a powerful tool to connect patients experiencing homelessness to health care.

(J Med Internet Res 2013;15(9):e195) doi:10.2196/jmir.2724

KEYWORDS

homelessness; mHealth; connectivity; emergency department

Introduction

Background

Patients who are homeless experience high levels of unmet health needs [1] and poor access to primary care [2]. Thus it is not surprising that people who are homeless represent a disproportionate share of emergency department (ED) patients [3]. Beyond accessing the ED for health care, they are also motivated by social needs such as food, shelter, and safety [4]. Communication and follow-up with ED patients experiencing homelessness is a major barrier. Such connectivity needs led us to explore "new media" as a means to better serve patients experiencing homelessness who routinely access the ED for their health care.

What Is New Media?

New media refers to on-demand access to content anytime, anywhere, using a digital device that includes interactive user feedback, creative participation, and community formation around the media content [5] and has characteristics of being manipulated, networkable, dense, compressible, and most importantly, interactive [6]. Examples of new media include the Internet, social networking websites, multimedia, video games, cell phones, and smart phones [6], as opposed to legacy media such as television, radio, film, magazines, or paper-based publications, unless they contain technologies that enable digital interactivity [7,8]. For the purpose of this study, mHealth is defined as "the delivery of health care services via mobile communication devices" [9].

Connectivity, identified by mHealth researchers, is crucial between patients, providers, and the system of care [10,11] prompting the Federal Communication Commission to create a task force on mHealth. The overarching goal given to the task force was to identify necessary steps to attain the following: "By 2017 mHealth, wireless health and e-Care solutions will be routinely available as part of best practices for medical care" [12]. What is missing from US health care goals is how to include patients who are experiencing homelessness in these important plans. To this end, this study attempts to determine whether the use of new media can improve the ED health care of patients experiencing homelessness and transcend health care service delivery barriers through connectivity.

What Are the Challenges in the Emergency Department of Treating Patients Experiencing Homelessness?

We must address issues of homelessness because they constitute a particularly vulnerable population of patients [3]. Patients without access to primary care have few alternatives, which contributes to overcrowding and nonemergency care being provided in the ED [4,13-18]. ED practitioners find that social needs must often be addressed before they can begin to address these patients' health care.

Connectivity for Patients Experiencing Homelessness?

The realization that new media might serve a powerful function in the care and well-being of patients who are homeless has been described more recently in a handful of studies [19-24], nor is it missing from the enhancement of health care outside the context of homelessness [25-28]. In fact, increasing connectivity through new media has been practiced globally for nearly two decades [29-33]. However, what is not known is the use of new media by patients in the ED who are experiencing homelessness and how this compares to other ED patients or the general population. Prior studies of adults who were homeless found that 44%-54% had cellular phones, but these studies were limited by using geographically limited convenience samples and were not specific to ED patients [24,34]. Ranney et al's study was the first to describe overall ED patients' preferences for technology-based interventions and the first to develop baseline data on use of computers, Internet, cell phone, and SMS text messaging, but they did not examine this in patients who were homeless [35]. The current study goes beyond their work by identifying patients who were homeless and differentiating the various modalities of new media beyond cell phone use derived from the communication literature [35].

Methods

Design

This study was an observational cross-sectional survey that continuously enrolled sequential patients in three EDs 24 hours per day, 7 days per week for 6 weeks (July-August 2012).

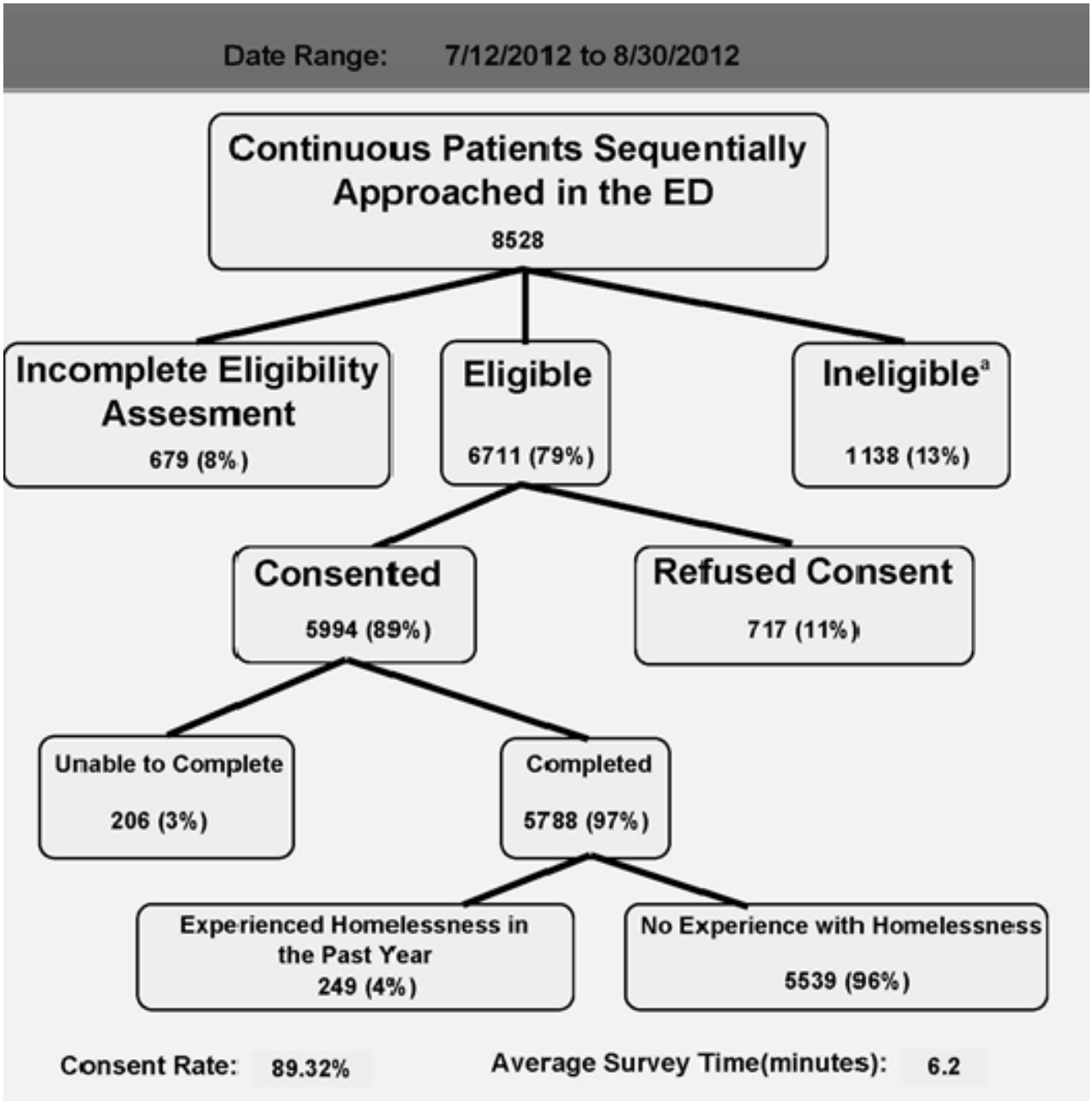
Setting

Patients were enrolled from three urban, high-volume EDs (Connecticut, USA) at Yale-New Haven Hospital (n=1922), Bridgeport Hospital (n=1900), and Hospital of St. Raphael (n=1966) for a total of 5788 patients.

Participants

Patients were excluded if they were under 18 years of age; presented as a trauma activation; presented with alcohol or other substance intoxication; spoke a language other than English or Spanish; presented with active psychosis, suicidal, or homicidal ideation; were in police custody, unable to consent due to life-threatening events or cognitive impairment; were in isolation for infectious concerns until cleared by provider; or were unable/unwilling to consent (Figure 1). For some prospective participants, study enrollment was delayed due to initial limited decisional capacity secondary to alcohol and or other substances, but they were approached at a later time. Overall, 89% of eligible patients consented to participate in this study (Figure 1). Patients were interviewed by trained research assistants.

Figure 1. Patient flow diagram.



Data Analyses

Our analysis included descriptive statistics, bivariate data analysis, and unadjusted and adjusted odds ratios.

Measures

Patients were asked a series of questions on homelessness: (1) how many nights they spent in their own home during the last week, (2) how many nights they spent at somebody else's house, in a motel, in a half-way house, in transitional housing, in an institution, in jail, in shelter, and outdoors, and (3) where else they stayed in the past week (to rule out vacations or family and friend visits that were recreational vs shelter seeking). After reviewing the different potential options, we asked also patients to (4) estimate the number of times they had been homeless in the past year. We used a broad definition of homelessness, which included patients living "doubled up" with family or friends, or in some other transitional living arrangement such as staying in a motel, at their place of work, in a church, or a car in addition to including patients who were living in shelters or on the streets or other public places not meant for nighttime residence. This definition is consistent with that used by the US Health Resources and Services Administration (HRSA) in providing guidance to Health Care for the Homeless centers [36] and was chosen to be inclusive of the broad spectrum of people vulnerable to the health risks associated with homelessness. In addition, because homelessness is most commonly a transient state, with people cycling into and out of homelessness or experiencing short episodes of homelessness [37], we included as homeless any patient who indicated an episode of homelessness over the past year.

Patients were also asked (5) if they owned a cell phone, (6) what their cell phone was used for, including phone calls, text

messaging, emailing, surfing the Internet, watching videos, listening to music, playing games, applications, and other, (7) what type of phone, provider, phone plan they had, and (8) frequency of use. Patients were asked about new media behaviors such as (9) seeking health information, and (10) tracking and managing health through a personal health record (PHR) or other application. Patients were asked about (11) use of computers, access, where accessed, and ownership. They were also asked about (12) accessing the Internet through cell phone, laptop, desktop, tablet; frequency of use; duration of use per day; purposes of use; social networking; and chatting; and (13) if would they be interested in receiving health information via each type of media about a variety of health issues. We included open-ended questions where patients could suggest other health topics of interest outside of those listed in the survey. The study ended with (14) the collection of demographics, health issues, access to health care, and insurance status.

Results

In total, 5788 subjects were enrolled in the study. Of these, 249 (4.30%) patients reported episodes of homelessness in the past year. Patients who had experienced homelessness were more likely to be male (54.6%, 136/249), younger (mean age 40 vs 46 years), African American (38.6%, 96/249) or Latino (25.3%, 63/249), and have lower income and less education than stably housed patients (Table 1).

Patients with a history of homelessness reported similar types of new media use as stably housed patients in terms of making phone calls, text messaging, emailing, surfing the Internet, social networking, using PHRs, and looking up health information (Table 2). Fewer homeless patients owned cell phones (70.7%, 176/249 vs 85.90%, 4758/5539; *P*=.001) or smart phones (43.2%, 76/176 vs 50.95%, 2424/4758; *P*=.04) as compared to the non-homeless ED patients (Table 2). Patients experiencing homelessness did own significantly different types of smartphones (*P*=.001) and had different types of cell phone and smart phone contracts (*P*=.001) compared to stably housed patients. Stably housed patients were more likely to own iPhones (44.55%, 1080/2424; *P*=.001) and have a contract plan with unlimited minutes (50.02%, 2380/4758; *P*=.001) whereas, patients who were homeless were more likely to own Android phones (70%, 53/76; *P*=.001) and own “pay-as-you-go” plans (33.0%, 58/176; *P*=.001).

Among those who owned a cell or smartphone, patients experiencing homelessness were slightly more likely to look up health information (64%, 52/81 vs 59.81%, 1317/2202) or track and manage their health using a PHR (20%, 16/81 vs 18.26%, 402/2202); however, these differences were not statistically significant (Table 2).

Regardless of media use, we questioned patients about their need and desire for health information. Table 3 shows unadjusted odds ratios (OR) comparing the desire for health information in patients experiencing homelessness to housing-stable patients. Patients experiencing homelessness were significantly more likely to want health information on mental health (OR 2.2), smoking cessation (OR 3.0), alcohol abuse (OR 1.9), pregnancy (OR 1.4), drugs/substance abuse (OR 2.8), and domestic violence (OR 2.4). When evaluating only smokers using adjusted odds ratios, homeless patients were still significantly more likely to want health information about smoking cessation than non-homeless patients (*P*=.01). Patients experiencing homelessness were similar to stably housed patients in their desire for health information on weight loss/nutrition and managing chronic diseases such as hypertension or diabetes. We also asked patients which other topics they would be interested in receiving health information about. Patients experiencing homelessness listed dozens of additional topics such as HIV, diabetes, heart disease, epilepsy, pain, fall prevention, cancer, health insurance, health care options, kidney stones, menopause, and multiple sclerosis to name a few.

Table 1. Demographics—Emergency Department Media Study, July 12-August 30, 2012.

Characteristics		Participants who were homeless ≥1 times in last year (n=249), n (%)[a]	Participants who were not homeless in last year (n=5539), n (%)[b]
Gender			
	Men	136 (54.6)	2270 (40.98)
	Women	113 (45.4)	3269 (59.02)
Age			
	18-29	78 (31.3)	1431 (25.83)
	30-49	100 (40.2)	1939 (35.01)
	50-64	59 (23.6)	1106 (19.97)
	65+	12 (4.8)	1063 (19.19)
Race/ethnicity			
	White, non-Hispanic	90 (36.1)	2320 (41.88)
	Black, non-Hispanic	96 (38.6)	1855 (33.49)
	Hispanic	63 (25.3)	1295 (23.38)
Annual household income			
	Less than $30,000/yr	193 (91.9)	2691 (62.64)
	$30,000-$59,999	10 (4.8)	818 (19.04)
	$60,000-$89,999	4 (1.9)	436 (10.15)
	$90,000+	3 (1.4)	352 (8.19)
Education level			
	No high school diploma	93 (37.3)	752 (13.58)
	High school grad	97 (39.0)	2353 (42.48)
	Some college	39 (15.7)	1350 (24.37)
	College+	20 (8.0)	1084 (19.57)

[a]Participants who reported being homeless one or more times in the last year.

[b]Participants who reported not being homeless at any time in the last year.

Table 2. Media usage by ED patients experiencing homelessness.

		Homeless ≥1 times in last year (n=249), n (%)	Not homeless in last year (n=5539), n (%)	*P* value
Cell phone ownership (% of total)		176 (70.7)	4758 (85.90)	<.001
Making phone calls (% of cell users)		175 (99.4)	4717 (99.14)	1
Text messaging (% of cell users)		126 (71.6)	3469 (72.91)	.7
Surfing the Internet (% of cell users)		81 (46.0)	2202 (46.27)	.95
	Look up health information (% of cell phone surfers)	52 (64.2)	1317 (59.81)	.43
	Track or manage health with app (% of cell phone surfers)	16 (19.8)	402 (18.26)	.73
Emailing (% of cell users)		74 (42.0)	2007 (42.18)	.97
Social networking (% of cell users)		67 (38.1)	1836 (38.59)	.89
Listening to music (% of cell users)		65 (36.9)	1503 (31.59)	.14
Playing games (% of cell users)		61 (34.7)	1355 (28.48)	.08
Using apps (% of cell users)		57 (32.4)	1436 (30.18)	.53
Watching online videos (% of cell users)		48 (27.3)	1294 (27.20)	.98
Smartphone ownership (% of cell users)		76 (43.2)	2424 (50.95)	.043
Type of smartphone (% of smartphone owners)				<.001
	Android	53 (69.7)	1064 (43.89)	
	iPhone	13 (17.1)	1080 (44.55)	
	Blackberry	7 (9.2)	171 (7.05)	
	Windows	3 (3.9)	52 (2.15)	
	Other	0 (0.0)	57 (2.35)	
Type of cell phone plan (% of cell users)				<.001
Contract plan with unlimited minutes		66 (37.5)	2380 (50.02)	
Pay-as-you-go plan		58 (33.0)	941 (19.78)	
Contract plan with limited minutes		35 (19.9)	1239 (26.04)	
Medicaid phone		16 (9.1)	197 (4.14)	
Other		1 (<1.0)	1 (<1.00)	
Internet use (% of total)		147 (59.0)	3767 (68.00)	.003
Email use (% of Internet users)		113 (76.9)	3173 (84.23)	.017
Social networking use (% of Internet users)		102 (69.4)	2606 (69.18)	.96

Table 3. Desire for health information by ED patients experiencing homelessness (% of adults in each group with desire for various health information).

"If we offered you free health information, which topics would you be interested in receiving?"(Check all that apply)	Homeless ≥1 times[a], n (% of total n=249 who said "Yes")	Homeless 0 times[a], n (% of total n=5531 who said "Yes")	OR	95% CI
Healthy weight / nutrition / weight loss	156 (62.7)	3626 (65.56)	0.88	0.67-1.14
Mental health	125 (50.2)	1755 (31.73)	2.16	1.68-2.79
Smoking	106 (42.6)	1101 (19.91)	2.98	2.30-3.86
Alcohol	54 (21.7)	719 (13.00)	1.85	1.35-2.53
Pregnancy	39 (15.7)	639 (11.55)	1.42	1.00-2.02
Drugs / substance abuse	59 (23.7)	553 (10.00)	2.79	2.06-3.79
Domestic violence	47 (18.9)	490 (8.86)	2.39	1.72-3.33
Managing chronic disease	119 (47.8)	2518 (45.53)	1.09	0.84-1.41

[a]Participants were asked: "How many times have you been homeless in the last year?"

Discussion

Principal Findings

This study provides the first estimates of new media use among ED patients experiencing homelessness. Surprisingly, overall new media ownership by ED patients is similar to that in the general population and only slightly higher than the media ownership by ED patients experiencing homelessness [38]. As 70.7% (176/249) of the homeless ED population already own cell phones with the ability to text and receive calls, ED providers can increase connectivity for all mHealth purposes including referrals, appointment and medication reminders, and providing relevant information for health management. We also found that the type of smartphone and cell phone contracts or plans were significantly different for these two ED populations, which has implications for health care and research. Given that patients who are homeless are more likely to pay-as-you-go rather than enter into a long-term contract, health care providers need to be cognizant of limitations. One solution to these limitations would be to provide patients experiencing homelessness with "minutes" to increase their connectivity for health care service and research purposes. The rates of cell phone ownership from this study are higher than those observed in prior convenience samples of adults who were homeless, which found that 44%-54% had cellular phones [24,34]. This difference may be due to sampling and definition of homelessness. Our study included a broad definition of homelessness including patients who were transiently homeless in addition to the chronically homeless. Regardless, the high rates of new media ownership, access, and use observed among ED patients experiencing homelessness suggest that providers can use this technology to communicate with patients who are homeless [38], which was unknown until this study.

Importantly, patients experiencing homelessness were similar to stably housed patients in types of new media use, modes of media, and frequency of use, defying popular assumptions of a large "digital divide" for patients who are homeless. This finding is consistent with prior research showing that young adults who were homeless versus non-homeless had very similar uses of social network technology [39] and suggests that such similarities may extend to older adults as well. In addition, homeless patients are similar to stably housed patients in "new media use", meaning they should not be thought of as different or unique from other patients. Both populations use mobile devices, both know their functionality, and both can benefit from mHealth. Thus, patients without a home are not remarkably different from those who were more stably housed in terms of media use and media knowledge. However, it is true that they are more likely to have problems with substance abuse and mental health with limited access to health care [40]. Patients experiencing homelessness often feel that they are treated as inferior when interacting with the health care system [41]. Interestingly, new media may be a strong facilitator of health equity. Those identifying as homeless were slightly more likely to look up health information (64%, 52/81) than stably housed ED patients (59.81%, 1317/2202) and twice as likely to look up health information than the general population as reported in previous studies (31%) [38]. While health status may be driving the health information-seeking behavior, we still find evidence that homeless patients are higher new media users and information seekers even when controlling for baseline health status factors; for example, even when controlling for smoking status, patients who were homeless were still more likely to desire information on smoking cessation. Thus, as new media use is a powerful tool in health care for all patient populations, this connectivity may be an even more important tool for homeless patients because they may not have access to health information from primary care providers or be exposed to health information through formal education. Smartphones can meet their Internet and application needs as they relate to health care when stable housing with landlines, desktops, laptops, and Wi-Fi access are not available. Cellular phones and smartphones are portable, offering connectivity regardless of where the patient resides or how often they move. Finally, new media offers health care providers an opportunity to connect with their homeless patients, leveraging mobile technology to improve patient health outcomes. The findings of this study suggest programs such as Lifeline or LinkUp America—Medicaid programs that provide cell phones/land lines for impoverished patients without health

insurance—do indeed increase connectivity with health care providers [42].

Finally, ED patients experiencing homelessness were significantly more likely to want information on chronic health and social problems such as mental health, smoking cessation, alcohol and other substance abuse, pregnancy, and domestic violence than their stably housed counterparts. Negative consequences of these conditions are often treated in the ED, and preventative interventions may in fact decrease ED visits, health care costs, and improve health.

Limitations

One limitation of our study is that patients who were intoxicated for long periods of time and/or actively psychotic were unable to give informed consent. This may have resulted in certain subsegments of ED patients who are homeless to be excluded from the study. In particular, patients who are chronically homeless suffer from disproportionately high levels of substance abuse and mental health disorders and thus may be underrepresented in the current study.

Conclusion

In summary, ED patients experiencing homelessness have high rates of cell phone ownership and are equal in new media use to stably housed patients adjusting for ownership. They are more likely to engage in all forms of mHealth. Our expanded knowledge about the desire for connectivity by patients who are homeless informs opportunities for prevention and intervention to improve the health of this vulnerable population and potentially decrease the cost of health care.

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Conflicts of Interest

None declared.

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Abbreviations

ED: emergency department
HRSA: Health Resources and Services Administration
PHR: personal health record

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Original Paper

Communicating Genetics and Smoking Through Social Media: Are We There Yet?

Sylviane de Viron[1,2,3], MPH; L Suzanne Suggs[4]; Angela Brand[2,3]; Herman Van Oyen[1]

[1]Operational Direction Public Health and Surveillance, Scientific Institute of Public Health, Brussels, Belgium

[2]Institute for Public Health Genomics (IPHG), Department of Genetics and Cell Biology, Maastricht University, Maastricht, Netherlands

[3]Research Institute GROW (School for Oncology & Developmental Biology), Faculty of Health, Medicine and Life Sciences, Maastricht University, Maastricht, Netherlands

[4]Institute for Public Communication (ICP), Faculty of Communication Science, Università della Svizzera italiana, Lugano, Switzerland

Corresponding Author:
Sylviane de Viron, MPH
Operational Direction Public Health and Surveillance
Scientific Institute of Public Health
J Wytsmanstraat 14
Brussels, 1050
Belgium
Phone: 32 2 642 5765
Fax: 32 2 642 5410
Email: sylviane.deviron@wiv-isp.be

Abstract

Background: Social media is a recent source of health information that could disseminate new scientific research, such as the genetics of smoking.

Objective: The objectives were (1) to evaluate the availability of genetic information about smoking on different social media platforms (ie, YouTube, Facebook, and Twitter) and (2) to assess the type and the content of the information displayed on the social media as well as the profile of people publishing this information.

Methods: We screened posts on YouTube, Facebook, and Twitter with the terms “smoking” and “genetic” at two time points (September 18, 2012, and May 7, 2013). The first 100 posts were reviewed for each media for the time points. Google was searched during Time 2 as an indicator of available information on the Web and the other social media that discussed genetics and smoking. The source of information, the country of the publisher, characteristics of the posts, and content of the posts were extracted.

Results: On YouTube, Facebook, and Twitter, 31, 0, and 84 posts, respectively, were included. Posts were mostly based on smoking-related diseases, referred to scientific publications, and were largely from the United States. From the Google search, most results were scientific databases. Six scientific publications referred to within the Google search were also retrieved on either YouTube or Twitter.

Conclusions: Despite the importance of public understanding of smoking and genetics, and the high use of social media, little information on this topic is actually present on social media. Therefore, there is a need to monitor the information that is there and to evaluate the population’s understanding of the information related to genetics and smoking that is displayed on social media.

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KEYWORDS

genetics; Internet; public health genomics; smoking; social media; Web 2.0

Introduction

Social media are increasingly recognized as important tools for information provision, gathering, and transfer. They allow the spread of information to many people through different means [1]. For example, someone can publish a video on YouTube where anyone can view, listen, and even download the video. They can also create a group on Facebook to promote that video.

In social media, every individual, regardless of credentials, is able to post and retrieve such information. Therefore, available information on social media is not exclusively based on experts' knowledge but both on experts' and laypersons' experiences [2].

Health consumers use social media for a variety of purposes. A recent consumer survey observed that 24% of consumers posted information about their health experiences on social media platforms; 16% of consumers posted reviews of medications, treatments, doctors, or health insurers. Health symptoms or behaviors were traced and shared for 18% of the consumers. Health-related causes were joined by 20% of the consumers and supported by 28%. Furthermore, 16% of consumers share health-related videos or images on social media. Consumer trust in information posted on social media varied by messenger source ranging from hospitals (55%), from others they know (46%), health insurance companies (42%), and from unknown patients (25%). Regarding their susceptibility to share their own health information on social media, 30% would share this information with other patients, 43% with hospitals, and 38% with health insurance companies [2,3].

To date, most studies assessing the exposure to information about smoking on social media focused on pro- and anti-smoking information. Among adolescents, exposure to tobacco content appeared to be limited in volume, with 43% of adolescents being exposed to a mean of 13 pages of pro-tobacco content during 1-month follow-up [4]. The rate was nearly similar for anti-tobacco content, with 45% of the adolescents exposed to a mean of 10 pages of anti-tobacco content [4]. Some studies focused on the content of YouTube posts specifically, most of them being on tobacco control. But other topics were also developed: anti-smoking and quit-smoking posts as well as smoking-sexual fetish posts [2]. Facebook and Twitter are important ways to monitor the tobacco industry and to facilitate tobacco control [5]. As proposed by Hefler et al, social media strategies may be integrated into tobacco control organizations [5]. Moreover, social media, such as Facebook, already include information about many disorders and genetic syndromes [6].

Given the use of social media for health purposes and the increasing research, academic papers, and public and policy attention to genetic testing and genetic relationships with disease, it is expected that social media platforms are likely to become an important source for obtaining and disseminating genome-based information [7].

Despite the vast amount of research and efforts to prevent smoking and support cessation, smoking is still a major public health problem worldwide. Factors influencing smoking behavior are both nongenetic and genetic. Nongenetic factors included a broad range of aspects, such as social factors (eg, smoking status of peers), economic factors (eg, level of income), or psychological factors (eg, weight concerns). For genetic factors, the two main factors are the genes influencing the nicotine metabolism and genes influencing the cascade theory of reward [8].

Genetics and smoking are highly covered topics on different media. For example, a search for "genetics" and "smoking" on PubMed (including scientifically based content) resulted in 15,948 results. A search on Google (including both scientifically and nonscientifically based content) revealed 9,970,000 hits. On YouTube, 1,300,000 posts were obtained, on Facebook 472,000, and 8020 on Twitter (using the searches "smoking + genetic + site:YouTube.com", "smoking + genetic + site:facebook.com", and "smoking + genetic + site:twitter.com"). We also conducted a search of a specialized social media platform, PatientsLikeMe, and found 167 hits. However, upon review of the posts, only one publication about chronic obstructive pulmonary disease (COPD) and genetics was listed (and this publication was displayed multiple times). The high number of results in both scientific and nonscientific search sources suggests that such information could also be available in popular social media and could be found by lay public using typical simple search strategies.

Given the reach of social media and the growing reliance on it for health purposes, combined with the importance of genetics and smoking, this study aims to explore the availability of genome-based information about smoking on three popular social media platforms (YouTube, Facebook, and Twitter). Questions examined include (1) What type of information about genetics and smoking is displayed on social media?, (2) What is the source (scientific or nonscientific) of the posted information?, (3) What is the role of the publisher?, and (4) What countries is information being posted from? We expected that the information would be posted primarily from scientific sources from research centers in the United States and Europe.

Methods

Sample

Posts from YouTube, Facebook, and Twitter were included. YouTube (video sharing), Facebook (social networking), and Twitter (social networking and microblogging) are each ranked among the top 10 most popular websites [9]; Facebook was positioned second place just after Google. YouTube and Twitter were respectively at positions 3 and 8. The other websites included in the top 10 were retail websites (eg, Amazon.com) or Web search engines (eg, Google). Therefore, YouTube, Facebook, and Twitter appeared to be the most relevant social media. The number of users on social media is growing daily; however, Facebook is still the top-used medium with around 1.01 billion active users in 2012 [10]. Twitter counts roughly 500 million users and 200 million active users [11], and over 800 million unique users visit YouTube [12] each month.

Search Strategy

We searched for the terms "genetic" and "smoking" in each of the three social media. These terms were selected because they were simple terms that the general population may use to get information on the topic. The search was performed using two time points: the first one on September 18, 2012, and the second on May 7, 2013. The first 100 posts available for each social media platform were examined. Posts on YouTube were searched with the "relevance" option (the default option). On Facebook, posts were searched using both the total results and results by "people", "pages", "groups", "apps", "events", "music", "public posts", and "posts in groups". On Twitter, only posts of the previous days (approximately 1 week

depending on the storage capacity of Twitter's database) were visible at Time 1. This changed at Time 2, when posts from the previous months were available. Posts were excluded if they did not express the link between genetics and smoking tobacco (including smoking initiation, addiction, cessation, and smoking-related diseases). Figure 1 shows an example of the posts retrieved from YouTube and Twitter.

The first 100 posts were searched on Google at Time 2 using the same search terms. The aim of searching the posts on Google was twofold: first, to indicate the type of information available on the Internet and second, to determine if there were other types of social media that discussed genetics and smoking (eg, health forums or blogs).

Figure 1. Screenshots of YouTube and Twitter results. (a) screenshot of YouTube; (b) screenshot of Twitter.

Data Extraction

From the different posts, the date of the publication and the country of the publisher were extracted. To understand, at least partially, the credibility of the information provider, the role of the publisher was coded and classified as a research center, news, medical news, independent user (ie, the person posting on social media was acting as an individual citizen and not on behalf of a group of people or organization or as a scientist), and other, if it belonged to none of the previous categories (eg, foundation such as "Arthritis Foundation" or companies such as "23andme"). The source of posted information was categorized as "scientific publication", "referring to a scientific publication", and "not referring to a scientific publication". This allowed us to understand the differences in types of content posted on the three social media. The content of the posts was classified into smoking initiation, addiction, cessation, and smoking-related diseases. At least a link between genetics and the specific category must have been mentioned to allow the classification. Moreover, one post may have been classified in more than one category. For smoking-related diseases, we extracted the disease of interest. When available, we extracted the number of views and the opinion (like or dislike) of the post.

Statistical Analyses

Univariate analyses were assessed by Pearson chi-square for categorical data and the Kruskal-Wallis one-way analysis of variance for continuous data (because the continuous variables were not normally distributed). Tests were two-sided with a significance rate of alpha=0.05. Tests were corrected for multiple testing through Bonferroni-Sidak. *P* values less than .001 remained significant after correction for multiple testing.

All statistical analyses were performed using Stata, version 10.1.

To show the content of the posts on Twitter, the titles of the posts on YouTube, and the most frequent words found in the titles of the Google search, word clouds were used. Word clouds visually represent the frequency of the words used in the posts with larger size for more frequent words. Word clouds were created with the "wordcloud" package using the R project for statistical computing (R, version 2.14.1).

Results

Characteristics of the Three Social Media

Across both data collection points, YouTube, Facebook, and Twitter retrieved a total of 200, 0, and 171 posts respectively. Among those, 31, 0, and 84 discussed the genetics of smoking. On YouTube, 16 posts were retrieved both at Time 1 and 2. Moreover, from the 9 posts selected at Time 2, three were published after Time 1. By contrast, Time 1 (September 2012) and 2 (January to May 2013) did not overlap on Twitter. Therefore, no posts were found at both data collection points in Twitter (Figure 2). The number of included and excluded posts was significantly different between the three different social media (*P*<.001). Twitter obtained a higher proportion of posts discussing genetics and smoking (49.1%, 84/171) in comparison to YouTube (15.5%, 31/200).

When comparing included posts obtained from Twitter and YouTube (Table 1), no differences in the source of information or in the country of the publisher were observed. However, the role of the publisher was significantly different between the two media (*P*<.001). Most publishers were independent users on Twitter (45.2%, 38/84), although it was the smallest role

category (3.2%, 1/31) on YouTube. On YouTube, most posts were published by news or medical news instead of independent users on Twitter. For the content of the posts, a higher number of YouTube posts reported an impact of genetics on smoking-related disease than on Twitter (P=.001). The other contents (smoking initiation, addiction, and cessation) obtained similar results on YouTube and Twitter. For smoking-related diseases, no comparison of the different types of disorders led to differences between YouTube and Twitter.

Between the two time points for both YouTube and Twitter, posts did not differ in the source of information, role of the publisher, country of the publisher, and characteristics of the posts. On YouTube, the content of the posts were not different between the two time points. By contrast, on Twitter, the content differed for smoking initiation (P<.001), addiction (P<.001), cessation (P<.001), and related disease (P<.001) (Table 2). Moreover, on Twitter, there was a significant difference in the number of days the posts were available (P<.001).

Comparison Between Social Media and Google Search

Of the first 100 websites retrieved from the Google search, 86 were related to genetics and smoking. No new social media channels were revealed from this search. Websites retrieved from Google search were different from the posts on YouTube and Twitter, both in source of information and role of publisher. On Google, websites were more often scientific publications (46.5%) than on YouTube (0.0%) or Twitter (5.9%), explaining also the difference in the role of the publisher (scientific database, 46.5%) (Table 1).

Some scientific publications referred to on YouTube were also found in the Google search (eg, Amos et al [13] was listed 5 times on YouTube and once on Google) and the same for Twitter (eg, Govidan et al [14] appeared 12 times on Twitter and 1 time on Google, and Belsky et al [15], 38 times on Twitter and 9 on Google). However, no scientific publication found on YouTube was also retrieved on Twitter.

Word Clouds of the Three Social Media and Google Search

Further exploration of the Twitter posts and the post titles on YouTube and Google search through word clouds (see Figure 3; frequency of words correlates to size of font) showed that the words “smoking”, “genetic”, and “cancer” were highly present. This result was in line with the high level of posts assessing smoking-related diseases. On YouTube, the word “Insidermedicine” was also highly reported. Over the 31 included posts, 6 were from Insidermedicine and summarized new studies published in scientific journals. The “2010” word in the graph is also due to Insidermedicine posts where the date of publication was written in the title. On Twitter, among others, the words “lung”, “addiction”, and “teens” were frequently reported. This referred to two scientific publications that were reported multiple times; 12 Twitter posts (14.3%) reported that smokers with lung cancer have tenfold genetic damage in comparison to never-smokers [14], and 38 posts (45.2%) referred to the genetic factors influencing addiction in teens [15]. In the Google search, the words “addiction”, “cessation”, and “risk” were most often used, giving an indication of the content of the websites.

Table 1. Characteristics of posts from YouTube and Twitter (*P* values from Pearson chi-square).

Variables	YouTube (n=31)	Twitter (n=84)	Google (n=86)	*P* value (YouTube vs Twitter)	*P* value (YouTube vs Twitter vs Google)
Source of information, n (%)				0.19	<.001[a,b]
Scientific publication	0 (0.0)	5 (6.0)	40 (46.5)		
Referring to a scientific publication	30 (96.8)	71 (84.5)	46 (53.5)		
Not referring to a scientific publication	1 (3.2)	8 (9.5)	0 (0.00)		
Role of the publisher, n (%)				<.001[a,b]	<.001[a,b]
Research center	8 (25.8)	4 (4.7)	4 (4.7)		
News	11 (35.5)	7 (8.3)	16 (18.6)		
Medical news	10 (32.3)	17 (20.2)	19 (22.1)		
Independent user	1 (3.2)	38 (45.2)	0 (0.0)		
Scientific database	0 (0.0)	0 (0.0)	40 (46.5)		
Other	1 (3.2)	18 (21.4)	7 (29.9)		
Country of the publisher, n (%) [c]				0.18	.003[b]
United States	21 (70.0)	42 (50.6)	61 (81.3)		
United Kingdom	2 (6.7)	1 (1.2)	7 (9.3)		
Canada	1 (3.3)	3 (3.6)	0 (0.0)		
Italy	0 (0.0)	3 (3.6)	1 (1.3)		
Other	2 (6.5)	14 (16.7)	15 (17.4)		
Characteristics of the post, median [percentile] [d]					
Total # of days available	876 [319; 1441]	12.5 [5; 39]	707 [229.5; 1950.5]	<.001[a,b]	<.001[a,b]
Duration (min)	1.61 [1.43; 2.77]	—	—	—	—
Total number of viewership	232 [64; 1037]	—	—	—	—
Total number of likes for the post	1 [0; 2]	—	—	—	—
Total number of dislikes for the post	0 [0; 1]	—	—	—	—
Content of the post, n (%)					
Smoking initiation	2 (6.5)	15 (18.1)	17 (19.8)	0.12	0.23
Smoking addiction	14 (45.2)	53 (63.9)	62 (72.1)	0.07	0.03[b]
Smoking cessation	8 (25.8)	23 (27.7)	32 (37.2)	0.84	0.31
Smoking-related diseases	21 (67.7)	29 (34.5)	34 (39.5)	0.001[a,b]	0.005[b]
Type of smoking-related diseases, n (%) [e]					
Lung disease	1 (4.8)	0 (0.0)	0 (0.0)	0.24	0.22
COPD	2 (9.5)	5 (17.2)	1 (3.0)	0.44	0.17
Lung cancer	12 (57.1)	16 (55.2)	21 (63.6)	0.89	0.78
Cancer in general	4 (19.1)	3 (10.3)	3 (9.1)	0.38	0.52
Cardiovascular disease	1 (4.8)	1 (3.5)	1 (3.0)	0.82	0.95
Multiple diseases	0 (0.0)	1 (3.5)	3 (9.1)	0.39	0.29

[a]Significant *P* values after Bonferroni-Sidak correction for multiple testing.

[b]Significant *P* values.

[c]On YouTube, there were 5 missing values, 21 on Twitter, and 2 on Google search.

[d]Median values with percentiles [p25; p75] and *P* value from Kruskal-Wallis one-way analysis of variance.

[e]Only posts referring to smoking-related diseases were used; COPD—chronic obstructive pulmonary disease.

Table 2. Comparison of the posts' content between Time 1 and 2 (*P* values from Pearson chi-square).

	YouTube			Twitter		
	Time 1	Time 2	*P* value	Time 1	Time 2	*P* value
Smoking initiation, n (%)	0 (0.0)	2 (22.2)	.02[a]	0 (0.0)	15 (31.9)	<.001[a,b]
Smoking addiction, n (%)	8 (36.4)	6 (66.7)	.12	13 (36.1)	40 (85.1)	<.001[a,b]
Smoking cessation, n (%)	6 (27.3)	2 (22.2)	.77	1 (2.8)	22 (46.8)	<.001[a,b]
Smoking-related disease, n (%)	17 (77.3)	4 (44.4)	.08	22 (61.1)	7 (14.6)	<.001[a,b]

[a]Significant *P* values.

[b]Significant *P* values after Bonferroni-Sidak correction for multiple testing.

Figure 2. Flowcharts of the post selection: YouTube, Facebook, and Twitter. (a) YouTube flow chart; (b) Facebook flow chart; (c) Twitter flow chart.

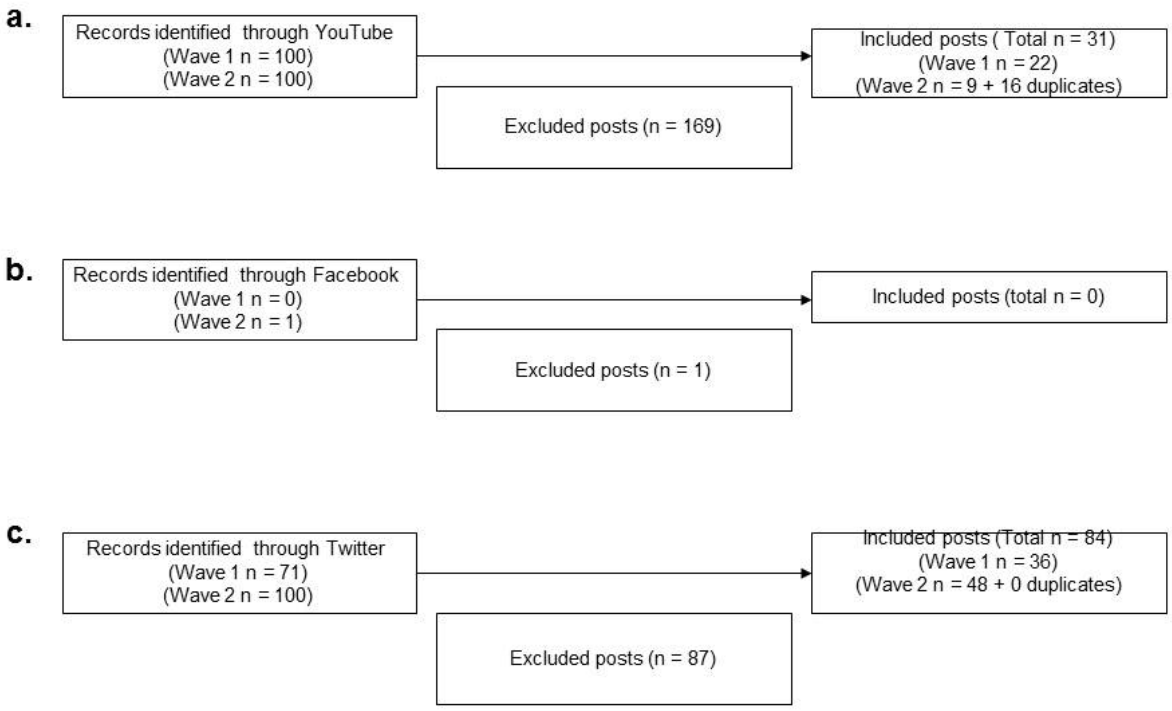
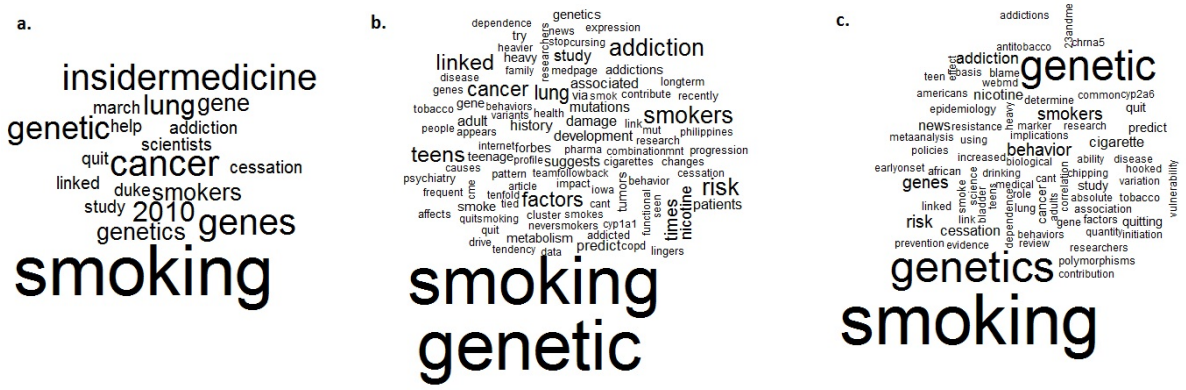


Figure 3. Word clouds presenting the most used words on YouTube, Twitter, and Google. (a) word cloud including the most used words in the title of YouTube posts; (b) the most used words from the posts in Twitter; (c) the most used words in Google. Each word's frequency is correlated with font size.



Discussion

Principal Findings

The current study introduced the availability of information regarding genetics and smoking in three different social media (YouTube, Facebook, and Twitter). This is, to our knowledge, the first study that investigated the availability of genetics and smoking in social media.

The results indicated that little information is available regarding the topic and even less on Facebook. The lack of posts on Facebook was not surprising given the specialized topic. However, we do expect the number of posts to grow dramatically as genetic testing and personalized medicine become more widely known. For YouTube and Twitter, most posts referred to scientific publications that were recently published.

The reason why no posts on genetics and smoking were retrieved using Facebook, versus the 472,000 posts obtained by using the search "smoking + genetic + site:facebook.com", is that Facebook is not a search engine and Google is. Interestingly, the same search strategy in another search engine resulted in a different number of retrieved posts (eg, 37,000 posts were found using Bing). Nonetheless, social media do not allow for such advanced search strategies and typical users do not typically use such search strings. Our objective was to know what information lay people find on genetics and smoking when using social media, so we developed our search within those social media and used typical search strategies.

The reason for the high number of posts coming from the United States in comparison to other countries may be explained by the size of the country and high Web adoption rate [16], rather than the importance of the topic in any country. For example, Facebook had the highest number of users in the United States (167,554,700 users). Brazil was second with 60,665,740 users. In comparison, the United Kingdom had 33,227,180 users and was in sixth position [17]. Despite the European ITFoM project (IT Future of Medicine) [18], PHGEN project (Public Health Genomics European Network) [19], the activities of the EAPM (European Alliance for Personalised Medicine) [20], and the significant attention to it at the policy level in Europe, the mere size of the continents and way in which each public accesses science information likely explain why the European posts were fewer than in the United States.

On Twitter, the period of availability of the posts changed between Time 1 and 2 (from approximately 1 week to several months). This may explain the highest number posts included in Time 2.

The contents of the posts mostly focused on genetics of addiction and smoking-related diseases. This result is consistent with the higher number of scientific publications on both topics than on any other topic linking genetics and smoking. The smoking-related disease of interest was mainly lung cancer; this is also in line with the knowledge of the general population. Simon et al reported that smoking as a risk factor for lung cancer was recalled by 85% of the population and recognized in a list of factors by 94% of the population [21].

The opinion about the posts on YouTube (measured by the number of likes and dislikes, as reported in Table 1) should be viewed cautiously due to the small number of observations. The range of "like" posts was between 0 and 16 and "dislike" between 0 and 4, while the number of viewers ranged from 17 to 10,350. Moreover, for the posts that were retrieved in both time points, the number of likes and dislikes did not change significantly.

The difference between YouTube and Twitter for the number of days of a post's availability on the Web (P<.001) is explained by the fact that the Twitter search was performed by date and that posts on YouTube were classified by relevance. The search by date for Twitter and relevance for YouTube were used because they were the default options and therefore, probably the most frequently used by the population. Nevertheless, no differences between YouTube and Twitter were reported in the source of information and the country of the publisher, making the information comparable.

When using Google search as an indicator of the information about genetics and smoking available on the Web, we first observed differences between the posts retrieved on social media. As we expected, most websites were scientific publications (46.5%) or referred to scientific publications

(53.5%). Six scientific publications were referred at least once in the Google search and either on YouTube or Twitter [13-15,22-24]. The second objective of searching on Google was to discover any other social media that included discussions of genetics and smoking. Despite our expectations, no social media, such as health forums or blogs, were retrieved. This might be explained by the novelty of the topic.

Information on genetic testing and smoking is already on the Web with direct-to-consumer testing such as 23andMe where they look for the *CHRNA3* gene, more specifically the variant rs1051730. *CHRNA3* is a nicotinic receptor. Tests on smoking-related disorders are also available on 23andMe for lung cancer. As proposed by Pray in 2008, "imagine reading this warning on a cigarette package: Smokers with a particular mutation have a dramatically higher risk of developing lung cancer. Would you get tested for this mutation?" [25]. In the future, this kind of message may also be displayed on social media.

The way that individuals understand the posts on YouTube and Twitter should be assessed in a further study. Indeed, it is becoming more common that people are looking to different social media to get information about their health [3]. As public health genomics, personalized medicine, and personalized health terms become more commonly known terms, the public, including the general population, patients, and health professionals, will certainly look to social media to learn more about them and discuss them. Hence, information must be translated and communicated in a way for the general public to understand, especially since genome-based information, which includes genetic information, is a complicated topic for the nonscientific population.

Providing health information via social media and developing methods to evaluate their impact may help in effectively increasing health literacy and risk awareness in an innovative way, with attention to avoiding the introduction or widening of health inequalities. However, to generate effective health information messages, different conditions may be needed depending, for example, on the topic, target group, or society, taking into account both environment (internal and external) and the process of information (automatic and rational) [26]. Therefore, there is a real need to develop efficient communication tools to improve the health and genetic literacy of the population. Moreover, any message should aim to be correct, clear, and adapted to the target population to maximize understanding of the content. Also, any ethical and legal issues of displaying such messages should be considered. Achieving these conditions is of critical importance to develop quality information that can be obtained and understood by those accessing it and those who need it.

Future research should examine the impact that information about genetics and smoking on popular social media has on target population literacy and behaviors. Exposure to genetic information about smoking in social media might be examined in various target populations (eg, university students and pregnant women) in controlled settings where the target population is exposed to different genetic information about smoking during a certain period of time (eg, 1 week). After the exposure step, the impact of the information and information channel on different outcomes (eg, behavior change, genetics and smoking knowledge) would be assessed. The exposure-outcome relationship might then be evaluated using advanced statistical methods, such as structural equation modeling. Finally, as with any communication channel, content spread through social media channels should be carefully scrutinized by the reader. All media have the potential to include biased and misleading information, but social media platforms can spread such information rapidly. At the same time, social media platforms also allow for corrections and dialog about content to occur quickly and transparently. Moreover, information may or may not be beneficial, but the ability to understand if the information is credible and ways in which to improve critical thinking and appraisal skills of social media users should be a priority of research and practice as well as codes of conduct for posting information.

Limitations

The most important limitation of our study is that we collected data from channels that change rapidly, at only two points in time. Consequently, the posts that were selected in our review may not be reflective of what is posted at another time. The collection of data at time points separated by 9 months may give better insights of the evolution of posts over time. However, as the content posted on social media happens constantly, data collected over time points may yield different results. Particularly on Twitter, our results are likely to be different depending on the time of the search. For example, at Time 1, we observed that 35.2% of the posts were based on the lyrics of a song, which are likely to be ephemeral. At Time 2, only 16.0% of the posts referred to that song.

The search strategy may have resulted in posts being missed. We limited the search to two search terms ("genetic" and "smoking") and the first hundred posts, which may not have captured all the relevant posts. However, the results obtained in our search provide a reasonable perspective of what someone interested in smoking and genetics would find on the topic on YouTube, Facebook, and Twitter. Facebook, as a relatively closed system, did not allow an in-depth look at the posts of users.

The limits on the three selected social media may influence the obtained results. Other social media such as health forums might lead to different results.

Implications for Practice and Research

This study focused on the availability of information on genetics and smoking and serves as a baseline measure from September 2012 and May 2013. Given the growing use of social media for health purposes, there is a need to monitor this situation over time to avoid the dispersion of false information. The topic of genetics and smoking is not currently widely discussed on the three social media platforms chosen. However, this is expected to change due to growing concerns about genetics in other media such as newspapers. This study did not provide any information on the profile of the viewers (eg, smokers or nonsmokers) or the use of that information (eg, subsequent change in smoking behavior). A future study assessing the habits and the

characteristics of the population looking for health information (eg, general population, patients, and health professionals) and more specifically, information about genetics and smoking, will be needed. Moreover, a better overview of the users' understanding of the displayed information will be of high importance. Also, from the scientific point of view, the concept of "genetic information" needs to be broadened towards "genome-based information", taking into account emerging knowledge from the whole "omics" field including epigenomics and the interaction of genomics and environment, such as in the case of smoking.

This study suggests that most of the information about genetics and smoking available on social media referred to scientific publications displayed by different kind of publishers (research center, news, and medical news). Increasing access to such information might improve the health and the genomic literacy of the population and, therefore, enhance smoking prevention and cessation.

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Conflicts of Interest

None declared.

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Abbreviations

CHRNA3: Neuronal Acetylcholine Receptor subunit Alpha-3
COPD: Chronic Obstructive Pulmonary disease
EAPM: European Alliance for Personalised Medicine
ITFoM: IT Future of Medicine
PHGEN: Public Health Genomics

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Original Paper

Online Mental Health Resources in Rural Australia: Clinician Perceptions of Acceptability

Craig Sinclair[1], BSc (Hons), PhD (Psych); Kristi Holloway[2], BSc (Hons); Geoffrey Riley AM[1], MBBS, FRCPsych, FRACGP, FRANZCP, FACRRM; Kirsten Auret[1], MBBS, FRACP, FAChPM

[1]Rural Clinical School of Western Australia, University of Western Australia, Perth, Australia

[2]Curtin Health Innovation Research Institute, School of Nursing and Midwifery, Curtin University, Perth, Australia

Corresponding Author:
Craig Sinclair, BSc (Hons), PhD (Psych)
Rural Clinical School of Western Australia
University of Western Australia
M701, University of Western Australia, Hackett Dve, Crawley, WA
Perth, 6009
Australia
Phone: 61 8 9842 0829
Fax: 61 8 9842 0821
Email: craig.sinclair@rcswa.edu.au

Abstract

Background: Online mental health resources have been proposed as an innovative means of overcoming barriers to accessing rural mental health services. However, clinicians tend to express lower satisfaction with online mental health resources than do clients.

Objective: To understand rural clinicians' attitudes towards the acceptability of online mental health resources as a treatment option in the rural context.

Methods: In-depth interviews were conducted with 21 rural clinicians (general practitioners, psychologists, psychiatrists, and clinical social workers). Interviews were supplemented with rural-specific vignettes, which described clinical scenarios in which referral to online mental health resources might be considered. Symbolic interactionism was used as the theoretical framework for the study, and interview transcripts were thematically analyzed using a constant comparative method.

Results: Clinicians were optimistic about the use of online mental health resources into the future, showing a preference for integration alongside existing services, and use as an adjunct rather than an alternative to traditional approaches. Key themes identified included perceptions of resources, clinician factors, client factors, and the rural and remote context. Clinicians favored resources that were user-friendly and could be integrated into their clinical practice. Barriers to use included a lack of time to explore resources, difficulty accessing training in the rural environment, and concerns about the lack of feedback from clients. Social pressure exerted within professional clinical networks contributed to a cautious approach to referring clients to online resources.

Conclusions: Successful implementation of online mental health resources in the rural context requires attention to clinician perceptions of acceptability. Promotion of online mental health resources to rural clinicians should include information about resource effectiveness, enable integration with existing services, and provide opportunities for renegotiating the socially defined role of the clinician in the eHealth era.

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KEYWORDS

mental health; Internet; rural health; qualitative research

Introduction

Rural mental health presents a unique set of challenges in which limited resources are available to service communities already burdened by significant risk factors for mental health problems, including social isolation [1,2] and financial uncertainty [3]. Research has indicated problems for people in rural areas in accessing conventional mental health services, due to service

provision shortages [4], attitudinal factors [5,6], financial and geographical barriers [7], and concerns about anonymity [7,8].

In Australia, recent developments in online technology and expanded infrastructure supporting Internet access [9] have opened the possibility for mental health services to be delivered over the Internet in rural areas [10]. In combination with a national program to upgrade access to high-speed Internet in regional areas, the Australian government has published a strategy for a nationally coordinated approach to online mental health, which includes online information resources and the development of a virtual clinic [9]. Online approaches to mental health service delivery include therapy delivered across the Internet [11], Internet support groups [12], and specific mental health websites, some of which are supported by technicians or therapists [13]. Research has established the efficacy of a number of standalone websites [14,15], and some have suggested that supplementing traditional mental health services with these online mental health resources may be effective in overcoming access issues in rural communities [10,13]. In this paper, we focus specifically on these mental health websites when using the term “online mental health resources”.

Recent studies have assessed different approaches to the delivery of online mental health resources, including community-based models [16], enhanced primary health care [17], and promotion in educational settings [18]. There is recognition that the implementation of online mental health resources in clinical settings is dependent on clinicians’ attitudes towards the resources [17,19]. Acceptability, defined as “the degree that patients, clinicians, or others are comfortable or at ease with a service and willing to use it” (p. 259 [20]), has been proposed as an important determinant of intentions to use online mental health resources. While a number of studies have demonstrated that consumers typically find online mental health resources to be acceptable [20-23], few studies have examined clinicians’ perceptions of the acceptability of online mental health resources or articulated the situations in which clinicians would consider referral of a client to online mental health resources as “acceptable”. A Norwegian study found that psychologists showed positive attitudes to therapy delivered over the Internet by a clinician, though a majority felt that this would work only as a supplement to face-to-face communication [19]. One survey of cognitive-behavioral therapists in the United Kingdom found that clinicians had low awareness of, and ambivalent attitudes toward, computerized cognitive behavioral therapy (cCBT) [24]. A systematic review of barriers to uptake of cCBT found that clinicians expressed more negative attitudes than clients [25]. Similar findings have emerged from early work in the area of online mental health resources. An Australian survey found that health professionals showed less positive attitudes toward online mental health resources than the general public and less intention to use these resources in the future [20].

While some have suggested that online mental health resources may make a significant contribution to rural mental health service delivery [10], little empirical data have been collected in rural settings [11,15]. Understanding the attitudes of rural clinicians toward the use of online mental health resources in the rural context will be important if these resources are to be widely implemented. This study adopted a qualitative approach, exploring rural clinicians’ perceptions of online mental health resources and their attitudes towards referral of clients to these resources, in the rural context.

Symbolic interactionism was employed as a theoretical framework for the study. Symbolic interactionism asserts that humans make decisions about action based on the symbolic meanings ascribed to these actions, which are learned through social interactions and reflection on the self from the imagined perspective of others [26]. In this way, a clinician’s decision about referral to online mental health resources can be thought of as a symbolic action, the meaning of which is defined based on his or her perceptions and through interactions with others. This perspective sensitizes the researcher to the contexts within which clinical decision making occurs and the importance of the social interactions that inform clinicians’ perceptions of the acceptability of online mental health resources.

Methods

This study adopted a qualitative descriptive approach [27,28] to facilitate a thorough exploration of clinicians’ perceptions relating to online mental health resources. The method of constant comparison was used to collect and analyze the data [29]. Recruitment took place in two defined phases, and data analysis occurred concurrently with data collection. In total, 21 rural clinicians participated in individual interviews (n=17) or a group discussion (n=4), which were conducted face to face (n=19) or by telephone (n=2) and lasted for an average of 51.6 minutes (SD 15.6). A brief demographic questionnaire was administered prior to the interview, and a summary of participant characteristics is provided in Table 1.

Table 1. Summary of participant characteristics.

Characteristic	Phase 1	Phase 2
Age, mean (SD), years	47 (10.6)	52 (7.9)
Gender (female, male)	10 female, 3 male	3 female, 5 male
Experience providing mental health services, mean (SD), years	18.2 (9.6)	16.9 (8.1)
Remote/very remote mental health service experience, n (%)	4 (31)	7 (87.5)
General practice (n)	4	4
Mental health specialists (n)	9	4

Phase 1

Sampling

In Phase 1, sampling was through formal invitations sent to community-based rural mental health organizations and convenience sampling of rural mental health specialists (psychologists, psychiatrists, and clinical social workers) and general practitioners. Two of the authors, a rural health researcher (CS) and an experienced rural psychiatrist (GR), developed an initial discussion guide in consultation with existing literature (see Multimedia Appendix 1). Open-ended questions were used to explore participants' awareness and perceptions of online mental health resources and their typical patterns of referral of clients to online mental health resources in the rural context.

"Quick Guide" Resource Sheet

Anecdotal reports from clinicians during study development and previous research [24] suggested low levels of awareness of online mental health resources among clinicians. Participants were provided with a quick guide to a selection of commonly used, evidence-based online mental health resources (ReachOut [30], MoodGym [31], and BluePages [32]), as well as a portal website (Beacon [33]), all of which are based in Australia. The quick guide facilitated practitioners' exploration of a selection of relevant websites prior to the interview, to encourage richer responses. It also encouraged participation by some who might otherwise have "self-selected" out of the study due to lack of prior experience with the resources. In this way, the present method goes some way to overcoming the self-selection bias present in a previous similar study, which recruited health professionals via the Internet [20].

Phase 2

Sampling

In Phase 2, purposeful sampling recruited clinicians with experience delivering mental health services in remote or very remote settings (Accessibility Remoteness Index of Australia >5.92) [34]. The discussion guide was refined to focus on issues specific to the rural and remote context (see Multimedia Appendix 1). The interview protocol also employed a set of vignettes designed to facilitate deeper discussion and explore clinicians' attitudes toward referral of clients to online mental health resources.

Vignettes

Based on data collection and analysis in Phase 1, the researchers developed a set of vignettes describing three hypothetical, rurally based clinical scenarios in which referral of a client to online mental health resources might be considered (see Multimedia Appendix 2). The clinically relevant aspects of the scenarios were standardized across interviews, but some aspects were optimized to each participant's situation (names of towns were personalized to the participant's catchment area, and terms such as "therapy" and "consultation" were used for mental health specialists and general practitioners respectively). Participants were asked to rate the overall plausibility of each scenario on 5-point Likert scales (1=highly implausible to 5=highly plausible) and give their opinions about the acceptability of referral to online mental health resources in each case. Eight participants recruited during Phase 2 completed the questionnaire as part of the interview protocol, and 7 participants recruited during Phase 1 were contacted again and responded by email. The mean plausibility ratings for each vignette were all greater than 4 (Vignette 1: mean 4.4, SD 1.2; Vignette 2: mean 4.6, SD 0.6; Vignette 3: mean 4.7, SD 0.6).

Analysis

Interview transcripts were analyzed using NVivo Version 10, following an iterative process of open, focused, and theoretical coding to extract codes, categories, and themes from the interview transcripts. Relational coding was used to articulate relationships between open codes and to identify categories [35]. Two rurally based health researchers (CS, KH), with training in psychology and nursing respectively, independently coded the first 10 transcripts and discussed any discrepancies until consensus. This led to the development of a preliminary coding framework. During ongoing data analysis (conducted by CS), an audit trail documented addition of any new codes or changes to the coding framework. Discussion of the themes among the research team, which included an experienced rural psychiatrist (GR), ensured the clinical relevance of the findings reported.

Rigor of the research process is demonstrated by its credibility, dependability, confirmability, and transferability [36]. Credibility was addressed by involving the interviewer throughout the analysis process. Dependability was enhanced by a thorough methodological process and clear audit trail. To address confirmability, exemplars are provided that illustrate key themes, and member checking was incorporated during Phase 2 [37]. The inclusion of health professionals from various mental health disciplines and locations of practice helps to establish the transferability of findings of this study.

The Human Research Ethics Committees of the University of Western Australia (RA/4/1/4660) and the Western Australian Country Health Service (2012:01) approved the study protocols.

Results

Overview and Key Themes

Clinicians framed their responses using examples drawn from their experiences delivering mental health services in the rural context. The key themes extracted from the transcripts were "perceptions of resources", "clinician factors", "client factors", and "the rural and remote context". An overarching theme of "integration with existing services" characterized participant responses.

Perceptions of Resources

Clinicians typically expressed positive perceptions towards online mental health resources and perceived that client use was on the increase. The perceived effectiveness of online mental health resources was attributed primarily to the provision of clear and easily accessible psychoeducation, which could be used in early intervention, helping clients normalize symptoms and encouraging future help-seeking. Most acknowledged that they received limited feedback from clients who were using the

resources, precluding direct comments about clinical efficacy. Some clinicians had identified their own "favorite" resources, which they referred to regularly and integrated into their clinical practice, often by printing handouts for clients. Clinicians emphasized that resources providing clear, quickly accessible information would be most appropriate for clients:

> *I mean one of the things I noticed is if you get to a home page and there are too many options and go here, go there, and all these things hanging off, it can be quite overwhelming and thinking about some of the minds and emotional states that my clients might be in and how this is going to feel for them.* [Psychologist]

An emphasis on "usability" had the added benefit of enabling clinicians to integrate the resources within the time demands of their clinical practice, allowing them to guide clients through an online resource or quickly access printable information. Others suggested that user-friendly online resources could be made available on public computers in clinic waiting rooms, assisting in psychoeducation, or providing material for further discussion with the clinician.

Clinician Factors

Clinicians preferred to be familiar with online mental health resources prior to recommending them to clients. However, they experienced difficulties finding time to explore the range of available resources:

> *The brief look I have had has been done on the run…with a specific client in mind just to see what was there…it hasn't been done with sufficient time and focus to really seriously engage and immerse myself with what is there…* [Psychologist]

Clinicians who were younger and trained more recently tended to show acceptance for the integration of online approaches within their everyday practice:

> *We're being trained and informed about these online resources. The older doctors, I don't imagine, are using them as much.* [General Practitioner Registrar]

Older, more experienced clinicians sometimes reported barriers associated with computer literacy, as well as a more general lack of exposure to online mental health resources during their training. For rural clinicians, this was compounded by the difficulties associated with accessing ongoing professional development. Some participants who had received professional development associated with a particular online mental health resource then felt more comfortable integrating it into their routine practice. Clinicians who were unable to access professional development looked to their professional networks for guidance, with mixed results. In one case, a clinician told of receiving criticism from some colleagues for raising a question about online approaches to mental health service delivery:

> *I recently asked…whether anyone had had any experience [using online mental health resources] among our group and everyone said, "No" and kind of suggested that even to consider that seemed ridiculous.* [Psychologist]

The benefits and concerns relating to online mental health resources showed some patterns of variation across professional groups. Mental health specialists (psychologists, psychiatrists, clinical social workers) were more likely than general practitioners to identify the provision of psychoeducation and early intervention as benefits. However mental health specialists also emphasized the importance of an ongoing therapeutic relationship as a mechanism for client recovery and were concerned that unsupervised use of online mental health resources might encourage self-diagnosis and "catastrophizing".

> *You can get people getting online and then getting into the information online and if you were anxious and a worrier before you started wait 'til you have spent a couple of hours online looking at how anxious and worried you really could be, so I think there can be a bit of a snowball, some catastrophizing can occur.* [Clinical Social Worker]

General practitioners, on the other hand, tended to identify the capacity for clients to access psychoeducation in their own time as a benefit. Both groups endorsed the ability of online mental health resources to enable greater access to mental health services, but were concerned about the lack of ability to follow up with clients about their progress.

Client Factors

Participants identified a range of client factors thought to influence suitability for referral to online mental health resources. Younger people (particularly adolescents) were perceived as having greater computer literacy and being more willing to seek information online. Those with common mental disorders such as anxiety or depression, and symptoms in the mild to moderate range, were also considered to be more suitable than clients with complex diagnoses or severe and persistent symptoms:

> *Any [condition] that sort of begs the question about psychoeducation, you know what can people find out themselves, how can they gather knowledge quickly and effectively themselves.* [Clinical Social Worker]

Clients who were prone to excessive rumination or who lacked the motivation or attention to read information online were considered less suitable. Participants also expressed concern that some clients in rural areas lacked private Internet access, had reading difficulties, or lower levels of computer literacy.

Rural and Remote Context

Clinicians consistently identified the rural and remote context as one in which people had less access to mental health services, and less choice among service providers. They reported that concerns about anonymity in small communities left many rural clients unwilling to access specialist mental health services. Online mental health resources provided an opportunity for rural clients to access information confidentially, and clinicians endorsed use of the resources where they might assist in normalizing symptoms and encouraging future help seeking. On the other hand, some clinicians identified the potential for certain rural environments to be a recipe for social isolation and

rumination and saw the potential for online mental health resources to have a negative impact, particularly if used as a sole source of information:

> *In certain particularly remote environments that might then intensify the focus on you know what comes through this [online] medium.* [Psychologist]

Clinicians reported that many rural clients lacked reliable Internet access or sufficient privacy to access online mental health resources confidentially. While regional centers were relatively well serviced, access was less consistent in more remote areas, and the lack of community resources marginalized poorer people. One clinician felt that this constituted an area of rural disadvantage:

> *Often online services have been looked at as, you know, the great hope for areas where there aren't real services for people, but where there isn't adequate Internet access, you are further marginalizing people who live in remote areas who now don't have access to two different services…* [Psychiatrist]

Some clinicians who expressed concerns about rural disadvantage feared that a reallocation of investment toward online mental health resources might compromise the provision of adequate community mental health services in rural areas.

Integration With Existing Services

In describing their current referral practices or responding to the hypothetical vignette scenarios, clinicians considered the interaction of clinician, client, and resource factors within the rural and remote context. Their responses were characterized by a preference for integration of online mental health resources alongside existing services. Clinicians acknowledged that referral came with the risk of negative outcomes, including the client feeling neglected, experiencing frustration due to poor Internet access or lack of computer literacy, or misinterpreting online information. Some foresaw that this could lead to a loss of trust in the ongoing relationship, perhaps resulting in disengagement, along with an escalation of symptoms, for which they felt personally responsible:

> *You send someone off to a machine and they kill themselves or their child or something. It would be very hard to live with, wouldn't it?* [General Practitioner]

Acknowledgment of these risks contributed to a preference for online mental health resources to be used as an adjunct, rather than an alternative, to face-to-face therapy. Clinicians managed the client's use of online mental health resources, fostering realistic expectations, and using online information as material to further develop their therapeutic relationship with the client:

> *So what I am trying to do there is…try and manage it so they have a good experience, you know, a positive experience, then they will keep using it, but if they have that sort of frustrating adverse [experience]…then they'll often overgeneralize and just disengage.* [Psychologist]

Referral decisions tended to be more polarized when the client experienced unwillingness or severe difficulty in accessing face-to-face services. Some clinicians feared that the use of online mental health resources in this situation might lead clients to disengage entirely from face-to-face services. Others suggested online mental health resources to clients who they felt were likely to disengage, in the hope of establishing a "bridge" for future contact. One clinician felt that the vignette describing "Matthew" (see Multimedia Appendix 2) was a situation where online mental health resources might be used to good effect to maintain a relationship with the client:

> *If you have the feeling that [client] is not going to come back again, because he can't be forced, it's not a decision of mine, it's a decision of his. Like that [online personality questionnaire] is actually very useful for them to come back…there's actually material that enables you to provide some more face-to-face work.* [Psychiatrist]

In some cases, the potential to refer clients to online mental health resources appeared to have changed the nature of the clinical relationship. Some clinicians referred clients to online mental health resources as a means of strengthening the therapeutic relationship. The "prescription" of homework validated the client's concern, and access to a second opinion enabled clients to evaluate the clinician's diagnosis and be more in control of their condition:

> *People then have permission to become a little bit expert themselves about whatever their condition is.* [Clinical Social Worker]

However, not all clinicians viewed this change in a positive way. One general practitioner referred to clients bringing information from online mental health resources to consultations to support their argument that they did not require medication:

> *I had a couple of young patients who very clearly were people that you would want to consider medication for, who actually quoted that site as evidence that, yeah, it didn't have a role.* [General Practitioner]

Discussion

Principal Findings

This paper addresses a gap identified in previous literature [11,15] reporting on the perceptions of clinicians towards online mental health resources, and their use of these resources, in the rural context. The barriers to accessing mental health services in the rural setting have been well documented [4-7,38,39]. Participants in this study were optimistic about the use of online mental health resources as an innovative means of overcoming some of the barriers to accessing rural mental health services, supporting previous literature [10,13]. However, concerns that referral to online mental health resources may have adverse effects in some situations contributed to a preference that online approaches were employed as an adjunct rather than an alternative to traditional forms of mental health service delivery. This finding is consistent with previous literature, which has shown that clinicians typically express less positive attitudes

towards online mental health resources than do clients [20,25,40].

Rural clinicians showed a preference for integrating online approaches with existing services. For example, the preference that online mental health resources present clear, simple, and quickly accessible information was motivated by concerns for the client but also by a desire to integrate these resources within the time demands of clinical consultations. Others suggested that providing public computers in clinic waiting rooms could be helpful. In both cases, usability was a key factor. The "technology acceptance" model proposes that the perceived usability and perceived usefulness of a technological aid will determine the extent to which it is accepted and adopted [41]. This model has been cited in previous literature relating to consumer acceptance of online mental health resources [42]; it may also be relevant in understanding acceptance and adoption by clinicians. However, it should also be noted that perceptions of "usability" are contextual and may differ between clinicians, clients, and website developers [40].

Researchers employing symbolic interactionism in the study of online behavior in nonclinical contexts have suggested that while transition to an online medium may "revolutionize" the surface features of social interaction, the underlying attributes of human action and interaction remain stable [43]. Robinson et al found that, after an initial process of redefining social rules in the online environment, the types of social interaction deployed online were characterized by an augmentation of existing practices, or "evolution", as opposed to "revolution" [43]. When considering referral of clients to online mental health resources, clinicians preferred to see them used as an adjunct rather than an alternative to existing services. When they did refer clients to online mental health resources, it was typically an attempt to strengthen or enrich an ongoing clinical relationship. Within the framework of symbolic interactionism, clinicians' preference for a carefully managed augmentation of existing services can be interpreted with reference to the socially defined role of the clinician and the symbolic significance of the act of referral. Our observation of social pressure exerted by some clinicians on their colleagues to reject online approaches illustrates how tension can arise when a treatment clashes with this socially defined role. From this perspective, clinicians incorporate intrinsic judgments of acceptability, along with the expectations accompanying their socially defined role, in responding to the clinical, ethical, and social implications of referral to online mental health resources. The socially defined expectations as to how mental health service delivery proceeds (client seeks help by reporting symptoms to a clinician, who establishes a relationship and delivers face-to-face therapy) may constitute a barrier to the implementation of online mental health resources in partnership with clinicians. However, research has shown how role expectations can respond to cultural shifts. One study found that general practitioners reported increasing numbers of patients bringing health information from the Internet to consultations and that some responded by restructuring their role from "gatekeeper to secondary care to facilitator of information interpretation and decision-making" (p. 93 [44]). A recent study showed that referral by a clinician to an online mental health resource resulted in higher levels of participation when the method of referral maximized the client's intrinsic motivation, through provision of patient-focused information, rather than reliance on clinician recommendation [45]. Interviews with clients using online mental health resources have illustrated the important ongoing role of the clinician as a provider of support and facilitator of deeper understanding of information accessed through online mental health resources [46]. Changing the socially defined role of the clinician to that of a facilitator of patient-directed information seeking and decision making may be an important precursor to more effective referral of clients to online mental health resources, resulting in greater uptake and reduced attrition.

It is important to recognize that the clinician's decision to refer to online mental health resources occurs from within a pre-existing clinical relationship. Research into the mechanisms of successful psychotherapy has stressed the importance of the clinical relationship or "therapeutic alliance" between the clinician and client [47]. Rodin and Janis theorized that the clinician's ability to encourage client adherence to clinical recommendations relies on the clinician's possession of "expert" power (possession of valuable information and skills) and "referent" power (social influence stemming from a strong and trusting clinical relationship) [48]. Clinicians acknowledged and endorsed the expert power of evidence-based online mental health resources to provide high quality psychoeducation. However, their concerns about the resources being used as an alternative to traditional face-to-face therapy may stem from the absence of referent power in the online environment or the potential for referral to online mental health resources to have a negative impact on the clinician's referent power. Concerns about negative impacts of referral to online mental health resources on the clinical relationship (eg, loss of trust, client feeling neglected) may partly explain the difficulties experienced in previous attempts to implement online mental health service delivery through referrals in primary health care settings [17].

Limitations

The convenience sampling method used in the present study is a limitation. It is possible that the sampling method may have led to a self-selecting bias, in which clinicians who were particularly opposed to the use of online mental health resources decided not to participate. The combination of data from a group discussion alongside that collected from individual interviews also adds a further layer of complexity to the analysis. However, we observed similar thematic content in both group and individual interview settings.

Another limitation is associated with the small number of public sector (government-employed) mental health professionals recruited. These professionals typically see a greater proportion of clients with severe and persistent mental illness and may be more sensitive to the risks of adverse consequences. Despite this limitation, those public sector employees who did participate were able to provide insight into the differences experienced in this context and the implications for the use of online mental health resources.

The use of vignette scenarios to frame discussions about referral to online mental health resources is useful for eliciting factors affecting decision making but does not enable reliable inferences

to be drawn about future behavioral intentions in similar situations [49]. However, the high plausibility ratings given by participants suggests that the vignette scenarios provided a useful foundation for more in-depth discussion about the specific factors influencing referral decisions in a number of concrete scenarios relevant to the rural context.

Implications

The referral of a client by their clinician is just one of a number of ways in which a client may discover and access online mental health resources. Research in Australia has mirrored trends across the developed world, showing that the public are increasingly using the Internet as a source of information about health conditions [22,50]. As health services evolve to meet changing societal expectations, it can be expected that rates of clinicians referring clients to online mental health resources will also increase. Further research is needed to explore the perceptions of health professionals in other rural and remote areas and the educational needs of clinicians relating to the use of online resources.

The argument that clinicians negotiate both intrinsic judgments of acceptability and the expectations accompanying their socially defined role, when making decisions about referral to online mental health resources, has a number of clinical and educational implications. First, it suggests that efforts to promote online mental health resources should target professional networks, as well as individual clinicians, using collaborative in-service approaches to address educational requirements and encourage cultural change.

The technology acceptance model suggests that both perceived usefulness and perceived usability will contribute to adoption of the technology [40]. This suggests that promotion of online mental health resource "usefulness" (by communicating results of clinical trials) should not be at the expense of the more basic enabling work, which underlies the perception of "usability" within the everyday clinical environment.

Conclusion

The impressive results yielded by some trials of online approaches to mental health service delivery have led some commentators to call for "disruptive innovation" to improve outcomes [51]. The present research suggests that in the rural context, clinicians favor a more conservative approach, in which online approaches augment traditional face-to-face approaches to mental health service delivery. Ongoing negotiation of the clinician's role in the emerging eHealth era will be a crucial factor in enabling widespread integration and implementation of online mental health resources.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Discussion guides used in Phases One and Two.

[PDF File (Adobe PDF File), 243KB - jmir_v15i9e193_app1.pdf]

Multimedia Appendix 2

Vignettes used during Phase Two.

[PDF File (Adobe PDF File), 241KB - jmir_v15i9e193_app2.pdf]

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Abbreviations

cCBT: computerized cognitive behavioral therapy

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Original Paper

An Internet-Based Intervention to Promote Mental Fitness for Mildly Depressed Adults: Randomized Controlled Trial

Linda Bolier[1,2], MSc; Merel Haverman[3], MSc; Jeannet Kramer[3], PhD; Gerben J Westerhof[2], PhD; Heleen Riper[4,5], PhD; Jan A Walburg[2,6], PhD; Brigitte Boon[1], PhD; Ernst Bohlmeijer[2], PhD

[1]Trimbos Institute (Netherlands Institute of Mental Health and Addiction), Department of Public Mental Health, Utrecht, Netherlands

[2]University of Twente, Department of Psychology, Health and Technology, Enschede, Netherlands

[3]Trimbos Institute (Netherlands Institute of Mental Health and Addiction), Innovation Centre of Mental Health & Technology I.COM, Utrecht, Netherlands

[4]VU University, EMGO institute for Health and Care research, Amsterdam, Netherlands

[5]Leuphana University, Innovation Incubator, Lueneburg, Germany

[6]Trimbos Institute (Netherlands Institute of Mental Health and Addiction), Board of Management, Utrecht, Netherlands

Corresponding Author:
Linda Bolier, MSc
Trimbos Institute (Netherlands Institute of Mental Health and Addiction)
Department of Public Mental Health
Da Costakade 45
Utrecht, 3521 VS
Netherlands
Phone: 31 302971100
Fax: 31 302971111
Email: lbolier@trimbos.nl

Abstract

Background: Depression is a worldwide problem warranting global solutions to tackle it. Enhancing well-being has benefits in its own right and could be a good strategy for preventing depression. Providing well-being interventions via the Internet may have synergetic effects.

Objective: Psyfit ("mental fitness online") is a fully automated self-help intervention to improve well-being based on positive psychology. This study examines the clinical effects of this intervention.

Methods: We conducted a 2-armed randomized controlled trial that compared the effects of access to Psyfit for 2 months (n=143) to a waiting-list control condition (n=141). Mild to moderately depressed adults in the general population seeking self-help were recruited. Primary outcome was well-being measured by Mental Health Continuum-Short Form (MHC-SF) and WHO Well-being Index (WHO-5); secondary outcomes were depressive symptoms, anxiety, vitality, and general health measured by Center for Epidemiological Studies Depression Scale (CES-D), Hospital Anxiety and Depression Scale Anxiety subscale (HADS-A), and Medical Outcomes Study-Short Form (MOS-SF) vitality and general health subscales, respectively. Online measurements were taken at baseline, 2 months, and 6 months after baseline.

Results: The dropout rate was 37.8% in the Psyfit group and 22.7% in the control group. At 2-month follow-up, Psyfit tended to be more effective in enhancing well-being (nonsignificantly for MHC-SF: Cohen's d=0.27, P=.06; significantly for WHO-5: Cohen's d=0.31, P=.01), compared to the waiting-list control group. For the secondary outcomes, small but significant effects were found for general health (Cohen's d=0.14, P=.01), vitality (d=0.22, P=.02), anxiety symptoms (Cohen's d=0.32, P=.001), and depressive symptoms (Cohen's d=0.36, P=.02). At 6-month follow-up, there were no significant effects on well-being (MHC-SF: Cohen's d=0.01, P=.90; WHO-5: Cohen's d=0.26, P=.11), whereas depressive symptoms (Cohen's d=0.35, P=.02) and anxiety symptoms (Cohen's d=0.35, P=.001) were still significantly reduced compared to the control group. There was no clear dose–response relationship between adherence and effectiveness, although some significant differences appeared across most outcomes in favor of those completing at least 1 lesson in the intervention.

Conclusions: This study shows that an online well-being intervention can effectively enhance well-being (at least in the short-term and for 1 well-being measure) and can help to reduce anxiety and depression symptoms. Further research should focus on increasing

adherence and motivation, reaching and serving lower-educated people, and widening the target group to include people with different levels of depressive symptoms.

Trial Registration: Netherlands Trial Register (NTR) number: NTR2126; http://www.trialregister.nl/trialreg/admin/rctview.asp?TC=2126 (archived by WebCite at http://www.webcitation.org/6IIiVrLcO).

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KEYWORDS

public health; prevention; depression; well-being; randomized controlled trial; Internet

Introduction

Relevance of Well-Being

Depression is a highly prevalent problem worldwide [1], which underscores the global urgency of tackling this mental illness [2]. The average lifetime prevalence estimates of major depressive episodes is 15%, with 1 in 20 people suffering from major depressive episodes at any given time [1]. In addition, many more people present subclinical depressive symptoms, putting them at greater risk of going on to develop a full-blown mental disorder [3]. The enhancement of well-being may be just as important in dealing with poor mental health as treating the symptoms of depression [4]. Ample studies show that the level of well-being is a predictor of psychopathology, independent of the influence of negative affect [5,6]. The presence of well-being is also beneficial in its own right. Well-being is associated with a healthier and longer life [7,8], prosocial behavior, and maintenance of high-quality relationships with family and friends [7]. Thus, well-being may play a role both in supporting health and human functioning and in reducing symptoms of mental illness.

Three different types of well-being have been identified in various studies. *Subjective well-being* refers to positive affect and/or life satisfaction [9], *psychological well-being* refers to the level of positive functioning, containing constructs such as meaning in life, goal setting, and mastery [10], and *social well-being* contains constructs such as the level of social integration and social contribution [11].

Positive Psychology

In the emerging field of positive psychology, interventions aimed at flourishing and positive functioning are being developed and evaluated. These interventions focus on individual competencies and strengths, rather than on mental symptoms and disorders [12]. Examples of interventions are "counting your blessings" [13], "practicing kindness" [14], "expressing gratitude" [13,15], and "using your personal strengths" [13]. Positive psychology also embraces other like-minded traditions, such as mindfulness [16] and life review [17].

Evidence of the effectiveness of positive psychological interventions was reviewed in 2 meta-analyses showing that these interventions enhance well-being and reduce depressive symptoms [18,19]. In addition, positive psychological interventions may reach people who are otherwise more difficult to connect with. People presenting subclinical depression or other problems, such as stress and anxiety, may find a well-being approach more appealing than a problem-oriented approach [20]. One of the main obstacles worldwide in mental health care is to reach people in need of treatment or prevention with good quality interventions [21]. By their inherent appeal, positive psychological interventions may help to narrow this mental health gap.

Combining Positive Psychological Interventions and the Internet

Providing positive psychological interventions via the Internet may offer synergetic opportunities. The effectiveness of online problem-based interventions (eg, in reducing depressive symptoms or anxiety [22] or problematic alcohol use [23]) has been demonstrated meta-analytically. Internet interventions, especially self-help interventions, may be more affordable and accessible for many people as opposed to face-to-face interventions [24]. Therefore, online positive psychological interventions may offer the most suitable and effective strategy for reaching large target groups. To date, a literature review of the effectiveness of online positive psychological interventions has shown mixed results [25]. In this review, 5 randomized controlled trials were included [26-30], of which 3 demonstrated enhanced well-being [27,29,30] and 3 showed significant symptom reduction [28-30]. The authors concluded that there is still an "effectiveness gap between offline and online formats" in positive psychological interventions [25]. In more recent studies of online positive psychological interventions, mixed results were also found. In a comprehensive study by Gander et al [31], 9 online positive psychological interventions were compared to a placebo exercise. Significant improvement in psychological well-being was found for 8 exercises, but not at all time points, and 5 of 9 exercises reduced depressive symptoms [31]. In the study of Layous et al [32] the online variant of the "best possible selves" exercise was just as effective as the face-to-face variant, and more effective than the placebo intervention. Schueller and Parks [33] showed that it might not always be effective to provide more exercises and content because a 2-exercise and a 4-exercise condition were more effective than the 6-exercise condition.

One of the reasons for a gap between face-to-face and online interventions could be the low adherence rates [25,34]. Adherence may be related to effectiveness such that the more people adhere to an intervention, the larger the effect sizes are [35,36]. This supposed relationship needs further clarification in online positive psychological interventions [25].

Current Study

The primary goal of the current study was to examine the effectiveness of Psyfit, an online positive psychological

intervention, in comparison with a waiting-list control group. This study distinguishes itself from former experimental research, which was limited to single-component interventions [27,29,30] or longer multiple and fixed-sequential interventions [26,28,33], in focusing on a multicomponent, flexible, online intervention. The intervention resembles a toolbox where people can pick and mix their personal training program. From self-determination theory, it can be reasoned that this idea would promote autonomy in the participant, leading to more intrinsic motivation to follow the program [37]. Indeed, experimental studies show that most people are better off with a tailored positive psychological intervention shaped to their personal preferences and needs [38,39].

We hypothesized that the online positive psychological intervention group would demonstrate a significant increase in well-being and a reduction in depressive and anxiety symptoms at 2- and 6-month follow-ups as compared to the control group. The second goal of the study was to examine the role of adherence. We hypothesized that the more people adhered to the intervention, the larger the effects would be. A third goal was to examine whether particular subgroups benefit more or less than others from the intervention (less vs more depressive symptoms at baseline, higher- vs lower-educated people, men vs women, older vs younger people). Because of the broad nature of the intervention, it was hypothesized that each of the subgroups was served equally well.

Methods

Study Design

We conducted a randomized controlled trial (NTR2126) of the online positive psychological intervention Psyfit as compared to a waiting-list control group. Online measurements were measured at baseline, 2 months, and 6 months after starting the intervention. Details of the study design and the intervention are reported more extensively in the study protocol that was published previously [40], but a summary is presented subsequently. The study was approved by the Dutch Medical Ethics Committee for Mental Health Care (registration number 9218).

Intervention

Psyfit is an online self-help intervention, without support from a therapist. Psyfit aims to enhance well-being by stimulating personal growth and positive functioning. A parallel goal is to reduce depressive and anxiety symptoms [41]. The intervention is based on positive psychological principles and addresses strengths and personal competencies rather than mental problems and deficiencies. It incorporates evidence-based exercises based on positive psychology and elements stemming from mindfulness, cognitive behavioral therapy, and problem-solving therapy [42]. In Psyfits' communication message, an analogy is made with physical fitness. Similar to the saying "an apple a day keeps the doctor away," Psyfit encourages people to complete their daily mental fitness training.

There are 6 modules in Psyfit, each containing a 4-lesson program: (1) personal mission statement and setting your goals, (2) positive emotions, (3) positive relations, (4) mindfulness, (5) optimistic thinking, and (6) mastering your life. Each week, the lesson consisted of psycho-education and a practical exercise. At the end of the week, participants received an email notifying them that the next lesson could be started. Participants could start or finish modules as they wished, as long as they were in sequence.

Participants allocated to the intervention group received an email with a personal username and password. After logging in, 2-month access to Psyfit was activated. Participants were advised to complete at least 1 module during the intervention period. Each module is a separate module on its own and may, in theory, improve well-being.

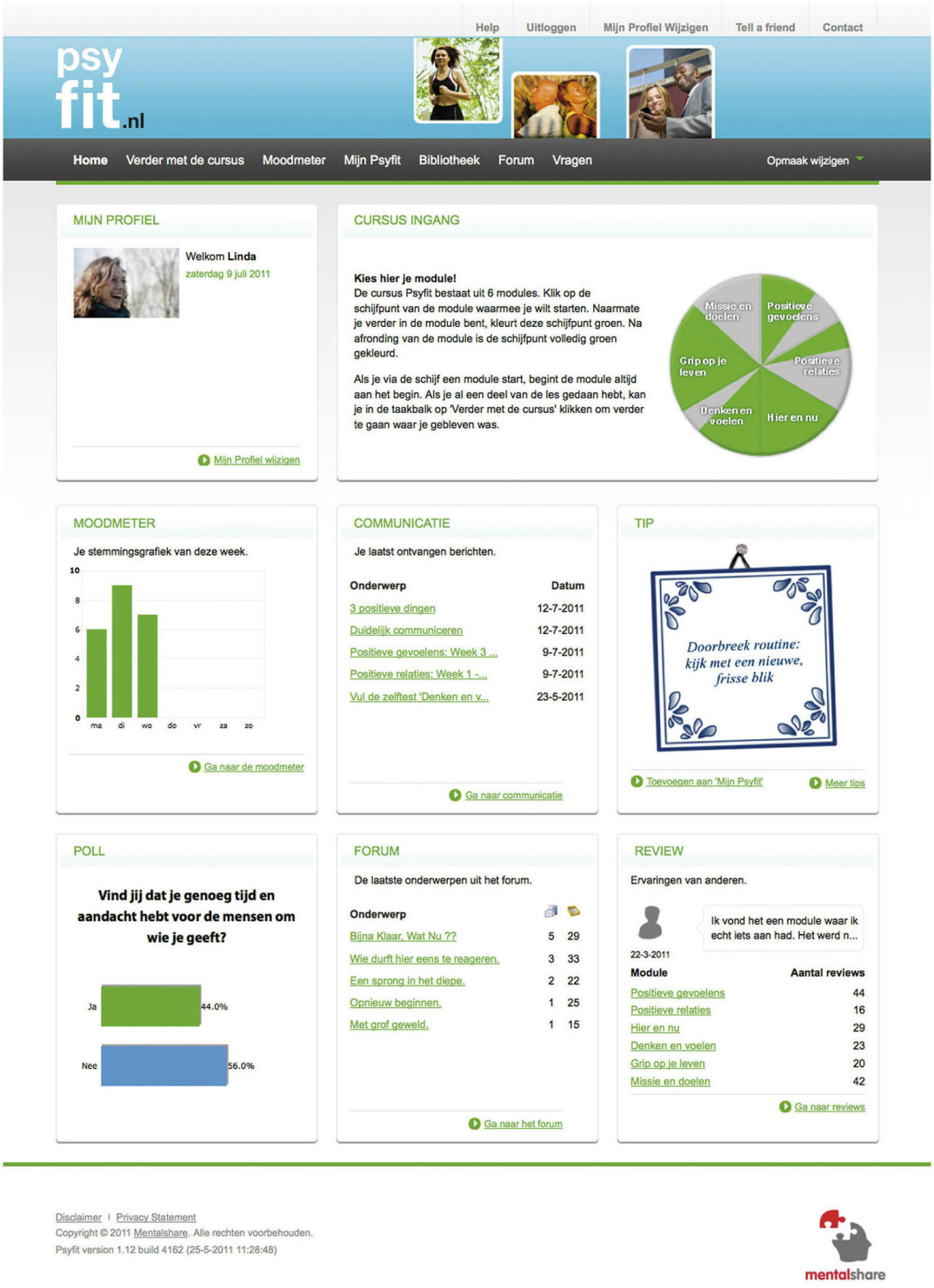
Control Group

Participants in the control group were told they were on a waiting list for 6 months before they received their login codes for Psyfit. A waiting-list control group is ethically acceptable when there is no immediate risk or treatment indication [43], thus fitting the preventive nature of this study. Participants in the control group had unrestricted access to professional help, if needed.

Participants

Participants were recruited from the adult well-being-seeking population in the Netherlands in March and April 2010. The recruitment message was formulated positively (not with a focus on symptoms and problems): "Would you like to increase your mental fitness? Improve your mental fitness and participate in our study of an online self-help program." Banners and advertisements were placed in free newspapers and on Facebook. Interested people registered at the Psyfit website (Figure 1) [44] and subsequently received an email with information on the study and a link to the online consent form and baseline questionnaire. Adult participants (21 years and older) were included when informed consent was obtained and if they presented mild to moderate depressive symptoms as represented by a score of 10-24 on the Center for Epidemiologic Studies Depression Scale (CES-D) [45] and a languishing or moderate level of well-being as measured with the Mental Health Continuum-Short Form (MHC-SF) in which the levels languishing, moderate, and flourishing can be distinguished [46]. Furthermore, they had to have access to a computer and Internet and have sufficient knowledge of the Dutch language. Participants with serious depressive symptoms (CES-D score ≥25) or active suicidal thoughts or plans (question from the Web Screening Questionnaire [47]) were excluded. Those meeting any of these exclusion criteria were advised to seek professional help. Those scoring too high on well-being according to the inclusion criteria were excluded, but were invited to do Psyfit after the study. Participants in both the experimental and control group had unlimited access to professional help, such as primary care and psychological support.

Figure 1. Screenshot of the Psyfit website.



Randomization

Randomization took place after baseline measurement and was carried out by using a computer-generated randomization list in blocks of 2, stratified by gender, education (higher/lower), and depression symptom level (CES-D scores 10-15 and 16-24).

Outcomes and Instruments

The primary outcome measure was well-being. This was assessed with 2 questionnaires: the MHC-SF which measures positive mental health in terms of subjective, psychological, and social well-being [46], and the World Health Organization 5-item Well-Being Index (WHO-5) [48,49], a short measure of overall well-being. Secondary outcomes were depressive symptoms, as measured with the CES-D [45,50]; anxiety symptoms, as measured with the Hospital Anxiety and Depression Scale, Anxiety subscale (HADS-A) [51]; and general health and vitality, as measured with 2 subscales from the Medical Outcomes Study 36-Item Short Form (MOS SF-36) [52]. All measurement instruments were self-reported and administered via email with a link to the questionnaire on the Internet. The instruments have been shown to have satisfactory reliability and validity (also see the protocol article for elaboration) [40]. Participant satisfaction was measured using the 8-item Client Satisfaction Questionnaire short form (CSQ-8) [53].

During the trial, usage data from the Web application containing log files were gathered, which enabled monitoring of intervention adherence.

Analyses

Analyses were conducted following the intention-to-treat (ITT) principle. Accordingly, all participants were analyzed in the group to which they were allocated. Missing data at 2-month and 6-month follow-ups were imputed using the estimation maximization (EM) method in SPSS version 19 (IBM Corp, Armonk, NY, USA). Reporting of the results follows the guidelines of the Consolidated Standards of Reporting Trials (CONSORT) eHealth checklist [54]. We applied unpaired *t* tests and logistic regression analyses to examine possible baseline differences between dropouts and nondropouts. A chi-square test (χ^2) was used to determine possible differential loss to follow-up between experimental group and control group. Dropout was defined as completing the baseline and 2-month follow-up questionnaire, but not the 6-month follow-up questionnaire, or completing the baseline questionnaire, but neither of the follow-up questionnaires.

The effectiveness of Psyfit was examined by regression analyses. We used the clinical outcomes on continuous measures (MHC-SF, WHO-5, CES-D, HADS-A, and subscales of the MOS SF-36) as dependent variables for the 2- and 6-month follow-ups separately. The intervention dummy and the baseline measurements of the corresponding outcome variables were used as independent variables.

The size of the effect was estimated by using Cohen's *d*. Cohen's *d* is calculated as the difference between 2 means divided by the pooled standard deviation. A Cohen's *d* of 0.5 indicates that the mean of the intervention group is half a standard deviation larger than the mean of the control group. Cohen's *d* from 0.56 to 1.2 is a large effect size, 0.33 to 0.55 is moderate, and 0 to 0.32 is considered small [55]. We calculated effect sizes (baseline to 2- and 6-month follow-ups, respectively) of each condition separately, and after that calculated the difference between experimental group and control group (Δd). As a sensitivity analysis, a completers-only analysis was conducted as well.

To examine the role of adherence, a dose–response relationship was analyzed. Five separate groups were made up of participants adhering to 0, 1, 2, 3, or 4 lessons from any module. Differences between these groups and a possible linear relation (time×group interaction) were investigated by means of a repeated measures ANOVA analysis. The levels of adherence were used as independent variables and the clinical outcomes at 2- and 6-month follow-ups as repeated measures. An unpaired *t* test was used to examine the difference between hardly adhered (adhered to 0 or 1 lesson) and at least some adherence (adhered to 2-4 lessons).

Finally, a moderator analysis was conducted to determine whether certain subgroups (men vs women; education level higher vs lower; mild vs moderate depressive symptoms: CES-D score ≤16 or >16; younger/older age group: ≤45 years or >45 years) benefited more or less from the intervention. This was done by regressing the outcome variable on the independent group variables, the condition dummy, and the interaction between subgroup and condition dummy while controlling for the baseline measurement.

For all analyses, we used 2-sided tests with a significance level of $P<.05$. We only used $P<.10$ for the adherence analysis because of the reduced number of participants and lower power.

Results

Flow of Participants

Figure 2 shows the flow of participants. A total of 845 persons were interested in participating in the study and registered with the website. After giving informed consent and filling out the online screening form and baseline questionnaire, 284 people were included in the study (33.6%). Participants were randomly assigned to the intervention (n=143) or the waiting-list control group (n=141).

Participant Characteristics

The demographic characteristics and baseline scores of the participants are shown in Table 1. The mean age of participants was 43.2 years (SD 11.8) and most were female (226/284, 79.6%). Participants were mostly highly educated (208/284, 73.2%) and most had paid employment (214/284, 75.4%). The mean CES-D depression score at baseline was slightly above the cut-off score of 16 (mean 16.80, SD 4.13) indicating a clinically relevant level of depressive symptoms [50], and the MHC-SF score was below the Dutch national mean of 3.98 (mean 3.47, SD 0.63) [46].

Figure 2. Participants' flow through the study.

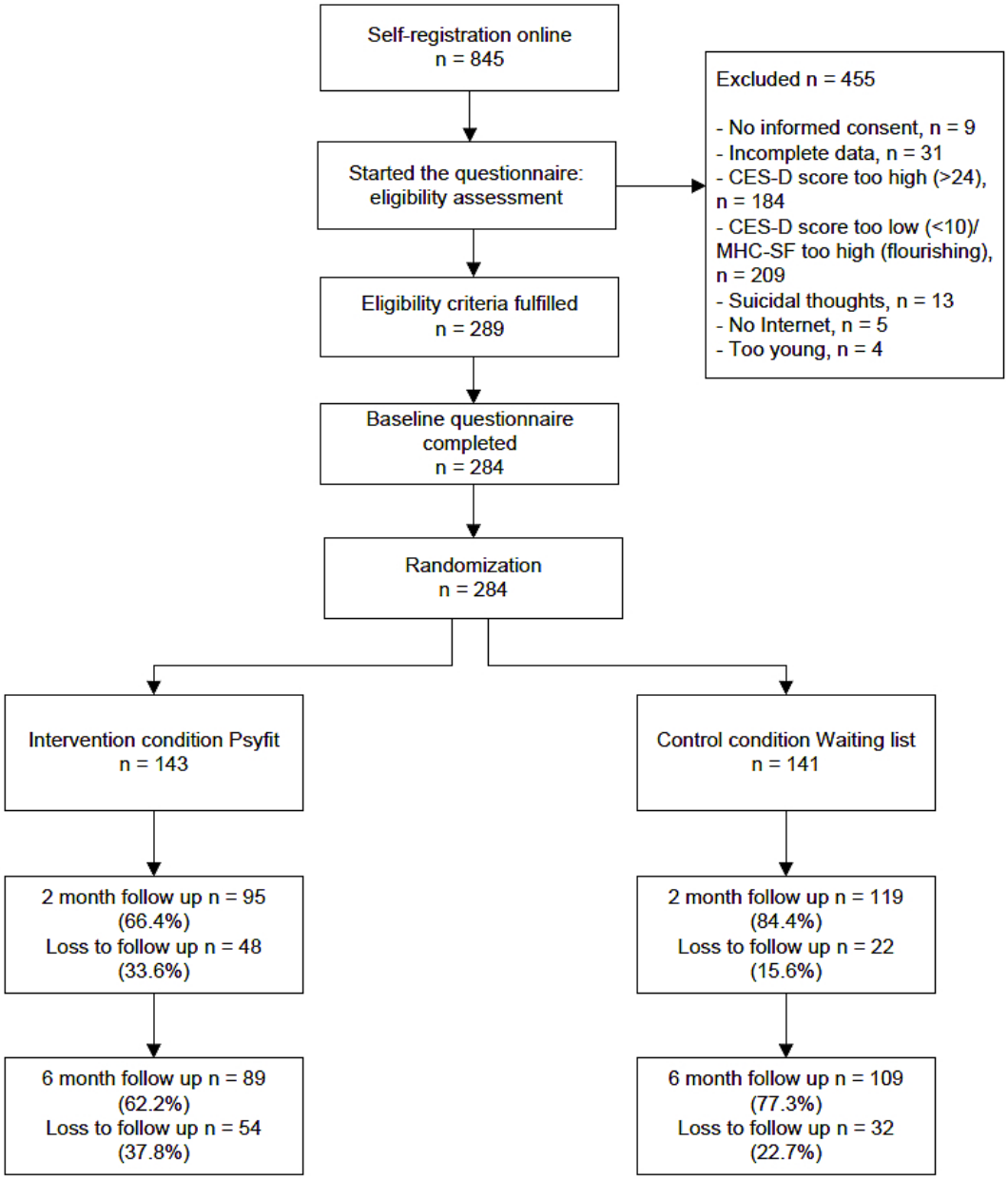


Table 1. Baseline characteristics of participants.

Characteristic	Psyfit (n=143)	Control group (n=141)	All (N=284)
Age (years), mean, (SD)	43.5 (11.7)	42.8 (11.9)	43.2 (11.8)
Age categories, n (%)			
21-34 years	36 (25.2)	37 (26.2)	73 (25.7)
35-64 years	100 (69.9)	101 (71.6)	201 (70.8)
65-100 years	7 (4.9)	3 (2.1)	10 (3.5)
Female, n (%)	114 (79.7)	112 (79.4)	226 (79.6)
Major negative life event (yes), n (%)	80 (55.9)	73 (51.8)	153 (53.9)
Education, n (%)			
Lower (up to high school and middle-level applied education)	39 (27.3)	37 (26.2)	76 (26.8)
Higher (academic/professional)	104 (72.7)	104 (73.8)	208 (73.2)
Daily activities, n (%)			
Paid employment	106 (74.1)	108 (76.6)	214 (75.4)
Unemployed/unable to work	20 (14.0)	10 (7.1)	30 (10.6)
Other (student, at home, retired)	17 (11.9)	23 (16.3)	40 (14.1)
Living situation, n (%)			
With partner, with or without children	92 (64.3)	84 (59.6)	176 (62.0)
No partner, with or without children	45 (31.5)	48 (34.0)	93 (32.7)
Other (dorm or with parents)	6 (4.2)	9 (6.4)	15 (5.3)
Test scores, mean (SD)			
MHC-SF (well-being)	3.45 (0.62)	3.50 (0.63)	3.47 (0.63)
WHO-5 (well-being)	10.81 (4.31)	11.52 (4.38)	11.17 (4.35)
CES-D (depression)	16.91 (4.16)	16.67 (4.11)	16.80 (4.13)
HADS-A (anxiety)	6.55 (2.86)	6.53 (2.96)	6.54 (2.91)
MOS SF subscale general health	18.57 (3.51)	17.95 (3.61)	18.26 (3.57)
MOS SF subscale vitality	14.46 (3.16)	14.62 (2.83)	14.54 (3.00)

Attrition

The response rate was 75.4% (214/284) at 2-month follow-up and 69.7% (198/284) at 6-month follow-up. The response rate was significantly higher in the control group compared to the Psyfit group at 2-month follow-up (84.4% vs 66.4%; $\chi^2_1 = 12.3$, $P<.001$) and 6-month follow-up (77.3% vs 62.2%; $\chi^2_1 = 7.6$, $P=.01$).

Tested at $P<.05$, dropout analysis revealed that there were several significant differences between dropouts and completers. Those who dropped out were more likely to be living in a dorm or with their parents ($\chi^2_2 = 9.9$, $P=.002$) and be of younger age ($\chi^2_1 = 4.2$, $P=.04$). No significant differences emerged between dropouts and completers regarding baseline symptoms. Examination of the interaction showed that dropouts in the control group scored significantly lower than dropouts in the Psyfit group on the MOS SF-36 general health subscale, indicating poorer health for dropouts in the control group ($F_{1,280} = 6.48$, $P=.01$).

Effects of the Intervention

Table 2 presents the means and standard deviations for the outcome measures at 2- and 6-month follow-ups plus effect sizes and the results of the regression analysis in the EM imputed ITT sample. In Figure 3, the results of Psyfit on the MHC-SF, WHO-5, and CES-D are depicted. From baseline to the 2-month follow-up, well-being (the main outcome measure) as measured with the MHC-SF was higher although this did not meet statistical significance (beta = 0.09, $P=.06$). A significant effect on the other well-being measure, the WHO-5, was found (beta = 0.12, $P=.01$). Between-group effects fell within the small range (MHC-SF: $d=0.27$; WHO-5: $d=0.31$). With regard to the secondary outcome measures, the intervention group showed a significant decline at 2-month follow-up in both depressive symptoms (beta = –0.13, $P=.02$) and anxiety (beta = –0.15, $P=.001$), and a significant improvement in both self-reported health (beta = 0.09, $P=.01$) and vitality (beta = 0.12, $P=.02$) versus the control group. Effect sizes were small (MOS SF general health: $d=0.14$; MOS SF vitality: $d=0.22$; HADS-A: $d=0.32$) to medium (CES-D: $d=0.36$). At 6-month follow-up, results were sustained for anxiety (beta = –0.17, $P=.001$) and

depressive symptoms (beta = –0.13, *P*=.02), presenting medium effect sizes (both *d*=0.35), but were no longer significant for well-being, health, and vitality.

The same trends in effects emerged in the completers-only analysis: positive effects for all outcomes at 2-month follow-up and sustained effects for anxiety and depressive symptoms at 6-month follow-up (Table 3). However, the effect of well-being at 2-month follow-up as measured with the MHC-SF was not significant in the completers-only analysis (beta = 0.08, *P*=.14, *d*=0.19) nor were there significant effects for depressive symptoms at 6-month follow-up (beta = –0.10, *P*=.14, *d*=0.26). Vitality was improved at 2-month follow-up, but this did not meet statistical significance (beta = 0.11, *P*=.06, *d*=0.19).

Table 2. Effects of Psyfit, intention-to-treat analysis.

Measures	Psyfit (n=143)			Control group (n=141)			Linear regression analysis			
	Mean	SD	*d*	Mean	SD	*d*	Beta	t_{281}	*P* value	Δ*d*
MHC-SF										
Baseline	3.45	0.62		3.50	0.63					
2-month	3.92	0.71	0.71	3.82	0.82	0.44	0.09	1.88	.06	0.27
6-month	3.88	0.79	0.61	3.90	0.71	0.60	0.01	0.13	.90	0.01
WHO-5										
Baseline	10.81	4.31		11.52	4.38					
2-month	12.75	4.47	0.44	12.12	4.63	0.13	0.12	2.47	.01	0.31
6-month	12.92	4.77	0.47	12.45	4.61	0.21	0.09	1.61	.11	0.26
CES-D										
Baseline	16.91	4.16		16.67	4.12					
2-month	13.67	6.69	0.57	15.39	7.64	0.21	–0.13	–2.33	.02	0.36
6-month	13.06	7.55	0.63	14.94	7.48	0.28	–0.13	–2.38	.02	0.35
HADS-A										
Baseline	6.55	2.86		6.53	2.96					
2-month	5.75	2.90	0.28	6.64	3.08	–0.04	–0.15	–3.29	.001	0.32
6-month	5.65	3.39	0.29	6.70	2.98	–0.06	–0.17	–3.38	.001	0.35
MOS SF health										
Baseline	18.57	3.51		17.95	3.61					
2-month	19.21	3.16	0.19	18.11	3.50	0.05	0.09	2.72	.01	0.14
6-month	18.65	3.41	0.02	18.20	3.51	0.07	0.00	–0.68	.95	–0.05
MOS SF vitality										
Baseline	14.46	3.16		14.62	2.83					
2-month	15.74	3.09	0.41	15.14	2.76	0.19	0.12	2.33	.02	0.22
6-month	15.70	3.57	0.37	15.20	3.01	0.20	0.09	1.70	.09	0.17

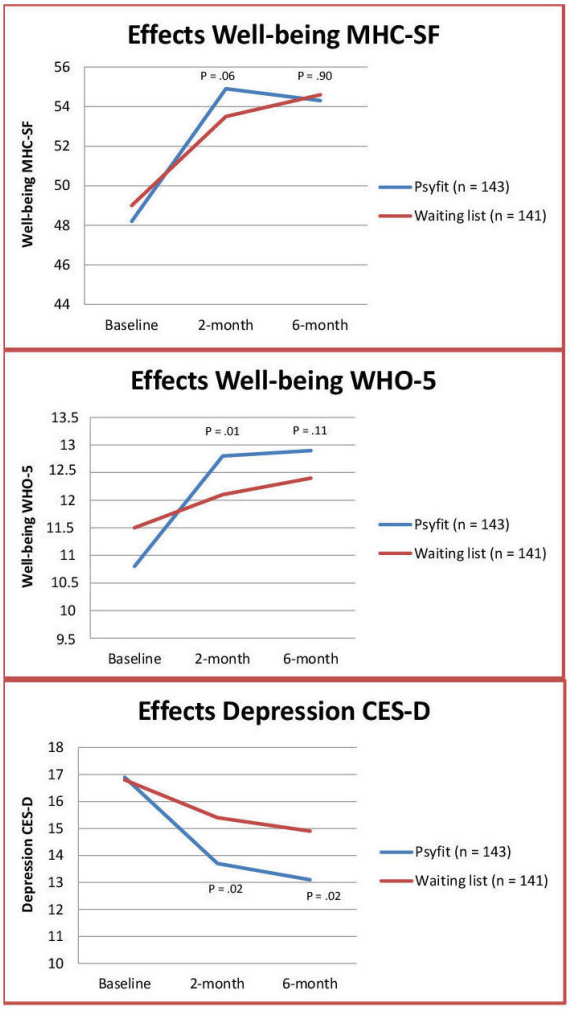
Table 3. Effects of Psyfit, completers-only analysis.

Measures	Psyfit[a]			Control group[b]			Linear regression analysis			
	Mean	SD	*d*	Mean	SD	*d*	Beta	*t* (df)	*P* value	Δ*d*
MHC-SF										
Baseline	3.52	0.63		3.51	0.63					
2-month	3.95	0.81	0.59	3.81	0.85	0.40	0.08	1.50 (211)	.14	0.19
Baseline	3.51	0.61		3.50	0.64					
6-month	3.89	0.84	0.52	3.91	0.76	0.58	–0.20	–0.32 (195)	.75	–0.06
WHO-5										
Baseline	11.27	4.45		11.45	4.32					
2-month	12.98	5.11	0.36	11.97	4.78	0.11	0.11	1.98 (211)	.049	0.25
Baseline	11.07	4.37		11.58	4.45					
6-month	12.72	5.44	0.33	12.59	4.84	0.22	0.04	0.57 (195)	.57	0.11
CES-D										
Baseline	16.57	4.12		16.55	4.18					
2-month	13.35	7.97	0.51	15.58	8.11	0.16	–0.14	–2.12 (211)	.04	0.35
Baseline	17.04	4.14		16.66	4.00					
6-month	13.35	8.64	0.54	14.87	8.04	0.28	–0.10	–1.50 (195)	.14	0.26
HADS-A										
Baseline	6.27	2.83		6.52	3.03					
2-month	5.49	3.18	0.26	6.68	3.24	–0.05	–0.16	–2.89 (211)	.004	0.31
Baseline	6.28	2.78		6.57	2.95					
6-month	5.55	3.78	0.22	6.69	3.23	–0.04	–0.14	–2.24 (195)	.03	0.26
MOS SF health										
Baseline	18.66	3.50		17.97	3.66					
2-month	19.40	3.31	0.22	18.09	3.61	0.03	0.11	2.59 (211)	.01	0.19
Baseline	18.39	3.40		18.39	3.35					
6-month	18.57	3.58	0.05	18.61	3.36	0.07	–0.01	–0.11 (195)	.91	–0.02
MOS SF vitality										
Baseline	14.67	3.17		14.66	2.82					
2-month	15.80	3.39	0.34	15.09	2.86	0.15	0.11	1.88 (211)	.06	0.19
Baseline	14.37	3.29		14.80	2.83					
6-month	15.53	3.99	0.32	15.39	3.15	0.20	0.048	0.74 (195)	.46	0.12

[a]2-month follow-up: n=95, 6-month follow-up: n=89.

[b]2-month follow-up: n=119, 6-month follow-up: n=109.

Figure 3. Depicted scores at baseline, 2-, and 6-month follow-ups for the MHC-SF, WHO-5, and CES-D (intention-to-treat sample).



Adherence

On average, 1.39 modules were started (SD 1.45). Most participants (74/143, 51.7%) started 1 module (mode and median). Participants most often enrolled in the positive emotions module (51/143, 35.7%), before personal mission statement and setting your goals (44/143, 30.8%), mindfulness (31/143, 21.7%), and optimistic thinking (29/143, 20.3%). Positive relations (22/143, 15.4%) and mastering your life (22/143, 15.4%) were the least popular modules.

In Table 4, different adherence grades and their effect sizes are shown for the experimental group (ITT sample). Adherence was defined as completing zero (31/143, 21.7%), 1 (46/143, 32.6%), 2 (24/143, 16.8%), 3 (29/143, 20.3%), or 4 lessons (13/143, 9.1%) from 1 or more modules. In plots, there is no clear dose–response relationship (the more adherence, the larger the effect size) recognizable. Tested at $P<.10$, repeated measures analysis (Table 5) showed significant effects for the MHC-SF at both 2- and 6-month follow-ups after completing 2 lessons ($F_{8,274}$ = 1.72, P=.09, Cohen's d pre-post 1.25 and 1.18). Significant effects were found for the MOS-SF general health subscale at 2-month follow-up after completing 4 lessons ($F_{8,274}$ = 2.16, P=.03, Cohen's d pre-post 0.71) and for the MOS-SF vitality subscale at 2-month follow-up after adhering to 2 lessons ($F_{8,274}$ = 1.75, P=.09, Cohen's d pre-post 0.74). When examining hardly any adherence (completing ≤1 lesson) versus at least some adherence (completing ≥2 lessons), 2 comparisons appeared to be significant (not presented in Tables 4 and 5). The effect sizes of the HADS-A anxiety scale at 2-month follow-up (d=0.16 vs d=0.43, t_{141} = 2.24, P=.03) and of the CES-D depression scale at 6-month follow-up (d=0.47 vs d=0.87, t_{141} = 1.84, P=.07) were significantly higher for the at least some adherence group compared to those who completed 1 lesson or less.

Participant Satisfaction

Results regarding participant satisfaction are based on the completers sample (93/95 filled in the satisfaction questionnaire). Regarding participant satisfaction, 40 of 93 participants (43.0%) in the experimental group expressed

satisfaction with Psyfit. The other 57.0% (53/93) were indifferent and/or dissatisfied. In the questionnaire, we were unable to separate the indifferent and the dissatisfied categories. Psyfit was found to be somewhat helpful in dealing with problems by 47.3% of the participants (44/93). Almost 70% (65/93) of the participants would recommend Psyfit to friends, and 66.7% (62/93) would do Psyfit (again), if needed. Adherence was positively related to satisfaction rate ($\chi^2_3 = 15.0$, P=.02).

Subgroup Effects

A moderator analysis with well-being (MHC-SF and WHO-5) and depression (CES-D) as dependent variables was conducted to explore which subgroups benefited more or less from the intervention. The only significant result was found for education level on the WHO-5 well-being measure at 6-month follow-up (d=0.46 for higher-educated participants vs d = –0.20 for lower-educated participants; $F_{1,280}$ = 6.23, P=.01). Other nonsignificant trends for educational level were found on WHO-5 well-being at 2-month follow-up (d=0.42 vs d=0.02; $F_{1,280}$ = 3.60, P=.06) and on the CES-D at 6-month follow-up (d=0.58 vs d = –0.13, $F_{1,280}$ = 3.66, P=.06), suggesting that higher-educated people profited more from the intervention than lower-educated people on these measures. For age, a nonsignificant trend was found on the CES-D at 6-month follow-up (d=0.61 for participants older than 45 years vs d=0.09 for younger participants, $F_{1,280}$= *3.62*, P = .06), suggesting that the older group benefited more from Psyfit. For the other 2 potential moderators, gender and depression status, no significant or relevant interaction effects were found.

Table 4. Adherence grades and effect sizes, intention-to-treat sample (experimental group, Cohen's *d* pre-post).

Measures	<1 lesson (n=31)		1 lesson (n=46)		2 lessons (n=24)		3 lessons (n=29)		≥4 lessons (n=13)	
	Mean (SD)	*d*	Mean (SD)	*d*	Mean (SD)	*d*	Mean (SD)	*d*	Mean (SD)	*d*
MHC-SF										
Baseline	3.46 (0.60)		3.46 (0.70)		3.17 (0.58)		3.52 (0.52)		3.69 (0.62)	
2-month	3.84 (0.61)	0.63	3.90 (0.64)	0.66	4.05 (0.81)	1.25	3.92 (0.68)	0.66	3.99 (1.04)	0.36
6-month	3.74 (0.69)	0.43	3.87 (0.79)	0.55	3.98 (0.78)	1.18	3.94 (0.76)	0.65	3.91 (1.09)	0.25
WHO-5										
Baseline	10.00 (3.59)		11.74 (4.22)		9.75 (5.33)		10.41 (4.45)		12.31 (3.22)	
2-month	12.00 (3.21)	0.59	12.83 (4.01)	0.26	13.34 (6.24)	0.62	12.09 (4.01)	0.40	14.69 (5.60)	0.52
6-month	11.56 (3.91)	0.42	13.28 (4.76)	0.34	13.29 (5.48)	0.65	12.80 (4.93)	0.51	14.55 (4.86)	0.54
CES-D										
Baseline	17.71 (4.19)		16.28 (3.71)		17.58 (4.74)		17.41 (4.33)		14.92 (3.73)	
2-month	15.21 (6.21)	0.47	13.73 (5.77)	0.53	13.99 (9.74)	0.47	13.61 (6.77)	0.67	9.31 (5.92)	1.13
6-month	14.06 (6.51)	0.67	14.42 (7.67)	0.31	12.16 (8.56)	0.78	12.03 (7.94)	0.84	9.85 (5.90)	1.03
HADS-A										
Baseline	6.90 (2.53)		6.52 (2.96)		7.04 (3.21)		6.00 (3.11)		6.15 (2.03)	
2-month	6.28 (2.47)	0.25	6.22 (2.88)	0.10	5.58 (3.62)	0.35	4.71 (2.58)	0.45	5.00 (2.80)	0.47
6-month	6.16 (3.19)	0.26	6.01 (3.37)	0.16	6.08 (4.00)	0.26	4.62 (2.94)	0.46	4.61 (3.40)	0.55
MOS SF health										
Baseline	18.52 (2.74)		18.46 (3.82)		19.00 (3.95)		19.14 (3.55)		17.00 (3.06)	
2-month	18.98 (2.74)	0.17	19.05 (3.14)	0.17	19.47 (4.05)	0.12	19.48 (2.80)	0.11	19.31 (3.43)	0.71
6-month	17.82 (2.81)	–0.25	19.07 (3.29)	0.17	18.88 (4.41)	–0.03	19.06 (3.30)	0.02	17.85 (3.34)	0.27
MOS SF vitality										
Baseline	14.03 (2.77)		15.04 (3.17)		13.96 (3.97)		14.00 (2.87)		15.38 (2.84)	
2-month	15.20 (2.16)	0.48	15.83 (3.29)	0.24	16.83 (3.81)	0.74	15.21 (2.82)	0.43	15.85 (3.24)	0.16
6-month	15.03 (2.77)	0.36	15.90 (3.64)	0.25	15.85 (4.23)	0.46	16.01 (3.67)	0.61	15.62 (3.91)	0.07

Table 5. Repeated measures analysis on adherence grades (see Table 4).

Measures	Time		Time×group	
	$F_{2,137}$	*P*	$F_{8,274}$	*P*
MHC-SF	34.20	<.001	1.72	.09
WHO-5	18.06	<.001	0.95	.48
CES-D	30.00	<.001	0.99	.44
HADS-A	9.20	<.001	0.53	.83
MOS SF health	14.29	<.001	2.16	.03
MOS SF vitality	13.53	<.001	1.75	.09

Discussion

Principal Results

This randomized controlled trial examined the efficacy of an online self-help course aimed at promoting mental fitness and subsequent well-being. The results at 2-month follow-up show that intervention group participants made a significant improvement in the level of overall well-being on one measure (WHO-5) than participants in the waiting-list control group and a nonsignificant improvement on the other well-being measure (MHC-SF). Furthermore, general health and vitality level were significantly enhanced, and depression and anxiety symptoms were reduced in comparison to the waiting-list control group. At 6-month follow-up, effects were maintained for depression and anxiety. All effects were in the small to medium range. Adherence analysis revealed no clear dose–response effect, although some larger effects appeared for people receiving at least a minimal part of the intervention. For well-being (only WHO-5) and depression, somewhat larger effects were found for higher-educated participants.

Comparison With Previous Work

The effects of taking part in Psyfit are comparable with effects of similar positive psychological interventions in self-help format with regard to well-being (0.14-0.33 in a meta-analysis at immediate follow-up), but appear to be larger for depression on average (0.15 in the same meta-analysis) [19]. When compared with separate studies of other online positive self-help interventions, the effect sizes at immediate follow-up in the current study are quite similar, and higher in some cases. For example, in the Seligman et al study [29], exercises that worked well had effect sizes of 0.23 for well-being and 0.14-0.28 for depression. In the study of Shapira and Mongrain [30], effect sizes of 0.03-0.18 were found for well-being and 0.09-0.30 for depression. Mitchell et al [27] found effect sizes ranging from 0.05 to 0.29 for well-being and an effect size of -0.17 for depression. At longer-term follow-up, effect sizes of the current study were comparable or higher for depression (up to 0.33 for Seligman [29], 0.42 for Shapira [30], and -0.04 for Mitchell [27]), and lower for well-being (up to 0.28 for Seligman [29], up to 0.30 for Shapira [30], and up to 0.33 for Mitchell [27]).

Adherence and Acceptability

More than three-quarters (78.3%) of the participants in the intervention group completed at least 1 lesson in Psyfit. The personal mission statement and setting your goals module and the positive emotions module were the most popular modules, each chosen by one-third of the total sample. This can be considered a satisfactory adherence rate in general because it is comparable with, or higher than, adherence rates in other online self-help interventions [34]. However, from a practical point of view, it is questionable whether this adherence rate deserves our endorsement because less than 10% fully adhered to 1 module (consisting of 4 lessons). The group who completed at least 1 lesson showed slightly larger effect sizes than the whole group analysis, indicating that following the self-help course could predict effect size to some extent, but these results were not convincing. The explanation for this is not immediately clear. Dose-response effects (the more adherence, the larger the effects) have been established in several online trials of mental health promotion [35]. On the other hand, not every trial demonstrated such an adherence effect [56], which is comparable to our results. Unfortunately, we collected no information on the reasons for quitting (or not even starting) the intervention. One possible explanation is that nonparticipants/dropouts felt disappointed, or not capable of proceeding with the intervention. We did determine that adherence rate was positively related to satisfaction rate. Alternatively, it could be argued that people stopped because they felt better and were no longer in need of help, which could explain the modest effects of adherence, implying that the nonadhering participants were doing better as well.

Still, the question of how to increase the engagement and adherence for this type of intervention is important. It is likely that by increasing adherence, people could benefit more. The incorporation of persuasive and gaming elements into an intervention may hold considerable promise because such elements may raise client satisfaction and can encourage participants to stick to the intervention [36,57,58]. Less than half (approximately 40%) of participants were satisfied with Psyfit, although a larger percentage (approximately 65%) would recommend the program to a friend or would do it again if needed. Persuasive elements may help to arouse and prolong participant motivation, which may ultimately contribute to sustainable behavioral change [57]. Although Psyfit already contains some engaging and motivating elements, such as email reminding and self-monitoring instruments, other persuasive functionalities could be added to make it a truly interactive and personalized device, such as tailored feedback and action planning [57]. In addition, minimal guidance (eg, telephone/email contact or coaching supervision) is worth

considering because this may increase adherence and effectiveness. There is some experimental evidence showing that tailoring positive psychological exercises to needs and preferences can indeed effectively enhance intervention engagement and adherence [39], although preference for a certain well-being activity appears to be not enough to guarantee intervention effectiveness [41]. For this reason, it seems warranted to ensure a good person-activity fit; a kind of diagnosis to determine which well-being enhancing exercise suits the participant best [38]. Features of the intervention (dosage and variety) as well as personal aspects, such as motivation and efficacy beliefs, should be taken into account [59]. Lastly, it has been found that lower-educated groups often lack the more sophisticated Internet skills that are needed to participate in an online intervention [60]. Increasing those skills in these groups might contribute to improved adherence and better performance in online interventions such as Psyfit.

Population Approach

A relatively slight increase in the overall level of health in a sizeable part of the population may have a larger preventive effect than targeting only the much smaller group of people who are already ill [61,62] . This principle may apply even more for mental health and well-being because stigma surrounding the formal use of mental health services may deter people in need from seeking help [63]. Considering that many people can be reached by Psyfit in a nonstigmatized way and in a relatively short length of time, even the small effect sizes that were demonstrated in this trial may contribute to an important improvement in population mental health. On the other hand, this trial only included a specific target group of people presenting mild to moderate depressive symptoms, which affects generalizability to the larger population. In a naturalistic study, it has been found that people seeking self-help interventions to improve well-being either show rather severe depression scores or hardly any signs of depression [41], whereas the present study targeted people with mild depressive symptoms. It would be insightful to examine if Psyfit is also effective in these other groups in a way that could be generalized to a larger population.

Limitations

A number of limitations in this study have to be recognized. First, there was a rather high attrition rate and differential dropout between the intervention arms. Although not an uncommon phenomenon in online trials [64], the dropout may have affected the results in a way that is not easy to predict. Thus, the results of our trial should be considered with caution. Second, the intervention used in this study was designed like a toolbox from which people could pick and mix their own personalized program. This can be considered a strength because it enables participants to tailor their own program, which is a unique feature of the intervention. However, it may also be considered a weakness because no reliable statements can be given about the comparative effectiveness of modules and other effective elements of the intervention. Third, we did not measure motivational level, self-efficacy, or readiness to change as is constructed, for example, in the Stages of Change theory by Prochaska and DiClemente [65]. Therefore, we could not examine whether the more motivated and better-equipped people adhered better to the intervention and accordingly benefited more. Fourth, the study used a waiting-list control group. This means there was no blinding of participants and possible placebo effects could not be established. Fifth, the CSQ-8 [53] contains ambiguous reply categories. As a result, some of the satisfaction rates were difficult to interpret. For further research, we recommend that these categories be adapted to an unambiguous Likert scale, for example. Sixth, the effect sizes that were found were mostly in the small range. The study was powered to detect medium-sized effects [40] and may, therefore, be underpowered to detect these small changes (eg, the nonsignificant finding for well-being/MHC-SF at 2-month follow-up).

Conclusion and Recommendations for Practice and Research

To the best of our knowledge, this is the first study of an online positive psychological intervention with a flexible multicomponent format to demonstrate both small, significant effects on well-being (for one of the measures) and on symptoms of mental disorder. Regarding the implications for public health, Psyfit could be used as an open and highly accessible mental health promotion tool, disseminated by relevant lifestyle and health-related websites and Internet forums, or referred to by health care professionals.

Regarding the future research agenda for online positive psychological interventions, emphasis should be placed on (1) increasing adherence and motivation by using persuasive design and/or providing minimal support, (2) determining what works best for whom and ensure a good person–activity fit, (3) serving lower-educated people better, and (4) considering the use of other control groups to overcome the limitations of a waiting-list control group. The target group could be expanded to present more variety in the depressive symptom spectrum. This will likely help to strengthen the generalizability of these results to a larger group of people.

One of the strengths of this study was the uncomplicated recruitment of participants (845 interested people within a 5-week timeframe), whereas in other randomized controlled trials of online health interventions recruitment can be a serious challenge [66]. As such, Psyfit and other online positive psychological interventions can be regarded as positive technology, a recently proposed concept that refers to the use of technology for improving the quality of personal experience by fostering positive emotions, self-empowerment, and social connectedness [67]. These technologies have the potential to evolve further and become available to many more people. As nonstigmatizing and nonmedicalized tools to address the promotion of mental health and subsequent prevention of depression, they contain the promise of a sustained positive effect on health care and society.

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Authors' Contributions

LB was the project leader, conducted the analyses, and wrote the manuscript. MH and LB together took care of the recruitment of participants and data collection. GW, JK, BB, HR, JW, and EB were advisors in the project. JW and HR obtained funding for the study. All authors contributed to the design of the study, provided comments, and approved the final manuscript.

Conflicts of Interest

Trimbos Institute is the developer of Psyfit and has a share in the social venture that implements the intervention. Neither the authors working at the Trimbos Institute nor the institute itself derive financial income from the interventions.

Multimedia Appendix 1

CONSORT-EHEALTH checklist V1.6.2 [54].

[PDF File (Adobe PDF File), 1000KB - jmir_v15i9e200_app1.pdf]

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Abbreviations

CES-D: Center for Epidemiologic Studies Depression Scale
CSQ-8: 8-item Client Satisfaction Questionnaire-short form
EM: estimation maximization
HADS-A: Hospital Anxiety and Depression Scale, Anxiety subscale
ITT: intention-to-treat
MHC-SF: Mental Health Continuum-Short Form
MOS SF-36: Medical Outcomes Study 36-Item Short Form
WHO-5: World Health Organization 5-item Well-Being Index

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Original Paper

Infodemiology of Alcohol Use in Hong Kong Mentioned on Blogs: Infoveillance Study

KL Chan[1*], MBBS; SY Ho[1*], PhD; TH Lam[1*], MD

School of Public Health, The University of Hong Kong, Hong Kong, China (Hong Kong)

[*]all authors contributed equally

Corresponding Author:
SY Ho, PhD
School of Public Health, The University of Hong Kong
21 Sassoon Road, Pokfulam
Hong Kong
China (Hong Kong)
Phone: 852 28199883
Fax: 852 28559528
Email: syho@hku.hk

Abstract

Background: In 2007 and 2008, the beer and wine tax in Hong Kong was halved and then abolished, resulting in an increase of alcohol consumption. The prevalence of the Internet and a high blogging rate by adolescents and adults present a unique opportunity to study drinking patterns by infodemiology.

Objective: To assess and explain the online use of alcohol-related Chinese keywords and to validate blog searching as an infoveillance method for surveying changes in drinking patterns (eg, alcohol type) in Hong Kong people (represented by bloggers on a Hong Kong–based Chinese blogging site) in 2005-2010.

Methods: Blog searching was done using a blog search engine, Google Blog Search, in the archives of a Hong Kong–based blog service provider, MySinaBlog from 2005-2010. Three groups of Chinese keywords, each representing a specific alcohol-related concept, were used: (1) “alcohol” (ie, the control concept), (2) “beer or wine”, and (3) “spirit”. The resulting blog posts were analyzed quantitatively using infodemiological metrics and correlation coefficients, and qualitatively by manual effort. The infodemiological metrics were (1) apparent prevalence, (2) actual prevalence, (3) prevalence rate, and (4) prevalence ratio. Pearson and Spearman correlations were calculated for prevalence rates and ratios with respect to per capita alcohol consumption. Manual analysis focused on (1) blog author characteristics (ie, authorship, sex, and age), and (2) blog content (ie, frequency of keywords, description of a discrete episode of alcohol drinking, drinking amount, and genres).

Results: The online use of alcohol-related concepts increased noticeably for “alcohol” in 2008 and “spirit” in 2008-2009 but declined for “beer or wine” over the years. Correlation between infodemiological and epidemiological data was only significant for the “alcohol” prevalence rate. Most blogs were managed by single authors. Their sex distribution was even, and the majority were aged 18 and above. Not all Chinese keywords were found. Many of the blog posts did not describe a discrete episode of alcohol drinking and were classified as personal diary, opinion, or emotional outlets. The rest lacked information on drinking amount, which hindered assessment of binge drinking.

Conclusions: The prevalence of alcohol-related Chinese keywords online was attributed to many different factors, including spam, and hence not a specific reflection of local drinking patterns. Correlation between infodemiological data (represented by prevalence rates and ratios of alcohol-related concepts) and epidemiological data (represented by per capita alcohol consumption) was poor. Many blog posts were affective rather than informative in nature. Semantic analysis of blog content was recommended given enough expertise and resources.

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KEYWORDS

alcohol drinking; blogging; blog search; Chinese; Hong Kong; infodemiology; infoveillance; Internet

Introduction

Alcohol Use and Tax Policies in Hong Kong

Although often overlooked, alcohol is a human carcinogen [1]. It causes 2.5 million deaths each year worldwide [2], and the United Nations has identified its harmful use as one of the four most important risk factors for noncommunicable diseases [3]. In Hong Kong, although alcohol consumption is still low, it is not uncommon. Alcohol is easily accessible by the general population due to a lack of regulation of minimum age for off-premises sales (with "premises" defined as restaurants and bars granted with a liquor license) [4,5]. Local studies have shown that almost one-third of adults and one-fourth of secondary school students drink alcohol [6]. The adverse health effects are daunting. According to the data released by the Department of Health in 2006-10, there was an annual average of more than 2000 episodes of in-patient discharges and deaths due to an alcohol-related disease [6].

Nonetheless, the Hong Kong Special Administrative Region (HKSAR) Government halved the duty on beer and wine with an alcoholic strength of not more than 30% in 2007 [7], and abolished it altogether in 2008 [8]. The duty rate on spirits with an alcoholic strength of more than 30% remained at 100% [8]. These unprecedented and anti-public health policies were aimed to help Hong Kong develop into an international wine trading hub, at the cost of increased alcohol-related harms to public health [9]. The Working Group on Alcohol and Health of the Department of Health noticed a surge in the alcohol consumption per capita in Hong Kong in 2008, which was attributed to the lowered price of beer and wine in the same year [4]. This echoed a meta-analysis of 112 studies, which found an inverse relation of alcohol tax or price with consumption [10]. In Finland, the one-third reduction of excise duties on alcoholic beverages in 2004 resulted in a clear rise in alcohol consumption and related harms [11], including hospitalization rate [12] and number of sudden deaths [13]. The drastic change of beer and wine tax policy in Hong Kong presents a unique opportunity to study alcohol drinking using infodemiology.

Infodemiology and Infoveillance

Infodemiology is a portmanteau of information and epidemiology, which is, according to Eysenbach, "the science of distribution and determinants of information in an electronic medium, specifically the Internet, or in a population, with the ultimate aim to inform public health and public policy" [14,15]. It is based on a bidirectional relation between population health status/attitudes/behavior and information patterns on the Internet [15,16]. Originally used to identify inaccurate health information on the Internet [17], it was later found that search engine query data could predict influenza epidemics [18]. Given its implication in public health and policy, infodemiology has since been used as a complement to traditional epidemiological studies [15,16], using analytical methods and metrics such as keyword prevalence and prevalence ratio [14]. The longitudinal tracking of infodemiology metrics for surveillance and trend analysis is called infoveillance [14,15].

Over the past decade, efforts have been made to overcome the difficulties in aggregating and analyzing the vast, unstructured information from the online database [15,16]. Examples of infodemiology within the public health sector include detection of disease outbreak or incidence by tracking search queries [16,18-20], investigating online search behavior for suicide-related information [21], monitoring public reactions towards health-related policy and campaigns [22,23], and identifying public health concerns from user posts in social networking sites such as Twitter [24]. Several computer tools have also been developed that allow more effective infodemiological analysis (eg, Technosocial Predictive Analytics [25], Infovigil [15], Global Public Health Intelligence Network, and HealthMap [26]). All these are underpinned by the technology of Web 2.0, which features individuation, open property, sociality, and microcontent [27]. One established example of Web 2.0 is online social networking.

Online Social Networking, Blogs, and Blog Searching

Online social networking is constantly evolving. With proper mining and analytic technique [28], it might be possible to extract useful information from these networking sites for research purpose. Blogs (also called weblogs) are a kind of social networking website that is regarded as a relatively new form of mainstream personal communication [29,30]. They are characterized as being personalized, Web-based, community-supported, and automated [31]. Blog contents are versatile. They could be about the blogger's life, commentaries, ideas, and emotions. They are also used to form and maintain community forums [32]. While some blogs are employed for political, educational, and commercial purposes [33], most are likened to diaries and are referred to as personal blogs [34]. People using blog services are referred to as bloggers.

Like other social networking sites, blogs are featured by their time stamps, consumer-generated content, and expansile database, making them potentially useful for longitudinal data retrieval and analysis [35,36]. In fact, blog analysis has become increasingly popular in various domains. Examples of its application include assessing a company's image strength or customer product, monitoring public opinion in presidential elections, evaluating public reaction to disasters, tracing online hate groups or people with suicidal intent, studying youth cultures, and analyzing linguistic patterns [34,37-40]. The prerequisite of blog analysis for public surveillance is that a large proportion of the population should use the social Web services regularly, so that online information can be kept up-to-date and truly reflect the contemporary interest or concern of the community [25].

Internet Use and Blogging in Hong Kong: Applying Blog Searches in Local Public Health Research

Internet use is ubiquitous in Hong Kong. In a survey by the HKSAR Government, Internet penetration of local population continued to rise over the years, from 56.9% in 2005 to 72.8% in 2012. Almost 70% of the online population were adolescents and adults aged 10-44 [41]. They also constituted the largest population engaging in online social networking activities including blogs and forums [42]. This was consistent with an older study by Blog-You.com and IN-Media in 2005, which found over 90% of local bloggers were aged 16-35 [43]. Infodemiology using blog searching data is therefore useful for

studying important health issues among Hong Kong adolescents and adults, such as alcohol use.

There are different methods of blog analysis. Some (eg, time series scanning, semantic analysis) require special software and significant investment of time and computing resources [35]. This has greatly reduced its practicability in public health research done by clinicians who might not otherwise know much about computer programming. On the other hand, blog searching using blog search engines, which are freely available online, provides a technically easy, straightforward, and user-friendly method to extract data from blogs. Unlike Web search engines, blog search engines mainly index blog posts and are dedicated to searching information from blog posts only, ignoring the rest of the database [44]. Since each blog post is time-stamped, a blog search engine could search for date-specific blog posts, allowing longitudinal blog tracking, even retrospectively.

Local public health research using blog search and Chinese keywords is rarely done at the moment. Should blog searching data be correlated with local epidemiological data, clinicians (and policy makers) could readily replace traditional surveillance methods with blog searching—which is real-time, cheap, and fast—for public health tracking. Even if there is no correlation, an explanatory study like this would still contribute to the development of health informatics by demonstrating the challenges of Chinese blog searches in an otherwise English-dominated research environment. The clear rise of alcohol consumption in Hong Kong due to zero beer and wine tax provides a sound framework under which blog searching data can be validated against local epidemiology.

Study Objectives and Hypotheses

Using currently available search tools and Web resources, this study aimed to: (1) assess and explain the online use of alcohol-related Chinese keywords, and (2) validate blog searching as an infoveillance method to survey changes in the drinking patterns (eg, alcohol type) of Hong Kong people (represented by bloggers in a Hong Kong–based Chinese blog service provider) following changes to the beer and wine tax in 2007-8.

Following are the hypotheses of this study:

(H1) The online popularity of alcohol-related concepts, in particular “beer or wine”, increased among Chinese bloggers after 2007-8 when local tax policy on beer or wine changed.

(H2) Infodemiological data (represented by prevalence rate and ratio of alcohol-related concepts) correlated significantly with local epidemiological data (represented by per capita alcohol consumption).

Methods

Study Design

To the best of our knowledge, this was the first research done in Hong Kong using blog searches to study a public health–related topic. The issue of alcohol drinking was chosen because of its public health interest and clear impacts by tax policy changes. Blogs were targeted for data extraction because regional interest could be maximized by choosing a blog service provider with the highest local rank and visitors, unlike other social networking sites such as Twitter or Facebook, which tend to cover a wide geographical area.

There were two main sets of data in this study: (1) infodemiology and (2) epidemiology. Infodemiological data stemmed from existing blogs indexed by a specific search engine, whereas epidemiological data were obtained from government documents covering the issues of public health. To reduce expertise and technology investment, this study used a free Web-based blog search engine, Google Blog Search, to extract data from the archives of a Hong Kong–based blog service provider, MySinaBlog, from 2005-2010. Three groups of Chinese keywords were used, each representing a specific alcohol-related concept. They were (1) “alcohol” (ie, the control concept), (2) “beer or wine”, and (3) “spirit”. The resulting blog posts were analyzed quantitatively using infodemiological metrics and correlation coefficients, and qualitatively by manual effort. The infodemiological metrics were (1) apparent prevalence, (2) actual prevalence, (3) prevalence rate, and (4) prevalence ratio. Pearson and Spearman correlations were calculated for prevalence rates and ratios with respect to per capita alcohol consumption in the same years. Manual analysis included (1) blog author characteristics (ie, authorship, sex, and age), and (2) blog content (ie, frequency of keywords, description of a discrete episode of alcohol drinking, drinking amount, and genres). The prevalence rate and ratio were used to assess the online popularity of alcohol-related concepts, whereas the correlation analysis and manual analysis were used to validate blog searching data as an infoveillance method for population survey.

Collection of Infodemiological Data

Blog Service Provider

The online database of the blog service provider enabled search tasks and collection of infodemiological data. Inclusion criteria were (1) free of charge, (2) currently under service, and (3) last updated in or after 2010. As such, 19 blogging sites were enlisted from 852.com [45], which was a Hong Kong-based Web directory, and TopTenREVIEWS [46], a media review website. Their online traffic data were obtained from two Web information companies, Alexa Internet [47] and StatsCrop [48], shown in Table 1. They were excluded if (1) the only available figures were from their non-blog domain server, or (2) data were not available. The rest were compared in terms of their local popularity (measured by Alexa traffic rank in Hong Kong and percentage of daily visitors from Hong Kong) and primary country/server location to maximize the regional interest. MySinaBlog, a Hong Kong-based blog service provider with a local rank of 201 and more than half of its visitors from Hong Kong, was eventually selected.

Table 1. Alexa traffic rank in Hong Kong, percentage of daily visitors from Hong Kong, and primary country[a] of selected free blogging sites (as on April 12, 2013).

URL	Alexa traffic rank in Hong Kong	Percentage of daily visitors from Hong Kong	Primary country
blogcity.me	1145	74.2	Hong Kong
blog.mingpao.com	94[b]	56.8[b]	Hong Kong
blog.yahoo.com/explorer/hk	4[b]	0.8[b]	United States
hk.xanga.com	571	5.4	United States
lifestream.aol.com	Data not available	Data not available	United States
mysinablog.com	201	50.8	Hong Kong
qooza.hk	417	35.7	Hong Kong
showhappy.net	Data not available	Data not available	United States
spaces.live.com	Data not available	Data not available	Iran
space.gogo.la	1352[b]	67.0[b]	Hong Kong
space.uwants.com/html/blog.html	22[b]	57.4[b]	Hong Kong
wordpress.com	Data not available	Data not available	United States
www.blogger.com	Data not available	Data not available	India
www.ezhk.net	Data not available	Data not available	Hong Kong
www.hkflash.com/diary	7012[b]	25.6[b]	South Korea
www.livejournal.com	Data not available	Data not available	Russia
www.mocasting.com	16,435	51.8	China
www.myspace.com	Data not available	Data not available	United States
www6.mobichai.com/blog	Data not available	Data not available	Hong Kong

[a]Or server location if the primary country was not known.

[b]Representing the only available data from its non-blog domain server.

Blog Search Engine and Search Query

The capabilities and limitations of 11 blog search engines were compared in one study by Thelwall [44]. Among them, Google Blog Search was the only one equipped with all of the following features: (1) full Boolean search, (2) user-specified date or date range search, (3) URL search, (4) language selection, and (5) word location. It was therefore employed in the present study.

In each search query, the following were included: (1) alcohol-related Chinese keywords connected by the Boolean operator "OR", and (2) URL of the blog service provider expressed as "site:mysinablog.com". To obtain the total number of blog posts, the keywords were substituted by a space. The date was specified as January 1 to December 31 of each year from 2005-2010. The timeframe was so decided because MySinaBlog started to run their service in 2005 [49], and epidemiological data regarding alcohol consumption per capita in Hong Kong was only up to 2010 [4]. The search results (ie, number of matched blog posts) were taken for infodemiology analysis.

Alcohol-Related Concepts and Keywords

Overview

Specific groups of alcohol-related keywords formed the basis of blog searching in this study. Each group corresponded to a concept and comprised multiple keywords connected by the Boolean operator "OR" (which would return blog posts containing any of the search terms) to explore the same concept, as suggested by Eysenbach in his framework on infodemiology and infoveillance [14]. The concepts were (1) "alcohol", (2) "beer or wine", and (3) "spirit". They were chosen because beer and wine contained an alcohol strength of not more than 30%, and it was upon this group of liquors that the HKSAR Government halved the duty in 2007 and then abolished it in 2008. To better compare the concepts of "beer or wine" and "spirit", "alcohol" was chosen as the control (ie, the broader) concept to calculate the prevalence ratios, in addition to the prevalence rates.

Figure 1 shows the concepts and keywords that were typed into the search field. All keywords were in traditional Chinese, which was more often used than simplified Chinese or English in Hong Kong. Compared to using keywords in both Chinese and English, it could (1) enhance the homogeneity of the output

data, and (2) reduce the size of the output data to ease subsequent manual analysis.

Keyword "Alcohol"

The English word "alcohol" was translated to Chinese using Lin Yutang's Chinese-English Dictionary of Modern Usage (Online Version) [50]. In general, two or more Chinese characters made up a Chinese word. Different Chinese words might share the same meaning, whereas some Chinese words might have more than one meanings. To reduce confusion and widen the search coverage, only the Chinese character shown in Figure 1 was used for alcohol, instead of other Chinese words with the same meaning. It should be noted, however, that some Chinese translations were simply taken from the phonics in English without including the Chinese character for alcohol (eg, champagne, whisky, brandy). It would be impossible (and impractical) to guarantee a full coverage of the search results for all kinds of beer, wine, and spirit using the single Chinese character for alcohol shown in Figure 1. Nonetheless, it already provided the largest inclusion as a control concept of this study.

Keywords "Beer or Wine" and "Spirit"

Keywords that belonged to the concepts "beer or wine" and "spirit" were chosen from a document released by the Customs and Excise Department of the HKSAR Government [51], which related to the budget proposals about changes in the beer and wine tax. They contrasted the impacts brought about by the tax policy. Generic terms with variable alcoholic strength were excluded (eg, sake, sugar spirit, reprocessing Chinese liquor). The rest were categorized under "beer or wine" if the alcohol strength was not more than 30%, or "spirit" if otherwise.

Figure 1. Alcohol-related concepts and their corresponding Chinese keywords typed into the search field.

Concepts	Chinese keywords (English translations)
"alcohol"	酒
"beer or wine"	香檳 (champagne) OR 啤酒 (beer) OR 砵酒 (port wine) OR 梨酒 (perry) OR 起泡酒 (sparkling wine) OR 雪利酒 (sherry wine) OR 無汽酒 (still wine) OR 蘋果酒 (cider) OR 椰子酒 (arrack)
"spirit"	威士忌 (whisky) OR 冧酒 (rum) OR 拔蘭地 (brandy) OR 伏特加酒 (vodka) OR 氈酒 (gin)

Collection of Epidemiological Data

Table 2 shows the per capita alcohol consumption extracted from a report released by the Department of Health of the HKSAR Government in 2011 [4]. It was adopted in our study because it was (1) freely accessible, (2) presented in a longitudinal form, and (3) subgrouped according to alcohol types. Data from 2011 were not available, and no updates of the data were seen hitherto.

Quantitative Analysis

Infodemiological Metrics: Apparent Prevalence, Actual Prevalence, Prevalence Rate, and Prevalence Ratio

Eysenbach advocated the use of relative indicators such as rates and ratios in lieu of absolute figures to represent information prevalence since the number of websites was constantly changing [15]. With slight modifications of his proposal, the following infodemiological metrics were used to indicate the online popularity of the concepts in blog posts: (1) apparent prevalence, (2) actual prevalence, (3) prevalence rate, and (4) prevalence ratio. The definitions/formulae of the metrics are shown in Figure 2. The apparent prevalence referred to an estimate by the blog search engine, and the actual prevalence was confirmed by the researcher who did the counting while accessing each website. The apparent prevalence instead of actual prevalence was used to calculate the prevalence rate because the total number of blog posts was again an estimate by the blog search engine. Similarly, the prevalence ratio was calculated using apparent prevalence instead of actual prevalence to avoid confusion in the correlation analysis.

Table 2. Total and per capita alcohol consumption in Hong Kong from 2005-2010 (adapted from the Department of Health of the HKSAR Government).

Year	Total pure alcohol consumption (in liters)		Population aged ≥15 years	Per capita alcohol consumption (in liters)	
	Beer and wine	Spirit		Beer and wine	Spirit
2005	9,382,633	5,376,813	5,844,300	1.61	0.92
2006	9,442,114	5,586,247	5,918,000	1.60	0.94
2007	9,878,382	5,927,246	6,004,700	1.65	0.99
2008	12,309,905	5,946,634	6,075,400	2.03	0.98
2009	11,973,446	4,244,254	6,130,300	1.95	0.69
2010	11,252,645	5,156,867	6,209,800	1.81	0.83

Figure 2. Definitions/formulae of the infodemiological metrics.

$$\textit{Apparent prevalence} = \text{Number of blog posts containing keywords of a particular concept within a specified period of time estimated by the blog search engine}$$

$$\textit{Actual prevalence} = \text{Number of blog posts containing keywords of a particular concept within a specified period of time accessible by users of the blog search engine}$$

$$\textit{Prevalence rate (in \%)} = \frac{\text{Apparent prevalence of any concept}}{\text{Total number of blog posts within the same period estimated by the blog search engine}}$$

$$\textit{Prevalence ratio} = \frac{\text{Apparent prevalence of a non-control concept}}{\text{Apparent prevalence of a control concept}}$$

Pearson and Spearman Correlations

A correlation analysis was done to validate the use of infodemiological data in surveying the drinking patterns of the local population, as shown in Table 3. Essentially, the infodemiological data (ie, prevalence rates and ratios) acted as the independent variable whereas the epidemiological data (ie, per capita alcohol consumption) acted as the dependent variable. Pearson and Spearman correlations were calculated using the Statistical Package for the Social Sciences (SPSS).

Qualitative Analysis

Once blog searching was done, the blog posts were saved in .html files for subsequent analysis to avoid discrepancy due to time lag. The manual analysis focused on (1) blog author characteristics (ie, authorship, sex, and age), and (2) blog content (ie, frequency of keywords, description of a discrete episode of alcohol drinking, drinking amount, and genres). They would provide further information about the validity of utilizing blog searching data in an epidemiological survey. Their subcategories and criteria are listed in Table 4.

Blog posts with “alcohol” keywords were not included for manual analysis since a large portion of them were expected to overlap with those that contained “beer or wine” and “spirit” keywords. They might not be particularly helpful in analyzing the drinking pattern (eg, choice of alcohol) of the population.

It was noteworthy that most of the free text analytic tools did not support Chinese language and had no way to identify position of the keywords within a blog (eg, header, main body, sidebar, footer, and comment). Currently available concordancers for Chinese language were not too user-friendly as they lacked an external encoder/decoder, keyword-in-context (KWIC) format, or built-in dictionaries for semantic analysis or opinion mining [52]. This was why manual analysis was chosen in this study as a preliminary measure to explore the blog author characteristics and blog content.

Table 3. Correlation of infodemiological and epidemiological data.

Infodemiological data	Epidemiological data
“alcohol” prevalence rate	Per capita consumption of all alcoholic types
“beer or wine” prevalence rate	Per capita consumption of beer and wine
“spirit” prevalence rate	Per capita consumption of spirits
“beer or wine” / “alcohol” prevalence ratio	Per capita consumption of beer and wine
“spirit” / “alcohol” prevalence ratio	Per capita consumption of spirits

Table 4. Categories, subcategories, and criteria for manual analysis of blog posts containing “beer or wine” and “spirit” keywords in MySinaBlog from 2005-2010.

Categories	Subcategories
Authorship	(1) Single author, or (2) multiple authors
Sex	(1) Female, (2) male, or (3) unknown
Age	(1) Below 18 years old, (2) 18 years old and above, or (3) unknown
Frequency of keywords	Not applicable
Description of a discrete episode of alcohol drinking	(1) Yes, or (2) no
Drinking amount	(1) Binge drinking, (2) non-binge drinking, and (3) undetermined
Genres	(1) Name of a place/person/entity not belonging to alcohol, eg, lyrics, (2) recipe/dish name, (3) news/copied article from an external source, (4) story narrative/film synopsis, (5) health/educational information, (6) non-opinionated featured article, (7) personal diary/opinion/emotional outlet, or (8) more than one of the above

Results

Overview

The blog search was done on April 12, 2013, and the manual analysis was completed by researcher, KL Chan, in the subsequent week. The results are described below.

Quantitative and Correlation Analysis

Apparent and Actual Prevalence

Table 5 shows that the total number of blog posts in MySinaBlog increased dramatically within 5 years' time, from less than 500 in 2005 to more than 20,000 in 2010. An increasing trend was also observed for the apparent prevalence of "alcohol", "beer or wine", and "spirit" except in 2010 when that of "beer or wine" and "spirit" dropped compared to the year before.

The apparent prevalence of "alcohol" was consistently higher than that of "beer or wine" and "spirit", which made sense as "alcohol" was the control concept. However, in 2005 the apparent prevalence of "alcohol" was only 3, compared to that of "beer or wine", which was 5. This might be explained by translation difficulties where the Chinese character of "alcohol" did not cover all keywords of "beer or wine" and "spirit". On the other hand, the apparent prevalence of "beer or wine" was higher than that of "spirits" in 2005-2007 and 2010. In 2008 however, the two were equal, and in 2009, the apparent prevalence of "spirit" surpassed that of "beer or wine" by a difference of 17.

The discrepancies between apparent and actual prevalence became more obvious when their values enlarged in all three concepts. For example, the apparent prevalence of "alcohol" in 2005 was 3 and was the same as the actual prevalence; but in 2006, as the former increased to 26, the two differed by 12. By the time the apparent prevalence of "alcohol" reached up to 1390 in 2010, the actual prevalence of "alcohol" was only 195, representing a difference of 1195. Of particular note, the actual prevalence of "spirits" of 12 in 2008 and 13 in 2009 was much lower than its apparent prevalence of 73 and 115, respectively, due to spams in blogs. The trends of the apparent and actual prevalence were grossly symmetrical for "alcohol" and "beer or wine" except that in 2010, the actual prevalence of "beer or wine" peaked instead of waning.

Table 5. Total number of blog post, apparent and actual prevalence of alcohol-related concepts in MySinaBlog from 2005-2010.

Year	Total number of blog posts	Apparent prevalence (actual prevalence)		
		"Alcohol"	"Beer or wine"	"Spirit"
2005	394	3 (3)	5 (5)	0 (0)
2006	1810	26 (14)	16 (15)	3 (3)
2007	5620	120 (59)	27 (15)	5 (5)
2008	11,500	1180 (150[a])	73 (28)	73 (12[a,b])
2009	16,000	1290 (190[a])	98 (25)	115 (13[a,b])
2010	20,400	1390 (195)	70 (41[c])	3 (3)

[a]Final figures included those blog posts that were initially hidden and prompted by the blog search engine.

[b]After excluding blogs with spams that actually contained no keywords.

[c]After excluding one blog post that was inaccessible due to security reasons.

Prevalence Rate and Correlation Coefficients

Table 6 shows that the prevalence rate of "alcohol" followed an inverted V shape, increasing steadily from 0.76% in 2005 to 2.14% in 2007, peaking at 10.26% in 2008, and decreasing to 8.06% in 2009 and then to 6.81% in 2010. The prevalence rate of "beer or wine" declined over the years with its first trough of 0.48% in 2007 and second trough of 0.34% in 2010. The prevalence rate of "spirit" was quite the opposite, initially hovering at a low level of 0% to 0.17% in 2005-2007, then surging up to 0.72% in 2008-2009, and eventually falling back to 0.01% in 2010.

The prevalence rate of "alcohol" was consistently higher than that of "beer or wine" and "spirit" except in 2005 when the prevalence rate of "alcohol" was only 0.76%, compared to that of "beer or wine", which was 1.27%. This might be explained by translation difficulties as stated before. The prevalence rate of "spirit" was the lowest among all three concepts in 2005-2007 and 2010. However, in 2008, it tied with the prevalence rate of "beer or wine", and in 2009, exceeded it altogether.

Per capita consumption of alcohol correlated strongly with the prevalence rate of "alcohol" (Pearson correlation=0.81, P=.05; Spearman correlation=1.00, P<.001). The linear relationship was marginally significant and the nonlinear relationship was significant. The prevalence rate of "beer or wine" was negatively and moderately correlated with per capita consumption of beer and wine (Pearson correlation=-0.48, P=.34; Spearman correlation=-0.43, P=.40). Both were nonsignificant. Similarly, the prevalence rate of "spirit" had a moderate negative linear correlation (Pearson correlation=-0.40, P=.43) and a weak negative nonlinear correlation (Spearman correlation=-0.09, P=.87) with per capita consumption of spirits. Again, both were nonsignificant.

Prevalence Ratio and Correlation Coefficients

Table 7 shows that the prevalence ratio of "beer or wine" / "alcohol" declined as a whole, troughing at 0.06 in 2008 and 0.05 in 2010. The prevalence ratio of "spirit" / "alcohol", on the other hand, peaked at 0.12 in 2006 and 0.09 in 2009. The former was higher in 2005-2007 and 2010. However, in 2008,

the two tied, and in 2009, the prevalence ratio of "spirit" / "alcohol" reached 0.09, surpassing that of 0.08 for "beer or wine" / "alcohol".

The prevalence ratio of "beer or wine" / "alcohol" had a strong negative correlation with per capita consumption of beer and wine (Pearson correlation=-0.65, *P*=.16; Spearman correlation=-0.77, *P*=.07). The correlation coefficients were nonsignificant. The prevalence ratio of "spirit" / "alcohol" was also negatively correlated with per capita consumption of spirits but only weakly (Pearson correlation=-0.10, *P*=.85; Spearman correlation=-0.03, *P*=.96). Again, both correlation coefficients were nonsignificant.

Table 6. Prevalence rate of alcohol-related concepts in MySinaBlog and correlation coefficients compared with per capita consumption of the same alcohol types in Hong Kong from 2005-2010.

		Prevalence rate (%)		
		"Alcohol"	"Beer or wine"	"Spirit"
Year				
	2005	0.76	1.27	0
	2006	1.44	0.88	0.17
	2007	2.14	0.48	0.09
	2008	10.26	0.63	0.63
	2009	8.06	0.61	0.72
	2010	6.81	0.34	0.01
Correlation coefficients (*P value*)				
	Pearson	0.81 (.05)	-0.48 (.34)	-0.40 (.43)
	Spearman	1.00 (<.001)	-0.43 (.40)	-0.09 (.87)

Table 7. Prevalence ratios of alcohol-related concepts in MySinaBlog and correlation coefficients compared with per capita consumption of the same alcohol types in Hong Kong from 2005-2010.

		Prevalence ratio (%)	
		"Beer or wine" / "alcohol"	"Spirit" / "alcohol"
Year			
	2005	1.67	0
	2006	0.62	0.12
	2007	0.23	0.04
	2008	0.06	0.06
	2009	0.08	0.09
	2010	0.05	0.00
Correlation coefficients (*P value*)			
	Pearson	-0.65 (.16)	-0.10 (.85)
	Spearman	-0.77 (.07)	-0.03 (.96)

Qualitative Analysis

Blog Author Characteristics

Figure 3 illustrates that a substantial number of blogs with alcohol-related keywords in MySinaBlog from 2005-2010 were written by single authors (97.1%, 134/138). For those single authors whose sex identity was known, their sex distribution was equal (female=38.1%, 51/134; male=38.1%, 51/134; unknown=23.9%, 32/134) (Figure 4). Most single authors also did not indicate their age (unknown age=75.4%, 101/134), while the rest were mostly adults (18 years old or above=22.4%, 30/134) (Figure 5). All parameters appeared to increase with time, possibly explained by the increase in the total number of blogs.

Blog Content

As shown in Figures 6 and 7, not all alcohol-related keywords were found in the blog posts of MySinaBlog in 2005-2010. Among "beer or wine" keywords, "beer" was the most common. It had an accumulated frequency of 324 from 2005-2010 and peaked at a point frequency of 153 in 2010. "Champagne" was the second most common, followed by "port wine", and lastly "perry". As for "spirit" keywords, "whisky" was the most

common. It had an accumulated frequency of 67 from 2005-2010 and peaked at a point frequency of 21 in 2010. “Rum” was the second most common, followed by “brandy”, and lastly “vodka”. The point frequency of the keywords seemed to rise over the years, possibly explained by an increase in the actual prevalence of the blog posts.

As shown in Figure 8, not all blog posts actually described a discrete episode of alcohol drinking (alcohol type specified by the keyword) by the author in Hong Kong and in the same year when the blog post was published. In fact, only 11.5% (19/165) of them did so, with limited information regarding the drinking amount and duration. It was thus difficult to differentiate between binge and non-binge drinking (binge drinking=0%; non-binge drinking=26.3%, 5/19; undetermined=73.7%, 14/19) (Figure 9; [35]). The others were mostly personal diary, opinion, or emotional outlet (28.1%, 41/146) (Figure 10). In Figure 10, the name is the name of a place, person, or entity not belonging to alcohol, eg, lyrics; recipe is recipe or dish name; news is the news/copied article from an external source; story is the story narrative/film synopsis; health info is the health or educational information; featured article is the non-opinionated featured article; personal diary is a personal diary, opinion, or emotional outlet. The immediate text surrounding the keyword(s) was first examined. If a decision was not made or the keywords were too disperse, the entire blog post was examined. Former options should be considered before latter ones.

Figure 3. Actual prevalence of blogs with alcohol-related keywords in MySinaBlog from 2005-2010 classified according to authorship (corporational or organizational blogs were counted as multiple authors; different blog posts by the same registered user in the same year were counted as one blog).

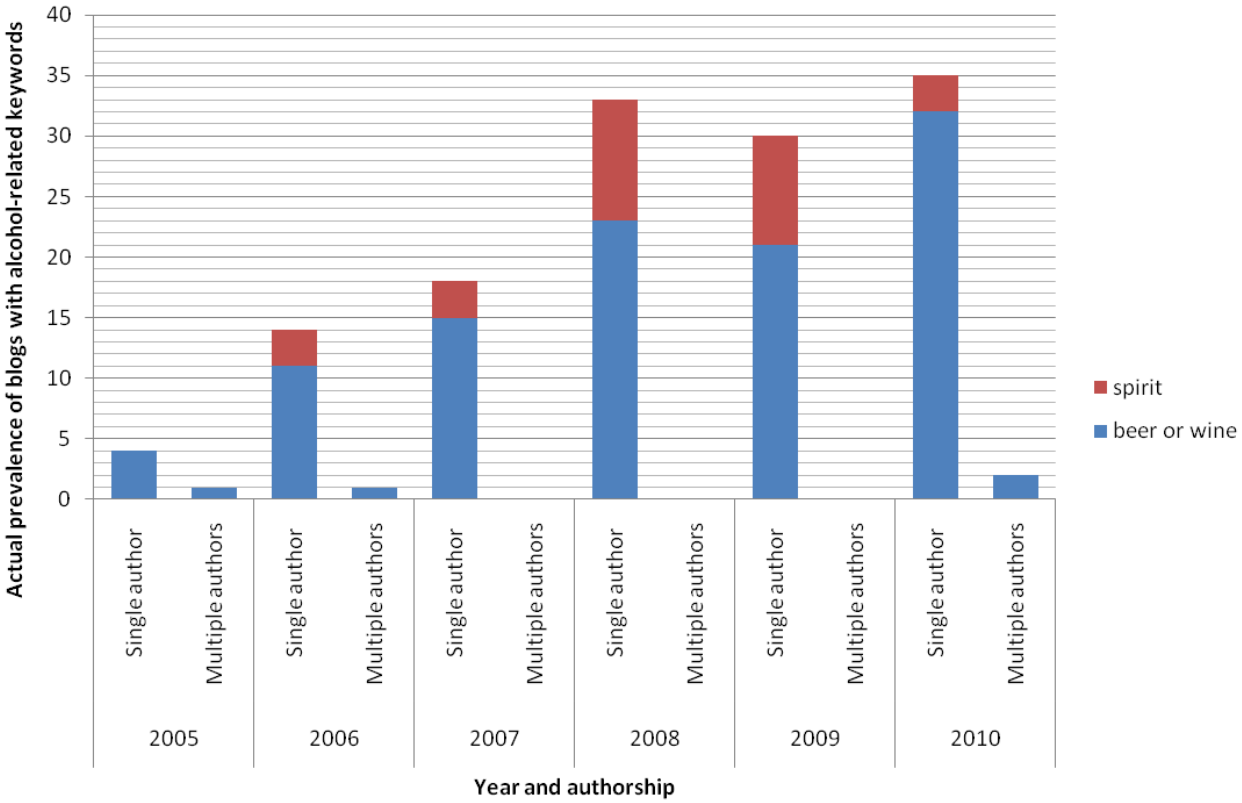


Figure 4. Actual prevalence of blogs with alcohol-related keywords in MySinaBlog from 2005-2010 classified according to sex of the single authors.

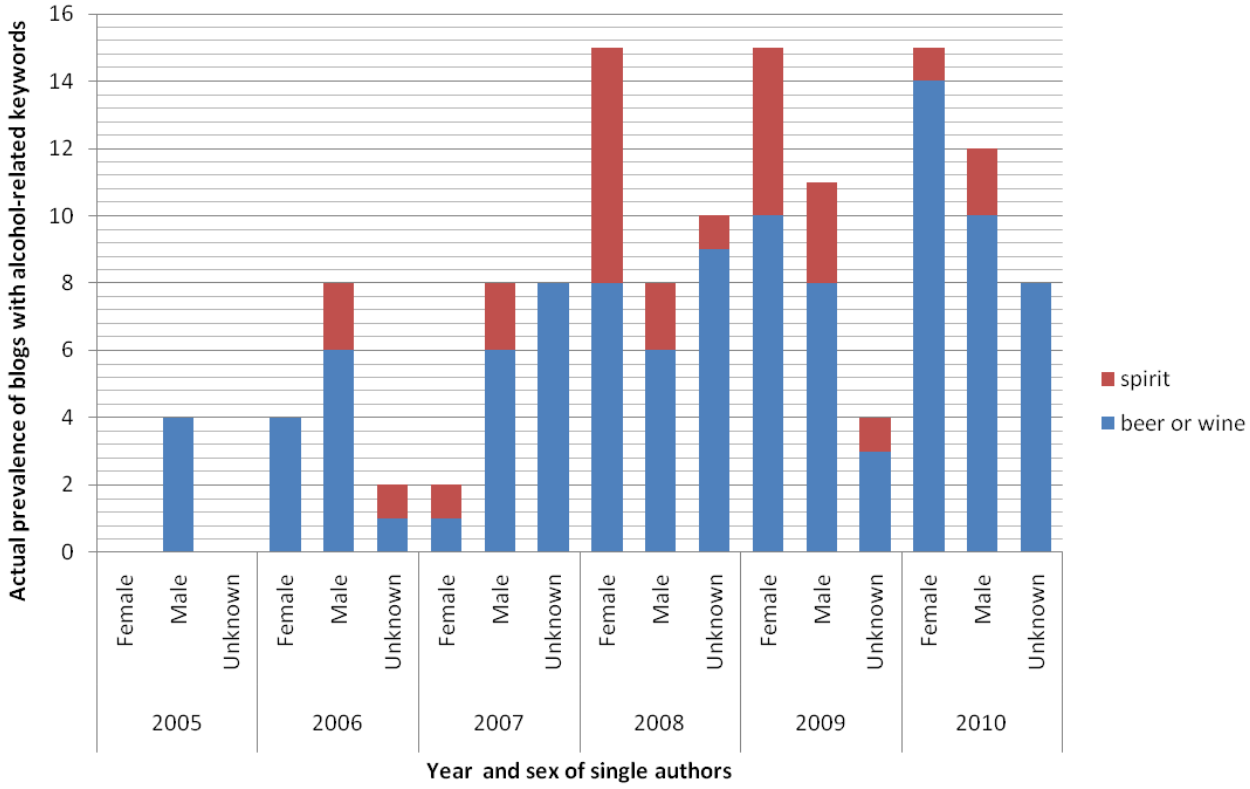


Figure 5. Actual prevalence of blogs with alcohol-related keywords in MySinaBlog from 2005-2010 classified according to age of the single authors.

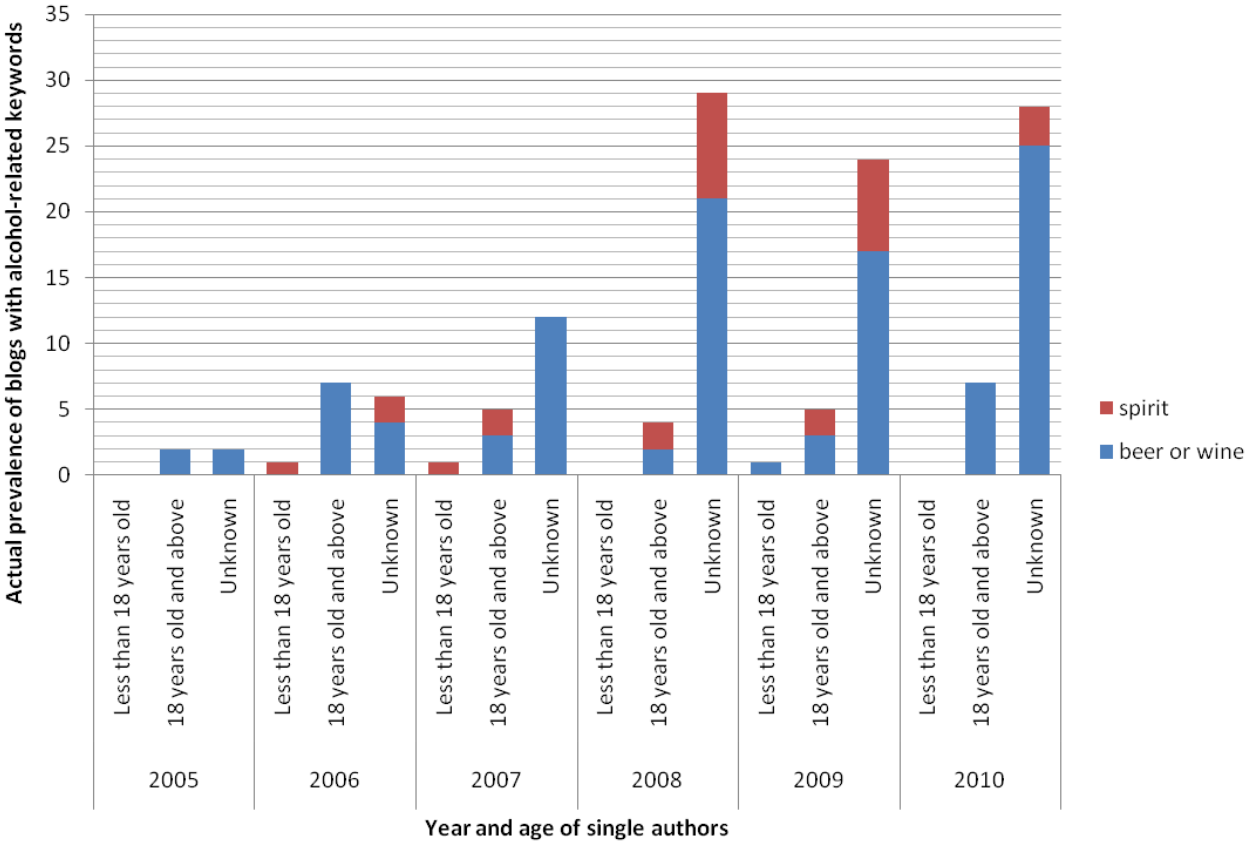


Figure 6. Point frequency of "beer or wine" keywords in main body of the blog posts of MySinaBlog from 2005-2010.

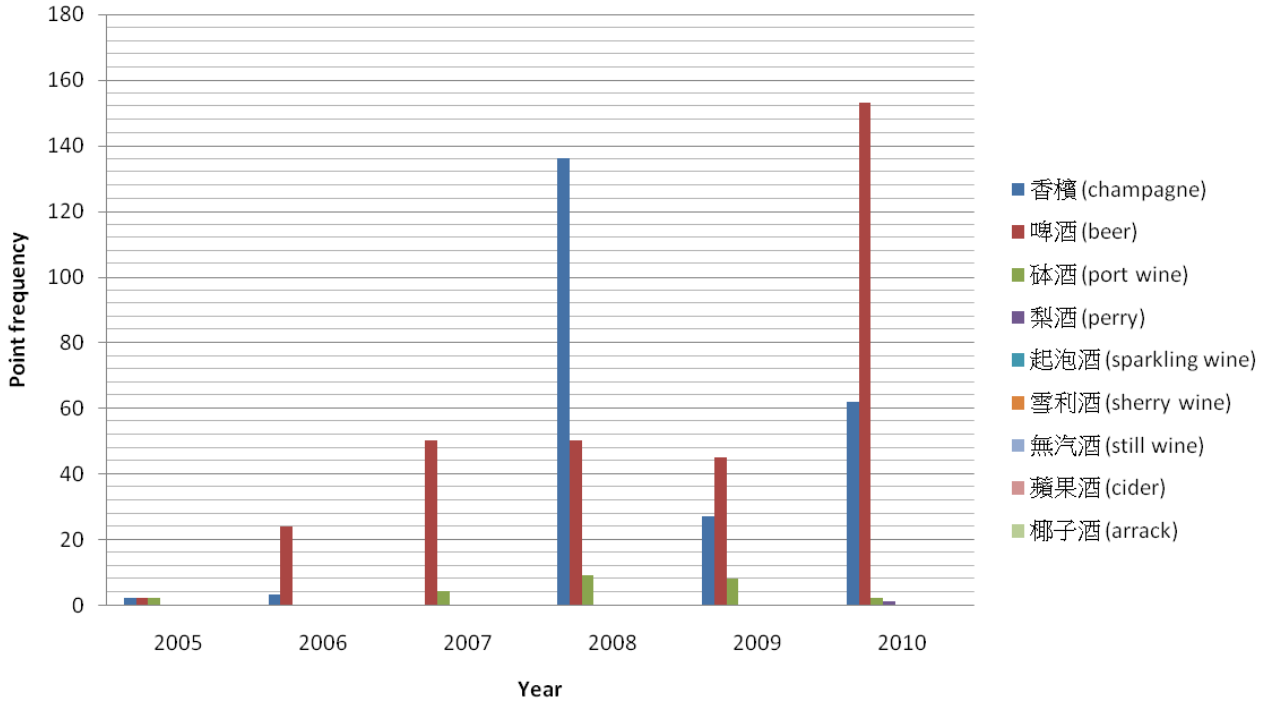


Figure 7. Point frequency of "spirit" keywords in main body of the blog posts of MySinaBlog from 2005-2010.

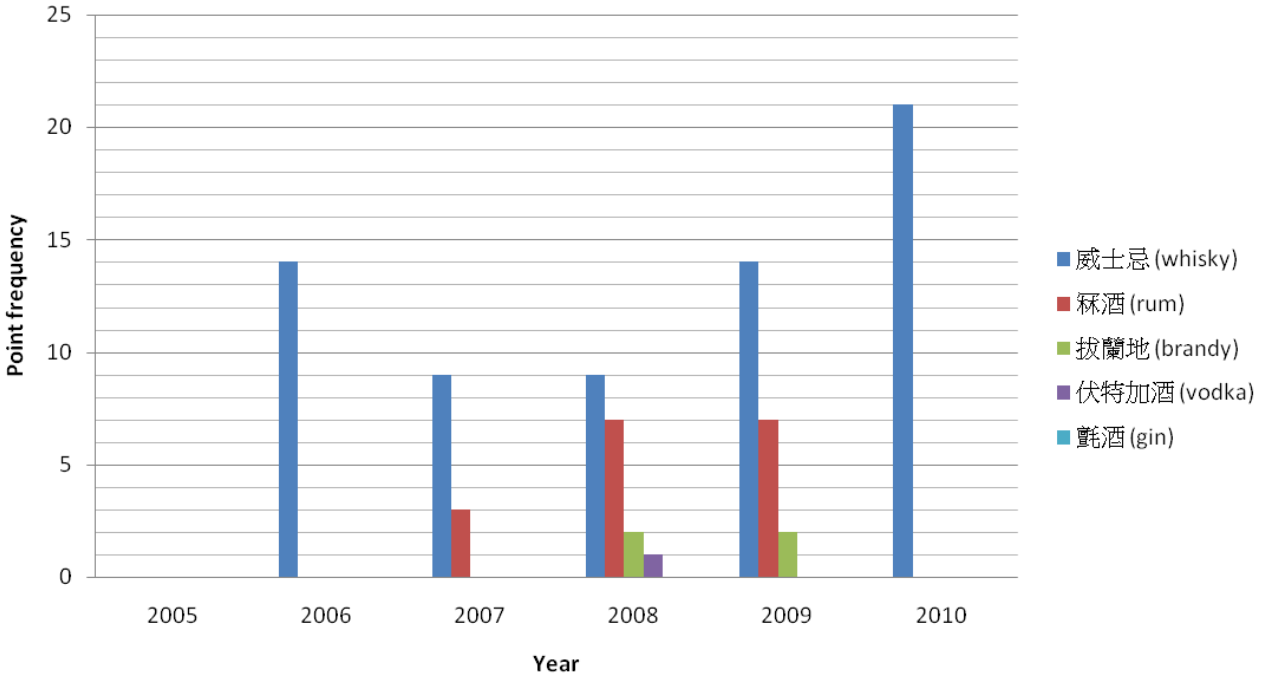


Figure 8. Actual prevalence of blog posts with alcohol-related keywords in MySinaBlog from 2005-2010 classified according to description of a discrete episode of alcohol drinking (alcohol used for cooking was excluded).

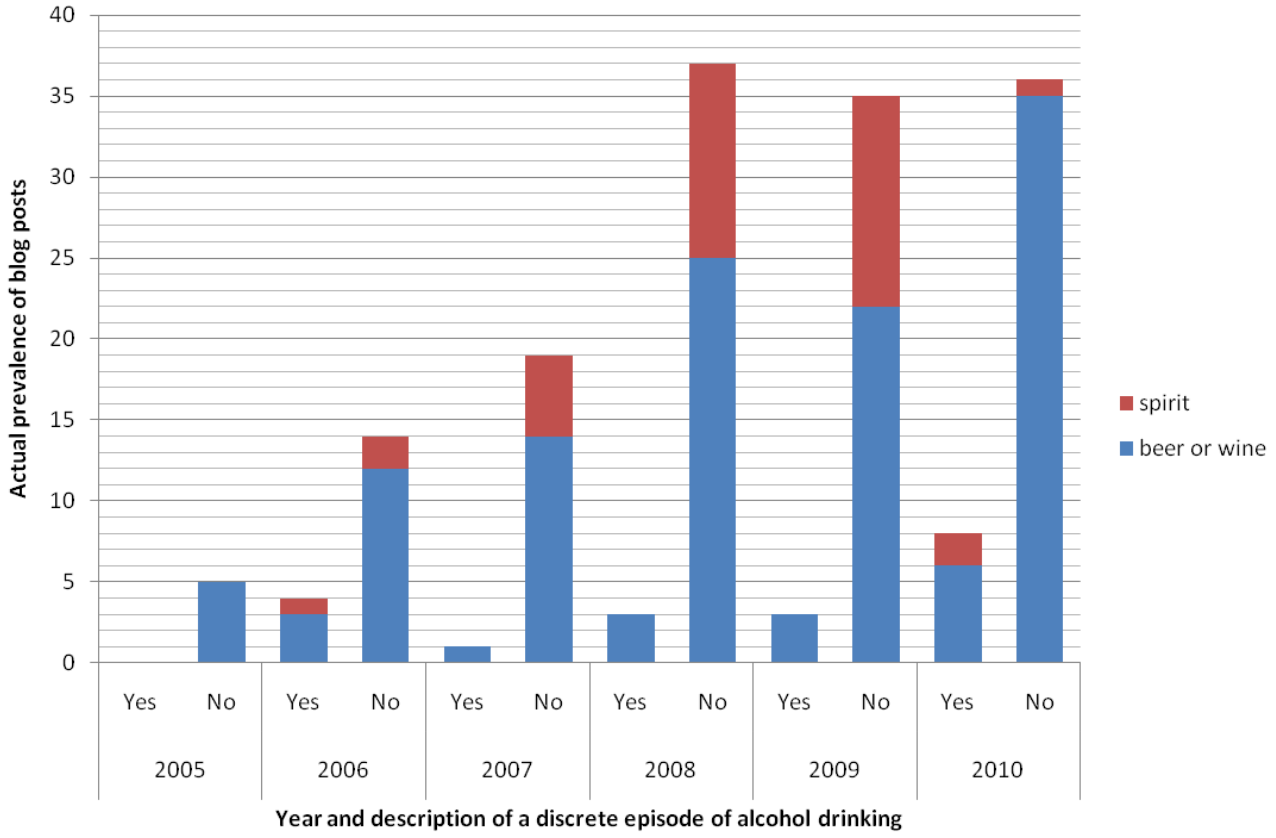


Figure 9. Actual prevalence of blog posts with alcohol-related keywords and description of a discrete episode of alcohol drinking in MySinaBlog from 2005-2010 classified according to drinking pattern (binge drinking defined as 5 alcoholic drinks in a row within a couple of hours).

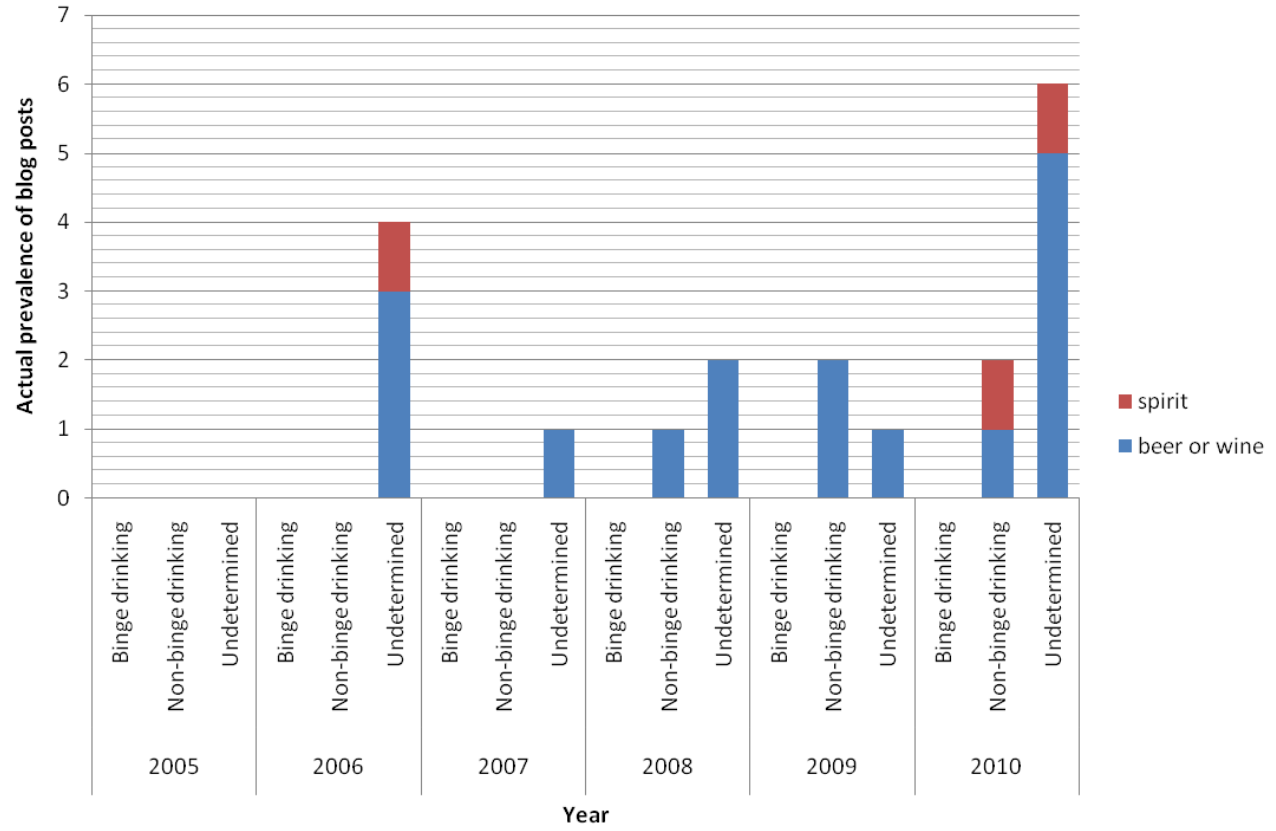
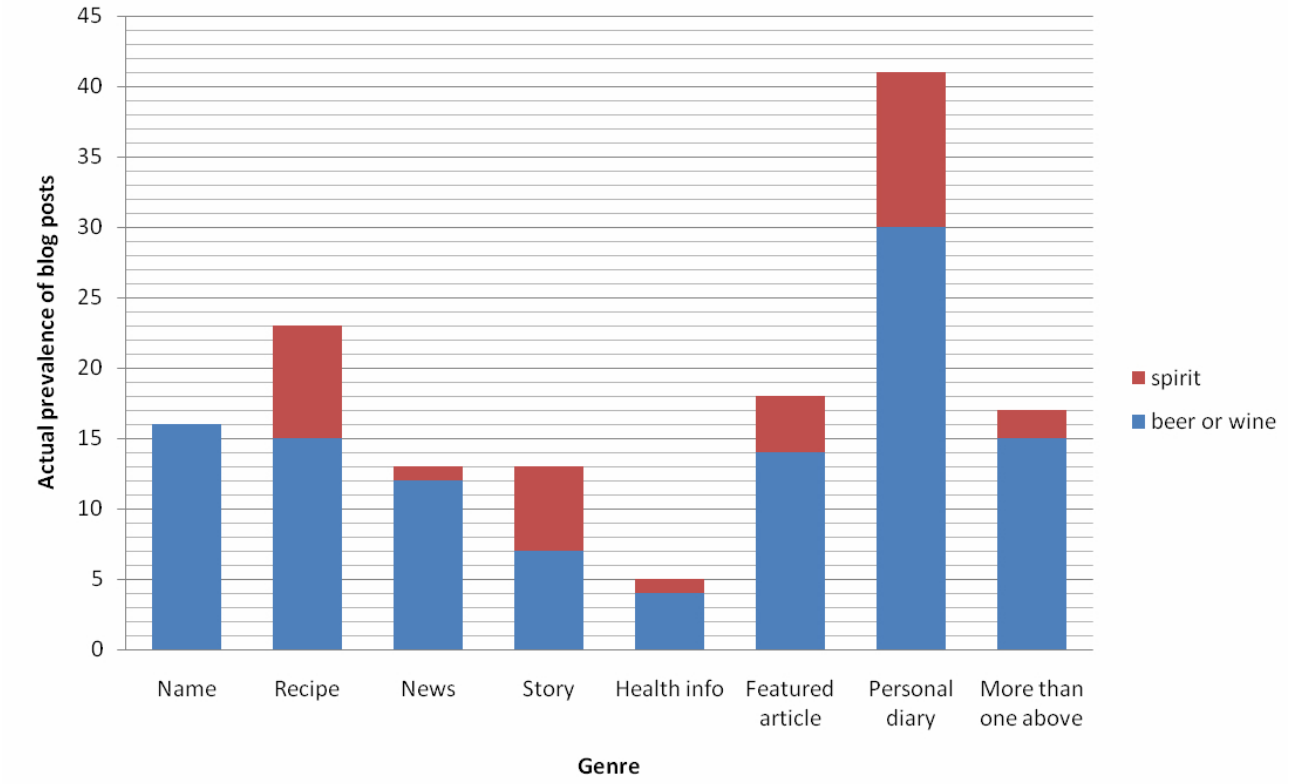


Figure 10. Actual prevalence of blog posts with alcohol-related keywords but no description of a discrete episode of alcohol drinking in MySinaBlog from 2005-2010 classified according to genre.



Discussion

Changes in the Online Popularity of Alcohol-Related Concepts

The online popularity of alcohol-related concepts was best represented by their prevalence rate and ratio, which normalized the effect of any changes in the total number of blogs [14]. In general, the concept "alcohol" was most popular in 2008. The concept "spirit" also experienced a short-lasting and somewhat erratic rise in its online popularity in 2008-2009. The concept "beer or wine", in contrast, became increasingly unwelcome with an overall declining trend in its online popularity over the years. The hypothesis that alcohol-related concepts became more popular after 2007-2008 was true only for "alcohol" and "spirit" but not "beer or wine".

One possible reason for the increase in the online popularity of "spirit" keywords in 2008-2009 was the presence of spam in the same years. This was masked in the apparent prevalence, which was used to calculate the prevalence rate and ratio. Indeed, after excluding the data in 2008-2009, the prevalence rate and ratio of the concept "spirit" remained relatively stable at a low level. The false elevation in the online popularity of "spirit" might also explain the peak prevalence rate of "alcohol" in 2008, although the latter appeared much larger in amplitude and there was still a chance for a genuine rise in keywords which were not included in "beer or wine" or "spirit" but "alcohol". The downhill course in the online popularity of "beer or wine" was probably a true reflection of bloggers' decreased interest over the topic. However, its relation to local drinking pattern remained doubtful, since many of the blog posts were in fact not describing a discrete episode of alcohol drinking. The same argument held true for the concepts "spirit" and "alcohol".

Validating Blog Searching as an Infoveillance Method for Surveying Drinking Patterns

Validation of blog searching data depended on correlation analysis and manual analysis of blog author characteristics and contents. The prevalence rate of "alcohol" was the only parameter that had a significant nonlinear and a marginally significant linear correlation with per capita alcohol consumption. The other correlations were all nonsignificant, although many of them demonstrated moderate to strong strengths. The hypothesis that infodemiological data correlated significantly with local epidemiological data was true only for "alcohol" prevalence rate. The statistical nonsignificance of other infodemiological metrics might be explained by the small number of blog posts relative to the population. This in turn could be attributed to the following:

1. Choice of keywords. The list of keywords for "beer or wine" and "spirit" could never be exhaustive since their types were many and expressions by bloggers were highly variable. Mixed code of Chinese characters and English letters was not uncommon for online communications among Hong Kong people. Some of them would actually type Cantonese (dialect of Yue Chinese) rather than standard Chinese [53]. They might use a different Chinese word as the translation of the same liquor. They might also use the brand name of the liquor they took. This was partly reflected by the frequency of individual alcohol-related keyword in the blog posts, showing that some were not used by bloggers at all. All these added difficulties in

selecting the appropriate keywords that gave an adequate coverage within the word limit of the search query.

2. Passive blogging behavior among Hong Kong people. In a survey done by the HKSAR Government in February to April 2011, 53.4% of Internet users had browsed contents at forums or blogs in the preceding 12 months, yet only around 15.8% had compiled or created webpages or blogs in the same period [42].

From the manual analysis, most blogs were managed by single authors, meaning that the number of blogs could be used to represent the number of individual attendants in a population survey. The sex distribution of the single blog authors was close to the local population, but their age range was slightly inclined to 18 years old and above [54]. It should be noted, however, that many of the bloggers did not disclose their identity online, making validation difficult.

Many of the blog posts were not about a discrete episode of alcohol drinking but personal diary, opinion, or emotion outlet. This was not surprising as new genres of blogs continued to emerge [55]. Rather than just being informative, many blogs were affective in nature requiring semantic analysis for meaningful interpretation [25]. While it was unlikely that bloggers recorded their alcohol intake on each occasion, they might reveal their understanding on alcohol drinking when commenting on a particular event, answering a particular question, and describing a childhood incident, etc, hence, the presence of alcohol-related keywords. While there were inadequate clues to support that changes in the online popularity of the alcohol-related keywords were related to an altered drinking pattern of the local population, one should not ignore its social implications and disregard its role in evaluating public reactions towards health-related policy including the zero beer and wine tax.

Research Limitations and Solutions

Using blogs as the source of information had several inherent limitations. For example, demographic data of individual blogger such as gender, age, and race might be deficient or disguised; bloggers tended to share common interests and backgrounds that were probably different from those of the general population; and acquisition of precise data such as drinking patterns was often difficult. In order to construct a larger framework in a timely and efficient manner, informatics researchers often had to compromise the individuality of each blogger by using certain infodemiological metrics. Moreover, language usage by bloggers tended to be complex and not easily decoded by the frequency of some pre-determined keywords. As a solution, semantic analysis of individual blog post might be useful to explore bloggers' opinions towards drinking, provided enough technical support. Face-to-face interviews and questionnaires might be conducted with individual bloggers to elaborate their viewpoints, preferably those who appeared to have the largest influence within a specific blog circle (using a social network analytic tool).

No single blog search engine indexed all blogs [56]. Despite its automaticity, a search engine might be subject to editorial choice and hence bias [57]. There were concerns that even in the same search engine, the search results may be different over time [14,44]. In our case, it might be explained by the (1) inherent limitation in the search algorithms of Google, which gave only an approximate estimate for query with large results, and (2) inconsistency of the search database due to a variable number of splogs (or spam blogs) and blogs that were previously not linked [35,44,56]. Of note, a large part of the Google Search algorithm was unknown to the public, aggravating sampling uncertainty in our study.

One challenge with the use of Chinese language in blog searching was that it tended to have a wide range of expressions owing to geographical difference and translation from English. Also, only a limited number of blog analytic tools supported the Chinese language. A self-designed research program with well-informed blog search algorithms and analytic functions especially for Chinese blogs would be most desirable, which would depend heavily on the availability of expertise and resources.

Conclusion and Recommendations for Future Research

Using blog searching data from a Hong Kong–based Chinese blog service provider, we concluded the following: (1) the online popularity of alcohol-related Chinese keywords was attributed to many different factors including spam, and hence not a specific reflection of local drinking patterns, (2) correlation between infodemiological data (represented by prevalence rates and ratios of alcohol-related concepts) and epidemiological data (represented by per capita alcohol consumption) was poor, and (3) many blog posts were affective rather than informative in nature. While blog searches using pre-defined Chinese keywords might not be an ideal method to survey epidemiological data such as alcohol consumption, semantic analysis of blog content would provide invaluable information on public reactions towards health-related policy, given enough expertise and resources.

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Conflicts of Interest

None declared.

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Abbreviations

HKSAR: Hong Kong Special Administrative Region

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Original Paper

An Exploration of Social Circles and Prescription Drug Abuse Through Twitter

Carl Lee Hanson[1*], PhD; Ben Cannon[1*], BS; Scott Burton[2*], PhD; Christophe Giraud-Carrier[2*], PhD

[1]Computational Health Science Research Group, Department of Health Science, Brigham Young University, Provo, UT, United States

[2]Computational Health Science Research Group, Department of Computer Science, Brigham Young University, Provo, UT, United States

[*]all authors contributed equally

Corresponding Author:
Carl Lee Hanson, PhD
Computational Health Science Research Group
Department of Health Science
Brigham Young University
213 Richards Building
Provo, UT,
United States
Phone: 1 801 422 9103
Fax: 1 801 422 0273
Email: Carl_Hanson@byu.edu

Abstract

Background: Prescription drug abuse has become a major public health problem. Relationships and social context are important contributing factors. Social media provides online channels for people to build relationships that may influence attitudes and behaviors.

Objective: To determine whether people who show signs of prescription drug abuse connect online with others who reinforce this behavior, and to observe the conversation and engagement of these networks with regard to prescription drug abuse.

Methods: Twitter statuses mentioning prescription drugs were collected from November 2011 to November 2012. From this set, 25 Twitter users were selected who discussed topics indicative of prescription drug abuse. Social circles of 100 people were discovered around each of these Twitter users; the tweets of the Twitter users in these networks were collected and analyzed according to prescription drug abuse discussion and interaction with other users about the topic.

Results: From November 2011 to November 2012, 3,389,771 mentions of prescription drug terms were observed. For the 25 social circles (n=100 for each circle), on average 53.96% (SD 24.3) of the Twitter users used prescription drug terms at least once in their posts, and 37.76% (SD 20.8) mentioned another Twitter user by name in a post with a prescription drug term. Strong correlation was found between the kinds of drugs mentioned by the index user and his or her network (mean r=0.73), and between the amount of interaction about prescription drugs and a level of abusiveness shown by the network (r=0.85, P<.001).

Conclusions: Twitter users who discuss prescription drug abuse online are surrounded by others who also discuss it—potentially reinforcing a negative behavior and social norm.

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KEYWORDS

prescription drug abuse; social media; social circles; Twitter

Introduction

Prescription Drug Abuse

Prescription drug abuse has become the fastest-growing drug problem in the United States [1], contributing to approximately 27,000 overdose deaths during 2007 [2]. Nearly one-third of individuals over the age of 12 who were first-time drug users in 2009 started by abusing a nonmedical prescription drug [3]. It is estimated that 48 million Americans (approximately 20% of the population) aged 12 and older have used prescription drugs for nonmedical reasons at some point in their lifetime [4].

Even though death only occurs in the most severe cases of abuse, the negative health consequences of prescription drug abuse are many, ranging from simple drowsiness and nausea to lack of

coordination, disorientation, paranoia, and seizures. A recent study also found that there may be an emerging trend of (ab)using prescription drugs among adolescents to facilitate unwanted sexual contact [5]. A teen addiction treatment center in Iowa similarly warns against unwanted sexual behavior as one of the consequences of prescription drug abuse [6]. While there does not seem to be evidence of more at-risk sexual behaviors, such as sex-for-drugs, since most people have easy access to prescription drugs either from friends and relatives or through "doctor shopping", this trend still raises concerns about the limited, yet real, danger of prescription drug abuse increasing exposure to and spread of HIV.

The Office of National Drug Control Policy (ONDCP) Prescription Drug Abuse Prevention Plan includes four major areas of focus: education, monitoring, proper medication disposal, and enforcement [7]. Current public health intervention strategies are largely aimed at prescribers and distributors. In many states, doctors receive training on how to identify abusers and patients that doctor shop. In some states, pharmacies and distributors are required to report the amount of controlled substances disbursed each week. While these measures have proven to reduce rates of overdose and overdose deaths, primary preventative measures among end users of prescription drugs have not been explored or implemented as widely. The inherent difficulty of identifying abusers and redirectors of prescription drugs fosters an easy environment for abuse without real threat of legal repercussion.

Social Networks and Social Media

Relationships embedded in one's social network are an important influencing factor and contributor to health behavior and outcome, even beyond individual attributes such as age, sex, education level, income, and occupation [8-12]. In the context of prescription drug abuse, a recent study of the co-usage network of a population of 503 prescription drug abusers in rural Appalachian areas shows that daily OxyContin use is significantly associated with higher effective size of ego networks (a measure of social capital), and thus "speak to the importance of peer networks in determining social capital and social norms, which has vast implications for intervention research" [13]. It has been found that people, including youth, often learn to abuse prescription drugs by observing a family member, or other members of their social network, model the abuse of prescription drugs [14,15]. Within families, the practice of "friendly sharing" of prescription drugs has become commonplace [16]. Recent research has also identified social groups or informal economic markets where drug transactions can occur. An established market for prescription drug distribution has been identified in junior high and high school classes. Among students in Nova Scotia who had been prescribed stimulants, about 22% reported giving away or selling their medications, while another 7.3% experienced theft or were forced into giving away their prescriptions [17].

Research has revealed that the Internet provides ready access to drugs, including prescription medications [16,18]. More recently, evidence also suggests that participation in social media sites may increase one's risk of substance abuse, especially among adolescents. The National Center on Addiction and Substance Abuse began collecting data to explore the influence of social networking and substance abuse in 2011. Their findings reveal that teens who spend time social networking online are five times more likely to use tobacco, three times more likely to use alcohol, and two times more likely to use marijuana [16].

While studies have demonstrated the influence of social relationships on prescription drug abuse in the real world as well as ready access to the drugs, little is known about these influences in cyberspace. Social media applications, such as Twitter, offer a way to observe the conversations of individuals and their social circles directly, providing a mechanism to monitor end users of prescription drugs. By monitoring individual conversations, studies have demonstrated the validity of identifying health topics on Twitter [19,20], including prescription drug misuse [21]. In addition, social media applications are platforms for networking and as such are rich with relationships. These relationships make up important social circles that have the capacity to influence behavior due to unique norms and values of the group. Indeed, no social media user is an island, and the *social* element of social media has particular relevance in public health research.

Infodemiology represents a new field of study where the Internet, even social media platforms, provides channels through which to explore the distribution and determinants of information [22,23]. A growing body of research demonstrates the validity of this methodology for understanding public health challenges [21,24-31]. This study extends previous health research in social media by analyzing not only the content of social media posts, but also the relationships among users. Specifically, online social circles of prescription drug abusers are identified with discussions and interactions of these networks are analyzed. Few studies have explored the influence of online relationships on alcohol and other drug use [32,33]. To the best of our knowledge, this is the first work to focus on the relational component of these networks through social media, with regard to prescription drug abuse.

The purpose of this study was to investigate the social circles of prescription drug abusers on Twitter and to observe the discussion and engagement of these users regarding prescription drug abuse. To fulfill the purpose of this study, the following hypotheses were explored:

H1: People discuss prescription drug abuse on Twitter.

H2: People who discuss prescription drug abuse on Twitter belong to social circles that engage with each other about prescription drug abuse.

H3: Social engagement about prescription drug abuse varies across social circles of those who discuss it, and higher engagement correlates with higher levels of abuse.

Methods

Overview

A distinction exists between prescription drug abuse and prescription drug misuse. The former refers to using a drug with the intent of deriving some side effect, usually of a euphoric

nature (ie, getting high). The latter refers to increasing dosage in an attempt to improve the drug efficacy or to sharing the drug with someone whose symptoms may call for it but to whom the drug has not been prescribed. Either way, one can easily argue that "no matter the intention of the person...taking a drug other than the way it is prescribed can lead to dangerous outcomes that the person may not anticipate" (page 1) [34]. Hence, throughout the paper, any improper use and user are referred to simply as abuse and abuser, respectively.

To evaluate the discussion of prescription drug abuse among social media users, Twitter users mentioning prescription drugs were identified, and their tweets as well as those of their network were analyzed.

Study Setting

Social media applications such as Twitter provide channels for social networking with others who may have similar interests and needs. Twitter provides users with a platform to share short messages ("tweets") among themselves. Twitter users can "follow" others to subscribe to a feed of tweets from users of interest; they can also broadcast their messages to all of their followers or direct messages at specific users ("mentions"). By default, tweets are public; hence, it is generally possible for a user, X, to see the tweets of a user, Y, even though X may not be following Y or Y did not mention X explicitly. Because Twitter users tend to post messages as events occur in their lives, tweets are an ideal source for researchers to observe natural and timely interactions among people. As such, Twitter was used to observe discussion and engagement with regards to prescription drug abuse.

This study was approved by the institutional review board at Brigham Young University, Provo, Utah.

Identifying Users and Networks

Twitter provides an application programming interface (API) that enables programmatic consumption of the content and the relationships of its tweets and users. The Twitter Streaming API provides a means of obtaining tweets as they occur, filtered by specific criteria, such as a list of keywords. The Twitter API also enables discovering the people following and followed by a given user, as well as retrieving up to 3200 of a user's most recent tweets.

To identify a set of tweets mentioning prescription drugs, the Twitter stream was filtered for prescription drug terms, producing a set of all tweets mentioning these terms from November 29, 2011 through November 14, 2012. From this set, potential prescription drug abusers were identified for analysis along with their networks. In order to select those Twitter users who had some discussion of prescription drugs, but that were still regular users, Twitter users that mentioned prescription drugs in at least 10 tweets but less than 100 were selected at random. Evaluation revealed that Twitter users in this range were most likely regular users as opposed to accounts devoted to online drug sales, automated feeds, and companies, which tended to tweet more frequently about prescription drugs. A sample of 25 networks was obtained for further analysis. In order to select the 25 networks, a member of the research team sampled networks and read through prescription drug tweets to verify evidence of prescription drug abuse based on a pattern of prescription drug tweets that matched one or more of the categories of abuse. Networks were excluded from the sample if prescription drug tweets did not match any of the categories of abuse. Likely prescription drug abusers tended to have tweets that matched the categories of abuse. For example, one of the 25 index users was selected because he/she had a pattern of tweeting about Adderall and Xanax (45 and 34 tweets respectively) and 26 of those tweets matched several of the abuse categories. Most alarming was that 11 of the abuse tweets were about co-ingestion. One of these co-ingestion tweets stated, "Adderall + Benadryl has put me in a weird awake/tired haze. Relatively certain that I'm saying things i wont [sic] remember in the morning".

The social circles of each of the 25 index Twitter users were discovered. Unlike a traditional ego network that consists of all the individuals ego has a direct connection to, a social circle is a densely connected set of mutually aware individuals that surround ego, where some may be included in the circle by virtue of their many connections to ego's alters. Social circles capture the intuition that someone who influences ego's alters may exert a stronger influence on ego, though indirectly, than some of ego's alters. Finding a social circle around one or a small group of individuals is an instance of the community search problem [35], a query-based version of the traditional community mining problem [36]. In the context of Twitter, however, there are two additional constraints: (1) the Twitter graph cannot be feasibly known, and (2) the "follow" relation in Twitter is directed. As a result, a local social circle discovery algorithm designed specifically for directed graphs must be used [37].

Intuitively, the algorithm initializes the social circle with the index Twitter user and then iteratively adds new members to the social circle until a prespecified size has been reached. At each step, the algorithm considers all Twitter users followed by at least one member of the current social circle, and selects the one with the highest score. The score of each candidate is the minimum of the number of individuals in the social circle it links to and the number of individuals it is linked from. To ensure that new members do not cause the social circle to drift away from the initial Twitter user, the value of a connection to a social circle member is discounted according to the step at which that member was added to the circle. Figure 1 shows the score of a candidate node n with respect to the social circle SC [37], where $e(x, y)$ is an edge indicator function (ie, $e(x, y) = 1$ if there is an edge from x to y and 0 otherwise), and $s(c)$ is the step in which node c was added to the social circle.

To increase the cohesiveness of the social circle, every 5 iterations, the Twitter user with the lowest score is removed from the social circle. Upon completion, the algorithm returns a social circle composed of dense connections of mutually aware nodes that surround the index Twitter user. Note that, in general, individuals belong to different social circles that may best be specified by including additional people in the query set (eg, work colleagues would likely produce a professional social circle, relatives would likely produce a family social circle). Here, however, the index Twitter user is used as the sole query node to avoid biasing the algorithm toward any specific social

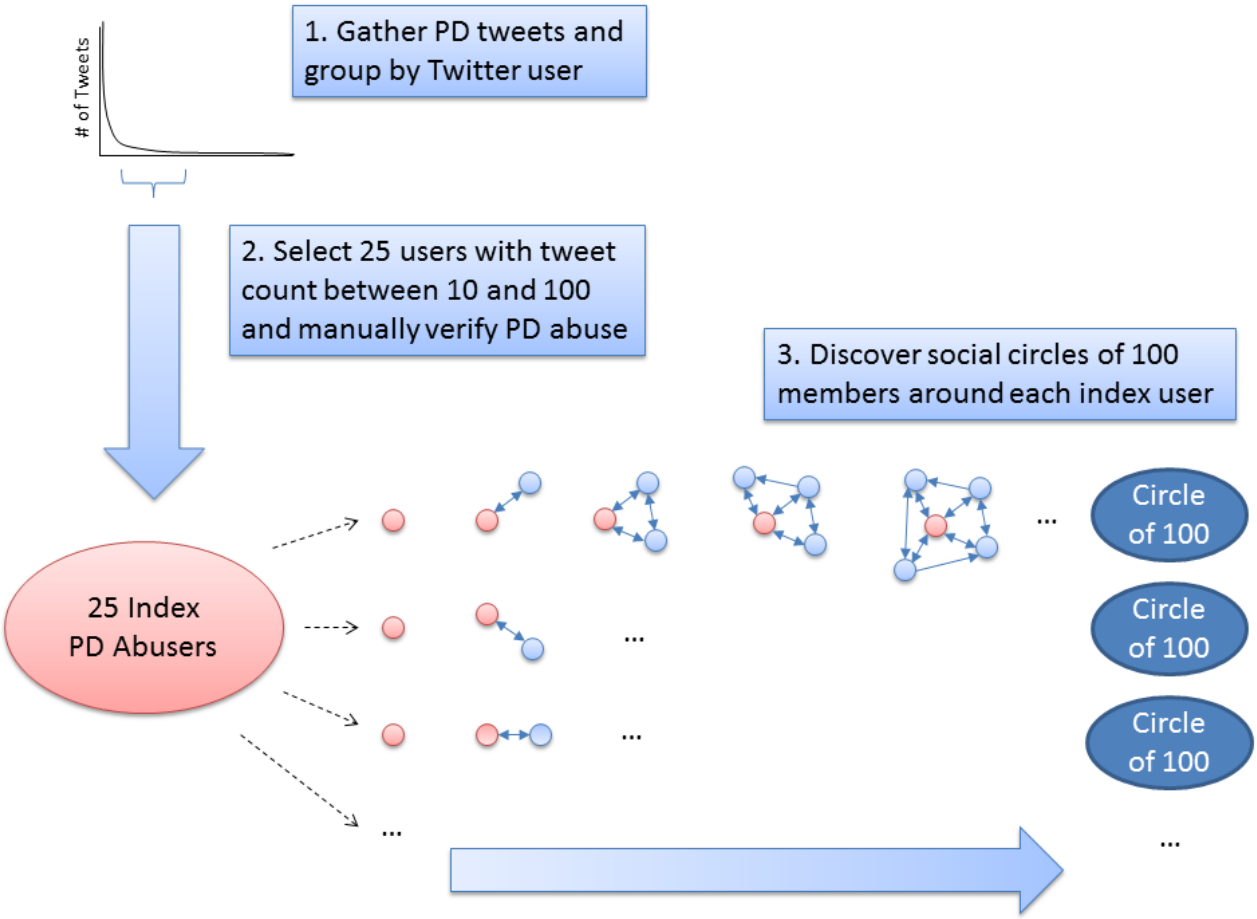
circle, and instead simply discovering the most natural dense set surrounding that individual. The process of identifying these social circles and users is illustrated in Figure 2.

To ensure consistent comparison across networks, a social circle of the same size was discovered around each index Twitter user. After each social circle was identified, the most recent tweets of each Twitter user in the social circle (up to 3200 per user, the maximum allowed by the Twitter API) were obtained for content analysis. The size of social circles was set to 100 since there are significant computational costs associated with extracting this content, most social media users effectively maintain only between 100 and 200 friends [38], and the closeness of friendship tends to decline as social circles grow.

Figure 1. Local social circle discovery measure.

$$\phi(n, SC) = \min\left(\sum_{c \in SC} e(c,n)s(c)^{-1}, \sum_{c \in SC} e(n,c)s(c)^{-1}\right)$$

Figure 2. Social circle discovery process.



Content Categorization

Once a social circle and its corresponding tweets were obtained, tweets were categorized by mention of a particular substance, and further categorized by the manner in which that substance was mentioned. Table 1 lists the drug categories and the filter terms used to categorize the tweet. For example, a tweet was categorized as mentioning painkillers if it contained terms such as “painkiller”, “oxycontin”, or “lortab”.

Tweets matching the drugs in Table 1 were further categorized into 8 different types of abusive or risk behaviors defined in Table 2: taking larger doses (overdose), co-ingestion, taking more frequent doses, alternative motives (dependence or need the drug due to addiction), alternative routes of admission, legitimacy of obtaining, redistributing (trading/selling), and seeking [39].

Tweets that matched the drugs in Table 1 were also further analyzed to determine if they contained “mentions” to other Twitter users (where an author references another user by the *@username* convention). Social network graphs were then constructed to show such connections among Twitter users. The graphs are directed and weighted. The weight of an edge is defined by the number of tweets from one user to another that included prescription drug terms.

Table 1. Keywords for prescription drugs.

Drugs	Keywords[a]
Adderall	adderall
Xanax	xanax
Klonopin	klonopin
Valium	valium; sleeping pills
Painkillers	painkiller*; pain killer*; narcotic painkiller*; oxycontin; vicodin; percodan; percocet; darvon; lortab; lorcet; dilaudid; demerol; lomotil; kadian; avinza; codeine; duragesic; methadone
Depressants	mebaral; nembutal; sodium pentobarbital; halcion; prosam; ativan; librium; depressant*
Stimulants	dexedrine; ritalin; concerta; amphetamines; stimulant*

[a]The "*" matches 0 or more additional characters.

Table 2. Keywords for risk/abusive behaviors.

Risk/Abusive Behaviors	Keywords[a]
Larger doses/overdose	too many; two; three; double; too much; overdose; crash; strong enough; max; too many
Co-ingestion[b]	alcohol; coffee; white; red; wine; vodka; shots; patron; booze; margarita; mimosa; xanax; painkiller; caffeine; alcohol; happy pills; adderall; concerta; cocaine; rum
More frequent doses	enough; pop; popping; not enough; another; enough; pop*
Alternative motives/dependence[c]	test; final; study; studying; problems; college; class; breakfast; rely; sleep; sleeping; work; family problems; sleep*; stress*; stressful; stress; skinny
Alternative routes of admission	snort; crush; inject; snort; inhale
Legitimacy of obtaining	steal*
Trading/selling	buy; sell; trade; share; spend; buy; bring
Seeking	need; want; needing; wanting; wish; need

[a]The "*" matches 0 or more additional characters.

[b]Co-ingestion keywords for xanax and adderall did not include the keywords "xanax" and "adderall" respectively.

[c]The keywords "test", "final", "study", and "studying" were exclusively used as keywords for Adderall. "Skinny" was exclusive to Stimulants.

Results

The tweets collected during the study period contained 3,389,771 references to prescription drug terms. Table 3 shows the number of co-occurrences of these references with one of the categories defined by the terms in Table 2. The large number of references to alternative motives was due primarily to discussion of Valium as a sleep aid.

The 25 social circles discovered around the 25 index Twitter users gave rise to a total of 2227 unique Twitter users, 7290 prescription drug tweets, and 2788 directed prescription drug tweets. Statistics of these social circles are shown in Table 4. As shown, the social circles range from 14% to 87% (mean 53.96%, SD 24.8) of the Twitter users in the social circle tweeting about prescription drugs at least once.

Index users and their social circles typically tweeted about similar drugs. For each index Twitter user, a topic vector was determined according to the proportion of his or her prescription drug tweets that matched each of our prescription drug categories, and a topic vector was also created for the aggregated tweets of the rest of the social circle. The topic vectors of index Twitter users were correlated with those of their social circle, and Pearson's correlation coefficients ranged from -0.14 to 0.99 (mean 0.73, SD 0.31). The mean of these correlation coefficients was computed by first applying Fisher's *z* transformation.

Using the abusive behaviors content categories of Table 2, each of the tweets of the index Twitter users and their social circles were categorized according to potential abuse. Although not a perfect metric for abuse, the number of abuse categories a Twitter user mentions is used as surrogate for a level of abuse. Thus, a Twitter user who has tweets matching four of the abuse categories is considered to be at a higher level than a Twitter user who only has tweets from one of them. As shown in Table 4, the mean number of the people in the social circle with tweets matching at least one abuse category was 33.2 (SD 18.8), and 16.8 (SD 10.9) users had tweets matching at least two. The level of abuse is strongly correlated with the number of Twitter users interacting with others about prescription drugs. Comparing the percentage of the social circle that interacts about prescription drugs to the percentage that matched at least one abuse category yields a Pearson's correlation coefficient of r=0.85 (P<.001), and comparing against those who matched two or more abuse categories, r=0.81 (P<.001).

In addition to the quantitative evaluation of these interactions, interesting patterns can also be observed through visual inspection of the graphs of interactions among Twitter users in

each social circle. Figure 3 shows three graphs, where the nodes represent users, and the edges indicate that the source user mentioned the destination user along with a prescription drug term. The weight of the edges (as shown by the thickness of the line) denotes the number of mentions. The size of the nodes represents the number of prescription drug tweets.

Table 3. Number of prescription drug tweets by drug category.

Category	Adderall	Xanax	Klonopin	Valium	Painkillers	Depress	Stim	Total
Drug total	412,314	486,670	58,527	917,805	1,215,574	17,364	281,517	3,389,771
Larger doses / overdose	11,397	9508	880	22,263	28,186	218	2085	74,537
Co-ingestion	44,179	24,794	5411	47,657	34,178	1027	3181	160,427
More frequent doses	10,636	18,070	567	15,808	22,764	107	2566	70,518
Alternative motives / dependence	39,459	18,664	105	617,672	38,135	806	1868	716,709
Alternative routes of admission	1316	1657	73	701	1641	17	265	5670
Legitimacy of obtaining	363	400	16	339	1032	6	117	2273
Trading / selling	20,941	63,763	17,000	65,926	95,962	4913	2873	271,378
Seeking	46,138	52,852	2069	165,955	63,165	675	8808	339,662

Table 4. Summary statistics for prescription drug tweets within social circles.

Network	Prescription drug Tweets		Prescription drug Tweet mentions[d]		Topic correlation	One or more abuse categories[e]	Two or more abuse categories
	n	n	n	n	*r*	n	n
	Tweets[f]	Users[g]	Tweets[h]	Users[i]		Users[j]	Users
1	136	48	55	32	0.28	25	9
2	99	28	22	12	0.26	13	1
3	67	14	26	11	0.06	8	2
4	508	84	290	72	0.59	38	18
5	352	46	97	34	0.69	34	22
6	258	72	37	29	0.92[a]	27	12
7	311	69	40	27	0.76[b]	39	18
8	52	17	14	9	0.1	8	6
9	553	61	142	40	0.83[b]	33	18
10	359	76	156	51	0.89[a]	58	21
11	159	32	73	26	0.72	18	11
12	449	77	300	71	-0.14	36	18
13	446	87	302	84	0.74	73	39
14	378	79	112	42	0.65	55	30
15	629	61	140	42	0.99[a]	34	21
16	75	31	36	23	0.82[b]	28	11
17	512	84	244	64	0.93[a]	58	33
18	91	25	35	20	0.89[a]	9	3
19	75	30	28	17	0.37	17	8
20	75	20	24	16	0.77[b]	10	5
21	143	46	80	36	0.3	25	11
22	512	79	91	48	0.86[b]	54	35
23	417	69	142	47	0.6	52	28
24	387	83	249	70	0.97[a]	60	30
25	247	31	53	21	0.61	19	10
Mean	291.6	53.9	111.5	37.8	0.73[c]	33.2	16.8
SD	183.5	24.8	94.9	21.2	0.31	18.8	10.9

[a]$P<.01$

[b]$P<.05$

[c]The mean of topic correlation coefficients was computed using Fisher's z transformation.

[d]Mentions refers to tweets directed at another user.

[e]Tweets matching abuse categories.

[f]Total prescription drug tweets from the social circle

[g]Number of people in social circle that produced tweets in column two

[h]Mention tweets (Subset of column two)

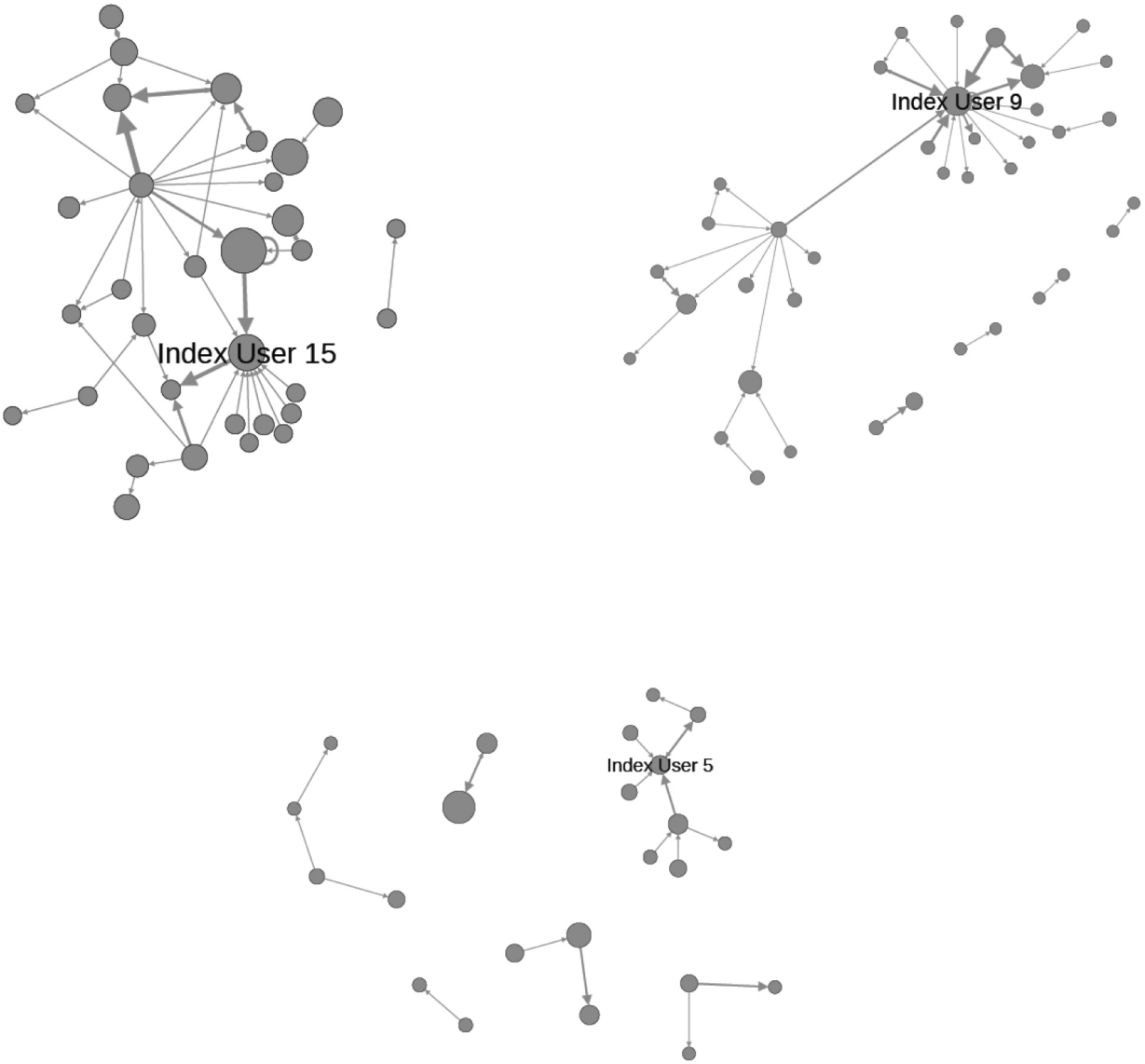
[i]Number of people in social circle that produced tweets in column four

[j]Number of people in social circle that had tweets classified into one or more abuse categories

In addition to simply talking about prescription drugs, Twitter users in these social circles also interact with each other about the topic, using the *@username* convention. Examples of mention tweets from the sample include, "@*** Haha! For me it's a nice ritalin/sangria combo :)", "RT @*** I

should win a lifetime achievement award...I've been taking Xanax for years without overdosing.", and "@*** lol thanks....but im [sic] pretty emotionally stable. It's called being in a Xanax haze". As shown in Table 4, the networks range from 9 to 84 (mean 37.8, SD 21.2) Twitter users in the social circle (n=100) interacting with another Twitter user about prescription drugs at least once.

Figure 3. Prescription drug interaction graphs.



Discussion

Principal Findings

The purpose of this study was to explore the online social circles of prescription drug abusers to observe the discussion and engagement of these Twitter users regarding prescription drug abuse. Findings revealed that for the identified prescription drug abusers on Twitter, their social circles consisted of other Twitter users who also discussed abuse of prescription drugs.

The study was guided by three research hypotheses. As shown in Table 3, significant discussion of prescription drug abuse was observed on Twitter (hypothesis 1). These findings are consistent with previous research exploring prescription drug abuse through Twitter [21]; however, the current study explores multiple prescription drug mentions beyond just Adderall. While not all of these tweets are necessarily in reference to abuse, those matching the abuse categories defined in Table 2 are very likely to be discussion of abuse of prescribed substances. Even if not all of these references denote actual behavior on the part of individuals, the simple act of discussing the behavior within a social circle can impact the social norms of those within that circle.

Those who are not engaged in prescription drug abuse are still being exposed to others' tweets concerning the matter. They may not be participating in the conversation, but they are

observing the sentiment and potentially forming ideas and norms about the abuse of prescription drugs. While actual drug abuse remains mostly a private affair, it seems to be discussed in a very open manner online for all to observe. It may be that abusers are now, through social media, finding support for their abuse and feel a sense of safety in opening up to others. Uses and gratification theory suggests that individuals make decisions about their media choice based on the extent to which that media gratifies a communication need [40]. Duffy and Thorson [41] expand this idea in their Health Communication Media Choice Model and suggest that connectivity is an important need that can be fulfilled through social media. They define connectivity as the "need to relate, support, engage with, and communicate with others face-to-face through media" (page 102) [41]. Social media facilitates the connectivity process by allowing people to engage with and observe others' sentiment on a given subject. Regardless of a person's openness about their behavior, prescription drugs are being discussed on Twitter and many are being exposed to tweets and conversations of an abusive nature through their social circles.

As shown in Table 4, there is a significant amount of discussion about prescription drugs in the social circles of the index Twitter users, with a mean of 53.9 (SD 24.8) users in the social circles posting about a topic at least once, and an mean of 291.6 (SD 183.5) tweets per social circle (hypothesis 2). In addition, the high correlation between the substances discussed by the index Twitter user and his or her social network, shows that these users are engaged in discussions with others of like minds. These findings confirm our hypothesis and also show consistency with the offline world about the social context of prescription drug abuse [14,15,17,42].

It is not clear whether index Twitter users developed their behavior from exposure to their online social circle, or whether they sought out the company of others supportive of their viewpoints. But it is clear that each of these Twitter users is in an environment that potentially supports their behavior. This may have interesting ramifications, because these users may not be in close proximity to one another physically, and yet they may find reinforcement for their attitudes from their online connections. Thus, while prescription drug abusers may not feel comfortable sharing their experiences with their physical neighbors, who might not approve of abusive behavior, they can develop online associations with those that do. These findings are consistent with recent research exploring the impact of online social circles on young adult alcohol use [32,33].

In addition to knowing that Twitter users are talking about prescription drugs, it is also relevant to discover if they are also talking *to each other* about prescription drugs (hypothesis 3). When Twitter users mention one another by their username (using the *@username* convention), these tweets are aggregated into a separate list in the interface, and can also produce other alerts (eg, email) raising the user's level of awareness of the tweet. In addition, the author may be directly soliciting a response from the user. Thus, the analysis of the number of tweets that discuss prescription drugs and also mention a specific user provides a quantified measure to observe engagement among these users about the topic.

The fact that, on average, 37.8 (SD 21.2) Twitter users in a social circle interact with another user at least once shows that there is indeed a significant level of engagement in addition to simply talking about the topic. Furthermore, hypothesis 3 is confirmed by the fact that the percentage of social circles interacting about prescription drugs correlates so strongly with the percentage of social circles having tweets that match risk/abusive behavior categories (r=0.85 for one category and r=0.81 for two categories). Social engagement can also be observed through the interaction graphs shown in Figure 3. It is interesting to observe how some users who discuss prescription drugs relatively frequently (as denoted by the larger size of the node), in many cases also have a large in-degree, showing that many others mention them in connection with prescription drugs.

With the rise of prescription drug abuse and its inherent danger, understanding the behaviors of abusers will be vital for public health professionals and prescribers in preventing overdose deaths and the blatant redirecting of the drugs. Many states are implementing prescription drug registries in response to the epidemic of abuse. These registries require prescribers and providers to report the distribution of controlled substances. While these registries can identify patients going to multiple doctors for the same medication, they do not address the growing problem of prescription drug redirection. This drug aftermarket is only facilitated by social media platforms like Twitter. The categorization keywords used in this study were able to identify users seeking, trading, and buying prescription drugs. For example, several seeking statements included, "Seriously. Need adderall. Will pay $$$. Help me." and "looking to buy ~20-40 mg adderall, email ***". While a drug registry may identify and limit an abuser in one state, that abuser can simply source drugs online from others in states where drug registries are not used and abusers are able to obtain excessive amounts of a drug. Another key risk behavior that drug registries cannot address is that of co-ingestion and nonmedical use. Co-ingestion is one of the deadliest drug abuse behaviors and a leading cause of overdose death.

Findings from this study have important implications for those professionals involved in the prevention and treatment of prescription drug abuse. Results indicate that Twitter is used as a platform for discussion about prescription drug abuse within social circles. As such, Twitter provides an additional "access point" to groups of individuals who are abusing prescription drugs. Innovative approaches to reaching these social circles might include online peer health advisors who have been trained to identify prescription drug abuse and appropriately intervene. In addition, enacting federal legislation meant to address the promotion of nonmedical use of prescription drugs through social media may help provide a safer online environment that is more supportive of healthy decision making, especially for adolescents who are most at risk [43].

Limitations

Results from this study should be interpreted in light of the following limitations. First, while a keyword-based approach for identifying and categorizing tweets may exclude misspellings of the term, it does result in a highly precise set for analysis

and, at a minimum, provides a lower bound for the amount of discussion. Second, through social media it is possible to observe only discussion, not actual behavior. Yet, as these are natural conversations among friends where people post about events that occur in their lives, there is no a priori reason to believe that on the whole people are falsifying their posts to portray events or behaviors that do not occur. Third, we may have underestimated the number of prescription drug abuse tweets. It is possible that there are other prescription drug abuse-related tweets that we missed because they were not covered by our keywords. It is also possible that not all tweets were delivered to us by the Twitter interface, although that is hard to know for certain. Also, tweets containing abuse-related keywords may not always refer to discussion of abuse. Last, this analysis was restricted to publicly available tweets, and as noted, it is possible that private tweets may in fact be more biased toward prescription drug abuse. Despite these limitations, it is likely that the general trends observed would not be affected.

Conclusions

Understanding the prevalence of a problem or issue through social media is a good place to start; however, prevalence data fails to take advantage of the key aspect of social media: social networks and relationships. This work extends previous work by examining the social context of those discussing an important public health topic. While a major focus of this work has been about the reinforcement of negative behavior, the analysis of the interactions between people can provide insights into the normative aspects of social media. Whereas Twitter is a social media platform used to discuss and reinforce prescription drug abuse, prevention specialists should be mindful of this communication channel as another setting for understanding and monitoring prescription drug abuse and potentially intervening online.

Conflicts of Interest

None declared.

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Abbreviations

API: application programming interface
ONDCP: Office of National Drug Control Policy

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Original Paper

Social and Self-Reflective Use of a Web-Based Personally Controlled Health Management System

Annie YS Lau[1], PhD; Adam G Dunn[1], PhD; Nathan Mortimer[2]; Aideen Gallagher[2], MPH; Judith Proudfoot[3], PhD; Annie Andrews[4]; Siaw-Teng Liaw[5], MBBS, PhD; Jacinta Crimmins[6], MBBS; Amaël Arguel[1], PhD; Enrico Coiera[1], MBBS, PhD

[1]Centre for Health Informatics, Australian Institute of Health Innovation, University of New South Wales, Sydney, Australia

[2]UNSW Medicine, University of New South Wales, Sydney, Australia

[3]Black Dog Institute and School of Psychiatry, University of New South Wales, Sydney, Australia

[4]UNSW Counselling and Psychological Services, University of New South Wales, Sydney, Australia

[5]Centre for Primary Health Care and Equity, School of Public Health and Community Medicine, University of New South Wales, Sydney, Australia

[6]University Health Service, University of New South Wales, Sydney, Australia

Corresponding Author:
Annie YS Lau, PhD
Centre for Health Informatics
Australian Institute of Health Innovation
University of New South Wales
Centre for Health Informatics, Australian Institute of Health Innovation, University of New South Wales
Sydney, 2052
Australia
Phone: 61 431599890
Fax: 61 293858692
Email: a.lau@unsw.edu.au

Abstract

Background: Personally controlled health management systems (PCHMSs) contain a bundle of features to help patients and consumers manage their health. However, it is unclear how consumers actually use a PCHMS in their everyday settings.

Objective: To conduct an empirical analysis of how consumers used the social (forum and poll) and self-reflective (diary and personal health record [PHR]) features of a Web-based PCHMS designed to support their physical and emotional well-being.

Methods: A single-group pre/post-test online prospective study was conducted to measure use of a Web-based PCHMS for physical and emotional well-being needs during a university academic semester. The PCHMS integrated an untethered PHR with social forums, polls, a diary, and online messaging links with a health service provider. Well-being journeys additionally provided information to encourage engagement with clinicians and health services. A total of 1985 students and staff aged 18 and above with access to the Internet were recruited online, of which 709 were eligible for analysis. Participants' self-reported well-being, health status, health service utilization, and help-seeking behaviors were compared using chi-square, McNemar's test, and Student's *t* test. Social networks were constructed to examine the online forum communication patterns among consumers and clinicians.

Results: The two PCHMS features that were used most frequently and considered most useful and engaging were the social features (ie, the poll and forum). More than 30% (213/709) of participants who sought well-being assistance during the study indicated that other people had influenced their decision to seek help (54.4%, 386/709 sought assistance for physical well-being; 31.7%, 225/709 for emotional well-being). Although the prevalence of using a self-reflective feature (diary or PHR) was not as high (diary: 8.6%, 61/709; PHR: 15.0%, 106/709), the proportion of participants who visited a health care professional during the study was more than 20% greater in the group that did use a self-reflective feature (diary: P=.03; PHR: P<.001).

Conclusions: There was variation in the degree to which consumers used social and self-reflective PCHMS features but both were significantly associated with increased help-seeking behaviors and health service utilization. A PCHMS should combine both self-reflective as well as socially driven components to most effectively influence consumers' help-seeking behaviors.

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KEYWORDS

personal health record; social networks; Internet intervention; health service; help-seeking; emotional well-being; physical well-being; preventative health; eHealth; consumer; university

Introduction

Personal health records (PHRs), tools that allow consumers to control and maintain their own health data and information, have been advocated as a next-generation technology that can significantly improve health behaviors and outcomes [1]. Well-designed PHRs can facilitate consumers' self-reflection of their health by personalizing evidence-based guidelines, and providing judicious prompts, decision aids and tools to assist in maintaining their own health data and associated information. They currently form a crucial component in many large-scale national eHealth reform strategies worldwide.

Since the definitions of PHRs were clarified in 2006 [2], there has been a vast amount of survey, observational, cohort/panel, and anecdotal evidence regarding the benefits and satisfaction that PHRs provide for patients and consumers [3-11]. However, a recent scoping review on PHRs concluded that more research is still needed in order to evaluate the effectiveness of PHR implementations [12]. Specifically, there is currently a lack of understanding regarding (1) the uptake and sustainability of PHRs (eg, what motivates patients' adoption and long-term use of a PHR), (2) how we can optimize the functionality and usability of these systems, and (3) whether PHRs play a beneficial role in supporting self-managed health care (ie, more quality evidence in the form of randomized controlled trials is needed) [12].

In parallel, the emergence of online social media means that the Internet is no longer being used only to search for information about diseases or treatments, but it is also being used to connect individuals previously unknown to each other (via asynchronous forums like PatientsLikeMe), and assist people to engage and keep in contact with their existing social networks (such as via Facebook). Social networks have been demonstrated to significantly inform our choices and affect our decisions in relation to health (eg, choice of hospital [13] and physical activity [14]), and social media interventions are now being developed (eg, via Facebook [15]), with preliminary findings on their feasibility and efficacy emerging in areas such as sexual health [16] and physical activity [17].

Considering these two major trends in consumer eHealth research (PHRs and online social networks), personally controlled health management systems (PCHMSs), which include a PHR, social networking features, self-management tools, and consumer resources, are rapidly being developed and deployed worldwide. While trials of PCHMSs are emerging in various health settings such as in vitro fertilization [18], hypertension [19], diabetes [20,21], influenza vaccination [22-24], medication accuracy [25], breast cancer management [26], physical and emotional well-being[27], and asthma [28], with some demonstrating acceptance and/or significant benefits among patients and consumers [18,20,21,23,26,27], there remains a lack of literature on how patients and consumers actually use these systems in their everyday settings and how the use of the PCHMS might affect their health behaviors and decisions.

Additionally, few studies have examined ways to incorporate social features in a PCHMS for the purpose of improving health behavior outcomes—where the social network *is* the treatment [29]. Earlier studies on systems such as PatientsLikeMe examined how patients in similar situations accessed each other's personal health information [30], and how having access to others' health outcomes and treatment decisions may have impacted their decisions in medication use and choice of doctors [31]. Our recent studies identified bundles of PCHMS features that were associated with increased help-seeking behaviors [27], and how consumers interacted with each other and health care professionals in a PCHMS [32]. To our knowledge, that was the only study identifying bundles of features in a PCHMS that were significantly associated with consumers' help-seeking behaviors [27].

To date, it remains unclear how we can best integrate online social networking features and self-reflective tools (such as PHRs) into the design of PCHMSs in order to maximize consumers' uptake, improve their health behaviors and outcomes, and facilitate their long-term use. In particular, few studies have examined the mutual relationship between self and the crowd in influencing one's health behaviors. Utilizing a multimethod approach (statistical, content analysis, and social network analysis), the aims of this paper were as follows: (1) to measure how consumers used the most common *self-reflective* features in a PCHMS, (2) to measure how consumers interacted within the community created by the *social* features of the PCHMS, and (3) to provide recommendations on ways to engineer a *socially driven and self-reflective* PCHMS that would improve individual health behaviors.

Methods

Study Data

This paper utilized the data gathered during our 2011 study [27]. Previous analyses of this study have been conducted, which identified bundles of PCHMS features that were associated with increased help-seeking behaviors [27] and consumers' patterns of usage for the social features of the PCHMS [32]. A full description of our study design is included in Multimedia Appendix 1.

Trial Design and Participants

A single-group pre/post-test online prospective study was conducted over a university academic semester (July to November 2011) to examine how participants used a PCHMS to manage their physical and emotional well-being. Participants were included if they were aged 18 or over and had at least monthly access to the Internet and email. Full details of the study protocol and the instruments used to measure participants' well-being and help-seeking behaviors (ie, COOP/WONCA charts [33], well-being self-ratings and lifestyle intention, health

advice-seeking and health advice-providing networks, and help-seeking behaviors and health service utilization) are described in Multimedia Appendix 1.

Healthy.me

The PCHMS (called Healthy.me) was iteratively developed between 2009 and 2013 at the University of New South Wales and was tested in settings such as in vitro fertilization, influenza vaccination, and breast cancer management [18,23,26]. The first version contained features such as journeys (which provide users with evidence-based, health-related information to promote engagement with clinicians and health services in an actionable way), a PHR, and online appointment booking with the university primary care service.

The version of Healthy.me (version 2.0) that was used in this study added online appointment booking with the university counseling services, a diary (private access by default but participants could set it to public for other PCHMS users to view), forums (moderated by a general practitioner [GP] and counselor), and polls. Full details of each PCHMS feature are described in Multimedia Appendix 1.

Data Analysis

Analysis Methods

We utilized multiple methods (statistical, content analysis, and social network analysis) to quantify how participants used each of these social (forum, poll) and self-reflective (diary, personal health record) features in support of their physical and emotional well-being. Polls are considered social features of the PCHMS because they reveal behavioral norms within the group and they offer participants a quick and anonymous way to evaluate their behavior against the "norms" of the group. These features were selected for further analysis because they were found to be significantly associated with consumers' help-seeking behaviors [27] or because consumers used them frequently and found them the most engaging [32].

Statistical analyses were used to provide a comparison of participants' self-reported well-being, health status, health service utilization, and help-seeking behaviors based on their usage patterns of each PCHMS feature. Content analysis was employed to provide an overview of the topics and issues contributed/discussed by participants in online forums and diaries. Social network diagrams were constructed to examine the online forum communication patterns between consumers and clinicians. Social network analysis and visualization provide the tools to delve deeper into the social network, identifying the most active members of the community (via network centrality) and exploring the intergroup relationships that exist between consumers and clinicians (via reciprocity).

Statistical Data Analysis

For each social and self-reflective PCHMS feature, help-seeking behaviors and health service utilization during the study were compared using chi-square analysis between users and nonusers. Self-reported well-being and health status were compared pre- and post-study using the McNemar's test and Student's *t* test for paired samples. Usage of each PCHMS feature was summarized using descriptive statistics. Statistical analysis was performed using IBM SPSS Statistics 20. Tests performed were two-tailed and assumed a cut-off of $P<.05$ for statistical significance.

Diary Entry Coding

Diary entries were coded to analyze for participants' topics of reflection, issues of concerns, and their past/present/future intended actions, where each entry could be coded multiple times within each code category. The coding process was informed by literature on young adults' physical and emotional well-being concerns [34,35] and how people used blogging or online systems for health and self-reflection [35].

Pre-codes were created by consensus prior to data coding based on topics, issues, and actions derived from a random selection of 20% of diary entries. While reviewing each diary entry, open codes were created to record topics, issues, and actions that were not anticipated in the pre-coding scheme. The coding process was conducted by one author (AG) and another author (AL) independently coded 10% of diary entries. Interrater reliability on entries coded by both authors was considered good according to Cohen's kappa statistic (κ=0.71).

Code categories for topics discussed include (1) physical only (eg, stomach pain, muscle cramp), (2) emotional only (eg, stress), (3) physical and emotional (eg, food, exercise, sleep), or (4) nonhealth (eg, finance, work/study, social, relationship). For participants' use of the diary, code categories include (1) activity recording (eg, what they did on the day), (2) self-reflection (eg, reflecting on concerns, observations and actions), (3) goal setting (eg, recording plans and/or intentions to act), and (4) progress recording (eg, food diary, exercise diary). Participants' actions recorded in the diary are coded according to (1) past action, (2) present action, and their (3) future intended action.

Forum Entry Coding

Three forums were available to participants: two were dedicated to men's and women's health issues, and the third forum was for discussion of general health issues related to lifestyle (Stay Healthy). Participants could seek answers from fellow participants, the GP, or the counselor on all three forums.

Posts on the forums were coded to analyze for topic of discussion and participants' response type, informed by literature on interaction patterns found in online social network and question-and-answering websites [36,37]. The coding scheme was pre-determined, where a random selection of 20% of forum posts were used to develop the coding scheme iteratively until consensus was reached on coding rules and the definition of each category before coding commenced. The coding process was conducted by one author (NM) and another author (AL) independently coded 10% of forum posts. Interrater reliability on entries coded by both authors was considered good according to Cohen's kappa statistic (κ=0.75).

Each forum post could be coded with more than one topic and participants' response type. Code categories for discussion topics included (1) medical (ie, seeking for advice on a medical issue), (2) lifestyle (eg, dietary, exercise), (3) emotional well-being (eg, distress, stress), (4) women's health (ie, topics

specific to women issues, such as Pap smear), and (5) miscellaneous (ie, topics that do not fit into any of the above-mentioned areas). For participants' response types, code categories included (1) asking a new/follow-up question, (2) providing advice/support/information, (3) sharing experience, and (4) expressing thanks.

Social Network Analysis

Social network analysis methods were used to classify the types of group-level behavior (patterns of communication within the forum community) and to consider the effects of group behavior on individual behavior, including the utilization of the PCHMS, and the decisions and behaviors of the participants. The metrics chosen for the analysis are typical indicators of forum behaviors—the relative importance of individuals within the network and the shift from one-on-one interactions to group discussions. We then discussed how the ongoing interactions in the social features of the PCHMS might improve utilization.

Degree centrality (an indicator of the relative importance of individuals in a social network) is calculated for each node in the network by counting the total number of connections to other nodes. Reciprocity (which indicates how common "conversations" are in a forum) was calculated by the proportion of connections that were returned. A reciprocal connection is one in which two people have responded to each other at least once each. To estimate the relative significance of the reciprocity in the networks, we tested the observed values against a random baseline using a method described elsewhere [38]. Social networks of online forum communication patterns among consumers and clinicians, namely a GP and a counselor, were analyzed using MATLAB 7.11.1 and illustrated using Cytoscape 2.8.2 [39].

Results

Participants

A total of 1985 participants met inclusion criteria and were recruited into the study. All completed the pre-study questionnaire. Of those, 709 (35.72%) completed the post-study questionnaire. Analyses were conducted on the 709 eligible participants who completed both the pre-study and post-study questionnaires. Of these, 80.7% (572/709) participants logged into the PCHMS at least once; where 93% (40/43) of those who posted on the forum, 60.0% (195/325) of those who answered a poll question, 90% (26/29) who wrote a diary entry, and 70.8% (75/106) of those who entered a PHR entry, logged into the PCHMS more than once.

Baseline and demographic characteristics of eligible participants are presented elsewhere [27]. During the study, 54.4% (386/709) of participants sought formal or informal help (for themselves or others) on physical well-being matters and 31.7% (225/709) for emotional well-being concerns [27]. Furthermore, 36.5% (141/386) of participants who sought help for a physical well-being matter and 32.9% (74/225) for an emotional well-being concern indicated their decision to seek help was influenced by other people. Among those who visited the university counseling service during the study, 54% (22/41) were first-time visitors.

For the 52 participants who self-rated as "extremely" bothered by their emotional problems at pre-study (as measured by the COOP/WONCA charts [33], which have been demonstrated to be a valid and feasible one-time screening assessment for mental disorders in primary care [33]), 44% (23/52) visited a health care professional for their emotional well-being during the study. On a scale from 1 to 5 (where higher scores indicate a poorer functional status), there was a significant improvement at post-study in these participants' self-rated ability to conduct usual activities or tasks, both at work/study, or inside and outside the home (pre-study: mean 3.3 [SD 1.0]; post-study: mean 2.9 [SD 1.1]; t_{51}=2.3; P=.028). At post-study, these participants also expressed being less bothered by emotional problems such as feeling stressed, anxious, depressed, irritable, or downhearted and sad compared to pre-study (pre-study: mean 5.0 [SD 0]; post-study: mean 2.6 [SD 1.1]; t_{51}=9.5; P<.001).

Social Features

Among the 709 participants eligible for analysis, the three features most participants accessed in the PCHMS were journey (84%, 95% CI 81-87), poll (46%, 95% CI 42-50), and forum (16%, 95% CI 13-19). Further, the poll and the forum (ie, the social features of the PCHMS) were the two features rated most frequently by participants as "useful" (poll: 32%, 95% CI 29-36; forum: 30%, 95% CI 27-34) and "fun or engaging" (poll: 35%, 95% CI 32-39; forum: 16%, 95% CI 13-19). Chi-square analyses showed that users of a PCHMS social feature (ie, poll or the forum) proportionally outnumbered nonusers in the following observed behaviors (see Table 1).

Forum

The most frequently posted topic category was "medical" for both the men's health (64%, 14/22) and women's health (61%, 20/33) forums. For the "Stay Healthy" forum, the most frequently posted topic category was "lifestyle" (52%, 15/29). Across all three forums, the most frequent interaction type was "providing advice/support/information"—men's health: 72% (34/47); women's health: 73% (40/55); and Stay Healthy: 46.6% (103/221). Chi-square analyses showed that forum posters proportionally outnumbered nonposters in the following observed behaviors (see Table 2).

Table 3 outlines the social networking characteristics for the three forums. The women's health forum most closely represented a star-shaped pattern (also known as the hub-and-spoke typology), centered on the GP (80%, 37/46 of the connections involved the GP) (Figure 1). The GP's position reflects a question-and-answer structure (featuring high levels of reciprocity), suggesting that the level of engagement was one-on-one conversations rather than community-wide discussions. The men's health forum was also centered on the GP but the level of engagement with other members of the forum was higher (48%, 22/46 of connections did not involve the GP) (Figure 2). This network also featured high reciprocity (39%, 18/46 of connections were returned), and all reciprocal connections involved the GP.

Although there were some individuals with higher numbers of incoming connections, the Stay Healthy forum least resembled the star-shaped pattern and also featured high levels of

reciprocity (28.8%, 42/146 of connections were returned) (Figure 3). However, clinicians in this forum did not play a central role (only 4.1%, 6/146 of connections involved the GP). The degree of centrality and the reciprocity in the Stay Healthy forum indicated a more conversational structure among participants compared to the men's or women's health forums.

Poll

Among participants who reported using the poll, 70.2% (174/248) reported that they enjoyed learning how their health compared with others, 41.1% (102/248) were surprised by others' answers about their health, and 33.1% (82/248) reported that the poll changed their perception of how healthy they were or how healthy others were compared to themselves (ie, perceived themselves being healthier than others).

In addition, 13% (32/248) reported that using the poll changed some of their health actions and decisions. The results of McNemar's test conducted on poll data shows that there was a significant increase in the number of participants reporting their perceived health as being better than others after using the poll compared to before usage (χ^2_3=41.57, P<.001). Chi-square analyses showed that poll users proportionally outnumbered nonusers in the following observed behaviors (see Table 4).

Table 1. Users of PCHMS social features (forum or poll) versus nonusers.

Observed behavior	Used social feature[a], % (n) (n=332)	Did not use social feature, % (n) (n=376)	Difference, %	χ^2	*df*	*P*
Visited a health care professional	62.3 (207)	50.0 (188)	+12.3	10.9	1	.001
Sought formal/informal help for physical well-being concern	59.3 (197)	50.0 (188)	+9.3	6.33	2	.04
Self-rated being physically fit at post-study	91.9 (305)	84.6 (318)	+7.3	8.88	1	.003
Reported a higher intention to practice a healthy lifestyle at post-study	58.4 (194)	50.8 (191)	+7.6	4.14	1	.05
Had at least one person in their advice-seeking network at post-study	89.5 (297)	83.8 (315)	+5.7	4.86	1	.03

[a]Posted on forum or answered a poll question.

Table 2. Table 2. Users of online forum versus nonusers.

Observed behavior	Posted on forum, % (n)	Did not post on forum, % (n)	Difference, %	χ^2	*df*	*P*
Reported a higher intention to practice a healthy lifestyle at post-study	79.1 (34)[a]	52.8 (351)[b]	+26.3	11.25	1	.001
Visited a healthcare professional	63.4 (121)[c]	53.0 (274)[d]	+10.4	6.06	1	.01

[a]Out of 43 participants who posted on the forum.

[b]Out of 665 participants who did not post on the forum.

[c]Out of 191 participants who accessed the forum.

[d]Out of 517 participants who did not access the forum.

Table 3. Table 3. Social network characterization for the three forums.

	Women's Health Forum	Men's Health Forum	Stay Healthy Forum
Size, n	35	33	67
Density, %	3.8	4.2	3.2
Degree centrality of Healthy.me GP (% of connections)	37/46 (80%)	24/46 (52%)	6/146 (4.1%)
Reciprocity (% of connections)	18/46 (39%)	12/46 (26%)	42/146 (28.8%)
Reciprocity percentile (vs random baseline)	1.00	1.00	1.00

Figure 1. Networks for the Women's Health forum. Black squares are female, grey circles are male, the Healthy.me GP and/or counselor is represented in the red triangle.

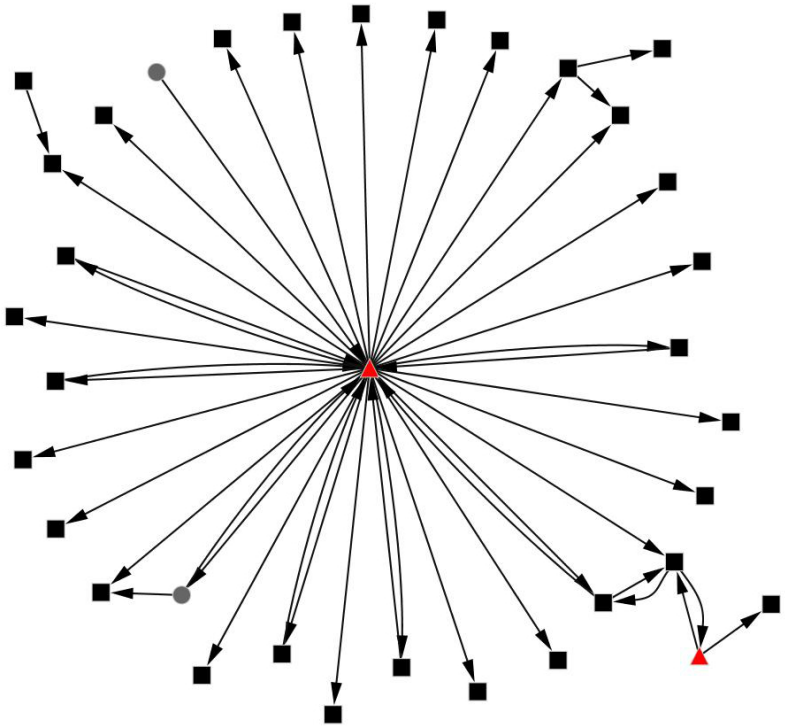

Figure 2. Networks for the Men's Health forum. Grey circles are male, black squares are female, the Healthy.me GP and/or counselor is represented in the red triangle.

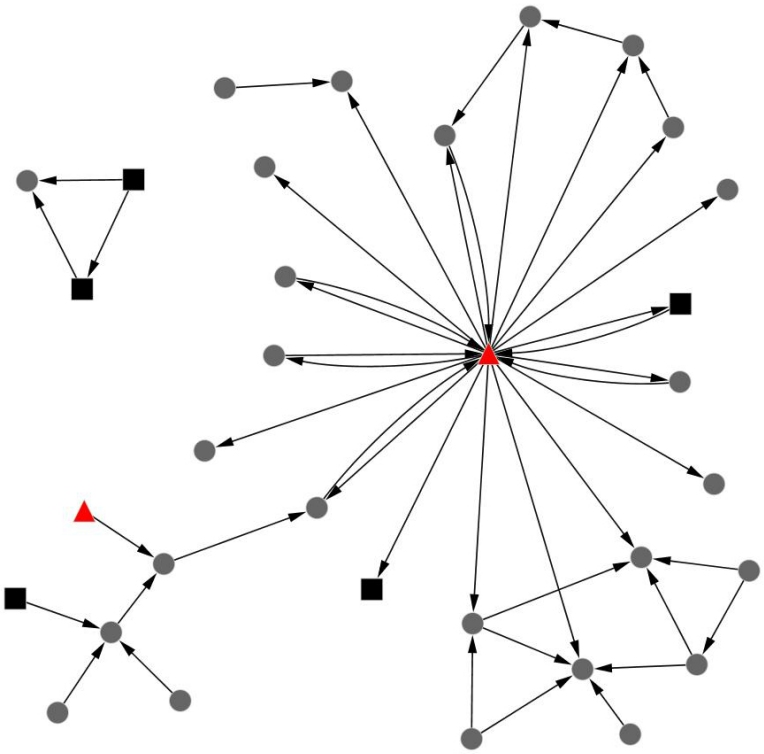

Figure 3. Networks for the Stay Healthy forum. Black squares are female, grey circles are male, the Healthy.me GP and/or counselor is represented in the red triangle.

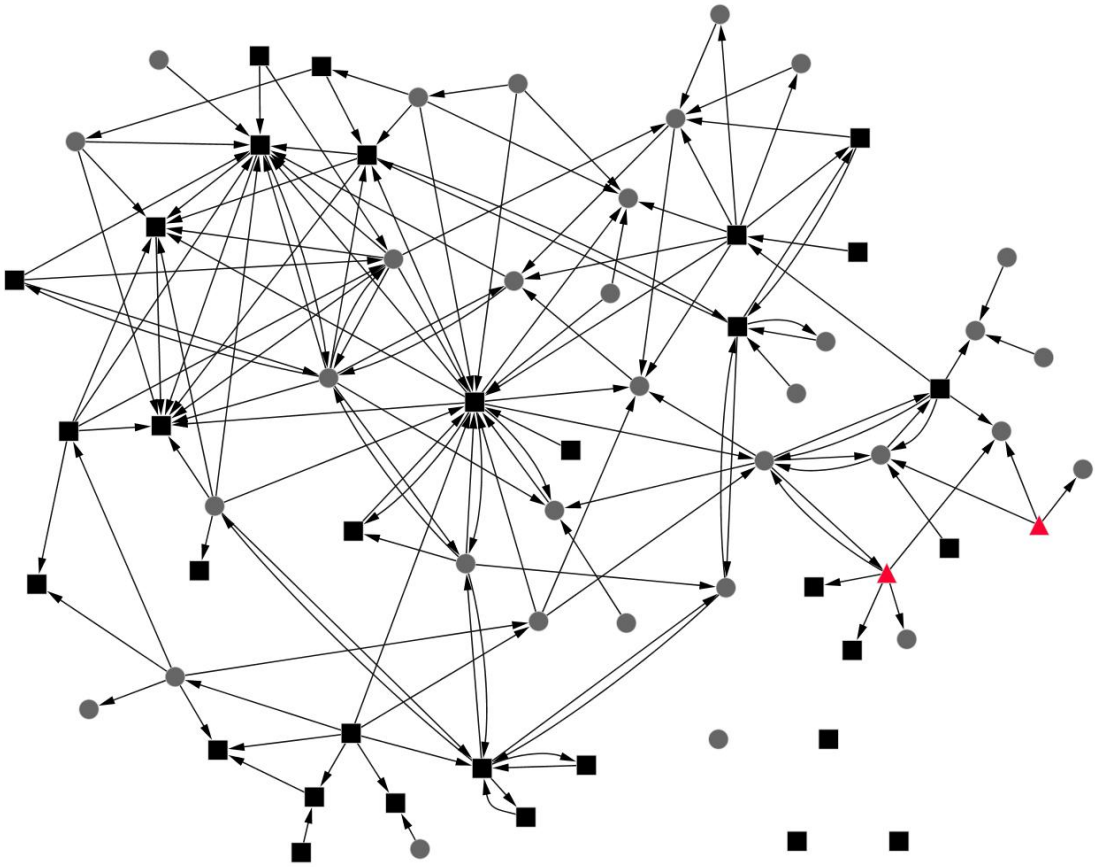

Table 4. Poll users versus nonusers.

Observed behavior	Answered poll question, % (n) (n=248)	Did not answer poll question, % (n) (n=460)	Difference, %	χ^2	*df*	*P*
Sought formal or informal assistance on an emotional health issue	37.9 (94)	28.3 (130)	+9.6	9.1	2	.01
Visited a health care professional	60.9 (151)	53.0 (244)	+7.9	4.1	1	.05

Self-Reflective Features

Personal Health Record (PHR)

Approximately 15% of participants (106/709) added at least one entry into their PHR (ie, either an entry about their health schedule, medication, health care team member, pathology test result, imaging test results, or procedure). Altogether, 282 entries were added by participants during the study, with an average of 2.7 entries and a range of 1 to 12 entries per participant. Chi-square analyses showed that PHR users proportionally outnumbered nonusers in the following observed behaviors (see Table 5).

Examples of medication entries, health team members, and medical test results entered by participants are presented in Multimedia Appendix 2, Tables 1-5. Medication entries include prescription medications (eg, Zoloft), off-the-shelf products (eg, Vitamin C), and complementary medications (eg, Jasmine). Team members comprise GPs, allied health professionals (eg, chiropractor, osteopath, physiotherapist), specialists (eg, dentist, gastroenterologist, cardiologist, sports medicine physician), and nonclinical members (eg, boyfriend). Tests entered included blood tests (eg, full blood count, thyroid, ferritin/iron), urine tests (eg, dipstick for protein), screening tests (eg, pap smear, serum hepatitis B), and imaging tests (eg, mammogram, MRI, ultrasound, dental x-ray, lung x-ray, and bone-related x-ray). Both invasive and non-invasive procedures (such as mole removal, gall bladder removal, fractured ankle, vision test, LETZ, cryotherapy, right knee arthroscopy, mammogram, and colonoscopy) were also entered by participants.

Schedule and Online Appointment Booking Service

A total of 8.0% (57/709) of participants used the online appointment booking feature on the PCHMS. Chi-square

analyses showed that users of online-appointment booking service outnumbered nonusers for the following behaviors (see Table 6).

Diary

Almost 9% (8.6%, 61/709) of participants completed at least one diary entry in the PCHMS. A total of 140 diary entries were written by 61 participants, covering 272 topics, 271 uses, and 272 actions. These participants on average wrote 2.3 entries (SD 4.9; mode 1.0), ranging from 1 to 38 entries per person. In a diary entry, participants expressed on average 2.0 topics (SD 1.1; mode 1.0; range of 1-6 topics), 2.0 issues (SD 1.0; mode 1.0; range of 1-5), and 2.0 actions (SD 1.1; mode 1.0; range of 1-5). No significant differences in the use of the diary (ie, topics/issues discussed, length of entries, number of entries per person) were detected between participants who sought help and those who did not seek help (P>.05), nor between those who reported an emotional/physical well-being concern and those who did not during the study (P>.05). Chi-square analyses showed that diary users proportionally outnumbered nonusers for the following behaviors (see Table 7).

Participants used the diary for both medical and nonmedical purposes, where the majority of entries were not medically related (Table 8). Most participants described their health concerns in terms of the encounters, changes, feelings, or symptoms they experienced in their everyday life (eg, food intake, feeling tired, light-headed, trouble going to sleep, crying) (Table 9). It was also uncommon for participants to use medical terminology to describe their experiences.

The diary was also used by participants to record past, present, and future-intended actions. Past actions include recalling past experiences (eg, remembering prior experience of ovarian cyst) and recording past activities (eg, saw a GP yesterday). Present actions include thought recording (such as concerns about bodily aches), reflection on relationships with family/friends, and discussion of current mood and state (eg, feeling down/sleepy). Future actions relate to activities that need to be completed (eg, reminder to book a medical appointment) or setting goals related to food intake and exercise routine.

Table 5. Personal health record (PHR) users versus nonusers.

Observed behavior	Entered PHR entry, % (n) (n=106)	Did not enter PHR entry, % (n) (n=602)	Difference, %	χ^2	*df*	*P*
Visited a health care professional	78.3 (83)	51.8 (312)	+26.5	25.61	1	<.001
Visited the university health service	28.3 (30)	16.3 (98)	+12	8.80	1	.003
Encountered someone who experienced a physical well-being concern	70.8 (75)	53.8 (324)	+17	10.51	1	.001
Sought formal/informal help for physical well-being concern	67.9 (72)	52.0 (313)	+15.9	9.22	1	.02
Sought formal/informal help for an emotional well-being concern	42.5 (45)	29.7 (179)	+12.8	6.74	1	.009

Table 6. Online appointment users versus nonusers.

Observed behavior	Booked appointment online, % (n) (n=54)	Did not book appointment online, % (n) (n=654)	Difference, %	χ^2	*df*	*P*
Visited the university counseling service	18.5 (10)	4.6 (30)	+13.9	18.16	1	<.001
Sought formal/informal help for an emotional well-being concern	44.4 (24)	30.6 (200)	+13.8	4.34	1	.04

Table 7. Diary users versus nonusers.

Observed behavior	Wrote diary, % (n) (n=29)	Did not write diary, % (n) (n=679)	Difference, %	χ^2	*df*	*P*
Visited a health care professional	75.9 (22)	54.9 (373)	+21.0	4.94	1	.03
Visited the university counseling service	20.7 (6)	5.0 (34)	+15.7	12.83	1	<.001
Encountered someone who experienced a physical well-being concern	82.8 (24)	55.2 (375)	+27.6	8.57	1	.003
Reported a higher intention to practice a healthy lifestyle at post-study	41.4 (12)	23.3 (158)	+18.1	5.00	1	.025

Table 8. Issues recorded by participants in their diary entries (n=140 entries).

Concerns / Intentions	Goals	Activities	Thoughts
Food	Study	Sleep diary	Feeling guilty about procrastination
Exercise	Fitness / diet plans	Food diary	Feeling worried about university progress
Physical and emotional well-being	Smoking cessation	Exercise routine	Brainstorming on food regimen
University demands		Symptom progress	Commenting on relationships
Relationship problems		Weight progress	Reflecting on daily experiences and new encounters
Finance		Daily activities	
Fatigue		University work	
Healthy eating/lifestyle		Actions taken towards physical and emotional well-being	
Seeking help for physical well-being concerns		Dietary intake	
Study plans			
Exercise/weight management			
Making plans for family/friends			

Table 9. Topics recorded by participants in their diary entries (n=140 entries).

Physical Health	Emotional Health	Physical and Emotional Health	Nonhealth
Headache/light-headedness	Post-traumatic stress disorder	Exercise	University
Nausea	Depression	Food	Work/life balance
Constipation	Mood swing	Sleep	Relationships (family, friends, romance)
Stomach pain/upsets	Anorexia nervosa	Diet	Daily activities
UTI/chlamydia screening	Anger	Weight	Social life
Injuries	Paranoia	Smoking	Finance
Cold/flu/cough	Panic	Binge eating	Hygiene
Ovarian cyst	Social anxiety	Fatigue/feelings of motivation	Death
Vaccines	Fatigue		Comments on Healthy.me
Sunburn	Sadness/crying		
Faint	Worry		
Back issues	Stress		
Vision	Feeling trapped		
Dental	Feeling lack of self-worth		
Skin rash			
Body aches			
Menstruation			

Discussion

Principal Findings

Social Versus Self-Reflective Features

This study compared how consumers used social and self-reflective features of a PCHMS. Our findings suggest that, although there is substantial variation in the use of social and self-reflective features, both are significantly associated with positive consumer health behaviors and outcomes.

Use of Social Features

In this study, social features (the poll and the forums) were two of the most frequently used features among consumers and were reported to be the most useful and most engaging. This study also contributes to our understanding of communication patterns

in an online community and shows that these patterns can differ depending on the purpose of the social space (eg, medical advice seeking vs personal experience sharing) and the types of people participating in the space (eg, consumer vs clinician).

Findings on network centrality and reciprocity suggest that when it comes to consumers seeking answers to medical questions, the forum follows a star-shaped pattern with the GP in the middle. An interpretation of this pattern is that when a person with perceived "authority" (eg, a GP) contributes to a medically oriented discussion, other participants may see this as a definitive answer or may be less likely to contribute if the interaction is perceived as a personal patient-doctor interaction. However, when it comes to sharing lifestyle experiences, the forum did not follow a star-shaped network topology. Rather, consumers freely communicated with each other and the GP no longer played a central role of mediating the conversation in the forum.

Use of Self-Reflective Features

Although only 15.0% (106/709) of participants entered an entry into their PHR, this is the single feature that was significantly associated with consumers' physical well-being help-seeking behaviors [27]. The use of the PHR, which encouraged participants to keep track of their personal health details (such as medication, test results, scheduled appointments, or health care team members), was significantly associated with more visits to a health care professional and help-seeking for physical well-being matters [27]. This may be related to increasing one's self-efficacy by being aware of past and upcoming tasks and results [40].

Although only 8.6% (61/709) of participants used the diary, it was also one of the features identified as being significantly associated with emotional well-being help-seeking behaviors and visits to the university counseling service [27]. A diary, which encouraged self-reflection (in accordance with the principle of self-monitoring), is one of the most common behavioral change techniques [41]. However, a controlled randomized protocol would have been necessary to investigate this potential causative relationship.

Implications for PCHMS Design and Future Research

Potential Considerations

This study suggests that there is potential for using the private spaces in a PCHMS (eg, diary and PHR) to enable participants to self-reflect and take action in regard to their health. As participants become more aware of their health status and concerns, they could then utilize the social environment in the PCHMS to (1) seek advice and support from similar others (eg, via online community forum), (2) engage with health professionals (eg, via expert-based question-and-answer forum), (3) verify whether they are "normal" compared to others (eg, via poll), or (4) use health service facilitation tools to connect with formal services for assistance (eg, online appointment booking).

In fact, consumers' usage patterns of a PCHMS could provide important "signals" of whether help-seeking assistance is needed. Based on the way a consumer uses these social and self-reflective features, the PCHMS could potentially facilitate help-seeking behavior by adaptively managing and promoting the individual's interactions with other consumers/health care providers, thereby elucidating the path to help-seeking through a method that would be most appropriate at that point in time.

Further, eHealth researchers should consider ways that the "crowd" (ie, social network around a person) can be systematically manipulated so that it can influence health behaviors and outcomes in a positive manner. If a PCHMS were able to "change" the crowd around a person, would that be sufficient for him or her to come into contact with a pivotal person who would encourage help-seeking and early intervention? If so, what "doses" of self-reflection and changes in social network formations are required in an intervention for an individual to take action?

Forum

Our social network analysis of online forums has revealed a spectrum of social interaction patterns—from question-and-answer structures to community discussions. It also provides a preliminary examination of how the presence of experts in online forums may change the patterns of communication among consumers.

Current evidence that guides the design of social features in consumer eHealth applications is sparse. More empirical and theoretical studies are needed to investigate ways to design an "optimally social-engineered communication space" [42], according to its intended purpose and the anticipated interaction mode. Choi and colleagues have recently proposed a typology for online Question-Answering (QA) forums with four categories: community-based, collaborative, expert-based QAs, and social [37]. When designing social components of a PCHMS, researchers should consider the following important questions:

(1) Which type of QA online space is most appropriate to address the needs of its audience? What is the optimal mix of participants that would allow interaction/moderation to be sustainable in the long-term?

(2) In a community-based forum, would it be more appropriate to have informed "expert peers" [43] rather than "medical professionals" to act as moderators? What method of moderation is most appropriate in order to encourage participant activity without compromising on the fluidity of interaction, the safety of the space, or the accuracy of the information exchanged?

(3) How can online spaces be optimally designed for different social and communication purposes (eg, with new acquaintances, family and friends, or health professionals)?

Poll

The poll was one of the most frequently used features in the PCHMS and was regarded as the most useful and engaging. Yet, its use in consumer eHealth applications is not widespread, its efficacy not thoroughly tested, and it remains unclear how we can effectively design and incorporate social norms information to influence health behaviors. As Christakis and Fowler have demonstrated in the past decade, social networks are associated with health behaviors and outcomes for a variety

of conditions (such as happiness, loneliness, depression, and obesity) [44-47]. When applied in the right context, social norms information has shown to significantly influence health behaviors (such as reducing alcohol consumption [48,49]). In addition, Centola has recently demonstrated that homophily (ie, similarity of social contacts) and social network structures can significantly influence *online* health behaviors [50,51].

Yet, to the best of our knowledge, no studies have examined how we can best utilize these social influence findings to inform the design of PCHMSs and other consumer eHealth applications. While previous literature and our own findings suggest that information about social norms (such as via the poll) is associated with significant changes in consumers' health beliefs and behaviors, eHealth researchers need to examine ways we can effectively utilize social norms information to encourage positive health behaviors. Similarly, there is a need to reduce the risk of "normalizing" negative health behaviors and beliefs, such as in cases when the "norms" may convey an incorrect or misleading view of what is considered healthy.

Diary and Personal Health Record

The poll and the forum promote social interactions with other people, whereas the PHR and the diary provide consumers an online private space in which to organize, reflect, and hopefully, advance their health. Usage patterns of the diary suggest that it was primarily used for self-reflection, personal problem solving, and goal setting. On the other hand, the PHR was primarily used for organizational purposes, which included the self-recording of personal health data and past/upcoming tasks.

Strengths and Limitations

Key strengths of this study include the employment of a multifaceted PCHMS and the utilization of PCHMS usage metrics to identify associations with key consumer behavior outcomes.

This study also presents several limitations: university setting, self-reports, self-entry functionality, causality versus association, and PCHMS engagement measures. First, participants in a university setting may have been more motivated and willing to try new technologies to manage their health than the general population [52,53]. The key limitations are the short duration and high attrition rate. High attrition rates are common in eHealth intervention studies, with a recent systematic review revealing that completion of protocol rates for depression sites ranged from 43% to 99% [54]. One of the possible reasons for the attrition rate of 64.28% (1276/1985) in this study is that participants were asked by email to complete their post-study questionnaire during the long university summer break, when students and staff were not as likely to check their university email. However, the number of participants eligible for analysis is still relatively large (n=709), with 80.7% (572/709) logging into the PCHMS at least once [27], providing a sufficient sample size to analyze whether level of PCHMS usage is associated with consumers' heath service and help-seeking utilization rates. Overall, future studies conducted in the university setting should strive to commence and complete the study during semester time.

Second, the study relied on self-reports by participants, which have been shown to be acceptable in studies of help-seeking, health service utilization, and mental health related studies among students [55-58]. The PCHMS currently relies on self-entry functionality, which may have caused lower usage of the tool. While it is possible that some participants could have used the PCHMS after visiting the university health services, we validated health service utilization rates by matching self-report from a subset of study participants with their health records at the University Counselling and Psychological Services, where system usage log files indicated that usage of the PCHMS preceded clinic visits.

Third, although findings in this study are limited by its design, the use of a convenience sample, and that we could attribute no causal relationships, our findings concur with Couper and colleagues' study, which found that website engagement was significantly associated with consumers' health behaviors [59]. In addition, our previous analyses showed that participants' pre-study characteristics and well-being ratings were uniformly distributed among different PCHMS log-in frequency thresholds [27], and we have demonstrated in a previous randomized controlled trial that use of the PCHMS is associated with significant uptake of the influenza vaccine [23]. Nevertheless, future studies will need to use a controlled randomized design to allow an interpretation in terms of causality.

Finally, this study focuses on some of the simplest website engagement measures (eg, number of PCHMS log-ins) and differed from previous studies that have used numerous metrics for measuring user engagement, such as number of website visits, time spent on a site, and number of features used [53,60]. Future studies should consider incorporating a qualitative component to elicit participants' context and reasons (eg, why and how) for engaging with the PCHMS.

Conclusions

Incorporating the two major trends in consumer eHealth research (ie, PHRs and online social networks) to inform the next generation design of consumer systems requires several novel considerations. This study provides preliminary findings that suggest a PCHMS should include both social and self-reflective features that allow consumers to become familiar with their personal concerns and connect with others to seek help. With the rapid growth of online social networking websites and PHRs, future designs of PCHMSs should explore novel ways in which we can intervene in a person's level of self-awareness and social network and examine their efficacy as a complex social and self-reflective intervention for health.

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Authors' Contributions

Study design: AL, JP, AA1, JC, STL, EC; Journey design: AA1, JC, AL; Data collection: AL, AA1, JC; Data analyses: AL, AD, NM, AG; First draft: AL; Draft revision: AL, NM, STL, AA2, AD, EC, JP, AG.

Conflicts of Interest

The University of New South Wales and some of the researchers (EC, AL) at the Centre for Health Informatics could benefit from the commercialization of the PCHMS.

Multimedia Appendix 1

Study protocol and intervention description.

[PDF File (Adobe PDF File), 52KB - jmir_v15i9e211_app1.pdf]

Multimedia Appendix 2

Personal health record entries entered by participants.

[PDF File (Adobe PDF File), 24KB - jmir_v15i9e211_app2.pdf]

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Abbreviations

COOP/WONCA charts: Charts developed by the Dartmouth Primary Care Cooperative Research Network (COOP) and the World Organization of National Colleges, Academies, and Academic Associations of General Practitioners/Family Physicians (WONCA).
GP: general practitioner
PCHMS: personally controlled health management system
PHR: personal health record
QA: question-answering

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Original Paper

Participant Profiles According to Recruitment Source in a Large Web-Based Prospective Study: Experience From the Nutrinet-Santé Study

Emmanuelle Kesse-Guyot[1], PhD; Valentina Andreeva[1], PhD; Katia Castetbon[2], PhD; Michel Vernay[2], PhD; Mathilde Touvier[1], PhD; Caroline Méjean[1], PhD; Chantal Julia[1,3], MD; Pilar Galan[1], PhD; Serge Hercberg[1,3], PhD

[1]Université Paris 13, Sorbonne Paris Cité, UREN, Inserm (U557); Inra (U1125), Cnam, Bobigny, France

[2]Université Paris 13, Sorbonne Paris Cité, USEN, Institut de Veille Sanitaire, Bobigny, France

[3]Département de Santé Publique, Hôpital Avicenne (AP-HP), Bobigny, France

Corresponding Author:
Emmanuelle Kesse-Guyot, PhD
Université Paris 13, Sorbonne Paris Cité, UREN, Inserm (U557); Inra (U1125), Cnam
UREN, SMBH Paris 13, SMBH
74 rue Marcel Cachin
Bobigny, 93017
France
Phone: 33 1 48 38 89 79
Fax: 33 1 48 38 89 31
Email: e.kesse@uren.smbh.univ-paris13.fr

Abstract

Background: Interest in Internet-based epidemiologic research is growing given the logistic and cost advantages. Cohort recruitment to maximally diversify the sociodemographic profiles of participants, however, remains a contentious issue.

Objective: The aim of the study was to characterize the sociodemographic profiles according to the recruitment mode of adult volunteers enrolled in a Web-based cohort.

Methods: The French NutriNet-Santé Web-based cohort was launched in 2009. Recruitment is ongoing and largely relies on recurrent multimedia campaigns. One month after enrollment, participants are asked how they learned about the study (eg, general newscast or a health program on television, radio newscast, newspaper articles, Internet, personal advice, leaflet/flyers) The sociodemographic profiles of participants recruited through operative communication channels (radio, print media, Internet, advice) were compared with the profiles of those informed through television by using polytomous logistic regression.

Results: Among the 88,238 participants enrolled through the end of 2011, 30,401 (34.45%), 16,751 (18.98%), and 14,309 (16.22%) learned about the study from television, Internet, and radio newscasts, respectively. Sociodemographic profiles were various, with 14,541 (16.5%) aged ≥60 years, 20,166 (22.9%) aged <30 years, 27,766 (32.1%) without postsecondary education, 15,397 (19.7%) with household income <€1200/month, and 8258 (10.6%) with household income €3700/month. Compared to employed individuals, unemployed and retired participants were less likely to be informed about the study through other sources than through television (adjusted ORs 0.56-0.83, P<.001). Participants reporting up to secondary education were also less likely to have learned about the study through radio newscasts, newspaper articles, Internet, and advice than through television (adjusted ORs 0.60-0.77, P<.001).

Conclusions: Television broadcasts appear to permit the recruitment of e-cohort participants with diverse sociodemographic backgrounds, including socioeconomically disadvantaged individuals who are usually difficult to reach and retain in long-term epidemiologic studies. These findings could inform future Web-based studies regarding the development of promising targeted or general population recruitment strategies.

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KEYWORDS

cohort study; Internet; selection bias; population characteristics

Introduction

Prospective epidemiological studies are invaluable in advancing scientific knowledge; however, they require very large samples when dealing with rare outcomes or when aiming to accurately establish small-scale associations [1]. In addition, traditional large population-based studies require material logistic and operational resources for survey printing and mailing, recruitment and training of interviewers, data entry and cleaning, and follow-up management. In addition, in such volunteer-based studies, certain subgroups of the population (eg, the socioeconomically disadvantaged, the elderly, and rural area residents) are often underrepresented which restricts the range of available exposure and confounder measures and may limit the internal validity of the findings.

The inherent financial burden and the steadily declining participation rates in telephone- or mail-based data collection surveys [2] argue for the need for innovative and attractive recruitment and data collection strategies for epidemiological studies.

In recent decades, the expansion of the Internet for personal and professional use has underscored important changes in the field of mass communication and has presented unique opportunities to enroll and follow individuals while collecting a wide range of epidemiological data [3]. Indeed, these innovative technologies have rapidly evidenced valuable advantages for epidemiologic research, including substantial savings in logistic and financial resources, greater convenience to the participants regarding the time/place of survey completion, and potentially superior data quality in specific domains [4]. Use of the Internet in epidemiology is now commonly referred to as *e-epidemiology* and represents the science of epidemiological assessment using Internet-enabled digital media (eg, personal computers, tablets, and smartphones) [3]. Also, e-epidemiology has the potential of lowering social desirability effects because of guaranteed greater levels of privacy and anonymity compared with traditional in-person data collection strategies, thus limiting potential prevarication bias [5]. Over the past decade, the Internet has been used to implement intervention trials for smoking cessation, physical activity promotion, alcohol abstinence, healthy eating promotion [6-8], and medication adherence [9]. In addition, these novel technologies have been advanced as an alternative follow-up method in preexisting cohorts, such as the Black Women's Health Study [10] and the Millennium Cohort Study [11]. However, few prospective cohort studies have used such innovative methods as the primary medium of contact, recruitment, and follow-up [12-15], and none has provided information about the profiles of enrollees according to the information source used.

Mass media campaigns, which are complementary to other outlets for the dissemination of public health messages, have shown promising results [16-18] and may be a feasible option for the recruitment of volunteers. In addition, the employment of multiple communication channels may help diversify participant backgrounds.

The NutriNet-Santé Study is a Web-based prospective cohort study launched in France in May 2009. With almost 40 million Web users older than 11 years (71% of the population), France provides an excellent context for Web-based scientific studies [19]. Unlike traditional epidemiological studies that often rely on recruitment through targeted postal mailings, telephone calls, or hospital/health insurance rosters, the NutriNet-Santé Study relies on a wide range of free-of-charge communication channels for disseminating the call for volunteers.

The aim of the present study was to evaluate the degree to which the sociodemographic profiles of the participants enrolled in the NutriNet-Santé Study on a voluntary basis varied across the communication source used. In particular, we expected that television, as a wide-reaching medium (99% of French households possess a television set), may aid in recruiting typically understudied population subgroups. Henceforth, we use the term *recruitment* in reference to the information channel by which the participants learned about the study before deciding to enroll in it.

Methods

Population

The present analysis was performed on data from participants in the NutriNet-Santé Study enrolled from May 10, 2009 through December 31, 2011. The rationale, design, and implementation of the study has been reported elsewhere [20]. Briefly, the NutriNet-Santé Study is an ongoing, large, Web-based prospective cohort study launched in France in May 2009. Its primary aim is to investigate the associations between nutritional factors and health outcomes and to elucidate the role of various determinants (eg, demographic, socioeconomic, cultural, and cognitive) of dietary patterns and nutritional status.

In the NutriNet-Santé Study, adult participants aged 18 years and older are recruited from the general population on a voluntary basis. All data are collected through a dedicated website [21] via adapted questionnaires using a secure and user-friendly HyperText Markup Language (HTML) interface. Individuals who fill out all baseline questionnaires (pertaining to sociodemographics, dietary behaviors, physical activity, anthropometrics, lifestyle, and health status) are included in the cohort [20]. All baseline questionnaires were first pilot-tested and compared with the traditional modalities (paper versions or dietitian interviews) [22-24]. Health events are monitored via questionnaires about hospitalizations and medication use as well as via a linkage with the national vital statistics database. The study was approved by the Institutional Review Board (IRB) of the French Institute for Health and Medical Research (IRB Inserm no: 0000388FWA00005831) and the Comité National Informatique et Liberté (CNIL no: 908450 and 909216).

Recruitment is scheduled for 5 years with an additional follow-up planned at 10 years. The call for volunteers is based on a vast, biannual, multimedia campaign (including print media, Internet websites and networks, and television and radio broadcasts).

At the launch of the study, the first campaign contained general information about the study and was carried out under the auspices of the Health Minister. Subsequent campaigns have

been built around specific findings from the study (eg, calls for reduction in salt consumption, increase in fiber intake, adherence to nutritional guidelines). Before each campaign, a press conference is organized and a press release is widely disseminated within a 72-hour period. Aspects related to academic endeavor, public health interest, scientific progress, confidentiality, and convenience regarding participation (ie, ≤20 min each month) are emphasized.

Additional dissemination strategies have also been used, such as short message service (SMS) text messaging for the initial mass media campaign especially (n=400,000 recipients), leaflets/flyers (n=50,000 recipients), and a nonpaid advertising display. For example, the SMS text messages were sent by a French mobile service provider to a random sample of their customers. Nonpaid advertising displays included postings in doctor's offices, health centers, worksites, public transportation, and on billboards, as well as video clips shown in post offices.

Data Collection

The baseline set of questionnaires includes information about date of birth, sex, area of residence, education, employment status, household composition, occupational category, and income. At 1-month follow-up, participants are asked to provide information about how they heard about the NutriNet-Santé Study and are given 18 response options including "I don't remember" or "other." Each participant is allowed to select only 1 response to this question. For the present analyses, these responses have been grouped into the following 9 recruitment sources: (1) general newscast or a health program on television, (2) radio newscast, (3) newspaper article, (4) Internet website or network, (5) SMS text message sent by a service provider, (6) advice from a friend/family member/health care provider, (7) leaflet/flyer, (8) nonpaid advertising display, and (9) other (including "I don't remember").

Statistical Analysis

For the present analysis, we focused on participants included in the NutriNet-Santé Study between May 10, 2009 and December 31, 2011. From the 104,020 participants meeting that criterion, we selected 88,238 individuals who provided information at 1-month follow-up on how they had learned about the study.

Income per household unit was first calculated and then divided by the number of household members (eg, 1 unit for the first adult in the household, 0.5 units for the other persons aged 14 years or older, and 0.3 units for children under 14 years of age) [25]. The occupation category for retired and unemployed people was defined as the last job held.

Sociodemographic characteristics of the sample, including age (<30 years, 30-45 years, 45-60 years, ≥60 years), education (primary/secondary, postsecondary <bachelor's degree, ≥bachelor's degree), current employment status (employed, unemployed, homemaker, retired, student), occupational category (never employed, farmer, manual worker, employees/medium-skilled labor, intermediate professions/skilled labor, self-employed, managerial/professional staff), type of area of residence (rural, urban <200,000 inhabitants, urban ≥200,000 inhabitants), and monthly household income (<€1200, €1200-€2700, €2700-€3700, >€3700 per household unit), are presented in a frequency/percent format for the entire sample and by recruitment source.

To better understand the selected sample, we compared the characteristics of included and excluded NutriNet-Santé Study participants using chi-square tests and Student *t* tests, as appropriate.

Crude and adjusted associations between the sociodemographic characteristics and the recruitment source were estimated using polytomous logistic regression (reference=television). Polytomous logistic regression generalizes the binary logistic regression model, allowing the dependent (outcome) variable to have more than 2 categories [26]. The multivariate model included the following covariates: age, sex, education, employment status, occupational category, area of residence, and monthly household income. Additionally, the model was adjusted for the interval between the most recent press release and the completion of the first follow-up questionnaire that included information about the recruitment source. Odds ratios (OR) and 95% confidence intervals (CI) are reported. We also performed a sensitivity analysis after exclusion of participants for which the most recent press release occurred between baseline and the first follow-up questionnaire. Tests of statistical significance were 2-sided and the type I error was set at 5%. Statistical analyses were performed using SAS software (version 9.2, SAS Institute Inc, Cary, NC, USA).

Results

Compared to included participants, those participants excluded because of missing data from the first follow-up questionnaire were younger (39.64 years vs 43.01 years), less often retired (11.35% vs 17.62%, $P<.001$), more often students (11.37% vs 7.69%, $P<.001$), and they were more likely to report a low (<€1200) monthly income (27.90% vs 19.70%, $P<.001$).

The sociodemographic characteristics of the sample and recruitment sources and the corresponding national estimates are presented in Table 1. In all, 22.40% (19,764/88,238) of the participants were men; the mean age was 43.0 years (SD 14.5). Approximately two-thirds (58,776/86542, 67.92%) of the sample had postsecondary education; 31.64% (22,464/70,995) were employed in managerial/executive or professional positions, and 32.20% (22,857/70,995) were employees engaged in medium-skilled work. The sample included 7.80% currently unemployed individuals (6751/86,542) and approximately one-fifth of the sample reported monthly income <€1200 euros per household unit (19.69%, 15,397/78,171). Over one-fifth of the participants lived in rural areas (21.24%, 18,741/88,238). The use of various dissemination channels allowed the recruitment of a wide range of sociodemographic profiles with a sizeable portion of older people aged 60 years or older (16.48%, 14,541/88,238), individuals with low levels of formal education without postsecondary education (32.08%, 27,766/86,542), and with low income defined as <€1200/month (19.69%, 15,397/78,171).

Television was the most common source of information about the study; 34.47% (30414/88,238) of the participants reported

learning about it through a general newscast or a health-related broadcast on television. Meanwhile, very few participants learned about the study from a noncommercial advertising display (0.61%, 542/88,238), SMS text messaging (0.86%, 760/88,238), or leaflets (1.69%, 1,494/88,238).

The number of participants enrolling over time is presented in Figure 1. There were recruitment peaks following each mass media campaign. The actual number of inclusions after each media campaign varied greatly according to the key scientific message of the campaign, the breaking news at the time, and the scope of the relay by the media. The highest peak was achieved after the first multimedia campaign that introduced the study to the public and was widely disseminated.

Crude and adjusted associations between participants' characteristics and the principal recruitment source are presented in Tables 2 and 3. In the multivariate models, compared to participants aged 30 to 45 years, older individuals (≥60 years) were more likely to be informed about the cohort through channels other than television (adjusted ORs ranging from 1.40 for radio newscast to 2.26 for personal advice). Compared to participants with postsecondary education, those with only primary/secondary education were less likely to be recruited through channels other than television (adjusted ORs ranging from 0.60 for newspaper articles to 0.77 for personal advice). Compared to employed individuals, participants who were unemployed or retired were most likely to be informed about the study through television (adjusted ORs ranging from 0.56 for newspaper articles to 0.71 for personal advice, and from 0.57 for Internet to 0.94 for newspaper articles). Compared to participants with monthly household unit income ranging from €1200 to €2299, those with low income (<€1200/month) were less likely to be informed through channels other than television (crude ORs ranging from 0.62 for radio to 0.80 for advice from a relative), but the differences did not remain significant in the multivariate model except for radio newscasts (adjusted OR 0.87, 95% CI 0.81-0.93, global *P* value for the income variable <.001).

Figure 1. Participant enrollment per month in the NutriNet-Santé Study from March 2009 to December 2011 in relation to mass media campaigns (N=88,238).

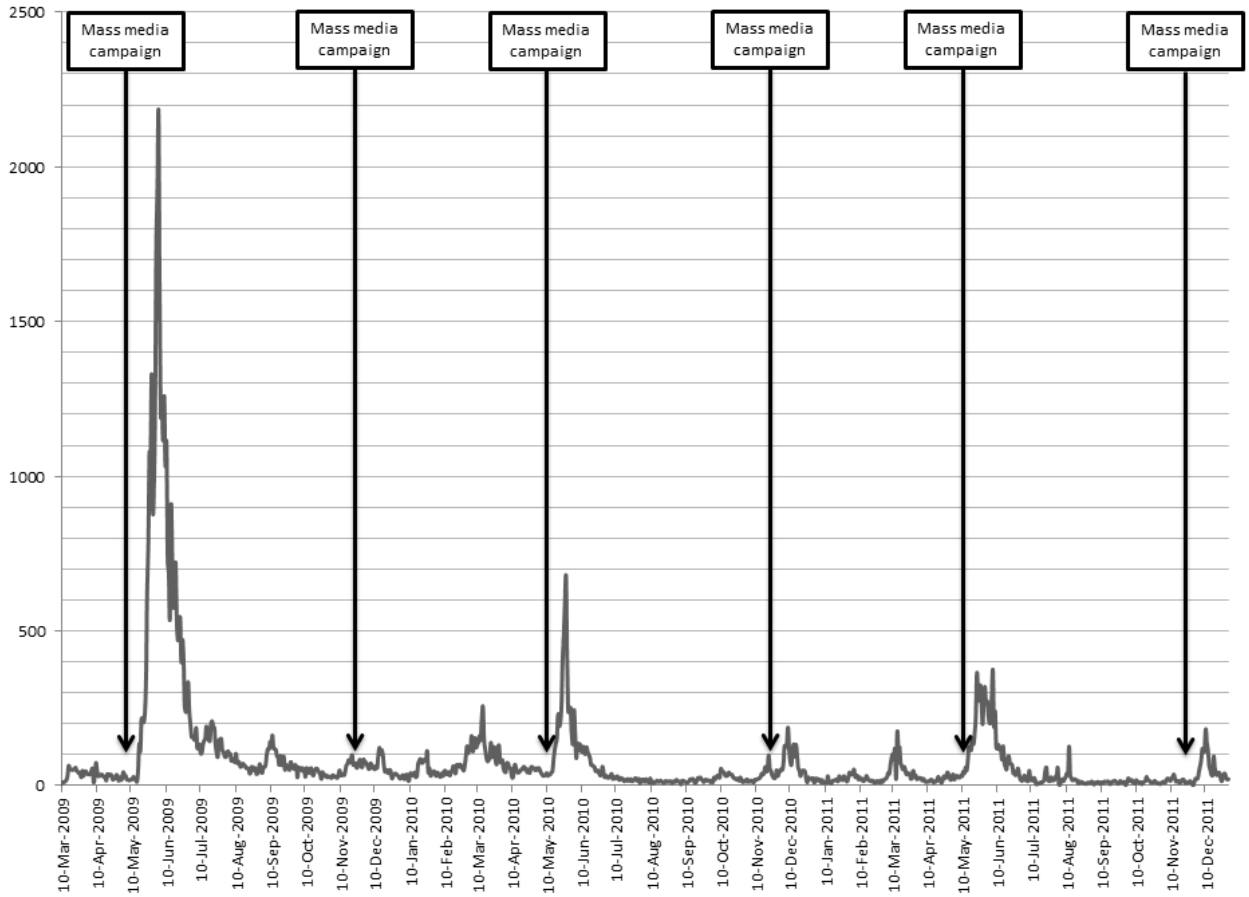

Table 1. Sociodemographic characteristics of the NutriNet-Santé Study sample (N=88,238) in comparison to the general population of France [30,31].

Sociodemographic characteristic	NutriNet-Santé, n (%)	France, %
Sex		
Male	19,764 (22.40)	47.6
Female	68,474 (77,60)	52.4
Age categories (years)		
<30	20,166 (22.85)	22.8
30-44	27,372 (31.02)	24.8
45-59	26,159 (29.65)	24.8
≥60	14,541 (16.48)	27.6
Education among people older than 20 years (n=86,542)		
Primary/secondary	27,766 (32.08)	75.3
Some college, associate degree	26,324 (30.2)	11.9
≥Bachelor's degree	32,452 (37.50)	12.6
Occupational category among nonretired people older than 20 years (n=70,995) [a]		
Never employed	3401 (4.79)	18.7
Farmers	272 (0.38)	1.1
Manual workers	2118 (2.98)	14.7
Employees/medium-skilled labor	22,857 (32.20)	18.1
Intermediate professions/skilled office work	17,966 (25.31)	14.9
Self-employed	1917 (2.70)	3.6
Managerial/professional positions	22,464 (31.64)	9.3
Current employment status (n=86,542) [b]		
Employed	55,168 (63.75)	55.1
Homemakers	3896 (4.50)	4.6
Unemployed	6751 (7.80)	11.3
Retired	15,547 (17.96)	28.7
Students	5180 (5.99)	2.5
Monthly income (€ per household unit) [c] **(n=78171)**		
< 1200	15,397 (19.69)	
1200-2299	34,764 (44.47)	
2300-3699	19,752 (25.27)	
> 3700	8258 (10.56)	
Area of residence		
Rural	18,741 (21.24)	
Urban (population <200,000)	29,619 (33.57)	
Urban (population >200,000)	39,878 (45.19)	
Recruitment source		
Television (general newscast or a health program)	30,414 (34.47)	
Radio newscast	14,309 (16.22)	
Newspaper articles	9613 (10.89)	
Nonpaid advertising display	542 (0.61)	
Internet websites	16,807 (19.05)	

Sociodemographic characteristic	NutriNet-Santé, n (%)	France, %
SMS text message sent by a service provider	760 (0.86)	
Leaflet/flyers	1494 (1.69)	
Advice from a friend/family member/health care provider	10,172 (11.53)	
Other	4127 (4.68)	

[a]Occupational category for unemployed people was defined as the most recent type of job held. For comparison purposes, occupational categories are shown for people who are not retired and are older than 20 years.

[b]For comparison purposes, employment status is shown for people older than 20 years.

Table 2. Crude associations between sociodemographic profiles and recruitment source using television as reference (n=72,264).

Sociodemographic characteristic	Recruitment source, OR (95% CI)[a,b]			
	Advice from a friend/family member/health care provider (n=10,172)	Internet websites and networks n=(16,807)	Newspaper articles (n=9613)	Radio newscast (n=14,309)
Sex				
Men	1.31 (1.24-1.39)	1.19 (1.13-1.24)	1.26 (1.19-1.34)	1.46 (1.39-1.53)
Women	1 (ref)	1 (ref)	1 (ref)	1 (ref)
Age categories (years)				
<30	1.44 (1.35-1.53)	0.93 (0.88-0.98)	0.85 (0.79-0.91)	0.54 (0.51-0.58)
30-44	1 (ref)	1 (ref)	1 (ref)	1 (ref)
45-59	1.19 (1.11-1.27)	1.19 (1.13-1.25)	1.27 (1.20-1.35)	1.13 (1.07-1.19)
≥60	1.86 (1.73-2.00)	1.18 (1.11-1.25)	1.55 (1.44-1.66)	0.90 (0.84-0.96)
Education				
Primary/secondary	0.71 (0.67-0.76)	0.69 (0.65-0.72)	0.67 (0.64-0.72)	0.54 (0.52-0.57)
Some college, associate degree	1 (ref)	1 (ref)	1 (ref)	1 (ref)
≥Bachelor's degree	1.88 (1.76-2.00)	1.72 (1.63-1.81)	1.69 (1.59-1.80)	1.81 (1.72-1.91)
Occupational category [c]				
Never employed	2.24 (2.00-2.50)	1.30 (1.17-1.45)	1.09 (0.95-1.26)	0.99 (0.87-1.13)
Farmers	1.27 (0.85-1.89)	0.69 (0.47-1.03)	1.00 (0.65-1.55)	2.12 (1.57-2.86)
Manual workers	0.70 (0.59-0.83)	0.77 (0.68-0.87)	0.69 (0.58-0.82)	0.87 (0.75-1.00)
Employees/medium-skilled labor	1 (ref)	1 (ref)	1 (ref)	1 (ref)
Intermediate professions/skilled office work	1.79 (1.68-1.91)	1.65 (1.56-1.74)	1.75 (1.64-1.87)	2.11 (1.99-2.24)
Self-employed	1.11 (0.95-1.30)	0.96 (0.85-1.10)	0.98 (0.83-1.15)	1.67 (1.48-1.89)
Managerial/professional positions	2.78 (2.61-2.96)	2.49 (2.36-2.62)	2.65 (2.49-2.82)	3.43 (3.25-3.63)
Current employment status				
Employed	1 (ref)	1 (ref)	1 (ref)	1 (ref)
Homemakers	0.47 (0.41-0.54)	0.43 (0.38-0.48)	0.54 (0.47-0.61)	0.63 (0.57-0.70)
Unemployed	0.58 (0.53-0.64)	0.60 (0.56-0.65)	0.46 (0.41-0.51)	0.46 (0.42-0.50)
Retired	1.30 (1.22-1.38)	0.86 (0.81-0.91)	1.23 (1.16-1.31)	0.78 (0.73-0.82)
Students	1.46 (1.34-1.60)	0.78 (0.72-0.85)	0.65 (0.58-0.73)	0.46 (0.41-0.51)
Income (€ /month per household unit)				
<1200	0.80 (0.75-0.86)	0.79 (0.75-0.83)	0.67 (0.63-0.72)	0.62 (0.58-0.65)
1200-2,299	1 (ref)	1 (ref)	1 (ref)	1 (ref)
2300-3699	1.55 (1.46-1.65)	1.37 (1.30-1.44)	1.58 (1.49-1.68)	1.60 (1.52-1.69)
>3700	2.05 (1.89-2.22)	1.68 (1.56-1.80)	1.85 (1.70-2.01)	2.03 (1.89-2.18)
Area of residence				
Rural	0.94 (0.88-1.01)	1.00 (0.94-1.06)	0.90 (0.84-0.96)	1.11 (1.05-1.18)
Urban (population <200,000)	1 (ref)	1 (ref)	1 (ref)	1 (ref)
Urban (population >200,000)	1.53 (1.45-1.62)	1.43 (1.37-1.50)	1.27 (1.20-1.34)	1.22 (1.16-1.28)

[a]Reference=television; for example, compared to participants aged 30-45 years, participants <30 years were less often informed about the study through the radio than through television (OR 0.54).

[b]All *P* values for the association between each sociodemographic variable and recruitment source (*P*<.001).

[c]Occupational category for retired and unemployed people defined as the most recent type of job held.

Table 3. Multivariate associations between the participant sociodemographic profiles and recruitment source using television as reference (n=72,264).

Sociodemographic characteristic	Reference source, adjusted OR[a] (95% CI)[b,c]			
	Advice from a friend/family member/health care provider (n=10,172)	Internet websites and networks (n=16,807)	Newspaper articles (n=9613)	Radio newscast (n=14,309)
Sex				
Men	1.10 (1.03-1.17)	1.04 (0.99-1.10)	1.05 (0.99-1.12)	1.25 (1.19-1.32)
Women	1 (ref)	1 (ref)	1 (ref)	1 (ref)
Age categories (years)				
<30	1.31 (1.22-1.41)	0.94 (0.88-1.00)	0.89 (0.82-0.96)	0.60 (0.56-0.64)
30-44	1 (ref)	1 (ref)	1 (ref)	1 (ref)
45-59	1.39 (1.30-1.49)	1.46 (1.38-1.54)	1.49 (1.39-1.59)	1.41 (1.34-1.50)
≥60	2.26 (2.00-2.57)	2.07 (1.86-2.30)	1.73 (1.53-1.96)	1.40 (1.25-1.57)
Education				
Primary/secondary	0.77 (0.72-0.82)	0.71 (0.66-0.75)	0.60 (0.57-0.64)	0.75 (0.71-0.80)
Some college, associate degree	1 (ref)	1 (ref)	1 (ref)	1 (ref)
≥Bachelor's degree	1.54 (1.44-1.65)	1.48 (1.38-1.58)	1.53 (1.44-1.62)	1.47 (1.38-1.56)
Occupational category [d]				
Never employed	1.33 (1.15-1.54)	1.31 (1.14-1.50)	1.25 (1.04-1.50)	1.26 (1.06-1.49)
Farmers	1.25 (0.83-1.87)	0.60 (0.40-0.89)	0.87 (0.56-1.36)	1.62 (1.19-2.20)
Manual workers	0.80 (0.67-0.95)	0.88 (0.77-1.01)	0.84 (0.70-1.00)	1.01 (0.88-1.17)
Employees/medium-skilled labor	1 (ref)	1 (ref)	1 (ref)	1 (ref)
Intermediate professions/skilled office work	1.43 (1.33-1.54)	1.35 (1.28-1.44)	1.30 (1.21-1.39)	1.50 (1.41-1.60)
Self-employed	0.97 (0.82-1.13)	0.84 (0.74-0.96)	0.80 (0.68-0.94)	1.31 (1.15-1.49)
Managerial/professional positions	1.58 (1.46-1.71)	1.58 (1.48-1.69)	1.46 (1.35-1.59)	1.73 (1.62-1.86)
Current employment status				
Employed	1 (ref)	1 (ref)	1 (ref)	1 (ref)
Homemakers	0.60 (0.52-0.70)	0.50 (0.45-0.56)	0.66 (0.57-0.75)	0.84 (0.76-0.94)
Unemployed	0.71 (0.65-0.79)	0.69 (0.64-0.75)	0.56 (0.50-0.62)	0.60 (0.55-0.66)
Retired	0.83 (0.74-0.93)	0.57 (0.51-0.63)	0.94 (0.84-1.05)	0.63 (0.57-0.70)
Students	1.64 (1.44-1.88)	1.02 (0.91-1.16)	0.98 (0.83-1.15)	1.09 (0.94-1.27)
Income (€ /month per household unit)				
<1200	0.94 (0.87-1.01)	1.04 (0.98-1.10)	0.94 (0.87-1.01)	0.87 (0.81-0.93)
1200-2299	1 (ref)	1 (ref)	1 (ref)	1 (ref)
2300-3699	1.16 (1.09-1.23)	1.02 (0.97-1.08)	1.16 (1.09-1.23)	1.15 (1.09-1.22)
>3700	1.25 (1.14-1.37)	1.00 (0.92-1.08)	1.08 (0.99-1.19)	1.12 (1.03-1.21)
Area of residence				
Rural	1.01 (0.94-1.09)	1.05 (0.99-1.12)	0.95 (0.88-1.02)	1.17 (1.11-1.24)
Urban (population <200,000)	1 (ref)	1 (ref)	1 (ref)	1 (ref)
Urban (population >200,000)	1.30 (1.22-1.37)	1.25 (1.19-1.31)	1.11 (1.05-1.18)	1.02 (0.97-1.08)

[a]For each predictor, the respective OR is adjusted for the remaining variables and for the interval (in days) between the most recent press release (days) and the survey completion.

[b]Reference=television; for example: compared to participants aged 30-45 years, participants <30 years were less often informed about the study through the radio than through television (OR 0.60).

[c]All *P* values for the association between each sociodemographic variable and recruitment source (*P*<.001).

[d]Occupational category for retired and unemployed people defined as the most recent type of job held.

Discussion

Principal Results

We examined how the sociodemographic profiles of participants in a large, Internet-based cohort differed according to the recruitment source used. The use of a number of different dissemination channels allowed the recruitment of a sizeable and diverse cohort. As expected, most participants enrolled after hearing about the study on television because this medium has the widest reach. In particular, television announcements permitted the recruitment of a larger proportion of members of population subgroups (eg, those belonging to lower socioeconomic strata) that are not typically well represented in population-based epidemiologic research. However, the elderly were more likely to be informed about the cohort through channels other than television suggesting that television did not necessarily represent the best information medium for all population subgroups. In turn, radio, newspapers, Internet, and personal advice also proved to be substantial means of disseminating information about this epidemiologic study to encourage participation.

Overall, the recruitment of participants from a wide range of sociodemographic backgrounds provides the study with a broader range of exposures and confounders than does a more homogeneous sample. This is of important concern when the overarching aim is to estimate associations between certain exposures and health/disease outcomes, as in the NutriNet-Santé Study [1,13,27,28].

Comparison With Prior Work

Among the initial efforts to recruit Web-based cohorts, in examining the literature we identified 1 study calling for participation in a cohort of smokers intending to quit, by using existing Internet panels intended for market research [12]. Another study recruited nurses and midwives through targeted email distribution [14]. A birth cohort study employed hospital advertising [15] and a pregnancy planning study made recruitment announcements on a health-related website [13]. To the best of our knowledge, this is the first study pertaining to the quantitative description of participant profiles according to the recruitment source.

Limitations

The main limitation of this analysis was the lack of information on participation/refusal rates because the call for participation was not delivered to a predefined and exhaustive list of randomly selected individuals. In turn, the results need to be interpreted in light of the fact that the actual effectiveness of the media channels cannot be estimated. Second, misclassification of recruitment source is also possible because the question about information source was asked 1 month after baseline. Additional misclassification about the recruitment source cannot be ruled out because participants may have been exposed to several information sources. For example, if a press release occurred during the interval between baseline and the completion of the first follow-up questionnaire, this may have led to an overreporting of the related information channels. However, the sensitivity analysis performed after removing these participants did not substantially modify the findings.

Cohort Profile and Aspects Related to Future Analyses of the Nutrinet-Santé Data

Concerns have been raised regarding the selection bias potentially inherent in cohorts followed via the Internet. Web users may present particular sociodemographic profiles, especially regarding sex, age, and education [3,10,29]. Our findings suggest that vast media campaigns coupled with expanding Internet access permit reaching individuals from a wide range of sociodemographic backgrounds.

As compared with national estimates [30-32], the NutriNet-Santé Study sample included proportionally more women (77.60% vs 52%) and individuals of relatively high socioeconomic status (managerial/professional staff excluding retired people: 31.64% vs 9.3% nationally; postsecondary education: 67.92% vs 24.3% nationally). This is consistent with existing knowledge regarding the characteristics of participants in volunteer-based studies dealing with health and nutrition [1]. Any additional selection bias is likely negligible given the wide range of recruitment channels used and the widespread access to the Internet in France, with a current penetration rate of 77% [33]. For example, 27% of the Web users in France are older than 50 years, which is relatively close to the respective proportion of individuals in that age range in the NutriNet-Santé Study (36%).

As suggested in the literature [28], the response rate and the related potential lack of representativeness, as observed in our study, is not critical in an etiologic context. However, this remains a key issue when descriptive information is provided. In the present study, 1 of the most important aspects pertained to the sizeable and heterogeneous cohort, including a wide range of sociodemographically diverse profiles, thus ensuring material variability in exposure factors. The use of various recruitment channels allowed meeting this objective by including specific subgroups of the population, such as those older than 60 years, those with low income, and/or with low levels of formal education.

It has also been recently postulated that in the context of a Web-based cohort of volunteers, the generalizability of etiologic findings depends on whether the studied associations might differ between those with and without Internet access, which seems unlikely [13].

Along with being geographically unrestricted, Web-based prospective cohorts present with many logistic and cost advantages compared to traditional samples [3,4,11,22,34,35]. Furthermore, use of the Internet entails lower social desirability effects, which could also facilitate the recruitment of participants exhibiting unhealthy behaviors or those with socially undesirable/stigmatizing backgrounds.

Conclusion

In conclusion, the present findings fill gaps in current knowledge about cohort recruitment by providing new insights about the sociodemographic profiles of adult volunteers. Our Web-based cohort study uses recurrent mass media campaigns and

numerous public outlets for encouraging participation. The various information channels allow the inclusion of individuals with diverse sociodemographic profiles. As expected, television appeared to be the most promising channel for reaching potential participants representing a wide range of sociodemographic backgrounds, including subgroups that are usually difficult to involve in long-term epidemiologic studies. Our findings could inform future Web-based studies regarding the development of operative targeted or general population recruitment strategies.

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Conflicts of Interest

None declared.

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Abbreviations

HTML: HyperText Markup Language
IRB: Institutional Review Board
SMS: short message service

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Original Paper

Parents Seeking Health-Related Information on the Internet: Cross-Sectional Study

Aida Bianco[1], MD; Rossella Zucco[1], MD; Carmelo Giuseppe A Nobile[1], MD; Claudia Pileggi[1], MD; Maria Pavia[1], MD, MPH

Medical School, Department of Health Sciences, University of Catanzaro "Magna Græcia", Catanzaro, Italy

Corresponding Author:
Maria Pavia, MD, MPH
Medical School
Department of Health Sciences
University of Catanzaro "Magna Græcia"
Via T. Campanella, 115
Catanzaro, 88100
Italy
Phone: 39 961 712371
Fax: 39 961 712382
Email: pavia@unicz.it

Abstract

Background: The Internet represents an increasingly common source of health-related information, and it has facilitated a wide range of interactions between people and the health care delivery system.

Objective: To establish the extent of Internet access and use to gather information about health topics and the potential implications to health care among the adult population in Calabria region, Italy.

Methods: This cross-sectional study was conducted from April to June 2012. The sample consisted of 1544 adults aged ≥18 years selected among parents of public school students in the geographic area of Catanzaro in southern Italy. A 2-stage sample design was planned. A letter summarizing the purpose of the study, an informed consent form, and a questionnaire were given to selected student to deliver to their parents. The final survey was formulated in 5 sections: (1) sociodemographic characteristics, (2) information about chronic diseases and main sources of health care information, (3) information about Internet use, (4) data about the effects of using the Internet to search for health information, and (5) knowledge and use of social networks.

Results: A total of 1039 parents completed the questionnaire, with a response rate equivalent to 67.29%. Regarding health-related information types, 84.7% of respondents used the Internet to search for their own medical conditions or those of family members or relatives, 40.7% of parents reported looking for diet, body weight, or physical activity information, 29.6% searched for vaccines, 28.5% for screening programs, and 16.5% for smoking cessation tools and products. The results of the multiple logistic regression analysis showed that parents who looked for health-related information on the Internet were more likely to be female (OR 1.53, 95% CI 1.05-2.25), with a high school diploma (OR 1.69, 95% CI 1.02-2.81) or college degree (OR 2.14, 95% CI 1.21-3.78), younger aged (OR 0.96, 95% CI 0.94-0.99), with chronic conditions (OR 1.94, 95% CI 1.17-3.19), not satisfied with their general practitioner's health-related information (OR 0.6, 95% CI 0.38-0.97), but satisfied with information from scientific journals (OR 1.99, 95% CI 1.33-2.98).

Conclusions: Our analyses provide important insights into Internet use and health information–seeking behaviors of the Italian population and contribute to the evidence base for health communication planning. Health and public health professionals should educate the public about acquiring health information online and how to critically appraise it, and provide tools to navigate to the highest-quality information. The challenge to public health practice is to facilitate the health-promoting use of the Web among consumers in conjunction with their health care providers.

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KEYWORDS

adult; consumer health information; cross-sectional studies; health survey; Internet; Italy; questionnaires

Introduction

The increasing use of the Internet over the past few years has allowed for a rapid and worldwide circulation and sharing of different information. The Internet also represents an increasingly common source of health-related information. An estimated 27.5% of the US adult population looked online for information about a health or medical issue in 2000 [1]. This figure increased to 40% in 2002 and to 61% in 2008 [2]. In contrast with the general information available from traditional information sources, such as magazines and television, people can systematically retrieve and obtain targeted health information through the Internet. The Internet has facilitated a wide range of interactions between people and the health care delivery system, and has become an indispensable source for the public, patients, and health care professionals to obtain information about health, diseases, and medical treatment. Health information on the Internet may make people better informed, leading to better health outcomes and more appropriate use of health service resources, although questions remain about its limitations, concerns regarding misinformation, and potential difficulties with the confidentiality of personal information. Health information on the Internet may be misinterpreted, compromising health behaviors and health outcomes.

The Internet has also grown in popularity among Italian citizens. The percentage of the Italian population between the ages of 15 to ≥75 years that uses the Internet has increased from 32.3% in 2005 to 52.1% in 2012 [3]. Understanding the extent to which the Internet is being used to obtain health-related information and the effects it has on health care use would help identify the benefits that are being realized and provide a context for fruitful discussions of the current and future role of the Internet in health care. Some advanced countries, such as the United States, have accumulated research on health information-seeking behavior through a number of population-based surveys [2,4,5], whereas studies investigating the active health information-seeking behavior of the Italian public are scanty.

Therefore, this study was designed to establish the extent of Internet access and use to gather information about health topics and the potential implications in health care among the adult population in the Calabria region, Italy.

Methods

Overview

This cross-sectional study was conducted from April to June 2012. The sample comprised 1544 adults aged ≥18 years selected among parents of public school students in the geographic area of Catanzaro in southern Italy.

A 2-stage sample design was planned. We divided the target population into kindergarten, elementary, middle, and high schools, which were used as first-stage sampling units. A simple randomization technique with replacement was adopted in selecting each school. A sampling frame of all students was then assembled for each selected school. At the second stage of sampling, a sample of students was randomly selected from each school. During school hours, each selected student was given a letter summarizing the purpose of the study and pointing out the voluntary and confidential nature of participation, an informed consent form, and a questionnaire to deliver to their parents.

Before starting data collection, a meeting with the head of each selected school was arranged to present the project and to discuss the research strategy.

The sample size was determined before study initiation. It was calculated assuming that 50% of the respondents look online to obtain health-related information in accordance with prior European studies, a margin of error of 5%, and a 95% confidence level. Consequently, a sample of 385 parents was sought. Anticipating a response rate of 45%, a total sample size of 789 parents was needed. We included an additional 250 parents in case the response rate among Internet users was not adequate.

The questionnaire was developed based on previous studies [6-8] and was pretested for length and content on a sample of 47 potential respondents.

The final survey was 2 pages in length, designed to be completed within 10 minutes and formulated into 5 sections: (1) sociodemographic characteristics (gender, age, marital status, level of education, and employment); (2) information about chronic diseases and the main sources of health care information; (3) information about Internet use, including whether participants had a computer at home and/or access to the Internet and, if the parent had access to the Internet, if he or she used the Web to search for health information; (4) data about the effects of using the Internet to search for health information; and (5) knowledge and use of social networks.

Each section elicited responses in a variety of formats: closed-ended questions with multiple answers possible, yes or no questions, and open-option questions. The questionnaire culminated with the option of providing additional comments.

The study protocol was approved by the Ethics Committee of the Mater Domini Hospital of Catanzaro (Italy) (2012/04/20).

Statistical Analysis

Multivariable backward stepwise logistic regression models were constructed to determine the explanatory variables independently related to dichotomous measures of whether or not the Internet was used for health-related information seeking. The model building strategy included the following steps: (1) univariate analysis of each variable considered, using the appropriate test statistic (chi-square test or *t* test); (2) inclusion of any variable whose univariate test has a *P* value <.25; (3) the results of the logistic regression analysis are presented as odds ratios (ORs) and 95% confidence intervals (CIs). A 2-sided *P* value for all tests of <.05 was considered a statistically significant difference. The significance level for a variable's entry to the model was set at .2 and at .4 for removal.

The following explanatory variables were included in the model: gender (male=0, female=1), age (continuous), satisfaction about information received from general practitioner (GP; dissatisfied=0, satisfied=1), education level (3 categories:

elementary/middle school=1, high school=2, university degree=3), number of visits to the GP (ordinal, once per year or less=1, 3-4 times per year=2, once per month=3, 2-3+ times per month=4) and presence of chronic conditions (no=0, yes=1), satisfaction about information received from TV/radio (dissatisfied=0, satisfied=1), and satisfaction about information received from scientific journals (dissatisfied=0, satisfied=1).

Stata version 11 (StataCorp LP, College Station, TX, USA) statistical software package was used in conducting all data analyses.

Results

Ten public schools were selected. A total of 1039 parents completed the questionnaire, with a response rate equivalent to 67.29% (1039/1544). The main sociodemographic characteristics of the study population are shown in Table 1. The GP represented the main source of health-related information among 65.16% (677/1039) of respondents. Other sources of health information were Internet (44.46%, 462/1039), TV/radio (27.62%, 287/1039), and scientific journals (15.21%, 158/1039).

The respondents' Internet use pattern is reported in Table 2. Most respondents (95.67%, 994/1039) had a personal computer at home and 58.16% (602/1035) used one at work. Among computer users, Web browsing was very frequent; most (85.76%, 891/1039) used the Internet, and almost three-quarters (72.6%, 647/891) had been using the Internet for 4 years or longer. Of the Internet users, 83.2% (741/891) reported Internet access at home, and 83.1% (740/891) used the Internet to search for health-related information. Regarding health-related information types, 84.7% (627/740) of respondents used the Internet to search for their own medical conditions or those of family members or relatives. When data about lifestyle and preventive care utilization were explored, 40.7% (301/740) of parents reported looking for diet, body weight, or physical activity information, 29.6% (219/740) for vaccines, 28.5% (211/740) for screening programs, and 16.5% (122/740) for smoking cessation tools and products. In all, 60.4% (447/740) of users searched for information about national and/or local health services providers. Most users (96.6%, 715/740) had never bought drugs or vitamins online. Only 22.9% (170/740) of parents communicated via email with their GP or specialists, although 61.8% (352/570) would like to do so.

Among parents who used the Internet to search for health-related information, 81.2% (599/738) said that it improved their understanding of health care issues and they learned more about an illness or a specific symptom, and 23.0% (170/738) reported that they used the Internet to obtain more information than that provided by their GP. More than half (58.5%, 432/738) considered the retrieved information very useful and 49.1% (362/738) stated that they were able to find online answers to their health care questions (data not shown).

Data quality on the Web may be of concern and criteria used by respondents were investigated. In all, 59.9% (438/731) stated that they visited websites sponsored by physicians or medical associations, and 16.9% (125/740) did not care about health-related information reliability. At univariate analysis, the Internet use for searching health-related information was significantly higher among female (χ^2_1=6.0, P=.01), younger participants (t_{889}=3.6, P<.001), with a higher level of education (χ^2_1 for trend=14.1, P<.001), who were more frequently unsatisfied by GP health-related information (χ^2_1=9.7, P=.002), but were satisfied about information received by scientific journals (χ^2_1=22.0, P<.001) or TV/radio (χ^2_1=4.6, P=.03; see Table 3). It was also higher for those who reported visiting their GP less than 5 times in a year but this did not meet statistical significance (χ^2_1 for trend =2.8, P=.09). The results of the multiple logistic regression analysis substantially confirmed the findings of the univariate analysis. Indeed, parents who looked for health-related information on the Internet were more likely female (OR 1.53, 95% CI 1.05-2.25), with a high school diploma (OR 1.69, 95% CI 1.02-2.81) or college degree (OR 2.14, 95% CI 1.21-3.78), younger (OR 0.96, 95% CI 0.94-0.99), with chronic conditions (OR 1.94, 95% CI 1.17-3.19), not satisfied with their GP's health-related information (OR 0.6, 95% CI 0.38-0.97), but satisfied about information received by scientific journals (OR 1.99, 95% CI 1.33-2.98; see Table 3).

Regarding influence of information obtained from the Web on health care–related behavior, 69.2% (512/740) of the Internet users indicated that the information they found modified the way they thought about their health. In particular, 57.8% (296/512) reported they had become more interested in health issues, and 36.7% (188/512) were less confused about health problems. Moreover, 43.5% (322/740) of the eligible parents started paying more attention to eating habits and food, and 33.9% (169/498) and 18.7% (138/738) started or increased physical activity and increased participation in screening programs, respectively (data not shown).

Among participants who used the Internet to search for health-related information, only 25.4% (188/740) discussed this with their GP. A total of 78.5% (581/740) of the eligible respondents believed that Internet use had not changed their relationship with their GP in any way; 13.4% (99/740) believed it had a positive effect and 8.1% (60/740) believed it had a negative effect. After using the Internet, 12.7% (94/740) of the sample had reduced their frequency of GP visits.

Regarding social networks, more than half of parents (56.9%, 505/886) said they had a profile on a social network; the most used social platform was Facebook (97.6%, 493/505). Almost half of these parents accessed it daily (49.5%, 250/505). A total of 40.8% (206/505) of participants used Internet for health-related social support and access to open forums or groups focused on medical issues in particular to ask for help in the management of a disease or a symptom (60.2%, 124/206) or to share illness experiences (43.7%, 90/206).

Table 1. Selected characteristics of the study population.

Characteristic	Overall sample (N=1039)[a]	Internet users (n=891)[a]
Gender, n (%)		
Female	704 (67.76)	590 (66.22)
Male	335 (32.24)	301 (33.78)
Age group (years), n (%)		
18-35	223 (21.46)	215 (24.13)
36-40	240 (23.09)	213 (23.91)
41-45	285 (27.43)	252 (28.28)
46-50	191 (18.39)	144 (16.16)
>50	100 (9.63)	67 (7.52)
Age, mean (SD)	41.2 (7.4)	40.4 (7.3)
Marital status, n (%)		
Married	865 (83.25)	733 (82.27)
Single/divorced/separated/widowed	174 (16.75)	158 (17.73)
Education level, n (%)		
No formal education/completed elementary/middle school	195 (18.76)	106 (11.89)
Completed high school	518 (49.86)	465 (52.18)
Holds a bachelor's degree or any college degree	326 (31.38)	320 (35.93)
Employment status, n (%)		
Unemployed/housewife/retired	312 (30.44)	215 (24.51)
Employed	520 (50.73)	476 (54.28)
Professional/autonomous work	193 (18.83)	186 (21.21)
Chronic conditions, n (%)	243 (23.38)	202 (22.67)
Frequency of visits to general practitioner		
Once per year or less	279 (26.85)	259 (29.07)
3-4 times per year	342 (32.91)	308 (34.57)
Once per month	276 (26.57)	226 (25.35)
2-3 times per month	142 (13.67)	98 (11.01)
Sources of health-related information, [b] n (%)		
General practitioner	677 (65.16)	558 (62.62)
Internet	462 (44.46)	461 (51.73)
TV/radio	287 (27.62)	228 (25.59)
Scientific journals	158 (15.21)	150 (16.83)
Magazines/books	43 (4.14)	35 (3.92)
Family members/friends/colleagues	26 (2.50)	24 (2.69)

[a]Total may not always sum to N because of missing data.

[b]Multiple responses allowed.

Table 2. Personal computer and Internet use patterns of respondents.

Use of Internet (number of respondents)	n	%
Having a personal computer at home (1039)	994	95.67
Having a personal computer at the workplace (1039)	602	58.16
Use of Internet (1039)	891	85.76
Duration of Internet use (891)		
<1 year	51	5.72
1-3 years	193	21.66
4-6 years	264	29.62
7-10 years	188	21.09
>10 years	195	21.91
Internet use to search for health-related information (891)	740	83.05
Webpages visited for health-related information [a] (731)		
Physicians or medical association	438	59.91
Ministry of Health	206	28.18
Chat	186	25.44
Hospitals	85	11.62
National scientific societies	81	11.08
International organizations competent for health	69	9.43
International scientific societies	48	6.56
Local organizations competent for health	30	4.10
Other	16	2.18
Internet use to better understand the meaning of a medical term (740)	672	90.81
Internet use to search more information about each of the following [a] (740)		
Disease diagnosis	636	85.94
Own, family member, or relative health status	627	84.73
Disease treatment	521	70.40
Health services provider	447	60.40
Drugs	393	53.11
Diet, weight, or physical activity	301	40.67
Vaccines and/or vaccinations	219	29.59
Screening programs	211	28.51
Smoking cessation	122	16.48
Internet use to buy drugs or vitamins (740)	25	3.37
Use email to communicate with the general practitioner (740)	170	22.97
Talk with general practitioner about information retrieved on the Internet (740)	188	25.41
Creating an online profile (886)	505	56.99
Social networks visited [a] (505)		
Facebook	493	97.62
Twitter	62	12.27
Google+	47	9.31
LinkedIn	14	2.72
MySpace	9	1.78

Use of Internet (number of respondents)	n	%
Viadeo	2	0.39
Frequency of visiting online social networking sites (505)		
Never/almost never	38	7.52
3-4 or less times per month	43	8.51
1 or less times per week	60	11.88
2-4 times per week	69	13.66
5-6 times per week	45	8.91
Daily	250	49.52
Internet use for health- related social support (505)	206	40.79

[a]Multiple responses allowed.

Table 3. Univariate and multivariate analyses of Internet use for health-related information seeking according to various explanatory variables.

Variable	Univariate						Multivariate	
	Mean (SD)	t_{889}	*P*	Health-related information seekers (n=740)[a]			OR	95% CI
				n (%)	χ^2_1 or χ^2_1 for trend	*P*		
Gender					6.0	.01		
Male				237 (78.7)			1.00[b]	
Female				503 (85.2)			1.53	1.05-2.25
Education level					14.1	<.001		
Elementary/middle school				74 (69.8)			1.00[b]	
High school				387 (83.2)			1.69	1.02-2.81
College degree				279 (87.2)			2.14	1.21-3.78
Age (years)		3.6	<.001					
Users	40.05 (7.35)						0.96	0.94-0.99
Not users	42.37 (6.83)							
Chronic conditions					2.4	.12		
No				565 (82)			1.00[b]	
Yes				175 (86.6)			1.94	1.17-3.19
Frequency of visits to general practitioner					2.8	.09		
Once per year or less				219 (84.6)			—[c]	—[c]
3-4 times per year				266 (86.4)				
Once per month				174 (77)				
2-3 times per month				81 (82.6)				
Satisfaction with information received from general practitioner					9.7	.002		
Dissatisfied				225 (89.3)			1.00[b]	0.38-0.97
Satisfied				515 (80.6)			0.6	
Satisfaction with information received from scientific journals					22.0	<.001		
Dissatisfied				381 (77.8)			1.00[b]	
Satisfied				349 (89.7)			1.99	1.33-2.98
Satisfaction with information received from TV/radio					4.6	.03		
Dissatisfied				361 (80.4)			—[c]	—[c]
Satisfied				374 (85.8)				

[a]Total may not always sum to N because of missing data.

[b]Reference category.

[c]Removed by the model.

Discussion

Principal Findings

The Internet is broadly recognized as a potentially important instrument for transforming medical care and public health [5,9]. It offers tremendous promise as a health communication and education tool [10,11], and it could be a key resource in health behavior change interventions and programs [12]. This study provides an outline of the prevalence of Internet use among adults aged 18 years and older, describes the variables associated with its use related to health or medical issues, and the impact of the information on health-related behaviors.

Internet access is a widely diffused technology in the surveyed area; approximately 85% of our sample accessed it. Searching for health information online appeared to be a prevalent activity among the population, and the Internet is considered the second most important source of health-related information, preceded only by health professionals who are still the main source of

health information by far. Nevertheless, among Internet users, 83.1% reported that they look online to obtain health-related information for themselves, family members, or relatives and the prevalence was higher than those reported in the United States in 2009 (61%) [2], in Japan in 2007 (24%) [13], and in other European countries in 2005 (42%) and in 2007 (52%) [14]. However, comparisons with previous studies must be interpreted cautiously because the time frame considered (in the present survey "at least once") may influence the prevalence of Internet use for health-related information. Indeed, the outcome is much less prevalent if measured in a shorter time frame; in the studies in which respondents had a narrower time frame prevalence diminished substantially.

The findings from this investigation shed considerable light on the variables related to Internet use for health-related information. Multivariate data analysis results regarding health information seekers characteristics were consistent with many preceding studies pointing out that younger people, females, those with a higher level of education, not satisfied with their GP's health-related information, and those with chronic conditions reported more frequent access to the Internet to seek health-related information [15-18]. In general, education was reported as 1 of the strongest predictors of whether someone has access to the Internet [2]. We tested the hypothesis that more educated participants were more likely to engage in a search for health-related information, and the current research found that only 10% of Internet users with less than a high school degree do so compared to 90% of participants with a high school or college degree. Moreover, we found that who looked for health-related information on the Internet was more frequently affected by chronic diseases and those not satisfied with the information provided by their GP. Because of health consultation time constraints, patients are often left with a sense of frustration and dissatisfaction with the information provided, whereas they would like to be fully informed and be part of the medical decision-making. Patients with chronic conditions usually use the Internet to gain supplemental knowledge to that received from their physician. Moreover, those patients' access to support groups, typically targeted to a particular disease, allow the ill individual to gain coping mechanisms.

As reported in previous research [18], in this study many adults surfed the Internet for additional information about disease diagnosis (85.9%) and/or treatment (70.4%). This result is important, particularly because only 25.4% of them talked with their GP about the information retrieved from the Internet. The behavioral discrepancy between searching for information on the Internet and not using this information with health professionals might be because of user conflict derived from not trusting health professionals whose attitude and behavior are incompatible with the information from the Internet. We supposed that, in response to the Internet-informed patient, the patient-health professional relationship can become health professional-centered with the health professional exerting his or her expert opinion. They will use the short consultation time to quickly and authoritatively steer the patient toward their choice of action. This figure could be an issue because the scientific quality of information is difficult to evaluate by the public. Although only limited evidence shows that Internet use for health-related information results in harmful health outcomes [19], past research suggests that many adults surf health information online to self-diagnose, to seek information on alternative treatments or medicine, or to engage in health care strategies inconsistent with medical recommendations [18]. In our opinion, it would be appropriate to use the Internet as a supplement to health services rather than as a replacement, and to share the information with one's GP. However, health professionals should be mindful of patients' desire for health information [20]. The triangulation of patient-Web-practitioner may have remarkable potential for improving the physician-patient relationship to include enhanced communication, shared decision-making, and more efficient use of clinical time.

In the present survey, we also examined the prevalence of Internet use related to wellness information (ranging from 40.7% for diet, weight, or physical activity to 16.5% for smoking cessation). Most health risks in the modern world are related to lifestyles (eg, overweight, unhealthy diet, physical inactivity, and smoking), and the observation that individuals actively sought these information could be a key in the prevention and management of risk conditions. This suggests that the Internet could provide an efficient channel for primary health promotion and disease prevention activities, encouraging many individuals to search the Internet for health information to maintain a healthy lifestyle. Results of the present survey may be relevant for future development and implementation of Web-based interventions aimed at improving lifestyle behavior. An Internet-based lifestyle intervention may overcome significant barriers to preventive counseling and facilitate the incorporation of evidence-based lifestyle interventions into primary care [21], providing methods and motivation for behavior change. It may create awareness of unhealthy behavior before chronic disease symptoms are present, by providing information about healthy behavior. This is a crucial step for those not yet ready for behavioral change [18].

In our Internet users sample, 22.9% reported using email to communicate with their GP, and this finding suggests that online communication with GPs is not widespread in Italy. Communication via email between health providers and health consumers represents an important topic that should be addressed in the future because it may offer opportunities for the public to interact interpersonally with health professionals [22].

Limitations

Although the findings of this study are meant to stimulate discussion about the role of the Internet in health promotion and disease prevention, there are several limitations to acknowledge. First of all, it should be noted that, because this study has a cross-sectional design, the relationship between the predictor variables and the dependent variables should not be taken as a cause-and-effect relationship; the study is able only to describe general associations. Second, although the data were produced using a rigorous methodology, they are from self-report assessments and may reflect certain biases as a result. As with any survey based on a self-administered questionnaire, information may not be entirely accurate, primarily because of

the long time frame used in the study that may introduce recall bias. On the other hand, longer time frames are useful for formulating broad prevalence estimates in a context in which no data are yet available.

Third, we collected data in 1 Italian region, which might not represent all adult population in Italy; therefore, concern about generalizability and comparability of the findings may arise. However, we are confident that the findings of the study may be representative of the Southern regions and may be referred to the whole country. Moreover, it is well known that the ability to generalize from a sample is limited by the sample frame, and we selected participants from parents of children and students attending kindergarten, elementary, middle, and high schools. This population, compared to the general population, probably underestimates people older than 50 years and excludes those who do not have children. However, we believe that these characteristics do not have a substantial impact on Internet use for health-related information because adults aged between 18 and 49 years are more likely than older adults to participate in social technologies related to health [2]. Therefore, our results may be generalized to adult Internet users.

Conclusions

Despite the limitations identified, our analyses provide important insights into Internet use and health information-seeking behaviors of the Italian population and contribute to the evidence base for health communication planning. Health and public health professionals should educate patients about acquiring health information online and critically appraising it [23], and provide tools for them to navigate to the highest-quality information. Understanding health information-seeking behavior in relation to use of the Internet is timely and important, given the rapid increase in the amount of information available online and the increasing influence of online health information seeking on health behaviors, health processes, and health outcomes. The challenge to public health practice is to facilitate the health-promoting use of the Web among consumers in conjunction with their health care providers.

Conflicts of Interest

None declared.

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Abbreviations

GP: general practitioner

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Original Paper

Online Access to Doctors' Notes: Patient Concerns About Privacy

Elisabeth Vodicka[1], MHA; Roanne Mejilla[2], MPH; Suzanne G Leveille[2,3], PhD, RN; James D Ralston[4], MD, MPH; Jonathan D Darer[5], MPH, MD; Tom Delbanco[2], MD; Jan Walker[2], RN, MBA; Joann G Elmore[1], MD, MPH

[1]Harborview Medical Center, University of Washington School of Medicine, Seattle, WA, United States

[2]Beth Israel Deaconess Medical Center, Harvard Medical School, Boston, MA, United States

[3]College of Nursing and Health Sciences, University of Massachusetts, Boston, MA, United States

[4]Group Health Research Institute, Group Health Cooperative, Seattle, WA, United States

[5]Geisinger Health System, Danville, PA, United States

Corresponding Author:
Elisabeth Vodicka, MHA
Harborview Medical Center
University of Washington School of Medicine
325 Ninth Avenue
Seattle, WA, 98104
United States
Phone: 1 781 258 7501
Fax: 1 206 744 6097
Email: evodicka@uw.edu

Abstract

Background: Offering patients online access to medical records, including doctors' visit notes, holds considerable potential to improve care. However, patients may worry about loss of privacy when accessing personal health information through Internet-based patient portals. The OpenNotes study provided patients at three US health care institutions with online access to their primary care doctors' notes and then collected survey data about their experiences, including their concerns about privacy before and after participation in the intervention.

Objective: To identify patients' attitudes toward privacy when given electronic access to their medical records, including visit notes.

Methods: The design used a nested cohort study of patients surveyed at baseline and after a 1-year period during which they were invited to read their visit notes through secure patient portals. Participants consisted of 3874 primary care patients from Beth Israel Deaconess Medical Center (Boston, MA), Geisinger Health System (Danville, PA), and Harborview Medical Center (Seattle, WA) who completed surveys before and after the OpenNotes intervention. The measures were patient-reported levels of concern regarding privacy associated with online access to visit notes.

Results: 32.91% of patients (1275/3874 respondents) reported concerns about privacy at baseline versus 36.63% (1419/3874 respondents) post-intervention. Baseline concerns were associated with non-white race/ethnicity and lower confidence in communicating with doctors, but were not associated with choosing to read notes or desire for continued online access post-intervention (nearly all patients with notes available chose to read them and wanted continued access). While the level of concern among most participants did not change during the intervention, 15.54% (602/3874 respondents, excluding participants who responded "don't know") reported more concern post-intervention, and 12.73% (493/3874 respondents, excluding participants who responded "don't know") reported less concern.

Conclusions: When considering online access to visit notes, approximately one-third of patients had concerns about privacy at baseline and post-intervention. These perceptions did not deter participants from accessing their notes, suggesting that the benefits of online access to medical records may outweigh patients' perceived risks to privacy.

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KEYWORDS

electronic medical records; patient access to records; patient portals; privacy; consumer health informatics; personal health records

Introduction

Secure patient portals—tethered Web-based applications that enable patients to access their health information online—can give patients more control over their personal health information by improving their access to medical records [1-9]. A Markle Foundation survey of 1580 US adults in 2008 found that nearly half were interested in using an online patient portal and among those not interested, concern for privacy was the main deterrent to adoption [10]. While patients want easy access to their health information, including their doctors' visit notes, concerns about the privacy of online medical data could limit the utility of patient portals [3,10,11]. Understanding patients' views toward privacy is especially important in the case of visit notes, which often contain detailed personal information about patients' medical, social, and family histories.

Despite calls for more discussion of patients' privacy concerns in primary care settings [12-16], little research has addressed the concerns that arise when patients are given online access to their health information. Existing studies are primarily qualitative or opinion-based [8,17-19] or limited to a single health care institution [2,3,20,21]. Most have examined issues of privacy related to health information exchange or personal health information in general. None discuss privacy in the context of providing patients with electronic access to their visit notes.

This paper describes patient-reported concerns about privacy prior to and after participation in OpenNotes, a 1-year quasi-experimental study in which patients were offered online access to the outpatient clinic notes written by their primary care doctors ("visit notes"). Study procedures are fully described in prior publications and briefly summarized in the next section for context [22-25]. A priori, we generated several research questions to guide our analyses: What percentage of patients report concerns about privacy at baseline, and what are the characteristics of patients according to their level of concern? Did their attitudes change during participation in OpenNotes, and if so, in what direction? Were concerns about privacy at baseline associated with their use of visit notes, their likelihood of showing or discussing notes with others, or their desire for continued online access to notes after the intervention concluded?

Methods

Setting

We surveyed primary care doctors and their patients in three locations: Beth Israel Deaconess Medical Center (BIDMC), a teaching hospital of Harvard Medical School, and community practices affiliated with BIDMC in urban and suburban Boston, MA; Geisinger Health System (GHS), a rural integrated health services organization serving patients in central and northeastern Pennsylvania; and the adult medicine and HIV/AIDS clinics at Harborview Medical Center (HMC), a county hospital affiliated with the University of Washington that serves primarily safety-net populations in Seattle, WA. Each participating institution received approval for the study from its Institutional Review Board.

Study Design

To be eligible for OpenNotes, patients at BIDMC and GHS had to be current users of their sites' patient portals, through which they could message their doctors, schedule appointments, and view components of their medical records (such as medication lists and test results). OpenNotes patients at HMC gained first-time access to their hospital's patient portal when they enrolled in the study. At all three sites, study participants gained first-time access to notes written by their doctors following the clinic visits that occurred during the intervention.

We surveyed patients both before and after the year-long OpenNotes study to gauge their attitudes toward and experiences with gaining online access to their visit notes. We used portal tracking data to confirm whether notes were generated for each participant during the intervention and whether participants chose to view notes that were available.

Study Participants

For this report, we examined data from patients who completed the OpenNotes intervention, responded to both the baseline and 1-year post-intervention surveys, and completed the privacy questions on the surveys. We did not include patients who were excluded from participation (ie, denied online access to notes) by their doctors, who withdrew from the study, who moved or died during the intervention, or whose portal accounts became inactive during the study period. Information about the differences among patients by participation status and site has been published previously [22-25].

As described previously [23,25], 13,564 patients who completed the study had one or more notes made available during the year-long intervention period. Among those, 41.05% (5568/13,564) submitted a post-intervention survey. Further, 28.56% (3874/13,564) submitted both a baseline and a post-intervention survey with privacy questions completed; they constitute the study sample for this analysis.

Patient Survey

Before developing the patient surveys, we conducted focus groups and individual interviews at the study sites to ensure that the surveys encompassed the major worries, expectations, and perceived benefits of online access to visit notes. Concern for the privacy of individual information was voiced by some patients during these focus groups and was particularly prevalent among patients at HMC [26]. The concerns about "privacy" that patients identified included login security, accessing their information in a public location (eg, library or hospital resource center), privacy breaches (eg, hackers or unauthorized hospital employees reading their medical information), and provision of their medical information to external organizations such as insurance companies and governmental agencies [26].

Based on focus group findings, we included an item addressing concerns about privacy in the baseline and post-intervention surveys, with responses on a 5-point Likert scale (baseline survey question: "If I could read my doctor's notes, I would be concerned about my privacy: Agree, Somewhat Agree, Somewhat Disagree, Disagree, Don't Know" and post-intervention survey question: "As a result of reading/having

access to my doctor's notes, I am concerned about my privacy: Agree, Somewhat Agree, Somewhat Disagree, Disagree, Don't Know").

In the baseline and post-intervention surveys, we also used the validated Ambulatory Care Experiences Survey (ACES) [27] and Perceived Efficacy in Patient-Physician Interactions (PEPPI) [28] instruments to assess participants' level of trust in and interactions with their providers. The ACES instrument addresses patients' self-reported quality of interaction and communication with their doctors, and PEPPI addresses levels of self-efficacy in communicating with doctors. Patients were also asked in the surveys to self-report demographic information including age, sex, race/ethnicity, education level, employment status, Internet use, and health status.

In the post-intervention survey, we asked patients a series of questions about whether or not they accessed their doctors' notes (ie, "Did you look at any of your visit notes [on the secure patient portal]?": Yes; No; I did not have any notes to look at because I did not see my doctor since notes were made available"), whether they would like OpenNotes to continue (ie, "I would like to continue to be able to see my doctor's notes online: Yes, No"), and whether they shared their notes with others (ie, "Did you show or discuss your visit notes with other people? Yes, No, Don't Know/Don't Remember").

As described in previous publications, we pre-tested the survey questions with patients for clarity and incorporated changes based on the patient feedback received. We conducted additional testing of online versions of the surveys prior to administering the surveys to participating patients [25]. See Multimedia Appendices 1 and 2 for the baseline and post-intervention survey instruments.

Statistical Analysis

To assess patient characteristics associated with concerns about privacy, we performed a chi-square analysis on categorical variables, with age, race/ethnicity, employment, and self-reported health variables dichotomized for analytic purposes. To evaluate perceived confidence in doctor-patient communication and trust in doctors, we report quartile scores of the ACES and PEPPI summary measures. We also performed logistic regression models to determine whether age, sex, education, race/ethnicity, frequency of Internet use, and PEPPI scores were independently associated with the likelihood of having concerns about privacy at baseline. We performed McNemar's test for paired data to determine whether patient attitudes toward privacy changed or persisted over the course of the intervention.

We analyzed data at both aggregated binary categories (collapsed categories into "Agree/Somewhat Agree" and "Disagree/Somewhat Disagree") and disaggregated levels ("Agree", "Somewhat Agree", "Somewhat Disagree", and "Disagree"). Unless otherwise stated, "concern for privacy" is reported as an aggregated percentage of both "Agree" and "Somewhat Agree" survey responses for improved clarity, and the findings were similar. For data that yielded significantly different results in the aggregate vs disaggregate, we report the findings separately. We used a confidence interval (CI) of 95% and defined statistical significance as a P value less than .05. All statistical analyses were conducted using SAS software, version 9.3.

Results

Privacy Concerns by Demographics

At baseline, about one-third of participants reported concerns about privacy related to online access to visit notes (Table 1). Compared to participants without such worries, they were more likely to be non-white, have fewer years of education (high school/GED or less), attend BIDMC, and report lower levels of trust and confidence in communication with their doctor. More modest associations were found according to age and sex (women worried more than men, under age 55 worried more than age 55 or older). We found no difference in levels of concern according to self-reported health status.

Following multivariable adjustment, differences according to gender, race/ethnicity, and confidence in communication remained significant (Table 2). Women were more likely to be concerned about privacy than men (adjusted OR 1.18, 95% CI 1.03-1.36). Non-white patients had greater concerns than white patients (adjusted OR 1.56, 95% CI 1.21-2.01). Patients who had less self-confidence about communicating with their doctors, based on their PEPPI scores, were more concerned about privacy than others who had more self-confidence about communication (adjusted OR 1.72, 95% CI 1.41-2.09 comparing lowest quartile to highest quartile of PEPPI score).

Privacy Concerns and Use/Perception of OpenNotes

Baseline concerns about privacy were not associated with whether or not patients reported that they accessed their notes during the intervention or shared their notes with others (Table 3). Similarly, 99% of patients wanted continued access to their notes after the intervention concluded, regardless of concerns about privacy at baseline. At the end of the study, only 27 patients (1%) disagreed with the statement "having online access to my doctor's notes is a good idea." Among this very small subgroup, 8 patients (30%) were concerned about privacy.

Privacy Concerns at Baseline and Post-Intervention

We found a modest increase in reported concerns about privacy following the intervention, with 32.91% (1275/3874) of patients concerned at baseline, and 36.63% (1419/3874) concerned after the intervention (χ^2_{stat}=436.4; P<.001; Figure 1).

For most patients, individual responses regarding privacy concern did not change over the course of the study period: 19% (750/3874) of patients reported concern at both baseline and post-intervention, and 45% (1757/3874) consistently reported none or little concern at baseline and post-intervention (Figure 2).

However, 28% (1095/3874) of patients reported changes in their level of concern from the beginning to the end of the study (see Multimedia Appendix 3 for individual patient responses at baseline versus their responses post-intervention). Patients who were concerned about privacy at baseline but not concerned post-intervention (12.73%, 493/3874) were slightly more likely

to be younger or female compared to those whose level of concern remained unchanged (χ^2_{stat}=7.50; *P*=.006; χ^2_{stat}=8.63; *P*=.003; data not shown). In contrast, those whose attitudes shifted from being not concerned at baseline to being concerned post-intervention (15.54%, 602/3874) were slightly more likely to be older than those whose level of concern remained constant (χ^2_{stat}=16.66; *P*<.001; data not shown). Other attitudes and behaviors—for example, whether or not patients read their notes, wanted continued access to their notes, thought online access was a good idea, or shared their notes with others—were not significantly associated with changes in patients' attitudes toward privacy (data not shown).

Table 1. Characteristics of patient respondents, stratified by baseline survey responses to statement: "If I could read my doctors' notes, I would be concerned about my privacy" (N=3874).

Characteristics	Agree, %[a]	Somewhat agree, %[a]	Somewhat disagree, %[a]	Disagree, %[a]	Don't know, %[a]	Total, n
Totals, n (%)	413 (10.66)	862 (22.25)	565 (14.58)	1853 (47.83)	181 (4.67)	3874 (100)
Demographics						
Age						
≥55 years old	11.89[c]	20.97	14.39	46.91	5.84	2036
<55 years old	9.30	23.67	14.80	48.86	3.37	1838
Sex						
Female	11.12[b]	23.36	13.29	46.94	5.30	2303
Male	9.99	20.62	16.49	49.14	3.76	1571
Race/Ethnicity						
White	9.94[c]	22.18	14.69	48.62	4.58	3540
Non-White[e]	19.57	22.46	13.77	39.49	4.71	276
Education						
High school/GED or less	15.90[c]	19.20	12.89	45.85	6.16	698
Some college	10.53	21.59	14.29	48.01	5.59	931
College graduate	9.09	23.44	15.24	48.40	3.83	2244
Employment						
Employed	10.05[b]	22.99	15.13	48.01	3.81	2518
Not employed	11.80	20.87	13.57	47.49	6.27	1356
Internet use						
Daily or almost daily	9.63[c]	22.34	15.02	48.91	4.11	3335
>2 times per week	18.40	23.60	12.00	39.60	6.40	250
Once per week	17.39	17.39	14.13	44.57	6.52	92
Once every 2 weeks or less	16.79	19.71	11.68	40.88	10.95	137
Not at all	14.71	20.59	5.88	50.00	8.82	34
Site						
Beth Israel Deaconess Medical Center	11.93[c]	25.44	14.71	43.36	4.55	2087
Geisinger Health System	8.84	18.56	14.83	52.79	4.98	1686
Harborview Medical Center	14.85	17.82	7.92	57.43	1.98	101
Health & Health Care Experiences						
Perceived confidence in communicating with physician (PEPPI) [d]						
Q1 (Lowest confidence communicating with physician)	12.04[c]	26.54	16.71	39.56	5.16	814
Q2	9.83	25.03	16.51	42.86	5.78	987
Q3	10.70	22.56	16.37	46.38	3.99	953
Q4 (Highest confidence communicating with physician)	10.34	16.28	9.80	59.62	3.96	1112
Perceived trust in physician score (ACES)						
<4.00 (Least trust in physician)	12.26[c]	28.42	16.52	38.54	4.26	563
4.00-4.99	12.55	27.26	17.54	37.92	4.72	741
5.00-5.99	9.65	21.33	15.00	48.56	5.47	1627

Characteristics	Agree, %[a]	Somewhat agree, %[a]	Somewhat disagree, %[a]	Disagree, %[a]	Don't know, %[a]	Total, n
6.00 (Greatest trust in physician)	10.03	15.55	10.47	60.75	3.20	907
Self-rated health status						
Good or excellent	10.74	22.55	14.46	47.71	4.55	3362
Fair or poor	10.27	19.71	15.61	49.28	5.13	487

[a]Row percentages total 100%.

[b]Chi-square test for between group difference result $P<.001$.

[c]Chi-square test for between group difference result $P<.01$.

[d]Quartiles of PEPPI score (Perceived Efficacy in Patient-Physician Interactions); lower score indicates less self-confidence about communicating with their doctor [28].

[e]Non-White race/ethnicity categorized as aggregate of Black or African American; American Indian or Alaska Native; Asian; Native Hawaiian or Pacific Islander; Other.

Table 2. Associations of characteristics with baseline privacy concerns[a] (N=3816).

Variable		Odds ratio	95% CI
Age			
	Under 55 years old	1.00	
	55 years old or older	1.04	(0.90-1.19)
Sex			
	Male	1.00	
	Female	1.18	(1.03-1.36)
Race/Ethnicity			
	White	1.00	
	Non-White	1.56	(1.21-2.01)
Education			
	College graduate	1.00	
	Some college	0.93	(0.79-1.10)
	High School/GED or less	1.07	(0.89-1.30)
Frequency of Internet use			
	Daily	1.00	
	Biweekly	1.53	(1.17-2.00)
	Once per week	1.12	(0.72-1.75)
	Every 2 weeks	1.18	(0.82-1.70)
	Not at all	1.09	(0.53-2.24)
PEPPI [b]			
	Q4 (Highest confidence communicating with doctor)	1.00	
	Q3	1.40	(1.15-1.69)
	Q2	1.51	(1.25-1.83)
	Q1 (Lowest confidence communicating with doctor)	1.72	(1.41-2.09)

[a]Adjusted odds ratios from multivariable adjusted logistic regression models including all of the variables in the table; model estimates odds of patient responding "agree" or "somewhat agree" with statement: "If I could read my doctors' notes, I would be concerned about my privacy" on the baseline survey.

[b]Quartiles of PEPPI score (Perceived Efficacy in Patient-Physician Interactions) [28].

Table 3. Post-intervention attitudes and behaviors regarding OpenNotes (N=3874).

	Total, n (%)	Agree/ Somewhat agree, n (%)	Disagree/ Somewhat disagree, n (%)	Don't know, n (%)	*P* [a]
Baseline survey privacy concerns	3874 (100)	1275 (32.91)	2418 (62.42)	181 (4.67)	
Post-survey question/ statement					
OpenNotes is a good idea					
Agree/Somewhat agree	3828 (98.81)	1264 (99.14)	2387 (98.72)	177 (97.79)	.40
Disagree/Somewhat disagree	27 (0.70)	8 (0.63)	17 (0.70)	2 (1.10)	
Don't know	19 (0.49)	3 (0.23)	14 (0.58)	2 (1.10)	
Did you look at your visit notes?					
Yes	3832 (98.91)	1258 (98.67)	2394 (99.01)	180 (99.45)	.70
No	41 (1.06)	17 (1.33)	23 (0.95)	1 (0.55)	
Don't know	1 (0.03)	0 (0.0)	1 (0.04)	0 (0.0)	
Did you share or discuss your notes with others?					
Yes	796 (20.55)	240 (18.82)	520 (21.51)	36 (19.89)	.22
No	3018 (77.90)	1017 (79.76)	1861 (76.96)	140 (77.35)	
Don't know	60 (1.55)	18 (1.41)	37 (1.53)	5 (2.76)	
Do you want OpenNotes to continue?					
Yes	3834 (98.97)	1266 (99.29)	2389 (98.80)	179 (98.90)	.36
No	40 (1.03)	9 (0.71)	29 (1.20)	2 (1.10)	

[a]*P* values derived from chi-square test.

Figure 1. Patients' level of agreement with statements regarding concern about privacy on baseline and post-intervention surveys (N=3874).

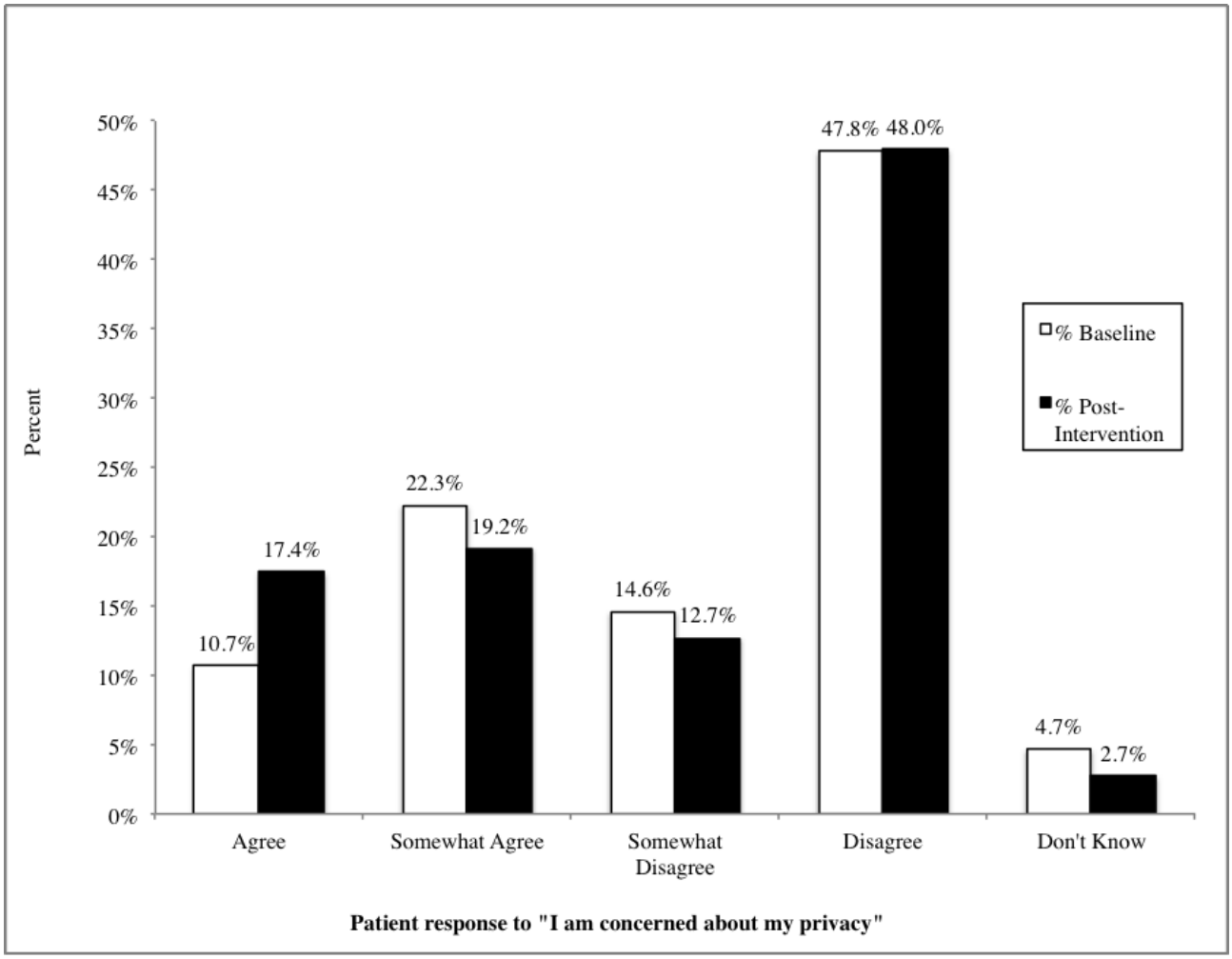
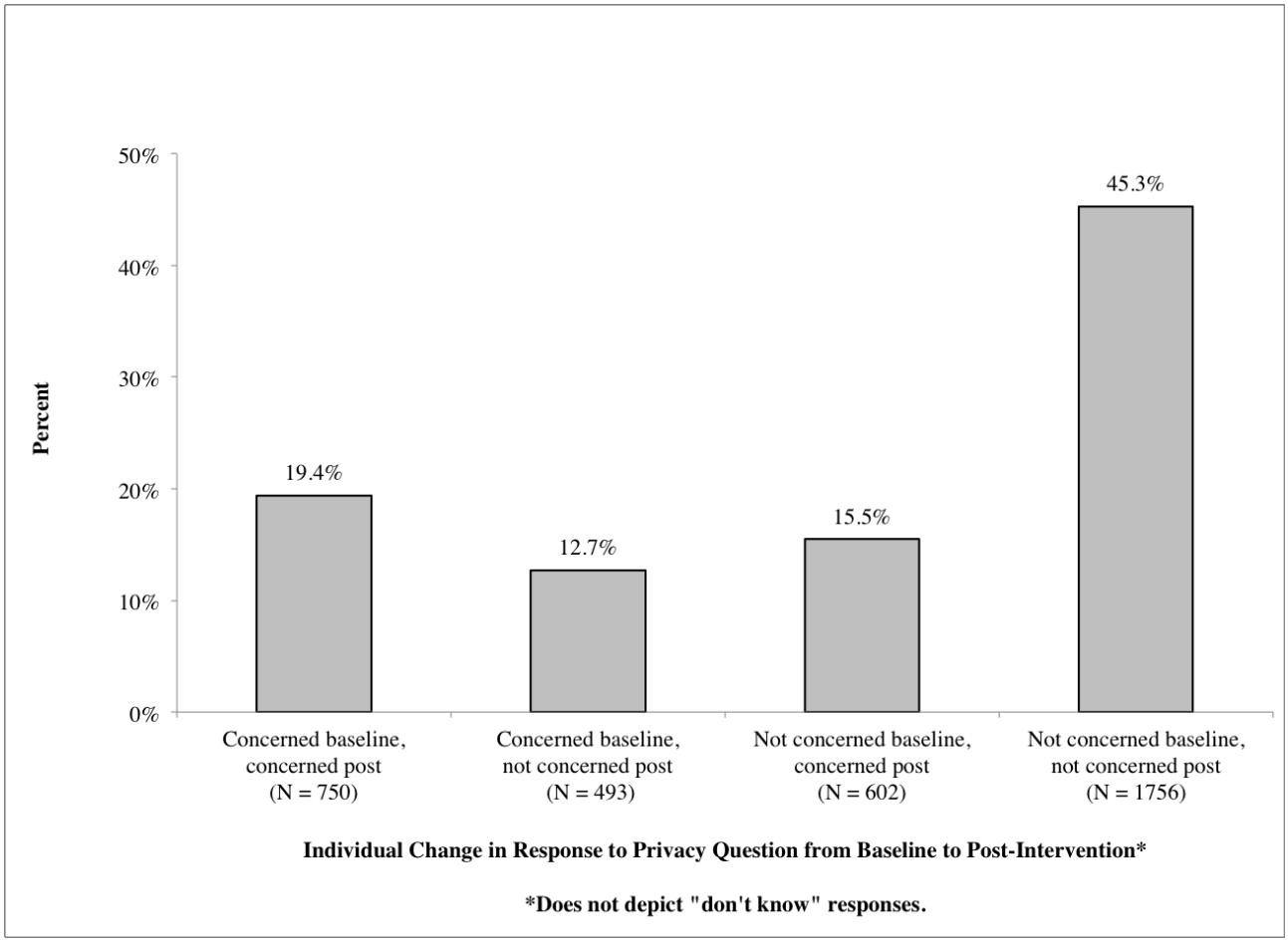


Figure 2. Change in individual patients' reported concern about privacy from baseline to post-intervention (N=3874).



Discussion

Principal Findings

Overall, approximately one-third of patients at baseline reported concerns about privacy when considering gaining online access to their doctors' visit notes. Nevertheless, this did not deter patients from accessing their notes and other medical information. Rather, nearly all patients wanted access to continue after the intervention despite the fact that nearly a third continued to worry about privacy. These findings are consistent with prior literature suggesting that patients want easy online access to their health information, despite concerns that might accompany such access [1,11,15,17,29].

The advancement of technologies such as patient portals carries the potential for a digital divide [30-36]. In our study sample that largely comprised experienced portal users, baseline concerns about privacy were more likely among individuals of non-white race/ethnicity, people reporting lower levels of self-confidence in communication, and those with less trust in their doctors. Lower education levels were also modestly associated with concerns about privacy. These associations are consistent with prior literature indicating that patients in these sociodemographic groups are, on the whole, less likely to enroll in patient portals and share personal health information [1,16,20,30-32,37,38]. Future research should consider whether worries regarding privacy might increase barriers to enrollment in patient portals among vulnerable populations, what factors associated with these sociodemographic groups contribute to privacy concerns, and how such concerns can be addressed.

Our study describes patients' attitudes toward privacy before and after gaining online access to their doctors' notes; however, it does not explore the reasons behind their concerns. The word "privacy" in itself carries different meanings for different people, and it may matter more to those who feel well than to individuals who are chronically or emergently ill [3,11]. But why did some patients become more concerned about privacy after a year's experience with OpenNotes, while others became less concerned? Did their mode of access (eg, home computer, mobile device, shared computer in a library or other public space) influence levels of concern about privacy? As patient portals become more prevalent, doctors' notes may become a common record component included in the information available to patients online. As such, how can doctors, administrators, and policy makers better address the future portal needs of patients, and how can they ensure that patients feel safe and secure logging on to read what the doctor has written?

Limitations

While this research study gathered perspectives from 3874 patients at three diverse sites and included highly vulnerable patients, several limitations should be highlighted. First, participants at two sites (BIDMC and GHS) had been using patient portals before the study began and may be considered early and experienced adopters of such technology. Other literature demonstrates that individuals who use patient portals

are typically less worried about privacy than nonusers [6,10], suggesting that the levels of concern reported by a substantial proportion of our respondents may not represent the general population. Nonetheless, while HMC patients received access to online health records for the first time through OpenNotes, they reported levels of concern on par with the average level of concern of registered portal users across study sites (approximately 33%; see Table 1).

In addition, the percentage of participants responding to both the pre- and post-intervention surveys was low, albeit consistent with other Internet-based surveys of patients [3]. And finally, while the topic of privacy was addressed in focus groups with patients before developing our survey [26] (a finding consistent with other focus group research on patient portals [39]) and the survey questions were vetted prior to administration, it is important to reiterate that the phrasing of the privacy question was used for the first time in the OpenNotes survey. Patients may not distinguish between the privacy risks of digitizing their health records (eg, hospital breaches of data security) and the risks of accessing those records online (eg, forgetting to log off a public computer, printing sensitive information). As a result, self-reported concerns about privacy may reflect diverse interpretations of potential associated risks.

Conclusions

As patient portals and shared medical records proliferate, health professionals need to be aware of patients' feelings about privacy. Our findings suggest that concerns about privacy among portal users do not deter them from accessing their visit notes and health information online. However, our findings also highlight the need to identify and address such concerns among specific demographic groups, particularly racial and ethnic minorities, patients with lower levels of education, and those with less trust in their doctors and lower confidence in their ability to communicate with them. If efforts to involve patients more actively in their care through Internet-based technologies are to move ahead, we need a far deeper understanding of the complex nature of "privacy" and how it interacts with the transparency that open visit notes represent.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Baseline survey instrument.

[PDF File (Adobe PDF File), 513KB - jmir_v15i9e208_app1.pdf]

Multimedia Appendix 2

Post-intervention survey instrument.

[PDF File (Adobe PDF File), 81KB - jmir_v15i9e208_app2.pdf]

Multimedia Appendix 3

Individual patient matched baseline and post-intervention response to survey question: "I am concerned about my privacy" (N=3874).

[PDF File (Adobe PDF File), 64KB - jmir_v15i9e208_app3.pdf]

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Abbreviations

ACES: Ambulatory Care Experiences Survey
BIDMC: Beth Israel Deaconess Medical Center
GED: General Educational Development test of high-school level academic skills
GHS: Geisinger Health System
HMC: Harborview Medical Center
OR: odds ratio
PEPPI: Perceived Efficacy in Patient-Physician Interactions score

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Original Paper

Monitoring Dietary Intake and Physical Activity Electronically: Feasibility, Usability, and Ecological Validity of a Mobile-Based Ecological Momentary Assessment Tool

Jorinde Eline Spook[1,2], MSc; Theo Paulussen[2], PhD; Gerjo Kok[1], PhD; Pepijn Van Empelen[2], PhD

[1]Faculty of Psychology and Neuroscience, Department of Work and Social Psychology, Maastricht University, Maastricht, Netherlands
[2]TNO, Expertise Group Life Style, Leiden, Netherlands

Corresponding Author:
Jorinde Eline Spook, MSc
Faculty of Psychology and Neuroscience
Department of Work and Social Psychology
Maastricht University
Universiteitssingel 40
Maastricht, 6200MD
Netherlands
Phone: 31 888661715
Fax: 31 888660604
Email: jorinde.spook@tno.nl

Abstract

Background: Despite the growing body of research on complex lifestyle behaviors (eg, Dietary Intake [DI] and Physical Activity [PA]), monitoring of these behaviors has been hampered by a lack of suitable methods. A possible solution to this deficiency is mobile-based Ecological Momentary Assessment (mEMA), which enables researchers to collect data on participants' states in real-time by means of a smartphone application. However, feasibility, usability, and ecological validity need to be anticipated and managed in order to enhance the validity of mEMA.

Objective: To examine the feasibility, usability, and ecological validity of a mEMA application (app) with regard to DI and PA among Dutch vocational education students.

Methods: The students (n=30) participated in the mEMA study for seven consecutive days. They downloaded the mEMA app on their smartphone. Feasibility and usability of the mEMA app were evaluated by completing an online evaluation after seven days of participation. Ecological validity was measured by assessing the degree to which the content of the mEMA app approximated the real-world setting that was being examined, through several multiple-choice questions.

Results: Compliance rates, as registered by the mEMA app, declined 46% over a seven-day period, while self-reported compliance, as measured with an online evaluation questionnaire afterwards, indicated a smaller decrease in compliance (29%). The students evaluated the mEMA app as feasible and usable. Ecological validity analyses showed that all DI and almost all PA multiple-choice options were covered with the compound response categories.

Conclusions: The mEMA app offers the opportunity to assess complex health behaviors (eg, DI and PA) in real-time settings, in which specifically routinized behaviors are involved. However, the mEMA app faced several challenges that needed to be overcome in order to improve its validity. Overall, the present study showed that the mEMA app is a usable and ecologically valid tool to measure DI and PA behaviors among vocational education students, but compliance is still limited.

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KEYWORDS

mobile-based Ecological Momentary Assessment (mEMA); feasibility; usability; ecological validity; dietary intake; physical activity

Introduction

Self-report of lifestyle behaviors, affect, and cognitions is often biased (eg, recall bias, availability, and recency) [1-5]. For instance, studies of fruit and vegetable consumption and their underlying determinants have shown that people generally overestimate their own consumption and, as such, behavior is less well predicted among those with an optimistic bias [6]. Similar findings have been observed for fat consumption and physical activity [7,8]. Similarly, Nordgren et al (2008) showed in a study targeting smoking behavior that health cognitions are unstable and dynamic [9].

Hence, it is important to find ways to more reliably assess determinants and behavior, in order to better understand and change behaviors. A method that could reduce the threat of recall bias, availability, and recency effects is ambulatory monitoring, such as Ecological Momentary Assessment (EMA) [10]. As Stone, Shiffman, Atienza, and Nebeling state: "The core rationale for EMA methods rests on three core benefits of the EMA approach: (1) avoidance of recall and its attendant bias, by collecting data on momentary states; (2) realization of ecological validity by collecting data in the real world; and (3) achievement of temporal resolution, enabling analysis of dynamic processes over time" (page 6, [5]). As such, EMA enables assessment of complex health behaviors and related factors of influence in real-time settings [11] and appears to be applicable to often routinized behaviors [1]. In general, a comparison of EMA with traditional recall-based methodologies has shown that EMA produces more reliable results [3].

With the increasing popularity of smartphones, recent studies have indicated the usefulness of mobile-based Ecological Momentary Assessment (mEMA) [12-19]. The advantage of mEMA is that it is incorporated in a tool that is frequently used in daily living. However, researchers have also suggested that mEMA faces challenges that need to be anticipated and managed in order to enhance its validity (eg, time of day, day of the week, concurrent activities or states, nonresponse, and missing diary entries [5]). As such, it is essential to achieve adequate compliance and to study the feasibility, usability, and ecological validity of mEMA and mEMA measurements. Within this study, feasibility and usability refer to the practical application of mEMA in daily life (eg, monitoring burden). Ecological validity refers to the extent to which the data are representative of the possible range of experiences in daily life [5] and we explicitly focused on the extent to which we included the range of most relevant social and physical environments.

To date, use of mEMA in health promotion research is limited, especially when focusing on weight-related factors (ie, Dietary Intake [DI] and Physical Activity [PA]). To ensure that mEMA can be used effectively to monitor determinants of DI and PA in future research, it is imperative that these challenges are examined prior to its actual deployment [20]. To examine mEMA, the present study examined three research questions concerning the validity of a mEMA app: Is the mEMA app (1) a feasible (ie, what is the level of students' compliance), (2) usable (ie, how is mEMA evaluated by the students), and (3) ecologically valid (ie, do the social and physical response items capture the most important day-to-day social and physical characteristics [5]) tool to measure determinants of DI and PA among vocational education students.

Methods

Participants

Data were collected from three vocational education schools in the Netherlands. Out of the 44 students who were approached to participate in the mEMA study, 30/44 students (68%) participated for 7 consecutive days (17/30, 57% were female), of which 17 students (aged 16-21 years) completed the online evaluation (regarding feasibility and usability of the mEMA app) after their 7 days of participation. Participatory incentives of ten €20 coupons were randomly distributed to the students at the end of the study. Those who participated for 7 days and filled in the online evaluation form doubled their chance of winning. All students consented to take part in the study and students aged ≤17 were provided with a passive consent form for their parents to complete. All procedures were approved by The Ethical Committee of Psychology (Maastricht University).

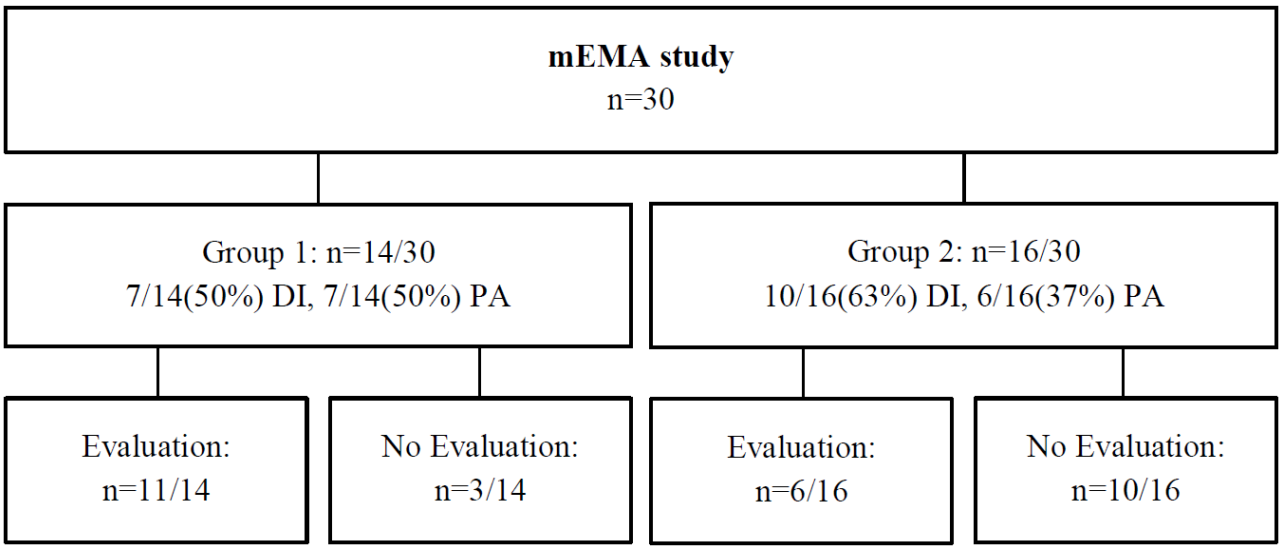
Measures and Procedures

In a study conducted prior to the mEMA study (n=305 vocational education students), an assessment was made of the type of smartphone platforms that were most commonly used among the vocational education students. The majority of the students (244/305, 79.9%) indicated that they used a smartphone operating on BlackBerry OS, Android, or iOS (respectively 151/305, 49.5%, 55/305, 18.1%, and 37/305, 12.1%). Estimating an increased use of the iOS and Android platforms, the mEMA app was built on all three platforms.

Mobile Ecological Momentary Assessment (mEMA) Study

In total, 44 students from three different vocational education schools in the Netherlands were approached by their teachers to participate in the present study, of which 30 students participated in the mEMA study. Students from the first two schools were allocated to the first group of participants (n=14) and were randomly assigned to the DI or PA condition (study design and participant distribution are illustrated in Figure 1). The students from the third school were allocated to the second group (n=16) and started using the mEMA app after several adjustments were made based on feedback from the first group (discussed in the Results section). Participants in the second group were encouraged to use the mEMA app similarly to those participating in the first group.

Figure 1. Study design and participant distribution.



Mobile Ecological Momentary Assessment App Use

Prior to the use of the mEMA app, students completed an online questionnaire regarding their DI or PA during the preceding 7 days. Data from this online questionnaire were collected for other study purposes. After completion, students who possessed a smartphone that operated on iOS (iPhone version 5.0), BlackBerry OS (version 6.0 or 7.0), or Android (version 2.2 and over) systems were eligible for participation, and downloaded the mEMA app from the BlackBerry OS, iOS, or Android app store (n=30). Students who possessed a smartphone with other operating systems or who did not own a smartphone were exempted from further participation. The students were invited to use the mEMA app for 7 consecutive days and gave their consent for participation. During these 7 days, participants were asked to fill in the same short questionnaires regarding their DI or PA during the preceding 3.5 hours, 5 times a day. Participants were able to close the app at any time.

Evaluation

All students who participated in the mEMA study were asked to fill in an online evaluation form concerning the feasibility and usability (ie, functionality and interface) of the mEMA app. Additionally, after participants from the first group filled in the online evaluation form, group discussions took place per school, led by one of the researchers.

Content Management System (CMS)

In order to upload content for the online questionnaire, mEMA app (both DI and PA conditions), and the evaluation, a content management system (CMS) was built. This CMS enabled researchers to monitor multiple complex health behaviors simultaneously (eg, DI and PA) and to adapt the content, text, and prompting sequence.

Implementation Procedure for Using the mEMA App

An interval-contingent schedule was used for the mEMA app, which initially prompted participants at 5 time periods per day (8:00am, 12:00pm, 3:30pm, 6:30pm, and 9:30pm with a range of 30 minutes each), tailored to the schedule of their schools. These prompts were formatted as auditory signals and were displayed on their smartphone screens. When a diary entry was missed or rejected, up to two reminder signals were sent, once after 30 minutes and the second after 60 minutes. After missing and/or rejecting the two reminders, the CMS noted the initial diary entry as “missed”.

First, participants received instructions about the study and the use of the mEMA app (ie, how to download and use the app). They were instructed to start with an online questionnaire regarding their DI or PA during the preceding week. Second, students were able to use the app during the first day to get familiar with it. From the second day, the mEMA app started prompting participants, asking them to fill in a short questionnaire. Students were instructed to respond to these prompts as much as possible.

During each diary prompting sequence, students who were allocated to the DI condition received a total of 14-16 questions regarding their mood, eating behavior, food cravings, self-evaluative emotions, location, activities, social context, soft and energy drinks, snack intention, hunger, and the availability of food, respectively (ie, 12-14 questions depending on their responses within the decision tree; see Figure 2 A). These questions were derived from Carels et al, White et al, Dijkstra and Buunk, Adriaanse et al, Thomas, Thomas et al, and Rijpstra et al [21-26]. Students in the PA condition received 12-14 questions concerning their mood, sedentary behavior, physical activity, need for physical activity, evaluative emotions, location, social context, behavior intention, active transport, possible barriers, and feelings of security, respectively (see Figure 2 B). The PA questionnaires were derived from Carels et al, Cranford et al, De Vries et al, Dunton et al, Dunton et al, Grow et al, and Prins et al [21,27-32].

Four different types of response categories were used: Visual Analogue Scale (VAS slider) (see Figure 3 A), multiple-choice bullets (see Figure 3 B), multiple-choice open field combined with VAS slider (see Figure 3 C), and binary (see Figure 3 D). In the DI condition, 5-point (VAS slider) scales were used to measure mood, hunger, availability, and intention (eg, mood: “At the moment, I’m feeling happy”). Multiple-choice bullets were used as response categories for daily meal, self-evaluative

emotions, location, activity, and social context (eg, location: "Where were you when you were having a snack?"). Multiple-choice open field combined with VAS sliders were used to indicate the type and frequency of fruits and vegetables, snacks, and sodas they had consumed (eg, "In the last three and a half hours, what type of snack(s) did you eat? And how many?"). These sliders ranged from 0-100, but the open fields enabled participants to fill in amounts that were larger than 100. Finally, binary response categories were used for decisions within the tree and food craving (eg, "In the last three and a half hours, have you eaten fruit or vegetables?"). All examples are translated from Dutch to English.

Figure 2. Decision trees of the mEMA app DI and PA questionnaire.

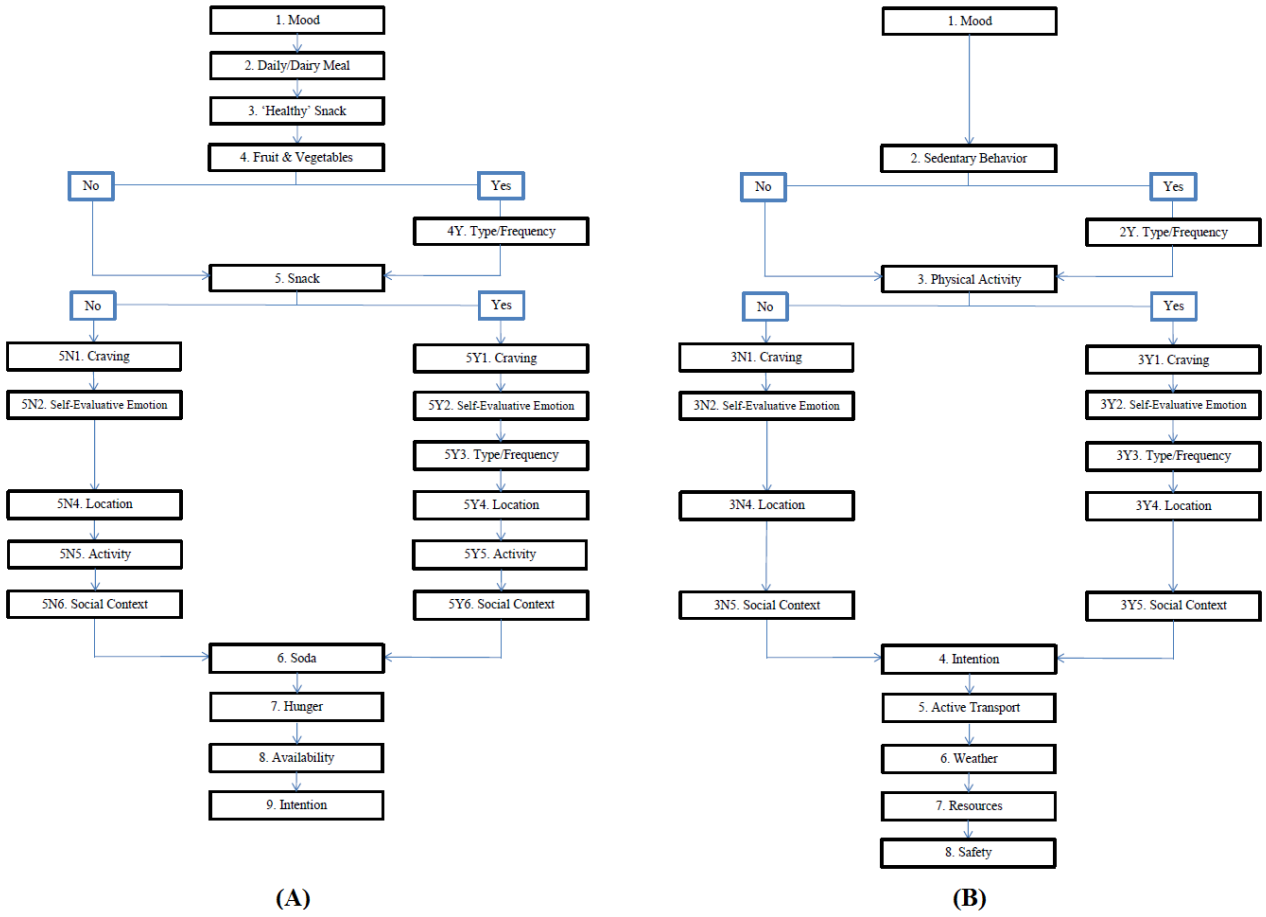
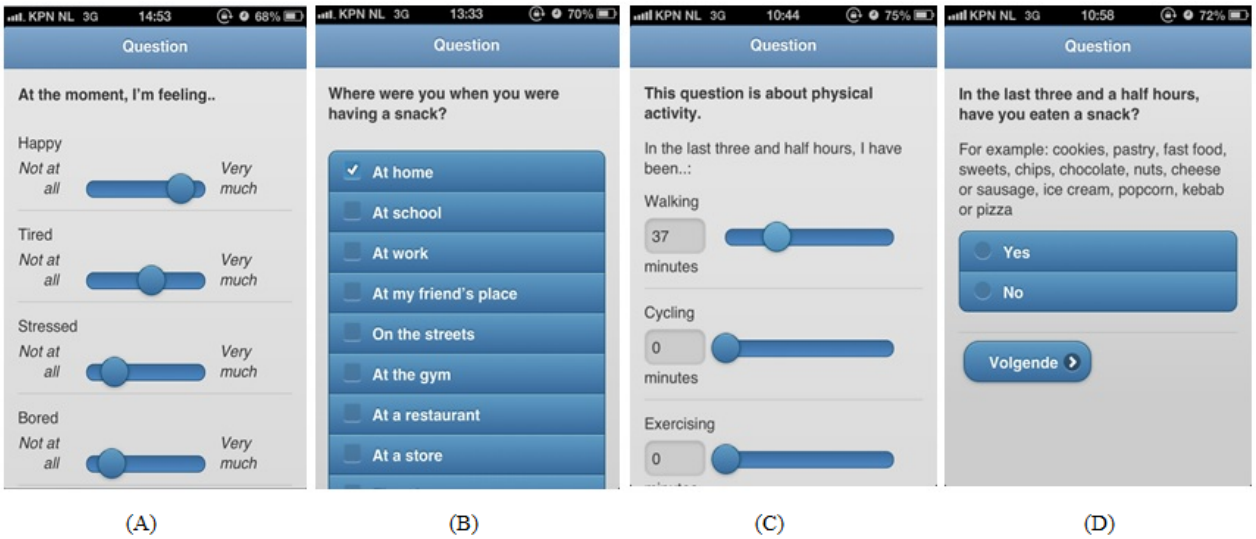


Figure 3. Screenshots of mEMA.



Feasibility and Usability Measures

Feasibility and usability measures were derived from previously completed studies [15,16]. These measures contained 17 statements about the students' subjective experience with the mEMA app (eg, "In my opinion, it was boring to work with the mEMA app"), the level of difficulty (eg, "In my opinion, the mEMA app was easy to use"), prompting sequence (eg, "In my opinion, the number of prompts that were sent during one week (5 times a day) was annoying"), length (eg, "In my opinion, the trial took too long"), and understanding (eg, "In my opinion, the questions were understandable"). Responses were scaled 1 (totally disagree) to 5 (totally agree). The midpoint of the scale was considered as a criteria for further interpretation (eg, scores above the midpoint of the usability scale were interpreted as "the mEMA app was easy to use"). Also, three open-ended questions were added to enable students to provide suggestions for further improvement of the mEMA app: (1) "Why did you ignore or postpone a prompt?", (2) "I would make the following change to the mEMA app…", and (3) "I would add the following to the mEMA app…").

Ecological Validity

Ecological validity was determined by assessing the degree to which the collected data represent the full-range of possible social and physical influences. The assessment for both DI and PA included two questions regarding the location and social context (eg, "Where were you while having a snack?" and "While you were being physically active, how many people were there with you?"). Response categories for both the location and social context were multiple choice and similar for DI and PA. Multiple-choice options included the following locations and social settings: at home, school, work, friend's house, outside, restaurant, cafeteria, supermarket, sports club, or elsewhere; and a friend, colleague, classmate, team member, sibling, parent, partner, child, teacher, stranger, or other, respectively for the social setting.

Data Analysis

SPSS version 20 was used for data analyses. Data from the mEMA app were transported from the smartphone into a secure computer system when participants had access to a Wi-Fi connection. Next, data from the computer system were converted to an SPSS database. With SPSS, descriptive statistics were generated (means and percentages) and compliance rates were calculated for the exploration of response patterns. Furthermore, a *t* test was done in order to examine gender differences in the perceived usability of the mEMA app. Prior to the analyses, normality was tested by means of Q-Q plots. Mean differences were analyzed using *t* tests when normally distributed and Mann-Whitney U test when they were non-normally distributed.

Results

Study Adjustments

After the first group had participated, technical problems were fixed and both feasibility and usability were evaluated by means of the aforementioned measurement procedures and group discussions. Based on the students' feedback, two adjustments were made: (1) the number of daily prompts was reduced from 5 prompts a day to 4 prompts a day, and (2) the time sequence was reduced from 8 to 7 days of participation, as the start and evaluation of the study took place during their physical activity classes (once a week). Also, students evaluated the VAS sliders (see Figure 3 A, C) as bothersome. However, due to practical constraints (ie, Likert scales did not fit within the boundaries of all smartphone screens), usage of VAS sliders was maintained. The second group made use of the same mEMA app as the first group, but they were prompted 4 times a day during 7 consecutive days, instead of 5 prompts a day during 8 consecutive days.

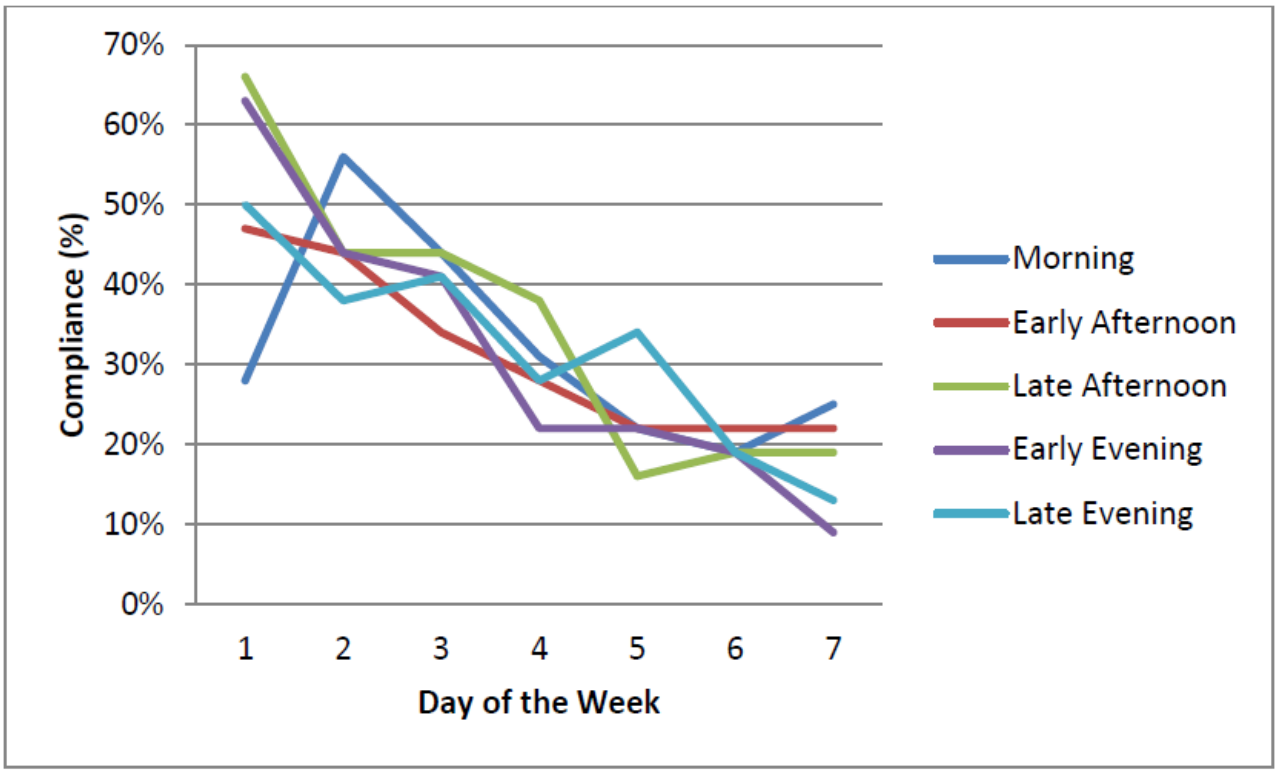
An independent sample *t* test was conducted to test whether the usability of the mEMA app increased after the number of prompts was decreased from 5 to 4 times a day and the time sequence was reduced from 8 to 7 consecutive days. The results showed a significant difference between the first group (n=11) and the second group (n=6) regarding the app's usability (t_{14}=–2.15, P=.05). The second group perceived the app as easier to use (mean 4.33, SD 0.82) compared to the first group (mean 3.36, SD 0.92). However, no significant differences between the first group and the second group were found regarding the duration of the study (P=.19) and their evaluation (ie, how annoying) of the amount of prompting (P=.86).

Compliance Rate

Students' compliance was reported per day (n=30). Thirty participants started using the mEMA app at Day 1 (100%), and 7 days later, 14 students still participated (44%). Compliance decreased 56%. Further exploration of times of day did not indicate clear differences in compliance between morning, early afternoon, late afternoon, early evening, and late evening (56%, 55%, 61%, 55%, and 56% respectively). The response patterns per time of day over 7 days of participation are projected in Figure 4. Interestingly, the mEMA app was used 23 times without being prompted (ie, user based). The overall mean completion time per response was 138.7 seconds (SD 65.6; for DI [mean 132.3, SD 63.7] and PA [mean 146.8, SD 67.4]).

Total response rates were assessed by calculating the percentage of answered prompts per day. From Day 1 through 7, total response rates were 63%, 54%, 48%, 35%, 31%, 23%, and 23% respectively (n=128 prompts per day). Over time, the total response rate decreased 40%.

Figure 4. Response rates per times of day (n=30).



Feasibility and Usability

Of all participants (n=30), 17 students (57%) completed the online evaluation form (ie, regarding the feasibility and usability of mEMA). Normality was assessed by means of Q-Q plots. These plots showed all items to be normally distributed. The mean scores (and standard deviations) of all items are displayed in Table 1. Participants reported that the mEMA app was relatively easy to use (mean 3.88, SD 0.93), that during the study they carried their smartphone with them every day (mean 4.65, SD 0.61), and that, according to them, the mEMA app worked well (mean 3.76, SD 1.09). Participants who took more time to complete the mEMA app questionnaires were also more likely to report that the time required to complete them was too lengthy (r=.154, P=.04). No significant differences in the perceived usability of the mEMA app between boys (mean 3.29, SD 0.95) and girls (mean 3.90, SD 9.99) were found (P=.88).

Table 1. Feasibility and usability measures (n=17).

Item	Mean score[a](SD)	Score>mean[b], %
1. The mEMA app is easy to use.	3.88 (0.93)	65
2. It is easy to carry the smartphone with me.	4.35 (1.06)	65
3. I carried my smartphone with me every day.	4.65 (0.61)	71
4. After the researcher's explanation I understood how the app would work.	4.24 (0.75)	41
5. It was fun to work with the app.	2.88 (1.27)	59
6. It was boring to work with the app.	2.88 (1.27)	59
7. The app worked well.	3.76 (1.09)	59
8. I experienced the prompts as reasonable.	3.00 (1.17)	71
9. The number of prompts was annoying.	3.47 (1.51)	53
10. I filled in the mEMA app questionnaires for 7 consecutive days.	3.76 (1.35)	71
11. I filled in the mEMA app questionnaires 4 times a day.	3.41 (1.42)	59
12. It was easy to fill in the mEMA app questionnaire on my smartphone.	4.24 (0.90)	47
13. The questions were well-displayed on my smartphone.	4.71 (0.47)	71
14. Filling in a mEMA app questionnaire was an interruption of my daily activities.	2.59 (1.46)	47
15. Filling in 1 mEMA app questionnaire took too long.	2.24 (1.20)	41
16. The study took too long.	2.24 (1.15)	35
17. I understood the questions that were asked.	4.71 (0.49)	77

[a]Scores were based on a 5-point Likert scale (ranging from 1 - totally disagree to 5 - totally agree).

[b]Score>mean illustrates the percentage of scores above the mean.

Ecological Validity Analyses

Ecological validity analyses were performed to indicate whether response categories covered all types of students' snacking in the DI condition and if response categories in the PA condition covered all types of physical activity. Table 2 shows that the consumed snacks could be categorized as cookies, pastries, fast food, sweets, chips, chocolate, nuts, cheese/sausage, popcorn, and kebab/pizza. Out of all prompts that participants responded to (128 out of 1020 prompts), 58 prompts were answered with "Yes, I have consumed an unhealthy snack during the past 3.5 hours". In total, 104 snacks were reported by participants, indicating that per snacking episode an average number of 1.8 snacks were consumed.

The reported PA could be broken down into the categories of walking, exercising, working (standing), biking, cleaning the house, doing groceries, shopping, and something else (eg, internship at a kindergarten; see Table 2). Out of all prompts that participants responded to (n=128), 48 prompts were answered with "Yes, I have been physically active during the past 3.5 hours". In total, 97 activities were reported, indicating that during several of these 48 time periods of 3.5 hours each, approximately 2 different activities were performed.

Table 2. Vocational education school students' Dietary Intake (DI) and Physical Activity (PA).

Condition	Category	Frequency
DI (n=58)		
	Cookies	19
	Pastry	19
	Fast food	18
	Sweets	12
	Chips	11
	Chocolate	6
	Nuts	6
	Cheese/Sausage	4
	Ice cream	4
	Popcorn	3
	Kebab/Turkish Pizza	2
	Total DI	104
PA (n=48)		
	Walking	28
	Sporting	22
	Working (standing)	15
	Biking	13
	Cleaning the house	11
	Doing groceries	3
	Shopping	3
	Miscellaneous	2
	Total PA	97

Social and Physical Categories

In addition to the ecological validity of response categories for DI and PA, ecological validity was analyzed for social context and location. These two context-related categories refer to the people that joined the participants and their exact location while they consumed a snack or were physically active. Results indicate that response categories for the social context fitted with 93% of all responses for DI and 98.3% for PA. Remaining responses were categorized as "Other" (including "family", "people from school", and "grandma" for DI, and "people from the gym" for PA). Regarding the location in which participants consumed snacks or were physically active, the developed response categories fitted with 90% for DI and 96% for PA. Remaining responses were categorized as "Elsewhere" (including "family", "car", "theater", and "camping site" for DI, and "gym" and "in town" for PA).

Table 3 provides an overview of the categorized social contexts and locations. The overall amount of DI and PA by all participants appeared to be higher than the amount of reported social contexts and locations, indicating that participants might have eaten different snacks and have performed different types of PA in the same setting.

Table 3. Dietary Intake (DI) and Physical Activity (PA) related to social context and location.

Condition	Social Context[a]	n	Location	n
DI				
	Alone	9	Home	23
	Friend	9	School	7
	Colleague	11	Work	12
	Classmate	5	Friend's	4
	Teammate	0	At the streets	5
	Sibling	8	Sports club	1
	Parent	14	Restaurant	2
	Partner	4	Mall	0
	Child	5	Elsewhere	6
	Teacher	0	-	-
	Stranger	0	-	-
PA				
	Alone	14	Home	18
	Friend	10	School	8
	Colleague	8	Work	11
	Classmate	5	Friend's	8
	Teammate	4	At the streets	8
	Sibling	3	Sports club	14
	Parent	4	Restaurant	0
	Partner	8	Mall	0
	Child	0	Elsewhere	3
	Teacher	1	-	-
	Stranger	2	-	-

[a]Multiple answers are allowed per data collection point.

Discussion

Principal Findings

In line with technological developments over the past few years, the mEMA technique is gaining in popularity with claims of better accuracy in ambulatory data collection [7]. The mEMA approach offers the opportunity to assess complex health behaviors in real-time settings, in which specifically routinized behaviors are involved (eg, DI and PA) [1]. However, the mEMA app faced several challenges that needed to be overcome in order to improve its validity. The present study showed that the mEMA app is a usable and ecologically valid tool to measure DI and PA behaviors among vocational education students, but compliance is still limited.

Vocational education students' self-rated compliance was 70.6% and is in accordance with compliance rates of previous electronic EMA studies [33]. However, the registered compliance rates of the in situ registration by the mEMA app indicated a compliance rate of only 43.8%. Such a discrepancy may be explained by an availability heuristic, indicating an overestimation of compliance when students evaluate their compliance retrospectively as with the online evaluation form used in this study. According to Stone et al (2007), noncompliance might be caused by several factors, eg forgetting and monitoring burden [5]. Up to 3 reminder signals were programmed in the mEMA app when participants did not respond, with time intervals of 30 minutes. Therefore, we assume that the chance of forgetting to respond to a mEMA prompt as a cause of noncompliance in the present study was small. Additionally, the number of prompts was reduced from 5 times a day to 4 times a day, based on feedback received from the first group. Accordingly, a significant decrease in monitoring burden was expected. However, the results from the online evaluation indicated that more than half of the students who filled in the online evaluation form (52.3%) still experienced the number of prompts as bothersome. Therefore, monitoring burden might be a cause of the students' noncompliance in the present study. Noncompliance in the present study might also be attributable to the educational level of the students, as higher noncompliance rates have been more commonly reported among less educated students [34].

The usability of mEMA was rated as good. However, it should be mentioned that on the online evaluation form participants commented that the VAS-slider (see Figure 3 A, C) was "difficult and sometimes bothersome to use." These comments are in line with experiences from adolescents who participated in an electronic chronic pain diary study [33]. These adolescents also perceived the VAS slider as "hard to control" and commented that when they dragged the slider, it did not move the way they wanted. However, they also mentioned that once they discovered how to use the VAS slider more effectively, they "got the hang of it" (page 300, [33]). Stinson et al suggested that VAS slider use could be improved by creating a thicker slider so it would move more easily, changing several sliders into radio buttons, and adding space for adolescents to enter their own responses. These adaptations were taken into account during the development of the mEMA app. But, despite these adaptations and rehearsal time prior to the study, the slider was still perceived as difficult and sometimes annoying to use. However, when the students received an explanation of the VAS sliders after they participated in the study (ie, due to practical limitations), support for the slider increased. Therefore, irritation might be prevented by providing a good rationale prior to study, including an explanation of ways to use the slider effectively. In addition to providing a good rationale, future studies are encouraged to develop new 5-point scale designs on smartphones, in order to find a viable alternative to VAS sliders.

To our knowledge, empirical research on the ecological validity of mEMA is still lacking. In the present study, the response categories used within the contexts of DI and PA appeared to cover (almost) all responses. This indicates that the collected data represents the full range of social and physical factors of influence. These categories could be used in future mEMA research on DI and PA behavior.

Besides the response categories used within the contexts of DI and PA, the mEMA app has potential use for future research on complex cognitions and (health-related) behaviors for behavioral research in general. The rationale for using mEMA rests on three central benefits of this methodology. First, retrospective recall (and the associated biases) is greatly reduced with mEMA because people report on current or recent states and events that occurred shortly prior to the received prompt. Second, mEMA occurs in natural settings, increasing external and ecological validity compared to clinical settings (eg, laboratory research). Third, multiple assessments occur over time, so temporal relationships among variables can be explored [3,35]. Fourth, the use of mobile-based EMA offers the opportunity to examine cognitions, affect, and behavior in the everyday context of people, using the natural handling and carrying of mobile phones. As such, mEMA offers a good opportunity for those behavioral, social, and health scientists and practitioners who aim to understand, intervene, and evaluate the effects of interventions on behavior (change), to examine individual differences as well as contextual differences.

Limitations

Finally, important limitations of the present study need to be addressed. First, not all students were able to participate in the mEMA study, because not all students possessed a smartphone that operated on (recent versions of) BlackBerry, Android, or iOS. Consequently, 14 out of 44 students were exempted from further participation in the mEMA study. In order to include these exempted students in future research, a solution may be found in the (temporary) provision of eligible smartphones. Second, the mEMA app may reduce the likelihood of various biases (eg, recall bias, availability, and recency effects), but other biases may still threaten the validity of responses, such as social desirability. Social desirability bias might play an important role in health-related behavior as, for instance, participants are expected to underreport their dietary intake and overestimate their physical activity [6-8,36,37]. However, Crutzen et al (2010) indicated with their study on social desirability and self-reported health risk behaviors in Web-based research that there was no meaningful association between social desirability and self-reported health risk behaviors in Web-based research [34]. Because students in the present study used the mEMA app in real time in the absence of the researcher, it might be that a meaningful association between social desirability and self-reported DI and PA in mEMA studies is lacking too. Therefore, a comparable study on social desirability in future mEMA research might be interesting. Nevertheless, correction for these types of biases might still be necessary. Third, time-based prompting and prompting frequency were adjusted to the school's schedule. However, in the Dutch vocational education system, students are required to work as interns for 2 days a week, which, according to our participants, prevented them from responding to all prompting sequences. Some students also mentioned their spring break as a reason for low compliance. Accordingly, flexible prompting (ie, adjustable by the participant) or encouragement of user-based entries could be taken into account in future deployments.

Conclusion

Overall, mEMA offers the opportunity to assess complex health behaviors (eg, DI and PA) in real-time settings, in which specifically routinized behaviors are involved. However, the study also revealed some challenges with regard to use of the mEMA app that need to be taken into account in order to improve its validity. In particular, compliance is a reason for concern.

Conflicts of Interest

None declared.

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Abbreviations

CMS: content management system
DI: dietary intake
EMA: Ecological Momentary Assessment
mEMA: mobile Ecological Momentary Assessment
PA: physical activity
VAS: visual analogue scale

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Viewpoint

A Web-Based Interactive Diabetes Registry for Health Care Management and Planning in Saudi Arabia

Khalid A Al-Rubeaan[1], MD, FRCPC; Amira M Youssef[2], BPharm; Shazia N Subhani[3], BE (CS), MSc Comp Sc; Najlaa A Ahmad[4], MBBCh, MPH; Ahmad H Al-Sharqawi[4], BSc; Heba M Ibrahim[2], BPharm

[1]Strategic Center for Diabetes Research, University Diabetes Centre, King Saud University, Riyadh, Saudi Arabia

[2]Registry Department, University Diabetes Center, King Saud University, Riyadh, Saudi Arabia

[3]Registries Core Facility, Biostatistics, Epidemiology and Scientific Computing, King Faisal Specialist Hospital and Research Centre, Riyadh, Saudi Arabia

[4]Biostatistics Department, University Diabetes Center, King Saud University, Riyadh, Saudi Arabia

Corresponding Author:
Khalid A Al-Rubeaan, MD, FRCPC
Strategic Center for Diabetes Research
University Diabetes Centre
King Saud University
PO Box 18397
Riyadh, 11415
Saudi Arabia
Phone: 966 11 282 5402
Fax: 966 11 477 5696
Email: krubean@ksu.edu.sa

Abstract

Background: Worldwide, eHealth is a rapidly growing technology. It provides good quality health services at lower cost and increased availability. Diabetes has reached an epidemic stage in Saudi Arabia and has a medical and economic impact at a countrywide level. Data are greatly needed to better understand and plan to prevent and manage this medical problem.

Objective: The Saudi National Diabetes Registry (SNDR) is an electronic medical file supported by clinical, investigational, and management data. It functions as a monitoring tool for medical, social, and cultural bases for primary and secondary prevention programs. Economic impact, in the form of direct or indirect cost, is part of the registry's scope. The registry's geographic information system (GIS) produces a variety of maps for diabetes and associated diseases. In addition to availability and distribution of health facilities in the Kingdom, GIS data provide health planners with the necessary information to make informed decisions. The electronic data bank serves as a research tool to help researchers for both prospective and retrospective studies.

Methods: A Web-based interactive GIS system was designed to serve as an electronic medical file for diabetic patients retrieving data from medical files by trained registrars. Data was audited and cleaned before it was archived in the electronic filing system. It was then used to produce epidemiologic, economic, and geographic reports. A total of 84,942 patients were registered from 2000 to 2012, growing by 10% annually.

Results: The SNDR reporting system for epidemiology data gives better understanding of the disease pattern, types, and gender characteristics. Part of the reporting system is to assess quality of health care using different parameters, such as HbA1c, that gives an impression of good diabetes control for each institute. Economic reports give accurate cost estimation of different services given to diabetic patients, such as the annual insulin cost per patient for type 1, type 2, and gestational diabetes, which are 1155 SR (US $308), 1406 SR (US $375), and 1002 SR (US $267), respectively. Of this, 72.02% of the total insulin cost is spent on type 2 patients and 55.39% is in the form of premixed insulin. The SNDR can provide an accurate assessment of the services provided for research purposes. For example, only 27.00% of registered patients had an ophthalmic examination and only 71.10% of patients with proliferative retinopathy had laser therapy.

Conclusions: The SNDR is an effective electronic medical file that can provide epidemiologic, economic, and geographic reports that can be used for disease management and health care planning. It is a useful tool for research and disease health care quality monitoring.

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KEYWORDS

diabetes mellitus; registries; geographic information systems; medical records systems, computerized; health planning; research report; data bank, factual; epidemiology

Introduction

The development of computerized applications and telecommunication for computer-based health care management tools has increased and helped patients, physicians, and health institutes better manage health and disease. Nowadays, eHealth is considered one of the most rapidly growing technologies worldwide. It aims to provide health services at a lower cost with good quality and availability. Chronic diseases are known for their high rate of morbidity, disability, and mortality, in addition to their high cost; they amounted to 75% of health care expenditures in the United States during the year 2000 [1]. Therefore, eHealth is expected to reduce the effect of such diseases on health and economy. Diabetes mellitus is the most important and frequent chronic disease, as reported by the International Diabetes Federation (IDF), with more than 366 million people suffering from this disease worldwide and the number likely to be 552 million by 2030 [2].

Diabetes morbidity is related to chronic complications, namely neuropathy, nephropathy, retinopathy, and vasculopathy making it the leading cause of blindness, renal failure, and lower limb amputation. The prevalence of mild to severe diabetic neuropathy ranges from 60% to 70% [3]. In 2004, more than 60% of nontraumatic lower limb amputations were related to diabetes [4]. Among both diagnosed and undiagnosed diabetic patients, the prevalence of retinopathy ranges from 17.6% to 33.2% [5], whereas the prevalence rate for vision-threatening retinopathy was 8.2% [6]. Coronary heart disease prevalence reported among adult diabetic patients was as high as 55% [7]. The prevalence of diabetic nephropathy among type 2 diabetic patients ranges from 7.6% to 55% [8].

Deaths attributed to diabetes globally increased by 5.5% in the year 2010 compared to the year 2007 [9]. This increase is largely because of a 29% increase in the number of deaths in North America and the Caribbean region, but also a 12% increase in the Southeast Asia region and an 11% increase in the Western Pacific region [10]. Diabetes is also known to be a leading cause of death largely because of increased risk of coronary artery disease and stroke. According to World Health Organization (WHO) data, more than 75% of patients with non-insulin-dependent diabetes mellitus die because of vascular accidents [11].

Saudi Arabia is considered to be 1 of the top 10 countries in terms of diabetes prevalence worldwide [12]. Diabetes prevalence has been estimated at 23.7%, and varies according to the geographic region of the Kingdom, being the highest in the Northern and Eastern regions, which account for 27.9% and 26.4% of cases, respectively. The Western and Central regions were 24.7% and 23.7%, respectively. The lowest prevalence is in the Southern region, which accounts for 18.2% [13].

The prevalence of diabetes chronic complications in Saudi Arabia has also been considered to be one of the highest worldwide, with 82% for neuropathy [14], 31% for retinopathy [15], and 32.1% for nephropathy [16]. Diabetes in Saudi Arabia has been found to be responsible for 30% to 45% of patients requiring dialysis [17], and 37% to 41% of patients with stroke [18].

From the currently available data on diabetes and its complications, it is very clear that this disease has reached an epidemic stage and has a medical and economic impact on health and economy of the Kingdom. This is associated with deficiency in the data required for proper action to prevent and manage this huge medical problem. In spite of the good health system and facilities currently available in the Kingdom, health care provided to diabetic patients has fallen short of achieving optimal clinical outcomes. This can be attributed to the large number of patients and the limited time allotted for each patient, in which new technology can contribute for good patient's monitoring and high level of clinical practice. Thus, using a diabetes registry can give us a better understanding of the disease and its impact on patients and the health system. It also provides a chance for research and better planning for disease management in setting the proper standards for medical care. Eventually, it could provide physicians with feedback on their medical care, guiding them to improve their clinical outcomes [19]. It also serves as the basis for epidemiology data, providing better insight into diabetes complications and associated diseases, and aiming to improve disease management and health care quality.

Disease registries currently available cover a wide spectrum of conditions, such as infectious diseases, cancers, congenital diseases, and rare diseases, such as cystic fibrosis. Chronic illnesses, such as diabetes, heart failure, end-stage renal disease, myocardial infarction, or stroke, have been the target for disease registries in many countries. A survey of 1040 US physician organizations showed that diabetes registries are used 40.3% of the time, asthma registries 31.2%, congestive heart failure registries 34.8%, and depression registries 15.7% [20]. There are limited numbers of diabetes registries globally, some of which are brief and disease-focused, whereas others are made to serve certain objectives. On the other hand, there is a third group of registries made to serve diabetic patients in hospital settings, or that considers diabetes as a component of chronic diseases. Joslin's Web-based Diabetes Registry and Risk Stratification System is a Web-based application using Joslin's evidence-based Clinical Guidelines to identify and intervene with patients who are most likely to develop costly, debilitating, diabetes-related complications [21]. On the other hand, Penn State Hershey Diabetes and Obesity Institute Registry (PSHDOI) is a custom-built application that assists in tracking clinical outcomes for diabetic patients [22]. The Chronic Disease Electronic Management System (CDEMS) has embedded

guidelines for a variety of chronic diseases (diabetes, atrial fibrillation, heart failure, coronary heart disease, hyperlipidemia, depression, asthma, and osteoporosis) [23]. None of the currently available registries has used a diabetes registry in a holistic approach or utilized geographic mapping and economic assessment of the disease countrywide.

The Saudi National Diabetes Registry (SNDR) was established with the primary goal of developing a database for diagnosed national diabetic patients living in the Kingdom of Saudi Arabia. The SNDR's objective is to function as an electronic medical file to provide medical teams with clinical, investigational, and management information. It also functions as a surveillance-monitoring tool for clinical and epidemiology practitioners by providing key performance indicators related to this disease in either acute or chronic circumstances. The SNDR will provide data related to the association of diabetes with hypertension, hyperlipidemia, and obesity.

Assessing the economic impact of this disease in the form of direct and indirect costs is part of the SNDR objectives. Social and cultural variables are used by the SNDR system to help in planning for primary and secondary prevention programs. Health facilities and management tool availability reports are produced periodically, which give health planners clear insights and invite proper solutions to be found. The SNDR acts as an advisory body for different heath regions by coordinating data, knowledge, and plans about diabetes and related medical conditions to both national and international institutes.

The registry uses a geographic information system (GIS) with its environmental correlation to produce a variety of maps and reports focusing on diabetes and associated diseases in different health regions. It will also map health care institutions and medical facilities availability and distribution in the Kingdom.

In this paper, an overview of the SNDR structure, functionalities, and reporting system is discussed, and different examples from the reporting systems are given.

Methods

The SNDR is a national government-funded project located in Riyadh, the capital of Saudi Arabia. The program began in1997 with hard copy registry files, which were converted into an electronic Web-based system in 2000. The design and development of the Web-based SNDR has been explained in a previously published article [24].

The registry includes both governmental and private hospitals in addition to primary health care centers. Based on reviews of hospital medical records, highly trained full-time data registrars are assigned to each health institute after an intensive training course on the diabetes registry.

Saudi patients with any type of diabetes, regardless of their age or gender, are eligible for the SNDR. The National Identification Number is used as a unique identifier to avoid any form of duplication. Case classification is performed using American Diabetes Association (ADA) criteria, which designate patients as type 1, type 2, impaired glucose tolerance (IGT), gestational diabetes mellitus (GDM), and secondary diabetes.

The patient's clinical data collection form includes the patient's name, residence location, complete contact details, date of birth, and marital status. Detailed diabetes history includes diabetes type, date of diagnosis, and associated diseases. Social history, including smoking, educational level, occupation, and income, is retrieved from the patient's file. Clinical parameters included are height, weight, and waist circumference. In addition to blood pressure and glycemic markers, fasting blood sugar, random blood sugar, 2-hour post-meal blood sugar, and glycated hemoglobin (HbA1c) are also collected. Laboratory measurements include urine analyses for glucose, protein, ketones, liver enzymes assessment, including alkaline phosphate, serum glutamic-pyruvic transaminase (SGPT), serum glutamic oxaloacetic transaminase (SGOT), and total protein; thyroid function test, including thyroid-stimulating hormone (TSH), T4, and T3; and lipids profile, including cholesterol, triglycerides, high-density lipoprotein (HDL), and low-density lipoprotein (LDL). Lifestyle related to diet and exercise and different therapeutic modalities, namely insulin and oral agents are also included in the registry file. The registry file includes chronic complications, including neuropathy, retinopathy, nephropathy, and vasculopathy, in addition to any associated diseases, such as hypertension, hyperlipidemia, thyroid disease, and others.

Both institutional and national auditing systems are adopted by the SNDR to ascertain data. Approximately 10% to 15% of the registry hard copy files from each institution are randomly selected by the institutional auditor for this purpose. All hard copy registry forms are archived in the national registry archiving room. Each data encoder uses a password-locked access code for data encoding in the registry Web-based software program. National data auditing, cleaning, and validation are performed by a well-trained national auditor, and all soft copy registry data form the data bank for the SNDR. The data bank has a very strong, secure system that protects data from viruses and hackers, as explained in detail in a previous publication [24].

The SNDR has a functionality to query maps by using GIS (Esri, Redlands, CA, USA) consisting of ArcGIS server and desktop ArcGIS version 10 for the design and publishing of all maps. For all designed maps, the World Geodetic System 1984 (WGS1984) geographic coordinate system (GCS) was used. Initial projection scale was 1:10,000,000. The data source for population and city coordinates was the Ministry of Planning and Ministry of Defense using the year 1428 hijri, representing the year 2007 data statistics [25]. Regional gradation on the maps is a representation of the Saudi population at the regional level. The point symbology is a representation of the patient count from various cities. Hospital locations/coordinates were identified using Google Earth [26].

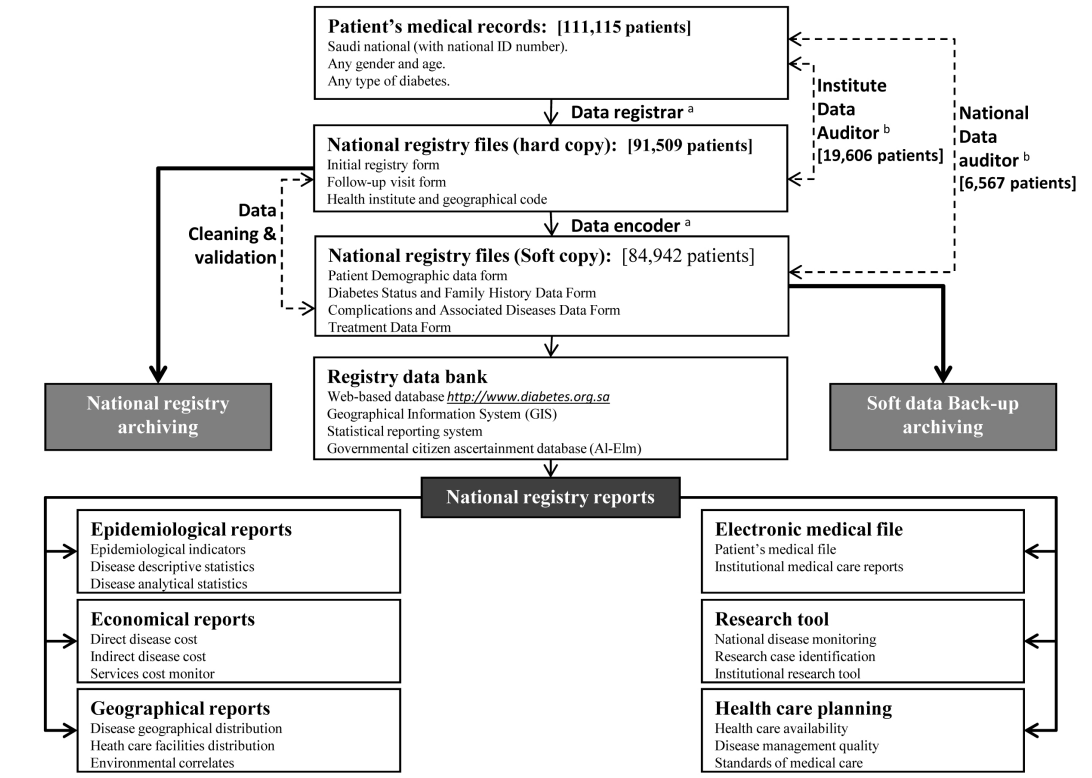
A customized statistical reporting system was used to produce different epidemiology tables and graphs. To input accurate data into this registry, the SNDR registry data are linked to the government citizen database, through the main electronic portal for government and financial sectors [27] that provides additional information that can be used for social and cultural studies.

Figure 1 demonstrates the structure for data collection, encoding, auditing, archiving, and the reporting system for the SNDR. National auditors are responsible for national data auditing, and continuous active cleaning and validation of patients' files before the soft copy file is archived electronically in the SNDR data bank. A highly specialized bioinformatics and statistical team is in charge of producing national registry reports, which include epidemiology, economic, and geographic reports. At the same time, an information technologist and public health specialist are responsible for upgrading the system and preparing reports, which can be used for disease surveillance and public health care planning.

The epidemiology reports generated by the registry include epidemiology indicators and both descriptive and analytical statistics, in addition to providing economic reports that give both direct and indirect disease cost based on the local cost estimate and specific cost analyses for different services and disease management processes. GIS reports provide a geographic description for disease and its chronic complications or associated disease spatial distribution and their environmental correlations. The geographic distribution of health care facilities and management availabilities can help stakeholders better understand the disease and detect gaps in continuum of care, such as lack of facilities or personnel.

The national registry database functions as a patient's medical file, and it is used by the institutions for the same purpose. The plan is to allow all registered patients to access their own files through their national ID number, and to allow them to print out their latest medical report. National disease monitoring and research case identification will be part of the SNDR to encourage researchers in this field at the national or institutional level. The SNDR will be helpful to health care planners through its regular reports on health care availability and disease management quality. For this reason, the SNDR sets the standards of medical care provided for diabetic patients in this country. The main objective of SNDR is to provide different reports that will be useful to health providers, scientists, economists, researchers, and health care planners.

Figure 1. The Saudi National Diabetes Registry structure of data collection, encoding, auditing, and archiving plus its reporting systems.



[a] Data registrars are certified paramedical personnel by a special diabetes registry training program and data encoders are certified secretaries on the diabetes registry encoding both training done at the Strategic Diabetes Research Center. [b] Data local auditor is responsible for internal auditing for specific health institute while the national auditor is responsible for external auditing for a group of health institutes

Results

Overview

The SNDR currently hosts data on 111,115 patients, of which 19,606 are currently audited by institutional auditors and 6567 are in the process of national auditing at the time of this paper preparation. A total of 84,942 patients have passed data auditing, cleaning, and verification and were used to test the national registry reporting system. Figure 2 demonstrates the growth of the SNDR population over the past 12 years from 6886 Saudi diabetics registered in 2000 to 84,942 patients audited at the end of 2012. The registry is growing by 10% annually. The gender distribution is higher in males, accounting for 51.10% in 2012. The distribution of diabetes types was almost identical each of the 12 years; distribution in the year 2012 was 7.83%, 83.50%, 1.29%, 7.29%, and 0.07% for type 1, type 2, IGT, GDM, and secondary diabetes, respectively. The IGT cases are increasing with time from 0.29% in 2000 to 1.29% in 2012.

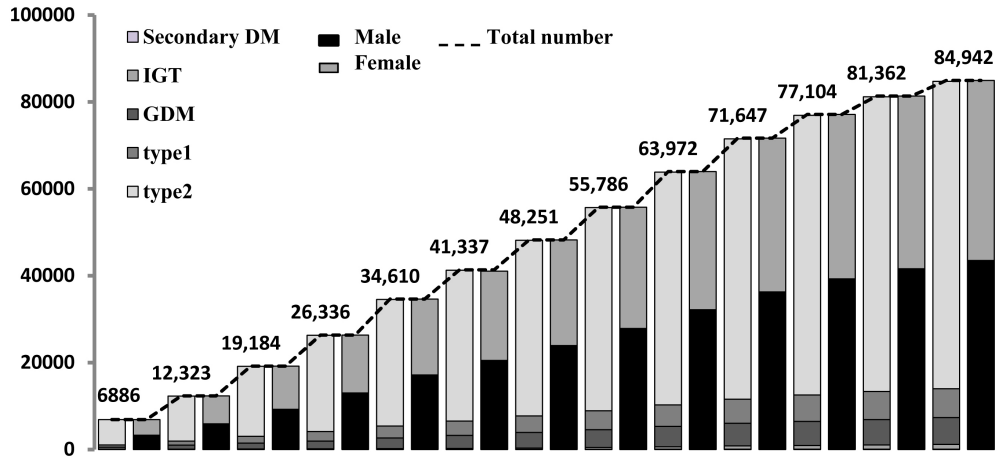
Epidemiology Reports

Table 1 presents a descriptive and analytical statistical report of data from 22 randomly selected hospitals. The data show the total number of diabetic patients, gender, and diabetes type distribution in addition to mean HbA1c for comparative assessment. The number of diabetic patients varies in some hospitals from more than 10,000 diabetic patients to less than 200. The variation is seen in gender distribution, in which males are more numerous than females in some hospitals, but it is the opposite for others. The distribution of diabetes types is representative of the national distribution pattern except for the facility with smaller number of patients (301023). Type 2 diabetes is highly prevalent, ranging between 7.18% and 94.70%, followed by type 1 diabetes (ranges from 4.42% to 77.44%). The range of GDM varies widely, between 0.04% and 37.24%, which is also the same for IGT cases ranging from 0% to 5.56%. The mean HbA1c, an indicator for patients' diabetes control and medical care provided in each institute, has a variable range between 7.3% and 13.6%.

Economic Reports

Table 2 shows an annual economic report on consumption and cost distribution of different insulin types according to diabetes type for a total of 30,414 insulin-using patients. Insulin users represented 35.81% of total registered patients. Among insulin users, 26.49%, 67.34%, and 6.16% are type 1, type 2, and GDM, respectively. The annual average insulin costs according to diabetes type in Saudi Riyals (SR) are 1155 SR (US $308), 1406 SR (US $375), and 1002 SR (US $267) for type 1, type 2, and GDM, respectively. The total cost of insulin therapy is 39,996,370 SR (US $10,665,699); 23.28% is spent on type 1, whereas 72.03% and 4.70% are spent on type 2 and GDM, respectively. Premixed insulin contributes to 55.39% of the total insulin cost per year, regular insulin was 14.49%, and 12.54% was neutral protamine Hagedorn (NPH). The insulin analogs annual costs were 13.47%, 3.82%, and 0.28% for Glargine, Aspart, and Lispro, respectively. Each type of insulin was used more often with type 2 diabetic patients, especially premixed, with the exception of Aspart and Lispro, which were used more often with type 1 diabetic patients.

Figure 2. The yearly total number of registered cases of diabetes according to gender (G) and type (T) of diabetes from the start of registry in 2000 to 2012.



Year	2000		2001		2002		2003		2004		2005		2006		2007		2008		2009		2010		2011		2012	
	T	G	T	G	T	G	T	G	T	G	T	G	T	G	T	G	T	G	T	G	T	G	T	G	T	G
Male	47.68%		47.78%		48.11%		49.44%		49.50%		49.54%		49.61%		49.94%		50.31%		50.65%		50.91%		51.12%		51.21%	
Female	52.32%		52.22%		51.89%		50.56%		50.50%		50.46%		50.39%		50.06%		49.69%		49.35%		49.09%		48.88%		48.79%	
2ry DM	0.07%		0.07%		0.05%		0.05%		0.05%		0.07%		0.07%		0.08%		0.08%		0.08%		0.07%		0.07%		0.07%	
Type2	84.23%		83.99%		83.90%		84.14%		84.18%		84.02%		83.81%		83.85%		83.77%		83.62%		83.50%		83.39%		83.50%	
Type1	7.52%		7.80%		8.20%		8.29%		7.99%		7.96%		7.84%		7.77%		7.74%		7.73%		7.86%		7.91%		7.83%	
IGT	0.29%		0.62%		0.62%		0.54%		0.51%		0.53%		0.61%		0.73%		0.88%		1.05%		1.11%		1.19%		1.29%	
GDM	7.51%		7.30%		7.02%		6.80%		7.09%		7.24%		7.46%		7.36%		7.31%		7.30%		7.21%		7.21%		7.29%	

Table 1. Number of patients and frequency distribution from 22 randomly selected health care institutes according to gender, diabetes type, and mean HbA1c values.

Health institute code	Total patients, n (%) (N=84,467)	Number of patients according to gender, n (%)		Number of patients according to diabetes type, n (%)				Mean HbA1c (%)[a]
		Male (n=43,261)	Female (n=41,206)	Type 1 (n=6624)	Type 2 (n=70,293)	IGT[b](n=1096)	GDM[c](n=6195)	
301003	16,308 (19.31)	8016 (49.15)	8292 (50.85)	1131 (6.98)	12,897 (79.58)	220 (1.36)	1959 (12.09)	8.9
301007	13,597 (16.10)	7085 (52.11)	6512 (47.89)	1502 (11.06)	11,013 (81.11)	248 (1.83)	815 (6.00)	8.9
301008	12,131 (14.36)	7321 (60.35)	4810 (39.65)	626 (5.16)	11,486 (94.70)	12 (0.10)	5 (0.04)	9.6
301001	11,995 (14.20)	5989 (49.93)	6006 (50.07)	737 (6.16)	10,238 (85.50)	402 (3.36)	597 (4.99)	8.3
301011	5578 (6.60)	2935 (52.62)	2643 (47.38)	413 (7.43)	4735 (85.15)	23 (0.41)	390 (7.01)	9.7
301010	5401 (6.39)	2375 (43.97)	3026 (56.03)	578 (10.73)	4581 (85.05)	16 (0.30)	211 (3.92)	9.2
302000	3982 (4.71)	1928 (48.42)	2054 (51.58)	544 (13.68)	3176 (79.84)	2 (0.05)	256 (6.44)	9.3
301016	2839 (3.36)	1714 (60.37)	1125 (39.63)	165 (5.84)	2574 (91.15)	21 (0.74)	64 (2.27)	8.8
302003	2685 (3.18)	1433 (53.37)	1252 (46.63)	138 (5.16)	2215 (82.77)	51 (1.91)	272 (10.16)	7.8
301029	2342 (2.77)	899 (38.39)	1443 (61.61)	112 (4.79)	1327 (56.81)	27 (1.16)	870 (37.24)	7.3
302001	1293 (1.53)	558 (43.16)	735 (56.84)	79 (6.11)	977 (75.62)	23 (1.78)	213 (16.49)	8.1
502007	1108 (1.31)	432 (38.99)	676 (61.01)	88 (7.96)	943 (85.34)	11 (1.00)	63 (5.70)	8.4
302002	857 (1.01)	470 (54.84)	387 (45.16)	72 (8.41)	657 (76.75)	4 (0.47)	123 (14.37)	9.2
301013	763 (0.90)	313 (41.02)	450 (58.98)	56 (7.38)	629 (82.87)	3 (0.40)	71 (9.35)	11.3
301024	633 (0.75)	288 (45.50)	345 (54.50)	28 (4.50)	439 (70.58)	3 (0.48)	152 (24.44)	8.6
301002	570 (0.67)	356 (62.46)	214 (37.54)	43 (7.54)	521 (91.40)	2 (0.35)	4 (0.70)	9.2
301055	554 (0.66)	186 (33.57)	368 (66.43)	45 (8.12)	491 (88.63)	0 (0)	18 (3.25)	13.5
301054	551 (0.65)	231 (41.92)	320 (58.08)	40 (7.38)	457 (84.32)	2 (0.37)	43 (7.93)	13.6
301050	472 (0.56)	246 (52.12)	226 (47.88)	29 (6.20)	387 (82.79)	26 (5.56)	26 (5.56)	9.0
301063	415 (0.49)	243 (58.55)	172 (41.45)	39 (9.40)	366 (88.19)	0 (0)	10 (2.41)	9.4
301038	197 (0.23)	175 (88.83)	22 (11.17)	8 (4.42)	170 (93.92)	0 (0)	3 (1.66)	8.4
301023	196 (0.23)	68 (34.69)	128 (65.31)	151 (77.44)	14 (7.18)	0 (0)	30 (15.38)	10.2

[a]Represents the mean HbA1c for all registered patients at each health institute.

[b]Health institutes without any impaired glucose tolerance (IGT) cases reflect unavailability of the oral glucose tolerance test (OGTT).

[c]Wide variations in the number of gestational diabetes (GDM) cases reflects unavailability of antenatal care.

Table 2. Distribution of consumption and cost of different types of insulin according to diabetes type from the Saudi National Diabetes Registry, 2012 data.

Insulin users and insulin types	Type of diabetes			Total
	Type 1	Type 2	GDM	
Registered patients, n (%)	8058 (26.49)	20,482 (67.34)	1874 (6.16)	30,414 (35.81)
Regular insulin				
Patients, n (%)	2452 (30.94)	4800 (60.56)	674 (8.50)	7926 (26.06)
Mean units/patient/year[a]	7012	8129	8877	7847
Total units/year	17,192,566	39,017,040	5,982,963	62,192,569
Total cost/year (%)[b]	1,602,371 (27.64)	3,636,442 (62.74)	557,620 (9.62)	5,796,434 (14.49)[c]
Neutral protamine Hagedorn (NPH)				
Patients, n (%)	2262 (29.72)	4695 (61.70)	653 (8.58)	7610 (25.02)
Mean units/patient/year [a]	9997	12,282	8012	11,237
Total units/year	22,614,006	57,665,164	5,231,673	85,510,842
Total cost/year (%)[b]	1,326,365 (26.45)	3,382,199 (67.44)	306,850 (6.12)	5,015,414 (12.54)[c]
Premixed insulin				
Patients, n (%)	1990 (16.70)	9518 (79.89)	406 (3.41)	11,914 (39.17)
Mean units/patient/year [a]	18,670	20,433	19,531	20,108
Total units/year	37,152,803	194,478,439	7,929,647	239,560,888
Total cost/year (%)[b]	3,435,974 (15.51)	17,985,798 (81.18)	733,351 (3.31)	22,155,123 (55.39)[c]
Glargine insulin analog				
Patients, n (%)	671 (36.04)	1,133 (60.85)	58 (3.11)	1862 (6.12)
Mean units/patient/year [a]	9877	9552	8734	9644
Total units/year	6,627,400	10,822,473	506,598	17,956,471
Total cost/year (%)[b]	1,988,932 (36.91)	3,247,904 (60.27)	152,034 (2.82)	5,388,870 (13.47)[c]
Aspart insulin analog				
Number of patients (%)	637 (62.39)	304 (29.77)	80 (7.84)	1021 (3.36)
Mean units/patient/year [a]	11,895	13,917	12,742	12,564
Total units/year	7,577,338	4,230,905	1,019,372	12,827,615
Total cost/year (%)[b]	903,219 (59.07)	504,324 (32.98)	121,509 (7.95)	1,529,052 (3.82)[c]
Lispro insulin analog				
Number of patients (%)	46 (56.79)	32 (39.51)	3 (3.70)	81 (0.27)
Mean units/patient/year [a]	11,465	15,593	22,995	13,523
Total units/year	527,374	498,970	68,985	1,095,329
Total cost/year (%)[b]	53,673 (48.15)	50,783 (45.55)	7021 (6.30)	111,477 (0.28)[c]
Cost of insulin therapy				
Total patients/year, n(%)	9,310,534 (23.28)	28,807,450 (72.03)	1,878,386 (4.70)	39,996,370 (100)
Per patient/year (SR)	1155	1406	1002	1315

[a]Mean insulin consumption in units/patients/year.

[b]Percentage of cost/year for each insulin type for different diabetes types. Cost is calculated in Saudi Riyals (SR), in which US $1=3.75 SR.

[c]Percentage of each insulin type cost in reference to the total insulin cost.

Geographic Reports

The SNDR has a designed function to provide a variety of maps for any covariates. Figure 3 shows examples of GIS map screenshots for major diabetes types and age distribution in the Kingdom. The map in part (a) shows a GIS screenshot of type 1 diabetic patients' distribution in the entire country represented by the total number of registered cases. This shows a larger number of type 1 diabetic patients located in the major cities. Part (b) shows type 2 diabetic patients' distribution in different health regions according to the total number of patients that show more distribution in medium-sized cities, in addition to large cities compared with villages and rural areas. Part (c) is a histogram of different age groups in different heath regions. The age groups 40 to 59 years and 60 to 79 years represent the highest percentage distribution in almost all health regions. A magnified version of the type 1 maps, showing the cities of patient's residence along with the distribution of hospitals, is provided in Figure 4.

The gradation on the maps is a representation of the Saudi population at the regional level. Riyadh, being one of the most densely populated regions, has the darkest gradation. Point symbology is a representation of patients registered from various cities of the Kingdom. Colors of the points are the representation of the total count of patients registered from that particular city. The symbol H represents a hospital.

Figure 5 provides regional patient counts for type 2 plus distribution of hospitals around the Kingdom.

The reason for including hospitals, along with a distribution of patients, was to determine the availability of health care facilities required for the targeted treatment and to ensure the communication with the Ministry of Health for provision of the required resources.

Research Tool

The SNDR has a wide range of search options by using different parameters and geographic choices. Figure 6 demonstrates examples of the search facilities, each providing a list of patient names, national IDs, hospital medical numbers, and registry serial numbers that can give direct access to the patients' medical files. In Figure 6, a total of 41,572 patients were found when searching for patients aged between 45 and 65 years, of which 21,268 were women. Of these female patients, 2300 were on premixed insulin only; of these on premixed insulin, 111 patients were found with proliferative retinopathy, microalbuminuria, hypertension, and hyperlipidemia.

Health Care Planning Report

The SNDR is a very useful tool for assessing health care systems and providing advice for future planning. Figure 7 uses ophthalmic examination as an example to test this system in which 84,942 patients' data were analyzed for fundus eye evaluation for retinopathy. Only 22,934 (27.00%) of those registered cases had an ophthalmic exam, of which 7063 (30.79%) were found to have retinopathy. Of all cases with retinopathy, 1779 (25.18%) had proliferative retinopathy warranting laser therapy. Only 1265 (71.10%) had laser therapy; 28.89% did not have access or refused this therapy. Applying the same percentages, of the 62,008 (73.00%) patients who did not have the fundus examination, 19,098 would be expected to have retinopathy, out of which 4812 would need laser therapy.

Figure 3. Geographic information system (GIS) maps demonstrating the diabetic patient distribution for (a) type 1 diabetes and (b) type 2 diabetes at the country level, and (c) the distribution of different age groups in all health sectors.

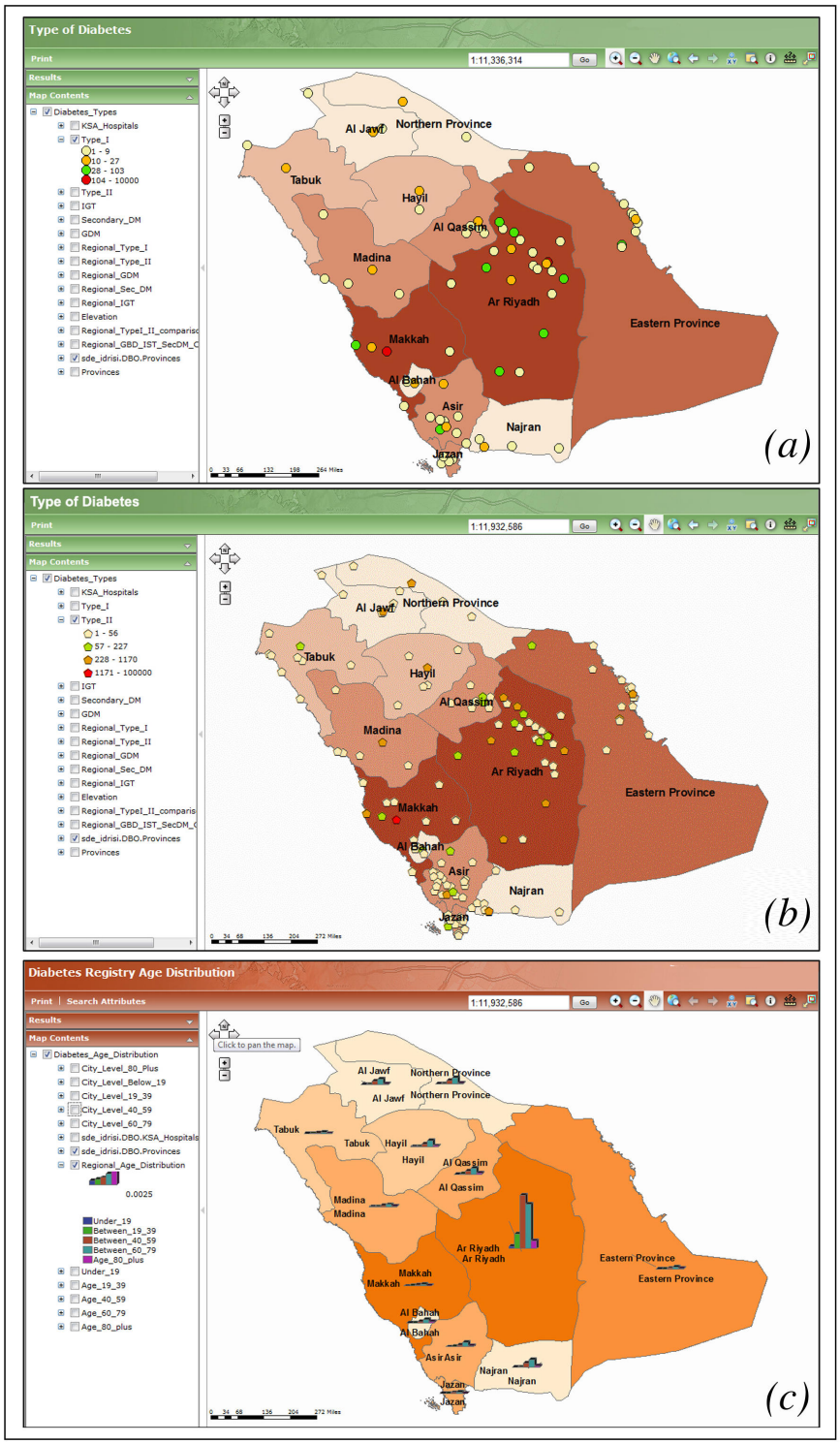


Figure 4. Distributions of (a) hospital (H) locations and (b) type 1 diabetes patients living in Ar Riyadh. The projection scale for these maps is 1:1,029,519.

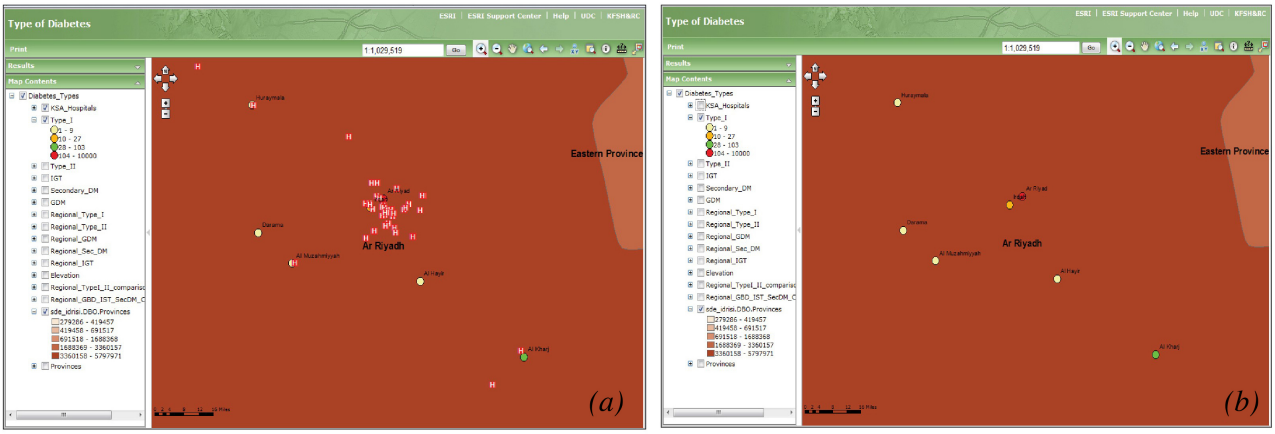


Figure 5. Regional distribution of type 2 patients and hospital (H) locations across the Kingdom. The projection scale for this map is 1:11,170,932.

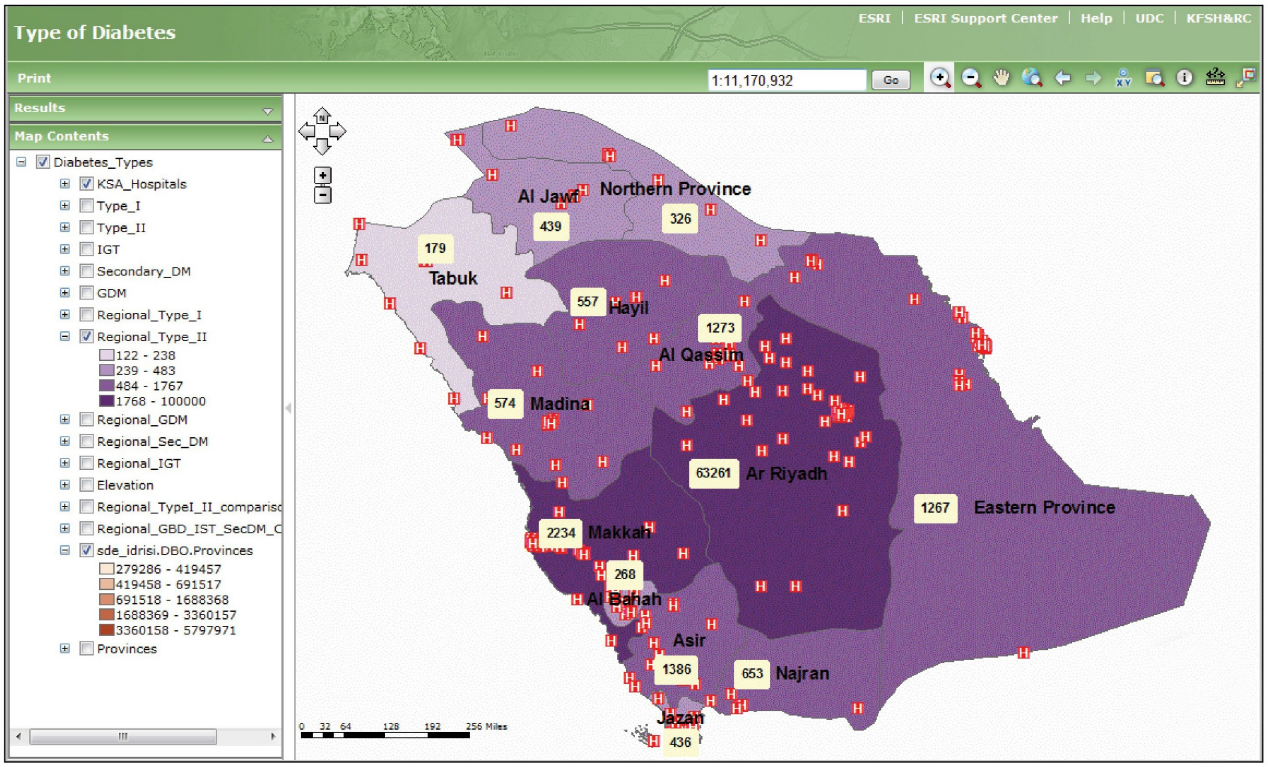
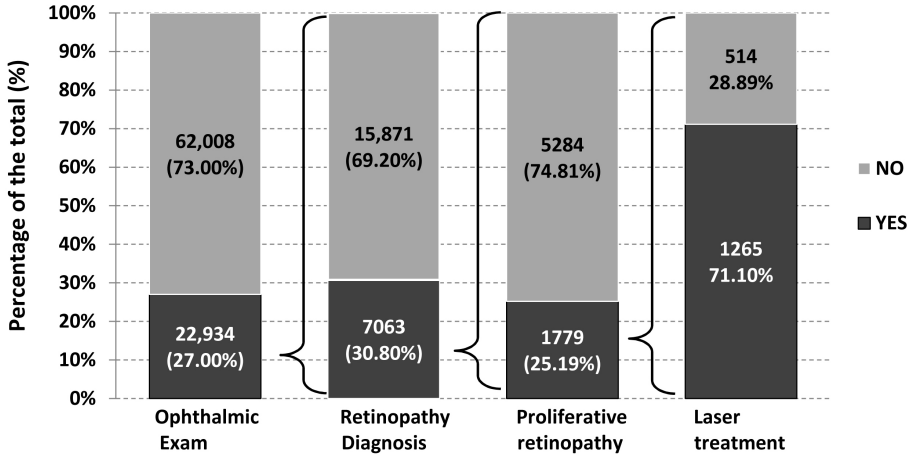


Figure 6. Lists of patient names, national IDs, and hospital and serial numbers generated by the search tool of the SNDR at different stages: (a) all patients between ages 45-65 years, (b) who are female, (c) using premixed insulin, (d) with proliferative retinopathy, microalbuminuria, hypertension, and hyperlipidemia.

Figure 7. The ophthalmic exam coverage and retinopathy diagnosed patients with proliferative retinopathy and those who received or missed laser therapy among the total registered patients.



Discussion

The SNDR is unique in its functionalities, which are not found in other diabetes registries that either risk stratification, such as Joslin's Web-based Diabetes Registry and Risk Stratification System [20], or track clinical outcome, such as the PSHDOI [21], or test embedded guidelines for chronic diseases, such as the CDEMS [22]. No other registry is available today that has similar functionalities and interaction designed for live data queries from the registry. This is the first of its kind to implement GIS as a query layer for a diabetes database, and has linkages to the live governmental citizen ascertainment database.

This descriptive study is the first report to test the functionalities after 12 years of development. The registry's current annual growth rate of 10% gives hope that most diabetic patients will be registered in the Kingdom in less than 10 years. The male to female ratio and different diabetes types are identical to what has been shown internationally. Gender distribution demonstrates the predominance of male gender, whereas the distribution of diabetes types is similar to what is known internationally [28]. The IGT cases were underestimated at the beginning of the registry in the year 2000, but more cases have been reported by the year 2012, which could reflect better case screening or the involvement of primary care centers, which are more likely to catch such cases. However, IGT cases are

still underestimated when compared with the expected number of cases in the Kingdom [12].

The SNDR provides epidemiological indicators, such as incidence, prevalence, mean, and median, that will help to better understand and plan for this disease management. The 22 randomly selected hospitals show variability in gender and diabetes types, which reflect the nature of the hospital (eg, general, pediatrics, or maternity), whereas patient number variations reflect the hospital bed count and outpatient services. The large discrepancies in the distribution of diabetes types can be explained by their diabetic population related to service availability. The mean HbA1c variation is a reflection of the health care management provided by those hospitals.

The SNDR is the first of its kind to provide health care planners with an instantaneous and accurate cost estimation of different aspects related to diabetes and its management. The registry system is capable of estimating both direct and indirect diabetes costs using diabetic population data and local services costs. The annual insulin cost used by the insulin-treated patients in the registry demonstrated that type 2 diabetics are the most frequent insulin users, secondary to the large number of patients and higher doses used per patient, similar to what was shown by Tomlin et al [29]. This confirms that the annual insulin cost is higher in type 2 diabetic patients than type 1 or gestational diabetes, similar to Kumamoto's study conducted in Japan in the year 2000 [30]. Premixed insulin, mostly delivered by insulin pen, consumed more than half of the total insulin cost, whereas mixing regular and NPH by syringes made up 12.54% and 14.49% of the cost. Fewer insulin analogs were used because of their limited availability in the Ministry of Health health care facilities.

The GIS mapping for diabetes types, risk factors, and complications in different health regions in relation to environmental or municipal variables shed further light on the relationship between this disease and different environmental factors. Mapping type 1 diabetes distribution showed that more patients were located in larger cities. This could be because they are more populated than smaller cities, and have specialized health care facilities for this type of diabetes. The higher aggregation of type 2 diabetic patients in medium-sized cities is a reflection of its high prevalence and a wider distribution of primary care centers that provide health care for such patients when compared to smaller cities. The SNDR geographic mapping with its statistical power can produce any countrywide clinical and nonclinical variables that can compare data from different health regions. This study has used age to map different groups in defined geographic areas. When examining the age group 45 to 65 years for the prevalence of diabetes, the result was consistent with local and international epidemiology studies that have found the highest concentration of diabetes among this population [31,32]. The GIS system, as shown, provides a link between the clinical data and health care facilities availability around the patient's location.

By using SNDR as a research tool, it can provide answers for queries related to registry data that will cover medical, social, and cultural parameters. It can provide researchers with patient lists related to specific inclusion and exclusion criteria, and give clinical details for the selected samples and provide answers for the research query. Because of the large number of registered patients, there is sufficient sample strength available to study even with the toughest inclusion and exclusion criteria. As shown in this study, selecting females aged between 45 and 65 years, using only premixed insulin, diagnosed with proliferative retinopathy with microalbuminuria, hypertension, and hyperlipidemia, yielded 111 patients, which is enough to conduct any retrospective or prospective studies.

To test the SNDR as a tool to investigate health care facilities and practice, retinal examination and laser therapy were used to assess medical services available in different health regions. The ophthalmic examination data available revealed that there was underscreening of more than 70% of diabetic patients and one-third of the patients who needed laser therapy did not get it either because it was not available or because of patients' misconception about this therapy. It is expected that one-quarter of the unscreened patients will need laser therapy, and the patients' vision may be threaten if not done. These findings give health planners the chance to discover such problems and give the right advice to overcome any obstacles in treating or preventing diabetic complications.

In conclusion, the SNDR as a data bank for diabetic patients' medical files is useful in monitoring the disease and its chronic complications or associated diseases. The developed epidemiology, economy, or geographic reporting system used in the SNDR is practical, useful, and accurate in assessing and forecasting this chronic disease monitoring and management. The SNDR reports provide health care planners, researchers, and governmental departments with data needed to understand this disease and will allow the launching of primary and secondary prevention programs that could reduce the size of the problem and its economic burden.

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Conflicts of Interest

None declared.

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Abbreviations

ADA: American Diabetes Association
CDEMS: Chronic Disease Electronic Management System
GCS: geographic coordinate system
GDM: gestational diabetes mellitus
GIS: geographic information system
HDL: high-density lipoprotein
IDF: International Diabetes Federation
IGT: impaired glucose tolerance
LDL: low-density lipoprotein
NPH: neutral protamine Hagedorn
OGTT: oral glucose tolerance test
PSHDOI: Penn State Hershey Diabetes and Obesity Institute
SGOT: serum glutamic oxaloacetic transaminase
SGPT: serum glutamic-pyruvic transaminase
SNDR: Saudi National Diabetes Registry
SR: Saudi Riyals
WHO: World Health Organization

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Original Paper

Evaluating Aspects of Online Medication Safety in Long-Term Follow-Up of 136 Internet Pharmacies: Illegal Rogue Online Pharmacies Flourish and Are Long-Lived

Andras Fittler[1*], PharmD, PhD; Gergely Bősze[1*], PharmD; Lajos Botz[1*], PharmD, PhD, Habilitation

Department of Pharmaceutics, Medical School, University of Pecs, Pecs, Hungary

[*]all authors contributed equally

Corresponding Author:
Andras Fittler, PharmD, PhD
Department of Pharmaceutics
Medical School
University of Pecs
Honved Street 3
Pecs, H-7624
Hungary
Phone: 36 205566509
Fax: 36 72 536 285
Email: fittler.andras@pte.hu

Abstract

Background: A growing number of online pharmacies have been established worldwide. Among them are numerous illegal websites selling medicine without valid medical prescriptions or distributing substandard or counterfeit drugs. Only a limited number of studies have been published on Internet pharmacies with regard to patient safety, professionalism, long-term follow-up, and pharmaceutical legitimacy verification.

Objective: In this study, we selected, evaluated, and followed 136 Internet pharmacy websites aiming to identify indicators of professional online pharmacy service and online medication safety.

Methods: An Internet search was performed by simulating the needs of potential customers of online pharmacies. A total of 136 Internet pharmacy websites were assessed and followed for four years. According to the LegitScript database, relevant characteristics such as longevity, time of continuous operation, geographical location, displayed contact information, prescription requirement, medical information exchange, and pharmaceutical legitimacy verification were recorded and evaluated.

Results: The number of active Internet pharmacy websites decreased; 23 of 136 (16.9%) online pharmacies ceased operating within 12 months and only 67 monitored websites (49.3%) were accessible at the end of the four-year observation period. However, not all operated continuously, as about one-fifth (31/136) of all observed online pharmacy websites were inaccessible provisionally. Thus, only 56 (41.2%) Internet-based pharmacies were continuously operational. Thirty-one of the 136 online pharmacies (22.8%) had not provided any contact details, while only 59 (43.4%) displayed all necessary contact information on the website. We found that the declared physical location claims did not correspond to the area of domain registration (according to IP address) for most websites. Although the majority (120/136, 88.2%) of the examined Internet pharmacies distributed various prescription-only medicines, only 9 (6.6%) requested prior medical prescriptions before purchase. Medical information exchange was generally ineffective as 52 sites (38.2%) did not require any medical information from patients. The product information about the medicines was generally (126/136, 92.6%) not displayed adequately, and the contents of the patient information leaflet were incomplete in most cases (104/136, 76.5%). Numerous online operators (60/136, 44.1%) were defined as rogue Internet pharmacies, but no legitimate Internet-based pharmacies were among them. One site (0.7%) was yet unverified, 23 (16.9%) were unapproved, while the remaining (52/136, 38.2%) websites were not available in the LegitScript database. Contrary to our prior assumptions, prescription or medical information requirement, or the indication of contact information on the website, does not seem to correlate with “rogue pharmacy” status using the LegitScript online pharmacy verification standards. Instead, long-term continuous operation strongly correlated (P<.001) with explicit illegal activity.

Conclusions: Most Internet pharmacies in our study sample were illegal sites within the definition of “rogue” Internet pharmacy. These websites violate professional, legal, and ethical standards and endanger patient safety. This work shows evidence that

online pharmacies that act illegally appear to have greater longevity than others, presumably because there is no compelling reason for frequent change in order to survive. We also found that one in five websites revived (closed down and reopened again within four years) and no-prescription sites with limited medicine and patient information are flourishing.

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KEYWORDS

online pharmacies; Internet pharmacy; online pharmaceutical services; online medicines; counterfeit medicines; patient safety

Introduction

The Internet has revolutionized communication, trade, and health services. Three-quarters of EU households have access to the Internet and one-third of Europeans used the Internet on mobile devices away from home or work [1]. One of the most popular uses of the Internet is to find medical information [2] and thus many patients rely on it as their main resource [3]. Although the Web offers numerous opportunities to improve health, it also presents an enormous health hazard since it represents an unregulated market with almost no consumer protection [4]. Internet-based commerce provides access to a large variety of health-related products, such as complementary medicines, over-the-counter medications (OTC), and prescription-only medicines via Internet-based pharmacies (also called online pharmacies, cyber pharmacies, or e-pharmacies) [5].

Online pharmacies can be beneficial to consumers (eg, convenience, privacy, free access to information, comparison shopping, etc) but can also carry with them numerous disadvantages (eg, lack of meaningful interaction with physician and pharmacists, misdiagnosis, inappropriate use of medicines, personal data protection, etc) [5-7]. These disadvantages and dangers are further exacerbated in the case of unlicensed and illegally operated online pharmacies.

Regrettably, the majority of online drug sellers violate safe pharmacy practices and laws, as numerous websites sell medicines without valid medical prescriptions and have been shown to distribute substandard, illegal, unapproved, or counterfeit drugs [4,6,8]. The likelihood of encountering such potentially dangerous medicines on the Internet is extremely high as the number of illegally operating online pharmacy sites is enormous [6] and legitimate sellers are crowded out by illicit websites [9]. In fact, more than one hundred million Web pages are indexed in Google when searching “no prescription required” [10] and out of more than 35,000 evaluated active pharmacy websites 95.0% were classified as not legitimate according to the LegitScript Internet pharmacy certification standards [11]. The latest report by the National Association of Boards of Pharmacy (NABP) also found that the vast majority of Internet pharmacy sites are operating in contravention of US federal and state pharmacy laws, as 96.7% of more than 10,000 reviewed Internet drug outlets selling prescription medications were identified as “not recommended” [12].

In many cases, customers are not aware that products offered by online pharmacies may not have the same quality that a retail pharmacy may offer [13,14] and often it is difficult to determine whether a website is legitimate or not [15], further making consumer differentiation between an original drug and a counterfeit version a difficult task [16]. Consequently, the growth of the unregulated drug market and the spread of counterfeit medications are becoming a serious public health risk [17,18], while also creating a financial burden on the health care system due to ineffective drug treatments, adverse events, and needed remedial care [9,17,19].

Although different classifications for online pharmacies have been published [6, 20-23], from the patient safety perspective, Internet-based pharmacies can be classified basically as (1) legitimate Internet pharmacy websites providing high-quality pharmacy services according to verification standards, and (2) illegitimate online pharmacies that are not verified and may not comply with national or international professional standards and regulations. Legitimate Internet pharmacies must adhere to both the laws and regulations of the country where the website operates from and the destination country [24]. These websites are verified, monitored, and require valid prescriptions for prescription-only medicines; thus, they are safe to use and can be recommended for patients. Illegitimate online pharmacies either have not been subject to a certification process or fail to comply with national or international standards and regulations. Such illegal online vendors may sell medicines without prescriptions or market counterfeit and substandard products [6,17]. Accordingly, the safety of illegitimate websites is not assured and these Internet pharmacies should not be recommended for patients. Illicit Internet pharmacies can further be divided into different subcategories based on how drugs are prescribed and dispensed. The term “rogue” Internet pharmacy (although often used interchangeably with “illegal”) refers to websites that facilitate the sale of drugs in a way that is not subject to sufficient regulatory oversight [24]. These rogue online vendors enable the sale of prescription drugs or other medicinal products (either directly on the website or indirectly by directing patients to another website) and violate applicable laws or regulations [24]. Those websites that provide drugs without a legitimate prescription from a physician are often titled “no-prescription online pharmacies” [25]. It is most likely that individuals who may be behind rogue websites are licensed neither as pharmacies nor as pharmacists [26]. Illegitimate websites often operate from developing countries with lack of regulatory oversight and enforcement regarding Internet-based commercial operations [27].

Owing to the principles of free movement of goods, capital, and services, especially in the European Union [28], but also in other parts of the world due to free-trade agreements and customs unions and the anonymous always-changing nature of the Internet, the illegal online sale of medicines is difficult to regulate. In fact, it is probably impossible to keep the Internet

free from illegal sites [13,29]. A global approach and international legal framework with adequate safety standards is needed to regulate online medical services [29-31]. Until a globally accepted and effective method is developed, it is important to evaluate and study online pharmacies as useful "snapshots" of this problematic issue.

Several papers have been published on the evaluation of online pharmacies and products obtained from such sources. Numerous important findings are summarized in a comprehensive review by Orizio et al on products offered, prescription requirement, online questionnaires, prices, drug information, etc [5]. Most studies confirm that the majority of online pharmacies do not require customers to possess a valid prescription [32,33] nor any medical information from patients [34]. Furthermore, patients have insufficient access to relevant medication information when ordering drugs online [35]. Despite the complexity of this issue and the different methods used for the evaluation of online pharmacies, consumer/patient safety is a commonly evaluated parameter of most studies [5]. Although numerous characteristics of online pharmacies can be evaluated, it is of great importance to determine specific parameters that may be considered as reliable indicators of trustworthy online pharmacies.

We have hypothesized that the quality of service is strongly related to the increasing age of the pharmacy, as illegal operators are either eliminated due to market forces driven by the public intervention of unsatisfied customers or as a consequence of law enforcement and legal regulations [22]. The requirement for a valid medical prescription is a widely studied parameter of online pharmacies [5] and its absence was considered to be a potential indicator of illegal activity. In addition, we believed that professional certifications are the most specific indicators of high-quality health content and medication safety, thus pharmacy accreditation logos and legitimacy verifications—such as Internet pharmacy classifications according to the LegitScript database—are important indicia of valid online pharmacy operations. Consequently, in this study we selected, evaluated, and followed 136 Internet pharmacy websites for four years, aiming to identify indicators of professional online pharmacy service and online medication safety.

Methods

Overview

A specific evaluation tool was developed, including questions regarding the longevity, contact information, and the geographical location of online pharmacies. Also, we documented the distributed product categories, requirement of medical prescriptions and health questionnaires, channels of information exchange, and patient safety (see Multimedia Appendix 1). Correlations between operational longevity (age effect), distributing medicines without valid prescriptions (prescription requirement), availability of drug information and online consultation (information exchange), street address and telephone number (contact information), and legitimacy certifications (approval by LegitScript) were assessed to evaluate potential indicators of medication safety.

Websites were identified using the Google search engine; the Internet search was performed with the aim of finding websites selling one or more of 15 previously selected active ingredients. The active ingredients were chosen arbitrarily by the inclusion of regularly used and popular pharmacological categories, based on the authors' professional experience, literature results, and pharmaceutical consumption databases. We aimed to simulate needs of different potential customers of online pharmacies; thus, a wide variety of drug classes were selected. We have included in our study anti-obesity drugs (sibutramine, orlistat) and medications used in erectile dysfunction (sildenafil), as the earlier Internet pharmacies tended to sell principally lifestyle medications [5]. An opioid analgesic (tramadol), two commonly used anxiolytics (diazepam, alprazolam), two antidepressants (venlafaxine, fluoxetine), and two nonsteroid anti-inflammatory drugs (diclofenac, acetaminophen/paracetamol) were also included. One commonly used antibacterial for systemic use (amoxicillin) and a systemic antiviral (oseltamivir) were also among our searched medicines. Although most medications used without medical control can have unfavorable consequences, corticosteroids for systemic use (methylprednisolone, prednisolone) and an antineoplastic agent (methotrexate) were also analyzed, as their inappropriate use is fraught with danger.

Online pharmacies were searched for using the search engine Google with the keywords "buy", "online", and "pharmacy", with the combination of the name of the active ingredient listed above (eg, "buy sibutramine", "sibutramine online", or "sibutramine pharmacy" as specific search terms). By documenting the first 20 references appearing in Google, we could simulate what patients can easily find and what websites they most probably visit when searching for online pharmacies, since 95% of search engine users click on the hits/records displayed on the first two search engine results pages [36]. Websites with multiple hits were included once in our database. Only websites operating in English were included in our study, as it was supposed that they are available to a broad clientele worldwide.

A total number of 300 records were gathered and screened between February and March 2008, which led to a database of 136 websites, excluding duplicates and websites that did not sell products. Numerous relevant professional characteristics of online pharmacies such as the longevity (time of existence) of the online pharmacy, location of operation, product categories sold, requirement of medical prescription, medical information exchange, payment and delivery conditions, user-friendliness, and applicability were recorded and evaluated by the authors (see Multimedia Appendix 1 for the complete list of questions). The data was summarized by descriptive analysis and a chi-square test was performed to evaluate correlations between legitimacy according to LegitScript verification database and potential indicators of medication safety (longevity, prescription requirement, information exchange, and displayed contact information).

Long-Term Accessibility of Online Pharmacies

The longevity of Internet pharmacies was assessed by documenting the online availability of the website's domain

name between February 2008 and February 2012 at 6-10 month interim periods. An Internet pharmacy was considered to be active if the pharmacy website was accessible and inactive if it was not available. Continuity of operation was calculated through the first disappearance (unavailability). Those websites that were available throughout the whole study interval of 48 months were considered as continuously operational, while those that were not available at one or more occasions but reopened again at some time were defined as reviving Internet pharmacies.

Location of Operation and Contact Information

Identification and accessibility of the medicine supplier is of significant importance as the anonymity provided by the Internet allows online pharmacies to conceal the street address and the telephone number of their companies. We aimed to gather data on the availability of contact information on the website and the actual geographical location of the server according to its IP address.

Each website was evaluated by the assessment of the main page, the copyright information, the contact information, the frequently asked questions, and the "about us" pages. We documented the year the site was established and any contact information (street address, telephone number) stated by the operators. The IP address was acquired by the "tracert" command in Microsoft Windows and the geographical location was determined by a free Web-based program available at www.IP2location.com.

Product Categories Offered

We assessed the variety (brand or generic) and types (OTC, prescription-only) of drugs sold and also how many active ingredients were offered by the online pharmacy website. During the evaluation of the ordering process, the billing, shipping, and payment options were documented.

Requirement of Medical Prescription

During the ordering and the payment process, the authors documented if the website requested medical prescriptions for prescription-only medicines. Countries may define pharmaceuticals differently according to prescription requirement but, since legitimate Internet pharmacies must also adhere to the regulations of the country the website offers to ship drugs to, we have taken Hungarian regulations into account and considered only two nonsteroid anti-inflammatory drugs (diclofenac and acetaminophen) as OTC.

Exchange of Medical Information

In our survey, we evaluated how online pharmacies gather data from their customers (information requirement) and also analyzed the quantity and quality of medical information patients can find (information availability). The authors evaluated whether the websites used online questionnaires or whether there was an opportunity to interact with the provider and/or health care professionals on the website via online chat, telephone, or email. The available medical information regarding the pharmaceuticals marketed was determined by assessing the general product information (introducing the medication and its effects) during the ordering process. We have also evaluated the online version of the patient information leaflet, which contains specific information about medical conditions, doses, side effects, storage, pregnancy, breast-feeding, etc. Both sources of medication information were categorized as (1) "detailed" if the authors judged the provided data to be enough to support safe use of the product, (2) "incomplete" when only a short description of the affect was highlighted or important sections of the patient information leaflet were missing, and (3) "not available" if no data was accessible regarding the medication.

Accreditation and Verification of Internet Pharmacy Websites

Several codes and seals of verification can be displayed on online pharmacy websites. In addition to different nonpharmaceutical verification methods (eg, TRUSTe logo confirming the identity of the company and VeriSign logo guaranteeing privacy principles and data protection), specific professional accreditation programs exist for Internet pharmacies in some countries like the United States (Verified Internet Pharmacy Practice Site or VIPPS [37], which is recommended by the US Food and Drug Administration, and LegitScript [11] whose standards are accepted by the US National Association of Board of Pharmacy), United Kingdom (Registered Internet Pharmacy [38] under the UK General Pharmaceutical Council), or Germany (German Institute of Medical Information and Documentation or DIMDI [39], which registers official pharmacies approved for a mail order permit of sales). In addition, private certification services without government sanction or recommendation also exist such as the Canadian International Pharmacy Association (CIPA) or PharmacyChecker. We searched for pharmacy-related private and professional organizational logos and seals on the main page of active websites at the end of the observation period.

Legitimacy According to LegitScript Verification Database

LegitScript is a private company monitoring online pharmacies; its pharmacy certification program adheres to NABP recognized standards [23]. Currently, the company maintains the world's largest database of Internet pharmacies and health-related websites, more than 35,000 and 290,000, respectively [11]. To evaluate the legitimacy of online pharmacy websites included in our research, we checked the URL addresses within the LegitScript database at the end of the four-year observation period in 2012. Internet pharmacy websites are classified by LegitScript into four categories (legitimate, unverified, unapproved, and rogue). "Legitimate" sites are those that have been through a verification process and are confirmed to meet LegitScript standards. "Unverified" Internet pharmacies are likely to comply or easily able to comply, with minimum adjustments to LegitScript requirements, but have not been subject to the certification process. "Unapproved" Internet pharmacies do not comply with LegitScript's verification standards or applicable laws or regulations, but do not meet the definition of being rogue. "Rogue" Internet pharmacies are those illegitimate websites that directly or indirectly facilitate the sale of prescription drugs or other medicinal products and violate, appear to violate, or encourage violation of US federal or state

law or regulation. These online vendors do not adhere to accepted standards of medicine and/or pharmacy practice (including standards of safety) and/or are engaged in fraudulent or deceptive business practices. Although LegitScript maintains a large database of websites, the ones that were not evaluated by the organization were labeled as “Not available in the database” in our study. Offline websites remain in the LegitScript database until the domain name registration expires.

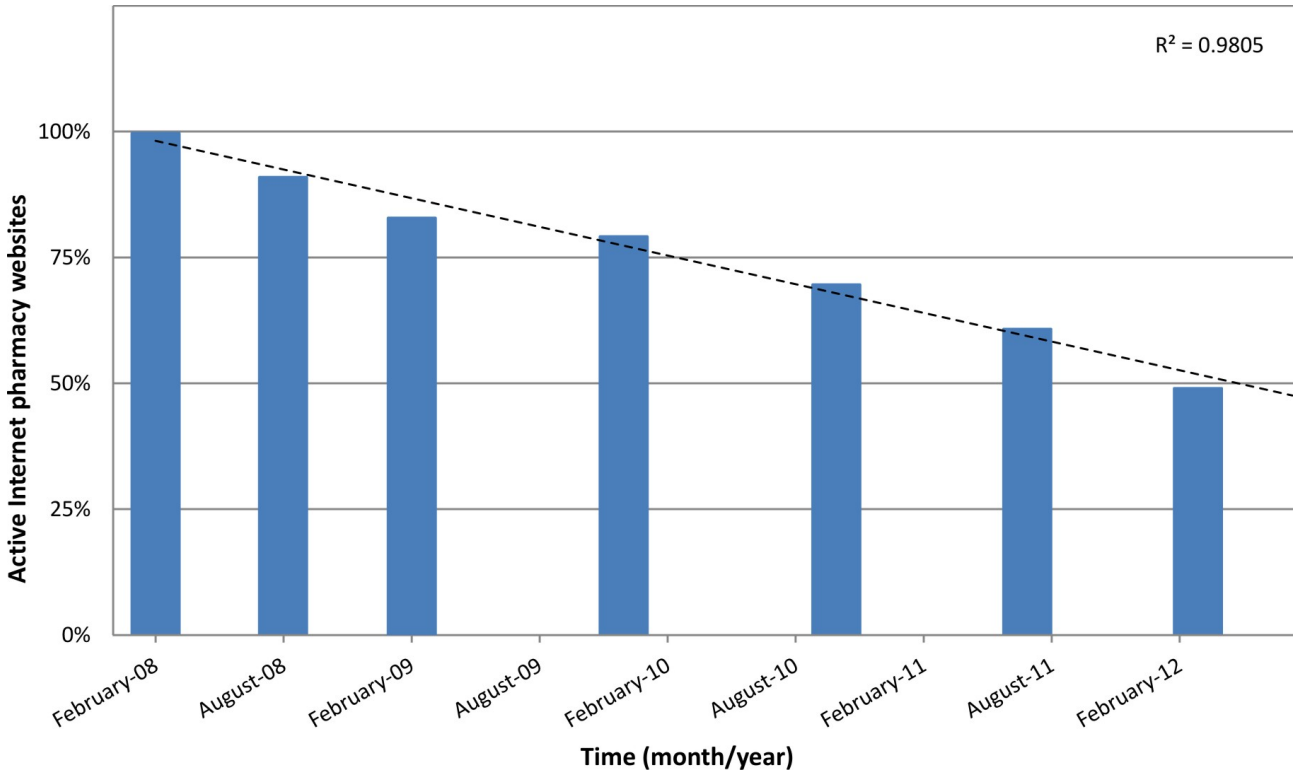
In the United States, the NABP operates VIPPS, a voluntary accreditation program that lists Internet pharmacies either as accredited or “not recommended”. The latter are Internet drug sellers that do not comply with state and federal laws and regulations and NABP’s criteria assuring patients’ health and safety [8]. The VIPPS accreditation was not chosen as a primary indicator, since to date NABP has reviewed a smaller sample of 10,000 sites and VIPPS is subject to application and annual participation fees.

Results

Long-Term Accessibility of Online Pharmacies

The number of active Internet-based pharmacy websites evaluated in our study was constantly decreasing (Figure 1). Within one year, 23 of 136 (16.9%) websites disappeared or ceased operation, while just 67 (49.3%) monitored Internet pharmacy websites were accessible at the end of the four-year observation period from the original sample of 136. The number of operating Internet pharmacies decreases with time; this trend shows a negative correlation (linear regression R^2= 0.9805). It is important to note that not all of the 67 websites operated continuously during the four years. We observed that about one-fifth (31/136) of all observed online pharmacy websites “closed down” (were inaccessible) at least once and became active again during the four-year time span (ie, revived). Only 56 of the 136 (41.2%) Internet-based pharmacies were in continuous operation for the four-year study period.

Figure 1. Percentage of active websites (including revival sites) from the original study sample of 136 Internet pharmacies.



Location of Operation and Contact Information

Thirty-one (22.8%) of the 136 online pharmacies did not display any contact information (postal address or telephone number), while only 59 (43.4%) displayed both pieces of information on the website. Although most Internet pharmacies (102/136, 75.0%) showed their telephone number for customers, only 63 (46.3%) gave details of the physical location on their website. Seventy-three (53.7%) of the 136 Internet pharmacies did not give information on postal address; 25 sites stated they were located in Europe (18.4%), 19 in North America (14.0%), 5 in the Pacific (3.7%), 4 in the Caribbean (2.9%), and 10 elsewhere (7.3%).

To test online pharmacy location claims, we compared the website’s declared physical location with the area of its domain registration according to the IP address. We found that the declared physical location did not correspond to the area of domain registration for most websites, as only 32 (23.5%) of 136 Internet pharmacy domains were registered in the same continent as the declared physical location of operation and only 13 (9.6%) sites operated their server within the borders of the same country. According to the identification of the IP address, website domains were most frequently located in the following countries: United States (69/136, 50.7%), United Kingdom (14/136, 10.3%), Russia (9/136, 6.6%), Panama (7/136, 5.1%), Israel (5/136, 3.7%), Canada (4/136, 2.9%),

Netherlands (4/136, 2.9%), New Zealand (4/136, 2.9%), and 20 (20/136, 14.7%) elsewhere.

Product Categories Offered

In general, online pharmacies in our study sample specialized in selling prescription only medicines (120/136, 88.2%) and few offered over-the-counter medications exclusively (16/136, 11.8%). Most Internet pharmacies (72/136, 52.9%) sell only generic drugs; roughly one-fifth (26/136, 19.1%) offered solely brand name products. Herbal, hygiene products, and cosmetics were infrequently offered in our sample.

With respect to the types of different active ingredients sold, online pharmacies divided themselves into two main categories. The great majority (111/136, 81.6%) were vendors of more than 10 different active substances. Lifestyle drugs (eg, sildenafil and orlistat) and opioid painkillers (eg, codeine and tramadol) were generally available on almost every website. Others (13/136, 9.6%) focused on marketing only one therapeutic, for example, tramadol or sibutramine. Further, it took only a couple of minutes to find doxorubicin, erythropoietin, or even stem cells marketed over the Internet.

Requirement for Medical Prescriptions

Similar to previous earlier reports of online medicine sales without valid medical prescriptions [32,33,40], here only 9 (6.6%) of the 136 online pharmacies in this study requested them. The remaining 127 (93.4%) allowed checkout (the last step of online shopping process) and credit card payment without any medical documentation.

Exchange of Medical Information

Online medical questionnaires were the major source of information on the health status of patients (84/136, 61.8%) but 52 sites (38.2%) did not require any medical information from customers before buying medicines. Sixty-six (48.5%) of the 136 studied online pharmacies made online consultation available on their website via online chat, telephone, or email (Table 1).

The availability of medical information was also limited on most websites (Table 2). General product information (medical use, description of pharmacological effect, and indications) was generally (126/136, 92.6%) not adequately displayed. Most sites may assume that customers know what they need and that people are making decisions exclusively based on product price. The patient information leaflet was found to be detailed on just one website (0.7%); it was incomplete in most cases (104/136, 76.5%), and the authors were not able to identify all its essential chapters on nearly every fourth website (31/136, 22.8%).

Accreditation and Verification of Internet Pharmacy Websites

At the end of the four-year observation period, we examined the 67 active Internet pharmacies and we could identify eight types of pharmacy-related seals posted on 11 (16.4%) websites. These included CIPA and PharmaCheck seals displayed on 3 websites each, TrustedRx and PharmacyChecker logo found on 2 sites each, and a Registered Internet Pharmacy (UK) seal on one website. A vast majority (56/67, 83.6%) of active study online pharmacies did not present any pharmaceutical or professional logo. The VIPPS or LegitScript legitimacy seals were not observed in our study sample.

Legitimacy According to LegitScript Verification Database

We checked the URL addresses of the online pharmacies in this study using the LegitScript database. Out of the 136 Internet pharmacies evaluated in our sample, 52 (38.2%) websites were not available in the database, 1 site (0.7%) was yet unverified, while 23 online pharmacies (16.9%) were unapproved. Numerous online operators (60/136, 44.1%) were defined as rogue Internet pharmacies, but no legitimate Internet-based pharmacies were among them. Table 3 shows the distribution of Internet pharmacies of different legitimacy codes within all evaluated sites and websites that were continuously operational for four years. As can be seen, the vast majority of long-lived websites are unsafe for patients, as they are either unapproved (17/56, 30.4%) or rogue (36/56, 64.3%).

The correlation between rogue online pharmacy legitimacy category and certain important characteristics of Internet pharmacies (longevity, prescription requirement, medical questionnaire, and contact information) was analyzed to evaluate which properties may indicate illegitimate operation or refer to patient health risks (Table 4). Our results did not support our initial hypothesis that rogue online pharmacies operate for a shorter time period. On the contrary, more rogue (36/56, 64.3%) online pharmacies operated continuously for 48 months. Somewhat less than half (57/127, 44.9%) of the websites not requiring medical prescriptions from the total study sample were rogue pharmacies. Similar results were obtained when the requirement of medical information in a medical questionnaire was evaluated, as out of 52 Internet pharmacy sites dispensing medicines without requesting customers to provider their medical status on an online form, 23 (44.4%) were rogue. Highlighting the physical location or the telephone number of the online pharmacy on the website did not seem to affect verification category (Table 4). Thus, only the time of continuous operation correlated (negatively) with legitimacy using LegitScript verification database.

Table 1. Sources of medical information exchange on Internet pharmacy websites (N=136).

		n (%)
Online consultation		
	Available	66 (48.5)
	Not available	70 (51.5)
Self-completed online medical questionnaire		
	Required	84 (61.8)
	Not required	52 (38.2)

Table 2. Information availability on marketed medicines (N=136).

		n (%)
General product information		
	Detailed	2 (1.5)
	Incomplete	8 (5.9)
	Not displayed	126 (92.6)
Patient information leaflet		
	Detailed	1 (0.7)
	Incomplete	104 (76.5)
	Not displayed	31 (22.8)

Table 3. LegitScript legitimacy code of total evaluated Internet pharmacies and continuously operational websites.

LegitScript legitimacy code categories	Evaluated Internet pharmacy websites, n (%)	Websites within the “48 months continuously operational” category, n (%)
Legitimate	0 (0)	0 (0)
Unverified	1 (0.7)	1 (1.8)
Unapproved	23 (16.9)	17 (30.4)
Rogue	60 (44.1)	36 (64.3)
Not available in the database	52 (38.2)	2 (3.6)
Total	136 (100)	56 (100)

Table 4. Correlation between various evaluated factors of 136 online pharmacies with rogue Internet pharmacy verification status according to LegitScript database.

Selected outcome parameters of our online evaluation process (n)		Rogue[a]	Not defined as rogue[b]	Chi-square test
Continuous long-term operation				
	Yes (56)	36 (64.3)	20 (35.7)	*P*<.001
	No (80)	24 (30.0)	56 (70.0)	
Prescription requirement				
	Yes (9)	3 (33.3)	6 (66.7)	*P*=.50
	No (127)	57 (44.9)	70 (55.1)	
Requirement of medical information in an online questionnaire				
	Yes (84)	37 (44.0)	47 (56.0)	*P*=.98
	No (52)	23 (44.2)	29 (55.8)	
Geographical location is stated on website				
	Yes (62)	28 (45.2)	34 (54.8)	*P*=.82
	No (74)	32 (43.2)	42 (56.8)	
Telephone number indicated on website				
	Yes (102)	47 (46.1)	55 (53.9)	*P*=.43
	No (34)	13 (38.2)	21 (61.8)	

[a]Rogue Internet pharmacies are websites that directly or indirectly facilitate the sale of prescription drugs or other medicinal products, and violate, appear to violate, or encourage violation of Federal or state law or regulation.

[b]Not defined as rogue online pharmacy category includes unapproved (that do not meet verification standards), unverified (not evaluated) online pharmacies, and websites not found in the LegitScript database.

Discussion

Principal Findings

Our longitudinal study of Internet pharmacies shows that the longevity of operations seems to be associated with illegal status and one-fifth of the websites revived during the four years. Further, the majority of websites are no-prescription Internet pharmacies and the limited availability of patient information and opportunity for patient discussions are negative determinants of patient and medication safety on many of these websites.

A great number of online pharmacies operate illegally and offer medicines to buyers without a valid medical prescription. However, of importance, they offer these illicit sales long term. As far as we know, this study provides the first evidence that, in fact, illegal activities are correlated with longevity success in the illicit online pharmacy market. However, with virtually all of these online sellers highly suspect because they provide little substantive information and incomplete patient information, they create patient safety risks. Perhaps even more importantly, they may subject their buyers to the risks of counterfeit, poor quality, and dangerous forms of medications without medical supervision.

In the longitudinal study of the survival of 136 Internet pharmacy websites, we searched the Internet with the key words “buy”, “online”, “pharmacy”, together with the combination of the names of 15 active ingredients. Numerous relevant professional characteristics of online pharmacies were recorded and evaluated (see Multimedia Appendix 1 for complete list of questions). It was observed that several (23/136, 16.9%) online pharmacies closed down within the first year while only half of them (67/136, 49.3%) were accessible at the end of the four-year observation period. We noticed that not all of these remained active continuously; more than one-fifth (31/136, 22.8%) of online pharmacies included in our study were classified as a “revival site”, where it ceased its continuous activity transitionally but resumed operation sometime later. Only 56 (41.2%) Internet-based pharmacies were in continuous operation while the remaining ones (80/136, 58.8%) were inaccessible at least one time during the four-year study period. It is also interesting to note that more than one-third (31/80, 38.8%) of these closed down websites revive. Thus, it is likely that more reviving websites could have been identified with more regular (possibly weekly or monthly) visits during follow-up.

These reviving sites may aim to temporarily disappear to avoid actions of legal authorities or unsatisfied customers. We have also observed that domain names of inactive websites are advertised. These domains are presumably sold to other Internet pharmacy operators who may take advantage of having well-known brand names or ones that rank high with search engines.

It is clear that the Internet and its support organizations allow entities to conceal their street address and the telephone number of their actual operators. Consequently, it is not surprising that less than half of the online pharmacies displayed their contact street address on their website. In fact, websites may fraudulently present false information to attract their customers.

For example, it has been reported that patients and potential customers who find Canadian online pharmacies more trustworthy buy products from websites displaying Canadian symbols, but in reality the website may be registered elsewhere and the products originate from other countries [41]. In our study, we found that the declared physical location (displayed on the website) did not correspond to the registration domain (according to IP address) for the majority of the studied Internet pharmacies, as only one of 10 online pharmacies' domain name registration was within the country of operation as declared on the website.

Although it would be difficult to draw unambiguous conclusions from these findings, it is a warning sign that numerous Internet pharmacies veil their contact information, while ones providing such details generally register their domains in countries other than displayed. Such great discordance between the location of domain registration compared with physical location may indicate that online pharmacies mainly operate from remote countries.

This may be an important warning sign; for example, the World Health Organization (WHO) has noted medicines purchased over the Internet from illegal websites that conceal their physical address have been found to be counterfeit in over 50% of cases [18].

Similar to other work, we found that few online pharmacies requested prescriptions and sub-optimum online consultations or questionnaires are the primary way to conduct information transfer. As befits the requirement for medical prescriptions, patients should have access to quality information regarding the risks, benefits, and optimal use of their medications. Similarly, consumers must partner with health care providers by sharing information about their health status, other medications, allergies, and other potential interactions to assist providers to help patients reach their health care goals.

The approaches used by existing and reviving websites would likely not fulfill these basic patient needs. Indeed, online questionnaires have been reported to be inadequate tools to assess the health status of consumers, aiming more at giving consumers a false sense of health assurance rather than performing an effective assessment of health status [40]. Further, these questionnaires de-emphasize the real nature and risks of drugs [34]. Ultimately, there is no guarantee that the online consultation (either chat, email, or telephone) is actually provided by a licensed physician or pharmacist, as the identity and licensure status of the professional who makes or reviews the prescription is usually not revealed [5].

These risks to patients from illicit online vendors are exacerbated by the limited general product information and incomplete patient information leaflets. One of the greatest dangers of obtaining medicines online is the potential health hazard from lack of professional information exchange and face-to-face communications between patients and health professionals. Fundamentally, patients cannot make informed decisions about the safe and appropriate use of their medications [35]. The risk of holding back relevant medical information or providing false data in online interactions is significantly higher than during traditional patient-physician consultations.

Today, it is almost impossible to keep the Internet free of illegal sites as the traditional laws that regulated the prescribing process previously are ineffective in regulating international Internet drug sales [13]. Urgent steps are required to combat the unregulated online sale of medicines and to protect people purchasing drugs from the Internet. Governmental and professional bodies are currently developing national and internationally harmonized regulations (eg, Ryan Haight Online Pharmacy Consumer Protection Act in the United States [42] or Directive 2011/62/EU of the European Parliament and of the Council in Europe [43]) and focusing on public campaigns regarding the dangers of online medicines and counterfeit drugs (eg, US Food and Drug Administration Consumer update on The Possible Dangers of Buying Medicines over the Internet [44] and the BeSafeRx national campaign [45]). We believe that adequate regulatory environment, effective law enforcement, and raising public awareness are key elements of safeguarding online medication safety.

Several professional organizations have developed accreditation/verification systems for Internet pharmacy websites to improve patient safety by distinguishing reliable websites from illegal operations. For example, the Health On the Net Foundation certification (HONcode) is an ethical standard aiming to offer quality health information [46], as well as specific pharmacy-based systems in the United Kingdom [38] and Germany [39], and cooperative public agency-accepted systems such as VIPPS [37]. Such verification systems seem to be promising solutions to help customers find legitimate websites and safe medicines because websites go through strict accreditation processes assessing licensure, facilities, personnel, privacy rules, etc. However, these are also limited as they are currently voluntary and, due to the scarcity or virtual absence of accredited vendors [47], patients are most likely to find rogue sites when browsing the Internet. Further, accreditation logos can also be misleading due to the unauthorized use of legitimacy seals [47] or because illegal operators can display fake seals or verification logos.

Likely none of these measures alone will be effective enough to combat illicit marketing and sales, as the vast majority of Internet pharmacy sites are currently rogue. The NABP's ".pharmacy" generic top-level domain is a promising initiative as the proposed new domain suffix would be restricted to legitimate pharmacies and other prescription drug-related organizations worldwide [12].

We believe that it would also be beneficial if search engines could more effectively set back illicit websites in their search result pages and simultaneously favor recommended Internet pharmacy websites in their search algorithms. Indeed, customers of online pharmacies are vulnerable to fraud and it is most likely that the majority of patients cannot differentiate illegal sites from legal online operations; for example, even university students with education in health sciences do not make appropriate judgments about health information provided on the Internet [19]. Accordingly, another possibility is to focus on the potential customers themselves and describe safe ways to purchase medicines over the Internet develop a methodology for patients to evaluate the safety and quality of online pharmacy sites. The distribution of medicines without valid prescriptions,

limited contact information on the website, and poor channels of information exchange (medical questionnaires, drug information) could potentially be negative indicators of online medication safety. It should be noted that these parameters did not reach significance in this study. However, it is likely that combined evaluation of various parameters together with longevity may provide an effective tool (see factors listed in Multimedia Appendix 1).

Limitations

Our study does have some limitations. We did not actually purchase any drugs; however, we believe that the evaluation of Web pages alone can indicate numerous signs of danger. Further, compared to the tremendous number of existing Internet pharmacy websites, we searched, evaluated, and followed a relatively small sample at various intervals. Furthermore, we accessed the data at 6-10 month intervals; by visiting websites more frequently, more accurate data could presumably have been gathered on longevity and revival activity. Finally, the abundance of illegitimate sellers and the regrettable fact that legitimate Internet pharmacies do not rank high on the search engine result pages (or inversely, illicit websites are not set back effectively by the search engine) resulted in not having any LegitScript "legitimate" approved sites in our study sample; although we performed what we believe are typical searches, our results may reflect an over-inclusion of illicit rather than LegitScript legitimate websites.

Conclusions

Overall, this work shows evidence that online pharmacies that act illegally appear to have greater longevity than others. We also found that one in five websites revive and no-prescription sites with limited medicine and patient information are flourishing. The findings suggest that illegitimate operators can provide fraudulent online services and disregard safe pharmacy standards without legal or commercial consequences worldwide. Consequently, a more effective international legislation and enforcement is needed to battle the complex globalized market of illegal vendors.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Website evaluation tool for the assessment and follow-up of Internet pharmacies.

[PDF File (Adobe PDF File), 70KB - jmir_v15i9e199_app1.pdf]

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Abbreviations

CIPA: Canadian International Pharmacy Association
HON: Health On the Net Foundation
HONcode: HON Foundation code of conduct
NABP: National Association of Boards of Pharmacy
OTC: over-the-counter medications
VIPPS: Verified Internet Pharmacy Practice Site
WHO: World Health Organization

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Original Paper

A Mobile and Ubiquitous Approach for Supporting Frailty Assessment in Elderly People

Jesús Fontecha[1], MSc; Ramon Hervás[1], PhD; José Bravo[1], PhD; Fco Javier Navarro[2], PhD, MD

[1]Esc Sup de Informática, MAmI Research Lab, University of Castilla-La Mancha, Ciudad Real, Spain

[2]Health Service of Castilla-La Mancha, Spain, Geriatric Services, Residencia Asistida de Ancianos, Ciudad Real, Spain

Corresponding Author:
Jesús Fontecha, MSc
Esc Sup de Informática
MAmI Research Lab
University of Castilla-La Mancha
Paseo de la Universidad, 4
Ciudad Real, 13071
Spain
Phone: 34 926295300 ext 96675
Fax: 34 926295354
Email: jesus.fontecha@uclm.es

Abstract

Background: Frailty is a health condition related to aging and dependence. A reduction in or delay of the frailty state can improve the quality of life of the elderly. However, providing frailty assessments can be difficult because many factors must be taken into account. Usually, measurement of these factors is performed in a noncentralized manner. Additionally, the lack of quantitative methods for analysis makes it impossible for the diagnosis to be as complete or as objective as it should be.

Objective: To develop a centralized mobile system to conduct elderly frailty assessments in an accurate and objective way using mobile phone capabilities.

Methods: The diagnosis of frailty includes two fundamental aspects: the analysis of gait activity as the main predictor of functional disorders, and the study of a set of frailty risk factors from patient records. Thus, our system has several stages including gathering information about gait using accelerometer-enabled mobile devices, collecting values of frailty factors, performing analysis through similarity comparisons with previous data, and displaying the results for frailty on the mobile devices in a formalized way.

Results: We developed a general mechanism to assess the frailty state of a group of elders by using mobile devices as supporting tools. In collaboration with geriatricians, two studies were carried out on a group of 20 elderly patients (10 men and 10 women), previously selected from a nursing home. Frailty risk factors for each patient were collected at three different times over the period of a year. In the first study, data from the group of patients were used to determine the frailty state of a new incoming patient. The results were valuable for determining the degree of frailty of a specific patient in relation to other patients in an elderly population. The most representative similarity degrees were between 73.4% and 71.6% considering 61 frailty factors from 64 patient instances. Additionally, from the provided results, a physician could group the elders by their degree of similarity influencing their care and treatment. In the second study, the same mobile tool was used to analyze the frailty syndrome from a nutritional viewpoint on 10 patients of the initial group during 1 year. Data were acquired at three different times, corresponding to three assessments: initial, spontaneous, and after protein supplementation. The subsequent analysis revealed a general deterioration of the subset of elders from the initial assessment to the spontaneous assessment and also an improvement of biochemical and anthropometric parameters in men and women from the spontaneous assessment to the assessment after the administration of a protein supplement.

Conclusions: The problem of creating a general frailty index is still unsolved. However, in recent years, there has been an increase in the amount of research on this subject. Our studies took advantage of mobile device features (accelerometer sensors, wireless communication capabilities, and processing capacities among others) to develop a new method that achieves an objective assessment of frailty based on similarity results for an elderly population, providing an essential support for physicians.

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KEYWORDS

frailty; mobile computing; similarity; elderly people

Introduction

Resistance and physiological reserves decrease in elderly people, leading to cumulative wear and an increased risk of adverse health effects; this leads to a frailty state. However, frailty is a difficult term to conceptualize and, in most cases, is related to aging, disability, and comorbidity. In the 1970s, this concept was first used to describe a group of elderly people who preserved their independence in a precarious way. Nowadays, there are many definitions and models of frailty. Woodhouse defined frail elderly people as "those greater than 65 years of age who are dependent on other people to perform their basic needs" [1], whereas Gillick (1989) described frail older persons as "old debilitated individuals who cannot survive without the help from others" [2]. More recently, Brocklehurst defined frailty as "the risk of losing the ability to live in the community" [3]. Meanwhile, Buchner and Wagner [4] proposed a definition from a biological point of view. Certainly, the frailty state is composed of multiple domains, as Rockwood describes [5]. Thus, the clinical syndrome of frailty is determined by different symptoms and signs, resulting in the phenotype of frailty proposed by Fried [6]. This author sets out five criteria to determine whether a person is frail or not.

Notably, Hamerman described the difficulty of addressing the concept of frailty due to the large number of parameters to be considered [7]. In fact, detection and diagnosis of frailty must be studied in the following domains: medical, functional, socioeconomic, cognitive, and institutional. The functional domain has been classically appreciated as the independence level of a person. This includes performing activities of daily living [8,9]. In this case, frailty is often equated with functional dependence in these activities, although frail elderly people are sometimes described in predominantly medical terms. However, it is difficult to standardize an operational definition of frailty while taking into account this broad perspective.

Nowadays, the results for frailty detection and diagnosis are based on global scores from standard questionnaires completed by physicians; an overview of the elderly person and his/her environment; measures from medical instruments; and an analysis of lab reports from the elderly patient.

Moreover, doctors do not take into account all the previous items at the final assessment, and their decision is based only on a subset of items. In addition, the first two items depend on the physician's viewpoint, thereby influencing the final result. For example, the assessments of gait and balance—two of the main indicators for frailty diagnosis—are obtained by several questionnaires. However, current technologies provide mechanisms to obtain the results in a more appropriate manner. For instance, the use of mobile phones with built-in accelerometers as medical instruments during gait and balance activities, in combination with other factors, can successfully generate more accurate and centralized results of frailty, providing much more information than the current tests. In the last decade, many researchers have included new technologies and standardized methods in their works on the frailty syndrome, due to the large number of factors under consideration. For this purpose, Martin presented an overview of the relevant tools (tests and scales) used by researchers in the field of frailty, studying the importance of each tool and the provided information [10]. Jones proposed a method to determine a frailty index from a detailed geriatric assessment focused on studying a set of variables, including balance, communication, cognitive state, nutrition, continence, activities of daily living, and comorbidity among others [11]. However, he mentioned that the best way to measure frailty remains unresolved. In another paper, Rockwood proposed a method based on the results of scales and a statistical study to establish a frailty index related to a specific population [12]. In the same manner, Searle et al proposed a quantification procedure for creating a frailty index from a dataset of variables [13]. In this case, non-numerical variables were coded. Additionally, Gobbens et al defined a conceptual framework to group the most important experimentally detected factors related to frailty [14]. These included cognitive factors, strength, balance, nutrition, physical activity, and mobility, while social and psychological factors were less important.

In recent years, the mobile computing paradigm and the use of mobile devices in health care systems have grown significantly, although integration and deployment remain a challenge [15]. In this paper, we present a system with a corresponding user-friendly mobile application to provide frailty assessments focusing on the analysis of the main parameters of frailty through the study of similarities between individuals, with the aim of supporting frailty decision making and subsequent treatments by doctors and geriatricians.

Methods

Overview

In this work, the detection and diagnosis of the frailty state includes two fundamental aspects. The first involves gathering and processing gait information through accelerometer sensors, an important element of frailty detection. The second is the study of all frailty risk factors found in the patient record (including information on gait analysis), providing valid results, and looking at the detection and diagnosis of frailty and pre-frailty in an accurate and objective manner, for interpretation by doctors on their mobile devices, such as mobile phones.

Identification of Frailty Factors

The identification of frailty factors involves identifying the relevant factors related to frailty. These factors must be included in the system as frailty variables. A set of relevant factors is to be taken into account when a physician conducts a frailty evaluation. Espinoza identified a group of possible risk factors from the frailty phenotype and a systematic review [16]. Additionally, the physical characteristics of frailty are considered; however, the importance of each one is not indicated, at least not in a quantitative manner.

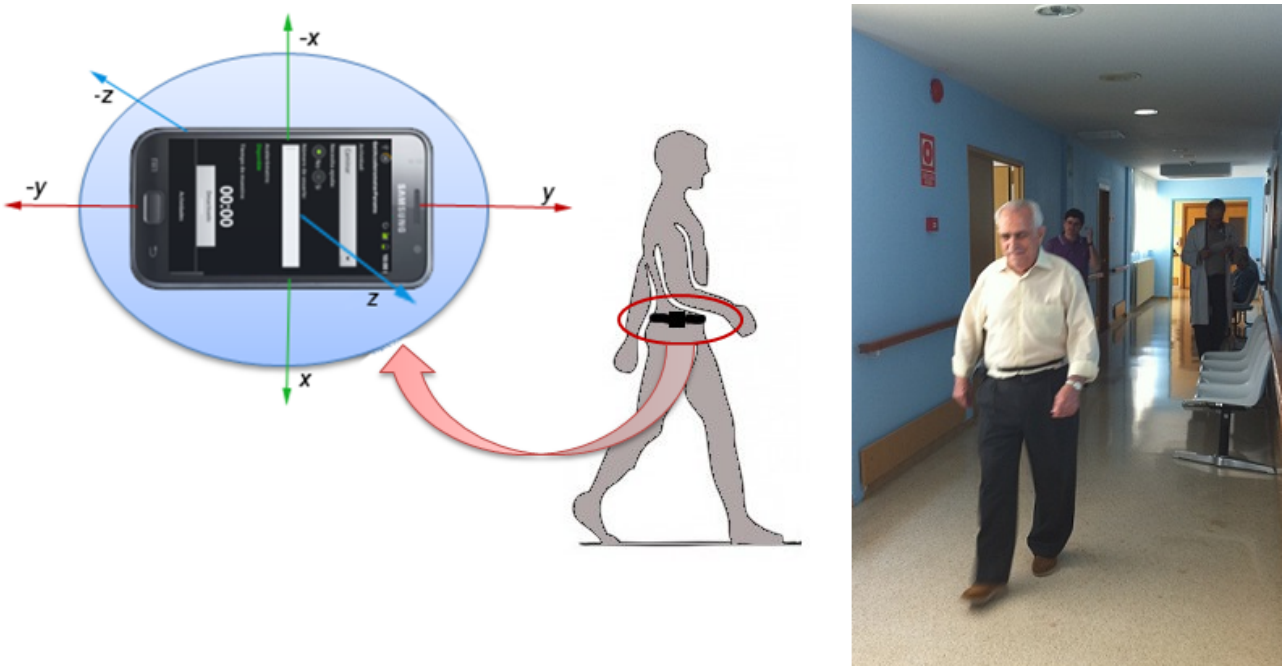
Clinical variables related to frailty come from the patient record as mentioned. The score from tests and scales, the results of lab reports, and general information, among others, are stored by physicians to be studied as needed. Meanwhile, social and psychological indicators are not considered because they do not have a direct relationship with the patient record. The most common indicators are associated with the clinical groups presented in Table 1 [17] (all these items can be quantified easily).

Functional assessment is the most important domain for determination of frailty and is the first to be studied. For this, the physician applies gait and balance tests to assess several features, mainly based on the Tinetti test [18]. The use of an accelerometer attached to the elder's waist during these activities collects relevant data on gait and balance. Fontecha et al identified the following indicators from the movement analysis as accelerometry indicators (for the three axes) [19]: arithmetic mean, standard deviation, absolute mean difference, acceleration mean, variance, amplitude, and Pearson coefficient of variation. This new group of parameters is also considered part of the frailty assessment. We propose collecting and analyzing these movement parameters using a mobile phone. (Figure 1 shows the correct position of the mobile device on the elder's waist.) Apart from these factors, new parameters can be identified to contribute to the final assessment.

Table 1. Frailty risk factors from the patient record [17].

Anthropometric and general data	Gender, age, size, weight, Body Mass Index, body mass, lean mass, fat mass, total water, drug number.
Functional assessment	Tinetti gait and balance score, Barthel index, Lawton & Brody score, Get-Up and Go score, need help in physical activities.
Independence in the activities of daily living	Elders can be independent, mild dependent, moderate dependent, great dependent, or serious dependent.
Geriatric syndromes	Checking for dementia, depression, incontinence, immobility, recurrent falls, polypharmacy, comorbidity, sensory deprivation, pressure ulcers, malnutrition, terminal illness.
Nutritional assessment	Total protein, serum albumin, cholesterol level, triglycerides, blood iron, ferritin, vitamin B12, serum folic acid, serum transferrin, leukocytes, lymphocytes, hemoglobin, calcium.
Cognitive assessment	Mini Mental Status score, "Cruz Roja" [17] mental scale.
Pathologies and diseases	Chronic diseases can be divided into several groups: cardiovascular, neurological, respiratory, digestive, endocrine, orthopedic, osteomuscular, eyes, "ear, nose, and throat" disorders, and dermatological.

Figure 1. Position of the mobile phone during the performance of the Tinetti gait test and real application.



The Frailty Diagnosis Model

The system developed is based on a model proposed in a previous work [20], which favors the development of mobile tools for the analysis of the identified frailty risk factors.

This model is divided into two parts: conceptual and functional. The conceptual part defines the set of entities that form the model (ie, which elements are necessary for the frailty assessment). In this case, the mobile phone is the crux of the model and the most important entity. These entities have been

grouped into five classes as follows: (1) Devices, referring to the necessary devices in the environment, ie, mobile phone, accelerometer, and server, (2) Users, referring to the physician and the elderly patient, (3) Artifacts, which consists of questionnaires and medical instruments that measure aspects related to frailty, (4) Procedures, corresponding to the elements related to the storage of clinical data (from the patient record as well as from the frailty assessment system), and (5) Services, corresponding to the internal services for data acquisition, data processing, data storage, and creation of results.

Additionally, each entity is responsible for one or more actions (known as the entity role). More detailed information about entities and their relationships is given in Multimedia Appendix 1.

Separately, the functional part describes "how" the previous items work according to their roles. Thus, functionalities will be offered by means of a service-oriented approach in which two kinds of services have been identified (mobile and Web services). The first includes the internal services that can be deployed by the mobile device or smartphone. The second is related to services hosted on a server as Web services. For this second kind of service, a network connection (via wireless network) between the mobile device and the server is required.

In a real scenario, the services are run in the order according to Table 2, with inputs and outputs. The inputs represent needed elements or processes to run the services, whereas the outputs are the results provided by the services.

If a patient is studied more than once, this implies the gathering of new values for the frailty variables. Therefore, considering all of the above, we can use a collection of the patient instances rather than a collection of the patients, where an instance consists of a complete set of frailty variables associated with a patient at a given moment, as Fontecha defined [19].

The Frailty Assessment Process

The main purpose of the tool relates to the frailty assessment, generating more accurate and centralized results for frailty, focusing on the analysis of the main parameters and the application of similarity algorithms. Additionally, we propose the use of hierarchical structures such as treemaps [21] to display the final results on the mobile device. A treemap is a method for displaying hierarchical information in a compact manner using nested colored rectangles, maximizing the available space (in this case, the display of the mobile device), favoring the interpretation of results.

The implementation of the frailty assessment process uses cluster analysis features and similarity algorithms, providing a coefficient for each elder related to a relative frailty assessment in a specific elderly population. This procedure includes three stages. The first is the selection of relevant variables, when the frailty risk factors previously detailed are selected for study. The second is the normalization of variables, which is a necessary procedure because the selected variables may have different types (quantitative, qualitative, or binary) and units. Thus, all identified variables are normalized or standardized before the similarity calculation. This implies that different instances of a variable (eg, weight) must be measured in the same unit (eg, kilos). The third stage is calculating similarity measures. The similarity measure indicates the strength of the relationship between two objects. In our case, each object refers to an elderly patient.

One of the main features of clustering is the calculation of a degree of similarity between individuals. There are several methods to calculate matrices of similarity, dissimilarity, and distance [22] among individuals in a population. At this time, Gower General Similarity Coefficient is one of the most popular measures of proximity or similarity when there are variables with different data types [23]. The Gower coefficient allows the determination of the degree of similarity between 2 individuals or cases (i, j) that present binary, qualitative, and quantitative data. Other algorithms do not allow these advantages. In Multimedia Appendix 2, mathematical formulas to calculate the similarity values based on the Gower coefficient are described in detail.

In our case, calculating similarity coefficients from frailty factors involves working with mixed variables (qualitative, quantitative, and binary) as we mentioned above, and even creating diagnostics depending on the situation; thus, the application of the Gower algorithm is quite suitable in this context. Through the use of this coefficient, it is possible to weight the frailty variables independently, depending on the importance the doctor determines in the moment. Therefore, physicians could perform a frailty assessment focusing on specific areas, such as physical, nutritional, cognitive, and anthropometric among others.

Table 2. Inputs and outputs of identified services (services are mobile or Web, depending on the running device, and their outputs are typically the inputs of the next service).

Service	Type	Description	Inputs	Outputs
Accelerometer data acquisition	Mobile	Responsible for accelerometer data gathering and storage at run time, when elderly people perform a specific gait and balance test. This also includes mobile communication between the smartphone and the accelerometer sensor.	Accelerometer signal	Accelerometer values in x,y,z axes
Accelerometer data processing	Mobile	Responsible for accelerometer data handling through data filtering and segmentation as well as calculation of accelerometry indicators.	Accelerometer values (x,y,z axes)	Accelerometry indicators (dispersion measures)
Patient record extraction	Web	Defines the mechanisms to obtain frailty risk factors from the patient record. The use of clinical standards could be necessary.	Patient record, accelerometry indicators	Frailty risk factors
Frailty study procedure	Web	Responsible for performing a comparison between frailty risk factors from the elderly patient studied and each of the patients stored in the database (known as patient stack).	Frailty risk factors, patient stack	Frailty assessment
Setting up a built result	Web	Parse the comparison results in a formal language, easily readable by the mobile phone.	Frailty assessment	Frailty assessment formalized
Visualization of frailty assessment	Mobile	Defines the method for frailty result preparation and visualization on the smartphone screen, after receiving data from the server.	Frailty assessment formalized	Information, tips, and charts for the physician
Storage into Patient Stack	Web	Stores the new patient data in the patient stack structure, increasing the patient stack size and improving the accuracy of frailty assessments in the future.	Risk factors from a new patient	Patient stack with new patient

Results

Summary

Figure 2 shows an overview of the developed system according to the specifications described in this paper. The model integrates all components and allows for the development of mobile applications to determine the final frailty assessment. The architecture of this system has been divided into layers and blocks corresponding to each described part. In this sense, the model ensures the interoperability between the rest of the elements, leading to the services that are used on the mobile phone for data acquisition, processing, and visualization of frailty results.

In this approach, a mobile application has been developed to provide a frailty assessment for each new incoming elderly patient by considering data from a group of previously studied elderly people. This application allows us to display the values of every frailty variable from the patient record, extract dispersion measures from a gait exercise, adjust the variable weights, and visualize the similarity results. Figure 3 shows the mobile application flow with the options to be chosen by the user, and Figures 4 and 5 show screen captures corresponding to these options.

The results are presented in a treemap view (see Figure 5), providing the physician with a visual as support for making the final diagnosis for the selected patient. In our case, this treemap consists of nodes, where each node (represented by a rectangle) is a dynamic object through which the user can access the full information of the patient instance represented by that particular node, including all values of frailty variables. Specifically, a node object contains the following attributes: Parent Instance ID, corresponding to the patient instance identifier of the parent node; Instance ID, referring to the identifier of the current patient instance (the instance to be studied) associated with the node; Age, referring to the age of the patient represented by that node; and Similarity Coefficient, showing the value of the similarity coefficient between the parent node and the current node.

Obviously, if there are large numbers of patient instances, the system will need more processing capacity, more storage resources, better memory management, and more time to generate the similarity results. However, in addition to the optimization of these system features, we propose reductions in the depth of the treemap (to a maximum of three levels) and the maximum number of child nodes for each parent node (to three). These recommendations are suggested because with greater numbers of tree levels and child nodes, the frailty assessment service would require greater processing time (depending on the stored patient instances), and the final results would also not be as useful to the physician (because the similarity coefficient values are lower at each tree level in relation to the studied instance, corresponding to the root node). In our case, the maximum time to generate a complete treemap on the mobile screen was 2.55 seconds working on 64 instances from 20 different patients (see next section). Although four node lists are calculated (for the root node and the three children of the second tree level), only the most representative nodes are shown depending on their similarity coefficients.

Figure 2. General overview of the architecture of the developed system.

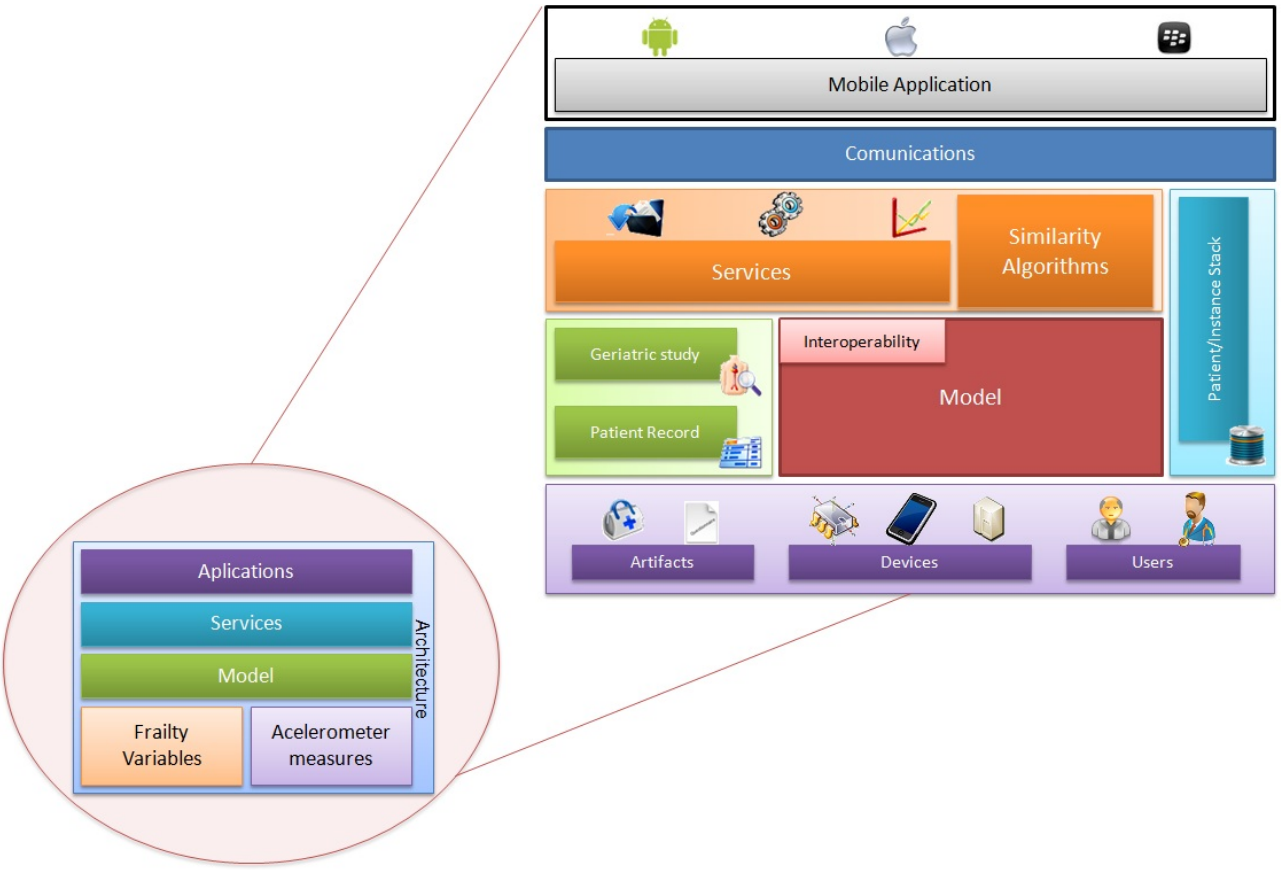


Figure 3. Flow diagram and screen capture of the application dashboard.

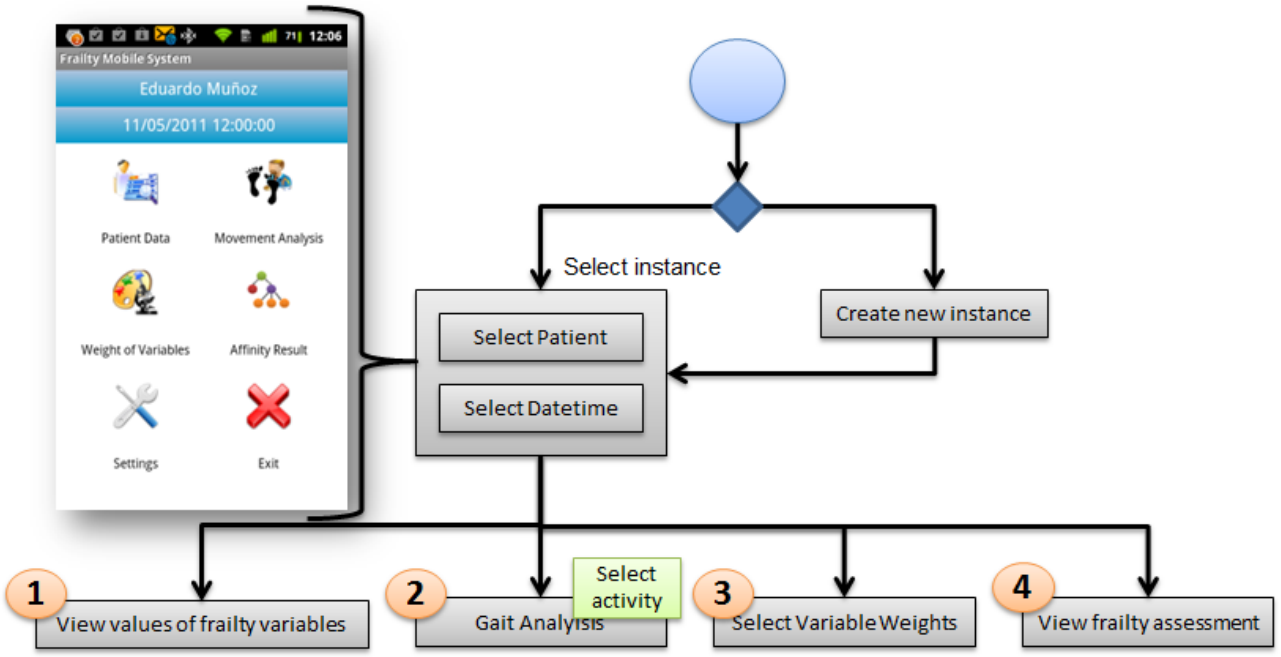


Figure 4. Screenshots from functionalities from mobile application flow: values of the frailty variables for a specific patient; movement analysis task before the activity selection and the start for a specific patient; and movement analysis task after the activity selection (gait) and before the start for a specific patient.

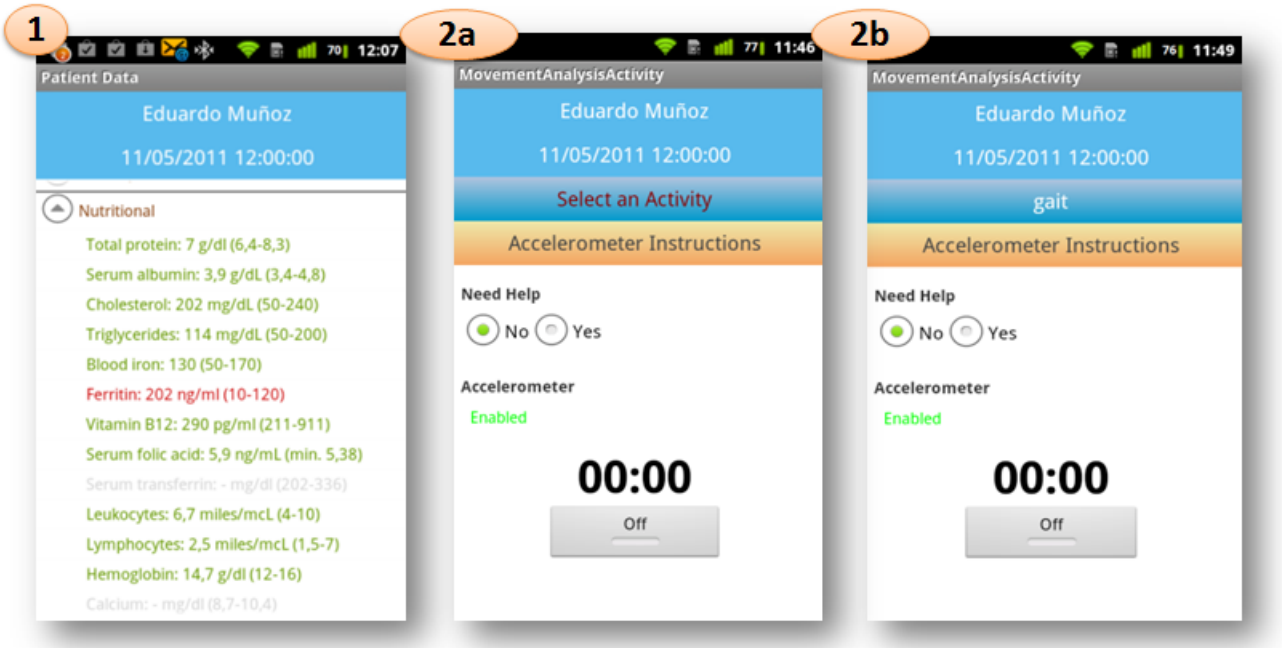


Figure 5. Screenshots from functionalities from mobile application flow: total weight of each group of frailty variables for a specific patient; editing of frailty variables weight for a specific group of variables and patient; and example of treemap calculated for a specific patient.

Study 1: Frailty Evaluation

The system was evaluated on 20 elderly patients with an average age of 83.58 years (SD 3.98), including 10 women (mean age 85.43, SD 3.22) and 10 men (mean age 81.80, SD 4.74). Information on each patient was collected on three occasions over a period of 1 year. The collected information included all possible values of frailty variables from the patient record and those related to gait exercise. In Tables 3 and 4, we present all studied instances considering six different domains (see "Identification of Frailty Factors" section): Anthropometric (with 9 variables), Functional (with 6 variables), Nutritional (13 variables), Cognitive (2 variables), Geriatric syndromes (11 variables), and Dispersion measures (20 variables).

Considering all the previous variables for each group (see table headings of Tables 3 and 4), we observed that there were some variables without value for two different reasons. First, when a variable was measured and its value was in range (within the normal clinical bounds), dependent variables of this were not measured (eg, "if total protein is in a normal range, serum albumin could not be given"); this consists of a clinical decision. And second, certain values simply do not appear. Table 5 shows a summary of the total number of existing values from Tables 3 and 4.

According to the values associated with the variables, the first iteration (from instances 1 to 20) presents more given values. Thus, we selected this iteration as the representative example for frailty assessment because more values imply more accuracy. Suppose the frailty assessment is made from instance 1 (with the maximum of importance for all variables: 100%). This instance is compared, through the similarity process, with the other 19 instances. Then, a list of nodes, based on their similarity

coefficients, is calculated from the current instance. This process is repeated for each child node (with a maximum of three nodes per tree level and two levels). Multimedia Appendix 3 presents these results, which are formalized in a treemap structure, their order by their similarity coefficients, and displayable on a mobile device.

In this case, instance 1 has a similarity degree of 73.4% with instance 12 (corresponding to Patient 12), 72% with instance 16, and 71.6% with instance 2. In the same way, similarity coefficients from these last instances were calculated. The instances of the last node present lower similarity values, as calculated from their parent nodes. In this case, the third node of the second level (with instance ID=2, corresponding to Patient 2) has the worst similarity coefficient, and its child nodes present similarity degrees of 71.9%, 71.6%, and 69.9%. This indicates lower degrees of similarity in relation to the rest of the nodes. This case can be extrapolated to any other generated tree. For the geriatrician, calculating more child nodes would result in a confusing interpretation with useless results.

However, taking into account the whole group of instances, those from the generated result correspond to patients within limited age ranges. In this case, no result shows similarity between the studied instance and those patients less than 80 years or greater than 90 years. In our experiment, we had a 92-year-old woman and 4 individuals aged less than 80 years. This indicates the importance of setting clusters based on sex and age before conducting the similarity calculations, optimizing the results of the system (which does not currently offer this feature).

These results help the physician to determine the frailty condition of a specific patient in relation to other patients in an elderly population. Additionally, from these results, the doctor can group the elders by their degree of similarity influencing their care and treatment.

Table 3. Values of frailty variables (anthropometric, functional, and nutritional) for all studied patient instances; the first iteration presents more variables with existing values (k=value kept, 0=values not recorded).

Patient	Sex	Instance ID			Anthropometric (max. 9)			Functional (max. 6)			Nutritional (max. 13)		
1	M	1	22	47	9	8	8	4	k	0	11	9	8
2	M	2	23	48	9	8	8	5	k	0	11	8	8
3	M	3	24	49	9	8	8	4	k	0	0	7	0
4	M	4	25	50	9	8	8	5	k	0	12	8	8
5	M	5	26	51	8	8	8	4	k	0	11	8	9
6	F	6	27	-	9	8	-	4	k	-	11	10	-
7	F	7	28	52	8	8	8	5	k	0	12	7	8
8	F	8	29	53	8	8	8	4	k	0	12	9	8
9	F	9	30	54	9	8	8	4	k	0	12	8	8
10	F	10	31	55	8	8	8	5	k	0	12	8	8
11	F	11	32	56	9	8	8	4	k	0	11	10	9
12	F	12	33	57	9	8	8	4	k	0	11	10	9
13	F	13	34	58	9	8	8	4	k	0	11	9	9
14	F	14	35	-	2	8	-	4	k	-	10	10	-
15	F	15	36	59	9	8	8	4	k	0	11	12	10
16	M	16	37	60	9	8	8	4	k	0	12	10	10
17	M	17	38	61	9	8	8	4	k	0	12	10	9
18	M	18	39	62	9	8	8	4	k	0	12	9	10
19	M	19	40	63	9	8	8	4	k	0	12	9	9
20	M	20	41	64	9	8	8	4	k	0	11	9	9

Table 4. Values of frailty variables (cognitive, getriatric syndromes, and dispersion measures) for all studied patient instances; first iteration presents more variables with existing values (k=value kept, 0=values not recorded).

Patient	Sex	Instance ID (It. 1/It. 2/t. 3)			Cognitive (max. 2)			Geriatric syndromes (max. 11)			Dispersion measures (max. 20)		
1	M	1	22	47	2	0	0	11	k	k	17	0	20
2	M	2	23	48	1	0	0	11	k	k	17	0	20
3	M	3	24	49	0	0	0	11	k	k	17	0	20
4	M	4	25	50	1	0	0	11	k	k	17	0	20
5	M	5	26	51	0	0	0	11	k	k	17	0	20
6	F	6	27	-	1	0	0	11	-	k	17	0	-
7	F	7	28	52	1	0	0	11	k	k	17	0	20
8	F	8	29	53	1	0	0	11	k	k	17	0	20
9	F	9	30	54	0	0	0	11	k	k	17	0	20
10	F	10	31	55	1	0	0	11	k	k	17	0	20
11	F	11	32	56	2	0	0	11	k	k	17	0	20
12	F	12	33	57	2	0	0	11	k	k	17	0	20
13	F	13	34	58	2	0	0	11	k	k	17	0	20
14	F	14	35	-	2	0	0	11	k	-	17	0	-
15	F	15	36	59	2	0	0	11	k	k	17	0	20
16	M	16	37	60	2	0	0	11	k	k	17	0	20
17	M	17	38	61	2	0	0	11	k	k	17	0	20
18	M	18	39	62	2	0	0	11	k	k	17	0	20
19	M	19	40	63	2	0	0	11	k	k	17	0	20
20	M	20	41	64	1	0	0	11	k	k	17	0	20

Table 5. Existing values (this indicates the total number of variables for each iteration item with a value).

Existing values	
1st iteration (instances 1-20)	1057
2nd iteration (instances 22-41)	644
3rd iteration (instances 47-64)	913

Study 2: Evolution in Frail Elderly Focusing on Nutritional Aspects

In a second study, the mobile application for frailty assessment was used to perform an evaluation on 10 elderly patients (5 men and 5 women) with nutritional deficiencies, from the initial group of 20 elderly patients, according to the criteria of the geriatrician. In this case, we consider only some frailty variables from the nutritional and anthropometric domains, specifically the following: weight, body mass index, fat mass, lean mass, total water, total protein, hemoglobin, serum albumin, and lymphocytes. The weight of these variables was set to 1 (100% of importance) in the mobile application, and the weights of the remainder variables were set to 0 (0% of importance).

The following three stages were established to assess each of the elders. Stage 1 is the Initial assessment, referring to the acquisition of the previous frailty parameters from the first instance of each patient stored in the system. Stage 2 is Spontaneous evolution, corresponding to the second assessment of the whole group of the parameters considered for the patients. After 9 months, a second instance of the patients was created and the values of their frailty variables were studied. Finally, Stage 3 is Assessment after protein supplementation, referring to the last assessment of the group of elderly patients. In this case, the elderly patients had taken 220 mL, twice a day, of a protein supplement for 2 months. After that, a third instance of the patients was created and the values from the frailty variables of the new instances were analyzed again.

From Stage 1, we made a general description of the group. We observed a higher weight average in males and higher values of lean mass and total water. However, females had higher values of body mass index and fat mass. According to the standard limits for the body mass index determined for the World Health Organization, 2 males and 1 female were at risk of malnutrition. Additionally, values of total protein and lymphocytes were too low. Table 6, Stage 1, shows the average

of the values of studied variables, for men and women, initially. Table 6, Stages 2 and 3 show the corresponding values for the same variables in the spontaneous evolution assessment and the assessment after protein supplementation.

From Stage 1 to Stage 2, most values decrease in both men and women. It indicates an increase in the frailty state of the elderly patients. Additionally, in the clinical spontaneous evolution, the geriatrician determined that the biochemical parameters were affected earlier than the anthropometric.

On the other hand, from Stage 2 to Stage 3, most variables maintain their values, and even some of these values are increased. This is due to the supplementation. In this case, women present a greater increase in the values of more variables than men. Figure 6 shows several charts regarding the values of the frailty variables in men and women, addressing Stages 2 and 3.

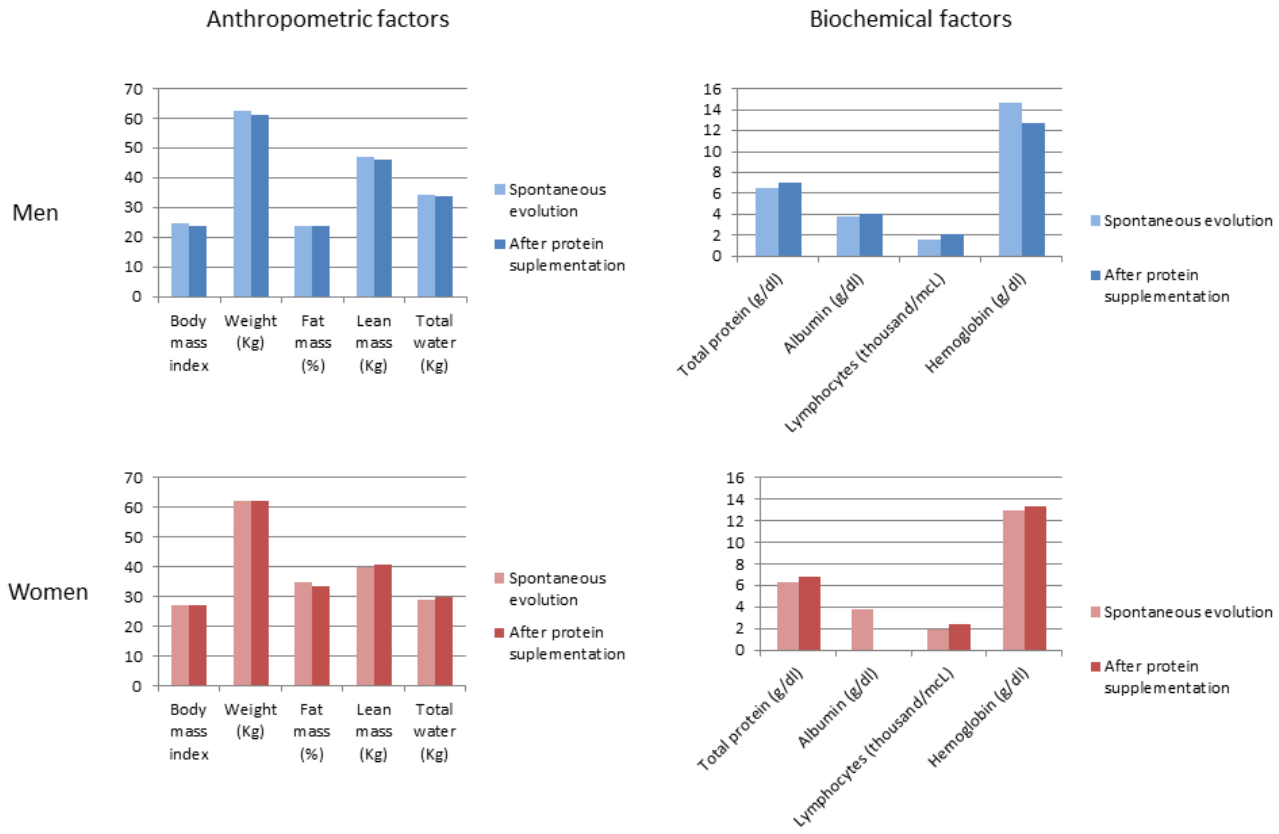
In this study, the frailty mobile application has been useful for performing an evolutionary analysis from a nutritional viewpoint, taking into account a subset of variables (modifying their weights from the application). Additionally, we observed the improvement of biochemical and anthropometric values after supplementation. In men, values from biochemical variables were improved. In women, values from anthropometric and biochemical domains were increased, observing that, from a nutritional viewpoint, the administration of protein supplements may help delay frailty in certain cases.

Table 6. Evolution of average values of selected frailty factors for the group of 5 men and 5 women (previously selected).

		Anthropometric					Nutritional			
	Sex	Body mass index	Weight (kg)	Fat mass (%)	Lean mass (kg)	Total water (kg)	Total protein (g/dl)	Albumin (g/dl)	Lymphocytes (thousand/mcl)	Hemoglobin (g/dl)
Stage 1: Initial assessment										
	Male	26.19	67.78	27.61	48.29	35.35	6.88	3.95	1.9	14.57
	Female	28.14	65.45	36.37	40.93	31.11	6.95	4.18	1.71	12.92
Stage 2: Spontaneous evolution										
	Male	24.58	62.42	23.99	47.23	34.58	6.48	3.83	1.58	14.64
	Female	27.2	62.2	35	39.68	29.04	6.3	3.83	1.86	13
Stage 3: Assessment after protein supplementation										
	Male	23.97	61.38	23.87	46.35	33.93	6.97	4	2.08	12.76
	Female	27.28	62.38	33.37	40.86	29.92	6.86	No data[a]	2.36	13.36

[a]Not enough data to calculate the average.

Figure 6. Values of the selected frailty variables for men and women in the stages: spontaneous evolution and assessment after protein supplementation.



Discussion

Principal Findings

The creation of an absolute index that determines the frailty condition of an elderly patient is still an unsolved issue. However, several proposals provide approximations toward this goal, as we have seen in some related works. In this work, we presented a model with several features to develop mobile tools for frailty assessment. Additionally, we implemented a mobile system based on this model to support elderly frailty diagnosis in a health care environment. The proposed system consists of a model that defines all the needed elements, relationships, and functionalities (using a service-oriented approach) for frailty assessment.

Nowadays, many physicians emphasize the lack of a centralized method to provide frailty assessments based on the results of existing tests and clinical information. For this purpose, we can take advantage of mobile device features such as accelerometer sensors, wireless communication capabilities, and processing capacities, among others, to develop new methods and mechanisms that lead toward an objective assessment of frailty. Additionally, this system can be deployed on other devices, especially for better results visualization (eg, widescreens); however, the mobile device is also used for this task due to the heterogeneity and mobility of the clinical environments, getting evaluations at any time (when the physician needs them).

In a complementary fashion, we consider the use of similarity algorithms, which take into account all relevant frailty variables from the patient record to support the clinical decisions regarding the frailty state of an elderly person in comparison to an elderly population. In this case, due to the nature of the studied variables (quantitative, qualitative, and binary), the Gower algorithm provides us with the most appropriate method to obtain similarity values from a group of patient instances. Moreover, the obtained results are transformed into objects called nodes, which are represented in a treemap structure according to the similarity values of each node. With more patient instances and existing values related to frailty variables, the system results will increase accuracy and reliability.

The lack of similar systems in the literature means that we cannot compare our proposal with other systems. However, the development of mobile computing in the health care domain and the interest in frailty studies because of the growth of the elderly population in developed countries are the main reasons why new systems with similar approaches are being developed.

In the two studies conducted, we checked the usefulness of the mobile application for supporting the frailty diagnosis as well as other kinds of related studies. In this case, we have also presented the use of the mobile application to perform an evolutionary analysis based on nutritional parameters and a subset of elderly patients.

Limitations

Finally, we can further evaluate the integration of clustering techniques in our system as a complement to a thorough study, taking into account different populations of adults and elderly patients. For this, it is necessary to have a large group of patient

instances with a wide range of ages. Although this feature can be applied to our evaluation group of elders, results would not be reliable because the sample is too small and it is difficult to establish generalized cutoffs based on ages. Additionally, possible optimizations related to processing and performance may be necessary to handle the corresponding large amounts of data.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Model entities and roles to develop frailty assessment tools.

[PDF File (Adobe PDF File), 301KB - jmir_v15i9e197_app1.pdf]

Multimedia Appendix 2

Gower's Coefficient equation.

[PDF File (Adobe PDF File), 307KB - jmir_v15i9e197_app2.pdf]

Multimedia Appendix 3

Values of the treemap nodes in table format.

[PDF File (Adobe PDF File), 96KB - jmir_v15i9e197_app3.pdf]

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Toronto, ON, M5A 3Y5
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