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Contents

Original Papers

Original Paper

Information and Communication Technology to Support Self-Management of Patients with Mild Acquired Cognitive Impairments: Systematic Review

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Abstract

Background: Mild acquired cognitive impairment (MACI) is a new term used to describe a subgroup of patients with mild cognitive impairment (MCI) who are expected to reach a stable cognitive level over time. This patient group is generally young and have acquired MCI from a head injury or mild stroke. Although the past decade has seen a large amount of research on how to use information and communication technology (ICT) to support self-management of patients with chronic diseases, MACI has not received much attention. Therefore, there is a lack of information about what tools have been created and evaluated that are suitable for self-management of MACI patients, and a lack of clear direction on how best to proceed with ICT tools to support self-management of MACI patients.

Objective: This paper aims to provide direction for further research and development of tools that can support health care professionals in assisting MACI patients with self-management. An overview of studies reporting on the design and/or evaluation of ICT tools for assisting MACI patients in self-management is presented. We also analyze the evidence of benefit provided by these tools, and how their functionality matches MACI patients' needs to determine areas of interest for further research and development.

Methods: A review of the existing literature about available assistive ICT tools for MACI patients was conducted using 8 different medical, scientific, engineering, and physiotherapy library databases. The functionality of tools was analyzed using an analytical framework based on the International Classification of Functioning, Disability and Health (ICF) and a subset of common and important problems for patients with MACI created by MACI experts in Sweden.

Results: A total of 55 search phrases applied in the 8 databases returned 5969 articles. After review, 7 articles met the inclusion criteria. Most articles reported case reports and exploratory research. Out of the 7 articles, 4 (57%) studies had less than 10 participants, 5 (71%) technologies were memory aids, and 6 studies were mobile technologies. All 7 studies fit the profile for patients with MACI as described by our analytical framework. However, several areas in the framework important for meeting patient needs were not covered by the functionality in any of the ICT tools.

Conclusions: This study shows a lack of ICT tools developed and evaluated for supporting self-management of MACI patients. Our analytical framework was a valuable tool for providing an overview of how the functionality of these tools matched patient needs. There are a number of important areas for MACI patients that are not covered by the functionality of existing tools, such as support for interpersonal interactions and relationships. Further research on ICT tools to support self-management for patients with MACI is needed.

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KEYWORDS

Assistive technology; Classification; Disability; Information and Communication Technology; Mild Acquired Cognitive Impairments; Self-management; Traumatic Brain Injuries

Introduction

Information and communication technology (ICT) is a means to cope with the increasing number of patients with chronic diseases in our aging society [1]. For individuals with chronic illness affecting cognitive capacities either directly (eg, dementia) or indirectly (eg, diabetes), ICT has become a fundamental part in their daily lives by providing a wide range of useful services and tools to use at home, work, or anywhere else [2-5].

Intensive research is ongoing regarding ICT support for patients with moderate or severe cognitive impairments. One group that has not received much attention, however, is people with mild acquired cognitive impairments (MACI).

Mild Acquired Cognitive Impairments

The new term *MACI* is used to differentiate patients with mild cognitive impairments (MCI) after acquired brain injury, such as traumatic brain injury (TBI), stroke, or other medical conditions or treatments, who are expected to reach a stable cognitive level over time from patients with a slowly deteriorating cognitive impairment, such as Alzheimer disease or schizophrenia [6].

The clinical definition of MACI is in line with the American Congress of Rehabilitation Medicine Special Interest Group on Mild TBI definition of mild TBI [7]: minor motor dysfunction/no motor dysfunction; appear to function well in social situations occasionally requiring support; may have a number of different cognitive disabilities, mostly within the area of attention, concentration, and memory; and may have a number of concomitant emotional problems. In order to be classified as having MACI a patient must meet the following 3 criteria: (1) the patient fits the general definition of having MCI, (2) the patient acquired this MCI as the result of a known medical condition, and (3) the patient's cognitive state is expected to improve over time with treatment.

The largest etiological groups within MACI are patients with TBI, stroke, and brain injuries [8]. Each year, more than 1.5 million people in the United States suffer from TBI [9]. Mild TBI and concussion are the most frequent combat-related injuries. Brain injuries are also common at all levels of athletic competition and have been noted as a serious long-term health problem for retired professional American football players [10,11]. Although the majority of people with mild TBI resume normal functioning fairly quickly, approximately 5% to 15% report persistent cognitive and emotional symptoms [12,13].

Mild cognitive disability is a significant health problem and can result from a number of conditions. It may result in problems performing daily functions, such as reduced efficiency and reduced pace when performing activities. Problems may be persistent and decrease the overall effectiveness of the patient in the performance of routine activities of daily living, while also decreasing their capacity to adapt to novel or problematic situations [14,15].

The initial symptoms of mild TBI also apply to MACI patients and include dizziness, nausea, and impaired concentration that will typically decline during the first 3 months after the injury [16,17]. However, subgroups of patients develop persistent symptoms [18]. Patients can have multiple cognitive and/or behavioral and emotional disabilities, such as depression, low self-esteem, anxiety, lack of initiative, inability to maintain previous work pace, cognitive problems, and poor stress tolerance [19]. For this group, daily life becomes a challenge and the condition brings reduction in life satisfaction [20].

Treatment and Self-management of Mild Acquired Cognitive Impairments

Patients with MACI are often of working age and can have quite complex and challenging problems; therefore, it is hoped that with the right tool, strategy, and treatment these patients may return to normal life and work. There are a number of challenges in treating these patients. Treatment strategies intended for moderate and severe acquired brain injuries are irrelevant for patients with MACI [13]. For example, the technologies developed to support MCI patients have focused primarily on Alzheimer disease and related problems, such as dementia. Treatment for MACI patients is quite different from those with moderate or severe injuries or Alzheimer disease for a variety of reasons. One issue is that patients with MACI need to be treated to handle a wider variety of situations than patients with moderate or severe injuries or Alzheimer disease. For example, they often need help to deal with interpersonal-emotional impairments, social situations, the work context, and with productivity-related skills [6,13]. Patients with MACI also do not have observable disabilities, such as motor and speech problems.

Treatment of MACI focuses on regaining lost skills and learning ways to compensate for lost abilities to allow patients to function well in all appropriate contexts and situations. For these reasons, the treatment options are also quite varied, and patients generally need individualized programs tailored to their capabilities, backgrounds, and interests. Treatment programs deliver assessment and reassurance by cognitive rehabilitation and stress management, and assist patients to return to work [21]. Studies have also shown that simple support in terms of education and group therapy appeared to provide extensive help for individuals with MACI with respect to their individual conditions and disabilities [21].

Because the goal of MACI treatment is often to help the patient become more independent and manage different life situations more effectively, an important aspect of the treatment is support for self-management. Self-management can be defined as "the individual ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition and disability" [22]. In this paper, our target is how to utilize ICT to enable the health care system so that it can support patients with MACI in self-management, for example, by recommending and/or providing the appropriate ICT tools to patients that can assist them. Self-management is a broad concept; therefore, the development of tools that support self-management must be conducted from a broad perspective [23]. Self-management programs have to emphasize the patients' central roles in managing their illness and include both the medical and social aspects of living to manage a long-term chronic condition [24].

New possibilities are offered by ICT to enhance treatment, including support for group therapy and improved individual follow-up of rehabilitation support for optimal self-management, where individually adapted information and self-management tools can be combined with the integrated knowledge obtained within the framework of group treatments. Currently it is unclear what the best strategies are to support treatment of MACI with ICT. There are no concrete design guidelines that can aid designers in the development of new ICT tools to support patients with MACI in self-management and treatment.

The goal of this paper is to provide a contribution to the direction of future research on ICT tools that can be used by health care professionals who are seeking to assist MACI patients in self-management. The development of these tools will require multiple perspectives to be considered, including the perspective of the patient in managing and coping with their condition, and of the health care workers who treat the patient and will need to understand the potential of these tools and how to recommend them to specific patients.

We present an overview of studies reporting on the design and/or evaluation of ICT tools for assisting MACI patients in self-management. We also provide an analysis of the features of these tools using the International Classification of Functioning, Disability and Health (ICF) checklist [25] as a framework because it is frequently used by MACI rehabilitation professionals and medical experts for clinical assessment of MACI patients. Since the ICF checklist is comprehensive, we used a subset of the most common and important problems for MACI patients, determined by an MACI expert located in Sweden (AB) for our analysis.

Specifically, we will explore the following research questions: (1) What functionality has already been explored and/or evaluated regarding ICT tools that can be used to assist MACI patients in self-management? (2) What level of evidence exists that this functionality can provide benefits for MACI patients? (3) What gaps exist with respect to the functionality and the assessment framework used by rehabilitation professionals treating MACI patients?

We seek to aid health informatics by clarifying what functionality should or should not be recommended for assisting patients with MACI in self-management, what functionality appears promising but needs further evaluation before clear recommendations can be made, and what functionality may have been ignored in previous studies and should be targeted in design studies of future ICT tools to assist with MACI.

Methods

Review of the Literature

A review of the existing literature about available assistive ICT for people with MACI was conducted. This study was based on a review of the scientific literature published between 1995 and 2011 and retrieved between June and September 2011. The sources of the literature were the following electronic databases: MEDLINE (PubMed), Association for Computing Machinery (ACM) Digital Library, ScienceDirect, Ovid, Physiotherapy Evidence Database (PEDro), SpringerLink, ISI Web of Science (Science Citation Index Expanded), and the Institute of Electrical and Electronics Engineers (IEEE) Xplore Digital Library. Table 1 shows the inclusion and exclusion criteria.

Table 1. Inclusion and exclusion criteria for literature review of information and communication technologies (ICT) used for minor acquired cognitive impairments (MACI).

Criteria	Study characteristics	Study participants
Inclusion	Original articles	Mild/moderate cognitive impairments and dysfunctions
	English language	Mild/moderate acquired cognitive impairment and dysfunction
	Adult participants only	Severe injury but the mild/moderate outcome after certain period of time
	Where the technology was either created, evaluated or applicable for MACI patients	Non-progressive diseases
	Studies focused on technologies and tools that are developed to support patients' self-management (involving patient's responsibility for managing some aspects of their condition together with care professionals)	
Exclusion	Conceptual frameworks and literature reviews	Severe cognitive impairments and dysfunctions
	Studies focused on technologies that are developed for patients with a more severe cognitive decrease than for MACI patients	Aphasia
	Studies focused on technologies and tools that are developed for assessment and diagnostic purposes	Alzheimer disease
	Studies that included participants with mild cognitive impairments but with severe physical dysfunctions	Schizophrenia
		Psychotic disorder
		Developmental cognitive disabilities

Since MACI is a new term, it was not possible to rely on using it alone as a keyword. Thus, we expanded our search terms to include more broad cognitive and traumatic impairments to see if studies on these issues also included technologies relevant for MACI patients. The search terms *cognitive impairment*, *mild cognitive impairment*, *mild acquired cognitive impairment*, *traumatic brain injury*, *mild traumatic brain injury*, *mild head injury*, *mild acquired brain injury*, *memory disorder*, *concussion*, *post-concussive*, and *mild acquired cognitive dysfunction* combined with *assistive technology*, *informatics*, and *information technology* were used (55 search phrases in total). All citations were imported into reference management software (Endnote X4) to manage bibliographies and references and to remove duplications. The software also helped to identify and follow the authors who published relevant articles in the field.

Using the inclusion and exclusion criteria, the retrieved articles' titles were read by the first author (AE) to eliminate the irrelevant articles. In the next phase, three authors (AE, JS, and SK) went through the abstracts and the full text if there was uncertainty about inclusion. The third author (AB) was also involved in the selection process in cases where there was ambiguity for the study from rehabilitation and medical point of view to make sure that the selection met the inclusion criteria. After final selection, the information was extracted from the full texts.

Analytical Framework

One strategy for analyzing the features of ICT tools to determine how well they fit patient self-management needs is to conduct the analysis based on current evidence-based practice [26]. In the absence of well-established clinical guidelines for treatment of MACI patients, we used the ICF checklist to build an analytical framework to classify impairments that MACI patients may have [25]. The ICF offers an international and interprofessional scientific base for understanding and studying health and it has been used to understand the ability of ICT to assist at functional/cognitive, activity, and participation levels. The ICF checklist is comprehensive; therefore, we also conducted our analysis on a subset of the ICF checklist consisting of the most common and important problems for MACI patients as determined by an MACI expert located in Sweden (AB). The resulting framework was used to identify gaps between the features of existing technologies and the variety of impairments encountered by patients, from the perspective of health care professionals assisting with self-management of their condition.

The ICF also provides a checklist of major categories as a practical tool to elicit and record information on the functioning and disability of an individual [25]. These categories are related to the following components: body functions, body structure, activity and participation, environmental factors, and personal factors. This original checklist had to be filled by the extent (severity) of the impairments, difficulties, barriers, and facilitators. The extent of impairments for some MACI patients would be mild, for some moderate, and in rare cases, a severe impairment might be observed in certain aspects [25].

Results

Review of the Literature

A total of 5969 publications were identified by initial keyword searches and 2075 were eliminated due to duplication. A further 2370 articles were excluded after reading the titles. The abstracts of 1524 articles were assessed. After exclusion of irrelevant articles, 762 articles were reviewed by reading the full text. In the end, 7 articles met the inclusion criteria. Because MACI is a new term, there is no standard way of bibliographic indexing for this filed yet, which required the authors to read the full text of a large number of articles. Figure 1 provides an overview of the journals and databases with numbers of selected and eliminated articles.

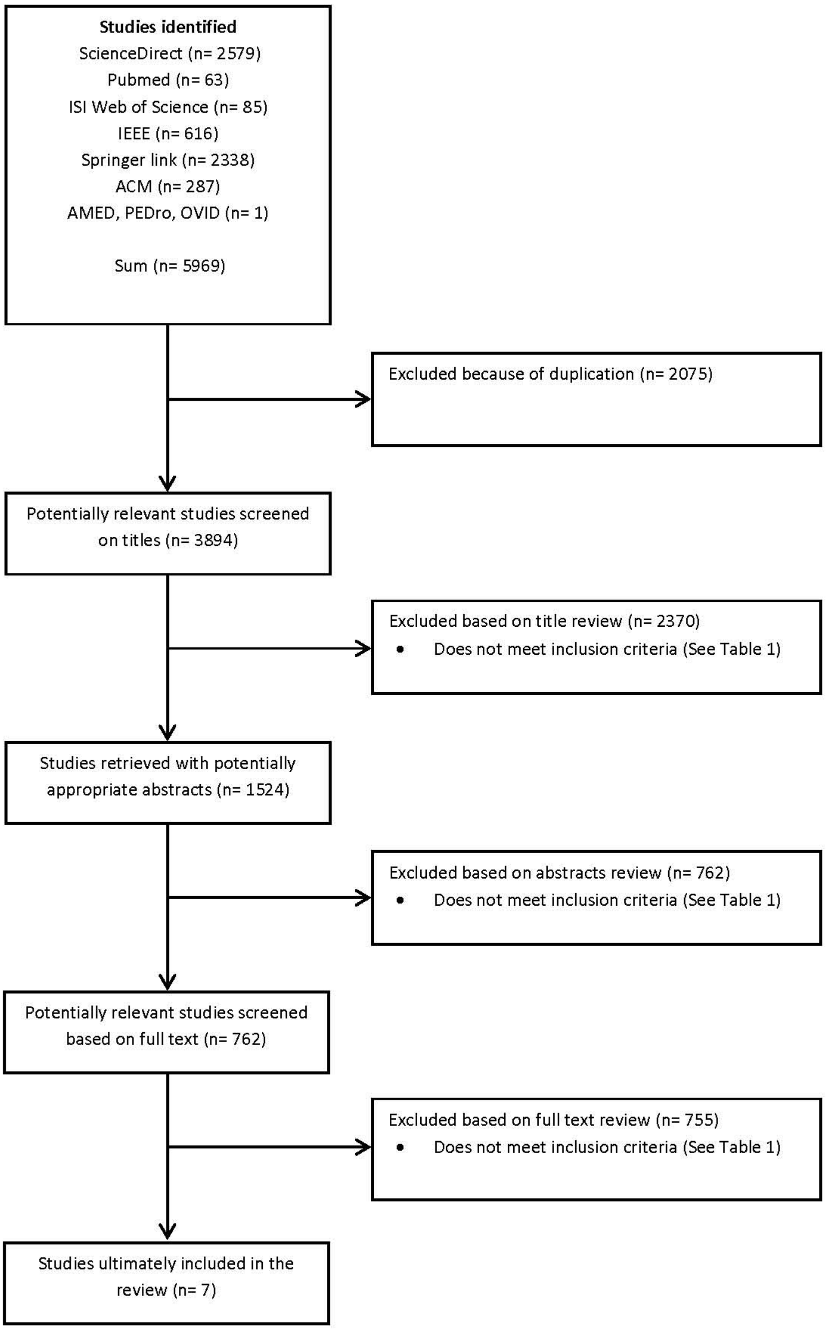
A total of 7 publications met the inclusion criteria. Table 2 displays the studies' and systems' names, countries of implementation or test, year of publication, type of publication, and references.

The analysis of identified articles showed that 2 of 7 articles (29%) were authored in the United States, 3 of 7 (43%) in Europe, and 2 of 7 (29%) in Asia.

Table 2. General details about the studies that met the inclusion criteria.

Title	Project	Year	Country	Type of articles	Journal/Conference
Designing a cognitive aid for the home: a case-study approach. [27]	Cognitive Aid for the Home	2003	United States	Conference proceedings	Association for Computing Machinery (ACM)'s Special Interest Group on Accessible Computing (SIGACCESS)
An interactive assistive system for prospective memory deficit compensation-architecture and functionality [28]	Mobile Extensible Memory Aid System	2003	Germany	Conference proceedings	SIGACCESS
A tele-cognitive rehabilitation platform for persons with brain injuries [29]	---	2006	Hong Kong	Conference proceedings	International technical conference of the Institute of Electrical and Electronics Engineers (IEEE) Region 10, the Asia Pacific Region
A cooking support system for people with higher brain dysfunction [30]	A cooking support system	2009	Japan	Conference proceedings	The ACM multimedia 2009 workshop on Multimedia for cooking and eating activities
Personal digital assistant (PDA) software aimed at improving workplace adaptation for people with cognitive disabilities [31]	Time and Task Manager (GTT)	2010	Spain	Conference proceedings	Computers Helping People with Special Needs
Computer based cognitive training for patients with mild cognitive impairment (MCI) [32]	Computer based cognitive training	2010	Greece	Conference proceedings	Pervasive Technologies Related to Assistive Environments
Electronic reminding technology following traumatic brain injury: effects on timely task completion [33]	Electronic reminding	2011	United States	Journal	The Journal of Head Trauma Rehabilitation

Figure 1. Flow diagram of the study selection process.



Study Details

Study Type, Methodology, and Level of Evidence

As shown in Table 3, study types were distinguished as prototypes (early stage of system design that is built to test a process, concept, or human interaction to support user-focused research) or case reports (individual patient or group of patients have tested/evaluated the system or product). We found the level of evidence was very low. Of the 7 studies, 5 (71%) had poor methodologies and did not describe their design process and evaluations using a robust methodology. Table 3 illustrates that patients were involved in the design process in only 2 studies [27,31] and only 1 of them [27] used the actual user-centered design method [34,35]. Most of the studies were designed based on existing systems and guidelines and also considering the requests for such services.

Table 3. Study type and research method.

Reference	Study type	Research method	Design process
[27]	Prototype development	Case study (design and creation)	User-centered design
[28]	Case report	Exploratory research	Design process was not clear (based on existing electronic memory aid systems and requisites of a memory aid)
[29]	Case report	Exploratory research	Design process was not clear (cognitive rehabilitation strategies for problem solving training were implemented with flash communication software)
[30]	Case report	Case study (design and creation)	Design process was not clear
[31]	Case report (method is not clear)	Exploratory research	Document review, collection of information about tasks, problems and needs, prototyping, evaluation, redesign, implementation. (incremental development)
[32]	Case report	Exploratory research	Not described
[33]	Case report	Exploratory research	Not described

Participants (Patients)

Table 4 shows the demographic information of participants in the 7 studies. Most were patients with TBI and MCI, and the studies fit the criteria of patients with mild to moderate impairments. One of the identified studies had a more moderately injured patient as a user where the technology described had the potential to be used by MACI patients [29]. In another study, the patient group was somewhat unclear. The authors described their work as being relevant for dementia and problems affecting the elderly in the introduction section, but the methodology described participants in the study as 59 MCI patients [32].

Table 4. Demographic information about study participants.

Reference	Participants/system users	Number of participants	Severity of cognitive impairment
[27]	Mild traumatic brain injury	1	Mild/moderate
[28]	Persons with mild to moderate memory problems	9	Mild/moderate
[29]	People from Hong Kong, aged from 18 to 55, demonstrated basic attention and communication abilities, had gone through inpatient euro-rehabilitation, were medically stable	25	Mild/moderate
[30]	39-year-old female, aphasic with cognitive and memory disorders, often had difficulty with multistep tasks	1	Moderate
[31]	Workers with mild cognitive impairment	8	Mild cognitive impairment
[32]	Mild cognitive impairment patients	59	Mild cognitive impairment/dementia
[33]	Traumatic brain injury patients and self-determined complaints of memory impairment	36	Mild/moderate

Study Features and Functionality

The development and implementation of assistive technologies in health care is usually intended to improve medical care and self-management [36]. The targeted studies were selected based on improving patients' independence and supporting their self-management. After initially reviewing the studies, there appeared to be some trends in the functionality included in the tools. The authors divided this functionality into the following subcategories as reflected by these trends: improving independence, memory, problem solving, working, and task completion.

All *stationary devices* were personal computers and *mobile devices* were smartphones, personal digital assistants (PDAs) [37], and/or wearable devices. There was one special prototype with its own hardware design used as a digital frame. Considering the number of mobile systems, a large percentage of the systems' input methods were through touch screens, but also buttons, PC input devices, and, in one case, a Nintendo Wii remote [30] (See Table 5).

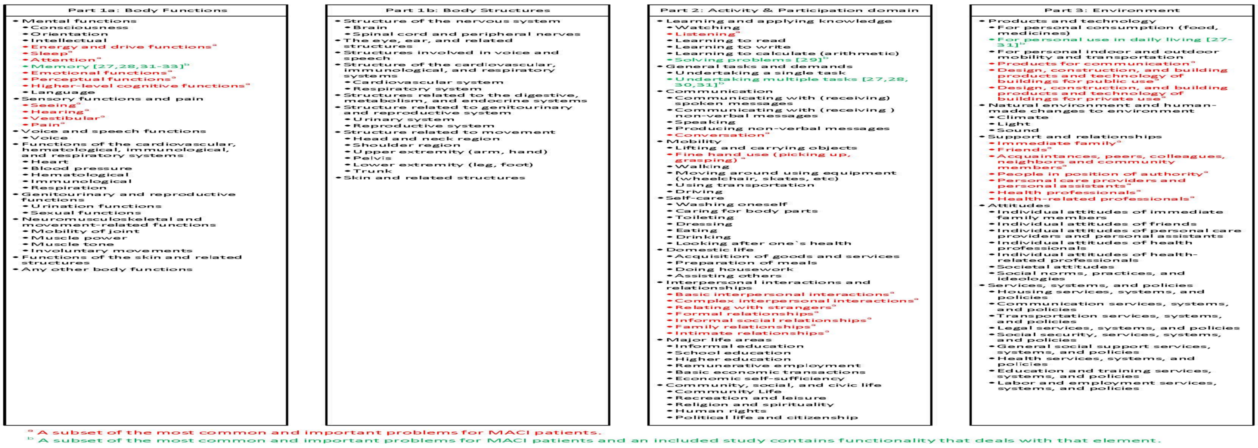
Table 5. Study features and functionality.

Reference	Functionality	Improvement aim	Type	Setting	Technology	Interaction type	Component hardware type
[27]	Increase individuals’ functional independence in the home environment by providing time and location based prompts	Independence	Memory aid	Mobile	Mobile-based	Display (seeing)	A display that can be mobile or mounted on wall
[28]	To support patients with deficits in the prospective memory after a brain injury	Memory	Memory aid	Mobile	Mobile and Web-based	Touch	Mobile
[29]	Problem-solving skill straining	Problem-solving skills	Rehabilitation	Stationary devices	Web-based	PC input devices	PC
[30]	Cooking support	Activities of daily life, Undertaking multiple task	Education and training	Stationary devices	Computer based	Nintendo Wii remote	PC
[31]	Learning support, acquiring job skills, risk prevention	Support in areas such as learning tasks, acquiring job skills, risk prevention	Memory aid	Mobile	Mobile-based	Touch	PDA
[32]	Verbal-arithmetic-logic-spatial and memory exercises	To investigate the effectiveness of a computer based training on visual spatial abilities, visual attention, executive function and visual memory	Memory aid	Stationary devices	Computer based	PC input devices	PC
[33]	Producing higher rates of timely task completion	Timely task completion	Memory aid	Mobile	Mobile-based	Touch	PDA

Analysis of Functionality Based on Analytical Framework

All identified studies were analyzed based on the analytical framework described previously in the methods section. The identified studies covered a few impairments from the ICF checklist for MACI patients, but most of the items in the ICT checklist were not addressed by the functionality of any of the systems that have been published. Figure 2 shows the ICF checklist and indicates which areas on the checklist correspond with the functionality of tools included in the study. The colored elements are the subset of the most common and important problems for MACI patients. The reference number next to some of the elements (green items) indicates which of the included studies contain functionality that deals with that element.

Figure 2. International Classification of Functioning, Disability and Health (ICF) checklist.



Part 1a: Body Functions

- Mental functions
  - Consciousness
  - Orientation
  - Intellectual
  - Energy and drive functions[a]
  - Sleep[a]
  - Attention[a]
  - Memory [27,28,31-33][b]
  - Emotional functions[a]
  - Perceptual functions[a]
  - Higher-level cognitive functions[a]
  - Language
- Sensory functions and pain
  - Seeing[a]
  - Hearing[a]
  - Vestibular[a]
  - Pain[a]
- Voice and speech functions
  - Voice
- Functions of the cardiovascular, hematological, immunological, and respiratory systems
  - Heart
  - Blood pressure
  - Hematological
  - Immunological
  - Respiration
- Genitourinary and reproductive functions
  - Urination functions
  - Sexual functions
- Neuromusculoskeletal and movement-related functions
  - Mobility of joint
  - Muscle power
  - Muscle tone
  - Involuntary movements
- Functions of the skin and related structures
- Any other body functions

Part 1b: Body Structures

- Structure of the nervous system
  - Brain
  - Spinal cord and peripheral nerves
- The eye, ear, and related structures
- Structures involved in voice and speech
- Structure of the cardiovascular, immunological, and respiratory systems
  - Cardiovascular system
  - Respiratory system
- Structures related to the digestive, metabolism, and endocrine systems
- Structure related to genitourinary and reproductive system
  - Urinary system
  - Reproductive system
- Structure related to movement
  - Head and neck region
  - Shoulder region
  - Upper extremity (arm, hand)
  - Pelvis
  - Lower extremity (leg, foot)
  - Trunk
- Skin and related structures

Part 2: Activity & Participation domain

- Learning and applying knowledge
  - Watching
  - Listening[a]
  - Learning to read
  - Learning to write
  - Learning to calculate (arithmetic)
  - Solving problems [29][b]
- General tasks and demands
  - Undertaking a single task
  - Undertaking multiple tasks [27,28, 30,31][b]
- Communication
  - Communicating with (receiving) spoken messages
  - Communicating with (receiving) non-verbal messages
  - Speaking
  - Producing non-verbal messages
  - Conversation[a]
- Mobility
  - Lifting and carrying objects
  - Fine hand use (picking up, grasping) [a]
  - Walking
  - Moving around using equipment (wheelchair, skates, etc)
  - Using transportation
  - Driving
- Self-care
  - Washing oneself
  - Caring for body parts
  - Toileting
  - Dressing
  - Eating
  - Drinking
  - Looking after one`s health
- Domestic life
  - Acquisition of goods and services
  - Preparation of meals
  - Doing housework
  - Assisting others
- Interpersonal interactions and relationships
  - Basic interpersonal interactions[a]
  - Complex interpersonal interactions[a]
  - Relating with strangers[a]
  - Formal relationships[a]
  - Informal social relationships[a]
  - Family relationships[a]
  - Intimate relationships[a]
- Major life areas
  - Informal education
  - School education
  - Higher education
  - Remunerative employment
  - Basic economic transactions
  - Economic self-sufficiency
- Community, social, and civic life
  - Community Life
  - Recreation and leisure
  - Religion and spirituality
  - Human rights
  - Political life and citizenship

Part 3: Environment

- Products and technology
  - For personal consumption (food, medicines)
  - For personal use in daily living [27-31][b]
  - For personal indoor and outdoor mobility and transportation
  - Products for communication[a]
  - Design, construction, and building products and technology of buildings for public use[a]
  - Design, construction, and building products and technology of buildings for private use[a]
- Natural environment and human-made changes to environment
  - Climate
  - Light
  - Sound
- Support and relationships
  - Immediate family[a]
  - Friends[a]
  - Acquaintances, peers, colleagues, neighbors and community members[a]
  - People in position of authority[a]
  - Personal care providers and personal assistants[a]
  - Health professionals[a]
  - Health-related professionals[a]
- Attitudes
  - Individual attitudes of immediate family members
  - Individual attitudes of friends
  - Individual attitudes of personal care providers and personal assistants
  - Individual attitudes of health professionals
  - Individual attitudes of health-related professionals
  - Societal attitudes
  - Social norms, practices, and ideologies
- Services, systems, and policies
  - Housing services, systems, and policies
  - Communication services, systems, and policies
  - Transportation services, systems, and policies
  - Legal services, systems, and policies
  - Social security, services, systems, and policies
  - General social support services, systems, and policies
  - Health services, systems, and policies
  - Education and training services, systems, and policies
  - Labor and employment services, systems, and policies

[a] A subset of the most common and important problems for MACI patients.

[b] A subset of the most common and important problems for MACI patients and an included study contains functionality that deals with that element.

Discussion

One of the most salient findings of the review portion of the study was that there is a general lack of published studies that report on the use of ICT to support self-management for MACI patients. The number of relevant articles found was very low (7 studies). The small number of studies that met the criteria for the review was not a result of a general lack of focus within the research community on studying ICT tools to aid patients with cognitive impairment. The problem was rather that a high number of studies reporting on ICT tools for self-management of patients with cognitive impairments were developed for patients with severe impairments, Alzheimer disease, and/or age-related deficiencies. Patients with MACI have different needs than these patients and have received far less attention from the research community.

Functionality Included in the Tools

With respect to the functionality of the tools that did meet the review criteria, we found the ICF checklist and a subset of the most common and important problems faced by MACI patients, identified and used by experienced rehabilitation professionals and MACI medical experts in Sweden, to be valuable as an analytical framework for investigating how their functionality meets patient needs and treatment options from the perspective of health care professionals that would assist them in self-management. All of the tools that met the inclusion criteria were focused on helping to support patients in managing daily activities, and all of them met the common and important problems criteria. This suggests that the line of research of tools to support MACI has been focused on highly relevant problems. More specifically, all of the studies helped aid patients with at least one of 3 things: (1) memory deficits [27,28,31-33], (2) undertaking multiple tasks at the same time [30], and (3) problem solving [29].

Although our analysis included health care professionals' perspectives on patients' needs by including MACI experts' experience and knowledge to identify relevant patient problems on the ICF checklist, in the future it would be interesting to improve the analytical framework by collecting data directly from patients to see whether this information differs from that provided by MACI experts. This could be useful for further analyzing ICT self-management and treatment tools and for other aspects of MACI treatment because this is a new area that needs further development. It could also be used as a basis for considering how to design tools that could be used for self-management of patients outside of the context of collaboration with health care professionals that we have targeted in this paper.

Study Methodology and Evidence of Benefit

Although the studies focused on issues that seemed important for MACI patients, a general limitation with the studies is that they did not report evaluations using a robust methodology that could provide a high degree of evidence on the usefulness of the tools investigated. We had hoped to be able to provide a discussion about whether or not the tools that were developed thus far were beneficial for patients. However, the quality of the studies was so low that it was not possible to do that at this time.

For example, only 1 study reported an evaluation of a system that included a control group and the findings were statistically significant in favor of the group using the tool versus the group that did not use the tool [32]. The rest of the articles either reported a case study or were exploratory in nature, and thus had a focus on identifying design issues rather than on providing clear evidence of benefits to patients for the tool being studied. Although the preliminary results do seem positive for the tools included in these studies, additional studies are needed to determine benefits for patients.

Another methodological limitation of the reported studies is that they often did not describe their own design process very clearly. In most cases, we could not comprehend the entire design process utilized. However, one of the studies did report the utilization of user-centered design methods by developing a prototype based on patients' preferences as identified during participatory design, and the system's capabilities [27]. This is consistent with suggestions that design processes for ICT services that will be utilized by patients should require users to be involved in the design process. Representative users should actively participate, early and continuously throughout the entire development process and throughout the system lifecycle

[38,39]. User-centered design will address the challenges about design approaches in health informatics, usability problems, visions for further development, and the necessary improvements in practical user-centered guidelines for designing ICT tools [40]. In the future, studies should clearly report on the design methodology and involve the users in the design process.

Gaps in the Functionality of the Tools

One of the goals of this paper was to identify unexplored functionality that could be useful for supporting MACI patients with self-management by finding issues on the subset of common and important problems taken from the ICF checklist that did not appear in any of the studies. A total of 34 items appeared on the subset, but only 4 of these items (13%) were covered in the functionality of the tools identified during the study. Therefore, the study indicates that there is much progress still to be made in the area and that new tools are worth exploring in order to expand the number of different ways that MACI patients can be supported with ICT.

The development and evaluation of additional tools provides the possibility to fill in the gaps for impairments noted in the ICF checklist that are not covered by the existing tools. The items on the list are also quite general and the MACI patients' impairments are very individual. This means that not all patients with an impairment that qualifies under a specific ICF subcategory will be able to obtain benefits from all ICT tools targeting that category.

Areas on the subset of common and important problems that are not covered by the tools in the study can be viewed as interesting areas for future investigations. One issue that seems highly relevant, for example, is that none of the tools supported interpersonal interactions and relationships although family support, social interaction, and relationships with friends, which are important issues for patients with MACI [13]. It may be interesting to explore the usage of the Internet and social media for these purposes [41]. Also, the long-term information exchange between patient, families, and caregivers, and the long-term effect of using such technologies and follow-ups are unexplored areas. None of the studies investigated utilized Medicine 2.0 [42] (ie, the use of specific Web tools for supporting and personalizing the health care collaboration and education) and these are interesting new areas that are being utilized to support social needs of patients.

Additional Issues

In addition to looking at how the individualized needs of MACI patients not addressed in the reported studies can be supported in the future, there is also the opportunity to benefit from investigating how to combine and/or configure different tools to meet the individualized needs of patients. Although it may be possible to address a variety of impairments associated with many different elements on the ICF checklist by one multifunctional tool, it is likely that multiple useful tools will be developed and evaluated independently, and that guidelines for how best to combine different tools to meet different patient needs will need to be developed.

It is possible that there will be a large role to play in this process through the use of open market tools rather than new tools specifically developed for MACI patients. The impairment of MACI patients is usually limited and they are capable of using computers, smartphones, and the Internet on their own. There also is a wide range of different applications available on open market platforms, such as smartphones and tablets, that might be able to address many of the challenges faced by MACI patients. Thus, it is interesting to see if providing patients with combinations of open market tools strategically selected to serve their individualized needs will provide benefits.

In addition to thinking about how the functionality of tools matches with the ICF checklist and the subset of common and important problems, there are some other notable issues that can be taken from the review that can help to guide future research. One issue, for example, is that the advancement of development tools and platforms now makes it possible for developers and software/hardware designers to computerize existing rehabilitation approaches. However, recent articles have not exploited this opportunity. It would be interesting to conduct studies that focus on how existing rehabilitation frameworks can be adapted to ICT tools to provide patients with improved self-management possibilities.

Limitations

This research provided an overview of peer-reviewed literature on this topic and the required design and direction for future research. However, this research was limited to all published articles before September 2011 because the reading of a large amount of full text was needed due to inconsistent bibliographic indexing of this fairly new field of research. We also might have missed assistive technologies, system developments, and implementations that were not published in the scientific journals, as well as the most recent developments.

Conclusion

In our review of ICT tools that can be used for health care professionals to support self-management of MACI patients, only 7 relevant studies were found. The existing studies provide an overview of some ways in which patients can be aided with memory problems, problem solving abilities, and handling multiple tasks. However, further studies are needed on how to support patients with these problems because the methodologies used for evaluating these tools were insufficient to provide clear clinical recommendations. The existing studies also did not describe their design methodology in detail; future studies could provide additional value by reporting such details.

The functionality of all of the tools that met the inclusion criteria for the review fell within the subset of the ICF checklist consisting of the most common and important problems for MACI patients. This provides some validation for using these criteria as an analytical framework because all the other groups independently ended up focusing on the same problems that have been identified by the medical experts. Further efforts to refine and standardize these criteria are needed because MACI is a new term and the criteria were developed from only a few experts in one country.

In addition to further exploring tools with functionality like those in the studies identified in the review, the list of common and important problems is useful for highlighting gaps where new tools can be developed to potentially aid patients in ways not supported by existing tools. There are a large number of items on the list that are not covered by existing tools. Therefore, there is a large opportunity for the research community to investigate improved support for MACI with ICT. In addition to the development of custom tools, evaluation of open market tools would be valuable, as well as investigating how to combine multiple tools to provide individualized support for patients.

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Conflicts of Interest

None declared.

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Abbreviations

ICF: International Classification of Functioning, Disability and Health
ICT: information and communication technology
MACI: mild acquired cognitive impairment
MCI: mild cognitive impairment
TBI: traumatic brain injury

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Original Paper

Persuasive System Design Does Matter: A Systematic Review of Adherence to Web-Based Interventions

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Abstract

Background: Although web-based interventions for promoting health and health-related behavior can be effective, poor adherence is a common issue that needs to be addressed. Technology as a means to communicate the content in web-based interventions has been neglected in research. Indeed, technology is often seen as a black-box, a mere tool that has no effect or value and serves only as a vehicle to deliver intervention content. In this paper we examine technology from a holistic perspective. We see it as a vital and inseparable aspect of web-based interventions to help explain and understand adherence.

Objective: This study aims to review the literature on web-based health interventions to investigate whether intervention characteristics and persuasive design affect adherence to a web-based intervention.

Methods: We conducted a systematic review of studies into web-based health interventions. Per intervention, intervention characteristics, persuasive technology elements and adherence were coded. We performed a multiple regression analysis to investigate whether these variables could predict adherence.

Results: We included 101 articles on 83 interventions. The typical web-based intervention is meant to be used once a week, is modular in set-up, is updated once a week, lasts for 10 weeks, includes interaction with the system and a counselor and peers on the web, includes some persuasive technology elements, and about 50% of the participants adhere to the intervention. Regarding persuasive technology, we see that primary task support elements are most commonly employed (mean 2.9 out of a possible 7.0). Dialogue support and social support are less commonly employed (mean 1.5 and 1.2 out of a possible 7.0, respectively). When comparing the interventions of the different health care areas, we find significant differences in intended usage ($p = .004$), setup ($p < .001$), updates ($p < .001$), frequency of interaction with a counselor ($p < .001$), the system ($p = .003$) and peers ($p = .017$), duration ($F = 6.068$, $p = .004$), adherence ($F = 4.833$, $p = .010$) and the number of primary task support elements ($F = 5.631$, $p = .005$). Our final regression model explained 55% of the variance in adherence. In this model, a RCT study as opposed to an observational study, increased interaction with a counselor, more frequent intended usage, more frequent updates and more extensive employment of dialogue support significantly predicted better adherence.

Conclusions: Using intervention characteristics and persuasive technology elements, a substantial amount of variance in adherence can be explained. Although there are differences between health care areas on intervention characteristics, health care area per se does not predict adherence. Rather, the differences in technology and interaction predict adherence. The results of this study can be used to make an informed decision about how to design a web-based intervention to which patients are more likely to adhere.

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KEYWORDS

Systematic review; web-based interventions; adherence; attrition; persuasive technology; behavior change

Introduction

Web-based interventions for promoting health and health-related behaviors are seen in many variations and health care areas. According to Barak et al. [1] a web-based intervention is:

> *...a primarily self-guided intervention program that is executed by means of a prescriptive online program operated through a website and used by consumers seeking health- and mental health–related assistance. The intervention program itself attempts to create positive change and or improve/enhance knowledge, awareness, and understanding via the provision of sound health-related material and use of interactive web-based components.*

A web-based intervention can involve therapy that lasts for a predetermined, fixed period of time. However, it can also be a continuous program with no specific end date that supports self-management among patients with a chronic condition. It is made up of different, inseparable aspects which, according to Barak et al [1], are as follows: program content, multimedia choices, interactive online activities, and guidance and supportive feedback.

Evidence exists to support the effectiveness of web-based interventions. Research has shown these interventions to be effective in different areas of health care [2-7]. However, many evaluations of eHealth interventions report either no positive effects at all or only limited ones [8-12]. One of the issues that is frequently addressed is the problem of non-adherence [11, 13-17], which refers to the fact that not all participants use or keep using the intervention in the desired way. Research suggests that non-optimal exposure to the intervention lessens the effect of these interventions [18, 19]. Gaining an insight into the factors that influence adherence should therefore be one of the main focus areas in any research study into web-based interventions. In this context, it is important to stress the difference between the terms “adherence” or “non-usage attrition” and “dropout.” Dropout, or dropout attrition, refers to participants in a study who do not fulfill the research protocol (eg, filling out questionnaires). This is not a focus area of this study. Adherence, or non-usage attrition, refers to the extent to which individuals experience the content of an intervention [13, 15]. This is the focus of our study.

When looking at literature about adherence to a therapeutic regimen [20, 21], adherence is seen as the extent to which the patient’s behavior matches the recommendations that have been agreed upon with the prescriber. The term is often seen as a reaction to the term “compliance,” which has a more coercive connotation. Consequently, in adherence, the patient plays an active role in achieving this behavior [21]. At the same time, there is also a norm or recommendation from a prescriber, which the patient tries to match. This recommendation is missing from the definitions of both adherence and non-usage attrition [13, 15]. In this study, we elaborate on the definition by introducing the concept of “intended usage.” Intended usage is the extent to which individuals *should* experience the content (of the intervention) to derive maximum benefit from the intervention, as defined or implied by its creators. This matches the norm or recommendation from the definition of adherence to a therapeutic regimen. By comparing the observed usage of an individual to the intended usage of a web-based intervention, we can establish whether or not this individual adheres to the intervention. In this context, adherence is a process that cannot be assessed solely by measuring usage at the beginning and end of the intervention. Rather, it has to be assessed throughout the entire process to establish whether or not an individual adheres to the intervention at each and every step of the way. Finally, by comparing the observed usage of each individual to the intended usage of the web-based intervention, the percentage of individuals that adhere to the intervention can be calculated. This results in a more objective measurement of adherence, which can then be compared to other interventions, even if the intended usage is different.

Adherence to web-based interventions has been the subject of research for some time. Many studies focus on whether and which respondents’ characteristics can explain variations in adherence [11, 13, 16, 22]. Although this is a very important line of study, it seems to take the technology of web-based interventions for granted. Technology as a means to communicate the content has been neglected in research. Indeed, this technology is often seen as a black box: a mere tool that has no effect or value and serves only as a vehicle for the delivery of intervention content. In line with a recent viewpoint paper, we propose to examine the technology from a holistic perspective and see it as a vital and inseparable aspect of the web-based intervention [12]. This approach has been recommended in recent literature [10, 11, 13, 23] and has been the key point in the field of persuasive technology [24], where there are examples of studies on the persuasive capacities of technology to support web-based interventions in the health care domain [25-28].

Recently, two systematic reviews on the influence of intervention factors on adherence to web-based interventions were published [29, 30]. Although both reviews provide valuable insights, we feel that there are shortcomings that limit the applicability of these results for our objectives. First, with regard to adherence, the study of Brouwer [29] takes exposure to interventions delivered via the internet as the outcome measure. Exposure is seen as the number of times the user or patient logged on, the time spent on site, page views, etc, but these are static measurements unrelated to the usage intended by these interventions. This gives limited insights into the process of usage and adherence, which makes it difficult to compare different interventions and specify how well certain interventions are doing. A review by Schubart [30] fails to distinguish between dropout and adherence. This approach limits the applicability of the results because, in real-life implementation of web-based interventions, there is no research protocol to adhere to, only the intervention. The results of Schubart’s review [30] cannot be generalized to these situations because we do not know whether engagement is due to the research or the intervention.

Furthermore, regarding the intervention factors, both studies use an ad hoc classification of these factors without a theoretical foundation, which makes it difficult to generalize and explain the results. We consider a web-based intervention as consisting of content, interaction, and technology. And, although these aspects are inseparable, they can be looked at in a structured manner. Both earlier reviews use a classification that, in our opinion, has substantial overlap in the goals to be achieved with these aspects. For example, in the review by Brouwer [29], a distinction is made between interactive behavior change strategies and interactive elements. It is stated that the goal of interactive elements is to "improve the attractiveness of the intervention or to provide the option for more information," but this is not mutually exclusive with interactive behavior change strategies. For example, a quiz is seen as an interactive element, but in our opinion it can also be used as a means of receiving tailored feedback or as a way to self-monitor your knowledge or behavior. Allocating a quiz to one of these categories is therefore problematic. The categorization of intervention factors in the review by Schubart [30] lacks depth and tries to encompass in one single categorization both modality (ie, the channel through which content is delivered; for example, email or telephone) and strategy (eg, feedback).

The current study attempts to overcome these shortcomings by employing a more objective and comparable measurement of adherence to web-based interventions and a classification of technology based on persuasive technology literature.

From the field of persuasive technology we learn that technology has the capacity to be persuasive through its role as a tool, a medium, and a creator of experiences [24]. Fogg's definition of persuasive technology limits this field to human-computer interaction and does not include computer-mediated communication (ie, including interaction with a person). However, we feel that it is unnecessary and undesirable to separate these two aspects of technology, particularly in the area of health care, because a web-based intervention is made up of different, inseparable aspects. We therefore propose a broader application of the term "persuasive technology" to include both human-computer interaction and computer-mediated communication. Accordingly, regarding the aspects of a web-based intervention, we propose a more pragmatic conceptual division between technology (ie, all the features of the web-based intervention, including multimedia and online activities) and interaction (ie, all interactions between the user or patient and the intervention, a counselor, or peers), which is slightly different from the aspects proposed by Barak. Following Fogg's work, Oinas-Kukkonen introduces a framework to classify technology in its persuasive functions [31]. This persuasive system design (PSD) model, which is used, for example, in a study by Lehto and colleagues [32], classifies features of the technology as primary task support, dialogue support, social support, and credibility support. By applying this model to web-based interventions, we can systematically look at how persuasive system design categories are used and investigate their possible influence on adherence.

This study investigates whether intervention characteristics and persuasive design affect adherence to a web-based intervention. Web-based interventions are applied in various health care domains and intuitively it seems that there are differences between web-based interventions aimed at people with a chronic condition, at lifestyle change, or at mental health, because of the target group, involvement with a health care professional, and duration of the interventions. However, the underlying principles may well be the same. Therefore, from an intervention perspective, there is no absolute need to see these areas as being so different from each other that they cannot be compared. Consequently, it is interesting to see whether the preconceptions about the differences can be confirmed and whether there is added value for researchers and designers in one area to look at interventions from a different area.

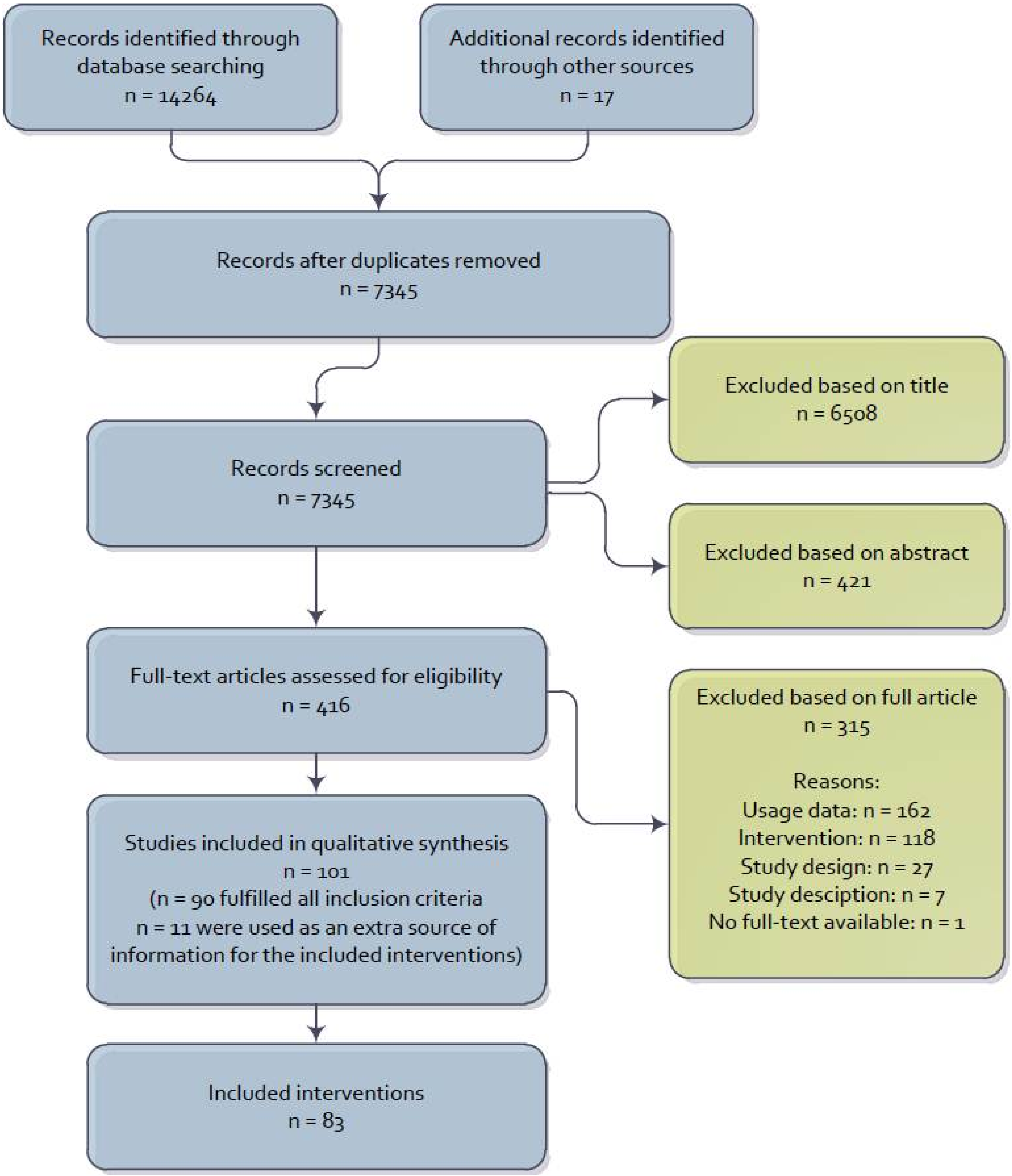
Our systematic review aims to answer the following research questions: (1) What are the key characteristics of web-based interventions in terms of technology and interaction? (2) Are there any differences in intervention characteristics between web-based interventions aimed at chronic conditions, lifestyle, or mental health? (3) What percentage of participants adhere to web-based interventions? (4) Which characteristics of web-based interventions related to technology and interaction are linked to better adherence? These insights can help us understand and reduce the impact of non-adherence.

Methods

Search Strategy

We conducted a comprehensive literature search using the following bibliographic databases: Web of Knowledge, EBSCOhost, PiCarta, SciVerse Scopus, and ScienceDirect. We used a combination of the constructs "web-based," "intervention," "adherence," and "health." For each construct, we used several keywords (see Multimedia Appendix 1) to ensure a broad coverage of published studies in our review. Following this search strategy, we identified 14,264 articles published up to 2011 Oct 26 (see Figure 1 for the full flow diagram of article selection).

Figure 1. Flow diagram of study selection.



Eligibility Criteria

The review is limited to studies of web-based interventions in the health care domain. The criteria used for including a study were: (1) it involved a web-based intervention for promoting health through behavioral change; (2) the web-based intervention was intended to be visited and used on more than one occasion; (3) the research included an assessment of the effect of the intervention; (4) the study reported objective, quantifiable measurements of usage for the intervention; and (5) the study was published in either English or Dutch. Exclusion criteria were as follows: (1) dropout attrition and non-adherence were indistinguishable; (2) the intervention was aimed at care providers or relatives of the “patient;” (3) the description of the intervention did not include information about the applied persuasive features of the technology; and (4) the web-based intervention was not primarily intended to be used through a computer or laptop at the user’s or patient’s home. In addition, we only included peer-reviewed, published articles.

Study Selection and Data Collection

The study selection was done in three steps. First, the titles of all retrieved articles were screened for eligibility by two authors (SK and RK). Second, the abstracts of all initially relevant articles were screened for eligibility by the same authors. Finally, the full text of all remaining publications was checked for inclusion by two authors (SK and RK or SK and JvG). In cases where the suitability of a study came into question during one of the steps, it was included in the next step. Disagreements about including the full text publication were discussed until agreement was reached. To check whether any eligible publications had been overlooked during the initial search process, the reference lists of all systematic reviews that were identified in the original search were checked to find additional publications that met our inclusion criteria.

The characteristics of all of the interventions that were included were coded by two researchers (SK and RK) using a data extraction form based on a protocol for the systematic review of eHealth technologies [33]. Where possible, data was extracted using the CONSORT-EHEALTH checklist [12]. For the extraction, we relied on information that was available in the published literature. The basis of the data extraction was the intervention, not the study itself. This meant that for some interventions data from more than one article was used. Furthermore, when a study described more than one web-based intervention (eg, a comparison of two web-based interventions), all web-based interventions were coded separately.

Data Items

The following characteristics were coded:

Intervention Name

The name of the intervention was recorded. If the intervention had no name, the intervention was named after the first author of the primary article about the intervention.

Behavior or Condition

The targeted behavior or condition of each intervention was recorded. Furthermore, we recorded the area of health care targeted by the intervention (chronic condition, lifestyle, or mental health).

Studies and Study Design

For each intervention, the studies that were used to code the characteristics of the intervention were recorded. Furthermore, we also recorded whether these studies were randomized controlled trials (RCTs) or observational studies without randomized control groups.

Intended Usage

Intended usage was defined as the extent to which the developers of the intervention felt that the intervention should be used to achieve the desired effect ([12] 5ix). When this information was not reported, it was inferred from the description of the intervention. For example, interventions requiring patients to monitor their behavior and receive feedback once a week to achieve the desired effect were coded as intended to be used once a week.

Actual Usage

All reported information regarding the usage of the intervention (related to its intended usage) was collected, including the number of times the user or patient logged on and the number of modules completed ([12] 6aii).

Adherence

A percentage of adherence was calculated to enable us to compare the different interventions. We did this by calculating the percentage of participants that adhered to the intervention. For example, when the intended use of an intervention was “complete 8 modules” and 60 out of 100 participants completed 8 modules, the adherence was 60%. For each intervention that was included, we calculated one overall adherence percentage. When more studies about the same intervention yielded different adherence percentages, we calculated the overall adherence percentage using a weighted average, based on the number of participants in each study. Furthermore, when the study included a waiting list and the respondents in this waiting list received access to the intervention at a later stage, the adherence was calculated based on usage data for all participants, including the waiting list group.

Updates

The frequency of content updates for the web-based intervention for a participant was recorded. This could be based on new information being uploaded for all participants or on a new lesson becoming available for a specific participant.

Duration

The duration of the intervention in weeks was recorded.

Setup

For each intervention, we created a record indicating whether the setup was modular (ie, content is delivered in a sequential order, whereby new content is made available when the user reaches a certain point) or free (ie, all the content of the intervention is available to the user from the start).

Interaction

All information about the interaction with participants was recorded ([12] 5viii, 5x, and 5xi). This interaction could be with the system (eg, automatic email reminders or a web-based automated response to filling out an exercise), with a counselor (eg, through email, telephone, or face-to-face meetings), or with peers (eg, through a discussion board, chat group, or face-to-face group sessions).

Modality

We recorded when interaction with the system, counselor, or peers took place through a different modality than web-based (face-to-face meeting, telephone, or SMS). An exception was made when the study protocol included a face-to-face meeting or telephone intake. This was not coded as interaction through a different modality because it was not part of the actual intervention.

Persuasive Technology in the Intervention

The applied principles of persuasive technology within the interventions were coded according to the PSD framework of

Oinas-Kukkonen and Harjumaa [31]. We omitted system credibility support because of an observed lack of reporting of these principles in the studies that were included. The elements from the PSD framework on primary task, dialogue, and social support, with the definitions and the coding scheme we used, are presented in Table 1. The coding scheme is somewhat modified for the purpose of this study and to account for the computer-mediated communication included. However, when coding the persuasive technology elements, the technology was central, not the content of the interaction. Therefore, when computer-mediated communication was present, the content of this communication was not coded as persuasive technology. For example, when a feedback message from a care provider contained praise, this was not coded as dialogue support. When the technology provided a praising message after the user had successfully filled out a diary entry, then it was coded. For each intervention, the elements that were present were coded, irrespective of whether the designers of the intervention deliberately included these elements as persuasive technology elements. To check for differences in interpretation when coding the persuasive technology elements, 10 interventions were coded by 2 researchers (SK and LvG). The interrater reliability, measured by Cohen's kappa, was 0.91.

Analyses

All data on each intervention was entered in SPSS version 19.0 (IBM Corporation, Somers, NY, USA), and we treated each intervention as a separate case. Descriptive data of the combined data of all included interventions on all variables were calculated using SPSS. Differences in variables between health care areas were calculated using Fisher's exact tests (because of the small expectation values) and one-way analyses of variance. To investigate whether the characteristics of the included interventions could predict the observed adherence, we performed a hierarchical multiple linear regression analysis, using a block-wise "enter" method. The first block was related to the context of the web-based intervention and included the health care area (coded as dummy variables) and the study design (RCT vs observational), which other researchers have proposed to influence adherence or the effect of web-based interventions [7, 29, 34]. The second block relates to our concept of interaction as one of the aspects of a web-based intervention and consists of the frequency of interaction with a counselor, the system, and peers, as well as the modality employed. The third and fourth blocks relate to our concept of technology in a web-based intervention, where the third block contains the intervention characteristics intended usage, setup, updates, and duration, and the last block contains the categories of persuasive system design. It is important to note that we chose to include the categories, and not the separate elements in the multiple regression, because (1) the results could be biased when some elements are hardly used and these elements are entered as predictors; (2) entering all 21 elements increases the chance of a type I error; and (3) the PSD model has grouped the elements on their key benefits (when the benefits of the specific elements in a category are similar, then looking at the specific elements could cause the overall influence of the category to be missed).

Table 1. PSD framework elements coding scheme.

Principle and definition according to PSD framework [31]		Coded as element included when the web-based intervention:	Example
Primary Task Support			
Reduction	A system that reduces complex behavior into simple tasks helps users perform the target behavior, and it may increase the benefit/cost ratio of a behavior.	Specifically divides the target behavior into small, simple steps	A web-based intervention for weight management includes a diary for recording daily calorie intake, thereby dividing the target behavior (reducing calorie intake) into small, simple steps of which one is recording calorie intake
Tunneling	Using the system to guide users through a process or experience provides opportunities to persuade along the way.	Delivers content in a step-by-step format with a predefined order	A web-based intervention for the prevention of depression that delivers the content in sequential lessons that can only be accessed when the previous lesson is completed
Tailoring	Information provided by the system will be more persuasive if it is tailored to the potential needs, interests, personality, usage context, or other factors relevant to a user group.	Provides content that is adapted to factors relevant to a user group, or when a counselor provides feedback based on information filled out by a participant	A web-based intervention for supporting self-management among patients with diabetes provides information adapted to patients based on whether they have diabetes mellitus type I or II
Personalization	A system that offers personalized content or services has a greater capability for persuasion.	Provides content that is adapted to one user (ie, the name of the user is mentioned and/or the user can adapt a part of the intervention)	A web-based intervention for increasing physical activity allows users to choose whether they want to see their weekly activity score on the home page or not
Self-monitoring	A system that keeps track of one's own performance or status supports the user in achieving goals.	Provides the ability to track and view the user's behavior, performance or status	A web-based intervention for the treatment of alcohol dependence provides a diary to track and view daily alcohol use
Simulation	Systems that provide simulations can persuade by enabling users to observe immediately the link between cause and effect.	Provides the ability to observe the cause-and-effect relationship of relevant behavior	A web-based intervention for smoking cessation includes a calculator that shows how much users will save when they quit smoking
Rehearsal	A system providing means with which to rehearse a behavior can enable people to change their attitudes or behavior in the real world.	Provides the ability and stimulation to rehearse a behavior or to rehearse the content of the intervention	A web-based intervention for supporting self-management in patients with epilepsy starts each lesson with the same important exercise for stress-management
Dialogue Support			
Praise	By offering praise, a system can make users more open to persuasion.	Offers praise to the participant on any occasion	A web-based intervention that aims to promote healthy nutritional habits compliments participants when they have eaten 2 pieces of fruit for 5 days
Rewards	Systems that reward target behaviors may have great persuasive powers.	Offers some kind of reward when the participant performs a target behavior relating to the use or goal of the intervention	A web-based intervention for the treatment of social phobia gives points to participants when they engage in exposure exercises
Reminders	If a system reminds users of their target behavior, the users will more likely achieve their goals.	Provides reminders about the use of the intervention or the performance of target behavior	A web-based intervention to support self-management among patients with rheumatic arthritis sends an automatic email message to remind the participant that the new lesson may begin
Suggestion	Systems offering fitting suggestions will have greater persuasive powers.	Provides a suggestion to help the participants reach the target behavior	A web-based intervention for weight management provides low-calorie recipes

Principle and definition according to PSD framework [31]		Coded as element included when the web-based intervention:	Example
Similarity	People are more readily persuaded through systems that remind them of themselves in some meaningful way.	Is designed to look familiar and designed especially for the participant	A web-based intervention for the treatment of panic disorder in teenage girls explains the exercises through a teenage girl with panic problems
Liking	A system that is visually attractive for its users is likely to be more persuasive.	Is visually designed to be attractive to the participants	During the design of a web-based intervention to increase physical activity in middle-aged women, a representative group is asked for feedback on the design and their feedback is subsequently incorporated in the new design
Social role	If a system adopts a social role, users will more likely use it for persuasive purposes.	Acts as if it has a social role (eg, a coach, instructor, or buddy)	A web-based intervention to support self-management among patients with migraine incorporated an avatar to guide the participant through the intervention
Social Support			
Social learning	A person will be more motivated to perform a target behavior if (s)he can use a system to observe others performing the behavior.	Provides the opportunity and stimulates participants to see others using the intervention or performing the target behavior	A web-based intervention for weight management provides the option, and stresses the importance, of posting physical activity self-monitoring data on the discussion board and commenting on the performance of others
Social comparison	System users will have a greater motivation to perform the target behavior if they can compare their performance with the performance of others.	Provides the opportunity for participants to compare their behavior to the target behavior of other participants and stimulates them to do this	A web-based intervention for drug abuse prevention for teenagers automatically compares the response of the participant to other users of the intervention
Normative influence	A system can leverage normative influence or peer pressure to increase the likelihood that a person will adopt a target behavior.	Provides normative information on the target behavior or the usage of the intervention	A web-based intervention to promote self-management among patients with COPD provides feedback on the level of physical activity of the participant by comparing it to the physical activity of well-managed COPD patients
Social facilitation	System users are more likely to perform target behavior if they discern via the system that others are performing the behavior along with them.	Provides the opportunity to see whether there are other participants using the intervention	A web-based intervention for smoking cessation includes a discussion board for users of the intervention
Cooperation	A system can motivate users to adopt a target attitude or behavior by leveraging human beings' natural drive to cooperate.	Stimulates participants to cooperate to achieve a target behavior	A web-based intervention for the promotion of physical activity stimulates participants to form groups and to achieve the group goal of a certain number of steps each week
Competition	A system can motivate users to adopt a target attitude or behavior by leveraging human beings' natural drive to compete.	Stimulates participants to compete with each other to achieve a target behavior	A web-based intervention for diabetes management among children includes a leaderboard in which the children who enter blood glucose levels at the right times receive the highest place
Recognition	By offering public recognition for an individual or group, a system can increase the likelihood that a person/group will adopt a target behavior.	Prominently shows (former) participants who adopted the target behavior	A web-based intervention treatment of anxiety includes a testimonial page where successful users of the intervention tell their story

Results

Study Selection

The search yielded 7345 unique titles. After title, abstract, and full-text screening, 101 articles on 83 interventions were included (Figure 1). In total, 315 articles were excluded based on the full text. The most common reason for exclusion was related to usage data: the lack thereof (n = 84) or the presentation of inadequate (ie, subjective or not usable for calculating adherence) usage data (n = 78). Other studies were excluded based on the studied intervention: not aimed at health promotion by changing behavior (n = 40); not primarily meant to be used from a computer or laptop at the user’s home (n = 41); not intended to be visited and used on more than one occasion (n = 34); or not targeted at the patient (n = 3). Twenty-seven publications were excluded because the study design did not include an assessment of the effect of the intervention (eg, when they only presented qualitative data on the design of an intervention) or when the study design did not provide unique usage data (eg, a study about the long-term effects of an intervention). Seven publications were excluded because of the description of the intervention or study: in 4 publications no information could be gathered on the applied persuasive features of the technology from the description of the intervention and in 3 publications the data on the number of participants and their usage of the intervention was unclear. Finally, in the case of one citation, the full text could not be retrieved; this citation was therefore excluded.

Characteristics of the Studies that Were Included

The 83 interventions that were included are presented in Multimedia Appendix 2. Overall, 19 interventions targeted a specific chronic condition (diabetes was targeted most often with 6 interventions). Sixteen interventions targeted a lifestyle behavior (weight management was targeted most often with 7 interventions). Smoking cessation was also often seen (5 interventions were targeted solely on smoking cessation and 1 intervention included smoking cessation as one of multiple targeted behaviors). Finally, mental health was targeted most often in the studies that were included. Of these 48 interventions, 12 focused on social phobia, although it should be noted that these interventions are only from two research groups that extensively studied their interventions. Depression, panic disorder, and anxiety were also targeted frequently in the interventions that we included (10, 8 and 7 interventions, respectively).

Table 2 presents an overview of the variables of the interventions that were coded and their distribution over the different areas (chronic condition, lifestyle, and mental health). Overall, we can see that most interventions were meant to be used once a week, were set up in a modular way, were updated once a week, and lasted for approximately 16 weeks (median duration 10 weeks). Face-to-face, telephone, and SMS support, or a combination of these modes, were infrequently used, with 4 interventions combining face-to-face and telephone support (interventions 3, 10, 33, and 72) and 2 interventions combining telephone and SMS support (interventions 24 and 81). Seventy-six per cent of the interventions included interaction of the participant with a counselor, and a similar percentage (73%) included some form of interaction with the system. A little over half of the interventions (53%) included interaction with peers, with and without counselor interaction. The average percentage of participants who adhered to an intervention is 50.3% (min 1%; max 93%). The values of each of the variables for each included intervention can be found in Multimedia Appendix 3.

Differences in Intervention Characteristics between Health Care Areas

When comparing the interventions of the different health care areas using Fisher’s exact tests, we find significant differences on intended usage (P = .004), setup (P< .001), updates (P < .001), frequency of interaction with a counselor (P < .001), the system (P = .003), and peers (P = .017). When looking at the standardized residuals (data not shown), we can see where these differences are manifested. We see that lifestyle interventions are more often intended to be used less than once a month than interventions in the other areas. We see that mental health interventions are less often free in terms of their setup than the other two areas. Lifestyle interventions are more often not updated or updated without a known frequency. Regarding interaction with a counselor, we see that lifestyle interventions more often do not employ this feature. Furthermore, we see that lifestyle interventions more frequently include interaction with the system less than once a week. Finally, on interaction with peers, chronic interventions more often have interaction for which the frequency is not specified. One-way analyses of variance show that there are differences in duration (F = 6.068, P = .004) and adherence (F = 4.833, P = .010). Bonferroni post hoc analyses show that the difference in duration is between lifestyle and mental health interventions (lifestyle interventions are longer), whereas the difference in adherence is between lifestyle and chronic condition interventions and between lifestyle and mental health interventions (lifestyle interventions have a lower adherence rate). In sum, lifestyle interventions are longer, the intended usage is less frequent, they have fewer updates, there is less interaction with the system and a counselor, and there is lower adherence than interventions aimed at chronic conditions and mental health. Mental health interventions are less often free in their setup and interventions aimed at a chronic condition include interaction with peers more often, for which the frequency is not specified.

Persuasive Technology

When examining the persuasive technology elements that are presented in Table 3, we see that a mean of 5.6 (median 5) out of a possible 21 elements were used within a web-based intervention. Primary task support shows the highest mean (2.9 out of a possible 7; median 3), while social support shows the lowest mean (1.2 out of a possible 7; median 1). One-way analyses of variance show that there is a significant difference between the use of persuasive technology elements for primary task support (F = 5.631, P = .005). A Bonferroni post hoc analysis shows that this difference is between lifestyle and mental health interventions, where lifestyle interventions employ a higher mean of elements than mental health interventions. Furthermore, we can see that in primary task support, tunneling is used most often (n = 75; 90%), closely followed by tailoring (n = 73; 88%). Tunneling is used in all included mental health interventions, but only in 10 (63%) of lifestyle interventions (significant difference; *P* < .001). Reduction and self-monitoring are less often used in mental health interventions than in the other areas (significant difference reduction, *P* = .033; and self-monitoring, *P* < .001). This is most strikingly seen in self-monitoring, which is used in 94% of lifestyle interventions, as opposed to 12% in the mental health interventions. Overall, rehearsal and simulation are used least of all out of the primary task support elements. From the dialogue support elements, reminders are most often used (n = 61; 74%) across all areas. Suggestion is the second most frequently used element (n = 24; 29%), although this is used more often in web-based interventions targeted at chronic conditions than in mental health (*P* = .008). Praise was not used in any of the interventions and rewards were used only in 3 interventions. In social support, we see that social facilitation is most often used (n = 43; 52%), with a significant difference between interventions aimed at a chronic condition (n = 14; 74% including social facilitation) and at lifestyle (n = 5; 31%; *P* = .046). Furthermore, social learning and social comparison are used reasonably frequently (respectively n = 31; 39% and n = 14; 17%), with mental health interventions predominantly contributing to these numbers (with a significant difference only for social learning: *P* = .044). Cooperation, on the other hand, is used in 2 lifestyle interventions and 1 chronic intervention, but in none of the mental health interventions (significant difference; *P* = .041). The other elements (normative influence, competition, and recognition) are hardly used. In sum, primary task support is most extensively employed while dialogue support and social support are sparsely employed. Tunneling, tailoring (primary task support), reminders (dialogue support), and social facilitation (social support support) are the most frequently used elements. On average, lifestyle interventions employ more primary task support elements than mental health interventions.

Predictors of Adherence

We performed a hierarchical multiple linear regression, using a block-wise "enter" method, to explore the predictors of adherence. Variables expected to predict adherence were entered in the analysis in blocks of related constructs, as specified in the methods section. The final model explained 55% of the variance in adherence. In this model, interventions studied with a RCT design (instead of an observational study), increased interaction with a counselor, more frequent intended usage, more frequent updates and more extensive employment of dialogue support significantly predicted better adherence.

Table 2. Descriptive variables of the included interventions per health care area

Variable		Chronic (N = 19), n (%)	Lifestyle (N = 16), n (%)	Mental (N = 48), n (%)	Total (N = 83), n (%)
Intended usage	<= 1/month	1 (5)	3 (19)	1 (2)	5 (6)
	1/month – 1/week	4 (21)	4 (25)	2 (4)	10 (12)
	1/week	13 (68)	6 (38)	40 (83)	59 (71)
	>1/week	1 (5)	3 (3)	5 (10)	9 (11)
Setup	Free	5 (26)	10 (63)	1 (2)	16 (19)
	Modular	14 (74)	6 (38)	47 (93)	67 (81)
Updates	None	1 (5)	5 (31)	1 (1)	7 (8)
	yes, FNS[a]	0 (0)	2 (13)	0 (0)	2 (2)
	<= 1/month	2 (11)	1 (6)	1 (2)	4 (5)
	1/month – 1/week	3 (16)	1 (6)	3 (6)	7 (8)
	1/week	12 (63)	6 (38)	42 (88)	60 (72)
	>1/week	1 (5)	1 (6)	1 (2)	3 (4)
Duration (weeks)	mean (sd)	18.2 (15.8)	29.8 (33.9)[b]	11.1 (18.5)	15.8 (18.5)
	Median	11	17	9	10
Interaction with counselor	None	2 (11)	8 (50)	10 (21)	20 (24)
	yes, FNS	3 (16)	3 (19)	2 (4)	8 (10)
	<1/week	5 (26)	3 (19)	2 (4)	10 (12)
	1/week	7 (37)	2 (13)	23 (48)	32 (39)
	>1/week	2 (011	0 (0)	11 (23)	13 (16)
Interaction with system	None	7 (37)	1 (6)	14 (29)	22 (27)
	yes, FNS	6 (32)	1 (6)	3 (6)	10 (12)
	<1/week	1 (5)	5 (31)	2 (4)	8 (10)
	1/week	2 (11)	6 (38)	14 (29)	22 (27)
	>1/week	3 (16)	3 (19)	15 (31)	21 (25)
Interaction with peers	none	5 (26)	10 (63)	24 (50)	39 (47)
	yes, FNS	10 (53)	4 (25)	10 (21)	24 (29)
	<1/week	2 (11)	0 (0)	1 (2)	3 (4)
	1/week	1 (5)	2 (13)	13 (27)	16 (19)
	>1/week	1 (5)	0 (0)	0 (0)	1 (1)
Face-to-face	included	3 (16)	1 (6)	1 (2)	5(6)
Phone	included	7 (37)	5 (31)	17 (35)	29 (35)
SMS	included	0 (0)	2 (13)	5 (10)	7 (8)
Adherence	mean (sd)	55.3 (19.8)	32.8 (23.0)	54.2 (27.4)	50.3 (26.2)

[a] FNS = Frequency not specified; [b] Based on 13 interventions. Three interventions (23, 26, and 27) did not specify duration.

Table 3. Persuasive technology in web-based interventions included in this study per health care area.

Variable		Chronic (N = 19), n (%)	Lifestyle(N = 16), n (%)	Mental(N = 48), n (%)	Total(N = 83), n (%)	*P* [a]
Primary Task Support	*mean (sd)*	*3.3 (1.0)*	*3.4 (1.3)*	*2.6 (1.0)*	*2.9 (1.1)*	
	median	*4*	*3.5*	*2*	*3*	
Reduction		10 (53)	10 (63)	14 (29)	34 (41)	.033
Tunneling		17 (90)	10 (63)	48 (100)	75 (90)	<.001
Tailoring		16 (84)	14 (88)	43 (90)	73 (88)	.814
Personalization		4 (21)	2 (13)	3 (6)	9 (11)	.209
Self-monitoring		12 (63)	15 (94)	12 (12)	39 (47)	<.001
Simulation		2 (11)	3 (19)	2 (4)	7 (8)	.118
Rehearsal		1 (5)	1 (6)	0 (0)	2 (2)	.175
Dialogue Support	*mean (sd)*	*1.6 (1.0)*	*1.4 (1.3)*	*1.6 (0.9)*	*1.5 (1.0)*	
	median	*2*	*1*	*1*	*1*	
Praise		0 (0)	0 (0)	0 (0)	0 (0)	
Rewards		0 (0)	2 (13)	1 (2)	3 (4)	.134
Reminders		13 (68)	11 (69)	37 (77)	61 (74)	.656
Suggestion		11 (58)	4 (25)	9 (19)	24 (29)	.008
Similarity		4 (21)	1 (6)	16 (33)	21 (25)	.088
Liking		2 (11)	4 (25)	8 (17)	14 (17)	.561
Social role		1 (5)	0 (0)	4 (8)	5 (6)	.819
Social Support	*mean (sd)*	*1.1 (0.7)*	*0.8 (0.9)*	*1.3 (1.2)*	*1.2 (1.0)*	
	median	*1*	*0.5*	*1*	*1*	
Social learning		5 (26)	3 (19)	24 (50)	31 (39)	.044
Social comparison		1 (5)	1 (6)	12 (25)	14 (17)	.088
Normative influence		0 (0)	0 (0)	1 (2)	1 (1)	1.000
Social facilitation		14 (74)	5 (31)	24 (50)	43 (52)	.046
Cooperation		1 (5)	2 (13)	0 (0)	3 (4)	.041
Competition		0 (0)	1 (6)	0 (0)	1 (1)	.193
Recognition		0 (0)	1 (6)	2 (4)	3 (4)	.767
Total	*mean (sd)*	*6.0 (2.2)*	*5.6 (2.5)*	*5.4 (2.0)*	*5.6 (2.1)*	

[a] Based on Fisher’s exact test. Note: results in *italics* are the mean (sd) and median number of elements used per intervention. Other results are presented as the number (%) of interventions that include a certain element.

Table 4. Predictors of adherence in a hierarchical multiple linear regression.

Step	Variable	*B*	*SE B*	*Beta*	*P*
1	Constant	0.40	.06		<.001
	Chronic	0.04	.07	.07	.55
	Lifestyle	-0.17	.08	-.25	.025
	Study design	0.18	.06	.30	.007
2	Constant	0.25	.09		.006
	Chronic	0.07	.07	-.11	.34
	Lifestyle	-0.11	.08	-.16	.17
	Study design	0.16	.07	.28	.014
	Freq. interaction with counselor	0.04	.02	.28	.055
	Freq. interaction with system	0.01	.02	.03	.79
	Freq. interaction with peers	0.01	.02	.05	.63
	Phone	0.09	.06	.16	.17
	Face-to-face	-0.08	.12	-.08	.48
	SMS	0.04	.10	.04	.69
3	Constant	-0.04	.21		.85
	Chronic	0.08	.07	.13	.26
	Lifestyle	-0.07	.09	-.09	.47
	Study design	0.18	.06	.30	.005
	Freq. interaction with counselor	0.02	.02	.12	.31
	Freq. interaction with system	-0.02	.02	-.09	.42
	Freq. interaction with peers	0.01	.02	.05	.60
	Phone	0.13	.06	.26	.027
	Face-to-face	-0.08	.11	-.08	.47
	SMS	0.02	.09	.03	.81
	Intended usage	0.09	.05	.23	.057
	Setup	-0.15	.11	-.22	.18
	Updates	0.10	.03	.43	.004
	Duration	-0.00	.00	-.06	.63
4	Constant	-0.12	.19		.51
	Chronic	0.08	.06	.14	.20
	Lifestyle	-0.04	.08	-.01	.96
	Study design	0.15	.06	.26	.008
	Freq. interaction with counselor	0.04	.02	.22	.039
	Freq. interaction with system	-0.04	.02	-.22	.058
	Freq. interaction with peers	-0.03	.03	-.15	.34
	Phone	0.05	.06	.10	.37
	Face-to-face	-0.10	.10	-.10	.31
	SMS	0.02	.08	.02	.85
	Intended usage	0.11	.04	.27	.014
	Setup	-0.16	.10	-.23	.11
	Updates	0.09	.03	.40	.002
	Duration	-0.00	.00	-.02	.88

Step	Variable	*B*	*SE B*	*Beta*	*P*
	Primary task support	-0.02	.03	-.11	.41
	Dialogue support	0.09	.03	.36	.006
	Social support	0.07	.04	.27	.095

Note R^2=.14 for step 1 (P = .08); ΔR^2 = .10 for step 2 (P = .16); ΔR^2 = .15 for step 3 (P = .006); ΔR^2 = .15 for step 4 (P < .001); cumulative variance explained in the final (step 4) model: R^2 = .55 (P < .001)

Discussion

In this systematic review, we have attempted to synthesize the combined knowledge of eHealth researchers to gain insights into the factors that affect adherence to web-based interventions in the areas of chronic conditions, lifestyle, and mental health. In this study, we viewed technology from a theoretical perspective and conceived adherence as an objective measurement that allows for comparison between different interventions.

Principal Results

We included 101 publications describing research into 83 interventions. Mental health interventions (n = 48) constituted the largest part of these interventions. Looking at the key characteristics of web-based interventions in terms of technology and interaction, it appears that the typical web-based intervention is meant to be used once a week, is modular in setup, is updated once a week, lasts for 10 weeks, includes interaction with the system, a counselor, and peers on the web, includes some persuasive technology elements, and results in about 50% of the participants adhering to the intervention.

However, to answer our second research question, there do appear to be differences between health care areas. Overall, lifestyle interventions are longer and less strict (more employ a free setup, less frequent intended usage, fewer updates, and less interaction) than interventions aimed at chronic conditions and mental health, which seems to result in lower adherence with lifestyle interventions. Mental health interventions follow the weekly, modular format the most, with only one intervention using a free setup. This may be explained by the difference in scope of lifestyle and mental health interventions: lifestyle interventions may be more oriented towards long-term changes, while mental health interventions are often aimed at treatment that is delivered in a short, strict format. However, interventions for a chronic condition are also aimed at a long-term change or goal, but these interventions are on average more strict than lifestyle interventions. More counselor involvement is likely to be an explanation because these interventions are often offered in a health care setting and we saw a significant difference between these areas.

Regarding persuasive technology, we see that primary task support elements are most commonly employed, especially in interventions aimed at chronic conditions and lifestyle. Tunneling, which is a technological result of a modular setup, is employed most often in mental health interventions and less frequently in lifestyle interventions. This difference is a logical result of the differences in setup between interventions in these areas. This finding is not surprising, taking into account that most mental health interventions are based on regular face-to-face therapy where psycho-education and behavior modification is usually delivered step-wise (see [3]). Tailoring, which is widely recognized as an important feature of effective health communication [35, 36], is used in one form or another in 88% of the interventions. Strikingly, rehearsal, which is also seen as very important in learning and behavior change [37, 38], is seldom employed. It may be that rehearsal is seen by the authors of the articles reviewed as such an obvious part of an intervention that a description of this process is omitted from the description of the interventions. If not, this should be a point of particular interest when (re)designing web-based interventions.

Only a mean of 1.5 out of a possible 7 dialogue support elements are employed per web-based intervention. It should be noted that we have not coded the elements that may be present in email-like messages sent by a counselor because we feel that this is part of the counselor interaction and not so much a part of the dialogue support that Oinas-Kukkonen [31] and Fogg [24] describe. Reminders are the most frequently employed element. Studies have shown the importance of reminders in increasing adherence and in increasing the effectiveness of web-based interventions [7, 39]. Therefore, we found it striking that 26% of the interventions did not include reminders in some way. Suggestion was the second most frequently used element and was employed more in interventions aimed at chronic conditions than mental health. This seems likely to be due to the focus of the interventions for chronic conditions being on coping with a condition and giving suggestions or strategies to achieve this, whereas in mental health interventions the focus is often more curative to “solve” a certain problem. Praise and rewards are seldom used, which may be a shortcoming when looking at the recent literature into serious gaming and gamification, where employing game-like strategies, such as praise and rewards, are expected to have positive effects on the outcomes of health interventions [40, 41].

Social support is widely recognized as an important strategy in behavior change [42, 43] and it might be disappointing to see that, on average, only 1.2 out of a possible 7 elements are used per web-based intervention. Social facilitation was used in more than half of the interventions. It must be noted that here social facilitation means providing the opportunity to contact others using the same intervention; it does not say anything about whether the opportunity is actually used. In practical terms, this means that when an intervention includes a discussion board, social facilitation is employed, even when there are no posts on the discussion board. Social learning and social comparison were employed through, for example, obligatory posts of exercise answers on a discussion board or by providing a story by a user (real or fictive), including how he or she dealt with the situation. Cooperation, competition, normative influence, and recognition are seldom used and therefore provide areas in which web-based interventions might be improved. However, in this study, social support did not affect adherence, so more research is needed to investigate whether or not this area provides added value.

Our third research question was about the percentage of participants that adhere to web-based interventions. We found an average adherence of 50%, which confirms that non-adherence is an issue in web-based interventions. There was a wide range in the level of adherence, with 6 interventions scoring below 10% adherence and 5 interventions scoring 90% adherence or higher. Our last research question was aimed at determining which characteristics of web-based interventions relating to technology and interaction are related to better adherence. Using a hierarchical multiple linear regression, our final model explains 55% of the variance in adherence, which, in our view, is a substantial amount that provides valuable insights into the issue of adherence.

Interestingly, the first two models (including the context of the intervention and the interaction within the intervention) were not significant. It was only when aspects relating to the format of the intervention and the technology employed were entered that the model reached significance. In the final model, an RCT, as opposed to an observational study, significantly predicted better adherence. A likely explanation is that the observational studies in our review were mainly small pilot studies and large real-life studies. Pilot studies are likely to show lower adherence rates because the interventions are not fully tested and are improved after the outcomes of the pilot are known. Real-life observational studies have been shown to have lower adherence rates, which suggests that the formal structure of a trial is important for participants to adhere to an intervention [34]. Furthermore, the selection processes of many RCTs make it likely that there is a difference in the participants in both settings, which contributes to the difference in adherence.

The frequency of interaction with a counselor was a significant predictor of adherence. This finding concurs with reviews of Brouwer [29], Schubart [30], and other studies (for an overview see [44]) that conclude that counselor or clinician support is related to greater exposure and engagement. Of the significant predictors in our study, this variable contributes the least. In our review, we have found no evidence that the frequency of interaction with peers is related to adherence. This is somewhat contrary to the results of Brouwer [29], who concluded that peer support was related to greater exposure. In that study, exposure was seen as the time visitors spend on the website, which is very different from our definition of adherence. Furthermore, in this study, we coded the frequency of interaction, not merely whether there was any interaction or not. This resulted in 29% of interventions being coded as, “Yes, there is interaction with peers, but the frequency is unknown.” This frequency may vary to a large degree between these interventions, but without clear information we cannot make a distinction, which may have influenced our results.

In the final model, the frequency of interaction with the system seems to negatively influence adherence, although not significantly. This surprising finding may be explained by the fact that more interaction with the system meant, in many cases, that there was no interaction with a counselor. More frequent intended usage also predicts better adherence. This might seem counterintuitive, but might also mean that when people are expected to be more active they become more engaged with the system. Moreover, more frequent intended usage will, in many cases, lead to more frequent reminders and we know that reminders can positively influence adherence [39]. That the provision of frequent updates is important was also seen in the review of Brouwer [29] and is confirmed in this study.

Finally, more extensive employment of dialogue support is related to better adherence. This outcome was predicted by the persuasive system design model [31], but this study is, to our knowledge, the first to confirm this outcome related to adherence in a health setting. When looking at the other persuasive technology categories, we see that social support shows a trend towards a significant contribution to better adherence. We feel that this trend warrants further investigation. It might be that it has no significant predictive value in this study because of the limited use of social support elements in the included interventions. Interestingly, primary task support does not show any predictive value for adherence. This may well be explained by the purpose of the employment of primary task support. As indicated in the name, these elements make the primary task (ie, the goal of the intervention) easier, and are not so much focused on the process (ie, using the intervention or adhering to the intervention). It seems likely that these elements play a more important role in the effect of the intervention than in the adherence.

A final comment on the model for the prediction of adherence is on the different health care areas. We see that in the first model, lifestyle interventions, as opposed to mental health interventions, predict a lower adherence, but when adding the characteristics of the interventions in the model, this predictive value is negated. It seems that the health care area *per se* does not predict adherence, but the differences in the characteristics of the interventions in these areas do predict adherence.

Implications and Recommendations

Taking into account the results of this study, it seems reasonable to not only hope for adherence, but to plan for adherence when designing web-based interventions. Although 33 studies that are included in this review state that they have planned for adherence, it is remarkable that 18 state that encouraging adherence is a task for the counselor [45-62] and one study included monetary incentives to promote adherence [63]. Of the 15 studies that mention adapting the design of the intervention to increase adherence, 8 studies do so without any theoretical basis or reference [64-71], 4 studies make the adaptation the focus of their study [72-75], and 2 studies have adapted the design based on a prior study on the same intervention [76, 77]. Overall, it seems that adapting web-based interventions to promote adherence is done in an ad-hoc manner and that a framework to guide researchers and developers in this area is needed. The PSD model [31] may provide such a framework for the design of web-based interventions.

Moreover, it seems valuable to look much further than the health care area for which the intervention is being designed. Although each health care area has its own demands and limitations, the different areas might learn from each other's strong points. Lifestyle interventions, although aimed at long-term goals, might benefit from incorporating segments with a more strict format and shorter duration. Mental health interventions might be extended to aim at more long-term goals like relapse prevention. They may therefore employ a less strict format, while being aware that adherence might become a larger problem. Moreover, mental health interventions might include the primary task support elements used in chronic condition and lifestyle interventions.

Furthermore, we now have evidence that certain intervention characteristics and persuasive technology can improve adherence. It seems that expecting a certain amount of engagement from the target group can actually be helpful in promoting adherence and is something that seems to be easy to implement in new and existing web-based interventions. We must keep in mind that the effect of intended usage might also be due to a bias among the participants when only those participants who agree in advance with a high level of engagement participate in such interventions. Duration seems harder to change. Cutting an intervention into shorter segments may be enough to improve adherence, but this should be investigated further. Including and possibly increasing the frequency of interaction with a counselor seems a more costly way to improve adherence and might, therefore, be a less than optimal starting point when specifically used as a strategy to increase adherence. Increasing dialogue support using persuasive technology seems to be a more cost-effective vantage point in this respect and may even be enhanced by the increasing use of mobile technology, which seems likely to, in turn, offer a valuable platform for introducing on-the-spot reminders and feedback.

Additionally, our results can be of value for blended care (ie, a combination of online and face-to-face care) by clarifying the crucial aspects for promoting adherence in web-based interventions. When it is not possible to adapt a web-based intervention to promote adherence, it may be feasible to include a face-to-face segment in the overall intervention at a crucial stage to make up for the predicted loss of adherence.

The results of this study can be used to make an informed decision about how to design a web-based intervention that has a greater likelihood of patient adherence. It must be noted, however, that we do not advocate a so-called "technology push" where technology is introduced only for the sake of the technology and the ability to create the technology. It should always be created in close collaboration with the target audience and with a clear goal to create a viable eHealth technology [12]. This study provides insights into the choices one can make with the target audience.

In this study, we defined adherence as being the proportion of participants who use the intervention as it is intended to be used. By doing this, we have created an adherence measurement from objective data that is comparable between interventions. We feel that the study shows that this is a promising approach and this adherence measurement can be used for a wide variety of studies. However, to date, few studies report adherence as the measurement we have chosen to use. For review studies, this means that researchers have to define the intended use, search for the usage data that corresponded to this intended use, and then calculate the adherence. This might lead to a different interpretation of the usage data than the original authors intended. However, from our experience, we can say that as long as there is enough information on the intervention and the usage, it is feasible to calculate an objective and comparable adherence measurement. For intervention studies, we would advise researchers to at least provide the information needed (ie, intended usage and usage data related to this intended usage) to calculate this adherence measurement and, preferably, to state the calculated adherence percentage for easy comparison between interventions.

Limitations

In this study, we have excluded many interventions because data about usage was absent or the usage data that was presented had no direct relationship to the intended use. For example, we excluded studies that only presented mean login data per week for all respondents and had an intended usage of once a week because these data do not show us which percentage of respondents logged in each week. This strict selection based on usage data might have introduced a bias in our included studies.

We have coded the web-based interventions included in this study based on the descriptions in the published literature. Although we have made an effort to find all the information in the published literature about each intervention, our coding was limited by the description of the interventions on paper. As is noted by other authors, the description of these interventions is varied [12, 29, 30], which makes it difficult to capture all the characteristics of each intervention, and this might have influenced our results. Initiatives to standardize and improve the description of web-based interventions like the consort statement for eHealth [12], a protocol for systematic reviews in eHealth [33], and guidelines for executing and reporting internet intervention research [78] are therefore very necessary and will hopefully improve the possibility to compare eHealth technologies and learn from each other.

Lastly, a limitation of this review might be that we have only focused on the published literature. We have not included grey literature and have therefore included little real-life adherence data. As noted by Christensen [34], there is a difference between the usage of web-based interventions in a research setting and in a more real-life setting. We have tried to cope with this by using a strict definition of adherence, separating it from following the research protocol and filling out questionnaires, and by coding all interaction that might be the result of being part of a study as part of the intervention. Nonetheless, the limited amount of real-life data in our review might have influenced the results.

Overall, our results confirm the conclusions of prior studies [29, 30] that interaction with a counselor and regular updates promote adherence. Furthermore, the results of this review elaborate on the role of intervention characteristics (duration, setup, and intended usage) and persuasive technology, especially elements to support the dialogue. Finally, this study has provided practical recommendations to increase adherence when (re)designing a web-based intervention.

Future Research

The data and results from this study provide numerous points of departure for future research. To increase our understanding of the characteristics of web-based interventions and their effect on adherence, it would be interesting to compare interventions that show high adherence with interventions that show low adherence using in-depth, qualitative analyses. The positive deviance approach used by Schubart [30] seems appropriate for this goal. Furthermore, it is interesting to test our statistical adherence model in experimental studies. Additionally, expanding the model by including the characteristics of participants seems to be relevant. Finally, exploring the relationship between persuasive technology, especially primary task support, and (clinical) outcomes of an intervention is likely to be a worthwhile line of research.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Keywords literature search.

[PDF File (Adobe PDF File), 29KB - jmir_v14i6e152_app1.pdf]

Multimedia Appendix 2

Included interventions, targeted behavior or conditions, and studies.

[PDF File (Adobe PDF File), 112KB - jmir_v14i6e152_app2.pdf]

Multimedia Appendix 3

Characteristics of, and adherence to, web-based interventions included in this study.

[PDF File (Adobe PDF File), 491KB - jmir_v14i6e152_app3.pdf]

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Original Paper

How Should Debriefing Be Undertaken in Web-Based Studies? Findings From a Randomized Controlled Trial

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Abstract

Background: Internet research may raise older ethical issues in new forms or pose new issues. It has been recommended that debriefing information online be kept very short, with further information including study results made available if requested by participants. There are no empirical studies that compare possible alternative methods of debriefing in online studies.

Objective: To undertake a randomized controlled trial evaluating how to implement the recommended approach by assessing the effects of two different approaches on accessing of additional information.

Methods: All 11,943 participants in the Effects of Study Design and Allocation (ESDA) study, which employed deception, were randomly assigned to one of two methods of debriefing: Group A received the debriefing information in the body of an email with links to protocol and results pages; Group B was presented with these links after clicking on an initial link in the body of the email to view the debriefing information on a website. Outcomes assessed were the proportions clicking on the links to the protocol and results summary and the time spent on these pages by those accessing them.

Results: The group who were presented with no debriefing information in the body of the email and went to a website for this information (Group B) were approximately twice as likely to subsequently access the protocol and the results summary. These differences between the two groups were highly statistically significant. Although these differences are clear, the overall proportions accessing such information were low, and there were no differences in mean time spent reading these pages. Only one quarter of Group B actually accessed debriefing information.

Conclusions: In circumstances where the uptake of fuller information on study design, methods, and findings is deemed important, debriefing information may be better provided via a link and not included in the body of an email. Doing so may, however, reduce the extent of receiving any debriefing information at all. There is a wider need for high quality empirical studies to inform ethical evaluations.

Trial Registration: Australian New Zealand Clinical Trials Registry, ACTRN12610000846022 (http://www.anzctr.org.au/)

(J Med Internet Res 2012;14(6):e157) doi:10.2196/jmir.2186

KEYWORDS

ethics; debriefing; deception; online; web-based; randomised controlled trial; methodology

Introduction

Behavior change interventions for public health purposes, as with health care itself, are increasingly being delivered and evaluated using the Internet [1-3]. This development may pose existing ethical questions in new forms, or pose new questions [4]. For example, it may be difficult to know whether research participants actually read study information and give genuinely informed consent. The adequacy of informed consent may also be difficult to assess in non-Internet studies [5], and dedicated investigations typically find that recall of consent is poor and may benefit from intervention [6]. Because of these challenges, ethical guidance for behavioral research on the Internet has been produced [2,7]. Among the recommendations are that debriefing information be kept very short, with further information including study results made available if requested by participants [7]. We are unaware of any empirical studies that compare possible alternative methods of debriefing in online studies. Such data would assist evaluation of ethical issues relating to debriefing.

The Internet is also a useful vehicle for methodological research on participant behavior, partly by virtue of the direct access to large numbers of study participants it affords. Blinding is recommended by the Cochrane Collaboration [8] and others as a means of constraining bias in intervention research. Social psychological research routinely uses deception for similar methodological reasons (for a review see [9]), although the use of deception has not been studied very much in relation to health [10]. Ethical guidance usually requires debriefing following deception [11] though the content of methods of debriefing has been neither widely considered nor studied [12]. Debriefing involves giving study information after the study has ended that would usually be provided prior to participation to permit informed consent. This is usually accompanied with a brief explanation of the rationale for the study design and where there is any potential for harm this can be explored.

This study is a randomized controlled trial evaluating how to implement the recommended approach to debriefing by assessing the effects of two different methods on participants' accessing of additional information indicative of successful engagement with debriefing.

Methods

We have previously undertaken a methodological study, the ESDA trial, investigating the possible effects of study design and allocation on participant behavior in the context of a study appearing to investigate alcohol consumption [13]. Almost 12,000 students from four universities in New Zealand participated and were randomized to one of three study conditions, which differed only in what the participants were told was the nature of the study and their role in it. One group believed they were participating in a cohort study, while the other two groups believed they were participants in the intervention and control groups respectively in a randomized controlled trial evaluating an alcohol education intervention, to which all three groups were given access [13]. After the collection of one month outcome data, for the present study we further randomized all participants to two alternative forms of debriefing.

All ESDA participants were randomly allocated to either Group A or Group B. Randomization was computerized and stratified by university, so that there were not imbalances in allocations within any of the 4 participating universities. This and all other study procedures were fully automated and could not be subverted. Allocation was thus fully concealed. Both Groups received an email, sent out on September 22nd, 2011. The initial contents of the emails for both groups are provided in Textbox 1. We allowed 6 weeks for students to respond to the emails, terminating the study on November 11th, 2011. Group A received the debriefing information presented in Textbox 2 in the body of the email, after the text provided in Textbox 1, with links to the protocol (on the journal website) and results pages (see Textbox 3) via [14]. Group B received an email containing no debriefing information, with links to the protocol and results via [15] where the basic debriefing information in Textbox 2 was presented. Group B thus looked at the debriefing information after clicking on a link to the website rather than in the body of the email. All available trial outcome data comprised the proportions clicking on the links to the protocol and the results summary in both groups and the time spent on these pages among those accessing them. We are also able to report on the proportion of Group B accessing the debriefing information on the website and on the time spent reading this page. We tested differences between groups in chi-squared tests for the former and Kruskal-Wallis tests for the latter, for which we report medians. The latter statistical test was chosen in light of the observed gross non-normality with some participants spending very little time with the pages open and others spending more time reading. A non-parametric test was judged preferable to a parametric test to analyze this distribution.

Textbox 1. Initial Email Contents for Both Groups.

Group A

Subject Line: Tertiary Student Health Project - Information for Participants

In 2010/11 you participated in an online survey about student drinking. Thank you for taking part. As promised, we would like to provide you with some more information about this study which is available below.

This is the last email you will receive about this study. Our database containing participant email addresses will now be deleted.

The iPads were won by students from University of Otago and Victoria University Wellington.

Group B

Subject Line: Tertiary Student Health Project - Information for Participants

In 2010/11 you participated in an online survey about student drinking. Thank you for taking part.

As promised, we would like to provide you with some more information about this study which is available here.

<LINK)

This is the last email you will receive about this study. Our database containing participant email addresses will now be deleted.

The iPads were won by students from University of Otago and Victoria University Wellington.

If you experience problems with this link, please copy and paste the link into a new window.

Textbox 2. Basic Debriefing Text in Body of Email for Group a Only, Accessed Via Link for Group B.

The study randomly assigned people to one of three groups (A, B or C). Group A was told they were completing two surveys. Group B was told they were in a Control Group in a randomised controlled trial evaluating brief alcohol education. Group C was told they were in an Intervention Group in the same trial. In fact, all participants received the same information about alcohol. Apart from what they were told about the nature of the study, there were no differences between the groups. Any differences in reported alcohol consumption were expected to be due to the type of research study people thought they were involved in.

It is unknown whether people change their drinking behaviour, or their reporting of it, according to what type of study they are in. This was worth knowing because it has implications for how research on drinking and other behaviours is conducted and interpreted. We did not find any differences between any of the groups.

As stated in the Information Sheet, no individually identifying information has been collected and your anonymity has been preserved throughout the study.

Textbox 3. Results summary (available to both Group A and Group B).

In this study we tested two hypotheses:

That knowledge of participation in a randomised controlled trial in comparison to a cohort (ie, before and after surveys) study alone will reduce drinking after 1 month. This was tested by comparing Group A versus Groups B and C together.

That knowledge of allocation to an intervention condition in comparison to a control condition in a randomised controlled trial will reduce drinking after 1 month. This was tested by comparing Group B versus Group C.

Both hypotheses were rejected, as no differences were found between Groups A, B and C. This means the type of study people believed they were in did not influence changes in their drinking behaviour or their reporting of it.

We interpreted the implications of each of the findings for the two hypotheses differently because of the way this study was conducted. In relation to hypothesis 1, it may be worth generating a stronger sense of being in a randomised controlled trial in a future study. We do not believe hypothesis 2 needs further testing.

Results

The CONSORT flowchart summarizing the study design and numbers included in the analyses is presented in Figure 1.

Group B was approximately twice as likely to have clicked on the protocol and results links, although the proportion doing so was less than 10% in each case (see Table 1). Group B was not likely to spend any more time reading this material. Approximately one quarter of this group visited the debrief page (see Table 1) and thus accessed any debriefing information at all, however, and we had no capacity to measure the extent of any reading of the debriefing information provided in the body of the email to Group A. Approximately one third of those who visited the debriefing page in Group B subsequently clicked on the link for results, and approximately one quarter did so for the protocol (see Table 1).

Table 1. All outcome data.

		Group A (N = 6051)	Group B (N = 5892)
Clicked on Results link		247 (4.1%)[a]	515 (8.7%)[a]
	Median time in seconds (interquartile range)	25.0 (37.2)[b]	25.3 (35.8)[b]
Clicked on Protocol link		202 (3.3%)[a]	362 (6.1%)[a]
	Median time in seconds (interquartile range)	3.5 (5.4)[c]	3.6 (3.9)[c]
Visited Debrief page		[d]	1427 (24.2%)
	Median time in seconds (interquartile range)	[d]	36.1 (49.2)

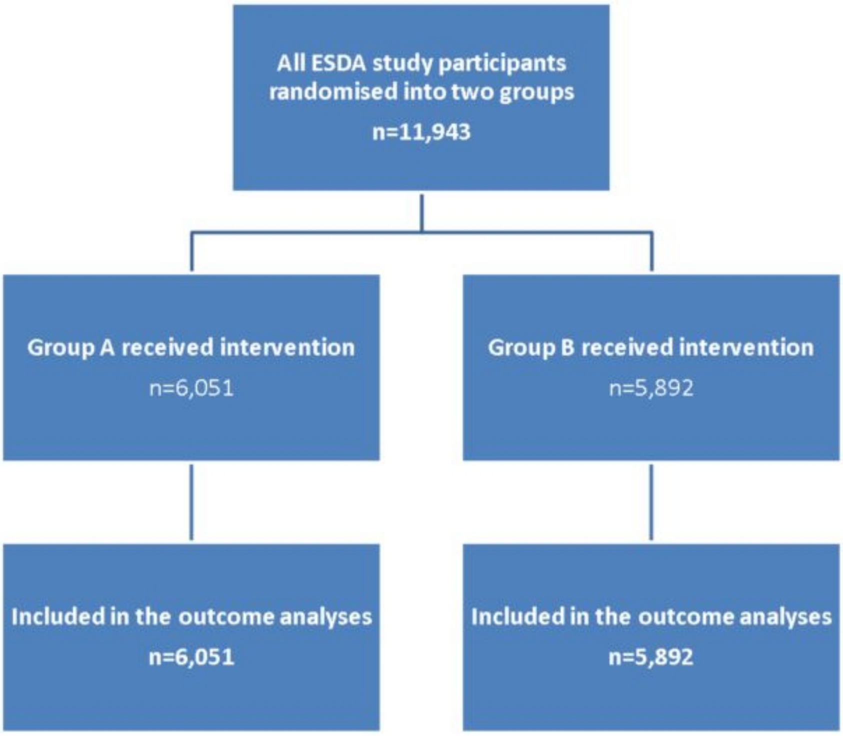
[a] *P* values for differences between groups in chi-squared tests are all <0.001.

[b] *P* value for difference between groups from Kruskal-Wallis test = 0.7419.

[c] *P* value for difference between groups from Kruskal-Wallis test = 0.9450.

[d] Not applicable to group A.

Figure 1. CONSORT flowchart.



Discussion

There are two main sets of findings to consider. First, the between-group differences in the trial demonstrate that providing a link to basic debriefing information (rather than doing so within the body of an email message) approximately doubles the probability that participants will access further debriefing information by clicking on follow-on links. Secondly, the low overall levels of accessing this further information warrant consideration as does the low level of receipt of any debriefing information provided on a website (for Group B) rather than in the body of an email (as for Group A). The robustness of these findings is considered prior to assessment of their ethical and methodological implications.

The messages were all delivered to the email addresses of students held by the universities and via which students participated in the ESDA trial. In the CONSORT flowchart (see Figure 1), we have defined intervention receipt as dispatch of email. We assume that almost all were received and almost all were opened; however, we have no confirmatory data. Some students may have ignored the messages or were no longer using their university email address. We also cannot know for certain how much of the text presented in Textbox 2 was actually read by those who opened the email (Group A) or visited the web page (Group B). Strictly speaking, our time spent on each page measure is of how long the page is open. It is likely that not all of this time was spent actually reading text if other distractions occurred; however, this should have been equally likely in both groups. A clear strength of the data reported here is that they are not reliant on self-report and subject to reporting biases, as they are objectively ascertained, both in relation to whether links were clicked and how long the pages were open. We did not measure email reading time, simply because we could not. One-time-only links to web pages were provided to ensure that participants were not counted twice.

It is possible that many more participants read at least some of the debriefing information in the Group A email and were satisfied with this, or otherwise decided that they did not want further information. To maximize the proportion of all participants having at least some debriefing information (for example, where moral accountability to the research participants is deemed most important [12]), putting the information in the body of the email, as was done with Group A, might be preferable. Alternatively, a key purpose of debriefing is to discover and act upon any harms identified. The reactions of those who have been subjected to any form of deception in research are important to consider in ethical evaluations. For example, according to the British Psychological Society, "If this led to discomfort, anger or objections from the participants then the deception was inappropriate"[11]. This was our primary research interest and why we believe that our outcome measures were well chosen: If research participants have concerns raised by online debriefing information, accessing further information is likely to be the first step in addressing these concerns, if it is made easily available. Where the uptake of more detailed information on study design, methods, and findings is deemed important, as may often be the case in studies involving deception, it appears that basic debriefing information could be better provided via a link and not included in the body of an email.

The low levels of access of the basic debriefing information in Group B remain, however, a matter of substantial concern, and they restrict the confidence that one may draw from the effects favoring Group B. Approximately three-quarters of these participants have received no debriefing information at all, and this appears to be a much bigger problem than we would have expected. If debriefing is worth doing, then it should be done as well as possible, in line with the motivating aims of the present study. This is true even in the absence of harms as they are usually conceived, in order to provide moral accountability for the infringement of the right to informed consent [12]. These considerations direct our attention to the initial content of the original emails, shown in Textbox 1. It may be worth exploring alterations to this brief text, for example making known the absence of informed consent, in ways specifically designed to encourage the uptake of debriefing information.

In this particular study we chose not to elicit feedback as we have done in other studies because participant willingness to articulate concerns may be compromised if the vehicle provided is to communicate with the investigators. Instead, we checked with the Ethics Committee and with the universities involved and confirmed that they had received no complaints from students concerning any aspect of the research. It is therefore not so straightforward to put the two sets of findings together and determine the most appropriate course of action on debriefing. There is merit in further investigating the uptake rates of any debriefing information observed here for Group B, which have the advantage of reliable measurement. If the present findings are confirmed, on balance, we would judge these uptake rates to be unacceptably low and may prefer instead to include the debriefing information in the body of the email, but we have no means of knowing to what extent there is any engagement with information provided there. Time spent reading the protocol was low. It appears it was largely inspected for a few seconds and then the page closed. The results summary was designed to be brief and can be fully read in around the median time spent with the page open. We cannot know, however, how deeply this information was processed or whether the issues involved were more than superficially considered. Longer reading time would be more encouraging in this regard.

Ethical scrutiny of our own practice is made stronger by the kind of data reported here. Study participants were not exposed to risks or harms beyond the infringement of their rights to informed consent, which we acknowledge is a profound harm in itself. Can we make any assumptions about those who did not read the debriefing information? We believe that we cannot, as it would seem unwise to consider either that they may be unconcerned about the infringement of their right to informed consent as research participants, or alternatively that they would be greatly concerned. There are few previous studies providing helpful data in this regard, though Fisher and Fyrberg [9] identified approximately 70% of university student participants as having a basically utilitarian attitude to infringements of such rights in research and approximately 30% who may be offended, among whom a much smaller proportion were deeply offended. These harms need to be balanced against the research and hence the social value of the data obtained.

In our ethical deliberations on this type of research, we were concerned that debriefing itself may constitute a source of harm by revealing an infringement of rights not previously known. The data in the present study are helpful to ongoing consideration of whether debriefing should be undertaken, as well as how. We found no evidence in this particular study that debriefing itself may be harmful and therefore no reason to discontinue it, although consideration of the cumulative impact of such debriefing, in populations such as students who are regularly invited to participate in research, as well as the use of deception in research more broadly, is warranted. For example, it is entirely possible that those who have been debriefed may be more cautious about participating in future research studies, which would diminish the value of the data obtained in those studies. This type of harm is both important and challenging to evaluate. Empirical data are of course no substitute for ethical reflection; however, they can also undoubtedly enrich it. The paucity of empirical data in relation to ethical decision-making has previously been commented upon [16]. We very much agree there is a wider need for high quality empirical studies, using experimental data in particular, to inform ethical evaluations of future methodological developments, online and elsewhere.

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Conflicts of Interest

None declared.

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Original Paper

Web-Based Cognitive Behavioral Self-Help Intervention to Reduce Cocaine Consumption in Problematic Cocaine Users: Randomized Controlled Trial

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Abstract

Background: Web-based self-help programs that reduce problematic substance use are able to reach hidden consumer groups in the general population. These programs are characterized by their low treatment threshold and nonrestrictive intervention settings. They are also cost effective, making them of interest to both low-income and high-income industrialized countries with ever-increasing health costs.

Objective: To test the feasibility and effectiveness of an anonymous, fully automated, Web-based self-help intervention as an alternative to outpatient treatment services for cocaine users.

Methods: A total of 196 cocaine-using participants were recruited through various online and offline media for a randomized controlled trial. Participants in the intervention group received interactive cognitive behavioral modules and a consumption diary to reduce cocaine use, whereas participants in the control group received online psychoeducative information modules. Web-based follow-up assessments were conducted after 4 weeks, 6 weeks, and 6 months. Treatment retention was examined and compared between the intervention and control groups. Severity of cocaine dependence was the main outcome measure. Secondary outcomes were cocaine craving, depression symptoms, and alcohol and other substance use.

Results: This Web-based intervention attracted older and more educated participants than existing outpatient treatment programs for which cocaine is the primary substance of abuse. Participants in the intervention group showed greater treatment retention compared with the control group ($P = .04$). Low response rates at the follow-up assessments restricted the explanatory power of the analyses. At the follow-up assessments, the severity of cocaine dependence did not differ between the intervention and control groups ($P = .75$). Furthermore, there were no differences in cocaine craving, depression, or alcohol and other substance use. Using the consumption diaries, the average number of cocaine-free days per week did not change significantly, whereas the weekly quantity of cocaine used decreased equally in both groups ($P = .009$).

Conclusions: For cocaine users with low dependence severity, a fully automated Web-based cognitive behavioral self-help intervention is a feasible alternative with limited effectiveness in outpatient treatment services. However, this type of intervention may attract specific user groups that are rarely reached by existing outpatient treatment and may help them to control their cocaine consumption anonymously.

Trial Registration: ISRCTN93702927; http://www.controlled-trials.com/ISRCTN93702927 (Archived by WebCite at http://www.webcitation.org/6CTMM10MR)

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KEYWORDS

Cocaine; Cognitive Behavioral Therapy; Internet; Randomized Controlled Trial

Introduction

Data on the prevalence of problematic cocaine use and addiction are lacking in Switzerland and many other developed countries, but there is no doubt that cocaine use has increased in Switzerland in recent years [1] and in other Western European countries [2]. In 2005, Swiss resident institutions reported, for the first time in history, that cocaine surpassed opiates as the most frequently abused substance [3]. This trend has also been observed in outpatient units [3]. This increase in treatment requests likely reflects only a minority of cocaine users. Typically, those cocaine users in outpatient treatment who do not report co-consumption of opiates are young and have low education levels [3]. Older and more educated cocaine users, who are likely to be better integrated into society, are rarely reached by standard treatment. Presumably, the majority of these individuals consume cocaine on a quasi-controlled basis and only a small fraction of them are likely to take advantage of treatment [4]. However, it is likely that some of these users will progress from controlled use to problematic use [5]. For more educated and integrated cocaine users, anonymous interventions that follow the principle of concurrent cover (ie, noninvasive, low-cost interventions in which therapeutic intensity can be enhanced and extended to face-to-face treatment according to need) appear to be more appropriate. Thus, the diversification of the available outpatient treatment services for cocaine users in this direction is favorable.

Over the past 12 years, a number of interventions enhanced by information and communication technology (ICT) have aimed to optimize various aspects of mental health care, such as the treatment of eating disorders [6], obesity [7], depression [8], and social phobia [9]. The majority of these approaches have been based on Internet and mobile phone technologies, such as text messaging [10]. Web-based self-help programs that reduce problematic consumption are able to reach hidden consumer groups in the general population because of their low treatment threshold and nonrestrictive setting for intervention [11]. Furthermore, these programs show a remarkably positive cost-benefit relation [12], which is of interest in industrialized countries with widespread Internet access and escalating health costs. These programs have been tested primarily in people with tobacco dependence or problematic alcohol use. The existing reviews and meta-analyses of Web-based interventions for tobacco smoking and alcohol use [13-16] show that these interventions are superior to no or minimal intervention; however, the effect sizes that have been reported are predominantly small. Evidence concerning their effectiveness compared with face-to-face interventions is inconclusive [13,17,18]. To date, few studies exist on the effectiveness of Web-based interventions for the treatment of illegal substance use. In a controlled trial, a Web-based intervention designed to help young people quit or reduce their cannabis use was tested [18]. Despite some methodological constraints, the results of this study showed that Web-based intervention is promising in the reduction of cannabis consumption compared to no intervention. To date, no research on the acceptance and effectiveness of a Web-based program for the treatment of problematic cocaine use has been conducted.

Snow Control, a 6-week Internet-based self-help intervention program for problematic cocaine users who intend to control, reduce, or stop their consumption of cocaine, was tested between March 2010 and December 2011 and compared with a control condition in a randomized controlled trial [19]. The treatment aim was moderation of cocaine use or cocaine abstinence, with participants in the Snow Control intervention group expected to show greater reductions in cocaine consumption after 6 weeks of treatment than the control participants. Moreover, we hypothesized that the participants in the intervention group would show greater improvements at the 6-week treatment termination point in secondary outcomes, including (1) cocaine craving, (2) alcohol intake, (3) use of illicit substances other than cocaine, and (4) symptoms of depression. We also anticipated the participants in the intervention group to show significantly greater retention. Overall, we aimed to test the feasibility and effectiveness of an anonymous, fully automated, Web-based self-help intervention as an alternative to outpatient treatment services for cocaine users.

Methods

Interventions

Snow Control is based on cognitive behavioral therapy (CBT) methods that have been tested on cocaine addicts [20,21], principles of motivational interviewing [22], current self-control practices, and the established relapse-prevention model [23-25].

The intervention is structured into 8 modules that are activated for week-by-week access in the first 3 weeks, with 4 additional voluntary modules that can be activated during weeks 4 to 6. A detailed description of the intervention can be viewed in the study protocol [19] (trial registration ISRCTN93702927). After successful registration, participants were randomized by computer program in a 1:1 ratio to 1 of 2 parallel groups. Participants were blinded to the interventions. After the first week in the intervention group, each log-in directed the participant to his or her consumption diary in which he or she was asked to specify, for each day, the amount of cocaine consumed in the past 7 days and the amount of cocaine he or she planned to consume each day for the next 7 days. The participant was then directed to the respective weekly module.

To assess the effectiveness of the Snow Control intervention, an appropriate psychoeducative online control condition was developed. Participants in the control condition received 8 psychoeducative information modules about risks, potential harm, and other important information about cocaine consumption followed by a quiz to evaluate their knowledge. The duration of the control condition was equal to the 6 weeks of the experimental intervention; however, the control condition did not include the whole consumption diary. Participants in the control condition were asked to specify the amount of cocaine consumed in the previous 7 days, but not the amount of cocaine they planned to consume in the next 7 days.

To avoid serious harm to the participants in the intervention and control condition during the study, a detailed consent procedure with thorough safety instructions was provided as well as a continuously accessible 24-hour emergency list (including the numbers of emergency help lines and contact information for the study team and the webmaster), regardless of whether participants withdrew or dropped out of the study. Moreover, during the 6-week intervention phase, the participants had the opportunity to contact a corresponding outpatient clinic in a nearby city by telephone (lists with opening hours, Web links, postal addresses, and telephone numbers were provided).

Measurement Instruments

All outcome measures were assessed through online questionnaires. After providing informed consent, participants who met the study entry criteria created a personal and secure log-in name and password and received an automated email notification with their access information. They were then directed to a baseline assessment Web page with questions regarding sociodemographic characteristics and consumption patterns. The primary outcome measures of cocaine consumption were recorded as the number of days and quantity of cocaine used, in milligrams, as specified in the consumption diary and reflected by the Severity of Dependence Scale (SDS) [26] score. The secondary outcomes consisted of the following: (1) the Cocaine Craving Questionnaire-Brief (CCQ-Brief) [27], (2) selected measures for the assessment of the past month's consumption and method of consumption for *Diagnostic and Statistical Manual of Mental Disorders* (Fourth Edition)/*International Classification of Diseases, Tenth Revision* (*DSM-IV*/*ICD-10*) substances of abuse derived from the European version of the Addiction Severity Index (EuropASI) [28], and (3) a short German version of the Beck Depression Inventory (BDI) [29]. In addition, we asked participants to provide feedback about any technical and substance use problems during the intervention. We assessed the qualitative feedback after 6 weeks of intervention. We also planned to explore participants' use of cocaine and other substances at a 6-month follow-up. Because we expected the follow-up rates to be low, compensation (€40) was offered to participants who logged in and completed the follow-up questionnaires.

Analyses

Generalized estimating equation (GEE) analyses were carried out to investigate the effectiveness of the intervention on different variables assessed at baseline and various follow-up points over the study period of 6 months. The GEE is a repeated-measures regression model that takes into account the correlation between the repeated measures of each person [30]. We performed logistic GEE analyses for the binary outcome variables and linear GEE analysis for continuous outcome variables. An alpha level of .05 (2-tailed) was chosen for all statistical tests in this study. Due to the low response rate at the follow-up assessments, we applied multiple regression imputation methods to impute missing data on the investigated variables using the imputation by chained equations (ICE) procedure of Stata's statistical software [31]. We applied the intention-to-treat principle and considered all randomized participants in the analyses. We crosschecked our results by running the analyses with the nonimputed dataset.

History data were analyzed with descriptive statistics and general linear models for repeated measures using group membership as a between-subject factor. Because retention was crucial in this study, we explored the baseline predictors of 6-week retention, defined as completion of the consumption diary, using binary logistic regression analyses. First, all potential predictor variables were entered into a preliminary regression model. Next, variables that were not significant ($P \geq .05$) were systematically removed; only variables that were significant ($P < .05$) were retained in the model.

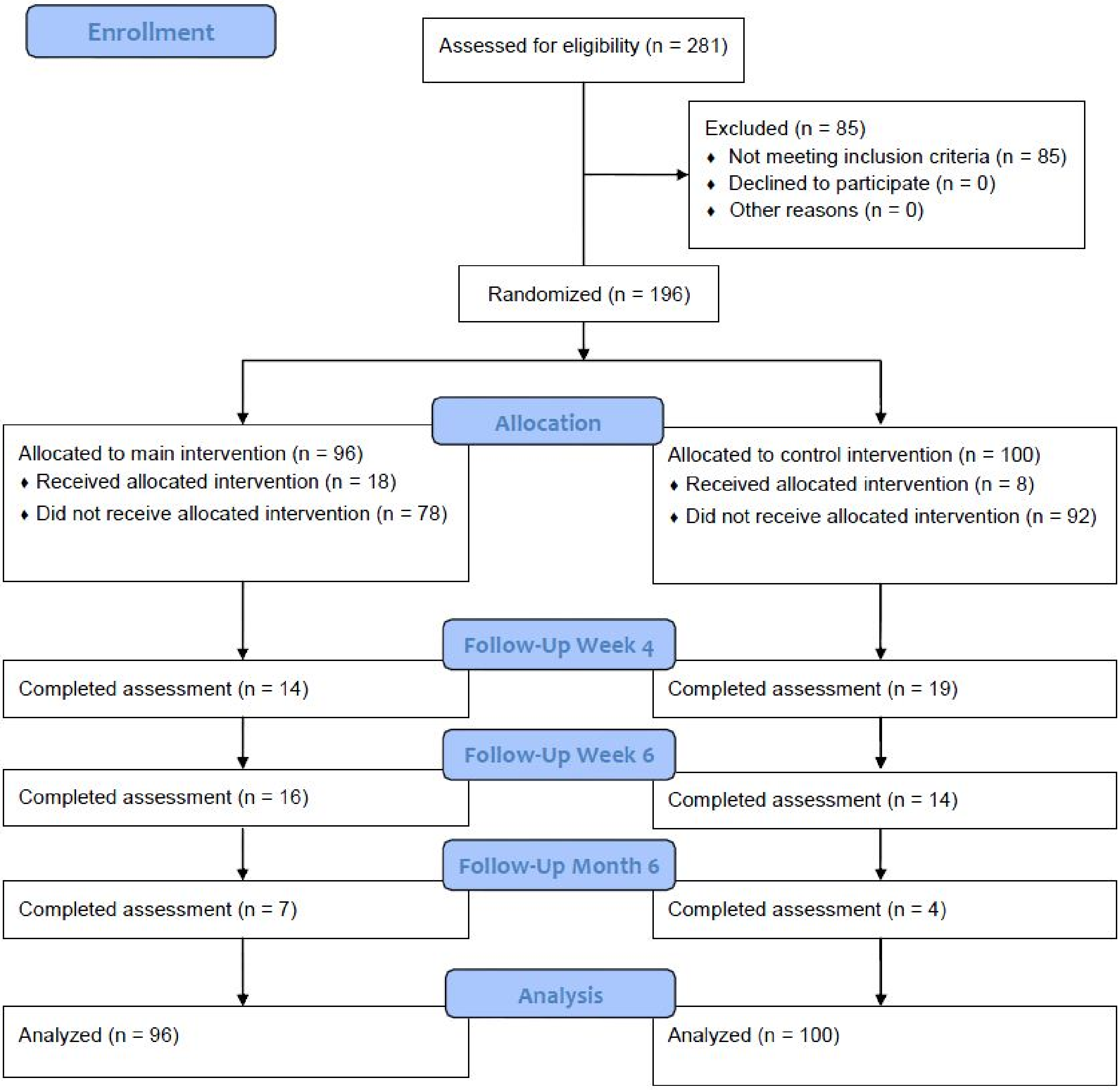
Recruitment

The study participants were recruited between March 2010 and October 2011 through the Snow Control website; websites of outpatient treatment centers in the Canton of Zurich, Switzerland; websites of national organizations for alcohol and drug prevention in nightlife settings; and tailored advertisements on national social media platforms. In addition, advertisements were placed on national Internet forums, newspapers, and on 2 television reports that were broadcasted on Swiss Television. People interested in participating received more information on the Snow Control website. The website explained the rationale of the study, the different assessments, assessment schedules, and the assessment duration. The participants were informed about (1) study inclusion and exclusion criteria, (2) the potential risks of participation, (3) safety arrangements during and after the study phase, (4) the inability of Snow Control to replace face-to-face therapy for problematic cocaine use/abuse, and (5) the circumstances under which they should contact their general practitioner or a professional from the medical advisory and emergency list that was made accessible at all times and how to make this contact. The participants were also informed that the study was reviewed by the ethics committee of the Canton of Zurich and given their declaration of no objection (*nihil obstat*). Moreover, they were informed about their right to withdraw from the study at any time without consequences. Informed consent was accepted when participants clicked on a field on the informed consent page and submitted the consent with a submission button.

The study inclusion criteria were a minimal age of 18 years and cocaine use on at least 3 occasions in the past 30 days. The exclusion criteria consisted of participation in other psychosocial or pharmacological treatments for the moderation or cessation of cocaine use, reports of opioid use in the past 30 days (with the exception of substitution maintenance treatment for opioid dependence without street heroin use in the last 30 days), and previous treatment for cardiovascular problems or apoplexy. The exclusion criterion of a BDI score > 55 was omitted because the average BDI depression characteristics were above the 55-point score.

The flow of study participants is depicted in Figure 1. A total of 281 participants successfully registered online, provided their informed consent, and completed the baseline assessment, but 85 (30.2%) did not meet the following eligibility criteria: (1) age ≥ 18 and (2) cocaine use on at least three occasions in the last 30 days [19]. Consequently, these participants were excluded from further analyses. A total of 69 participants (24.6%) reported less than 3 days of cocaine consumption in the past 30 days (n = 31 in intervention group and n = 38 in control group), but 7 of these participants (2.5%) reported frequent use of amphetamines and began using Snow Control to control their amphetamine use (n = 5 in intervention group and n = 2 in control group). Another 8 participants (2.8%) who were not excluded for other reasons reported street heroin use in the past 30 days (n = 3 in intervention group and n = 5 in control group); and 8 participants (2.8%) were currently being treated for cardiovascular diseases (n = 3 in intervention group and n = 5 in control group). Therefore, 196 participants who met the inclusion criteria entered the study and were randomly allocated to the intervention or control conditions using the background database. Participants who were not randomized because they did not meet the inclusion criteria were allowed to participate in the intervention. Recruitment ended after the intended number of participants in the study protocol was exceeded (n = 196).

Figure 1. Flowchart of study participants.



Results

Baseline Characteristics

There were no differences between the Snow Control intervention group and the control group in the examined baseline variables (Table 1). Compared with the participants whose main substance problem was cocaine who entered Swiss outpatient addiction treatment (n = 429) during 2010, the participants in this study (n = 196) were older (Chi-square [χ^2_1] = 3.3, P = .001, Cohen's effect size w [w] = 0.132) and more educated (university degree: 11.7 vs 3.9; higher professional education: 23.5 vs 6.4; high school degree: 15.8 vs 11.6; apprenticeship/vocational school: 39.8 vs 67.2; and obligatory school: 9.2 vs 12.0, χ^2_1 = 6.6, P = .001, w = 0.196).

Table 1. Baseline characteristics of the participants in the Snow Control (intervention) group and control group.

Characteristics		Snow Control (n = 96)	Control group (n = 100)	Total (N = 196)	*t* test [a] (t_{194})	Chi-square[a] (χ^2_1)
Gender n (%)						
	Female	22 (22.9)	21 (21.0)	43 (21.9)		0.3
	Male	74 (77.1)	79 (79.0)	153 (78.1)		
Age, mean (SD)		34.9 (9.1)	33.4 (8.5)	34.2 (8.8)	1.150	
Highest degree of education, n (%)						
	Obligatory school	7 (7.3)	11 (11.0)	18 (9.2)		0.5
	Apprenticeship, vocational school	39 (40.6)	39 (39.0)	78 (39.8)		
	High school degree	15 (15.6)	16 (16.0)	31 (15.8)		
	Higher professional education degree	24 (25.0)	22 (22.0)	46 (23.5)		
	University degree	11 (11.5)	12 (12.0)	23 (11.7)		
Questionnaire scores, mean (SD)						
	Severity of Dependence Scale (SDS)	7.8 (3.3)	8.2 (3.0)	8.0 (3.1)	1.006	
	Cocaine Craving Questionnaire-Brief (CCQ-Brief)	44.3 (9.8)	43.9 (10.6)	44.1 (10.3)	0.095	
	Beck Depression Inventory (BDI)	55.5 (12.6)	57.7 (14.9)	56.6 (13.9)	1.309	
Years of cocaine consumption, mean (SD)		6.2 (6.2)	7.2 (7.5)	6.7 (6.9)	0.992	
Method of cocaine consumption (multiple answers possible), n (%)						
	Nasal	86 (89.6)	96 (96.0)	182 (92.9)		0.1
	Smoked	14 (14.6)	12 (12.0)	26 (13.3)		1.7
	Oral	11 (11.5)	12 (12.0)	23 (11.7)		0.5
	Injected (nonintravenous)	1 (1.0)	4 (4.0)	5 (2.6)		1.3
	Injected (intravenous)	3 (3.1)	2 (2.0)	5 (2.6)		0.6
Lifetime substance use, n (%)						
	Amphetamines, ecstasy	20 (20.8)	27 (27.0)	47 (24.0)		1.1
	Cannabis	53 (55.2)	59 (59.0)	112 (57.1)		0.8
	Benzodiazepines, barbiturates	11 (11.5)	7 (7.0)	18 (9.2)		1.1
	Heroin	4 (4.2)	4 (4.0)	8 (4.1)		0.1
	Methadone	3 (3.1)	1 (1.0)	4 (2.0)		1.0
Treatment for addiction-related problems during lifetime, n (%)		19 (19.8)	21 (21.0)	40 (20.4)		0.0
Substance use at least once last 30 days before baseline assessment, n (%)						
	Amphetamines, ecstasy	18 (18.7)	19 (19.0)	27 (18.9)		0.0
	Cannabis	37 (38.5)	49 (49.0)	86 (43.9)		1.8
	Benzodiazepines, barbiturates	14 (14.6)	8 (8.0)	22 (11.2)		1.4
	Heroin	0 (0)	0 (0)	0 (0)		—
	Methadone	2 (2.1)	2 (2.0)	4 (2.0)		1.0
	Alcohol use	82 (85.4)	86 (86.0)	168 (85.7)		0.6

Characteristics	Snow Control (n = 96)	Control group (n = 100)	Total (N = 196)	*t* test [a] (t_{194})	Chi-square[a] (χ^2_1)
Binge alcohol use	40 (41.7)	36 (36.0)	80 (40.8)		0.6

[a] None of the comparisons was significant ($P \leq .05$).

The participants in this study reported an average of 6.7 years (SD 6.9) of cocaine use and their most frequent method of use was snorting cocaine (182/196, 92.9%). Most of the participants had not used heroin (188/196, 95.9%) or methadone (192/196, 98.0%) in their lifetimes. The use of amphetamines or ecstasy, substances typically consumed during local nightlife activities [23], was reported by 47 (24.0%) participants. Of the included participants, 54 (27.6%) had been previously treated for a depression disorder, 20 (10.2%) had been treated for an anxiety disorder, and 12 (6.1%) had been treated for other diseases, such as attention deficit disorder/attention deficit hyperactivity disorder (6/196, 3.0%), anorexia (2/196, 1.0%), psychosis (3/196, 1.5%), and borderline personality disorder (1/196, 0.5%). A total of 8 participants (4.1%) reported being positive for the human immunodeficiency virus. The relevant baseline variables did not differ between groups (Table 1). In addition, the intervention and control groups did not differ with respect to the receipt of treatment for addiction-related problems ($\chi^2_1 = 0.0$, $P = .83$, w = 0) or mental health-related problems (depression: $\chi^2_1 = 0.2$, $P = .63$, w = 0.001; anxiety: $\chi^2_1 = 0.7$, $P = .40$, w = 0.004).

Intervention Participation

Participants in the Snow Control intervention group completed more modules (mean 2.60, SD 2.04) than those in the control group (mean 1.80, SD 1.60; $t_{194} = 3.086$, $P = .002$, Cohen’s d [d] = 0.438). Because intervention modules were accessible week-by-week in both groups, this result also reflects the average time, in weeks, that participants remained in their intervention. Overall, the average number of days that elapsed between the first and last log-ins did not differ between the intervention group (mean 32.53, SD 31.52) and the control group (mean 27.44, SD 20.53; $t_{194} = 1.335$, $P = .28$, d = 0.191).

Retention

According to the consumption diary data, retention in the intervention group (see Figure 2) was significantly greater than that of the control group (week 6: $\chi^2_1 = 2.1$, $P = .04$, w = 0.220). The contact rate for questionnaires at the 6-month follow-up was very low for both the Snow Control intervention group (7/96, 7.3%) and the control group (4/100, 4%).

Table 2 depicts the final predictor model for treatment retention. Inclusion in the intervention group was related to retention at week 6 (odds ratio [OR] = 2.65, CI 1.04 - 6.77, $P = .04$). Other relevant factors were age (OR = 1.05, CI 1.01 - 1.10, $P = .047$) and depression symptoms (OR = 1.06, CI 1.02 - 1.11, $P = .004$). The severity of cocaine dependence was associated with treatment retention and was below 1.0 (OR = 0.76, CI 0.64 - 0.92, $P = .005$) indicating that participants with higher severity scores showed poorer treatment retention.

Table 2. Logistic regression of baseline variables for retention at Week 6.

Variables	Odds ratio (95% CI)	*P*
Condition (0 = control group, 1 = intervention group)	2.65 (1.04-6.77)	.04
Age (range 18-56)	1.05 (1.01-1.10)	.047
Severity of dependence (SDS, range 1-10)	0.76 (0.64-0.92)	.004
Depressive symptoms (BDI, range 20-91)	1.06 (1.02-1.11)	.005

Figure 2. Retention in the Snow Control online self-help intervention (n = 96) and the control condition (n = 100).

Study Outcome Results

Table 3 presents the results of the GEE analyses using the imputed dataset for continuous outcomes. As seen in Table 4, no significant group × time interactions in the severity of cocaine dependence (*P* = .75) were seen. Furthermore, no significant group × time interactions were observed in the secondary outcomes of cocaine craving (*P* = .90) or depression (*P* = .57).

Table 5 presents the results of the GEE analyses using the imputed dataset for binary outcomes.

As seen in Table 6, no group × time interactions were found between in the consumption of cannabis, cocaine, or alcohol at the follow-up assessments (P ≥ .05). We observed similar results for the GEE analyses of the nonimputed dataset, which resulted in no significant group × time interaction terms for any of the investigated variables.

Table 3. Descriptive statistics of the continuous outcome variables from the imputed dataset.

Continuous outcome variables	Baseline	4 weeks	6 weeks	6 months
Severity of Dependence Scale, mean (SD)				
Intervention group	7.8 (3.3)	7.3 (5.2)	5.2 (3.4)	3.8 (2.1)
Control group	8.2 (3.0)	7.1 (5.3)	5.4 (3.4)	4.0 (2.2)
Cocaine Craving Questionnaire-Brief, mean (SD)				
Intervention group	44.3 (9.8)	46.3 (12.1)	48.5 (11.2)	47.4 (7.2)
Control group	43.9 (10.6)	45.1 (14.1)	47.8 (11.4)	46.6 (7.6)
Beck Depression Inventory, mean (SD)				
Intervention group	55.5 (12.6)	—	51.8 (16.3)	45.0 (10.5)
Control group	57.7 (14.9)	—	54.3 (16.9)	45.6 (10.6)

Table 4. Results from linear generalized estimating equation (GEE) models examining the effect of study group (control group vs Snow Control intervention), time, and study group × time interaction terms on cocaine dependence, cocaine craving, and depression.

Continuous outcome variables	Beta	Standard error	*t* test	*P*
Severity of Dependence Scale (SDS)[a] (degrees of freedom [df] = 8.4)				
Study group (control vs intervention)	–0.36	0.74	–0.49	.63
Time	–1.45	0.23	–6.25	.000
Study group × time	0.07	0.22	0.33	.75
Cocaine Craving Questionnaire-Brief (CCQ-Brief)[a] (df = 7.3)				
Study group (control vs intervention)	0.67	1.92	0.35	.73
Time	1.07	0.78	1.37	.21
Study group × time	0.07	0.60	0.12	.90
Beck Depression Inventory (BDI)[b] (df = 6.5)				
Study group (control vs intervention)	–2.86	2.69	–1.06	.29
Time	–4.45	1.09	–4.08	.006
Study group × time	0.43	0.76	0.57	.57

[a] Variable was assessed at baseline, and at 4-week, 6-week, and 6-month follow-ups.

[b] Variable was assessed at baseline, and at 6-week and 6-month follow-ups.

Table 5. Descriptive statistics of the binary outcome variables from the imputed dataset.

Binary outcome variables	Baseline	4 weeks	6 weeks	6 months
Cannabis consumption within previous month, %				
Intervention group	38.5	57.1	66.7	84.0
Control group	48.6	60.2	69.4	89.2
Cocaine consumption within previous month, %				
Intervention group	100	75.8	71.2	66.9
Control group	100	76.6	76.4	62.4
Alcohol consumption within previous month, %				
Intervention group	85.4	73.5	76.9	100
Control group	86.0	74.4	77.2	100
Binge drinking within previous month, %				
Intervention group	41.7	60.2	52.5	74.2
Control group	36.0	62.8	59.6	71.4

Table 6. Results from logistic generalized estimating equation (GEE) models examining the effect of the study group (control group vs Snow Control intervention), time, and the study group × time interaction terms on the consumption of different substances.

Binary outcome variables[a]	OR (95% CI)[b]	Standard error	*t* test	*P*
Cannabis consumption within previous month (df = 9.4)				
Study group (control vs intervention)	0.73 (0.30 - 1.79)	0.33	–0.69	.49
Time	1.92 (1.32 - 2.79)	0.32	3.93	.003
Study group × time	1.03 (0.72 - 1.47)	0.18	0.18	.86
Cocaine consumption within previous month (df = 4.0)				
Study group (control vs intervention)	0.78 (0.17 - 3.55)	0.22	–0.07	.95
Time	0.42 (0.07 - 2.50)	0.45	–0.58	.59
Study group × time	1.08 (0.70 - 1.67)	0.24	0.36	.72
Alcohol consumption within previous month (df = 10.0)				
Study group (control vs intervention)	0.95 (0.42 - 2.15)	0.39	–0.13	.89
Time	1.42 (1.06 - 1.90)	0.19	2.61	.02
Study group × time	1.01 (0.74 - 1.37)	0.15	0.07	.95
Binge drinking within previous month (df = 5.0)				
Study group (control vs intervention)	1.13 (0.45 - 2.84)	0.52	0.28	.78
Time	1.57 (0.77 - 3.21)	0.44	1.64	.16
Study group × time	0.94 (0.66 - 1.34)	0.16	–0.35	.73

[a] Variables were assessed at baseline, and at 4-week, 6-week, and 6-month follow-ups.

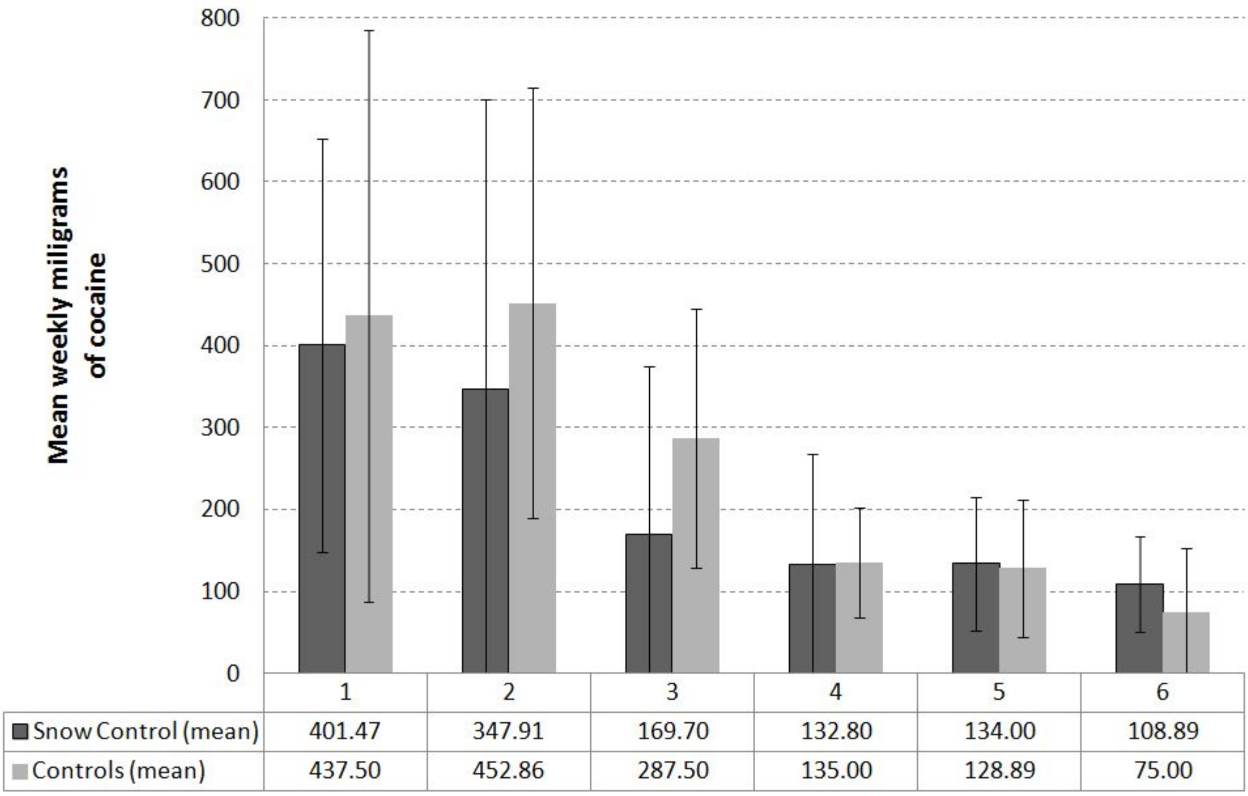
[b] OR: odds ratio.

Consumption Diaries

According to the consumption diaries (see Figure 3), there were no differences in the reduction of the average weekly use of cocaine (in milligrams) between the intervention and control groups at week 4 ($t_{37} = 0.077$, P =.94, d = 0.010) or week 6 ($t_{24} = 0.544$, P = .59, d = 0.245). Similarly, the mean number of cocaine-free days per week recorded in the consumption diaries did not differ between groups at week 4 ($t_{46} = 2.225$, P = .31, d = 0.512) or week 6 ($t_{30} = 0.841$, P = .94, d = 0.079). Overall, the average number of cocaine-free days per week did not change significantly between week 1 and 6 ($t_{31} = -1.189$, P = .24, d = 0.311, imputed data set: $t_{195} = 1.26$, P = .21), whereas the weekly quantity of cocaine used decreased equally in both groups between week 1 and 6 ($t_{25} = 3.188$, P = .004, d = 0.761, imputed data set: $t_{195} = 2.63$, P = .009) as seen in Figure 4.

Figure 3. Mean weekly cocaine-free days for weeks 1 to 6.

Figure 4. Mean weekly milligrams of cocaine for weeks 1 to 6.



	1	2	3	4	5	6
■ Snow Control (mean)	401.47	347.91	169.70	132.80	134.00	108.89
■ Controls (mean)	437.50	452.86	287.50	135.00	128.89	75.00

Adverse Events and Additional Help

During the study, 13 participants (6 in Snow Control intervention and 7 in control group) contacted outpatient treatment services for additional help as indicated on the website. Of these participants, 5 received medical advice by telephone (3 in Snow Control intervention and 2 in control group), and 8 (3 in Snow Control intervention and 5 in control group) entered an outpatient treatment service because they found the help received through the website to be insufficient. Most of these participants reported impulsive cocaine use and/or severe psychiatric comorbidity.

Discussion

According to the results of our study, the implementation of a fully automated cognitive behavioral online self-help intervention for the reduction of cocaine use is feasible, but of limited effectiveness when compared with a psychoeducative active control condition in a sample of relatively treatment-naive cocaine users. There was not a greater improvement in the severity of cocaine dependence in the Snow Control intervention group than in the control group. Participants in the intervention group who remained in treatment reduced their average weekly use of cocaine (in milligrams) to a similar level as that observed in the control group; the average weekly cocaine-free days were somewhat higher in the control group, but did not change substantially in either group. Cocaine craving, alcohol use, binge drinking, use of illicit substances other than cocaine, and depression characteristics also did not improve compared with controls. Study retention and intervention participation were higher in the Snow Control intervention group, suggesting that this type of intervention was more attractive to participants than the alternative psychoeducative information, corresponding quiz, and limited consumption diary that was presented to the control group.

One reason that only very small differences were observed between the intervention and control group might lie in the comparable durations for each module and the similar stepwise weekly access to the modules. Sessions for both groups were designed to demand similar time from their users [19], and a short consumption diary was even implemented in the control condition to ensure comparability. Thus, a significantly greater reduction in cocaine consumption in the Snow Control intervention would have reflected the superiority of a fully automated cognitive behavioral self-help intervention to an active control condition.

One obvious reason why we did not find a greater reduction in the frequency of cocaine use or in the severity of cocaine dependence was the fact that the majority of participants chose to reduce the quantity of cocaine consumed, but did not choose to increase the number of cocaine-free days. This finding was the case although we communicated that this intervention was intended to help participants control or reduce cocaine use or to achieve cocaine abstinence [19]. Thus, the users of the Snow Control intervention focused on moderation of cocaine use and prevented the weekly escalation of cocaine use by controlling their quantity when using, but not by increasing their number of cocaine-free days. In other words, they followed a harm-reduction strategy.

Limitations

Although the number of questionnaires was limited, the participants demonstrated a clear aversion to completing the questionnaires. This aversion was the primary flaw in the study design. Many participants filled out the consumption diary and used the designed modules or read the psychoeducative texts, but they simply closed their Internet browsers when the questionnaires began. The implementation of telephone contact to increase study retention, as performed in similar studies for the reduction of alcohol [14] or tobacco use [13], was clearly rejected in the pilot study [19] because cocaine users may fear repressive activities by the police or other authorities. Furthermore, the compensation (€40) for the follow-up assessment did not motivate the participants to log in again and complete the questionnaires. A similar compensation at week 6 was not possible due to budget constraints and it was not initially included in the study protocol [19].

The dropout rates for completion of the consumption diary (81.2% in the intervention and 92% in the control group) were higher than we expected (70%) when we designed the study as a randomized controlled trial. In addition to inclusion in the intervention group, factors that contributed to the retention of participants in treatment until week 6 included the low severity of symptoms of cocaine dependence, age, and depression symptoms, suggesting that the online self-help format is difficult to follow for more severely cocaine-dependent participants and has better retention for depressed and older cocaine users.

Future variations of the intervention will attempt to increase retention by implementing personal, but anonymous, chat contacts similar to those implemented in an online self-help intervention for cannabis users [32]. Additionally, the integration of Snow Control into a national addiction online counseling portal in which it will be possible to compare this self-help intervention with professional online counseling by email contacts is planned. Future studies will integrate modules addressing depression symptoms and will attempt to prevent users from failing to complete the evaluation questionnaires.

We strongly recommend the development of a consumption diary as the primary outcome measure for Internet-based studies aimed at the reduction of illicit substance use. Additionally, if feasible, contingency management (compensation for online-intervention attendance) might increase treatment retention. Unfortunately, in addition to the financial limitations of this study, this contingency management strategy was not feasible in this study in Switzerland due to the structure of the treatment supply center and the probable strong rejection from health authorities and politics.

Conclusions

We conclude that a fully automated Web-based cognitive behavioral self-help intervention is feasible, but of limited effectiveness compared with a psychoeducative control group for cocaine users with low dependence severity. This type of intervention may attract older and more educated participants than existing outpatient treatments for which cocaine is the primary substance of abuse and might help to control participants' cocaine consumption. Future studies should attempt to improve treatment retention through additional Web-based approaches, such as anonymous chat sessions, and investigate the program's effectiveness in more detail.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

CONSORT Ehealth Checklist V1.6 [33].

[PDF File (Adobe PDF File), 569KB - jmir_v14i6e166_app1.pdf]

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Abbreviations

BDI: Beck Depression Inventory
CBT: cognitive behavioral therapy
χ2: Chi-square test
CCQ-Brief: brief version of the Cocaine Craving Questionnaire
d: Cohen’s d
DSM-IV: Diagnostic and Statistical Manual of Mental Disorders (Fourth Edition)
EuropASI: European version of the Addiction Severity Index
GEE: generalized estimating equation
ICD-10: International Classification of Diseases, Tenth Revision
ICE: imputation by chained equations
ICT: information and communication technology
OR: odds ratio
SDS: Severity of Dependence Scale
t: t test
w: Cohen’s effect size w

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Original Paper

Improving Diabetes Management With a Patient Portal: Qualitative Study of a Diabetes Self-Management Portal

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Abstract

Background: Effective management and care of diabetes is crucial to reducing associated risks such as heart disease and kidney failure. With increasing access and use of the Internet, online chronic disease management is being explored as a means of providing patients with support and the necessary tools to monitor and manage their disease.

Objective: The objective of our study was to evaluate the experience of patients and providers using an online diabetes management portal for patients.

Methods: Participants were recruited from a large sample population of 887 for a follow-up questionnaire to be completed after 6 months of using the patient portal. Participants were presented with the option to participate in an additional interview and, if the participant agreed, a time and date was scheduled for the interview. A 5-item, open-ended questionnaire was used to capture providers' opinions of the patient portal. Providers included general practitioners (GPs), nurses, nurse practitioners (NPs), dieticians, diabetes educators (DECs), and other clinical staff.

Results: A total of 854 patients were consented for the questionnaire. Seventeen (8 male, 9 female) patients agreed to participate in a telephone interview. Sixty-four health care providers completed the five open-ended questions; however, an average of 48.2 responses were recorded per question. Four major themes were identified and will be discussed in this paper. These themes have been classified as: facilitators of disease management, barriers to portal use, patient-provider communication and relationship, and recommendations for portal improvements.

Conclusions: This qualitative study shows that online chronic disease management portals increase patient access to information and engagement in their health care, but improvements in the portal itself may improve usability and reduce attrition. Furthermore, this study identifies a grey area that exists in the roles that GPs and AHPs should play in the facilitation of online disease management.

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KEYWORDS

Diabetes Mellitus Type 2; self care; self management; online; internet; online management portal; patient portal; patient-physician interaction

Introduction

Diabetes can be a debilitating chronic disease, with a large number of associated co-morbidities. Effective management requires extensive patient engagement and external support [1,2]. As a result, this population is often studied when exploring innovative chronic disease management tools.

There have been a number of investigations into the ability of Internet-based tools to facilitate diabetes self-management, and some have produced encouraging results [3,4]. Research into the use of diabetes portals has typically shown that access to information and support via online patient-centered tools is capable of improving health indicators for patients and engaging them in the management of their disease [4-6]. Portal use and access have typically been seen favorably by patients, but technological barriers remain (such as with using sophisticated blood glucose monitoring programs). Long-term adherence is the most commonly reported barrier to greater usage of diabetes portals, and findings are mixed in terms of the effectiveness of ongoing follow-up [7]. There is some evidence to suggest that a combination of personalized content, goal setting, and automatic follow-up is effective in keeping patients engaged beyond the short-term [8-11]. Studies on provider acceptance of diabetes portals have shown that providers are often reluctant to adopt these technologies because of lack of knowledge about the Internet or information technology systems [12,13].

Many issues remain unexplored with respect to the scope of online diabetes management portals. Most studies are of Type II diabetics with highly educated, computer-savvy patient participants [3,5-7,14]. Some studies collect “self-management” data, but more commonly previous research has focused on portal use, and success was measured by quantifiable health outcomes (typically changes in HbA1c) [3,6,15,16]. Few studies have sought to assess portal feasibility and usage qualitatively. Those that have do not often consider the health care providers’ experience with the portal, nor do they include the experience of both patients and providers [5,17]. Thus, while Internet-based diabetes management tools have been shown to improve health indicators for diabetics and engage patients in the short term, further research is needed into the scope of such tools and the role played by providers [18].

We conducted a qualitative study to explore the experience of patients and providers with a diabetes management portal implemented by the Waterloo Wellington Local Health Integration Network (WWLHIN).

Methods

Patient Portal

The patient portal is an online site that was designed for use by physicians and their patients. Its purpose is to engage patients in self-care and empower them to take a more active role in their diabetes management. The site features disease management tools that allow patients to log health metrics and providers to monitor these patient-entered health metrics, which include blood glucose, blood pressure, and body weight. The portal provides access to two key resources: (1) a “Health Library”, which hosts interactive diabetes education materials for patients and providers, and (2) access to “Personal Health Records”, which is a secure online system that allows patients to consolidate their personal health information. The latter includes contact information, medical and family history, medication details, lifestyle choices, and test results [19], which can be managed by patients and provide them with a comprehensive picture of their health status and health trends.

A patient portal, specifically an online diabetes management tool for patients, was implemented as a pilot program by the Waterloo Wellington Local Health Integration Network (WWLHIN) with patient recruitment lasting for four months. Participants were given an introduction to the portal interface, and technical aspects (such as blood glucose recording) were explained. Based on the severity of the patient’s condition and the self-management needs, participants were stratified into one of three portal use regimens: GREEN, YELLOW, or RED. Participants in the GREEN regimen were asked to record their health metrics 1-2 times per week, those in the YELLOW regimen were asked to record their health metrics 3-6 times per week, and participants stratified into the RED regimen were asked to record their health metrics 7 times a week. Each regimen was tailored by the patient’s clinician to meet the patient’s specific needs (eg, one patient may be required to record their body mass, while another may not); however, it was standard for all patients to record blood glucose measurements at the prescribed frequency.

To evaluate the portal, a six-month follow-up Benefits Evaluation was employed with ethical approval from Institutional Review Board Services, Aurora, Ontario (“HEALTHeCONNECTIONS Project—Benefits Evaluation Program” Version 3.0 dated 2009-06-17). The Benefits Evaluation utilized both survey tools and measures of physiological parameters. Participants were asked to record physiological measures as per the severity of their conditions. Surveys were completed pre- and post-intervention using QuestionPro, an online survey service. Qualitative data collected from this evaluation were used to identify emerging themes to describe the patient and provider experiences with the portal. Results of the surveys are reported elsewhere. This manuscript reports on the results of the qualitatively gathered data.

Participant Recruitment

Participants were selected from a larger sample population (N = 887) and recruited for the Benefits Evaluation of the patient portal as part of the HEALTH eCONNECTIONS Project. Patients who consented to participate in the Benefits Evaluation were asked to complete a follow-up questionnaire after using the patient portal for a period of six months, and an option for participating in an interview was presented. Those who agreed were considered for an interview. Purposive sampling was used to ensure that respondents to the interviews reflected the demographic of the larger study population. Patients selected by purposive sampling were contacted and, if they agreed to participate, an interview date and time were scheduled. If a patient declined to be interviewed, or could not be reached, alternative patients were selected using the same criteria. This process was carried out until saturation was achieved.

Providers' responses were gathered through the analysis of responses to five open-ended questions included in a post-study questionnaire. Thematic analysis of responses was conducted, and emergent themes were identified. Providers included a mix of general practitioners (GPs), nurses, nurse practitioners (NPs), dietitians, diabetes educators (DECs), and other clinical staff.

Data Analysis

Text from transcribed interviews with patients and open-ended responses from providers was coded (by key terms and phrases) and sorted by theme (parent and subtheme). Qualitative data analysis was completed independently by two different members of the research team (EL and ZK). A third member of the team (SU or DW) reviewed all themes and acted as an additional reviewer when consensus was not reached. Emerging themes from the two analyses were compared and contrasted and considered in light of relevant literature. NVivo version 8 software (QSR International, Doncaster, Victoria, Australia) was used to facilitate the coding and sorting process.

Results

Seventeen patients (eight male, nine female) agreed to participate in semi-structured telephone interviews. There was at least one interviewee from each of the participating WWLHIN Family Health Teams. Sixteen of the 17 patients interviewed were patients with Type II diabetes. The remaining patient had Type I diabetes.

A total of sixty-four health care providers completed the five post-study, open-ended questions regarding their experience with the patient portal. Not all respondents answered each of the 5 open-ended questions. An average of 48 provider responses per question were recorded for the five questions, with a range of 41-58 responses depending on the question.

Four major themes were identified through an analysis of the data, each with several subthemes. The themes were classified as (1) facilitators of disease management, (2) barriers to portal use, (3) patient-provider communication and relationship, and (4) recommendations for portal improvements. Below we present each of the four themes together with the subthemes.

Theme 1: Facilitators of Disease Management

Patient Awareness of their Disease

Patient responses generally indicated that the graphs displaying health data, which illustrate significant trends, were very helpful and improved their self-awareness of their health status. They were better able to track their disease. Access to credible health information was said to increase awareness of potential side effects and co-morbidities and often encouraged better disease management.

Provider responses indicated that the concept of the portal was valuable. Providers noticed an improvement in patient awareness and felt that patients perceived they were better managing their disease.

However, providers cautioned that those patients reporting health measures through the portal frequently and consistently may have already been inclined to do so with or without the portal. Providers expressed a perceived concern that too much patient self-care, resulting in a potential for reduced quantity of medical care, was also of some concern. It was occasionally reported that the providers thought some patients would skip necessary appointments or fail to alert a provider of a high blood sugar reading.

Access to Information

Analysis revealed that the Health Library was not used extensively by patients. It was thought that this feature could be improved, and it was recommended that information about healthy food options and resources for low-income families should be available. However it was agreed that the information provided was generally viewed positively and thought to be valuable by those that required and accessed it.

Providers also viewed the health information available on the portal positively but felt that accessing the right information at the right time had often proved difficult. Occasionally, the Health Library was not used due to frustration with the portal interface. Some providers who had accessed the library found it cumbersome to navigate.

Self-Efficacy and Behavior Change

Patient responses strongly indicated that the portal was used to make small changes to disease self-management behaviors. There was feedback that viewing blood sugar and weight values on the portal alerted them to the fact that they were not adequately controlling their diabetes. As a result, adjustments were made in diet and exercise regimen. Responses indicated that there were patients who felt they were managing their diabetes well and did not feel they needed to make any changes to their self-care regimen.

Providers reported that patients recorded their blood sugar frequently, and there was a perception that viewing trends/graphs had positive outcomes for patients. The reporting and tracking of blood glucose and other health indicators were believed to be the most useful features of the portal for both patients and providers. The portal provided an added source of motivation especially useful for "new diabetics" learning to manage their disease.

Table 1. Theme 1—Facilitators of disease management.

Subtheme	Patient quotes	Provider quotes
Patient awareness	“It helped me understand that, so it made me watch my sugar more often when I was in pain. I would check my sugar to find out if it was high or low and try to tie in the highness of the sugar with the pain I was in or you know, stuff like that and with the eyesight as well it took a lot of, like, what I was really worried about was the eyesight when I found I was diabetic and it helped me with that quite a bit...”	“The more that pts [patients] understand their issues the more they are motivated to be responsible…”
		“*Occasionally a patient used the portal to report symptoms that should have triggered an office visit. Also, I am concerned they would use this instead of having their regular formal lab evaluation and follow-up visit”*[a]
		“They are probably the patients that would bring accurate records to their [appointments] anyway.”
Access to Information	“I found it easy to use and with using the health portal, using that section I found it much easier and faster because it gave me the topics that were relevant to what I was looking for and not a list of suggestions, that might be relevant as well, it just gave me what was relevant to what I was looking for…”	“[The most useful feature was] the Health Library”…
		“*Sharing care could be useful, but it did not seem like mydoctor.ca was utilized as anticipated due to the time it took to use…cumbersome, lots of unnecessary/irrelevant information, little added value…”*[a]
Self-efficacy and behavior change	“I also found it kind of, you know, embarrassing because I would look on it and say, okay, I haven’t put a blood record in in 52 days and I haven’t really checked my blood, I guess I'd better do that, you know. Like, it gave me the kick in the butt, on the butt to...oh, gee, I better start putting logs again and that.”	“Allowing patients to receive their lab results/data without having to phone in or come in for an appointment. This allows them to receive their health information faster, which may help them be more proactive in their health care.”
		“Patient self management [is the most useful feature], but having someone look over their results for intervention if needed. Best used for new diabetics to help them see patterns, educating as they become used to dealing with their disease.”

[a] Italicized quotes denote contrasting opinions.

Theme 2: Barriers to Portal Use

Usability and Discoverability

Patients found the patient portal easy to navigate and user-friendly. However, improving the convenience of the portal seemed to be important to many patients. Barriers included, but were not limited to, slow dial-up Internet access, the time required to enter data, and the difficulty of data entry.

Providers were generally dissatisfied with the portal’s usability and discoverability (ease with which they could find elements of the portal). When asked what improvements could be made, responses often focused on technical issues. When asked whether they would like to increase or decrease portal use, many who responded *decrease* in portal use cited usability and discoverability as the reasons.

Appropriateness

It was often reported that other life events had taken priority over disease self-management and use of the portal. Although not a significant trend, apathy toward the portal and toward disease management in general was occasionally apparent. Some patients felt that they were controlling their diabetes well or found that their health measurements had been fairly stable and therefore did not feel the need to enter information. There was also a tendency for patients to see some information input as trivial or less useful.

Providers believed that accessing patient information was time consuming and sometimes redundant (eg, due to manual data entry). There was often concern that engaging with the portal would decrease the time they could spend with patients. Providers were concerned patients would report health indicators online in addition to calling the clinic office, thereby resulting in a duplicate of provider efforts and a reduction in the quality of care, although there were few reports of this taking place. There were also providers who remained unsure if diabetes was the right chronic disease for the portal as it was believed that this population is already fairly proficient at monitoring their disease.

Table 2. Theme 2—Barriers to portal use.

Subthemes	Patient quotes	Provider quotes
Usability and discoverability	"I didn't enjoy using it. And it was a real pain and it took a lot of time and would rather have had something like, you gave me a blood monitor and I just downloaded it…"	"The problems were largely infrastructure: the program versions; the hardware; the connectivity issues; the actual program for care was fine."
	"I can't take a half a day to sit in front of the computer to put the information in."	"The system is cumbersome and needs an interface that addresses the needs of patients and data entry requirements."
		"I hate computers and find most interactions frustrating. This is for the future and most of my patients with disease are even less computer knowledgeable than I."
Appropriateness	"I've got other things that are pressing on my mind that I've taken, you know, precedence and overridden everything else that's going on and until those matters get taken care of I've put a lot of stuff that I shouldn't, especially the diabetes and that on the back burner until the other stuff gets taken care of…"	"…many patients brought in sheets of info they felt were important or clinically relevant (eg, individual glucose graphs), which had limited use, but instead served to increase visit time as I educated why the measure was not as important as other indicators. Longer visits, little added benefit."
	"No, I don't think so, really. Just 'cause...I mean...see, I've been a diabetic and high blood pressure that has been under control...for a very long time. Well, I know myself probably better than the doctor does, you know what I mean?"	"The messaging system is great yet can be utilized negatively by patients increasing workload on mydoctor.ca and decreasing time for other patient interactions in office. The messaging system has also increased expectations from patients for immediate response."

Theme 3: Patient-Provider Communication and Relationship

Role of Allied Health Professional

It was shown that patients interacted primarily with an allied health professional (AHP) via the portal. The providers who actively used the portal included dietitians, nurses, nurse practitioners, and diabetes educators. The portal is described as "physician driven", but it was clear that other health professionals monitored patient health indicators more frequently than physicians.

For those providers that self-identified, it was clear that AHPs interacted with patients more frequently via the portal than family physicians. Although many physicians responded to the questionnaire, they often referred to AHPs in their responses.

Provider Engagement Challenging

Although communication seemed to occur primarily with a nurse, dietitian, or other AHP via the portal, patients often wished their physician had taken more of an interest in the program and had reviewed the information they had entered on the portal during their clinic visits (this was also largely done by AHPs). Responses revealed that it would have been beneficial if a health care provider had referred them to information in the Health Library. The responses typically reflected a widespread notion that physicians were often busy and may be unable to fulfill this role as much as they would have liked.

Providers commonly viewed patients' interactions with the portal positively and their own interaction negatively. Negative comments typically concerned time constraints and technical barriers. There were instances where providers indicated that they believed the portal may be more beneficial for patient self-education than for significant provider usage.

Patient Support

When asked, patients generally felt that the portal experience would be improved if there was greater access to clinical support. These patients would have liked to have had a clinician available to explain health information and answer questions that the Health Library could not (eg, about online lab results). Patients often reported reduced anxiety about their health knowing that a health care professional was monitoring their health status. Patients who responded this way also felt reassured knowing they had "access" to their health care professional via the portal at any time of the day. There were also requests for greater ongoing support, as adherence typically declined over the 6-month study period.

It was clear that providers appreciated the ability to view patients' blood sugar and blood pressure trends, partly because it allowed them to manage patients without in-person appointments and alert them if a health indicator was out of normal range. Some providers expressed concern that patients assumed providers were watching their health status on the portal *all of the time* and might therefore leave problems unreported (ie, some patients assumed that an elevated blood sugar level would be flagged by a health care professional and therefore did not contact their provider).

Table 3. Theme 3—Communication and relationship with provider.

Subthemes	Patient quotes	Provider quotes
Role of AHP	"They went over them. [The dietitian] went over [them] when I saw [her] and [the nurse] went through them. [The doctor] never really did go through them… he left it to, like the dietitian and the nurse to go through with me…"	"[The portal] enabled the FHT DM nurse to become better integrated into the communication and care loop with my patients and myself."
	"Well, the doctors are so busy these days and you really hate to bother them and the nurse was always available."	"[It was important]…that pts can review their results and can communicate with our diabetic care team; ultimately hopeful that self-management increases and fewer MD visits required"
Provider engagement challenging	"No...I found it easy to use and I guess I would have liked to have seen it more central in my discussions and my appointments with the doctor but that's not a...not a major issue."	"*Some of this assumes Drs are sitting around with nothing better to do but review volumes of patient lab results*"[a]
	"Like, I know he checked it once when I was there to see what my records and that were when I was with him and...but that's just because I was there with them and I believe that even then it came up that it was checked by [the nurse] on the behalf of [the Dr.] not him checking it and I thought that was a little weird. I thought it should be the fact that the doctor actually checked it.	"*[The portal was] somewhat useful for health professional….*" [a]
		"*…in a busy clinic- we would require to put time aside more to manage patients, which is not actually our mandate in the community.*" [a]
Patient support	"If I would have had more support from the doctor saying, okay [anonymous], we haven't heard from you for a while, can you ASAP your information to us so we can keep on contact with you.	"[The portal] allowed timely access to view blood sugar readings entered by patients—I would be able to titrate medications based on values sooner than I would have been able to if having to come in for app'ts."
	"I really think there should have been more as to what were we expecting our numbers to be? What was appropriate numbers? And where were you at and could you compare your A1C and talk to your doctor every third month because we did this for six months wasn't it or something…"	"*Some patients take less responsibility in their self-management of the disease as they feel that the health care provider is in constant review of their blood sugars.*" [a]
	"I felt more comfortable because I knew that somebody was getting my results and they were looking at them and if there was a problem they could email through the portal and just tell me if there's, you know, you should be doing this or that the other thing."	

[a] Italicized quotes denote contrasting opinions.

Theme 4: Recommendations for Portal Improvements

Access to Information

Patients generally responded that the portal content was more than adequate but found it occasionally difficult to access. It was reported that an online tutorial would have been very useful so they could learn and navigate at their own pace. It was difficult for patients to remember the large amount of content taught to them at the portal orientation, and many were not aware of important portal features.

Provider responses revealed that neither they nor the majority of their patients were able to use the portal easily. More training and improved portal usability testing were said to be needed for the portal to be used more effectively. Issues with specific features such as the display of health indicators and with reading weight and exercise values were mentioned less by respondents.

Technical Aspect

Patients generally believed that access to information via the portal was easy and more trustworthy than a generic search engine (eg, Google). It was evident, however, that the portal was not used extensively beyond blood sugar reporting and typically the usage declined over time. It emerged that some patients would have appreciated enhanced technical support.

Comments from providers suggested that they often viewed the portal as cumbersome and confusing. Providers commonly responded that communication was slow and the interface difficult to navigate for themselves, other providers, and for patients. However, it is unclear how often these providers interacted with the portal or whether these responses were from GPs or AHPs.

Table 4. Theme 4—Portal improvements.

Subthemes	Patient quotes	Provider quotes
Access to information	"[We] were never instructed when we went for our little introduction to doing this, instructed where our numbers should be, what we should do with our numbers, what the heck they were doing…"	"I needed much more orientation, coaching. Nobody seemed to notice I was not engaged."
Technical aspect	"I did enter my data and in this case I had several months of...I had been collecting data for a num...and I wanted to enter all that data but I had to go back and retroactively enter it and I found that very cumbersome and awkward to do. As soon as I would get a piece of data entered the computer would keep bouncing back to the current date and I had to scroll all the way back again to the next day and enter that data. So, it was very time consuming and awkward."	"Patients reported that it wasn't always the most user-friendly system. They found the entering of back dates often difficult."
		"…the technology itself has many little but significant barriers"
		"…cumbersome, redundant, inefficient"
		"If the system was more user-friendly and quicker to navigate it would be more useful."

Discussion

In general, patients were satisfied with the features offered by the portal and felt more aware of their health status. However, apart from recording blood sugar readings, patients seemed to use only a small number of features offered by the portal. It is unclear from the results of this study if that is because the features required too much effort or if it was because they were not needed by the patients. It is also important to note that frequency of use varied between patients and often declined over time. Difficulty with fostering long-term adherence is frequently cited in the literature as a barrier to portal use [20]. Portal adherence is difficult to maintain, and the perceived relative value of portals often decreases over time [11,20-22]. This may be because initially patients who use the portal gain an inflated sense of self-management, and therefore no longer view the portal as valuable in their diabetes care [11,22]. The decline in usage may also be explained by the difficulties patients expressed in navigating the portal. Patients reported that an online tutorial would have helped them learn to navigate the portal and its features. This raises concern about the current design of the portal and whether the system was adequately designed for patient use. It is documented in the literature that proper design of information health systems is crucial for maximizing patient adherence and minimizing attrition [9-11,23]. Others have reported similar findings [10]. Russell et al report that, while they could not identify a series of patient characteristics that can be linked to improved engagement in self-management portals, developing a patient-centered, culturally appropriate portal that considers varying levels of health literacy and numeracy may engage a greater number of patients and result in greater overall portal usage [10].

Patients and providers reported a number of small but significant barriers to using the patient portal optimally. These barriers include inadequate ongoing support, poor Internet connections (dial-up versus high-speed Internet), poor orientation, slow data entry, access restrictions (ie, the need to log in with a username and password to view even general health information), and issues with usability and discoverability. Such barriers are common in the literature but have gradually been reduced as more people become familiar with the Internet and high-speed connections begin to reach rural areas [9,24]. Although the results in the literature are mixed [7], usage decline may be overcome by improving access to personalized information, paired with significant ongoing support and improved integration with clinical care [8,9,11,20,25]. Involving patients and providers in the development of a diabetes portal may also be useful in developing a meaningful portal [26].

Patients and providers believed blood sugar reporting was the most useful feature of the portal. This is consistent with the literature, which suggests that diabetes self-management portals see the greatest usage in their blood glucose logging features [10,11]. Research into diabetes management has shown that stricter control of blood sugars leads to reduced health complications, improved quality of life, and may ultimately reduce health care costs [11,22,27-18]. Some studies report that portal users monitoring their blood sugar saw reduced HbA1c levels [6,16]. Patients in our study reported that the portal helped them better monitor their blood sugar; however, information about health behaviors and other health indicators (eg, HbA1c) was not collected. It is also possible that some patients in our study did not realize significant differences in health indicators as a result of portal use. This may be because they became apathetic toward portal use (as suggested by a noted usage decline) and did not realize the benefits of increased blood glucose monitoring over time or their diabetes was already well controlled. This phenomenon has been observed in other studies reporting on the benefits of portal use, where improvements in self-management occurred in patients who are already empowered [11,18], as well as those patients who have access to and a greater understanding of the necessary technology [14]. In this regard, however, the literature is mixed: one study found that patients with a greater perceived need were more engaged and received the most benefit in the use of a self-management portal [11].

Allied health professionals (AHPs) were more active users of the patient portal even though the portal is described as “physician driven”. Provider (often physician) concerns about time constraints (and occasionally, mandate) may indicate that AHPs should act as liaisons between patients and their doctors in portal use, although most patients wished that their attending physician was more involved. The self-management literature suggests that, for patients whose disease is under control, AHPs are the most appropriate health care provider and physicians should be consulted only when the disease is not adequately controlled with self management [29]. In one study, nurses provided the clinical support for users of a diabetes self-management portal exclusively [11]. Few studies examine both patient *and* provider engagement in online diabetes management tools. However, one study found that physicians were hardly engaged at all, while another found that there was no difference in the attitudes of providers [12,18].Involving physicians in the development and design of health portals such as the one analyzed in this paper could enhance their adoption and usage, as the literature suggests that engagement of providers from the inception of health information systems results in greater adherence [30].

Our results suggest that providers generally perceived the portal less favorably than patients. The perception of many of the clinician respondents was that the portal might reduce patient quality of care, as a result of possible missed appointments and a false assumption of provider monitoring of patient entered data. There was also concern that time spent on portal usage would result in less time available for direct patient care. Others have reported additional clinician concerns, including a feeling of “loss of control” as patients become more engaged in their care. As a result, clinicians may be less likely to provide the option of online services to their patients [18]. Although not evident from our results, the communication tools (ie, email) offered by some portals have been identified as another concern for clinicians. Concerns over how to best interpret, document, and respond to patient communications have all been raised. In addition, many current systems do not have a way of verifying the email sender, which raises legal concerns regarding the implications of providing information that may be inaccurate to the sender [14]. Addressing these clinician concerns can help to ensure successful adoption of self-management portals.

Limitations

Patients who were selected for interviews were representative of the larger study population; however, providers were most likely not representative of the total provider population. It is possible that providers who completed the post-study questionnaire represent a biased sample. Therefore, the generalizability of these results may be limited.

Semi-structured interviews retain internal validity but may lack reliability (a script was used to counter this) and external validity. Open-ended responses retain reliability and some external validity but lack internal validity. While the data *collection* methods used in this study complement each other, there are limitations in comparing and contrasting data *types* (ie, interview versus questionnaire *and a* representative population versus a convenience sample).

In addition, the patient portal was available only for 5-10 months (depending on when patients enrolled) and was a pilot test. Patients and providers may have needed even more time to adjust to the portal and may not have been aware of many features due to poor orientation to the system. Provider responses also could have been biased because they may have been commenting on something with which they did not significantly interact (particularly GPs).

Finally, in the instances where this occurred, it was also recognized that limitations exist when making inferences about patients, or providers, based on one’s speculation about the experience of the other.

Conclusions

The patient portal was shown to be conceptually sound and capable of facilitating patient awareness and perceived empowerment in this population.

Patients were mostly satisfied with the services offered by the patient portal and believed it to be a valuable initiative. Provider responses were less favorable (although most believed the concept was good), and some reported concerns that the portal may actually reduce care in some cases.

Frequency of usage was low for many patients and providers, and it was clear that there were small but ultimately significant barriers that either prevented usage or saw its decline over time. Measures are thus needed to keep patients and providers engaged if and when their usage drops. Personalized information, directed ongoing support, and greater involvement in portal design are possible options (although their success has not been proven) to improve patient and provider adoption of any health portal.

This qualitative study of a WWLHIN patient portal shows that such health portals increase patient access to information and consequently improve awareness of, and engagement in, their health care. This study also reveals that defining roles for care (in portal interaction) may be an important next step for diabetes portal development, particularly with respect to the interaction of GPs, AHPs, and patients.

This study contributes to the current body of knowledge on Internet-based health portals, specifically on patient use, perspectives, and health outcomes of these types of portals, and identifies areas in which future research of Internet-based health portals should address. Future qualitative research should thus focus on continued engagement of patients *and* providers in portal development, usage, ongoing patient support and encouragement (clinically and technologically), and the nature of patient-provider interaction via health portals, including mobile applications.

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Conflicts of Interest

None declared.

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Original Paper

The Computer-Assisted Brief Intervention for Tobacco (CABIT) Program: A Pilot Study

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Abstract

Background: Health care providers do not routinely carry out brief counseling for tobacco cessation despite the evidence for its effectiveness. For this intervention to be routinely used, it must be brief, be convenient, require little investment of resources, require little specialized training, and be perceived as efficacious by providers. Technological advances hold much potential for addressing the barriers preventing the integration of brief interventions for tobacco cessation into the health care setting.

Objective: This paper describes the development and initial evaluation of the Computer-Assisted Brief Intervention for Tobacco (CABIT) program, a web-based, multimedia tobacco intervention for use in opportunistic settings.

Methods: The CABIT uses a self-administered, computerized assessment to produce personalized health care provider and patient reports, and cue a stage-matched video intervention. Respondents interested in changing their tobacco use are offered a faxed referral to a “best matched” tobacco treatment provider (ie, dynamic referral). During 2008, the CABIT program was evaluated in an emergency department, an employee assistance program, and a tobacco dependence program in New Jersey. Participants and health care providers completed semistructured interviews and satisfaction ratings of the assessment, reports, video intervention, and referrals using a 5-point scale.

Results: Mean patient satisfaction scores (n = 67) for all domains ranged from 4.00 (Good) to 5.00 (Excellent; Mean = 4.48). Health care providers completed satisfaction forms for 39 patients. Of these 39 patients, 34 (87%) received tobacco resources and referrals they would not have received under standard care. Of the 45 participants offered a dynamic referral, 28 (62%) accepted.

Conclusions: The CABIT program provided a user-friendly, desirable service for tobacco users and their health care providers. Further development and clinical trial testing is warranted to establish its effectiveness in promoting treatment engagement and tobacco cessation.

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KEYWORDS

technology; tobacco use cessation; smoking cessation; referrals

Introduction

For a tobacco intervention to be implemented routinely in most health care settings—especially fast-paced settings like a hospital emergency department or a busy primary care clinic—it must be brief, convenient, and require little specialized training [1,2]. Traditionally, tobacco cessation interventions have not met these requirements, contributing to a lack of translation of empirically supported interventions into clinical care [3,4].

Computer programs have the potential to make tobacco screening and cessation more convenient, tailored to the individual patient, and uniformly applied, while taking less provider time and requiring less provider training to implement properly. Prior research supports the feasibility and effectiveness of a variety of technological components useful for tobacco assessment and intervention, including computerized assessments [5-13], video education [10,11], provider prompts [11,14-18], personally tailored feedback reports [5,6,11,12,19-22], and the option for an automated self-referral to tobacco cessation providers [5].

To our knowledge, there are currently no programs that blend these features into one integrated program that can be used in busy health care settings. For this reason, we created the Computer-Assisted Brief Intervention for Tobacco (CABIT) software, which is designed to facilitate brief tobacco cessation treatment and referrals during or immediately after a health care visit. It was designed to be used even in time-demanding settings like a hospital emergency department. This paper describes our development of the CABIT, its functionality, and our initial pilot testing and evaluation.

Methods

CABIT Overview

Using the published literature [8,13,20-22] and our project team's experience, we created an initial draft of the CABIT and assessed its design and functionality. During this process, we identified areas where further input from end users was needed. Then we conducted focus groups and key informant interviews with end users. Our sample was comprised of 22 health care professionals from various specialties (eg, emergency medicine, internal medicine, etc) and 13 smokers with varying levels of motivation to quit. We gathered opinions pertaining to the features that would make the CABIT (1) practical, (2) effective at improving motivation to quit smoking, and (3) useful in facilitating linkage with tobacco treatment resources. This qualitative data guided the refinement of the CABIT's technical specifications. Figure 1 provides a conceptual model of the CABIT program and its hypothesized mechanisms of action.

The CABIT is a web-based program comprised of 4 integrated modules: (1) a computerized assessment of tobacco use and related psychosocial variables, (2) a stage-of-change-based video intervention, (3) a referral generator, and (4) a report generator. Theoretically driven, each CABIT module was informed by principles derived from Motivational Interviewing (MI) [23], the Transtheoretical Model (TTM) [24,25], the Decisional Balance Theory [26,27], and the Social Learning Theory [28]. MI was the primary treatment approach used to guide the choice of assessments utilized in the program and to design the message framing for the feedback reports [23]. MI seeks to help the patient resolve ambivalence about change. Essential to the approach is a respectful, compassionate, client-centered attitude that emphasizes autonomy and choice. The CABIT incorporates prominent MI-based principles. First, it assesses motivation for change and self-efficacy. Second, it provides tailored feedback of the assessments, including nicotine dependence, decisional balance, and self-efficacy, to help reduce ambivalence. Third, MI is the primary therapeutic approach used to design the message framing for the videos and feedback reports. The videos and reports offer nonauthoritative and nonconfrontational guidance for behavior change and encourage the health care provider to adopt this approach as well. The CABIT also stresses collaborative goal setting, using a menu of treatment options. Finally, the CABIT focuses on treatment entry. The CABIT's development was also influenced by the TTM, which is highly compatible with MI and includes components from the Decisional Balance Theory [26,27] and the Social Learning Theory [28]. Specifically, we used measures of the stages of change, pros and cons of smoking, and self-efficacy, all of which are well-validated components of TTM. The stage-of-change assessment was the primary organizing structure used to cue the stage-matched videos, reinforce the overall "personally tailored" tone of the Patient Tobacco Feedback Report and the Health Care Provider Report, and provide specific content for the reports (ie, pro/con evaluation, high-risk situations). Altogether, each component of the CABIT is designed to directly or indirectly address a patient's motivation to quit, motivation to use effective treatment, knowledge of treatment resources, and ability to access and use treatment resources.

Patient Assessment

The CABIT software's response-adaptive programming logic ensures each participant is presented with questions appropriate to his or her situation and previous responses. For example, a patient is asked, "Which tobacco products have you ever used?" A patient is then only asked about current use for types of tobacco that he or she indicated ever using. Further, assessments specific to type of tobacco use were chosen and the general wording of remaining assessment items were tailored to type of tobacco use. Based on a commonly used staging algorithm [24,25], each individual is assigned a stage of change: precontemplation, contemplation, preparation, or action. Patients in the precontemplation stage are current tobacco users not intending to quit or intending to quit over 6 months in the future. Those in the contemplation stage are current tobacco users intending to quit in the next 6 months. Patients in the preparation stage are current tobacco users intending to quit in the next 30 days. Those in the action stage quit using tobacco for longer than 1 day less than 6 months ago. These stages of change serve as the cue for the stage-matched videos and guide the overall tone and content of the counseling guide for the health care provider (Health Care Provider Report) and the tailored feedback report for the patient (Patient Tobacco Feedback Report). Information obtained from the assessment, including patient-selected items from a menu of treatment options and tobacco educational resources, is integrated into the tailored Patient Tobacco Feedback Report. Patients indicating interest in quitting or staying quit are offered an automated faxed referral to a local tobacco treatment provider (ie, a dynamic referral, further discussed in the Referral Generator section). More detail regarding the CABIT assessment is included in the Measures section below. Figures 2-5 provide examples of screenshots from the program.

Figure 1. Conceptual model of the CABIT program and its mechanism of action.

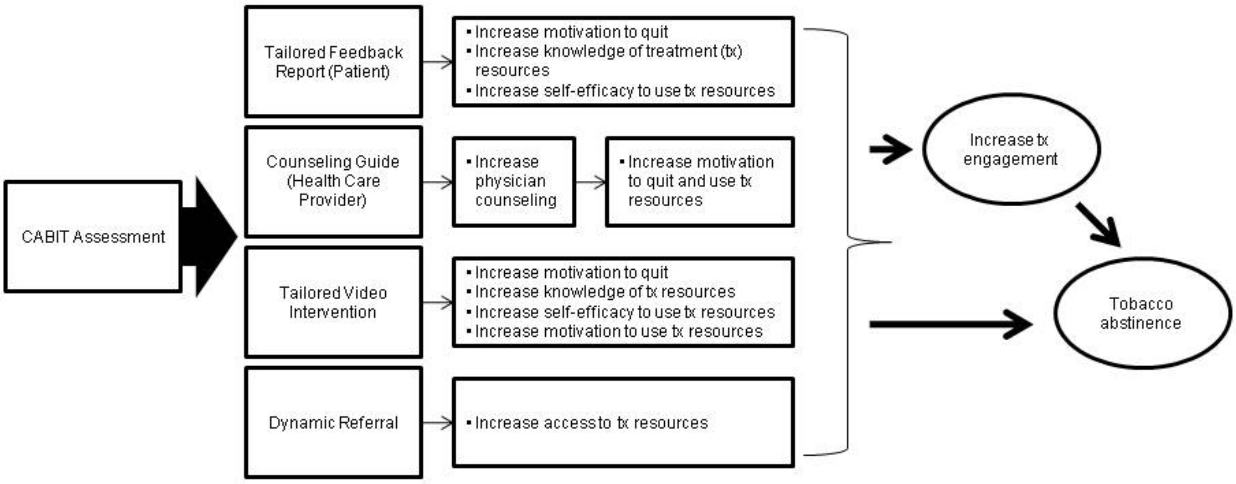
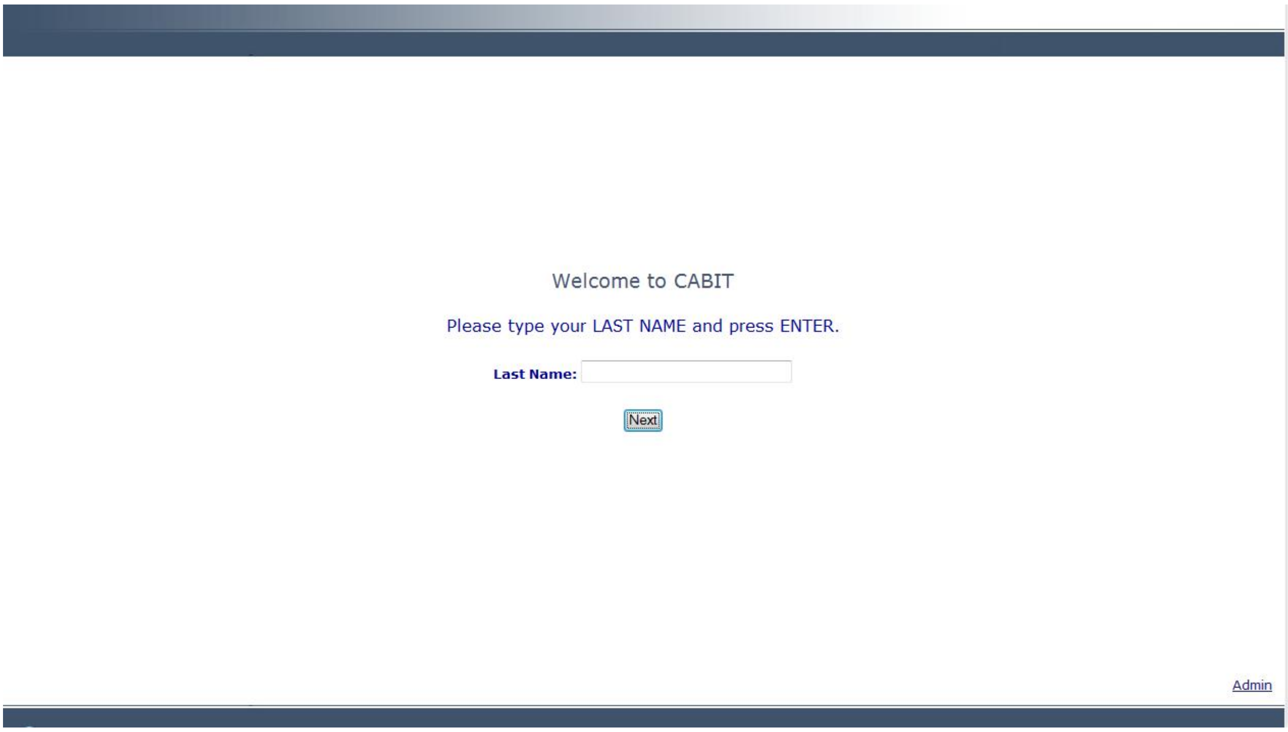


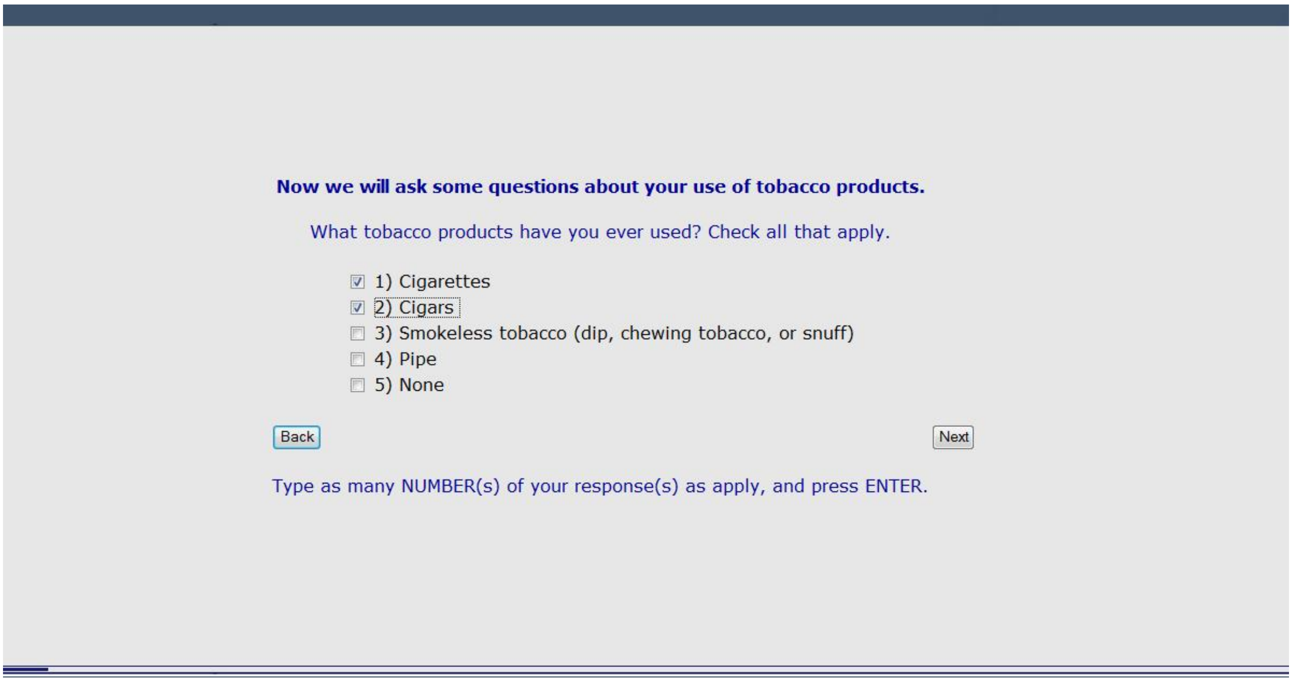
Figure 2. The welcome screen of the CABIT program.


Welcome to CABIT

Please type your LAST NAME and press ENTER.

Last Name:

Figure 3. Screenshot from the CABIT program showing questions about tobacco products used.



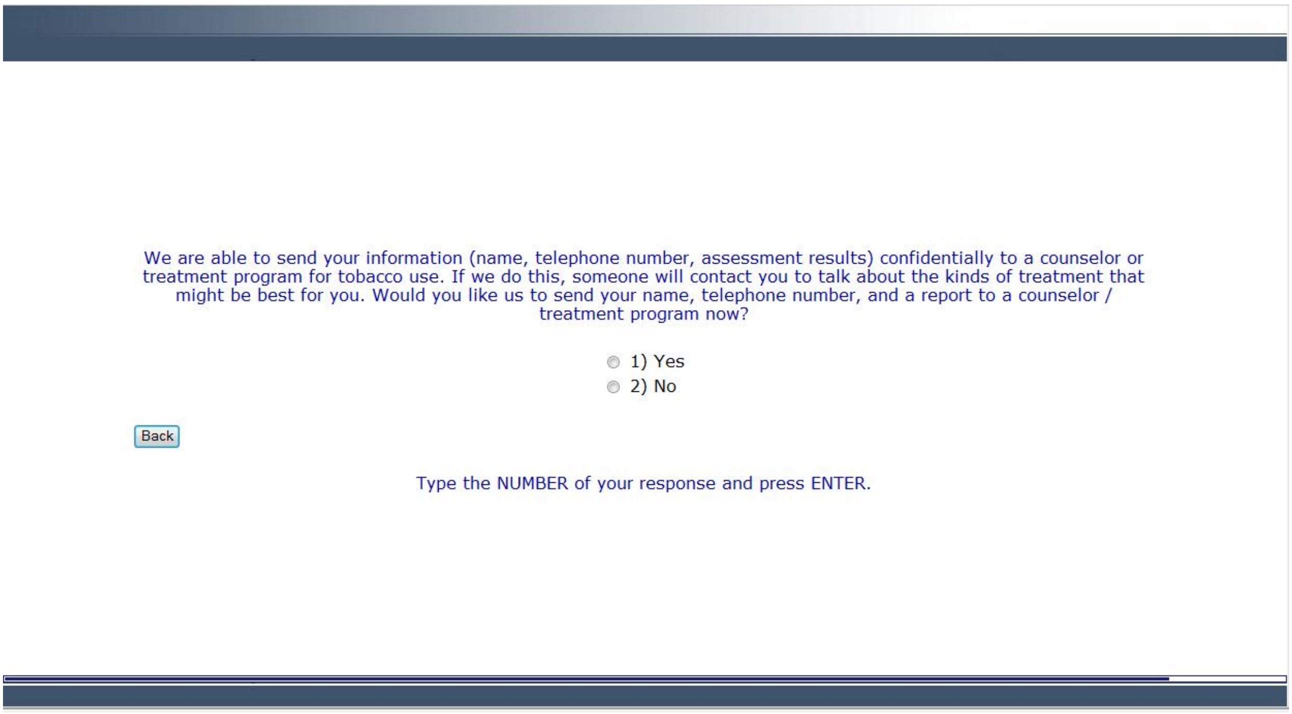
Now we will ask some questions about your use of tobacco products.

What tobacco products have you ever used? Check all that apply.

☑ 1) Cigarettes
☑ 2) Cigars
☐ 3) Smokeless tobacco (dip, chewing tobacco, or snuff)
☐ 4) Pipe
☐ 5) None

Type as many NUMBER(s) of your response(s) as apply, and press ENTER.

Figure 4. Screenshot from the CABIT program showing how patients are asked if they would like a referral to a treatment program.

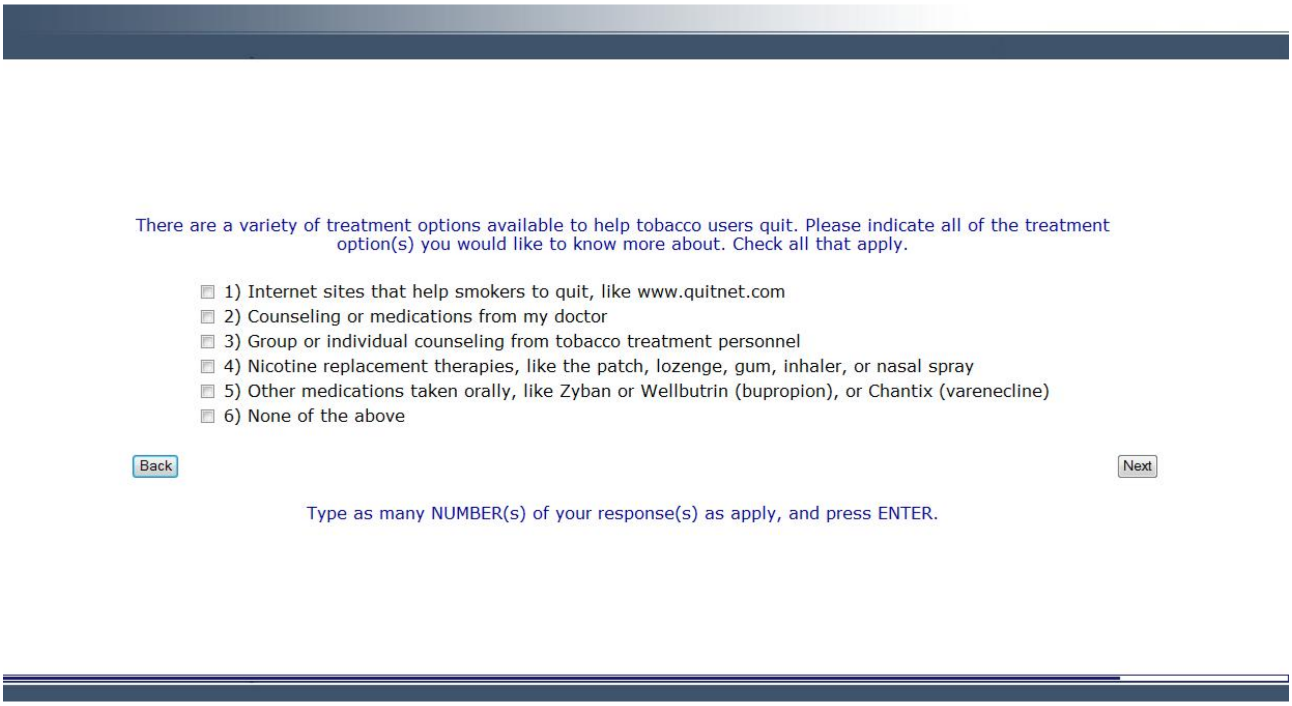


We are able to send your information (name, telephone number, assessment results) confidentially to a counselor or treatment program for tobacco use. If we do this, someone will contact you to talk about the kinds of treatment that might be best for you. Would you like us to send your name, telephone number, and a report to a counselor / treatment program now?

○ 1) Yes
○ 2) No

Type the NUMBER of your response and press ENTER.

Figure 5. Screenshot from the CABIT program showing treatment options for patients.



There are a variety of treatment options available to help tobacco users quit. Please indicate all of the treatment option(s) you would like to know more about. Check all that apply.

☐ 1) Internet sites that help smokers to quit, like www.quitnet.com
☐ 2) Counseling or medications from my doctor
☐ 3) Group or individual counseling from tobacco treatment personnel
☐ 4) Nicotine replacement therapies, like the patch, lozenge, gum, inhaler, or nasal spray
☐ 5) Other medications taken orally, like Zyban or Wellbutrin (bupropion), or Chantix (varenecline)
☐ 6) None of the above

Type as many NUMBER(s) of your response(s) as apply, and press ENTER.

Video Intervention

Upon completion of the assessment, the CABIT cues the appropriate stage-matched tobacco education video. Three already available educational videos tailored to 4 stages of change (precontemplation, contemplation, preparation, and action) were used. Although not ideal from a tailoring perspective, patients in both the contemplation and preparation stages viewed the same video. This 6-7 minute video was professionally produced and used appealing graphics to reinforce and illustrate important points related to tobacco use and cessation. For example, videos provided information about the stages one progresses through when getting ready to quit, consequences of tobacco use, benefits of quitting, and tips on quitting and available resources.

Referral Generator

The referral generator uses technology developed in a previous study called the Dynamic Assessment and Referral System for Substance Abuse (DARSSA) [5]. In addition to receiving a printed list of tobacco dependence treatment programs tailored to the individual's geographic location and insurance type (ie, passive referral), patients considering quitting are given the option of an automated faxed referral (ie, dynamic referral). If the participant agrees to release his personal contact information, the CABIT faxes the referral to the "best matched" provider in the referral library based on the patient's zip code and insurance status. The tobacco dependence programs in the referral library agreed to contact the patient within 5 days of receiving a dynamic referral to complete an initial phone screening, discuss treatment options, and, if interested and appropriate, schedule an intake assessment.

Report Generator

The report generator produces 3 reports based on information the patient provided through the CABIT assessment: (1) Patient Tobacco Feedback Report, (2) Health Care Provider Report, and (3) Tobacco Treatment Referral (generated only for participants who choose a dynamic referral).

Patient Tobacco Feedback Report

The patient received a personally tailored report written at an eighth-grade reading level. It was crafted using principles of Motivational Interviewing [23] and gain-frame (versus loss-frame) messaging strategies [29]. The length of the feedback report varies based on participant's assessment responses and information requested. The report includes a referral summary, which lists tobacco treatment resources the patient may contact and information about where the dynamic referral was sent, if it was chosen. The report also includes a personalized summary with feedback on the participant's tobacco use history, stage of change, readiness to quit, benefits of quitting, money spent on tobacco, level of addiction, temptations or triggers to using tobacco, and perceived risks of quitting. Additionally, participants are provided with information about resources for quitting and other tobacco-related topics that he or she selected when completing the assessment. See Multimedia Appendix 1 for an example of a Patient Tobacco Feedback Report.

Health Care Provider Report

The one-page counseling guide for the health care provider summarizes the tobacco use information that we deemed most important for clinical decision making based on our focus groups and in-depth interviews. It uses responses patients provided in the CABIT to provide evidence-based guidance for counseling the patient based on the NCI's Five As (Ask, Advise, Assess, Assist, Arrange follow-up) [3]. The Ask/Assess section provides a summary of the patient's assessment, including the patient's smoking history, perceived symptoms or illnesses related to tobacco use, readiness to quit, factors related to poor outcomes (eg, living with a smoker, depression), and interest in assistance from provider. The Advise/Assist section provides counseling guidance for the provider, including presenting a clear but nonjudgmental recommendation that the patient consider quitting tobacco use and stage-based suggestions to help facilitate quitting. The Refer/Arrange section includes the list of resources provided to the patient and where the dynamic referral was sent if the patient opted to receive one. See Multimedia Appendix 2 for an example of a Health Care Provider Report.

Tobacco Treatment Referral

This report, faxed to the “best matched” provider for patients who choose a dynamic referral, provides patient contact information and a summary of the patient's assessment. In particular, this report provides information on the patient’s tobacco use, level of addiction, tobacco-related illnesses or symptoms, past attempts to quit, methods used to quit, and readiness to quit. It also included personal factors related to poor prognosis and the patient’s readiness to quit ruler. See Multimedia Appendix 3 for an example of a Tobacco Treatment Referral.

Setting and Population

The CABIT program was implemented in three settings in a large hospital system in New Jersey (Cooper University Hospital): the Emergency Department; the Employee Assistance Program serving employees of the hospital system; and the outpatient Tobacco Dependence Program associated with the hospital. The Emergency Department is an academic, urban, Level I trauma center serving a catchment area of approximately 2 million people. The annual census is approximately 47 000 visitors, 20% of whom are admitted to the hospital. The Emergency Department and Employee Assistance Program demonstrate the CABIT’s utility across environments with different paces, procedures, staffing, patient characteristics, and foci of care. The Tobacco Dependence Program, with its specialized focus on tobacco treatment, yielded a cohort of smokers, recent quitters, and tobacco treatment counselors who were able to provide topical advice on the program.

Participant Selection

The recruitment protocol in the Emergency Department was similar to our published studies [30-32]. Research assistants approached adult patients at their bedside after they had been clinically evaluated and stabilized. In the Employee Assistance Program, participants were recruited with a system-wide email under the auspices of the program announcing a new computerized tobacco cessation program for employees. Interested employees were directed to contact the research staff. In the Tobacco Dependence Program, participants were recruited by counselors and those interested were referred to the research assistants. Adults in these three settings who were current tobacco users or who recently quit (in the past 6 months), who could read and understand English, who could read words on a computer screen, and who did not meet exclusion criteria were invited to participate in the study. Exclusion criteria included being under 18 years of age, being a nonsmoker or having quit over 6 months ago, having severe illness or distress (eg, intubation, severe pain, vomiting), having cognitive insufficiency (eg, dementia, psychosis, altered consciousness), having insurmountable language barriers (eg, non-English speaking), and refusing to participate. Participants were reassured that neither prior computer experience nor a desire to quit was required in order to participate.

Procedure

After the prototype of the CABIT finished laboratory testing, we completed a pilot test with 20 patients recruited from the Emergency Department. This pilot test was designed to assess global functionality, gain experience with the CABIT in a clinical setting, and reconcile problems with the software. Following resolution of problems, the CABIT was fully administered with updated components in the Emergency Department, the Employee Assistance Program, and the Tobacco Dependence Program during 2008. This was referred to as the Field Evaluation Study because the intent was to assess how feasible it was to fully integrate the CABIT into these clinical field settings. This research was approved by the institutional review boards for Cooper University Hospital and Polaris Health Directions, Inc.

Patients were verbally asked to participate in the study if they agreed to answer screening questions and were eligible to participate based on their responses. This involved describing the study and the risks and benefits of participating to potential participants, and advising participants that they may withdraw from the study at any point in time. Written consent was obtained from all participants who verbally agreed to participate.

The assessment was self-administered and research assistants were available to answer questions and to solve problems, if needed. Following completion of the patient assessment and viewing of the stage-matched video, research assistants reviewed feedback reports with the patients. Research assistants then conducted a satisfaction assessment following completion of the CABIT program to obtain impressions from participants in all settings and from the participant’s health care provider (ie, physician, nurse, or counselor) in the Emergency Department and Tobacco Dependence Program. Since participants from the Employee Assistance Program were recruited directly, they essentially did not have a provider to evaluate the program.

To gather more detailed evaluations, 15 of the 67 pilot test participants completed an in-depth interview pertaining to a particular component of the CABIT program (assessment, $n = 5$; video intervention, $n = 5$; tailored patient feedback report, $n = 5$). After patients completed the program, they were asked the satisfaction assessment questions and additional open-ended questions about the randomly assigned CABIT components. These interviews were recorded for later review and analysis for themes.

Four-Week Follow-Up

Research assistants contacted Field Evaluation Study participants 4 weeks after they completed the CABIT program to determine treatment initiation and to re-assess tobacco use. Subjects recruited from the Tobacco Dependence Program were not followed because they were already in tobacco treatment. For participants who chose a dynamic referral, a research assistant contacted the tobacco treatment provider 4-8 weeks after the participant completed the CABIT program to verify the patient's report of entering treatment.

Measures

CABIT Assessment

Because of the pilot nature of the study, we included a broad range of well-established instruments that are robustly associated with tobacco abstinence and rooted in the theoretical traditions listed in the CABIT Overview section. Table 1 provides a description of the measures and the references.

Table 1. Assessment measures used or adapted for the CABIT.

Assessment Measure	Construct	Source
Behavioral Risk Factor Surveillance System (BRFSS) survey questionnaire	Tobacco use	Centers for Disease Control and Prevention (CDC), 2006 [33]
Fagerström Test of Nicotine Dependence (FT-ND)	Level of nicotine addiction	Heatherton et al., 1991 [34]
Fagerström Test of Nicotine Dependence—Smokeless Tobacco (FTND-ST)	Level of nicotine addiction for smokeless tobacco	Ebbert et al., 2006 [35]
Smoking: Stages of Change (short form)	Stage of change	DiClemente et al., 1991 [36]; Velicer et al., 1995 [37]
Readiness Rulers	Importance, readiness, and commitment to tobacco cessation	Biener and Abrams, 1991 [38]
Perceived Risks and Benefits Questionnaire (PRBQ)	Perceived risks and benefits associated with tobacco cessation	McKee et al., 2005 [39]
Reasons for Quitting (RFQ)	Reasons for tobacco cessation	Curry et al., 1990 [40]
Wisconsin Inventory of Smoking Dependence Motives (WISDM-68)	Motivation for tobacco use	Piper et al., 2004 [41]
Smoking: Self-Efficacy for Smoking/Temptation (short form)	Self-efficacy for smoking cessation and temptations for smoking	Velicer et al., 1990 [42]
Smoking Consequences Questionnaire (SCQ)	Smoking outcome expectancies	Brandon and Baker, 1991 [43]
Decisional Balance for Smoking (short form)	Pros and cons of smoking	Velicer et al., 1985 [44]
Perceived Health Risks	Perceived health risk of tobacco use	Bock et al., 2001 [45]
Perceived Risks	Perceived risks of tobacco use	Hampson et al., 2000 [46]
Patient Health Questionnaire-2 (PHQ-2)	Two-item depression screener	Kroenke et al., 2003 [47]

Satisfaction Assessment

Patient Satisfaction Assessment

The satisfaction assessment for patients consisted of semi-structured interviews assessing impressions of the CABIT assessment program, reports, and referrals, along with quantitative ratings. Suggestions for improving the CABIT were also elicited. Quantitative ratings were obtained for domains using a 5-point scale (1 = Very Poor; 2 = Poor; 3 = Fair/Average; 4 = Good; 5 = Excellent). Domains assessed with participants included those related to the different components of the CABIT. For the assessment domain, participants were asked about clarity of instructions, ability to read words on the computer screen, ease of responding to questions using the keyboard, understandability of how to return to the previous question, length, comfort in answering honestly, and appropriateness of questions. For the video, participants were asked about length, understandability and usefulness of information presented, ability to maintaining interest, and effectiveness in changing attitude regarding tobacco use. For the Patient Tobacco Feedback Report, participants were asked about understandability and usefulness of information, effectiveness in changing attitude regarding tobacco use, and usefulness of resources. These domains were patterned after published work on the Dynamic Assessment and Referral System for Substance Abuse (DARSSA) [5].

Patient Satisfaction Assessment with Depth Interview

In addition to the quantitative ratings, participants who completed the depth interviews were asked open-ended questions about a randomly assigned CABIT component (assessment, video intervention, or tailored feedback report). This included questions to help participants further elaborate their feedback on the domains from the satisfaction assessment, overall impressions of the program, and allow for suggestions for improvement.

Health Care Provider Satisfaction

For participants enrolled in the pilot test through the Emergency Department or Tobacco Dependence Program, the participant's treating physician, nurse, or counselor provided satisfaction ratings of the CABIT process and the Health Care Provider Report, including: understandability and usefulness of information, length, overall format, provision of information not assessed, effects on how provider would manage the patient, and whether the patient would have received a referral if he or she did not participate in the CABIT program.

Statistical Analysis

Nonparametric summary statistics, including means and standard deviations, were calculated for all variables, including the end-user satisfaction ratings, completion time for the assessment, and 4-week outcomes. *A priori*, we choose a target mean satisfaction rating of ≥ 4.00 on the 5-point scale for each domain assessed by the end user. The domains failing to meet this goal would need to be modified and reassessed prior to the Phase II efficacy trial. Since the present study is a proof-of-concept study designed to assess the functioning, usefulness, and acceptance of the CABIT, treatment initiation and abstinence were considered secondary outcomes.

Results

Descriptive Characteristics

For the Field Evaluation Study, 426 patients were approached for participation in the Emergency Department. Of these patients, 169 did not smoke, 115 were too sick, 25 did not speak English, there was concern about mental status for 45 patients, 25 patients refused to be screened or participate, and 4 had other reasons for not participating. A total of 43 patients were enrolled during the Field Evaluation Study in the Emergency Department, but 3 failed to complete the program. Twenty-four participants were enrolled in the Employee Assistance Program and 3 from the Tobacco Dependence Program. Information about the number of patients invited to participate in the Employee Assistance Program was not recorded as hospital employees contacted research staff directly. Similarly, research staff were provided with contact information for interested patients in the Tobacco Dependence Program, so the number of patients invited to participate from this program was not recorded. A total of 67 participants completed the CABIT assessment across all settings (Emergency Department, *n* = 40; Employee Assistance Program, *n* = 24; and Tobacco Dependence Program, *n* = 3) (see Figure 6). Reasons for not completing the assessment included patients being discharged or being taken for a procedure or testing. Table 2 summarizes the participants' characteristics.

Figure 6. Enrollment of participants in the Field Evaluation Study of the CABIT program. Participants were recruited from the Emergency Department (ED), Employee Assistance Program (EAP), and Tobacco Dependence Program (TDP). Screening data was only available for participants from the emergency department. Follow-up was not completed with patients in the tobacco dependence program as they were already receiving treatment. Treatment initiation was confirmed through contact with tobacco dependence specialists in the referral library.

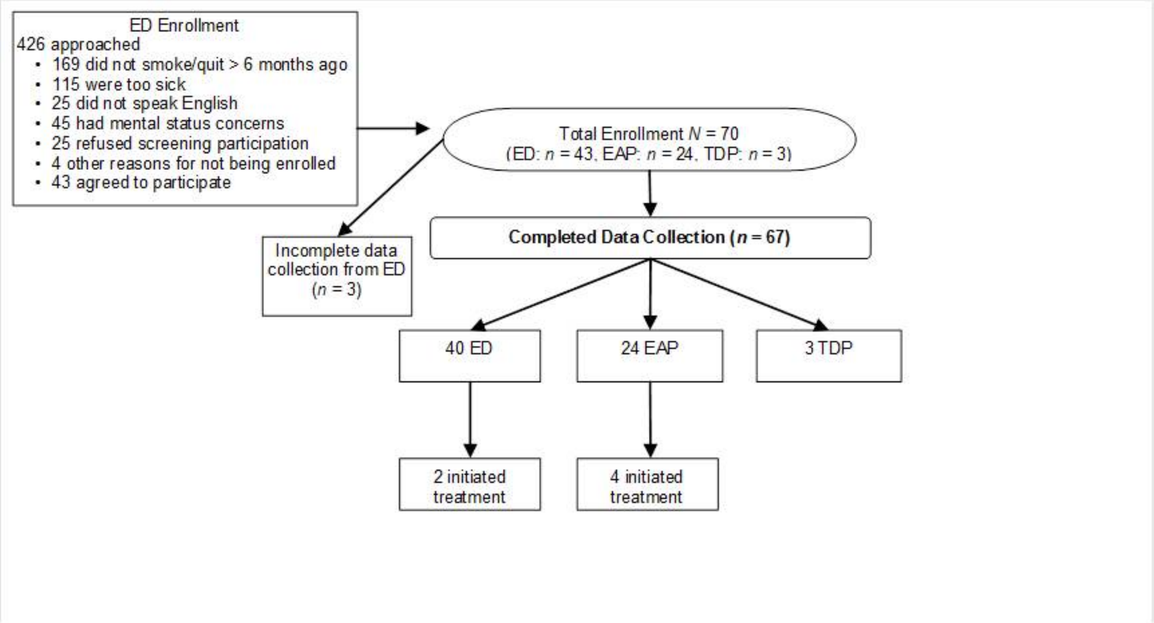


Table 2. Demographic and smoking characteristics of participants who completed the CABIT program (n = 67).

Characteristic	Data
Age	*M* = 42 (*SD* = 12.69)
Gender	
Male	21 (31%)
Female	46 (69%)
Marital status	
Never married	23 (34%)
Married or remarried	22 (33%)
Divorced or separated	9 (13%)
Other marital status	13 (19%)
Race/ethnicity	
Caucasian	35 (52%)
African-American	21 (31%)
Hispanic only	6 (9%)
White Hispanic	1 (2%)
Black Hispanic	0 (0%)
Other	4 (6%)
Education level	
8th grade education or less	0 (0%)
Some high school	13 (19%)
High school graduate	24 (36%)
Some college	20 (30%)
College graduate	9 (13%)
Some graduate work	1 (2%)
Average years of tobacco use	*M* = 26.22 (*SD* = 11.98)
Current tobacco use (some or every day)	
Cigarettes	58 (87%)
Cigars	9 (13%)
Pipe	1 (1%)
Smokeless tobacco	0 (0%)
Daily amount of tobacco use by type for tobacco of choice [a]	
Cigarettes	(*n* = 57)
1-10 per day	26 (46%)
11-20 per day	20 (35%)
21-30 per day	11 (19%)
Cigars	(*n* = 4)
2-3 per day	2 (50%)
4-5 per day	1 (25%)
6 or more	1 (25%)
Stage of change	
Precontemplation	17 (25%)
Contemplation	25 (37%)
Preparation	20 (30%)

Characteristic	Data
Action	5 (8%)
Positive on depression screen	17 (25%)
Positive on risky alcohol screen	27 (40%)
Positive on drug use screen	16 (24%)

[a] Data was not available for pipe and smokeless tobacco use as participants did not indicate that these products were the most frequently used.

Satisfaction

Patient Satisfaction

Satisfaction ratings on all categories for the assessment, video intervention, and patient feedback reports were above our goal of a mean ≥ 4.00 (Good), ($M = 4.48$; $SD = 0.70$). Figures 7-9 illustrate domain satisfaction scores for participants. The items of relative weakness were the length of the assessment, length of the videos, interest of the videos, and the potential for the videos to motivate change. Qualitative evaluations also reinforced that the length of the assessment, as well as the ability of the videos to engage and motivate, while acceptable, could be improved. Suggested improvements for the videos included making the narrator more interesting and matched to the end user, presenting personal testimonials, and culturally tailoring the content by addressing issues that are of particular concern for different racial or ethnic groups.

Figure 7. Mean CABIT assessment satisfaction scores for patients (n = 67). The target satisfaction score was 4.00 (Good).

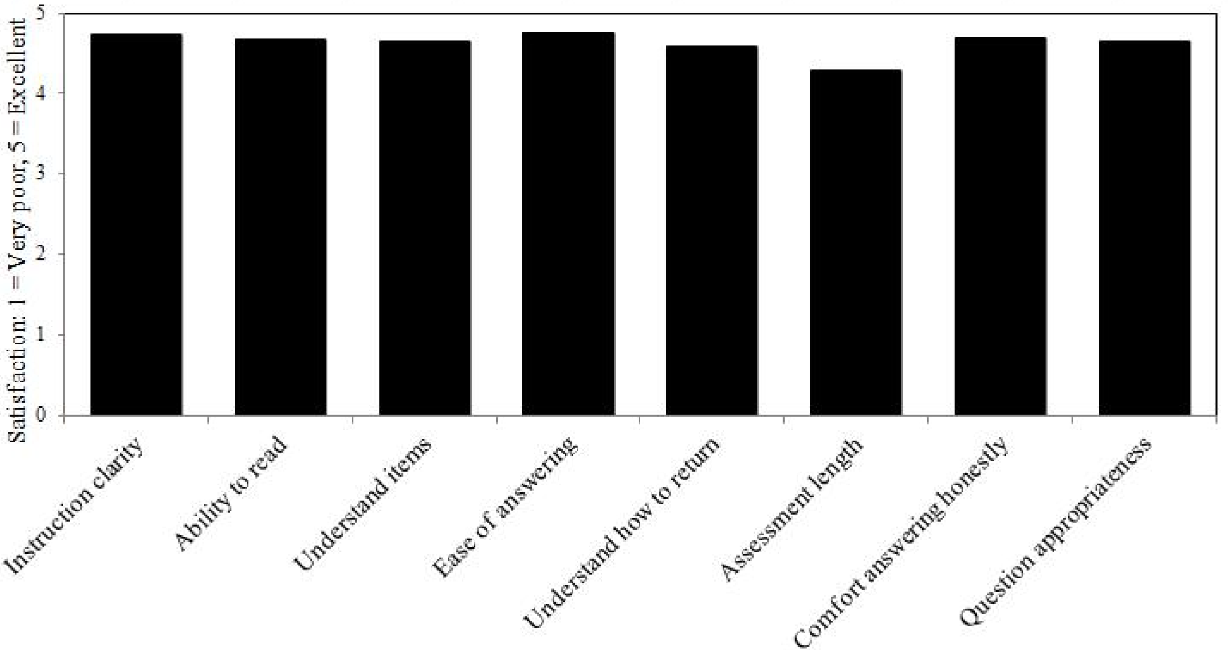


Figure 8. Mean CABIT video satisfaction scores for patients (n = 67). The target satisfaction score was 4.00 (Good).

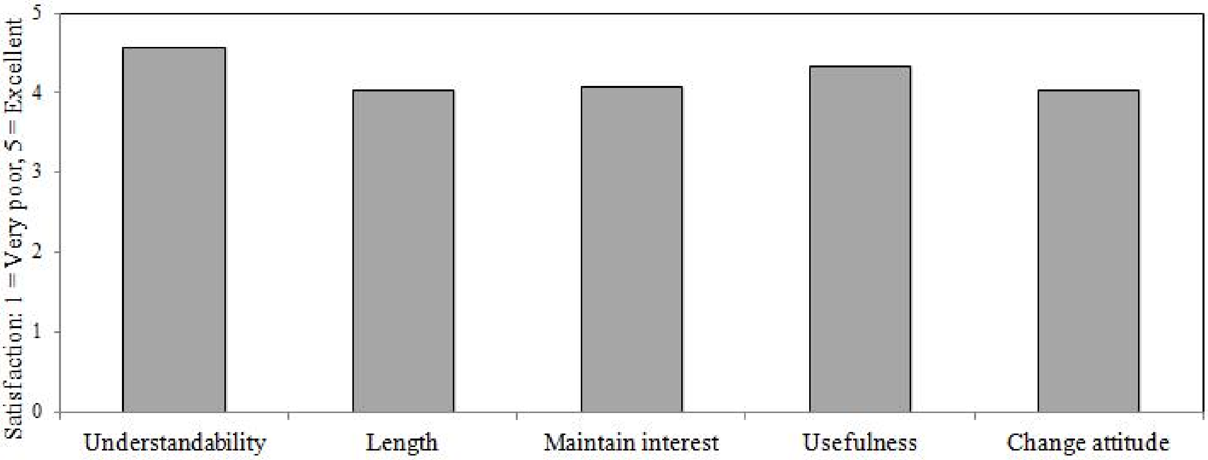
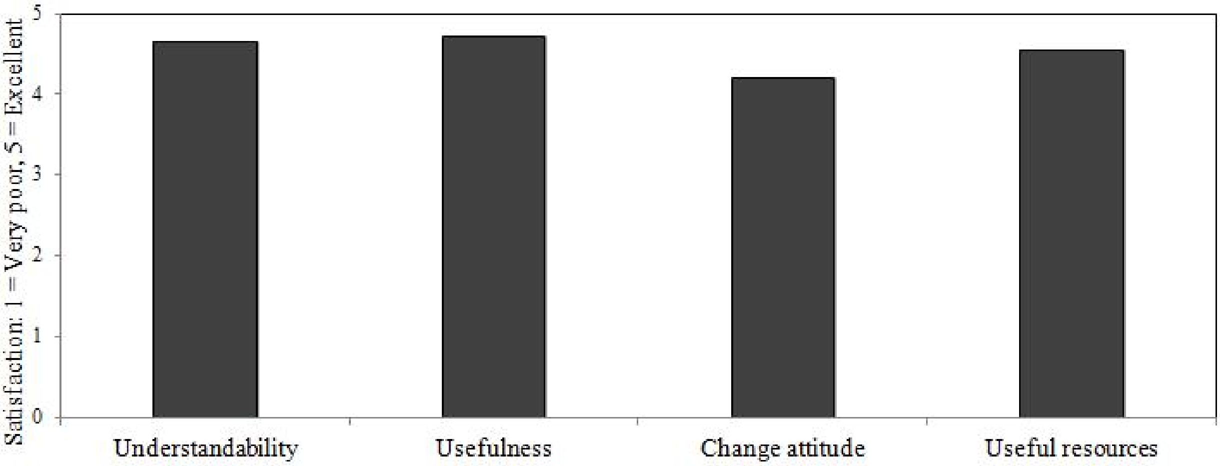


Figure 9. Mean CABIT Patient Tobacco Feedback Report satisfaction scores (n = 67). The target satisfaction score was 4.00 (Good).



Satisfaction Assessment with Depth Interviews

Themes that arose from the 15 depth interviews (5 based on each component: assessment, video intervention, and tailored patient feedback report) were integrated into the Master Theme Summary. Themes included in the Master Theme Summary were those endorsed by at least 3 respondents. Themes for the assessment included: the questions were understandable; instructions were clear; it was clear how to navigate the screens; the assessment length was appropriate; and it would be practical to administer this during visits to an emergency department, tobacco dependence program, or employee assistance program. Regarding the educational videos, the themes included: the video had good information; the video was not as useful as it could be; the situations portrayed in the videos are universal to all smokers; the videos were the appropriate length to hold your interest; the video format was useful; and the video was easy to understand. For the tailored feedback reports, the themes included: the report was informative; nothing should be changed with the report; the report was useful; the report was tailored to the participant; the report was the appropriate length and well-formatted; the report was understandable; and the report increased motivation to quit.

Health Care Provider Satisfaction

Of the 43 participants who completed the CABIT in the Emergency Department or Tobacco Dependence Program, 39 (91%) had a physician, nurse, or counselor complete satisfaction ratings of the Health Care Provider Report. Mean ratings exceeded our goal of 4.00 (Good) across all domains (*M* = 4.31, *SD* = 0.62), including: understandability (*M* = 4.44, *SD* = 0.55), usefulness (*M* = 4.26, *SD* = 0.68), length (*M* = 4.23, *SD* = 0.67), and overall format (*M* = 4.31, *SD* = 0.57). Providers indicated that the assessment gave them information not gathered during their standard evaluation for 34 out of 39 patients (87%). Additionally, 35 out of 39 patients (90%) received a referral that would otherwise not have been provided during routine clinical care.

Completion Time

The median completion time was 22 minutes (IQR: 14-26 minutes). This time for the assessment alone included interruptions by providers, which were impossible to quantify, so the recorded completion times overestimate the true administration time by an unknown amount. The educational videos, which were 6-7 minutes in length, were not included in the time it took to complete the assessment.

Dynamic Referral

Of the 45 participants not currently in treatment who expressed interest in changing their tobacco use and were offered a dynamic referral, 28 (62%) agreed to have their information sent to a best-matched tobacco treatment provider. While we did not assess the reason for not accepting a dynamic referral, we suspect these patients were not ready to quit or not interested in getting assistance to quit.

Treatment Initiation

Of the 64 participants who were followed (ie, Emergency Department and Employee Assistance Program participants), we successfully contacted 44 (69%) for the follow-up assessment. We did not follow-up with patients from the Tobacco Dependence Program because they were already enrolled in treatment. Based on the follow-up information from the 44 participants contacted, combined with follow-up data obtained from the tobacco treatment sites where dynamic referrals were sent, we determined that 6 out of 64 patients (9%) had initiated tobacco treatment within 8 weeks of their baseline assessment. Of these 6 patients, 5 had received a dynamic referral and 1 had received a passive printed referral at the completion of the CABIT. Reasons for not entering treatment included not being ready, disliking the programs, living too far away, other appointments, transportation problems, and medical problems or surgery.

Tobacco Use at Follow-up

Of the 44 participants interviewed for the follow-up assessment, 21 (48%) reported going at least 24 hours without smoking even a puff in the past 4 weeks (ie, a quit attempt), and 4 (9%) reported abstaining from tobacco use in the 7 days prior to the follow-up phone call (ie, 7-day point prevalence abstinence).

Discussion

While research supports the effectiveness of provider-based interventions for improving tobacco cessation [3,48], clinicians often lack the time, training, and resources to carry out these interventions [1,2]. The CABIT program was created to help overcome these barriers by providing a brief individualized intervention with feedback in “real time,” a stage-matched video intervention, and optional dynamic referral to a tobacco cessation provider. Additionally, the CABIT required little staff time because it is self-administered, making it easier to integrate into busy medical settings.

In the Emergency Department, of the 426 patients approached to be screened for the study, and of those who were eligible, 43 were enrolled in the study. Twenty-four participants responded to emails to participate in a tobacco treatment intervention through the Employee Assistance Program and 3 patients who were in a Tobacco Dependence Program agreed to participate in the study after being asked by counselors. Three patients failed to complete the program in the Emergency Department because they were discharged or sent for testing or a procedure. Overall, there were 67 participants who completed the CABIT program.

Clinicians found the program to be useful. They rated the understandability, length, usefulness, and overall format of the Health Care Provider Report between 4 (Good) and 5 (Excellent) on a 5-point scale. Additionally, the CABIT proved to be useful to clinicians by providing information not obtained in the standard clinical assessment for 34 of 39 patients (87%). Providers indicated that 35 out of 39 patients (90%) evaluated would not have received a referral to a tobacco cessation program if the CABIT had not been administered.

For automated interventions to be widely disseminated into clinical practice in medical settings, they will need to be brief so they do not impede clinical flow. Our early end-user input from a range of health care providers suggested that the entire intervention, from start to finish, should be completed within 10 minutes for the majority of patients. The CABIT fell short of this goal, with a mean time of 22 minutes. It is important to note that this estimate is contaminated by down-time arising from interruptions from health care providers, especially in the Emergency Department setting. Additionally, we were overly inclusive in our assessment instruments, which included considerable redundancy. Eliminating the redundancy would undoubtedly shorten the assessment. Additional work will have to be done on the CABIT program to shorten the length of administration before efficacy testing can be completed. In developing computerized clinical interventions, a careful balance must be struck between obtaining enough information to be useful to individuals using the system and the strong demands to have a simple, efficient system that does not impede clinical flow. However, despite the shortcomings, the result of only 3 out of 43 patients in the Emergency Department failing to complete the assessment due to discharge or clinical care supports the feasibility of a program like the CABIT and the willingness of patients to participate even in a fast-paced environment.

Participants rated all aspects of the CABIT assessment, stage-matched video intervention, Patient Tobacco Feedback Report, and treatment referral locations between 4 (Good) and 5 (Excellent) on a 5-point scale. Connecting individuals with specialized tobacco treatment is an important goal of the CABIT program, considering the evidence that smokers who quit with assistance are more likely to succeed [3]. The dynamic referral proved to be a highly attractive component of the CABIT program with 28 of the 45 current tobacco users (62%) who were interested in quitting accepting the referral offer. Six (9%) of the participants we followed after baseline enrollment initiated tobacco dependence treatment with a specialist. The significance of this is difficult to evaluate, since we did not include a control condition. However, a previous study conducted with 577 smokers treated in an emergency department found that < 1% initiated treatment after they received a passive referral [32]. While 9% may not seem large in absolute terms, it may represent a significant increase in treatment engagement compared to treatment as usual (a passive referral). Moreover, even small effect sizes can translate into important public health and economic benefits. For example, the United States Preventive Services Task Force (USPSTF) recommends that primary care providers universally screen for tobacco use and give brief counseling. This recommendation is based on fairly modest increases of about 3-5% in abstinence rates over control conditions [49]. Further randomized, controlled clinical studies should provide more of a definitive evaluation of whether dynamic faxed referrals can promote treatment initiation and, ultimately, abstinence when compared to brief advice alone or passive printed referrals.

Limitations

Limitations to the study included sample selection bias, which may have been present for those who were illiterate or not able to read at an eighth-grade level and for those who were computer illiterate despite our effort to assure patients that no computer knowledge was needed. Additionally, sample selection bias may have been present for those we excluded due to reasons of being too sick, not speaking English, and concerns about cognitive limitation. The sample size was relatively small, though this is mitigated by the proof-of-concept nature of the study. Follow-up limitations were possible with the 4- to 8-week follow-up window, which may have been too brief to catch all patients initiating treatment. Lastly, patient tobacco cessation at follow-up was based on patient report and not validated through biochemical means. Since this was not an efficacy trial, tobacco cessation was a secondary analysis.

Conclusion

The CABIT proved to be an innovative and usable program that assisted providers in identifying tobacco users, providing brief individualized treatment with the stage-matched video intervention and feedback reports, and providing an automated referral to a tobacco treatment specialist. The program was highly accepted, easily implemented, and elicited a high level of satisfaction. Phase II of the CABIT will address the creation of a more user-friendly program, including a shorter assessment and production of videos that are more engaging and motivational. Lastly, future clinical trial testing is warranted to assess efficacy in promoting treatment engagement and tobacco cessation.

Acknowledgments

The study was performed while Edwin Boudreaux, Ph.D., was employed by Cooper Health System and faculty with Robert Wood Johnson Medical School in Camden, NJ. He is currently employed by the University of Massachusetts Medical School. This research was supported by a Small Business Technology Grant from the National Institute on Drug Abuse (R41DA019718) to Polaris Health Directions, Inc.

Conflicts of Interest

Dr. Boudreaux provides paid consultation to Polaris Health Directions, Inc, the company that was awarded the grant and that produced the CABIT. Dr. Grissom is currently employed by Polaris Health Directions, Inc. and Dr. Lord was employed there at the time of the study completion.

Multimedia Appendix 1

Example of a Patient Tobacco Feedback Report from the CABIT program.

[PDF File (Adobe PDF File), 99KB - jmir_v14i6e163_app1.pdf]

Multimedia Appendix 2

Example of a Health Care Provider Report from the CABIT program.

[PDF File (Adobe PDF File), 96KB - jmir_v14i6e163_app2.pdf]

Multimedia Appendix 3

Example of a Tobacco Treatment Referral from the CABIT program.

[PDF File (Adobe PDF File), 114KB - jmir_v14i6e163_app3.pdf]

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Original Paper

Impact of Interactive Web-Based Education With Mobile and Email-Based Support of General Practitioners on Treatment and Referral Patterns of Patients with Atopic Dermatitis: Randomized Controlled Trial

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Abstract

Background: The effects of various educational strategies have been examined in continuing medical education. Web-based learning has emerged as an alternative to ordinary classroom lessons.

Objective: To investigate whether an interactive Web-based course including personal guidance via email or cellular phone texting may be used to improve practice behavior of general practitioners in the management of atopic dermatitis.

Methods: General practitioners from all over Norway were eligible for this randomized controlled educational trial. During a period of 6 months, doctors in the intervention group were offered the opportunity to participate in a Web-based course on the management of atopic dermatitis. This was combined with guidance via email or multimedia messaging service (MMS) through mobile phones from a dermatologist. In the control group there was no education or guidance. Main outcome measures were the duration of topical steroid treatment prescribed to patients with atopic dermatitis (primary outcome), number of treatment modalities, and number of referred patients.

Results: We enrolled 46 physicians: 24 doctors were allocated to the intervention group and 22 doctors to the control group. They reported a total of 190 patient treatments. There were no statistically significant differences in the duration of topical steroid treatment or number of treatment modalities between the groups. The lack of effect on the primary outcome may be due to attrition as 54% (13/24) of the participants did not complete the course. 42% (10/24) of physicians sent at least one educational request via email or MMS. While 11% (8/73) of treatment reports in the intervention group were referred to a health care specialist (eg, dermatologist or pediatrician), 30% (21/71) of treatment reports in the control group did so. This difference in the number of referrals was significant ($P = .03$).

Conclusions: A Web-based educational intervention aimed at general practitioners combined with personal support can reduce the number of atopic dermatitis patient referrals to specialists.

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KEYWORDS

Atopic dermatitis; Internet; continuing education

Introduction

Atopic dermatitis (AD) is a common chronic inflammatory skin condition that may affect children as well as adults [1]. In Northern and Western Europe, the prevalence of AD in children was estimated to be 15-25% [2,3], whereas approximately 2-5% of adults were affected [4]. The majority of patients with AD suffer from a mild to moderate form of the disease and is most often treated in primary health care [3,5]. However, general practitioners (GPs) may find the management of patients with AD challenging [6], as guidelines commonly present a wide range of therapeutic modalities [1,7]. For instance, doctors are recommended to identify relevant trigger-factors based on a thorough case history before setting up a specific treatment plan [1,7]. Secondary skin infections are common in AD and warrant special attention [1,7]. Compared to other doctors, dermatologists use more complex treatment regimens including the liberal use of topical steroids [8,9]. In contrast, GPs appear to be more conservative in the use of steroids in terms of potency and treatment duration [6].

The aim of continuing medical education (CME) is to maintain and increase professional competence [10]. A variety of educational strategies and their effects on practice behavior have been examined [11,12]. Web-based CME has emerged as an alternative to ordinary classroom lessons [13]. Benefits include easy access from almost any location, no need for travelling, self-directed and self-paced learning [14]. Studies have shown that Web-based education has similar outcomes compared to traditional face-to-face education [15-18]. Despite participants commonly being physically separated in Web-based education, learners may interact with other learners or teachers through discussion forums or via email [13]. Discussion appears to have a significant effect on knowledge and behavioral change [17].

The aim of this study was to assess whether an interactive Web-based educational intervention may be used to improve practice behavior of GPs in the management of AD patients. The primary outcome was the duration of topical steroid treatment prescribed by GPs. Secondary outcomes were the number of treatment modalities prescribed and the number of referrals to a health care specialist.

Methods

Study Design

The study was a randomized controlled educational trial with a two group parallel design and, an allocation ratio of 1:1.

Participants

Between May 2010 and June 2011 we recruited GPs from all over Norway through advertisements in national medical journals and on the website of the Norwegian Medical Association. All physicians currently employed in general practice were eligible for inclusion. Physicians employed as interns or board certified specialists in dermatology or pediatrics and physicians who previously had participated in our Web-based course were excluded. The study period was 6 months.

Interventions

"Help, it's itchy!" is a Web-based asynchronous CME course on the management of AD in primary health care. A team of medical experts, web developers, and instructional experts planned and produced the course. The course was designed and delivered via the standard learning management system of the Norwegian Centre of Integrated Care and Telemedicine [19]. The target audience for "Help, it's itchy!" are primary care physicians and nurses. The educational boards of family medicine, dermatology, and pediatrics of the Norwegian Medical Association and the Norwegian Nurses Organization approved the course for CME credits. The course has been held regularly every year since it was launched in 2008. Learners were required to register beforehand in order to get access during the 8 week course period.

The instructional design of the course was based on the theories of constructivist and experiential learning. The content was presented as narrative text and in audiovisual format (Figure 1). Patient cases were used to explain typical clinical scenarios. Specialist nurses showed how to apply emollients, wet wraps, and facial dressings in 3 instructional videos (Figure 2). Advice on how to deal with cortisone fear was presented in a 7 minute video lecture.

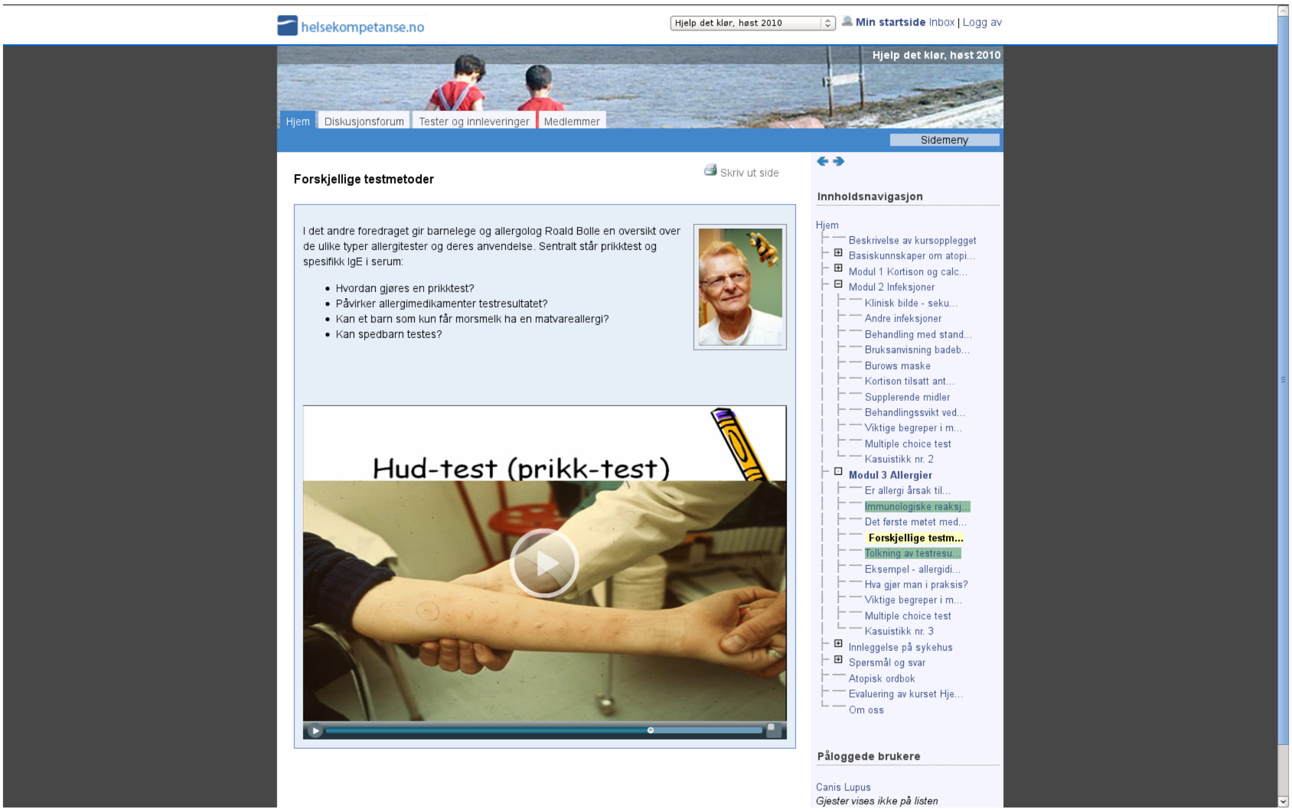
The course was organized into 3 modules (Table 1). Every module contained a set of 8-9 multiple choice questions for self-assessment. Learners received automatic feedback on the screen immediately after completion of the test set. In every module there was also a homework assignment containing a clinical case. Photographs of eczema skin changes were provided in the assignments of module 1 and 2 for better understanding. Learners were asked to present a treatment plan for each case. Physicians who wished to receive CME credits had to submit and pass the homework assignments within the first 6 weeks after initial login. The course instructor (author TS) provided learners with detailed, personalized feedback on the assignments 5-7 days after submission.

Learners were free to discuss with other learners and the course instructor in a forum. In addition, the instructor was accessible via email or multimedia messaging service (MMS).

Table 1. Course content.

Section	Topics
Introduction	Etiology; natural history; diagnosis; skin care; management of pruritus.
Module 1 Steroids and calcineurin inhibitors	Use of steroids on various body sites; dosage and tapering-off; side effects; maintaining control; steroid fear; calcineurin inhibitors.
Module 2 Infections	Features of infected eczema; differential diagnosis of infections; procedures for topical treatment; treatment failure.
Module 3 Allergies	Diagnosis of allergies; testing.
Appendix	Specialist treatment; phototherapy.

Figure 1. Audiovisual lesson on allergy testing.

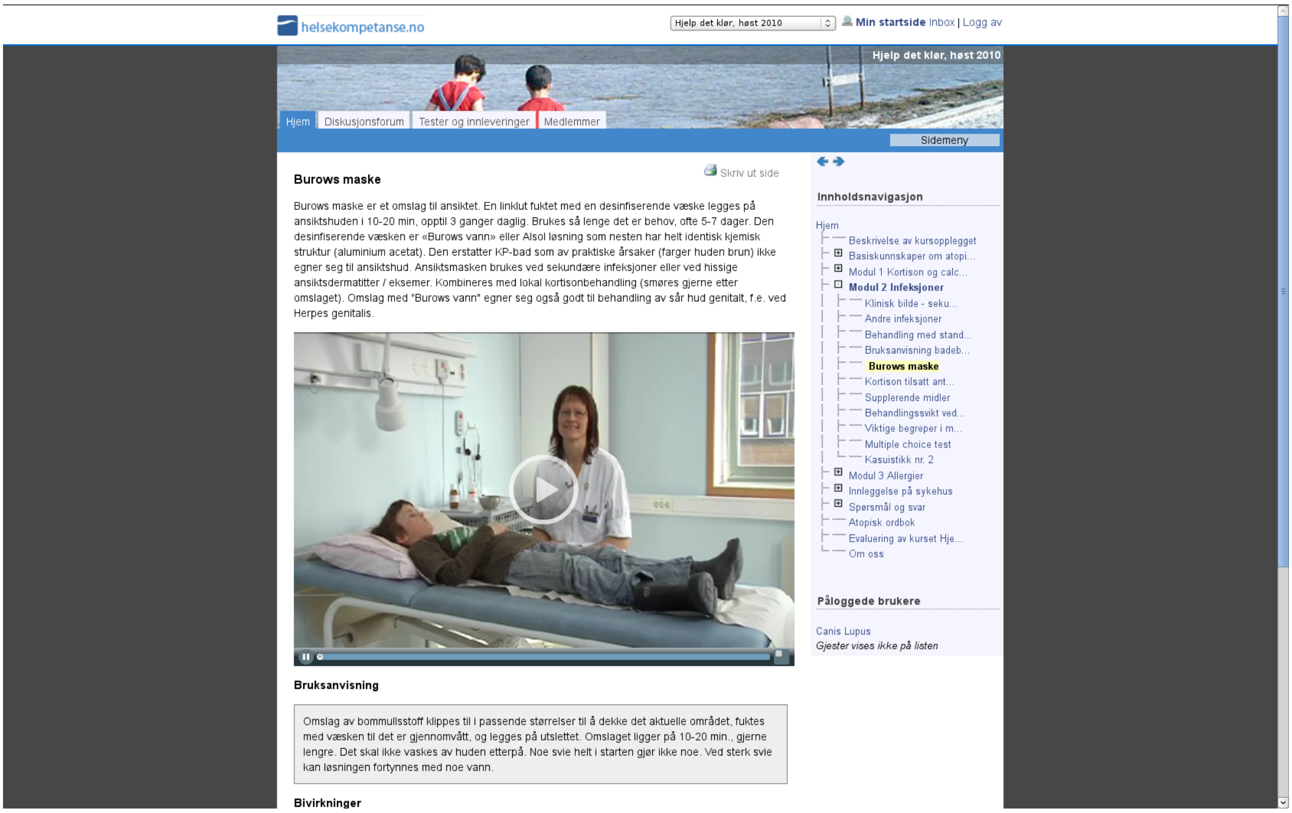


Forskjellige testmetoder

I det andre foredraget gir barnelege og allergolog Roald Bolle en oversikt over de ulike typer allergitester og deres anvendelse. Sentralt står prikktest og spesifikk IgE i serum:

- Hvordan gjøres en prikktest?
- Påvirker allergimedikamenter testresultatet?
- Kan et barn som kun får morsmelk ha en matvareallergi?
- Kan spedbarn testes?

Figure 2. Video showing the use of a facial dressing.



Burows maske

Burows maske er et omslag til ansiktet. En linklut fuktet med en desinfiserende væske legges på ansiktshuden i 10-20 min, opptil 3 ganger daglig. Brukes så lenge det er behov, ofte 5-7 dager. Den desinfiserende væsken er «Burows vann» eller Alsol løsning som nesten har helt identisk kjemisk struktur (aluminium acetat). Den erstatter KP-bad som av praktiske årsaker (farger huden brun) ikke egner seg til ansiktshud. Ansiktsmasken brukes ved sekundære infeksjoner eller ved hissige ansiktsdermatitter / eksemer. Kombineres med lokal kortisonbehandling (smøres gjerne etter omslaget). Omslag med "Burows vann" egner seg også godt til behandling av sår hud genitalt, f.e. ved Herpes genitalis.

Bruksanvisning

Omslag av bommullsstoff klippes til i passende størrelser til å dekke det aktuelle området, fuktes med væsken til det er gjennomvått, og legges på utslettet. Omslaget ligger på 10-20 min., gjerne lengre. Det skal ikke vaskes av huden etterpå. Noe svie helt i starten gjør ikke noe. Ved sterk svie kan løsningen fortynnes med noe vann.

Bivirkninger

The Intervention Group

Physicians allocated to the intervention group were offered to participate in the Web-based course "Help, it's itchy!" including personal guidance via email or MMS on their cellular phone. They were registered for the online course and received information regarding access to the course including a username and password. There was unlimited access to the Web-based curriculum for the entire study period starting 1-3 days after randomization. Physicians in the intervention group were free to send educational requests via email or MMS to the course instructor (author TS) during the entire study period. While the Web-based course was focusing on the treatment of AD, physicians were encouraged to send requests about all topics within the field of AD via email or MMS. They were specifically offered to discuss real cases from their practice and could attach close-up photographs showing the patient's skin lesions provided that the patient had given informed consent. The course instructor responded to requests within 1-2 working days by sending an answer via email or MMS. The requests were for educational purposes only. Physicians were instructed to ensure that no data or images that could possibly lead to the identification of the patient were transferred. They were informed prior to the study that sending requests was not possible for the referral of patients to specialist health care.

The Control Group

Physicians in the control group neither had access to the Web-based course nor could they send educational requests via MMS or email. After the 6 month trial period ended, we offered all physicians in the control group to continue in a second trial phase. They were offered to participate in a subsequent Web-based course but without the option to send requests via email or MMS. A follow-up questionnaire was sent to these doctors 4 weeks after completing the Web-based course.

Data Collection

Physicians in both groups were requested to fill in a short online survey (Multimedia Appendix 1 and 2) reporting their treatment prescriptions every time a patient consulted them with AD during the 6 month study period. For the purpose of this study we defined a patient with AD as a person of any age with a clinical diagnosis of AD, or a person probably having AD as judged by the participating physicians. In addition, physicians were asked to fill in online questionnaires about working experience, attitudes and habits regarding the management of AD at start-up and at the end of the study period. In the intervention group there were also questions concerning satisfaction of sending educational requests via email or MMS. Doctors were asked to rate their agreement on 4 statements concerning satisfaction by the use of a Likert-type rating scale containing 5 levels.

The start-up questionnaire and one treatment survey had to be submitted before randomization. Physicians were not required to report treatments immediately after they had seen the patient but were advised to do this at the end of the working day. A reminder message was regularly sent by email every 3 weeks to all participants. The online form used to collect data on the treatments had multiple-choice questions. Physicians were asked to report the number of days they had instructed the patient to use steroid creams or ointments, including tapering. Numerous treatment modalities were listed on the form and doctors had to check off which modalities they had prescribed. Treatment modalities included were emollients, baths, dressings, topical steroids (specifying potency class I-IV: I mild, IV very potent), topical calcineurin inhibitors, wet wrap dressings, oral antihistamines, oral antibiotics, oral steroids and dietary eliminations. Finally there were questions about referral to specialist health care. The physicians were asked to indicate whether they intended to refer the patient and if so, to specify the reasons for referral and to which specialty. Reasons for referral included uncertainty about the diagnosis, flare of the disease, poor response to treatment, need for allergological investigation, and other reasons. We made no attempt to collect data on the severity of AD because we considered it unrealistic to train participants in using a validated scoring algorithm for AD.

After collecting the data according to the study protocol, we also performed a content analysis of the educational requests sent via email or MMS. Common themes were identified and grouped accordingly. The authors TS and VF did the content analysis independently. Disagreement was resolved by consensus.

Sample Size

The design of the trial was based on a significance level of 5% and a power of 80% against a difference of 3 days (SD=4) in the duration of topical steroid treatment between the groups. This difference appeared meaningful based on our clinical experiences. In calculating the sample size we had to consider the number of treatment reports that each participating physician was going to submit. Assuming an average of 4 measurements per physician, 20 participants would be required in order to show a statistically significant difference in the primary outcome. In the case of only one treatment report per physician, 59 participants would be required. Since the number of measurements per participant was difficult to estimate prior to the trial, we aimed at reaching a sample size of 59 participants. Allowing for a 20% drop out rate, 74 participants had to be enrolled.

Randomization

Randomization was arranged consecutively from September 2010–June 2011 via the central telephone randomization service at the Clinical Research Department of the University Hospital of North-Norway. We decided on permuted-block randomization to avoid uneven group sizes. As the severity of AD (and consequently the practice behavior of the participants) may be influenced by seasonal climatic variations, bias could be introduced when more treatments were reported in one of the groups during a specific season (eg, winter). Randomization lists were computer generated using block randomization with random block sizes 4, 6, and 8. The investigators were blinded to the block sizes. Participants were informed by email to which group they had been allocated and started in the trial immediately.

Statistics

Data were analyzed on an intention-to-treat basis. We used a generalized estimating equations model in all outcome analyses to account for random effects introduced by doctors reporting more than one treatment during the study period. An exchangeable covariance structure handled treatment data as within-subject repeated measurements. All data analyses were performed using the IBM SPSS 19 program (IBM, New York, USA).

Ethical Considerations

The Regional Committee for Medical and Health Research Ethics in Northern Norway (REK-Nord) reviewed the study protocol and concluded that the study did not need approval as this was a non-clinical trial that did not investigate health outcomes. For the same reason, the study was not included in a clinical trials registry (Editorial note: JMIR published this trial despite failure to register, as, according to the International Committee of Medical Journal Editors, registration is not necessary if the purpose of a trial is to examine the effect on health care providers). The protocol (in Norwegian) can be downloaded from the Internet [20]. All physicians gave informed consent before enrolment.

Results

Overall, 76 general practitioners were eligible for the study (Figure 3). At the end of the recruitment phase, 46 physicians had submitted a full set of questionnaires. The intervention group consisted of 24 physicians and the control group had 22 physicians. Baseline demographic data for enrolled physicians are shown in Table 2.

The doctors reported a total of 190 patient treatments including baseline data (intervention group: 97 treatments, control group: 93 treatments). Overall 35.4% (67/189) of the treatments were related to adult patients (intervention group: 34/97, 35.1%; control group: 33/92, 35.9%). Treatment reports were submitted on average 10.2 (SD=6.8) weeks after randomization (range 1-26). A summary of reported treatments at baseline is shown in Table 3. The enrolled physicians were representing 43 health centers from all over Norway.

The duration of topical steroid treatment prescribed by the physicians is shown in Table 4. There was no significant difference between the groups (*P*=.82). However, there was a significant increase in the duration of topical steroid treatment compared to baseline for both groups (*P*=.02). The mean number of treatment modalities prescribed at baseline was 2.3 in both the intervention and control group (SD= 1.0 and 0.9 respectively). During the study period physicians in the intervention group prescribed on average 2.3 modalities (SD=1.0) and for physicians in the control group we found 2.0 modalities (SD=0.9). This difference was neither significant between the groups (*P*=.19) nor compared to baseline (*P*=.27). Details of the treatment modalities reported are presented in Table 5.

Overall, 15 doctors (intervention group: 7, control group: 8) reported at least one referral during the study period. 11% (8/73) of treatment reports in the intervention group indicated referral to specialist health care, whereas 30% (21/71) of treatment reports in the control group did so. The difference in the number of referrals was significant (Wald χ^2_1= 4.70, *P* = .03). For details of the referrals see Table 6.

While 63% (15/24) of physicians in the intervention group had logged into the course website at least once, 46% (11/24) of physicians completed the course and received CME credits. A total of 32 educational requests were received via email or MMS. 42% (10/24) of physicians had sent at least one educational request via email or MMS. 29% (7/24) of physicians had neither logged into the course website nor sent any educational requests via email or MMS. Three postings were made in the discussion forum on the course website. Table 7 shows results concerning satisfaction of sending requests via email or MMS. Common themes identified in the educational requests are presented in Table 8.

As only 5 physicians in the control group submitted follow-up questionnaires, the planned comparison of follow-up questionnaires in the two groups was omitted.

Table 2. Characteristics of enrolled physicians (N=46).

		Overall	Control	Intervention	Test of significance
All physicians		100% (46/46)	48% (22/46)	52% (24/46)	
	Male	43% (20/46)	41%[a] (9/22)	46%[a] (11/24)	X^2= 0.002; *P*= .97
	Female	57% (26/46)	59%[a] (13/22)	54%[a] (13/24)	
Working experience					
	Mean (years)	7.5	6.1	8.8	*F*= 1.97; *P*= .16
	Range	1-27	1-27	1-25	

[a] Percentage within groups

Table 3. Baseline data of reported treatments (N=46).

	Overall	Control[b]	Intervention[b]
Treatment modalities			
Topical steroid	96% (44/46)	96% (21/22)	96% (23/24)
Topical steroid class[a]			
I	34% (15/44)	27% (6/22)	38% (9/24)
II	34% (15/44)	41% (9/22)	25% (6/24)
III	30% (13/44)	27% (6/22)	29% (7/24)
IV	2% (1/44)	0% (0/22)	4% (1/24)
Potassium permanganate bath	4% (2/46)	5% (1/22)	4% (1/24)
Burow's solution wet dressing	0% (0/46)	0% (0/22)	0% (0/24)
Wet wrap dressing	4% (2/46)	0% (0/22)	8% (2/24)
Elimination diet	15% (7/46)	14% (3/22)	17% (4/24)
Referred	22% (10/46)	23% (5/22)	21% (5/24)

[a] N=44

[b] Percentage within groups

Table 4. Duration of topical steroid treatment (N=150).

	Control[a]	Intervention[a]
Baseline	16.0 (SD=7.1)	15.7 (SD=7.1)
Study period	19.3 (SD=9.9)	20.6 (SD=11.3)

[a] Mean number of days

Table 5. Treatment modalities used (N=144).

	Overall	Control[a]	Intervention[a]
Emollients	79.2% (114/144)	78% (55/71)	81% (59/73)
Topical steroid	83.3% (120/144)	83% (59/71)	84% (61/73)
Potassiumpermanganate bath	9.7% (14/144)	3% (2/71)	16% (12/73)
Burow's solution wet dressing	3.5% (5/144)	1% (1/71)	6% (4/73)
Calcineurin inhibitor	5.6% (8/144)	6% (4/71)	6% (4/73)
Wet wrap dressing	4.9% (7/144)	3% (2/71)	7% (5/73)
Oral antihistamine	13.9% (20/144)	14% (10/71)	14% (10/73)
Oral antibiotic	1.4% (2/144)	0% (0/71)	3% (2/73)
Oral steroid	3.5% (5/144)	3% (2/71)	4% (3/73)
Elimination diet	7.6% (11/144)	6% (4/71)	10% (7/73)

[a] Percentage by study group

Figure 3. Flow diagram.

Table 6. Referral characteristics (N=29).

		Overall	Control[a]	Intervention[a]
Referred		20.1% (29/144)	30% (21/71)	11% (8/73)
	To dermatologist	83% (24/29)	86% (18/21)	75% (6/8)
	To pediatrician	17% (5/29)	14% (3/21)	25% (2/8)
Reason [b]				
	Diagnosis uncertain	35% (10/29)	33% (7/21)	38% (3/8)
	Flare	35% (10/29)	33% (7/21)	38% (3/8)
	Treatment failure	41% (12/29)	38% (8/21)	50% (4/8)
	Investigation of allergies	35% (10/29)	38% (8/21)	25% (2/8)
	Other reasons	10% (3/29)	14% (3/21)	0% (0/8)

[a] Percentage within groups

[b] Several reasons possible

Table 7. Satisfaction with sending requests (N=9).

	Mean score[a]	Range
Sending requests was easy	4.5	4-5
The advice given was useful	4.7	4-5
Wish for similar service in other specialties	4.8	4-5

[a] 1=strongly disagree; 5=strongly agree

Table 8. Common themes in the educational requests[a] (N=32).

General questions (not related to a case)		25% (8/32)
Discussion of a case		91% (29/32)
	Diagnosis	19% (6/32)
	Feedback on treatment given	63% (20/32)
	What to do next	50% (16/32)
	Referral	9% (3/32)

[a] Several entries for each request possible

Discussion

The educational intervention in our trial combined a Web-based course with the possibility to discuss both general issues and concrete cases from the GPs' own practices with a dermatologist. The main findings are that physicians in the intervention group referred fewer patients to secondary health care and that there were no differences between the groups in the duration of topical steroid treatment and the number of treatment modalities prescribed. The reasons for referral appeared to be similar in both groups. Treatment failure and flare were the reported reasons for referral in more than half of the cases.

In Northern and Western Europe, most patients with AD are treated in primary health care [3,5]. This is in line with the intention of policy makers who wish to move chronic care away from hospitals and into the communities [21]. Patients with severe AD, uncertain diagnosis, treatment failure, or complications may require referral to a specialist [7]. However, according to the literature, the majority of referred AD patients had mild to moderate disease [5,9,22]. Because of the high prevalence of AD, even a small reduction in referral rates may have a considerable impact on the workload of dermatologists and pediatricians dealing with AD patients. Reducing referrals may also have economical consequences. In 2010 there were 5406 hospital-based outpatient consultations with children with AD registered in Norway [23]. Every consultation was reimbursed with at least 273 NOK [23]. In contrast, the reimbursement in primary health care for a similar consultation was 136 NOK [24]. Based on a 20% reduction in referrals and a potential saving of 137 NOK per referral [23,24], there would be a national annual saving of 148 124 NOK. The development of Web-based education is costly, but may still be cost-efficient in the long run [15]. Future research on the cost effectiveness of educational interventions should also consider possible changes in referral behavior.

Our data suggest that a Web-based educational intervention aimed at primary care physicians may help to reduce referrals of AD patients. In a review, Akbari and coworkers reported that educational activities led by secondary care providers had a significant effect on referral behavior [25]. In contrast, the passive dissemination of guidelines appeared ineffective [25].

It seems that some topical treatment modalities, for example potassium permanganate baths and Burow's solution dressings, were used more frequently in the intervention group compared to the control group. The use of class I steroids was lower in the intervention group, whereas class III steroids were more frequently used. But there was no significant difference in the secondary endpoint, the mean total number of treatment modalities.

Concerning the duration of topical steroid treatment, the primary outcome of the trial, there was no significant difference between the groups. Regarding sample size, the number of participants appeared sufficient to show a difference in the primary outcome. On average, every doctor in our trial submitted 4.1 (SD=3.5) treatment reports. According to the assumptions we made when sample size was calculated, 20 doctors would be required in the trial.

The lack of effect on the primary outcome may be due to attrition as half of the participants did not complete the course. On the other hand, more than two thirds of the participants used the intervention at least once.

However, we found a significant increase in the duration of topical steroid treatment as compared to baseline for both groups. This might be a Hawthorne effect [26,27]: it seems possible that the awareness of being studied may have influenced the participants' behavior. The doctors in both groups were fully aware of being part of an investigation. They also probably understood that topical steroid therapy was under investigation since several questions in the survey addressed this topic. It is possible that this awareness influenced the behavior-doctors in both groups were keen to follow current treatment guidelines. However, since the exact mechanisms behind Hawthorne effects are unknown, it seems difficult to draw any firm conclusions regarding their influences on the participants [26,27].

Another possible explanation for the increase in steroid treatment duration might be the online form used for the collection of data. On the form, various treatment options were listed. Repeatedly using this form, physicians in both groups may have realized shortcomings in their knowledge of the management of AD. This might have stimulated physicians to reflect and learn which, in turn influenced treatment in both groups.

There are certain limitations in this study. First, it is likely that some GPs did not report all of their treatments during the study period. On the other hand, it seems unlikely that missed patients would have different effects across the two groups.

Second, doctors who enrolled in the trial possibly had a more positive attitude towards Web-based education. Other physicians may still perceive barriers to engage in eLearning and the applicability of our results may therefore be limited. There are currently no other Web-based dermatology courses in Norwegian, but the national CME program contains a variety of online courses in different specialties [28]. Furthermore, online course materials are now being used by many medical schools [29] and we believe that in the future nearly all physicians will become familiar with the use of Web-based educational activities [30].

Finally, our data are based on a 6 month study period. We do not know the effects of our intervention from a long-term perspective. The educational intervention might not affect the total number of referrals in the long run but rather just postpone them. This needs further investigation.

We believe that our findings are applicable to other medical fields within a general practice setting. More than two thirds of the physicians in the intervention group used either the Web-based course or sent educational requests for guidance via email or MMS. The instructional methods used in the course may suit other CME courses in general practice.

In conclusion, as many AD patients who are referred to specialist health care have only mild to moderate disease, there seems to be a potential to reduce unnecessary referrals [5,9,22]. Our study suggests that a Web-based educational intervention aimed at primary care physicians may help reach this goal.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Online questionnaire used to collect treatment data (in Norwegian).

[PDF File (Adobe PDF File), 42KB - jmir_v14i6e171_app1.pdf]

Multimedia Appendix 2

Translation of questionnaire.

[PDF File (Adobe PDF File), 61KB - jmir_v14i6e171_app2.pdf]

Multimedia Appendix 3

CONSORT-EHEALTH Checklist V.1.6.1 [31].

[PDF File (Adobe PDF File), 1MB - jmir_v14i6e171_app3.pdf]

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Abbreviations

AD: atopic dermatitis
CME: continuing medical education
GP: general practitioners
MMS: multimedia messaging service

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Original Paper

Mindless Eating Challenge: Retention, Weight Outcomes, and Barriers for Changes in a Public Web-Based Healthy Eating and Weight Loss Program

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Abstract

Background: Most dietary programs fail to produce lasting outcomes because participants soon return to their old habits. Small behavioral and environmental changes based on simple heuristics may have the best chance to lead to sustainable habit changes over time.

Objective: To evaluate participant retention, weight outcomes, and barriers for changes in a publicly available web-based healthy eating and weight loss program.

Methods: The National Mindless Eating Challenge (NMEC) was a publicly available, online healthy eating and weight loss program with ongoing recruitment of participants. This volunteer sample consisted of 2053 participants (mean age 39.8 years, 89% female, 90% white/Caucasian, BMI mean 28.14). Participants completed an initial profiling survey and were assigned three targeted habit change suggestions (tips). After each month, participants were asked to complete a follow-up survey and then receive new suggestions for the subsequent month.

Results: In terms of overall attrition, 75% (1549/2053) of participants who completed the intake survey never returned to follow up. Overall mean weight loss among returning participants was 0.4% of initial weight (P=.019). Participants who stayed in the program at least three calendar months and completed at least two follow-up surveys (38%, 189/504) lost on average 1.8 lbs (1.0%) of their initial weight over the course of the program (P=.009). Furthermore, participants who reported consistent adherence (25+ days/month) to the suggested changes reported an average monthly weight loss of 2.0 lbs (P<.001). Weight loss was less for those who discontinued after 1-2 months or who did not adhere to the suggested changes. Participants who reported having lost weight reported higher monthly adherence to suggestions (mean 14.9 days, SD 7.92) than participants who maintained (mean 12.4 days, SD 7.63) or gained weight (mean 12.0 days, SD 7.50; F=14.17, P<.001). Common reported barriers for changes included personally unsuitable or inapplicable suggestions, forgetting or being too busy to implement changes, unusual circumstances, and emotional eating.

Conclusions: Because the bulk of the free and commercially available online diet and nutritional tools conduct no evaluation research, it is difficult to determine which aspects of a program are successful and what are reasonable expectations of results. The results of this study suggest that online interventions based on small changes have the potential to gradually lead to clinically significant weight loss, but high attrition from publically available or “free” programs still remains a challenge. Adherence to and effectiveness of small habit changes may be improved through further tailoring to individual circumstances and psychological needs.

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KEYWORDS

Adherence; Barriers; Habits; Internet; Self report; Small changes; Weight loss programs

Introduction

Effective healthy eating interventions are needed to reverse the global obesity trend [1]. Most current weight loss programs and diets have failed to produce sustainable changes, partially due to the difficulty of maintaining healthy eating behaviors in an environment that constantly urges people to consume unhealthy food in excess [2]. Furthermore, programs that focus on education about calories and nutritional guidelines may place such high demands on participants' cognitive abilities that long-term adherence will be difficult [3].

Recent research suggests that small and concrete habit changes that gradually lead towards larger lifestyle changes may be the best way to achieve sustainable results [1]. Habit is starting to be considered as one of the most powerful predictors of eating behavior, and habits are mainly cued by situational factors [4]. Simple heuristics that are applicable in a wide variety of situations can help people to modify their automatic responses to food triggers in their environment to form new healthier habits [5]. In this way, healthful choices become activated by cues in the environment without effortful deliberation, intentions, or willpower [6].

The small-changes approach has been successfully embraced by various individuals and policy makers [1], but the challenge for interventions is to provide easy and effective habit change suggestions for each individual. Tailoring interventions to match individual characteristics and needs can lead to significant improvements in their effectiveness and relevance to recipients [7-9]. Dietary counselors can do tailoring in person-to-person interactions, but the resources for individual counseling are limited. The reach of habit change interventions can be best widened to the general population through partially or wholly automated web-based programs. Web-based weight loss and maintenance programs have demonstrated moderate efficacy in behavioral change [9-11], and randomized controlled trials have shown varying outcomes ranging from no weight loss to an average loss of 16.8 lbs (7.6 kg) [12]. Individualized counseling and feedback appear to improve outcomes [13].

The small-changes approach is still a relatively new concept in web-based intervention programs. To our knowledge, only one online intervention thus far has utilized the approach to support participants in making small sustained changes in dietary or physical activity behaviors [14]. The results of a randomized controlled trial showed that this intervention had positive effects on eating habits and the amount of physical activity, but it was no more effective than generic information [14]. Another online intervention, Daily Challenge, sends participants daily suggestions of small actions to improve well-being [15]. Its impact on well-being has not yet been evaluated.

The aim of this research was to evaluate the retention and weight outcomes of an online, tailored healthy eating and weight loss program, National Mindless Eating Challenge (NMEC), and recognize barriers for small habit changes. The NMEC program provides participants a tailored set of habit change suggestions for each month and offers them a checklist for self-monitoring and accountability [5]. The suggestions are based on findings from laboratory research about eating behavior [16]. Prior pilot trials of the NMEC program indicate that it can result in a slow and steady weight loss through small lifestyle changes that have the potential to become permanent [5].

Methods

Intervention

The National Mindless Eating Challenge (NMEC) was a publicly available, Internet-based dietary intervention program designed to aid participants in making small, effective eating-related changes in their daily lives [5]. Multimedia Appendix 1 shows the main page of the program. The program was offered passively from December 2006 until July 2009 as a resource to the public who found the program via search engines or hyperlinks or were directed to the program by a member of the research group as a response to their inquiry for assistance in weight management. The move to a new platform in June 2007 offered a more complete capture of data. This study was conducted with participants who were involved with the program for any period of time between July 2007 and July 2009. Participants who signed up in the freely available program completed an initial survey consisting of self-report measures of demographics, physical characteristics, and psychological characteristics. After completing the survey, they selected their initial eating goals (lose or maintain weight, eat healthier, eat more, or help their family eat better) and subobjectives. They were then randomly assigned three different environmental, behavioral, or cognitive suggestions that were relevant to the eating goal and subobjective they had chosen.

The habit change suggestions were selected from a pool of 232 different research-based suggestions, such as using smaller plates at meals, never eating directly from a package, or drinking water with every meal and snack [16]. The suggestions were phrased in an active form (such as "Put down your utensils between bites"). Some suggestions provided a brief explanation on why the change would work (such as "This will allow you to slow down the pace of your eating"). Additionally, the program contained references to the *Mindless Eating* book [17], which details the underlying research and contains similar suggestions for changing one's habits and environment.

After receiving the suggestions, participants were asked to estimate their adherence to the changes and how easy it would be to accomplish each change. To help them with adherence, they were asked to write down potential barriers that could prevent them from accomplishing each change. For each barrier, they were then asked to write down a strategy that would help them overcome this barrier. Participants were encouraged to adhere to the suggestions every day during the following month. To make this easier, they received a printable checklist to check off their adherence to changes on a daily basis. They also had an option to define their own small change they wanted to make in addition to the three suggestions and could choose to receive weekly reminders.

At the beginning of the following month, participants were sent an email inviting them back to the website, where they completed additional questions and were assigned new suggestions or tips for the subsequent month. The process repeated itself every month. Study procedures were approved by the Institutional Review Board.

Participants

Participants were voluntary individuals who registered on the National Mindless Eating Challenge website between July 2007 and June 2009 and gave their consent for researchers to use their data for the purposes of the study (n=2053). The characteristics of all registered participants and returning participants (those who completed at least one follow-up survey) are presented in Table 1. The proportion of returning participants was 25% (504/2053). The returning participants were slightly older, more educated, and weighed slightly less than nonreturning participants (those who never returned for follow-up surveys after registration). Nonreturning participants were excluded from outcome analyses.

Table 1. Baseline characteristics of participants.

Characteristics	All participants (n=2053)	Returning participants (n=504)	*F* test, returning & nonreturning (*P* value)
Age (years) [a]	39.8 (12.80)	42.6 (12.08)	32.737 (< 0.001)
Female [b]	1829 (89)	458 (91)	1.215 (0.270)
White/Caucasian [b]	1840 (90)	463 (92)	3.608 (0.058)
United States [b]	1672 (81)	410 (81)	0.004 (0.951)
College degree [b]	1641 (80)	423 (84)	6.667 (0.010)
Household income < $50,000 [b]	558 (27)	114 (23)	3.673 (0.055)
Weight (lbs) [a]	172.2 (42.28)	168.9 (37.80)	4.119 (0.043)
Body mass index [a]	28.1 (6.51)	27.9 (6.24)	1.030 (0.310)
Initial eating goal [b]			
Lose weight	1709 (83)	455 (88)	0.601 (0.438)
Maintain weight	106 (5)	24 (5)	0.219 (0.639)
Eat healthier	197 (10)	30 (6)	10.262 (0.001)
Help family eat better	37 (2)	5 (1)	2.478 (0.116)

[a] Values are expressed as mean (SD).

[b] Values are expressed as n (%).

In addition to the United States, participants were from Canada (11%), the United Kingdom (2%), Australia (0.5%), Germany (0.5%), France (0.5%), and 32 other countries. Most participants (83%) had weight loss as their initial eating goal. Ten percent wanted to eat healthier, 5% wanted to maintain their weight, and 2% aimed to help their family eat better. Four participants did not specify whether they wanted to lose or maintain weight. Eating healthier was slightly more common as an initial eating goal among nonreturning than returning participants.

Measures

Participant retention was measured by the number of monthly surveys participants completed in the program between July 2007 and July 2009 and by the number of calendar months participants stayed in the program (months that passed from the registration to the last completed follow-up survey).

All measures about participant characteristics were self-reported during registration or during follow-up surveys. Demographics (age, gender, race, education level, annual household income, and country) were asked in the registration survey. Weight and height were asked in the registration survey and in each follow-up survey.

Weight loss outcomes were calculated as the difference between the weight reported at the last follow-up survey a participant completed and the weight reported in the registration survey. Hence, the length of the follow-up varied between participants.

Adherence to habit change suggestions was measured as the number of days (0-31) participants reported having followed the suggestions they had been given. Perceived effectiveness of changes was measured on a 1-9 scale (Not Very Effective – Very Effective). The total amount of effective changes for each month was calculated as the number of changes that were rated as 6 or above in effectiveness. Participants' experiences with changes were collected through free-form entries in follow-up surveys.

Analyses

Descriptive statistics were used to characterize participant retention. Student *t* tests were performed to assess the overall significance of weight changes over time. Analyses of variance were used to compare the adherence to changes and the perceived effectiveness of changes between participants who lost, maintained, or gained weight between subsequent surveys. The suggestions with high adherence were examined by taking a subset of cases where at least 20 participants had reported adherence of at least 20 days. Student *t* tests were used to examine the significance of weight changes associated with suggestions with high adherence. The suggestions that participants considered as the most and the least effective were derived based on the mean effectiveness ratings of suggestions that had been received by at least 25 participants (approximately 5% of the sample). Demographic differences in tip perceptions were assessed with analyses of variance.

Reported experiences with changes were analyzed with qualitative content analysis methods. The experiences were categorized into main themes of barriers and facilitators, under which findings were further categorized under emerging subthemes. The total occurrences of themes were counted to identify recurring themes.

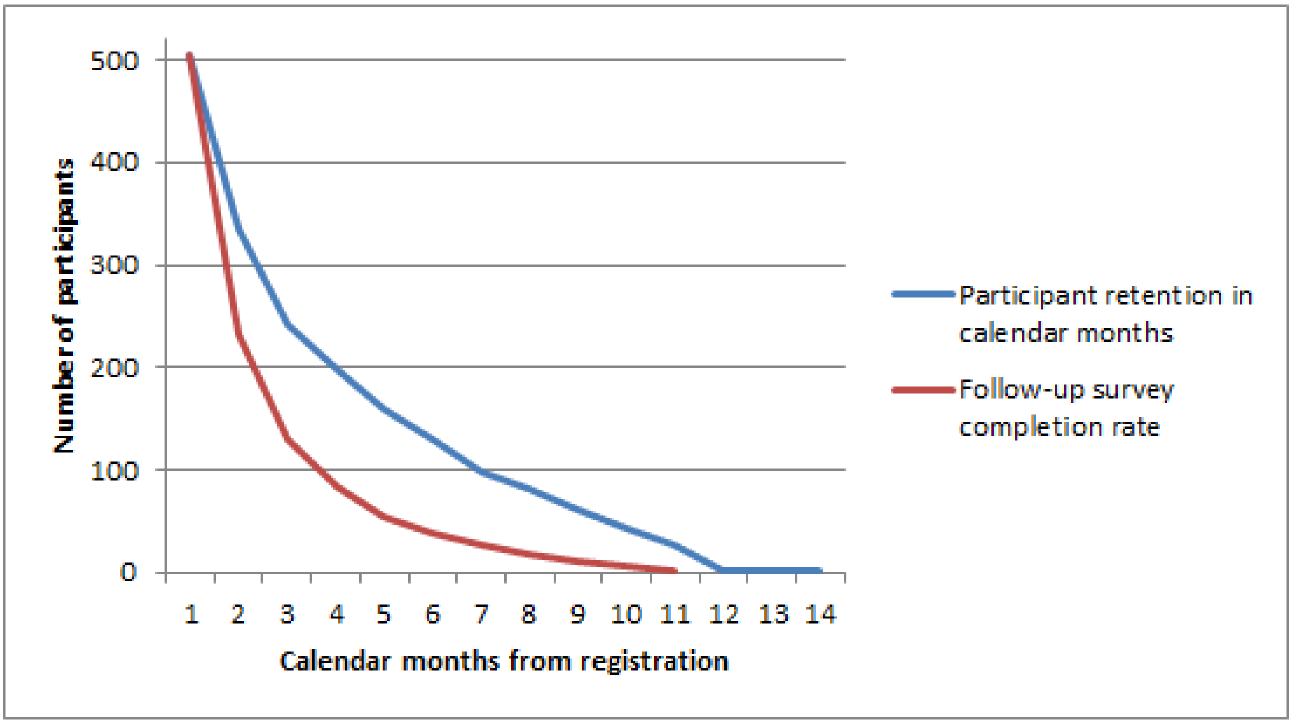
All quantitative analyses were done using SPSS version 19.0. *P* values less than .05 were considered statistically significant.

Results

Participant Retention

Figure 1 shows the adherence to the program over the course of the 14 months after signing up. Participant attrition was 75% after the initial registration: 1549/2053 participants never completed the intake survey or never returned for a follow-up survey. The participants who returned for at least one follow-up stayed in the program on average 3.7 calendar months (SD 3.10) and completed on average 2.2 follow-up surveys (SD 1.93). Most of them (88%, 445/504) had weight loss as their initial eating goal. Out of the returning participants, 38% (189/504) stayed in the program for more than two months and completed at least two follow-up surveys.

Figure 1. Participant retention and follow-up survey completion rate.



Weight Changes

Over the course of the program, 42% of returning participants (213/504) lost weight (mean 3.24% of initial weight, SD 2.94), 29% (145/504) gained weight (mean 3.35%, SD 3.68), and 27% (136/504) maintained their weight over the course of the program. Weight change data were missing from 2% (10/504) of the participants. Overall mean weight loss was 0.41% (0.75 lbs) of the initial weight (t=-2.346, P=.019). Participants who had weight loss as their initial goal lost on average 0.48% (0.9 lbs) of their initial weight (t=-2.534, P=.012). Clinically significant weight loss, 5% or more of initial body weight, was achieved by 7% of the participants (36/504).

Table 2 presents the weight and BMI changes of participants with different levels of engagement in the program. The participants who stayed in the program for at least three months and completed at least two follow-up surveys (38% of the returning participants) lost on average 1.0% (1.8 lbs) of their initial weight (t=-2.622, P=.009). The mean time these participants stayed in the program was 6.4 months (SD 2.77), and they completed on average 4.0 follow-up surveys (SD 2.20).

Table 2. Weight and BMI changes among returning participants.

	Level of engagement		
	One-time visitors[a]	Two-month participants[b]	Three+ month participants[c]
Number of participants	271	44	189
% of returning participants	54	9	38
Mean weight change, lbs (SD)	-0.06 (5.746) *P*=.868	-0.69 (3.982) *P*=.263	-1.77 (8.574) *P*=.006
Mean weight change, % (SD)	-0.04 (3.156) *P*=.853	-0.38 (2.306) *P*=.285	-0.97 (5.012) *P*=.009
Mean BMI change (SD)	-0.09 (1.892) *P*=.471	-0.01 (0.664) *P*=.900	-0.26 (1.511) *P*=.023

[a] Completed only 1 follow-up survey.

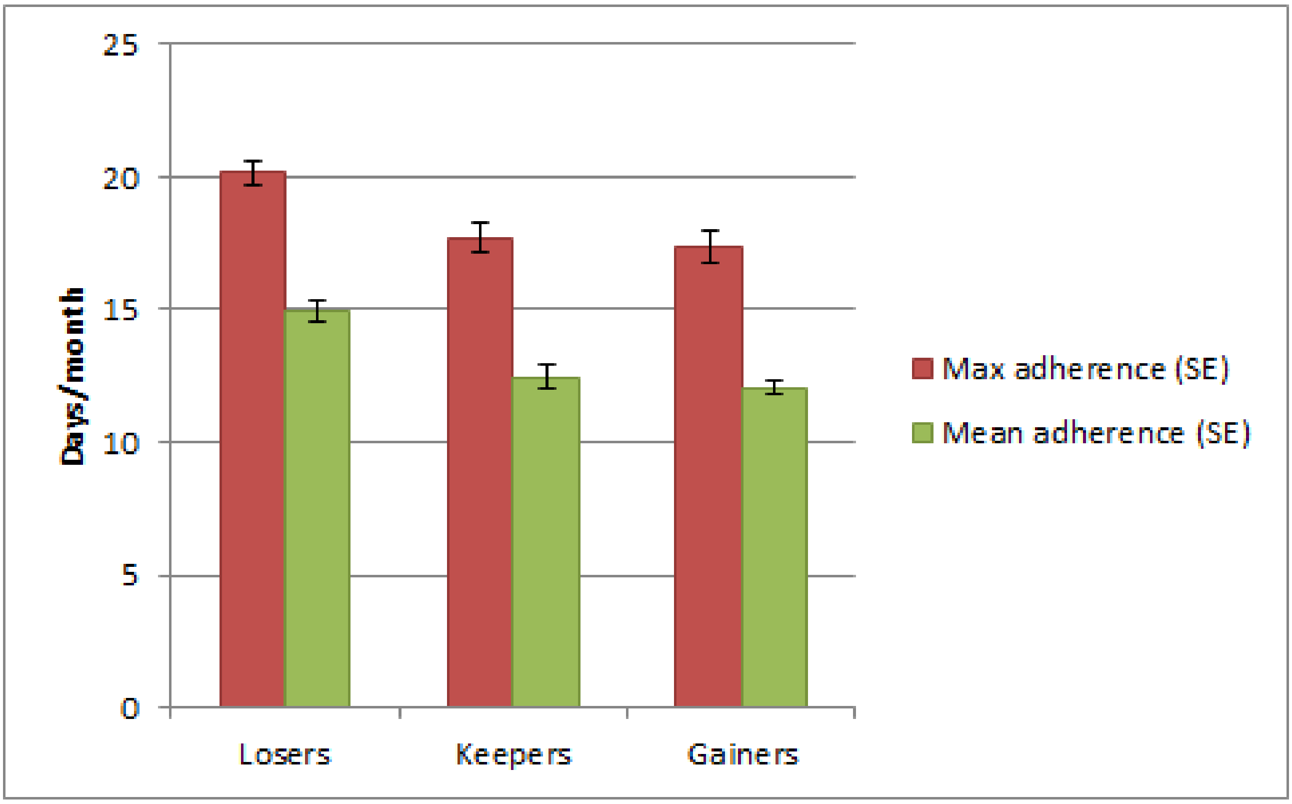
[b] Completed 1-2 follow-up surveys and stayed in the program for 2 months.

[c] Completed at least 2 follow-up surveys and stayed in the program for at least 3 months.

Adherence to Changes

Adherence to changes was reported in 88% (979/1107) of all follow-up surveys. The days the participants reported having adhered to the habit change suggestions were on average 13.3 days (SD 9.77) over 1 month. Participants who had lost weight between subsequent surveys reported higher monthly adherence to suggestions (mean 14.9 days, SD 7.92) than participants who had maintained their weight (mean 12.4 days, SD 7.63) or who had gained weight (mean 12.0 days, SD 7.50; *F*=14.17, *P*<.001); see Figure 2. Similarly, maximum adherence was highest among weight losers.

Figure 2. Adherence to three changes among participants who lost, maintained, or gained weight between any two surveys.



Adherence and Weight Outcomes

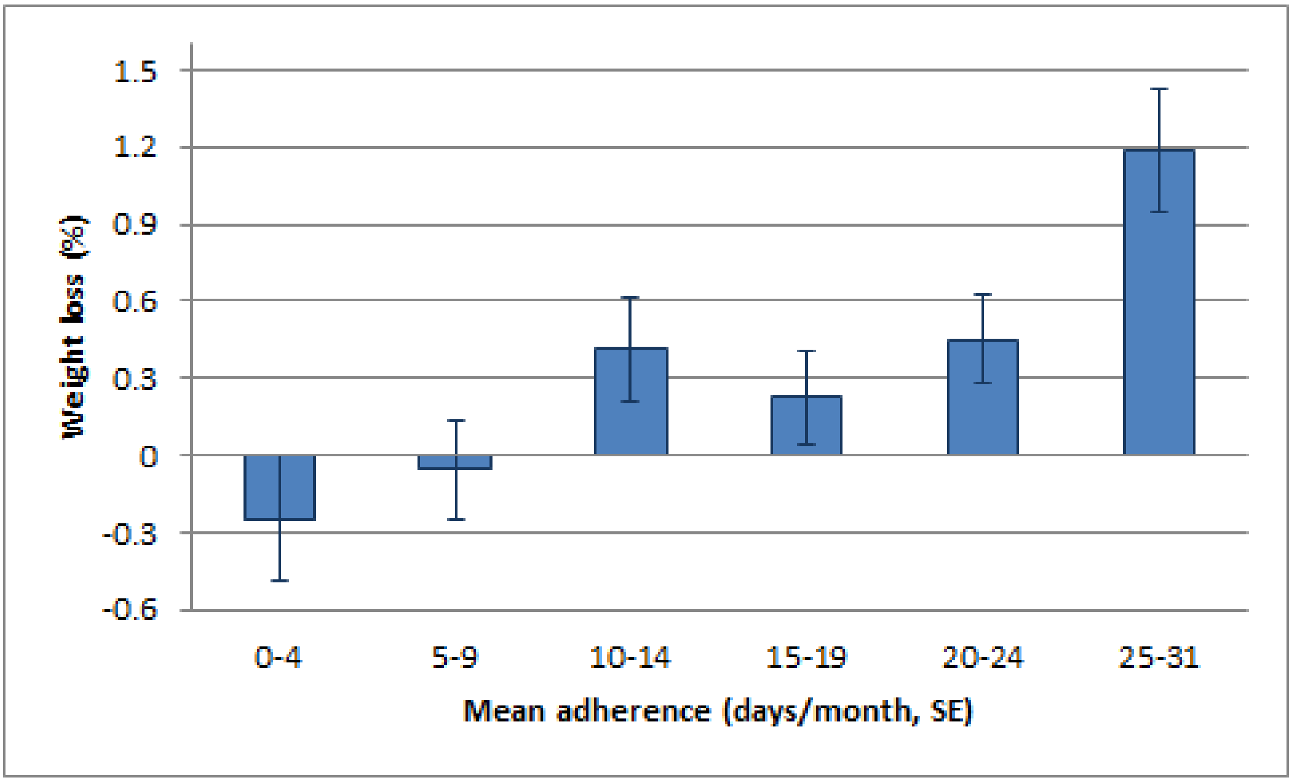
Participants who reported consistent adherence (at least 25 days in a month) to the suggested changes reported an average monthly weight loss of 2.0 lbs (*P*<.001). Figure 3 displays the percentage weight loss for different levels of mean adherence to suggestions. Participants whose mean adherence was 25 days or more had a mean weight loss of 1.2%, a significantly higher number than participants who adhered only 0-4 days (*F*=3.991, *P*=.001) or 5-9 days (*P*=.014). Mean adherence to suggestions was positively correlated with weight loss percentage (*r*=.166, *P*<.001). Moreover, adherence to a suggestion was correlated with perceived ease (*r*=.622, *P*<.001).

Table 3 presents the mean weight outcomes of a subset of cases in which suggestions had adherence reports of at least 20 days from at least 20 participants. Two suggestions in this subset of 14 suggestions were associated with significant weight loss and one on borderline significance.

Table 3. Weight outcomes of suggestions with high adherence.

Tip	n of cases	Mean weight change, lbs (SD)	*t* test (*P* value)	Mean adherence (SD)	Mean effectiveness (SD)	Mean ease (SD)
Put down your utensils between bites. (This will allow you to slow down the pace of your eating.)	23	-2.48 (3.85)	-3.089 (.005)	24.96 (4.14)	7.70 (1.64)	6.48 (2.09)
Allow yourself an afternoon snack only if you've first eaten a piece of fruit.	24	-1.88 (4.46)	-2.062 (.051)	24.42 (4.02)	7.00 (1.96)	6.86 (1.93)
Any time you think you might eat when you're not hungry, go ahead and do so, but only if you first say (out loud): "I'm not hungry, but I'm going to eat this anyway".	20	-1.58 (2.94)	-2.400 (.027)	22.90 (2.90)	6.05 (2.09)	6.00 (2.08)
Drink 8 cups of water a day (that's only two full 32-oz glasses).	39	-1.29 (5.33)	-1.509 (.140)	24.32 (3.74)	6.20 (2.39)	7.10 (1.93)
Have a glass of water with every meal and snack.	30	-1.23 (5.75)	-1.173 (.250)	25.47 (4.13)	7.57 (1.83)	7.52 (1.68)
Use the Half-plate Rule: at dinner, load up the right side of your plate with salad, fruit, or vegetables. The other side can be starches and meat.	20	-1.05 (3.46)	-1.359 (.190)	24.05 (3.68)	7.20 (1.51)	7.10 (1.37)
Restrict your eating to the kitchen or dining room. (Doing this will make it more inconvenient to mindlessly eat between meals.)	24	-0.91 (4.02)	-1.107 (.280)	24.33 (3.97)	6.21 (2.59)	6.50 (2.23)
Eat something hot for breakfast at home within the first hour of waking up.	25	-0.79 (3.03)	-1.306 (.204)	26.16 (3.34)	6.92 (2.58)	7.42 (2.15)
Avoid going more than 3-4 hours without have something small to eat. (That way, you will be less likely to overdo it at meals.)	43	-0.75 (6.87)	-0.711 (.481)	25.51 (4.01)	6.69 (2.02)	6.93 (2.00)
Avoid eating anything directly from its bag, container, etc.	27	-0.66 (4.34)	-0.790 (.437)	24.67 (4.19)	6.89 (2.17)	6.30 (2.30)
Use smaller plates on meals.	21	-0.35 (2.98)	-0.542 (.594)	24.41 (3.91)	7.73 (1.16)	7.36 (1.99)
Never eat directly from a package − always portion food out into a dish so you need to face exactly what you will eat.	21	0.27 (4.81)	0.257 (.800)	23.71 (3.64)	7.19 (1.81)	6.86 (2.33)
Pack a baggie of precut veggies and fruit for at least one snack per day.	22	0.46 (3.69)	0.590 (.561)	23.87 (3.76)	7.17 (1.95)	7.17 (1.72)
Keep counters clear of all foods but the healthy ones.	21	0.86 (5.17)	0.760 (.456)	27.00 (3.46)	6.86 (2.24)	8.29 (1.49)

Figure 3. Percentage weight loss for different levels of adherence.



Perceived Effectiveness of Changes

The average amount of suggestions that the returning participants perceived as effective was 1.46 (SD 1.06). The average perceived effectiveness of all suggestions was 5.12 (SD 2.73) on a 1-9 scale. Table 4 presents the five most effective and five least effective suggested changes. The table also displays the total numbers of participants who received the suggestion as well as the mean values for ratings of effectiveness and ease, reported adherence, and weight changes from the time the suggestion was received by a participant to the time of the follow-up.

Participants who lost weight between subsequent surveys reported a higher amount of effective suggestions (mean 1.66, SD 1.03) than participants who maintained weight (mean 1.38, SD 1.03) or gained weight (mean 1.24, SD 1.07; *F*=15.256, *P*<.001). Effectiveness was strongly correlated with adherence (*r*=.610, *P*<.001) and ease (*r*=.691, *P*<.001).

Some demographic differences were found in participants' perceptions of suggestions. The mean effectiveness ratings for suggestions were higher among participants who were white/Caucasian (5.2 vs. 4.7, *F*=5.162, *P*=.023) or had at least a college degree (5.2 vs. 4.8, *F*=6.336, *P*=.012). Moreover, the mean ease ratings were higher among participants who were white/Caucasian (4.9 vs. 4.4, *F*=4.573, *P*=.033) or who were from the United States (4.9 vs. 4.6, *F*=4.070, *P*=.044).

Barriers and Facilitators for Changes

Experiences of changes were reported in 745 follow-up surveys. Common barriers and facilitators for changes that emerged from the reported experiences are summarized in Tables 5 and 6. The identified barriers were roughly divided into change-related, personal, and external barriers. The most common change-related barrier was that the suggestion was in some ways unsuitable for the participant: for example, too specific to certain situations, actually making the problem worse, or inconvenient to do. In addition, several participants stated that some changes were not applicable to their lifestyles at all or that they were just difficult to implement in most situations. Within personal barriers, simply forgetting to make the changes and being too busy to pay attention to changes were the most common ones. Emotional eating (due to negative emotions, tiredness, or stress) and losing track or motivation ("I did not even try") also came up often. The most commonly mentioned external barrier was unusual circumstances when eating behavior was less under one's own control (such as vacations or staying with someone else).

Facilitators for lifestyle changes were divided into program-related and personal facilitators. The most prevalent statement was that changes were "easy". This statement was not usually elaborated further. Other program-related facilitators were reminders (calendar checklist, email reminders, or concrete environmental cues) and goal-setting. Personal facilitators were mostly related to gradual changes in awareness or behaviors and the feelings these changes evoked. Many participants commented that specific changes were less important than becoming aware of eating habits and paying attention to behaviors that had been mindless. Positive feelings as well as noticing results (such as enjoying food more and having energy) were other common themes.

Table 4. Most and least effective suggestions.

Suggestions	n of cases	Mean effectiveness (SD)	Mean ease (SD)	Mean adherence (SD)	Mean weight change, lbs (SD)
Most effective					
1. Keep counters clear of all foods but the healthy ones.	31	6.8 (2.01)	7.6 (1.80)	23.8 (7.22)	0.3 (4.69)
2. Never eat directly from a package – always portion food out onto a dish so you need to face exactly what you will eat.	52	6.7 (2.13)	5.9 (2.62)	16.1 (7.93)	-0.2 (3.70)
3. Eat something hot for breakfast at home within the first hour of waking up.	42	6.3 (2.82)	6.6 (2.89)	20.0 (9.83)	-0.2 (3.56)
4. Avoid going more than 3-4 hours without have something small to eat. (That way, you will be less likely to overdo it at meals.)	90	6.2 (2.35)	6.2 (2.49)	18.1 (9.04)	-0.8 (5.57)
5. Put down your utensils between bites. (This will allow you to slow down the pace of your eating.)	72	6.1 (2.64)	4.7 (2.58)	13.5 (9.62)	-1.7 (5.29)
Least effective					
1. Cinch your belt up 1 notch tighter than usual before you start to eat.	33	3.1 (2.79)	3.2 (2.86)	7.5 (9.65)	-0.9 (2.48)
2. Brush your teeth when you feel like snacking (10:30 and 3:45 are the most tempting times).	48	3.4 (2.68)	3.6 (2.67)	6.3 (7.61)	0.2 (2.64)
3. Use the 3 Bite Rule: eat whatever you want, but limit it to 3 small/medium-sized bites.	55	3.6 (2.32)	3.1 (2.27)	7.9 (7.53)	-0.8 (3.02)
4. Exercise at a time when you usually snack. (This way you are not only removing calories that you would have normally eaten, you are also burning calories.).	26	3.8 (2.27)	3.6 (2.40)	7.2 (6.07)	-1.3 (2.46)
5. After dinner, brush and floss your teeth to prevent evening snacking.	47	3.9 (2.71)	3.7 (2.76)	8.6 (7.95)	-0.5 (3.21)

Table 5. Common barriers to changes based on participants' experiences.

Barrier	Prevalence	Common explanations
Change-related barriers		
Unsuitable changes	87	Too specific (9), dislike (9), problematic to fit in the schedule (8), made problem worse (6), changes were incompatible (5), already a habit (5), wasting food felt difficult (5), irrelevant (4), inconvenient (3)
Inapplicable changes	37	Situation not encountered (21), did not fit the schedule (4)
Difficult changes	34	Difficult to do outside home (12), too much effort (7), difficult month (4), hard to plan ahead (4), hard to be consistent (2)
Personal barriers		
Forgetting	83	Distractions (9), simply forgetting about changes
Being busy	49	Lack of time (11), stress (11), busy schedule (5), major deadline (2)
Not even trying	31	Lack of motivation (10), not feeling committed (5)
Losing track	31	Losing motivation (11), no regular tracking (11), losing focus (8)
Need to eat	30	Hunger (10), cravings (8), danger times (7), availability of food (6), overeating (5)
Emotional eating	17	Stress eating (5), compulsive eating (2)
Ingrained habits	14	Falling back into old patterns
External barriers		
Unusual circumstances	57	Vacation (18), lack of control over food choices (14), traveling (12), holiday season (11)
Health issues	18	Own (12), sickness (5), family (1)
Social pressure	13	Partner's/family's habits, social gatherings
Unavailability of food	11	Healthy food not at hand (5), no access to healthy food (3), fruit not in season (2)

Table 6. Common facilitators of changes based on participants' experiences.

Facilitator	Prevalence	Common explanations
Program-related facilitators		
Easy	75	Creating habits that can last (8), small change to existing habits, simple changes
Reminders	21	Checklist and other concrete reminders (12), email reminders (5), environmental cues (4), accountability (4)
Having goals	17	Thinking about goals (5), determination (3), strategies (3), regular tracking (3)
Personal facilitators		
Increased awareness of eating habits	41	What, how, and when one eats, recognizing mindless eating habits
Positive feelings	28	Not feeling deprived (6), not feeling hungry (6), enjoyment of food (3), feeling better (3)
Modifying or expanding the changes	19	Continuing with earlier changes (6), making additional changes (3)
Changes in eating habits	19	Eating more slowly (8), portion control (7), mindful eating (2)
External support	15	Mindless Eating book (5), other health program (4), availability of healthy food (3), social support (2)
Seeing results	13	Improvement from small changes (5)
Planning ahead	11	Learning to plan and prepare
Already a habit	9	Easy to increase frequency
Psychological changes	9	Overcoming food-related issues (3), sense of control (2)

Discussion

In this study, we evaluated weight outcomes and participant retention in a publicly available web-based healthy eating and weight loss program based on a small-changes approach. The results of the study showed significant but modest weight loss outcomes, with larger effects among participants who were more engaged in the program, stayed in it for a longer time, and completed more follow-up surveys. That is, those who completed at least three months of the program or adhered at least 25 days per month to the suggested changes reported a significantly higher average monthly weight loss than those who dropped out early or who did not adhere to the suggested changes. The small-changes approach shows promise, but encouraging adherence and finding suitable changes for each person still remain a challenge.

Participant Retention

One fourth of the participants who registered and received the first set of habit change suggestions returned for follow-up. Loss of participants over time was fairly quick, with only half of those who returned for follow-ups staying in the program for more than two months. This kind of high attrition is typical for voluntary online programs, in which the intervention is neither mandatory nor critical to participants [18-21] and that do not provide additional incentives other than positive feedback and benefits to health and well-being. Attrition rates in weight loss interventions vary considerably even in face-to-face settings, with reported rates ranging from 10% to more than 80% [22]. In the case of NMEC, we can only speculate the reasons for participant attrition. We could propose three main reasons why participants stopped returning for follow-up: 1) they were satisfied with the results, 2) they decided that the program was not worth their time anymore, or 3) they just forgot about it while going on with their busy lives. It is likely that the main contributor is a decrease in motivation after the initial interest [10]. In addition, email reminders were the only method of communication with participants, and there was no real human contact that could have resulted in higher engagement to the program [21].

Nevertheless, rapidly decreasing retention is not necessarily an indication of the program failing to reach its aims. It has been suggested that the main role for web-based programs in prevention and treatment of obesity may be to deliver short positive messages and reminders that can lead to increased awareness and seeking of assistance from other sources [23]. The participants of the NMEC program may have needed the initial boost to get started with concrete habit changes, but after the initial month or two, some voluntarily reported that they had already gained enough awareness and skills to start making up their own changes that would best suit their individual circumstances. The strength of the small-changes approach is that the principle is simple and quick to learn [1,5]. Additionally, it is possible that some participants decided to acquire the book that was referred to in the program and felt no need to return to the online program after reading it. The book and the online program could be viewed as complementary self-help resources. In fact, it might be beneficial for participants if intervention programs contained references to external resources based on their needs as an alternative to combining treatment strategies for comorbidities into the same intervention [24]. For example, if there is a reason to suspect that a participant suffers from depression or anxiety, a weight loss program could guide them to interventions that handle such issues.

Weight Outcomes and Effectiveness of Changes

Nearly half of participants lost weight over the course of the program, and the average amount they lost was 3.2% of their initial weight. Although the other half of participants either maintained or gained weight and the overall mean weight loss was modest, the results suggest that small-changes approach is promising in weight loss and maintenance, considering that effect sizes in online healthy eating and weight loss interventions have been generally small [9,25]. Moreover, most participants were overweight, not obese, and the focus of the program was not primarily losing weight but rather healthier and more mindful eating. Small weight losses or even maintenance of current weight are valuable achievements and useful in preventing weight gain [12]. High adherence was associated with larger outcomes: for those whose adherence to changes was 25 or more days per month, weight loss averaged 2.0 lbs in a month.

Half of the suggestions in the program were generally perceived as effective, and participants who lost weight rated a higher amount of suggestions as effective. Some tips that were reported as effective were associated with small (although not statistically significant) weight gain. This may have been due to other factors, but it may also indicate that people perceive effectiveness in different ways. Tips that were associated with weight gain or weight maintenance were likely to either increase the amount of healthy food consumed (“keep counters clear of all foods but the healthy ones”) or give a good start to each day (“eat something hot for breakfast”). Therefore, effectiveness could have meant that participants succeeded in changing the habit, ate healthier, and felt better about themselves even if they did not lose weight. This notion was supported by several participants’ comments.

Effectiveness, ease, and adherence were all strongly correlated. Hence, finding relevant and easy habit changes for each individual would be essential. Tailoring interventions to individuals generally increases effectiveness [7,8]; the NMEC program tailored suggestions simply based on participants’ eating goals. Further tailoring to individual circumstances and psychological characteristics would likely improve outcomes and adherence, and participants’ own predictions about ease and effectiveness of habit changes should be used to screen out changes that have a very low probability to succeed. Moreover, suggestions in the NMEC program were considered somewhat more effective and easy by white/Caucasian participants, more effective by those with higher education level, and easier by Americans. Because suggestions were developed based on research done in the United States, suggestions and the program itself may have been more suitable or attractive for an audience with similarities to the developers. Cultural tailoring in terms of language, graphics, and consideration of common eating habits and environments could increase participant adherence and satisfaction [26], although the most basic suggestions are likely to be widely applicable even without tailoring.

Adherence to Changes

Not surprisingly, participants who lost weight adhered more to suggested changes than participants who maintained or gained weight. Even though the difference was small (a couple of days more per suggestion), it may be enough to tip the scale to the side of weight loss. Adherence was also strongly correlated with perceived effectiveness and ease, which suggests that no matter what the changes were, participants benefited from them if they committed to making them and found them easy to do. These findings are in line with earlier research that has associated higher intervention adherence with better behavioral outcomes [20,25]. If adherence to actual changes is low, the intervention does not have a lot of chance to impact behavior, except in the rare cases in which the impact results from keeping the goals in mind.

Considering that high adherence was associated with higher weight loss, identifying the best suggestions for weight loss could be possible by analysis of suggestions that received high adherence ratings. Among the 14 suggestions that were adhered to for at least 20 days by at least 20 participants, 2 were associated with significant weight loss. Both of them required some willpower but did not restrict the amount of eating or food choice; rather, they drew attention to eating pace or eating choices. Indeed, several participants commented that these kinds of suggestions helped to increase awareness of eating habits. Even though data about prior history of dieting were not collected in the program, several female middle-aged participants may have had earlier unsuccessful dieting experiences [3]. Many diets are characterized by restrictive rules that may lead to feelings of deprivation [17,27], binge eating [28], or eating bouts [29]. A small-changes approach could result in healthier attitudes towards food and eating in response to hunger and satiety signals since it does not restrict eating but makes people more conscious of their eating habits, if they are able to adhere to changes.

Adherence is likely to be mediated by the strength of the existing habits that need to be changed: if a new habit is supposed to replace an existing strong habit, the change is likely to be more difficult than if the habit to be replaced is weak or nonexistent [6,30]. This came up in several participants' comments about deeply ingrained habits. Difficulty of a habit change influences how much time it will take to form a new habit. Lally and colleagues did a study with 96 participants and found that habit formation took on average 66 days, but there was a large variation from 18 days to 254 days depending on the complexity of the habit [31]. In the NMEC program, some participants said that they would have wanted to continue with the changes from the prior month rather than receive new suggestions. This may indicate that they were still struggling with habit formation or that they had been in unusual circumstances where changes were not applicable. Ideally, suggested changes should be generic and flexible enough so that they are doable every day. As some participants mentioned, this will provide a sense of accomplishment, improve self-efficacy, and encourage them to continue with further changes [32].

Barriers and Facilitators for Changes

Analysis of participants' experiences with changes indicates that habit change suggestions were perceived as more effective and easy to adhere to if they matched participants' personal situation, lifestyle, and psychological needs. Unsuitable, inapplicable, or difficult changes were soon discarded as requiring too much effort or being irrelevant. Furthermore, unusual circumstances such as vacations and busy schedules with deadlines made it difficult to adhere to suggestions that concerned environmental changes and food choices, especially if the suggestions were situation-specific. To accommodate people's changing circumstances such as travels and holiday seasons that disrupt existing habits [30], it may be most beneficial to provide flexible heuristics that are applicable to any situation. Another possibility is to attempt to profile participants' needs frequently and adapt the advice for changing situations [33,34].

Losing track of changes or forgetting them completely was relatively common among participants. Email reminders and a calendar checklist helped several to monitor their behaviors and stay on track, but not everyone benefited from periodic prompts and reminders, which is in line with earlier studies [35]. Concrete cues and reminders in the environment, such as having the checklist in the kitchen, appeared to be helpful for several participants. Participants' adherence to daily changes might be improved by encouraging and advising them to set concrete but unobtrusive triggers and cues in places where they can frequently see them [6,36]. The simple small-changes intervention could also lend itself ideally to mobile phones, which are carried around most of the day and accessed frequently.

Having easy changes to make, having goals in mind, and learning to plan ahead were helpful for participants [32], and suggestions that increased their awareness about their eating habits appeared to be especially useful. Such suggestions typically involved either modifying their eating environment or learning to focus and slow down. These kinds of suggestions could be used to overcome emotional eating, which was a fairly common stumbling block. A lot of needless eating in today's society is caused by emotional needs that cannot be fulfilled, and some people use food instead to fill the emotional void or to fight their tiredness or stress [37]. Indeed, depression and obesity have been shown to have a reciprocal link [38]. Addressing the problematic relationship with food may require additional strategies that focus on improving self-esteem, self-control, and constructive coping [38].

Limitations

The voluntary setting with no active recruitment or promotion of the program is both a limitation and strength of this study. That is, the program involved no human contact, and participants reported their own weight and their adherence. The results should be interpreted with caution because all measures were self-reported. Weight in subsequent surveys could have been reported on different times of the day or different weekdays, which can mask small actual changes in weight. Furthermore, there was no control group and participant attrition was high. Since only 25% of participants who registered to the website returned to the follow-up surveys, it is possible that the intervention effect is overestimated. Yet even in the absence of a control group, in this kind of a setting, the behavior of the participants was likely to resemble behavior of ordinary users of online weight loss and healthy eating programs; some of the people who registered may have just been curious and had no serious intention to start the program. Moreover, since data were collected across 2 full years, the results are generalizable across seasons and cannot be explained by seasonality (ie, people might lose more weight over the summer or gain more over the holidays). In the general population, all reports of changing weight point to a general increase and not a decrease [39-42].

In the analyses of the most and the least effective suggestions, the potential influence of the other suggestions that participants received cannot be ruled out. The pool of different suggestions was so large that only a relatively small number of participants received individual suggestions, which limits the possibilities to identify significant differences. To discover the most suitable and effective tips for different individuals, further studies would be needed.

Conclusions

This study illustrates that an online intervention based on a small-changes approach can help individuals lose weight, especially if they adhere to changes consistently. Participants who were adherent to their suggested changes 25 or more days per month reported an average loss of 2 lbs each month. What is not fully known is how long this rate of slow and steady weight loss would continue. In general, adherent participants who continued past the 3-month mark lost a small but significant proportion of their weight. It's important to note that these people were self-selected and may be much more diligent or motivated than the average person who joins a small-change nutrition and weight loss program.

High attrition remains a challenge that can potentially be solved with further tailoring to individual needs and tighter connection to participants' everyday lives. For instance, asking more detailed screening questions during the initial profiling survey could provide more tailored suggestions and increase perceived relevance and anticipated adherence. Ensuring that changes are easy and require little effort from participants provides them opportunities to experience success and increased awareness of their eating habits and benefits of healthy eating, motivating them to continue on the chosen path. In addition, encouraging participants to place concrete cues and reminders in their environment could work even better than notifications through email or mobile devices. Such changes in a person's food environment could lead them to become slimmer by design [43].

Long-term follow-up is needed to evaluate the maintenance of habit changes and weight loss. Of particular interest would be to better predict how likely a participant would be to adhere to a particular suggestion. Being able to better predict adherence could lead to more relevant and effective advice. Further research could also expand the small-changes approach to other important health behaviors such as physical activity or stress management.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

The Mindless Eating Challenge home page.

[PNG File, 2MB - jmir_v14i6e168_app1.png]

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Original Paper

Features Predicting Weight Loss in Overweight or Obese Participants in a Web-Based Intervention: Randomized Trial

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Abstract

Background: Obesity remains a serious issue in many countries. Web-based programs offer good potential for delivery of weight loss programs. Yet, many Internet-delivered weight loss studies include support from medical or nutritional experts, and relatively little is known about purely web-based weight loss programs.

Objective: To determine whether supportive features and personalization in a 12-week web-based lifestyle intervention with no in-person professional contact affect retention and weight loss.

Methods: We assessed the effect of different features of a web-based weight loss intervention using a 12-week repeated-measures randomized parallel design. We developed 7 sites representing 3 functional groups. A national mass media promotion was used to attract overweight/obese Australian adults (based on body mass index [BMI] calculated from self-reported heights and weights). Eligible respondents (n = 8112) were randomly allocated to one of 3 functional groups: information-based (n = 183), supportive (n = 3994), or personalized-supportive (n = 3935). Both supportive sites included tools, such as a weight tracker, meal planner, and social networking platform. The personalized-supportive site included a meal planner that offered recommendations that were personalized using an algorithm based on a user's preferences for certain foods. Dietary and activity information were constant across sites, based on an existing and tested 12-week weight loss program (the Total Wellbeing Diet). Before and/or after the intervention, participants completed demographic (including self-reported weight), behavioral, and evaluation questionnaires online. Usage of the website and features was objectively recorded. All screening and data collection procedures were performed online with no face-to-face contact.

Results: Across all 3 groups, attrition was high at around 40% in the first week and 20% of the remaining participants each week. Retention was higher for the supportive sites compared to the information-based site only at week 12 ($P = .01$). The average number of days that each site was used varied significantly ($P = .02$) and was higher for the supportive site at 5.96 (SD 11.36) and personalized-supportive site at 5.50 (SD 10.35), relative to the information-based site at 3.43 (SD 4.28). In total, 435 participants provided a valid final weight at the 12-week follow-up. Intention-to-treat analyses (using multiple imputations) revealed that there were no statistically significant differences in weight loss between sites ($P = .42$). On average, participants lost 2.76% (SE 0.32%) of their initial body weight, with 23.7% (SE 3.7%) losing 5% or more of their initial weight. Within supportive conditions, the level of use of the online weight tracker was predictive of weight loss (model estimate = 0.34, $P < .001$). Age (model estimate = 0.04, $P < .001$) and initial BMI (model estimate = -0.03, $P < .002$) were associated with frequency of use of the weight tracker.

Conclusions: Relative to a static control, inclusion of social networking features and personalized meal planning recommendations in a web-based weight loss program did not demonstrate additive effects for user weight loss or retention. These features did, however, increase the average number of days that a user engaged with the system. For users of the supportive websites, greater use of the weight tracker tool was associated with greater weight loss.

(J Med Internet Res 2012;14(6):e173) doi:10.2196/jmir.2156

KEYWORDS

Internet; obesity; dietetics

Introduction

Overweight and obesity remain serious concerns for a high proportion of people, with the World Health Organization estimating that 1.5 billion adults were overweight or obese in 2008 [1]. The expanding reach and capability of electronic tools has resulted in increasing interest in eHealth weight loss strategies.

While the evidence surrounding eHealth strategies is evolving, they remain a popular option for delivering health behavior change programs to a widening population. In Australia, the Internet has the potential for wide reach with over 70% of people having access in their home [2]. The potential impact of Internet-delivered programs at a population level is one of its many appeals [3]. Internet-delivered obesity interventions may be more cost-effective than in-person interventions [4,5], with one study indicating that use of a web-based program can reduce actual health care costs [6].

Several reviews of the effectiveness of web-based weight loss interventions have concluded that the evidence is mixed owing, in part, to the diversity of intervention programs evaluated [7-11]. Nevertheless, the American Heart Association [12] recently released a scientific statement suggesting that the Internet could be a promising tool for promoting weight loss. Website usage and self-monitoring seem to be consistently associated with weight loss [10,11].

A point of contention regarding online interventions is their effectiveness in the absence of personal contact. Some reviews suggest that the Internet may provide an effective alternative to traditional face-to-face programs [11], while others question the utility of this approach [13]. Relatively few studies report on web-based weight loss interventions without personal contact. For example, interventions have provided web-based weight maintenance sites after traditional in-person weight loss programs [14,15] or incorporated online components together with face-to-face counseling [16,17]. Those studies that have evaluated the efficacy of pure Internet interventions have largely failed to find additive weight loss benefits of web-based programs relative to control conditions without an Internet component [18,19]. In a recent intervention targeting dietary and physical activity behaviors (not strictly weight loss), Kelders et al [20] also found no differences in behaviors between users who had free access to a website compared to a wait-listed control group. Although these studies have not found additive benefits of Internet delivery relative to usual-care controls, Internet intervention groups often demonstrate a mean weight loss. For example, Gold et al [21] report weight loss of 3.3±5.8 kg over 6 months when participants used the site eDiets.com (with no personal support) but found better weight loss for their comparison website, which included individualized support from a therapist.

One of the issues with purely Internet-delivered interventions is maintaining participant engagement with the sites provided [20,22]. McConnon et al [18] reported 53% of their participants accessed their website. It is possible that enhanced features and social networking tools act to improve engagement with an online intervention, which consequently improves compliance to the weight loss program. A randomized controlled trial comparing the efficacy of enhanced website features at achieving weight loss, while retaining limited contact with participants, indicated that a more intelligent system (ie, one with action plans and self-help advice personalized to individual characteristics) may be beneficial for weight loss relative to basic information presented online [23]. More recently, van Genugten et al [24] compared a structured and interactive weight maintenance website to a static one but found no differences for body mass index (BMI) or weight circumference at 6 months. In the realm of physical activity, Internet interventions have shown promising results for more interactive websites in terms of behavior change [25] or retention [26]. However, not all results have supported additive effects of interactivity for increasing physical activity in web-based interventions [27].

Limited studies have attempted to evaluate the relative advantage of different styles of weight loss websites while also restricting in-person contact with volunteers. Intervention characteristics such as face-to-face contact and individual emails constructed by professionals reduce the real-world translation of web-based interventions and limit the advantages of “direct-to-consumer” [22] programs. The aim of this study was to investigate whether enhanced features and perceived social support through social networking tools in an Internet-only intervention lead to engagement and improved weight loss. We anticipated that higher levels of interactivity, in particular the addition of interactive features including social networking features, as well as personalized planning assistance, would be associated with greater retention and weight loss. Finally, we also aimed to investigate whether particular site features would be associated with higher weight loss.

Methods

Study Design

We assessed the effect of different features of a web-based weight loss intervention using a 12-week repeated-measures randomized parallel design. All study components including the intervention, registration and screening processes, randomization, and questionnaires were completed online thereby excluding personal contact with participants within all aspects of the study. This study was approved by the CSIRO

Human Research Ethics Committee in December 2010. Due to an administrative oversight, the study was not registered prospectively in a clinical trials registry; the original study protocol is provided in lieu of registration (see Multimedia Appendix 1).

Seven versions of the website were developed (see Multimedia Appendix 2). Many of these sites had the same basic functionality but varied according to different information and communication technology features for the purposes of evaluating human-computer interaction (see [28]). The 7 sites represented 3 functional groups (see Table 1): (1) Information-based: a static non-interactive version of the weight loss program, (2) Supportive: a social, interactive website that provided dietary information as provided in the information-based site, in addition to interactive tools such as real-time dietary compliance visualizations, an interactive meal planner, and social support through a social networking platform (ie, personal profiles, friend networks, blogs, discussion forums, and news feeds), and (3) Personalized-supportive: identical to the supportive version with the addition of a personalized meal planner. This meal planner offered 3 breakfast, lunch, and dinner suggestions personalized to user preferences through a purpose-built algorithm that collated data on user preference ratings of a collection of recipes and previous planning.

Table 1. Functionalities of different versions of the websites.

Version	Diet and exercise information	Interactive Planner	Compliance feedback	Social support system	Diet & weight self-monitoring	Personalized planning
Information-based	Y	N	N	N	N	N
Supportive	Y	Y	Y	Y	Y	N
Personalized-supportive	Y	Y	Y	Y	Y	Y

Participants and Procedure

In July 2010, the Online CSIRO Total Wellbeing Diet (TWD) [29] study was promoted in national mass media using the tag line, “CSIRO are looking for participation in an online diet study”. Interested participants were instructed to register online. To be eligible to participate in the trial, registrants needed to be adults (18 years and over) with a BMI >25kg/m^2 (calculated using self-reported heights and weights), confirm that they had regular access to the Internet, and agree to undertake the TWD for 12 weeks. Participants with any serious medical conditions that would prohibit them from dieting (eg, cancer, bowel disease) were excluded. All eligibility screening was completed online automatically using simple rules/filters. No data were collected regarding the number of ineligible participants. After a brief screening, eligible participants were shown an online information sheet and provided their consent to participate in the study.

Following screening, 8112 people successfully registered to be part of the trial and were randomized to one of the original versions of the TWD portal balanced by age, sex, and BMI. This randomization was achieved through a script designed by our software engineer. Registered participants were queued for condition allocation according to decreasing BMI. The queue was partitioned into 6 buckets that split the users according to gender and age, for which there were 3 buckets. Allocating users to experimental conditions involved processing each bucket in turn and allocating the next available condition number to the next user, thus ensuring that each condition received the correct proportion of users of that age, gender, and BMI. Only a small number of participants were allocated to the information-based site since one of the major interests of the study was a comparison of interaction with specific website features (Multimedia Appendix 2), and these were minimal for the information-based site.

Participants were blinded as to the condition they were allocated. All were told that CSIRO was evaluating a newly developed online version of the TWD program. Participants were not aware of the features available or the differences between website conditions at any point of the study.

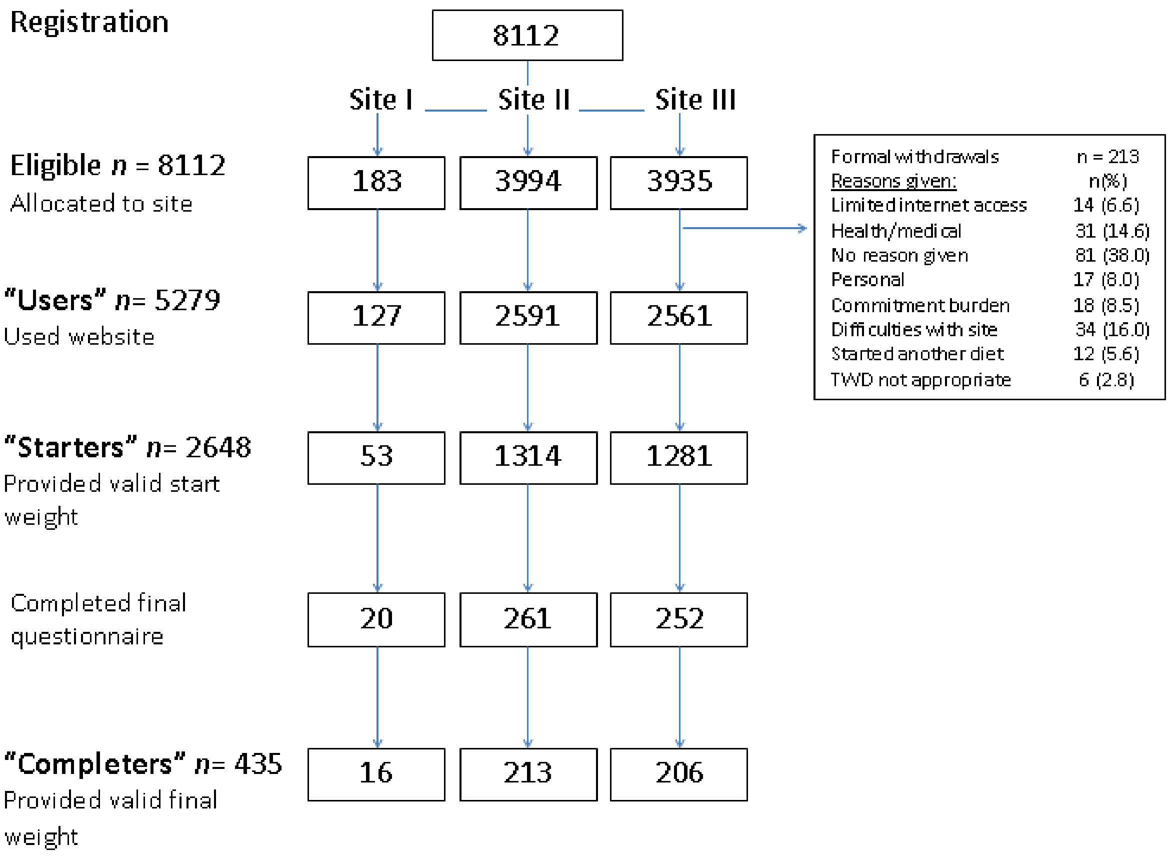
The successful registrants were sent an email thanking them for enrolling in the study and informing them of the projected study start date (approximately 4 weeks later). Due to the unexpected volume of interest in the study, this date was revised by a further 2 weeks and participants were informed via email.

Of those who registered, 65.1% (n = 5279) actually accessed the website when it became available (Figure 1). This group was classified as “Users” of the website. Of the users, 2648 provided a valid baseline weight at the commencement of the 12-week trial (6 weeks after registration) and became our sample for the purposes of the weight loss data (referred to as “Starters”).

Once the trial began, participants had unlimited, free access to the version of the website they were randomized to. Participants randomized to the supportive site conditions could use the discussion forum to contact the study team with any technical or dietary enquiries. All users, including those randomized to the information-based site, could also email the team. During the 12 weeks, 7 group emails were sent from the “The Online TWD Team”, which thanked users for their involvement in the trial, described some group-level data (eg, number of users on the site), and encouraged them to visit the site.

At the end of the 12-week period, participants were further thanked for their participation and asked to complete a follow-up questionnaire and an evaluation survey. As an incentive to complete this survey, participants were offered the chance to win one of 3 vouchers for 150 AUD during week 12 of the study. Just over 5% of those who originally registered provided follow-up weight values; these users are referred to as “Completers” (Figure 1).

Figure 1. Allocation of participants to websites and numbers remaining at each stage. Site I= Information-based; Site II=Supportive; Site III=Personalized-supportive.



The Online TWD Portal

The Online TWD Portal was built using a customized version of the open source Liferay Portal software [30] running on an Apache Tomcat server and using an Oracle database for relational and non-relational data (see Figure 2). Using Liferay allowed the Online TWD to be assembled from existing and custom social, content management, administration, and other portlets, themes, layouts, and plugin hooks. Portlets such as the meal planner and an activity feed were custom built for the TWD Portal.

Access to the website was restricted to those registered for the study. Usernames and encrypted passwords were required to access the site. Each user account was associated with a unique email address. Cookies were not used to deter the creation of multiple accounts, but usernames and passwords were provided to participants via their email only, thus verifying the validity of the email address. Each feature of the website is described briefly below. Further details and screenshots are viewable in Multimedia Appendix 2.

Figure 2. Example of a screenshot from the TWD Online portal.

Diet and Exercise Information

The information pages included details on the diet, including 160 recipes, 22 exercises, menu plans and shopping lists, alcohol management recommendations, success stories, quizzes [31], and other health-related links. These pages formed the complete website for users randomized to the information-based site and one component of the supportive website.

Dietary and exercise prescriptions were taken from the TWD commercial books [29,32]. The TWD is a structured, nutritionally balanced eating plan for weight control that was developed on the basis of clinical research surrounding the efficacy of high-protein diets for promoting weight loss [33]. The high-protein diet on which the TWD is based has demonstrated weight losses of 7.6±0.4 kg over 12 weeks under clinical research conditions (including face-to-face sessions with dietitians).

Homepage

For those participants randomized to one of the supportive websites, several additional tools and services were provided in addition to the dietary information. Access to each component was achieved through a central homepage. This page was mostly functional, updating individuals on activity on the site and providing easy access to tools and information that they may have required.

Diet Tools

For weight self-monitoring, a simple weight tracker was provided. Participants could enter their weight as often as they wished. Graphical feedback on progress was provided in real-time.

As the TWD book incorporates a static meal planner detailing 2 weeks of structured meals, this was provided to all groups in the form of a table under the “Diet Information” section. Those in either of the supportive site conditions received an interactive planner that aimed to assist participants in planning their daily food intake. A simple drag-and-drop functionality allowed meals from the provided recipes as well as user-contributed items to be added and removed from a daily plan. The planner provided real-time feedback on the compliance of a plan to the rules of the TWD diet, through a compliance bar located below the plan. For those in the personalized-supportive site condition, intelligent recommendations were generated through a custom-designed algorithm that combined information about user preferences for certain recipes (assessed via a short survey at the beginning of the study) with previous meal plans to make personalized meal suggestions.

Social Support

The Online TWD portal facilitated social support through a social networking platform. Within the social networking system, each participant was represented by a Profile Page, which contained space for a photograph and image gallery, personal details, a message board, and a personal or public blog. Users could change default profile names (firstname.lastname) at any time during the study. Friendships between participants could be requested with requests confirmed or denied as the recipient saw fit (referred to as "Friending"). Access to all content on a profile page was restricted to confirmed "friends".

In the discussion forum, participants could ask questions, provide support, seek advice, and discuss ideas and thoughts with the community at large. Technical and dietary questions were addressed through the forum by an appropriately qualified member of the research team who did not participate in the subsequent analysis. Summary information pertaining to the social networking activities of friends was presented via a News Feed on the homepages. The list of activities in the feed was hyperlinked, such that each activity linked to the relevant page or component of the site and the profile of the user that performed the activity. Finally, participants could interact with a Social Quiz by voting for those of their friends who met certain descriptions (eg, "Best Blogger"). These quizzes were based on interaction with the site and not weight loss.

Website Updates During the Trial

At the launch, technical difficulties were experienced by the site, which took 5 days to resolve fully. Participants were informed about these delays by email and advised when they had been rectified. Usage data were collected after this period. User feedback informed a series of updates to color and text size changes as well as minor reorganization of content links to provide quick access to popular content such as meal plans.

Study Measures

Weight

Weight was self-reported in an online questionnaire at both baseline and 12 weeks. Percentage of baseline weight lost was calculated and used as the primary outcome. Baseline weight was considered as the first weight entered online during week 1 or 2 of the trial and was available only for starters (n = 2648). Final weight was taken from the final questionnaire and was available for completers (n = 435). Although 533 participants completed some aspect of the final questionnaire, they either failed to provide a weight or did not enter a valid weight. Implausible values were determined through a series of screening procedures utilizing scatterplots and outlier analyses.

Participant Characteristics

Body dissatisfaction [34], proactive coping (Proactive Coping Scale)[35], Weight-Loss Self-Efficacy [36], perceived need to lose weight (single item), and perceived behavioral control and behavioral intentions to stay on the diet for 12 weeks based on the Theory of Planned Behavior [37] were measured using an electronic questionnaire.

At baseline, further data were collected about participants including sex, age, location of residence, and how they use the Internet [38].

Usage

The level of usage of the site was assessed via 3 metrics: the total number of days that the site was used, the day during the study when a user's final action was performed (ie, the last day the site was used), and the number of days that a user was a "member" of the site (days between first and last use of the site).

All interactions with the Online TWD were digitally logged such that each user action type was recorded in our secure database. Fifty-six potential usage activities were summarized into 16 activity groups. The total number of days on which a user recorded an activity from each of the groups was used to operationalize use of the online features. Thus these potentially ranged from 0-84 days.

Evaluation

At the end of the study, participants completed an evaluation survey that asked their attitudes toward the website using questions developed by the authors. These questions included "Overall how much did you like the TWD website?" and "How much did the website help you stick to the TWD?", which were rated on a 9-point bipolar scale from 0 (not at all) to 9 (completely). Perceived ease of use was asked, "How difficult was it to use the website?", and rated on a scale from 0 (very challenging) to 9 (not at all challenging).

Statistical Analysis

Retention data were analyzed for all users, whereas other analyses were based on the sample of starters. These analyses were performed by a statistician who was not involved with data collection and randomization of participants.

A multiple imputation (MI) method using the MICE package [39] in the R statistical package [40] was used to impute missing weight loss values for the purposes of intention-to-treat analyses. Final weight loss values for starters who did not complete were imputed using the initial weight, the weight loss calculated from the last online entered weight (taken from the weight tracker), and the date of the last online weight entry as predictive variables. Predictive mean matching was used for the MI [39]. One hundred datasets with imputed values of final weight were generated, and the results of analyzing each of these were combined using the pooling approach [41], thus allowing for the uncertainty in the imputed values.

Analysis of weight loss data was performed using 3 predictive models for both the intention-to-treat and completers datasets. The first of these models assessed the predictive value of website condition (information-based, personalized or personalized-supportive) and participant characteristics for weight loss. The second analyzed how usage of different features of the website and participant characteristics predicted weight loss. This was performed excluding the information-based site users who did not have access to a majority of features. The third and final model was performed to assess whether feature usage found to be predictive in the second model could be predicted by any participant characteristics. For all models, a predictive model was developed by selecting variables using the Bayesian information criterion (BIC) due to correlations between predictors [42]. All potential predictors for each of the 3 models are presented in Multimedia Appendix 3.

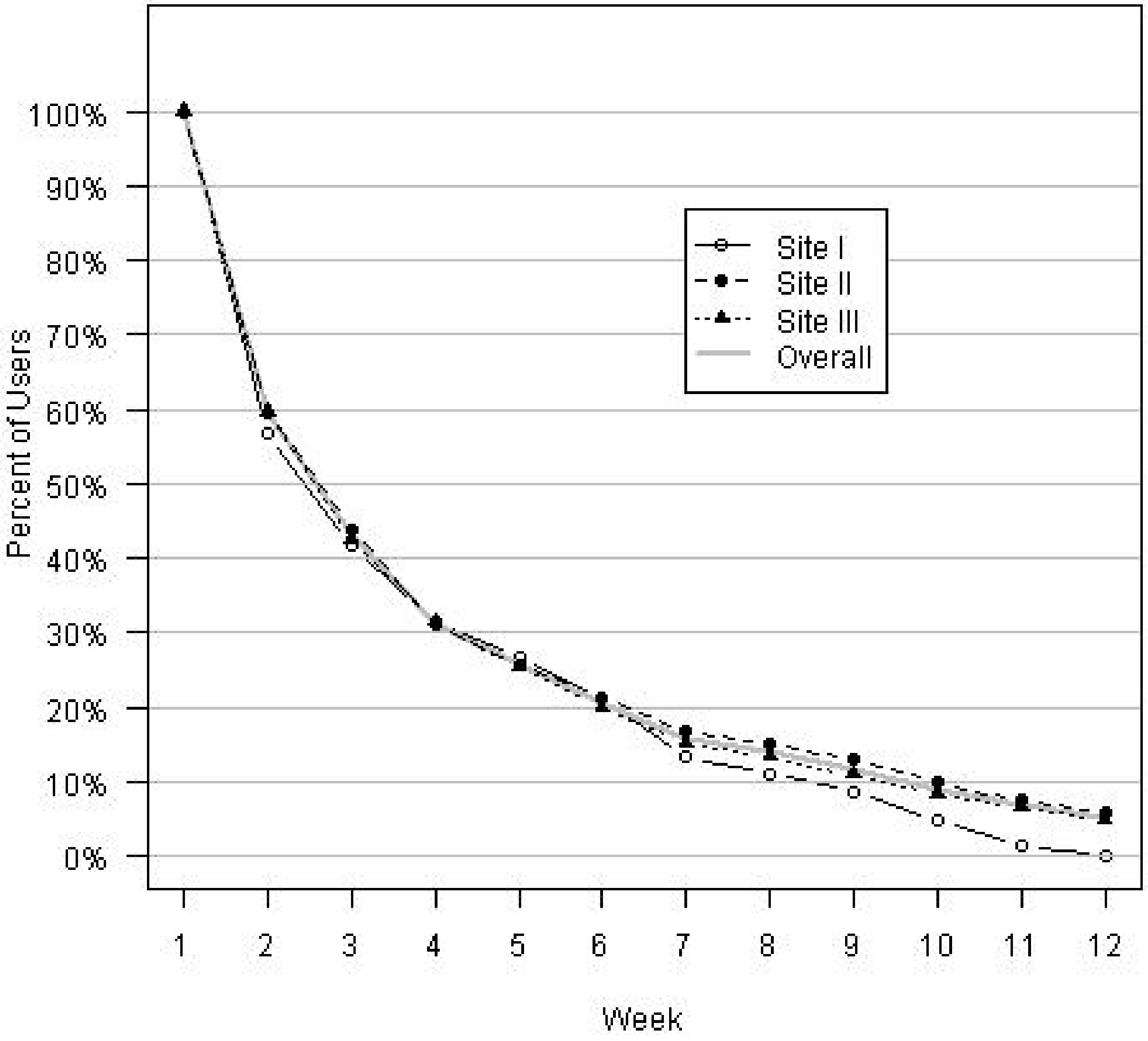
Results

Retention of Users

The retention in terms of the proportion of users remaining on the site each week is shown in Figure 3. In the first week of the study, about 40% of users were lost while there was a steady 20%/week attrition of users from week 2 onwards. A total of 5.2% of users had some activity in week 12. The retention each week was compared between sites using a chi-square test. There were no statistically significant differences in retention between the supportive sites (all *P* values >.05). The information-based site had significantly lower retention than the others only at week 12 (*P* = .01).

The median number of days on which a user accessed the site was 2. The maximum was 83 (of a possible 84) resulting in a skewed distribution. Usage difference between websites was statistically significant (*P* = .02) with the average days the site was used at 3.43 (SD 4.28), 5.50 (SD 10.35), and 5.50 (SD 10.35) for the information-based, supportive, and personalized-supportive websites respectively.

Figure 3. Percentage of users still active in the website throughout the 12 weeks. Site I= Information-based; Site II=Supportive; Site III=Personalized-supportive.



Participant Characteristics for Starters

Demographic characteristics can be seen in Table 2. Most participants resided in the Eastern states of Australia (80.7%), although there were representatives from each of the nation's states and territories.

Table 2. Summary statistics of initial questionnaire measures for starters.

		Non-completer n = 2213 M (SD)	Completer n = 435 M (SD)	Total n = 2648 M (SD)
Female (%) [a]		82.1	90.1	83.4
Age (years) [a]		44.5 (11.9)	47.4 (11.9)	45.0 (11.9)
BMI		34.0 (6.6)	33.6 (6.4)	34.0 (6.5)
	25-29 (%)	30.9	32.4	31.2
	30-40 (%)	52.7	53.1	52.8
	>40 (%)	16.4	14.5	16.0
PBC [b] **(1 min; 7 max)** [c]		6.32 (0.63)	6.33 (0.62)	6.32 (0.63)
Intention [d] **(1 min; 7 max)**		6.75 (0.53)	6.80 (0.47)	6.76 (0.52)
PCS [a,e] **(1 min; 4 max)**		3.06 (0.45)	3.01 (0.44)	3.05 (0.45)
WLSE [f] **(1 min; 4 max)**		2.22 (0.64)	2.24 (0.64)	2.22 (0.64)
Internet use (%)				
	<1 to 4 hr	10.8	9.0	10.4
	5 to 10 hr	34.8	33.8	34.6
	11 to 20 hr	24.3	25.3	24.4
	>20 hr	30.2	32.0	30.5

[a] $P < .001$.

[b] PBC: Perceived behavioral control over staying on diet.

[c] $P < .05$.

[d] Intention: Behavioral intention to stay on diet.

[e] PCS: Proactive coping scale score.

[f] WLSE: Weight loss self-efficacy score.

Completion Bias

There were differences between starters who did not complete and completers in terms of sex ($\chi^2 = 16.86$, $P < .001$), age ($t(2646) = -4.62$, $P < .001$), and proactive coping ($t(2646) = 2.07$, $P = .039$), as shown in Table 2. Completers were more likely to be female and were slightly older. Starters who did not complete the study had higher proactive coping than completers, though the effect size was small. Finally, there was a difference in the percentage of completers between the website conditions with starters allocated to the information-based site more likely to complete. Examination of cell counts suggested that a higher proportion of starters who were randomized to the information-based site (30.2%) provided final weights relative to those randomized to the supportive site (16.2%) or the personalized-supportive site (16.1%).

Usage of Features by Starters

Summary statistics for each of the website usage measures for all starters are given in Table 3. Note that the counts of Blog use and Profile updates were each divided into two different subgroups, since these were found to relate differently to overall retention of users on the site [32]. Blog use was divided into active (contribution) and passive engagement (consumption) with the blog.

Table 3. Website features and uptakes for starters (n = 2648).

Features		Description	% using	Range		Median	IQR[a]	
				min	max		Lower	Upper
General usage [b]								
	Day of last action	Last time that an activity was recorded for the user	–	0	87	14	4	39
	Days site used	Number of days that an activity was recorded	–	0	83	3	2	8
	Membership length	Time from the user's first activity to their last activity	–	0	87	13	2	38
Diet information [b]		View diet or exercise content	99	0	80	3	1	6
Diet tools [c]								
	Weight tracker	Enter an online weight record	100	1	71	1	1	3
	Meal planner	Use the meal planner	68	0	78	1	0	2
	Compliance	View one's compliance with TWD	36	0	77	0	0	1
Social support [c]								
	View profile: own	View one's own profile	85	0	82	1	1	3
	View profile: else	View someone else's profile	30	0	80	0	0	1
	Profile: Text	Add personal information to one's own profile	30	0	15	0	0	1
	Profile: Image	Add an image to one's own profile	13	0	22	0	0	0
	Friending	Invite a friend or accept or reject an invitation	14	0	50	0	0	0
	News feed	Follow a feed link	22	0	35	0	0	0
	Blog: View	View a blog	38	0	81	0	0	1
	Blog: Add	Contribute to or comment on a blog	14	0	81	0	0	0
	Discussion forum	Forum posts and comments on others' posts	49	0	78	0	0	2
	Wall	Contribute to a wall	17	0	78	0	0	0
	Social quiz	Comment on a comparison between two other users	1	0	21	0	0	0

[a] IQR: Interquartile range.

[b] Includes the information-based site starters (n = 53) who had access only to Diet Information.

[c] Excludes the information-based site starters.

While there were many features available, many of them were not used. The most used feature was Diet Information, although even for this feature, 75% of starters viewed content on only 6 days of the study period. All starters on supportive sites used the weight tracker, but most used it only a few times. Only 14% established online friendships with another participant.

Weight Loss

The distribution of weight loss at the end of 12 weeks is shown in Figure 4, both for completers and using multiple imputed values. The percentage of weight loss from baseline according to MI (n = 2648) was 2.76% (SD 3.56) with 23.7% of starters losing a clinically relevant amount of their baseline weight (>5%). Completers (n = 435) lost 4.10% (4.05) of their initial body weight on average, with 37.6% losing over 5% of their initial weight.

Figure 4. Combined model for variables predicting percentage weight loss.

The Effect of Website Condition and Participant Characteristics on Weight Loss

Average weight losses among completers were 4.15% (SD 4.26), 4.22% (SD 4.34) and 3.97% (SD=3.73) for those who received the information-based, supportive, and personalized-supportive websites respectively.

Results for models predicting percentage weight loss are based on values derived from intention-to-treat analyses using multiple imputation methods rather than completers' data, as, while specific estimate values differed, significant predictors were the same.

The pooled model fit to predict percent weight loss from the participant characteristics and website condition found no predictors with coefficients significantly different from zero, indicating no differences in weight loss between the 3 groups. The number of predictors selected using variable selection with the BIC criterion in the 100 MI datasets varied from 0 to 4 with no predictor selected in over 50% of the datasets.

Predicting Weight Loss From Feature Usage

Fitting a model using all of the predictors to the MI datasets gave pooled parameter estimates given in Multimedia Appendix 3. The only predictor that had parameter estimates significantly different from zero was the number of days the weight tracker was used. Between the 100 datasets, the number of predictors selected varied from 1 to 5 using the BIC. Days the weight tracker was used were selected in all of the models while no other predictor was selected in more than half of the models. The average value of R^2 for the selected models was 10.6.

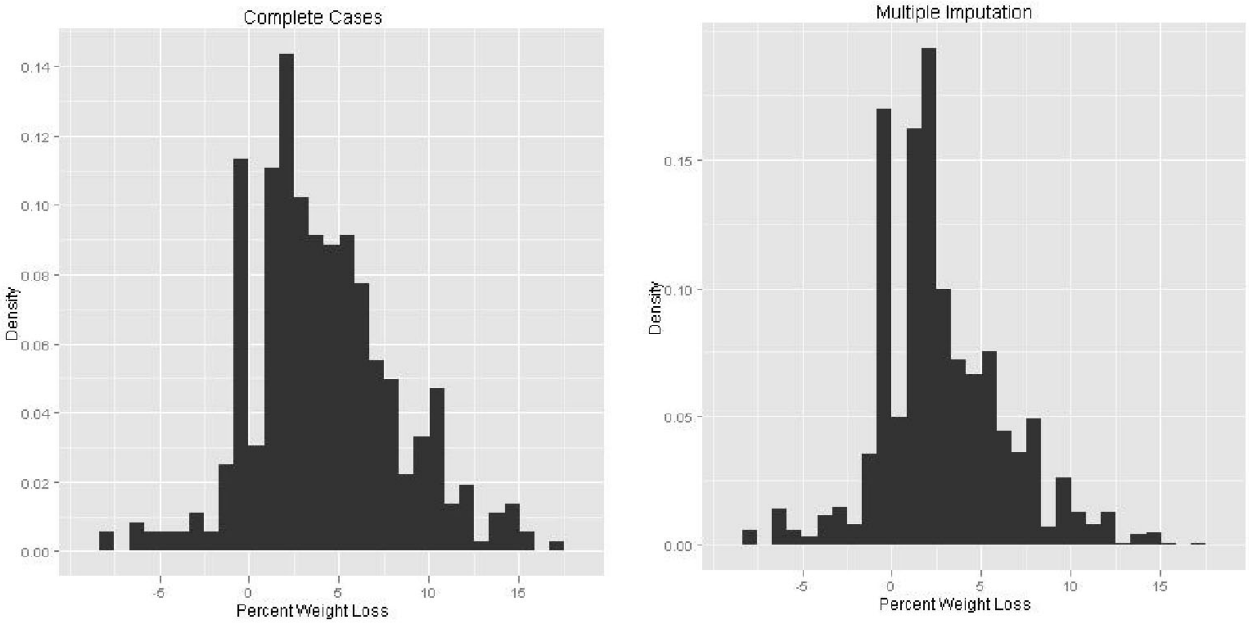
Prediction of Site Usage Measures From Participant Characteristics

As usage of the weight tracker was predictive of weight loss, a model predicting use of the weight tracker from participant characteristics was created. Age and initial BMI were selected using the BIC as predictive of uses of the weight tracker (Table 4). Age was a highly significant predictor with older participants providing more days of weight record. Individuals with higher initial BMI recorded their weight less often. Combining the results of both analyses leads to the model depicted in Figure 5.

Table 4. Summary of parameter estimates for prediction of percent weight loss and use of the weight tracker (data from the supportive site and III starters only).

		Estimate	*SE*	*t*	*P*
Weight loss prediction from feature usage and participant characteristics					
	Constant	1.82	0.42	4.32	<.001
	Weight Tracker	0.34	0.04	7.64	<.001
Weight tracker prediction by participant characteristics					
	Constant	1.95	0.41	4.71	<.001
	AGE	0.04	0.01	7.40	<.001
	Starting BMI	-0.03	0.01	-3.26	.001

Figure 5. Histogram of percentage weight loss for Completers (left) and estimated using multiple imputation (right).



Evaluation

Evaluation data were provided by 431 users. There were no significant differences between the supportive sites for any of the evaluation questions. Comparing the information-based site with the pooled results for supportive sites showed significant differences for ratings of liking and the usefulness of the website for supporting the diet, but there was no difference for difficulty of use (Table 5). Regardless of website condition, the most frequent response to “How much did the website help you stick to the TWD?” was “not at all” (a score of 0). While over half of the people in the supportive site (58.4%) and personalized-supportive (57.8%) conditions would recommend the site to a friend, only 27.8% of those in the information-based condition would recommend it ($\chi^2 = 6.48$, *P* = .039).

Table 5. Means, standard deviations, and *P* values for ratings of liking, difficulty to use, and helpfulness of the websites presented by website condition (labelled means without a common letter differ significantly according to Bonferonni-adjusted pairwise comparisons, *P* < .05).

	Information-based n = 18		Supportive n = 209		Personalized-supportive n = 204		
	M	SD	M	SD	M	SD	*P*
Overall how much did you like the TWD website?[a]	2.72^{a}	2.24	4.50^{b}	2.69	4.36^{b}	2.52	.021
How difficult was it to use the website?[b]	4.39^{a}	3.31	4.47^{a}	2.73	4.44^{a}	2.57	.985
How much did the website help you stick to the TWD?[a]	2.39^{a}	2.45	4.43^{b}	2.91	$4.03^{a,b}$	2.88	.012

[a] Response format: 0 (not at all) to 9 (completely).

[b] Response format: 0 (very challenging) to 9 (not at all challenging).

Discussion

This is one of a limited number of papers to investigate the impact of an interactive/supportive, purely web-based weight loss program. The different levels of support and personalization studied appeared to have little effect on retention, although they were associated with higher average use of the site. We had expected that enhanced functionality, including social support, interactivity features, and/or personalized meal planning, might improve weight loss, but this was not the case for the website evaluated. For those in our sample who received a supportive version of the program, use of the online weight tracker was the only predictor of weight loss.

Rothert et al [23] reported 50% greater percentage of weight loss from baseline for participants who used a tailored/expert versus static system. In contrast, van Genugten et al [24] reported no differences in anthropometric measures between a static and interactive weight management intervention and suggested that “sub-optimal” use of the interactive system may be responsible for their null effects. Unfortunately, Rothert et al [23] did not include objective usage data in their paper and did not report detailed information on their system usage. The more interactive websites in our study were not more effective than the static site in terms of weight loss or weekly retention. It is possible that the level of interactivity provided by the Online TWD was not sufficient to provide any additive effects beyond the diet, which has a high level of structure and which was already available as a commercial book.

Completers in our study lost just over 4% of their initial body weight, on average, with 37% losing a significant amount of body weight (>5%). Other studies of large cohorts of subscribers to commercial weight loss programs have reported slightly higher but comparable weight loss results. Completer analysis of 837 members of the site, vitkklubb.se, indicated an average of 6.1% weight loss at 3 months with close to half of these members reporting clinically significant losses [43]. Evaluation of a cohort of members of the site, biggestloserclub.com.au, was similar with a mean of 6.2% weight loss at 3 months, although fewer members of this site achieved clinically relevant losses (21%) [44]. The average weight loss of around 4% was about half that found in clinical trials of the TWD but reached a larger segment of the population with a considerably smaller investment of resources.

Retention rates are a critical aspect of web-based interventions [45]. Despite the national reach that the Online TWD Portal achieved at the registration stage, retention and uptake of the site were low. Roughly 65% of registrants used the website, which resembles that reported in similar lifestyle interventions [20]. As well as uptake, nonuse attrition is common in web-based studies. Despite up to 21 email reminders, Rothert et al [23] lost 70% of their sample at a 12-week follow-up. At 12 weeks, other purely web-based weight loss programs have reported retention rates of 6% to 35% [43,44]. In contrast, Stevens et al [46] reported that 80% of their sample were still logging into their weight maintenance system after 12 months of intervention. Frequent email and telephone prompts may have contributed to this high retention rate. At the end of our trial period, we retained less than 6% of initial registrants and 16.3% of users who provided a start weight. The Online TWD program included limited prompts, was not commercial, and had no membership fees, which may have reduced the commitment of participants and inflated attrition levels.

Interaction data suggested that many of the features provided in the interactive sites were not heavily utilized. Despite the presence of interactive features, participants' average scores for liking of the site were low, and this may have reduced their interaction with the portal. Alternatively, participants may not have been experienced with some of the concepts of social networking (such as friending) or hesitant to send requests to people not familiar to them as much of the sample were strangers at commencement of the study (friending was used by only 14% of starters). Relative to previous studies, the uptake of our features may not be as low as they appear. Kelders et al [20] found that under half of their sample accessed their site more than once. The most utilized feature in Binks and van Mierlo's [22] study was used by only 57.8% of their sample.

Salient questions regarding how to keep people engaged and using a website without relying on high levels of participant contact remain. The inability to translate intention into actual behavior has been well documented in health psychology, and the finding that less than half of overweight/obese people interested in starting the diet actually accessed the site probably reflects this. Providing prescriptive individual goals has shown promising results for the promotion of physical activity [47]. Other behavioral strategies (such as implementation intentions) could be used in future studies to encourage interested participants to translate their initial motivation into action [48]. Likewise, more intelligent system designs may also be able to improve uptake of features and improve user engagement with web-based systems in future trials.

The weight tracker appeared to be a critical feature of our supportive websites, as it was the only feature significantly associated with weight loss. This is consistent with literature on the benefits of self-monitoring for general behavior change including weight loss [49]. In their evaluation of a weight maintenance program, Funk et al [50] also reported that the number of weight entries participants entered was associated with less weight regain. Therefore, future studies are needed to further understand how this feature may have positive effects for weight management. It was interesting that use of the weight tracker was a stronger predictor than overall usage of the website for our trial. This suggests that interaction alone may not be the strongest predictor of weight loss and that the form of this interaction is worth consideration.

There is little debate regarding the need for social supportive web-based programs [8], yet constructing a social and dynamic system remains a challenge. Other papers have reported low uptake of forums and social support and even suggested people prefer to meet face-to-face than virtually [15,18,44]. Yet, results of an analysis of live users (n = 84,828) of a web-based health intervention suggested that “social ties” were a critical feature for user engagement with the site and completion of goals [51]. Our finding that participants using a supportive system visited the site more days than those with the static site offers some support to this observation. Replicating and achieving virtual support, especially without personal contact, remains a challenge for web-based interventions.

Completers were older than people who started without finishing. Age was also predictive of greater use of the weight tracker. Interestingly, similar observations regarding age have been made in previous studies [20,50,52]. The idea that older users have higher engagement with a web-based system seems contrary to statistics indicating that fewer older people access the Internet (37% of 65 or older compared to 96% of those under 55 in Australia in 2010) [53]. Although reach may be limited in older groups in terms of Internet-delivered interventions, older members who do commit to an online program seem to utilize the website more. This may be due to higher free time in this age group who have almost double the minutes of free time per day than those between the ages of 15 and 64 [54]. Consequently, those 65 and older who do access the Internet may be particularly receptive to web-based interventions.

The study we have reported on has strengths and weaknesses that need to be considered in the interpretation of results. Although we used intention-to-treat analysis for our sample of starters, this represented a subgroup of all registrants. The self-selected nature of interaction with the system and provision of a starting weight among users may have biased the results and limited the efficacy of randomization. Attrition also left a small number (n = 16) of completers in the information-based condition. Nonetheless, post-hoc calculations suggested that we had over 90% power to detect a 3% difference in weight loss between this site and the supportive sites.

In order to retain higher ecological validity, we did not require participants to attend our clinic to have objective anthropomorphic measurements taken. This means that our weight loss results are based on self-reported data. Despite careful screening of these data, care needs to be considered in the interpretation of our results.

Unlike previous purely web-based weight loss interventions, the Online TWD was based on a validated diet program that has been proven successful through other delivery mechanisms. Despite their relative marketing successes, few commercial programs are supported by an evidence-base [55]. Thus, although the content of our program was not theoretically derived, it was based on an efficacious weight loss program.

Finally, our intervention sites were prototypes and not built to commercial standards. Among the many factors surrounding Internet intervention, “look and feel” can be important drivers of successful uptake [56]. Although it is virtually impossible to disentangle the specific aspects of the site that led to low average liking scores, piloting usability and look and feel may improve attitudes towards the website in future trials.

Previous reviews have attempted to identify the characteristics of successful eHealth weight loss interventions but have not clearly separated Internet and face-to-face delivered components of the programs. Despite limitations, purely online approaches are essential if the value of such interventions for weight loss is to be understood. Our results suggest that provision of a weight tracker may be a promising web-based feature for weight loss; however, more studies are needed to establish why and how this tool can be utilized to promote greater weight loss.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Study protocol originally submitted to Research Ethics Board.

[PDF File (Adobe PDF File), 73KB - jmir_v14i6e173_app1.pdf]

Multimedia Appendix 2

Screen shots of the TWD Online Portal includes examples of homepage, diet and exercise information, diet tools, social support features.

[PDF File (Adobe PDF File), 597KB - jmir_v14i6e173_app2.pdf]

Multimedia Appendix 3

Pooled parameter estimates for model using all of the predictors to the Multiple Imputation datasets.

[PDF File (Adobe PDF File), 99KB - jmir_v14i6e173_app3.pdf]

Multimedia Appendix 4

CONSORT eHealth V1.6.1 checklist [57].

[PDF File (Adobe PDF File), 1MB - jmir_v14i6e173_app4.pdf]

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Original Paper

Web-Based Nursing Intervention for Self-Management of Pain After Cardiac Surgery: Pilot Randomized Controlled Trial

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Abstract

Background: Most adults undergoing cardiac surgery suffer from moderate to severe pain for up to 6 days after surgery. Individual barriers and attitudes regarding pain and its relief make patients reluctant to report their pain and ask for analgesic medication, which results in inadequate pain management. More innovative educational interventions for postoperative pain relief are needed. We developed a Web-based nursing intervention to influence patient's involvement in postoperative pain management. The intervention (SOULAGE-TAVIE) includes a preoperative 30-minute Web-based session and 2 brief face-to-face postoperative booster sessions. The Web application generates reflective activities and tailored educational messages according to patients' beliefs and attitudes. The messages are transmitted through videos of a virtual nurse, animations, stories, and texts.

Objective: The aim of this single-blinded pilot randomized trial was to investigate the preliminary effects of a virtual nursing intervention (SOULAGE-TAVIE) to improve pain relief in patients undergoing cardiac surgery.

Methods: Participants (N = 60) were adults scheduled for their first cardiac surgery. They were randomly assigned to the experimental group using SOULAGE-TAVIE (n = 30) or the control group using usual care, including an educational pamphlet and postoperative follow-up (n = 30). Data were collected through questionnaires at the time of admission and from day 1 to day 7 after surgery with the help of a blinded research assistant. Outcomes were pain intensity, pain interference with daily activities, patients' pain barriers, tendency to catastrophize in face of pain, and analgesic consumption.

Results: The two groups were comparable at baseline across all demographic measures. Results revealed that patients in the experimental group did not experience less intense pain, but they reported significantly less pain interference when breathing/coughing ($P = .04$). A severe pain interference with breathing/coughing (pain ranked ≥ 7/10) was reported on day 3 after surgery by 15% of the patients in the experimental group (4/27), as compared to 44% (7/16) in the control group. On day 7 after surgery, participants in the experimental group also exhibited fewer pain-related barriers as measured by the Barriers Questionnaire-II (mean 10.6, SD 8.3) than patients in the control group (mean 15.8, SD 7.3, $P = .02$). No difference was found for pain catastrophizing. However, in both groups, means revealed a lower tendency to catastrophize pain before surgery as measured by the Pain Catastrophizing Scale (control group mean 1.04, SD 0.74; experimental group mean 1.10, SD 0.95) and after surgery (control group mean score 1.19, SD 0.94; experimental group mean score 1.08, SD 0.99). Finally, the experimental group consumed more opioid medication (mean 31.2 mg, SD 23.2) than the control group (mean 18.8 mg, SD 15.3, $P = .001$).

Conclusions: This pilot study provides promising results to support the benefits of this new Web-tailored approach that can increase accessibility to health education and promote pain relief without generating more costs.

Trial Registration: Clinicaltrials.gov NCT01084018; http://www.clinicaltrials.gov/ct2/show/NCT01084018 (Archived by WebCite® at http://www.webcitation.org/6CoTBkIoT)

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KEYWORDS

postoperative pain; cardiac surgery; patient education; Internet; pilot study; randomized controlled trial

Introduction

Acute pain is the most commonly experienced pain [1]. October 2010 to October 2011 was the Global Year Against Acute Pain in recognition of its prevalence. Like any pain problem, postoperative pain has physiological, psychosocial, and financial consequences [2-4]. Uncontrolled acute pain results in complications and delayed mobilization of patients after surgery, increased length of stay following surgery, and the risk of chronic pain [1]. It has been estimated that most adults undergoing cardiac surgery suffer from intense pain for up to 6 days after surgery [5-8]. Cardiac surgery, a frequent procedure involving sternotomy, is a source of acute pain and also may contribute to persistent postoperative pain in 17% to 56% of patients [6,9,10]. Analgesic medication is the most common method to relieve pain after this type of surgery, although low doses are often administered [11].

Patients' attitudes regarding pain and its relief often make them reluctant to report their pain and take analgesic medication [11-13], which could explain inadequate levels of analgesia particularly when patient-controlled analgesia (PCA) is the promoted mode of administration. Moreover, most people expect to suffer from severe pain after cardiac surgery [11]. It has been shown that pain cognitions, such as pain catastrophizing, may influence postoperative pain intensity, activity levels, and analgesic consumption [14,15]. Patients who tend to catastrophize pain may also be hypervigilant and avoid movement, which may cause postoperative complications and persistent pain [16].

Current reviews of traditional nursing educative interventions for surgical populations, including cardiac patients, report unclear objectives and mixed effects on pain [17-19]. Clinically relevant results and statistically significant effect sizes of computer-tailored and Web-based interventions have been recognized for health behavior change with diverse populations [20-22]. Hence, interactive health technologies seem to be powerful and promising media for health education [23-24]. Computers and information technologies have been part of our lifestyle for some time and they can facilitate the implementation of interventions influencing pain behaviors. Computer-tailored interventions have not been integrated into acute pain management approaches, although they seem to be a feasible alternative for surgery. There is a clear lack of innovation in the field of pain education because interventions and conclusions have not changed over almost 20 years [18,19,25]. The challenge is to propose an innovative approach.

SOULAGE-TAVIE (*Soutien à l'autogestion - traitement - assistanceVirtuelle Infirmière - enseignement* or "self-management support - treatment - virtual nursing assistance and education") was developed by using a pragmatic and evidence-based approach [26]. The Web application was created with the help of a prototype developed by the University of Montréal's Chair for Research into New Practices in Nursing [27]. Computer-tailored technology was used to offer a complementary and personalized tool to empower patients without adding a burden to the clinicians in the busy environment of acute care. Based on tailored communication [28] and persuasive communication [29] strategies for behavioral change, this tool screens the patient's pain barriers [30] and tendency to catastrophize pain [31]. It then generates a 30-minute tailored preoperative session on a computer animated by a virtual nurse that guides the participant through the learning process about pain management (Figure 1). Two face-to-face booster sessions of 5 to 10 minutes were also provided. Before this study, the content was validated with clinicians and the Web application's usability was pretested.

The objective of this pilot study was to assess the preliminary effects of SOULAGE-TAVIE on pain intensity, pain interference with daily postoperative activities, patients' pain barriers, tendency to catastrophize in face of pain, and analgesic consumption.

Figure 1. Home page of the SOULAGE-TAVIE website showing the determine profile function and start intervention function.

Une intervention virtuelle pour vous aider dans la gestion de la douleur

Methods

Study Design and Randomization Procedure

A single-blinded pilot randomized trial was used to assess the preliminary effects of SOULAGE-TAVIE for patients awaiting cardiac surgery, including coronary artery bypass graft (CABG) or/and valve replacement, during the first week following their operation.

Approval of the protocol was obtained from the University of Montréal Research Committee and from the Ethics Board of the Centre hospitalier de l'Université de Montréal (CHUM). The principal investigator (GM) was responsible of the recruitment and informed consent procedures at the time of admission (usually the day before surgery) and explained the main objective of the study (ie, assessing a new way of educating patients about pain and pain relief) and the components and timing of interventions and follow-up for each group. The randomized allocation through the use of concealed envelopes was also clarified. Each potential participant was given a copy of the informed consent and time to consider whether he or she wanted to participate. After the consent was signed and baseline measures were collected, participants were randomized into 2 groups by the principal investigator: (1) a group to use the SOULAGE-TAVIE application and the usual care procedures (experimental group), and (2) a group to receive solely the usual care procedure, ie, a pamphlet describing general principles of pain management (control group). Permuted-block randomization with an allocation ratio of 4 was used to generate a list through computer software. The list and envelopes were prepared by a colleague who was not involved in this study. An experienced research assistant was blinded and responsible for the face-to-face data collection, except for the medical records that were examined by a trained nurse also blinded to group allocation. Clinical staff was blinded to group allocation and to the roles of the research assistant and principal investigator in the study (data collection vs intervention).

Participants

Because the pilot study was not expected to be powered to detect statistically significant differences, there is no universal calculation rule to determine sample size. Usually, 20 participants per group is required to be able to make assumptions of homogeneity and normality of variances [32]. However, Hertzog [32] suggests that 30 to 40 patients per group is necessary when no meaningful difference is known and when the researchers would like to proceed to sample size calculation for a larger study. We decided to recruit 60 participants, 30 per group.

Patients were selected according to the following criteria: (1) age 18 years and older, (2) elected for a first-intention cardiac surgery involving sternotomy (CABG, valve replacement, or both procedures) at the cardiac surgery unit of the CHUM, and (3) able to understand and complete questionnaires in French. Patients were not eligible for the study if they (1) had previous cardiac surgery, (2) were planned to be on a postoperative epidural protocol, and/or (3) were unable to consent because of a cognitive or psychiatric disorder.

Initial Assessment

All participants completed baseline measures in the cardiac surgery unit either a few days before or the day before surgery (T0). Usual sociodemographic variables (ie, age, sex, civil status and living conditions, education level, employment status, and annual income) were collected. Presence of chronic pain before surgery was also documented. Baseline psychological well-being measures were assessed with the Hospital Anxiety and Depression Scale (HADS) [33,34]. The HADS includes 14 items (Likert-type scale ranging from 1 to 4) divided into 2 subscales of anxiety (7 items) and of depression (7 items). Two scores are calculated, but a total score can also be obtained by summing the results of the 2 subscales. The validity and reliability of the HADS is well established [33,35].

Treatment Conditions

After completing initial measures, all participants received the preoperative education usually provided on the cardiac surgery unit of the CHUM. It consisted of a pamphlet to read in the preoperative phase at the time of admission. This pamphlet presented diverse aspects about the experience of a cardiac surgery. Regarding pain, it explained the use of the pain intensity numeric rating scale (ranging from 0 to 10). It also emphasized the importance of not waiting for the pain to become severe or reaching greater than 4 (out of 10) before asking for analgesic medication or informing the health care staff. Pharmacological and nonpharmacological options were also discussed.

Patients from the experimental group also received the SOULAGE-TAVIE intervention. During the intervention's development, the elaboration likelihood model [29] guided the choice of 2 strategies to promote attitude change through reflection and deep processing of information. Firstly, messages were built according to tailored communication that included the generation of profiles according to a screening of behavioral determinants, and the combination of different types of feedback (descriptive, comparative or normative, and evaluative) [28]. The messages provided were specifically tailored to the participants' profile according to real-time answers (dynamic tailoring) as displayed in Table 1, but also according to a predetermined algorithm (static tailoring). The algorithm was based on the mean scores obtained on each of the 7 subscales of the Barriers Questionnaire-II (BQ-II) [30] and the Pain Catastrophizing Scale (PCS) [31], because no cutoff was identified for these tools. However, the use of subscales' scores instead of total scores allowed the provision of more refined messages. Two profiles (mild vs moderate-high), and consequently 2 types of activities and/or messages, were outlined for each subscale (Table 2). If a score from 0 to 2 was recorded, the application generated a reinforcement message (mild profile). If a score between 2 to 5 on the BQ-II or between 2 to 4 on the PCS was obtained, the application generated a reflection activity (moderate-high profile). Persuasive communication also contributed to the development of messages through the consideration of the source, channel, receiver, and arguments [29]. For example, the source had to be trustworthy and credible. A virtual nurse was chosen as the messenger and different shots were planned depending on the type of messages. Regarding messages, other patients' experience and research results were used to strengthen arguments on the consequences of behavior and promote self-assessment.

Table 1. Example of reflection activity on pain definition based on real-time answers to the question: "What is the pain intensity between 0 and 10 that you expect to feel the day after surgery?"

Feedback	User response	
	0 to 3	7 to 10
Descriptive/comparative	"Between 0 and 3, pain is considered mild. Most people feel moderate to severe pain the first day after cardiac surgery."	"Some people feel severe pain (between 7 and 10) and, as they expected it, they think it is normal to endure it."
Reinforcement message through persuasive communication	"You could feel pain higher than 4 if you move for example, although you should target a mild level of pain to facilitate your recovery."	"Studies recommend maintaining a mild level of pain to promote a good recovery."
	"Do not let your pain exceed 4!"	"Do not let your pain exceed 4!''

Table 2. Example of tailored message according to score on the Pain Catastrophizing Scale (rumination subscale).

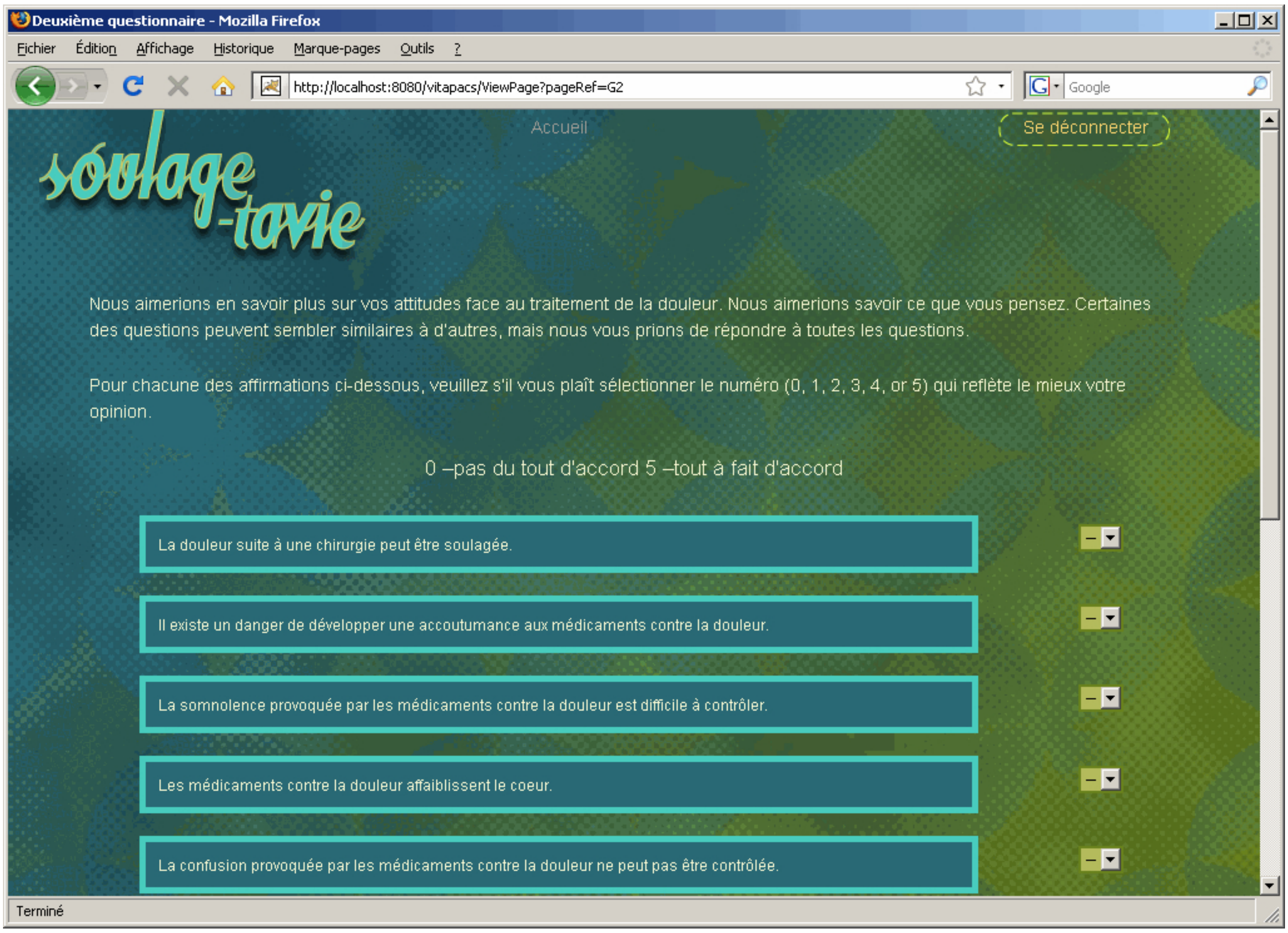
Response	Profile	
	Mild (score ≤ 2)	Moderate-high (score > 2)
Message	When you feel pain, you think about it sometimes but you are able to concentrate on something else. Bravo! It is good to have this attitude when dealing with pain. When people focus their mind on pain, they stop moving, it slows down their recovery, and can also lead to pain elevation.	When you are in pain, you tend to concentrate your mind on it. It is normal because pain is unpleasant! However, by doing so you stop thinking about solutions and you avoid doing your recovery activities to avoid pain.

After the screening (Figure 2), the Web session was divided into 3 sequences: definition of pain, individual reaction to pain, and pain management. A total of 47 videos of a virtual nurse were shot and placed on 34 pages, including 4 types of content:

4 screening pages, 15 information pages, 8 question and feedback pages, and 7 integration/consolidation animated pages. The 3 sequences started with an introductory video and general content, followed by activities according to individual scores. Reflective activities included questions and choices of answers. Feedback through a virtual nurse's advice or an animated video was then provided. Each sequence ended with a video of the virtual nurse or an animation (eg, case history) integrating various elements toward the elaboration of an action plan for postoperative pain (Figure 3). At the end of the session, the virtual nurse reminded the person that he or she would be visited postoperatively by a nurse as a follow-up to the preoperative session.

The Web session usually took place on the surgical unit a few days or the day before surgery through the use of a laptop because a dedicated room and a wireless Internet connection were not available. A nurse (GM) was present to assist participants if technical problems occurred. The 2 boosters were delivered on the surgical unit face-to-face by the principal investigator (GM). The first booster was provided on day 2 after surgery, because this is when patients are usually transferred from the intensive care unit to the surgical unit. The objective was to review the main concepts of medication intake and communication relative to pain level and postoperative activities. The second booster was provided on day 3 after surgery because patients start moving a bit more and the analgesic strategy is usually modified. Moreover, some patients are transferred back to their health centers on day 3. The second booster's objective was to review specific items based on the preoperative screening of pain barriers and catastrophizing.

Figure 2. Screening page of the SOULAGE-TAVIE website.



Nous aimerions en savoir plus sur vos attitudes face au traitement de la douleur. Nous aimerions savoir ce que vous pensez. Certaines des questions peuvent sembler similaires à d'autres, mais nous vous prions de répondre à toutes les questions.

Pour chacune des affirmations ci-dessous, veuillez s'il vous plaît sélectionner le numéro (0, 1, 2, 3, 4, or 5) qui reflète le mieux votre opinion.

0 –pas du tout d'accord 5 –tout à fait d'accord

La douleur suite à une chirurgie peut être soulagée. –

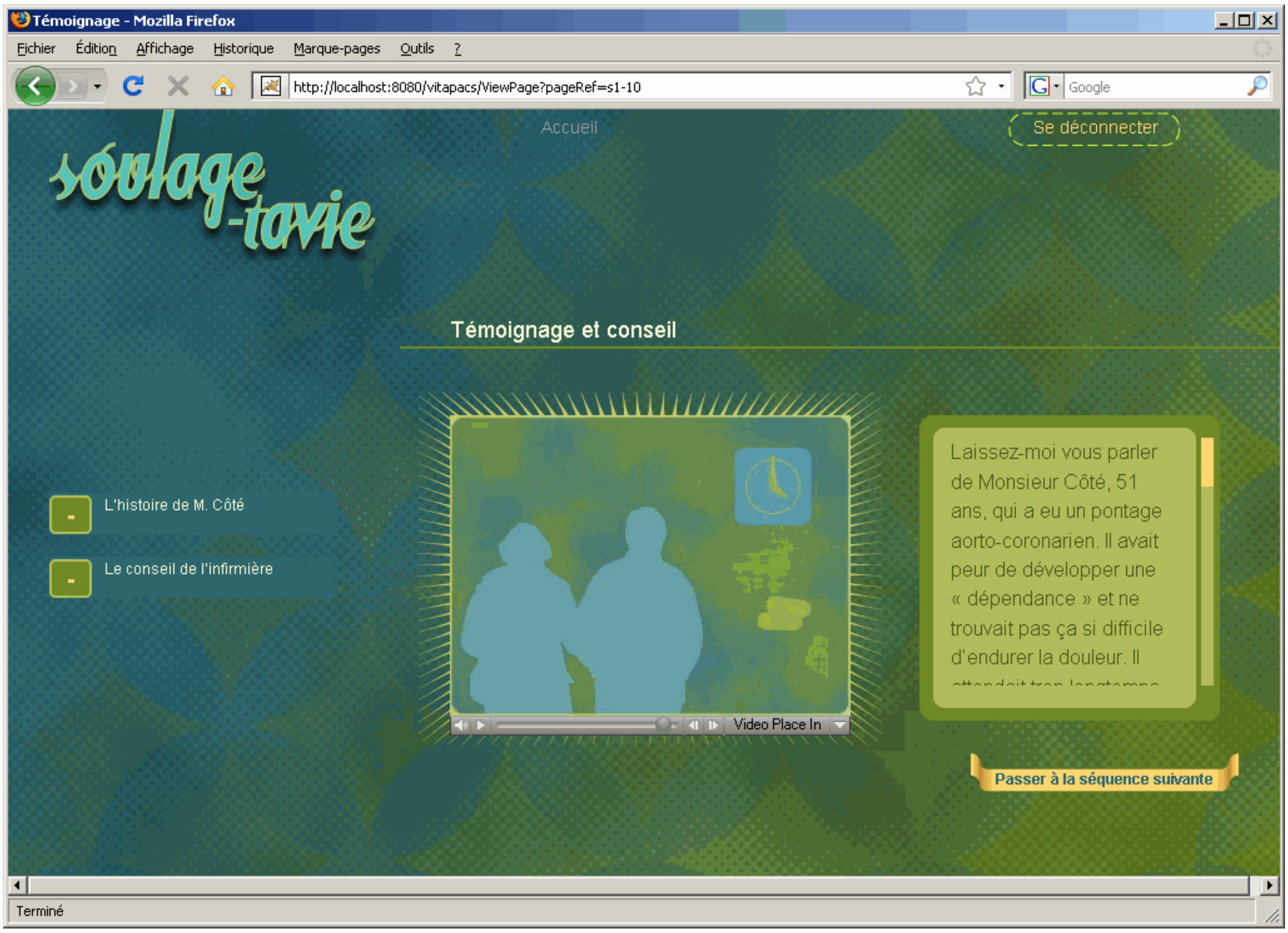
Il existe un danger de développer une accoutumance aux médicaments contre la douleur. –

La somnolence provoquée par les médicaments contre la douleur est difficile à contrôler. –

Les médicaments contre la douleur affaiblissent le coeur. –

La confusion provoquée par les médicaments contre la douleur ne peut pas être contrôlée. –

Figure 3. Animated integration page of the SOULAGE-TAVIE website displaying case history and nurse's advice.



http://localhost:8080/vitapacs/ViewPage?pageRef=s1-10

Laissez-moi vous parler de Monsieur Côté, 51 ans, qui a eu un pontage aorto-coronarien. Il avait peur de développer une « dépendance » et ne trouvait pas ça si difficile d'endurer la douleur. Il

Primary Outcome Measures

Postoperative measures were taken in the intensive care unit (ICU) and in the surgical care unit (SCU).

Pain Intensity

Pain intensity was assessed at 24 (day 1), 48 (day 2), and 72 hours (day 3), and at 7 days (day 7) postsurgery using a numerical rating scale (NRS) with a range from 0 to10 (0: no pain at all; 10: worst possible pain) [36,37]. Four different measures of pain intensity were taken: (1) average pain upon movement in the past 24 hours, (2) worst pain upon movement in the past 24 hours, (3) present pain upon movement, and (4) present pain at rest.

Pain Interference With Daily Postoperative Activities

As suggested by the Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials (IMMPACT) group in regard to pain core domains in clinical trials [38], the impact of pain on various aspects of daily living was assessed with interference items of the Brief Pain Inventory (BPI) [39,40], which has been successfully validated with cardiac surgery patients [11,41]. It includes 7 items and evaluates the impact of pain on general activity, mood, walking, work, relationships, sleep, and enjoyment of life. Some items were added in the context of the present study to measure the pain-related interference on appetite, concentration, and breathing/coughing. Each item represents a subscale and can be scored and analyzed individually with a range between 0 and 10 (0: does not interfere; 10: completely interferes). A total interference score was also calculated by taking the sum of all the items.

Pain Barriers and Catastrophizing

Patients' barriers toward pain management and tendency to catastrophize were assessed before surgery and intervention (T0) and were reassessed on day 7 after surgery using validated tools. The BQ-II [30] includes 27 items divided into 4 subscales: beliefs regarding secondary effects of medication (12 items), their harmful effects (6 items), fatalism about the control of pain (3 items), and attitudes regarding pain report to health care professionals (6 items). Each item is rated on a 0 to 5 scale (0: totally disagree; 5: totally agree). A total score and scores for each subscale can be calculated by taking the sum of the items. This questionnaire and its subscales have shown internal consistency and sensitivity to change [30,42]. Because a French version of this tool does not exist, we conducted a forward-backward translation protocol [43], and we adapted specific items to the context of cardiac surgery. The final version was reviewed by a group of experts (ie, a psychologist, a physician, and a nurse who were all involved in pain research with the same patients), and tested with 4 patients (2 women and 2 men).

The PCS was used to assess patients' tendency to catastrophize in the face of pain. It includes 13 items divided into 3 subscales: rumination (4 items), magnification (3 items), and helplessness (6 items). Each item is rated on a 0 to 4 scale (0: not at all; 4 all the time). A total score and scores for each subscale can be calculated by taking the sum of the items. The PCS has demonstrated an excellent internal consistency [31,44] and its sensitivity to psychosocial interventions has been established in the field of chronic pain [45,46].

Analgesic Consumption

The analgesic mode of administration (eg, PCA, intravenous injections, and oral medication) was documented. The dose of every opioid received postoperatively was transcribed and converted into standardized parenteral morphine equivalents [47]. A total in milligrams was calculated for each day, and means were obtained and analyzed for both groups at each postoperative day (days 1 to 7).

Medico-Surgical Assessment

Medico-surgical characteristics (ie, type of surgery and number of grafts, type and length of anesthesia, presence of postoperative complications, duration of ICU stay, and total postoperative length of stay) were assessed to describe sample and compare groups preoperatively and postoperatively.

Statistical Analyses

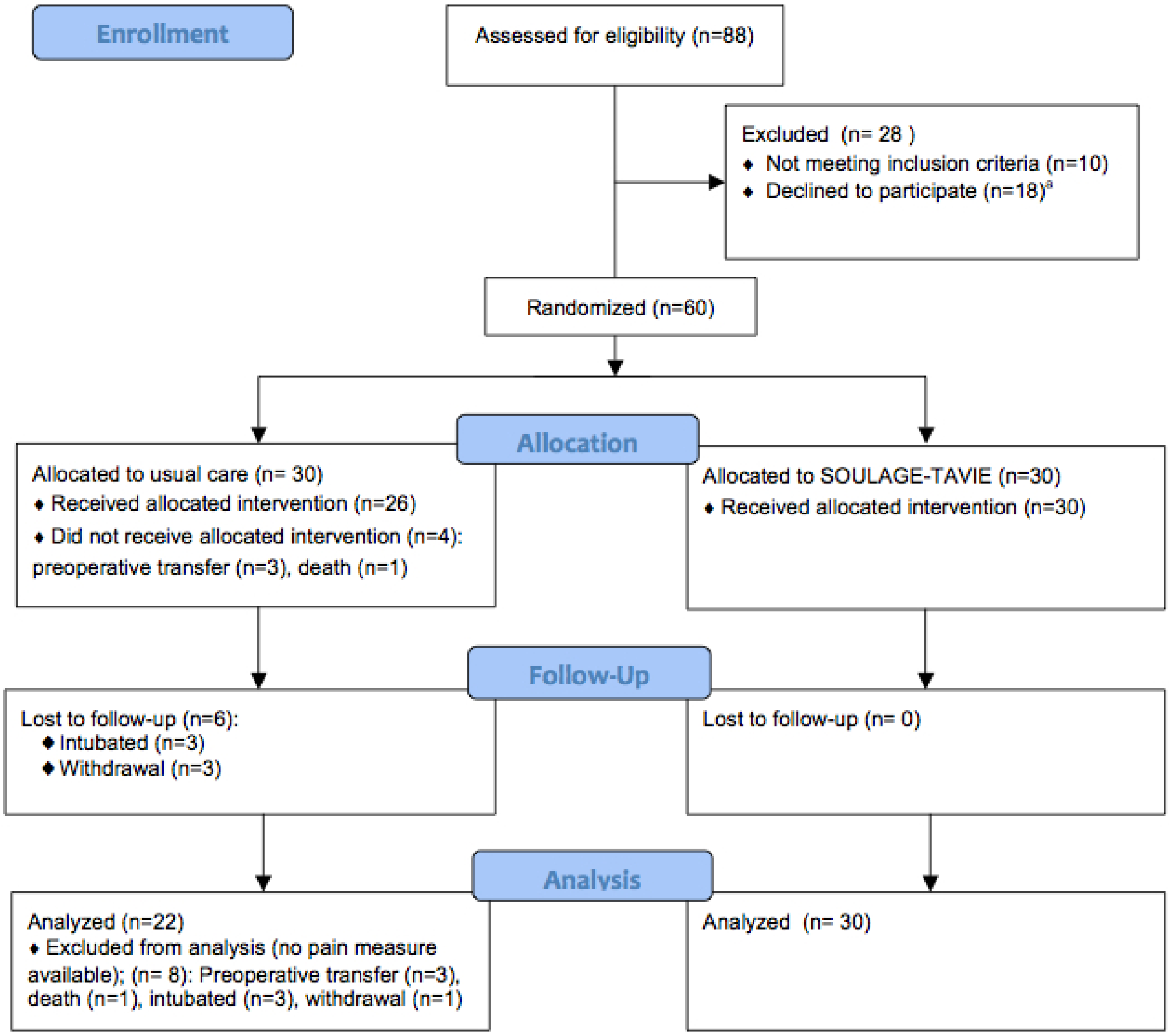
The protocol privileged an intention-to-treat approach for the analysis of results. If patients had completed the baseline and one of the postoperative measures, they were included in the study. An alpha = .05 level of significance was used for all analyses. Descriptive statistics (frequency tables, means, and standard deviations) were summarized at each time point. Student’s *t* tests or Chi-square tests were performed for each sociodemographic, medico-surgical, and baseline psychological variables to assure that equivalence of groups was obtained through randomization, although this procedure is not mandatory [48].

The evolution of pain intensity, pain interference, and analgesic consumption in the 7 postoperative days for both groups was examined with 2-way analysis of variance (ANOVA) with repeated measures on 1 factor, such as time with 4 levels (day 1, day 2, day 3, and day 7), and 1 nonrepeated factor (group) with 2 levels (experimental group and control group). The same type of analysis was used to assess the evolution of the patients’ pain barriers and tendency to catastrophize at baseline and on day 7. If interactions were found ($P < .05$), post-hoc comparisons were performed. Independent *t* tests were conducted at each time to compare groups and 1-way repeated-measure ANOVA for each group to study time effects. Chi-square tests were conducted to compare the proportion of patients with pain intensity and pain-related interference ≥ 7/10.

Results

A total of 88 potential participants were approached. Of these, 10 (11%) did not meet the selection criteria (4 were not French-speaking, 1 was deaf, 3 were scheduled for a second surgery, 1 had a stent, and 1 had a cognitive disorder), and 18 (20%) refused to participate (males: 13/18, 72%; females: 5/18, 28%). A sample of 60 patients was recruited over 4 months from February to June 2010. The number of participants at each phase of the trial is illustrated by the Consolidated Standards of Reporting Trials (CONSORT) diagram (Figure 4) [48]. Four patients in the control group did not receive allocated intervention. All patients from the experimental group received SOULAGE-TAVIE (Web session plus 2 booster sessions). Six patients were lost at follow-up in the control group. A total of 52 patients were included in the analysis. Eight patients were excluded from analysis because pain measures were not available.

Figure 4. CONSORT flow diagram of participants.



[a] Reasons for refusal were: patient's frustration related to cancellation of surgery (n=3); bad experience with research (n=1); participation in another project (n=4); stress/fatigue (n=6); not interested/personal beliefs (n=4)

Sample Characteristics

Descriptive data for sociodemographic, psychological, and medico-surgical variables are presented in Table 3. The sample included 21% (11/52) of women and 79% (41/52) of men with a mean age of 64 years (range 41-85). No statistically significant differences between the control group and the experimental group were found at baseline for their sociodemographic characteristics. The two groups were comparable in their anxiety level (HADS) before surgery (control group mean 8.32, SD 5.17; experimental group mean 6.77, SD 4.44) and on day 7 after surgery (control group mean 5.84, SD 3.25; experimental group mean 5.37, SD 4.15). The same was true for their depression levels (HADS) prior to surgery (control group mean 2.86, SD 2.29; experimental group mean 3.67, SD 3.40) and after surgery (control group mean 4.21, SD 4.01; experimental group mean 4.30, SD 3.32). No statistically significant differences were found in the medico-surgical variables, except for the number of grafts. The experimental group had a higher number of grafts than the control group. The control group spent more time in the ICU and SCU. These results are explained by one outlier in the control group for both measures. Medians were similar with 17 hours in intensive care for the control group and 14 hours for the experimental group and 7.5 days in postoperative care for the control group and 7 days for the experimental group.

Table 3. Demographic and clinical characteristics of the participants in the control and experimental groups.

Variables		Control group n = 22	Experimental group n = 30	*P* value
Sex, n (%)				.81
	Female	5 (23)	6 (20)	
	Male	17 (77)	24 (80)	
Age, mean (SD)		63.2 (9.9)	64.6 (8.2)	.58
Marital status, n (%)				.89
	Single	1 (4)	1 (3)	
	Married or free union	14 (64)	21 (70)	
	Separated/divorced/widowed	7 (32)	8 (27)	
Living arrangements, n (%)				.11
	Lives with spouse (with or without children)	14 (64)	22 (73)	
	Lives with family member or friend	3 (14)	0 (0)	
	Lives alone	5 (22)	8 (27)	
Education level, n (%)				.19
	Primary	6 (27)	6 (20)	
	Secondary	6 (27)	8 (27)	
	High school	2 (9)	10 (33)	
	University	8 (37)	6 (20)	
Employment status, n (%)				.10
	Full time/part time	10 (45)	14 (47)	
	Unemployed/student	3 (14)	4 (13)	
	Retired	9 (41)	12 (40)	
Annual income, n (%)				.77
	< CAD $25,000	9 (41)	10 (36)	
	< CAD $55,000	10 (45)	12 (43)	
	≥ CAD $55,000	3 (14)	6 (21)	
Presence of chronic pain, n (%)		9 (41)	10 (33)	.57
Duration of chronic pain in months, mean (SD)		111.3 (157.1)	142.4 (187.5)	.70
Type of surgery, n (%)				.48
	CABG	11 (50)	20 (69)	
	Valve replacement (VR)	5 (23)	4 (14)	
	CABG + VR	6 (27)	5 (17)	
Presence of postoperative complication(s), n (%)		15 (68)	13 (45)	.10
Use of patient-controlled analgesia, n (%)		13 (59)	17 (59)	.97
Number of grafts, mean (SD)		2.47 (1.0)	3.29 (1.1)	.02
Anesthesia duration in minutes, mean (SD)		204.9 (82.6)	210 (70.2)	.82
Opioid dose during surgery expressed into morphine equivalents, mean (SD)		51.0 (36.7)	50.3 (35.7)	.95
Intensive care length of stay in hours, mean (SD)		84.7 (202.7)	32.0 (24.8)	.17
Postoperative length of stay in days, mean (SD)		11.2 (9.6)	7.5 (3.3)	.06

Pain Intensity

Statistical analyses revealed no significant group by time interactions for the 4 pain intensity measures (average and worst pain upon movement in the past 24 hours, present pain upon movement, and present pain at rest). Pain intensity scores decreased significantly over time in both groups ($P = .001$). Because the experimental group had significantly more grafts than the control group, a repeated-measures analysis of covariance (ANCOVA) was performed including the number of grafts as a covariate for pain intensity results. Conclusions were similar to those of the ANOVA. No statistically significant difference was found between groups in the proportion of participants suffering from severe pain (intensity ≥ 7/10) on the 4 measures of pain for each time point.

Pain Interference With Daily Postoperative Activities

No significant group by time interactions were found for the total pain interference BPI scores. The same was true for each subscale of the BPI measuring pain interference with different aspects of daily living. The items *walking* and *appetite* were removed from analysis at day 1; most patients did not answer this item because it did not apply to their condition. However, patients of the experimental group tended to report that their pain interfered less with deep breathing and coughing ($F_{1,31} = 4.09$; $P = .05$), as expressed by their postoperative mean on this subscale at each time (day 1 mean 4.7, SD 2.5; day 2 mean 4.9, SD 2.7; day 3 mean 3.6, SD 1.9; and day 7 mean 3.4, SD 2.6) compared to the control group (day 1 mean 6.2, SD 2.8; day 2 mean 6.1, SD 3.2; day 3 mean 5.4, SD 3.8; and day 7 mean 5.0, SD 3.8).

A second set of analyses was carried out to compare the percentage of patients in each group who reported severe pain interference (score ≥ 7/10) on the different subscales of the BPI. As shown in Table 4, a statistically significant difference in favor of the experimental group was found on the deep breathing and coughing subscale on day 3 ($P = .04$) and a result close to statistical significance emerged on day 7 ($P = .06$). A significantly lower percentage of patients in the experimental group also reported severe pain-related interference on their appetite on day 7 when compared to the control group ($P = .02$). Results close to statistical significance were also observed in the experimental group with regards to pain interference with walking ($P = .06$) and concentration ($P = .06$) on day 2 postoperatively.

Table 4. Number and percentage of patients who reported severe pain interference (≥ 7/10) in specific activities as assessed by the Brief Pain Inventory (BPI) in the control and experimental groups.

Activities	Day 1		Day 2		Day 3		Day 7	
	n/N (%)	*P* value	n/N (%)	*P* value	n/N (%)	*P* value	n/N (%)	*P* value
Walking		n/a[a]		.06		.19		.42
Experimental group	n/a[a]		2/21 (9)		3/27 (11)		4/30 (13)	
Control group	n/a[a]		5/14 (36)		4/15 (27)		4/18 (22)	
Appetite		n/a[a]		.50		.98		.02
Experimental group	n/a[a]		4/26 (15)		5/27 (18)		1/30 (3)	
Control group	n/a[a]		4/17 (23)		3/16 (19)		5/19 (26)	
Concentration		.18		.06		.23		.93
Experimental group	4/25 (16)		3/26 (11)		3/27 (11)		5/30 (17)	
Control group	6/18 (33)		6/17 (35)		4/16 (25)		3/19 (16)	
Breathing and coughing		.23		.28		.04		.06
Experimental group	8/25 (32)		8/26 (31)		4/27 (15)		3/30 (10)	
Control group	9/18 (50)		8/17 (47)		7/16 (44)		6/19 (31)	

[a] n/a: not applicable to the patients' condition

Pain Barriers and Catastrophizing

A significant group by time interaction was found for attitudes related to harmful effects of analgesic medication ($F_{1,46} = 5.61$; $P = .02$), as shown in Table 5. Post-hoc tests revealed that the experimental group had significantly fewer of these barriers than the control group at day 7 ($P = .03$). Since groups were not significantly different at baseline ($P = .61$), it seems that they experienced a different evolution after surgery that made them significantly different at day 7.

Table 5. Mean scores on the Barriers Questionnaire-II (BQ-II) for the control and experimental groups.

	Baseline, mean (SD)		Day 7, mean (SD)		*P* value		
	Experimental	Control	Experimental	Control	Group	Time	Interaction
Subscales of BQ-II							
Secondary effects	20.4 (12.4)	25.1 (12.2)	17.7 (14.7)	26.9 (15.1)	.06	.81	.22
Harmful effects	12.6 (8.0)	13.4 (8.5)	10.6 (8.3)	15.8 (7.3)	.18	.80	.02
Fatalism	1.8 (2.5)	1.7 (2.6)	2.2 (2.5)	0.8 (1.0)	.23	.46	.07
Communication	11.1 (8.5)	8.2 (6.4)	9.7 (7.6)	10.6 (7.7)	.62	.65	.07
Global score on the BQ-II	45.9 (25.9)	47.9 (19.5)	40.2 (29.4)	53.3 (27.7)	.29	.95	.07

The experimental group exhibited fewer pain-related attitudes on day 7 than the control group, although this did not meet statistical significance (*P* = .07). Since groups were equivalent at baseline (*P* = .36), patients of the experimental group tended to exhibit fewer pain-related attitudes at day 7, as expressed by their means (prior to surgery mean 45.9, SD 25.9; day 7 mean 40.2, SD 29.4) compared to the control group (prior to surgery mean 47.9, SD 19.5; day 7 mean 53.3, SD 27.7). Since the study involved a restricted sample, this result may suggest a lack of power to detect a treatment effect on global pain-related barriers. A power calculation was then run regarding the evolution of means for the global score on the BQ-II between day 2 and day 7 after surgery, group sample sizes of 56 (N = 112) achieve 80% power to detect a difference in mean scores with a significance level (alpha) of .05 by using a 2-sided 2-sample *t* test.

Results obtained on the PCS revealed no group by time interaction. However, mean scores for both groups suggest that patients showed a low tendency to catastrophize in face of pain before (control group mean 1.04, SD 0.74; experimental group mean 1.10, SD 0.95) and after surgery (control group mean 1.19, SD 0.94; experimental group mean 1.08, SD 0.99).

Analgesic Consumption

As seen in Table 6, results of the statistical analysis revealed a group by time interaction with regard to opioid consumption after surgery indicating that the intake was higher in the experimental group than the control group ($F_{6,240} = 4.06$; *P* = .001). However, post-hoc tests revealed that the group difference was statistically significant only on day 2 (*P* = .006).

Table 6. Opioid dose after surgery expressed into milligrams (mg) of morphine equivalents for both control and experimental groups.

Postsurgery day	Opioid dose (mg morphine)		*P* value
	Control group mean (SD)	Experimental group mean (SD)	
Day 1	21.9 (13.4)	26.4 (16.2)	.65
Day 2	18.8 (15.3)	31.2 (23.2)	.006
Day 3	13.3 (12.6)	17.7 (15.4)	.11
Day 7	3.2 (4.5)	4.3 (7.1)	.57

Discussion

This study examined the preliminary effects of a Web-based nursing intervention for postoperative pain after cardiac surgery and showed promising results supporting the short-term benefits of SOULAGE-TAVIE for improving important postoperative pain-related outcomes. Our findings showed that patients who received the intervention reported significantly less pain interference when breathing and coughing, exhibited fewer pain-related barriers, and consumed more opioid medication than those of the control group. However, delivery of the intervention did not translate into less-intense postoperative pain.

Significant Results

Pain severity can be assessed by its intensity and also by its impact on various aspects of daily living [38,49]. In the present study, no group difference was found for pain intensity, but patients of the control group reported significantly more pain interference with breathing/coughing. An earlier randomized controlled trial (RCT) [11] evaluated the effects of an educative pamphlet with the same population. They recorded a difference between groups regarding pain impact on breathing/coughing on day 5. However, in the current study, the difference was observed earlier (day 3) and results suggested that this tendency was maintained until day 7. At the usual time of discharge (day 7), patients from the control group still experienced a moderate level of pain interference with breathing/coughing compared to a mild level for the experimental group. Important results from a clinical point of view were also found for concentration, appetite, and especially walking. Breathing/coughing and walking are practiced early in the postoperative phase and are crucial activities for patients' recovery [50,51].

Because SOULAGE-TAVIE was meant to promote self-management, one of the most interesting results is that it had an effect on analgesic consumption. Several studies underlined the lack of analgesia in the surgical population [8,11,12]. Until now, no intervention, even when targeting pain-related barriers, had an effect on opioid intake [11,42]. Results of our study revealed that, compared to the control group, the experimental group consumed significantly more opioids on day 2 (ie, after their transfer from intensive care) although modes of analgesia required more involvement (PCA vs as needed). For that matter, a booster session of SOULAGE-TAVIE was given at that time point. A difference of 60% in the opioid consumption was recorded when patients started moving more (day 2).

The presence of pain barriers has already been associated with a low analgesic intake [30,42,52]; therefore, it is not surprising that the intervention also modulated the evolution of attitudes toward harmful effects of medication (ie, one of the targets of the intervention). Indeed, the experimental group exhibited significantly fewer of these pain-related attitudes on day 7. A previous RCT on an educative intervention (pamphlet and group meeting) in the same population had found a significant difference between groups on some negative pain-related attitudes on day 5 [11]. Another RCT tested an individualized intervention targeting pain-related barriers in persons suffering from cancer pain and showed a greater decrease of these attitudes in its experimental group [42]. These studies reported interesting results, but the present one showed that groups evolved differently after their surgery.

It is difficult to delineate the specific contribution of the intervention's components. However, some principles were considered during the development of SOULAGE-TAVIE and can be taken into account. It should first be noted that the elaboration likelihood model and predictors, such as pain barriers and catastrophizing, were used to select intervention techniques and develop messages. This procedure was found to be more effective to influence behavior change, particularly with Internet-based interventions [22,28]. The main difference between SOULAGE-TAVIE and previous tested interventions (standardized, individualized) for pain relief is the computer-tailoring approach that improves health behaviors through the delivery of highly personalized messages [20,24,28]. Such messages stimulate the motivation to reflect on attitudes and suggested behavior [28,29]. This thoughtful process is associated to higher persistence of attitude change, stronger resistance to counter-persuasion and consistency between attitude and behavior [29,53]. The combination of computer-tailoring and persuasive communication techniques generated the use of various strategies to build messages, which was also found to increase the effect of Internet-based interventions [22]. SOULAGE-TAVIE used three strategies of tailoring (personalization, content matching, and feedback). The combination of these strategies increases the consideration of messages [20,28,54]. However, feedback seems to be the most efficacious [20,28]. The combination of various types of feedback, ie, descriptive, comparative (normative), and evaluative, is also known to be more beneficial [20,24,28]. Moreover, promoting social comparison (comparative feedback) and providing feedback on performance (evaluative feedback) through Internet-based interventions was found to influence behaviors [22].

Interactive health technologies (IHT) also contributed to the success of SOULAGE-TAVIE because of their attractiveness, diversity, and flexibility [23,27,55]. The SOULAGE-TAVIE application allowed the mix of modalities (animation, quiz, case history, and virtual nurse's advice) that helped to avoid redundancy of messages and to keep the participant's attention [23,24,29]. The virtual nurse was an original way to convey educational messages, because computer-tailored messages are still primarily transmitted in a written format even when the intervention is provided through the Internet [20,24]. The goal was not to replace a real patient-nurse relationship, but the personification of feedback was meant to give the sense of an interaction and personalized consultation [27]. Personal contact seems to support behavior change in Internet-based interventions [22]. Finally, because of IHT, not only static tailoring (predetermined algorithm) was possible, but dynamic tailoring (in real time) was also provided, which has already been associated with larger effects on behaviors [20].

Nonsignificant Results and Limitations

As mentioned, pain intensities were not affected by our intervention as observed earlier [11]. Some authors highlighted unspecific effects in intervention research that could explain this phenomenon, such as therapeutic alliances but also patients' expectations [56-58]. However, this result is more surprising in this study, because the experimental group consumed more opioid medication. This finding could be explained by the fact that the experimental group experienced less pain interference and consequently practiced more postoperative activities resulting in more pain. Hence, from a clinical point of view, the experimental group reported less postoperative complications than the control group (45% vs 68%).

The tendency to catastrophize in face of pain was found to be quite low in both groups of patients and the recruitment timing might explain this phenomenon. Patients were recruited at the time of admission on the cardiac surgical unit. The announcement of their diagnosis and open-heart surgery was often made a few hours before as the surgeons avoided the use of a waiting list. Pain catastrophizing has been studied in elective cardiac surgical patients, but authors did not underline the timing of the announcement versus recruitment [15]. Other authors studied pain catastrophizing in relation to postoperative pain with a variety of clienteles excluding emergency and cardiac surgical patients [14] (ie, in patients who are in a less life-threatening situation).

The present study has some limitations. With respect to internal validity, unblinding of the research assistant could have occurred although the data collection took place on two departments (ICU and SCU) and at different times than the intervention. Contamination was possible postoperatively during boosters, but the main content was given preoperatively through the Web session. It should also be noted that the intervention was always provided by the same person. This may have increased uniformity in the intervention's delivery, but increased the possibility of a practitioner effect on patient outcomes as well [57,59,60].

Future Research

SOULAGE-TAVIE is a first and promising attempt at educating people on pain relief, particularly in the acute care setting, as recent reviews on computer-tailored and Web-based interventions do not report interventions targeting pain [20,24]. Research avenues are numerous with regard to this approach because of computer tailoring and IHT. For instance, the influence of sociodemographic variables (eg, sex differences) on learning and clinical outcomes has been observed in the cardiac surgery population [61-63]. Because it was not possible to examine these differences in the context of a pilot study with a restricted sample, it would be interesting to further explore these patients' characteristics in a large-scale study on the efficacy of SOULAGE-TAVIE. The influence of mediators and/or moderators related to delivery of computer-tailored interventions through IHT has not really been investigated [20]. Again, individual characteristics and related preferences could influence the impact of this media. In the case of SOULAGE-TAVIE, there is a need to examine whether the presence of the virtual nurse complemented the benefits of the highly personalized messages.

Conclusions

In conclusion, it seems possible to influence pain management behavior with a brief intervention if educative messages are tailored and personally relevant for the individual. The findings of this pilot RCT provide promising support for the benefits of a Web-based and tailored nursing intervention on postoperative pain management. In contrast to other educational approaches for pain management, SOULAGE-TAVIE included specific mechanisms and strategies of personalization and feedback. The preliminary effects are encouraging enough to warrant further efficacy and long-term effectiveness evaluation of this new educational tool.

Nursing holds a privileged place to intervene in the primary prevention of pain. Improving health information before and after surgery can decrease barriers to pain management through patient empowerment and self-management of pain [33]. Since this intervention could be offered on the Web, this format can increase accessibility to health education without generating more costs [8,42,51]. The development of new and cost-efficient ways to care for patients with acute pain, the most commonly experienced pain, is crucial to decrease the gap between evidence and practice results of undertreatment [32,35].

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Conflicts of Interest

None declared.

Multimedia Appendix 1

CONSORT-EHEALTH checklist V1.6.1. [64].

[PDF File (Adobe PDF File), 434KB - jmir_v14i6e177_app1.pdf]

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Abbreviations

ANCOVA: analysis of covariance
ANOVA: analysis of variance
BPI: Brief Pain Inventory
BQ-II: Barriers Questionnaire-II
CABG: coronary artery bypass graft
CHUM: Centre hospitalier de l’Université de Montréal
HADS: Hospital Anxiety and Depression Scale
ICU: intensive care unit
IHT: interactive health technologies
IMMPACT: Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials
NRS: numerical rating scale
PCA: patient-controlled analgesia
PCS: Pain Catastrophizing Scale
RCT: randomized controlled trial
SCU: surgical care unit
VR: valve replacement

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Original Paper

Differences in Reach and Attrition Between Web-Based and Print-Delivered Tailored Interventions Among Adults over 50 Years of Age: Clustered Randomized Trial

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Abstract

Background: The Internet has the potential to provide large populations with individual health promotion advice at a relatively low cost. Despite the high rates of Internet access, actual reach by Web-based interventions is often disappointingly low, and differences in use between demographic subgroups are present. Furthermore, Web-based interventions often have to deal with high rates of attrition.

Objective: This study aims to assess user characteristics related to participation and attrition when comparing Web-based and print-delivered tailored interventions containing similar content and thereby to provide recommendations in choosing the appropriate delivery mode for a particular target audience.

Methods: We studied the distribution of a Web-based and a print-delivered version of the Active Plus intervention in a clustered randomized controlled trial (RCT). Participants were recruited via direct mailing within the participating Municipal Health Council regions and randomized to the printed or Web-based intervention by their region. Based on the answers given in a prior assessment, participants received tailored advice on 3 occasions: (1) within 2 weeks after the baseline, (2) 2 months after the baseline, and (3) within 4 months after the baseline (based on a second assessment at 3 months). The baseline (printed or Web-based) results were analyzed using ANOVA and chi-square tests to establish the differences in user characteristics between both intervention groups. We used logistic regression analyses to study the interaction between the user characteristics and the delivery mode in the prediction of dropout rate within the intervention period.

Results: The printed intervention resulted in a higher participation rate (19%) than the Web-based intervention (12%). Participants of the Web-based intervention were significantly younger ($P<.001$), more often men ($P=.01$), had a higher body mass index (BMI) ($P=.001$) and a lower intention to be physically active ($P=.03$) than participants of the printed intervention. The dropout rate was significantly higher in the Web-based intervention group (53%) compared to the print-delivered intervention (39%, $P<.001$). A low intention to be physically active was a strong predictor for dropout within both delivery modes ($P<.001$). The difference in dropout rate between the Web-based and the printed intervention was not explained by user characteristics.

Conclusions: The reach of the same tailored physical activity (PA) intervention in a printed or Web-based delivery mode differed between sociodemographic subgroups of participants over 50 years of age. Although the reach of the Web-based intervention is lower, Web-based interventions can be a good channel to reach high-risk populations (lower PA intention and higher BMI). While the dropout rate was significantly higher in the Web-based intervention group, no specific user characteristics explained the difference in dropout rates between the delivery modes. More research is needed to determine what caused the high rate of dropout in the Web-based intervention.

Trial Registration: Dutch Trial Register (NTR): 2297: http://www.trialregister.nl/trialreg/admin/rctview.asp?TC=2297 (Archived by WebCite at http://www.webcitation.org/65TkwoESp).

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KEYWORDS

Web-based; print-delivered; physical activity; older adults; response; reach; adoption; attrition; dropout; tailored advice

Introduction

During the last few decades, computer tailoring has become an important method to provide individuals with personalized health promotion advice [1]. Computer tailoring is a method that uses questionnaires to assess individual participants and to automatically produce feedback, based on the assessment, using computer-based data-driven decision rules. The feedback is automatically adapted to the personal characteristics of the participant [2,3]. Several studies confirmed the effectiveness of computer tailoring in terms of behavioral change by providing tailored health promotion advice [2,4,5].

While printed materials were previously one of the most used communication channels of tailored interventions, the Internet has become more popular in recent years. The Internet has the potential to provide large populations with individual advice at a relatively low cost and without intensive labor [6]. Recently, an enormous increase in Internet use has taken place in older age groups and lower socioeconomic status (SES) groups [7]. In Europe, Internet access ranges from 45% of the population in Bulgaria to 94% of the population in the Netherlands (where the current study was performed) [8]. Although home Internet access in the Netherlands is still relatively low (68%) for people over the age of 65 years, 91% of people between the age of 55 and 65 had home Internet access in 2010 [7]. Furthermore, differences in Internet access between SES groups have become much smaller (87% in low SES groups, 98% in high SES groups [7]). This indicates that low SES and old age are no longer barriers for Web-based interventions. Evidence-based Web-based interventions are particularly relevant for older age groups, as they are the fastest growing online user group and tend to have the most interest in and need for health-related subjects [9]. Of people over 55 years of age who use the Internet, 81% are interested in finding health information online [10].

Despite the high rates of Internet access, Web-based interventions do not often reach the intended target population. Different demographic groups, based on age or SES for example, use and respond to Web-based interventions differently [7,11,12]. The response rates to Web-based questionnaires are often significantly lower than the response rates to similar printed questionnaires [13-15]. Furthermore, Web-based interventions often experience high attrition rates. For Web-based interventions to achieve the optimal impact on public health, more insight related to reach and attrition of such interventions is of major importance. To our knowledge, no previous studies have been performed to compare the reach and attrition of a Web-based intervention to a print-delivered intervention targeted at a population over 50 years of age.

Several models have emphasized the importance of gaining insight into the reach and attrition of an intervention, including the RE-AIM framework [16,17] and McGuire's persuasion-communication matrix [18]. The RE-AIM framework argues that the public impact of an intervention is a function of 5 factors: reach, efficacy, adoption, implementation, and maintenance [19]. According to McGuire's persuasion-communication matrix [18], the channel of an intervention (ie, the delivery mode) and the characteristics of the user may influence decision making on the use of an intervention. Insight into the specific characteristics of the users of the intervention in different delivery modes could help future researchers choose the appropriate delivery mode for a particular target audience. It may also facilitate and optimize the adoption, reach, and impact of evidence-based tailoring of interventions for public health in the future.

To determine whether differences in reach and attrition rates are related to the delivery channel and not to the intervention itself, this study compares a Web-based and print-delivered tailored intervention with similar content. The Dutch Active Plus intervention, which can be delivered as a print or Web format, consists of tailored advice designed to stimulate physical activity (PA) among the aging population [20-23]. Previous studies have proven that the print-delivered intervention is effective in stimulating PA among people over the age of 50 [23,24]. The printed version was translated into a Web-based version [22], and the effectiveness of the online version is currently being evaluated. Preliminary results show that the printed and Web-based interventions are equally effective in promoting PA behavior after 6 months [25]. On 3 different occasions, the intervention provided tailored advice based on individual assessments from a questionnaire. Since this intervention contains multiple instances of advice, our study was concerned with both the reach of the intervention and the attrition to the follow-up advice. For thorough, overall insight into the impact of an intervention such as Active Plus, in addition to the effectiveness we need insight into the selective reach and attrition of the intervention in the different delivery modes [26].

Based on epidemiological evidence and previous studies, we expect that Web-based interventions will have a lower reach to the low SES and older age groups compared to print-delivered interventions [7,27-29]. It is not clear whether participation in Web-based interventions will be gender dependent in an older population. Earlier studies of tailored PA advice distributed to adults via the Internet showed that more women than men participated in Web-based interventions [12,30]. However, epidemiological evidence suggests that Internet access rates are higher among men in an older population [7,8]. The differing results from these studies may be due to differences in age, and more research will be needed to clarify the gender-dependent participation rates. This study provides insight into the differences in user characteristics related to the reach and attrition of a Web-based intervention compared to a print-delivered intervention among people over 50 years of age. Especially in older populations, Web-based tailored interventions might be more desirable and have advantages over printed tailored interventions. To our knowledge, no previous studies have investigated which user characteristics are related to the participation and attrition of a tailored intervention for an older population in different delivery modes. Differences in the usage and dropout rates between two delivery modes of an intervention can be a metric for the usability of a system and might be useful in determining the best distribution strategy [26]. Identifying which user characteristics are related to both the reach and attrition of an intervention can guide the appropriate selection of the delivery mode to a target subgroup, thereby increasing the public impact of future interventions.

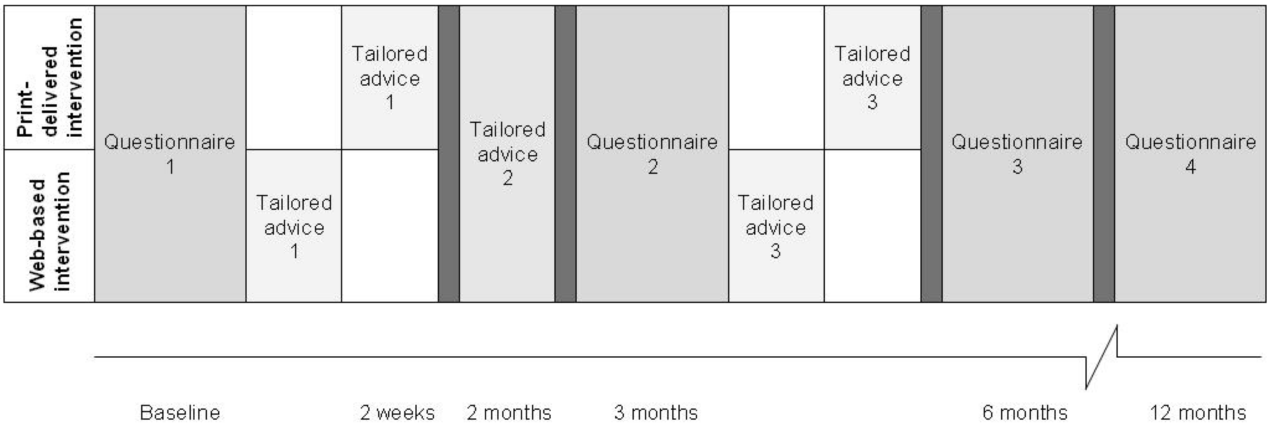
Methods

Study Design

This study is part of a randomized controlled trial (RCT). For the assessment of the effectiveness of the intervention, a control group (which received no advice) was included in this study. Since the scope of this paper includes the reach and attrition of the intervention (which is compared between the Web-based and the print-delivered intervention group), the control group was excluded from this analysis.

Participants of both the print-delivered and Web-based intervention received tailored advice on 3 occasions, based on 2 questionnaires (written or Web-based) that they completed. Participants completed the first questionnaire at the start of the intervention (as input for the first and second sets of tailored advice) and a second questionnaire after 3 months (as input database for the third tailored advice). Figure 1 gives an overview of the timeline for this intervention. For analytical purposes, additional assessments took place at 6 and 12 months after the baseline, including a process evaluation (at the 6-month questionnaire) to assess how many individuals followed the advice. The 6- and 12-month questionnaires are not considered part of the intervention.

Figure 1. Timeline of the study.



Tailored Intervention

The Active Plus interventions are designed to stimulate or maintain PA among people over 50 years of age. These computer-tailored, theory- and evidence-based interventions were systematically developed using the intervention mapping protocol [20,22]. Originally, 2 print-delivered Active Plus interventions were developed and tested for effectiveness. The first was a basic computer-tailored intervention (tailored to personal and psychosocial characteristics). The second was the same intervention extended with additional environmental components that focused on giving tailored advice on local options and initiatives for being physically active. The additional environmental components intended to positively change peoples' perceptions of the possibilities to be physically active in their own locale [21]. Both interventions aimed to influence awareness, initiation, and maintenance of PA by targeting premotivational constructs (ie, awareness and knowledge), motivational constructs (ie, attitude, self-efficacy, social influence, intrinsic motivation, and intention), and post-motivational constructs (ie, commitment, strategic planning, self-regulation skills, action planning, and coping planning) [20]. Previous studies showed that both print-delivered interventions were effective in stimulating PA among people over 50 years of age [23,24].

In 2010, both of the print-delivered interventions described above were adapted and translated into a Web-based intervention [22] using the RE-AIM framework. The content of the Web-based intervention was identical to that of the print-delivered interventions, but the display output of the interactive components in the Web-based version was different (eg, static modelling pictures were transferred into videos, a print-delivered map was transferred into Google Maps, and several hyperlinks were added).

Based on their answers given in the assessments [20,22], participants received tailored advice on 3 occasions (Figure 1):

(1) within 2 weeks after the baseline assessment, (2) 2 months after the baseline assessment, and (3) within 4 months after the baseline assessment (based on the second assessment). The Web-based intervention participants received an email with a link that connected them with their online tailored advice. Additionally, they received an email with a copy of the personal advice in the same format as the print-delivered version. The tailored advice contained between 5 and 11 pages of text and illustrations, depending on changes in PA behavior and determinant scores. A more detailed description of the intervention content can be found elsewhere [20,22].

Participants and Procedure

Intervention participants (adults over 50 years of age) were recruited via direct mailing in communities of the participating Municipal Health Council (MHC) regions (N=5; excluding control group participants). To prevent participants from the different intervention conditions contaminating each other, the intervention conditions were located in separate but comparable MHC regions. The regions were randomly assigned to one of the different intervention conditions (ie, Web-based basic, Web-based environment, printed basic, or printed environment). All participants were assigned to one of the intervention conditions based on their region and could not make a choice in the delivery mode of the intervention. This design offers optimal insight into the consequences for response and attrition when using only 1 of the 2 modes for intervention delivery.

For each intervention condition, we selected 14 (matched) neighborhoods: 6 less urban neighborhoods (500-1000 addresses per km^2) and 8 modestly urban neighborhoods (1000-1500 addresses per km^2, Figure 2). We matched the neighborhoods based on their urban character, percentage of people with a low SES, percentage of people with a high SES, percentage of immigrants (also to ensure that we reached mostly Dutch-speaking people), and the percentage of people over 50 years of age. This information was provided by the Dutch Central Bureau for Statistics. Each MHC provided a random sample of eligible participants living in the selected matched neighbourhoods after stratification for age. Therefore, the distribution of differences in age and SES among the invited adults was expected to be equal between the intervention conditions.

In the regions of the print-delivered intervention, a sample of eligible participants (n=4648) received an invitation for the print-delivered intervention. This invitation included an information letter, a questionnaire, a prepaid return envelope, and a form to give informed consent. Because we expected a lower response in the Web-based intervention conditions, we included a larger sample of eligible participants (n=7168) in the regions of the Web-based intervention. Eligible participants received an invitation via written mail, containing a similar information letter about the project, additional information about how to complete an online questionnaire, and a personal username and password to log on to the Active Plus website. People who did not receive an invitation could not participate in this program. A power calculation (effect size=0.4, power=80%, intracluster correlation coefficient =.1) showed that at baseline about 420 participants were needed for each intervention condition (considering a dropout rate of 40% during the 1-year follow-up based on a previous Active Plus study) [22].

Within both the Web-based and print-delivered intervention groups, participants received the basic tailored intervention or the basic intervention with additional environmentally tailored information, depending on their MHC region. Since the aim of this study was only to investigate how the delivery channel (printed or Web-based) and user characteristics are related to dropout and attrition, and not to determine how the content of the message (eg, providing additional environmental information) influences attrition, both of the print-delivered and both of the Web-based intervention groups were considered together. Dropout analyses were corrected for the possible influence of the intervention type.

Participants were enrolled when they completed the baseline questionnaire. For the second assessment, participants of the print-delivered intervention group received an invitation by written mail, which included the follow-up questionnaire and a prepaid return envelope. Participants of the Web-based intervention group received invitations for the follow-up assessment by email, which included a link to the Web-based questionnaire. All participants were asked to complete the questionnaire within 2 weeks. Participants of the print-delivered intervention group who did not complete the questionnaire received a reminder by mail after 2 weeks. Since the response was lower in the Web-based intervention group than in the print-delivered intervention group and sending reminders electronically does not result in additional postage costs, for the follow-up assessment the Web-based intervention group received multiple reminders (9 days and 18 days after the invitation). Since it was not guaranteed that our target population received the online reminders (eg, redirected to spam folders), this group also received an additional reminder by written mail.

This study is approved by the Medical Ethics Committee of Atrium-Orbis-Zuyd (code 10-N-36) and was registered in the Dutch Trial Register NTR 2297.

Figure 2. Flowchart showing selection of participants for the print-delivered and Web-based intervention groups.

Measurements

The baseline questionnaire included questions about demographics, PA behavior, and sociocognitive determinants of PA behavior. Demographic variables included age, gender, height, weight, and highest education level completed. Education level was categorized into low (primary, basic vocational, or lower general school) and high (higher general secondary education, preparatory academic education, medium vocational school, higher vocational school, or university level), according to the Dutch education system. Body mass index (BMI) was calculated by dividing weight in kilograms by height in metres squared [23]. Participants were classified as being underweight (BMI < 18.5 kg/m^2), a healthy weight (BMI 18.5–24.9 kg/m^2), or overweight (BMI > 25 kg/m^2).

Total weekly days and minutes of PA were measured using the validated self-administered Dutch Short Questionnaire to Assess Health Enhancing Physical Activity (SQUASH) [31]. This questionnaire allows the calculation of the total minutes of moderate- and vigorous-intensity activity per week. It also helps classify participants according to the international guideline for sufficient PA (PA guideline), which is being physically active with moderate to vigorous intensity for at least 30 minutes per day at least 5 days per week [32,33]. The participants' intention to be sufficiently physically active (according to the international PA guideline) was assessed using three items on a 10-point scale (eg, “To what degree do you intend to be sufficiently physically active?” 1 = Absolutely not, to 10 = Absolutely).

For process evaluation purposes, we asked participants whether they had actually read the advice (“Yes” or “No”) in the second questionnaire (after 3 months, following the first and second sets of tailored advice) and again in the third questionnaire (after 6 months, following the third provision of tailored advice).

Statistical Analysis

Response and Baseline Characteristics of the Study Population

We analyzed data for participants who completed the baseline questionnaire. We performed descriptive statistics on age, gender, education level, BMI, baseline PA, and intention to be sufficiently physically active to describe the characteristics of the participants. We used univariate one-way analyses of variance (ANOVA) and chi-square tests to determine whether the participants in the print-delivered and Web-based interventions differed on baseline characteristics. Furthermore, we used a chi-square test to find out whether the intervention types (ie, the basic tailored intervention or the tailored intervention with additional environmental information) were equally distributed to the print-delivered and Web-based intervention groups. There was no need to correct baseline data for the intervention type because the content of the baseline questionnaire was similar for all intervention groups.

Dropout Analysis

We performed hierarchical logistic regression analyses to determine whether participants’ characteristics were predictors of dropout at the 3-month questionnaire, correcting for intervention type (ie, basic or environmental intervention). We added the user characteristics (ie, age, gender, SES, BMI, intention, and PA behavior) to the second block of the regression analysis. To study whether the delivery mode of the intervention was related to participant dropout, we added the intervention delivery mode to the third block of the regression analysis. The influence of the delivery mode on participant dropout was thus corrected for by user characteristics. The fourth block of the regression analysis contained the interaction terms between the delivery mode and the user characteristics, to determine whether participant dropout was related to certain user characteristics in a specific delivery mode. Because the interaction terms have less power, the significance levels the interaction terms are defined at *P*=.10 [34]. When a significant interaction term was found, we performed subgroup analyses separately for the print-delivered and Web-based groups. All analyses were performed using SPSS version 18.0.

Results

Response and Baseline Characteristics of the Study Population

A total of 874 adults participated in the print-delivered intervention (response rate of 18.8%) and 855 adults participated in the Web-based intervention (response rate of 11.9%, Figure 3). Baseline characteristics for both intervention groups are shown in Table 1. We found significant differences between the intervention groups with respect to several characteristics. The sample for the Web-based intervention consisted of more men than the sample for the printed intervention (*P*=.01). Participants in the Web-based intervention were significantly younger (*P*<.001) and had a significantly higher BMI (*P*=.001) than the participants of the print-delivered intervention. We found no significant differences between low and high education level among the participants. Regarding PA behavior, the total minutes of moderate to vigorous PA did not differ significantly between the groups. The print-delivered intervention group had a significantly higher intention to be sufficiently physically active (*P*=.03). Participants of the print-delivered and Web-based intervention groups were equally distributed with respect to the basic and the environmental intervention types.

Table 1. Sociodemographic and behavioral baseline characteristics for the print-delivered and Web-based intervention groups.

			Print-delivered tailored advice(n=874)	Web-based tailored advice(n=855)	*P* value
Demographics					
	Gender (%)				.01
		Male	45.7	51.7	
		Female	54.3	48.3	
	Mean age in years (SD)		63.5 (9.06)	61.3 (7.32)	<.001
	Weight category (%)				.001
		Underweight	1.9	0.4	
		Healthy weight	47.5	42.6	
		Overweight	50.6	57.0	
	Education (%)				.51
		Low	45.4	47.0	
		High	54.6	53.0	
PA					
	Moderate- and vigorous-intensity PA, mean minimum/week (SD)		755.83 (786.92)	741.74 (840.65)	.72
	Intention to be sufficiently physically active, mean[a](SD)		7.73 (1.63)	7.56 (1.58)	.03
Intervention type (%)					.81
	Basic intervention		50.1	49.5	
	Environmental intervention		49.9	50.5	

[a] Likert scale, from 1 (“absolutely not”) to 10 (“absolutely”)

Figure 3. Flow diagram showing the reach, attrition, and usage of the print-delivered and Web-based Active Plus interventions.

Dropout Analysis

Of the Web-based intervention group, 402 respondents (402/855, 47.0% of baseline participants) completed the second questionnaire and received their third piece of tailored advice. In the print-delivered intervention group, 534 respondents (534/874, 61.1% of baseline participants) completed the second questionnaire. Figure 3 shows an overview of the response and attrition during this study. The figure also provides an insight into the number of participants who, in addition to filling in the second questionnaire, reported that they actually read the tailored advice (based on process evaluation data retrieved from the second and third questionnaires). The percentage of participants who reported to have read the advice is expressed as the number of people who reported to have read the advice, divided by the number of people who filled in the program evaluation question. The number of participants who reported that they read their advice was substantially smaller in the Web-based intervention than in the print-delivered intervention ($P<.001$).

At the 3-month measurement, significant differences in user characteristics between both intervention groups remained the same as the baseline measurement. Table 2 provides an overview of the predictors of participant dropout within the intervention period (ie, filling in the 3-month questionnaire). The explained variance (Nagelkerke R^2) of the different models is also presented in this table. The participants' intention to be physically active and the delivery mode of the intervention were both significant predictors of participant dropout. A higher intention was positively related to the completion of the intervention (*P*<.001), and participants of the Web-based intervention were more likely to drop out (*P*<.001). No other demographic characteristics (ie, baseline PA, age, SES, gender, BMI, and intervention type) were predictors of participant dropout. We found a significant interaction between age and the delivery mode (Exp(B)=1.026, SE=0.013, *P*=.05). No other significant interaction terms were found between the delivery mode of the intervention and the participants' characteristics. Subgroup analyses showed that in the print-delivered intervention group, age was not a significant predictor of participant dropout (Exp(B)=0.993, SE=0.009, *P*=.45). Analyses for the Web-based intervention group showed that a higher age might be an indicator for completion of the intervention (Exp(B)=1.019, SE=0.010, *P*=.05).

Table 2. Hierarchical logistic regression to study the relation between user characteristics, the intervention delivery mode and its interactions, in the prediction of attrition within the intervention period.[a]

	Step 1 (R^2=.001)			Step 2 (R^2=0.024)			Step 3 (R^2=0.051)			Step 4 (R^2=0.058)		
	Exp(B)	SE	*P*	Exp(B)	SE	*P*	Exp(B)	SE	*P*	Exp(B)	SE	*P*
First block												
Type[b]	0.876	0.099	.18	0.881	0.100	.21	0.884	0.101	.22			
Second block												
Baseline PA				1.000	0.000	.45	1.000	0.000	.45			
Intention				1.171	0.033	.000	1.159	0.033	.000			
Age				1.010	0.006	.12	1.005	0.006	.48			
SES[c]				0.956	0.104	.66	0.934	0.105	.51			
Gender[d]				1.044	0.104	.68	1.007	0.105	.95			
BMI				0.904	0.100	.31	0.928	0.101	.46			
Third block												
Delivery mode[e]							0.550	0.102	.000			
Fourth block												
Delivery x PA										1.000	.000	.50
Delivery x Intention										.951	.067	.45
Delivery x Age										1.026	.013	.05
Delivery x SES										.985	.212	.94
Delivery x Gender										.855	.211	.46
Delivery x BMI										1.304	.203	.19

[a] participants scoring 1 are more likely to complete the intervention, whereas scores of 0 indicate that participants are more likely to dropout

[b] basic coded 0, environmental coded 1

[c] low SES coded 0, high SES coded 1

[d] men coded 0, women coded 1

[e] printed coded 0, Web-based coded 1

Discussion

Response

The present study aimed to assess differences in user characteristics related to participation and attrition when comparing a print-delivered intervention and Web-based intervention to stimulate PA among people over 50 years of age. Our study showed that, in this population, the response rate to the print-delivered PA intervention (n=874/4648, 18.8%) was higher than the response rate to the Web-based intervention (n=855/7168, 11.9%). This finding indicates that using a computer might still be a barrier to participation. The difference in response rate may be due to a lack of motivation or limited skills in using the Internet among the target population. This difference is also acknowledged by Venkatesh's unified theory of acceptance and use of technology (UTAUT). According to this theory, performance and effort expectancy explain a large proportion of the variance in the intention to use a new technology [35]. This may imply that older adults' skills and self-efficacy in computer usage need to be increased to stimulate the adoption of Web-based interventions. Future researchers should study these barriers further, and may need to incorporate additional information or computer training in their recruitment or intervention to increase the computer skills and self-efficacy of older adults. However, differences in self-efficacy and computer skills among generations might decrease rapidly, since the adults of the current generation have more developed computer skills and are the elderly of the future.

Response rates in Web-based interventions reported in the literature vary substantially between studies. Differences can be caused either by the methodology of the study or by the characteristics of the population. Researchers have conducted several Web-based interventions in populations with known access to the Internet, which resulted in higher response rates than studies in populations without known access [15]. Discovering a lower response rate to a Web-based intervention compared to a print-delivered intervention is in agreement with the findings of a study by Kongved et al [15] that was conducted in a population without known Internet access. The study further showed that after a reminder, when the participants were free to choose between delivery modes, the total response rate was similar in the 2 groups. Similarly, a study by Ekman et al [36] showed that response rates were highest when 2 response methods (ie, print-delivered and Web-based) were offered. In our study, participants of the Active Plus intervention could not choose between delivery modes because different intervention conditions were located in different regions, which prevented participants contaminating each other's responses. Offering both delivery modes to the participants might have resulted in higher response rates, but would not have provided insight into the actual use of different single-delivery modes.

Another reason for the low response rate could be the length of our questionnaire. A review [37] to identify effective strategies to increase the response to postal and electronic questionnaires showed that the odds of response increased by more than half when participants received shorter questionnaires. The response rate improved with shorter print-delivered questionnaires (odds ratio (OR) 1.64) as well as in studies using electronic questionnaires (OR 1.73), compared to participants given longer questionnaires. Due to research requirements, filling in the Active Plus questionnaires took quite some time (the baseline questionnaire is about 24 pages). In a real-life setting, when no additional questions for research purposes are required, the length of the questionnaires can be shortened, which might result in a higher response rate and limit the dropout rates of the intervention.

We found significant differences between the print-delivered and Web-based intervention groups with respect to several characteristics. The sample for the Web-based intervention was significantly younger and consisted of more men. Both findings can be supported by epidemiological evidence that shows that Internet access is still lower in the over 65 age group, and that men use the Internet more frequently and intensively than women [7,8].

Furthermore, participants of the Web-based intervention had a significantly higher BMI and a lower intention to be sufficiently physically active. This might indicate that adults over 50 years of age who have a low intention to be sufficiently physically active might best be reached using a Web-based intervention. Together with the finding that the majority (480/842, 57.0%) of the Web-based intervention group had an unhealthy BMI, Web-based interventions might be the preferred medium to reach this high-risk population. These differences in user characteristics between print-delivered and Web-based intervention groups should also be taken into consideration when determining the possible effects of the intervention in different delivery modes. However, differences in participant dropout rate between both delivery modes should also be acknowledged.

In contrast to our expectations, no differences were found in education level between the Web-based and print-delivered intervention groups. This is in contrast to several other studies that show that Web-based interventions have a higher reach among high SES populations [38,39]. Possibly, education level is less important to Internet usage in an older population than in the general population. This finding can be explained further by the fact that one of the highest shares of home Internet access in Europe was recorded in the Netherlands (94% in 2011) [8], where differences in Internet access between SES groups has declined rapidly. As epidemiological data shows, in 2010, at the moment of implementing the Active Plus interventions, 87% of the low SES group and 98% of the high SES group in the general population had Internet access [7]. In 2011, the low SES group further increased their Internet access to 90% [7].

Dropout

Since the Active Plus intervention contains multiple provisions of advice, it is important that people continue their participation in the intervention. Our results show that only 61.1% (534/874) of the print-delivered intervention group and only 47.0% (402/855) of the Web-based intervention group filled in the second questionnaire and were thus eligible to receive the third follow-up tailored advice. Furthermore, the number of participants who reported reading their advice was substantially smaller in the Web-based intervention than in the print-delivered intervention. Participant dropout within the intervention period was therefore significantly higher in the Web-based intervention group than in the print-delivered intervention group. The difference in participant dropout rate between the intervention conditions was not explained by user characteristics. We found a significant interaction between the delivery mode and the participants' age in the prediction of participant dropout. Subgroup analyses showed that whereas age was not a predictor of participant dropout in the print-delivered group, there was an indication (almost significant predicator (P=.05)) that younger participants were more likely to drop out from the Web-based intervention. The finding that older adults are more likely to revisit the website is in line with other studies [12,40].

In both delivery modes, a low intention to be physically active was a significant predictor of participant dropout. It is self-evident that people with a lower intention to remain physically active are less likely to continue their participation. Since we also found that low intention participants more often participate in Web-based interventions, this would consequently lead to a higher dropout rate for Web-based interventions. Hence, additional strategies are needed to motivate adults with a low intention to continue their participation in health-promoting interventions. If these participants are less motivated by their health intention, this group needs additional motivators to continue. For example, motivation could be improved by making the intervention more exciting by including gaming elements or by focusing on other aspects besides health, such as news elements, sports games, or social activities.

Since participant dropout was significantly higher in the Web-based intervention and no significant factor was found for user characteristics explaining the differences in dropout rate between the delivery modes, the higher dropout in Web-based interventions must be related to other characteristics. A possible explanation is that it might require more planning to fill in a Web-based questionnaire than a print-delivered questionnaire. A print-delivered questionnaire can be filled in anywhere at anytime, while filling in an online questionnaire restricts one to a computer. Furthermore, in a printed questionnaire, the time required to fill in the questionnaire is more visible (you see the total package in one overview), and it is easier to continue filling in a printed questionnaire after pausing, rather than continuing a Web-based questionnaire, due to loading times and additional log-ins.

Strengths and Limitations

Although this study provides interesting data, some limitations should be noted. First of all, no information was available on those who did not respond to the intervention. We could have performed more predictive analyses if information about the nonparticipants was available to provide insight into the selection process. Second, participants could not choose between the different modes of delivery. They could only choose whether they would like to participate in the intervention with the particular delivery mode that was offered. Giving participants the option to choose between the delivery modes could provide additional insights into the reasons why people participate in a certain intervention. However, not allowing participants to choose between the delivery modes is also a strength—it gave us the opportunity to study the resultant absolute participation and attrition rates for a given delivery mode. In a real-life setting, an intervention is usually offered in only 1 delivery mode because offering both delivery modes results in additional planning and administration. The current design offers optimal insight into the consequences of using 1 of the 2 delivery modes.

Another limitation of this study is that the program evaluation (to assess whether the participants had read the advice) took place several months after the participants received their tailored advice. As a result, some recall bias might have occurred. For future evaluation studies, we recommend sending a short program evaluation questionnaire after each tailored advice to limit recall bias, or to include multiple questions to validate their report.

To our knowledge, this is the only study that compares the characteristics of users related to the use and participant dropout rate of a Web-based intervention and a print-delivered intervention with similar content in an older population. Since older adults are one of the fastest growing online user groups and tend to have the most interest in and need for health advice compared to other age groups [9,10], it is important to gain more insight into this population’s user characteristics. Furthermore, we conducted our study on a large and diverse target population in which both low and high SES subgroups were represented. By stratifying invitees by age and SES at a neighborhood level, we could compare the response rates of the print-delivered and Web-based intervention conditions.

Conclusion

The results of our study suggest that the response to a Web-based intervention is significantly lower than a print-delivered intervention among Dutch people over 50 years of age, and participants with different characteristics were attracted by different delivery modes. Participants with a low intention to be physically active and a high BMI were more attracted by the Web-based intervention, indicating that Web-based interventions might be a good medium to reach this high-risk population.

Although participant dropout was significantly higher in the Web-based intervention, no significant factors were found for user characteristics explaining the differences in participant dropout between the delivery modes. This indicates that the higher dropout rate in Web-based interventions is potentially relevant for all demographic groups and related to characteristics not measured in this study.

Our study has provided important new insights into the differences in user characteristics of participants in a print-delivered or Web-based intervention in an older population. These findings are important when selecting the delivery mode of an intervention that aims to optimize exposure to a certain subgroup and when interpreting and generalizing results of randomized controlled effectiveness trials. Since Internet use is growing rapidly in older populations, more research is needed to explore the prolonged use, appreciation, and effectiveness of Web-based interventions compared to print-delivered interventions in this population. The low cost of Web-based interventions can provide an opportunity to reach more of the population, if the effectiveness of the intervention method can be improved. Furthermore, more research is needed to investigate strategies that limit the high dropout rates in Web-based interventions (especially among participants with a low PA intention) and to ensure a sustained intervention effect.

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DPE wrote the first draft of the manuscript. MVS designed the original (print-delivered) intervention. RGO and DPE translated this intervention into a Web-based intervention. Both processes have been supervised by ELE, HDV, CBO, and AMU. DPE and RGO conducted the study. All authors read, modified, and approved the final manuscript.

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Conflicts of Interest

None declared.

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Abbreviations

ANOVA: univariate one-way analyses of variance
BMI: body mass index
MHC: Municipal Health Council
OR: odds ratio
PA: physical activity
RCT: randomized controlled trial
SES: socioeconomic status
SQUASH: short questionnaire to assess health enhancing physical activity
UTAUT: Venkatesh’s unified theory of acceptance and use of technology

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Original Paper

Increasing Physical Activity With Mobile Devices: A Meta-Analysis

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Abstract

Background: Regular physical activity has established physical and mental health benefits; however, merely one quarter of the U.S. adult population meets national physical activity recommendations. In an effort to engage individuals who do not meet these guidelines, researchers have utilized popular emerging technologies, including mobile devices (ie, personal digital assistants [PDAs], mobile phones). This study is the first to synthesize current research focused on the use of mobile devices for increasing physical activity.

Objective: To conduct a meta-analysis of research utilizing mobile devices to influence physical activity behavior. The aims of this review were to: (1) examine the efficacy of mobile devices in the physical activity setting, (2) explore and discuss implementation of device features across studies, and (3) make recommendations for future intervention development.

Methods: We searched electronic databases (PubMed, PsychINFO, SCOPUS) and identified publications through reference lists and requests to experts in the field of mobile health. Studies were included that provided original data and aimed to influence physical activity through dissemination or collection of intervention materials with a mobile device. Data were extracted to calculate effect sizes for individual studies, as were study descriptives. A random effects meta-analysis was conducted using the Comprehensive Meta-Analysis software suite. Study quality was assessed using the quality of execution portion of the *Guide to Community Preventative Services* data extraction form.

Results: Four studies were of “good” quality and seven of “fair” quality. In total, 1351 individuals participated in 11 unique studies from which 18 effects were extracted and synthesized, yielding an overall weight mean effect size of $g = 0.54$ (95% CI = 0.17 to 0.91, $P = .01$).

Conclusions: Research utilizing mobile devices is gaining in popularity, and this study suggests that this platform is an effective means for influencing physical activity behavior. Our focus must be on the best possible use of these tools to measure and understand behavior. Therefore, theoretically grounded behavior change interventions that recognize and act on the potential of smartphone technology could provide investigators with an effective tool for increasing physical activity.

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KEYWORDS

Behavior change, exercise, meta-analysis, mobile phone, physical activity, review

Introduction

It is well documented that regular physical activity is associated with reduced morbidity and mortality attributable to such diseases as cardiovascular disease, diabetes, and some cancers [1-4]. Unfortunately, participation rates have remained dismally low in spite of significant scientific endeavors to enhance participation, reduce attrition, and increase maintenance of this important health behavior. In 2007, less than half of all adults in the United States achieved recommended levels of physical activity [5]. Furthermore, past research suggests that among those beginning a new exercise program, 50% will drop out within six months [6]. The advent of new and ubiquitous technologies offers a potential solution to increasing the effectiveness of and adherence to physical activity interventions. One such technology is the mobile telephone, which has shown promise as a delivery mechanism for health behavior interventions. These devices have become a more pervasive part of society with usage rates increasing exponentially. For example, in the United States some 83% of adults own mobile phones, while in younger populations (ie, 18-24 year olds) as many as 95% own mobile phones [7]. In the United States [8], Australia [9], and Western Europe [10], activated mobile phones outnumber citizens.

Declining cost and enhanced versatility in features are likely contributors to the rapid increase in mobile phone usage, and short message service (SMS, ie, text-messaging) has become an almost universal way to engage in brief conversations and convey short messages. In the United States, 73% of all adult cell phone users send daily text messages, at an average rate of 39.1 per day. Among younger Americans, a staggering 97% of mobile phone users send text messages at an average rate of 87.7 messages per day [7]. In total, nearly 2.1 trillion messages were sent in 2010 [8]. In the late 2000s, the growth of feature phones (ie, devices capable of basic voice and multimedia functions) was supplanted by surging growth in the smartphone market. These devices originally combined the computing power of handheld computers with mobile communication features serving primarily adult professionals. As of May 2011, 35% of all mobile consumers in the U.S. owned smartphones, and rates were higher in ethnic minorities [7]. Smartphones are equipped with advanced technological features that distinguish them from the feature phone. Typically they are capable of sending and receiving information via the Internet, connecting to local wireless networks and Bluetooth devices, utilizing global positioning system (GPS) data and allowing users to download countless mobile applications straight to their device from just about any location.

Behavioral scientists have begun to realize the potential of mobile devices to understand multiple health behaviors, and meta-analyses have supported the efficacy of mobile technology for influencing behaviors including diabetes management [11] and smoking cessation [12]. It is clear that some of the unique qualities of these devices would be attractive features for physical activity interventions allowing scientists to: collect objective and self-report measures of activity in real time; provide feedback and support at the point of decision; provide interactive, immersive, and individualized content that is automatically generated; and deliver materials on a device that is already carried by the individual [13]. A number of reviews exist examining the use of technologies that offer similar benefits to mobile devices and their effects on health behaviors. For example, Goode et al [14] reviewed telephone-based interventions for influencing physical activity and dietary behaviors. Multiple researchers have examined aspects of Internet-delivered interventions [15,16]. Others have examined the use of mobile technology to aid in disease prevention and management [17], as well as the influence of SMS technology on various health behaviors (eg, smoking cessation, diabetes self-management, asthma self-management; [18]). To date, however, no meta-analysis has been conducted that examines the efficacy of mobile devices for changing physical activity behavior. Given the increase in research applications of such devices, we believe that a comprehensive analysis of the influence of mobile devices on physical activity behavior would afford future researchers a foundation for guiding subsequent interventions. Herein, we present a meta-analysis of interventions that have utilized mobile devices (ie, PDA or mobile telephones) to influence physical activity behavior.

Methods

Search Strategy

An extensive search of online electronic databases (PsychINFO, PubMed, Scopus) was conducted between August 15, 2011, and July 3, 2012, in which we sought articles published since the year 2000. The following search string was utilized across the three databases: ((mobile phone) OR (cell phone) OR PDA OR SMS OR (text message)) AND ((physical activity) OR exercise).

Inclusion and Exclusion Criteria

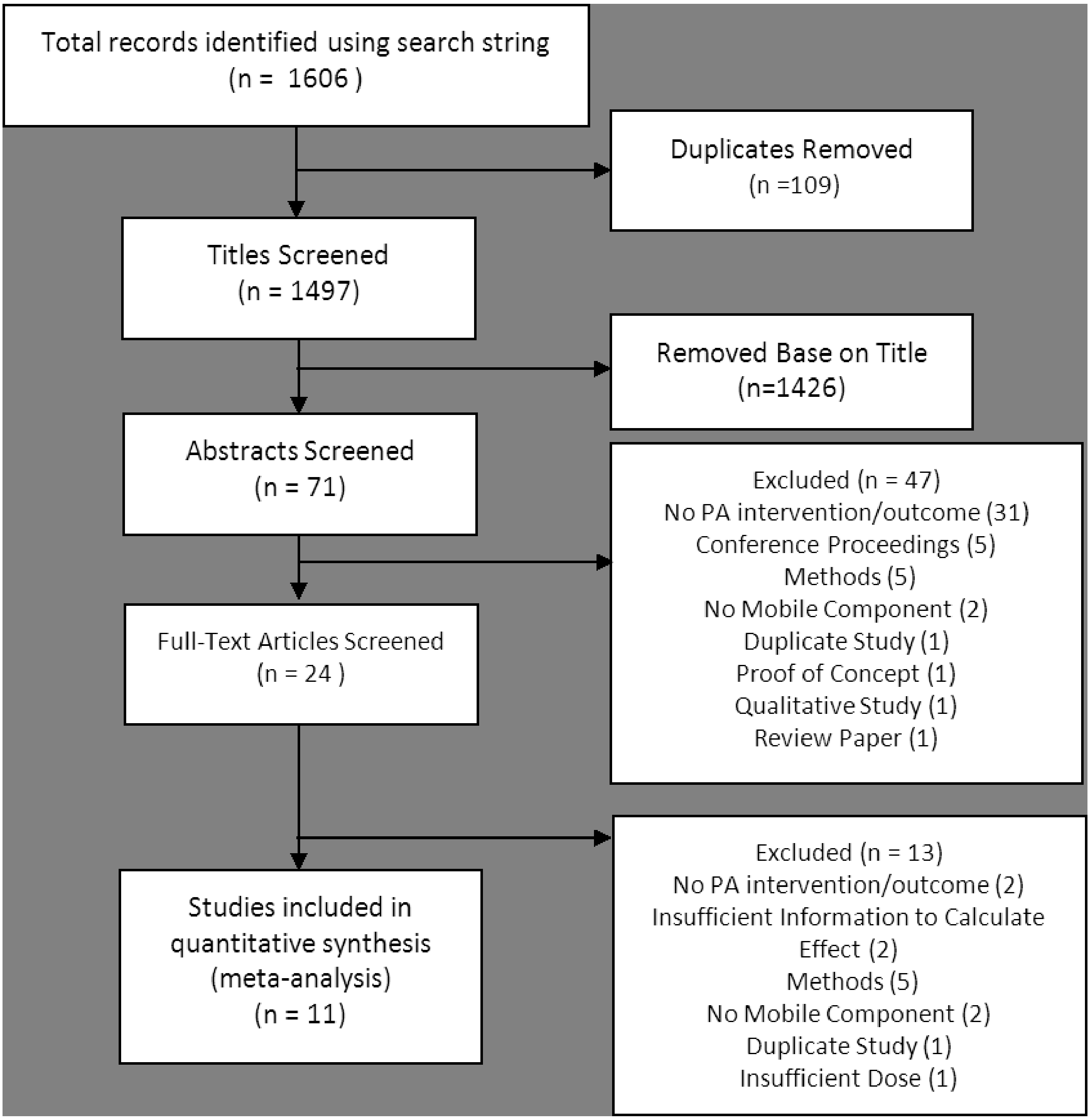
For inclusion in this analysis, studies were required to be published or in press, in the English language, and to incorporate mobile technologies in the collection or dissemination of intervention materials meant to positively influence physical activity behavior. This included data collection or conveyance of intervention information via SMS, as well as implementation of native mobile device software or hardware. Studies were required to include a comparison group and to provide original data sufficient for calculating Cohen’s *d* effect sizes (ie, baseline and follow-up means and baseline standard deviation). These criteria are intentionally broad, as relatively few relevant studies have been published.

Articles that described proof-of-concept trials, conference proceedings, or review articles were excluded from this analysis. Outcomes from studies that were not explicitly related to physical activity were also excluded, as were studies in which participants interacted with the mobile component less than one time per week.

Review Procedure

Study selection was conducted in four phases (see Figure 1). During the initial stage, all citations from each database query were imported into a central citation manager (EndNote X5 [19]), which facilitated removal of duplicates. Next, the first two authors searched titles for publications that referenced physical activity and a mobile device, removing those that definitively did not match inclusionary criteria. In the following stage, both reviewers examined abstracts of the remaining articles, further screening out articles that did not meet criteria. During the final stage, full-text citations were reviewed to make sure that all criteria were met, and study descriptives were extracted and tabulated. When study length was reported in months rather than weeks, a four-week month was assumed. Following this review, search results were compared between the two authors, with the third author acting as arbiter to any inconsistencies. When physical activity outcomes were reported but were not sufficient to calculate effect sizes, study authors were contacted to determine means and standard deviations at all time-points (n = 7). In the event that this information could not be obtained, the effect was excluded from analysis (n = 3 [20-22]). Reference lists of included articles and relevant reviews were searched for additional articles, and direct requests were made to experts in the area of mobile health for additional studies in review or in press.

Figure 1. Flow diagram of study selection.



Study Quality Assessment

In order to assess quality at the study level, the quality of execution portion of the *Guide to Community Preventative Services* data extraction form was used [23]. This form addresses six categories of threats to study validity (ie, population and study description, sampling, measurement, data analysis, interpretation, and other limitations). There are nine possible limitations across these six categories. Studies with 0-1 limitations are deemed to be of "good" quality, those with 2-4 limitations are of "fair" quality, and those with more than four limitations are deemed to be of "poor" quality. This assessment is meant for descriptive purposes only, and as such no studies were excluded due to their quality rating.

Synthesis of Results

For each study we computed standardized mean differences (Cohen's *d*) by subtracting the mean change in the control group from the mean change in the treatment group. Pre- and post-intervention means were used to calculate mean change in order to remain consistent across all studies. This was divided by the pooled baseline standard deviation [24]. Baseline sample size was utilized in calculating pooled standard deviation. For multiple group versus control comparisons, pooled means and standard deviations were calculated in accordance with the *Cochrane Handbook for Systematic Reviews of Interventions* [25].

After obtaining standardized mean differences, we conducted a random-effects meta-analysis, using the Comprehensive Meta-Analysis [26] software suite. Random-effects meta-analyses account for heterogeneity of included measures, if they are indeed related (ie, they measure physical activity [27]). From the software, we obtained Hedge's *g* for the overall effect, which is less biased for small sample sizes, as well as for the duration of moderate to vigorous physical activity duration (MVPA duration) and steps, as these were the only outcome measures reported across multiple studies. Finally, we calculated the effect for studies that utilized mobile phones as well as those that distributed materials on PDA devices. We also obtained a heterogeneity statistic (Q) for each of these effects, which we used to calculate I^2. This allows one to examine the percentage of observed variance that is real, with low percentages indicating that most variance is spurious (pp.117-119) [28].

Results

Study Selection

Our initial search yielded 1606 publications, of which 109 were removed as duplicates. From the remaining 1497 titles, 1426 were removed based on title. Subsequently, 47 of 71 remaining publications were removed after abstracts were screened, and an additional 13 were removed upon review of the full text article. Reasons for removal are detailed in Figure 1. We contacted 7 authors in order to obtain data sufficient to calculate effect sizes. Of these, 2 could not be reached, therefore those publications were removed.

Study Quality

Four studies were classified to be of "good" quality [29-32], and seven studies were classified to be of "fair" quality [33-39]. The most frequently violated items from the data extraction form were: "Was the population that served as the unit of analysis the entire eligible population or a probability sample at the point of observation?" [33,34,36-38], "Was there an attempt to measure exposure to the intervention?" [32,33,37-39], and "Did the authors control for differential exposure to the intervention?" [30,31,34,37,38].

Intervention Characteristics

Eleven unique studies were included in this analysis (n = 1351). Of these, eight reported use of SMS [31-35,37-39], four reported use of native mobile software [29,30,36,37], and two reported use of a personal digital assistant (PDA) rather than a mobile phone [29,30]. Several studies were classified in more than one category (eg, mobile phone & SMS). Five studies reported duration of moderate to vigorous physical activity (MVPA duration) [30,31,34,35,39], three reported pedometer step counts [33,36,37], one reported frequency of MVPA (MVPA frequency) [34], another reported percent of active time spent in MVPA (% MVPA) [37], one study reported accelerometer counts per minute [31], two reported metabolic equivalents (METs) [29,32], and one reported number of days per week of walking for exercise as well as number of days exercising per week [38]. Intervention duration ranged from 2 to 52 weeks and averaged 14.6 weeks. Sample sizes ranged from 17 to 357 participants (M = 121.1 participants), and mean participant ages ranged from 8.7 to 68 years. Detailed characteristics of all studies included in the meta-analysis can be found in Table 1.

Data Synthesis

From the 11 included studies, 18 effects were extracted and synthesized. From these effects, the random-effects meta-analysis yielded a significant moderate overall weighted mean effect size of g = 0.54 (95% CI = 0.17 to 0.91, P = .005). The heterogeneity within these studies was significant (Q = 87.79, df = 10, P < .001, I^2 = 88.61%), supporting the use of random effects meta-analysis.

Table 1. Intervention characteristics.

Study authors	n	Mobile component	Utilization	Length (weeks)	Age M (SD)
Cheung, Chow, & Parfitt (2008) [33]	52	SMS[a]	Relay information about PA benefits	6	INT[b]: 38.9 (10.8) CON[c]: 26.5 (1.9)
Conroy et al (2011) [29]	210	PDA[d] & PDA + feedback (FB)	Tailored, automated FB	~24	47.3 (8.8)
Fjeldsoe, Miller, & Marshal (2010) [34]	88	SMS	Tailored SMS. SMS also sent to dedicated social support individual	12	30 (6)
Hurling et al (2007) [35]	77	SMS	Relay reminders & motivational messages	9	40.4 (7.6)
King et al (2008) [30]	37	PDA	PDA self-monitoring, weekly FB, goal setting, support	8	60.2 (7.1)
Kirwan et al (2012) [36]	200	Smartphone App	Self-monitoring of steps using the mobile app and/or the intervention website	12	39.9 (12.3)
Lubens et al (2012)[31]	357	SMS	Relay social support	52	13.8 (0.45)
Nguyen et al (2009) [37]	17	Native App & SMS	Mobile self-monitoring with tailored SMS feedback	~24	68 (11)
Prestwich, Perugini, & Hurling (2010) [38]	134	SMS	Relay implementation intention or goal reminders	4	23.4 (5.6)
Shapiro et al (2008) [39]	40	SMS	Daily self-monitoring messages with automated, tailored feedback	8	8.7 (2.3)
Sirriyeh, Lawton, & Ward (2010) [32]	120	SMS	Relay affective messages, instrumental messages, or combined messages	2	17.3 (.7)

[a] SMS: Short Message Service.

[b] INT: Intervention group.

[c] CON: Control group.

[d] PDA: Personal digital assistant.

Although there are insufficient numbers of studies to reliably examine between outcomes differences, for illustrative purposes, we examined MVPA duration (five studies) and pedometer steps (three studies) independently, as they were the most frequently reported outcomes. Effects for each study can be found in Table 2 and are also displayed in Figure 2.

Table 2. Study outcomes.

Study authors	Quality	Outcomes	INT[a] M Change (Baseline SD)	CON[b] M Change (Baseline SD)	d
Cheung, Chow, & Parfitt (2008) [33]	"Fair"	Steps to work	-1.5 (14)	1.2 (18.7)	-0.18
		Steps at work	1.3 (2.5)	-1.8 (2.5)	1.26
		Steps off work	4 (6.6)	0.4 (8.4)	0.52
Conroy et al (2011) [29]	"Good"	MET[c]-hours (combined PDA[d])	6.31 (17.87)	7.57 (15.17)	-0.08
Fjeldsoe, Miller, & Marshal (2010) [34]	"Fair"	MVPA[e] frequency	1.82 (1.48)	0.24 (1.44)	1.09
		MVPA duration	18.26 (170.46)	16.36 (170.49)	0.01
Hurling et al (2007) [35]	"Fair"	Accelerometer counts spent in MVPA	-9.5 (52.1)	-5.5 (53.1)	-0.08
King et al (2008) [30]	"Good"	MVPA duration	177.7 (114.5)	-80 (215)	1.55
Kirwan et al (2012) [36]	"Fair"	Total days logged	22.76 (12.8)	1.26 (12.1)	1.76
		Steps	159.89 (3308.36)	-4360.7 (3987.2)	1.19
Lubens et al (2012) [31]	"Good"	Accelerometer counts/min	-90.9 (420)	-43.7 (395.4)	-0.12
		MVPA duration	-13.1 (36.8)	-8.3 (35.1)	-0.13
Nguyen et al (2009) [37]	"Fair"	Steps	609 (3020.76)	-1017 (3021)	0.57
		% MVPA	4.4 (7.64)	-3.5 (7.8)	1.09
Prestwich, Perugini, & Hurling (2010) [38]	"Fair"	Days/wk walking > 30 min	1.4 (1.19)	0.47 (1.17)	0.79
		Days/wk exercising > 30 min	1.85 (1.48)	0.94 (1.52)	0.62
Shapiro et al (2008) [39]	"Fair"	MVPA duration	34.4 (48.5)	-15.1 (126.3	0.51
Sirriyeh, Lawton, & Ward (2010) [32]	"Good"	MET-minutes	3145.26 (11681.71)	819.45 (11347.71)	0.20

[a] INT: Intervention group.

[b] CON: Control group.

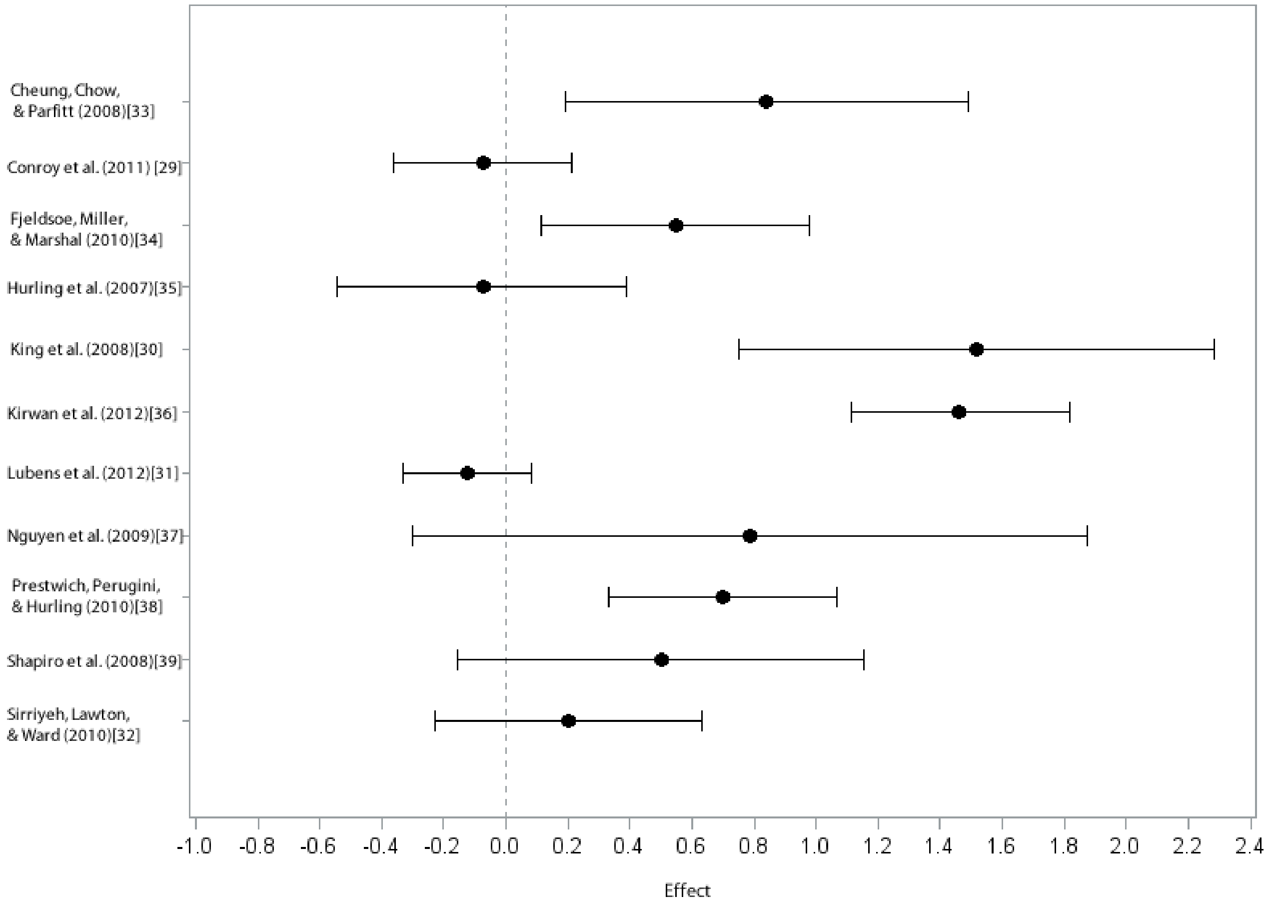
[c] MET: Metabolic equivalents of task.

[d] PDA: Personal digital assistant.

[e] MVPA: Moderate to vigorous physical activity.

There was significant moderate to large effect for pedometer steps (g = 1.05, 95% CI = 0.75 to 1.35, $P < .01$). When examining intervention components specifically, those delivered via mobile phone yielded a significant moderate effect (g =.52, 95% CI = 0.11 to .94, P = .01). The effects were non-significant for both MVPA duration (g = 0.20, 95% CI = -0.19 to 0.60, P = .31) as well as for PDA delivered (g = .68, 95% CI = -0.88 to 2.25, P = .39), with lacking significance in the latter likely due in large part to the small number of studies and considerable heterogeneity.

Figure 2. Forest plot of individual effect sizes (d).



Discussion

Previous reviews and meta-analyses have identified the mobile platform as an effective means to influence multiple health behaviors, including diabetes management [11] and smoking cessation [12]. The present meta-analysis provides some preliminary support for interventions using mobile technology to increase physical activity behavior. Although the use of mobile technology in physical activity research is still in its infancy, we believe that this finding serves as an important foundation for informing the development of appropriate and efficient intervention techniques using such technology to enhance this important health behavior.

However, this initial enthusiasm must be tempered by consideration of the limitations inherent in the individual studies reviewed. First, because of its broad accessibility during most of the included interventions, SMS is the primary technology utilized in this review, which hampers our ability to make evidence-based statements regarding the efficacy of interventions that utilize smartphones. Further, one primary weakness in the studies reviewed here is the inability to determine the unique contribution of the mobile device component to changing physical activity behavior. For the most part, mobile devices have been used primarily as data collection methods (eg, steps reported via SMS) or as supplemental materials (eg, provision of feedback via SMS) to a broader behavior change intervention relying on more traditional methods (eg, face-to-face counseling). When incorporated into larger interventions, SMS messages present a nimble and efficient means to relay feedback and information to participants, provide participants freedom in accessing the intervention message, and to an extent, SMS allows for real-time assessment of behavior.

For example, Fjeldsoe et al [34] developed an SMS-based intervention to increase physical activity in post-natal mothers who were sent bi-weekly, social cognitive-based motivational messages tailored to the study participants. In addition to these messages, a goal-setting refrigerator magnet and face-to-face and telephone counseling were provided at baseline, and telephone counseling alone was provided at week six. The researchers created a useful and innovative model of population-specific text-messaging; however, the inclusion of the counseling and magnet components highlights the inability of current SMS-based interventions to be all-encompassing. This is in contrast to the current movement by many in the area of Internet-based health research who recommend full automation (ie, minimal researcher contact, few supplementary materials, and automatic generation of individualized user content). Hurling et al [35] used an automated design in creating an Internet-based physical activity intervention that utilized SMS to deliver motivational and reminder messages to participants. The intervention was effective; however, our understanding of the efficacy of the mobile component is again clouded by its role as an SMS supplement to the broader, Internet-based trial.

Unfortunately, the simple adoption of mobile technologies does not ensure effective intervention methods. Theoretical frameworks should guide interventions to help researchers understand which components were most effective in successful (or unsuccessful) trials. For example, Prestwich et al [38] instructed participants to develop implementation intentions and a goal relative to brisk walking. These intentions are based in part on Gollwitzer's [40] position that anticipating and planning goal-directed responses removes some burden of responsibility from the individual and delegates it to the situation. That is, implementation intentions are formed in such a way that one self-regulates in a manner following "when I encounter X, I will respond by Y" [40], thus ensuring that when a particular situation is encountered, the desired response occurs automatically. After forming goals and implementation intentions, subjects were assigned to one of three groups: one that received SMS reminders of their implementation intentions, one that received SMS reminders of their brisk walking goal, and a control group. Both SMS groups significantly increased the amount of walking relative to control. Further, the SMS plus goal group better recalled their goals, while the SMS plus implementation intentions group better recalled their implementation intentions, indicating that this form of mobile intervention successfully supported the underlying theoretical principles of the study.

It is worth considering, however, that much can be added to current theoretical models of behavior change so that they are better suited to design mobile interventions and interpret results. Ritterband et al [41] have developed a behavior change model for Internet-based interventions that can be used to guide mobile interventions, given the similarities of the two platforms. The authors note that at the time of writing, no theoretical model existed to guide development and testing of Internet-based interventions. More recently, Riley and colleagues [13] questioned whether or not current behavioral theories are adequate for designing and implementing mobile interventions. They acknowledge that current models account for the state of the participant at baseline and challenge that they do not adequately account for the interplay between user experiences and the dynamic and adaptable nature of mobile interventions. For Internet and mobile interventions alike, theories that account for inter- and intra-individual change over time may be a better fit.

One of the unique and advantageous features of mobile devices, and smartphones in particular, is their use of the popular and widespread native applications or "apps". Rather than relying on Internet connectivity to deliver content that resides on a remote server (ie, the method utilized by "web apps"), native apps are developed for the mobile operating system, reside on the user's mobile device, and may store data locally or exchange it via the Internet. Importantly, native apps allow a greater degree of flexibility and complexity to software and intervention designers. Since 2008, application development has continued to grow across multiple platforms at an exponential rate and has mirrored the increase in smartphone users worldwide [42]. Though limited in number at the time of writing, research using native applications gives cause for optimism. For example, King et al [30] developed software that cued individuals to participate in a short survey twice daily. This survey assessed types of physical activity, context of physical activity, and behavioral/motivational factors. The physical activity program was grounded in social cognitive principles and included an assessment of barriers and enablers; self-regulation of step counts; and a goal-setting component, from which personalized PDA-delivered graphical/textual feedback was developed. The authors reported a mean increase in moderate to vigorous physical activity of 177.7 minutes per week, as compared with a mean decrease of 80 minutes in the control group over eight weeks. This early native application−based intervention demonstrated the versatility and potential efficacy of this mode of delivery.

Finally, inclusion of advanced sensors (eg, integrated accelerometer and GPS devices) holds promise for more accurate assessment of physical activity behavior in real time. Ecological Momentary Assessment (EMA) is a measurement strategy that aims to collect data reflecting behavior and the social/physical context that influences such behavior. Often this is accomplished by providing a prompt to the participant, cuing them to submit reports relative to, for example, their current location, the type of activity they are currently participating in, and their social context [43-45]. In combination with smartphone technology, integrated motion sensing can bolster the accuracy of activity measurement, while GPS data may provide geographic location information, allowing for a more detailed examination of the environmental context in which activity does or does not occur [44]. Bergman et al [46] have questioned the validity of mobile phone−based accelerometry, although their study examined only a single mobile application meant to estimate number of steps taken. Recently, Wu et al [47] used accelerometer and gyroscope data obtained by smartphone devices to classify activity types using machine learning algorithms. They found that they could accurately classify walking and jogging activities with greater than 90% accuracy. However, there still remain issues to resolve relative to the best location on the body to obtain accurate movement data on larger and more diverse populations, and the most accurate algorithms for quantifying different types and intensities of activity.

Strengths and Limitations

A primary strength of this study is its status as the first meta-analysis examining the influence of mobile devices on physical activity behavior. Acknowledging the efficacy of current interventions while addressing advances in technology can help to guide future intervention development. We must also note several limitations inherent in this meta-analysis. First, the small number of published studies necessitated broad inclusionary criteria, thereby including studies that varied greatly in population characteristics, study design, and use of mobile components. Further, study heterogeneity, as denoted by the I^2 statistic, should be interpreted with caution, particularly due to the small number of effects included. However, aggregation of study effects and designs is important in order to effectively utilize and improve on current designs.

Conclusion

Given that smartphones only recently acquired enough market penetration to warrant implementation as a health behavior change platform, it is not surprising that there has been little rigorous study of the influence of this technology on physical activity. Fortunately, innovative research using SMS, PDAs, and the Internet has laid a foundation on which smartphone research can be built. As the field increasingly utilizes this novel technology, our focus must not be on any one specific device but on the best possible use of these tools to measure and understand behavior. Indeed, scientifically rigorous, theoretically grounded behavior change interventions that recognize and act on the potential of smartphone technology (eg, integrated accelerometry, Internet connectivity, ubiquitous presence) could provide investigators with an efficient and effective tool and participants with an immersive and exciting experience.

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Conflicts of Interest

None declared.

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Abbreviations

CI: Confidence Interval
CON: Control Group
EMA: Ecological Momentary Assessment
FB: Feedback
GPS: Geographic Positioning System
II: Implementation Intentions
INT: Intervention Group
MET: Metabolic Equivalent of Task
MVPA: Moderate to Vigorous Physical Activity
PDA: Personal Digital Assistant
SMS: Short Message Service (ie, text messaging)

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Original Paper

Factors Affecting Mobile Diabetes Monitoring Adoption Among Physicians: Questionnaire Study and Path Model

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Abstract

Background: Patients with type 1 and type 2 diabetes often find it difficult to control their blood glucose level on a daily basis because of distance or physical incapacity. With the increase in Internet-enabled smartphone use, this problem can be resolved by adopting a mobile diabetes monitoring system. Most existing studies have focused on patients' usability perceptions, whereas little attention has been paid to physicians' intentions to adopt this technology.

Objective: The aim of the study was to evaluate the perceptions and user acceptance of mobile diabetes monitoring among Japanese physicians.

Methods: A questionnaire survey of physicians was conducted in Japan. The structured questionnaire was prepared in a context of a mobile diabetes monitoring system that controls blood glucose, weight, physical activity, diet, insulin and medication, and blood pressure. Following a thorough description of mobile diabetes monitoring with a graphical image, questions were asked relating to system quality, information quality, service quality, health improvement, ubiquitous control, privacy and security concerns, perceived value, subjective norms, and intention to use mobile diabetes monitoring. The data were analyzed by partial least squares (PLS) path modeling.

Results: In total, 471 physicians participated from 47 prefectures across Japan, of whom 134 were specialized in internal and gastrointestinal medicine. Nine hypotheses were tested with both the total sample and the specialist subsample; results were similar for both samples in terms of statistical significance and the strength of path coefficients. We found that system quality, information quality, and service quality significantly affect overall quality. Overall quality determines the extent to which physicians perceive the value of mobile health monitoring. However, in contrast to our initial predictions, overall quality does not have a significant direct effect on the intention to use mobile diabetes monitoring. With regard to net benefits, both ubiquitous control and health improvement are significant predictors. Net benefits in turn significantly motivate physicians to use mobile health monitoring, and has a strong influence on perceived value. Perceived value and subjective norms are predictors of intention to use. In our sample, concerns over privacy and security risk have no significant effects on intention to use mobile diabetes monitoring. Among the 3 control variables, only age significantly affected intention to use mobile diabetes monitoring, whereas experience and gender were not significant predictors of intention.

Conclusions: Physicians consider perceived value and net benefits as the most important motivators to use mobile diabetes monitoring. Overall quality assessment does affect their intention to use this technology, but only indirectly through perceived value. Net benefits seem to be a strong driver in both a direct and indirect manner, implying that physicians may perceive health improvement with ubiquitous control as a true utility by enhancing cost-effective monitoring, and simultaneously recognize it as a way to create value for their clinical practices.

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KEYWORDS

Blood glucose self-monitoring; Diabetes mellitus; Internet; Diabetes self-management; Health informatics; Mobile health; Mobile device; Mobile diabetes monitoring; Path analysis

Introduction

Context and Prior Work

The increased need for real-time data management and the advances in mobile communication technology are developing markets for a new form of remote diabetes data management systems [1-3]. Mobile diabetes monitoring (MDM) can provide a more personalized and flexible means of control through which physicians can get immediate medical data and achieve continuous control over patients' health, while patients can satisfy their desire to receive timely clinical feedback and lower the cost of long-term medical care [4,5]. A recent review of 101 commercial mobile apps found that insulin and medication recording (62%), data export and communication (60%), diet recording (47%), and weight management (43%) are the most prevalent features [1]. The adoption of mobile diabetes monitoring has been examined in several situations. A clinical pilot trial in Austria indicated that a diabetes management system was well accepted by patients and practical for daily usage. A similar application was tested in a randomized and crossover clinical experiment with 10 type 1 diabetic patients aged 21 to 62 years in Spain [6]. The patients showed high acceptability and interest in the system as recorded in usability and utility questionnaires. Martínez-Sarriegui et al [3] tested personal digital assistant (PDA) monitoring with a continuous glucose sensor on 5 diabetic patients in Spain. They found that all patients were satisfied and would recommend the system. In South Korea, a mobile blood glucometer system was tested with 20 elderly patients older than 65 years. Despite complaints related to short battery life and difficulties in operating mobile phones, the patients' satisfaction was 8.59 of 10 points.

Significance of the Study

Our literature review indicates that most published studies focus on the use or clinical evaluation of mobile diabetes monitoring from the patients' perspectives. Empirical research on mobile diabetes monitoring adoption from the physicians' perspective is almost nonexistent, thus the present study makes a significant contribution to our existing knowledge. Although understanding end users' (ie, patients) adoption mechanisms is important, the adoption of mobile diabetes monitoring needs to be understood from the operators' (ie, physicians) perspectives for two reasons. First, unlike typical commercial transactions, patients are not really the customers who choose mobile diabetes monitoring. It is the physicians, along with other health professionals, who make the ultimate clinical decision to introduce information technology (IT) designed to support highly specialized tasks and services [7]. Second, prior research indicates that a close collaboration between physicians and the medical device industry is essential for device innovation [8]. In this view, physicians provide essential knowledge of technology and medical practice that becomes incorporated into new devices. Physicians' involvement in clinical trials and testing is increasingly important, thus the industry needs profound knowledge about the mechanisms of their adoption behavior.

Theoretical Background and Model

Our theoretical model is based on the updated DeLone and McLean Information System (IS) Success Model, which covers different perspectives of evaluating information systems (Figure 1). DeLone and McLean [9] reviewed the existing definitions of IS success and their corresponding measures, and proposed a basic model. Later, this model was revised by incorporating 7 major variables connected in structural relationships [10]. System quality is defined as the desirable characteristics of an IS, whereas information quality means characteristics of the output offered by the IS. Service quality refers to the quality of the support that system users receive from the IS department and IT support personnel. Net benefits explain the effect an IS has on an individual, group, organization, industry, or society, and influence both the usage extent of the IS and the level of resulted satisfaction [11,12].

Our research closely follows this model for two reasons. First, prior research suggests that the original DeLone and McLean IS Success Model has been one of the most widely cited IS models [11,12]. Second, the updated DeLone and McLean IS Success Model is among the few options that have incorporated quality and net benefits dimensions that we consider to be crucial determinants of mobile diabetes monitoring adoption.

The updated DeLone and McLean IS Success Model can be considered as a conceptual scheme of IS success in a given organization. However, measurements of each variable were only loosely suggested. In an attempt to explicate physicians' adoption of mobile diabetes monitoring, we extend the updated DeLone and McLean IS Success Model by introducing some new variables. We posit 9 different major hypotheses (H1-H9); our research model is shown in Figure 2.

Overall quality is conceptualized as a second-order hierarchical model in which each first-order factor is a cause of the construct [13]. That is, overall quality is defined as the ultimate result when the IS achieves information, system, and service quality. The reason for this high-order construct is because although the updated DeLone and McLean IS Success Model explains that an information system can be evaluated in terms of information, system, and service quality, no overall quality construct was suggested in the model. The extant research on service quality perception has always embraced such a hierarchical view [14]. We posit that physicians are likely to perform mental calculus by summing up individual quality assessment for information, system, and service. Thus, we hypothesize that system quality will directly and positively affect overall quality of mobile diabetes monitoring (H1a), information quality will directly and positively affect overall quality of mobile diabetes monitoring (H1b), and service quality will directly and positively affect overall quality of mobile diabetes monitoring (H1c).

In the updated DeLone and McLean IS Success Model, each quality dimension affects the subsequent intention to use the IS. By the same token, our model contemplates that overall quality determines the intention to use mobile diabetes monitoring. Actual use is excluded from our model, because the current diffusion level of mobile diabetes monitoring is still in its infancy. For example, industry reports indicate that although the number of home health monitoring devices with embedded cellular connectivity may reach 2.47 million by 2016; only 570,000 were in use worldwide as of 2011 [15]. Nonetheless, we argue that physicians could judge their intention to use mobile diabetes monitoring without real usage experience, because “intention” is an attitude, whereas “use” is a behavior [10]. Therefore, our secondary hypothesis is that overall quality will directly and positively affect intention to use mobile diabetes monitoring (H2).

DeLone and McLean [10] argue that satisfaction is an important success measure of system adoption because it captures the balance of positive and negative impacts of its use. In our model, satisfaction is replaced by perceived value because of the same reason mentioned previously—low penetration of mobile diabetes monitoring. Here, we view value as the performance improvement in functionality, efficiency, productivity, and practicality because of mobile diabetes monitoring adoption as weighed against the associated costs. Because only a limited number of physicians may have actually used mobile diabetes monitoring, the level of satisfaction is not a realistic measure. Instead, we posit that physicians could perceive certain value—perceived trade-off between improved patient care and costs—toward the system. However, such value cannot be perceived without a good understanding of overall quality. For example, within the general diabetes treatment program, the impact of mobile diabetes monitoring on patients cannot be viewed as valuable unless physicians fully evaluate the overall performance quality it delivers to the clinical practitioners. Thus, our third hypothesis is that overall quality will directly and positively affect perceived value (H3).

DeLone and McLean [10] suggest that net benefits must be determined by the context and objectives of the IS investment by asking the following questions: What qualifies as a “benefit”? For whom? And at what level of analysis? In this regard, we conceptualize net benefits as a composite effect of two variables: ubiquitous control and health improvement. Ubiquitous control is defined as flexible patient care without time and place restriction. Ubiquity has been suggested to be the most important utility of mobile device [16], and thus the heart of mobile diabetes monitoring benefits. Health improvement in this context encompasses the clinical advantages physicians could achieve through the use of mobile diabetes monitoring, which have been suggested by several trial experiments [3,6,17]. We therefore expect that ubiquitous control will directly and positively affect net benefits (H4a), and health improvement will directly and positively affect net benefits (H4b).

Prior research measures net benefits as improvements in job performance and finds that they significantly impact intention to use knowledge-management systems [18,19]. Similar findings have been reported in IS literature [12], thus leading us to hypothesize that net benefits will directly and positively affect intention to use mobile diabetes monitoring (H5).

If physicians indeed perceive important benefits derived from mobile diabetes monitoring (ie, ubiquitous control and health improvement), they may ultimately see an opportunity to create value for their clinical practice. Prior research suggests that such value creation would lead to a stronger intention to adopt IS [20]. Thus, the net benefits will directly and positively affect perceived value (H6), and perceived value will directly and positively affect intention to use mobile diabetes monitoring (H7).

Next, theory of planned behavior (TPB) states that behavioral intentions are determined by three primary dimensions: attitude, subjective norm, and perceived behavioral control. All three factors are influenced by a set of cognitive beliefs about the innovation and their respective importance. Of special interest to the present study, subjective norm can be defined as a “person’s perception that most people who are important to him think he should or should not perform the behavior in question” [21]. Prior research based on TPB finds that subjective norm has the strongest effect on physicians’ behavioral intentions to share knowledge [22,23]. This finding implies that peer influence may play a central role in the adoption of mobile diabetes monitoring, leading to the hypothesis that subjective norms will directly and positively affect intention to use mobile diabetes monitoring (H8).

Finally, a general concern for privacy and security risk in mobile commerce may be applicable to the adoption of mobile diabetes monitoring. In fact, both industry practitioners and scholars have debated potential risks involved in electronic medical records [24-26]. Thus, the treatment of personal data and data security can be a negative driver of usage intention. Therefore, we posit that privacy and security risk will directly and negatively affect intention to use mobile diabetes monitoring (H9).

Purpose

The purpose of our empirical survey is to validate the explanatory power of our research model, which is a theoretical extension of the updated DeLone and McLean IS Success Model. A set of key attitudinal and perceptual factors of mobile diabetes monitoring adoption are assessed from the physicians’ point of view.

Figure 1. Updated DeLone and McLean Information System (IS) Success Model.

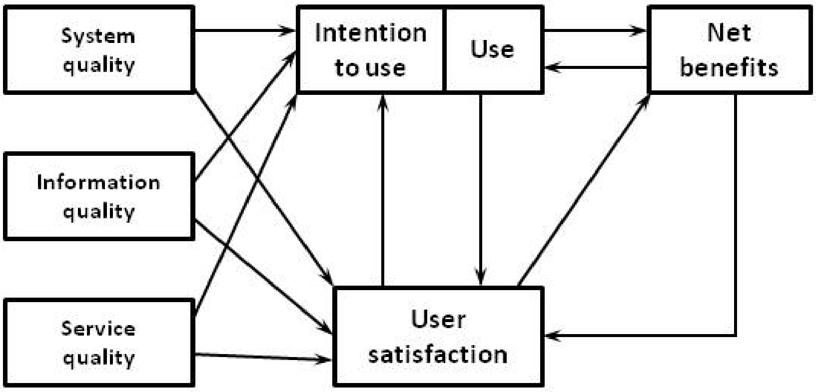
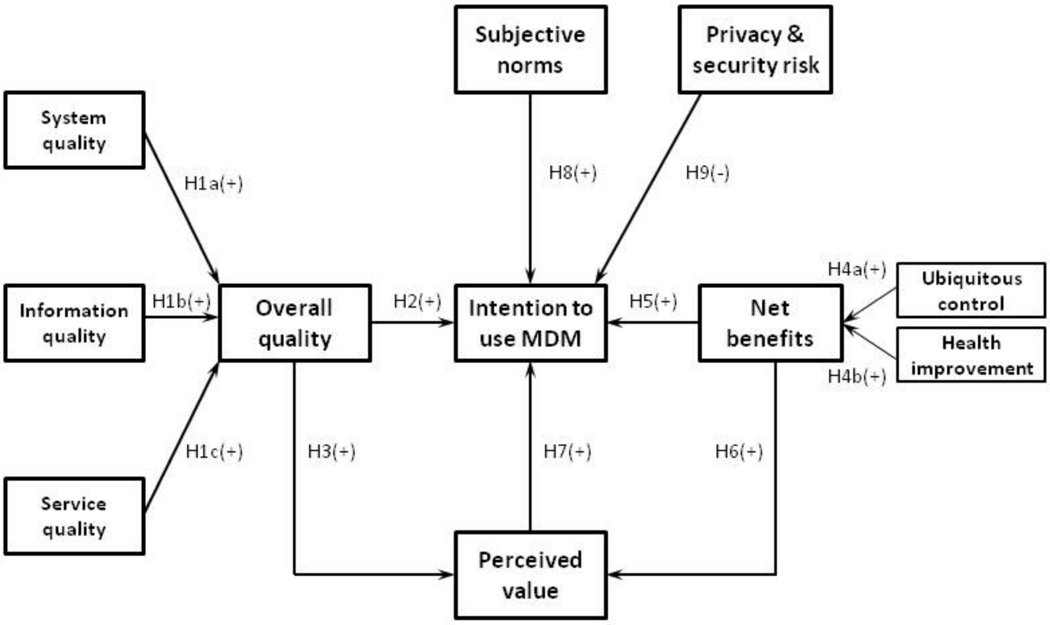


Figure 2. Theoretical model of mobile diabetes monitoring adoption among Japanese physicians showing various hypothesized (H) relationships. A plus sign or minus sign signifies an increase or decrease, respectively, in the dependent variable evoked by an increase in the independent variable (ceteris paribus).



Methods

Site of the Study

Japan served as the site for this study for several reasons. First, it has one of the highest mobile broadband penetration rates: In 2011, there were 122 million 3G subscribers with 95% penetration rate [27]. Second, Japan is the country with the eighth-largest number of diabetes patients worldwide in 2010, with approximately 7.3 million adults aged 20 to 79 years [28]. According to the World Health Organization (WHO), this number is expected to reach 8.9 million by 2030 [29]. Thus, an innovative treatment approach for diabetes would draw much attention from physicians. Third, with aging of the Japanese population, the health care costs associated with chronic diseases are becoming a serious burden in Japan's social security system. To address this issue, there have been various strategic initiatives, of which the first two were targeted toward diabetes and depression [29]. Fourth, the direct health care costs of diabetes are due to increased costs associated with hospital admissions and outpatient visits, as well as the costs of medications. Oishi and colleagues [30] performed a study in 2003, examining the time and costs in caring for patients with newly identified type 2 diabetes and other lifestyle diseases in Japan. The mean number of monthly doctor visits was similar for newly diagnosed patients with diabetes and for patients with hypertension and/or hyperlipidemia, but the total time of these visits for patients with diabetes was greater [30]. Thus, the adoption of mobile diabetes monitoring could significantly reduce potential costs associated with keeping these patients' diabetes under control. All these reasons ensure the ecological validity of the study, and thus justify the use of Japan as the site of the study.

Definition of Mobile Diabetes Monitoring

This study defines mobile diabetes monitoring as a system of self-monitoring blood glucose in diabetic patients by means of 3G-enabled mobile device. Typically, mobile diabetes monitoring enables the following functions: (1) self-monitoring of blood glucose, weight, physical activity, diet, insulin and medication, and blood pressure; (2) disease-related data export and physician-patient communication; and (3) synchronization with personal health record systems at the hospital's information hub. This technical definition is consistent with prior research [1], and leading Japanese medical informatics laboratories and firms (eg, University of Tsukuba, Fujitsu) developed a similar system [31,32].

Questionnaire

A questionnaire survey was conducted in Japan. At the beginning of the questionnaire, we asked the medical specialty of the respondent and their level of clinical experience (in years). We then showed a graphical image of a mobile-based blood glucose self-monitoring system developed by the University of Tsukuba [32]. In addition, a detailed description of the system purpose, functions, and usage procedures were provided. We asked whether the respondents had used mobile diabetes monitoring. If the answer was affirmative, we then asked them to rate each item according to their usage experience; otherwise, their assessments were based on the description provided in the questionnaire. In the next section, we listed the questions related to the model constructs explained in the previous section: system quality, information quality, service quality, perceived health improvement, privacy and security concerns, perceived value for medical control, subjective norms, ubiquitous control, and intention to use mobile diabetes monitoring. Construct measures were adapted from previous research in information systems, health care, and consumer behavior [14,16,33-43]. All constructs were measured by multiple-item scales with a 7-point Likert scale, except perceived value that was measured by a 7-point semantic differential scale. At the end of the questionnaire, some demographic questions, such as age, gender, and geographical area (ie, prefecture), along with other relevant questions (eg, usage experience and frequency of Internet and mobile device use), were included. All constructs' measures used in the present study are listed in Multimedia Appendix 1.

Participant Recruitment

The survey participants were recruited by a professional research agency in Japan. The agency posted a recruitment notification on its website. As a result, 590 physicians signed up to participate in the survey. As an incentive, the respondents were paid 5000 yen (approximately US $60) for their participation. The survey website was created and the invitation was sent to the participants. Although our sampling was not probabilistic (ie, judgment sample), the respondents were drawn from 47 prefectures in Japan, and thus not clustered in certain regions of Japan.

Analytical Approach

We applied partial least squares (PLS) path modeling as implemented in SmartPLS 2.0 M3 [44] as means of statistical analysis. PLS has found widespread use in technology adoption and information systems literature [45], primarily because of its suitability for exploratory studies in early stages of research when the focus lies on saturated, prediction-oriented models. We used the factor-weighting scheme as our inner weighting scheme because of its robustness [46]. Two of our constructs, overall quality and net benefits, were modeled as second-order constructs by using the repeated-indicators approach [45]. We applied bootstrapping with 5000 bootstrap samples to obtain inference statistics.

We performed a PLS analysis with two nested samples. First, we conducted the PLS analysis with the total sample. The reason for this is that mobile-based monitoring systems can be applied not only to diabetes, but also to epidemiology of other medical fields. Thus, the inclusion of other medical experts increases external validity of our proposed model. Moreover, the reliability and validity of the measures were assessed with the total sample, based on the criteria formulated by Ringle et al [45]. The internal consistency reliability was estimated using Cronbach alpha and Jöreskog's rho. Convergent validity was assessed by using the average variance extracted (AVE). We relied on the Fornell-Larcker criterion [47] to assess discriminant validity. Second, because diabetes is normally treated by physicians of internal medicine and gastrointestinal medicine, we limited the sample only to those respondents specialized in these areas. Gastrointestinal symptoms are reportedly common in diabetes [48]. This validation with the specialist subsample should reflect more accurate perceptual, attitudinal, and behavioral responses from the physicians specialized in this specific disease category.

Results

Sample Characteristics

During August 2011, 505 physicians responded to the survey. However, there were 34 responses with exaggerated extremity preferences (all 1s or 7s). They were considered to be due to extreme response bias, and were eliminated from the final dataset. Therefore, the total usable sample size was 471, with an effective response rate of 79.8%.

The respondents belonged to diverse specialties (Table 1), including general medicine (20.6%), surgery (10.4%), and gastrointestinal medicine (7.9%), among others. The average clinical experience of the respondents was 19.3 years. Approximately 87% and 13% of the respondents were male and female, respectively, aged 25 to 65 years. A cross-tabulation of sex and age group is shown in Table 2.

Table 1. Medical specialties of all respondents (N=471) and those respondents in the subspecialties of general internal medicine and gastrointestinal medicine (n=134) to a survey in Japan about mobile diabetes monitoring.

Specialty	Total sample		Specialist subsample	
	n	%	n	%
General internal medicine	97	20.6	97	72.4
Psychosomatic medicine	1	0.2	0	0
Respiratory internal medicine	7	1.5	0	0
Gastrointestinal medicine	37	7.9	37	27.6
Cardiovascular medicine	21	4.5	0	0
Neurology	13	2.8	0	0
Nephrology	12	2.5	0	0
Hematology	4	0.8	0	0
Psychiatry	28	5.9	0	0
Surgery	49	10.4	0	0
Obstetrics and gynecology	14	3.0	0	0
Ophthalmology	19	4.0	0	0
Otorhinolaryngology	13	2.8	0	0
Dermatology	15	3.2	0	0
Urology	9	1.9	0	0
Radiology	17	3.6	0	0
Anesthesiology	25	5.3	0	0
Others	90	19.1	0	0

Table 2. Age and sex distribution of respondents to survey in Japan about mobile diabetes monitoring.

Age	Sex, n (%)		Total, n (%)
	Male n=410	Female n=61	n=471
20-29 years	9 (2.2)	11 (18.0)	20 (4.2)
30-39 years	74 (18.0)	24 (39.3)	98 (20.8)
40-49 years	174 (42.4)	18 (29.5)	192 (40.8)
50-59 years	125 (30.5)	6 (9.8)	131 (27.8)
≥ 60 years	28 (6.8)	2 (3.3)	30 (6.4)

In terms of personal use, approximately 42% of the respondents accessed the Internet with their mobile device on a daily basis; 9% did so more than 10 times a day. By contrast, 26.9% did not access the Internet with mobile device. On average, the respondents used the Internet with their mobile device for approximately 7 years. In terms of professional use, approximately 30% of the respondents used the Internet for their patient care or other clinical practices. With regard to mobile diabetes monitoring, only 0.8% of the respondents actually used mobile diabetes monitoring previously. Although 25.9% were aware of its functions but did not use mobile diabetes monitoring, 73.2% were not well informed.

Measurement Validation

All our constructs exhibit sufficient levels of internal consistency reliability, exceeding the recommended threshold of .70 [49]. All AVE values were above the critical value of .50 [47], which indicates that all constructs are unidimensional, thus implying convergent validity. In Table 3, we report Cronbach alpha, Jöreskog's rho, and the AVE.

Table 4 shows the construct correlations as well as the square root of the AVE as the basis for assessment of discriminant validity. Comparing the square root of each construct's AVE with its largest absolute correlation shows that the Fornell-Larcker criterion is met. Therefore, discriminant validity can also be confirmed.

Table 3. Quality indicators of the constructs, including Cronbach's alpha, Jöreskog’s rho, and average variance extracted (AVE).

Construct	Number of items	Cronbach's alpha	Jöreskog’s rho	AVE
Age	1	—	—	—
Experience	1	—	—	—
Gender	1	—	—	—
Health improvement	4	.90	.93	.77
Information quality	11	.96	.97	.73
Intention to use mobile diabetes monitoring	3	.92	.95	.87
Perceived value	8	.96	.96	.77
Security/privacy concerns	8	.96	.97	.78
Service quality	9	.96	.96	.74
Subjective norms	3	.94	.96	.89
System quality	10	.91	.93	.56
Ubiquitous control	6	.94	.96	.78

Table 4. Construct correlations and square root of the AVE.

Construct		Construct correlations[a]											
		1	2	3	4	5	6	7	8	9	10	11	12
1	Age	—											
2	Experience	.00	—										
3	Gender	–.30	.08	—									
4	Health improvement	.04	–.06	–.04	*.88*								
5	Information quality	.00	–.02	–.06	.80	*.85*							
6	Intention to use	–.08	–.03	–.04	.64	.70	*.93*						
7	Perceived value	.01	–.07	–.07	.72	.81	.72	*.87*					
8	Security/privacy concerns	–.05	–.07	.03	.17	.30	.20	.24	*.88*				
9	Service quality	.08	.00	–.02	.70	.66	.49	.62	.04	*.86*			
10	Subjective norms	.06	.00	–.10	.67	.70	.76	.72	.15	.60	*.94*		
11	System quality	.09	.00	–.07	.69	.75	.57	.71	.13	.74	.64	*.75*	
12	Ubiquitous control	.08	–.05	–.04	.71	.78	.72	.77	.27	.60	.77	.69	*.88*

[a] Diagonal elements in italics are the square root of the construct’s AVE (all other elements are correlations between the constructs).

Model Validation with Total Sample

The results of the PLS analysis on the total sample are shown in Figure 3. The model estimates largely confirm our conceptual model. System quality, information quality, and service quality all contribute significantly to the overall quality. Remarkably, the indirect effect of overall quality on the intention to use mobile diabetes monitoring is positive (indirect effect = 0.11) and significant ($P < .001$). However, the total effect of overall quality on the intention to use mobile diabetes monitoring is not significant (total effect = 0.05, $P = .21$). As the indirect effect of overall quality already suggests, both the effect of overall quality on perceived value and the effect of perceived value on the intention to use mobile diabetes monitoring are significant. Ubiquitous control and health improvement contribute significantly to the formation of net benefits. Net benefits, in turn, have significant positive effects on the intention to use mobile diabetes monitoring and perceived value. Also, the indirect effect (indirect effect = 0.11, $P < .001$) and the total effect (total effect = 0.38, $P < .001$) of net benefits on the intention to use mobile diabetes monitoring are significant. As anticipated, subjective norms have a significant positive effect on the intention to use mobile diabetes monitoring. Finally, privacy and security risk does not have a significant effect on the intention to use mobile diabetes monitoring. The control variables tested (age, experience, and gender of the respondents) did not produce any effect with one exception: the negative influence of the age of physicians on intention to use mobile diabetes monitoring. The older respondents have a significantly lower intention to use mobile diabetes monitoring than the younger respondents, suggesting that the younger the physicians, the more likely they will be to adopt and use mobile diabetes monitoring. This effect is likely because of the widely documented adverse relationship between age and new technology acceptance.

Model Validation with Specialist Subsample

Table 5 lists the results from the PLS analysis of the specialist (internal and gastrointestinal medicine) subsample juxtaposed with those from the total sample validation. As far as statistical significance is concerned, no discrepancy was found between the two results. Except for two paths (ie, overall quality → intention to use mobile diabetes monitoring, and privacy and security risk → intention to use mobile diabetes monitoring), all hypothesized relationships were supported. Furthermore, the magnitudes of standardized beta coefficients were also very similar.

Hypotheses Testing

Hypotheses testing results are summarized in the far right column of Table 5. Based on the results from both the total sample and the specialist subsample, we could confirm that all but two hypotheses are supported by our data. More specifically, system quality, information quality, and service quality significantly affect overall quality, providing support for hypotheses 1, 2, and 3. Our results also indicate that overall quality determines the extent to which physicians perceive the value of mobile health monitoring. However, in contrast to our initial predictions, overall quality does not have a significant direct effect on the intention to use mobile diabetes monitoring. Thus, hypothesis 2 does not gain support but hypothesis 3 does. With regard to net benefits, both ubiquitous control and health improvement are significant predictors, which ring true for hypotheses 4a and 4b. Net benefits in turn significantly motivate physicians to use mobile health monitoring, while exercise strong influence on perceived value. Thus, both hypotheses 5 and 6 are supported. Perceived value is found to be a strong predictor of intention to use, which provides support for hypothesis 7. In the same token, as predicted in hypothesis 8, subjective norms significantly affect intention to use. Finally, concerns over privacy and security risk have no significant effects on intention to use mobile diabetes monitoring. Thus, hypothesis 9 is not supported.

Figure 3. Partial least squares (PLS) analysis results of the theoretical model of mobile diabetes monitoring adoption among Japanese physicians. The numbers indicate standardized beta coefficients.

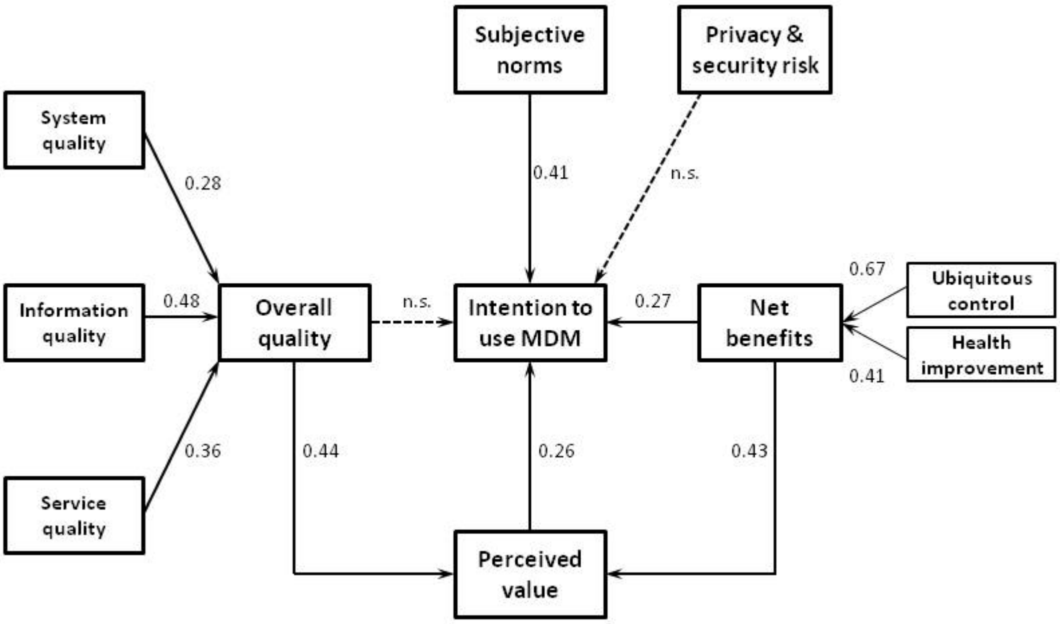


Table 5. Summary of partial least squares (PLS) estimation from the total sample and the specialist (internal and gastrointestinal medicine) subsample.

Hypotheses	Path[a]	Total sample (n=471)		Specialist subsample (n=134)		Hypothesis testing results
		Beta coefficients	*P*	Beta coefficients	*P*	
Hypothesis 1a	System quality → overall quality (+)	.28	< .001	.30	< .001	Supported
Hypothesis 1b	Information quality → overall quality (+)	.48	< .001	.46	< .001	Supported
Hypothesis 1c	Service quality → overall quality (+)	.36	< .001	.33	< .001	Supported
Hypothesis 2	Overall quality → intention to use (+)	−.07	.15	−.07	.44	Unsupported
Hypothesis 3	Overall quality → perceived value (+)	.44	< .001	.47	< .001	Supported
Hypothesis 4a	Ubiquitous control → net benefits (+)	.67	< .001	.65	< .001	Supported
Hypothesis 4b	Health improvement → net benefits (+)	.41	< .001	.40	< .001	Supported
Hypothesis 5	Net benefits → intention to use (+)	.27	< .001	.20	< .05	Supported
Hypothesis 6	Net benefits → perceived value (+)	.43	< .001	.41	< .001	Supported
Hypothesis 7	Perceived value → intention to use (+)	.26	< .001	.28	.01	Supported
Hypothesis 8	Subjective norms → intention to use (+)	.41	< .001	.54	< .001	Supported
Hypothesis 9	Privacy and security risk → intention to use (−)	.02	.22	.09	.09	Unsupported
Control variable	Age → intention to use	−.12	< .001	−.09	.06	n.a.[b]
Control variable	Experience → intention to use	.00	.48	.04	.36	n.a.[b]
Control variable	Gender → intention to use	−.01	.33	.01	.89	n.a.[b]

[a] The plus (+) or minus (–) sign in parentheses denotes whether a positive or negative effect is anticipated.

[b] n.a. = not applicable.

Discussion

Principal Results

Our proposed model was successfully validated by the total sample and also by the specialist subsample. The statistical significance and the strength of standardized coefficients were almost identical for all the hypothesized paths. Therefore, for the sake of simplification, our principal results are described based on the total sample validation.

In terms of direct effects, physicians' intention to use mobile diabetes monitoring is primarily influenced by net benefits, perceived value, and subjective norms. Our PLS results indicate that the multivariate coefficient of determination (R^2) value of intention to use mobile diabetes monitoring was 0.67 ($R^2 = 0.82$ for the specialist subsample), indicating that more than two-thirds of the variance of this construct can be explained by the model. This value can be described as "substantial" according to Chin [50].

Net benefits not only have a direct effect on intention, but also an indirect effect through perceived value. We thus find evidence for a partial mediation. The hypothesized direct effect of overall quality on intention cannot be confirmed, but we find a significant positive indirect effect. More specifically, although neither the direct effect nor the total effect of overall quality on the intention to use mobile diabetes monitoring is significant, the indirect effect of overall quality on the intention to use mobile diabetes monitoring is significant. Given the correlation between overall quality and intention to use mobile diabetes monitoring (total $R^2 = 0.67$; specialist subsample $R^2 = 0.70$), the influence of overall quality on usage intention appears to be fully mediated by perceived value. This means that overall quality contributes to forming the intention to use mobile diabetes monitoring only if an increase in overall quality is perceived as value added.

Privacy and security concerns seem to be negligible in terms of their impact on the intention to use mobile diabetes monitoring. This is surprising given that there is much documented evidence about such concerns in wireless medical devices [51]. One possible explanation is that perhaps the respondents of this study might have been more experienced in the use of innovative medical devices. Prior research indicates that frequent and experienced users of electronic health records were significantly less concerned about privacy and security than nonusers [52]. On the other hand, there seems to exist evidence that, compared with general business practitioners, many physicians are not particularly technology literate, despite their highly demanding educational and specialized training [7]. This lack of computer literacy may have made them fail to acknowledge the severity of privacy and security concerns in mobile diabetes monitoring. We deem the latter to be a more reasonable and realistic explanation.

Limitations

The sample size of physicians specialized in internal medicine or related specialties was modest. Future studies should ensure a larger sample to increase the generalizability of the findings.

Similarly, although the sample consisted of physicians all across Japan (ie, 47 prefectures), the selection was not probabilistic; thus, it may not accurately reflect the entire Japanese medical community. Third, we did not examine how physicians' personal propensity to use new information and communication technology affects the model variables, which was far beyond the scope of our study. Because of the preceding reasons, this study should be considered as an initial stepping-stone and any generalization of the results should be done with caution.

Conclusions and Practical Implications

Physicians from a wide range of clinical expertise most valued perceived value as a mediator of the effects exercised by both overall quality and net benefits over intention to use mobile diabetes monitoring. This fact seems even more significant given the absence of direct effect of overall quality on intention to use mobile diabetes monitoring because physicians apparently seem to weigh exactly what kind of value they can get out of the system. In health care, value is defined as the patient health outcomes achieved relative to the inputs (or cost) required [53]. Because net benefits already take into account health outcome (ie, health improvement) and device utility (ie, ubiquitous control), our perceived value seems to crystallize the importance of the output-input relationship derived from the mobile diabetes monitoring. Prior research suggests that the power of quality improvement to drive down costs is greater in health care than in any other field [53]. Thus, our results may suggest that physicians tend to look into the efficiency and cost-effectiveness of mobile diabetes monitoring before forming their usage intention. This implies that the medical device industry should be increasingly keen on these aspects in marketing wireless medical monitoring systems.

The impact of subjective norms on intention to use mobile diabetes monitoring was solid, but this finding seems somewhat contradictory to the literature. Prior research on telemedicine finds no impact of subjective norms on intention, suggesting that physicians may value their own assessments over others' opinions and suggestions [7]. Similarly, the effects of subjective norms on intention to use clinical guidelines were reported to be much weaker among physicians than among nurses and other clinical professionals [54]. Our interpretation is that because many physicians are not particularly computer- or Internet-literate, they may rely more on their peers' or colleagues' help and suggestions regarding mobile diabetes monitoring adoption (ie, medical and IS adoption decisions), whereas they tend to be more independent or self-reliant for other knowledge-based practices (ie, purely medical decisions). Given the solid effects of subjective norms on intention to use mobile diabetes monitoring, it would be wise to organize workshops, seminars, or informative sessions so that knowledge and familiarity could be disseminated through word-of-mouth among peers and colleagues.

Finally, this study would help physicians understand the usefulness of mobile-based health care systems. Diabetes is a leading disease in most developed countries and requires constant and continuous monitoring. For example, according to the US Department of Health and Human Services, diabetes mellitus was listed as the seventh leading cause of death in 2010 [55]. Mobile technology could encourage diabetic patients to lead healthier lives and facilitate earlier discovery of life-threatening symptoms.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Construct measures used in the study.

[PDF File (Adobe PDF File), 49KB - jmir_v14i6e183_app1.pdf]

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Abbreviations

AVE: average variance extracted
IS: information system
IT: information technology
MDM: mobile diabetes monitoring
PDA: personal digital assistant
PLS: partial least squares
TPB: theory of planned behavior

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Original Paper

A Text Messaging-Based Smoking Cessation Program for Adult Smokers: Randomized Controlled Trial

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Related Article:

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Abstract

Background: Despite promising data in Western countries, there is a dearth of research into the efficacy of text messaging-based smoking cessation programs in other settings, including the Middle East, where smoking prevalence rates are higher.

Objective: This paper reports cessation rates observed in SMS Turkey, a text messaging-based smoking cessation program for adult smokers in Ankara, Turkey.

Methods: This study was a small-scale, parallel-group randomized controlled trial (RCT) conducted in Ankara, Turkey. Participants were adult daily smokers who were seriously thinking about quitting in the next 15 days and living in Ankara, Turkey. The text messaging intervention, SMS Turkey, provided 6 weeks of daily messages aimed at giving participants skills to help them quit smoking. Messages were sent in an automated fashion, except 2 days and 7 days after the initial quit day. On days 2 and 7, the research assistant manually assigned participants to content “paths” based on whether they were still not smoking or had relapsed. The control arm received a brochure that provided similar information about smoking cessation. The main outcome measure was self-reported 3-month sustained abstinence, verified by carbon monoxide (CO) readings. Neither participants nor researchers were blinded to arm assignment.

Results: The 151 participants were randomly assigned to 1 of 2 groups: 76 to the SMS Turkey intervention group and 75 to the brochure control group. Using intention to treat, all 151 participants were included in analyses. Three-month cessation trends were not significantly higher in the intervention group: 11% intervention vs 5% control had quit (χ^2_1=1.4, *P*=.24; R^2=2.0, 95% CI 0.62-6.3). When the sample was stratified by sex, female intervention participants (14%, n=5) were significantly more likely to have quit at 3 months than female control participants (0%, n=0; χ^2_1=3.7, *P*=.05). Among light smokers (ie, those smoking less than 20 cigarettes per day), intervention participants (17%, n=5) also were significantly more likely to have quit compared to control participants (0%, n=0; χ^2_1=5.3, *P*=.02). We noted no difference in cessation rates for males or heavy smokers. Participants experienced significant technology problems during the study. Some participants received duplicate text messages at least once during the trial; others failed to receive some program messages. Neither receiving duplicate messages (χ^2_1=0.12, *P*=.73), or missing 5 or more program messages (χ^2_1=0.75, *P*=.39) negatively affected quitting rates.

Conclusions: Although the study was not powered to detect statistically significant differences, as the primary aim was to provide estimates of effect size that could be used to better inform a power analysis for a larger trial, findings provide optimism that SMS Turkey may be able to affect quitting rates in environments with high smoking prevalence, such as Ankara, Turkey.

The SMS Turkey software program did not work as well as it did 2 years previous. The system will need to be updated to maintain software compatibility with ongoing technology evolution.

Trial Registration: Clinicaltrials.gov NCT00912795 http://clinicaltrials.gov/ct2/show/NCT00912795 (Archived by WebCite at http://www.webcitation.org/6Ch1cIA8l).

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KEYWORDS

smoking cessation; Middle East; text messaging; pilot study

Introduction

Cigarette smoking is a major contributor to morbidity and mortality in Turkey [1,2]. Compared to the United States, where 23% of men and 18% of women are current smokers [3], an estimated 44% of men and 12% of women smoke daily in Turkey [2]. Despite Turkey's high smoking prevalence rate, data suggest a demand for cessation services—over half of all smokers desire to quit and 45% have made a quit attempt in the past year [2].

The smoking landscape changed dramatically in Turkey when it became the third country in Europe to go 100% smoke free in 2009 [4,5]. Turkey is a signatory of the World Health Organization (WHO)'s Framework Convention on Tobacco Control [6], which mandates the adoption of governmental policies that reduce the supply and demand for tobacco. Turkey has been lauded for its recent success in increasing its efforts to reduce smoking [4,7]. Pharmacotherapies for cessation, such as Zyban, are available at pharmacies without a prescription and a national telephone quit line was implemented in the last few years. However, there is some indication that few smokers avail themselves of cessation services. Unalacak [8] reports that only 3% of current smokers used a smoking cessation intervention (eg, nicotine replacement therapy and cognitive behavioral therapy, CBT) as part of their quit attempt.

To increase cessation rates, smoking cessation programs need to be easily accessible and to reach a large number of people. An estimated 84% of adults in Turkey own a cell phone, 64% of whom use text messaging [9]. Because cell phones are 3.8 times more common than landline telephones [10], text messaging-based programming may represent an underutilized public health opportunity that is both scalable and cost effective [11,12]. Emerging evidence generally supports the efficacy of text messaging-based health behavior change programs [13,14]. This evidence also specifically supports the efficacy of text messaging-based smoking cessation programs in Western countries, at least in the short term [15,16]. Despite these promising data, research is lacking from non-Western cultures and those with higher smoking prevalence rates where the relative morbidity and mortality rates are higher. Unlike in the United States, where tobacco use is considered a "hardening of the target" [17], smoking is normative and very much a social experience in Turkey [18-20]. If text messaging-based programs can be as effective in these high-prevalence settings, the potential public health benefits will be even greater.

Preliminary data from Ankara, Turkey suggests that text messaging-based smoking cessation programs are feasible and acceptable [21,22]. In this paper, we report findings from the small-scale randomized controlled trial (RCT) of short message service (SMS) Turkey, a 6-week text messaging-based smoking cessation program. Given the relative novelty of conducting text messaging-based public health efforts in the Middle East, we also report process measures, including technology issues experienced during the trial and program retention.

Methods

Overview

This study was a parallel-group RCT conducted in Ankara, Turkey. Chesapeake IRB and Hacettepe University Ethical Committee reviewed and approved the research protocol. The clinical trial registration number is: NCT00912795.

Participants

Participants were daily smokers 18 years of age and older living in Ankara, Turkey. Additional eligibility criteria included: owning a mobile phone and having sent or received at least 1 text message in the past year; seriously thinking about quitting in the next 15 days; and not having a chronic or serious illness defined as emphysema, heart disease, or lung disease (because this population would likely require a different type of intervention).

Study Setting

As the capital of Turkey, Ankara is the second largest city in Turkey after Istanbul. The city is in the heart of the Anatolian peninsula and is part of a main trading route for tobacco [23]. It is estimated that at least 1 smoker resides in 70% of the houses in the southeastern region of Anatolia, which is similar to rates in the country as a whole [24]. In Ankara, 41% of adults are smokers, which ranks the city third in smoking prevalence behind Istanbul (44%) and Izmir (44%) [25]. Ankara's high smoking prevalence is characteristic of many cities in the Middle East.

Intervention and Control Group Design

As reported elsewhere [26], the content of the SMS Turkey program was developed following a review of components found in telephone-based counseling approaches to smoking cessation, particularly those using CBT [27-33]. CBT content focuses on altering the individual's way of thinking (cognitive processes) and acting (behavioral actions). Smokers are encouraged to identify new behaviors that can be substituted for smoking-related activities, make a commitment to quitting, recognize the harmful effects of continued smoking, identify methods to control cues that may trigger the urge to smoke, and reward themselves for not smoking [34]. Self-efficacy theory [35-38] and relapse prevention [28,39-41] are additional components key to an effective smoking cessation program. SMS Turkey integrates these topics into the content and is tailored to where participants are in the quitting process. For example, messages in the "pre-quit" phase encourage the participant to clarify reasons for quitting and to understand his or her smoking patterns and tempting situations/triggers/urges (Table 1). Messages in the "early quit" phase talk about common difficulties and discomforts associated with quitting and emphasize the use of coping strategies. Messages in the "late quit" phase encourage participants to recognize relapse in a different way (eg, situations, confidence, etc) and provide actionable information about how to deal with issues that arise as a non-smoker (eg, stress, moods). Development activities and content were "frozen" and did not change for the life of the trial.

Table 1. Example of SMS Turkey content received by the intervention group (actual messages translated into Turkish).

Program arm	Example text message
Pre-quit	When and why do you smoke? Start a smoking diary. Keep track of when you smoke, what you're doing (the activity), how you feel, and your craving (from 1-3).
Quit day	Withdrawal symptoms are unique to everyone. Frustration, impatience, and depression are common but usually only last a week or two.
Early quit	Treat every day like your quit day. Pretend as though it is the first day without cigarettes and be ready for temptation.
Late quit	Call your "special supporter" and make plans for your 2-week anniversary—it's just 3 days away!
Relapse	Becoming a non-smoker is like learning to ride a bike—it's hard at first and then you learn how to do it—and enjoy the ride!
Encouragement	Whatever you decide about smoking, believe in yourself. You CAN quit smoking if you put your mind to it and have a plan for success.

Previous research into the efficacy of telephone quit lines conducted in the United States suggests that most smoking relapse occurs within 2 days of quitting, and at 7 days, the relapse curve begins to flatten out [32]. As such, different content "paths" were created for participants based on whether or not they were smoking 2 days after quit day; and again at 7 days after quit day. If participants reported smoking at either 2 or 7 days after quit day, the research assistant (RA) manually assigned the participant to the "relapse" arm, which provided content that focused on helping them get back on track and recommit to quitting. If participants were smoking at both 2 and 7 days after quit day, they were directed to the "encouragement" arm that focused on norms for quitting and suggested that the person try again when she or he was ready.

Intervention participants began receiving program messages the day after enrollment and continued to receive messages daily through the end of the program. The frequency that participants received messages changed over the course of the program: participants generally received 5 messages per day in the pre-quit phase and then received more messages as the quit day approached. The highest number of messages was sent on the quit day and the day after; and then the number of messages began to taper down. In the last week of the program, participants were sent 1 message per day. Depending on the participant's content path, the total number of messages received ranged from 91 (for those assigned to the encouragement arm) to 146 (for those who relapsed and then were assigned to the late quit messages).

Intervention messages were created in English, translated into Turkish, and then back-translated to ensure an accurate and appropriate translation. Messages were unidirectional: participants received but did not respond to messages. Research staff did not prompt or remind participants to engage with the intervention.

Previous text messaging-based smoking cessation trials have included a minimal contact control group that received 1 text message per week reminding them they were in the study [16,42]. Control participants in the SMS Turkey RCT were given general quitting information in a 7-page brochure, but they did not receive any text messages. Although the brochure was not designed to exactly mirror the content of the SMS intervention, some information overlapped (eg, setting a quit date, creating a diary to understand their smoking behavior, practicing quitting, and coping strategies for withdrawal). For example, the following text was included in the "It's Quitting Time" section of the brochure: "First, set a quit date in the next 30 days. Tell everyone when you're going to stop smoking. Sign a contract and put it on the fridge so that you see it every day. If you smoke 10 or more cigarettes each day, make an appointment with your doctor to talk about medicines that will really help you quit smoking. They may cost money, but think about all of the money you spend on cigarettes!" The brochure encouraged smokers to follow 5 steps: (1) set a quit day and sign a contract, (2) find out about their smoking patterns-why they smoke, (3) practice quitting and change their patterns, (4) involve their family and friends, and (5) learn to be a self-supporter.

Outcomes

The primary outcome measure was sustained abstinence 3 months after quit day, confirmed with a carbon monoxide (CO) reading of 8 ppm or less [43]. Sustained abstinence was defined as 5 or fewer cigarettes smoked since the quit date, per West et al [44]. Participants were asked: have you smoked at all, even just a puff, since your quit day? Response options were: (1) no, not a puff, (2) 1-5 cigarettes, and (3) more than 5 cigarettes. CO was measured by the RA, who was trained by the project physician (SE) to use the CO device to produce a valid measurement.

Secondary outcome measures included: 7-day and 28-day point prevalence of smoking behavior at 3 months; CO-verified 7-day point prevalence at 4 weeks; and reduction in cigarettes per day for those who are smoking at 3 months. Program acceptability measures included how well intervention participants liked the program and how likely they were to recommend it to others. Participants were also asked if they had suggestions to improve the program and, if so, what the improvement would be.

Covariates included smoking behavior, quitting characteristics, and psychosocial characteristics.

Smoking Behavior

Participants provided information about their smoking history (eg, age at time of first cigarette) and smoking dependence [45]. Perceptions and norms related to smoking were queried using items developed for research among Turkish smokers [46]. Participants were also asked questions about how different triggers (eg, stress, when someone offers you a cigarette) affected their smoking and about how difficult it was not to smoke in various situations (eg, when with friends) [46].

Quitting Characteristics

At baseline, participants were asked how important quitting was and how confident they were that they would be able to quit smoking [47]. They also reported quit attempts in past years that lasted for 24 hours or longer, and whether or not they planned to use an evidence-based quitting aid (eg, pharmacotherapy). Reasons for quitting (eg, for family) were queried and a sum was created to reflect the total number of reasons each person had for quitting [46]. Similarly, a sum of 10 different concerns about quitting (eg, I will be more stressed) was created to reflect the total number of concerns participants had about quitting [46]. Finally, we created a summary of good (2 items) and bad (6 items) things about quitting (eg, I will be proud when I quit smoking; I will be less social when I quit smoking).

Psychosocial Characteristics

Social support is a significant factor in successful cessation efforts [48]. The Multidimensional Scale of Perceived Social Support [49] has 3 subscales: friends, a "special person", and family (eg, my family really tries to help me). Alcohol dependence is associated with decreased likelihood of cessation [50]. We used the 4-item CAGE measure of alcohol use. CAGE is an acronym for the four questions: (1) have you ever felt the need to *C*ut down, (2) have people *a*nnoyed you by complaining about your drinking, (3) do you ever feel *G*uilty about drinking, and (4) have you ever felt you needed a drink the first thing in the morning (an *E*ye-opener) [51]. We coded endorsement of at least 1 of the 4 drinking-related experiences queried as "problem drinking."

Sample Size

We targeted a sample size of 150 participants for feasibility reasons based on the project budget and timeline.

Randomization and Masking

Participants chose 1 of 2 identical mailing envelopes. Inside, a slip of paper read either "SMS Turkey" (intervention group) or "brochure" (control group). Neither the participant nor the researcher knew which slip of paper was in each envelope.

An imbalance favoring the intervention arm was detected after approximately 100 participants were enrolled. The procedure was then modified so that the RA pulled a slip of paper from a hat that read either "SMS Turkey" or "brochure." To ensure an equal number of participants in each arm, the number of slips of paper was equal to the number of places that remained in the intervention and control groups.

Participants were told that researchers had developed 2 different programs to help people quit smoking and that the aim of the study was to see if the programs help people quit. The intervention of interest was not specified. Once allocated to a particular arm, neither the RA nor the participant was blind to the participant's arm assignment.

Procedures

Participants were recruited and randomized between December 14, 2010, and June 16, 2011, through in-person outreach at local shopping malls and advertisements in local newspapers. Additionally, flyers were posted at Hacettepe University. Smokers indicated their interest by either calling the study office or speaking directly with the RA at the shopping mall. An in-person meeting was then scheduled, during which the RA explained the study, confirmed eligibility criteria, obtained informed written consent, and collected baseline data. The RA also set the participant's quit day to be 15 days after enrollment. This time frame was chosen to align with the 14-day pre-quit phase for those assigned to the intervention group, although a quit day was set for all participants regardless of their arm assignment. Given that participants needed to be seriously thinking about quitting in the next 15 days to be eligible, this quit date seemed to be acceptable to all participants. The RA encouraged all participants who smoked 10 cigarettes or more per day to consider pharmacotherapy, regardless of their study arm.

Participants had contact with a human being during enrollment, at 2 and 7 days after their quit day (intervention participants only), at data collection follow-ups, and whenever there were technology problems (intervention participants only). Research incentives are not culturally normative in Turkey, so we did not use them in our study.

Data Collection

The RA collected self-reported survey data and CO readings, which detect cigarette smoking in the previous 24 hours, at the study office at baseline, at 4 weeks after quit day, and at the 3-months follow-up point. We measured program acceptability among intervention participants at 4 weeks. This time point was chosen over the 3-month follow-up point so that participants would have a stronger memory of the program experience.

Participants completed the survey online in a private room at the study office. The survey was pilot tested for validity when delivered online prior to the RCT: 75 adult smokers completed the survey online and 75 completed a paper-and-pencil version of the survey. Responses were similar across mode (unpublished data). If the participant could not come to the office at follow-up, the RA queried smoking status over the telephone by asking the same question included in the survey.

Statistical Analyses

Analyses were presented in 2 ways. Intent-to-treat (ITT) analyses included all randomized individuals in the analysis (all participants lost to follow-up were assumed to still be smoking). Per-protocol analyses (PPA) included only participants who completed the follow-up measures. It should be noted that PPA is a self-selected sample. Therefore, results are no longer an unbiased sample from a randomized trial. Non-responsive (ie, decline to answer) replies to variables included in the analyses are imputed using best-set regression [52]. All variables have less than 5% of data imputed. We used the “cs” command in Stata to calculate the risk ratio and risk difference [52]. Research suggests that the quitting process may be different for males and females [53] and for heavy (20+ cigarettes per day) versus light smokers [54], so we stratified the sample by each of these 2 characteristics and examined cessation rates by study arm. Finally, to maximize data and therefore increase power, we used a marginal model with generalized estimating equations (GEE) to estimate the population-average odds of CO-verified quitting across the 2 follow-up periods (4 weeks and/or 3 months) as a function of being in the intervention versus control group, while accounting for clustering in the data within person over time. We assumed an exchangeable correlation is assumed and calculated robust standard errors. Baseline characteristics that differed significantly between the intervention and control groups were included in the GEE models. These adjusted estimates are denoted as aOR (adjusted Odds Ratios). All analyses were conducted using Stata 11 [52].

Results

As shown in Figure 1, of the 247 people who expressed interest in participating, 230 were eligible for the study. Reasons for ineligibility included living outside of Ankara and having a serious health condition. There were 79 people who enrolled in appointments but did not attended. A total of 151 adults (66% of those eligible) attended the enrollment meeting, where they consented to take part in the research study and were randomly assigned to either the intervention or control group.

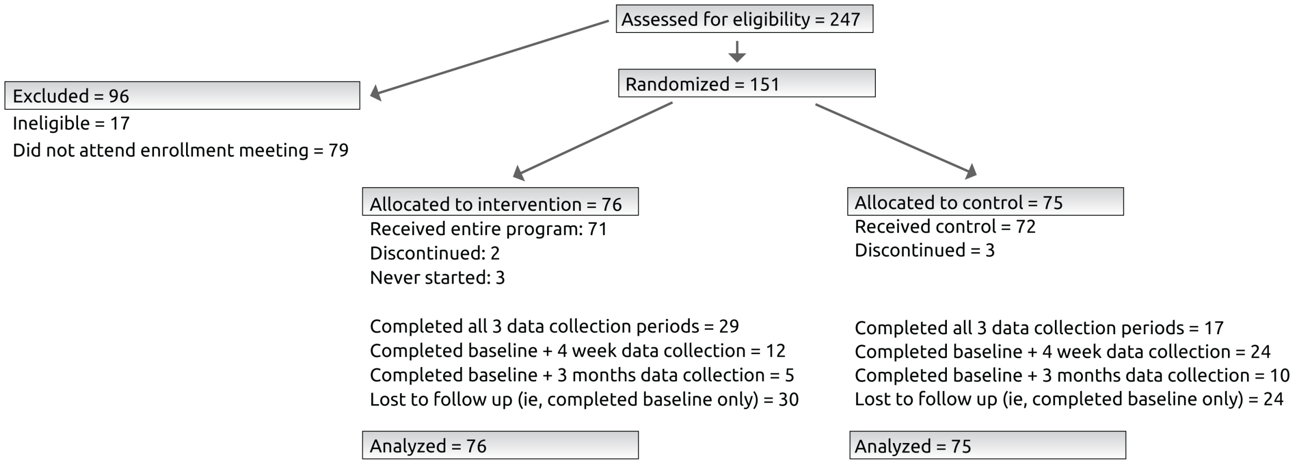
As shown in Table 2, the experimental groups were generally well balanced on demographic, smoking, and quitting characteristics. Exceptions were the control participants who were significantly more likely to report a low household income, have fewer smoking triggers, have fewer difficulties not smoking when faced with triggers, and identify less strongly with negative things associated with smoking. Conversely, intervention participants reported significantly higher social support from their family and a “special person” in their lives than control participants.

Table 2. Sample characteristics by study arm (n=151).

Personal characteristics		Control (n=75) Mean (SD) or % (n)	Intervention (n=76) Mean (SD) or %(n)	Statistical comparison	*P* value
Demographic characteristics					
	Age (range 19-62 years)	35.6 (10.3)	36.1 (9.5)	t_{149}=-0.30	0.76
	Female	32.0% (24)	46.1% (35)	χ^2_1=3.1	0.08
	Low income (< 2000 Turkish lira per month)	49.3% (37)	30.3% (23)	χ^2_1=5.7	0.02
	Married	65.3% (49)	55.3% (42)	χ^2_1=1.6	0.21
	Low educational attainment (high school education or lower)	50.7% (38)	36.8% (28)	χ^2_1=2.9	0.09
Smoking characteristics					
	Average number of cigarettes smoked per day (range 7-40)	20.4 (9.2)	18.7 (7.2)	t_{149}=1.2	0.21
	Age at first cigarette (range 6-29 years)	17.1 (3.6)	17.5 (3.7)	t_{149}=-0.71	0.48
	Fagerström score (range 0-10)	4.9 (2.5)	4.8 (2.3)	t_{149} =0.27	0.79
	Smoking triggers (range 17-65)	38.3 (9.2)	41.9 (7.3)	t_{149}=-2.7	0.01
	Difficulty not smoking when faced with stressors (range 13-45) [46]	32.4 (7.8)	34.8 (5.8)	t_{149}=-2.2	0.03
	Good things about smoking (range 3-15) [46]	5.8 (2.2)	5.9 (2.7)	t_{149}=-0.43	0.66
	Bad things about smoking (range 8-40) [46]	33.1 (8.0)	35.5 (6.2)	t_{149}=-2.1	0.04
	Narghile smoking (ever in the past year)	24.0% (18)	25.0% (19)	χ^2_1=0.02	0.89
	Smoker living in the household	48.0% (36)	42.1% (32)	χ^2_1=0.5	0.47
Quitting characteristics					
	Importance of quitting to self (range 4-10) [47]	9.0 (1.4)	8.9 (1.6)	t_{149}=0.37	0.71
	Confidence in one's ability to quit (range 0-10) [47]	6.0 (2.5)	6.0 (2.4)	t_{149}=0.00	0.99
	Number of quit attempts in the past year (range 0-5+)	2.4 (1.5)	2.4 (1.5)	t_{149}=-0.09	0.93
	Number of reasons to quit (range 1-8)	2.7 (1.7)	2.9 (1.6)	t_{149}=-0.81	0.42
	Number of concerns about quitting (range 1-10)	3.5 (2.0)	3.9 (1.9)	t_{149}=-1.3	0.20
	Good things about quitting (range 2-10) [46]	7.6 (1.9)	8.2 (1.7)	t_{149}=-1.8	0.07
	Bad things about quitting (range 6-29) [46]	18.3 (5.1)	18.8 (4.8)	t_{149}=-0.64	0.52

Personal characteristics		Control (n=75) Mean (SD) or % (n)	Intervention (n=76) Mean (SD) or %(n)	Statistical comparison	*P* value
	Planning on using a evidence-based quitting aid	34.7% (26)	31.6% (24)	χ^2_1=0.2	0.69
Psychosocial characteristics					
	Social support from a “special person” (range 4-20)	14.9 (4.0)	16.1 (3.6)	t_{149}=-2.0	0.05
	Social support from family (range 4-20)	15.7 (3.5)	16.8 (3.2)	t_{149}=-2.0	0.05
	Social support from friends (range 4-20)	15.4 (3.1)	16.3 (3.2)	t_{149}=-1.8	0.07
	Problem drinking	29.3% (22)	40.8% (31)	χ^2_1=2.2	0.14

Figure 1. SMS Turkey randomized controlled trial profile.



Cessation Results

At 4 weeks, 78% (n=59) of intervention group and 80% (n=60) of control group participants provided cessation data. In addition, 54% (n=41) of intervention group and 55% (n=41) of control group participants provided CO data (χ^2_1=0.008, *P*=.93). Data for the 12-week cessation and CO were available for 40% (n=61) of participants: 45% (n=34) intervention group and 36% (n=27) control group (χ^2_1=1.2, *P*=.27).

Three-month cessation rates, based upon ITT analyses, were statistically similar for the 2 arms: 11% intervention group versus 5% control group (χ^2_1=1.4, *P*=.24; R^2 = 2.0, 95% CI 0.62-6.3, Table 3). Results were similar when analyzed per protocol: 24% (n=8) in the intervention group versus 15% (n=4) in the control group (χ^2_1=0.72, *P*=.40; R^2=1.6, 95% CI 0.53-4.70). ITT-based population average odds of quitting were similar for those in the intervention group versus control group (aOR=1.7, 95% CI 0.72-4.04).

Table 3. Primary and secondary outcomes of the SMS Turkey trial.

	PPA				ITT analysis			
	Control (n=27) % (n)	Intervention (n=34) % (n)	Relative risk (95% CI)	Risk difference (95% CI)	Control (n=75) % (n)	Intervention (n=76) % (n)	Relative risk (95% CI)	Risk difference (95% CI)
Primary outcome								
CO-verified sustained abstinence at 3 months	15 (4)	24 (8)	1.6 (0.53-4.7)	0.09 (-0.11-0.28)	5 (4)	11 (8)	2.0 (0.62-6.3)	0.05 (-0.03-0.14)
Secondary outcomes								
CO-verified 7-day point prevalence abstinence at 4 weeks[a]	12 (7)	15 (9)	1.3 (0.52-3.3)	0.04 (-0.09-0.16)	9 (7)	12 (9)	1.3 (0.50-3.2)	0.03 (-0.07-0.12)
Self-reported 7-day point prevalence abstinence at 3 months	15 (4)	29 (10)	2.0 (0.70-5.6)	0.15 (-0.06-0.35)	5 (4)	13 (10)	2.5 (0.81-7.5)	0.08 (-0.01-0.17)
Self-reported 30-day point prevalence abstinence at 3 months	15 (4)	24 (8)	1.6 (0.53-4.7)	0.09 (-0.11-0.28)	5 (4)	11 (8)	2.0 (0.62-6.3)	0.05, (-0.03-0.14)

[a] 4-week PPA n=119 (ie, the 59 intervention and 60 control participants who provided cessation data at 4-weeks)

Investigation of Cessation Results by Important Subpopulations

When the sample was stratified by biological sex (Table 4), ITT-based quitting rates were similar for male intervention group (7%, n=3) and control group participants (8%, n=4; χ^2_1=0.009, *P*=.93). Among females, however, intervention group participants (14%, n=5) were significantly more likely to have quit at the 3-month point than control group participants (0%, n=0; χ^2_1=3.7, *P*=.05). Population averaged odds suggested that intervention group females were 4.5 times more likely to quit than control group females (95% CI 1.2-16.0), but no differences were noted for males (aOR=0.54, 95% CI 0.12-2.3). Data also suggested that among light smokers, intervention group participants (17%, n=5) were significantly more likely to have quit compared to control group participants (0%, n=0; χ^2_1=5.3, *P*=.02). Population averaged odds of quitting were over 4 times higher for light smokers in the intervention group versus control group, but the estimate was not significant (aOR=4.04, 95% CI 0.87-18.6). We did not note a difference in cessation rates for heavy smokers (aOR=0.63, 95% CI 0.16-2.6). Females were significantly more likely than males to be light smokers (58% versus 27%, respectively; *P*<.001), suggesting considerable overlap between females and light smokers.

Table 4. Effect of SMS Turkey intervention on the primary outcome by subgroup.

	PPA			ITT analysis		
	Control (n=27) % (n)	Intervention (n=34) % (n)	Statistical comparison	Control (n=75) % (n)	Intervention (n=76) % (n)	Statistical comparison
Biological sex						
Males (n=92)	24 (4)	17 (3)	χ^2_1=0.26, *P*=.61	8 (4)	7 (3)	χ^2_1=0.009, *P*=.93
Females (n=59)	0 (0)	31 (5)	χ^2_1= 3.9, *P*=.05	0 (0)	14 (5)	χ^2_1=3.7, *P*=.05
Smoking intensity						
Light smokers (n=59; < 20 cigarettes per day)	0 (0)	33 (5)	χ^2_1=3.8, *P*=.05	0 (0)	17 (5)	χ^2_1=5.3, *P*=.02
Heavy smokers (n=92; 20+ cigarettes per day)	22 (4)	16 (3)	χ^2_1=0.25, *P*=.62	9 (4)	7 (3)	χ^2_1=0.15, *P*=.69

Outcomes for Participants Still Smoking at Study End

Among the 47 participants who provided data and were smoking at the 3-month follow-up, the average number of cigarettes smoked daily by intervention group participants (mean 11.9 cigarettes, SD 7.7) was lower, but not significantly so, compared to that reported by control group participants (mean 16.5, SD 9.9; t_{43}=1.8, *P*=.09). On average, participants who were still smoking at follow-up reduced their daily cigarette consumption from baseline to the 3-months point by 5 cigarettes. However, the reduction in cigarettes was not significantly different for intervention group (mean 5.7, SD 7.3) versus control group participants (mean 4.5, SD 8.9; t_{43}=0.51, *P*=.61).

Intervention Acceptability

The intervention group had 2 people actively drop out: 1 no longer wanted to be in the program and 1 was unreachable because the phone number changed. The control group had 3 people drop out: 2 because they no longer wanted to be in the program and 1 was unreachable because the phone number changed.

Of the 59 intervention group participants who responded at the 4-week follow-up, 69% (n=41) said they somewhat or strongly liked the program and 78% (n=46) were somewhat or very likely to recommend the program to others. When asked what the ideal number of text messages per day would be, the average answer was 5.5 (SD 3.8, range 1-20). The most common suggestion to improve the program was to provide in-person contact, followed by the idea to provide psychological support. Other ideas included talking more about both the benefits of quitting and the dangers of smoking.

Technology Performance

The software program used to deliver the SMS Turkey program was developed in 2009. Despite functioning well for the pilot feasibility study [22], software challenges were severe enough by the end of the RCT that 2 participants who were randomized to the intervention group could not start the program because the messaging system had failed and could not be resolved. Additionally, 1 person randomized to the intervention group had a phone that was incompatible with the text messaging software program and could not receive messages.

We encountered 2 serious issues with the software program during our study. First, the software program failed to send at least 1 program message to 58% (n=44) of intervention group participants. Most of the affected participants (64%) missed fewer than 5 intervention messages. Intervention participants who missed 5 or more program messages were somewhat less likely than those experiencing fewer interruptions to have a CO-verified smoking status at 3-months: 5% (n=1) vs 12% (n=7; χ^2_1=0.75, *P*=.39).

Second, 66% (n=50) of intervention participants were sent a duplicate text message at least once during the trial. Half (50%) of these participants received 22 or more duplicate messages (range 1-342 duplicate messages). Quitting rates were similar for intervention participants who received any number of duplicate text messages versus those who did not receive duplicate messages (11% versus 9%, respectively; χ^2_1=0.12, *P*=.73). Furthermore, receiving duplicate messages during one's quit day–which may be more disruptive in the quitting process–was unrelated to smoking status at 3 months: 12% of those who received duplicate messages within 2 days of their quit day versus 12% of those who received duplicate messages at some other time in the program had quit at follow-up (χ^2_1=0.0001; *P*=.99). Six participants were particularly affected and received over 100 duplicate messages. Two of these participants received over 300 messages within a 24-hour period. Unexpectedly, the quit rate among these 6 participants was significantly higher than that for other participants receiving duplicate messages (50% vs 7%, respectively; χ^2_1=9.3, *P*=.002).

Discussion

Despite the public health need to disseminate cost-effective, evidence-based smoking cessation programs, there is a paucity of research regarding the efficacy of these types of smoking cessation programs in Turkey and other countries with cultures that differ from the Western world. If we are to reduce smoking-related morbidity and mortality on a global level, this knowledge is critical in settings with high smoking prevalence rates, such as Turkey [55,56]. Findings from the small-scale RCT of SMS Turkey suggest that the intervention has the potential to affect quitting rates at the 3-month point for women and light smokers who live in Ankara and use text messaging. Results need to be replicated in a well-powered RCT before conclusions can be drawn. Given that literature suggests that males and females have different quitting experiences [53], as do heavy and light smokers [54], understanding which subpopulations may benefit most from these types of cessation services is an important aspect of the larger public health efforts to create an arsenal of evidence-based smoking cessation services that together can meet the varied needs of adult smokers who want to quit.

It is possible that other factors aside from the intervention content affected cessation rates. For example, although participants were told that 2 potentially equal programs were being tested, they may have been able to surmise that the text messaging-based program was the program of interest. If true, then perhaps participants in the text messaging-based program were more motivated and those in the brochure-based program were less motivated to quit. Because both groups received information about quitting, it seems equally possible that the participants believed the explanation that neither program was known to be better and therefore did not have expectations that the brochure should be inferior. Another potential influence on behavior may have been the interaction between the intervention participant and RA at 2 and 7 days after quit day. Even though the RA simply inquired about the participant's smoking status, this check-in itself could have had some therapeutic effect. Indeed, it may be that text messaging programs that include brief human interaction have enhanced results. This should be studied further.

The SMS Turkey software program did not work as well as it did during the 1-arm feasibility pilot 2 years' previous. However, it is interesting to note that indicators of program acceptability in this RCT are similar to those found in the previous study [22]. No changes were made to the software program between the time of the feasibility pilot and this RCT. Indeed, the lack of change likely led to the problems. Both our SMS gateway service and our remote server provider updated their software program several times during the course of the seven months we were in field. By June 2011, the software program had stopped functioning altogether and the last 2 people allocated to the intervention group never received program messages. These challenges affected our participants. These problems also affected our recruitment rates because we had to pause recruitment several times to resolve the issues and get the messaging system back on track. Technology is a cost-effective tool that has the promise of widely delivering public health programming. Nonetheless, our experience demonstrates the need to ensure infrastructure to keep this technology up to date. Ongoing technology evolution means that constant updating is necessary to keep software compatible.

Of the eligible participants, 34% did not attend the initial enrollment meeting. Perhaps they did not show up because they were no longer interested in the program or reassessed their readiness to quit smoking. It is possible, however, that they were interested but could not attend because of other commitments. Subsequent trials should consider offering an online enrollment option to investigate whether this option increases the enrollment rate among eligible smokers. Also, the 40% response rate at the 3-month point is suboptimal. This response rate likely reflects the burden of needing to go to the study office to complete study measures. It may also represent the disengagement by intervention group participants who experienced significant technology problems and by control group participants who received minimal study contact. It is possible that this low overall follow-up rate introduced differential bias into the findings, but this seems less likely given that dropout rates were similar between the intervention and control groups. Future trials should consider using follow-up strategies that do not require participants to come to the office (eg, completion of the online survey at home or via text messaging; mail-in saliva *cotinine* tests).

It should be noted that CO tests measure cigarette smoking in the past 24 hours. If participants reported at the 3-month follow-up that they had not had a cigarette since their quit day, but they had actually had a cigarette only a week previous, it would not be detected in the CO test. This limitation would apply equally to control group and intervention group participants, so it is unlikely that it affected the interpretation of the results. Moreover, a review of the literature suggests that biochemical verification is unlikely to change the interpretation of results in minimal contact interventions [57] such as used in this study.

Another important limitation is the study's small sample size and, therefore, limited power to statistically detect significant differences. As a preliminary RCT, the primary aim was to provide estimates of effect size that could be used to better inform a power analysis for a larger trial. As such, analyses–especially subanalyses–were underpowered. Also, the original randomization technique did not seem to be assigning participants to the study arms equally. Because the 2 arms are balanced on most factors, it appears that allocation concealment was achieved. However, without a visual recording of each enrollment meeting, there is no way to be absolutely certain.

Finally, compared to the national population of smokers in Turkey [2], the study sample was more educated (eg, 32% of smokers in Turkey have a university education, while 56% of trial participants had a university education). Participants in this study also had a profile associated with greater smoking addiction: more had their first cigarette when they were 15 years of age or younger (19% of smokers in Turkey vs 32% of trial participants), more smoked 20 cigarettes a day or more (15% of smokers in Turkey vs 60% of trial participants), and more smoked within 30 minutes of waking (38% of smokers in Turkey vs 57% of trial participants). Future studies should aim to recruit participants with lower educational attainment, and perhaps those with less smoking addiction, to better understand how the program affects smoking cessation in these groups.

Conclusions

Data from this preliminary RCT provide reason for optimism that SMS Turkey has the potential to affect quitting rates–especially for women and light smokers. These findings provide further support for the hypothesis that, despite their brevity, smoking cessation information can be effectively communicated through a series of 160-character messages. Future research should focus on understanding mechanisms that affect the efficacy of the SMS Turkey program with the aim of eventually including it in the arsenal of evidence-based smoking cessation programs available to Turkish smokers who want to quit.

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Authors' Contributions

MY was the principal investigator of the project; she analyzed the data and wrote the first draft of the manuscript. TB trained the research staff and monitored data collection; she also contributed to the revision of the manuscript. JK provided consultation on methodology and contributed to the revision of the manuscript. SE was the principal investigator for the Turkey team and oversaw the implementation of the project; he also contributed to the revision of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

CONSORT-eHealth Checklist V1.6 [58].

[PDF File (Adobe PDF File), 649KB - jmir_v14i6e172_app1.pdf]

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Abbreviations

aOR: adjusted Odds Ratio
CBT: cognitive behavioral therapy
CO: carbon monoxide
GEE: generalized estimating equations
ITT: intent-to-treat
PPA: per-protocol analysis
RA: research assistant
RCT: randomized controlled trial

SMS: short message service
WHO: World Health Organization

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Original Paper

Increased Use of Twitter at a Medical Conference: A Report and a Review of the Educational Opportunities

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Abstract

Background: Most consider Twitter as a tool purely for social networking. However, it has been used extensively as a tool for online discussion at nonmedical and medical conferences, and the academic benefits of this tool have been reported. Most anesthetists still have yet to adopt this new educational tool. There is only one previously published report of the use of Twitter by anesthetists at an anesthetic conference. This paper extends that work.

Objective: We report the uptake and growth in the use of Twitter, a microblogging tool, at an anesthetic conference and review the potential use of Twitter as an educational tool for anesthetists.

Methods: A unique Twitter hashtag (#WSM12) was created and promoted by the organizers of the Winter Scientific Meeting held by The Association of Anaesthetists of Great Britain and Ireland (AAGBI) in London in January 2012. Twitter activity was compared with Twitter activity previously reported for the AAGBI Annual Conference (September 2011 in Edinburgh). All tweets posted were categorized according to the person making the tweet and the purpose for which they were being used. The categories were determined from a literature review.

Results: A total of 227 tweets were posted under the #WSM12 hashtag representing a 530% increase over the previously reported anesthetic conference. Sixteen people joined the Twitter stream by using this hashtag (300% increase). Excellent agreement ($\kappa = 0.924$) was seen in the classification of tweets across the 11 categories. Delegates primarily tweeted to create and disseminate notes and learning points (55%), describe which session was attended, undertake discussions, encourage speakers, and for social reasons. In addition, the conference organizers, trade exhibitors, speakers, and anesthetists who did not attend the conference all contributed to the Twitter stream. The combined total number of followers of those who actively tweeted represented a potential audience of 3603 people.

Conclusions: This report demonstrates an increase in uptake and growth in the use of Twitter at an anesthetic conference and the review illustrates the opportunities and benefits for medical education in the future.

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KEYWORDS

Twitter messaging; Social Media; Conferences; Congresses; Anesthesiology

Introduction

Twitter [1] is a mobile microblogging and social networking service through which its subscribers can send and read small text-based messages known as *tweets*. Tweets have a message size limit of 140 characters based on the size of the Short Message Service (SMS) messages used on mobile phones at the time of Twitter's creation in 2006. Twitter is a technology that still has to be adopted by much of the anesthetic community. Twitter is easily accessed through a number of platforms: the Twitter website, applications (apps) developed for smartphones and tablets, and through SMS from mobile phones (in certain countries). Less than half of the tweets posted are through the Twitter website; most users prefer to use mobile apps on their smartphones or tablets [2].

Although most consider Twitter primarily a method of personal communication, it is gaining traction in business and is beginning to be used in academia for many purposes, including rapid sharing and dissemination of information and for citing articles [3]. Organizers, delegates, and speakers at meetings and conferences have found tweeting to be beneficial in their own domains and as a tool for online discussion [4]. This function of Twitter is achieved by the use of a digital "backchannel," which is a nonverbal, real-time projection of the tweet [5]. During digital backchannel use, the speaker presents in the traditional manner in the "front" area, while the audience and people distant from the meeting can communicate with one another simultaneously by using the "back" area. This use of Twitter and other social media has the potential to change the health communications space associated with conferences.

There are only a few published reports of the use of Twitter at medical conferences [5-12]. The only report in the anesthetic literature describes an attempt by a delegate to use Twitter at the Association of Anaesthetists of Great Britain and Ireland (AAGBI) Linkman conference (September 2011, Edinburgh) who failed to attract any tweets [13]. Despite this failure, a further attempt to use Twitter for the AAGBI Annual Conference (September 2011, Edinburgh) [13] was made by the same delegate, and this time some spontaneous Twitter activity was demonstrated with no involvement from the reference conference organizers.

The aim of this study was to describe the introduction and uptake of Twitter at a major anesthetic conference with prior involvement and support from the conference organizers and analyze subsequent author use and purpose.

Methods

A hashtag (represented by the symbol "#") acts like a metadata tag and can be used for searches of the word/phrase strings it precedes. This makes it possible to quickly and easily collate the tweets being made at a particular conference, and even certain topics at, or subdivisions of, that conference. A hashtag (#WSM12) was created by the AAGBI 6 weeks before the start of their Winter Scientific Meeting held in London in January 2012. This hashtag was actively promoted by the organizers by using their Twitter stream, on posters around the venue, and as part of a PowerPoint presentation shown before each conference session started.

All tweets containing the #WSM12 hashtag were recorded. This record was commenced when the hashtag was first advertised and continued 14 days post conference. Any tweets made under the hashtag unrelated to the conference were excluded.

The tweets were divided into 3 main sections: (1) before the congress, which included the period from December 3, 2011 (when the hashtag was first advertised) up to 8:59 am on January 18, 2012; (2) during the conference, which included all tweets posted during the conference from 9:00 am on January 18 to 5:00 pm on January 20, 2012; and (3) after the conference, which included any tweets posted under the hashtag from 5:01 pm on January 20 to 12:00 pm on February 4, 2012.

The resulting tweets were analyzed to determine who was tweeting, during which time period of the congress they were tweeting, and to categorize the purpose of each tweet. These categories were informed by a literature review [7,10,12,14] and based on purpose of the tweet, not its content. The categories were then reclassified to be more representative of an anesthetic conference and then subclassified. These methods of classification relate to the 3 main sections: (1) before the congress (Table 1); (2) during the conference (Table 2); and (3) after the conference (Table 3). If there was any doubt as to the category of the tweeter, the tweeter was contacted directly through Twitter for confirmation.

In order to assess internal reliability of the tweet classification, the content of each tweet made during the conference was independently scrutinized by 2 of the authors (DM and GC). Each observer classified each tweet into one of the 11 categories listed in Table 2 and the kappa statistic was calculated to assess internal agreement. A kappa value more than 0.75 denotes excellent agreement; a value between 0.4 and 0.75 represents fair to good agreement [15]. All analyses were performed using the SPSS version 17 (SPSS Inc, Chicago, IL, USA).

The Twitter profile of each contributor was viewed within 2 days of the end of the conference to record the number of "followers" each tweeter had at that time. Any organizations or individuals specifically mentioned in this paper have been contacted to obtain their consent to display their Twitter profile in this publication.

Table 1. Tweets sent *before* the January 2012 Association of Anaesthetists of Great Britain and Ireland (AAGBI) conference.

Main category Tweeter	Subcategory Purpose of tweet	Definition of tweet
Organizer	Advertising	By the AAGBI only advertising the event
	Promoting	By the AAGBI only promoting key sessions to be held at the conference
Potential delegates		By anesthetists or anesthetic groups who might potentially attend the conference
	Plans	Concerning any plans being made to attend the conference
	Advertising	Actively promoting the conference
Trade		From anesthetic trade organizations, exhibitors, or their representatives
Speakers		By any speakers at the conference who promoted their session
Others		From any other people contributing to the Twitter stream

Table 2. Tweets sent *during* the January 2012 Association of Anaesthetists of Great Britain and Ireland (AAGBI) conference.

Main category Tweeter	Subcategory Purpose of tweet	Definition of tweet
Organizer		By the AAGBI only
Trade		By anesthetic trade organizations, exhibitors, or their representatives
Speakers		By any speakers at the conference who promoted, or discussed events during, their session
Anesthetists		By delegates attending the conference; by anesthetists not attending the conference but contributing to the Twitter stream
	Notes or learning points	Posting tweets which contained gems of information from a talk or a workshop
	Discussion	Discussing matters at the conference directly with one another; posting controversial or non-learning points from a talk
	Social	Personal discussions, social events such as dinners, coffee and lunch breaks; social posts made by the organizers
	Which session am I going to?	Tweets which described the session being attended stating the name of either the talk and or the speaker
	Encouraging speakers	Tweets directed to speakers by way of encouragement or comment
	Poster	Tweets about the posters on display
	Questions	Tweets posing questions to speakers about their presentation
Others not in attendance		Tweets by people who did not attend the conference except where those tweets directly involved discussion and encouraging a speaker

Table 3. Tweets sent *after* the January 2012 Association of Anaesthetists of Great Britain and Ireland (AAGBI) conference.

Main category Tweeter	Subcategory Purpose of tweet	Definition of tweet
All tweeters	Continue discussions	Tweets which continued discussions and/or displayed photographs or videos of talks from the conference
	Thanks	Tweets which expressed thanks to delegates, speakers or industry, or for the meeting itself
	Reflections	Tweets mentioning the potential to use tweets posted as a method of reflecting for revalidation
	Advertising future meetings	Tweets posted to advertise future meetings, symposia, or conferences
	Feedback	Tweets containing or requesting feedback for either the conference or the speakers
	Statistics	Any statistics from the meeting presented by the organizers

Results

A total of 227 tweets were posted under the #WSM12 hashtag during the 9 weeks of the study period surrounding the AAGBI Winter Scientific Meeting in London. An additional 18 Twitter posts from 12 people were not related to the Winter Scientific Meeting and were excluded from the current analyses. All of the excluded tweets related to a meeting involving Wireless technology usage that also used the #WSM12 hashtag for a brief period, but either changed to an alternative hashtag after realizing the duplication or completed their discussion.

Sixteen people contributed to the Twitter stream by using the #WSM12 hashtag. These 16 people consisted of the organizer and the conference venue, 3 members of trade organizations, 3 delegates attending the meeting, and 2 speakers at the meeting. The remaining 6 people who joined the Twitter stream did not attend the meeting and they were either actively promoting the meeting before the conference, contributing to discussion during the meeting, or passively retweeting some of the tweets posted by attendees.

The number of followers for each of the people who contributed to the Twitter stream for the #WSM12 hashtag ranged from 3 to 8335 (Figure 1). The 16 tweeters had a combined total of 12,609 followers. Tweeters who contributed actively (access their accounts more than once a month) to the Twitter stream had 3603 followers. A retweet enables the user to share someone else’s tweet with all their own followers. A total of 32 retweets were sent during the period of the conference and, of these, 28 were sent by tweeters who were actively contributing to the Twitter stream and are also included in that group. Only 4 of the retweets were sent by people who were not actively contributing to the Twitter stream; these 4 people had a combined following of 9006 contributing to a second tier of amplification of the Twitter stream.

Of the tweets posted under the #WSM12 hashtag, 80.5% (182/227) were sent during the conference itself, 14.5% (33/227) were posted before the meeting, and 5.3% (12/227) after the conference ended. Table 4 shows the results of the internal reliability analyses on the 182 tweets sent during the conference. Excellent agreement (κ = 0.925, *P*<.001) was seen in the classification of tweets across the 11 categories with agreement of the 2 raters on 95.1% (n=173) of the 182 tweets.

Table 4. Interobserver reliability of the different uses of Twitter during the conference.

Category	Number of tweets coded	
	Observer 1	Observer 2
Organizers	29	28
Trade	5	5
Speakers	2	2
Notes or learning points	100	98
Discussion	8	12
Social	6	6
Which session am I going to?	21	19
Encouraging speakers	2	3
Posters	3	3
Questions	0	0
Not at congress	6	6
Total	182	182

Prior to the conference, the conference organizer posted the most tweets. Almost half (15/33, 45%) of the preconference Twitter stream was to advertise the hashtag and the conference, and 6% (2/33) to promote sessions which would be happening at the meeting. Potential delegates also advertised the meeting and the hashtag and posted 27% (9/33) of the total preconference tweets for this purpose. Another 6% of tweets (2/33) posted related to plans potential delegates were making for the meeting. A member of the anesthetic trade exhibitors also promoted the meeting in a tweet. A speaker posted a tweet promoting a session in which he would be speaking at the congress. Three other organizations used the hashtag to retweet postings advertising the meeting.

During the conference, the organizers posted 15.4% (28/182) of the tweets. They used this period of the conference to welcome delegates and advise on registration, promote trade exhibits, and to advise on various sessions and events happening at the meeting including parallel sessions, poster sessions and awards, and social events (eg, the conference dinner). The trade exhibitors at the conference posted 2.7% (5/182) of the tweets sent during the meeting to advertise their wares and special events happening at their stands. Speakers posted 1.1% (2/182) of the tweets during the meeting, with one promoting their session and the other advising of attendance and the quality of questions at their session. Anesthetists either attending the meeting, or not attending but directly contributing to the Twitter stream, posted 76.9% (140/182) of the tweets sent during the conference. Over half (100/182, 54.9%) of the tweets posted during the actual meeting were notes or learning points from various sessions at the conference. A total of 11.5% (21/182) of the tweets posted described which session people were attending, and 4.4% (8/182) of the tweets were made as a method of discussion between delegates about sessions or previously posted tweets. This discussion was joined by an anesthetist who was not able to attend the meeting. Only 3.3% (6/182) of the tweets posted related to conference social events and interactions. Another 1.6% (3/182) of the tweets related to the poster session, and 1.1% (2/182) provided support for speakers who were about to give a presentation. A total of 3.8% (7/182) of the tweets posted were sent by people not attending the meeting and not actively contributing to the Twitter stream by retweeting messages from the conference. There were no tweets posted which asked questions of any of the speakers.

There were 12 tweets posted after the conference. One-third (4/12, 33%) of the tweets were used to continue discussions started at the conference. A further 4 tweets (33%) were by way of thanks from the organizers, venue, trade, and from an anesthetist who had not attended the meeting, but appreciated the learning points generated in the Twitter stream. Another 3 tweets (25%) promoted the use of the learning points documented within the Twitter stream as a method of reflection for the purposes of revalidation. A further tweet was posted by the organizers to advertise a future meeting (1/33, 3%).

The pattern of tweeting by each of the main groups around the conference is shown in Figure 2. The organizers posted most of the tweets before and after the conference. The delegates started to post large numbers of tweets on the second and third day of the conference as they gained confidence in the technique (personal communication from delegates). The trade exhibition representatives tended to post their tweets advertising their products and their stands early on during the meeting.

Figure 1. The number of people following each of the 16 people who tweeted at the January 2012 Association of Anaesthetists of Great Britain and Ireland (AAGBI) conference.

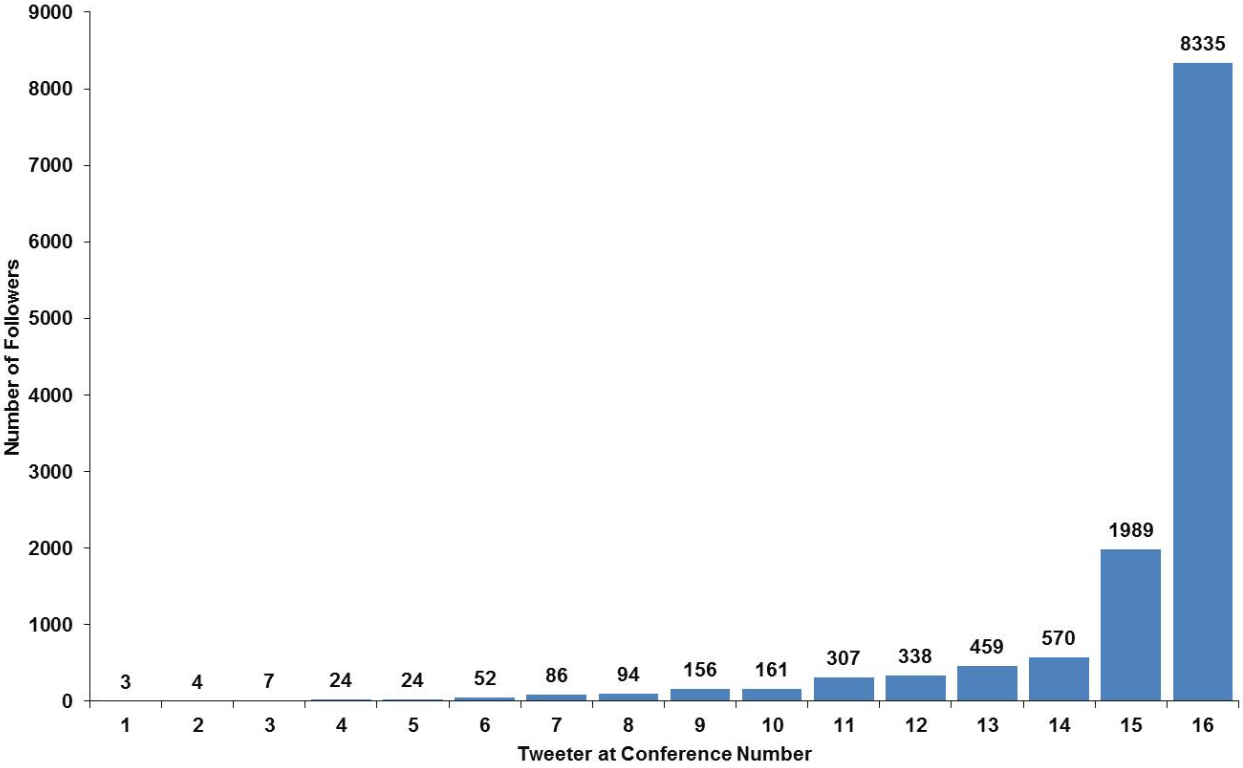
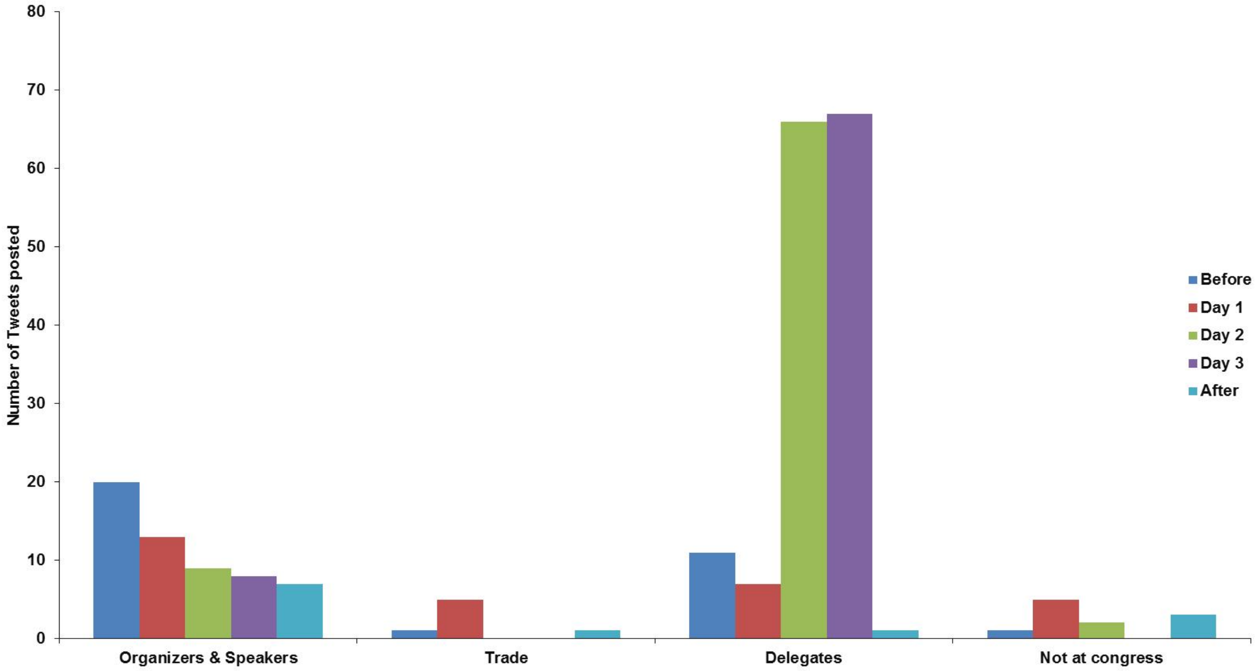


Figure 2. Pattern of tweets posted by the various groups of tweeters stratified by timing of the tweets. Each group is subdivided to show how many tweets they posted before the conference (Before), on which of the 3 days during the conference (day 1, day 2, and day 3), and after the meeting (After).



Discussion

This is the first report to describe the uptake and use of a Twitter stream as an integral part of the communication structure of an anesthetic conference. The total number of 227 tweets posted under the #WSM12 hashtag represents a 530% increase over the 36 tweets that “erupted” spontaneously at the 2011 AAGBI conference as reported by McKendrick [13]. Sixteen people contributed to the Twitter stream by using the #WSM12 hashtag, a 300% increase over the 4 people who spontaneously tweeted at the previous conference [13]. Although overall numbers are small, these increases become even more significant when one considers that the total attendance at this conference of 655 delegates was 16% less than the 781 delegates who attended the 2011 AAGBI conference as reported by McKendrick [13].

Although the number of people joining the Twitter stream is low (2.4% of the total number attending the conference), this is in keeping with previous studies surveying academic activity on Twitter [16]. Furthermore, this percentage may actually be representative of anesthetists who use Twitter—a recent survey of AAGBI members reported Twitter usage of 8% [17] and only 60% of Twitter account holders are active [18]. Despite these small numbers, our findings are similar to those previously described at both medical and nonmedical conferences [5-12,14]. Twitter usage has grown in a viral manner and has more than 200 million accounts with the number of daily tweets increasing by 110% during 2011 to more than 230 million tweets per day [18]. The AAGBI membership survey [17] would suggest that anesthetists have yet to embrace the exponential adoption of this new technology.

Internal reliability analyses of our classification of tweets during the conference showed a statistically significant level of intraobserver agreement that suggests that our classification system was robust.

There are many ways to use Twitter at a medical conference to enhance the experience for both those at the conference and those unable to attend. Each conference should have a Twitter profile, as should the organizer. These profiles should be promoted well in advance to maximize the number of followers, and the usefulness, of Twitter at the conference. Conference organizers should also agree on a hashtag in advance and publicize it extensively with members. The hashtag should be as short as possible to leave as much of the 140 characters for the message itself.

The conference organizers used Twitter effectively during the period before the conference to generate excitement and interest, advertise keynote presenters and workshops, and to guide delegates about registration details as illustrated in Figure 3. Attendees did not use Twitter before the conference to plan their trip, accommodation, coordinate their arrangements, or share information with colleagues [14]. Reasons could include the low number of Twitter users and Twitter naïveté, and this is an area for conference organizers to consider in the future.

Most of the tweets were sent during the congress itself. Twitter usage was not maximized by the organizers to update delegates on last-minute changes or to remind participants of parallel sessions or additional sessions, such as sponsored lunchtime meetings. Attendees at the conference used Twitter to take notes from presentations (as illustrated in Figure 4). Because of the small length of tweets, these usually take the form of learning points or salient messages [19-22]. This can be a useful way to remember the little gems of information learned at a congress. Looking at what other people at the congress tweeted or retweeted can further reinforce the “real” learning points from each talk or session [12].

Questions were not posted by any of the Twitter stream contributors to the #WSM12 hashtag probably because of the small numbers involved, but also because systems for posting questions to the presenters had not been arranged by the organizers of the conference nor advertised to the delegates of the meeting in advance. Questions could have been posted by attendees or by people who were not at the meeting who might have questions relating to information posted on tweets. This could have led to a Twitter debate to argue, discuss, seek clarification, and post questions and answers during a presentation. This is usually done on mobile devices during the talk, and is often far less disruptive than whispering to one's neighbor. The tweets for a particular talk can be collected together and displayed on a Twitter Wall, which is a live display of current tweets for that particular session. Although this can provide a useful means of discussion and posting questions, it can be distracting for speakers and is occasionally subject to abuse [10] and, therefore, not recommended. Perhaps a better option may be to display a list of questions generated on mobile devices during the session at the end of that session to use as a basis for discussion. By viewing posts, asking questions, and joining discussions, Twitter can even allow delegates to participate in parallel sessions at the same time [14]. Discussion points were not used at all in the 2011 AAGBI conference as reported by McKendrick [13]; however, several points of discussion were raised at this conference.

The speakers used Twitter to promote their topic or take-home messages under the #WSM12 hashtag (as illustrated in Figure 4), but no questions were posted by delegates for them to respond to. There was also no feedback from the delegates to the speakers through tweets on their presentation, in which comments about the composition and legibility of slides, for example, could influence future presentations [12]. This is known as self-correction. However, occasionally the opposite can occur with a perpetuation of the original error [7].

Twitter has a maximum time limit of 10 days on its search facility. The tweets can still be found in each individual user's account, but can no longer be easily grouped together by using the search function. Therefore, it is imperative to create an archive of the Twitter Search results well in advance of this expiry time if one plans to use Twitter as a means of record keeping [23].This method of record keeping was suggested by some of the tweets posted under the #WSM12 hashtag (as illustrated in Figure 4) for the purposes of recollection, continuous professional development [8], and demonstrating reflection during the meeting for revalidation.

Twitter can be further used as a method of amplifying the congress to a wider audience. Tweets posted by delegates can be read by people who were not present at the meeting, who then in turn retweet the message to their followers, creating a second tier of information spreading. This retweeting can continue for many tiers. Some Twitter users have hundreds of thousands of followers and information can be disseminated very quickly over a short span of time.

The tweeters who contributed actively to the Twitter stream in this study presented a potential audience of 3603 people as a first tier of information spreading. A second tier of information spreading, or amplification, was demonstrated in this report by 4 tweeters who did not actively contribute to the Twitter stream, but who retweeted #WSM12 tweets to their 9006 followers. These 4 tweeters only represent a small proportion of the 3603 first-tier followers, the rest of whom potentially could also have retweeted to all their followers creating a "viral" dissemination of the message to a much larger audience than the 9006 demonstrated in this study. However, this assumption presupposes that all a user's followers are still active on Twitter, and that there is a low rate of redundancy.

Before the conference, in addition to the organizer, 3 other tweeters contributed to the advertising of the congress by retweeting tweets that promoted the conference. These 3 tweeters included the conference venue, a major London publicity organization, and an anesthetic blogger. These 3 organizations had a combined following of 10,894, which provided a significant boost to the advertising power of the organizers and enhanced the promotion and awareness of the conference.

The social element of Twitter could have been better used. Although messages relating to the official conference dinner were posted, no tweets related to lost-and-found items, unofficial social events and dinners, tips for accommodation, or places to go for food and entertainment were posted. In addition, physical meetings could have been arranged with other tweeters at a conference (a "tweetup").

The final session of the conference should not be seen as the end of that conference's Twitter stream. This report demonstrates an enhanced use of Twitter after the congress, with 12 tweets being posted compared to 1 tweet in the 2011 AAGBI conference, as reported by McKendrick [13]. The tweets posted displayed the ability to continue discussions previously started at the conference, advertise future meetings, thank attendees, thank colleagues for posting useful information, and illustrating methods of using the Twitter stream for revalidation. To achieve maximum potential from the postconference period, the organizers of the meeting could also have gathered feedback from the delegates, posted interesting statistics, and reflected on various aspects of the conference [14].

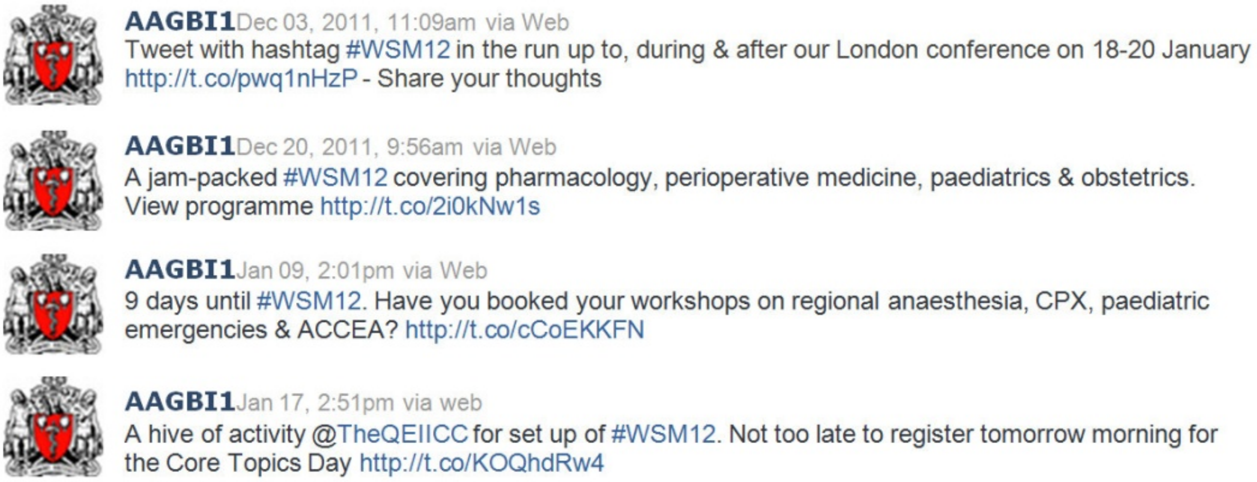
Although there are many advantages to Twitter, there are some potential pitfalls. Twitter collects personal information about its users and shares that information with third parties. Third parties can search for characteristics and thereby target users on the basis of their Twitter history and content. Advertisers have even been known to quote users' tweets in their advertisements [24]. Although Twitter did not initially advertise, in 2010 it introduced a veiled form of advertising called "promoted tweets" [25].

By default, all tweets are made public unless an individual changes the settings or sends the message as a direct message. As an individual posting tweets, it is critically important not to broadcast any information or views on Twitter that might conflict with or defame employers, colleagues, students, academics, researchers, and other University stakeholders [26]. Although it is possible to delete a tweet, often the damage has already been done by that stage. It is essential for those in the public eye to manage their online reputation with great care, and there have been several recent high profile cases paraded in the media for Twitter indiscretions.

Health care professionals have concerns about the use of Twitter that need to be addressed, including patient, personal, and other health care professional’s privacy. Such concerns are increasingly being recognized and discussed [27], and guidance is now being produced by organizations such as the British Medical Association to provide practical and ethical advice to assist doctors [28]. Conference organizers have an obligation to educate participants about Twitter etiquette, protecting their personal identity, and appropriate legal and ethical considerations.

In conclusion, this is the first report to describe the uptake and use of a Twitter stream as an integral part of the communication structure of an anesthetic conference. The usage of Twitter at the 2012 AAGBI Winter Scientific Meeting closely followed trends described for other medical and nonmedical conferences. Therefore, Twitter has potential to be a useful tool at future anesthetic conferences, but there are pitfalls that should be recognized.

Figure 3. A selection of tweets posted by the conference organizers before the conference demonstrating the use of Twitter.



AAGBI1 Dec 03, 2011, 11:09am via Web
Tweet with hashtag #WSM12 in the run up to, during & after our London conference on 18-20 January http://t.co/pwq1nHzP - Share your thoughts

AAGBI1 Dec 20, 2011, 9:56am via Web
A jam-packed #WSM12 covering pharmacology, perioperative medicine, paediatrics & obstetrics. View programme http://t.co/2i0kNw1s

AAGBI1 Jan 09, 2:01pm via Web
9 days until #WSM12. Have you booked your workshops on regional anaesthesia, CPX, paediatric emergencies & ACCEA? http://t.co/cCoEKKFN

AAGBI1 Jan 17, 2:51pm via web
A hive of activity @TheQEIICC for set up of #WSM12. Not too late to register tomorrow morning for the Core Topics Day http://t.co/KOQhdRw4

Figure 4. A selection of tweets posted during the January 2012 Association of Anaesthetists of Great Britain and Ireland (AAGBI) Winter Scientific Meeting. Top: The use of Twitter to post a learning point; Middle: a tweet posted by a speaker; and Bottom: part of a discussion suggesting the use of tweets as a form of reflection for revalidation purposes.

drspikes Jan 19, 9:40am via TweetDeck
#WSM12 #A4AS TAP blocks: can reduce morphine requirements in major surgery including prostatectomy and LSCS for up to 48 hours.

BGSMDS Jan 19, 8:39am via Twitter for Android
@AAGBI1 Speaking about #Parkinson's disease and#anaesthesia at 9:50 #wsm12

doug_mckendrick Jan 30, 10:22am via Twitter for iPad
@drspikes You can use the tweets you posted at #WSM12as evidence of #reflection for #Revalidation. @AAGBI1. Please RT if u agree.

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Conflicts of Interest

None declared.

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Abbreviations

AAGBI: Association of Anaesthetists of Great Britain and Ireland
SMS: Short Message Service

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Original Paper

Crowdsourcing Malaria Parasite Quantification: An Online Game for Analyzing Images of Infected Thick Blood Smears

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Abstract

Background: There are 600,000 new malaria cases daily worldwide. The gold standard for estimating the parasite burden and the corresponding severity of the disease consists in manually counting the number of parasites in blood smears through a microscope, a process that can take more than 20 minutes of an expert microscopist's time.

Objective: This research tests the feasibility of a crowdsourced approach to malaria image analysis. In particular, we investigated whether anonymous volunteers with no prior experience would be able to count malaria parasites in digitized images of thick blood smears by playing a Web-based game.

Methods: The experimental system consisted of a Web-based game where online volunteers were tasked with detecting parasites in digitized blood sample images coupled with a decision algorithm that combined the analyses from several players to produce an improved collective detection outcome. Data were collected through the MalariaSpot website. Random images of thick blood films containing *Plasmodium falciparum* at medium to low parasitemias, acquired by conventional optical microscopy, were presented to players. In the game, players had to find and tag as many parasites as possible in 1 minute. In the event that players found all the parasites present in the image, they were presented with a new image. In order to combine the choices of different players into a single crowd decision, we implemented an image processing pipeline and a quorum algorithm that judged a parasite tagged when a group of players agreed on its position.

Results: Over 1 month, anonymous players from 95 countries played more than 12,000 games and generated a database of more than 270,000 clicks on the test images. Results revealed that combining 22 games from nonexpert players achieved a parasite counting accuracy higher than 99%. This performance could be obtained also by combining 13 games from players trained for 1 minute. Exhaustive computations measured the parasite counting accuracy for all players as a function of the number of games considered and the experience of the players. In addition, we propose a mathematical equation that accurately models the collective parasite counting performance.

Conclusions: This research validates the online gaming approach for crowdsourced counting of malaria parasites in images of thick blood films. The findings support the conclusion that nonexperts are able to rapidly learn how to identify the typical features of malaria parasites in digitized thick blood samples and that combining the analyses of several users provides similar parasite counting accuracy rates as those of expert microscopists. This experiment illustrates the potential of the crowdsourced gaming approach for performing routine malaria parasite quantification, and more generally for solving biomedical image analysis problems, with future potential for telediagnosis related to global health challenges.

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KEYWORDS

Crowdsourcing; Malaria; Image Analysis; Games for Health; Telepathology

Introduction

Crowdsourcing methodologies leveraging the contributions of citizen scientists connected via the Internet have recently proved to be of great value to solve certain scientific challenges involving "big data" analysis that cannot be entirely automated [1]. In the GalaxyZoo project, citizen scientists classified imagery of hundreds of thousands of galaxies drawn from the Sloan Digital Sky Survey and the Hubble Space Telescope archive [2]. Crowdsourced contributions can be achieved with different motivation strategies, such as micropayments or games. The "serious games" concept refers to an intention not only to entertain users, but also to train or educate them [3]. The "gamification" [4] of the crowdsourcing approach enables a higher motivation of the participants and, using the Internet as a vehicle, untaps an underexploited resource for scientific research [5,6]: it is estimated that 3 billion hours per week are spent playing computer and videogames worldwide [7]. For instance, Fold-It, an online game where players solve 3-dimensional puzzles by folding protein structures, has resulted in several breakthrough scientific discoveries [8-10]. Another recent growing trend is the use of crowdsourcing techniques for participatory health research studies in which individuals report in real time a variety of health conditions [11], providing a promising complement to traditional clinical trials. Considering crowdsourced image analysis, collective processing has been recently explored for earthquake damage assessment from remote sensing imagery [12]. However, this methodology has not yet been mainstreamed for biomedical image analysis.

In this context, analysis of microscopic images of malaria-infected blood samples is an appealing goal. Worldwide, there are more than 200 million malaria cases and approximately 800,000 deaths annually, mainly in children [13,14]. Careful optical microscopic examination of a well-stained blood film remains the gold standard for malaria diagnosis [15]. Confirmation of a negative diagnosis is ultimately dependent on the technician's expertise and can take up to 20 minutes. In addition, as malaria prevalence decreases in one specific place over time, microscopy technician skills may now be needed in other regions. Fast, cheap, ubiquitous, and accurate diagnosis is a priority in the Agenda for Malaria Eradication [16]. Although automated processing methodologies have been used extensively for the analysis of digitized blood smears [17,18], currently there are no completely automated image processing systems that can achieve perfect parasite recognition [19-24]. The main problem in computer-aided malaria diagnosis is that algorithms are usually not very robust with respect to the variable appearance of the parasites and changing image acquisition conditions.

The goal of this research was to test the feasibility of a crowdcomputing approach for malaria parasite quantification in which nonexperts count parasites in digitized thick blood smears through an online game (crowdsourcing) and a decision algorithm combines the data generated by several players in order to achieve a collective detection with a higher accuracy rate than an individual analysis. This idea—gaming for distributed malaria image analysis—has been also explored in a recent study by Mavandadi et al [25], in parallel to and independently of this study. These researchers designed a video game and a processing pipeline to investigate whether nonexperts can assess if a single-cell image extracted from a digitized thin blood sample is infected with malaria or not. Although this study and the present research share a similar vision and goal, the research questions posed and solutions adopted differ substantially in terms of the data analyzed, the nature of the participants, the main task required of them, and the processing methodologies.

The proposed system in this study provides a new tool for parasite counting, but not malaria diagnosis, which is a more complex problem [26]. For this purpose, the microscopist protocol will need to be translated completely into a gaming protocol, including assessing the presence or absence of parasites, the parasite species, and growth stages and prognostic markers, such as schizonts or gametocytes, or pigment load. In the long run, crowdsourced remote telediagnosis from images acquired with optical microscopy and distributed worldwide through the Internet and possibly with systems that integrate the microscope into mobile phones [27,28], might have a potential impact for malaria-endemic countries because diagnosis availability and its cost could be optimized. However, in addition to the need for conventional laboratory processing and imaging equipment to prepare the material to a sufficiently high standard, this kind of analysis will require a communications infrastructure with enough bandwidth to distribute the images over the Internet and a critical number of online participants in order to ensure timely analysis of the images.

This work presents a proof-of-concept system that explores the feasibility of an online game-based, crowdsourced solution for malaria parasite quantitation in digitized images of thick blood smears.

Methods

We selected an image database of malaria-positive blood films that had been previously analyzed by experts to generate gold standards. These images were then incorporated into an online game. The player's task was to click on the parasites. When a player found all the parasites present in 1 image (constituting a level) within a limited amount of time, the game continued by presenting a new image. Otherwise, the game was over. All the players' clicks were registered in a database. After 1 month, all the collected data was preprocessed in order to group all the clicks that players placed around the different objects in the image: parasites, white blood cells (leukocytes), and background noise. Finally, an algorithm that combined the different games to increase accuracy was developed and evaluated.

Ethics Statement

The malaria images used in this research were previously used to evaluate automated image analysis methods [20]. Original blood samples and resultant test images were collected and used with ethical approval from the Human Research Ethics Committee (Medical), University of the Witwatersrand, Johannesburg, South Africa (protocol number M051126). No new ethical review board approval was required since the digital images used in our work were not linked to any patient data or diagnosis and were digitally shared for microscopic training evaluation purposes. The data analyzed in this research were anonymously produced by online volunteers who agreed to play an Internet game. The participants were informed of the research purposes of the game on the game webpage.

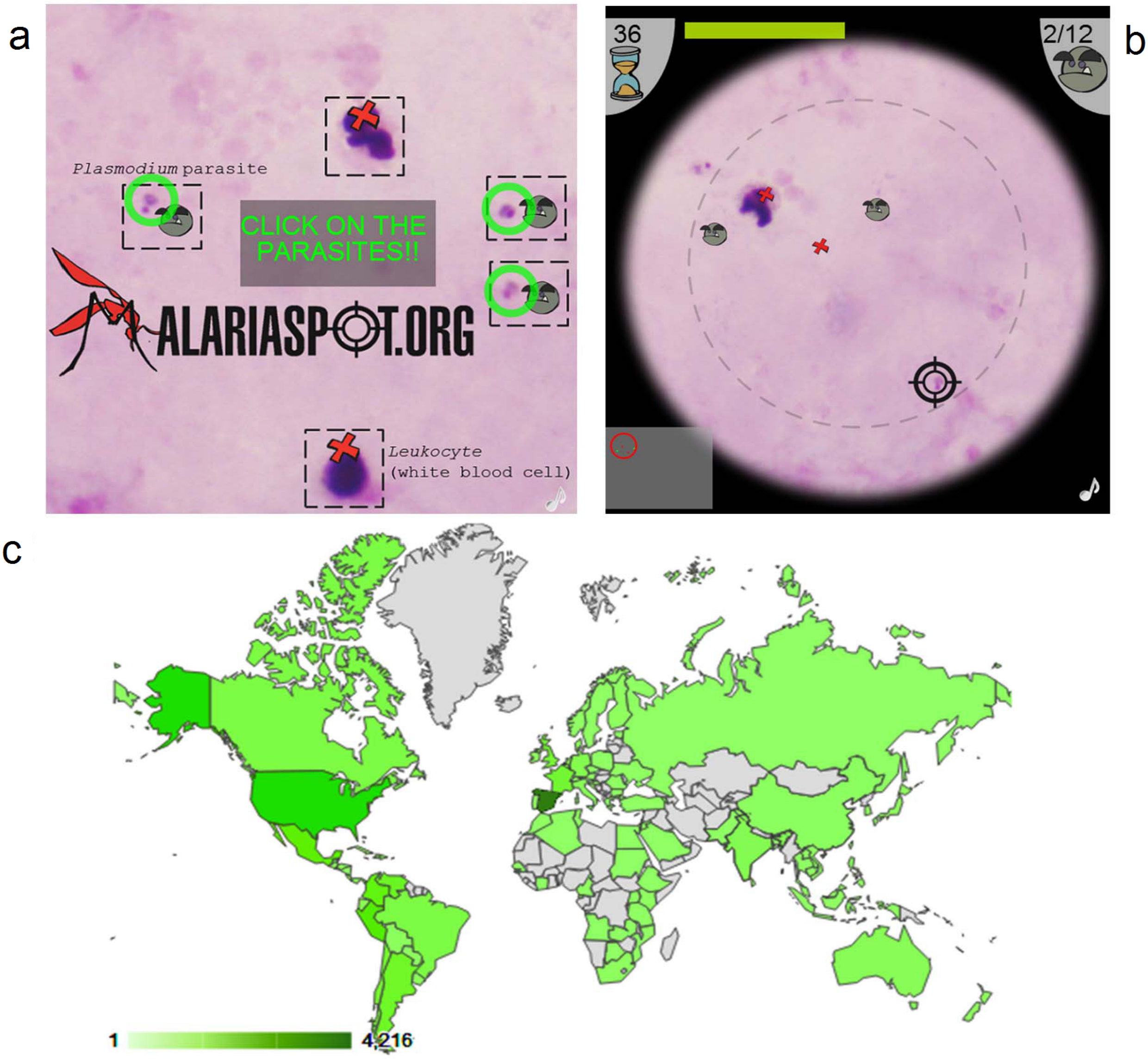
Image Database

The image database was compiled from 28 Giemsa-stained thick films made from blood infected with malaria (*Plasmodium falciparum*) parasites, acquired using a 50× objective in a conventional laboratory optical microscope. Medium to low parasitemia images were selected for the game because of its design (1-minute games) and the fact that discrepancies between automatic counting methodologies and manual expert counting tend to be greater in low parasitemia cases. A gold standard mask image was generated for each of the 28 images to evaluate player performance.

Game Architecture

The objective of the MalariaSpot game was to tag as many parasites as possible in an image in 1 minute. The instructions—what is a parasite and what it is not—were briefly explained in the splash screen of the game website (Figure 1a). During the game, if the player found all the parasites in 1 image in the allowed time, a new image was presented (Figure 1b). Therefore, a player could analyze several images (levels) in a single game. In order to reinforce the game's addictive nature, the players were given continuous feedback: each click was compared with the gold standard and an icon was placed immediately at the tag position to indicate a correct or incorrect selection. In addition, if the player misidentified an object and clicked in a wrong location (eg, on a leukocyte), the player was penalized by reducing the remaining time available to solve the level. Players were confronted with different, randomly selected test images. The difficulty of the levels increased as the time penalty for wrong tags grew with each level. As a motivation strategy, at the end of the game players were invited to register and provide their name, email address, and country in order to be included in the table of high scorers depicting the top daily, weekly, and monthly players.

Figure 1. MalariaSpot example screens and player distribution. (a) Splash screen of MalariaSpot game website showing the game instructions. (b) Example of MalariaSpot game screen. (c) Map showing the geographic distribution of players during the evaluation period (the darkness of the country is proportional to the number of visits).



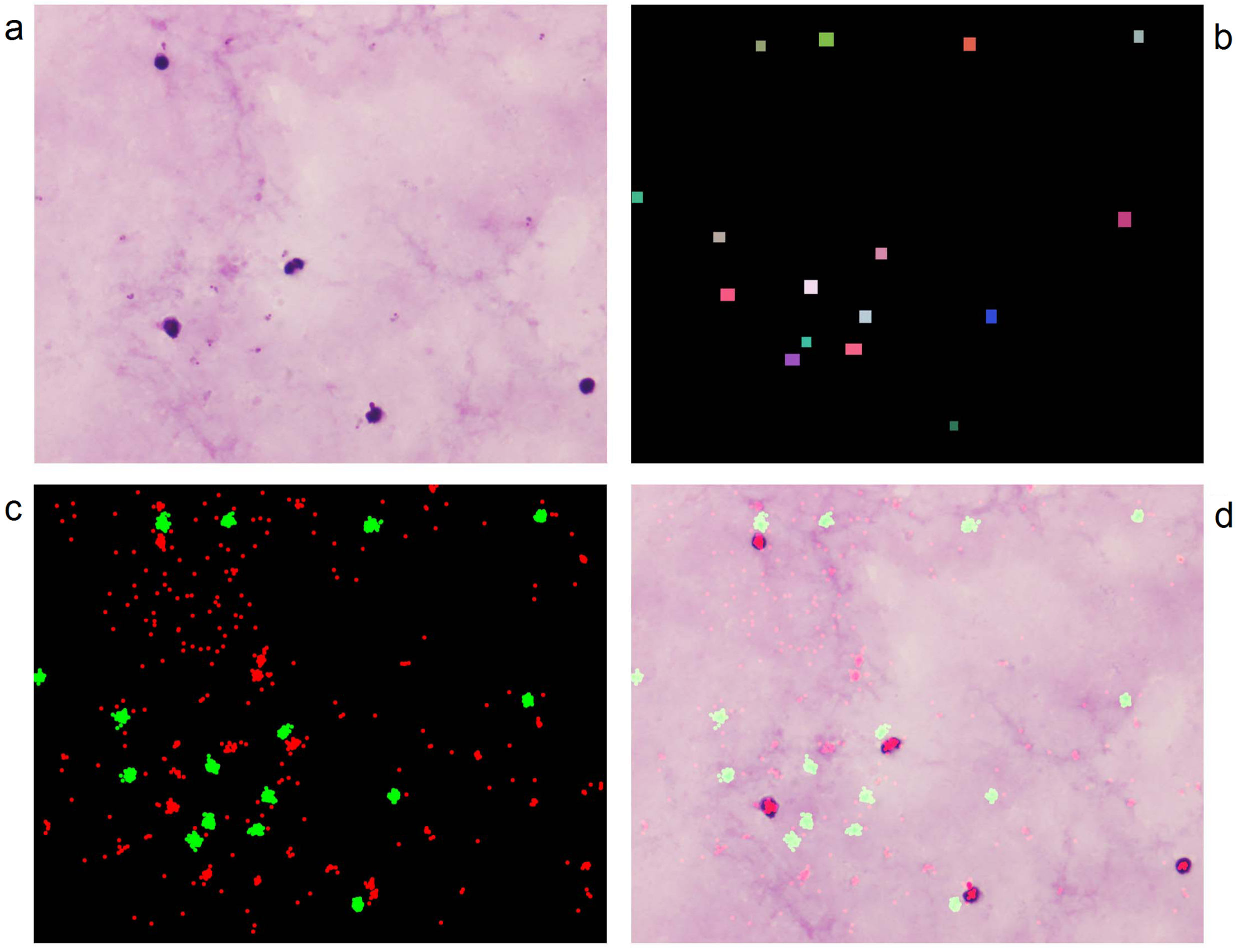
Data Collection

The MalariaSpot game webpage was launched on April 25, 2012 (World Malaria Day). During the following month, more than 6000 players from 95 different countries (Figure 1c) visited the game webpage according to the number of Internet Protocol (IP) addresses reported by Google Analytics, although the actual number of players was probably larger because those connecting from big institutions, such as universities, share the same IP address and other players may have blocked the Google Analytics script. Online volunteers played a total of 12,105 games that resulted in the analyses of 20,049 images and generated a database of 270,207 tags. Social media was the main traffic source; approximately 30% of the players originated from a Facebook link and 30% came from a Twitter reference. Most of the remaining visits were through links in digital newspapers and blogs, especially from Spanish-speaking countries.

Data Preprocessing

All the players' clicks were saved into a database containing the user identification number, image identification number, x-position and y-position on the game screen, time of the click (from the start of the level), and whether the click was on a true parasite or not (see Figures 2a-d and Multimedia Appendix 1). In a preprocessing step, we generated a binary matrix, $I_n(g,p)$, for each test image n, where each row g contains a different game and each column p corresponds to a parasite. A value of 1 at a certain position, $I_n(g_i,p_j) = 1$, means that the parasite with index j has been clicked in the game i. Otherwise, $I_n(g_i,p_j) = 0$. The number of rows is the number of games that have been played at each test image n. The number of columns corresponds to the number of parasites for a given level in the gold standard plus the number of phantom parasites. We defined a phantom parasite as an object in the image that is not a parasite and that has been tagged by ≥ 1 players. The phantom parasites were defined in order to group together all the clicks that were around the same position, but not on the identical pixel (eg, all the clicks that were inside a leukocyte were considered to be pointing at the same phantom parasite). An image processing pipeline that grouped together clicks that were at a distance of less than the typical parasite size was implemented in order to generate all the connected components in each image that corresponded to phantom parasites (Figure 2c). Therefore, the output of this preprocessing stage consisted of 1 binary matrix per test image that characterized the performance of all the games played for each image. Additionally, filtered versions of these matrices were created by selecting only the data from games in which at least 1 level was completed, 2 levels were completed, and so on.

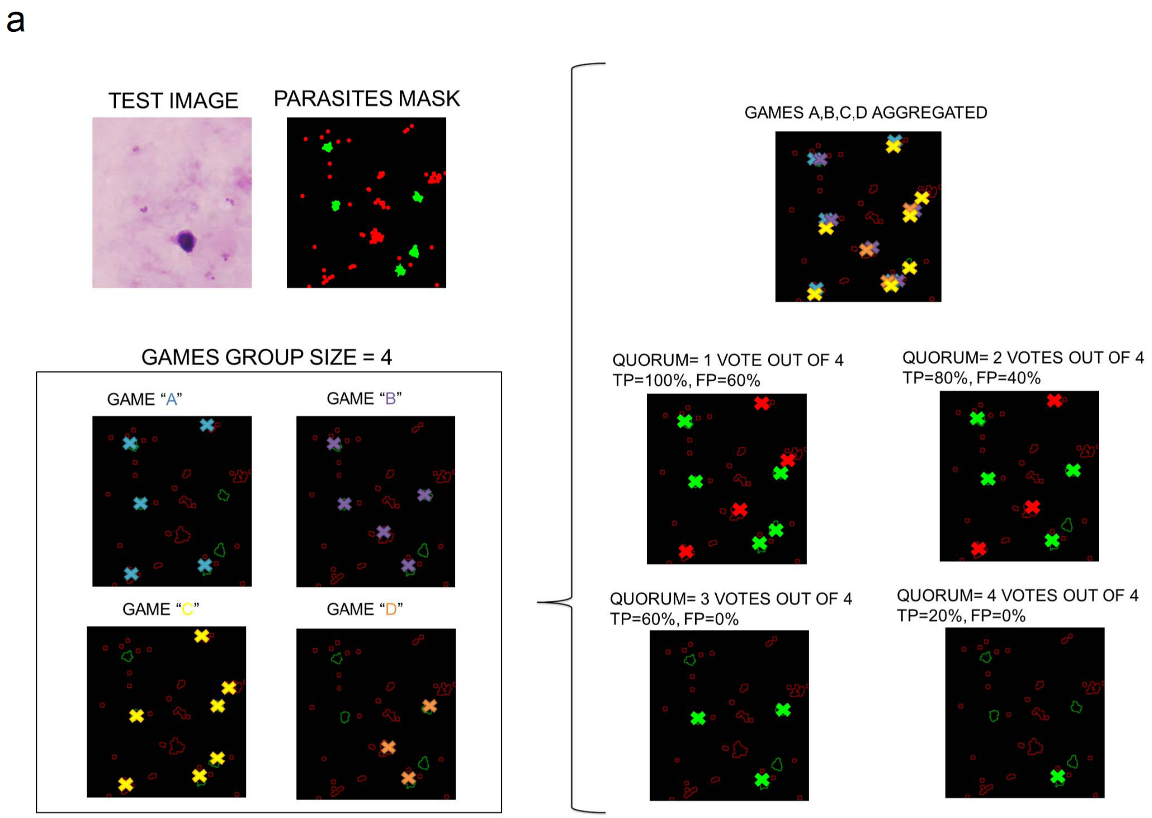
Figure 2. Crowdsourced image analysis of thick blood film infected with malaria. (a) Test image analyzed in the game. (b) Gold standard image in which each label corresponds to a parasite. (c) Aggregation of gamer's clicks where green regions correspond to correctly tagged parasites and red regions to players' mistakes. (d) Gamers' clicks superimposed on raw image.



Collective Parasite Detection: Quorum Algorithm

A critical aim of this research was to show how individual nonexpert analysis can be combined to achieve higher accuracy rates. In order to combine the games of several players and produce a single "detection," we implemented a quorum algorithm. The output of the quorum collective detection features all the image objects (both true parasites and phantom parasites) in one image that have been tagged in at least *X* individual games out of a larger group of *Y* games (Figure 3). The idea is simple: an object is considered in the collective detection if it has been tagged ("voted") in at least X out of Y (X ≤ Y) games. Typically, when the quorum value increases, there are fewer true positives and false negatives. In order to evaluate the performance of different group sizes and quorum values, we randomly selected 1000 subsets of games per (X,Y) couple with a maximum group size of Y = 30 games. For each individual subset of Y random games in 1 image, the collective detection performance was measured for all quorum values of X ≤ Y. Performance evaluation was also measured taking the subset of games that passed at least level 1, level 2, level 3, and level 4.

Figure 3. Illustrative example of the quorum algorithm. Parasite detection results on test image obtained from the combination of 4 games processed with different quorum values.



Results

Out of a total of 270,207 clicks, 78.65% tagged a true parasite. Analysis of the levels reached by the players reveals that approximately one-third of the players were able to find all the parasites in an image, independent of the level (see Figure 4d). Additionally, once players successfully completed level 5, they became game experts and no longer followed the 1 in 3 chance of passing to the next level—they could complete as many as 22 levels (achieved by the best player so far). Interestingly, the overall number of clicks on each of the parasites in 1 image was similar, meaning that although 2 of 3 players usually did not complete the level, all the parasites were equally difficult to identify (Figures 4a and b). This fact was corroborated in a special case for image ID6, where the probability of tagging one particular phantom parasite was as high as the typical probability for a true parasite. A further look into the gold standard revealed that, in fact, this phantom parasite was a true parasite that was not included in the gold standard by mistake (Figure 4c).

We performed an exhaustive evaluation of the collective gamers performance using the quorum algorithm evaluated 1000 times for all group sizes ranging from 1 to 30 games over each of the test images under the different training conditions (completing 1 level can be considered as a 1-minute training) (Figure 5a). Results show a monotone smooth behavior for the true positive (TP) and false positive (FP) rates depending on the group size and quorum value: the bigger the group size or the smaller the quorum required, the more true parasites were tagged and the higher the TP rate, but also more phantom parasites were collectively tagged, increasing the FP rate (Figure 5b). Analysis of the discrimination index (DI) function (DI = TP – FP) revealed that there was an optimal quorum number that maximized the DI for each group size (Figure 5c). For instance, the optimal quorum value was 3 for a group size of 7 games (randomly chosen among all games) achieving a DI = 90%, whereas the optimal quorum for a group of 10 games was 4, providing a mean DI = 95%. When comparing the performance of the collective analysis based on the training time (levels completed), we observed a clear dependence between training and DI (Figure 5d). The number of games needed to be combined in order to achieve a DI = 99% was 22, 13, 10, 9, and 4, respectively, for the subset of games that successfully completed 0, 1, 2, 3, and 4 game levels.

The maximum DI for each group size (obtained with its optimal quorum value) at all training levels was fitted to a model equation DI = f(group size, training time) using the scientific data mining software Eureqa [29]. A multivariate optimization process was used to find the following collective detection equation:

$$DI(group,training) = 1 - e^{-(alpha + beta\ group + gamma\ group\ training)}$$

where group size ranged from 1 to 30 games and the coefficient of determination (R^2) goodness of fit with (alpha = 0.69, beta = 0.24, and gamma = 0.13) is greater than 0.97 for each training value {0,1,2,3,4} levels (or minutes) (Figure 6). This equation highlights the product group·training, meaning that the accuracy increase provided by adding 1 game to the group size can almost be compensated (the term beta·group varies when increasing the group size) by 1 minute training or vice versa.

We also evaluated the collective performance detection against the automated image recognition methodology presented by Frean [20]. For each image, we calculated the minimum number of gamers needed to perform as well as the automatic system and we found that it was required to combine 7.2, 4.6, 3.9, 3.0, and 2.3 games, respectively, from the subset of players that successfully completed 0, 1, 2, 3, and 4 game levels (see Multimedia Appendix 2).

Figure 4. Individual gamer's performance. (a) Tagging probability for true parasites and phantom parasites on image ID1 based on all games. (b) Tagging probability field superimposed on raw image. True parasites (gold standard) are signaled by white squares. (c) Aggregated tagging probability for true parasites and phantom parasites on image ID6. Note that the probability of the phantom parasite (tagged in yellow) is as high as the true parasites. Detailed analysis showed that it was a mistake on the gold standard. (d) Number of games played at each level.

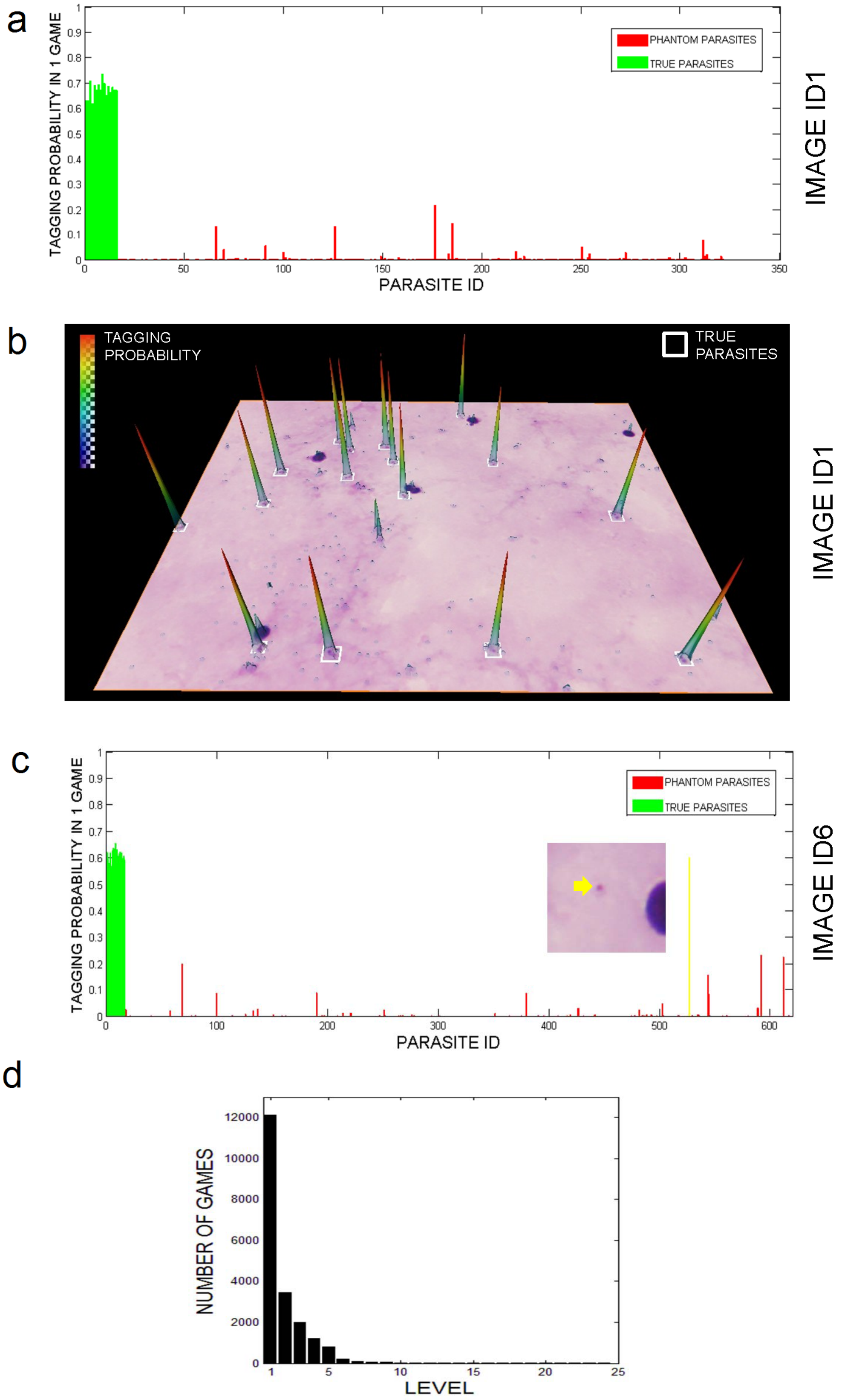
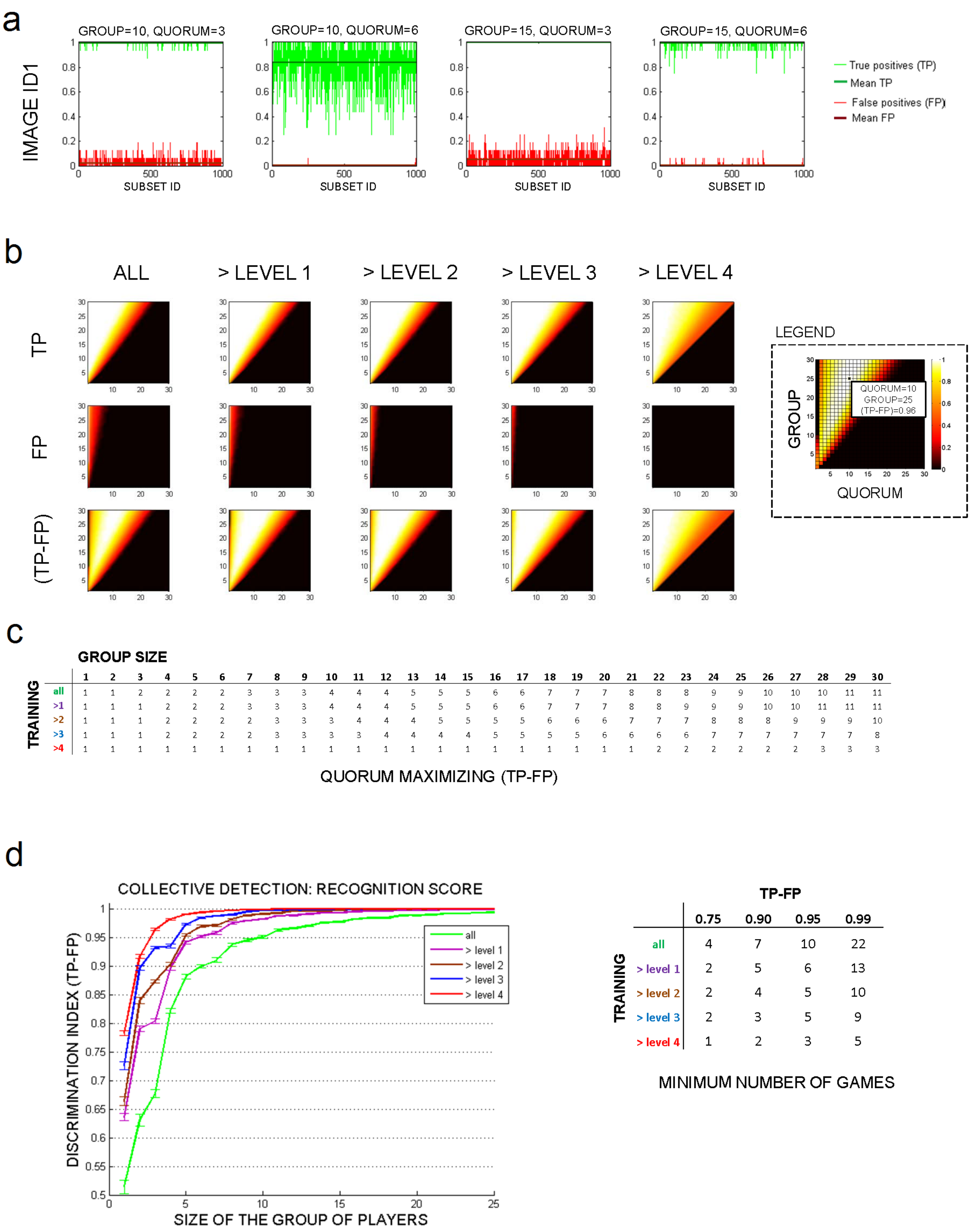


Figure 5. Collective parasite detection. (a) Accuracy results in 1000 random groups run over image ID1 with a group of 10 and 15 games and a quorum of 3 and 6 votes. (b) Mean results of true positives (TP), false positives (FP), and TP – FP for 1000 experiments of all the group sizes and quorum values with different experience. (c) Quorum values that maximize the TP – FP rate for all group sizes and training levels. (d) Maximum recognition score for each group size and training level. Values represent the mean and standard deviation among the regular test images.



GROUP SIZE

TRAINING	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30
all	1	1	2	2	2	2	3	3	3	4	4	4	5	5	5	6	6	7	7	7	8	8	8	9	9	10	10	10	11	11
>1	1	1	1	2	2	2	3	3	3	4	4	4	5	5	5	6	6	7	7	7	8	8	9	9	9	10	10	11	11	11
>2	1	1	1	2	2	2	2	3	3	3	4	4	4	5	5	5	5	6	6	6	7	7	7	8	8	8	9	9	9	10
>3	1	1	1	2	2	2	2	3	3	3	3	4	4	4	4	5	5	5	5	6	6	6	6	7	7	7	7	7	7	8
>4	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	2	2	2	2	2	2	3	3	3

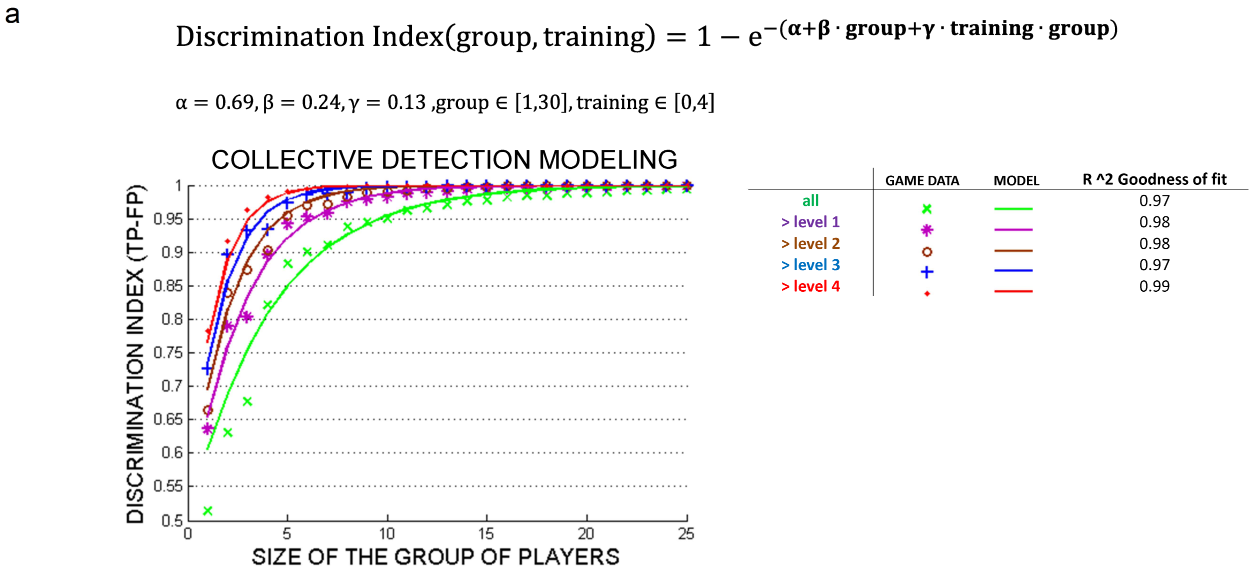
QUORUM MAXIMIZING (TP-FP)

TP-FP

TRAINING	0.75	0.90	0.95	0.99
all	4	7	10	22
> level 1	2	5	6	13
> level 2	2	4	5	10
> level 3	2	3	5	9
> level 4	1	2	3	5

MINIMUM NUMBER OF GAMES

Figure 6. Model of the collective detection of malaria parasites. Curve fitting of the mean accuracy rate for all group sizes and training levels.



$$\mathrm{Discrimination\ Index(group, training)} = 1 - e^{-(\alpha+\beta\cdot \mathbf{group}+\gamma\cdot \mathbf{training}\cdot \mathbf{group})}$$

$$\alpha = 0.69, \beta = 0.24, \gamma = 0.13, \mathrm{group} \in [1,30], \mathrm{training} \in [0,4]$$

	GAME DATA	MODEL	R ^2 Goodness of fit
all	×	—	0.97
> level 1	✱	—	0.98
> level 2	o	—	0.98
> level 3	+	—	0.97
> level 4	·	—	0.99

Discussion

In this study, a crowdcomputing image analysis system was developed that identifies malaria parasites in digitized images of thick blood smears using an online game played by nonexpert volunteers. Results for the images analyzed showed that the performance of the quorum algorithm that combines the games from different players can be as high as both human expert counting and automated processing methodologies. Indeed, the results showed that, on average, the combination of 22 games or more, regardless of the players' experience, was enough to obtain almost perfect parasite counting (99%) in the tested images. This performance could also be obtained by combining 13 games from players trained for 1 minute. However, no conclusions could be drawn about detecting extremely low parasitemias (as low as 1 parasite per 30 or more images).

Feedback from several players stressed the need for clearer game instructions. Although our strategy was learning by doing, commenters suggested that an explanation screen and/or an initial training level would lead to better results, at least for those players who did not complete the first level. The collective detection equation allowed us to model the system performance in terms of the number of games and the training of the players. An important question arising from this model is whether any crowdsourced image analysis system that roughly consists of detecting spots in images will have a similar behavior. In the affirmative case, the model could be used in the future to design and evaluate new crowdsourced biomedical image analysis applications.

The overall results endorse the online gaming approach to the task of counting malaria parasites in thick blood films using a crowdsourcing methodology, validated "in the wild" by thousands of anonymous online players. This conclusion extends the findings of Mavandadi et al [25], but from a different perspective. The methodology of the present research involves finding parasites in images from thick blood samples whereas in the study by Mavandadi et al the main task was to make binary decisions (infected versus uninfected) of single-cell images extracted from thin blood samples [25]. Both thin and thick blood films are used in malaria microscopy [26]. The thick film, consisting of many layers of red and white blood cells, is used to search for malaria parasites and to count them as an indicator of the severity of the disease. The thin film, a single layer of red and white blood cells, is mainly used to confirm the malaria parasite species and sometimes to enumerate parasites and evaluate other prognostic features. In addition to the type of data analyzed (thin versus thick blood film) and the task required of the participants (binary decisions in single-cell images versus parasite detection and location), the nature and number of participants varies, from 31 controlled volunteers [25] versus > 6000 anonymous online contributors in the current research. The studies can be considered complementary and directed toward the same goal; the different methodologies and experiments lead to the global conclusion that nonexperts are able to rapidly learn and identify the typical features of malaria parasites in digitized thin and thick blood films, and that the combination of the analyses of several users can provide similar accuracy rates for parasite quantification as expert microscopists.

Future developments of the current research should include the exploration of new algorithms that combine the games of several players in a more complex way than the quorum algorithm. For instance, if players' identities are logged and tracked, it would be possible to adapt algorithms to differentially weight the analysis of players depending on their profile, experience, past performance, or gaming strategies [30-33]. Automated processing methodologies report accuracy rates that are high, but still not as good as human visual inspection; therefore, we expect that combined man-machine diagnosis systems will be the most effective strategy. Note that, for instance, in the present study the players' detection performance was similar for all the images, whereas the automated detection algorithm [20] had heterogeneous performances for different images. Therefore, in hybrid systems, humans could be used first to train the recognition algorithm and later to analyze the more complex cases (supplementing the automatic processing methodologies), whereas the easy cases would be automatically processed.

In summary, this proof-of-concept research has shown that malaria image analysis for parasite quantification, obtained by combining the detection of several online nonexperts with minimal training, can be as good as the results provided by an expert microscopist. Although the game score is generated by comparing the user tags with previously analyzed images, in future, the observation protocol from expert microscopists could theoretically be translated into a game and images that have not yet been assessed by professionals could be introduced into that game. This raises the possibility of establishing a global specialized task force of remote gamers-workers able to perform online malaria parasite detection and quantitation. The validity of this approach for malaria diagnosis is still unclear and will depend on the method's speed, efficiency, robustness, cost, and above all, accuracy. Constraints related to production of the high-quality images required for malaria species identification will have to be addressed. Specifically, the performance should be compared to current diagnostic tools and trends, such as rapid immunochromatographic diagnostic tests that offer a cost-efficient solution. However, rapid tests have limitations, such as restricted malaria species recognition and an inability to quantitate parasite load and monitor parasitological response to treatment. In general, we suggest that the methodology presented in this research could be applied to other biomedical image analysis tasks with potential impact on global health challenges, such as enumeration of acid-fast bacilli in sputum smears for tuberculosis diagnosis. An inherent benefit from this distributed telediagnosis system is that it is scalable and resilient. Among other positive externalities of this research, there is a clear educational impact because more than 6000 players have learned how malaria parasites appear in thick blood films. In addition, as we allowed players to introduce their nicknames into the table of high scorers, we could identify approximately 100 players who now can be considered as experts in parasite counting, within the system's limitations. Citizen science projects of this kind could impact future educational paradigms: they are a clear opportunity for engaging with young people and offer a hands-on experience that could be used in online learning platforms [34,35].

Concerning the evolution of the MalariaSpot platform, next steps might explore the feasibility of developing a new game version that mimics, if possible, all the relevant steps of the microscopist protocol in real-life conditions (eg, decisions about presence or absence of malaria parasites, parasite stages and species, and quantitation), but this is a much more complex and challenging process. Assuming image quality concerns can be addressed, this system could potentially be completed by integrating the online platform for rapid diagnosis with the recently developed cellphone-microscope systems [36] that allow data transfer directly from field workers and health centers, distributing the data worldwide through the Internet.

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Authors' Contributions

Miguel A Luengo-Oroz conceived and directed this research, designed the experiment and the MalariaSpot game, performed data analysis, interpreted the results, and wrote the manuscript. Asier Arranz implemented the game software. John Frean provided the image data, advised on microscopic aspects of malaria diagnosis and parasite enumeration, and contributed to revising and editing the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Raw data collected during the experiment: Data_MalariaSpot.csv containing 270207 rows - 1 per parasite tag- in the format: [user id, image id, true/phantom parasite, x position, y position, time].

[CSV File, 7MB - jmir_v14i6e167_app1.csv]

Multimedia Appendix 2

Comparison between crowdsourced parasite counting and automatic image analysis counting methodology.

[PDF File (Adobe PDF File), 17KB - jmir_v14i6e167_app2.pdf]

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Abbreviations

DI: discrimination index
FP: false positive
TP: true positive

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Original Paper

Use of Web 2.0 to Recruit Australian Gay Men to an Online HIV/AIDS Survey

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Abstract

Background: Continuous prevention efforts for human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) are recommended among those men who have sex with men (MSM). Creative use of e-technologies coupled with a better understanding of social networks could lead to improved health interventions among this risk population.

Objective: The aims of the study were to (1) compare the impact of various advertising strategies on recruiting MSM participants to an online HIV/AIDS survey, and (2) explore the feasibility of using a social network service (SNS) for study advertising.

Methods: A cross-sectional online survey was conducted in 2009. South Australian men over 18 years were invited to participate if they had had sexual intercourse with men in the previous year. A short questionnaire was used to collect demographics and information on sexual behavior, HIV history, use of the Internet for dating purposes, and sources of health information. The survey was promoted in community settings and online, including advertisements through social networks.

Results: A total of 243 men completed the online survey during the 8-week data collection period. Online advertisements recruited 91.7% (220/240) of the sample. Conversely, traditional advertisements in the community recruited only 5.8% (14/240) of the sample. Ten volunteers were asked to advertise on their personal SNS application, but only 2 effectively did so. Only 18/240 (7.5%) of the respondents reported having learned of our study through the SNS application. In this sample, 19.3% (47/243) of participants had never been tested for HIV. Among the participants who had been tested, 12.8% (25/196) reported being HIV-positive. Regarding Internet use, 82.3% (200/243) of participants had dated online in the previous 6 months. Among the participants who had dated online, most (175/200, 87.5%) had found an Internet sexual partner and two-thirds (132/200, 66.0%) had had anal sex with these partner(s). Among men who had anal sex with an Internet partner, 68.2% (90/132) used a condom during sex.

Conclusions: The MSM participants in this study had high-risk profiles for HIV and other sexually transmitted diseases (STDs), which highlights the need for ongoing health interventions among this group. In this study, the SNS marketing strategy did not appear to create a viral effect and it had a relatively poor yield.

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KEYWORDS

Internet; advertising; HIV; Australia; homosexuality; male

Introduction

South Australia (SA) is an Australian state with a population of 1,618,200 people of whom approximately 73% live in Adelaide, the capital city [1]. Information on the South Australian men who have sex with men (MSM) population is limited [2]. In 2001, it was estimated that 12,315 men in South Australia (2.1% of South Australian men over 16 years) were homosexual/bisexual [2].

In Australia, the MSM population constitutes the primary group affected by the human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) [2,3]. In South Australia, the MSM group accounts for 60%-70% of new HIV diagnoses [4,5].

Researchers have argued that new information technologies, such as the Internet, may have contributed to the global HIV epidemic [6]. The Internet appears to be particularly popular among MSM [7,8]. It is likely to have unique appeal to them because of the limited availability of venues where they can meet without fear of negative social consequences [9].

In an Australian online survey, most gay/bisexual male respondents had met someone in person after chatting online. The most frequent outcome of meeting following online contact was having casual sex (82%). However, many men reported having formed friendships (77%) and longer-term sexual relationships (41%) after such meetings [8]. In South Australia, an increasing proportion of MSM have reported using the Internet to look for male sexual partners [10]. In 2007, the Internet was the most popular venue for seeking partners, surpassing traditional venues such as bars and saunas [10].

The role of the Internet in the HIV epidemic among MSM is unclear [11,12]. A number of studies have shown an association between high-risk sexual behavior and using the Internet to look for sex among MSM [13-17]. The underlying causes are not completely understood [12,18], although there has been documented evidence of online promotion of high-risk sexual behaviors [6,19].

On the other hand, the Internet also offers great opportunities for expanding health promotion interventions [6,13,20]. In this unique setting, protective factors may operate simultaneously with risk factors [9]. For example, some websites targeting MSM already promote risk-reduction strategies, such as frequent HIV testing, limiting the number of sexual partners, and serosorting (the practice of choosing sexual partners with the same HIV status)[6]. In addition, it has been proposed that the Internet could provide better access to hard-to-reach groups of MSM who tend to receive less health promotion information, such as men who live in rural areas, men with culturally and linguistically diverse backgrounds, and men who do not overtly identify with the gay community [7,18,21].

Social network services (SNSs), such as Facebook, MySpace, Orkut, LinkedIn, Hi5, and BeBo,are increasingly popular. Using SNSs to recruit for health studies has emerged to be a cost-effective tool in recent years [11,22].

Facebook was the focus of this study. At the time of this study, Facebook had more than 300 million users worldwide including 7 million Australian users (6.2 million over 18 years), and its popularity was growing [23-25].Within 50 miles of the Adelaide city center, there were more than 500,000 active Facebook users (364,000 over 18 years) including 157,000 adult men at the time of study [25].

Public health approaches to health promotion can benefit from taking advantage of the possibilities created by the Internet, especially by SNSs [23].A better understanding of Internet use and social networks among MSM could lead to improved health promotion initiatives in this specific population.

This study aimed to (1) compare the impact of various advertising strategies on recruiting MSM participants to an online survey, and (2) explore the feasibility of using an SNS for study advertising.

Methods

A cross-sectional online survey was performed between June 26 and August 21, 2009. It was advertised as the “SA Men Online Survey” in both community and online settings.

Study Advertising

Advertising in the South Australian Gay Community

The survey, endorsed by the AIDS Council of South Australia (ACSA) and approved by the University of Adelaide Human Research Ethics Committee, was advertised in a newspaper for the South Australian gay community (*Blaze*) and through posters and business-sized cards distributed in the Adelaide area in gay venues and gay health service clinics (Table 1). The materials contained the study webpage URL that potential respondents were encouraged to access.

Table 1. Media utilized for study advertising.

Media		Description	Location
Online advertising			
	Web banner	Continuous banner placement	acsa.org.au; Gaydar.com.au
	Invitation in chat room	Message displayed on a few occasions	Gaydar.com.au
	Email signature	Banner attached to emails of 3 staff members	Email to potential respondents
	E-newspaper	Weekly e-news sent via email to 800 male members	Email to potential respondents
	SNS	Via webpage, ad placement, and advertisement on social networks	SNS application
Community advertising			
	Gay newspaper (*Blaze*)	8500 copies of a single issue, color ad on 1/8 of A4 page	Adelaide city center and two other cities
	Business-size cards	250 color cards	Sex-on-premises venues (2), bar (1), general practice clinic (1), HIV/AIDS support service (1)
	Posters	50 color posters, A4-size	As above
	Word of mouth	Word of mouth encouraged on materials	Community

Online Advertising

Gaydar.com.au is a UK company with a repertoire of chat rooms dedicated to MSM based on geographic location. A Web banner was placed on the home pages for "South Australia-Adelaide" and "South Australia-Rest." The Web banner contained the University of Adelaide and the ACSA/Gay Men's Health (GMH) logos and read, "SA Men Online Study. A 5-Minute Survey. To Join Now, Click Here"(Figure 1).

Educators from the ACSA/GMH offer peer-based information and support inthe Gaydar.com.au chat rooms as part of their routine duties. They provided information about the study and were instructed to refer the chatters to the study coordinator to address concerns or complex questions. During the study period, educators displayed a general message containing study name, study URL, and an invitation to participate in the South Australia-Adelaide chat room of Gaydar.com.au.

In addition, the study banner was displayed on the ACSA/GMH website. Approximately 800 male members subscribe to an e-news service provided by the ACSA/GMH and they were also invited to participate in the study. In addition, three educators from the ACSA/GMH attached the study banner to their email signature block during the study period.

Figure 1. Banner advertisement used to recruit potential men who have sex with men for an online HIV/AIDS survey, South Australia, 2009.

SNS Advertising

Ten MSM were approached initially to advertise the study using their personal Facebook account and three agreed to participate. They met with the project coordinator and were provided with written information on study advertising using their SNS. When the survey was launched, they were contacted by the project coordinator via email to provide information about posting the study name and URL link on their personal page. No incentive was provided, but they were offered the results at the conclusion of the study.

Ideally, volunteers would have been identified on the basis of objective social leader characteristics using appropriate methods [26]. However, our request to advertise on their personal SNS may have been perceived as intrusive. As a result, recruitment was made on a voluntary basis only.

A webpage entitled "SA Men Online" was also placed on Facebook free of charge with page access restricted to people over 18 years. As a result, people could not access this page directly from an external website or from a search engine. Only logged-in users of that particular SNS over 18 years (as stated in their profile) could potentially view it.

Volunteers were asked to identify themselves as fans of this Facebook page. Updates on study progression, number of respondents, and some general comments from previous respondents were posted on this webpage.

To reach additional respondents, a banner advertisement was also placed on the Facebook sidebar for a 2-week period targeting men over 18 years, living within an 80-kilometer radius of Adelaide city center, who were interested in men. An estimated 1540 users were targeted by the advertisement. Clearly, this strategy would only access individuals who were willing to identify their sexual orientation on a SNS.

Online Survey

Design

The target population consisted of all South Australian men over 18 years who have had sex (oral/anal) with men in the previous year. A convenience sample was drawn from this population and a cross-sectional survey was conducted over an 8-week study period in 2009.

Institutional Review Board Approval and Informed Consent Process

The study was approved by the Human Research Ethics Committee of the University of Adelaide, Australia.

Before accessing the survey questionnaire, all potential respondents had to access the official study webpage placed on the University of Adelaide website. The informed consent form appeared on the main webpage and contained details about survey length, data storage, and study investigators. It explained possible positive and negative outcomes related to study participation. At the end of this page, men who agreed to participate could signify so by clicking a button that lead to the questionnaire screen. The online questionnaire did not collect identifiable personal information such as name, date of birth, or email address.

Electronic survey data were stored in a locked office, in an appropriate password-protected computer on a password-protected network within the firewalled computing environment of the Discipline of Public Health, University of Adelaide, Australia.

Development and Pretesting

The questionnaire was built using validated questions from previous surveys [8,10,27]plus additional questions. A paper version of the questionnaire was pretested with 5 MSM community volunteers. Minor changes were made to the questionnaire in accordance with their feedback.

The final questionnaire collected demographic data (age, educational level, and postal code), sexual identity, use of websites for meeting partners (types of websites, number of partners met, and condom use with last partner), HIV history (status and date of last test), usual sources of health information, and information on study advertising media. The questionnaire included additional items on each of the selection criteria (gender, place of residence, and sex with men history) and a comments section.

The commercial software chosen for this study significantly facilitated the online survey design process because it did not require technical expertise in computer programming. The company also collected respondents' data via secure sockets layer (SSL) encryption and they initially hosted the database. The company ensured that only the research team would be able to access the data via password. Time constraints and associated costs were considered in choosing the software package.

The questionnaire was tested using both Internet Explorer and Firefox Web browsers. At a pretesting stage, an email containing the survey URL was sent to 5 designated respondents who took part in the survey and provided comments.

Recruitment Process

The survey was open to all visitors to the study webpage, which was not password-protected. The selection criteria for study participation were highlighted clearly.

The survey was advertised offline and online. Regardless of the adverting strategy, ultimately all respondents were directed to the study webpage to complete the questionnaire online.

Survey Administration

The survey was made accessible exclusively through the webpage created on the University of Adelaide website to facilitate the consent process. The study webpage was placed under "Research Projects" in the Discipline of Public Health. Because of the number of steps (9 successive clicks) required to access the study webpage from the main university webpage, it appeared relatively unlikely that people would access it without having been exposed to any study advertisements.

The survey itself was voluntary. Participants were informed that results would be posted online and, apart from links provided to useful resources on the website, no other incentive was offered.

The survey was available online for an 8-week period. The questions were displayed in identical order to all respondents. Depending on previous responses in the questionnaire, some questions were skipped. The questionnaire was kept short to encourage maximal participation.

The questionnaire comprised 8 screens so that questions that could potentially be skipped were placed on separate pages. There were 1-5 items per screen and 17 items in total. No item was mandatory and incomplete questionnaires could be submitted. Participants were able to change their answers from previous pages using a "previous" button.

Response Rates

During the study period, there were 544 unique visitors to the study webpage on the University of Adelaide website. However, the software company used to launch the survey did not provide figures for unique visitors to the questionnaire itself. Specifically, the company did not record the number of respondents who exited without completing or submitting the first page of the questionnaire. Therefore, the participation rate could not be calculated.

The completion ratio (ratio of the number of people who submitted the last survey page divided by the number of people who submitted the first survey page) was 0.946 (247/261).

Considerations Regarding Potential Multiple Entries from the Same Individuals

Given the topics assessed in the survey, for ethical reasons the research team was unaware of the Internet protocol (IP) addresses of the respondents' computers and the team did not use cookies. However, the company that provided the software did use cookies and was able to identify the IP addresses. The company noted that this information was necessary for the proper functioning of the online software and that it was used in an aggregated manner for administrative purposes only.

Multiple entries from a single IP address were not restricted because more than one person in a given household may have been eligible and attempted to participate. Secondly, one IP address could be shared by several computers. Moreover, restricting multiple submissions from the same IP address did not necessarily prevent individuals from submitting multiple surveys from computers with different IP addresses.

However, the database was screened for potential duplicate submissions. Questionnaires with an identical combination of age, educational level, and postal code were checked for the dates of last HIV test and HIV status. None were identical; therefore, all files were retained in the final analysis.

An examination of the time for completion did not reveal any aberrant results. The shortest completion time was 1.17 minutes, but the answers were credible. Therefore, no survey was eliminated because of a too-short completion time. Median time for survey completion was 3.27 minutes.

Surveys were checked for completion. Seven respondents did not complete the last page, but they did complete the 7 previous pages. Overall, given that some questions were not applicable to all respondents, all surveys had at least 75% completion of applicable questions and all were kept in the analysis.

Statistical Analysis

Descriptive statistics were performed using Predictive Analytics Software (PASW) Statistics 17.0 software [28]. No method (ie, weighting of items or propensity scores) was used to adjust for the non-representative sample.

Results

In total, 261 questionnaires were completed during the 8-week data collection period (June 26 to August 21, 2009). Eighteen were excluded because they did not meet the inclusion criteria based on gender (7/261, 2.7%), age (1/261, 0.4%), place of residence (1/261, 0.4%), or history of sex with men in the previous year (9/261, 3.4%). The remaining 243 surveys formed the database for the final analyses.

Study Advertising

Over the study period, advertisements were introduced in a staggered manner so it was possible to examine the relative success of each recruitment strategy (Figure 2). The advertising was limited in the first 2 weeks to allow for eventual technical adjustments. Overall, recruitment was low in the final 10 days and data collection was stopped.

In Figure 2, the arrows refer to the dates that the advertising strategies were implemented. They are:

1. Web banner attached to e-signature of 3 staff members of the ACSA/GMH.

2. Card and poster distribution in gay venues and health clinics in the Adelaide area.

3. Web banner placement on Gaydar.com.au and message display in chat room of Gaydar.com.au.

4. E-news sent weekly by ACSA/GMH to 800 members and Web banner placement on the ACSA/GMH website.

5. Advertisement in newspaper for gay men.

6. SNS: Study name and URL posted on personal Facebook page by volunteer #1.

7. SNS: Study name and URL posted on personal Facebook page by volunteer #2.

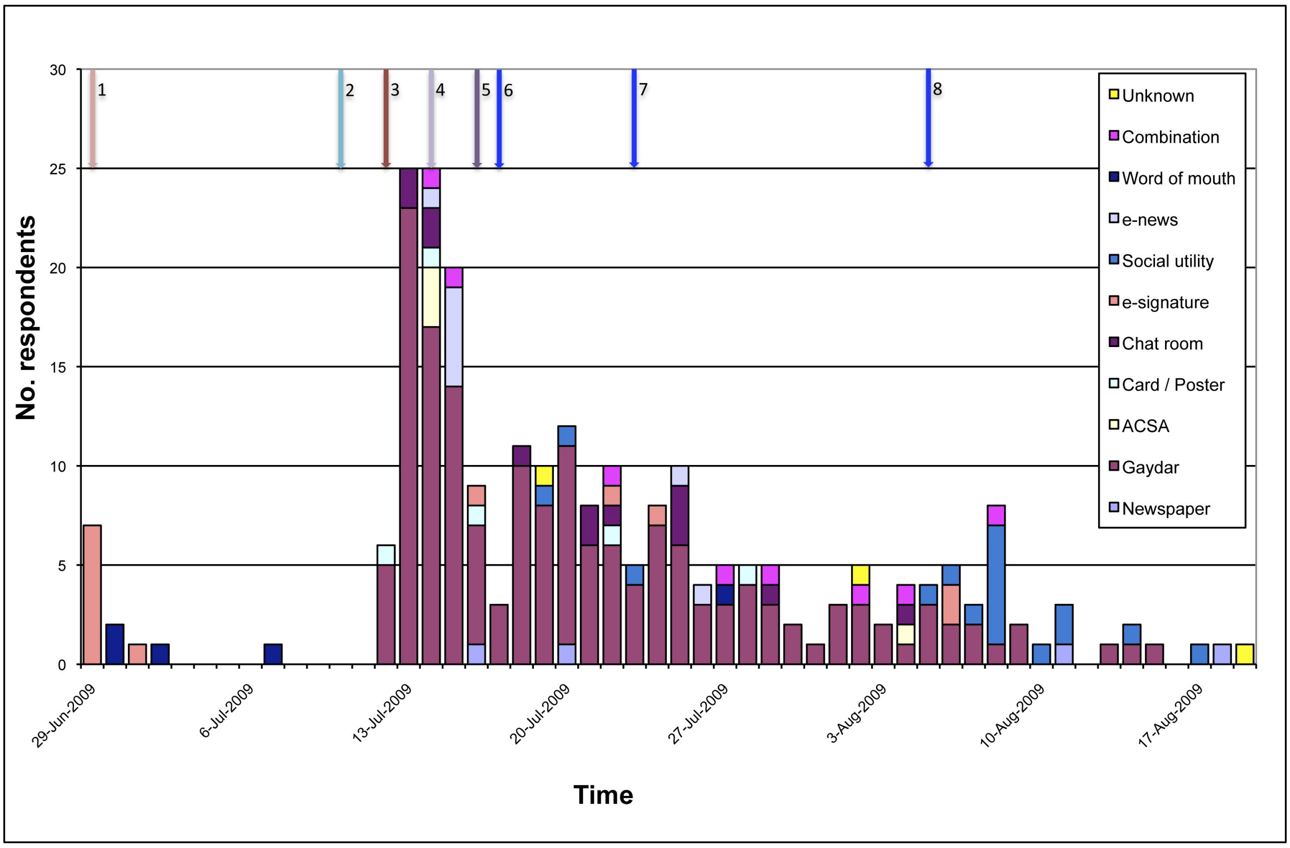
8. SNS: Ad placement on Facebook.

When men were asked about the media that alerted them to the study, 232 out of the 240 men (96.7%) reported only 1 source and 8 men reported 2 sources. The advertisement banner posted on Gaydar.com.au attracted 70.0% (168/240) of respondents with an additional 6.3% (15/240) recruited through the chat room on Gaydar.com.au. Eighteen (7.5%) respondents reported having learned of our study through the SNS application. The ad launch on that application recruited some respondents in the first week, but plateaued in the second week.

Overall, the online advertising made in chat rooms, on the SNS application, via banners and emails recruited 220/240 (91.7%) respondents. Community advertising through posters, business cards, the newspaper, and word of mouth, recruited only 14/240 (5.8%) respondents. In all, 6/240 (2.5%) reported having been exposed to both online and offline media.

Data (eg, impressions and click-throughs) regarding the banner advertisements could not be obtained because specific arrangements were not made with ACSA/GMH and Gaydar.com.au to track such information.

Figure 2. Number of men who have sex with men recruited to an online HIV/AIDS survey by type of media between June 26 and August 21, 2009, in South Australia.



SNS Advertising

During the study period, 2 of the 3 volunteers who had initially agreed to advertise the study on their SNS advertised the study effectively. They had a cumulative social network of approximately 100 friends, which is relatively small considering the average Facebook user has 130 friends [29]. In addition, the webpage created on the SNS application did not have high access rates.

Over 14 days, the advertisement on the SNS was displayed 55,000 times with 53.5% of total impressions being directed toward the 18-24 year group, and an additional 22.0% toward the 25-34 year group. Daily, 400-870 distinct users were shown the advertisement. On a given day, individuals who were shown the advertisement would see it 5 times on average. Only 31 people clicked on the advertisement itself, thus 0.06% (31/55,000) of all impressions resulted in a click. This approach incurred relatively modest fees of Aus $12.36 for 31 clicks (average Aus $0.40 per click).

Online Survey

General Characteristics of the Sample

Table 2 describes characteristics of survey respondents. The age range was between 18 and 68 years, with a median age of 34 years. Most respondents (140/243, 57.6%) were aged 25-44 years. The sample was highly educated, with 119/242 (49.2%) having completed a university degree or a College of Advanced Education (CAE) course.

Table 2. Characteristics of South Australian MSM recruited online, 2009.

Characteristics[a]		n	%
Age (n = 243)			
	18-24	50	20.6
	25-34	73	30.0
	35-44	67	27.6
	45-64	52	21.4
	≥ 65	1	0.4
Education (n = 242)			
	Less than or up to 3 years of high school/Year 10	22	9.1
	Year 12/South Australian Certificate of Education (SACE)	52	21.5
	Tertiary diploma or trade certificate/Technical and Further Education (TAFE)	49	20.2
	University/College of Advanced Education (CAE)	119	49.2
Area of residence (n = 241)			
	Metropolitan Adelaide	212	88.0
	Rural area	21	8.7
	Remote area	8	3.3
Socioeconomic Index for Area (SEIFA) [b] **(n = 241)**			
	1st quintile (most disadvantaged)	57	23.7
	2nd quintile	41	17.0
	3rd quintile	59	24.5
	4th quintile	49	20.3
	5th quintile (least disadvantaged)	35	14.5
Sexual identity (n = 242)			
	Gay/homosexual	196	81.0
	Bisexual	43	17.8
	Heterosexual	0	0
	Unknown/other	3	1.2
Lifetime HIV test history (n = 243)			
	Never tested	47	19.3
	Tested at some point	196	80.7
Declared HIV status according to last test result (n = 196)			
	Negative	170	86.7
	Positive	25	12.8
	Unknown	1	0.5
Declared time of last HIV test for tested men without a HIV-positive result (n = 171)			
	< 3 Months	43	25.2
	3-6 Months	39	22.8
	7-12 Months	34	19.9
	1-2 years	24	14.0
	> 2 years	31	18.1

Characteristics[a]		n	%
Sources of health information (n = 234) [c]			
	Books	47	20.1
	Family and friends	49	20.9
	Gay media	60	25.6
	Gay Men’s Health website	63	26.9
	Gay Men’s Health (resources other than the website)	33	14.1
	Health care provider	97	41.5
	Health department	36	15.4
	Internet	160	68.4
	Men’s magazine	71	30.3
	Newspaper/news magazine	53	22.6
	Professional education	54	23.1
	Radio	25	10.7
	Television	81	34.6

[a] The number of respondents answering each question varied slightly because of missing values; question related to HIV status was automatically skipped for 47 untested men.

[b] The Index of Relative Socioeconomic Disadvantage (IRSD) includes attributes such as low income, low educational attainment, high unemployment and jobs in relatively unskilled occupations, and refers to the area in which a person lives [30].

[c] More than one option possible.

Most participants (212/241, 88.0%) resided in metropolitan Adelaide, but men from rural (21/241, 8.7%) and remote (8/241, 3.3%) South Australia were also represented. A socioeconomic index was obtained from the area of residence of participants. There was no clear gradient, but proportionally fewer men (35/241, 14.5%) were in the least disadvantaged quintile than the most disadvantaged quintile.

Most respondents (196/242, 81.0%) considered themselves as homosexual/gay whereas 43/242 (17.8%) described themselves as bisexual.

Regarding HIV testing, 47/243 (19.3%) men reported never having been tested. Among men who had been tested at some time, 25/196 (12.8%) reported being HIV-positive, 170/196 (86.7%) reported being HIV-negative, and 1/196 (0.5%) reported an unknown status according to the last test result. Among tested men who did not report an HIV-positive result, 43/171 (25.2%), 39/171 (22.8%), and 34/171 (19.9%) participants reported having had an HIV test in the previous 3 months, previous 3-6 months, and previous 7-12 months, respectively. Fifty-five participants (32.1%) had been tested more than a year previously.

Participantsreported various sources of health information, with the Internet as the most noted source (160/234, 68.4%). A health care provider (97/234, 41.5%), television (81/234, 34.6%), men’s magazines (71/234, 30.3%), and Gay Men’s Health website (63/234, 26.9%) were also frequently reported.

Online Dating and Sex

Regardingonline dating, 200/243 (82.3%) participants reported having looked for male sexual partners on the Internet in the previous 6 months (Table 3). These men were further asked about their online dating habits and related sexual behavior. Most (175/200, 87.5%) had met at least one male sexual partner through the Internet in the previous 6 months. Approximately half of the participants who had met Internet partners (86/175, 49.1%) had found 2-5 partners. Of the participants who reported having looked for male partners online, 132/200 (66.0%) had anal sex with an Internet partner, 68.2% (90/132) of whom reported having used a condom during their most recent sexual encounter. In the subgroup of participants who reported unprotected anal sex during their last intercourse, 9/42 men (21%) had never been HIV tested. Among tested participants, 5/33 (15%) reported being HIV-positive. The only 2 participants surveyed who reported having had more than 50 Internet partners also reported having unprotected anal sex during their last sexual encounter.

Table 3. Online dating and sex among South Australian MSM, 2009.

Characteristics[a]		n	%
Online dating with males in previous 6 months (n = 243)			
	Yes	200	82.3
	No	43	17.7
Websites utilized for dating (n = 200)[b]			
	Gaydar.com.au	178	89.0
	Manhunt	109	54.5
	Squirt	50	25.0
	Facebook	16	8.0
Number of male sexual partners met through Internet in previous 6 months (n = 200)			
	None	25	12.5
	1	39	19.5
	2-5	86	43.0
	6-10	29	14.5
	11-50	19	9.5
	> 50	2	1.0
Anal sex with a male partner met through the Internet in previous 6 months (n = 200)			
	Yes	132	66.0
	No	68	34.0
Condom use during last anal sex with a male partner met through the Internet (n = 132)			
	Yes	90	68.2
	No	42	31.8

[a] The number of respondents answering each question varied only because of automatically skipped questions.

[b] More than one option possible.

Discussion

Principal Results

Online advertising was a less costly and more efficient approach to recruit in comparison to community advertising during the relatively short recruitment phase. Our findings suggest that in this gay community that is well educated and mostly urban, online advertising is likely to be a more successful method of recruiting participants to an online survey unless the community approach is considerably intensified.

Our results also indicate that MSM who participated in this study constitute a high-risk group for sexually transmitted diseases (STDs) and HIV infections. For instance, nearly half (102/218, 46.8%) of the non-HIV-positive participants had not had an HIV test in the previous year. In addition, 13% of the participants who underwent an HIV test were HIV-positive. This proportion is higher than that of previous surveys [8,10] and is suspected to be higher than the South Australian MSM population HIV prevalence rate overall [2]. Thus, men recruited on dating websites may be at higher risk for HIV infection [21]. Furthermore, participants were recruited with the active involvement of an HIV/AIDS organization that may have reached a higher proportion of HIV-positive respondents. Finally, one-third of participants had unprotected anal sex during last intercourse with their Internet partner.

In this online recruited sample, the Internet was the most popular source of health information, which highlights the need for continuing and developing creative Internet-based interventions.

Comparison with Prior Work

Regarding study advertising, previous online surveys assessing HIV risk have mainly recruited MSM from sites that were primarily gay-identified or that were sexual meeting sites [18,31-35]. As mentioned previously, statistics regarding banner placement on Gaydar.com.au and the ACSA/GMH website could not be obtained for comparison.

In an American study, MSM were recruited to an online survey through SNS advertisements. The click-through rate for the banner advertisements on MySpace.com was0.37% [11]. The researchers concluded that this strategy allowed recruiting large numbers of MSM (n = 9005) in a short period of time of approximately 1 month [11]. These figures differ from ours; our click-through rate for the banner advertisements on Facebook was 0.06% and the overall SNS marketing strategy had a relatively poor yield with only 18 participants recruited in 8 weeks.

Comparison with previous Australian studies can be made in regards with our survey findings. The Gay Community Periodic Survey (GCPS), a pen-and-paper survey in Australia, was conducted among MSM of Adelaide in 2007. Findings from that study differed to ours, mainly in regards to lifetime uptake of HIV tests (in the GCPS, 10.4% of men had never been tested for HIV versus 19.3% in this study) and the reported HIV status (5.7% versus 10.3% of men reported an HIV-positive status). These differences could be due to chance, given our limited sample size. However, online and offline recruited samples are known to have different characteristics [36]. Therefore, it cannot be excluded that a higher-risk group was selected in our online sample. In addition, the anonymity provided by the Internet may have encouraged more men to divulge their positive HIV status because the Internet may be more favorable for respondents to disclose information on sensitive topics [37].

In Private Lives, an online survey conducted across Australia in 2005 [8], the proportion of men who had been tested for HIV at least once (78%) was similar to our findings (80.7%). Among tested men, nearly two-thirds had been tested in the previous year in both studies (65% in Private Lives versus 67.8% in our study) [8]. Similarities in the advertising and survey methods of both online surveys could explain these figures. However, in Private Lives, a lower proportion of HIV-tested men had a positive test result (9.7%) in comparison with 12.8% from our findings [8].

Strengths

This is one of the few studies [11] to make use of SNS as a practical tool to recruit MSM in a health research project, which makes it innovative. It shows that a paid SNS advertisement is easy to implement, but that the utilization of naturally existing social networks could be a challenge. The creation of a public page on a SNS application is also an interesting strategy, although stimulating interaction around it warrants detailed planning.

Interestingly, a search on October 27, 2009, for keywords in the medical subject headings (MeSH) list did not return accurate results (using “social networking,” “social network,” “network,” “online network,” “network service,” “social network service,” “Facebook,” and “MySpace”). The closest result was related to the idea of “social support.” This reinforces the idea that the concept of SNS is relatively new in the health research field and needs to be further considered given its impact and omnipresence in everyday life.

This pilot project was designed to make an efficient use of time and material resources. Responses were obtained from 243 respondents within an 8-week time frame. The total additional expenditure incurred by the research team, excluding human resource expenditure and costs related to regular ongoing activities at the ACSA, was approximately Aus $460 which is less than Aus $2 per respondent. One-third of the total amount was paid to the software company over a 3-month period. Most of the expenditure related to printing of materials that were distributed in the community. In this study, online advertising was relatively inexpensive because the ACSA already had an agreement with Gaydar.com.au and study advertising on that website did not incur additional costs. Fees incurred with advertising on the SNS were minimal given the relatively poor yield of that strategy.

Limitations

Limitations of this study should be acknowledged. The online self-selected sample, mostly recruited on a MSM dating website, may not be representative of the whole MSM population of South Australia [38,39]. However, it does capture a high-risk group of men that could be reached via online interventions as part of a comprehensive health promotion strategy.

The deliberately short questionnaire could not fully assess all factors of interest. For instance, in regards to sexual behavior, men were not asked about the presumed status of their partner nor were they asked about the use of risk-reduction strategies. It is possible, among men who did not use a condom at last anal sex with an online partner, that their decision was based on assumptions of concordant HIV status [40].

For ethical concerns related to the survey-specific content (ie, HIV status) the research team deliberately chose not to gather the respondents’ IP addresses and to not use cookies. Therefore, potential multiple entries coming from a single computer were not restricted. The database was screened for potential duplicate submissions based on an identical combination of answers to some key questions. However, this approach does not prevent intentional deception. This may have biased the study results.

Some technical limitations were encountered during this project. Firstly, respondents had to report the media that made them aware of our survey. Ideally, it would have been preferable to be able to directly track the pathway of each respondent.

Secondly, there were limitations associated with the creation of the study webpage on a university website. On the one hand, having the webpage on a university website may have reassured some respondents of the project legitimacy. However, this resulted in a lack of flexibility regarding the webpage features, such as its location (and correspondingly long URL) and the automatic display of images in the sidebars of the webpage.

Finally, the use of a commercial software, although user friendly and reasonably priced, imposed some constraints, such as not providing all the survey traffic statistics that would have been of interest (eg, the number of people who dropped out without completing the first questionnaire page).

Because this study did not appear to create a viral effect, this warrants reflection on the conditions required to make study participation more attractive to potential respondents and their networks [23]. The addition of a pleasant interactive Web tool could facilitate this phenomenon. This could have various formats: an interactive story, a “test-your-knowledge” tool, a decision-support tool [41], a game related to the topic, among others. Public health researchers have been successful in creating a viral marketing strategy [41,42].

Conclusion

The MSM who were surveyed in this online study constitute a high-risk group in regards to STDs and HIV infections. Our findings highlight the need for continuous interventions among this group.

This study explored some avenues for health care research in the MSM population using SNSs. In this study, the SNS marketing strategy did not appear to create a viral effect and it had a relatively poor yield. Nevertheless, it illustrates that SNSs can be practically used for public health research.

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Conflicts of Interest

None declared.

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Abbreviations

ACSA: AIDS Council of South Australia

AIDS: acquired immune deficiency syndrome
CAE: College of Advanced Education
GCPS: Gay Community Periodic Survey
GMH: Gay Men’s Health
HIV: human immunodeficiency virus
IP: Internet protocol
IRSD: Index of Relative Socioeconomic Disadvantage
MeSH: medical subject headings
MSM: men who have sex with men
PASW: Predictive Analytics Software
SA: South Australia
SACE: South Australian Certificate of Education
SEIFA: Socioeconomic Index for Area
SNS: social network service
SSL: secure sockets layer
STD: sexually transmitted disease
TAFE: Technical and Further Education

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Original Paper

Pro-Anorexia and Pro-Recovery Photo Sharing: A Tale of Two Warring Tribes

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Abstract

Background: There is widespread use of the Internet to promote anorexia as a lifestyle choice. Pro-anorexia content can be harmful for people affected or at risk of having anorexia. That movement is actively engaged in sharing photos on social networks such as Flickr.

Objective: To study the characteristics of the online communities engaged in disseminating content that encourages eating disorders (known as “pro-anorexia”) and to investigate if the posting of such content is discouraged by the posting of recovery-oriented content.

Methods: The extraction of pro-anorexia and pro-recovery photographs from the photo sharing site Flickr pertaining to 242,710 photos from 491 users and analyzing four separate social networks therein.

Results: Pro-anorexia and pro-recovery communities interact to a much higher degree among themselves than what is expected from the distribution of contacts (only 59-72% of contacts but 74-83% of comments are made to members inside the community). Pro-recovery users employ similar words to those used by pro-anorexia users to describe their photographs, possibly in order to ensure that their content appears when pro-anorexia users search for images. Pro-anorexia users who are exposed to comments from the opposite camp are less likely to cease posting pro-anorexia photographs than those who do not receive such comments (46% versus 61%), and if they cease, they do so approximately three months later. Our observations show two highly active communities, where most interaction is within each community. However, the pro-recovery community takes steps to ensure that their content is visible to the pro-anorexia community, both by using textual descriptions of their photographs that are similar to those used by the pro-anorexia group and by commenting to pro-anorexia content. The latter activity is, however, counterproductive, as it entrenches pro-anorexia users in their stance.

Conclusions: Our results highlight the nature of pro-anorexia and pro-recovery photo sharing and accentuate the need for clinicians to be aware of such content and its effect on their patients. Our findings suggest that some currently used interventions are not useful in helping pro-anorexia users recover. Thus, future work should focus on new intervention methods, possibly tailored to individual characteristics.

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KEYWORDS

Medical Informatics; Internet; Photo; Eating Disorder; Anorexia Nervosa; Social Network

Introduction

Background

Eating disorders, such as anorexia nervosa and bulimia, are highly prevalent in most developed countries [1]. These disorders are a major public health concern due to their high mortality and co-morbidities [2]. Anorexia nervosa commonly appears during adolescence and can be devastating to patients' well-being and eventually may cause death [1,2].

Although generally viewed as highly negative by the general public, there is an online movement of people promoting anorexia as a lifestyle choice [3,4]. These communities are variously referred to as pro-anorexia, pro-ana, or simply "ana". Several studies of content published on pro-anorexia websites and forums have identified the following characteristics of pro-anorexia communities [3-5]. Members of these communities use particular websites to share photographs and text designed to inspire members to lose weight (or maintain an immoderately low weight), as well as tips on how to lose weight to extremes that are far beyond reasonable. These websites also frequently operate forums where members can discuss issues related to their positive view of anorexia and to support each other in maintaining their disease (known as having a "pro-ana buddy") [5]. As explained below, pro-anorexia content can be harmful and it is a public health concern.

An increasing percentage of the population in Europe and America use the Internet to find health-related information [6,7]. Unfortunately, not all the online health-related information is trustworthy or harmless. In addition to pro-anorexia online content, there are examples of online content overemphasizing possible harmful effects of vaccinations [8], reinforcing self-injury behavior [9], and even teaching asphyxiation techniques [10]. The rise of harmful content is a serious concern, since it is possible that people searching for trustworthy information (for example, healthy weight loss) may come across pernicious content (such as tips about inducing vomits). Furthermore, the use of online content promoting anorexia as a lifestyle is highly prevalent [11,12]. Custers et al found that 12% of Belgian female students in 6th, 9th and 11th grade had viewed pro-anorexia content [12]. Consumption of pro-anorexia content has been found to correlate with worsening of anorexia [11,13,14]. Rouleau et al in a recent review described three potential risks associated with pro-anorexia webs: the prevention of help-seeking, reinforcement of disordered eating, and operating under the guise of support [14].

Online pro-anorexia content is a case of societal concern and some health authorities and organizations have been attempting to curb its effects. For example, the Israeli government promoted the banning of advertisements that show severely underweight models [15]. Driven by public pressure, social content-sharing sites such as tumblr.com and pintrest.com have attempted to ban pro-anorexia content [16]. Lewis et al suggested intervening in the search results in order to prevent people from accessing pro-anorexia content [17]. Finally, warning labels have been added by the Internet Service Provider (ISP) when users try to access pro-anorexia content [18]. Except for the latter (which has been shown effective in reducing the risk to exposure to such content), it is unclear if these interventions are effective. One should also note that all these interventions are likely to be more effective at preventing new users from starting to engage with pro-anorexia content than in dissuading existing users from continuing to consume such content.

The pro-anorexia online communities have come under scrutiny by several research groups. Norris et al conducted an in-depth analysis of 12 pro-anorexia websites and found that the most prevalent themes in them were related to inspiration and assistance in achieving or maintaining anorexia [3]. A more recent study examined 180 pro-anorexia websites and found similar results [4]. Mulveen examined 15 discussion threads on a pro-anorexia site to discover the main themes of the discussion and to understand the reasons for participation in such threads [5]. However, the small number of threads investigated makes it difficult to draw conclusions from this investigation. In addition, there is a lack of studies addressing the characteristics of the pro-anorexia communities in comparison with those that featured anorexia simply as a disease.

Previous studies were relatively limited in the volume of data they examined, as well as in the fact that they focused solely on the pro-anorexia communities. However, the study of the different anorexia-related communities is highly relevant since these communities are dynamic and members are expected to change from pro-anorexia to pro-recovery communities and vice versa. In our study, we examined a very large body of pro-anorexia and pro-recovery data.

Our data were extracted from a social sharing site, which allows users to create multiple social networks. Thus, beyond an examination of the pro-anorexia and pro-recovery communities, we investigated the interactions between them. Following Wilson et al [11], we define pro-anorexia sites as those encouraging disordered eating. Pro-recovery sites are those that express a recovery-oriented perspective. Both sites, of which the former are more numerous [11], include individual expressions and community tools (such as discussion boards). In our study, we defined a pro-anorexia user as one who is actively involved in the creation and dissemination of content that takes a positive and encouraging attitude towards eating disorders, anorexia nervosa in particular. Conversely, pro-recovery users are those who share views of eating disorders as diseases from which one will want to recover and that take a negative view of them.

In addition, there is a lack of knowledge of the different pro-anorexia communities that are emerging in general content-based social networks. For example, to the best of our knowledge there are no studies on pro-anorexia videos disseminated on sites such as YouTube. In addition, image-sharing platforms, such as Flickr and Pinterest, are very popular and form a perfect venue for the dissemination of pro-anorexia photos (eg, ultra thin models) [16]. In this study, we focus on the study of anorexia-related communities on Flickr, which is an image-sharing platform supported by Yahoo Inc. Flickr is one of the most popular photo-sharing websites with nearly 80 million monthly visitors worldwide [19,20]. Moreover, as described below, several kinds of social connections are induced within the site, allowing for a thorough analysis of social effects within the site.

Objectives

We aimed to study anorexia-related communities on Flickr, which is an image-sharing platform. Our main hypothesis is that there are two different and interrelated pro-anorexia and pro-recovery communities within Flickr. Specifically, our aims are: (1) To understand the community dynamics of the pro-anorexia and pro-recovery communities, and (2) To investigate why pro-recovery users post their content and to understand if this facilitates the recovery of pro-anorexia users.

Methods

Materials

We used data from Yahoo’s photo-sharing site Flickr. Our data comprises four kinds of links: Contacts, favorites, comments, and tags. See Figure 1 for an example of an image and its annotations from the pro-anorexia community [21]. The photograph is shown on the top left hand side. A textual description is below it. Comments by other users are shown below it, as are markings showing if this photograph is chosen as a “favorite” by any user. On the right hand side are the tags used to describe the image. Figure 2 is an example from the pro-recovery community [22].

Flickr users can post both public and private data. In our analysis, we used data that was public on Flickr during February 2012. Most data were obtained through the Flickr API [23] except for information on who “favorited” a particular image, which was obtained by crawling actual pages.

We identified a set of (potentially) pro-anorexia and pro-recovery users using four methods:

1. Searching for photos that matched at least one of the search terms: “thinspo”, “thinspiration”, or “pro-ana”. Matches could occur in the tags, the photo title, or its description. All users who uploaded at least two such photos and whose profile still existed were added to the set of seed users. There were 162 such users.
2. Finding all users who uploaded at least two photographs to the anorexia-related Flickr groups “Eating Disorders Art” [24], “Anorexia Nervosa” [25], “Anorexia Help” [26], and “ED Healing” [27]. There were 71 such users.
3. Finding all users who commented on at least two photos that had one of the aforementioned tags or that was posted in one of the aforementioned groups. There were 669 such users.
4. Finding all users whose profile still existed who favorited (ie, marked as “favorite”) at least two photos that were tagged as both “thinspo” and “skinny” as well as one of “pretty”, “cute”, or “beautiful”. There were 14 such users.

For each of these users, we obtained the information on their activity on the Flickr site as follows:

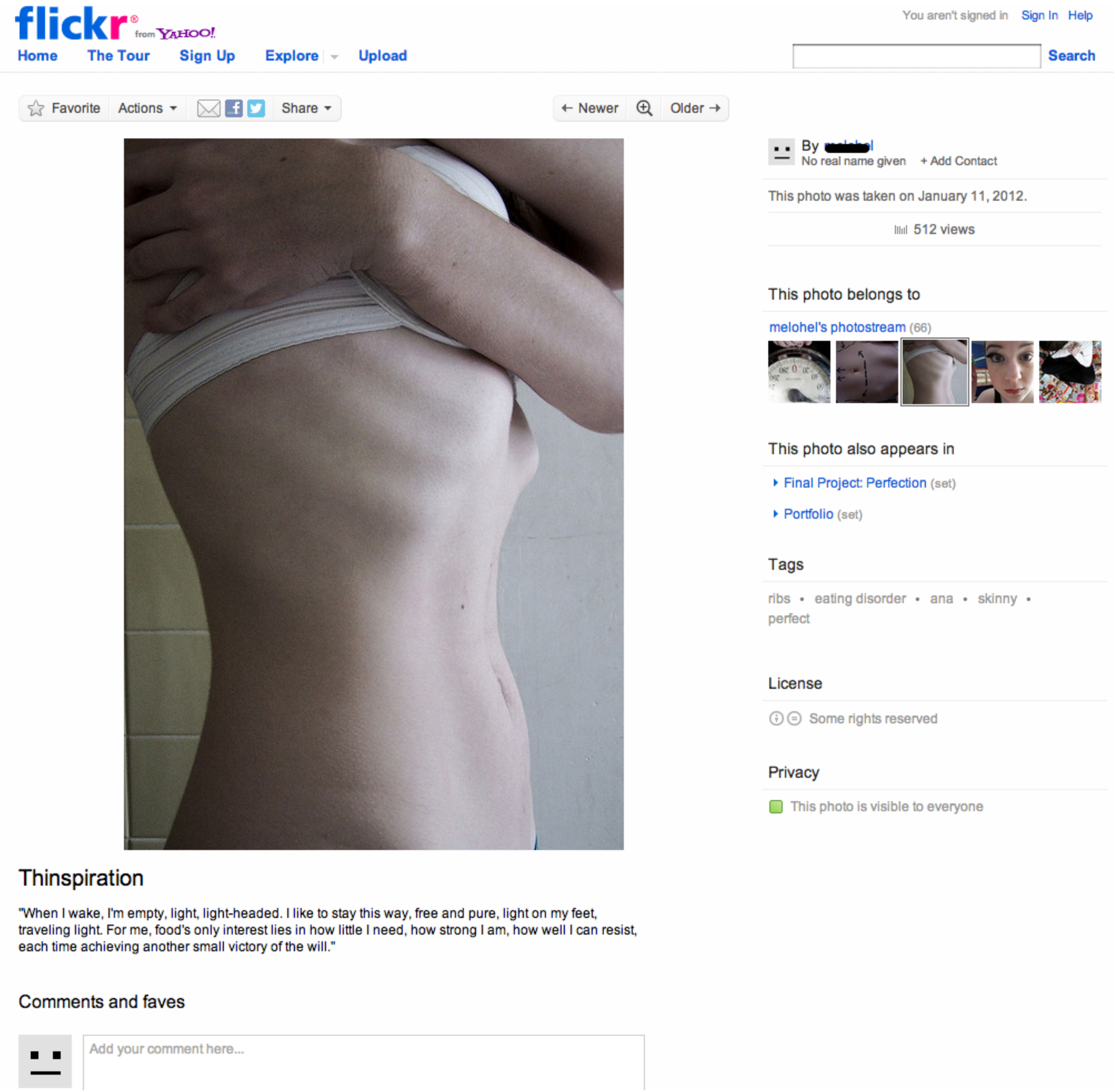
1. Photo meta-information: We obtained meta-information for the 5000 most recent photos posted by each user. This information includes title, tags, description, date posted, the number of times that the photo was viewed, as well as geographic location information, where available. In total, we obtained information for 543,891 photos.
2. Comments for photos: We extracted comments for the 500 most recent photos of each user. This information includes the comment text, an identifier of who left the comment and the time stamp of when it was left. In total, we gathered 2,229,489 comments left for 106,877 photos uploaded by 739 users.
3. Favoriting of photos: We extracted the list of users who marked each of the 500 most recent photos of each user. In total, there were 642,317 such instances, pertaining to 88,337 photos uploaded by 753 users.
4. Public contacts: The list of contacts of each user was obtained. In total, the (directed) contact graph contained 237,165 outgoing edges for 721 seed users. Of these, 2821 edges were between two seed users, pointing to 543 distinct users.

Five researchers independently labeled the users to their degree of pro-anorexia or pro-recovery stance. The researchers were asked to classify users according to their support of pro-anorexia or pro-recovery content using a Likert-based scale. The labels provided by the researchers were averaged and used to classify the users into different classes. Kappa agreement in labeling was 0.51 ($P< .001$) [28]. Thus, good agreement is achieved on the view of users. Following labeling, our data consisted of 172 pro-recovery users and 319 pro-anorexia users. Anecdotally, while many pro-anorexia users self-identify as having an eating disorder, pro-recovery users rarely self-identify, and when they do, we found that approximately 19% of users identify as having formerly suffered from an eating disorder.

We identified tags related to anorexia content (both pro-anorexia and pro-recovery) by representing the tags using a vector space model and selecting all tags that appeared solely in this content or were at least 10 times more likely compared to content that was identified as neutral by the labelers. A total of 25,689 photographs, which we refer to as “highly relevant” photos, contained at least one of these tags.

Processing of data was performed using Matlab 7.3, graph layouts were performed with Gephi 0.8.1. All research described herein was approved by the Yahoo internal research board on human research and consisted solely of observational data. We did not extract identifying information (eg, names, emails) but simple usernames (which are usually pseudonyms). The example pictures (Figure 1 and Figure 2) are licensed under the Creative Commons license and identifying details of the users have been removed.

Figure 1. Example of a pro-anorexia image on Flickr [21].



By [redacted]
No real name given

This photo was taken on January 11, 2012.

512 views

This photo belongs to

melohel's photostream (66)

This photo also appears in

- Final Project: Perfection (set)
- Portfolio (set)

Tags

ribs • eating disorder • ana • skinny • perfect

License

Some rights reserved

Privacy

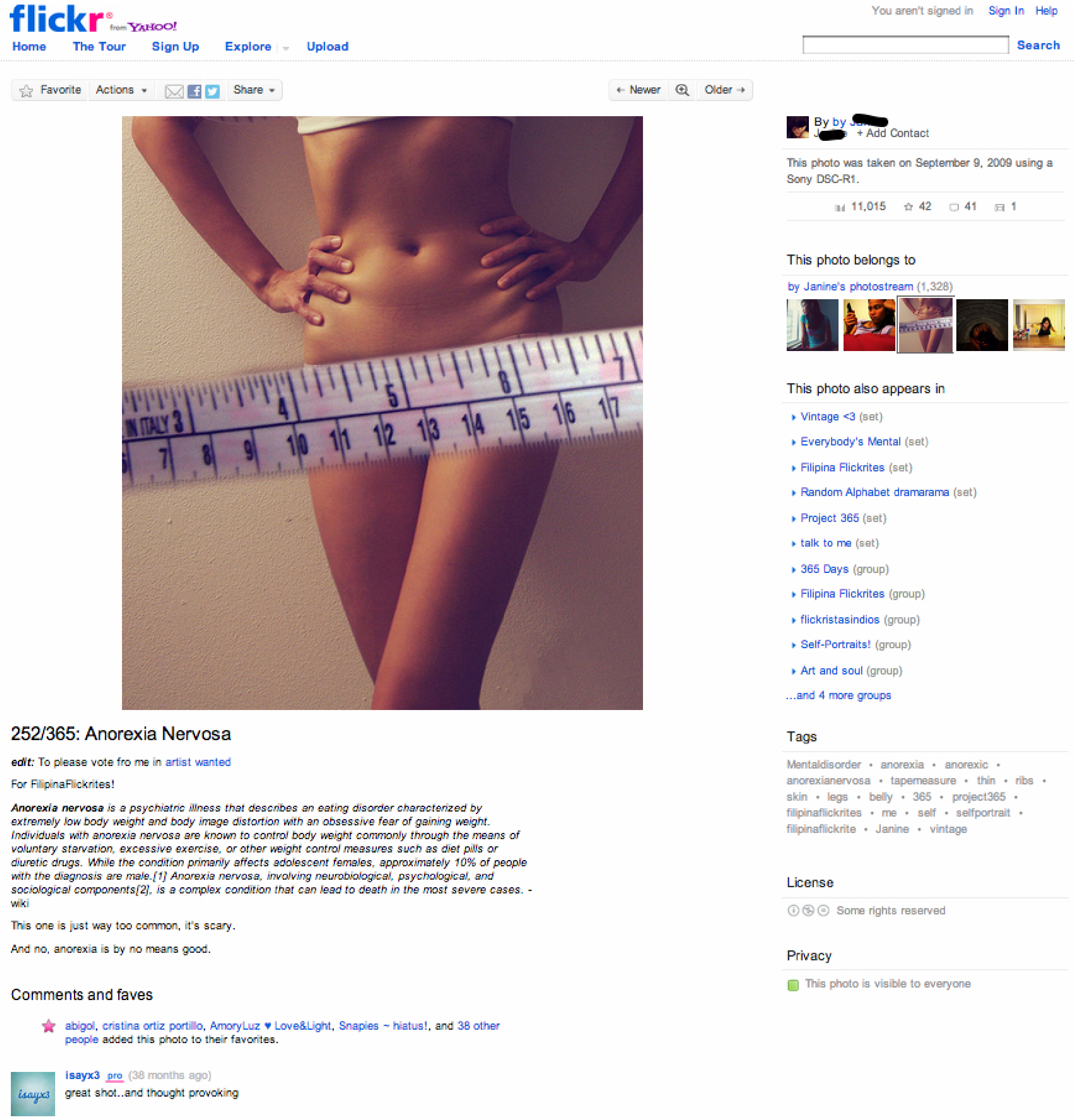
This photo is visible to everyone

Thinspiration

"When I wake, I'm empty, light, light-headed. I like to stay this way, free and pure, light on my feet, traveling light. For me, food's only interest lies in how little I need, how strong I am, how well I can resist, each time achieving another small victory of the will."

Comments and faves

Figure 2. Example of a pro-recovery image on Flickr [22].



By by [redacted] [redacted] + Add Contact

This photo was taken on September 9, 2009 using a Sony DSC-R1.

This photo belongs to

by Janine's photostream (1,328)

This photo also appears in

- Vintage <3 (set)
- Everybody's Mental (set)
- Filipina Flickrites (set)
- Random Alphabet dramarama (set)
- Project 365 (set)
- talk to me (set)
- 365 Days (group)
- Filipina Flickrites (group)
- flickristasindios (group)
- Self-Portraits! (group)
- Art and soul (group)

...and 4 more groups

Tags

Mentaldisorder • anorexia • anorexic • anorexianervosa • tapemeasure • thin • ribs • skin • legs • belly • 365 • project365 • filipinaflickrites • me • self • selfportrait • filipinaflickrite • Janine • vintage

License

Some rights reserved

Privacy

🟩 This photo is visible to everyone

252/365: Anorexia Nervosa

edit: To please vote fro me in artist wanted

For FilipinaFlickrites!

***Anorexia nervosa** is a psychiatric illness that describes an eating disorder characterized by extremely low body weight and body image distortion with an obsessive fear of gaining weight. Individuals with anorexia nervosa are known to control body weight commonly through the means of voluntary starvation, excessive exercise, or other weight control measures such as diet pills or diuretic drugs. While the condition primarily affects adolescent females, approximately 10% of people with the diagnosis are male.[1] Anorexia nervosa, involving neurobiological, psychological, and sociological components[2], is a complex condition that can lead to death in the most severe cases. -* wiki

This one is just way too common, it's scary.

And no, anorexia is by no means good.

Comments and faves

abigol, cristina ortiz portillo, AmoryLuz ♥ Love&Light, Snapies ~ hiatus!, and 38 other people added this photo to their favorites.

isayx3 pro (38 months ago)
great shot..and thought provoking

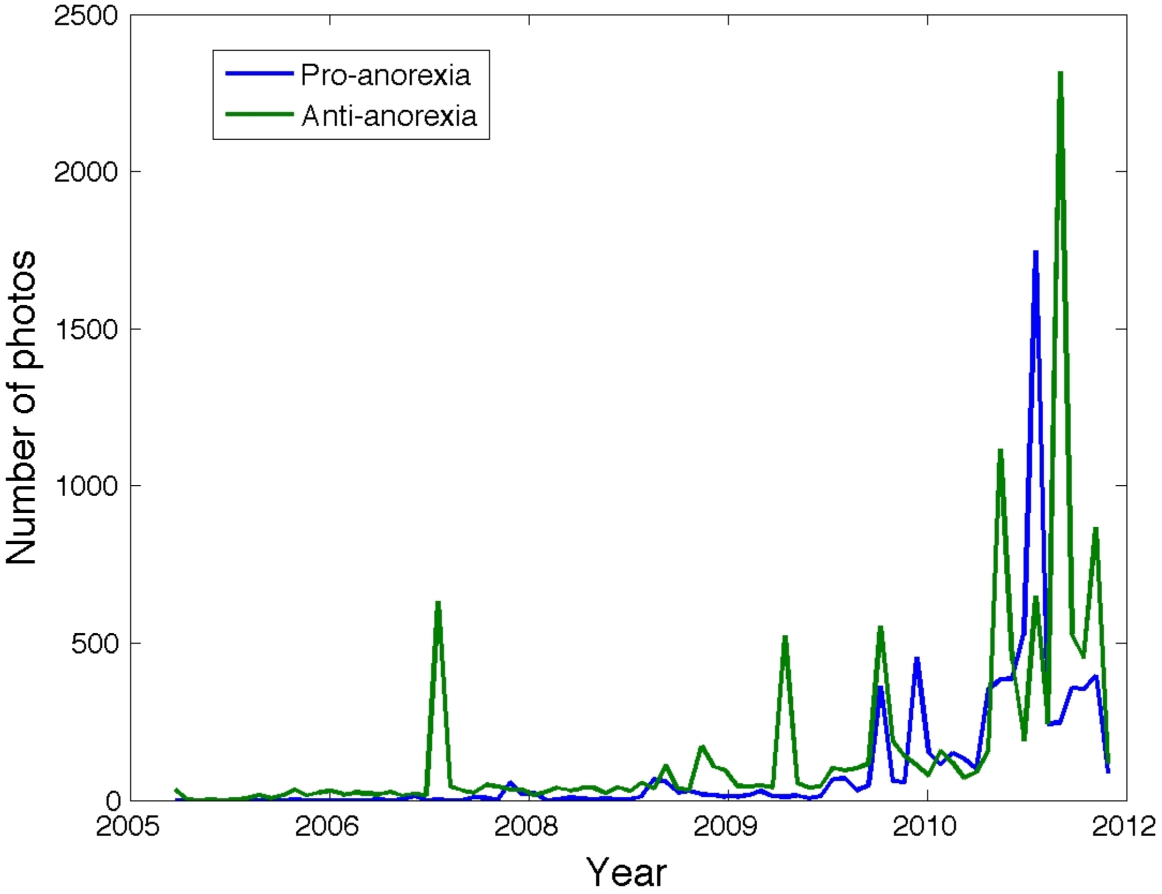
Results

Posting Volume

Figure 3 shows the number of highly relevant photographs per month, separated by class. As the figure shows, both types of content are similar in volume and have grown rapidly since 2009. The Spearman correlation between the two time series is 0.82 ($P < 10^{-5}$), demonstrating an extremely high correlation. In general, pro-recovery users are more active, posting a median of 196 photos, compared to 105 photographs by pro-anorexia users (statistically significant, ranksum, $P < 10^{-5}$).

We examined tags that identify the photo as pertaining to the photographer him or herself. These included the tags “self”, “self-portrait”, and “me”. Pro-anorexia users are responsible for 24% of photographs with these tags, which is a low proportion considering that 40% of the photographs are posted by these users. However, these tags appear in 42% of the highly relevant photos (where 40% of the photographs are posted by pro-anorexia users). Therefore, pro-recovery users generally tend to post more photographs of themselves. When dealing with anorexia-related issues, both pro-anorexia and pro-recovery users are similarly interested in their own images.

Figure 3. Number of highly relevant photos posted per month (not cumulative, just per month), divided by pro-ana and pro-recovery.



Most Indicative Tags

We computed the probability of using a tag by users from each class (pro-anorexia and pro-recovery) and found the tags for which the ratio of probabilities was highest in each of the classes. The tags with the highest probability for usage by pro-anorexia users, compared to pro-recovery users, were (in descending order of probability ratios): “thinspiration,” “doll,” “thinspo,” “skinny,” “thin,” “cigarette,” “sexy,” “landscape,” “legs,” “abstract,” “long,” “day,” “street,” “body,” “blonde,” “sister,” “nikon,” “up,” “life,” and “model.” For pro-recovery users, these words were: “home,” “sign,” “selfportrait,” “glass,” “cars,” “plants,” “building,” “mother,” “sunshine,” “bird,” “plant,” “autumn,” “garden,” “female,” “fence,” “dog,” “warm,” “architecture,” “stone,” and “birds.”

Therefore, the most important tags for pro-anorexia users refer to body image. Also of note is the use of the tag “cigarette”, which is frequently cited as a way to decrease hunger in the pro-anorexia community. Pro-recovery users have a more varied set of tags, for which we did not discover an underlying theme.

Inter- and Intra-Community Connectivity

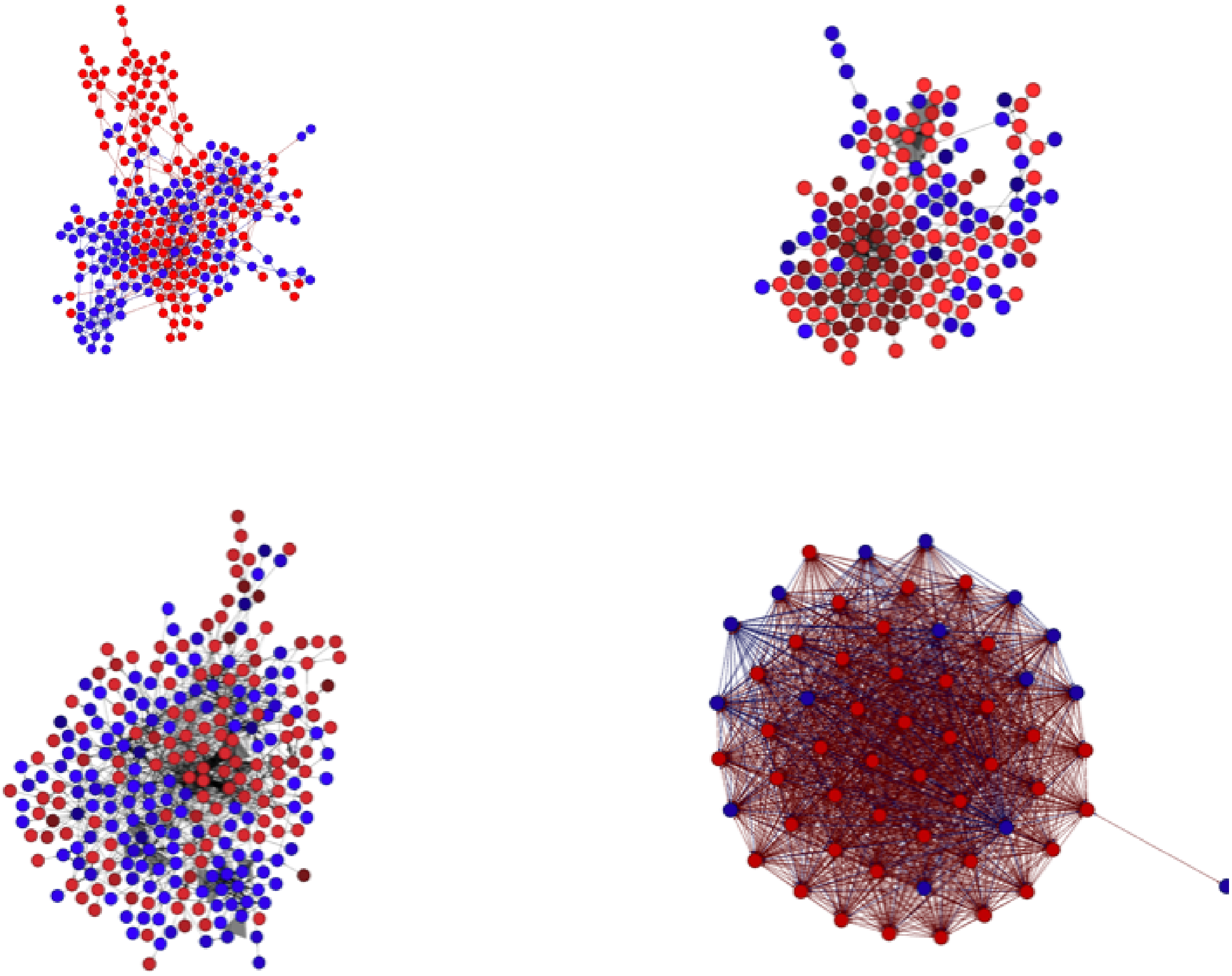
Contacts are more likely in the same class: 72% of contacts by pro-recovery users were to users of the same class, while 59% of the contacts by pro-anorexia users were to users of the same class ($P< 10^{-5}$, chi^{2}test). Similarly, comments are more likely in-class than between classes, with 83% of the comments by pro-recovery users and 74% of comments by pro-anorexia users being made to users of the same class ($P< 10^{-5}$, chi^{2}test).

Pro-recovery users are as likely to favorite a photo regardless of the posting users’ stance (56% vs. 44%), but pro-anorexia users are 8.4 times more likely to favorite a photo posted by a pro-anorexia user than by an pro-recovery user (89% vs. 11%, statistically significant at $P< 10^{-5}$, chi^{2}test).

We modeled the tags used by users to describe their photos using a vector-space model weighted by the Inverse Document Frequency (TF-IDF) [29] and measured the distance between photos using cosine similarity. The average similarity of tags between photographs made by pro-anorexia users was 0.259, between pro-recovery users 0.202, and between the tags of pro-anorexia and pro-recovery users 0.225 (differences significant at $P< 10^{-5}$, ranksum test). Therefore, the similarity between pro-recovery and pro-anorexia users is greater than within pro-recovery users. This is partly because pro-recovery users have a broader range of interests (as noted above), but also because pro-recovery users often use tags associated with the pro-anorexia camp: the tag “thinspiration” and its variations are used by 36.8% of pro-anorexia users and by 6.6% of the pro-recovery users. Even more striking is that the tag “pro-anorexia” (and its variations) are used by 1.7% of pro-anorexia users, but 2.4% of pro-recovery users. Overall, the Spearman correlation between tag frequencies in both communities is 0.67 ($P < 10^{-5}$).

Figure 4 shows the networks according to the four types of connections between users. Each node is a user. Blue represents a pro-recovery user, and red represents a pro-anorexia user. Only the main connected component is shown in each graph. For tags, we considered two users to be similar in their tags if the cosine distance between their tags was greater than 99%, so as to obtain a sparsity level similar to that of the three other networks. As evident from the graphs, the two classes are intermingled, but are most highly so when observing tags. In order to estimate the separation between classes according to the different networks, we labeled each user according to the difference between the numbers of his or her neighbors of each class. The predictive ability of each network was estimated by the area under the ROC curve [30]. The ROC using the comments or contacts was 0.74, whereas the area using favorites was 0.53 and 0.52 using the tags network. Thus, comments from people of a given class and the class of one's contacts are the best predictor of one's class.

Figure 4. Network graphs according to four connection types (from top left, clockwise): Contacts, Favorites, Tags, Comments.



Inter-Community Posting as an Intervention

In order to measure the correlation between attributes of social interaction with the cessation of posting pro-anorexia or pro-recovery photographs (while continuing to post other content on the site), we identified users who stopped posting relevant (either pro-recovery or pro-anorexia) content but continued to post other photographs. We defined posting cessation as stopping posting highly relevant pictures for 3 months or more, while continuing to post other pictures. This definition was used in order to ascertain that the user did not abandon the site (which could happen for several reasons) but continued to use the site for other purposes. In order to measure the effect of comments on cessation, we measured, for each image, whether it was followed by a posting cessation.

The cessation rates and the average days to cessation are shown in Table 1. As the table shows, comments by pro-anorexia users have the same effect on both types of users. However, comments by pro-recovery users decrease cessation in pro-anorexia users and increase it in pro-recovery users. This is also evident in the average days to cessation, which are higher for pro-anorexia users when comments are from the opposite camp, but converse for the pro-recovery camp.

Table 1. Rates of stopping posting highly relevant photos by pro-anorexia (PA) and pro-recovery (PR) users.

		Cessation rate		Average days to cessation	
		Commented by…		Commented by…	
		PA	PR	PA	PR
Posting user					
	PA	61%	46%	225	329
	PR	61%	71%	366	533

Another way to quantify these effects is through the use of a Cox hazard regression model [31]. For each of the classes, we built a separate model, where the attributes were the log-transformed list given in Tables 2 and 3, normalized to zero mean and unit variance. We computed these features at a resolution of 10 days and attempted to predict the hazard of posting a highly relevant image in the following days.

Table 2. Hazard model coefficients; all previous times.

	Class	
	Pro-anorexia	Pro-recovery
Number of highly relevant photos	-0.223[a]	0.013
Number of views	0.212[a]	-0.072[a]
Number of views of highly relevant photos	0.164[a]	0.023
Number of comments from same-class users	-0.057	0.057[a]
Number of comments from other-class users	-0.117[a]	-0.247[a]
Fraction of comments from same-class users	-0.268[a]	-0.027

[a]These numbers are statistically significant at *P*< .05.

Table 3. Hazard model coefficients; recent features (calculated using data from the preceding 30 days).

	Class	
	Pro-anorexia	Pro-recovery
Number of highly relevant photos	-0.022	-0.094[a]
Number of views	0.029	0.163[a]
Number of views of highly relevant photos	-0.007	0.199[a]
Number of comments from same-class users	-0.068[a]	0.024
Number of comments from other-class users	0.057[a]	-0.002
Fraction of comments from same-class users	0.061[a]	0.172[a]

[a]These numbers are statistically significant at *P*< .05.

The results of this model show that pro-anorexia users are encouraged to post additional photographs when many people view the photos they have posted and, in the short term, by comments of the pro-recovery group. Pro-recovery users are encouraged by viewings and by comments of their own group but discouraged by comments from pro-anorexia users.

Discussion

The manifestation on the web of anorexia nervosa content can be divided into pro-recovery content, supporting people trying to recover from the disease, and pro-anorexia content, which supports and even encourages people to continue their current behavior. In this paper, we have investigated these two communities and the interactions between them. These two communities interact by means of users changing from one community to the other and more generally by commenting on, following, and browsing the content from the antagonist community.

We found that comments and contacts are more likely in-community than between communities. Favorites by pro-recovery users are equally likely to be members of the two communities, but pro-anorexia users are 8.4 times more likely to favorite pro-anorexia photos. Taken together, these show two active communities of users, who mostly interact in their own community. The main divergence from this behavior is in marking favorite photographs. This is most likely because the receiving user can delete comments and contacts but not favorite markings. Therefore, it is likely that the figures for comments and contacts are following filtering by the receiving user.

Our results show that the two communities coexist separately according to the (moderated) comments and contacts, but interestingly, they are intermingled according to the tags and (unmoderated) favorite links. A possible explanation for this is that the pro-recovery group is trying to expose itself to pro-anorexia users through the use of similar tags, thus causing images posted by them to surface in search of the pro-anorexia users. The reason for this is that search for images is conducted by comparing the user's query with the tags as well as the textual description of the image. Furthermore, by marking as favorites pro-anorexia images, they may be causing the users who posted them to be exposed (indirectly) to pro-recovery content.

However, by modeling the likelihood of discontinuing posting photos, we found that an intervention of comment posting by pro-recovery users is counter-productive, causing pro-anorexia users to continue posting for longer and, if they cease posting, to do so later. Previous studies have found that pro-anorexia users perceive themselves as isolated in the physical world [32]. It may be that pro-recovery comments reinforce this feeling, entrenching users in their behavior.

Thus, pro-recovery users undertake two kinds of interventions. First, they expose pro-anorexia users who search for pro-anorexia content to pro-recovery content. Second, they post comments to pro-anorexia content. The latter, at least, is detrimental, as measured by the cessation of posting.

There are several unique aspects to our study, which is based on a social photo-sharing site, that need to be taken into account since they do not necessarily generalize to all pro-anorexia websites. Flickr is a general-purpose photo-sharing platform where users can easily create their own groups, and there are nearly no limitations on the interaction between different communities. In this context, pro-anorexia and pro-recovery communities have to co-exist on the platform and therefore interactions are likely to happen. Previous studies of pro-anorexia communities have been performed in online forums used exclusively by the pro-anorexia community [3-5,11-13,17,18]. Our study findings cannot be generalized to all types of pro-anorexia sites, but they are most likely to be similar within general social networks where pro-recovery and pro-anorexia users are more likely to interact.

In addition to the risks of pro-anorexia webs reviewed by Rouleau et al [14], we identified other risks inherent from the interaction of pro-anorexia and pro-recovery users. Individual pro-anorexia users have the possibility of influencing members of pro-recovery communities. As explained below, in this highly dynamic social network environment to fully understand the communities' interactions is of vital importance so as to reduce the influence of pro-anorexia users and content.

Clinical Relevance

The understanding of these communities is of key interest to public health officials aiming to prevent anorexia and minimize the impact of pro-anorexia content online. Our results show that the pro-anorexia and pro-recovery communities in Flickr have grown in their volume in a similar manner over time. Consequently, it is important to study the two communities and the interactions between them. That information can be extracted automatically as we did in this study in order to enact surveillance of the prevalence of the community online. As shown in this study, there are cases where pro-anorexia users actively try to persuade members of pro-recovery communities. Public health interventions on content-based social platforms, such as Flickr and YouTube, must be aware of the possibility that social network dynamics may undermine the effects of their intervention. Burton highlighted the importance of public health community mining for public health professionals [33]. In fact, to understand the dynamics of health communities, it is of vital importance to design online social methods for health promotion [34].

Automatic analysis of the pro-anorexia communities can be used to improve online interventions, such as warning messages that have been already piloted with promising results [11]. The suggested intervention by Lewis and Arbuthnott [17] to prevent access to pro-anorexia websites from the search results can benefit from our findings about the different tagging patterns used by the pro-anorexia community. An online intervention aimed at people affected by anorexia nervosa can be displayed when users are searching for pro-anorexia related terms. In addition, the network dynamics described in this paper can guide public health officials disseminating content in social networks at how to gain more visibility and reputation within the different online communities.

Our study provides deeper understanding of the online behavior of people affected by eating disorders. Clinicians should consider assessing the online activity of their patients to identify contributing factors, such as engagement in pro-anorexia communities, and provide guidelines about a safe use of the Internet since a simplistic approach based on banning Internet will limit access to trustworthy health information and to support from pro-recovery communities.

Similar approaches have been suggested in the area of online content related to self-injury [35,36]. Self-injury online content is currently starting to raise concerns due to its pernicious nature [8,35-38].

Limitations

Our study has several limitations: First, our study is limited to communities within Flickr (as discussed above). Second, while users identified by manual labeling are highly likely to be correctly assigned to their respective community (high precision), our collection method does not ensure high recall, ie, we are likely missing users who were not identified by our collection method. Third, as our data collection relied on public APIs, we have very little interaction data such as specific viewing behavior of users. Thus, for example, users who only browse content but never post any photo, comment, or favorite link will be missing from our data, as will the effect of such viewing on individual behavior. Finally, our data does not contain any clinical indication of users' actual state. This is especially evident in using posting cessation as a measure of engagement, where actual information on recovery or otherwise would have been of immense value. However, privacy concerns make it unlikely that such ground-truth labels can be obtained.

Future work will focus on identifying successful intervention strategies, tailored to the traits of specific users. We envision a system that will learn the particular characteristics of each user (for example, distinguishing between first-time viewers and active pro-anorexia content contributors) in order to apply one of a set of possible interventions, including warning labels, content blocking, reports to guardians (as in parental control software), or semi-automated comments to posting of pro-anorexia content. In addition, we will explore if our findings are applicable to other online communities based on a different type of content (eg, videos). We expect our results to be similar in other communities based on sharing multimedia content such as images and videos.

Conclusions

Our investigation of photo sharing behavior by the pro-anorexia community and the pro-recovery community has uncovered significant differences between the two. Better understanding of the pro-anorexia community can guide public health officials designing online interventions for people at risk of eating disorders or to mitigate the effects of such communities on individuals. In addition, our study is a first step towards the design of advanced filtering tools that will prevent pro-anorexia content from reaching vulnerable individuals.

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Authors' Contributions

All the authors were involved in the study design and the discussion of the results. EYT and IW led the data collection and analysis of the study. LFL provided the expertise within the domain of health social media and medical informatics. EYT and LFL led the manuscript drafting in collaboration with the rest of authors who have read and approved the final manuscript.

Conflicts of Interest

None declared.

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Original Paper

Applying Social Network Analysis to Understand the Knowledge Sharing Behaviour of Practitioners in a Clinical Online Discussion Forum

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Abstract

Background: Knowledge Translation (KT) plays a vital role in the modern health care community, facilitating the incorporation of new evidence into practice. Web 2.0 tools provide a useful mechanism for establishing an online KT environment in which health practitioners share their practice-related knowledge and experiences with an online community of practice. We have implemented a Web 2.0 based KT environment—an online discussion forum—for pediatric pain practitioners across seven different hospitals in Thailand. The online discussion forum enabled the pediatric pain practitioners to share and translate their experiential knowledge to help improve the management of pediatric pain in hospitals.

Objective: The goal of this research is to investigate the knowledge sharing dynamics of a community of practice through an online discussion forum. We evaluated the communication patterns of the community members using statistical and social network analysis methods in order to better understand how the online community engages to share experiential knowledge.

Methods: Statistical analyses and visualizations provide a broad overview of the communication patterns within the discussion forum. Social network analysis provides the tools to delve deeper into the social network, identifying the most active members of the community, reporting the overall health of the social network, isolating the potential core members of the social network, and exploring the inter-group relationships that exist across institutions and professions.

Results: The statistical analyses revealed a network dominated by a single institution and a single profession, and found a varied relationship between reading and posting content to the discussion forum. The social network analysis discovered a healthy network with strong communication patterns, while identifying which users are at the center of the community in terms of facilitating communication. The group-level analysis suggests that there is strong interprofessional and interregional communication, but a dearth of non-nurse participants has been identified as a shortcoming.

Conclusions: The results of the analysis suggest that the discussion forum is active and healthy, and that, though few, the interprofessional and interinstitutional ties are strong.

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KEYWORDS

Web 2.0; health knowledge; attitudes; practice; knowledge management; information dissemination; pain; pediatrics; pediatric hospitals; education; professional; electronic mail

Introduction

Objectives

The provision of quality patient care necessitates that health practitioners be informed about the best evidence concerning clinical diagnostic and therapeutic strategies, and more importantly be able to translate this knowledge into their clinical practices. Research has demonstrated, however, that vital medical research is often underutilized in clinical practices [1-3], resulting in suboptimal care. Studies have shown that 30-40% of patients do not receive treatment supported by evidence-based knowledge, and up to 25% receive unnecessary or potentially harmful care [4,5]. It is important, therefore, to develop innovative mechanisms that can help to effectively translate explicit knowledge into clinical practice to improve patient care.

Knowledge translation (KT) entails the implementation and enactment of knowledge dissemination strategies to effectuate the rapid uptake of new health knowledge into clinical practice [6]. Traditional KT strategies—including face-to-face sessions, workshops, oral presentations, and published media—have been successfully applied to translate new findings, methods, and policies into practice. Pursuing KT as a collaborative exercise can encourage peer-driven growth, an essential component of a community of practice [7]. A community of practice comprises a group of people that share a common interest but differ in knowledge and experience, and are interested in interacting with each other in order to share and advance their knowledge and the subject area. KT in a community of practice, therefore, can be perceived as the sharing of best evidence, contextualizing that evidence with personal experiences and observations, and operationalizing the evidence via practical situation-specific strategies and recommendations.

The emergence of Web 2.0 tools offer opportunities to pursue innovative approaches for health KT [8-10]. Web 2.0 tools, such as discussion forums, blogs, and mailing lists, provide an alternative to face-to-face knowledge dissemination activities by offering a virtual KT environment where community members from different geographical locations, different professional backgrounds, and different expertise levels can congregate and collaborate to disseminate explicit knowledge and influence practice change [7]. In practice, an online discussion forum engages participants in an asynchronous KT dialogue through which not only the intended explicit knowledge is disseminated, but also experiential knowledge - the professional experiences, insights, and observations of what worked and what did not work in specific clinical scenarios - can be shared in relation to this explicit knowledge. This contextualization of the explicit knowledge assists the KT exercise by allowing participants to see how the published knowledge can be applied to their clinical context. Notwithstanding the benefits of direct face-to-face KT strategies, Web 2.0 based KT methods can establish an active community of practitioners that interact with each other to share and translate knowledge into practice.

In this paper, we discuss a Web 2.0 KT environment targeting knowledge sharing within a community of practitioners interested in improving pediatric pain management. The Thai Pediatric Pain Discussion Forum was developed to facilitate knowledge sharing between an online community of practitioners around the topic of pediatric pain management [11]. This KT intervention was part of a broader global health project, conducted in collaboration with Canadian and Thai research teams, that aims to improve the awareness of pain in children and to reduce the knowledge gaps in pediatric pain management in 7 different hospitals in Thailand [11]. The objectives of the project were to elevate awareness of pediatric pain amongst health practitioners, standardize pediatric pain management across hospitals, share knowledge between practitioners to reduce knowledge gaps, and improve practices about pediatric pain management. The discussion forum was designed as a KT tool, intended to engage practitioners from different hospitals and professions to foster a pediatric pain community of practice.

The online discussion forum has been active for over 3 years and has provided a viable medium for pediatric care professionals to instigate a number of topic-specific discussions to share both their experiential knowledge and explicit knowledge resources (such as guidelines, research articles, presentations, etc) with the intent to collaboratively reduce the knowledge gaps that exist with regards to pediatric pain management. The knowledge sharing process generally proceeds as follows: (1) a practitioner seeks a solution or advice to a problem by presenting it to the discussion forum, (2) members of the community with interest and expertise related to the problem respond and moderate the discussion, (3) an online dialogue ensues in which practitioners highlight best evidence, shared experiences, and related theory to help address the question posed by a community member, (4) the knowledge shared in the discussion is disseminated via the discussion forum to the entire community of practitioners. An important aspect of the pediatric pain discussion forum is that the discussions – manifested as a series of messages on a specific subject, referred to as a “thread” – are archived and can be analyzed for both the knowledge content of the discussions and also for understanding the KT patterns between the community of practitioners.

To understand the dynamics of the knowledge sharing with the pediatric pain community, we investigated the following aspects of knowledge sharing:

1. What are the participation behaviors across different hospitals and different occupations? Are there dominant institutions or professions within the community?
2. What is the relationship between reading and posting within the forum? Are there members of the discussion forum that are active in one but not the other?
3. Who are the most active and most influential members of the community?
4. Can a central group of active members be identified and differentiated from the rest of the community?
5. Is there strong interaction between members from different occupations and/or different hospitals?

The first 2 questions were answered using statistical analysis and visualizations, while the last 3 were addressed using Social Network Analysis (SNA). We investigate the research questions above through our analytical tools and provide a quantitative measurement, in terms of social networks and communication patterns noted within the online community of practice. We conclude with a discussion on the utility of Web 2.0 tools for KT, particularly in the context of knowledge sharing within special interest online communities.

Background

The use of Internet to facilitate social interaction and KT is a well-studied area. Wellman and colleagues [12] surveyed a large number of Internet-based communities to investigate how the principles of online communities could be used in workplace interactions. They explored primitive communication tools such as email, list servers, and usenet groups to establish how these tools could improve communication by bridging physical boundaries. In a series of papers [13-16], Wellman and others extended this analysis to explore online communities as social networks and, using SNA, presented analytical methods to develop a better understanding of how people communicate in an online environment. Using SNA as a tool for understanding online communities forms the basis of our research project to observe and understand the communication patterns in the pediatric pain discussion forum.

The Web has become a choice medium for discussion forums and online communities around health. Eysenbach and colleagues [17] found 24,000 health-related discussion groups within Yahoo groups alone (in 2004). The authors attempted to review the efficacy of discussion forums as a medical intervention, but found a dearth of quality papers. They found 45 papers representing 38 studies, of which only 6 studied internet-based interventions as the primary focus of the project. One of the conclusions drawn by the authors was that there is no robust evidence that online communities impacted health outcomes, but that there are clear health benefits when seeking information from online communities. It was noted that as the number and size of virtual health communities increases, it is vital to understand the implications of these communities on health attitudes, knowledge, and outcomes. One of the objectives of our project is to outline how SNA can be used as a tool to understand online communities, so that their efficacy as an intervention may be more properly addressed.

Virtual communities succeed when there is an “intrinsic desire” to communicate and share health knowledge and experiences within the community [17]. This finding is confirmed in more recent experiences of using discussion forums to facilitate education and KT. For example, in a study where students in an anatomy class had 8% of their grade linked to their participation in a discussion forum, 83% of the students found the boards useful in improving their team building and critical analysis skills [18]. This finding was replicated by Kuhn et al [19] who found that a moderated pretest discussion forum as a tool for facilitating communication between nursing students significantly improved students' grades. Valaitis et al [20] designed a discussion forum to facilitate the establishment of a virtual community of practice for Community Health Nurses. For a dispersed community with a dearth of quality knowledge [20], a discussion forum provided a key KT tool for the participants, providing them with a way to connect to their peers. The authors noted that “the development of effective Communities of Practice is dependent upon the ability of individuals in the community to critically interpret, respond, and share information with colleagues” [20].

In contrast, when participation is neither required (via grades) nor requested by the community, it has been noted that participation tends to wane. In a study comparing online journal clubs to face-to-face journal clubs, researchers found a huge gap in participation rates, with lower participation in Internet journal clubs. [21]. Though the authors stated that journal clubs were mandatory, there was no punishment for not participating. With no explicit inducement to participate and no intrinsic desire from the residents, the discussion forum faltered. Therefore, we argue that it is important to not just provide another communication tool to practitioners, but to build a community of practice [22] within which people can communicate with their peers and share information such that the entire community benefits from the insights led by a few individuals.

Communities of practice [22] are defined as a group of people who share a concern or a passion for something they do, who interact regularly to learn how to improve. A community of practice has 3 dimensions: the domain, the community, and the practice [7]. The domain is the area of interest defined by the group. The community is the individuals with a common interest to learn from one another. These individuals do not have to work together on a daily basis, nor do they have to meet face-to-face. The defining quality of the community is that the individuals interact to learn from each other**.** The practice is what the community members are striving to improve, taking the knowledge they glean from the community and putting it to use in their everyday activities.

To establish a viable online community of practice, it is important to take a methodical approach for both the development and operation of the online KT environment. One such approach is presented by the Leveraging Internet for Knowledge Sharing (LINKS) model, which presents a conceptual framework to help establish online communities of practice for specialized knowledge sharing using Web 2.0 tools [10]. The LINKS model identifies the key determinants of an online knowledge sharing environment in order to systematically conceptualize and implement a purposeful health knowledge sharing environment for an online community of practice. The LINKS model characterizes healthcare knowledge sharing solutions at 3 interrelated levels: concepts, operations, and compliance. The conceptual level stratifies knowledge sharing into 3 dimensions: the knowledge modality, the knowledge sharing context, and the knowledge sharing medium. The operational level addresses technical infrastructure issues pertaining to establishing a culture of collaboration between the stakeholders. The compliance level addresses the underlying issue of perceived trust in the system. For this project, we used the LINKS model to guide the development and operation of the Pediatric Pain Discussion Forum. A more detailed explanation of the implementation process for the discussion forum is described in the original paper [11].

Methods

The objective of this project is to evaluate the communication patterns within an online community of practice. The archives of the discussion forum from April 2009 until June 2011 were used to evaluate the usage of the discussion forum and to study the communication patterns observed within the community.

Simple statistical summaries are used to provide a broad overview of the members and their participation in the social network. Visualizations of the communication patterns within the social network can provide insights into the participation behaviors of different hospitals and different professions (question 1), and the relationships between reading and posting on discussion threads (question 2). Because of the extremely non-normal distribution of posts and reads per person, Kruskal-Wallis tests were used to investigate whether people from specific institutions or specific occupations tend to post or read more. SNA was used to delve deeper into the underlying network structure of the discussion forum. Below we provide a detailed account of the SNA methods and results.

Social Network Analysis (SNA) builds on the principles of graph theory to study the relations between actors, and how they influence the overall network. SNA represents communication in terms of *nodes* (which represent actors/members), and *edges* (which represent communication ties) [23,24]. Whereas traditional statistical analysis focuses on actors and their personal attributes, SNA focuses on the relations between actors, and not the actors themselves.

Discussion forums can be represented as 2-mode networks, in which there are 2 classes of nodes, and the edges go from one class to another (see Figure 2 for the 2-mode and 1-mode networks). For this project the 2 classes of nodes are: (1) the discussion forum members, and (2) the threads they communicate on, and an edge indicates that a specific member has communicated on a specific thread. Representing the data as a 2-mode network allows the threads to be viewed as a KT event that community members participated in. Because many SNA methods are designed for 1-mode networks, a transformation of the 2-mode network is sometimes necessary. An undirected 1-mode network is created from the discussion forum members, in which a tie between 2 members indicates they have communicated on a thread, and the value of the tie is the number of threads they have both communicated on. Note that a 1-mode thread network could also be created, but that was not used for this project, as it did not provide any meaningful insight into the network.

Centrality measures can be used to identify the most active and influential members of the community (question 3). They can provide insight into the most important actors in the social network; those that are at the center of the network in terms of communication between individuals. 3 different centrality measures will be used: (1) degree centrality measures the number of ties an individual node has, (2) closeness centrality measures how quickly a single node can reach all other nodes, and (3) betweenness centrality deems a node central to the network if they are often used as a path between 2 other actors. All 3 measures are normalized to a (0,1) scale for simpler interpretation (see Wasserman [23] and Hanneman [24] for the technical calculations of these values, and Borgatti et al [25] for adaptations to 2-mode networks).

Finding a central group of community members (question 4) can be done using core-periphery analysis. Core-periphery analysis is a clustering algorithm that assumes that there is a core set of nodes at the center of the social network, and a periphery set of nodes that connect to that core [25,26]. It will be used to identify the members and threads that are at the center of the 1- and 2-mode networks. For the 1-mode member network, a measure of “coreness” can be calculated. Coreness is the measure of how central that member is to the network and can be thought of as another measure of centrality.

Finally, the interaction between different hospitals and professions (question 5) needs to be studied using group-level centrality measures [27]. For this analysis, group-level measures were calculated across both occupation and hospitals to explore the intergroup communication patterns. The same 3 individual level centralities can be calculated across groups: Group degree measures the number of connections from within a group to members outside it, group betweenness measures the proportion of shortest paths between 2 non-group members that pass through the group, and group closeness measures how close the group is to all other members in terms of direct ties and paths. The purpose of group-level analysis is to determine whether there are groups of members (either of a certain profession or from a certain institution) that are influencing the flow of information through the social network. The plots of reads and posts in Figure 4 demonstrate that nurses and members from Sringagrind hospital are the most active in terms of participation, but group-level measures will provide insight into whether these or other groups are facilitating more communication or are at the center of the community.

Results

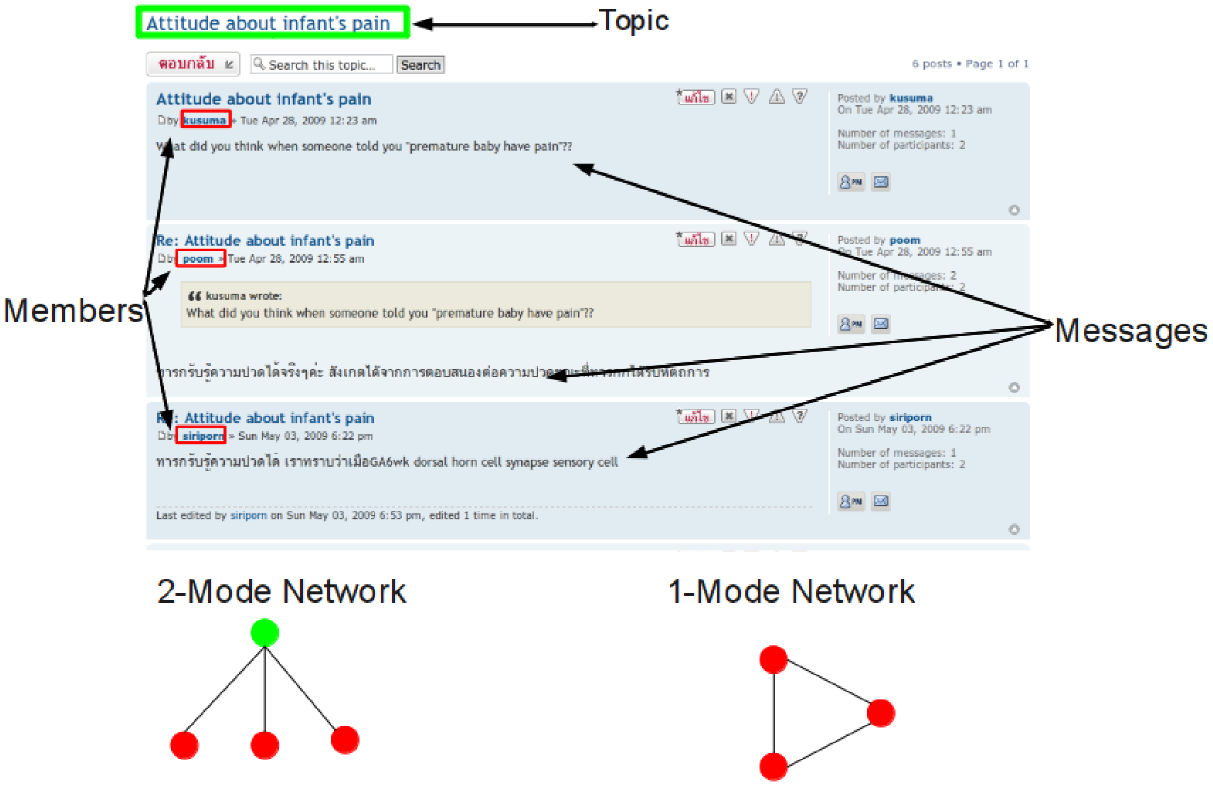
Data

The data for this project were extracted from the forum in June 2011, and represent the communications from the initiation of the discussion forum, April 1, 2009, up to June 30, 2011. The data were analyzed using the statnet library in R version 2.12.2 [28] and UCINET [29].

For every post on the discussion forum, the database records the member that made the post, the thread in which the post was made, and the time the post was made. The system also records the most recent time that a member has read a specific thread. Figure 1 contains an example of how the data is presented in the forum, and the origin for the information used in the study.

The discussion forum has 46 unique members, of whom 31 have posted at least once. There were 568 posts to the discussion forum on 115 threads, resulting in an average thread length of 4.94 (range of 1-25 posts per thread, median of 3). Of the 31 active posting members, 12 have posted to 10 or more threads, and 23 have read 10 or more threads. Figure 2 presents the 2 social networks being studied.

Figure 1. An example thread from the discussion forum, identifying how the threads are presented, where the data is extracted from, and how the 1- and 2-mode networks are created.



Attitude about infant's pain
by kusuma » Tue Apr 28, 2009 12:23 am
What did you think when someone told you "premature baby have pain"??

Posted by kusuma
On Tue Apr 28, 2009 12:23 am
Number of messages: 1
Number of participants: 2

Re: Attitude about infant's pain
by poom » Tue Apr 28, 2009 12:55 am

> kusuma wrote:
> What did you think when someone told you "premature baby have pain"??

ทารกรับรู้ความปวดได้จริงๆค่ะ สังเกตได้จากการตอบสนองต่อความปวด [illegible] ได้รับหัตถการ

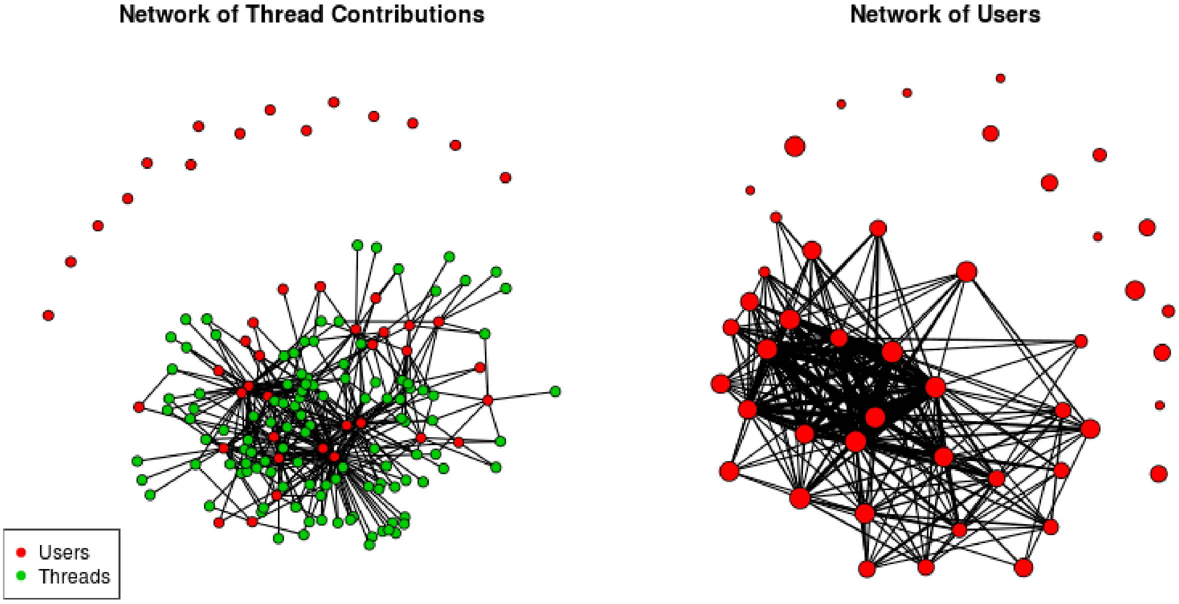
Posted by poom
On Tue Apr 28, 2009 12:55 am
Number of messages: 2
Number of participants: 2

Re: Attitude about infant's pain
by siriporn » Sun May 03, 2009 6:22 pm
ทารกรับรู้ความปวดได้ เราทราบว่าเมื่อGA6wk dorsal horn cell synapse sensory cell

Last edited by siriporn on Sun May 03, 2009 6:53 pm, edited 1 time in total.

Posted by siriporn
On Sun May 03, 2009 6:22 pm
Number of messages: 1
Number of participants: 2

Figure 2. Plots of the 2-mode network (left), and member network (right). For the member network the width of an edge is determined by the edge value, and the size of the member node represents the number of threads that the user has read.



There were 21 threads (18%) that did not receive a response in the discussion forum. These threads averaged 6.8 reads per thread (range of 2-12 reads, median of 7), with all receiving at least one and all but one receiving more than 3. Not all threads are expected to receive a response: many of them are conference or workshop announcements, or informing the community that a new resource has been added to the resource center. Without more insight into the content of the thread it is difficult to determine if the thread was left unanswered because the question was difficult, the community was uninterested, or it was simply an announcement. For a community to successfully form, it is imperative that questions be answered in a timely manner in order to encourage participation. With only 18% of the threads being isolates, and many of those being expected, the isolate rate on the forum is acceptable, but efforts should always be made to ensure that threads are responded to in a timely manner.

To get a better understanding of the persistence of a thread/topic—the duration over which the thread is relevant to the community—we used the timestamps of the messages that were posted to a thread (the software does not capture the read times in the system, therefore we cannot determine thread persistence based on it being read). Figure 3 presents the number of posts per thread and the number of hours between the first and last post to the thread. Note that the threads that did not receive a response are omitted from this graph (as they only have 1 timestamp, and thus have a duration of 0).

Table 1 shows some interesting characteristics of their discussion forum with regards to thread activity. For instance, 52 threads were active for a relatively long period spanning more than a week, whereas there were 10 threads that were active only for an hour but in this short time period the activity level (in terms of number of posts) was extremely high. We argue that such short-duration threads could have been practice-related questions that received a rapid response from a few active community members, whereas the more persistent threads could have been discussions that did not relate to critical patient care, resulting in a more drawn out and in-depth discussion. Without a content analysis it is difficult to investigate this phenomenon any further, but the thread durations do suggest a variety of knowledge sharing characteristics.

Figure 3. A plot detailing the number of posts and duration of threads as a function of time in the forum. The x-axis represents the date of the first post in the thread, the y-axis represents the time between the first and last post (note that the y-axis is in a log-scale). Each square represents a thread, and the size and colour of the square are defined by the number of posts in the thread.

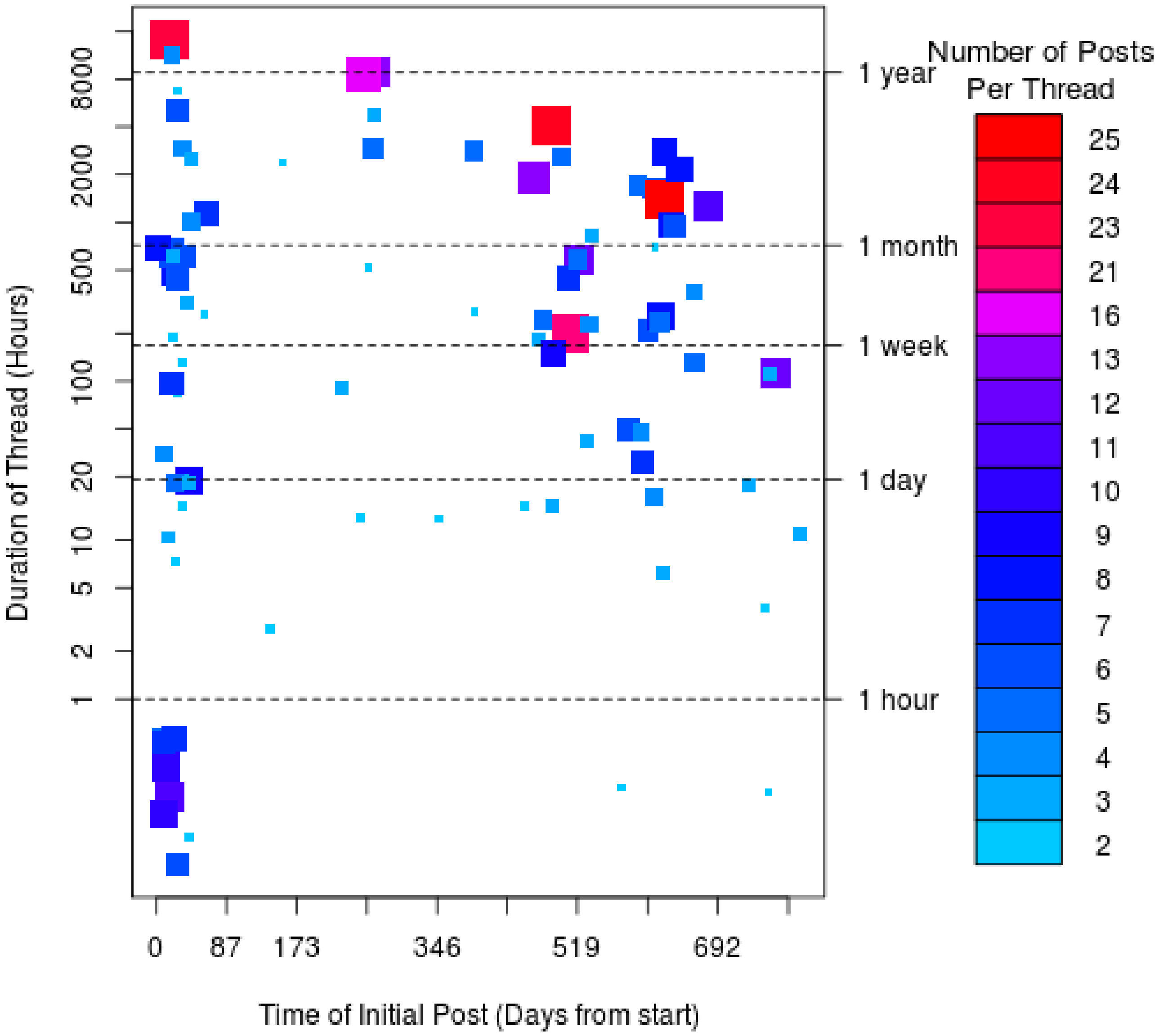


Table 1. The number of posts per thread for each of the thread duration categories.

	Number of threads	Mean number of posts	Min	First quartile	Median	Third quartile	Max
≤ 1 hour	10	6.2	2	2.75	6.5	9.25	11
≤ 1 day	18	3.1	2	2	3	3	9
≤ 1 week	14	4.9	2.	3	4	6.75	12
≤ 1 month	25	5.6	2	3	5	6	21
≤ 1 year	24	7.5	2	3.75	5.5	8	25
> 1 year	3	13.3	4	8.5	13	18	23

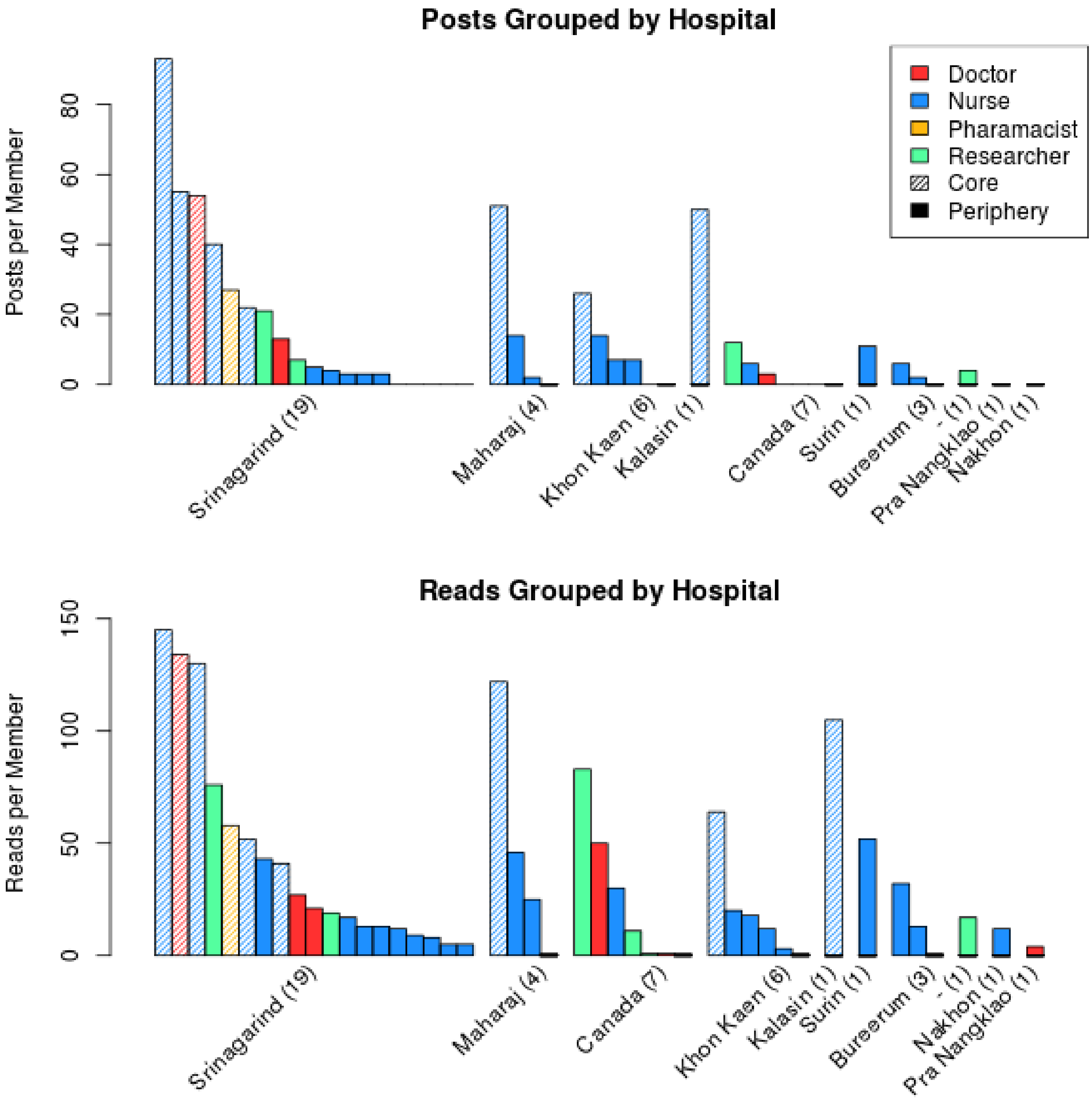
Understanding Participation Across Institutions and Occupations

In the first question we wanted to understand the participation behavior of community members belonging to different institutions, as this will inform us about the propensity for a knowledge sharing culture within the institution. Participation in the online discussions was measured based on reading and posting activities performed by each community member. Figure 4 presents the number of posts and reads from the discussion forum, stratified by institution, with the colour of the bar identifying the profession of the community member. The results show that the hospital in Srinagarind is by far the most active, accounting for 62% of the posts and 51% of the reads across the discussion forum. Though there are more community members from Srinagarind there is no evidence to suggest that members from Srinagarind are either posting or reading more individually. Kruskal-Wallis tests resulted in *P* values of 0.51 and 0.56, so there is no evidence to suggest that there is a difference in posting or reading rates per person across institutions.

Next, we analyzed the participation behaviors across different professions in order to understand the propensity for knowledge sharing and translation from an occupational standpoint. The colours of the bars in Figure 4 indicate the profession of each member. The Figure demonstrates that nurses are the most active professionals involved in the discussion forum–nurses accounted for 77% of the posts and 67% of the reads, with one doctor and one pharmacist significantly contributing to the discussion forum. A Kruskal-Wallis test was again performed to study whether there was a difference in posting or reading rates per person between occupations. *P* values of 0.54 and 0.73 for posting and reading respectively demonstrate that there is no evidence that people from different occupations post or consume content from the discussion forum at different rates.

Looking at the interaction of institution and occupation, we observe that the majority of the smaller hospitals only engaged nurses in the project: of the 5 doctors in the community, 3 are from Srinagarind and one is Canadian, so only one Thai doctor outside the major research center engaged in the community. As well, the only active pharmacist is from the most active hospital.

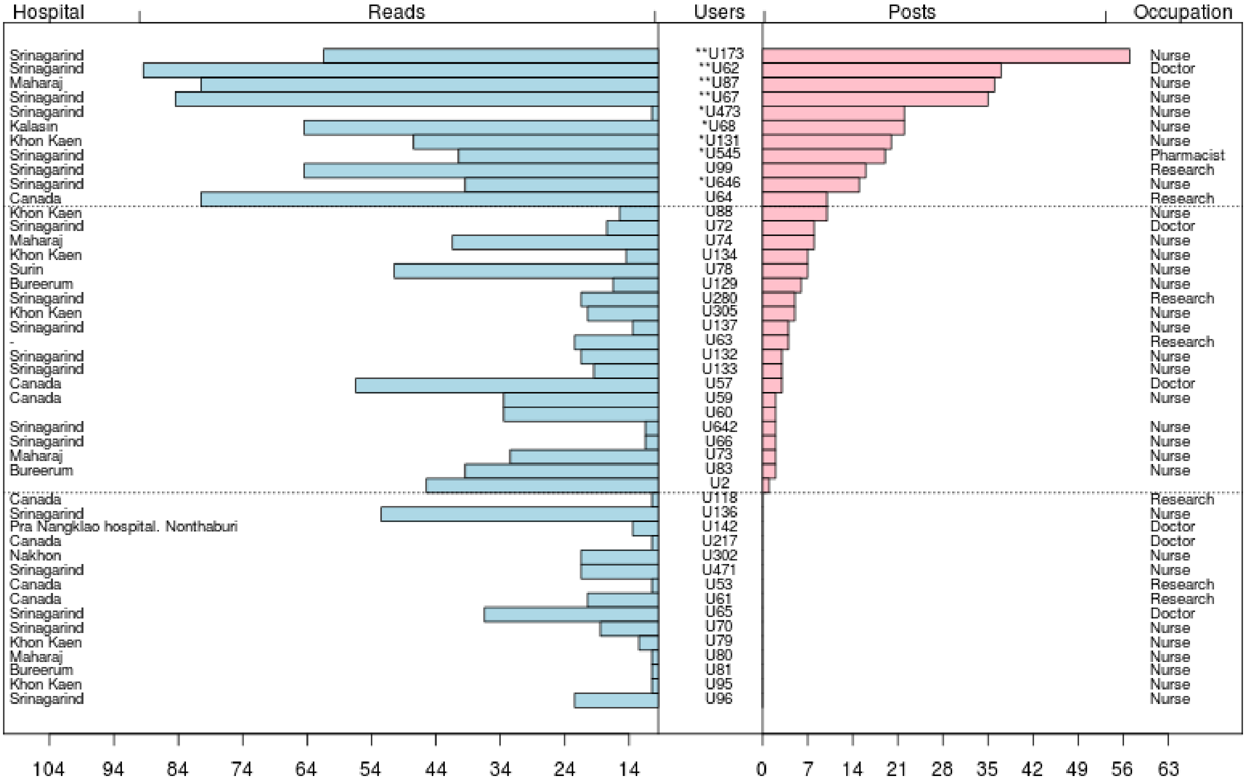
Figure 4. The number of posts and reads, grouped by hospital, with the number of community members in each group denoted within the brackets. Each bar within a hospital represents an individual member. The colour of the bar is an indication of their occupation and the shading on the bar indicates if they are a member of the core or not (see Table 6).



Comparison of Reading and Posting on the Discussion Forum

For KT purposes, it is important that practitioners engage with the online discussions even if it is to the extent of reading and then internalizing the experiential knowledge shared by other practitioners. Figure 5 presents the number of posts compared to the number of reads per member, ordered by number of posts. It was noted that those members who post a lot also read a lot, representing a potential group of “super-users” that are active in many threads within the community. The members in the middle section of the Figure have low posting numbers but high read numbers; these members were regarded as active in the discussion forum, with a tendency to contribute selectively but read a broad spectrum of topics. The final group are those members that have not posted but have read threads, and we have noted that there are several members that are participating in the network by reading threads but not contributing to them. This is not a negative outcome, as the intent of the discussion forum is to share knowledge across a community, so it was anticipated that some community members might not be in a position to contribute for various reasons.

Figure 5. Comparing reads and posts for individual members (note that the partitioning of the figure into 3 sections is done arbitrarily). For this figure, posting is not counted as reading, so the reads represent a member reading a thread and not commenting on it. Members with * by their name are from the 1-mode core (Table 6), and members with ** by their name are from the 2-mode core (Table 5).



Member and Network Centrality

Centrality measures can provide information about the activity levels of the individual members, along with the overall activity status of the social network. Based on the online discussion data, we developed two 2-mode social networks, one for posting and one for reading. We then calculated standard centrality measures to identify the most active (or central) community members. Closeness, betweenness, post degree, and coreness are all from the post network, while read degree is from the read network.

Table 2 lists the centrality measures for the discussion forum for each member, and Figure 6 presents the distribution and summary statistics (mean and standard deviation) for each of the measures.

Table 2. A sample of centrality for social network members, ordered by coreness.

User	Closeness[c]	Betweenness	Post degree	Read degree	Coreness[c]
U173[ab]	0.88235	0.17551	57	52	0.47111
U62[ab]	0.90909	0.1281	37	80	0.43945
U87[ab]	0.90909	0.13642	36	71	0.40202
U68[b]	0.73171	0.02931	22	55	0.30356
U67[ab]	0.88235	0.15055	35	75	0.29276
U473[b]	0.76923	0.05866	22	1	0.25582
U646[b]	0.73171	0.03615	15	30	0.20707
U545[b]	0.69767	0.01607	19	31	0.20382
U131[b]	0.75	0.05669	20	38	0.17414
U99	0.75	0.05245	16	55	0.16883
U64	0.71429	0.04947	10	71	0.08668
U88	0.68182	0.02582	10	6	0.07642
U280	0.6	0	5	12	0.06166
U134	0.66667	0.0203	7	5	0.05432
U305	0.56604	0	5	11	0.04753
U73	0.625	0.00123	2	23	0.04276
U78	0.68182	0.02474	7	41	0.04188
U74	0.6	0.01207	8	32	0.04162
U60	0.58824	0	2	24	0.04099
U66	0.6	0	2	2	0.03835
U83	0.58824	0	2	30	0.03577
U57	0.6	0.00477	3	47	0.03419
U63	0.58824	0.0012	4	13	0.02502
U132	0.6	0.00231	3	12	0.02448
U72	0.61224	0.01586	8	8	0.02405
U129	0.58824	0.00131	6	7	0.02199
U133	0.55556	0	3	10	0.01979
U2	0.57692	0	1	36	0.01928
U137	0.53571	0	4	4	0.01398
U642	0.52632	0	2	2	0.01176
U59	0.51724	0.00099	2	24	0.0105
U53		0	0	1	
U61		0	0	11	
U65		0	0	27	
U70		0	0	9	
U79		0	0	3	
U80		0	0	1	
U81		0	0	1	
U95		0	0	1	
U96		0	0	13	

User	Closeness[c]	Betweenness	Post degree	Read degree	Coreness[c]
U118		0	0	1	
U136		0	0	43	
U142		0	0	4	
U217		0	0	1	
U302		0	0	12	
U471		0	0	12	

[a] These users were members of the core of the 2-mode network

[b] These users were members of the core of the 1-mode network

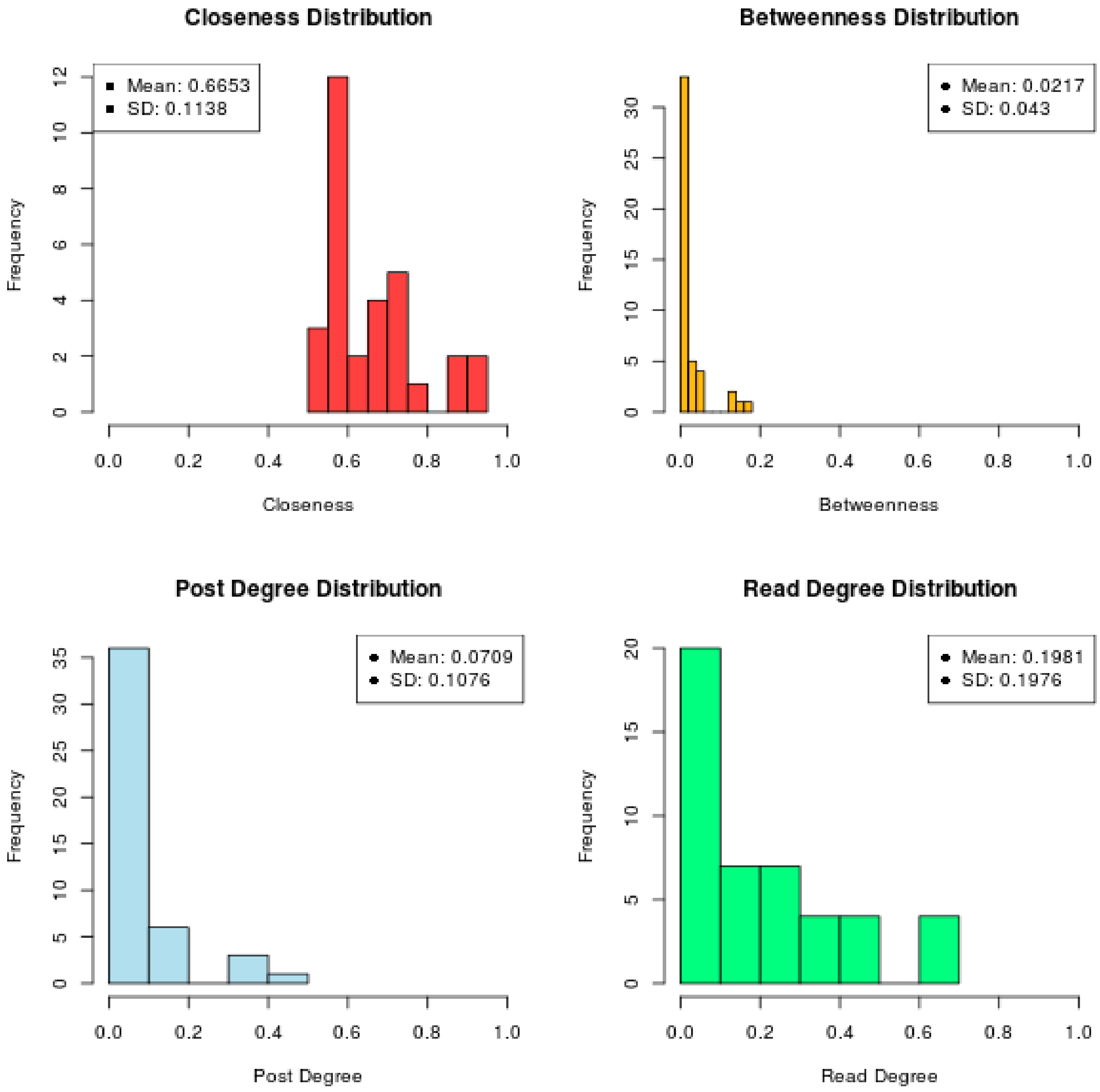
[c] Isolate actors had to be dropped for these metrics

The max normalized degree in the network is 0.496, indicating that one member has communicated on nearly 50% of the threads. Looking at the posting histogram in Figure 6, however, the majority of the post degrees are below 0.2 and the mean is .07, indicating that members are not all contributing to all the threads. This is a positive finding, as a social network in which a single member or set of members have very high degrees means that a single member or set of members is dominating the social network. The read distributions are also encouraging. A mean of 0.20 means that the average member is reading around 20% of the content on the discussion forum, which represents around 23 threads.

The closeness results are high, which is a positive finding, and an expected one in a network with high degree values. A max closeness of 0.91 indicates that there are 2 members who have communicated directly with 91% of the other members on a single thread. With a mean closeness of 0.665 and a minimum closeness of 0.517, there is strong evidence to suggest that the community is well connected, and members can quickly connect to all other members of the social network via their shared thread communications. The isolates in the network are not included in the closeness calculations, but their disconnectedness is an issue that needs to be addressed.

Finally, the betweenness measures are quite low, which is a positive result, particularly given the high degree values. A high betweenness value indicates that that member acts as a communication gateway for the social network, and with very low betweenness values (a mean of 0.02 and a max value of 0.175) there is little evidence to support the idea that there are members acting as information conduits for the social network. This means that members of the community have multiple avenues to connect to their peers, which encourages more communication and knowledge sharing opportunities.

Figure 6. The distribution and summary statistics for the centrality measures.



Identifying a Core Group of Users

Core-periphery analysis helps identify the community members that are at the center of the network in terms of posting. The analysis was performed on both the 1-mode and 2-mode networks to try and identify which members and threads are at the center or edges of the network. Core-Periphery analysis on the 1-mode network identifies those actors that have strong connections with many other members, while analysis on the 2-mode network identifies the most central threads, and the actors that are associated with them. Once again, the isolate actors are dropped from the 1-mode analysis as their coreness cannot be calculated.

Table 2 presents the coreness of the members in the 1-mode network along with membership in the core for the 1- and 2-mode networks. The histograms in Figure 4 demonstrate where the core members fall in terms of occupation and hospital, and Multimedia Appendices 1 and 2 presents the 1-mode and 2-mode networks as matrices with the core and periphery clearly identified. The image matrices (denoting the average tie density of each of the sections of the network) are available in Tables 3 and 4 for the 1- and 2-mode networks respectively.

For the 2-mode network, the core members communicate, on average, in 43% of the core threads, and 27% of the periphery threads. The periphery actors, meanwhile, contribute to only 8% of the core threads and 5% of the periphery. For the 1-mode network, the core actors share 8.6 threads, and 1.3 threads with the periphery actors, who only share 0.277 threads with each other.

Table 3. Communication densities stratified by the core-periphery structure in the 2-mode network.

2-Mode network	Core	Periphery
Core (4 members; 27 threads)	0.438	0.273
Periphery (27 members; 55 threads)	0.083	0.051

Table 4. Communication densities stratified by the core-periphery structure in the 1-mode network.

1-Mode network	Core	Periphery
Core (9 members)	8.593	1.308
Periphery (22 members)	1.308	0.277

These results confirm the findings from previous sections, about the presence of a core-group of “super-users” that seem to generate the bulk of the content within the community.

Calculating Group Centrality Indicators

The objective of the group centrality analysis is to explore the interactions between group members in order to determine how different types of professionals (such as nurses and doctors), or professionals from different institutions, interact as a community. The analysis is important to understand whether the online discussion forum managed to break the professional or institutional barriers that are typically prevalent in a healthcare system. We calculated group-level centrality indicators across both occupations and institutions, presented in Tables 7 and 8 respectively. Note that, since we are not considering read statistics in this analysis, we removed the disconnected members, as they would not contribute to the calculations of the group indices.

There are 215 ties in the 1-mode network representing ties between individual users, and the value of those ties represents the number of threads those 2 users have shared. The total value of the ties in the network is 674, with 431 (64%) being between different hospitals and 340 (50%) being between occupations. These values suggest that there is significant communication between occupations and between hospitals, but group centrality analysis can provide more insight into the relations. Tables 5 and 6 contain the communication counts between occupations and between hospitals respectively. The diagonal terms in these tables represents the intra-occupation communications, and the off-diagonal terms represent the interoccupational communications.

Table 5. The interoccupation communications.

	Doctor	Nurse	Pharmacist	Research
Doctor	4[a] (0.0229)[b]	149 (0.851)	7 (0.04)	15 (0.0857)
Nurse	149 (0.242)	316 (0.513)	54 (0.0877)	97 (0.157)
Pharmacist	7 (0.101)	54 (0.783)	0 (0)	8 (0.116)
Research	15 (0.122)	97 (0.789)	8 (0.065)	3 (0.0244)

[a] The number of messages sent

[b] The proportion of total messages sent by that group

Table 6. The interhospital communications.

	no recorded hospital	Bureerum	Canada	Kalasin	Khon Kaen	Maharaj	Srinagarind	Surin
no recorded hospital	0 (0)	1 (0.0769)	0 (0)	0 (0)	6 (0.462)	1 (0.0769)	4 (0.308)	1 (0.0769)
Bureerum	1 (0.04)	0 (0)	0 (0)	2 (0.08)	4 (0.16)	2 (0.08)	14 (0.56)	2 (0.08)
Canada	0 (0)	0 (0)	1 (0.0196)	2 (0.0392)	4 (0.0784)	8 (0.157)	34 (0.667)	2 (0.0392)
Kalasin	0 (0)	1 (0.0105)	2 (0.0211)	0 (0)	5 (0.0526)	13 (0.137)	73 (0.768)	1 (0.0105)
Khon Kaen	3 (0.0236)	3 (0.0236)	3 (0.0236)	2 (0.0157)	12 (0.0945)	18 (0.142)	81 (0.638)	5 (0.0394)
Maharaj	1 (0.0073)	2 (0.0146)	5 (0.0365)	2 (0.0146)	7 (0.0511)	3 (0.0219)	115 (0.839)	2 (0.0146)
Srinagarind	3 (0.0090)	10 (0.0301)	18 (0.0542)	9 (0.0271)	29 (0.0873)	26 (0.0783)	226 (0.681)	11 (0.0331)
Surin	1 (0.0667)	1 (0.0667)	1 (0.0667)	1 (0.0667)	3 (0.2)	1 (0.0667)	7 (0.467)	0 (0)

For the occupations, as would be expected from the histogram in Figure 4, the nurses seem to dominate the social network. As a group they are connected to the rest of the network by a single step (see the normalized closeness of 1), and there is a nurse on 60% of the shortest paths between 2 members (Table 7). Looking at the other professions, the doctors and researchers are well connected, and the doctors fall on a number of shortest paths (13%), which is a promising result. The high closeness and betweenness scores indicate that there is interaction between professions.

It is difficult to interpret a number of the hospital results, as several hospitals are underrepresented, but Srinagarind is by far the most influential hospital, being completely connected to the other members in one step, and having 58% of the shortest paths go through them (Table 8). Also of note is the hospital at Maharaj, which is very well connected despite having only 3 active members. Once again, the high degree and betweenness measures are strong indicators that there is communication between hospitals.

Table 7. Occupation centrality indicators.

Group	n	Degree	Normalized degree	Closeness	Normalized closeness	Betweenness	Normalized betweenness
Nurse	22	9	1	9	1	0.6073	0.5398
Research	5	22	0.8462	30	0.8667	0.0852	0.082
Doctor	3	26	0.9286	30	0.9333	0.1301	0.1255
Pharmacist	1	17	0.5667	43	0.6977	0.0227	0.0219

Table 8. Hospital centrality indicators.

Group	n	Degree	Normalized degree	Closeness	Normalized closeness	Betweenness	Normalized betweenness
Srinagarind	14	17	1	17	1	0.5823	0.548
Khon Kaen	4	18	0.6667	36	0.75	0.1182	0.1138
Canada	4	18	0.6667	36	0.75	0.0296	0.0285
Maharaj	3	26	0.9286	30	0.9333	0.1369	0.132
Bureerum	2	15	0.5172	43	0.6744	0.0023	0.0022
-	1	9	0.3	51	0.5882	0.0021	0.002
Kalasin	1	19	0.6333	41	0.7317	0.0375	0.0363
Surin	1	16	0.5333	44	0.6818	0.0266	0.0257

Discussion

This study investigated the dynamics of knowledge sharing through a Web 2.0 based medium - an online discussion forum - involving a specialized community of healthcare practitioners. Practice knowledge (also referred to as experiential knowledge) elicits peer-generated insights by health professionals about what worked, what did not work, and what to do in specific situations. There is a growing recognition that practice-related knowledge is a vital knowledge resource, supplementary to evidence-based resources, for health care practitioners who have to deal with complex and at times atypical clinical situations for which evidence-alone is at times not sufficient [30-32] Practice-related knowledge is not necessarily evidence-driven, yet it entails critical decisions, judgements, practices, and outcomes performed and observed by peer practitioners in specific clinical situations. We argue that both the experiential knowledge content and the associated mechanisms for its collection and translation to practice are of importance from a KT perspective. In this project, we examined the knowledge sharing dynamics in an online communication environment.

With the rapid adoption of social computing and mobile computing technologies, it is prudent to explore the application of new computing technologies to pursue new methodologies and methods for instituting KT programs. Web 2.0 based social interactions between like-minded practitioners offer new avenues for the creation and critique of experiential knowledge in an incremental and inclusive manner within a public space that is accessible to a wider audience where both the knowledge sharing medium and the inherent knowledge content serve as a KT resource. We believe that for KT, Web 2.0 based social computing technologies provide a ubiquitous and inclusive knowledge sharing method that can potentially overcome the geographical, temporal, social, and hierarchical barriers that challenge traditional KT methods [9,33,34] The efficacy of Web 2.0 tools for KT can be determined by analyzing the knowledge content being created and shared via an online discussion forum, whereas the effectiveness of Web 2.0 based KT programs can be gauged through the levels of user participation and knowledge sharing, which can be measured by analyzing the communication patterns between the online community of practice. In this project, we analyzed the communication dynamics of an online community of pediatric pain practitioners and our results not only explain the knowledge sharing patterns within the community of practice but can be generalized to serve as recommendations for developing a Web 2.0 based KT program.

In this study we posed 5 research questions to investigate the dynamics of knowledge sharing within a virtual community of practice. The objective of these research questions was 3 fold. First, to measure the participation rates of members belonging to different institutions and professions in order to understand whether certain institutions or professionals are more inclined to participate in online discussions. Second, to identify whether certain members have emerged as central figures to the various discussions, in order to identify and designate knowledge brokers/KT champions within individual institutions. Finally, to examine the degree of collaboration, in terms of knowledge sharing ties, which may have transpired across professionals from different institutions via the online discussion forum, since it allows geographically dispersed professionals to communicate and collaborate in a more ubiquitous manner. Our findings provide insights, leading to objectively derived recommendations, about the design of new models for KT, especially the use of Web 2.0 based collaboration technologies for KT across a virtual community of professionals.

We investigated the participation rates of the community members belonging to different professional groups and institutions. Based on both the post and read frequencies, it was noted that there is no difference between the participation rates of members belonging to different institutions, and that participation in the online discussions is driven more by an individual's engagement with the online community rather than the member belonging to a specific institution. This is an interesting observation as it delineates participation level from the institution, suggesting members are self-motivated to participate in knowledge sharing as opposed to being influenced by their institution. It is worth noting that although the discussion forum has more members associated with a large urban hospital at Srinagarind, this did not mean that individuals from Srinagarind are more likely to contribute to the forum.

With regards to professional groups, our analysis shows a predominance of nurses being engaged in the discussions, though it should be noted that the project did engage a relatively large group of nurses for membership to the discussion forum. What is interesting to note is the lack of participation from the physicians—only one physician significantly contributed to the discussion forum. It is important to factor the influence of external motivational strategies geared to engage members to the online discussions. In the Thai project, each institution was assigned a nurse facilitator (ie, a KT champion) who was responsible for routinely encouraging pediatric professionals in his/her institution to participate in the knowledge sharing activities, including the online discussion forum. Indeed, the energy, expertise and enthusiasm of the individual nurse facilitators had an influence in the overall participation rates of institutions and professional groups. We did observe that some nurse facilitators were more successful than others in promoting the online discussion forum and engaging professionals to participate in online discussions. In moving forward with Web 2.0 interventions, it is important to ensure that the facilitators are willing and capable of engaging all potential users of the community, including those from outside their profession.

As both the medium of Web 2.0 based discussion forums and the method for knowledge sharing are new to some practitioners, there may be apprehension towards the use and utility of online discussion forums. We propose that to institute a vibrant Web 2.0 based KT program, it is prudent to implement certain member engagement strategies. One method is to promote the specialized online discussion forum as a knowledge resource by demonstrating the value of sharing/using experiential knowledge derived from peer practitioners. Another is to pursue active engagement and support of the members, especially in the initial stages of the online KT environment, to ease them into using the online discussion forum with ease and trust. We found that designated KT champions can both engage members and facilitate online discussions, which in the long run helped to maintain high-levels of participation, contribution, and KT. In our study, we notice that once members are properly engaged there was no significant difference between the participation rates across the different professions.

Social network analysis of the communication patterns of the entire community determined that the network is fairly well connected. High closeness scores indicate that members can readily connect to each other, and low betweenness scores suggest that the network does not depend on a single member for relaying information through the network. These are promising communication patterns, as they indicate that the community is not overly dependent on a single member or set of members to share knowledge, and that even disconnected members can readily connect through mutual friends. The centrality measures highlighted the presence of a set of highly active community members with high centrality rankings across all measures, and core-periphery analysis identified the same members as central to the community.

We investigated the relationship between reading versus posting at the online discussion forum. Our analysis identified 3 groups of users: actives posters, selective posters, and non-posting consumers (or lurkers) as indicated by the 3 bands in Figure 5. These findings were confirmed by the core-periphery analysis, which identified a core group of 4 users and a secondary group of 5 other users that accounted for the bulk of traffic on the forum. . This finding is consistent with other research that has found evidence of a core group of users producing the bulk of the content within online communities. The exact size of the core creating the content in varies by application. Some studies have found the core to comprise upwards of 50% of the users [35-37], while other studies have found the numbers to be smaller [38]. Since large networks are expected to contain more lurkers [37], there would be an expected relationship between increasing the size of the network and decreasing the proportion of users in the core. This project identified 13% and 29% in the 2-mode and 1-mode cores respectively, confirming the findings in previous research. The coreness measures in Table 4 range from 0.47 to 0.01, demonstrating that the members that are at the very core of the network (ie, with the highest coreness ratings) are not fully connected to every other member of the network.

It is not a requirement that all community members contribute, and the presence of lurkers within discussion forums is well established [39], but encouraging participation is a key component of the KT process, and it is easier to connect knowledge sharers to knowledge seekers when the knowledge seekers make themselves known. A reasonable number of members were selective posters or lurkers, which from a KT perspective is acceptable, as these members are still participating in the KT exercise by receiving the shared knowledge and applying it to their clinical practices. It is prudent to harmonize the knowledge sharing levels of all members of the community, whereby lurkers are better encouraged and engaged so that they can contribute to the discussions they are reading. By engaging non-contributing knowledge seekers with the knowledge sharers, the ties within the community will strengthen, which in turn will instigate the emergence of discussion topics, validation of existing knowledge and improved flow of knowledge throughout the community. Tools should be developed to allow lurkers to connect with the users contributing knowledge, while active knowledge sharers need mechanisms to inform them when their contributions are used.

It is interesting to note that due to their own interest and activity certain members evolved as KT champions within the community without being explicitly engaged as such by the research team. This organic assumption of leadership and centrality roles, without an official designation or explicit responsibilities, is good for the sustainability of the KT program as it shows that members are engaged and are willing to facilitate the KT exercise because they see the value of the experiential knowledge being shared. From a KT perspective, we believe that it is these individuals who should be engaged as champions or knowledge brokers in future KT programs. Note that these central KT champions need not be experts in their fields, or even necessarily contributing valuable knowledge. Junior members that have a passion for KT and actively use the online discussion forum for knowledge seeking can engage other members of the community to contribute to the discussions, increasing the connectivity of all members within the community. Knowledge seeking activity plays a vital role within the community, as it instigates discussion and encourages communication between members.

Given that a Web 2.0 based discussion forum provides open access to all its members, we investigated whether the online community was exploiting this open communication medium to interact with practitioners from different institutions and professions. At the onset of the project there was a concern that nurses may not be comfortable communicating with physicians (and vice versa) as this was the case in face-to-face practice, but it was encouraging to observe strong interprofessional ties within the discussion forum. This confirms that in an online setting, where there is no face-to-face interaction, professionals felt more comfortable to interact with not just their peers but also with their seniors/juniors. Likewise, we note strong interinstitution ties between members, indicating that regional or institutional preferences were not a factor. From a KT perspective, this finding is particularly relevant as it suggests that an online communication medium is a more open and accessible KT medium for health practitioners, especially for those practitioners who perceive hierarchical and professional classifications as barriers to their knowledge seeking and sharing aspirations.

We would like to point out certain shortcomings of our research. We could not perform any content analysis of the actual online discussion because the discussions were in a foreign language. Our previous research [40] provided a method to process the content of online conversations and to link it to medical keywords. However, due to the language constraint we were unable to apply our method [40], which we believe could have provided a second 2-mode network, linking threads to keywords, thus allowing the analysis of the community in terms of their usage of salient keywords and concepts. In the future, we plan to pursue the translation of the content of the Thai discussion forum, either manually or using automated tools, processing the content of the discussion and then assigning a cloud of medical keywords (based on a medical terminology system, such as MeSH) to the threads.

There is a temporal nature to the data that was not explored in detail. Investigations into response times for new messages, temporal usage patterns for individuals and groups, the time over which an individual thread receives new posts, and the time after the last post that a message receives views are some examples of how time can be incorporated into the analyses. We believe that future investigations into such temporal methods may be able to provide more insights into how users are accessing the system, and in particular to evaluate the culture of collaboration within the LINKS model and how users are integrating the system into their daily work flow.

We believe that more complex SNA methods can be used to evaluate additional aspects of the discussion forum, particularly the use of Exponential Random Graph Models (ERGM) [41,42] can be used to test specific hypotheses about the social network, as well as to incorporate the member and thread attributes into the analysis. ERGM can answer specific hypothesis questions related to the structure of the network, and can connect those hypotheses to components of the LINKS model. In the future, the social network analysis could also be expanded by exploring direct ties within the 1-mode network. The current 1-mode network uses undirected ties to represent 2 users communicating on the same thread, which represents a kind of “friendship”. A directed implementation of the data changes the interpretation of a tie from representing friendship to representing direct communication. Directed networks would present the network in a different light, and would allow the use of other SNA methods, such as prestige centrality [23,24].

The LINKS model was designed as a way to facilitate KT using Web 2.0 tools, but it did not include an evaluation system for the model. This paper has demonstrated how SNA can be used as a tool to evaluate the performance of a discussion forum, but further research is needed. Future work should focus on how SNA methods can be used to directly evaluate the principles of the LINKS model. Once this is done, a set of pre-determined tests can be developed for evaluating systems as they evolve, providing a feedback mechanism for monitoring the health of Web 2.0 tools and ensuring that they are providing the best possible service to their members.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

The 1-mode network, partitioned into the core (top-left) and the periphery. The number in cell [i,j] indicates that those users have communicated on that many threads together. Note that this is a symmetric matrix as the number of messages between users [i,j] is the same as [j,i].

[PDF File (Adobe PDF File), 55KB - jmir_v14i6e170_app1.pdf]

Multimedia Appendix 2

This is the 2-mode network, partitioned into core (top-left) and periphery. A 1 indicates that a user (columns) communicated on a thread (rows).

[PDF File (Adobe PDF File), 56KB - jmir_v14i6e170_app2.pdf]

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Abbreviations

KT: Knowledge Translation
SNA: Social Network Analysis
LINKS: Leveraging Internet for Knowledge Sharing
ERGM: Exponential Random Graph Models

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Original Paper

Should Health Organizations Use Web 2.0 Media in Times of an Infectious Disease Crisis? An In-depth Qualitative Study of Citizens' Information Behavior During an EHEC Outbreak

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Abstract

Background: Web 2.0 media (eg, Facebook, Wikipedia) are considered very valuable for communicating with citizens in times of crisis. However, in the case of infectious disease outbreaks, their value has not been determined empirically. In order to be able to take full advantage of Web 2.0 media in such a situation, the link between these media, citizens' information behavior, and citizens' information needs has to be investigated.

Objective: The goal of our study was to assess citizens' Web 2.0 media use during an infectious disease outbreak and to determine which Web 2.0 medium is used for which goal. With this information, we wanted to formulate recommendations for health organizations that consider using Web 2.0 media as part of their communication strategy during an infectious disease outbreak.

Methods: A total of 18 student participants kept an information diary for 4 weeks during the 2011 enterohemorrhagic E. coli (EHEC) outbreak in Germany. Of them, 9 lived at the epicenter of the outbreak and 9 of them at some distance. The diaries were supplemented by a qualitative pre-survey (demographics) and postsurvey (questioning their satisfaction with information provision during the outbreak).

Results: The Internet appeared to be the most popular medium for passively receiving EHEC-related information, with news websites and websites of newspapers as the most consulted sources. Twitter was used for receiving information to a small degree, while Facebook played virtually no role. Participants indicated that they thought information posted on Twitter or Facebook was not reliable or was out of place. When actively seeking information, online newspapers and wikis were important sources. Several causes for (dis)satisfaction with information provision were uncovered: source credibility, contradicting messages, and a need for closure.

Conclusions: During an infectious disease outbreak, our small sample of students did not see social media (like Facebook and Twitter) as suitable or reliable sources for communicating information, but primarily viewed them as a tool for communicating with friends. Wikis, however, did fill several information needs, especially when citizens are actively searching for information. For many, source credibility is an important asset of information usefulness. Finally, we provide several general recommendations for communicating with citizens during an infectious disease outbreak.

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KEYWORDS

Disease Outbreaks; Foodborne Diseases; Health Communication; Information Dissemination; Information Seeking Behavior; Social networking

Introduction

Crisis situations drastically alter the context in which public health organizations communicate with citizens. The course of events in these situations is highly unpredictable, the stakes are high, citizens are aroused or stressed, and the media is eager for breaking news [1]. Public health organizations need to keep the public informed about the situation in general and should instruct individuals on how to act in times of a health crisis [2]. In the case of an infectious disease outbreak, it also of vital importance that citizens are persuaded to comply with health advice in order to minimize the spread of the infection. Following the definition of the World Health Organization, we see an infectious disease outbreak as a situation in which the occurrence of cases of disease is in excess of what would normally be expected in a defined community, geographical area, or season [3]. Research on risk communication has provided public health officials and communicators with a large set of guidelines for achieving these goals. For example, in the initial phase of an outbreak, one should inform the public about the risks involved in the simplest terms, while citizens should be taught to understand the risks they run themselves in the following, so-called, “crisis maintenance” phase [4].

One crucial aspect of communication during an infectious disease outbreak is selecting the communication channels that will have the highest degree of coverage and impact among the target populations and to tailor messages towards their context. By means of a large-scale telephone survey, Avery [5] uncovered that for American citizens, physicians are the preferred source of information due to their expertise and credibility, followed by television news broadcasts. During the A(H1N1) influenza outbreak in 2009, the three main sources of information for Malaysian citizens appeared to be the newspaper, television, and family members. Their main information needs were information on how to prevent and treat an infection [6]. In the Netherlands, this outbreak taught us that, in order to increase compliance with preventive measures and to gain trust, health organizations should constantly keep the public updated, especially about things that are uncertain [7]. The 2003 SARS outbreak showed that the Dutch obtained information mostly from television and newspapers [8], while a study in Finland indicated that very active media coverage triggers citizens’ interest and increases their knowledge [9].

The rise of Web 2.0 media (such as Facebook, Twitter, and Wikipedia) has offered new possibilities for communicating with and learning from citizens during an infectious disease outbreak. The latter, infodemiology, deals with automatically analyzing user behavior (eg, search behavior) or user-generated content (eg, tweets) in order to detect outbreaks and to inform health professionals [10]. Although the interest of researchers in infodemiology has exploded in recent years [11,12], studies uncovering citizens’ use of 2.0 media in order to fulfill their information needs during an infectious disease outbreak are lacking. However, social media did appear to be valuable in different crisis situations like disaster relief [13] and the uprisings across the Middle East and North Africa [14].

This study focuses on uncovering citizens’ information behavior in times of an infectious disease outbreak, with a special interest in the use of Web 2.0 technologies. We see information behavior as:

> *The totality of human behavior in relation to sources and channels of information, including both active and passive information seeking, and information use. Thus, it includes face-to-face communication with others, as well as the passive reception of information as in, for example, watching TV advertisements, without any intention to act on the information given. [15]*

This definition implies that information behavior is a very broad concept and includes a person’s rationale for using a specific communication channel or source, his or her usage of information and information search technologies, and a person’s evaluation of information. By applying this broad interpretation, we will able to understand exactly why and how a person makes use of information during an infectious disease outbreak.

At the time of our research, this topic of investigation had received no scholarly attention. Thus, we conducted a novel and explorative study and asked 18 persons to keep a diary during a large international EHEC outbreak in which they described what information they received about EHEC, with whom they talked about EHEC, and how they searched for an answer on questions they had about EHEC. The results we gathered allowed us to formulate recommendations for health communicators who are dealing with an infectious disease outbreak and who have to create a communication strategy in which they aim to use Web 2.0 technologies to their maximum potential. Our research question was: Do citizens use 2.0 media during an infectious disease outbreak for being kept up to date and to find answers to their questions, and if so, which 2.0 medium is used for which goal?

Case: the EHEC-Outbreak

The enterohemorrhagic E. coli (EHEC) bacterium is transmitted via the consumption of contaminated foods or by direct contact with patients. It can cause abdominal cramps, (bloody) diarrhea, fever, and vomiting. For most patients it is a self-limiting disease, but it is serious in some patients (mostly the elderly and young children). Infection can lead to the hemolytic-uremic syndrome (HUS) in 20% of reported cases. HUS shows acute kidney failure and is lethal in 3-5% of diagnosed cases. Worldwide, several large EHEC outbreaks have been reported, for example, the Japanese outbreak in 1996 with 6561 schoolchildren infected after eating lunch prepared with contaminated white radish sprouts [16].

In May 2011, a large EHEC outbreak started in Germany. By the end, 3816 patients were diagnosed with EHEC, of which 845 were with HUS; 40 patients died as a result of the infection

[17]. The peak of the outbreak was on 21st and 22nd of May 2011, and the outbreak ended in June 2011. The epicenter of the outbreak was in the northeastern region of Hamburg. Related cases were also diagnosed in France, Sweden, the United States of America, and the Netherlands [18]. In the Netherlands, bordering the epicenter region, only a few cases linked to the outbreak were registered (11 EHEC cases, of which 4 were HUS cases, and no deaths) [19]. In the end, the source of the outbreak turned out to be fenugreek sprouts [20] from a contaminated batch originating in 2009 from Egypt [21].

Media coverage of the EHEC outbreak was extensive. The vehicle of transmission was unknown for a long time, and speculations dominated the news reports. Furthermore, official public persons and organizations in Germany fed this speculation by giving warnings about the safety of certain types of food (eg, cucumbers, tomatoes, and lettuce), which they later had to retract as that turned out to be untrue. In the Netherlands, at a distance from the epicenter and with only low numbers of patients, it sufficed for the Public Health Institute to provide regular updates with the number of reported cases and with information that there was no risk involved in consuming any type of Dutch food.

An infectious diseases outbreak usually begins as a local incident. In the Netherlands, during a local outbreak, the task of communicating lies initially with the local health authorities. Based on the information at the Municipal Health Service, the Ministry of Health, Welfare and Sport needs to be informed. The Ministry decides, in consultation, when it is necessary to "scale" communication to the national level. When there is an imminent outbreak of an infectious disease, professionals communicate about the threat and the policies to prevent the outbreak. Their communication message focuses on the precautions taken and the resources the government has deployed to monitor the outbreak. Once the outbreak is a "fact", the emphasis shifts to communicating about the outbreak itself: how can a citizen recognize disease patterns and what can he or she do to prevent further spread of the disease. In Germany, local health offices send reports about (imminent) outbreaks to state ministries. These ministries then send the information to the Robert Koch Institute (RKI), which takes on the involved laboratory investigations. The German Federal Institute for Risk Assessment performs the outbreak investigation. The two latter parties both communicate with the public about their findings.

Method

Diary Study

In order to assess EHEC-related information behavior during the 2011 outbreak, we conducted a diary study with a running time of 4 weeks. The collection of diaries allowed us to gain in-depth insight into the information behavior of our participants and to determine whether one event could lead to another (eg, the television news leaving a person with a question who then looks for an answer on Wikipedia) [22]. We used two kinds of diary methods, each with a specific diary entry form (classification by Wheeler and Reis [23]):

1. An interval-contingent form. We asked participants to report their passive consumption of EHEC-related information (eg, seeing a report about the EHEC outbreak on the evening news). Furthermore, they had to report their conversations with other people about EHEC. This had to be done on a daily basis.
2. An event-contingent form. We asked participants to report their active information behavior when a question about EHEC arose and they actively searched for information.

The interval-contingent diary form can be found in Multimedia Appendix 1. It allowed the participants to describe any EHEC-related information they consumed via TV, radio, newspapers, the Internet, and elsewhere. There was also room to describe who they talked to about EHEC and what this conversation was about. The event-contingent diary was based on a diary form by Price and colleagues [24] and can be found in Multimedia Appendix 2. On this form, participants were requested to enter when the search took place, what question triggered it and how important it was for them, where they found an answer, and how satisfied they were with it. Both forms were converted into eForms.

Before participants could take part in the study, we asked them to complete a demographics questionnaire and an informed consent form. They were also ensured of their anonymity in this study. As diary study participants often find it difficult to expect what will be requested of them [22], we sent along an instruction booklet with the diary forms, including examples of completed forms. Next, we asked the respondents to update their interval-contingent diary form at the end of each day. They needed to complete an event-contingent form every time they conducted a search on EHEC-related information. Every week, we asked them to email us the forms with their entries, after which they started on a new form. After they submitted their final diary forms, they were asked to complete a questionnaire about their satisfaction with the information provision about EHEC, their preferred source for EHEC-related information in the previous 4 weeks, and their reasons for (not) using social media in order to receive EHEC-related information. The study lasted from June 10 to July 7, 2011.

Recruitment of Participants

Participants were recruited from two student populations: one from Hamburg (the outbreak epicenter in Germany), and one from Twente (a region in the Netherlands bordering the Hamburg region). We selected these regions to map the information behavior of those directly affected by the outbreak and people indirectly affected by it; Vartti et al [9] have shown that the proximity of the outbreak affects media coverage and citizen interest. Students were selected as participants for two reasons. First, they were "heavy users" of Web 2.0 technology and thus, could provide us with a thorough understanding of the potential of these technologies in times of an infectious disease outbreak. Second, it was extremely difficult to find participants during the outbreak period to take part in a longitudinal diary study. Recruitment of students using a financial incentive worked well in the required short time period. German participants were recruited via a convenience sample and Dutch participants via a study participant pool.

Initially, we recruited 20 participants (10 in Hamburg and 10 in Twente). After the completion of the demographics questionnaire, 2 participants (1 in Hamburg and 1 in Twente) decided not take part in the study. As the requested time and effort were large, participants received a payment of €50 on submission of a complete diary.

Analyses

All participants' entries on their diary forms and questionnaires were recorded in a Microsoft Excel database. The classification of closed questions (eg, senders of passively consumed information such as radio channels) was done deductively by two authors (LvV & JW), and any conflicts were resolved by means of a discussion. The analysis of open-ended questions on the diary forms was done via thematic analysis. If the body of data was small and coding reliability could not be assessed, data were interpreted by two authors (LvV & JW). Themes were assessed deductively, following guidelines by Braun and Clarke [25]. In order to code the content of each message that was consumed by the participants (a large body of data), a coding scheme was created deductively. Following guidelines by Pope, Ziebland, and Mays [26], we took the following steps:

1. One author (LvV) familiarized himself with the data and created a first coding scheme.
2. One author (LvV) then coded all messages using this coding scheme. Whenever a category needed to be altered or a new category needed to be added, he redid the coding of data from the start.
3. When all data were coded without needing to alter the coding scheme, one author (JW) coded a subset of the data (50 entries) with the coding schemes.
4. Disagreements were discussed, which led to alterations to the coding scheme. This coding scheme was finalized and can be found in Multimedia Appendix 3.
5. One author (LvV) recoded all entries using this final coding scheme and a second author (JW) independently recoded 100 entries. On this basis, Cohen's kappa was calculated at .73. According to Landis and Koch [27], this stands for substantial to almost perfect agreement.

Results

Demographics

The participants were studying a variety of subjects, including communication sciences, psychology, and mechanical engineering. Six of the German participants were studying health sciences. Table 1 displays the participants' demographics. It shows that about half had a newspaper subscription, which is in line with the Dutch [28] and the German [29] average. Television consumption was slightly below average for the Dutch participants [30], as well as for the German participants [31]. Radio consumption was slightly above average for the Dutch participants [30], but below average for the German participants [32]. Finally, Internet use was far above average for the Dutch participants [30] and above average for the German participants [32]. The use of Web 2.0 services, such as Facebook, Twitter, Hyves (a Dutch social network), and StudiVZ (a German social network), among both Dutch and German participants was very high, which is normal for the age group of our respondents [33,34]. As Table 2 shows, there is a high variation in Twitter use among our participants. Two German participants already subscribed to tweets from @EHEC_Watch, a feed about EHEC from the Helmholtz Centre for Infection Research. The other participants did not subscribe to Twitter feeds on health information.

Table 1. Participant demographics.

	Sex	Age	Newspaper subscription	Television consumption (hrs/day)	Radio consumption (hrs/day)	Internet use (hrs/day)	Which 2.0 media do you visit?	Which 2.0 media do you have an account with?
NL1[a]	M	19	Yes	0–1	1–4	1–4	Facebook / Twitter	Facebook / Twitter
NL2	F	22	No	2–4	4–8	1–4	Hyves / Facebook / Twitter	Hyves / Facebook / Twitter
NL3	F	21	Yes	0–1	0–1	4–8	Facebook / Twitter	Facebook / Twitter
NL4	F	19	No	0–1	4–8	4–8	Hyves / Facebook / Twitter	Hyves / Facebook / Twitter
NL5	F	21	No	1–2	4–8	4–8	Hyves / Twitter	Twitter
NL6	F	22	No	1–2	1–4	4–8	Hyves / Facebook / Twitter	Hyves / Facebook / Twitter
NL7	M	22	Yes	Never	1–4	4–8	Facebook / Twitter	Facebook / Twitter
NL8	F	22	Yes	Never	4–8	> 8	Facebook / Twitter	Facebook / Twitter
NL10	F	26	No	2–4	1–4	1–4	Twitter	Twitter
G1	F	25	No	2–4	0–1	1–4	Facebook / Twitter	Facebook / Twitter
G2	F	27	Yes	1–2	0–1	1–4	StudiVZ / Facebook / Twitter	StudiVZ / Facebook / Twitter
G4	F	21	No	1–2	0–1	4–8	StudiVZ / Facebook / Twitter	StudiVZ / Facebook / Twitter
G5	F	32	No	0–1	0–1	1–4	Facebook / Twitter	Facebook / Twitter
G6	F	28	Yes	0–1	0–1	1–4	Facebook	Facebook / Twitter
G7	M	22	Yes	2–4	0–1	1–4	Facebook / Twitter	Facebook / Twitter
G8	F	20	No	1–2	1–4	1–4	StudiVZ / Facebook / Twitter	StudiVZ / Facebook / Twitter
G9	F	28	No	1–2	0–1	1–4	Facebook	Facebook / Twitter
G10	F	24	Yes	1–2	0–1	1–4	StudiVZ / Facebook	StudiVZ / Facebook / Twitter

[a] NL = Dutch participants; G=German participants.

Table 2. Participants' Twitter activity (data gathered June 20, 2011).

	Tweets	Number of Twitter feeds followed	Number of followers	Health/EHEC related streams followed[a]
NL1	9,084	418	237	none
NL2	11	22	16	none
NL3	0	17	5	none
NL4	1,870	111	110	none
NL5	1	10	2	none
NL6	3	12	11	none
NL7	[protected]	7	1	[protected]
NL8	28	54	48	none
NL10	909	199	172	none
G1	1	17	4	none
G2	0	17	6	none
G4	0	7	2	none
G5	6	4	2	none
G6	4	3	3	none
G7	[protected]	9	1	[protected]
G8	4	9	4	@EHEC_Watch
G9	0	5	2	@EHEC_Watch
G10[b]	50	44	15	none

[a] Search among people followed on Health/EHEC/gezond/gesund.[b] Participant used someone else's account on Twitter; data are for holder of Twitter account.

At the start of the diary study, all of the participants had heard of the EHEC bacteria, but they found it difficult to remember where and when they first heard of it. Four German participants recalled first hearing of EHEC through the mass media (radio or TV) in May. Only one Dutch participant could answer this question (he first heard of it on June 1st, having read about it in the newspaper).

Passive Reception of Information

Passive reception of information deals with information that was passively consumed by the participants: no active searches preceded the consumption of information. Most reports of passive reception were made by the German participants at 146. The Dutch participants reported 93 instances of information consumption.

Figure 1 shows that Dutch participants mainly consumed EHEC-related information provided via the Internet, followed by information provided by radio and newspapers. During the 4 weeks of data collection, the number of messages consumed by the participants decreased, in line with the decreasing number of messages provided by the media as the outbreak decreased. A somewhat different picture emerged from the German respondents (see Figure 2). In line with the Dutch participants, the Internet was the source that provided most EHEC-related information. However, the German participants also received a lot of information via the TV. Radio and newspapers were least popular.

Next, we took a closer look at the actual online sources of information where the participants passively consumed EHEC-related information. As Table 3 shows, most information was stumbled upon on a news website. In particular, one popular Dutch news website (nu.nl) accounted for 23% of information passively consumed via the Internet. Interestingly, websites hosted by traditional media outlets were also very popular: websites of newspapers or newsmagazines accounted for 30% of the total passively consumed online information, followed by websites of TV channels or networks (16%). Facebook was a social medium that delivered virtually no information on EHEC to the participants (1%). Twitter, on the other hand, delivered 10% of the passively consumed online information. It needs to be said that 7 out of these 10 instances were Tweets sent by either a Twitter feed managed by a newspaper or a TV channel (for the other 3, the source could not be established). None of these tweets were sent by @EHEC_Watch.

Table 3. Internet sources that provided information passively (n=100).

Source	Percentage of total	Number of unique websites
News website	35%	8
Website newspaper / newsmagazine	30%	17
Website TV channel / TV network	16%	6
Website academic journal	3%	2
News website with discussion forum	2%	1
(Semi) Government website	2%	2
Website health insurance company	1%	1
Twitter	10%	
Facebook	1%	

After looking at the media and sources of passively consumed information, we analyzed the content of these messages. The Dutch participants reported 129 messages, the German participants 235 messages. Tables 4 and 5 display the message subjects that were transmitted most, divided over the media that facilitated the transmissions. The following themes were reported most (terms in brackets refer to column headings in Tables 4 and 5):

1. Presence EHEC bacteria (Presence). Messages about the (proven or not proven) prevalence of the EHEC bacteria in a country, on a product (group), on a company, or in a river, or messages about the starting point of the EHEC outbreak
2. Preventive measures (Preventive). Messages about preventive measures that are being taken to prevent the spread of, or infection with the EHEC bacteria, including messages about the (un)safety of a specific product group
3. Number of deaths (Deaths). Messages about the number of deaths as a result of the EHEC outbreak
4. Number of infections (Infections). Messages about the number of infections as a result of the EHEC outbreak
5. Geographical spread (Spread). Messages about a specific area where the EHEC bacteria has been encountered or could be present for the first time, where people have become ill for the first time, or have died for the first time as a result of the EHEC bacteria
6. Pathogenesis of EHEC (Pathogenesis). Messages about the way the EHEC bacteria spreads or infects a human being
7. Economic consequences (Economy). Messages about the economic consequences of the EHEC outbreak for private citizens, entrepreneurs, or the economy in general, and the actions that governments take in order to minimize these consequences

Table 4. Origin and content of messages consumed by Dutch participants (total number of codings = 129).

	Presence	Preventive	Deaths	Infections	Spread	Pathogenesis	Economy
TV	6	1	0	1	3	0	0
Radio	9	5	2	3	4	0	2
Newspaper	6	6	10	3	3	2	7
Internet	14	5	7	3	2	1	6
Total	35	18	19	10	12	4	15
(% of total codings)	(27.13%)	(13.95%)	(14.73%)	(7.75%)	(9.30%)	(3.10%)	(11.63%)

Table 5. Origin and content of messages consumed by German participants (total number of codings = 235).

	Presence	Preventive	Deaths	Infections	Spread	Pathogenesis	Economy
TV	14	10	4	7	5	5	4
Radio	9	6	2	3	1	3	2
Newspaper	6	5	2	4	1	3	2
Internet	22	17	10	13	6	10	4
Total	52	40	19	27	13	22	12
(% of total codings)	(22.13%)	(17.02%)	(8.09%)	(11.49%)	(5.53%)	(9.36%)	(5.11%)

In the Dutch context, most messages focused on the presence of the EHEC bacteria on a product, followed by messages about the number of EHEC-related deaths and preventive measures that were taken by the government or could be taken on an individual level. In Germany, more attention was focused on the preventive measures and the pathogenesis of the EHEC bacteria. Messages on the number of deaths, economic consequences of the outbreak, and its geographical spread were not broadcast as often.

Figure 1. EHEC-related Information consumption by Dutch participants.

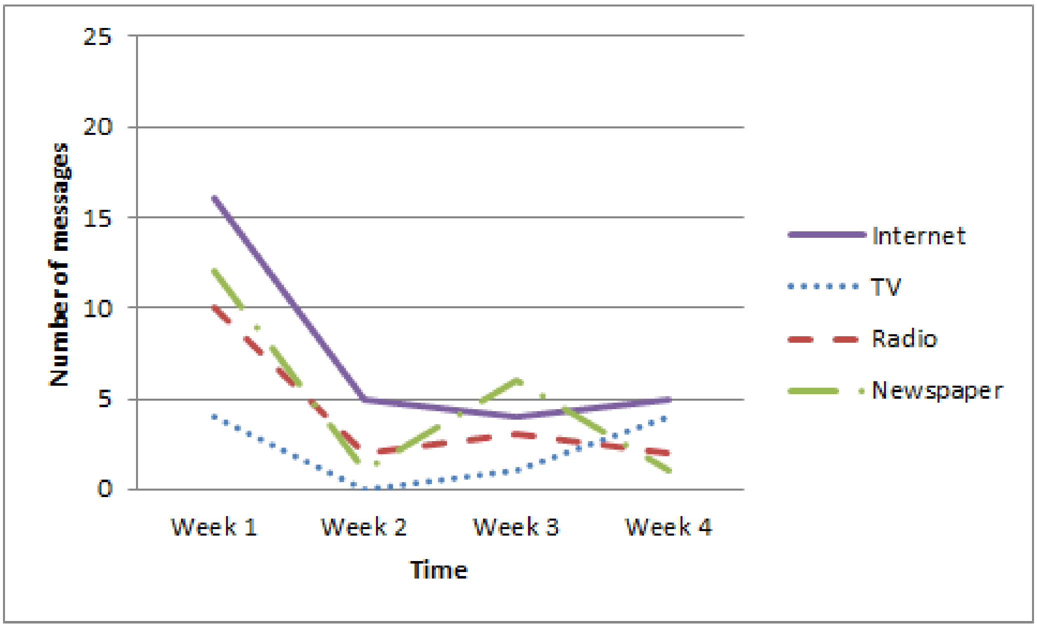
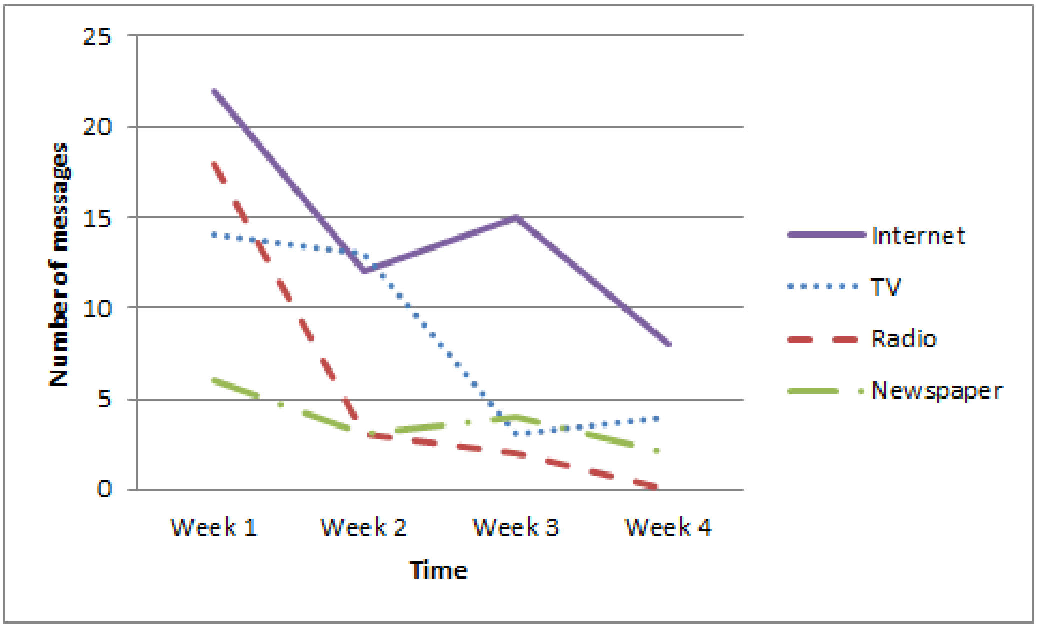


Figure 2. EHEC-related Information consumption by German participants.



Conversations About EHEC

Our participants held 39 conversations; 13 of these conversations were reported by Dutch participants, 26 by German participants. Most conversations were held with friends (19), followed by conversations with family members and colleagues.

The conversations held by the Dutch participants covered a wide range of topics. However, one topic was discussed most: dietary choices. Several participants talked with other people about whether or not they should consume certain types of food.

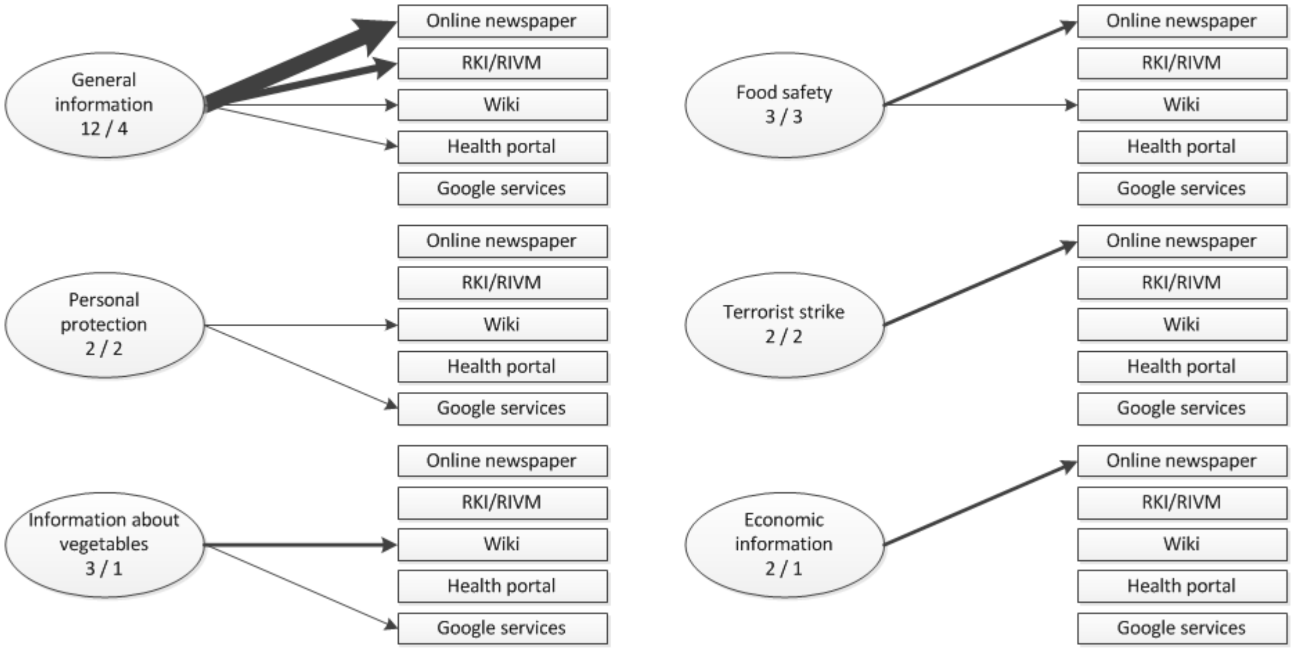
> *With a friend I talked about eating "possibly infected food". We were eating and also ate cucumber. Nonetheless, everybody dared to eat it, as we know that chances of infection are just very small.* [NL5]

Among the German participants, three topics were discussed most. First, they discussed dietary choices. Second and related, they talked about the products on which the EHEC bacteria were found. Third, they talked about the reliability of the media coverage of the outbreak and discussed their critique of it.

Active Information Seeking

In total, the participants reported 24 searches for EHEC-related information on their event-contingent forms: 7 by Dutch participants and 17 by German participants. All of these searches were conducted over the Internet, mostly with Google as a starting point. Figure 3 gives an overview of the information the participants sought and where they found it. We could discern 6 types of information that participants needed.

Figure 3. Searches for EHEC information: topic and information source.



Note. Left number below topic = number of searches; right number below topic = number of unique participants who conducted a search on this topic.

General Information

Several participants felt a need to search for general information on EHEC: “How can one be infected with EHEC?” (G1), or “What is the current situation on EHEC like?” (G8). Several German participants wanted to know more about the current situation on EHEC, after not having heard about it in the mass media for a few days. All but one search was concluded successfully. Most participants thought their question was very important and found an answer in an article published by an online newspaper. Some German participants also used the website of the RKI to get informed. All searches were concluded with a satisfactory or very satisfactory result.

Food Safety

Three participants wondered at some point in time whether a certain type of vegetable was infected with the EHEC bacteria. These searches differed in importance to the participants and were all concluded to a satisfactory level by looking up information on online newspapers or a wiki.

Personal Protection

Two persons had a question about personal protection, which they believed important. One person (NL3) had a general question: “How can I protect myself against EHEC?”, while the other person (NL8) wanted to know whether a town in which EHEC was diagnosed was nearby the residence of her parents.

Terrorist Strike

Two German participants wondered whether the EHEC outbreak was the result of a terrorist strike. This information was very important to them, and they both found an answer to their question in an online newspaper with which they were satisfied or neutrally satisfied.

Information About Vegetables

One participant (NL8) wanted more information about vegetables, like “I wanted more general information about bean sprouts because I don’t really know what it looks like.” To her this information was (very) important. She found her information on Wikipedia or Google images. She was either satisfied or neutrally satisfied with the information she found.

Economic Information

One participant (G1) sought information about the economic consequences of the EHEC outbreak. These matters were very important to her. She found a very satisfactory answer to her questions in online newspapers.

A topic that was brought forth by some participants on their diary entries was source credibility. Several participants indicated that they valued a trustworthy source for information on this particular topic. One participant said:

> *I know the Robert Koch Institute, but there are many people who don’t know this serious source and rather use Bild [a German tabloid newspaper focused on*

> *sensational news] to get informed. I don’t think this newspaper is a suitable source to get informed about EHEC!* [G6]

Apparently, not all participants valued source credibility that much. One participant (NL3) who searched for information on “How to protect myself against EHEC?” (see above) found information on a Dutch wiki-like website. The writer of this information was an amateur who had also written articles on the website with the titles “How to find a good restaurant” and “How to save energy with glass wool”. Nonetheless, participant NL3 was highly satisfied with the information provided by this amateur.

Finally, we expected there to be some interaction between passive information consumption and actively searching for information. For example, two friends discussing the safety of cucumbers could have led to a Google search about the vegetable’s safety. However, our data did not uncover such patterns. This suggests that during an infectious disease outbreak, active information searches are relatively small, personal activities.

Satisfaction With Information Provision

The Dutch participants were reasonably satisfied about the information provision on the EHEC outbreak. They appreciated the high frequency of information updates and the honest manner in which information was communicated. However, they noted a lack of information from local or national government organizations but did not really mind as the risks associated with the outbreak were small in the Netherlands. The greatest source of dissatisfaction for the Dutch participants were the warnings on the safety of vegetables. Often, these were given for vegetables that turned out to be perfectly safe. This resulted in uncertainty about what to do.

> *I understand that they are eager to show to people that they are working hard at it, and that they have probably found a source, but I’d rather that they’d wait with strong statements until they are sure. Now producers of tomatoes and cucumbers have high damages because, in the beginning, they were suspected of being the source. If researchers don’t know, then they should just say so and should not cause confusion or panic by hastily drawing conclusions.* [NL5]

The Dutch participants were unanimous about information they lacked most: information about the conclusion of the outbreak. In their eyes, the media coverage of the outbreak silently came to an end and they asked for the media to inform the public of the end of the outbreak and a final verdict of its source. The preferred information source during the EHEC outbreak was the Internet for Dutch participants, and especially one news website (nu.nl).

For the German participants, being satisfied or not seemed to hinge on two issues: (1) was it made clear or not to the participant what the source of the outbreak was, and (2) did they find a single, credible source that provided all information in a well-written manner? Other sources of satisfaction were the warnings they received for different kinds of vegetables, while others appreciated the high frequency of information updates. In line with the Dutch participants, the German participants were also not happy with the constantly changing warnings about the safety of different types of food. They also disliked the alarming tone of the media and the different government organizations blaming each other for the long time it took to find the source of the outbreak. Among the German participants, the preferred sources were diverse: the television news, a German news channel (NTV), the radio, and finally, several websites like Yahoo! news, the RKI website, and the Spiegel newspaper website. Interestingly, several participants stated their preference to check EHEC-related news on mobile devices, using apps provided by news media.

Use of Social Media

None of the Dutch participants used Twitter as an information source, either because they did not use Twitter (for receiving this kind of information), or they thought it was not a reliable source. Several German participants did use Twitter for receiving information, via the Twitter feed of online news sites, TV news channels, or the dedicated Twitter feed @EHEC_Watch. The German participants who did not use Twitter thought Twitter was not reliable enough or was not a suitable medium for this kind of news. The Dutch participants also did not use Facebook or Hyves to get informed about EHEC. They thought these social networks were meant for communicating with friends only and thought information provided here was unreliable. The German participants had similar reasons for not using Facebook or StudiVZ: they thought information on social networks was unreliable or wanted to use them only for communicating with friends.

Discussion

Crisis communication literature suggests that Web 2.0 technologies can be valuable instruments for organizations for informing the public and keeping them involved [35], and the uprisings across the Middle East and North Africa have suggested the same. Our results indicate, however, that social media (like Facebook and Twitter) are not seen as suitable or reliable sources for communicating information during an infectious disease outbreak. These media are primarily viewed as a tool for communicating with friends. Health organizations presenting themselves on such forums to their public to inform them about an outbreak would be viewed “out of place”. And for many people, health-related information communicated via Facebook or Twitter would render it unreliable outright. Despite these strong negative feelings, several participants did use Twitter for keeping up to date with the latest news on the outbreak. The senders of these tweets, however, were primarily traditional media outlets like newspapers or a dedicated Twitter news feed from an expert source. This suggests that for a certain group of people, Twitter is a suitable source for being updated during an infectious disease outbreak, but only if the source’s credibility is spotless. One 2.0 service that was used more often were wikis. When people were actively searching for information, they used these collaborative efforts. Apparently, people view wikis as extensive and useful information sources, and source credibility does not play an important role here. We find this remarkable, as often these wikis are written by amateur writers who lack the necessary expertise. There may be work here for health organizations to keep an eye on, and if necessary, contribute to wikis during an infectious disease outbreak (eg, pages about the pathogen or disease carriers).

An item that we have already discussed but that affects more media than social media alone is source credibility. Most people attached great importance to receiving reliable information from a credible source. As other studies have already pointed out, quality seals can enhance the credibility of information [36] or can increase compliance with health advice [37]. We think that the use of these seals should be increased, but this presents problems for many websites that publish user-generated content, like wikis, as their content is constantly changing. The development of automated information quality evaluation tools [38], which use marker constructs such as the presence of an editorial review to determine information quality "on the fly" may solve this problem.

The diaries and pre- and postsurveys identified several citizen information needs during an infectious disease outbreak that health organizations should watch out for. They should:

1. Keep citizens updated on the status of the outbreak. Citizens want to know just how bad the situation is at a given moment and what caused the outbreak. For this, they primarily rely on media such as news websites, or traditional news outlets, such as newspapers (in print or online) and television news (either via television or their website). The primary function of health organizations here would be informing these media.
2. Help citizens in protecting themselves. Information on how to protect oneself ("How can I prevent being infected?" Or in the context of the EHEC outbreak, "Which types of food are safe for me to eat?", "Can I safely travel to Germany?") is, for the most part, broadcast by the same news media: news websites, newspapers (in print or online), and television news (either via television or their website). Additionally, they refer to friends, family, or colleagues, or they search for information on the Internet. In case of the latter, they not only refer to online newspapers but also to Web 2.0 services like wikis and maps. Health organizations need to inform the media about this topic and, where possible, monitor and contribute to relevant Web 2.0 services (eg, by contributing to relevant Wikipedia pages).
3. Communicate the end of the outbreak. In case of an infectious disease outbreak, citizens need closure. Health organizations need to relay a firm statement at the end of an outbreak to citizens, with a clear description of its cause. As this information is related to the current status of the outbreak, it makes sense to broadcast this information via the media that citizens use to stay up to date about the outbreak.
4. Provide unequivocal information. In Germany during the EHEC outbreak, citizens received different messages from the organizations and administrators, while these administrators also blamed each other for the slow progress in finding the cause of the outbreak. This caused dissatisfaction among the participants in our study. During an infectious disease outbreak, government organizations and administrators should unite and talk with one voice.

Finally, in our study we assessed the information behavior of people living at the epicenter of an infectious disease outbreak and people living further away. The media coverage of the outbreak was greater at the epicenter than in a region 300 kilometers away. The outbreak kept citizens in the epicenter busier than people at distance: they talked more about the outbreak with others and more often searched actively for information. The information needs also differed. Citizens at a distance took a more passive stance towards gathering information and used the same information sources. Citizens at the epicenter used a wider variety of information sources. The factors that led to (dis)satisfaction between the two different groups were quite similar. Health organizations can rely on the news media when they have to deal with an infectious disease outbreak where the epicenter is not in the immediate vicinity. When a health organization has to deal with an infectious disease outbreak in their service region, they need to monitor and provide information as described above.

Limitations of the Study

When conducting a diary study, one ideally wants to collect data from the beginning of the outbreak to the end. In practice, this is impossible as one cannot predict when and where an infectious disease outbreak will take place. As a result, researchers can only contact organizations that will help them with recruiting participants when an infectious disease outbreak is deemed worthy of investigation. This made finding organizations that had the time and energy available extremely difficult. Local health authorities were the ideal partners, but they were very busy with the outbreak. After trying to collaborate with them for some time, we realized this would not work and resorted to an alternative set-up: collaborating with universities and using student participants.

This has led to two limitations of this study. First, we lost valuable time finding participants. This means that we could not collect data covering the pre-crisis and initial crisis phase, but only during the maintenance and resolution phase (classification by [4]). We therefore missed the opportunity to collect data about the participants' first confrontation with the infectious disease. We tried to compensate for this by asking them about it in the demographics survey, but many participants were already unable to recall this experience. In the future, this shortcoming could be avoided by, for example, conducting interviews with people on the street right after an infectious disease outbreak has been announced. Second, we used student participants, who are not representative of the general population: they are young, healthy, and do not necessarily have responsibility for a family. Furthermore, a number of them studied health sciences, and as a result, they might have had a relatively high knowledge level about infectious diseases or a relatively high interest in the outbreak. Students are also not "average" 2.0 media users but are considered heavy users. It is therefore interesting that our results showed little use of social media. If our participant group did not use it significantly, the total population most probably would not either, or even to a lesser extent.

Finally, the scope of this study has been limited. We have investigated one outbreak with a small, selective group of respondents. However, this study is the first of its kind: it addresses information behavior from the citizens' point of view in depth and is the first to critically investigate the role of Web 2.0 media in this context. Previous research has analyzed Web 2.0 media output only, assuming that these media are useful and widely used during an infectious disease outbreak. We are the first to have taken a closer look at the truth behind this assumption. The explorative, qualitative nature of our study limits its generalizability but provides valuable input for future quantitative research on this topic.

Conclusions

In this study, we investigated the use of Web 2.0 media during an infectious disease outbreak. Contrary to the prevalent opinion, social media (like Facebook and Twitter) played only a marginal role in the information provision towards citizens. Wikis, however, did play a role. They were consulted when people actively searched for outbreak-related information. Future research should therefore focus on the role wikis can play for informing the public during an infectious disease outbreak.

The findings of this study should be verified for different kinds of outbreaks. The EHEC outbreak was large. Citizens' information behavior may differ for infectious disease outbreaks on a smaller scale, like a scabies outbreak in a nursing home. In addition, health organizations often have different procedures for these kinds of relatively small outbreaks, which influences speed of information dissemination and media coverage.

One goal that 2.0 media can serve, but which we have not discussed in this paper, is informing journalists. This is a distinctly different population from citizens with their own information needs and behavior. It is possible that social networks can be valuable for health organizations when communicating with these professionals. When several health organizations are involved in the outbreak and each owns a part of the communication to stakeholders (as in the German context), journalists should be the people who make sense of press releases and communicate this to the public at large. Studies should assess whether this is actually the case and what form this communication should take.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Interval-contingent diary form given to the participants to record their passive information behavior.

[PDF File (Adobe PDF File), 75KB - jmir_v14i6e181_app1.pdf]

Multimedia Appendix 2

Event-contingent diary form given to the participants to record their active information behavior.

[PDF File (Adobe PDF File), 74KB - jmir_v14i6e181_app2.pdf]

Multimedia Appendix 3

Final coding scheme for content of passively consumed EHEC-related messages.

[PDF File (Adobe PDF File), 84KB - jmir_v14i6e181_app3.pdf]

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Original Paper

Young Men, Mental Health, and Technology: Implications for Service Design and Delivery in the Digital Age

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Abstract

Background: Young men are particularly vulnerable to suicide, drug, and alcohol problems and yet fail to seek appropriate help. An alternative or adjunct to face-to-face services has emerged with widespread uptake of the Internet and related communication technologies, yet very little evidence exists that examines the capacity of the Internet to engage young men and promote help seeking.

Objective: To explore young people’s attitudes and behaviors in relation to mental health and technology use. The aim was to identify key gender differences to inform the development of online mental health interventions for young men.

Methods: A cross-sectional online survey of 1038 young people (aged 16 to 24 years) was used.

Results: Young men are more likely than young women to play computer games, access online video/music content, and visit online forums. More than half of young men and women reported that they sought help for a problem online, and the majority were satisfied with the help they received. Significant gender differences were identified in relation to how young people would respond to a friend in need, with young men being less likely than young women to confront the issue directly.

Conclusions: Online interventions for young men need to be action-oriented, informed by young men’s views and everyday technology practices, and leverage the important role that peers play in the help-seeking process.

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KEYWORDS

Young men; mental health; technology; service design and delivery; digital age; Internet use; games

Introduction

Young men in Australia have higher rates of completed suicide, antisocial behavior, and alcohol or other substance misuse problems than young women [1,2]. They are also less likely to seek help with only 13% of young men aged 16 to 24 years seeking help when experiencing a mental health difficulty compared with 31% of young women [3].

The factors associated with poorer help-seeking practices in young men are complex [4]. Research suggests that young men have poorer mental health knowledge and higher mental health stigma than young women [5,6]. Additionally, Western norms of masculinity can function as a barrier to effective help-seeking, with males feeling social pressure to be self-reliant, suppress emotions, and manage their personal problems independently [7,8]. In order to promote help-seeking behavior for young men, it is now being argued that innovative improvements must be made to the design and delivery of mental health services to ensure that they are relevant and meet the unique needs of this demographic [4,8-10].

An alternative or adjunct to face-to-face services has emerged with widespread uptake of the Internet and related communication technologies, such as mobile phones, game consoles, and tablet computers [11]. These information and communications technologies (ICTs) are ideally suited to accommodate young men's preferences for autonomous and anonymous channels for seeking help [12,13]. Studies of free access online programs designed to improve mental health outcomes (eg, MoodGYM, Reach Out Central) have shown promise in trials with young people [14-16]. However, these studies have also highlighted the difficulty and importance of sustained engagement (particularly for young males) if results are to be maximized [16,17]. This represents a key challenge for self-directed Internet-based programs. Both the academic and policy literature has identified the urgent need to develop evidence-based mental health strategies that target young men and leverage their ICT use to promote help-seeking [11,12,18]. Although considerable research exists regarding barriers to help-seeking and stigma among young people, more needs to be known about their ICT use and help-seeking preferences [9]. Specifically, we must understand how young men and women differ in their attitudes and behaviors in relation to mental health and ICT use if we are to develop new methods that are specifically tailored to meet their needs and expectations [19]. Here, we report the findings from a national online survey that explored young people's attitudes and behaviors towards mental health, online habits, and technology use, as well as their experiences of using the Internet for information, help, or support.

Methods

Survey Design and Sample

A survey was administered online for a three-month period, from January 25 to March 27, 2010. Recruitment was achieved via snowball sampling, leveraging online social networking services. Online sampling was used as a way of reaching young people who are normally difficult to access via random-digit dialing or panel methods, and as a way of reducing social desirability effects [20]. Following recent trends in recruitment [21], an advertisement was placed on Facebook, a popular online social networking site, and participants were encouraged to promote the survey to their peers, who then completed the survey and further promoted the study through their networks. The Facebook advertisement was specifically targeted to appear on the pages of Australian Facebook users between the ages of 16 to 24 years. The advertisement consisted of a short title ("mental health and technology"), an image, and a longer description ("tell us what you think about how technology might be used to encourage young people to engage with mental health services". A total of 1484 people clicked on the Facebook advertisement (the average cost per click was $0.42), and individuals who chose to participate were taken to the online questionnaire, which was hosted on the third-party website SurveyMonkey. The survey was also specifically advertised through youth-serving organizations, including youth centers and clinics, online service providers, charities, colleges, universities, and relevant government organizations, via a flyer and link to the survey, which was distributed via email.

This study had ethics approval from the University of Sydney Human Research Ethics Committee (Protocol No. 11209). Participants gave consent online and understood that their participation was voluntary, confidential, and non-identifiable. No incentives were offered for taking part. Participants included 1038 young people aged 16 to 24 years.

Survey Measures

Technology Use

Two key questions were developed to examine young people's use of a range of technologies. The first question asked about their use of various ICTs (eg, computers, PlayStation, Facebook, multiplayer games). The second question asked about their frequency of use of various types of media and entertainment (eg, newspapers, Internet for music, Internet for social networking, television) over the previous three months. Respondents rated this question on a six-point Likert scale (1 = "everyday" to 6 = "never").

Attitudes and Behaviors Towards Mental Health

Two sets of questions were selected from the *headspace* community survey [9]. The first set of questions asked respondents what they would do if they thought a friend might be experiencing a mental health problem (eg, "keep out of their way", "tell them to just get over it", "try to include them in social activities with other friends"), with items being rated on a five-point Likert scale (1 = "very likely" to 5 = "very unlikely"). The second set of questions asked respondents whether they have ever talked about their problems on the Internet ("yes/no"), and if so, whether chatting with other people via the Internet helped ("yes/no"). Finally, respondents were asked how satisfied they were with the information/support they received on the Internet (1 = "very dissatisfied" to 4 = "very satisfied").

Psychological Distress

The six-item Kessler Psychological Distress Scale (K6) [22] assesses the frequency with which an individual experiences symptoms of general psychological distress such as nervousness, tiredness, hopelessness, and restlessness on a five-point Likert scale (0 = "none of the time" to 4 = "all of the time"). Scores are then summed to create a total score that ranges from zero to 24.

Technology and Mental Health

A set of questions was developed to measure preferences for receiving mental health information and support through technology including: accessing a website with information and/or factsheets; a website with a question and answer service that sends short message service (SMS) or emails; a website with online clinic; interactive single-player games teaching life skills; and interactive multiplayer games teaching life skills.

Data Analysis

The survey data were analyzed using the Statistical Package for the Social Sciences (SPSS) version 20.0. All surveys, both completed and uncompleted, were analyzed. Differences between young men and women were assessed using either chi-square analysis for nominal and ordinal dependent variables with two to four categories or analysis of variance (ANOVA) for ordinal dependent variables with five or more categories. A P value < .05 was considered statistically significant. For a select number of questions, we examined the results separately for the total sample and the psychological distressed sample (ie, those whose K6 scores were equal to or greater than 13) [23].

Results

Survey Participants

A total of 1038 young people (aged 16 to 24 years) participated in the survey (53.2% female; n = 552/1038; mean age = 18.84 years; SD age = 2.75). The majority of participants provided complete data (completion rate = 71.9%). The survey had good national coverage with respondents from all Australian States and Territories. 41.9% (n = 432/1030) were from New South Wales and Australian Capital Territory; 24.6% (n = 254/1030) were from Victoria and Tasmania; 18.1% (n = 186/1030) were from Queensland; and 15.3% (n = 158/1030) were from Western Australia, South Australia, and the Northern Territory. Seventeen people (2.2%; n = 17/790) identified themselves as Aboriginal and/or Torres Strait Islander origin; and 21.1% (n = 168/797) spoke a language other than English at home. Most of the sample were in full-time study at school, Technical and Further Education (TAFE) or university (63.7%, n = 475/746), while 16.0% (n = 119/746) were employed full-time (30 or more hours per week), and 8.4% (n = 63/746) were employed part-time (less than 30 hours per week).

Young People’s Interests and Technology Use

The vast majority of respondents used mobile phones (98.0%, n = 878/896), iPod/MP3 players (89.7%, n = 802/894) and computers (desktops, 77.1%, n = 691/896; laptops, 84.0%, n = 752/895). Facebook was by far the most popular social networking website (92.7%, n = 831/896), with only 37.6% (n = 337/896) of the sample using MySpace and only 22.1% (n = 198/896) using Twitter. As shown in Table 1, the most noticeable gender differences were for game play, with significantly more males playing single-player, multiplayer, and interactive games than females. Other significant differences were found with more males accessing video websites and forums, and more females visiting Facebook and information sites.

Table 1. Gender differences in ICT use; N = 896[a].

	Males (yes) n (%)	Females (yes) n (%)	χ^2
N	403	493	
Mobile phone	388 (96.3)	490 (99.4)	10.92[b]
Facebook	363 (90.1)	468 (94.9)	7.77[b]
iPod/MP3 player	355 (88.5)	447 (90.7)	1.10
Laptop computer	328 (81.6)	424 (86.0)	3.21
Information websites	320 (79.4)	426 (86.4)	7.81[b]
Landline phone	321 (80.0)	394 (79.9)	0.00
Desktop computer	323 (80.1)	368 (74.6)	3.81
MSN	310 (76.9)	359 (72.8)	1.97
Video websites	343 (85.1)	321 (65.1)	46.22[c]
Forums	250 (62.0)	255 (51.7)	9.58[b]
Interactive games	249 (61.8)	237 (48.1)	16.80[c]
Nintendo/Wii	201 (49.9)	223 (45.2)	1.92
Single-player games	268 (66.5)	137 (27.8)	134.16[c]
PlayStation	213 (53.0)	191 (38.7)	18.14[c]
MySpace	151 (37.5)	186 (37.7)	0.01
Xbox	205 (51.0)	117 (23.7)	71.45[c]
Multiplayer games	220 (54.6)	99 (20.1)	115.18[c]
Bulletin boards	158 (39.2)	157 (31.8)	5.27[d]
Skype	148 (36.7)	148 (30.0)	4.51[d]
Twitter	83 (20.6)	115 (23.3)	0.96
Bebo	53 (13.2)	69 (14.0)	0.13

[a] Denominators vary due to missing data. Rows are ordered according to frequency of endorsement.

[b] $P < .01$.

[c] $P < .001$.

[d] $P < .05$.

Respondents were also asked more broadly about the kinds of media and entertainment they use. The most popular forms of media and entertainment across the sample were the Internet for social networking or communicating (74.1% use it daily, n = 657/887), the Internet for music (62.6% use it daily, n = 556/888), and the Internet for general information (58.2% use it daily, n = 516/886). Internet use was significantly more popular than watching TV (52.7% use it daily, n = 470/892) or listening to the radio (36.1% use it daily, n = 318/881). However, as shown in Table 2, males used the Internet to access games and music more frequently than females. Males also played games on a console or computer far more frequently than females. On the other hand, females listened to the radio and went to the cinema more frequently than males.

Table 2. Gender differences in media and entertainment use; N = 892[a].

Level of usage (1 = “everyday” to 6 = “never”)	Males M (SD)	Females M (SD)	F
Internet for social networking or communicating	1.54 (1.19)	1.44 (0.96)	1.75
Internet for general information	1.70 (1.19)	1.68 (0.96)	0.07
Internet for music	1.58 (1.13)	1.80 (1.19)	7.55[b]
TV	1.98 (1.38)	1.81 (1.24)	3.64
Radio	2.76 (1.74)	2.44 (1.63)	8.00[b]
DVDs or videos	3.00 (1.27)	3.11 (1.21)	1.59
Newspapers	3.15 (1.63)	3.03 (1.43)	1.30
Games on a console or computer	2.62 (1.66)	3.91 (1.75)	125.26[c]
Internet for games	3.06 (1.83)	3.74 (1.86)	29.84[c]
Magazines	3.95 (1.43)	3.88 (1.26)	0.54
Cinema	4.14 (0.93)	4.27 (0.87)	4.92[d]

[a] Rows are ordered according to frequency of endorsement.

[b] *P* < .01.

[c] *P* < .001.

[d] *P* < .05.

Young People’s Attitudes and Behaviors Towards Mental Health

Respondents were asked what they would do in the next few days if they noticed a friend was going through a tough time. The vast majority of the sample reported that they would be “likely” or “very likely” to listen to their friend and try to help them work out what to do (94.8%, n = 886/934), encourage them to focus on the positive things in life (88.3%, n = 825/934), and try to include them in social activities with other friends (87.5%, n = 812/928). However, as shown in Table 3, there were significant gender differences on most items with males being more likely than females to: “tell them to just get over it”; “tell them about their own worries to help them put their problems in perspective”; and “keep out of their way to give them some space”. On the other hand, females were significantly more likely than males to report that they would: “listen to them and try to help them work out what to do”; “try to include them in social activities with other friends”; “talk with someone else who knows them well about what to do”; and “encourage them to focus on the positive things in life”.

Table 3. Gender differences in what young people would do for a friend experiencing a mental health problem; N = 934.

Likelihood (1 = “very likely”; 5 = “very unlikely”)	Males M (SD)	Females M (SD)	F
Keep out of their way to give them some space	2.92 (1.00)	3.04 (0.84)	4.03[a]
Listen to them and try to help them work out what to do	1.71 (0.75)	1.43 (0.61)	40.32[b]
Encourage them to focus on the positive things in life	1.84 (0.88)	1.65 (0.78)	12.82[b]
Tell them about your worries to help them put their own problems in perspective	2.73 (1.08)	2.98 (1.02)	13.14[b]
Tell them that things will improve soon	2.20 (0.99)	2.21 (1.00)	0.00
Tell them about others who have got over similar problems	2.65 (1.08)	2.53 (1.06)	3.35
Tell them to just get over it	3.62 (0.86)	3.91 (0.49)	42.39[b]
Try to include them in social activities with other friends	2.04 (1.02)	1.70 (0.80)	31.03[b]
Encourage them to avoid situations that might upset them	2.15 (1.06)	2.07 (1.02)	1.42
Talk with someone else who knows them well about what to do	2.17 (1.12)	1.89 (0.96)	16.59[b]

[a] *P* < .05.

[a] *P* < .001.

The most “likely” or “very likely” sources of help respondents would suggest to a friend with a mental health problem would be: friends (88.0%, n = 816/927); a counselor (75.5%, n = 703/931); doctor (74.9%, n = 698/932); family member (68.5%, n = 637/930); and websites (45.9%, n = 422/920). They would be least likely to recommend posters or pamphlets, a church leader, teacher, or community member or center. However, there were significant gender differences on all variables apart from friends, with males being less likely to recommend each of the sources of help than females (see Table 4).

Table 4. Gender differences in sources of help young people would suggest to a friend with a mental health problem; N = 931[a].

Likelihood (1 = “very likely”; 5 = “very unlikely”)	Males M (SD)	Females M (SD)	F
Friends	1.78 (0.86)	1.70 (0.81)	2.20
Counselor	2.21 (1.07)	1.89 (0.98)	22.08[b]
Doctor	2.25 (1.05)	1.87 (0.88)	35.21[b]
Family	2.33 (1.11)	2.08 (1.02)	12.52[b]
Websites	2.72 (1.02)	2.52 (1.02)	8.18[c]
Telephone helplines	2.89 (1.05)	2.55 (1.02)	25.35[b]
Community center	3.04 (0.98)	2.72 (1.09)	22.11[b]
Trusted community member	2.99 (0.96)	2.78 (0.98)	10.68[c]
Teacher	3.04 (0.98)	2.75 (0.94)	20.47[b]
Posters or pamphlets	3.16 (0.89)	2.94 (0.92)	12.70[b]
Church leader	3.26 (1.05)	3.08 (1.05)	6.80[c]

[a] Rows are ordered according to frequency of endorsement.

[b] $P < .001$.

[c] $P < .01$.

Young People’s Internet Use for Information, Help, or Support

The average time respondents spend using the Internet each day was 4.7 hours (4.4 hours for females and 5.2 hours for males). Significantly more males than females used the Internet after 11 p.m. at night (75.4% compared with 62.1%; χ^2=17.53, $P <$ .001), and significantly more females than males had talked about their problems online (62.1% females vs. 54.9% males; χ^2 = 4.53, P = .020). Most females said that talking online “helped” (81.9%, n = 245/299) and that they were “satisfied” or “very satisfied” with the online help they received (85.1%, n = 256/301). Similarly, most males said that talking online “helped” (81.3%, n = 169/208) and that they were “satisfied” or “very satisfied” with the online help they received (82.9%, n = 174/210).

Of the total sample whose K6 scores were indicative of psychological distress (males: n = 130; females: n = 189), 69.4% (n = 221/318) said they had sought help for their problems online. Again, significantly more females than males had talked about their problems online (73.5% of females vs. 63.6% of males; χ^2=3.60, P = .038). However, a similar proportion of females and males reported that talking online “helped” (79.0% compared with 71.6%; χ^2=1.54, P = .141).

The survey also asked participants to indicate their preferences for receiving mental health information and support through technology (see Tables 5 and 6). The top two responses for males and females across the total sample were: website with information and/or fact sheets (males: 48.1%, n = 234/486; females: 59.6%, n =329/552) and website with online clinic (males: 38.5%, n = 187/486; females: 48.7%, n = 269/552). Similarly, the top two responses within psychologically distressed sample were: website with information and/or fact sheets (males: 62.3%, n = 81/130; females: 70.4%, n = 133/189) and website with online clinic (males: 51.5%, n = 67/130; females: 56.1%, n = 106/189).

Table 5. Gender differences in preferences for receiving mental health information and support through technology; Total sample[a].

	Males n (%)	Females n (%)	χ^2
N	486	552	
Website with information and factsheets	234 (48.1)	329 (59.6)	13.66[b]
Website with online clinic	187 (38.5)	269 (48.7)	11.03[c]
Website with question and answer service	140 (28.8)	230 (41.7)	18.63[b]
Website promoting well-being	118 (24.3)	243 (44.0)	44.41[b]
Website with multimedia content	144 (29.6)	165 (29.9)	0.01
Interactive single-player game teaching life skills	87 (17.9)	145 (26.3)	10.43[c]
Interactive multiplayer game teaching life skills	88 (18.1)	119 (21.6)	1.93

[a] Denominators vary with missing data. Rows are ordered according to frequency of endorsement.

[b] $P < .001$.

[c] $P < .01$.

Table 6. Gender differences in preferences for receiving mental health information and support through technology; Psychologically distressed sample[a].

	Males n (%)	Females n (%)	χ^2
N	130	189	
Website with information and factsheets	81 (62.3)	133 (70.4)	2.27
Website with online clinic	67 (51.5)	106 (56.1)	0.64
Website with question and answer service	55 (42.3)	92 (48.7)	1.26
Website promoting well-being	36 (27.7)	90 (47.6)	12.80[b]
Website with multimedia content	50 (38.5)	60 (31.7)	1.54
Interactive single-player game teaching life skills	29 (22.3)	59 (31.2)	3.06
Interactive multiplayer game teaching life skills	28 (21.5)	47 (24.9)	0.48

[a] Denominators vary with missing data. Rows are ordered according to frequency of endorsement.

[b] $P < .001$.

Discussion

Despite considerable investment in mental health over the last decade, there has been no shift in national data on young men's help-seeking [3]. The results of this survey clearly signal that ICT plays a central role in young people's lives and may present an alternative or adjunct solution. The young men in this study used ICT predominantly for entertainment and socializing, but they also used the Internet to find information and support. We found that more than half of all males and two-thirds of psychologically distressed males used the Internet for help-seeking. Furthermore, the males in this study reported high levels of satisfaction with their online help-seeking experiences. These results provide evidence for further investment into ICT-based mental health service provision—particularly to increase engagement with young men.

The data provide important information on young men's ICT preferences and use. They were drawn to websites with video/music content and were far more likely than young women to play computer games. These insights suggest that the challenge of relevancy and engagement faced by mental health services may be addressed by action-oriented (rather than information or talk-based) strategies that target young men [24]. These strategies must be user-driven [10] and informed by young men's views and everyday technology practices.

Importantly, the results highlight gender differences in how young people would respond to a friend who is experiencing a mental health problem. In comparison to females who would be more likely to respond proactively and intervene, young men stated that they would be less likely to confront the issue directly. This is consistent with previous research showing that young men have limited experience relative to young women in helping someone with an emotional concern and would be less likely to offer advice [5]. Thus, online strategies that encourage and empower males to help their friends with emotional concerns should be explored, especially given the important role that peers play in the help-seeking process [10].

Limitations

Three potential limitations should be considered when interpreting the results of this study. First, given that we recruited participants using online methods, our sample was limited to young people with Internet access. Nevertheless, Internet access and use in Australia is very high: 97% of young people have personal access to the Internet [25], and the results of this study concerning ICT use are comparable with previous research [26,27]. Secondly, our sample appears to be skewed towards respondents with higher levels of psychological distress than we would expect from the general population. While our results may thus not be generalizable to the entire population, our success in recruiting young people with potential mental health issues is noteworthy and suggests that online snowball sampling techniques may be a particularly effective way to recruit young people with mental health issues to research—a group typically very hard to recruit. Thirdly, we cannot be certain that the observed gender differences are a result of gender per se or are the result of other factors, such as poor mental health knowledge or higher mental health stigma [5,6]. Future research aimed at exploring gender differences while controlling for these other factors will help elucidate this issue and give us a more comprehensive understanding of how to engage young men.

Conclusion

Despite these limitations, the results of this study present a compelling argument for investment in ICT-based mental health initiatives that target young men. Investment should increase the visibility of already known and trusted youth mental health services as well as support the development of new interventions. The results suggest that further development of online mental health services that can respond effectively to young men’s questions with direct links to experts. Furthermore, online services that include the principles of gaming and music/video content, as well as provide opportunities to seek information and support autonomously and anonymously, could be particularly appealing to young men, although further research in this area is warranted. Social networking technology may also provide a powerful tool to promote social connectedness of young men that can support help-seeking and warrants further research. Finally, this survey was unable to account for the recent and rapid proliferation and popularity of tablets, smart phones, and mobile phone applications [28]. Further research should pay particular attention to the role of mobile media and applications in the delivery of strategies to promote help-seeking in young men.

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Conflicts of Interest

None declared.

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Original Paper

"Right Time, Right Place" Health Communication on Twitter: Value and Accuracy of Location Information

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Abstract

Background: Twitter provides various types of location data, including exact Global Positioning System (GPS) coordinates, which could be used for infoveillance and infodemiology (ie, the study and monitoring of online health information), health communication, and interventions. Despite its potential, Twitter location information is not well understood or well documented, limiting its public health utility.

Objective: The objective of this study was to document and describe the various types of location information available in Twitter. The different types of location data that can be ascertained from Twitter users are described. This information is key to informing future research on the availability, usability, and limitations of such location data.

Methods: Location data was gathered directly from Twitter using its application programming interface (API). The maximum tweets allowed by Twitter were gathered (1% of the total tweets) over 2 separate weeks in October and November 2011. The final dataset consisted of 23.8 million tweets from 9.5 million unique users. Frequencies for each of the location options were calculated to determine the prevalence of the various location data options by region of the world, time zone, and state within the United States. Data from the US Census Bureau were also compiled to determine population proportions in each state, and Pearson correlation coefficients were used to compare each state's population with the number of Twitter users who enable the GPS location option.

Results: The GPS location data could be ascertained for 2.02% of tweets and 2.70% of unique users. Using a simple text-matching approach, 17.13% of user profiles in the 4 continental US time zones were able to be used to determine the user's city and state. Agreement between GPS data and data from the text-matching approach was high (87.69%). Furthermore, there was a significant correlation between the number of Twitter users per state and the 2010 US Census state populations ($r \geq 0.97$, $P < .001$).

Conclusions: Health researchers exploring ways to use Twitter data for disease surveillance should be aware that the majority of tweets are not currently associated with an identifiable geographic location. Location can be identified for approximately 4 times the number of tweets using a straightforward text-matching process compared to using the GPS location information available in Twitter. Given the strong correlation between both data gathering methods, future research may consider using more qualitative approaches with higher yields, such as text mining, to acquire information about Twitter users' geographical location.

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KEYWORDS

Twitter; GPS Location; Infodemiology; Surveillance; Intervention; Social Media

Introduction

People's daily use of technology creates "digital breadcrumbs—tiny records of [their] daily experiences" that, when mined and analyzed, can provide insight into health behavior and health outcomes [1]. Traditional behavioral assessments rely on self-report or observation, but increased use of mobile communication devices linked to the Internet and social media applications (apps) are creating unprecedented opportunities for collecting real-time health data and delivering health innovations. For example, mHealth represents a new form of health care delivery and treatment where patients are able to interact with their health care providers through mobile devices—providing additional "breadcrumbs" for studying/mining health behaviors and health outcomes [2].

Although some researchers have expressed concerns about the use of social media in public health [3], an increasing number of researchers welcome the novel opportunities offered by social media to complement (and partially replace in some cases) existing practices in public health and health communication [4-6]. A number of recent studies have demonstrated the value of online information for understanding public health problems and their determinants in areas as diverse as influenza and cholera outbreaks [7,8], tobacco-related issues [9-11], problem drinking [12], dental pain [13], breastfeeding [14], and others [15,16]. This new real-time observation and analysis of user-generated health content in social media has given rise to the terms infoveillance and infodemiology (the study and monitoring of online health information) [17].

Social media connect a wide variety of individuals around many topics and provide a new way for them to share information, reach out, and exchange ideas. As recently editorialized by Ratzan [18], "This change to the way people learn, think, and communicate has revolutionized the context in which health information...needs to be communicated." Not only is the context different, so is the sheer volume and scale. Millions of individuals worldwide can be reached almost instantaneously with textual, pictorial, and video messages that could alter health behaviors. Additionally, the distribution of social media usage suggests that health disparities may be reduced, and traditionally underrepresented groups and low-income populations may be reached more effectively [19].

As a kind of "listening ear" to the conversations of the world, social media enable health surveillance in completely novel ways. Whereas researchers have relied on questionnaires and focus groups to understand the opinions and behaviors of the public in the past, by using social media they can now observe Internet postings about users' attitudes and behaviors, many of which can be accessed in real time. These approaches are optimistic because they are typically less expensive and may better reflect the real-life context of behavioral indicators as part of everyday living than traditional assessments of health behaviors. Further, online surveillance enables researchers to study trends as they happen, removing the delay that often arises from designing, administering, and collecting questionnaire-style responses. In addition, by observing users as they interact naturally with one another and their environment, researchers can study true feelings and avoid the Hawthorne effect where the investigator's presence can cause unintended influence [20]. Thus, these social media channels "are quickly becoming dominant sources of information on emerging diseases" [21].

In addition to using social media for surveillance, these technologies could also be harnessed for health communication and intervention. Although still largely underutilized, social media provide the ability to communicate with people in a completely tailored manner, which has been shown to significantly improve the chances of affecting actual behavior change [22-24]. Furthermore, the real-time nature of the data and the location information of social media provide the opportunity for truly "right time, right place" communication where a person receives the message exactly when and where it is needed. Consider, for example, the possibilities of direct intervention with a potential drunk driver before leaving a party or of a diet reminder reaching a person as they walk into a fast food restaurant. Identifying—and reacting to—health needs in such a timely manner is consistent with Patrick et al [25] and Heron and Smyth [26] who referred to this process as "ecological momentary interventions" or as Intille et al [27] call it, "just-in-time."

Despite its promise, location in social media is not well understood or well documented. Although proponents of research using social media have pointed to the geolocation information provided by many platforms, such as Twitter, as a means of pinpointing the exact location of users [28], others have cautioned that location information may be underspecified and that location "based on user-identified location or the time zone" could be of questionable quality [3]. The exact Global Positioning System (GPS) coordinates available in some social media platforms could help mitigate this risk because they are direct measures and more difficult to misrepresent. However, unless GPS use is widespread, this does not address the problem of underspecification. Until research is conducted to assess location availability, usability, and the limitations of this data, health practitioners may have limited capacity to observe time- and place-based interventions for determining risks or health conditions.

The objective of this study is to fill this gap in our understanding of location information in social media, especially as it relates to Twitter. The major contribution of this work is to present the different types of location that can be ascertained from Twitter users and to document the prevalence of each type in an attempt at informing future infoveillance, infodemiology, and health communication research of the availability, usability, and limitations of such location data.

Methods

Twitter is a social network in which users post status updates, or tweets, that are restricted to 140 characters in length. Users can "follow" others to be notified of their updates, but tweets are also generally available to the public. Because of the public nature of the tweets, users do not have any expectation of privacy, so researchers may openly observe the content. Additionally, Twitter provides a rich application programming interface (API) that enables programmatic searching and retrieval of the data. Twitter users tend to be young and affluent [29]; therefore, one could conclude that they are not representative of entire populations. However, this should not diminish perceptions of Twitter's utility as a public health tool because it may be an appropriate mechanism for studying attitudes and behaviors of the demographic most represented among its users (ie, young and affluent individuals).

Location Indicators in Twitter

Twitter users provide varying degrees of information about their thoughts, attitudes, and behaviors in their profile description and through their tweets. Similarly, they may or may not provide information about their location. When they wish to provide location information, Twitter users have 4 options: (1) exact GPS coordinates associated with a tweet, (2) GPS coordinates of a place (eg, a city or metropolitan region), (3) free-text location information listed in the public profile description, and (4) time zone associated with the user account. Options 1 and 2 are combined into a single setting, the Twitter Location feature, which is disabled by default so that a user must opt-in to use it. Further details about each option and its functionality follow.

Many users post to Twitter from smartphones or other GPS-enabled devices, and have the ability to broadcast their exact GPS coordinates alongside the text of their tweet. This setting is disabled by default, but when used, this GPS information provides reliable and accurate data about a Twitter user's location.

Users posting from their computers and other devices without GPS via the Twitter website can still broadcast their location by providing a GPS "place." This place is defined by a bounding box of GPS coordinates and often refers to a city or a metropolitan area. This place is inferred by Web browsers, such as Firefox and Google Chrome, and on other browsers through the use of extensions or add-ons. In the case of a GPS-enabled device, this place can be determined directly by the GPS coordinates.

When users create accounts on Twitter they can fill out a public profile that includes personal information, such as their name, website, bio, picture, and location. Location is an optional text field in which users can enter anything they want. Many users provide their geographical position, such as a city and state/country, but many opt to specify something humorous (eg, "somewhere in my imagination :)" or "a cube world in Minecraft"), sarcastic (eg, "in yhur [bleep!!!] face…" or "Here...obvious!"), or just leave the field blank. The free-text nature of the user-specified location field poses serious challenges. First and most obvious, humorous, sarcastic, and missing entries do not correspond to any identifiable physical location. Second, the entry requires some amount of text processing to correct spelling errors, interpret "textese" and emoticons, and handle abbreviations. Third, the information may be incomplete or ambiguous, such as when a city name is given, but no state or country is provided. Finally, even if the location field can be recognized as a specific location, it is still possible that users chose to provide a location different from where they actually are or that the information is not up-to-date.

Twitter automatically infers a time zone when a user account is created, probably from the local time on the user's computer or device, and selects it for the user by default. The user can subsequently change this default value, if desired. Although time zones do not denote specific locations, they can still be used to distinguish between major world regions, such as North America and Europe, or the East and West Coasts of the United States. This time zone information could also be helpful in resolving ambiguous city names from profile descriptions.

In addition to these mechanisms supported directly by Twitter, users can also provide location context indirectly in the text of their tweets (eg, "My plane just landed at JFK") or through third-party applications, such as foursquare (https://foursquare.com/). In some cases, these applications will broadcast GPS coordinates via the standard Twitter mechanisms. In other cases, they may broadcast text or links that would point users elsewhere to see the location. For clarity and to avoid the bias of catering to specific conventions or applications, this study focuses exclusively on the mechanisms supported directly and explicitly by Twitter.

Data Collection Methodology

The Twitter streaming API provides the ability to receive a portion of the real-time stream of all tweets. This stream can be filtered by certain criteria, such as keywords or a bounding box of GPS coordinates. If no filtering criteria are used (or if the criteria are too general and more than 1% of the tweet stream would be retrieved), the streaming API will return 1% of the total tweets sampled by taking every 100th tweet. As of June 2011 (3 months prior to our data collection), Twitter estimated that approximately 200 million tweets were posted every day [30], resulting in a daily sample of approximately 2 million tweets when using the streaming API with no filter.

Using the Twitter streaming API, we observed the stream of tweets for 2 weeks: October 1-7 and November 7-14, 2011 (approximately 6 hours of the early morning on November 14 were not observed due to a server error). We did not find significant differences between the data of the 2 weeks; therefore, the results presented here are an aggregation of the 2 weeks' data. By not applying a filter, we received the maximum random sample of 1% of all tweets, yielding a total of 23.8 million tweets posted by 9.5 million unique users. Additionally, because we did not use a filter, our results are not biased by a choice of language or any other artificial means. For each tweet, we recorded the associated location information, both from the tweet itself and from the corresponding user's profile when applicable.

Frequencies for each of the location options were calculated to determine the prevalence of the various location data by region of the world, time zone, and state within the United States. Furthermore, data from the US Census Bureau were compiled to determine the proportion of the total United States population living in each state. Pearson correlation coefficients were used to compare states' populations with the prevalence of Twitter users who enable the GPS location option.

Results

Table 1 shows the total number of tweets and users, and their distribution over 3 types of location information: exact GPS coordinates (GPS-exact), GPS coordinates of a place (GPS-place), and time zone. In addition, the table shows the percentage of those who had either type of GPS coordinates, which is less than their sum because many users who supplied one also supplied the other. This aggregate value gives a more accurate picture of the amount of reliable (although less specific) location information directly available from tweets.

There was an average of 2.5 tweets per user. The extremely rapid rate of posting on Twitter (200 million posts per day amounts to more than 2000 tweets per second) and the streaming API's sampling mechanism (every 100th tweet) mean that it is unlikely that any user is overrepresented or underrepresented. Indeed, the probability that a user could post in exact sync with the streaming API's sampling is virtually zero. The larger proportions of users who have enabled GPS as opposed to tweets containing GPS information may be explained by the fact that user accounts that run automated applications (ie, bots) are less likely to be GPS-enabled, but may post more frequently and account for more tweets in the sample than regular users. We have not attempted to identify such users here. The remainder of our results are based on unique users identified by their tweets during the 2-week time period.

Worldwide Distribution

To see whether the number of users and their location information varied across the world, we used the time zone information to overlay these values on a map of the world. The result is displayed in Figure 1, which shows the number of unique users in each time zone who enabled GPS, including the percentage of GPS-exact and GPS-place data. Although the time zones of North and South America have a high number of tweets, European time zones have a higher proportion of tweets that provide GPS information.

Profile Description Location Information

To parse the free text of the user-supplied information, we used a simple method of looking for text followed by a comma and a state name or abbreviation (ie, “text, state name” or “text, state abbreviation”). This simple parsing method could be improved, yet it provides a useful conservative estimate in its simplicity and efficiency. This method is inherently biased toward English-speaking locations and locations within the United States; therefore, results are shown only for users with time zones listed as one of the US time zones. As a matter of interest, the top 10 pairs parsed (with number of users) are Atlanta, Georgia (10,935); Los Angeles, California (10,244); Chicago, Illinois (8980); Houston, Texas (8147); New York, New York (7804); Washington, District of Columbia (6751); Miami, Florida (5734); Dallas, Texas (5688); Boston, Massachusetts (5562); and Austin, Texas (4678).

Table 2 and Figure 2 show the number of users who matched our parsing criteria for the 4 continental US time zones, specifically Greenwich Mean Time (GMT) −5:00 to −8:00. When restricting to the US time zones, there is ambiguity about whether to include those that are specifically labeled as a US time zone, such as “Pacific Time (US & Canada)”, or simply those that contain a time zone offset that falls within the range of continental US time zones. For example, the time zone “Mexico City” is not labeled as a US time zone, yet its offset of GMT −6:00 is the same as Central Standard Time in the United States. Because the time zone may be automatically inferred by the user's local time when creating an account, many users in the United States may have their time zone set to a different zone with the same offset. Thus, focusing on those specifically labeled as “US and Canada” is likely to miss some users, but focusing on those within the offset range is likely to include many Central and South American users. We have included results for both cases.

Table 1. Tweets and users providing location indicators.

Location indicator	Tweets		Users	
	n	%	n	%
Total (with and without location)	23,830,273	100	9,496,448	100
GPS-exact	216,900	0.91	140,451	1.48
GPS-place	458,295	1.92	241,010	2.54
GPS-exact or GPS-place	481,179	2.02	256,059	2.70
Time zone	18,347,947	76.99	6,831,414	71.94

Figure 1. Distribution of Twitter users by time zone (time zones are aligned with longitudes not accounting for deviations based on country borders).

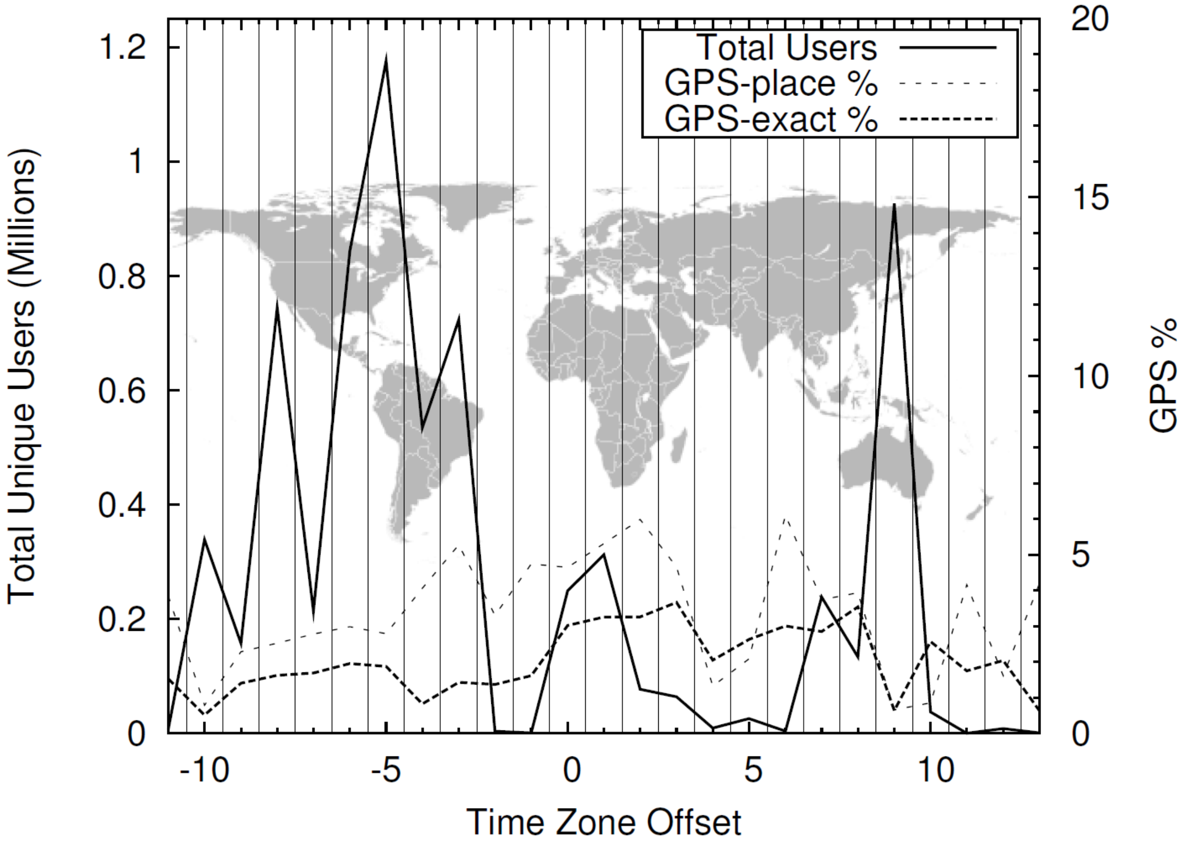


Table 2. Location of Twitter users within the time zones of the United States.

Location indicator	Labeled "US & Canada"		Time zones GMT −5:00 to −8:00	
	n	%	n	%
Total (with and without location)	2,117,064	100	2,904,103	100
GPS-exact	41,416	1.96	53,997	1.86
GPS-place	60,979	2.88	82,322	2.83
Parsed state	315,819	14.92	379,576	13.07
Any (GPS-exact, GPS-place, or parsed state)	362,663	17.13	445,800	15.35

Accuracy of User-Supplied Data

Users enter their location information in their user profiles themselves; thus, there is potential for inaccuracy. To evaluate the accuracy of the user-supplied profile location, we compared parsed state data and GPS coordinate data when both were available. City data may be too difficult to parse because individuals may live in one city and work or go to school in another. Therefore, a comparison of state data is more appropriate provided the same individuals are less likely to cross state boundaries repeatedly on a daily basis.

When GPS-exact data were available, we used the Yahoo! Place Finder API [31] to determine the state's identity through a reverse GPS lookup service. When GPS-place data were available, we extracted the state name based on the Twitter Place Type (directly, when supplied, or using a reverse GPS lookup as described previously). We compared the state name obtained by these methods with the state name parsed from the user-supplied location information. Table 3 shows the results.

Figure 2. Twitter users providing location indicators in the US time zones.

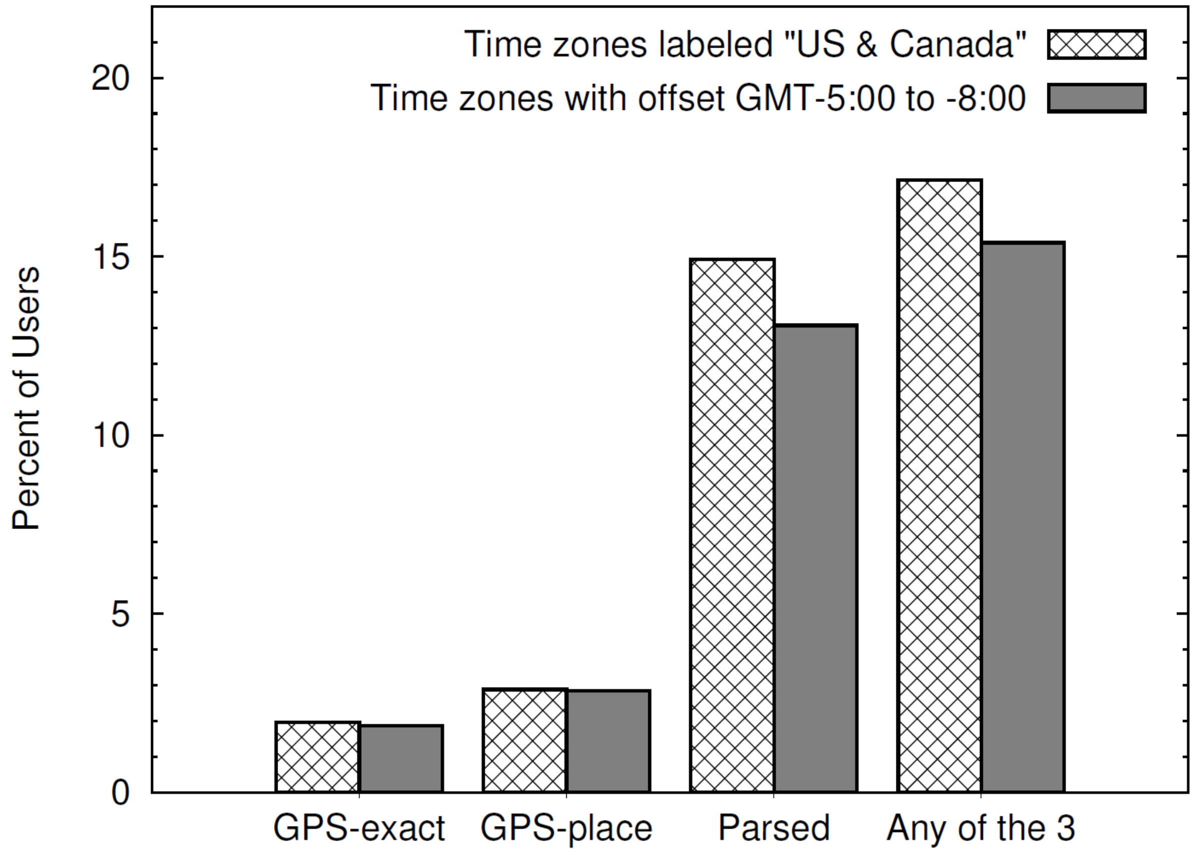


Table 3. Comparison of GPS location data to parsed location data.

GPS location indicator	State name parsed from user profile (n)	Matching parsed and GPS data	
		n	%
GPS-exact	16,009	13,935	87.04
GPS-place	21,092	18,599	88.18
Total	37,101	32,534	87.69

Distribution in the United States

With the parsing method in place, we extended our analysis of location information in Twitter to include parsed state data for the United States. Parsing international location data is a complex task, requiring such tools as standardization, place authority, and handling diverse conventions and languages. Figure 3 shows the proportions of users with parsed state data, with GPS-exact data and with GPS-place data in each state, and the proportions of 2010 US census population in each state. All of the location indicators correlate strongly ($P < .001$) with the population data (GPS-exact $r = 0.97$, GPS-place $r = 0.97$, and parsed $r = 0.98$).

Figure 4 complements Figure 3 by showing the number of Twitter users in each state per capita (ie, divided by the census population) and the median value (0.0015) for the states identified through parsing. This does not represent the total number of registered Twitter users, but rather the number of unique users who posted during our sample period. The relatively high number of Twitter users in the District of Columbia, compared to its population is likely because users identify with and tweet from the metropolitan area, but actually reside in outlying suburbs in different states.

Figure 3. The proportion of Twitter users identified in each state and the proportion of the 2010 US census population in each state, ordered by census population.

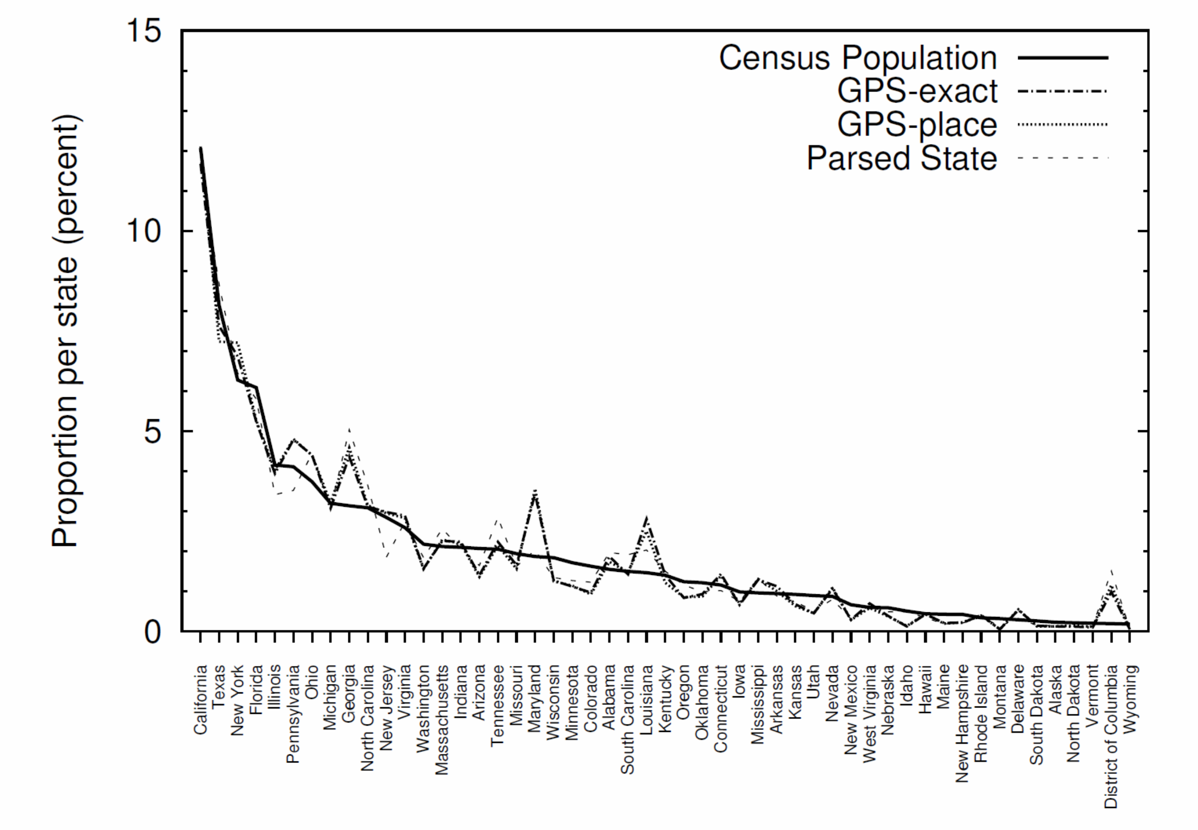
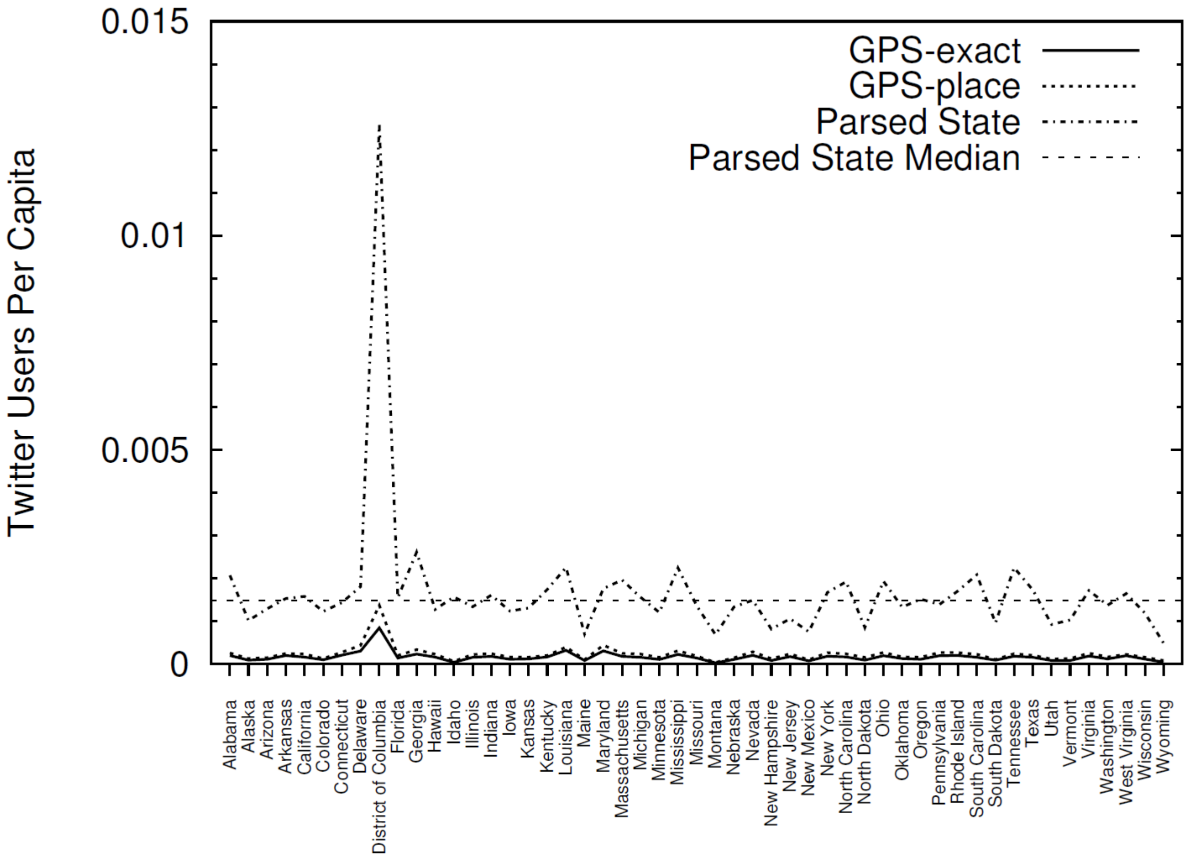


Figure 4. The number of geolocated Twitter users per capita in each state.



Discussion

The purpose of this study was to document the prevalence of the location identification options available through Twitter and to present an estimate of the usability of each option. We have shown that there are several location indicators in Twitter and, when taken together, they offer a sizable sample of individuals whose location can be accurately inferred. This has clear implications for infoveillance, infodemiology, and "right time, right place" health communication.

Although only a small percentage of Twitter users provide reliable GPS coordinates (2.70%), there is actually a large number of users (and tweets) with GPS data because of the size of the overall data set. In the 2-week period of this study, the 2.02% of tweets that contained GPS information corresponded to 481,179 tweets. Because the sample is only 1% of the overall traffic on Twitter during those 2 weeks, if the same proportion were to hold true in the larger sample, we could infer that there were about 48 million tweets with GPS information posted during that period. With 2.5 tweets per user, this would correspond to approximately 19 million individuals. Furthermore, we saw that user-supplied location information matched GPS data in 87.69% of cases (in the United States). Hence, one could reliably use location information for between 15.35% and 17.13% of users. Interestingly, Keeter and colleagues compared the results of a 5-day survey employing the Pew Research Center's methodology (with a 25% response rate) to those from a more rigorous survey conducted over a much longer field period and achieved a higher response rate of 50% [32]. In 77 of 84 comparisons, the 2 surveys yielded results that were statistically indistinguishable. Thus, it appears that surveys with lower response rates (20%) were only minimally less accurate. As a result, researchers can have additional confidence to value the location information available from Twitter, a real-time and real-place benefit of social media over traditional survey methodology.

Table 1 also shows that 2.70% of Twitter users broadcast their GPS location. Interestingly, this is a significantly lower figure than the 14% of social media users who use automatic location tagging on posts reported in a recent publication by the Pew Internet and American Life Project [33]. An obvious difference is that the Pew research considers all social media, whereas we have focused exclusively on Twitter. Additionally, some of the respondents represented in the Pew report could be using third-party location-tagging applications (eg, foursquare), which data may not appear in our sample, or they may be tweeting so infrequently that they would be underrepresented in our tweet-based sample. However, even considering these possibilities, the magnitude of the difference suggests that there may be additional factors. This difference warrants future research to determine the extent to which users are even aware that broadcasting GPS location is possible. It is plausible that users are largely unaware of such features or have minimal understanding with respect to how they function, both of which may attribute to this discrepancy.

An additional explanation for this (rather significant) discrepancy between 2.70% and 14% may be the distinct data collection approaches employed: questionnaires administered via phone interviews versus direct observation of user behavior on Twitter. Questionnaires can only report on what people perceive as opposed to what may actually be happening. For example, the question asked in the Pew questionnaire leading to the above result was "Thinking about the ways people might use social networking sites...Do you ever...Set up your account so that it automatically includes your location on your posts?" The answers included "Yes, do this: 14%" and "No, do not do this/have not done this: 84%."

It is possible that respondents believed that GPS location was a default setting. This would lead to the conclusion that they had enabled location tagging for social media on their device, although GPS coordinates were not broadcast. From our own experience with the iPad 1, we found that the device itself may be GPS-enabled, yet the Twitter application on the device is not. Furthermore, the application could be GPS-enabled, yet coordinates are not broadcast because the location setting is not activated in the Twitter profile. In that sense, it is possible that someone may think that their tweets are location-tagged when, in fact, they are not. In this way, public health may benefit from eliciting additional location information that can be provided in the actual tweet. Twitter users who are otherwise willing to reveal their location, but are unaware of the default privacy settings, could be encouraged to provide such information. For example, followers of Twitcident (http://twitcident.com), a Dutch-based system for filtering emergency-related tweets, may feel inclined to tweet the location of emergency situations in an effort to assist emergency responders. Twitter prompts that ask users to tweet about their favorite locations to exercise may be useful in helping authorities allocate resources for promoting active lifestyles in areas where they are most likely to be successful.

As observed in this study, the parsed state data matched the GPS-derived state data 87.69% of the time. A mismatch does not necessarily mean that the user-supplied location was inaccurate or purposefully misleading, but it could represent a user tweeting from a business trip or vacation, or working in a metropolitan area across state lines. In this regard, the percentages in Table 3 are a lower bound and validate that the majority of the user-supplied locations are accurate for those users who provide GPS data and have profiles that can be parsed with our method. However, there is a potential bias in that users who are willing to broadcast their location might be more likely to tell the truth in their profile. Also, users who are unwilling to give an accurate profile location may be more likely to leave it empty or provide a non-descriptive location, as opposed to supplying an inaccurate, yet well-formed, location. This could be the focus of future research aimed at determining the extent to which Twitter users enable/disable GPS broadcasting and their reasons for doing so. For example, Twitter users vacationing in an exotic location may wish to enable GPS broadcasting, whereas others may disable broadcasting if their desire is to remain anonymous. This assumes that these users are aware of the toggle settings available for GPS broadcasting. Studies of this nature could establish the basis for determining the representativeness of GPS-enabled tweets. Moreover, this finding may question Twitter's utility as a means for providing "right time, right place" tailored interventions, considering the location may not reflect the user's actual setting, provided he or she knowingly deactivates location.

As presented in this study, there is a significant level of consistency between the proportion of location-tagged tweets and state populations in the United States. This finding indicates that, at least within the United States, there is no evidence of disproportionate GPS enabling among states. Although much more information is needed to assess the true qualitative representativeness of Twitter (eg, ethnicity, age, and gender), this quantitative consistency is promising. Whereas it was beyond the purview of the current study to assess the validity of social media data, for public health researchers and communicators to dismiss such data sources without further consideration would be premature because it may miss an opportunity to observe, reach, and communicate with people in unprecedented ways. And although it is unlikely that social media could ever completely replace more traditional research methods (eg, questionnaires), it can certainly complement them and add a further dimension to research.

In conclusion, we note that we have focused our attention on what users can do explicitly to specify their own location information. Although Twitter's opt-in policy for location information is ethically sound, it would be interesting to study what could be done to encourage increased opt-in, for example, by working on dispelling concerns about how information is used or by demonstrating how information can be used for the good of all (eg, the Twitcident app). Furthermore, recent studies have demonstrated that it may be possible to infer location information based on either the words appearing in a user's tweets [34] or the location of a user's friends [35]. Further exploration of these ideas and other means of geographical prediction could augment the amount of location information available in social media.

Acknowledgments

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Conflicts of Interest

None declared.

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Abbreviations

API: application programming interface
app: application
GPS: Global Positioning System
GMT: Greenwich Mean Time

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Original Paper

Searching for Truth: Internet Search Patterns as a Method of Investigating Online Responses to a Russian Illicit Drug Policy Debate

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Abstract

Background: This is a methodological study investigating the online responses to a national debate over an important health and social problem in Russia. Russia is the largest Internet market in Europe, exceeding Germany in the absolute number of users. However, Russia is unusual in that the main search provider is not Google, but Yandex.

Objective: This study had two main objectives. First, to validate Yandex search patterns against those provided by Google, and second, to test this method's adequacy for investigating online interest in a 2010 national debate over Russian illicit drug policy. We hoped to learn what search patterns and specific search terms could reveal about the relative importance and geographic distribution of interest in this debate.

Methods: A national drug debate, centering on the anti-drug campaigner Egor Bychkov, was one of the main Russian domestic news events of 2010. Public interest in this episode was accompanied by increased Internet search. First, we measured the search patterns for 13 search terms related to the Bychkov episode and concurrent domestic events by extracting data from Google Insights for Search (GIFS) and Yandex WordStat (YaW). We conducted Spearman Rank Correlation of GIFS and YaW search data series. Second, we coded all 420 primary posts from Bychkov's personal blog between March 2010 and March 2012 to identify the main themes. Third, we compared GIFS and Yandex policies concerning the public release of search volume data. Finally, we established the relationship between salient drug issues and the Bychkov episode.

Results: We found a consistent pattern of strong to moderate positive correlations between Google and Yandex for the terms "Egor Bychkov" ($r_s = 0.88$, $P < .001$), “Bychkov” ($r_s = .78$, $P < .001$) and “Khimki”($r_s = 0.92$, $P < .001$). Peak search volumes for the Bychkov episode were comparable to other prominent domestic political events during 2010. Monthly search counts were 146,689 for “Bychkov” and 48,084 for “Egor Bychkov”, compared to 53,403 for “Khimki” in Yandex. We found Google potentially provides timely search results, whereas Yandex provides more accurate geographic localization. The correlation was moderate to strong between search terms representing the Bychkov episode and terms representing salient drug issues in Yandex–“illicit drug treatment” ($r_s = .90$, $P < .001$), "illicit drugs" ($r_s = .76$, $P < .001$), and "drug addiction" ($r_s = .74$, $P < .001$). Google correlations were weaker or absent–"illicit drug treatment" ($r_s = .12$, $P = .58$), “illicit drugs ” ($r_s = -0.29$, $P = .17$), and "drug addiction" ($r_s = .68$, $P < .001$).

Conclusions: This study contributes to the methodological literature on the analysis of search patterns for public health. This paper investigated the relationship between Google and Yandex, and contributed to the broader methods literature by highlighting both the potential and limitations of these two search providers. We believe that Yandex Wordstat is a potentially valuable, and underused data source for researchers working on Russian-related illicit drug policy and other public health problems. The Russian Federation, with its large, geographically dispersed, and politically engaged online population presents unique opportunities for studying the evolving influence of the Internet on politics and policy, using low cost methods resilient against potential increases in censorship.

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KEYWORDS

Russia; search engine; drug dependence; policy

Introduction

This is a methodological study investigating the online responses to a national debate regarding an important health and social problem in Russia. Russia has the largest Internet market in Europe, exceeding Germany in the number of users. However, Russia is unusual in that the main search provider is not Google, but Yandex. By exploring the relationship between Yandex and Google, this study contributes to the methodological literature on analysis of search patterns for public health policy.

Theory

Studies of Internet search patterns provide a low cost, rapidly accessible data source across a range of disciplines. Underpinning these studies is the principle that each Internet search is a behavioral measure of an issue’s importance to an individual [1]. If individuals are concerned or interested in an issue, they are more likely to search for information related to that issue. The relative importance of an issue can thus be inferred from the volume of search queries for a specific term or terms representing that issue.

Infodemiology and Infoveillance

The first studies of Internet search patterns were related to medicine. These initial studies examined the quality of online information [2], searches for cancer related information [3], and influenza surveillance use diverse data sources including Google advertisements [4], and Yahoo search trends [5]. However it was the release of Google Insights For Search (GIFS) [6] and the publication of 3 influential articles in 2009 that provided an impetus to this emerging field. The 3 influential articles are Ginsberg's study of influenza surveillance using Google data in Nature [7], Brownstein's review of online surveillance in the New England Journal of Medicine [8], and Eysenbach's consolidation of infodemiology as a distinct field of medical inquiry [9]. Eysenbach describes infodemiology as “the science of distribution and determinants of information ...specifically (on) the Internet, or in a population, with the ultimate aim to inform public health and public policy...(including) data on what people browse, buy, and read”. Where infodemiology methods are used for epidemiological surveillance, Eysenbach refers to this as infoveillance. Since 2009, Google data has been the main data source for infodemiology studies, across a wide range of health problems including dengue [10], depression [11], abortion [12], tobacco control [13], and the global Google Flu Trends site [14].

Analysis of Search Patterns in Political Communications

Infodemiology methods have also been applied to the study of political communications and policy processes [1,2-20]. These studies are generally founded on agenda setting theory, and use Internet search patterns as a data source to complement opinion polling or traditional media (ie, television and print) coverage. Agenda setting theory suggests that issues prominently covered in traditional media are subsequently ranked as important (or salient) in public opinion polls [21,22]. The transfer of issue salience from reporting in the media to influence public opinion is an important concept in agenda setting theory [23]. Agenda setting theory appears in health advocacy studies [24], but has not yet been incorporated into studies of Internet search patterns for health policy processes.

Agenda Setting Online

Since the early 2000s, studies of issue salience have increasingly focused on the interplay between traditional, online media, and the public agenda. A study of online bulletin board discussions found that media reports were rapidly reflected in online discussions [25]. Rather than several weeks, themes emerged in online discussions within days of traditional media reports. More recent studies have used GIFS to measure and analyse search patterns in responses to prominent media issues. Granka suggests that issue importance can be inferred from overall changes in search query volume, and that search volumes rise and fall rapidly with public interest [1]. Similarly, Scharkow suggests search patterns are the behavioral effects of salience, and provide valid and reliable measures of the public agenda [18].

Is the Issue Salience Applicable Outside High Income Liberal Democracies?

Most studies of issue salience using search have been conducted in the United States and Organization for Economic Cooperation and Development (OECD) countries. However, there is some uncertainty as to whether the transfer of salience from traditional or online media to public opinion is universally applicable in low and middle income countries with different institutional arrangements. For example McCombs suggested that agenda setting effects require a reasonably free political system and media [26]. Other authors too, have noted the lack of research into how media shape public opinion in less-than-democratic nations. For example, Moy and colleagues point to "a glaring absence of (research about)... how citizens in these states respond to specific televised messages or their attitudes regarding certain political and social issues" [27]. This means it is difficult to infer public opinion from findings of issue salience in online media outside of high income liberal democracies.

The State of Russian Traditional and Online Media

The Russian Federation is a middle income country with institutional arrangements that sharply contrast to those in the US or European Union (EU). Contemporary Russia has been described as a managed democracy [28] and an authoritarian state [29]. Several studies have pointed to a complex relationship between Russian traditional media, online media, and public opinion. A study of Russian's reactions to news broadcasts in 2005 reported marked differences between Russian and US viewer reactions to television news [30]. Russians were found to adopt a range of cognitive strategies, routinely reinterpreting the frames presented in television news stories using complex reasoning outcomes. These strategies were, the authors suggested, consistent with Soviet-era television viewing. Others have noted unique patterns of online media use. In 2009, Russians were the most engaged social media users globally [31]. Further, Russians engaged in unusually heterogeneous debates ranging across the political spectrum, as distinct from the partisan “echo chambers” that characterize online debate in the US [32]. These studies caution against a simple transposition of agenda setting and issue salience theories to traditional and online media. This suggests more complex process than that suggested by agenda setting and issue salience theories.

Importance of Online Search in the Russian Federation

In 2011, Russia overtook Germany as the European country with the highest number of unique visitors online [33]. Russian Internet users grew from 43% of the population in 2010 [34] to 55% in 2012 [35]. In May 2011, Google provided 84% of Internet search queries globally [36]. The structure of the Russian-language Internet market is unique. Yandex provided 60% of Russian Internet searches in 2010-2011, compared with Google's 25% [37]. Further, Yandex offers the Wordstat (YaW) search pattern analysis tool as a direct competitor to GIFS (Table 1).

Table 1. Comparison of GIFS and YaW.

	GIFS	YaW
Daily data availability	2004-present for specified range	No
Weekly data availability	2004-present by default	12 months
Monthly data availability	2004-present for specified range	2 years
Time lag to availability	24 hours	8 weeks
Data display	Relative to 100% in selected date range (eg, 73% on 4 June over June - July 2011 range)	Absolute raw figure(eg, 213515)
Normalized and scaled	Yes; algorithm non-transparent	No; raw absolute values
Threshold value	Yes; algorithm non-transparent	No; raw values
Issue comparison	Yes	No
Geographic specificity	Limited	Detailed sub-regional data
Comparison concurrent terms	Yes	No
Non-English search terms	Yes	Yes

Russian Online Media

In response to political and media constraints, Russian political debate increasingly moved online during the 2000s, using platforms such as LiveJournal [38], and more recently, Twitter [39]. RuNet has been described as a catalyst for social activism [40] political mobilization [41], as well as a channel for an alternative news agenda [42]. As Internet use grew, corruption and abuses of government power emerged as important themes online. (See for example the anticorruption blog Rospil.net [43]). By 2012, the proliferation of Russian social commentary blogs prompted a Harvard study to described Russian online media as a “transparency watchdog” [39].

RuNet's rapid growth led Russian media commentators to speculate that the Internet had eclipsed television’s traditional agenda setting function in importance [44,45]. However, other observers have cautioned against overstating the importance of Russian online media, or its distance from mainstream practices. Less optimistic observers have described pro-government blogging campaigns [46], cyber attacks [47], monitoring dissent [48], and sophisticated security filtering through SORM 2 [49]. National surveys too, suggest a more modest role for online media in shaping public opinion. A 2012 survey found 63% of Russians mostly or completely believe traditional media, while 43% mostly believe online sources [50]. In summary, as elsewhere, online media provide Russians with an information source complementing traditional media.

Method

This is a methodological study that makes use of the unique characteristics of the Russian Internet search market. Firstly, we aimed to validate Yandex search patterns against those provided by Google. Secondly, we tested this method's adequacy for investigating online interest in a 2010 national debate over Russian illicit drug policy. In order to achieve these two aims we sought answers to the following questions:

1) What is the relationship between Google and Yandex search results?

2) What do search intensities and patterns reveal about the relative importance of an event?

3) How timely and geographically precise are GIFS and YaW results?

4) How do the search patterns during a national debate relate to salient drug issues?

Methodological Considerations

Researchers have devoted considerable effort to establishing the validity of search pattern studies. Validity is the extent to which a test measures what it claims to measure [51]. The initial studies using GIFS established a correlation between search patterns and epidemiological surveillance data for influenza [7]. Other studies focusing on issue salience, established a correlation between search patterns, traditional media [1], and opinion polling [17]. Studies with large data sets have commonly employed ARIMA tests [52] vector auto regression and visual comparison [53], and multivariate regression [17]. Studies with smaller sample sizes have generally conducted bivariate analysis with little or no data preparation [18,54].

Several common warnings concerning validity recur in studies of search patterns. The unrepresentative demographic sampling of GIFS populations is the most frequently cited concern. The Internet user population is generally regarded as younger and wealthier than the overall population, although this cannot be elicited from search data directly [53]. Scharkow et al expand on this concern, questioning whether survey populations from traditional surveys and search pattern studies are comparable [18].

The second concern relates to the disambiguation of search terms. Individual search terms may return ambiguous search results. Care with selection of search terms, and an appropriate range of search terms is necessary to capture the breadth of potential search terms for a concept [55].

Third, several problems are associated with the limited transparency of Google's treatment of data. Google does not reveal the threshold search volume used to determine whether data is reported on a search term in GIFS [56]. This can produce unexpected zero values in time series. Further, Google provides results as relative rather than absolute data (That is, GIFS results are provided as a percentage relative to 100% during the user-defined date range-eg, 30% during June 2010). In addition, GIFS data is normalized and scaled, making comparisons between countries, regions and time spans difficult. Despite these limitations, there is a general consensus in the scholarly literature cited above that GIFS is a valid, low cost and flexible field research method. By analyzing online response to a Russian illicit drug policy episode, we hope to develop further develop the methods of search pattern analysis.

The Bychkov Episode

Illicit drug use is a serious social and policy problem in Russia. Russian public opinion surveys have consistently rated illicit drug use among the most serious of domestic social problems [57,58]. However, Russian policy responses to this problem are generally regarded as punitive, unsupported by scientific evidence, and ineffective [59]. The punitive aspect of Russian drug policies is exemplified in 2010 by a law prohibiting dissemination of drug related health information [60]. In this complex environment, Russian reformers have compared attempts at influencing drug policy to "throwing spaghetti against a wall, and seeing what will stick” [61].

We selected the public debate surrounding the court case against socially conservative drug policy reformer Egor Bychkov as our case study. Bychkov was the president of an NGO operating a non-medical drug rehabilitation center in the provincial Urals city of Nizhny Tagil, 1900 kilometers east of Moscow. In October 2010, a local court convicted Bychkov of holding several rehabilitation clients hostage. His subsequent imprisonment sparked widespread coverage in the Russian national media. Although Bychkov was outspoken in expressing reactionary social attitudes [62] and his belief in harsh, unscientific treatment methods, he won support from socially liberal as well as conservative commentators for bringing the fight against corrupt local courts and police into the open [63]. In November 2010, following national media support, and presidential intervention, Bychkov was released on parole [64]. In June 2011, all criminal charges against Bychkov were finally annulled [65]. In 2011, having achieved national prominence, Bychkov collaborated with leading liberal bloggers and opposition politicians in Moscow [66]. In summary, the Bychkov episode was one of several concurrent episodes of opposition to Russian government policies. In each case, traditional media sparked and spread popular outrage, leaving patterns of online search.

Questions

What is the Relationship between Google and Yandex Search Results?

We took the approach that this was an initial investigation with a small data set, and following earlier studies, did not cleanse data [54]. This approach had the added advantage of allowing us to quantify threshold and relative data problems in GIFS. Our data collection and analysis involved the following steps.

First, we used the terms "Bychkov" and "Egor Bychkov" to represent the Bychkov episode. We used additional terms unrelated to the Bychkov episode to provide additional context for the Bychkov episode, and to test for the validity of correlation between GIFS and YaW. We identified the main Russian domestic news events of 2010 from end-of-year compilations on government and non-government media organizations (Table 2). Further detail about this process appears below.

Second, we extracted search data series for terms representing the Bychkov episode and concurrent events from GIFS and YaW. Studies demonstrating online responses to media events typically use weekly or daily GIFS data (eg, [16]). Weekly GIFS data and monthly YaW data were available. Daily GIFS data was unavailable, and most weekly GIFS data series recorded zero values for one or more weeks during this date range. We managed this by combining the weekly GIFS ratios, including zero values, to produce a GIFS value for each month.

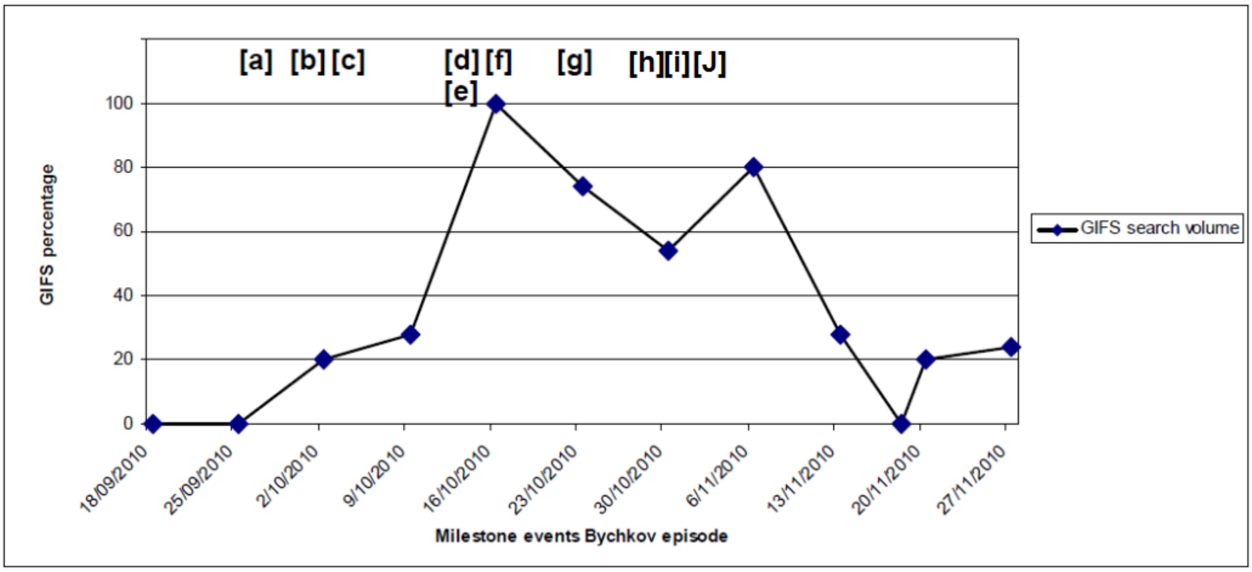
This produced one time series of monthly GIF values, and another of YaW monthly values. We used monthly data in the date range between March 2010 and March 2012, as these were the maximum data points available in YaW. While this produced fewer data points than some previous studies, these were sufficient to conduct a correlation analysis. We were aware monthly data was not sufficiently frequent to establish relationships between salient media issues and online search patterns.

Third, in the absence of daily or weekly data, we corroborated events during the peak period of interest in the Bychkov episode with other available measures. We created a graph plotting GIFS daily searches against relevant media reports identified in Bychkov's blog (Figure 1). We anticipated that the one month time range between data points would make it difficult to distinguish changes in the relationship between individual news events and increased search. We therefore turned to a weekly GIFS series to provide visual corroboration of the relationship between traditional media and search patterns over the period of maximum public and media attention to the Bychkov episode.

Fourth, we conducted bivariate analysis of GIFS and YaW data. We plotted peak monthly GIFS and YaW monthly search values to produce two time series for each search term (Table 3). Given the diversity of approaches in previous studies and limitations in available data, we chose to restrict our statistical analysis to Spearman Rank Correlations only, with the aim of establishing convergent validity between GIFS and YaW results. In the case of the GIFS time series, the zero GIFS values were artifices of censoring. This meant that variations in the GIFS searches were restricted, and therefore the correlation was biased downwards. The true correlations were likely to be stronger than the estimated statistic.

Consistent with our study aim to minimize treatment of data, we did not adjust for seasonality. Moreover, we did not assess stationarity or autocorrelation in the data, or conduct formal time-series analyses, partly because this was consistent with the study aims, and also in response to the threshold issues in the GIFS data, which would bias any attempts to stationarize the data or measure autocorrelation.

Figure 1. Google Insights for Search (GIFS) and milestone events in the Bychkov episode. [a] 25 September 2010 Radio Echo Moscow national broadcast about Bychkov episode 1 [11] [b] 30 September 2010 Egor Bychkov Youtube public message posted [67] [c] 2 October 2010 Radio Echo Moscow national broadcast about Bychkov episode 2 [68] [d] 12 October 2010 Nizhny Tagil Court sentences Bychkov to 3.5 year prison term [69] [e] 12 October 2010 President Medvedev publicy promises to resolve Bychkov issue [70] [f] 13 October 2010 National current affairs program dedicated to Bychkov episode [71] [g] 23 October 2010 Russian MPs debate Bychkov case on national TV [72] [h] 30 October 2010 National current affairs program dedicated to Bychkov episode [73] [I] 1 November 2010 National current affairs program dedicated to Bychkov episode [74] [j] 3 November 2010 Bychkov released from prison [75].



What do Search Patterns Reveal about the Relative Importance of an Event?

The Bychkov episode was one of a series of important domestic Russian political events in the second half of 2010. Other concurrent events included the mismanagement of nation-wide forest fires, the Khimki forest clearance protests [76], and the "blue buckets" protests against the abuse of road privileges by economic elites [77]. We identified seven protest-oriented Russian domestic events concurrent with the Bychkov episode from end-of-year compilations on government and non-government media organizations (Table 2). We selected a single term to represent each event from the terms contained in the end-of-year compilations. We used these additional search terms to provide additional context for the Bychkov episode in a complex political and media environment, and as an additional source of data with which to test the correlation between GIFS and YaW.

We then conducted limited corroboration of search patterns against opinion polls. We incorporated data from the openly accessible FOMnibus weekly national opinion poll [78] for each concurrent event. Please refer to Table 3. From FOMnibus, we used single peak values only, as an indicative measure of peak public awareness.

Table 2. Main events in 2010 from national Russian sources.

WCIOM [a]	RIAN [b]	Russia Today [c]	Gazeta.ru [d]
Non-government source(partially ranked)	Government source(ranked)	Government source(unranked)	Non-government source(unranked)
Forest fires	Forest fires	Moscow metro bomb	Forest fires
2018 soccer world cup	Civil society actions including Khimki forest, Egor Bychkov, blogger Kashin assault, Manezhnaya riots	START treaty	Luzhkov fired
Winter Olympics Sochi	Moscow metro bomb	Polish President killed in Smolensk plane crash	Khodorkovsky trial
Manezhnaya race riots	START treaty	65 years of Soviet Victory WW2	Manezhnaya race riots
Luzhkov fired	Administrative reforms	Forest fires	US spy scandal
	2018 soccer world cup	Luzhkov fired	Wikileaks
	Wikileaks	Khodorkovsky trial	START agreement
	US spy scandal	2018 soccer world cup	
	Police reforms		

[a] wciom.com 2010: Persons and events of the year 2010 [79]

[b] RIAN Main events of the year: fires, drought, terrorism in the metro and START 2010 [79]

[c] rt.com Russia’s ups and downs in 2010: the final cut 2010 [80]

[d] gazeta.ru Between fire and ice - main political events of the year 2010 [81]

How Timely and Geographically Precise are GIFS and YaW Results?

In order for search pattern data to complement existing data sources, it should offer advantages in cost, timeliness or access to data. It was the availability of valid search data in advance of traditional surveillance that initially generated interest in this field. There are several differences related to the timing and geographic precision of data released by Google and Yandex. A comparative overview of the properties of public data released by these two search providers is outlined in Table 1. In Table 3, we compared the GIFS and YaW search term results for the Bychkov episode and concurrent events for Moscow, and separately for the remainder of Russia. Importantly, neither Google nor Yandex release all their data. For example, YaW can determine the physical location of individual users to their postcode, through Internet Service Provider (ISP) hardware locations [82]. However, YaW only reveals public location data aggregated to the sub-provincial level, after two months. Google enforces similar restrictions on data availability. Commercial considerations by both search providers selling online advertising, rather than data availability, limit the release of precise and timely geographic location data.

How do the Search Patterns during a National Debate Relate to Salient Drug Issues?

Illicit drug use and treatment are important Russian social and policy problems. We examined search patterns in order to establish the relationship between online responses to the Bychkov episode and illicit drug issues. Firstly, we identified the two main themes associated with the Bychkov episode. These were corruption (police and judicial), and drug issues. In order to identify these high level themes, we hand coded all 420 primary posts published on Bychkov’s personal blog [83] in the date range March 2010 to March 2012. In order to identify these themes, two Russian-speaking researchers coded the primary and secondary themes in the body of each blog post, but excluded comments from readers. This resulted in 28.6% of blog posts coded as drugs (including addiction, illicit drugs, drug treatment, alcohol and tobacco), 18.3% as corruption (all sources including police and judicial) and 53.1% covering 17 other codes (including the Bychkov court case, Russian politics, the Orthodox Church, nationalism, pollution, sport, disability and philanthropic services). We assessed intercoder reliability on a random third of the total primary posts across the three themes (*Kappa* = 0.78). Consistent with the aims of this study, we then focused on the drug theme only.

Second, from Bychkov’s blog we identified the main drug themes in media reports about the Bychkov episode. We identified 57 separate national media reports referring to the Bychkov episode on Bychkov's blog within the study date range. These media reports were coded, and aggregated to two main themes, drugs and /or corruption. From the reports covering drugs, we then identified three main drug sub-themes. These were "addiction" (*narkomania*), "illicit drugs" (*narkotiki*), and "drug treatment" (*lechenie narkomanii*), which resulted in 29.2% coded for drugs (including sale and purchase), 30.1% for addiction (including use and dependence), and 39.8% for drug treatment (including medical and non-medical rehabilitation). We then assessed intercoder reliability on a random one-third sample of the total coded articles (*Kappa* = 0.75). All events referred to in Bychkov’s blog posts were corroborated using the websites of government news agency RIA-Novosti and non-government news sources.

Third, we established the relationship between search patterns for drug themes and the Bychkov episode. We did this by defining search terms, date ranges and minimizing confounding between search providers. We used the three drug themes (addiction, illicit drugs, and drug treatment) as search terms representing salient drug issues. We then investigated the relationship between these terms and the Bychkov episode, through Spearman Rank Correlations. To increase sensitivity and minimize ambiguity, we restricted search to “Egor Bychkov” to represent the Bychkov episode. Further, we restricted the date range to June 2011- June 2011. This date range search coincided with the period of Bychkov's maximum national media exposure. Finally, we conducted separate correlations within GIFS and within YaW, to prevent confounding between search providers.

Results

We were able to gather data to achieve the two aims of this study. We gathered data with which to validate Yandex search patterns against those provided by Google. Secondly, we gathered data to test the adequacy search pattern analysis for investigating online interest in a 2010 national debate over Russian illicit drug policy. Our results are discussed in more detail below.

What is the Relationship between Google and Yandex Search Results?

Google and Yandex search results were positively correlated overall. We found a consistent pattern of strong to moderate positive correlations between the two search indices for the same term, both for the Bychkov episode and concurrent political events (Table 4). However, the relationship was weaker than anticipated. For example, “illicit drugs” has a weak negative relationship (r=-0.15). This was likely the result of GIFS returning zero values over several weeks during the specified data range. For example, GIFS searches for the term “Bychkov” displayed zero values in April, June and August 2010. During this period, YaW consistently recorded 54,000-68,000 searches per month. This is an example of the GIFS “threshold value” problem identified in earlier studies [18,65]. Within any selected date range, GIFS scales search results relative to a 100% value within that range. This scaling produces different results depending on the date range selected. This effect on GIFS data is only evident when compared with YaW data. For example, GIFS search for the term “illicit drug addiction” returned 100% in October 2010 (date range March 2010-March 2012), and 100% in November 2011 (date range November-December 2011). YaW values for these peaks GIFS dates were 132,000 and 167,102, respectively (Table 4). In summary, we were able to quantify patterns of missing data identified in earlier studies based on the use of GIFS data.

Visual examination of weekly results (Figure 1) suggests weekly peaks in GIFS indices corresponded to major milestones during the Bychkov episode. This provided further non-statistical corroboration, and face validity to the relationship between media reports and GIFS searches during the Bychkov episode.

Table 3. Correlation between GIFS and YaW of monthly frequency of search terms from March 2010 to March 2012.

Search item	Russian	Correlation (rs)	*P*	Percentage of searches originating in Moscow according to YaW
Bychkov episode				
Egor Bychkov	Егор Бычков	.88	< .001	32
Bychkov (surname)	Бычков	.78	< .001	26
Illicit drug addiction	Наркомания	.72	< .001	21
Illicit drugs	Наркотики	-0.1	.64	23
Drug addiction treatment	лечение наркомании	.53	.008	38
Concurrent events 2010				
Fires	Пожары	.88	< .001	25
Forest fires	лесные пожары	.62	< .001	20
Khimki forest protests	Химкинский Лес	.92	< .001	65
Yury Luzhkov(Moscow mayor Luzhkov forced resignation)	Юрий Лужков	.82	< .001	50
Central Moscow football and race riots, and death	Манежная	.76	< .001	51
Jailed oligarch Khodorkovsky court proceedings	Ходорковский	.8	< .001	43
Blue buckets car protests	синие ведерки	.86	< .001	64

What do Search Patterns Reveal about the Relative Importance of an Event?

We found search volumes for the Bychkov episode were comparable to other prominent domestic political events during 2010 (Tables 4 and 5). GIFS values provide indicative comparisons of the relative importance of an event. However, YaW provides detailed raw numbers, allowing direct comparison of search patterns for an event across regions and across time. These tables provide comparative measures of the search volumes for the Bychkov episode and other concurrent events.

Table 4. Peak interest in the Bychkov episode based on Public Opinion Foundation (FOM) GIFS and YaW during 2010.

Search term	Peak weekly national opinion poll - FOM - % of respondents" Which events reported in the media over the last week attracted your attention?"	Peak week GIFS (100%) (week ending)	Peak month YaW(absolute counts)
Egor Bychkov [84]	6-7 Nov 2011 <3% (bundled with criminal events and court cases)	16 Oct 2010	Oct 2010 (48,084)
Bychkov [84]	6-7 Nov 2011 <3% (bundled with criminal events and court cases)	16 Oct 2010	Oct 2010 (146,689)
Illicit drug addiction	Topic not measured in FOM	22 May 2010 and 4 Dec 2010	Nov 2010 (170,485)
Illicit drugs	Topic not measured in FOM	22 May 2010	Nov 2010 (490,026)
Drug treatment	Topic not measured in FOM	Weekly data unavailable 100% in Oct 10	Nov 10(9512)

Table 5. Peak interest in Russian domestic events concurrent with the Bychkov episode based on Public Opinion Foundation (FOM) GIFS and YaW during 2010.

Search term	Peak weekly national opinion poll - FOM - % of respondents "Which events reported in the media over the last week attracted your attention?"	Peak week GIFS (100%) (week ending)	Peak month YaW (absolute counts)
Fires [85]	6-7 August 2010 67% (Anomalous heat, drought, loss of the harvest, forest fires, natural catastrophes)	2 August 2010	August 2010 (22,122,660)
Forest fires [85]	6-7 August 67% as above	7 Aug 2010	August 2010 (215,397)
Manezhnaya race riots [86]	18-19 December 2010 30%	18 Dec 2010	December 2010 (408,283)
Khodorkovsky [87]	15-16 January 2011 1%	1 Nov 2011	December 2010 (199,262)
Yury Luzhkov [88]	25–26 September 2010 2%	Unavailable	September 2010 (151,743)
Khimki forest protests [89]	4-5 Sept 2010 <2% (bundled with other domestic events)	2 Oct 2010	October 2010 (53,403)
Khimki forest protests [90]	18-19 Sept 2010 <2% (bundled with other domestic events)	As above	As above
Blue buckets	Nil 0%	24 April 2010	September 2010 (39,140)

How Timely and Geographically Precise are GIFS and YaW Results?

Google potentially provides timely search results, whereas Yandex provides more accurate geographic localization. However, both GIFS and YaW place restrictions on the data made available to the public. These restrictions are outlined in Table 1. Whereas GIFS potentially provides detailed, near real time daily data, we found gaps in actual data availability. For example, only weekly data was available for the search terms "Bychkov" and "Egor Bychkov". We described these gaps above in relation to GIFS threshold, scaling and normalization policies.

GIFS does not provide detailed subnational geographic location data in Russia. However, YaW provides disaggregated search data to the level of individual Russian provincial cities. This differentiation is important, as several of the most important domestic political events during 2010 were associated with events around the Russian capital Moscow. For example, the widely-reported Khimki forest and blue buckets protests, revealed an average of 65% and 64% of searches originating in Moscow (Table 3). This result suggests the protests were relatively more important to Moscow residents, even while Russian and international commentators ascribed national significance to these events [91,92]. By contrast, only 26% of searches for the term "Egor Bychkov" came from Moscow, and the remainder from other parts of Russia. The Bychkov episode also generated greater absolute search volumes. These two results suggest the Bychkov episode was more important across Russia than the metropolitan protests.

How do the Search Patterns during a National Debate Relate to Salient Drug Issues?

We found moderate to strong positive correlations between search terms representing the Bychkov episode and terms representing salient drug issues in Russian media. In YaW, we found a moderate positive correlation of the term “Egor Bychkov” with the terms "illicit drugs" (r_s = .77), "drug addiction" (r_s = .74), and a strong correlation with “illicit drug treatment” (r_s = .90). These correlations suggest searches for “Egor Bychkov” were positively correlated to salient Russian drug issues (Table 6). GIFS produced weaker or absent correlations. We attribute this to missing data as described earlier.

Table 6. Relationship between Bychkov episode and substantive drug policy issues.

	Date range	r_s	P
GIFS correlations			
Egor Bychkov & Illicit Drugs	June 2010-June 2011	-0.29	.17
Egor Bychkov & drug addiction	June 2010-June 2011	.68	< .001
Egor Bychkov & illicit drug treatment	June 2010-June 2011	.12	.58
Yaw correlations			
Egor Bychkov & Illicit Drugs	June 2010-June 2011	.76	< .001
Egor Bychkov & drug addiction	June 2010-June 2011	.74	< .001
Egor Bychkov & illicit drug treatment	June 2010-June 2011	.90	< .001

Discussion

This study contributes to the methodological literature on the analysis of search patterns for public health policy. Firstly, we aimed to validate Yandex search patterns against those provided by Google. GIFS results have been validated against relevant offline measures across a range of scholarly domains, and across a range of countries. We were able to establish strong to moderate correlations for most search terms between GIFS and YaW. This suggests the use of YaW is a valid measure of online behavior in Russia.

We tested this method's adequacy for investigating online interest in a 2010 national debate over Russian illicit drug policy. Our use of available monthly data was insufficient to establish a statistical relationship between media reporting and search patterns for the Bychkov episode. However, we corroborated the relationship between media reporting and the Bychkov episode through the use of GIFS data within a restricted date range, opinion polling data, and media coverage. We were able to establish face validity. This suggests that media reporting influenced online behavior during the Bychkov episode. These findings are discussed in more detail below.

Google and Yandex Search Results are Positively Correlated.

Previous studies have established the validity of GIFS data through relevant offline measures. This is the first study to validate GIFS results through YaW. We believe this approach has several advantages in the Russian-language context. By exploring the relationship between Google and Yandex search patterns in response to a drug policy debate, we were able to quantify several previously identified limitations of GIFS. We demonstrated shifting GIFS threshold values, and the extent of GIFS scaling and normalization of data through reference to YaW search results.

The presence of zero values in GIFS results merits additional discussion. The zeroes are artifices of censoring and that this means that variation in GIFS has been restricted, and therefore the correlation is biased downwards. The true correlation is likely to be stronger than the estimated statistic. The logic for the expected downward bias is that GIFS and YaW appear not to be substitutes, based upon the positive data observed.

Although time series in nature, the data were not adjusted for seasonality or non-stationarity, and autocorrelation was not assessed. This might have biased the results towards stronger, but spurious, correlation. However, this cannot currently be assessed due to the effect of the threshold used in reporting the GIFs data. If GIFS and YaW were substitutes this would bias the results in favor of a stronger negative correlation, which was not observed; if GIFS and YaW were complements (or if seasonality was strong), this would bias the results in favor of a stronger positive correlation. These issues will need to be explored in further analyses using larger and more transparent data.

At the same time, this result highlights some of the current limitations of publicly available search tools as a data source. Search pattern studies have emerged as an opportunistic response to the availability of GIFS and YaW marketing tools. The data Google and Yandex make available through these tools is only a small portion of that collected. Most of the limitations on data availability described in this paper are in fact constraints on data release imposed by the search providers themselves. Further, search providers routinely make changes to their services. For example, in September 2012, Google merged GIFS into the Trends online analysis service, incorporating GIFS capabilities into the latter [93].

The Bychkov Episode was a Relatively Important Domestic Political Event.

Several studies have deployed GIFS to determine the importance of political episodes, as a low cost and rapid alternative to opinion polling [1,17]. We analyzed domestic events unrelated to the Bychkov episode to provide additional context for the Bychkov episode. We found search volumes for the Bychkov episode were broadly comparable to other concurrent domestic news events. For example, the controversy surrounding the jailed oligarch Mikhail Khodorkovsky was both reported in the domestic media, and produced high search volumes, suggesting this was an important issue. Conversely, the Khimki Forest and Blue Buckets protests produced low search volumes. While all three of these issues attracted international media coverage, our results suggest the last two of these were not important to Russians nationally. We did not set out to examine constraints on traditional media on Internet search. Future search pattern studies in Russia should account for the influence of mainstream media constraints on issue salience and Internet search.

Google Potentially Provides Timely Search Results, whereas Yandex Provides More Precise Geographic Results.

Previous studies have described GIFS potential to complement existing public health data sources by providing timely, geographically precise [10,18], and otherwise inaccessible data [54]. Our results suggest timely GIFS data may not always be available in Russia. If GIFS data is missing, researchers will need to wait two months before YaW results are made available. While GIFS may not provide timely data useful for analyzing unfolding events, YaW is certain to provide delayed and detailed data. Geography is especially important in the Russian context. It is a large country, with many provincial cities, and considerable demographic variation. By comparing YaW raw data across specific regions, analysts may discern changes in search patterns for specific search terms across regions and across time. Based on our findings, we believe that YaW offers a potentially valuable tool to Russian drug policy researchers and advocates.

The Bychkov Episode was Positively Correlated with Salient Drug Issues.

Illicit drug use has long been among one of the most important social problems troubling Russians [57]. We demonstrated a positive correlation between searches for Egor Bychkov and drug terms appearing in media reports associated with the Bychkov episode. This relationship merits further analysis. First, based on these results we are not able to distinguish between personal or sociotropic motivations for search [94]. That is, we were unable to determine whether the concurrent increase in searches for the terms "drug use", "addiction", and "drug treatment" were motivated by individual's health problems, or an interest in drug policy issues. This is consistent with Reis and Brownstein's observations concerning searches for US abortion information [12]. Second, unlike opinion polls, search patterns do not provide valency information. That is, search patterns offer no insight as to whether individuals support or oppose a specific issue. Further search terms to differentiate personal and sociotropic motivations, and to gauge valence should be considered in future search studies.

In conclusion, the Bychkov episode provides an opportunity to advance the science of search patterns. This paper investigated the relationship between Google and Yandex, and contributed to the broader methods literature by highlighting both the potential and limitations of these two search providers. We believe that YaW is a potentially valuable and underused data source for researchers working on Russian-related illicit drug policy and other public health problems. The Russian Federation, with its large, geographically dispersed, and politically engaged online population presents unique opportunities for studying the evolving influence of the Internet on politics and policy, using low cost methods resilient against potential increases in censorship. As online use grows further, primary sources of available online data will also grow. Adapting and refining research methods to best take advantage of these constantly evolving primary data sources is likely to present researchers in health policy and political communications with ongoing challenges.

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Conflicts of Interest

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Abbreviations

EU: European Union
FOM: Public Opinion Foundation
GIFS: Google Insights For Search
NGO: Non Government Organization
OECD: Organization for Economic Cooperation and Development
RuNet: Russian Internet
SORM: 2 Russian federal government internet and telecommunications monitoring service
YaW: Yandex Wordstat

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Original Paper

What E-patients Want From the Doctor-Patient Relationship: Content Analysis of Posts on Discussion Boards

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Abstract

Background: People with long-term conditions are encouraged to take control and ownership of managing their condition. Interactions between health care staff and patients become partnerships with sharing of expertise. This has changed the doctor-patient relationship and the division of roles and responsibilities that traditionally existed, but what each party expects from the other may not always be clear. Information that people with long-term conditions share on Internet discussion boards can provide useful insights into their expectations of health care staff. This paper reports on a small study about the expectations that people with a long-term condition (diabetes) have of their doctors using information gleaned from Internet discussion boards.

Objective: The aim of this study was to ascertain what people with diabetes who use Internet discussion forums want from their doctors. The study objectives were to identify what people with diabetes (1) consider their role in condition management, (2) consider their doctor’s role in managing their condition, (3) see as positive elements of their interactions with medical staff, and (4) find problematic in their interactions with medical staff.

Methods: The study used qualitative methodology to explore the experiences, views, and perceptions of individuals participating on 4 Internet message boards. Posts made on the discussion boards were analyzed using the principles of qualitative content analysis. The meanings of sections of data were noted using codes that were developed inductively; those with similar codes were merged into subcategories and related subcategories were combined to form categories.

Results: The key themes identified in the study were ownership of condition management, power issues between people with long-term conditions and doctors, and ways in which people seek to manage their doctors.

Conclusions: People with diabetes valued doctors who showed respect for them and their knowledge, and were willing to listen and openly discuss their options. Patients felt that they could and should take responsibility for and control of their day-to-day disease management. They saw doctors as having a role in this process, but when this was lacking, many people felt able to use alternative means to achieve their goal, although the doctor’s function in terms of gatekeeping resources could create difficulties for them in this respect.

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KEYWORDS

Physician-patient relations; consumer health informatics; eHealth; participatory medicine

Introduction

Management of long-term health conditions is important in terms of costs to health services, and the personal and financial costs to individuals [1]. This includes people receiving the appropriate therapies and how they manage the day-to-day practicalities of their condition.

In many health care cultures, there has been a move away from the idea that health care professionals should take the lead role in how long-term conditions are managed toward encouraging those who are affected to take greater control and ownership of their condition and its management [2]. It has been suggested that greater partnership and sharing of expertise between staff and patients is needed [2]. This changes the relationship that has traditionally existed between health care staff and patients so that how each party sees and enacts their role—and the expectations they have of one another—has become an important part of managing long-term conditions. This study focuses on the expectations that e-patients with a long-term condition (diabetes) have of their doctors.

Background

Long-term conditions have been defined as conditions that affect a person's health that cannot, at present, be cured but can be controlled by medication and other therapies [3]. Having a long-term condition affects the individual's life, but also increases their level of expertise about their health. This has led to the recommendation that people with long-term conditions and health care staff share their expertise to better understand one another's perspectives and develop treatment regimes that meet clinical needs and accommodate the lifestyles and priorities of individuals [2].

Although the ideal is the sharing of expertise between health care professionals and patients and the development of self-management skills in people with long-term conditions, some issues have required clarification or further exploration. If expertise is to be shared, what knowledge each party is expected to contribute merits debate. The UK Department of Health [2] suggests that people with long-term conditions are experts in how their condition affects them, their social circumstances, and attitudes toward risk, values, and preferences, whereas health care professionals have expertise in the diagnosis, disease processes, prognosis, treatment options, and outcome probabilities. Doubts have been expressed about whether patients can attain expertise in the theory behind disease processes and management [4]; however, there have also been suggestions that people who live with long-term conditions may attain greater medical or technical knowledge of their condition than some health care staff [5,6]. In addition, although the principle of sharing expertise is regularly articulated, whether health care staff accept that patient expertise is as valid and important for condition management as their own has been questioned [4].

The principle of enabling people with long-term conditions to manage their health needs requires an acknowledgment of a person's right to make their own decisions about their health [3,7]. This may not always be easily enacted in practice, especially when a patient's views are at odds with those of health care staff [8,9]. How differences of opinion between health care staff and those seeking to take greater control of managing their conditions will be reconciled requires some thought [10,11]. The focus of debates on the development of expert patients has tended to be on how staff view and accept patient expertise, including knowledge of the physiology, pathophysiology, and treatment options related to their condition. Ahmad et al [12] explored the perceptions of doctors toward patients who bring Internet information into consultations. Although negative perceptions were common, doctors were found to have favorable perceptions of "self-educators" (patients with established conditions who used Internet information to support medical visits without challenging the expertise of the doctor).

Less is known about the expectations patients seeking greater control of their health conditions have of medical staff and how they view the contributions doctors make to their condition management. This move of patients taking greater control of their care merits consideration.

People use a variety of information sources to help them take control of managing their health needs, and Internet discussion boards and other networking sites are an increasingly popular source of such information. In the United States, the Society for Participatory Medicine supports the concept of the e-patient [13]. In this instance, the *e* in e-patient, according to "Doc Tom" Ferguson, the founder of e-patients.net [14], refers to patients who are "empowered, engaged, equipped, and enabled." However, Fox [15] uses the *e* in much the same way as it is used in the term *eHealth*, identifying e-patients as "Internet users who have looked online for health information." Thus, the term *e-patient* may refer to more than one phenomenon. In this paper, it is applied to people who are diagnosed with a long-term condition (diabetes) who use the Internet to gain information, advice, or support from their peers. There are many Internet forums devoted to specific conditions managed or moderated by health care staff or by people who live with the condition(s) in question that supply a mixture of information, advice, and support. They may be "open access" boards that require a sign-in process to make posts but are readable by anyone using the Internet, or "restricted access" boards that require some form of membership and a sign-in process to both make and read posts. The type of information shared through Internet discussion boards may provide very useful insights into the perspectives of people who live with long-term conditions, including their perceptions of their responsibilities and those of health care staff. The postings may also give an indication of the types of knowledge that people with long-term conditions share with one another and how they view this information.

The discussion boards included in this study were not moderated by health professionals. Previous research has looked at the use of websites and discussion boards from a professional perspective. Glasgow et al [16] conducted a randomized controlled trial that allocated patients with diabetes to an education website or to the website and human support. Richardson et al [17] conducted a randomized controlled trial about increasing physical activity for several groups of patients, including some with Type 2 diabetes. These types of studies place the health professionals at the center of the interaction and includes patients who are not already e-patients by the nature of the research design. Hartzler and Pratt [18] assert that health professionals have little understanding of how information shared by patients compares to their expertise and that this understanding is necessary to underpin the development of peer-support tools. Therefore, this study approached the question from the perspective of patients and focused on people who were discussing their self-management needs with their peers in arenas not managed by health professionals.

Study Aims

The relative lack of information on persons with diabetes' expectations of their doctors and the potential value of the information available on Internet message boards led to the research question: What do people with diabetes who use Internet discussion forums (e-patients) want from their doctors?

The objectives of the research were to identify (1) what e-patients with diabetes consider their own role and their doctor's role in managing their condition, (2) what e-patients with diabetes see as positive elements of their interactions with medical staff, and (3) what e-patients with diabetes find problematic in their interactions with medical staff.

Methods

Qualitative methods of data collection and analysis were used because the intention was to explore the perspectives of people living with diabetes. The aim of the study was to explore an individual's perceptions, not to make judgments as to whether the information provided or the recommendations made were right or wrong.

Method of Data Collection

Analysis of posts made on Internet discussion boards was carried out using qualitative content analysis. All the subjects and threads within the discussion boards selected for the study were examined. The posts and responses to posts deemed to contain relevant data were copied verbatim from the boards into Word documents. These documents were used for further analysis. The selected boards were all moderated and the moderators' roles included editing and removing posts deemed to be offensive or inflammatory.

When posts were removed from the boards, this was indicated by an annotation from a moderator. This was occasionally seen on all boards included in the study and may have affected the data gathered because some opinions, particularly those that disagreed in strong terms with the views of other participants, were not available for analysis. Although no editing was seen in the posts and responses to posts that were deemed to be relevant to the study, we cannot know whether other deleted posts would have been relevant.

Sample

Internet discussion boards about diabetes were selected for this study. Diabetes was selected as the long-term condition because a variety of suitable diabetes message boards existed. However, the focus of the research was not on diabetes per se, but on the management of a long-term condition. Eight open access boards moderated by people with diabetes were identified. Boards moderated by diabetic patients rather than health care professionals were selected because it was thought that these might give the most uncensored views of participants' experiences of health care. The 4 most active boards were selected for this study. Two of the boards were owned by organizations from the United States and 2 were owned by organizations from the United Kingdom, but participants on these boards came from all over the world. All of the posts made onto these 4 boards during November 2010 were included in the analysis.

All the threads on the boards were examined and posts relevant to the study aims were extracted from these threads. A summary showing the numbers of threads relevant to the study for each board, relevant posts within these threads, average number of posts per thread, the number of unique contributors to the discussions across these threads during the study, and the average number of posts relevant to the study made by each poster are presented in Multimedia Appendix 1. Although these were the unique contributors for each board, individuals could contribute to discussions on more than one board. The extent of this is impossible to determine with any certainty because an individual could adopt a different screen name for each board they participated on. However, 5 identical names appeared across all 4 boards. Therefore, although 4 different discussion boards were used, some of the contributors were not unique to each board.

All of the posts made during the study period (November 2010) were included in the study, regardless of the type of diabetes individuals reported having because the focus was on expectations of doctors, not the medical specifics of condition management. Although the term *e-patients* is used to refer to those using the boards in question, one limitation of the sampling frame is that those who posted on the boards may not be representative of the entire population of people with diabetes, or even those who use the Internet as a source of information and support. Those who use the boards, especially those contributing regularly, are likely to be the most vocal of this group.

Data Analysis

Two researchers used qualitative content analysis to analyze the data. Data were analyzed manually rather than electronically because of frequent use of abbreviations and "web speak." Data were analyzed inductively and sections of data were coded by meaning. After all the data was coded, sections with similar codes were merged into subcategories; related subcategories were combined to form categories. Each researcher coded the posts from 2 of the 4 boards and then each researcher coded 1 of the other researcher's boards. The researchers then compared codes and codings. The intention of this cross-analysis was to increase the depth of analysis by having a second coder provide another perspective and ensure that nothing was missed. Where there were differences in the codes used for sections of data, these were discussed and agreement reached. Agreement between the 2 researchers was reached in all cases. The differences in code allocation related to 1 researcher identifying more issues in sections of data than the other, rather than disagreement over the meaning of the data.

Ethical Issues

Because the study used information posted on open boards, contributions were regarded as being in the public domain [19,20]. It is good practice to anonymize contributions from open message boards when they are used for research purposes to protect the individual's personal or online identity; therefore, the names and online identities of contributors were replaced by pseudonyms.

Although it is standard practice in qualitative research to use direct quotes to show precise meanings and nuances of a situation, reproducing exact quotes from Internet discussion boards would make it possible to trace an individual's identity by searching for the quoted phrase. Therefore, some minor changes were made to the quoted messages [21,22]. Key phrases or expressions were kept intact to maintain the meaning of posts, but minor changes were made to "filler" words, some abbreviations were removed, and spelling errors were corrected. The principles of good practice in research using open boards were maintained by not naming the websites used, using pseudonyms rather than user identities, and not using verbatim quotes [23-26].

Results

The codes and subcategories developed from the data were clustered into the categories (1) ownership of diabetes management, (2) power issues between diabetic patients and doctors, and (3) ways of managing doctors. The findings related to these categories are summarized subsequently with quotes from contributors to the discussions used for illustration.

These categories were developed from written statements, but another category was developed from what was not written: a relative lack of postings about doctors. Although a number of postings referred to doctors and encounters with them, the vast majority of posts, including posts about what might be deemed to be about medical matters, made no reference to (or only passing reference to) medical staff. There was sometimes a suggestion that doctors were a necessary, but not always key, part of diabetes management and that a significant part of their necessity related to how health care systems worked and the gatekeeper role that doctors had rather than their knowledge or expertise. "Barry" summed this up: "Doctors are only useful because they can write prescriptions and order blood tests."

Ownership of Diabetes Management

The majority of contributors considered themselves to be responsible for their condition management. This was perhaps why most posts did not refer to medical staff because decision making and responsibility was felt to rest primarily with the individual. This was, for many, the only logical option. For example, "Sarah" posted: "We know and care more about our bodies than anyone else, and have to take responsibility for our own health."

Although the prevailing opinion was that diabetic patients needed to be in control of their own condition and its management, many contributors valued doctors who worked in partnership with them, learning with and from them. "Jason" commented: "I like a doctor to understand that someone with over 20 years of experience with diabetes might know a thing or two about the condition."

Within this relationship of mutual learning, what was seen as important was not necessarily that diabetic patients and doctors agreed, but that they were respectful of one another and willing to work together. "Mary" had no problems if she and her doctor had differing opinions: "We may not always agree, but I can trust them, and they trust me. We have an open, frank, and honest relationship."

When they received information or advice from health care staff, many diabetic patients appeared to use this as a part of, but not the main or even most reliable, aspect of the evidence that they considered in order to decide how to manage their condition. There was a feeling among many contributors that diabetes required the development of self-reliance as well as self-management, and that they learned to rely primarily on themselves to manage the range of information available and decide what advice to follow. "Zena" commented: "You shouldn't trust anyone except yourself to know about and manage your diabetes."

However, some contributors felt that medical staff did not encourage self-reliance. Partly for this reason, despite a general consensus that diabetic patients had to make their own decisions, contributors did not always choose to share these with their doctors. "Sharon" explained: "——— reduced my statin dose and I followed his advice. What gives with this distrust of doctors?"

Even those who advocated making one's own decisions still felt that there were times, especially immediately following diagnosis, when medical advice was vital and should be followed. "Paul's" advice to a fellow poster: "For now, you need to follow your doctor's advice and use the insulin dose he prescribes. Later on you can adjust and fine tune your doses to get better and better control."

One of the complexities of ascertaining how and why contributors chose what information and advice to follow was that although some valued the advice given by medical staff, others did not find the level or type of advice they received helpful or adequate. There was a suggestion that many would have liked more input from their doctors, but developed alternative resources in its absence. Several posts indicated that this was a common problem on initial diagnosis, especially with Type 2 diabetes. Recalling when he was first diagnosed, "Kevin" posted: "I was given a prescription and an instruction sheet, and that was pretty much it."

This suggestion of a lack of clear guidance or support at a critical point meant that an opportunity for the establishment of a good relationship between diabetic patients and their doctors was lost, and difficult to reinstate. This might account for why in later stages in the course of their disease, many contributors seemed to consider it their responsibility to own and manage their condition, but at the same time suggested that this was not entirely a matter of choice and that they had no option but to do so because of the unreliability of information from health care staff. By choice or by default, they often developed what seemed to be in-depth medical knowledge that they were confident to share with others. "Stephanie" advised a fellow poster: "I'd suggest that you ask your doctor to go off metformin for a while. Type 1s can and do use it, usually if they have insulin resistance issues (indicated by things like high doses or poor insulin action). The benefits of metformin in that situation might be reduced insulin use, less carb spikes, or some other improvement in control."

This suggestion that diabetic patients often developed what appeared to be medical knowledge was supported by one new board contributor, who posted: "The way you all talk here, you would think you were doctors!"

Power Issues

Regardless of how knowledgeable or experienced patients were in their diabetes management, an issue for many diabetic patients was that the power lay in the hands of professionals because of their gatekeeping function. This became problematic if their decisions required prescriptions or access to services that doctors did not deem necessary. "Zena" reported asking her doctor for a specific treatment: "My blood sugar has begun to fluctuate more and I am struggling to control it, but when I asked my doctor to prescribe me insulin, he declined and increased my metformin instead."

Although many diabetic patients saw power as falling unhelpfully in favor of the health care system, some felt they retained the power of choice over which professional they would consult with. "Yasmin" explained: "My advice is to search for endocrinologists in your area, set up meetings, and interview them like you would a potential employee. Find out how they would respond to certain situations and about things that are important to you. It's OK to decide not to choose a doctor you don't feel comfortable with."

Although the idea of selecting doctors was more common where a National Health Service (NHS) did not exist, even within the constraints of the NHS provision, contributors sought and found ways to achieve choice. "Teresa" described how she "...swapped doctors within the practice until I found one that suited me."

Managing Health Care Staff

For many diabetic patients, a major aspect of their requisite toolkit for effective condition management was knowing how to manage the medical professionals they encountered. Most people felt that having as good as possible a relationship with doctors was important. "Imogen" posted: "If you are happy with your doctor, it makes a world of difference."

A part of achieving this good relationship was finding the right doctor. "Stephanie" explained: "It's kind of first base to get a doctor who accepts and acknowledges what is wrong with you and has some idea of what they are talking about."

Being clear, confident, assertive, and insistent were skills many considered necessary to effectively manage medical staff. "Millie's" recommended approach: "Rather than asking, you could just tell them. Asking invites them to offer their opinion. Telling, in a non-confrontational way, does not."

Having good information and being able to present it was also recommended. "Nathan" explained how he set about making sure he felt an equal of the professionals: "I learned as much as I could about diabetes treatment options and took the time to learn all the medical terminology. Armed with this, I spoke to my family physician and practice nurse and convinced them that I know what I am doing. You need to learn all you can so you can talk to staff on a level standing."

Preparing for encounters with staff and anticipating their probable responses was advocated because this demonstrated the ability to effectively self-manage. It was sometimes felt to be necessary to be slightly subversive in order to manage health care staff. "Robin's" approach was not to get into an argument with doctors: "If you are not happy with your doctor's advice, but can't change doctor, then listen, smile, and say, 'Oh, OK.' And then go and do your own thing anyway."

Some people shared hints about the practicalities of managing the system and whom it was important to influence in order to get what they felt they needed. "Judy" suggested: "Win the diabetes nurse over with a sensible argument and she will put your point across to the endocrinologist, who trusts her judgment. He will then pass instructions down the line to the family physician"

Although these themes were the key aspects of contributors' discussions about what made for good and bad encounters with medical staff, there was also an acknowledgment that they themselves influenced the encounter. "Paula" posted: "I usually find that any problems I have with staff stem from my own attitude. If I go in with a negative manner, that's what I get back."

Although those who were posting were often clear about their views and had a similar approach to managing their condition, they also acknowledged that their approach might not be the same as that of their peers. "Bill" felt that he and others contributing to the website represented a particular group of diabetic patients: "Too many diabetics are not controlling their condition, so be glad you found this site of knowledgeable people who want to live."

Discussion

Principal Results

The contributors to these boards came from a range of countries. None of the issues identified appeared to be country-specific, although the solutions to problems sometimes were. For example, ways in which medical provision could be accessed or how supplies or prescriptions could be obtained differed, but the issues involved seemed broadly similar. Likewise, although the specifics of diabetes management were different for people with Type 1 or Type 2 diabetes, the issues they raised regarding medical input into their condition management were very similar.

The current ethos in health care is that individuals have the right to make decisions about their health and to be viewed as partners with health care staff in decision making [27,28]. Although many diabetic patients described taking control of, and responsibility for, managing their condition, this did not always extend to a partnership with staff. Many individuals would have appreciated a greater partnership and felt that, although they were responsible for making their own choices, doctors had an important consultative role to enable them to explore their options with a knowledgeable colleague and to make the decision that best met their needs. The problem seemed to be less that diabetic patients did not want medical involvement than that they sought involvement that included equality of status and respect for their knowledge and experience.

The focus of the knowledge that diabetic patients sought recognition of contrasts to much of the literature on expert patients where medical staff are seen as experts on physiology, pathophysiology, and pharmacology, and patients are seen as experts in their own lifestyle, values, and priorities [2,4,29,30]. In this study, there was a suggestion that although doctors did or should have medical knowledge, diabetic patients also had or developed knowledge within what is considered the medical domain. This not only contrasts with the usual perception of how expertise is shared between patients and health care professionals [2,4], but also runs counter to suggestions that patients who are experts in their condition are likely to be more compliant with prescribed treatment [11]. The suggestion from these message boards is that diabetic patients might be more inclined to question medical advice and to seek their own solutions to the medical management of their condition. In the United Kingdom, the Department of Health [2] has long recognized the importance of health care staff respecting and valuing the knowledge of expert patients, but there was a suggestion that the diabetic patient's expertise, particularly when this included medical knowledge, and especially if it contrasted with medical staff's views, was not always welcomed.

Although the ideal for many diabetic patients was an egalitarian partnership, they sometimes suggested that the information they gained outside the health care community was superior to that provided by medical staff. This might have been a natural consequence of exploring posts on an online forum because those who had gained adequate information or information that they found acceptable from health care staff might be less likely to use such forums or might be less vocal within the discussions. As Mandana [31] suggests, health care staff giving or perceiving themselves to have given information does not guarantee understanding. In addition, health care staff giving information does not guarantee that it is accepted as valid by those with long-term conditions.

The model that the discussion board contributors described as their ideal is very similar to evidence-based practice. Evidence-based practice is based on the premise that a range of evidence sources are needed to inform practice, including knowledge gained from research sources, other forms of documentary evidence, expertise in practice, the experience of staff, and the experiences and views of patients [32,33]. The difference in the model described by the diabetic patients in this study was that they seemed to place their own research sources, other documentary evidence that they found, their own experience and expertise as the key tenets, with the knowledge, experience, views, and expertise of health care professionals as a separate entity that they considered alongside their own bank of more reliable evidence. Whereas health care staff might question the validity or reliability of a patient's knowledge [4], diabetic patients often seemed to take this same approach to information offered by medical staff.

Some people with diabetes felt that information and instruction from health care staff would be especially useful in the early stages of their disease. However, initial diagnosis was a time when there was often a perceived lack of advice or guidance from health care professionals, and when individuals turned to other information sources, including other diabetic patients, and began to trust them rather than health care staff. An early opportunity for medical staff and diabetic patients to develop good decision-making partnerships may be lost. This might be a time when a greater focus on developing such a relationship needs to be established.

As well as developing their knowledge and practical skills in diabetes management, diabetic patients described developing skills in managing their interactions with health care staff so as to get the best out of the encounter, often maneuvering their way to achieving the outcome they wanted. This included choosing which decisions or actions they would share so that what they needed or valued from the medical staff's input was not withdrawn or affected by the choices they made. It has been suggested that empowering individuals with the skills needed to negotiate treatment regimens will encourage positive health decisions and improved outcomes [34]. This study also suggests that people with diabetes see a part of the skills required to achieve improved outcomes as developing skills in managing encounters with staff and negotiating a way to the treatment they feel they need. This often meant that although the relationship between patients and doctors was superficially good, they were unable to be completely open about their approach to condition management, and that doctors remained uninformed about the realities of what did or did not work for individuals.

There appeared to be a complex link between the development of medical knowledge and the tactics that diabetic patients used to get the most out of health care encounters. Some contributors suggested that having this kind of knowledge was a key to being able to negotiate with health care staff, whereas others apparently complied with their doctor's instructions, but really followed alternative, undisclosed information. These decisions seemed to rest, in part, on how they felt their apparent knowledge and use thereof would affect the outcome of their consultation. What was clear was that diabetic patients felt that having medical knowledge and managing their interactions with health care providers were key aspects of their condition management.

This study showed that some people with diabetes were functioning as effective e-patients where the *e* stands for being empowered, engaged, equipped, and enabled. They showed themselves to be adept at gathering and assessing a range of information from various sources, including medical staff, and making decisions about its relative worth, which did not always fall in favor of the information given by doctors.

Limitations of the Study

The findings from this study are not intended to be a generalizable picture of the views or experiences of all diabetic patients. The study used a small number of boards and a sample that was chosen primarily for convenience. The findings represent the views of a small number of individuals who may not be typical of the wider population, and may be those who are the most vocal and are less reliant on health care professionals for input about their condition than others are. Some forum users suggested that they were probably more interested in and inclined to take responsibility for the control of their diabetes than many other diabetic patients were, and although there were a high number of posts each day on the boards studied, these were from a small number of individuals in comparison to overall membership numbers. In addition, because some contributors used more than one board, the apparent findings may be skewed by regular, but repeated, postings across boards from a few key individuals. Because the posts from the boards were downloaded once, any that had been deleted by moderators were lost. The patients, however, are among those who have actively adopted self-management, making them early adopters of the movement desired by many health services. As such, the findings are very relevant to practice because the lessons learned from early adopters can be very valuable in supporting diffusion through an adoption curve.

Conclusion

This study has found that this particular group of e-patients place themselves at the forefront of managing their condition and gather information from peers and professionals in a variety of ways, including through the Internet and in face-to-face interactions. Their expectations and perceptions of health care staff vary, but they do have a baseline set of ideal expectations for their interactions with doctors.

Although diabetic patients did not expect doctors to always agree with them, they did expect to be listened to and respected for their knowledge of diabetes management, both in theoretical and practical terms. They often had or developed knowledge that was within the usual remit of medical staff. When they presented this for discussion, they expected it, and their presentation of it, to be taken seriously and listened to, even if their doctors did not agree with them. In practice, this emphasizes the need for health care professionals to listen to and engage with patients, and to be prepared to discuss information they have gathered and the reasons why this may or may not be applicable, relevant, or helpful in their particular circumstances.

The study suggests there may be a vital point at the time of diagnosis when medical staff and diabetic patients have the opportunity to establish a relationship that can develop into a sound decision-making partnership. However, there is also some evidence in this study that this opportunity is often missed, leading diabetic patients to seek information elsewhere. It may be at this point that decisions about what information considered to have value are made; once made, these decisions or priorities may be hard to reverse. This suggests that early consultations are pivotal in ongoing health care relationships and condition management.

Doc Tom Ferguson's [14] definition of the *e* in e-patient was for "empowered, engaged, equipped, and enabled." This study has identified two more:

1. Evaluating. This refers not only to the information e-patients find, but also to the source of that information, be it a Web page, a peer, or a health care professional. It also suggests that this evaluation begins, and trust in sources is established, at an early stage.

2. Equal. The e-patient expects to be an equal member of the team. There is evidence from this study that when this situation is not encouraged by professionals, individuals develop mechanisms to manage situations that place them in a location of equal power, but without the open and honest relationship that is also valued.

This study focused on one condition and used a group of people who may be more interested in self-management or more dissatisfied with their current health care inputs than the average patient is; however, it does introduce some interesting thoughts about the expectations that people with long-term conditions have of doctors and their input into their condition management.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Summary of the characteristics of boards included in the study.

[PDF File (Adobe PDF File), 6KB - jmir_v14i6e155_app1.pdf]

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Abbreviations

NHS: National Health Service

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Original Paper

Telemedicine Service Use: A New Metric

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Abstract

Background: Policy makers and funding agencies require relevant information on current practices of the use of telemedicine infrastructure and services. Several metrics have been used to describe average use of telemedicine services. None are adequate.

Objective: To identify and assess a new metric–consultations per site per week (C/S/W).

Methods: To determine existing usage, all papers and abstracts published between January 2005 and December 2009 in the Journal of Telemedicine and Telecare and Telemedicine Journal and eHealth were reviewed. Pilot studies, research projects, services reporting less than one year's data and teleradiology services were excluded.

Results: In total, 210 reports of telemedicine services were identified, 77 of which provided sufficient data to calculate C/S/W. Average use was low, 1.8±3.5 (median 0.7) C/S/W, with 61% of services reporting less than 1 C/S/W and 71% reporting 2 or fewer C/S/W. Studies reporting on data from 2006 to 2009 showed less use (average 1.5±2.3; median 0.7 C/S/W) than earlier reports from 1996 to 2005 (1.7±2.5; median 0.7 C/S/W).

Conclusions: The use of this new metric, C/S/W, is proposed as a standard measure of telemedicine service use. The generally low results opens debate about how well current clinical services are used.

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KEYWORDS

telemedicine use, telemedicine metrics, telemedicine utilization, economics, evidence based, literature review

Introduction

Telemedicine, the delivery of healthcare services over distance using information and communication technologies, is slowly maturing. New telemedicine networks and programs are being implemented and established networks are growing. In recent years, some networks have reported tens of thousands of teleconsultations [1-3]. Telemedicine holds great promise for developing nations which, faced with large rural populations and few health professionals, are being encouraged to develop eHealth policies and strategies [4]. The African Union and the Pan American Health Organization (PAHO) have also both recently initiated work to develop collaborative-health strategy processes to harmonize continental activity. With limited budgets, poor existing telecommunication infrastructure, and expensive bandwidth [5], governments of developing countries seek to learn from the experiences of the developed world-hoping to bypass the pilot project cycle of telemedicine and implement sustainable projects. It is important that policy makers and planners have realistic expectations of telemedicine and set achievable goals. To do so, they require relevant information on the current norms of the use of telemedicine infrastructure and services.

What is the appropriate information? Different metrics have been used to report growth and use of telemedicine programs. In the first study to describe the growth in North American telemedicine activity between 1994 and 1999, Grigsby and Bennett reported the following metrics on an annual basis: the number of programs identified, the total number of teleconsultations across all programs, the average number of consultations per responding program, the total number of telemedicine sites reported and, the average number of sites per program. A steady annual increase was seen for all parameters [6].

While growth reported in this manner is useful, it does not describe the use of telemedicine at the level of the lowest common denominator, the referral site. When the number of programs and sites increases, there is likely to be an increase in the annual total and average number of consultations. This does not necessarily reflect activity at preexisting sites, which may be increasing, remaining constant, or even decreasing. A more relevant measure of telemedicine activity would be the number of teleconsultations per referral site per week. Using this metric on the data from Grigsby and Bennett's study, which reported annual increases in all parameters, the number of consultations per site per week (C/S/W) fell from 1.07 in 1997 to 0.75 C/S/W in 1998, and rose slightly in the first quarter of 1998 to 0.95 C/S/W (Table 1). The low use of telemedicine when reported in this way is surprising and raises the question of what constitutes average telemedicine use now, over 10 years later? It also highlights the need for consistent and common metrics that better describe telemedicine use.

Table 1. Growth in North American telehealth activity, 1994-1999, excluding teleradiology services [6].

	1994	1995	1996	1997	1998	1999[a]
Number of programs	24	49		132	157	179
Number of consultations	2110	6138	21,732	41,740	52,223	74,828
Average consultations per program	88	125	253	316	428	608
Total number of facilities				747	1345	1521
Average facilities per program				8.3	10.3	11.3
C/S/W				1.1	0.8	1.0

[a] The 1999 data are based on predictions based on the first quarter data.

The aim of this study was to determine reported telemedicine service usage, based on the new metric that measures C/S/W by reviewing all papers, abstracts, and letters published in 2 leading telemedicine-focused journals over the past 5 years.

Methods

We reviewed all papers, abstracts, reports, and letters published between January 2005 and December 2009 in the 2 leading telemedicine journals, Telemedicine and e-Health and the Journal of Telemedicine and Telecare. Data from telemedicine programs were abstracted and confirmed by both authors. Data gathered included program duration, the number of teleconsultations, the number of referral sites, the nature of the telemedicine consultation (videoconferenced, email, Web, or telephony based), the unit or regional health service reporting the program and the country in which the program took place. Papers reporting services of less than one year's duration and designated research or pilot projects were excluded. In keeping with Grigsby and Bennett's paper, reports of radiological services were also excluded to enable direct comparison [6]. We have chosen not to include Diabetic Retinopathy screening services in the analysis of clinical consultative services, but to present them separately. Where the same service was reported more than once, only the most recently reported annualized data were recorded. Where papers report data on an annual basis, the serial data were also recorded separately to reflect change in service.

The average number of C/S/W was calculated by dividing the total number of consultations reported per program by the number of referral sites and then dividing this result by the duration of the program, expressed in weeks. The relative frequencies of services measured in C/S/W were calculated and categorized into 4 groups: those reporting 0-1, 1.1-2, 2.1-5, and more than 5.

Further analysis was made of the available serial data from programs, where available. As more recently reported services may show higher usage, studies that included only data gathered between 2006 and 2009 were compared with those that reported data gathered before 2006.

Data sets are reported as the mean and standard deviation, and the median is given when data are not normally distributed. Frequencies were compared using Fisher's exact test. Means were compared using a Mann-Whitney test or the Kruskal-Wallis test when the data were not normally distributed. Alpha was set at 5%.

Results

A total of 2510 papers, reports, letters, and conference abstracts were reviewed, in which 210 telemedicine services were reported in 187 papers and abstracts. Use was calculated as C/S/W using data from 49 papers and 36 abstracts, covering programs of 1 to 10 years' duration, from 19 countries, with 7 international services (Multimedia Appendix 1). Of the 85 programs, 46 (54%) were in the US, 16 (19%) in the EU, 5 in Canada, and 4 in Australia. The average teleconsultations per week, number of referral sites, and C/S/W for clinical services and diabetic retinopathy screening services are summarized in Table 2.

The relative frequencies of use of clinical and diabetic retinopathy screening services are shown in Table 3.

There were 5 clinical services reporting more than 5 C/S/W. These included 2-single referral site programs in dermatology (5.7 C/S/W) [7] and intensive care (10.3 C/S/W) [8], a prison service (8.9 C/S/W) [9], a primary care service (11.2 C/S/W) [10], and an emergency room service (25.6 C/S/W)[3].

Serial data were available for 11 clinical programs. Average use increased by 0.13±0.37 C/S/W, ranging from −0.54 to 1.02 C/S/W. The number of C/S/W decreased in 2 of these programs due to an increase in the number of referral sites without a concomitant increase [11] or reduction in workload [12]. Only 3 programs reported annual data over several years. The first was a paediatric burn service, in which the C/S/W rose annually from 0.02 in 2001 to 0.08 in 2006 [13]. The second was a dermatology service [14], where C/S/W started at 0.8, maximized to 1.1, then fell to 1. The third was a neurology service [15], where C/S/W started at 2.6, rose to 4.4, and then fell to 3.6.

Pre-2006 data were reported in 35 papers with an average use of 1.7±2.5 C/S/W (range 0.03-11.2, median 0.7, and 95% CI:0.6-1.7) and 20 papers reported data from 2006–2009 with an average use 1.5±2.3 C/S/W (range 0.06-10.3, median 0.7, and CI:0.4-2.5). The relative frequencies are shown in Table 4.

There was no difference between the 2 groups for the average number of C/S/W, (*P* =.81). Comparison of the relative frequencies was made by consolidating the data and comparing the number of programs with 2 or fewer C/S/W with those that had 2 or more C/S/W as there were fewer than 5 programs reported in 5 of the 8 frequency ranges. No significant difference was found (*P* =.84).

The number of referral sites ranged from 1 to 48,707 sites in a telephony based service [16] (median 10). Differences in the number of referral sites were noted between the various telemedicine modalities but these were not statistically significant (*P* = .38): email (n=14, range 1-271, median 10.5), videoconferencing (n=45, range 1-700, median 8.5), Web (n=5, range 1–120, median 5.0), mixed modalities (n=4, range 1–390, median 154.0), telephone (n=2, range 896-48,707, median 24,801.5). Comparison of the mean C/S/W for videoconferencing, email and Web based services showed no significant difference (*P* = .14). Telephone (n=2) and modem services (n=5) were excluded from analysis as the sample sizes were too small.

Table 2. The number of consultations per week, the number of referral sites in the program, and the number of C/W/S expressed as the average (±standard deviation), median, minimum, and maximum for 77 clinical services and 8 diabetic retinopathy screening services.

		Consultations/week	Referral sites	C/S/W
Clinical services (n=77)				
	Average	107.9±345.4	690.0±5545.9	1.8±3.5
	Median	6.8	10.0	0.7
	Min	0.04	1	0.01
	Max	1923.1	48,707	25.6
Diabetic retinopathy services (n=8)				
	Average	403.7±776.3	50.6±84.2	39.0±62.3
	Median	168.7	3.5	11.5
	Min	3.1	1	1.75
	Max	2307.7	200	185.9

Table 3. The number of programs (n) and percentage frequency based on the 4 categories of use for clinical telemedicine and diabetic retinopathy screening services.

C/S/W category		≤1	1.1-2	2.1-5	>5
Clinical services (n=77)					
	n	47	8	17	5
	Frequency (%)	61	10	21	7
Diabetic retinopathy services (n=8)					
	n	0	1	1	6
	Frequency (%)	0	13	13	75

Table 4. The number of programs (n), percentage frequency, average (±SD), and median number of C/S/W for services reporting pre- and post-2006 data.

C/S/W		≤1	1.1-2	2.1-5	>5
2006-2009 (n=20)					
	n	14	2	3	1
	Frequency (%)	70	10	15	5
	Average C/S/W	0.5±0.3	1.3±0.2	3.1±0.3	10.3
	Median	0.5	1.3	3.0	
1996-2005 (n=35)					
	n	21	4	9	3
	Frequency (%)	60.0	11.4	20.0	8.6
	Average C/S/W	0.3±0.03	1.6±0.4	2.6±0.8	8.6±2.8
	Median	0.3	1.7	2.3	8.9

Discussion

Using the new metric of C/S/W, average use of telemedicine sites as reported in the telemedicine literature is low, with 61% of telemedicine sites sending less than 1 case a week and 71% of sites sending less than 2 cases a week. The consistently limited use may indicate a relative ceiling that limits the number of cases that can or will be referred from a site, based on the practice population, incidence and prevalence of pathology, and the experience of the referring doctor.

When compared to Grigsby and Bennett's 1997 to 1999 data, reporting an average of 0.9 C/S/W [6] we show a doubling of use, albeit it off a low base, to 1.8 C/S/W. No difference was seen between studies reporting data from 2006 onwards and pre-2006 data. Even the serial data extracted from programs show little change over time. In 2007, a large network of 700 referral sites reported 30,000 consultations a year, equivalent to 0.8 C/S/W [2]. In a presentation to the American Telemedicine Association Meeting in 2009, these figures had increased to 53,000 consultations a year and 1500 referral sites, but C/S/W had decreased marginally to 0.7. This exemplifies the need for a metric that reflects actual use.

Diabetic retinopathy screening services use the infrastructure more frequently (39 C/S/W) and some services are mobile. These services were reviewed separately as their inclusion would markedly skew the results of the other clinical services, in the same way that teleradiology services were excluded from Grigsby and Bennett's review.

These results can only be taken as indicators of telemedicine use as there are limitations to this study. The review was of only 2 telemedicine journals, and large clinical telemedicine series may only have been reported in specific specialty journals. Also, large regional services may have reached a state of maturity and are no longer reported. Furthermore, aggregation of data over several years may mask changes in use, and changes in the number of referral sites in a service during the reporting period may skew the average use per site.

One of the problems inherent in many of the reports is that they focused on one clinical activity and did not report use of the same infrastructure for other activities such as other clinical services, videoconferenced education or administrative and research meetings. Additional difficulties included inconsistent terminology as to what is defined as a site or a consultation, and imprecision in presentation of dates (eg, saying the period was from ‘2002 to 2005’ could be interpreted as either 3 or 4 years, or 156 to 208 weeks; for this study, it was interpreted as 3 years), causing error in calculation of C/S/W. Over half (55%, 104/189) of the services identified in this study did not provide enough data to determine C/S/W.

Despite these shortcomings, the new metric of C/S/W provides a simple measure of telemedicine use. Our study shows that C/S/W is low, and this should be taken into account when planning new services. These data suggest that new infrastructure should be shared between clinical disciplines and used for non-clinical activities as well to provide efficiencies of scale.

We encourage consistent application of this new metric, and the reporting of adequate data by which to calculate it, including: explicit information about dates (year/month/day for the reporting period), the total number of sites within the network or service during the reporting period), differentiation of volumes or percentage of clinical, administrative, research, and education (CARE) activities, and the total number of consultations made during the reporting period to reflect clinical activity. We suggest that this metric is a useful way of evaluating use of telemedicine services.

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Both authors designed the study and were responsible for the literature review and data collection. MM performed the statistical review and both authors were involved in writing and reviewing the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Summary of data and sources.

[PDF File (Adobe PDF File), 167KB - jmir_v14i6e178_app1.pdf]

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Abbreviations

C/S/W: Consultations per site per week
EU: European Union
PAHO: Pan American Health Organization

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Original Paper

Acceptance of Internet-Based Health Care Services Among Households in Poland: Secondary Analysis of a Population-Based Survey

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Abstract

Background: Polish society is benefiting from growing access to the Internet, but the use of advanced e-services is still limited. The provision of Internet-based health services depends not only on the penetration of the Internet into society, but also on the acceptance of this technology by potential users.

Objective: The main objective of this study was focused on the assessment of predictors of acceptance of Internet use for provision of health services (eg, sociodemographic status, the use of information technologies, and consumption of health care services) among households in Poland.

Methods: The study was based on a secondary analysis of the dataset from the 2011 Social Diagnosis survey (a biannual survey conducted since 2001 about economic and non-economic aspects of household and individual living conditions in Poland). Analysis of the questionnaire results focused on the situations of the households included in the study. The predictors for 2 outcome variables describing the acceptance of households for Internet use for provision of a full health care service, or at least access to information and download of required forms, were assessed using multivariate logistic regression.

Results: After excluding those households that would not consider the use of health care services or for which predictor variables assumed missing values, the final analyses were conducted on data from 8915 households. Acceptance of the use of the Internet for provision of full health care services in Polish households was significantly higher among households in urban locations with ≥ 200,000 inhabitants than among households in rural areas; it was also higher with salaried employment as the source of income than with self-employment in agriculture (odds ratio [OR] = 0.53, 95% CI 0.40 - 0.70), retirement pension (OR = 0.46, 95% CI 0.39 - 0.54), disability pension (OR = 0.48, 95% CI 0.34 - 0.68), or with several simultaneous income sources (OR = 0.66; 95% CI 0.57 - 0.79). Furthermore, acceptance of Internet-based health care was higher in households with a higher monthly net income per capita (OR = 2.11, 95% CI 1.75 - 2.53 for households from the lowest and the highest income interval), among households with > 1 child aged < 15 years (OR = 1.38, 95% CI 1.20 - 1.59), among households with at least some books (with OR = 3.33, 95% CI 2.39 - 4.64 for household with no books and those with over 500 books). Acceptance was also higher in households with a computer (OR = 1.86, 95% CI 1.35 - 2.56), Internet access (OR = 1.95, 95% CI 1.37 - 2.76), and Internet access for a longer duration (OR = 1.36, 95% CI 1.06 - 1.75 and OR = 1.81, 95% CI 1.40 - 2.33 for households with access < 1 year versus those with access for 1-5 years and > 5 years, respectively). Greater self-declared confidence in using technology was also associated with higher acceptance of the Internet for health care services (OR = 2.94, 95% CI 2.21 - 3.91 for the least confident households versus those with the highest confidence). Furthermore, recent use of health care services increased acceptance of using the Internet for at least some health-related services (OR = 1.49, 95% CI 1.16 - 1.91), but not for full provision of online health care services (OR = 1.20, 95% CI 0.92 - 1.55). Neither the hospitalization of a member of a household nor the opinion about satisfying health care needs of a household affected the degree of acceptance.

Conclusions: The acceptance of health care services through the Internet is higher in households from larger cities, with stable income from an employee salary, as well as with higher income levels per capita. Furthermore, general computer and Internet use in the household influenced the perception of eHealth. Paradoxically, the use of health care services or the level of satisfaction with the coverage of the household's health needs has a limited influence on acceptance of Internet-based health care services.

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KEYWORDS

eHealth; health care service; Internet use; computer use

Introduction

Internet use has increased considerably in Poland over the past decade. The percentage of households with Internet access when Poland joined the European Union (EU) in 2004 was 26% [1]. According to the statistical office of the European Community (Eurostat), it reached 62% in 2011 [2]. The accession to the EU opened new prospects for the development of e-services, mainly due to the structural funds and special programs available for supporting business models and administrative services based on electronic communication [3-6]. Although there is a visible growth trend in the information society in Poland, the availability of advanced e-services differs considerably between specific domains. This applies particularly to the field of eHealth, which shows relatively slow progress [7]. Apart from access to information about health and health care, the more advanced eHealth services, such as telemonitoring or Internet-based appointment bookings with a physician, are not commonly used [8,9]. Some eHealth services are not available due to legal restrictions (eg, e-prescriptions) although they are becoming increasingly common in other EU member countries. Furthermore, there are no established reimbursement schemes for eHealth services in the publicly funded health care system in Poland.

User acceptance is a key condition for wide implementation of innovative information and communication technology (ICT) solutions, including eHealth [10]. So far, awareness and acceptance of eHealth among Polish citizens has not been studied thoroughly. According to a survey by Staniszewski et al [11] in 2007, the percentage of respondents who declared that they are familiar with the term *telemedicine* was only 32.1%. The awareness of the term *eHealth* was not surveyed. This is understandable because eHealth is rarely used in the media, although it is used (instead of *telemedicine* or *health ICT*) in policy documents issued by governmental bodies [12]. The main focus of most surveys to date has been the use of the Internet for the conduct of health-related activities [2,11]. The opinion of Polish households about the use of the Internet for specific activities has been surveyed in recent versions of the Social Diagnosis study (a biannual survey conducted since 2001 about economic and non-economic aspects of household and individual living conditions in Poland). The number of households that expressed acceptance of the full delivery of health care services online has not significantly changed since 2007. In 2007, acceptance was approximately 30% and it has remained stable since then [13].

The main goal of this study was a secondary analysis of data collected during the most recent Social Diagnosis study (2011). The scope of the study is broad and covers many areas, including household living conditions, individual quality of life, the state of civil society and economic status, the usage of new communication technology, and social exclusion. The methodology and primary analysis of the collected data was published by Czapinski et al [14]. The database containing the survey results is publicly available [15]. The focus of our study was the assessment of possible predictors for the household acceptance of the use of the Internet for provision of health care services in Poland.

Methods

The data included in the current analysis were obtained from households included in the Social Diagnosis survey in 2011. The data were collected using 2 questionnaires. The first questionnaire, covering household structure and living conditions, and the sociodemographic characteristics of its members, was completed by professional canvassers employed by the Central Statistical Office who interviewed the household representatives with the most complete knowledge of their circumstances. The second questionnaire was designed to be completed by all household members aged ≥ 16 years. The selection of households for participation in the survey was the result of a 2-level stratified sampling. It was preceded by stratification of households according to *voivodeships* (main territorial unit in Poland roughly corresponding to state or county in other countries), and then within voivodeships according to area of residence (eg, rural or urban). A detailed description of the sampling procedure is given in the relevant report on the study [16]. The structure of the questionnaires used for the survey may be viewed on the study website [17].

The analysis described in this paper was conducted on data originating in the questionnaire about household circumstances. In section M of the questionnaire, the items related to the use of the Internet to accomplish specific types of services were included, such as vehicle registration, handling cases related to personal documents (eg, identity cards), and business activities. One of the items enquired about the household's view on using the Internet to provide health-related or health care services.

The household representative answering this item could select one of 4 responses: (1) "I do not need the Internet for this service," (2) "I would like to obtain information or download the required forms online and then proceed in the traditional way," (3) "I would like to be able to complete the entire transaction online (including payment)," and (4) "I do not anticipate the use of such a service." Only cases with a valid response to this item were extracted from the database containing all the data collected in 2011 and used for further analyses (12,015 of 12,386 households) [15].

Two outcome variables for this item were defined for the logistic regression analysis. The first outcome variable assumed the value *yes* if the respondent selected option 3 and the value *no* if they selected option 1 or 2. The second outcome variable assumed the value *yes* if option 2 or 3 was chosen and the value *no* for option 1. Cases with option 4 chosen as a response were excluded from the analysis. A total of 10,315 cases were included for further analysis.

From the 2011 data, 14 variables were derived and included in the logistic regression procedure as predictors. The variables were selected according to their potential influence on the acceptance of the use of the Internet for health care services.

Statistical analysis was conducted using the Epi Info version 3.5.4 software (Epi Info, Centers for Disease Control and Prevention, Atlanta, GA, USA). Descriptive statistics were calculated for all variables. Logistic regression was performed in order to assess potential predictors for the acceptance of the use of the Internet for provision of health care services. All cases with missing values (1400/10,315) for any of the predictor variables included in the model were excluded from the analysis. Finally, multivariate logistic regression was calculated on the dataset of 8915 cases.

Results

Characteristics of the Sample of Households

The frequencies for the categorical variables are shown in Table 1. The sample included 39.81% households from rural areas. Furthermore, income from employment was the main source of income for 44.60% of households, retirement pension for 28.03%, and more than 1 type of income for 10.32% of households. There was 1 child aged < 15 years in 17.51%, 2 in 10.85%, and > 2 in 3.50% of households. The economic status as assessed by a household representative improved in comparison to the status 2 years previously in only 10.79% of households, and remained unchanged in 56.87%. A total of 10.84% of households received some form of external support. The number of books in the household was > 100 in only 22.25% of households.

Table 1. The characteristics of households included in the multivariate logistic regression analysis (N = 8915).

Characteristic		n	%
Acceptance of the Internet use for provision of health care services (variant I: provision of full service)			
	No	6259	70.21
	Yes	2656	29.79
Acceptance of the Internet for provision of health service (variant II: access to information/forms or full service provision)			
	No	4895	54.91
	Yes	4020	45.09
Place of residence (number of inhabitants)			
	Rural	3549	39.81
	Urban <20,000	1167	13.09
	Urban 20,000-100,000	1803	20.22
	Urban 100,000-200,000	611	6.85
	Urban 200,000-500,000	926	10.39
	Urban >500,000	859	9.64
Source of household income			
	Employment (wages and salaries)	3976	44.60
	Self-employment in agriculture	404	4.53
	Self-employment outside agriculture	384	4.31
	Retirement pension	2499	28.03
	Disability pension	468	5.25
	Non-employment source other than retirement or disability pensions	264	2.96
	Numerous parallel income sources	920	10.32
Monthly household net income per capita, Polish zloty (PLN) [a]			
	< 700	2106	23.62
	≥ 700 and < 1000	2284	25.62
	≥ 1000 and < 1500	2101	23.57
	≥ 1500	2424	27.19
Opinion about economic status of household compared to 2 years ago			
	Worsened	2883	32.34
	Unchanged	5070	56.87
	Improved	962	10.79
Reception of aid from external sources			
	No	7949	89.16
	Yes	966	10.84
Number of children aged < 15 years in household			
	0	6075	68.14
	1	1561	17.51
	2	967	10.85
	>2	312	3.50
Number of books in household			
	None	1007	11.30
	≤ 25	2034	22.81

Characteristic		n	%
	26-50	2028	22.75
	51-100	1862	20.89
	101-500	1505	16.88
	>500	479	5.37
Computer in household (PC or notebook) [b]			
	No	3041	34.11
	Yes	5874	65.88
Internet access in household			
	No	3448	38.68
	Yes	5467	61.32
Duration of Internet access			
	< 1 year	3693	41.42
	1-5 years	2940	32.98
	>5 years	2282	25.60
Opinion about being up-to-date with modern technology			
	Strongly disagree	2450	27.48
	Somewhat disagree	2496	28.00
	Neither agree nor disagree	1710	19.18
	Somewhat agree	1922	21.56
	Strongly agree	337	3.78
Use of health care services in the last year [c]			
	No	419	4.70
	Yes	8496	95.30
Hospital admission of a household member household in the preceding 12 months [d]			
	No	6519	73.12
	Yes	2396	26.88
Opinion about satisfying of health needs of a household in comparison to the situation 2 years ago			
	Worsened	2391	26.82
	Unchanged	6309	70.77
	Improved	215	2.41

[a] The median and quartile values of monthly household net income per capita were calculated for the initial set of 12,015 households with valid data on the acceptance of Internet use for the provision of health services (median 1000 Polish zlotys [PLN], lower quartile 700 PLN, and upper quartile 1500 PLN). These values were used to determine 4 intervals for categorizing monthly household net income per capita. 1 PLN = US $0.31 (mid-market rate November 19, 2012).

[b] Yes: at least one member of the household owned a personal computer or mobile computer (eg, notebook, laptop, iPad, or tablet); no: no personal or mobile computer in a household.

[c] Yes: the household used health care services funded by the National Health Fund or paid out of pocket or paid by employer in past year; no: the household did not use health care services in the past year.

[d] Yes: at least one member of the household was admitted to hospital in past year; no: no hospitalization of members of household in past year.

Regarding computer use, 65.88% of households had a personal or mobile computer, and 61.32% had Internet access. Only 25.60% of households had Internet access for more than 5 years. Approximately one-quarter of households (25.34%, 2259/8915) felt that they were “up-to-date with modern technologies.”

Most households (95.30%) declared that their members used health care services with 26.88% having members of their household admitted to hospital in the preceding year. In the opinion of 70.77% of households, the coverage of their health needs had not changed in comparison with 2 years ago, and had improved in only 2.41% of households.

Less than half of the households (45.09%) included in the analysis accepted Internet use for full or at least partial (access to information and document download) delivery of health care services. The percentage of households expressing an opinion in favor of Internet use for complete provision of health care services was 29.79% (2656/8915).

Factors Related to the Acceptance of the Use of the Internet for Health Care Services

The results of the analysis revealed that predictors of the acceptance of the use of the Internet for full provision of health care services included: monthly household income per capita, place of residence, number of children aged < 15 years, source of income, reception of aid from external sources (social care), availability of a computer (PC or mobile) in a household, Internet access and its duration, opinion about being up-to-date with modern technologies, and the number of books in the household.

The acceptance of the use of the Internet for full health care services, or for at least access to information and downloading documents, was predicted by the same variables and additionally by the use of health care services during the past year. The odds ratios (ORs), confidence intervals (CIs), and *P* values resulting from the multivariate logistic regression are presented in Table 2.

Table 2. The results of multivariate logistic regression model for factors affecting the acceptance of Internet-based health care services.

Variable		Acceptance of reception of health services by the Internet			
		Full service provision		Full service provision or only access to information and forms	
		Odds ratio (95% CI)	*P*	Odds ratio (95% CI)	*P*
Place of residence			< .001		< .001
	Rural	1		1	
	Urban < 20,000	0.92 (0.77 - 1.09)	.33	0.93 (0.79 - 1.09)	.36
	Urban 20,000-100,000	1.13 (0.97 - 1.31)	.11	1.23 (1.06 - 1.42)	.005
	Urban 100,000-200,000	0.96 (0.77 - 1.19)	.68	1.13 (0.92 - 1.40)	.24
	Urban 200,000-500,000	1.57 (1.31 - 1.89)	< .001	1.63 (1.35 - 1.97)	< .001
	Urban > 500,000	1.96 (1.61 - 2.37)	< .001	2.42 (1.97 - 2.97)	< .001
Source of household income			< .001		< .001
	Employment (wages and salaries)	1		1	
	Self-employment in agriculture	0.53 (0.40 - 0.70)	< .001	0.61 (0.48 - 0.78)	< .001
	Self - employment outside agriculture	0.94 (0.75 - 1.19)	.62	1.04 (0.81 - 1.34)	.74
	Retirement pension	0.46 (0.39 - 0.54)	< .001	0.47 (0.40 - 0.54)	< .001
	Disability pension	0.48 (0.34 - 0.68)	< .001	0.53 (0.40 - 0.71)	< .001
	Non-employment source other than retirement pensions or disability payment	1.05 (0.74 - 1.48)	.79	0.99 (0.72 - 1.37)	.97
	Numerous parallel income sources	0.66 (0.57 - 0.79)	< .001	0.70 (0.60 - 0.83)	< .001
Monthly household net income per capita (PLN)			< .001		< .001
	< 700	1		1	
	≥ 700 and < 1000	1.38 (1.17 - 1.63)	< .001	1.25 (1.08 - 1.49)	.004
	≥ 1000 and < 1500	1.62 (1.36 - 1.94)	< .001	1.41 (1.19 - 1.67)	< .001
	≥ 1500	2.11 (1.75 - 2.53)	< .001	1.70 (1.42 - 2.03)	< .001
Economic status of household compared to 2 years ago			.56		.93
	Worsened	1		1	
	Unchanged	0.84 (0.74 - 0.95)	.009	0.78 (0.69 - 0.88)	< .001
	Improved	0.98 (0.81 - 1.17)	.79	1.12 (0.93 - 1.36)	.23
Reception of aid from external sources			.02		.045
	No	1		1	
	Yes	1.18 (0.97 - 1.44)	.09	1.14 (0.95 - 1.37)	.16
Number of children aged < 15 years			< .001		< .001
	0	1		1	
	1	1.38 (1.20 - 1.59)	< .001	1.38 (1.20 - 1.59)	< .001
	2	1.33 (1.12 - 1.58)	.001	1.38 (1.16 - 1.64)	< .001
	> 2	1.41 (1.06 - 1.88)	.018	1.31 (1.00 - 1.73)	.05
Number of books in household			< .001		< .001
	None	1		1	
	≤ 25	1.46 (1.11 - 1.92)	.007	1.38 (1.10 - 1.74)	.005
	26-50	1.47 (1.12 - 1.93)	.006	1.59 (1.26 - 1.99)	< .001
	51-100	1.72 (1.30 - 2.26)	< .001	1.91 (1.52 - 2.40)	< .001
	101-500	2.07 (1.56 - 2.74)	< .001	2.36 (1.86 - 3.01)	< .001

Variable	Acceptance of reception of health services by the Internet			
	Full service provision		Full service provision or only access to information and forms	
	Odds ratio (95% CI)	*P*	Odds ratio (95% CI)	*P*
> 500	3.33 (2.39 - 4.64)	< .001	3.46 (2.52 - 4.75)	< .001
Computer in household		< .001		< .001
No	1		1	
Yes	1.86 (1.35 - 2.56)	< .001	2.14 (1.66 - 2.76)	< .001
Internet access in household		< .001		< .001
No	1		1	
Yes	1.95 (1.37 - 2.76)	< .001	1.72 (1.27 - 2.32)	< .001
Duration of Internet access		< .001		< .001
< 1 year	1		1	
1-5 years	1.36 (1.06 - 1.75)	.02	1.59 (1.26 - 2.01)	< .001
> 5 years	1.81 (1.40 - 2.33)	< .001	2.02 (1.58 - 2.57)	< .001
Consider self up-to-date with modern technology		< .001		< .001
Strongly disagree	1		1	
Rather disagree	1.31 (1.11 - 1.55)	.002	1.23 (1.06 - 1.43)	.006
Neither agree nor disagree	1.67 (1.40 - 2.00)	< .001	1.78 (1.52 - 2.09)	< .001
Rather agree	1.77 (1.49 - 2.10)	< .001	1.73 (1.47 - 2.04)	< .001
Strongly agree	2.94 (2.21 - 3.91)	< .001	2.92 (2.13 - 4.00)	< .001
Use of health care services in last year		.22		.002
No	1		1	
Yes	1.20 (0.92 - 1.55)	.18	1.49 (1.16 - 1.91)	.002
Hospital admission in last year		.60		.31
No	1		1	
Yes	1.05 (0.93 - 1.18)	.47	0.95 (0.85 - 1.07)	.41
Opinion about satisfaction of health needs of a household		.59		.95
Worsened	1		1	
Unchanged	1.00 (0.88 - 1.15)	.95	1.01 (0.89 - 1.14)	.92
Improved	1.22 (0.87 - 1.70)	.25	1.07 (0.75 - 1.52)	.73

Households from urban areas with at least 200,000 inhabitants were more likely to accept the use of the Internet for health care services (for both variants of the outcome variable). In addition, households with a retirement or illness pension, farmer's income, or several sources of income were less inclined to accept the use of the Internet for this purpose than those with an employee's salary as the main source of income. Internet acceptance also depended on monthly household net income per capita, with growing acceptance at higher income levels (in comparison to values below the lower quartile). The OR for the outcome variable assuming acceptance of full health care services provided online were 1.38 (95% CI 1.17 - 1.63), 1.62 (95% CI 1.36 - 1.94), and 2.11 (95% CI 1.75 - 2.53), respectively for income levels.

The presence of 1 or 2 children aged < 15 years increased Internet acceptance of health care services in comparison to households without children in that age range. The values of OR for full provision of the service in the Internet were 1.38 (95% CI 1.20 - 1.59), 1.33 (95% CI 1.12 - 1.58), and 1.41 (95% CI 1.06 - 1.88) for 1, 2, and > 2 children in a household, respectively.

The reception of aid from external services, presumably from social care, was associated with both outcome variables in the general multivariate regression model. However, in the model with specified dummy variables derived from the main variables, this significant relationship was not maintained.

Households with at least some books revealed a higher acceptance of the use of the Internet for health care provision in comparison to households with no books at all. This relationship was valid for both outcome variables. Both outcome variables showed a significant association with the availability of a personal or mobile computer in a household, with OR = 1.86 (95% CI 1.35 - 2.56) and OR = 2.14 (95% CI 1.66 - 2.76) for full and at least partial acceptance of the Internet for the provision of health care services, respectively. Access to the Internet and duration of Internet access lasting at least 1 year increased the probability of acceptance of full online health care services in comparison to households without Internet access or access of less than 1 year.

Self-confidence in being up-to-date with modern technologies was associated with higher acceptance. The difference between households with the least confidence and those being less up-to-date, undecided, or confident (rather or strongly agree) was statistically significant, with the outcome variable assuming full service provided online OR = 1.31 (95% CI 1.11 - 1.55), OR = 1.67 (95% CI 1.40 - 2.00), OR = 1.77 (95% CI 1.49 - 2.10), and OR = 2.94 (95% CI 2.21 - 3.91), respectively.

The use of health care services or admission to hospital of a member of a household in the preceding year did not influence acceptance of the use of the Internet for the provision of full health care services. The use of health care services in the preceding year was related to acceptance for at least partial delivery of health care services on the Internet.

Discussion

The overall acceptance of the use of the Internet for the provision of full health care services has remained at the same level since 2007 when these items were first included in the questionnaire used for assessment of Polish households as part of the Social Diagnosis study (the percentage changed only from 28.1% in 2007 to 29.1% in 2011) [13]. In the subset of households included in the logistic regression model, the acceptance of the use of the Internet for full health care service provision was approximately 30% (2656/8915, 29.79%) and at least for access to information and downloading necessary forms, 45.09% (4020/8915). These levels are relatively high considering that only 61.32% of households surveyed had Internet access and the actual availability of eHealth services to patients in Poland is not extensive. On the other hand, the percentage of European citizens using the Internet for more interactive services than simply reading health-related information included in the survey of Kummervold et al [18] in 2007 was as high as 22.7%. The analysis of data from the 2007 Health Information National Trends Survey performed by Wen et al [19] showed that nearly 86% of adults in the United States rated electronic access to their personal health record as important, which is far higher than the degree of acceptance of at least partial delivery of Internet-based health care services among Polish households in 2011.

In our study, we did not analyze the actual use of eHealth services, but another survey indicates that the Internet was used to access health-related information by 23% of individuals in Poland in 2011 [20]. The percentage of the adult population accessing health-related information online in Poland appears to be at least 2 times lower than the percentage of households accepting to some extent the use of the Internet for health care service provision.

Relatively high acceptance of at least partial provision of Internet-based health care services is likely related to a general dissatisfaction with the health care system in Poland. Poland’s health care system has been undergoing a continuing process of reforms since the transition to a market economy in the early 1990s. The establishment of Regional Health Funds was one of the key changes in the late 20th century, followed by the return of a centralized funding of the health care system with the establishment of the National Health Fund in the early 21st century. Poland’s health care system is still based on public hospital services and outpatient care by private providers paid mainly from the Fund [21]. Access to health care services contracted by the Fund is subject to a queue system, and patients frequently wait months for certain specialist services. The gap between expectations for high quality care and access to services for patients and their families, and the actual capability of the system, remains a major source of frustration [22,23]. This creates an opportunity for providers or organizations developing new types of health services, especially originating from the eHealth domain.

Most surveys reported elsewhere about the acceptance or the use of eHealth services have been related to the experience of individuals representing a whole population or selected groups, such as patients with specific disorders. Nonetheless, for at least some of the predictors resulting from the multivariate logistic regression carried out for households in Poland, corresponding findings from other surveys may be indicated.

The disparities between rural and urban areas in the use of ICT have been described previously in Poland and in other countries [24-29]. In our analysis, the differences were significant only between households from rural and highly urbanized (> 200,000 inhabitants) areas. This result seems to confirm the general perception of a relatively poor information infrastructure in smaller cities and rural areas in Poland.

The lower acceptance of eHealth services was also revealed in households where the main income was from retirement or disability pensions. This observation illustrates the lower Internet penetration and literacy in the older strata of society, as well as lower access to modern communication technologies among people with disabilities. The relationship between the source of income and the acceptance for eHealth services is in line with general findings that professionally active people are more involved in using the Internet and computers than those who are retired or receiving disability pensions [30-34]. In addition to lower acceptance of the use of the Internet for health care services in households from rural areas, households with a main income from self-employment in agriculture showed lower acceptance in comparison to households where the main sources of income related to employment.

In our study, acceptance was consistently associated with higher household income per capita (comparison between lowest and higher quartiles). This finding is consistent with the results of studies performed in other countries [28,35,36]. In earlier surveys conducted in Poland, it was found that the presence of a child in the household is a driver of ICT use [24]. The results of logistic regression showed that this is also true in relation to acceptance of health care services provision through the Internet. The study performed by Hsu et al [35] in Northern California also revealed that households with children were more likely to have access to eHealth services provided by a service provider in this area.

The number of books in a household was included in the analysis in order to observe the influence the level of general literacy may have on the acceptance of the Internet as a tool for health care. Interestingly, the availability of at least some books in a household significantly affected the acceptance of using the Internet for health care services.

Our study also revealed that the factors related to ICT use in households were predictors of the acceptance of the Internet for the provision of health care services. The availability of a computer in a household, Internet access, and its duration in the household increased the level of acceptance. These findings seem to confirm the importance of the development of the information society on the acceptance of eHealth services. Similar results have been reported by other authors, both in relation to variables related to actual Internet use [27,36,37] and computer use [27]. The households included in the survey also expressed their opinion about familiarity and use of modern technologies. Higher confidence in this area was associated with higher acceptance of Internet use in the health care domain. This shows that acceptance of innovation and technology in itself results in a more open approach to new media for service provision in specific domains.

Interestingly, variables related to actual use of health care services by households had a limited impact on the acceptance of the use of the Internet for health care service provision. This was true for all 3 variables included in the logistic regression model apart from the use of health care services in the preceding year and increased acceptance of partial provision of health care on the Internet. The results of surveys performed in other countries indicate that households with at least 1 member with a high expected need for clinical services [35], include an individual with a history of cancer [26], actual use of health care services [27], current health problems in an individual or relatives [36,37], and have chronic disease or a poor perception of one's own health [38] were associated with household or individual acceptance or use of the Internet for eHealth services. On the other hand, the survey carried out by Gracia et al [39] among older people in Spain revealed that Internet users had better self-rated health than non-users. A similar trend was described by Wang et al [29] who analyzed data from the 2001 National Household Travel Survey and found that individuals with medical conditions reported less frequent Internet use than those without medical conditions. In our study, satisfaction levels for the coverage of household health needs in comparison to 2 years ago had no impact on the acceptance of Internet-based health care.

The surveys which focused on individual opinions also showed that predictors of Internet acceptance or use for health-related activities included age [26,28,31,33], female gender [26,27,37,38], higher education level [28,31,33,38,40], marital status (being married or separated/divorced in comparison to being unmarried) [38], and helping another to deal with health issues [37]. These factors were not included in the multivariate logistic regression model used because it was based only on variables describing the households participating in the study.

Limitations

The assessment of acceptance levels for eHealth services is usually undertaken in relation to individual respondents. In this study, the responses registered by the canvasser were given on behalf of the whole household. Thus, the selection of potential factors which could influence the household's acceptance of using the Internet as a tool for delivering health care services was made from the variable which could characterize household's readiness to accept eHealth services.

The use of the concept of household acceptance in relation to eHealth services may be misleading because it is likely that not all members of a household share a common view and opinions may be diverse. On the other hand, the use of health care services usually depends on the decision of the individuals responsible for the household and their perception probably dominated in the views expressed during the canvasser interviews.

The main objective of the Social Diagnosis study was not focused on the eHealth field. Instead, it was oriented toward general issues about the household economic status and individual's quality of life. Furthermore, the aspects of the use of ICT and the phenomenon of social divide were targeted. The strategy employed in our paper was to assess the acceptance of eHealth in Polish society using the data available from a study encompassing the whole population in a well-established and methodologically proven study.

The number of cases included in the multivariate logistic regression model presented in our paper was reduced from 12,386 to 12,015 due to missing values of key variables used to define outcome variables in the model. Furthermore, households that did not anticipate using health care services in the near future were excluded, and cases with missing values for predictors used in the model were omitted. As a result, data from 8915 households were used in the logistic regression model.

The number of missing values for outcome variables was not high (3.00%, 371/12,386), and its significance is difficult to assess due to a lack of information about potential reasons for the lack of response. The exclusion of households that did not anticipate using health care services in the near future (13.73%, 1700/12,386) was a potential source of bias in the results of the analysis. It is possible that households without sufficient levels of understanding of using the Internet for health care services provision, or those that do not accept such use, may have selected this response in order to hide their actual position. Thus, the exclusion of this group of households could suggest that a higher number of households actually accept using the Internet for this purpose. As for cases excluded from the final logistic regression model due to missing values in predictor variables (11.30%, 1400/12,386), the highest drop-out rates were related to the lack of data about monthly household net income per capita (4.28%, 530/12,386), the perception of current economic status of a household (3.17%; 393/12,386), the opinion on satisfying health care needs of a household (2.28%; 282/12,386), and hospitalizations of household members (0.99%, 123/12,386).

Interpreting missing values within these variables is difficult because of the association with the acceptance of Internet use. It is possible that households with extremely low or high monthly income rates per capita could be more prone to withholding information about their actual income. This could also be valid for the relatively high number of missing values in the variable related to the opinion of a household about its economic status in comparison to the preceding period. Assuming that the number of households with very low incomes in Poland is significantly higher than the number of households with high incomes, and because poverty is linked to a lower acceptance of ICT technologies, the relationship between income and the acceptance of the Internet for health care services is likely to be closer than shown.

As for the variables related to the opinion about satisfying health care needs of the household and hospitalization of a household member in the past year, any potential bias in the assessment of final results is not clear. These variables did not have a significant effect on the acceptance of using the Internet for health care services provision. The households that were reluctant to respond to these items could be generally dissatisfied with health care services and did not think that the Internet could provide a working solution. It is also possible that a lack of response to this item was due to the household not having used health care services extensively in the preceding period. Furthermore, hospitalization of a household member in the preceding months is likely to have resulted in focusing on the current situation instead of emerging solutions. However, the net effect of missing values within these variables is not clear.

Conclusions

The acceptance of health care services via the Internet was higher in households from larger cities, with stable income from an employee salary, as well as with higher income levels per capita. Furthermore, general computer and Internet use in the household influenced the perception of eHealth. Paradoxically, the use of health care services or the level of satisfaction with the coverage of the household's health needs exerted a limited influence on acceptance of Internet-based health care.

Conflicts of Interest

None declared.

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Abbreviations

EU: European Union
ICT: information and communication technology
OR: odds ratio

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Original Paper

Patient Perceptions of a Personal Health Record: A Test of the Diffusion of Innovation Model

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Abstract

Background: Personal health records (PHRs) have emerged as an important tool with which patients can electronically communicate with their doctors and doctor’s offices. However, there is a lack of theoretical and empirical research on how patients perceive the PHR and the differences in perceptions between users and non-users of the PHR.

Objective: To apply a theoretical model, the diffusion of innovation model, to the study of PHRs and conduct an exploratory empirical study on the applicability of the model to the study of perceptions of PHRs. A secondary objective was to assess whether perceptions of PHRs predict the perceived value of the PHR for communicating with the doctor’s office.

Methods: We first developed a survey capturing perceptions of PHR use and other factors such as sociodemographic characteristics, access and use of technology, perceived innovativeness in the domain of information technology, and perceptions of privacy and security. We then conducted a cross-sectional survey (N = 1500). Patients were grouped into five groups of 300: PHR users (innovators, other users, and laggards), rejecters, and non-adopters. We applied univariate statistical analysis (Pearson chi-square and one-way ANOVA) to assess differences among groups and used multivariate statistical techniques (factor analysis and multiple regression analysis) to assess the presence of factors identified by the diffusion of innovation model and the predictors of our dependent variable (value of PHR for communicating with the doctor’s office).

Results: Of the 1500 surveys, 760 surveys were returned for an overall response rate of 51%. Computer use among non-adopters (75%) was lower than that among PHR users (99%) and rejecters (92%) ($P < .001$). Non-adopters also reported a lower score on personal innovativeness in information technology (mean = 2.8) compared to 3.6 and 3.1, respectively, for users and rejecters ($P < .001$). Four factors identified by the diffusion of innovation model emerged in the factor analysis: ease of use, relative advantage, observability, and trialability. PHR users perceived greater ease of use and relative advantage of the PHR than rejecters and non-adopters ($P<.001$). Multiple regression analysis showed the following factors as significant positive predictors of the value of PHR for communicating with the doctor’s office: relative advantage, ease of use, trialability, perceptions of privacy and security, age, and computer use.

Conclusion: Our study found that the diffusion of innovation model fits the study of perceptions of the PHR and provides a suitable theoretical and empirical framework to identify the factors that distinguish PHR users from non-users. The ease of use and relative advantage offered by the PHR emerged as the most important domains among perceptions of PHR use and in predicting the value of the PHR. Efforts to improve uptake and use of PHRs should focus on strategies that enhance the ease of use of PHRs and that highlight the relative advantages of PHRs.

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KEYWORDS

Personal health record (PHR); perceptions; innovation; electronic health records (EHRs); meaningful use

Introduction

In the last decade, electronic personal health records (PHRs) have emerged as an important Internet-based tool with which patients can communicate with their doctor's offices for tasks such as accessing components of the electronic health record (EHR), requesting appointments and prescription refills, and asking non-urgent medical questions. The Markle Foundation's Connecting for Health was a landmark report in recognizing the potential value of PHRs [1]. Since then, a number of reports and reviews have also discussed the importance of PHRs in helping patients take a more active role in their health care [2-6]. The regulations associated with meaningful use of electronic health records (EHRs), developed as a result of the Health Information Technology for Economic and Clinical Health (HITECH) Act [7], have underscored the importance of PHRs in the United States, and they include several core and menu measures for the electronic exchange of information between providers and patients that are likely to substantially increase adoption rates of these tools. In addition, a number of empirical studies have focused on adoption and use rates and patient satisfaction with PHRs [8-20].

Collectively, the empirical studies and reviews of PHR adoption and use offer some insights into the experience with PHRs over the last decade. The first is the emergence of two basic types of PHRs categorized as tethered (to the EHR of the provider) and untethered (or standalone) [2,6]. There has been a steady increase in implementation and uptake of tethered PHRs in the United States. For example, Kaelber and colleagues [3] reported that about fifty million patients have access to the MyChart PHR tethered to the Epic EHR system, and another twenty million veterans have access to My Health*e*Vet, the Department of Veterans Affairs PHR. Standalone PHRs are either created and maintained by the individual on a personal computer or accessible as Internet-based applications such as Microsoft's HealthVault. Internet-based standalone PHRs have been less successful in terms of uptake compared to tethered PHRs, and one prominent standalone PHR, Google Health, was discontinued in January 2012 because of lack of widespread adoption.

As the uptake and use of tethered PHRs grew, empirical research emerged on adoption and use rates of and satisfaction with PHRs. In terms of PHR use, the most commonly used functionalities of PHRs are review of medical test results (laboratory and radiology results), requests for medication refills, and clinical messaging with the provider and practice [9,11,12,14,15,18,20]. Among sociodemographic factors influencing use, race (being Caucasian) and income (high socioeconomic status) have been found to be significant predictors of use, suggesting the presence of a digital divide [9,12,17,20]. Patients with high expected need of clinical services and presence of chronic/comorbid conditions are more likely to use the PHR [9,13,14]. An outcome of interest in most empirical studies on use has been patient satisfaction, with patients reporting high levels of satisfaction with PHRs [8,11,14,21]. In terms of clinicians, some studies have reported that clinicians are less likely than patients to anticipate benefits from PHRs and were concerned with the impact on workload, especially unreimbursed work, as a result of PHR use [22,23]. However, clinician workload from PHRs has been found to be lower than anticipated and clinicians are generally satisfied with PHRs [8,11,21,24]. Nonetheless, clinician encouragement and use of PHRs has been found to be an important driver of patient adoption and use of PHRs [18].

The third set of insights related to the PHR experience focuses on issues such as functionality or purpose, system attributes, and privacy and security. Kaelber and colleagues [3] summarized four primary functions of a PHR: (1) Information collection (from the EMR as well as patient-entered data); (2) Information sharing (one-way sharing of information with others); (3) Information exchange (two-way exchange of information); and (4) Information self-management (such as tracking information and decision support). Of these functions, existing PHRs are predominantly aimed toward information exchange and information self-management. The information collection component, specifically patient-entered data in the PHR, lags behind for several reasons including: logistical (eg, workflows around who should review and accept the data into the PHR) and legal (eg, liability if data is not reviewed on a timely basis) [5]. Similarly, patient sharing of PHR information across organizations remains problematic because of interoperability issues. In the case of privacy and security issues associated with PHRs, the role of privacy and security in influencing adoption of PHRs and the need to balance enhanced security of information in PHRs with ease of use of PHRs has been noted [3,6]. However, several studies have reported that once patients adopt and use PHRs, they are less likely to be concerned with privacy and security issues [8,25].

In spite of the progress on research on PHRs, several gaps remain in the current literature. First, our review of PHR research as well as that conducted by others [6] has found an overwhelming emphasis on patient satisfaction as an outcome measure and a corresponding lack of inclusion of other outcome measures. For example, one outcome of interest identified by

Archer and colleagues [6] is sustainability or the degree of PHR use after adoption. Our analysis of PHR research has identified the perceived value of the PHR as an outcome measure. Beyond outcomes, there has also been little research conducted in terms of factors such as perceptions of PHRs and their impact on outcomes. For example, if patients perceive a PHR to be easy to use and having an advantage over a traditional approach such as calling the doctor's office for tasks such as medication refills or appointment requests, then they will likely perceive greater value of the PHR. Thus, there is a need to go beyond satisfaction as an outcome measure and at the same time understand the role of predictors such as perceptions on outcomes. Second, most of the PHR research has focused on adopters, and we know little about characteristics of non-adopters and how non-adopters perceive and value PHRs. Finally, little work has been done to apply theoretical frameworks to the study of patient adoption and use of PHRs. A suitable theoretical framework and associated concepts can not only advance our understanding of why patients adopt and use the PHR but also generate prescriptive findings on improving the adoption and use of this important tool. For example, such prescriptive findings can consist of strategies that organizations can adopt to promote positive perceptions of PHRs in order to influence adoption and use rates.

In this paper, we seek to collectively address these three gaps in the research on PHRs. A PHR represents an innovation for patients as it partially replaces the existing practice of calling the doctor's office for an appointment request or a prescription refill with an electronic, Internet-based approach to the same tasks. Moreover, as Rogers [26] points out, it is the perception of the innovation that matters since it is perceptions rather than actual attributes that will influence adoption. Tang and colleagues [2] have noted that "widespread adoption and use of PHRs will not occur unless they provide perceptible value to users, are easy to learn and easy to use". Therefore, in this study we applied a well-known and widely recognized theoretical framework, the diffusion of innovation model [26], in assessing patient perceptions of PHRs. Given the different functions of the PHR identified in the introduction above, the focus of our application of the diffusion of innovation model is to assess perceptions of PHR as a partial replacement for calling the doctor's office for communication functions such as appointment requests, medication refills, or asking the doctor a non-urgent medical question.

Methods

The Diffusion of Innovation Model

After a review of hundreds of innovation studies spanning fields such as agriculture, information technology, and pharmaceuticals, Rogers [26] identified five perceived attributes in the diffusion of innovation model that are most likely to influence the adoption of an innovation: (1) Relative Advantage, or the degree to which an innovation (such as a PHR) is perceived as being better than the idea it supersedes (for example, calling the doctor's office); (2) Compatibility, or the degree to which an innovation is perceived as consistent with existent values, past experiences, and needs of potential adopters (as, for example, past experience with using the Internet); (3) Complexity, or the degree to which an innovation is perceived as easy to understand and used as a whole or in incremental parts; (4) Trialability, or the degree to which an innovation can be experimented with on a limited basis (for example, trying a PHR for tasks such as appointment requests or secure messaging); and (5) Observability, or the degree to which the benefits of an innovation are visible to intended adopters. Each of these five perceived attributes is positively related to the rate of adoption of an innovation as well as its use.

A comprehensive approach to empirical research in this area was undertaken by Moore and Benbasat [27] who proposed that the focus of research should be on perceptions of innovation *use* rather than perceptions of innovation attributes since behavioral intentions are best explained by use perceptions (following Fishbein and Ajzen's theory of the relationship between attitudes and behaviors) [28]. As a result, Moore and Benbasat developed a survey to measure perceptions of innovation use. Our study followed the approach of Moore and Benbasat to focus on perceptions of the use of the PHR. We selected and modified a set of survey items developed by Moore and Benbasat concerning perceptions of use of a personal work station (PWS) to fit perceptions of using a PHR. For example, one of the items in the domain of Relative Advantage developed by Moore and Benbasat was "Using a PWS gives me greater control over my work". We modified the wording of this item to fit our study as follows: "Using a PHR gives me greater control over my care". Our modification of the wording also reflected our focus on non-users of a PHR in this study. For non-users, our survey item for the previous example captured potential use of a PHR: "Using a PHR will give me greater control over my care". We developed items for the five domains of perceptions in the diffusion of innovation model identified by Rogers: relative advantage, compatibility, ease of use (or complexity), trialability, and observability.

Beyond perceptions of innovation use, other research on adoption and use of innovations has focused on factors that may modify perceptions of innovations. One such set of factors, personal innovativeness in the domain of information technology (PIIT), was developed by Agarwal and Prasad [29]. PIIT is defined as "the willingness of an individual to try out new information technology" [29] and captures individual-level differences in the innovation-decision model. PIIT may play a particularly important role in distinguishing PHR users from non-users; for example, do PHR users have greater levels of PIIT than non-users? Moreover, such individual-trait variables have not been examined in existing research on PHRs, which has focused for the most part on sociodemographic characteristics [9,11-17]. For our study, we selected, without any modifications, four survey items capturing PIIT developed by Agarwal and Prasad [29]. These items were generically worded to fit our study as, for example: "I like to experiment with new information technologies" and "Among my peers I am usually the first to try out new information technologies". A third set of items included in our study pertains to the privacy and security of information in the PHR as concerns about privacy and security can play a key role in whether patients adopt and use PHRs [3-6]. In addition to these items on perceptions, we included items on sociodemographic characteristics (for example, age, gender, income, education, and race), and technology use and access.

The outcome measure of interest in this study is the perceived value of the PHR for communicating with the doctor's office. Several studies have pointed to the importance of assessing this outcome measure. As noted above, Tang and colleagues [2] call attention to the "perceptible value" of the PHR for users. They also point to the importance of understanding whether the cost (financial and effort) of adopting a PHR can be justified related to the perceived value of the PHR. In suggesting additional topics of research related to their analysis of eHealth services, Hsu and colleagues [9] recommend a study of perceived need and value of such services compared to alternatives. Finally, Kaelber and colleagues [3] distinguish between measurable value of PHRs such as improved quality and better patient satisfaction and perceived value of PHRs. They argue that perceived value may drive PHR adoption and use even if PHRs do not provide measurable value. Therefore we adopted the perceived value of the PHR for communicating with the doctor's office as the outcome measure for this study. We measured perceived value of the PHR for communicating with the doctor's office on a scale from 1 to 10 with 1 indicating no value at all and 10 indicating highly valuable.

To summarize, based on the literature on diffusion of innovations we identified five perceived attributes of innovation use: relative advantage, compatibility, ease of use, trialability, and observability. From the literature on information technology use, we identified a variable, personal innovativeness in information technology, which may help distinguish the level of innovativeness between PHR users and non-users. From the PHR literature, we identified several factors that play a role in the adoption and use of PHRs: perceptions of privacy and security, sociodemographic characteristics, and technology use including computer and Internet use. All these variables comprise our predictor variables. The PHR literature also yielded the outcome measure of the study, perceived value of the PHR in communicating with the doctor's office. To achieve the objective of our study, we will empirically test the application of the diffusion of innovation model to PHRs. That is, we will test for the presence of the five perceived attributes of PHR use. We will then assess the significance of the various predictors including the perceived attributes of innovation use in predicting our outcome measure. We will also conduct analysis to compare users and non-users with respect to the different predictors and the outcome measure.

Our approach is a cross-sectional survey of users and non-users of the PHR. First we developed a draft survey based on relevant items and findings from the existing literature as discussed above. Once the survey was developed, we conducted an internal test of the survey using several staff, some of whom were users while others were non-users of a PHR. Based on this testing, we eliminated some items and revised others. For example, we adopted some reverse-worded items to minimize response bias in the survey. We developed two versions of our survey: (1) a user version in which we asked about patient perceptions of using a PHR; and (2) a non-user version aimed at non-users of the PHR in which we asked about perceptions of potential use of the PHR. Appendix 1 shows the set of items in the user version of the survey.

Recruitment

To select the patients for the study, we relied on the definitions of adopter groups in the diffusion of innovation model. Rogers [26] identified five adopter groups in his diffusion of innovation model with respect to their time of adoption: innovators (usually first to adopt an innovation), early adopters, late adopters, early majority, and laggards (generally last to adopt an innovation). For this study, we combined the middle three groups (early adopters, late adopters, and the early majority) into one group called other users and divided patients who used the PHR into three groups: innovators, laggards, and other users. We defined innovators as patients who enrolled (signed up) for the PHR and used it at least once (eg, for a medication refill request or secure messaging with their provider) in a ninety-day (three-month) period after their practice went live with the PHR. Thus innovators were among the first group of patients to adopt the PHR. By specifying that they used the PHR at least once during the ninety-day period, we also ensured that innovators are users. Laggards were defined as adopters who enrolled for the PHR one year after their practice went live with the PHR and then waited for one more year to use the PHR. Thus our definition of laggards considers the lag in time in both adoption and use. Other users were all patients other than innovators and laggards who used the PHR at least once. We realize that these are heuristic definitions of three types of adopter groups based on the diffusion of innovation model. In this initial evaluation, our approach was to develop and apply a simple set of definitions of the adopter groups. We believe that the groups we created allow an initial test of the diffusion of innovation model in PHR research. The three groups of patients—innovators, laggards, and other users—comprise PHR users in our study. Rogers [26] does not consider non-users in his categories of innovators, but we identified two groups of non-users in our research. The first group, which has been the focus of most PHR research, is the non-adopter group comprising patients who never adopted the PHR. The second group of patients is the rejectergroup, ie, patients who adopted the PHR but never used it (these are patients who signed up for the PHR but never used their account even once after enrolling). Thus, our study population was divided into five groups labeled: innovators, laggards, other users, rejecters, and non-adopters.

The study was implemented in the ambulatory care practices of two academic medical centers (Brigham and Women's Hospital and Massachusetts General Hospital) at Partners HealthCare, an integrated delivery system (IDS) located in Eastern Massachusetts. Partners developed its own tethered-PHR, Patient Gateway, following its strategy of developing and implementing its own electronic health record, the Longitudinal Medical Record (LMR). The Partners PHR was first implemented in 2002 and, at the time of this study, about 80,000 patients had enrolled in the PHR at the two academic medical centers. The PHR has functionality similar to other tethered PHRs including requests for appointments, prescription refills and referrals, access to certain components of the EHR such as laboratory results, and secure messaging with the practice and provider.

The PHR transactions are stored permanently in the Partners clinical information systems and can be accessed for research purposes after IRB approval. We analyzed transactions such as the PHR account created date and the use of different PHR functionalities to identify patients in four of our five groups: innovators, laggards, other users, and rejecters. In the case of non-adopters, we used our scheduling system to identify patients who had a visit at a practice using the PHR but who did not have a PHR account. We selected a random sample of 300 patients for each group for a total of 1500 patients for the patient survey. In the case of non-adopters, we also specified that the patients must have one of four chronic conditions (asthma, CHF, hypertension, or diabetes), which we identified through the problem list in our EHR system. We selected these chronic conditions for non-adopters to ensure that non-adopters have a perceived need and potential reason for using a PHR to communicate with their doctor's offices. We adopted Dillman's tailored design method (TDM) to enhance response rates [30]. We sent an introductory letter informing patients that they would be receiving a survey and allowed them the opportunity to opt out of the survey. After removing patients who refused participation in the study in response to the introductory letter, we sent the survey with a $2 cash incentive. We then sent a reminder postcard followed by a reminder survey. All study materials and methods were approved by the Partners HealthCare Institutional Review Board.

Statistical Analysis

We present frequencies and means of sociodemographic characteristics, patient characteristics, and factors related to technology access and use for our five patient groups. To assess for differences between the five groups, we conducted chi-square tests for categorical data (Pearson's chi-square for dichotomous and nominal variables) and robust one-way ANOVA for continuous variables. We also computed post-hoc Bonferroni *P*values. We used factor analysis to identify the factor structure of the items pertaining to perceptions of PHR use. Given the exploratory nature of our study, our factor analysis was also exploratory and consisted of principal components analysis with varimax rotation and extraction based on eigenvalues greater than 1 and confirmed by scree plot. We reviewed the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy and Bartlett's Test of Sphericity to ensure appropriateness of factor analysis for the data [31]. Based on the results of the factor analysis, we created scales for the different factors using an average of the original data for the items comprising each scale. We also employed multiple regression analysis using a forced entry method to assess predictors of our dependent variable, value of PHR for communicating with the doctor's office. All analyses were conducted using the SPSS 19.0 statistical software package.

Results

Response Rates

Of the 1500 surveys, 760 surveys were returned for an overall response rate of 51%. Response rates varied considerably between the PHR user and non-user groups. In the user group, 173 of 300 (57.7%) of innovators, 179 of 300 (59.7%) of other users, and 162 of 300 (54%) of laggards returned the survey. In comparison, in the non-user group, 118 of 300 (39.3%) of rejecters and 116 of 300 (38.7%) of non-adopters returned the survey. Our response rate for users (innovators, other users, and laggards) exceeds that of previous studies on patient satisfaction with PHRs [8,10]. Our response rate for non-users (rejecters and non-adopters) is comparable to the response rates of users in these studies. Non-responders were younger than responders in the case of innovators and laggards, but there were no differences among the other groups. There were no differences between non-responders and responders with respect to age or gender.

Sociodemographics Characteristics Among Survey Respondents

Table 1 shows data on sociodemographic characteristics among survey respondents. Innovators were younger (mean age = 55 years) than other users (60 years) and non-adopters (62 years) ($P = .001$), but there were no differences in age among the other groups. Women were represented less in the laggard group (52%) than among innovators (79%), rejecters (75%), and non-adopters (72%) ($P < .001$). The percentage of Caucasian non-adopters (76%) was lower than the percentage of Caucasian innovators (94%), laggards (94%), and other users (86%) ($P < .001$). Only 50% of non-adopters had a four-year college degree or more compared to 76% of the innovators, 71% of laggards, and 69% of other users ($P = .001$), and only 41% of non-adopters had a total household income of $75,000 or more compared to 75% of laggards, 72% of innovators, and 63% of other users ($P < .001$). Non-adopters also differed from innovators and laggards on marital status (47% married; $P < .001$). In terms of overall health status, non-adopters reported a lower rating of overall health compared to innovators and laggards, and other users and rejecters reported lower overall health status than innovators. Innovators also reported a smaller number of comorbidities (mean = 2.8) than other users, rejecters, and non-adopters (mean = 3.7).

Table 1. Sociodemographics and self-reported health status of survey respondents.

Groups	Age (years)	Gender (% female) (n)	Race (% Caucasian) (n)	Education[a]	Income[b]	Marital status (% married)	Rating of overall health[c] (mean)	Self-reported comorbidities[d] (mean)
Innovators	55.4	79% (136/173)	94% (163/173)	76% (126/166)	72% (108/150)	68% (117/173)	3.8	2.8
Other users	59.8	65% (116/179)	90% (161/178)	69% (120/173)	63% (96/153)	63% (112/179)	3.5	3.4
Laggards	59.0	52% (84/162)	94% (152/162)	71% (112/157)	75% (103/137)	70% (114/162)	3.6	3.3
Rejecters	58.3	75% (89/118)	86% (101/118)	61% (68/112)	58% (61/105)	64% (76/118)	3.4	3.5
Non-adopters	61.7	72% (84/116)	76% (88/116)	50% (55/109)	41% (41/101)	47% (54/116)	3.2	3.7
P value[e]	*P*=.001	*P*<.001	*P*<.001	*P*=.001	*P*=.001	*P*=.001	*P*=.001	*P*=.001

[a] Education is captured as 4-year college graduate or more.

[b] Income is captured as $75,000 or more in total household income from all sources before taxes.

[c] Rating of overall health is captured as: Excellent (5), Very Good (4), Good (3), Fair (2), or Poor (1).

[d] Self-reported comorbidities included 11 conditions such as: allergies, high blood pressure, high cholesterol, diabetes, heart disease, and asthma or emphysema.

[e] *P* value for comparison of all five groups.

Access and Use of Technology

We asked patients about their access to technologies such as a DVD player, iPod/MP3 player, and cell phones and smart phones, use of computers and the Internet, and patient perceptions of personal innovativeness in information technology (PIIT; Table 2). We also gathered data on self-reports of use and satisfaction with the PHR among the three PHR user groups. The three user groups (innovators, other users, and laggards) did not differ from each other on technology access, computer use, Internet use, self-reports of PHR use, and satisfaction with and value of PHR for communicating with their doctor's office (Table 2). As a result, for the remaining analysis, we combined the three groups (innovators, other users, and laggards) into one group called PHR users, leaving us with three groups for the study: users, rejecters, and non-adopters.

With respect to non-adopters, in terms of technology access (such as use of an iPod/MP3 player, and smartphone/BlackBerry), non-adopters reported access to a smaller number of technologies (mean = 6.1) compared to users (mean = 7.8) and rejecters (mean = 7.0) ($P < .001$). Computer use among non-adopters was also lower with 87 of 116 (75%) reporting that they used a computer compared to 509 of 514 (99%) for users and 109 of 118 (92%) for rejecters ($P < .001$). Internet use was reported by 82 of 116 (71%) of non-adopters compared to 509 of 514 (99%) for users and 106 of 118 (90%) for rejecters ($P < .001$). Non-adopters also reported a mean PIIT score of 2.8 compared to 3.6 and 3.1, respectively, for users and rejecters ($P < .001$). Thus, non-adopters differed systematically from users of PHRs on sociodemographics, use of technology, and personal innovativeness in information technology. Non-adopters also differed from rejecters of a PHR on access and use of technology, PIIT, and the value of PHR for communicating with the doctor's office. Overall, the differences between non-adopters and users were greater than those between rejecters and users.

Table 2. Access and use of technology among survey respondents.

Groups	Technology access[a] (mean)	Computer use[b] (% patients) (n)	Internet use[c] (% patients) (n)	PIIT[d] (mean)	Value of PHR[e] (mean)	Mean # of requests via PHR[f]	Mean satisfaction with PHR[g]
Innovators	7.8	99% (172/173)	99% (172/173)	3.7	6.4	10.0	3.6
Other users	7.8	99% (177/179)	99% (177/179)	3.6	6.7	6.7	3.6
Laggards	7.8	99% (160/162)	99% (160/162)	3.4	6.8	8.3	3.4
Users	7.8	99% (509/514)	99% (509/514)	3.6	6.7	4.1	3.5
Rejecters	7.0	92% (109/118)	90% (106/118)	3.1	6.1	—	—
Non-adopters	6.1	75% (87/116)	71% (82/116)	2.8	4.9	—	—
P value[h]	*P*<.001	*P*<.001	*P*<.001	*P*<.001	*P*<.001	.23	.26

[a] A factor developed by adding ten items on access to technology such as a VCR, DVD player, Camcorder, iPod/MP3 player, and smartphone/BlackBerry. A score of 0 indicates that the patient did not have access to all 10 technologies, whereas a score of 10 indicates that the patient had all 10 technologies.

[b] Computer use means that patient was able to use a computer at any of the following locations on at least an occasional basis: home, work, school, library, friend's house, community center, and other.

[c] Internet use means that patient was able to go online to use the Internet from home, work, or elsewhere.

[d] PIIT refers to personal innovativeness in the domain of information technology.

[e] Value of PHR for communicating with the doctor's office is measured on a scale from 0 to 10, with 0 meaning no value at all and 10 meaning highly valuable.

[f] Requests made via PHR in a twelve-month period for functions such as appointments, referrals, address and telephone corrections, medication refills, and asking questions about care.

[g] Satisfaction with PHR is measured as: 1 = Excellent, 2 = Very Good, 3 = Good, 4 = Fair, 5 = Poor. Item was reverse coded for results reported in the table.

[h] *P* value for comparison of user, rejecter, and non-adopter groups except for log-on to PHR and mean satisfaction with PHR for which *P*value is comparison of innovators, other users, and laggards.

Diffusion of Innovation Theory and Perceptions of Using a PHR

Given that little empirical research has been conducted on the application of diffusion theory to adoption and use of PHRs, we employed exploratory factor analysis with orthogonal rotation to identify the factor structure in our data and assess whether the factors that emerged reflect the theoretically specified domains (such as Relative Advantage and Ease of Use). Our initial factor solution yielded four factors. In this solution, however, items from one domain — Compatibility — loaded highly on several factors indicating that the items on this domain mixed with other domains such as Relative Advantage (the discussion section below elaborates on this finding). In addition, an item on ease of use also loaded highly on several factors and an item on trialability loaded on the ease of use factor, suggesting that these two items were either too complex or did not capture their domains as intended. We removed all such items and conducted the exploratory factor analysis again with the remaining items. Table 3 shows the results of this factor analysis. Four factors with eigenvalues greater than 1 emerged accounting for 72% of the variance in the data. Each factor represents a domain in the diffusion of innovation theory: Factor 1, Ease of Use; Factor 2, Relative Advantage; Factor 3, Observability; and Factor 4, Trialability. Ease of Use accounted for 25% of the variance in the data, Relative Advantage for 21%, Observability 14%, and Trialability 12%.

Table 3. Factor analysis of perception items (rotated component matrix[a]).

	Component			
	1 (Ease of use)	2 (Relative advantage)	3 (Observability)	4 (Trialability)
Learning to use PHR was easy for me. (EU[b])	0.83			
Using PHR is frustrating. (EU)	-0.83			
Using PHR requires a lot of mental effort. (EU)	-0.81			
Overall, I believe that PHR is easy to use. (EU)	0.81			
Using PHR improves the quality of care I receive. (RA)		0.84		
Using PHR gives me greater control over my care. (RA)		0.78		
The effectiveness of care I receive will not improve by my using PHR. (RA)		-0.72		
Using PHR enables me to contact my doctor's office more quickly. (RA)		0.70		
I have seen what others can do using PHR. (OB)			0.91	
I have talked to others about using PHR. (OB)			0.87	
I tried PHR on a trial basis to see what it can do for me. (TA)				0.85
I really did not lose much by trying PHR, even if I would not have liked it. (TA)				0.80
Eigenvalue	4.4	1.6	1.4	1.3
Percent variance	25	21	14	12
Cronbach alpha for scale	0.88	0.85	0.76	0.57
Mean of scale for PHR User, Rejecter, and Non-Adopter groups	User: 4.0 Rejecter: 3.4 Non-adopter: 3.2	User: 3.4 Rejecter: 3.2 Non-adopter: 2.9	User: 2.5 Rejecter: 2.6 Non-adopter: 2.1	User: 3.5 Rejecter: 3.8 Non-adopter: 3.2
P value for comparison of scale among patient groups	*P*<.001	*P*<.001	*P*<.001	*P*<.001

[a] Values below 0.40 have been suppressed.

[b] Indicates the domain of diffusion of innovation that the item belongs to: EU = Ease of Use; RA = Relative Advantage; OB = Observability; TA = Trialability

Our next step was to create scales for each of the four domains. Table 3 also shows the results of the reliability analysis (Cronbach alpha) for each scale (as represented by the factor or domain). Cronbach alpha was very good for Ease of Use (0.88; 4 items) and Relative Advantage (0.85; 5 items), satisfactory for Observability (0.76; 2 items), and fair for Trialability (0.57; 2 items). We then created a scale for each domain by averaging the scores of the items for each domain. Next, we conducted analyses to assess whether our patient groups (PHR users, rejecters, and non-adopters) differed on the four domains. PHR users perceived a greater ease of use of the PHR (Mean = 4.0) than rejecters (Mean = 3.4) and non-adopters (Mean = 3.2), but rejecters and non-adopters did not differ from each other. The same finding holds for relative advantage for which PHR users perceived a greater relative advantage of the PHR (Mean = 3.4) than rejecters (Mean = 3.1) and non-adopters (Mean = 2.9), but rejecters and non-adopters did not differ. In the case of Observability, PHR users and rejecters perceived greater observability of the PHR than non-adopters but did not differ from each other. In the case of Trialability, all three groups differed from each other with rejecters reporting greater perceptions of trialability than users and non-adopters.

Predicting the Value of a PHR for Communicating With the Doctor's Office

Our final analysis assessed the role of different variables in predicting our dependent variable, patient perceptions of the value of the PHR for communicating with their doctor's office measured on a scale from 0 = no value at all to 10 = highly valuable. Our independent variables consisted of: sociodemographic variables such as age, gender, education and income, access and use of technology, PIIT, a factor on patient perceptions of privacy and security (created by combining three items on privacy and security; Appendix 1), and the four scales representing the domains of the diffusion of innovation model from Table 3. We also retained our patient groups of PHR users, rejecters, and non-adopters in the analysis. Table 4 shows the results of the multiple regression analysis when all variables are entered into the model.

The R-square for the model fit is 0.51 ($P<.001$). Six items are significant predictors of the value of the PHR for communicating with the doctor's office. Three of the items are domains of perceptions of innovation use from the diffusion of innovation model: Relative Advantage, Ease of Use, and Trialability. The greater the relative advantage, ease of use, and trialability of the PHR, the more patients value the PHR for communicating with their doctor's office. The fourth domain from the diffusion of innovation model, observability, did not emerge as a significant predictor of the value of the PHR. The remaining three significant predictors are: Privacy/Security, Computer Use, and Age. More positive perceptions of privacy and security of information in the PHR are associated with greater perceived value of the PHR. The use of a computer is associated with a greater perceived value of the PHR. Finally, age has a small but positive effect on perceived value of the PHR.

Table 4. Results of multiple regression with the value of PHR for communicating with the doctor's office as the dependent variable.

Model[a]	Unstandardized coefficients		Standardized coefficients	*t*	Sig.
	B	Std. Error	Beta		
Constant	-7.71	1.08		-7.13	.000
User versus Rejecter[b]	-0.32	0.27	-.05	-1.18	.24
User versus Non-Adopter	-0.04	0.30	-.01	-0.12	.90
Rejecter versus Non-Adopter	0.28	0.35	.03	0.81	.42
Age	0.02	0.01	.08	2.19	.03[c]
Gender[d]	0.30	0.21	.05	1.42	.16
Race[d]	0.07	0.32	.01	0.20	.84
Education[e]	-0.06	0.23	-.01	-0.25	.80
Income	-0.02	0.25	-.004	-0.10	.92
Marital status	0.11	0.23	.02	0.50	.62
Rating of overall health	0.07	0.11	.02	0.64	.52
Self-reported comorbidities	0.06	0.06	.04	1.05	.29
Technology use	-0.002	0.06	-.002	-0.04	.97
Computer use	1.22	0.60	.07	2.03	.04[c]
PIIT	0.13	0.12	.04	1.04	.30
Privacy and security	0.40	0.12	.11	3.25	.001[f]
Ease of use	0.49	0.14	.14	3.44	.001[f]
Relative advantage	1.87	0.14	.51	13.07	.000[g]
Observability	0.13	0.10	.04	1.35	.18
Trialability	0.31	0.11	.09	2.76	.006[c]

[a] $R^2 = 0.51$; Adjusted $R^2 = 0.49$; $R^2\Delta = 0.51$; $F\Delta = 29.92$; df1 = 18, df2 = 520; Sig. F change = .000.

[b] The model contains the three pair-wise comparisons for the three groups.

[c] $P < .05$.

[d] Gender is coded as Female = 1, Male = 0; Race is coded as Caucasian = 1, Other = 0.

[e] For definitions of all other variables, refer to Tables 1-3.

[f] $P < .01$.

[g] $P < .001$.

Discussion

Principal Results

Our overall objective was to apply a theoretical model, the diffusion of innovation model, to the study of PHR adoption and use. We adopted two conceptual approaches to achieving this overall objective. First, we classified patient groups into the categories of innovators, laggards, other users, rejecters, and non-adopters. We did not find differences between innovators, other users, and laggards on factors such as use of technology, and use of and satisfaction with the PHR. Although innovators were younger than other users and the proportion of females was greater for innovators than laggards, we did not find any differences between the three PHR user groups on two important socioeconomic variables identified by Rogers [26] in his diffusion of innovation model: education and income. Our findings differ from Rogers' [26] propositions that innovators are highly educated and possess substantial financial resources compared to laggards. One possible explanation for this difference is neither technology nor socioeconomic characteristics distinguish among users of a PHR. A tethered-PHR such as the one that is the focus of this study is not associated with a financial cost of adoption on the part of patients as the innovation is provided by their health care organizations. In contrast, many of the innovations that Rogers studied for his diffusion of innovation model were financially costly to adopt and led Rogers to conclude that socioeconomic status and innovativeness go hand in hand. The other potential explanation for our difference from Rogers' findings has to do with the heuristic definitions we adopted for our three groups. It is possible that there are other classifications of innovators and laggards that exist that might reveal differences in socioeconomic and technological characteristics. For example, laggards in our study had lower personal innovativeness in information technology than innovators. Thus, one area for additional research on this topic could be the classification of patients as innovators and laggards based on new functionality in the PHR that is driven by personal innovativeness in information technology use.

Our study did find systematic differences between those who use a PHR and those who did not adopt a PHR on income, education, technology use and access, and personal innovativeness in information technology. Non-adopters were not only less educated and had lower income but also had lower use of technology in general and less personal innovativeness in information technology. These results are indicative of the presence of the digital divide in PHR that we and others have reported [9,16,17,20]. However, most of the existing studies on the digital divide associated with PHRs have reported adoption and use rates of PHRs or relied on data from surveys of Internet use. We believe that our study is the first to report on the digital divide through a patient survey of PHR users and non-adopters. As far as we are aware, this is also the first empirical study that shows that the digital divide associated with PHR extends to an individual-trait variable such as perceived innovativeness in the domain of information technology. Non-adopters not only have significantly lower use of technology in general and computers in particular, but they also have significantly lower personal innovativeness in information technology (PIIT) compared to users of PHR. Lower PIIT can have antecedent and consequent impacts on perceptions of the PHR [29]. An antecedent impact of lower PIIT is that non-adopters will likely have to rely on more communication channels to learn about a PHR. A consequent impact of lower PIIT is that non-adopters will need to have more positive perceptions with respect to behavioral intentions toward adopting and using a PHR. As a result, non-adopters with lower PIIT face greater challenges in adopting and using a PHR.

Our second approach to applying the diffusion of innovation model to the study of PHRs was to develop and implement a survey on perceptions of using a PHR (or potential use among non-users) using the five domains identified in the model: relative advantage, compatibility, ease of use, observability, and trialability. Our initial factor analysis of the perception items found that compatibility did not emerge as a distinct domain. This finding is similar to that of Moore and Benbasat [27] who found that compatibility merged with the domain of relative advantage in their study on perceptions of use of personal work stations. Rogers [26] has reported that other studies have found that compatibility and relative advantage are not empirically related. There are two potential explanations for this finding. Compatibility is the degree to which an innovation is perceived as consistent with existent values, past experiences, and needs of potential adopters [26]. It is possible that patients do not perceive the compatibility of using a PHR as a domain for consideration given their past experience with using the Internet. That is, the prior use of the Internet gives patients the meaning and congruence for using an Internet-based tool such as the PHR thereby excluding or mitigating compatibility as a perceptual domain. As a result it is other perceived domains—such as ease of use and relative advantage—that dominate the perceptual space of PHR use. On the other hand, it is possible that the items on compatibility that we adopted in our survey need to be modified, or new items on compatibility need to be developed, to better capture perceptions of compatibility of PHR use that are empirically distinct from relative advantage.

Our final factor analysis yielded four domains hypothesized by the diffusion of innovation model. Ease of use and relative advantage emerged as the top two factors in the model. This suggests that PHRs must be perceived as easy to use and must show a perceived relative advantage over existing practices. The finding on ease of use provides empirical support for the importance of usability of PHRs as reported in the literature [2,3,6,8]. The finding on relative advantage contributes to the literature by showing the importance of demonstrating the relative advantage of PHRs over traditional approaches such as calling the office. Our factor on trialability suggests the importance of allowing patients to try the PHR on a trial basis, while observability reflects the importance of patients being able to observe how a PHR can be used. The scales developed from each of the factors also yield findings that are intuitively expected. PHR users perceive greater ease of use and relative advantage than rejecters and non-adopters. In terms of observability and trialability, PHR users and rejecters perceive greater observability and trialability than non-adopters.

Our final analysis used multiple regression with forced entry to predict the perceived value of the PHR for communicating with the doctor's office from a number of independent variables. In this study, none of the sociodemographic variables except age were significant predictors of patient perceptions of the value of the PHR for communicating with the doctor's office. We found age to have a small but positive impact on the perceived value of the PHR. While some studies have reported that age-related cognitive limitations pose a barrier to PHR adoption and use [16], others have not found a digital divide with respect to age in PHR use [11]. Our finding is more aligned with the second study by Tang and Lansky [11], which found that one-third of patients in their sixties and a quarter in their seventies had signed up for the PHR and found it to be valuable.

Further research is needed on how older patients adopt, use, and value PHRs given that the relationship between age and use and value of the PHR is moderated by several factors such as socioeconomic status, access and use of computers and the Internet, and literacy and numeracy.

Two self-reports capturing health of patients—overall health status and number of comorbid conditions—were not significant predictors of the perceived value of the PHR for communicating with the doctor's office. This result is contradictory to several studies that have found that expected need of clinical services and presence of chronic/comorbid conditions are associated with PHR adoption and use [9,13,14]. One possible explanation for the difference is that our outcome variable is perceived value of communicating with doctor's office and not adoption or use. Thus, while expected need or presence of comorbid conditions may predict adoption and use, it may play less of a role in perceived value of the PHR. In the case of patients with chronic conditions, Archer and colleagues [6] have noted "Simply providing online access to medical records is not useful unless the technology is integrated with the patient's existing health and psychosocial support infrastructure". Perhaps patients in our study reflected this view in assessing the perceived value of PHRs thereby generating a lack of relationship between health status and perceived value. On the other hand, the lack of a relationship between health status and perceived value may be specific to the patient population in our study. We also relied on self-reports of health status instead of capturing health status through documented comorbidities in the EHR. Additional research is needed to understand the impact of expected need of clinical services and chronic conditions on perceptions of value of the PHR.

Positive perceptions of privacy and security of information in the PHR were positive related to the perceived value of the PHR. While privacy and security may pose a barrier to adoption of PHRs as reported by several researchers [3,4], PHR users may be less concerned about the privacy and security of information in the PHR as found by Hassol and colleagues [8]. A survey of users similarly found that a majority of users were not worried about privacy of information in the PHR [25]. Our finding also suggests that positive framing of the privacy and security of information in PHRs could lead to positive perceptions of the value of the PHR and thereby influence uptake of the PHR as some have suggested [6].

Among the domains of perceptions of use, relative advantage was the strongest predictor of perceived value of the PHR by far followed by ease of use and trialability. Observability did not emerge as a significant predictor. As this is one of the first studies to report such findings, additional research is needed to confirm these findings or suggest alternative findings. Previous analyses of PHRs have identified a set of attributes of the ideal PHR [1,4]: (1) PHRs should be protected, private, and secure; (2) PHRs should be accessible from any place, at any time, and transparent; (3) Ownership of the PHR should lie solely with the customer; (4) The patient should approve storage and use of data; and (5) The data should be in a format that is understandable. Our research, which defines a PHR as an innovation and focuses on perceptions of PHR use, suggests that the following attributes are also important: (1) The PHR must be easy to learn and use; (2) The PHR must provide a relative advantage over traditional approaches such as a phone for contacting the doctor's office; (3) The PHR must be trialable in that patients must have adequate opportunities to try a PHR; and (4) The PHR must be observable so that patients have an opportunity to observe its features and functionality.

Concluding Remarks

We conclude that the Rogers model of diffusion of innovations fits well for this innovation and offers insights that are both prescriptive and theoretical in nature with respect to PHR adoption and use. The criteria of meaningful use of EHRs of the HITECH Act that pertain to patient engagement in health care in both Stage 1 [7] as well as subsequent stages place a spotlight on PHR adoption and use given the potential role of the PHR in implementing such criteria. The findings of our study have prescriptive relevance for improving the adoption as well as the use of PHRs so that they can better facilitate the implementation of meaningful use. To improve PHR adoption, especially among rejecters and non-adopters of the PHRs, our study suggests that the most important domains are relative advantage and ease of use of the PHR. While this statement may appear to be fairly straightforward, many PHRs in current use were developed several years ago and it is not clear whether evaluative studies on the ease of use of these PHRs, especially where non-adopters are concerned, have been conducted (at least we have not come across them in the research or practitioner literatures). Additionally, efforts to improve uptake of PHRs among non-adopters could focus on strategies that highlight the relative advantage of a PHR. For example, an intervention to increase the uptake of PHRs could focus on the role of a PHR in avoiding phone tag with a nurse for a prescription refill or the benefits of asynchronous communication offered by the PHR for non-emergent medical questions (eg, patients can email their doctor at their convenience). Practitioners can also address trialability of PHRs among non-adopters, as for example through a computer in a waiting room or through group sessions that educate patients about the use of PHRs. As implementation of meaningful use of EHRs accelerates, it would be worthwhile for practitioners to conduct and share the results of studies that facilitate improvements in domains of perceptions such as ease of use, relative advantage, and trialability of PHRs. In terms of improving the use of PHRs, given that PHR users do not differ with respect to technology and socioeconomic characteristics regardless of their time of adoption, our study suggests that initiatives to improve use of PHR can target all users and do not have to be tailored on whether the patient is an innovator or a laggard. Nonetheless, innovators may be able to play a role as change agents or opinions leaders in the diffusion of PHRs, and this is an important area for further exploration from the standpoint of both research and practice.

Furthermore given that perceived ease of use and relative advantage emerged as important domains in our study, an alternative model for consideration in future research is the Technology Acceptance Model (TAM) proposed by Davis [32,33]. TAM draws upon the work of Fishbein and Ajzen on the relationship between attitudes and behaviors [28]. In TAM, Davis developed a concept called perceived usefulness defined as the “degree to which an individual believes that using a particular system would enhance his or her job performance” [33:477]. Davis found that perceived usefulness was more important than perceived ease of use in predicting usage of technology (our finding in this study is similar in that we found that relative advantage was by far a better predictor of perceived value of the PHR). As Moore and Benbasat [27] point out, the perceived usefulness construct proposed by Davis is similar to the construct of relative advantage in the diffusion of innovation model. The strength of TAM is the inclusion of concepts such as attitudes and behaviors and their linkages to perceptions of use of technology. In a development of TAM, called TAM2, Venkatesh and Davis [34] also incorporate the role of subjective norms in the model. In discussing the use of PHRs for patients with chronic conditions, Winkelman and colleagues [35] reviewed the conceptual relevance of the TAM model for predicting PHR use in such patients but questioned its applicability to the PHR setting given its origins and development for understanding technology use by individuals in the organizational setting.

From a theoretical perspective, our study found evidence to support the application of the diffusion of innovation model to perceptions of the PHR. However, further research is needed in two areas with respect to the model: (1) Are there other definitions of innovators and laggards with respect to PHR use and do these definitions highlight any differences among these groups?; and (2) Is compatibility a perceived domain of PHR use that can be captured separately from relative advantage and ease of use? Another area for potential research is the application of the diffusion of innovation model to standalone PHRs. As reported in the principal results section, contrary to Rogers’ [26] propositions we did not find that innovators are highly educated and possess substantial financial resources compared to laggards. This may be the case with a tethered PHR, which is the focus of this study. But in the case of standalone PHRs, it is possible that innovators differ based on education and financial resources. The factors predicting adoption and use of standalone PHRs may also differ. For example, perceived ease of use may play a more important role in standalone PHRs than relative advantage, as standalone PHRs unlike tethered PHRs do not replace traditional approaches of calling the doctor’s office.

In addition, there is a need to understand the impact of perceptions on such factors as attitudes and behavioral intentions to adopt the PHR as well as the use and sustainability [6] of use of the PHR after adoption. Alternative models to use in such research on PHRs include the TAM model discussed above and the theory of planned behavior developed by Fishbein and Ajzen [28]. In these models, perceptions and attitudes are upstream variables and outcomes such as behaviors, perceived value of the PHR and sustainability are downstream variables. Appendix 2 presents a conceptual framework of different constructs for behavioral research on PHRs. For example, perceptions may influence behavioral intentions to adopt a PHR directly or indirectly through attitudes. Perceived value of the PHR, on the other hand, may be impacted by perceptions directly as this study found or indirectly through behaviors such as the use of specific PHR functionalities. We do not claim that the constructs and relationships shown in Appendix 2 are exhaustive but offer these as a first step in identifying a conceptual framework for behavioral research on PHRs.

Furthermore, the hypothesized relationships in our conceptual framework may not be static but can be dynamic in nature. With respect to perceptions, the lack of stability of the perceived attributes of an innovation was pointed out by Greenhalgh and colleagues [36]. For example, a patient may initially perceive a relative advantage in using the PHR for asynchronous secure communication with the provider. However, if the patient has a negative experience with the use of the PHR for such communication along the way (a lack of response or delayed response from provider), then the perceived value of the PHR for this functionality could drop and the patient may discontinue the use of PHR for such communication. Thus, along with cross-sectional studies, there is a need for longitudinal studies of perceptions of PHRs and the impacts of changes in perceptions on outcomes such as sustainability of PHR use.

Finally, while it is important to understand individual-level factors such as perceptions as examined in our study, a focus on such individual-level factors may lead to what Rogers [26] has called “individual blame” in diffusion of innovation studies. Under the individual blame approach, the patient is blamed for lack of adoption and use of the PHR and inadequate attention is paid to other factors that also impact adoption and use. Here again, Greenhalgh and colleagues [36] offer some important contributions to the literature based on their analysis of innovations in service delivery and organization. Some of the key factors identified by Greenhalgh and colleagues include: (1) psychological antecedents or traits associated with trying and using innovations such as tolerance of ambiguity and motivation; (2) the meaning of the innovation for adopters, which may differ from the meaning of the innovation for the organization implementing the innovation; (3) the context—technological, political, and cultural—within which the innovation is adopted; and (4) organizational-level factors such as structures, processes, and culture. Similar factors have been identified in existing reviews and empirical studies of PHRs including the meaning of the PHR for patients [35], cultural trends in information technology use [2], political and technological factors influencing EHR adoption [6], policies for interoperability of PHRs [4], and organizational strategy for EHR and PHR implementation and use [3,18]. Yet another important factor in counteracting the individual blame approach in PHR adoption and use is the role of provider encouragement and use of the PHR [18]. In field studies that we have conducted on PHR adoption and use, we have repeatedly heard from providers, staff, and patients that if providers are enthusiastic and encourage patients to adopt and use PHRs then patients are more likely to adopt and use PHRs. Thus as the implementation of EHRs and PHRs accelerates under HITECH, we recommend that providers play an active role in the uptake of PHRs and their subsequent use.

Limitations

This study has several limitations. It is an exploratory study and one of the first to apply the diffusion of innovation model to the empirical study of PHRs. It was conducted in only one system and region, and the results may not be generalizable to other settings. In addition, although as we indicated our response rates were comparable or exceeded many existing studies, the response rates were just over 50%, and non-responders to the survey may have had different perceptions than responders. Non-users and users were not matched also (and you can see this reflected in non-adopters' greater number of co morbidities). Two of our domains—observability and trialability—had only two items in each domain. Future research should develop and implement more items in each of these domains. Finally, we focused on perceived value of the PHR for communicating with the doctor's office as our outcome variable. However, as we show in Appendix 2, other relevant outcomes can be examined such as PHR-related behaviors or sustainability of PHR use. Similarly, other predictors may play a role such as attitudes, self-efficacy, and psychological traits. Herein lies the complexity of behavioral social science research related to PHRs. A number of models exist (eg, diffusion of innovations, technology acceptance model, and theory of planned behavior) each providing its own set of predictors and outcomes. At the same time, limited funding and the logistics of research (for example the need to keep surveys short to enhance response rates) force the researcher to select a given model and an associated set of variables as we have done in this study. Hopefully cumulative research over time with different models and frameworks like the one we adopted in this study will build the knowledge base for much needed behavioral research on patient adoption and use of PHRs.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Survey items on perceptions of PHR use, personal innovativeness in information technology (PIIT), and privacy and security.

[PDF File (Adobe PDF File), 18KB - jmir_v14i6e150_app1.pdf]

Multimedia Appendix 2

A conceptual framework and hypothesized relationships for behavioral research on PHRs.

[PDF File (Adobe PDF File), 17KB - jmir_v14i6e150_app2.pdf]

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Original Paper

The Impact of Electronic Patient Portals on Patient Care: A Systematic Review of Controlled Trials

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Abstract

Background: Modern information technology is changing and provides new challenges to health care. The emergence of the Internet and the electronic health record (EHR) has brought new opportunities for patients to play a more active role in his/her care. Although in many countries patients have the right to access their clinical information, access to clinical records electronically is not common. Patient portals consist of provider-tethered applications that allow patients to electronically access health information that are documented and managed by a health care institution. Although patient portals are already being implemented, it is still unclear in which ways these technologies can influence patient care.

Objective: To systematically review the available evidence on the impact of electronic patient portals on patient care.

Methods: A systematic search was conducted using PubMed and other sources to identify controlled experimental or quasi-experimental studies on the impact of patient portals that were published between 1990 and 2011. A total of 1,306 references from all the publication hits were screened, and 13 papers were retrieved for full text analysis.

Results: We identified 5 papers presenting 4 distinct studies. There were no statistically significant changes between intervention and control group in the 2 randomized controlled trials investigating the effect of patient portals on health outcomes. Significant changes in the patient portal group, compared to a control group, could be observed for the following parameters: quicker decrease in office visit rates and slower increase in telephone contacts; increase in number of messages sent; changes of the medication regimen; and better adherence to treatment.

Conclusions: The number of available controlled studies with regard to patient portals is low. Even when patient portals are often discussed as a way to empower patients and improve quality of care, there is insufficient evidence to support this assumption.

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KEYWORDS

Medical records; patient access to records; patient participation; patient portals; systematic review

Introduction

Background

The progress of modern information technology (IT) is changing and challenging health care. Clinical information systems as well as electronic health records have offered new opportunities for efficient and high-quality patient care [1].

The emergence of the Internet and of the electronic health record (EHR) has brought new opportunities for a new and more active role of the patient [2-4]. The patient's role is changing from a patronized patient to an informed patient and further to a responsible, autonomous and competent partner in his or her own care [5]. An active integration of the patient in his/her treatment bears multiple potential benefits such as fostering the quality of care as well as the compliance of the patient [6,7].

One precondition for a more active patient's role is to give the patient access to a providers' documentation on previous or planned treatment. In many countries, patients have the right to access their clinical information whenever they request [8]. The Institute of Medicine argues that "patients should have unfettered access to their own medical information" and that this may help to increase quality of care and reduce medical errors [9]. However, patients demanding record access is not a common situation, due to cultural and practical reasons [10,11] and in part due to concerns by health care practitioners [8, 12]. Compared to paper-based solutions, information technological concepts such as electronic patient portals and personal health records (PHRs) seem to provide the opportunity to facilitate patients' access to their clinical information.

PHRs have been defined as "a set of computer-based tools that allow people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it" [13]. PHRs focus on functionalities where patients can document health-related data and can, if wanted, make them available to others, for example to their health care providers or families [14]. PHRs are typically owned and administered by the patients themselves.

Electronic Patient Portals

Electronic patient portals comprise provider-tethered applications that allow patients to electronically access health information that is documented and managed by a health care institution [15]. Patient portals are owned and administered by health care institutions (such as hospitals). As part of a patient portal, institutions may offer patients (typically web-based) access to selected clinical data that is governed by the respective institutions as part of the patients' EHR. The patient can then access clinical data, read and print it, or integrate it into any (electronic or paper-based) type of patient-owned record. Besides providing access to EHR data, electronic patient portals may also offer additional services and functions to the patients. These include medication refills, appointment scheduling, access to general medical information such as guidelines, or secure messaging between a patient and an institution [15].

In order to provide a distinctive definition for the current review, we define electronic patient portals as the class of applications provided and maintained by health care institutions that primarily allow access to clinical EHR data and secondarily may offer functions and services that are targeted towards enhancing medical treatment. For reasons of simplicity, all of these applications are called patient portals, regardless of their actual implementation e.g. as part of a PHR.

The Impact of Electronic Patient Portals

The idea of providing patients access to clinical information is not new. Traditionally, this has been done by providing a patient with paper-based copies of extracts from clinical documents [16-18]. Ross et al [8] have reviewed the effects of paper-based access to medical records and found that it has the potential for modest benefits for patient care, for example in enhancing doctor-patient communication, with only minimal risks such as increasing patient worry or confusion.

In 2007, Ferreira et al [10] reviewed 14 papers that dealt with the effects of electronic patient portals on medical practice. He concluded that some studies indicated benefits of electronic patient portals, for example by enhancing communication, but that the studies also showed patients' concerns about confidentiality and understandability of the content. The majority of the papers reviewed were surveys and interviews with patients and clinicians, without including a control group. Therefore, these studies were not able to objectively identify any benefits of patient portals when added to traditional patient care.

To our knowledge, no systematic review of controlled studies on the impact of electronic patient portals has been conducted to date. With the further emergence of electronic patient portals in recent years, and the growing interest in evidence-based health informatics [19], we see the need to review the benefits of patient portals. The focus of this review is on the benefit of electronic patient portals for the patient, thus we focus on the impact of electronic patient portals on patient care. We did not predefine specific endpoints, but included all studies with endpoints, which were supposed to represent an impact on patient care by the study authors. For example, electronic patient portals may improve communication between provider and patient, or increase a patient's adherence to medication treatment. Both could contribute to better patient care. Whether these benefits in fact arise when electronic patient portals are introduced needs to be shown by controlled trials and systematic reviews.

Objectives

The main objective of this paper is to systematically review the impact of electronic patient portals on patient care by analyzing controlled studies on the use of patient portals. The structure of this paper and the presentation of the results follow the PRISMA statement for reporting systematic reviews [20].

Methods

Eligibility Criteria

Papers were eligible if they presented controlled studies on the impact of patient portals. Impact could be visible in outcome-oriented parameters such as changes in mortality or morbidity or in costs of care. Also process parameters such as changes in therapy adherence or in patient satisfaction with the provided care were included, even when these parameters are merely surrogates for clinical outcome. With regard to study design, we included experimental (e.g. RCT) or quasi-experimental (e.g. controlled before-after trials) studies.

In accordance with the definition given in the introduction for patient portals, patient portals are characterized by the following attributes:

- electronic applications, typically web-based
- provided and maintained by health care institutions

- targeted towards providing functionality to all or a subgroup of patients
- basic functionalities to access (a subset of) a patient's clinical data
- optional, additional functionalities such as communication modules, prescription refills, appointment scheduling, or educational guidelines

The basic criterion for inclusion of a study was, however, that the application allowed the patient to access clinical data provided by a health care institution. We did not include papers that focused on telemonitoring systems, where the focus was on patients actively or passively providing data for their clinicians, or those that focused only on tailored messaging (e.g. of prevention information) from clinicians to patients such as Lin et al [21]. On the other hand, we included applications that were introduced as PHRs and looked for the functionality of an electronic patient portal, namely the possibility to access clinical information from a patient's health care provider.

We did not limit the search to a specific clinical setting, thus we included portals both in inpatient and outpatient areas. We included studies independent of the patient subgroup or disease (e.g. general portals, but also portals for diabetes patients).

We limited the search to papers after 1990, as we did not expect to identify patient portal papers before that date. We excluded all papers where the intervention consisted of a paper-based copy of the medical record, as a systematic review on this topic has already been done [8]. We included papers in English, German and French.

Information Sources

We performed a literature search in April 2012, in PubMed Cochrane Library, CINAHL, EMBASE, ACM Digital Library and UMIT's own Evaluation Database for relevant studies. Bibliographies of the included studies as well as of the reviews of Ross et al [8] and Ferreira et al [10] were used to identify additional studies.

Search

We used a combination of two queries (see Textbox 1). The first query searched for all papers about medical record systems that dealt with access to information or active patient participation. As the usage of MeSH headings was not consistent in all cases, we added a second query that looked at the term "patient portal" anywhere in the title or abstract.

Textbox 1. Description of Queries.

Query 1:

("Medical Records Systems, Computerized"[mh] OR "Health Records, Personal" [mh] OR "Electronic Health Records" [mh] OR "Medical records" [mh])

AND

("Access to Information"[mh] OR "Patient participation" [mh] OR "Patient access to records" [mh])

AND

("1990"[PDAT] : "2011"[PDAT])

Query 2:

"patient portal" OR "patient web portal"

AND

("1990"[PDAT] : "2011"[PDAT])

After retrieving the results of the two queries, we imported all references to the Endnote reference manager and eliminated duplicates.

Study Selection

Two authors independently screened the titles and abstracts of all references to confirm whether the inclusion criteria were fulfilled. Differences were resolved by having a third author judge the paper. For all preselected papers, full text versions were retrieved and two authors independently determined whether the inclusion criteria were fulfilled. Differences were again resolved by consulting a third author.

Data Collection Process

Each included study was systematically described addressing clinical setting, type of intervention, type of study as well as outcome measures. Data extraction was done independently by two researchers. Results were compared and any differences were resolved by discussion.

Data Items

The following data items were documented for each study:

- Time of study
- Clinical setting
- Type of patients included
- Description of intervention
- Description of control
- Study design
- Number of participants
- Outcome measures
- Study findings

Assessment of Study Quality

The study quality was assessed using the methodology checklists for RCT studies and for cohort studies of the National Institute for Health and Clinical Excellence (NICE) [22]. These checklists were applied independently by two reviewers (PSI, EA). Differences in judgment were solved by discussion.

Synthesis of Results

We systematically described the characteristics and results of the included studies in evidence tables. Further synthesis of results in the form of a meta-analysis was initially planned, but not possible due to the different outcome measures examined in the studies.

Results were ordered according to the type of outcome measured, namely objective criteria and subjective criteria.

Results

Study Selection

The queries in PubMed were performed in April 2012. Query 1 found 1,098 references, Query 2 found 52 references. Overall, when eliminating duplicates, we identified 1,136 references. We then checked Cochrane Library, CINAHL, EMBASE, ACM Digital Library and our own Evaluation Database at UMIT for relevant studies. We could not identify any further studies meeting our inclusion criteria. We also checked the reviews of Ross et al [8] and Ferreira et al [10] and citations in the included studies, but did not identify further studies.

From the identified 1,136 papers, only 13 had an experimental or quasi-experimental study design (Multimedia Appendix 1). Of those 13 papers, 5 papers [23-27] presenting 5 distinct studies were finally eligible and then analyzed in detail. Two papers [26,27] describe the same study. Therefore, an overall total of 4 controlled studies were included in the review.

Study Characteristics

The 5 study papers presented evaluations of 4 different patient portals. Two papers [26,27] described different aspects of the same study. One portal was designed for patients undergoing IVF (in-vitro fertilization) treatment [23], one for diabetes mellitus patients [25], one for patients with congestive heart failure [26,27] and one was a general patient portal [24]. Three of the portals were located in the U.S. and one in the Netherlands. For details, see Table 1.

Three of the studies were randomized controlled trials (RCT); one was a retrospective matched cohort study. The number of participants in each study ranged from 81 to 6,402 patients. The studies evaluated the impact on a variety of outcome criteria. One study focused on changes in clinical outcome parameters, including HbA1c, blood pressure, LDL, and medication adjustments [25]. One study focused on changes of resource consumption, including office visit rates and telephone contacts [24]. One study focused on changes of more subjective parameters such as patient satisfaction, patient knowledge, and patient anxiety [23]; these were measured by validated questionnaires. The fourth study combined changes of mortality, treatment adherence and resource consumption (message number) with subjective parameters (subjective health status, patient empowerment, medication adherence) [26,27].

Impact of Patient Portals on Outcomes

There were no statistically significant changes between intervention and control group in the 2 randomized controlled trials [25-27] investigating the effect of patient portals on endpoints measuring health or proxies for health (mortality, emergency room visits, hospitalizations, heart failure practice visits or risk factors). The use of patient portals showed no effect on all measurement scales to operationalize patient empowerment in one study [23].

Statistically significant changes in the patient portal group, compared to a control group, could only be observed for the following parameters: quicker decrease in office visit rates and slower increase in the number of telephone contacts [24]; increase in number of messages sent [27]; changes of the medication regimen [24]; and better adherence to treatment [27]. For details on study design and measured outcomes, see Table 2.

Table 1. Details of included studies – description of setting, intervention and control.

Author/ Year	Time of study (MM/YY)	Clinical setting	Inclusion criteria	Intervention group	Control group
Tuil, 2007 [23]	Start: 01/04 End: Unclear	Radbound University Nijmegen Medical Center, Fertility clinic	All adult couples that were scheduled for their first IVF (in-vitro fertilization) or ICSI (intracytoplasmic sperm injection) treatment cycle and had internet access during the inclusion period (Jan. – July 2004) were invited to participate	Access to a web site that offered: • Access to general information about infertility, IVF and the fertility clinic • Access to own medical record with all available information concerning the patient's IVF or ICSI treatment • Tailored, context-sensitive clarification of clinical information • Communication options such as e-mail, discussion forum, chat room	No access to the web site
Zhou, 2007 [24]	09/02 – 08/05	Kaiser Permanente Northwest Region, located in Oregon and Washington	Patients that used KP Health Connect Online for longer than 13 months and that had used at least one feature were invited.	Web-based access to KP HealthConnect, offering: • Access of parts of their individual health record • Health summary with problem list, medications, allergies • Health record with immunizations • Secure provider messaging • Administrative requests (update medical record, appointments etc.) • Visit-related inquiries such as after-visit summary, future appointments • Educational materials	Period 3- 14 months before KP Health-Connect Online registration
Grant, 2008 [25]	09/05 – 03/07	11 primary care practices (with 230 physicians) within the Partners Health care System (Massachusetts)	Patients with diabetes mellitus type 2 who had at least one visit with their designated primary care provider in the study in the prior year, and who had logged in at least once in PatientGateway, the patient portal.	Access to a diabetes-mellitus-specific application offering: • Medication module to review medications and edit inaccuracies • View most recent results and current treatments (glucose, blood pressure, LDL-C, preventive care) • Enter therapy concerns and request • Answer short questions on therapy adherence and adverse effects • Generate a diabetes care plan based on patients' responses to the questions, to be used at the next clinical visit	Access to limited functionalities: • Update family medical history; • Review preventive services. Comment:Both groups (control and intervention) were active users of a general online portal called PatientGateway (PG), offering: • Update registration information • Confirm appointments • Sending non-urgent clinical messages • Request prescription refills
Earnest, 2004 [26] Ross, 2004 [27]	01/02 – 12/02	Academic subspecialty clinic for patients with congestive heart failure at University of Colorado Hospital, Denver, Colorado	Adult patients with congestive heart failure and internet access.	Access to web-interface of SPPARO ("System Providing Patients Access to Records Online") offering: • Online access to clinical notes, laboratory test results, other test results • Patient information packet • Send messages to the clinic and receive messages	No access to the SPPARO

Table 2. Details of included studies – study design and outcome

Author/ Year	Study description	Outcome criteria (differentiated between primary and secondary outcome) and finding of study (first number intervention group, second number control group)
Tuil, 2007 [23]	Randomized controlled trial Duration of intervention: unclear Number of participants in intervention group: 102 patients Number of participants in control group: 78 patients	Primary endpoint: Patient empowerment measured as multidimensional concept composed of: • General Self-Efficacy scale and IVF-specific self-efficacy measure • Objective knowledge about IVF treatment • Subjective knowledge level regarding IVF treatment • Problem-Solving Decision-Making Scale Further used instruments on secondary variables: • Patient Satisfaction Questionnaire • Illness Cognition Questionnaire • Inventory for Social Support • State-Trait Anxiety Inventory • Beck Depression Index for Primary Care • Utrecht Coping List Result: There were no statistically significant changes and no differences between effect measures on the above listed variables, measured by validated questionnaires in both groups pre and post: Summary by the authors: “The interactive online medical record did not result in significant changes in patient empowerment.”
Zhou, 2007 [24]	Retrospective matched-control study comparing 3-14 months before and 2-13 months after registration of the user in the portal The intervention group was compared to a control group matched by age, sex, selected chronic conditions and primary care physician. Duration of intervention: 2 – 13 months Number of participants in intervention group: 3,201 patients Number of participants in control group: 3,201 patients	Primary endpoint: Physician workload measured as primary care office visit, documented telephone contact rates Annual adult primary care office visit rates in the intervention group decreased from 2.44 (95% CI 2.35-3.54) to 2.19 (95% CI 2.11-2.27) (=10.3%) (*P*<0.001). Annual adult primary care office visit rates in the control group decreased from 2.15 (95% CI 2.08- 2.23) to 2.07 (95% CI 2.00-2.15) (=3.7%) (*P*<0.003). The difference in decrease -0.17 (*P*<0.01) (=6.7%) between both groups was statistically significant (p<0.003). Documented telephone contact rates in the intervention group increased from 2.0 (95% CI 1.89- 2.11) to 2.32 (95% CI 2.21-2.43) (=16.2%) (*P*<0.001).Documented telephone contact rates in the control group increased from 1. 74 (95% CI 1.63-1.85) to 2.26 (95% CI 2.14-2.37) (=29.9%) (*P*<0.001). The difference in increase 0.20 (*P*<0.001) (=13.7%) between both groups is statistically significant (*P*<0.01). Conclusion by the authors: “Patient access to the secure messaging feature of KP HealthConnect Online was associated with decreased rates of primary care office visits and a smaller increase in documented telephone contacts.”
Grant, 2008 [25]	Cluster randomized controlled trial Practices were grouped in 4 strata; practices within each stratum were then randomly assigned to either intervention or control arm. Duration of intervention: 12 months Number of participants in intervention group: 4 practices with 126 patients Number of participants in control group: 7 practices with 118 patients	Primary endpoint: More effective treatment of DM-related risk factors (hyperglycemia, hypertension, hyperlipidemia), measured by: Decline in HbA1c after one year: 0.16% vs. 0.26% (*P*=0.62) Mean HbA1c after 1 year 7,1% vs. 7,2% (*P*=0.45) Changes in blood pressure after one year: slight improvement, no significant differences between groups (data not shown) Changes in LDL-C after one year: slight improvement, no significant differences between groups (data not shown)Subgroup of patients who submitted PHR journals: Changes in DM-related medications in subsequent care episodes: 53% vs. 15% (*P*<0.001) Medication adjustment for hyperglycemia: 29% vs. 15% (*P*=0.1)Medication adjustment for hypertension: 13% vs. 0% (*P*=0.02) Medication adjustment for hyperlipidemia: 11% vs. 0% (*P*=0.03) Conclusion by the authors: “Users of the diabetes mellitus-specific PHR were markedly more likely to have their medical regimens changed at their next clinic visit. Lack of an overall impact on DM-related risk factor levels.”

Author/ Year	Study description	Outcome criteria (differentiated between primary and secondary outcome) and finding of study (first number intervention group, second number control group)
Earnest, 2004 [26] Ross, 2004 [27]	Randomized controlled trial: Duration of intervention: 12 months Number of participants in intervention group: 38 patients Number of participants in control group: 43 patients	Primary endpoint: Change in the self-efficacy domain of the Kansas City Cardiomyopathy Questionnaire with minimal significant difference of 7.7 Health status (measured by Kansas City Cardiomyopathy Questionnaire scored from 0 to 100): Difference in change between intervention and control group after 12 months: Self-efficacy domain: +6 points (95% CI 1 - 11), *P*=0.08 Symptom stability domain: +17 points (95%-CI 4-29), *P*<0.01, *P*<0.06 adjusted for multiple comparisons Not statistically significant differences between groups after 12 months between -4 to +2 points in the subdomains “symptoms”, “quality of life”, “functional status”, “clinical summary”, “physical limitations”. (“a change of 5 points is considered clinically important”) Patient satisfaction (measured with the adapted Art of Medicine Questionnaire scored from 1 to 5): 6 subitems with differences between -0.2 to +0.4 points between groups, not statistically significant after adjustment for multiple comparisons. Adherence to medication (measured by Morisky questionnaire scored from 0 to 4)): Difference between intervention and control group after 12 months +0.2 p=0.15 General adherence to medical regimens (measured by General Adherence Scale scored from 0 to 100): Difference between intervention and control group after 12 months +6.4 p=0.02 adjusted Phone and electronic messages: Number of total messages per patient (phone + electronic) in the intervention group was significantly higher 350 vs. 267 (*P*=0.02) Mortality: 11% in intervention group, 11% in control group, p=1.0 Emergency department visits:Number of patients visiting an emergency room: 20% in intervention group, 13% in control group, *P*=0.44 Number of visits in an emergency room: 20 in intervention group, 8, in control group, *P* = 0.03 Hospitalizations: 20% in intervention group, 23% in control group, *P*=0.81 Heart failure practice visits: 93% in intervention group, 92% in control group, *P*=1.0 Patient Empowerment Score (self-defined, calculated from 8 questions with a 5-point Likert scale): Patient Empowerment Score both at baseline as well as after 12 months did not show significant differences between intervention and control group (data not shown in the study) Patient Empowerment Score in both groups declined between baseline and 12 months (from 89% to 74% that agreed with at least 4 of the 8 questions, *P*=0.01). Summary by the authors: “No differences developed between the subject and the control groups, but the Patient Empowerment Score declined for patients as a whole… We did not demonstrate a significant effect on self-efficacy, [but] there was an improvement in general adherence to medical advice, and there were trends towards improvement in patient satisfaction with doctor-patient communication.”

Risk of Bias

Overall risk of bias is unclear in 3 studies [24-27] and high for 1 study [23]. One RCT had no adequate concealment of allocation; for two RCTs the information was lacking. In the observational study, groups were matched for primary care physician, age, sex, and selected chronic conditions, but were potentially confounded by other factors eg, education cannot be excluded. Whether this could have led to a bias is unclear.

In addition, in the 3 prospective studies, due to the nature of the intervention, patients and clinicians were not completely blinded to patients’ allocation. For example, as soon as the patient contacts the physician via secure messaging or brings along print-outs of the portal’s information, his or her allocation is known to the clinician. It is unclear, however, whether this may have led to a more intensive treatment of the patient and, if yes, whether this can be seen as a desired effect of portals, or as a possible source of bias. One study [23] additionally suffered from high drop-out rates. Here, too, the impact on the results is not clear.

The studies used different methods and instruments to assess different types of impact. In most cases, the used questionnaires were based on validated survey instruments. Table 3 summarizes the risk of bias of each study. For details on each criterion, please see the NICE checklists for the respective RCT cohort studies [22].

Table 3. Assessment of the quality of studies

Question		Grant [25]	Earnest [26] Ross [27]	Tuil [23]	Zhou [24]
Type of study		RCT (checklist: RCT)	RCT (checklist: RCT)	RCT (checklist: RCT)	Matched- control study (checklist: cohort study)
Selection bias (A1 – A3)		unclear [a]	unclear	unclear	unclear
A1	*Appropriate method of randomization* was used to allocate participants to treatment groups (for RCT)	unclear	yes[b]	no[c] (used order of reception of forms)	Not relevant
	Method of allocation to treatment groups was unrelated to potential confounding factors (for cohort study)	not relevant	not relevant	not relevant	unclear
A2	*Adequate concealment of allocation*, such that investigators, clinicians and participants cannot influence enrolment or treatment allocation (for RCT)	unclear	unclear	no (uses alternate allocation)	not relevant
	Any attempts made to *balance* the comparison groups *for potential confounders* (for cohort study)	not relevant	not relevant	not relevant	yes
A3	Groups were *comparable at baseline*, including all major confounders/prognostic factors	no (differences in age)	unclear	yes	yes
Performance bias (B1 – B3)		unclear	unclear	unclear	low risk
B1	Comparison groups *received the same care* apart from the interventions	unclear	unclear	unclear	yes
B2	*Patients* receiving intervention were *kept blind* to treatment allocation	unclear	no	no	yes
B3	*Clinicians* were *kept blind* to treatment allocation	unclear	no	no	yes
Attrition bias (C1 – C3)		low risk	low risk	high risk	low risk
C1	All groups were *followed up* for an equal length of time	yes	yes	unclear	no
C2	Groups were *comparable for treatment completion*.	yes	yes	nodrop-outs in control groups	yes
C3	Groups were comparable with respect of the *availability of outcome data*.	yes	yes	nodrop-outs in control groups	yes
Detection bias (D1 – D5)		unclear	low risk	unclear	unclear
D1	Study had an *appropriate length of follow-up*	yes	yes	unclear	unclear
D2	Study employed a *precise definition of outcome*	yes	yes	yes	yes
D3	Study used a *valid and reliable method* to determine the outcome	unclear	yes	yes	unclear
D4	*Investigators* were kept *blind* to patients' exposure to the intervention	unclear	unclear	unclear	unclear
D5	*Investigators* were kept *blind* to other important confounding/prognostic factors	unclear	unclear	unclear	unclear
Overall rating		unclear	unclear	high risk	unclear

[a] unclear = not sufficient information in the paper to assess quality criterion

[b] yes = criterion is fulfilled

[c] no = criterion is not fulfilled

Discussion

We systematically searched the literature and found 4 controlled studies focusing on the impact of electronic patient portals. Given the fact that patient portals have been in use in the U.S. for several years, the number of controlled studies seems quite low.

The studies were quite heterogeneous with regard to clinical setting, functionality of the intervention, and measured outcome. The different outcome parameters used made any further aggregation of results impossible, and showed how little evidence is available for each single outcome parameter. Most of the measured parameters did not show a statistically significant difference between intervention and control group. In particular, no statistically significant changes could be observed for parameters related to clinical outcome. Two studies found changes in contact patterns: quicker decrease in office visit rates and smaller increase in telephone contacts [24]; increase in number of messages sent [27]. Two studies found changes in medication regimen: higher changes of medication regimen [24]; better adherence to medication [27].

Impact of Patient Portals

We defined patient portals as presenting clinical information to the patients. Can we expect that giving patients access to clinical information can in general have an impact? The review of Ross et al [8] - who is, also the author of one of the studies we reviewed [27] - was dedicated to this question. It reviewed the outcome of 29 descriptive or controlled studies on adult patients' access to (paper-based) medical records. Several studies showed an improvement of doctor-patient communication by patient-accessible medical records. There were, however, conflicting findings on improvements in treatment adherence, patient education, and patient empowerment; some controlled studies showed an improvement, while others did not. Ross et al [8] summarized that studies show potential for modest benefits, for example in enhancing doctor-patient communication, but that more research is necessary.

Compared to paper-based access to records, electronic (web-based) patient portals allow a patient to access the information independently and repeatedly; the information is better legible; and the user can link the information to further sources of medical information available on the Internet [8]. Also, patient portals can be adapted to the patient's wishes and knowledge level [23]. They can also be completed by secure communication links with health care providers or other functions. Overall, we could expect a higher impact of online portals compared to paper-based access. However, as our results show, the impact of patient portals, indicated by the studies reviewed here, is of a limited nature. In the following sections, we will discuss the findings of the 4 studies with regard to different topics.

Impact on Clinical Outcome

Grant et al [25] assessed changes in clinical parameters related to diabetes patients (such as HbA1, blood pressure, and LDL-C). He did not find statistically significant differences between both groups in general. But he found statistically significantly higher rates for medication adjustments of diabetes-mellitus related drugs. The portal they evaluated, however, included a module where a diabetes care plan was generated automatically based on the patient's responses to short questions; these care plans may have led to the higher rate of medication adjustments in the intervention group, not so much the presentation of clinical data itself. In the study of Ross et al [27], mortality was compared between both groups and no differences could be seen. Overall, there are not sufficient studies to decide on the impact of patient portals on clinical outcomes.

Impact on Health Resource Consumption

Zhou et al [24] found a stronger decrease of annual primary care office visits in the intervention group compared to the control group when the intervention group used a patient portal with secure messaging. As explanation, Zhou mentions that a quarter of portal users indicated they would have scheduled an appointment in lieu of electronic messaging; so there seems to be a possibility of saving resources by a portal with electronic messaging. Ross et al [27] assessed a statistically significant increase of visits in the emergency room in the intervention group, but without temporal relationship between portal use and visits; also, no differences in hospitalization or visits to heart failure practice visits were observed. Thus, while the study of Zhou et al may indicate that a portal with electronic messaging may reduce the number of office visits, there is not sufficient data to decide conclusively on this.

Impact on Patient Adherence

Only the study of Ross et al [27] assessed adherence and found an increase in general adherence; this was measured by a validated questionnaire, not by objective data. Adherence to medication also increased, but did not reach statistical significance. In an earlier review, Ross et al [8] found 1 study with increased adherence, but 5 studies that could not support this. It seems plausible that better-informed patients show higher adherence to treatment or to clinical advices, but there is not sufficient evidence to support this assumption.

Impact on Patient-Physician Communication

Some of the reviewed studies addressed aspects of patient-physician communication. The general patient portal (KP HealthConnect) assessed by Zhou et al led to a slower increase of telephone contacts, and a quicker decrease of primary care office visits, compared to the control group [24]. In the study of Ross et al, the SPPARO portal for patients with congestive heart failure led to a statistically significant increase of the number of overall messages (electronic + phone) per patients [27], compared to the control group that just used phone. The authors argue here that SPPARO "appeared to supplement, rather than replace, telephone messages". A consistent finding of these changes, or any related change in quality of communication, is not possible based on this data.

Impact on Patient Empowerment

Three of the reviewed studies addressed the concept of patient empowerment. The term "patient empowerment" has been controversially discussed in the literature [28], and a generally accepted definition seems to be missing [23, 29]. Consequently, each of the found studies used a different approach to measure patient empowerment.

Tuil et al [23] measured a multidimensional concept composed of self-efficacy (using the General Self-Efficacy Scale [30]), actual and perceived knowledge, and patients' involvement in the decision process. He did not find a statistically significant impact on any of those scales. Earnest et al [26] used a self-developed patient empowerment scale consisting of 8 questions (including feeling more in control, better prepared, feeling more reassured, trust, etc.); this study found a statistically significant decrease in patient empowerment scale scores over the study period in both groups, but no significant differences between both groups. Ross et al used the Kansas City Cardiomyopathy Questionnaire [31] to assess the health status of the participants; one subscale of it is devoted to self-efficacy. He found a trend (p=0.08) for an increase in self-efficacy in the intervention group, but with 6 points it was less than the predefined meaningful difference of 7.7 points. Overall, no study was able to show impact on patient empowerment. In their review of paper-based record access, Ross et al [8] also found some improvement in patient empowerment in randomized controlled trials, where patients felt “more in control” and “less helpless”; however, other controlled trials failed to support this finding. Overall, portals may have an impact on patient empowerment, but the evidence is not sufficient on this question.

A review conducted by Samoocha [29] about the effectiveness of web-based interventions on patient empowerment arrives at the same conclusion. There are disease-specific self-efficacy effects that could be found, but a general increase in self-efficacy could not be identified, as evidence is not sufficient.

Impact on Patient Satisfaction

Tuil et al [23] used the Patient Satisfaction Questionnaire [32] and found no differences between both groups. Ross et al [27] assessed patient satisfaction with the Art of Medicine Questionnaire and found improvements in two questions: How well patients felt their problems were understood, and how well doctors explained information. For the other four questions, no impact was seen. After adjustment for multiple testing, there was no statistically significant effect at all. The review of paper-based access of Ross et al [8] found 6 studies focusing on this topic, none of them showed statistically significant differences. Overall, access to information is probably only one facet of patient satisfaction; it is therefore questionable whether the impact of a patient portal on patient satisfaction is measurable.

Meaning and Generalizability of Findings

The results presented by the 4 studies did not contain convincing evidence for a general positive impact of electronic patient portals on clinical outcome, resource consumption, patient satisfaction or other variables compared to conventional ways of communication. Three of 4 studies were conducted in the U.S. The generalizability to health care settings in other countries is unclear.

Outcome research regarding patient portals is still at its beginning, and most of the analyzed studies could not show clear benefits for the patient regarding quality of patient care. Given the large resources needed to build and maintain patient portals, health care institutions should carefully weigh costs and (expected) benefits.

There may be several explanations for the missing evidence of the benefit of patient portals:

Electronic portals provide information from the medical record to patients. However, better-informed patients are not necessarily healthier patients [27, 33]. Descriptive evidence from a large number of studies suggests that patients are interested in access to their patient records, and that they find it helpful and useful [10, 34-36]. These findings, however, do not guarantee that there is in fact a measurable impact on health, as a better-informed patient is only one (possibly minor) factor contributing to the quality of care.

Studies in which a patient portal was combined with further services, such as secure messaging, interactive decision-support or health-related reminders, showed more positive impact on patient outcomes, patient-provider communication, disease management, and patient satisfaction, as a recent review of diabetes portals showed [37]. The interactive guiding and coaching of patients may be more effective than purely presenting clinical information without further advice.

Especially patients with chronic diseases (for example, with diabetes mellitus, congestive heart failure) and patients with intensive and long-time treatment (for example, IVF) may be more willing to use electronic portals [27]. Nevertheless, these groups may be already actively communicating with their physicians, therefore a portal does not show additional impact. This could explain that the studies in our review (with 3 of 4 studies focusing on these types of patients) did not show statistically significant impact.

Finally, only a minority of patients may be interested in using patient portals. Less computer literate, less motivated or less ill patients may not be interested. For example, in the Kaiser Permanente Northwest region (Oregon and southwest Washington), only 6% of all members have registered to the patient portal [24], and Weingart reports [38] a 11% utilization rate among primary care patients. Some study authors report difficulties in recruiting participants for the study [25], and some found that study participants are typically higher educated and have higher income than non-participants [27]. All this leads to the question whether patient portals may increase the digital divide, an issue also discussed by others [38].

Limitations

Quality of the Studies

Three studies had sample sizes with less than 200 patients. Only one (retrospective) study included more than 6,000 patients. There was one study with a high risk of bias and no study with a low risk of bias. Crucial criteria to assess the risk of study bias, such as randomization method, concealment of allocation or blinding, were not reported in all publications.

None of the studies gave clear information as to how often the participants in the study group used the portal. Only the authors of the SPPARO study [26,27] mentioned that 80% of participants used the portal at least once, with a median of eight days during a one-year study period, which correlated roughly to the number of office visits during this time. The authors concluded that the patients did not use the portal repeatedly between these visits. In the other studies, no information on usage patterns is given; therefore, it is not clear whether the patients really exploited the offered functionalities. This may have reduced the measurable impact of the portals.

All electronic patient portals included in this review, offered functionality in addition to sole access clinical data. This renders comparison of studies difficult. In addition, it makes it difficult to identify to which functionality (clinical data access or additional functions) the measured effect can be attributed.

Completeness of the Review

We conducted a systematic literature search, but may have overlooked studies that were unpublished or in the grey literature.

With 4 identified studies, the available evidence is quite limited. Despite a comprehensive query, we cannot be sure to have identified all related studies, as the terms used in the title, abstract, and keywords are not uniformly used. For example, the concept "patient portal" has been circumscribed in the literature as shared medical record, access to medical record, online PHR, or online medical record.

It can be questioned how the benefit of patient portals can be operationalized at all – did the studies use the correct operators (e.g. number of phone contacts)? In the future, more research seems necessary on meaningful indicators that measure the effects of patient portals, and more patient portals should undergo systematic evaluation studies.

Conclusion

Even if electronic patient portals are often seen as a way to empower patients and improve patient care, the available evidence does not support this assumption. Further studies of larger sample size and with harmonized outcome indicators are needed to investigate this question.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Excluded papers.

[XLS File (Microsoft Excel File), 220KB - jmir_v14i6e162_app1.xls]

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Abbreviations

DM: Diabetes Mellitus
EHR: Electronic Health Record
ICSI: Intracytoplasmic Sperm Injection
IVF: In-Vitro Fertilization
NICE: National Institute for Health and Clinical Excellence
PHR: Personal Health Record
RCT: Randomized Controlled Trial
SPPARO: System Providing Patients Access to Records Online

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Original Paper

Student Perceptions of a Hands-on Practicum to Supplement an Online eHealth Course

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Abstract

Background: Since 2000, the Centre for Online Health (COH) at The University of Queensland has offered a range of online eHealth courses at the undergraduate and postgraduate level. While online learning has a number of advantages, in some domains, it can present some challenges to the development of practical skills and experience.

Objective: To assess students' perceptions of the value of an eHealth practicum.

Methods: To supplement our online learning program, we introduced an eHealth practicum component that aimed to expose students to a range of clinically relevant learning experiences. Subsequently, by means of a questionnaire, student perceptions of the practicum were assessed.

Results: Over two semesters, a total of 66 students participated in the eHealth practicum, and questionnaire responses were very positive. The majority of students agreed that the practicum allowed them to gain necessary skills in eHealth applications (59%) and provided them with an opportunity to explore ways of using different eHealth tools for the delivery of health care at a distance (62%).

Conclusions: The study shows that a practical component in eHealth teaching was well received by students. While online teaching is appropriate for providing knowledge, the opportunity to develop practical skills may encourage students to use eHealth techniques in their future practices.

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KEYWORDS

Telemedicine; Remote consultation; Education and training; curriculum

Introduction

Background

eHealth is an umbrella term that describes the use of information communication technologies (ICT) in health care. eHealth encompasses the areas of telehealth and telemedicine, which provide health services at a distance [1]. Evidence is emerging that eHealth can be useful in clinical, administrative, educational, and research settings [2-5].

One of the barriers often attributed to the slow uptake of eHealth is the lack of appropriate training and education. Research has shown that health professionals have limited knowledge and skills necessary for the effective use of eHealth applications [6,7]. A study conducted at a tertiary hospital in Australia showed that, although nurses were keen to use eHealth, they had limited opportunity to acquire appropriate knowledge and practical skills [8,9].

Theoretical Framework

There are a range of published resources that qualify the role of higher education in providing key skills for professional life [10-12]. Education research has highlighted the problems relating to a skills-mismatch between university graduates and the demand of the labor market [13-15].

Research suggests that skills acquired through university education have an effect on the performance of graduates in their professional life [16,17]. Evidence also suggests that there is a direct correlation between the core skills acquired through university education and the subsequent employability of university graduates [18,19]. Research has shown that university graduates seek jobs in the labor market where their skills are optimally rewarded [20,21].

Various educational reforms around the world are testimony to the attempts to address these issues [22-24]. The Dearing Report in the United Kingdom in 1997 emphasized the need for universities to “equip graduates with skills appropriate for work”. The report also recommended universities closely look at the needs of employers while developing curriculum [24].

Education research relating to skills development within higher education suggests that skills and competencies required for professional life vary widely across different disciplines and professions [25-27]. Therefore it is important to identify key skills and competencies that need to be addressed when developing learning activities. This argument is central to the pedagogical concept of the “alignment of learning objectives with learning outcomes” [28]. Research shows that learning activities must be designed with a thorough consideration of learning outcomes. Ramsden (2003) emphasized the importance of considering the views of various stakeholders to identify learning outcomes that must be met by the educational activities. Ramsden recommended gaining the opinions of students, lecturers, and employers as a valuable source of information in this regard [25].

Depending on the expected outcomes, the learning methods and activities may vary. Pedagogical research relating to learning methods is a dynamic area. Problem-based learning, work-based simulation, and experiential learning are some of the established educational methods. Changes in the learning environment, intended outcomes, and introduction of new technologies have prompted curriculum developers to seek new teaching and learning methods [29-31].

Since 2000, the Centre for Online Health (COH) at The University of Queensland, Brisbane, Australia, has offered a range of eHealth courses at undergraduate and postgraduate levels. While the courses have been successfully delivered in an online mode, a survey of students (n=47) revealed that the majority (n=40, 86%) did not have the technological know-how or practical expertise to establish or to use eHealth systems. However, most of the students (n=37, 79%) believed that relevant practical skills would be useful in their future practice, and most students (n=41, 88%) also indicated that they would be keen to attend an in-person practicum to acquire such skills.

A curriculum development team was established within the COH. The team consisted of eHealth teaching staff and COH telehealth researchers. The team held regular meetings to discuss issues relating to the content and delivery mode of the practical sessions (practicum). In the process of developing the eHealth practicum, extensive consultation was conducted with relevant stakeholders. The organizations such as the Queensland Health Statewide Telehealth Services and the Australian Defence Force (ADF) were included as key stakeholders because they have a specific interest in eHealth. The staff members of these organizations are regular participants in eHealth courses.

The practicum was designed to supplement the online learning program. It aimed to offer students an opportunity to identify the relevance of eHealth in clinical practice, gain knowledge about technical options available for clinical eHealth, compare and contrast eHealth and conventional clinical communication, and develop communication skills relevant for eHealth. The practicum had four specific objectives: (1) to give students practical skills in various eHealth applications, (2) to allow students to explore ways of using different technologies in the delivery of health care, (3) to raise students’ awareness of the potential and limitations of the use of technology in health care, and (4) to allow students to reflect on key areas previously covered in their eHealth course.

Methods

A 1-day eHealth practicum was introduced into the undergraduate eHealth course. It was delivered at the COH, based at the Royal Children’s Hospital, Brisbane, Queensland, and was an assessed component of the course. The practicum included a range of activities including introductory oral presentations, 4 hands-on practical exercises, observation of clinical teleconsultations, and visits to relevant sites within the hospital.

For quality assurance purposes, the university routinely evaluates all teaching programs. This study used routine student evaluation data. Completion of the evaluation form by participants was voluntary and anonymous.

Structure of the Day

Orientation

The day commenced with an oral presentation on aspects of clinical eHealth followed by an overview of the activities of the day.

Practical Activities

Subsequently, the students cycled through 4 hands-on practical activities that were designed to provide a variety of relevant experiences for the students. The activities were based on active research projects within the COH, and learning was guided by research staff. The activities required students to complete practical tasks, including the role play of clinical interactions. Following each practical activity, the students were provided with a short debrief by the supervising member of the research staff. This allowed the opportunity to reinforce learning objectives, for students to reflect on the activity, and for them to ask questions.

Observation of Clinical Teleconsultations

While present in the COH, students were able to observe clinical teleconsultations between the tertiary hospital and referring hospitals. During these sessions, students could observe the nature of the clinical interactions between the tertiary specialists and the clinicians, patients, and families at the referring hospitals. The types of specialty teleconsultations observed included neurology, endocrinology, and burns depending on clinical activity within the hospital on the day of the practicum.

Site Visits

In addition to the activities conducted within the COH, students visited two other relevant facilities within the hospital campus. First, the students visited the Queensland Health Skills Development Centre (SDC), which is a specialist facility equipped with leading-edge simulation technology for the education and training of health professionals. In the SDC, students were given an overview of a range of technologies used including simulation applications. Second, the students visited the medical imaging department where they were provided with demonstrations of the use of a large-scale picture archiving and communication system (PACS).

Description of the Hands-on Practical Activities

Activity 1: Standards-Based Videoconferencing—Familiarization With Equipment and Simulated Clinical Consultation

The rationale for the activity was to: (1) provide students with direct exposure to videoconferencing equipment, including identification of components and configuration of a working system, (2) provide students with an understanding of the benefits and limitations of clinical consultation using videoconferencing, and (3) compare and contrast the limitations and benefits with those experienced in Activities 2 and 3.

Students were introduced to a fully configured telemedicine room, and key features such as videoconferencing and ancillary equipment, room lighting, and soundproofing were explained and demonstrated. Subsequently, students were provided with a kit of equipment and guidance to configure a basic videoconferencing endpoint. On completion of this task, students used the equipment to place a video call to a distant site (in this case, to their student colleagues in an adjacent room). Using the video link, students participated in a simulated clinical consultation which was designed to demonstrate the quality of audio, images, and movement. Students were guided to make calls at different data rates (128 kbit/s, 256 kbit/s, and 384 kbit/s) and to observe the changes in image and audio fidelity. During the consultation, students also used peripheral equipment consisting of a video document camera and a video-otoscope. Figure 1 shows students using videoconferencing equipment.

Figure 1. Students using standards-based videoconferencing.

Activity 2: Internet and Webcam-Based Video Consultation

The rationale for this activity was to: (1) provide students with direct exposure to the benefits and limitations of clinical consultation using Internet and webcam-based video communication, and (2) compare and contrast the benefits and limitations with those experienced in Activities 1 and 3.

Students were introduced to a webcam-based palliative care telehealth application (see Figure 2). Subsequently, students participated in a room-to-room role play teleconsultation. The role play was designed to simulate a low-cost approach to linking clinicians at a tertiary hospital with a patient at home. As with Activities 1 and 3, students were guided to assess the quality of the audio, clarity of images, and reproduction of movement. In this activity, a single low-bit rate link was used to simulate that typically available to the home.

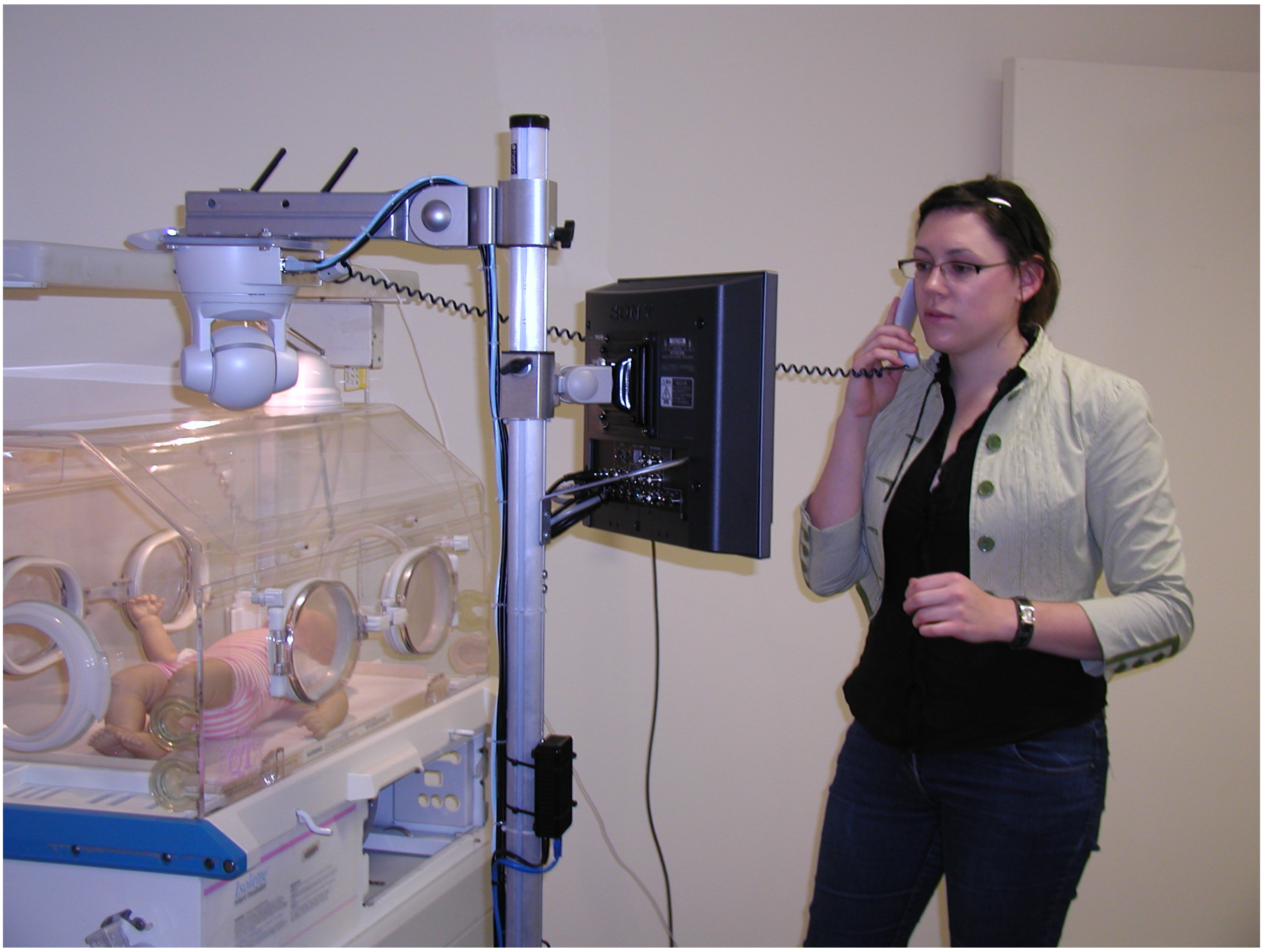
Figure 2. Students role playing home-telehealth using a webcam based system.

Activity 3: Simulated Consultation Using a Custom-Built Neonatal Intensive Care Teleconsultation System

The rationale for the activity was to: (1) provide students with direct exposure to the benefits and limitations of a teleconsultation system that had been highly customized to a particular clinical problem, and (2) compare and contrast the benefits and limitations with the generic communication approaches experienced in Activities 1 and 2.

Students were introduced to a specialized telemedicine system that had been designed for providing remote specialist advice in neonatal care (see Figure 3). The highly customized system consisted of two parts: (1) a mobile wireless trolley with two cameras and a high degree of remote control for the referring hospital, and (2) a personal computer-based system for the specialist at the tertiary hospital. Using this system, students conducted a consultation that simulated a link between a tertiary intensive care nursery and a referring hospital with a sick newborn infant. The consultation included the viewing of high-quality live images of an infant mannequin, X-ray images, and the observation of a simulated patient monitor.

Figure 3. Simulated consultation using a specialized telemedicine system.



Activity 4: Techniques of Digital Photography for eHealth

The rationale for the activity was to provide students with knowledge and experience in taking clinically useful digital still images.

In contrast to the interactive nature of the previous 3 activities, this task was of relevance to store-and-forward telehealth. Clinical disciplines relevant to this task may include dermatology, wound care, or burns. Students were introduced to the features of standard digital cameras and techniques to capture clinically useful digital images. Guided through a series of 5 photography exercises, students experimented with aspects of focus, resolution, compression, lighting, angle, and background (see Figure 4). Following capture of images, students were required to upload and transfer the images by email to the lecturer for assessment.

Figure 4. Students practicing aspects of clinical photography.

Evaluation

The aim of the evaluation was to assess students' perceptions of the practicum, and hence a qualitative approach was taken. An evaluation questionnaire was designed and provided to all students on the day of the practicum. Students were requested to complete and return the questionnaire after the academic activities of the day had been completed. The questionnaire posed questions on certain themes as described in Table 1.

Table 1. Themes and assessment scale.

Theme	Response
The extent to which practicum objectives had been met (5 questions)	5-item Likert scale with neutral center value
Overall relevance of the practicum to the eHealth course (1 question)	5-item Likert scale with neutral center value
Structure and delivery (5 questions)	5-item Likert scale with neutral center value
Duration of the practicum (1 question)	3-item scale where center value represented "ideal"
Appropriateness of the level of the material presented (1 question)	3-item scale where center value represented "ideal". Free text response was allowed for additional comments.
Overall assessment	Ordinal scale range 1 to 5 with 5 representing the highest level of satisfaction

To gain further insight, students were asked to provide free text responses for the following 5 themes:

1. Whether the practicum met the student's expectations
2. The perceived strengths of the practicum that should be retained in the future
3. Suggestions for improvement
4. Participant's area of work (eg, nursing, physiotherapy, information technology)
5. Speculation of how the skills gained may be useful in the student's future practice

Results

A total of 66 students took part in the eHealth practicum during 2010 (semester 1, 37 students and semester 2, 29 students). These undergraduate students had a health background. Students majoring in occupational therapy (n=29, 44%), physiotherapy (n=20, 30%), speech therapy (n=10, 15%), psychology (n=4, 6%), and bachelor of health sciences (n=3, 5%) participated in the practicum. A summary of questions and the results are shown in Table 2.

The majority of students (n=59, 89%) agreed that they obtained necessary practical skills in various eHealth applications. Similarly, the majority of students agreed that the practicum provided them an opportunity to explore ways of using different technologies in delivering health care while making them aware of both the potential and the limitations of eHealth. Students thought that the practicum was an opportunity to reflect on key areas covered in the eHealth course.

Students also agreed that the practicum was aligned with overall course objectives and provided skills relevant to eHealth practice; 63 students (95%) agreed that the practicum was totally relevant to the course.

When asked if the eHealth practicum met their expectations, 37 (56%) students noted that the practicum exceeded their expectations, indicating that the practicum was informative, enjoyable, interesting, and useful.

There was a mixed response to the structure and some features of the practicum. The majority of students (n=62, 94%) agreed that the practicum was structured well and the activities were designed to develop practical skills (see Table 3). The students thought that the instructors provided useful guidance during the practicum. However, students thought that lectures provided at the beginning of the practicum day were not useful. Some suggested that those lectures were a repetition of the material provided in the online course. Similarly, they suggested that the quality of hand-outs should be improved.

In addition, 57 students (86%) agreed that the duration of the practicum was appropriate. Only 6 (9%) students felt that the practicum was too long. The majority of students (n=59, 89%) also agreed that the practicum was pitched at a level appropriate to their knowledge and technical ability.

When asked whether the hands-on skills acquired from this practicum would be useful in their future practice, 60 students (90%) noted that the skills would be extremely useful.

Multimedia Appendix 1 shows extracts from the written comments provided in the students' evaluation forms in relation to the usefulness of the skills acquired through the practicum.

Table 2. Content of the eHealth practicum.

Objectives: This practicum enables you to...	Responses (%)	Strongly disagree (%)	Disagree (%)	Uncertain (%)	Agree (%)
1. obtain necessary hands-on skills in various eHealth applications	66 (100)	0	0	7 (11)	59 (89)
2. explore ways of using different technology in the delivery of health care	66 (100)	0	0	4 (6)	62 (94)
3. raise awareness of the potential and limitations of the use of technology in health care	66 (100)	0	0	11 (17)	55 (83)
4. reflect on key areas covered in your eHealth course	66 (100)	0	0	3 (5)	63 (95)

Table 3. Summary of responses related to the organization of the practicum.

Practicum	Responses (%)	Strongly disagree (%)	Disagree (%)	Uncertain (%)	Agree (%)
1. This practicum was appropriately structured.	66 (100)	0	0	4 (6)	62 (94)
2. The activities were designed to develop necessary skills.	66 (100)	0	0	0	66 (100)
3. The oral presentations were useful.	66 (100)	0	0	30 (45)	36 (55)
4. Hand-outs were useful.	66 (100)	0	0	45 (68)	21 (32)
5. Instructors' guidance was adequate.	66 (100)	0	0	10 (15)	56 (85)

Discussion

E-learning (online learning) offers many advantages. Evidence shows the potential of e-learning to facilitate better access, better learning outcomes, and cost savings in medical and health education. However, the suitability of e-learning methods depends on the educational outcomes intended.

eHealth is an emerging discipline. While evidence for the benefits of eHealth is growing, the use of eHealth in mainstream health care is still limited. Among other reasons, the lack of appropriate education and training has been cited. eHealth involves not only the use of new technologies in health care settings but also new ways of practicing health care. eHealth changes the dynamics of communication and interaction of parties involved. While a conceptual understanding of these changes is important, the practice of eHealth requires specific practical skills and competencies. E-learning may not always be capable of facilitating the development of such skills and competencies. In some cases, traditional experiential learning methods such as a work-based practicum may be better suited to provide such skills and competencies.

In this study, a practicum was incorporated into an eHealth course, which was previously offered entirely online. The practicum was carefully designed to develop a set of skills that would help students to practice eHealth in their future professions. The majority of students who attended the practicum had a health sciences background, and they were planning to work in rural and remote areas after their graduation.

The activities in the practicum were based primarily on the COH projects [32,33]. A range of activities were selected to offer students the opportunity to obtain experience using different types of eHealth applications (eg, real time and store-and-forward) and various equipment (eg, commercial, web-based, and purpose-built videoconference systems). While students had learned about eHealth applications in the course, the practicum was an opportunity to experience and reflect on key areas covered by the course. The results of the study showed that the practicum was well received by the students. Students agreed that the practicum enabled them to obtain necessary skills in various eHealth applications. Students noted that the practicum provided the opportunity to explore ways of using different technologies in delivering health care at distance.

The practicum not only engaged students in establishing eHealth units and set up communication links but also provided the opportunity to observe how eHealth is practiced for clinical purposes. Students were able to attend some eHealth sessions where clinicians provided consultations to remote patients. Students also had the opportunity to ask clinicians questions after these sessions. The observation of actual eHealth interactions complemented by scenario-based role play allowed students to appreciate both the potential and the challenges of using eHealth in clinical settings. In their written comments, students noted that the practicum was useful for them to reflect on the relevance of eHealth activities in their future practices.

The reported high student satisfaction can be explained by the novelty of the activities and the relevance of skills and competencies developed during the practicum. In the design of the practicum, the curriculum team paid particular attention to the views of various stakeholders including students, lecturers, and the potential employers. Close communication with the stakeholders offered the opportunity to understand the expectations of relevant parties.

Compared with ratings for the simulation activities, student ratings for the didactic lectures that took place on the day were low. This finding, which occurred early in the program, prompted the educators to refocus the structure of the practicum entirely on simulation activities. This reinforces the suitability of e-learning for didactic delivery and the in-person practicum approach for the development of practical skills. However, it may also be the case that relative to the practical activities, the lectures were simply less interesting to the students.

To the best of the authors' knowledge, this is the first study in the literature that describes an attempt to design, deliver, and evaluate a practicum to supplement an online eHealth course. The integration of eHealth into mainstream health care requires systematic education and training of current and future health professionals. Therefore, research into eHealth education and training must be given more attention. eHealth education must focus not only on the provision of knowledge about eHealth applications but also the development of relevant practical skills and competencies that will be useful in practice. This study shows the significance of work-based experiential learning in developing skills in eHealth.

Conclusions

This study showed that the opportunity to participate in an eHealth practicum as a part of an undergraduate online course was highly valued by students. Having practical skills may encourage clinicians to use eHealth in their clinical practice. Therefore, education and training in eHealth must incorporate the development of such skills and competencies. The study showed the value of a blended learning approach, using e-learning to teach theoretical aspects and experiential learning for students to develop practical skills. Given the opportunity, students may use knowledge and skills relating to eHealth in their future practices. The emphasis on education and training of eHealth may be an important step to address the slow uptake of eHealth in the workplace. Future studies must formally assess the effectiveness of eHealth education and training.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Students' written comments.

[PDF File (Adobe PDF File), 97KB - jmir_v14i6e182_app1.pdf]

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Original Paper

An Evaluation of Web-Based Clinical Practice Guidelines for Managing Problems Associated with Cannabis Use

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Abstract

Background: Cannabis is the most widely used illicit substance, and multiple treatment options and avenues exist for managing its use. There has been an increase in the development of clinical practice guidelines (CPGs) to improve standards of care in this area, many of which are disseminated online. However, little is known about the quality and accessibility of these online CPGs.

Objective: The purpose of study 1 was to determine the extent to which cannabis-related CPGs disseminated online adhere to established methodological standards. The purpose of study 2 was to determine if treatment providers are familiar with these guidelines and to assess their perceived quality of these guidelines.

Methods: Study 1 involved a systematic search using the Google Scholar search engine and the National Drugs Sector Information Service (NDSIS) website of the Alcohol and Other Drugs Council of Australia (ADCA) to identify CPGs disseminated online. To be included in the current study, CPGs needed to be free of charge and provide guidance on psychological interventions for reducing cannabis use. Four trained reviewers independently assessed the quality of the 7 identified guidelines using the Appraisal of Guidelines for Research and Evaluation (AGREE II) tool. Study 2 assessed 166 Australian cannabis-use treatment providers' (mean age = 45.47 years, SD 12.14) familiarity with and opinions of these 7 guidelines using an online survey. Treatment providers were recruited using online advertisements that directed volunteers to a link to complete the survey, which was posted online for 6 months (January to June 2012). Primary study outcomes included quality scores and rates of guideline familiarity, guideline use, and discovery methods.

Results: Based on the AGREE II, the quality of CPGs varied considerably. Across different reporting domains, adherence to methodological standards ranged from 0% to 92%. Quality was lowest in the domains of rigor of development (50%), applicability (46%), and editorial independence (30%). Although examination of AGREE II domain scores demonstrated that the quality of the 7 guidelines could be divided into 3 categories (high quality, acceptable to low quality, and very low quality), review of treatment providers' quality perceptions indicated all guidelines fell into 1 category (acceptable quality). Based on treatment providers' familiarity with and usage rates of the CPGs, a combination of peer/colleagues, senior professionals, workshops, and Internet dissemination was deemed to be most effective for promoting cannabis use CPGs. Lack of time, guideline length, conflicts with theoretical orientation, and prior content knowledge were identified as barriers to guideline uptake.

Conclusions: Developers of CPGs should improve their reporting of development processes, conflicts of interest, and CPGs' applicability to practice, while remaining cognizant that long guidelines may deter implementation. Treatment providers need to be aware that the quality of cannabis-related CPGs varies substantially.

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KEYWORDS

Cannabis; Marijuana Abuse; Addiction; Psychotherapy; Standards; Information Dissemination; Health Plan Implementation; Internet

Introduction

Clinical practice guidelines (CPGs) can facilitate appropriate clinical decision making and improve standards of care [1], but their effectiveness relies upon their quality [2]. Unfortunately, early research found that most CPGs published in the peer-reviewed medical literature, including those guidelines developed by specialty societies, were of poor quality [3,4]. Flawed guidelines may provide inaccurate scientific and clinical advice to treatment providers, thereby harming patients because of suboptimal or ineffective treatment delivery [2]. Therefore, the benefits of CPGs are contingent upon their development process. Although efforts have been made to improve the quality of peer-reviewed CPGs [5-7], many continue to lack rigorous development, editorial independence, and applicability to practice, or at least fail to adequately report on these issues [8-10]. The poor quality of CPGs may be perpetuated by the growing trend of publishing CPGs online that do not require peer review or the documentation of a systematic literature review unless they are indexed in a CPG database.

Although Internet dissemination is purported to increase accessibility by making CPGs freely available and by reducing publication delays associated with peer-reviewed journal submission, it may not have a corresponding effect on implementation [11,12]. A systematic review of dissemination strategies found that passive dissemination of educational material alone was not very effective for improving professional practice, but that the impact of educational material was enhanced when it was delivered through interactive educational meetings [13]. Other reviews have found that incorporating a combination of different activities is usually the most effective approach for getting health practitioners to change their behavior [14,15]. Based on these findings, the success of CPGs is not only dependent upon their quality, but it may also depend on which or how many dissemination strategies are used.

Treatment providers should choose which CPG to adopt based on a rigorous review process. Unfortunately, this may not be possible for those who do not have the training and/or time to scrutinize the methods by which guidelines were developed. Given that cannabis is the most frequently used illicit substance [16] and that multiple treatment options (eg, motivational enhancement therapy, cognitive behavior therapy, and family therapy) [17] and avenues (eg, inpatient, outpatient, rehabilitation, and primary care) [18] exist for managing cannabis use, there is a clear need for qualified individuals to evaluate the quality of cannabis-related CPGs, especially those disseminated online.

The purpose of study 1 was to demonstrate the extent to which cannabis-related CPGs adhere to established methodological standards using the validated Appraisal of Guidelines for Research and Evaluation (AGREE II) tool [19]. Its predecessor, the AGREE, is the most promising critical appraisal tool for CPGs and has been used to evaluate numerous CPGs across a variety of health issues [20]. The AGREE II was developed to improve upon the AGREE's reliability and usability. The purpose of study 2 was to determine treatment providers' familiarity with and views about the CPGs identified in study 1. Study findings will assist treatment providers in identifying high quality CPGs and assist guideline developers in improving their reporting and dissemination practices.

Methods

Study 1

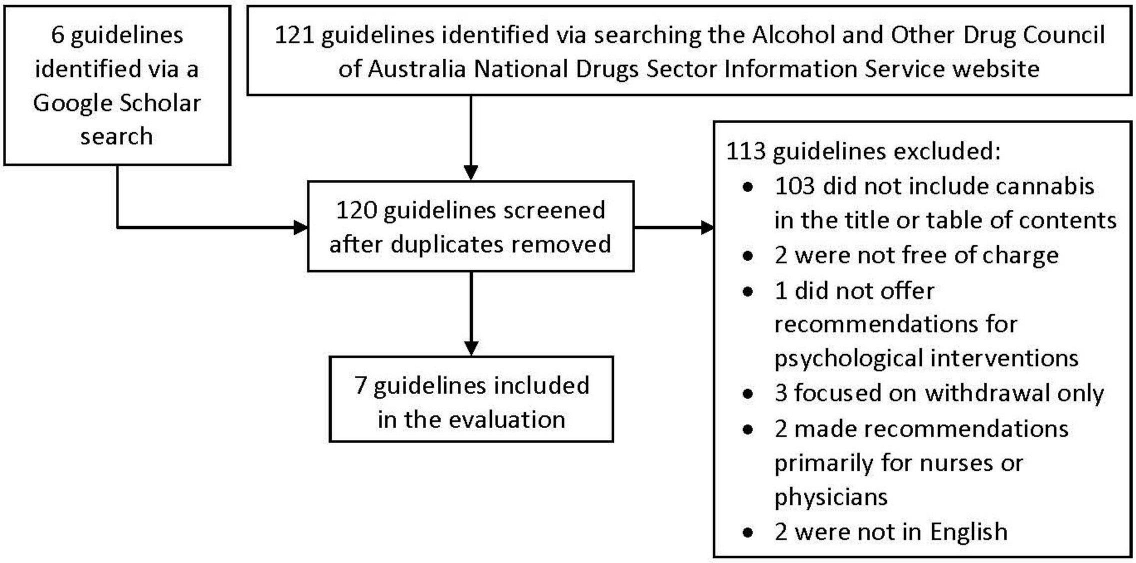
Selection Criteria

To be included in the current study, CPGs needed to provide guidance on psychological interventions for reducing cannabis use. Interventions needed to target cannabis use broadly rather than one specific facet of reducing/ceasing use (eg, withdrawal). In addition, CPGs needed to be developed for professionals whose primary role is to provide counseling (ie, psychologists or counselors) and be available free of charge via the Internet. Further, CPGs were included only when the word *cannabis* (or a similar term) was in the title or in the table of contents (or similar summary list). Guidelines that primarily targeted professionals whose secondary role may include counseling (eg, nurses or general practitioners) or guidelines that were published in any language other than English were excluded. Client population was not an exclusion criteria.

Search Strategy

Two authors (MMN and SER) independently conducted a search of cannabis treatment guidelines using the Google Scholar search engine and the National Drugs Sector Information Service (NDSIS) website of the Alcohol and Other Drugs Council of Australia (ADCA), a service that provides direct and indirect access to guidelines through links [21]. The NDSIS contained 11 links to websites containing guidelines, but did not have a search facility. All websites accessed via links on this site were searched using the terms *marijuana*, *cannabis*, and *guidelines* if they had a search facility, otherwise links were followed to appropriate guidelines. Four websites contained eligible guidelines or contained links to other websites that had eligible guidelines: the Medical Observer [22], the National Guideline Clearinghouse [23], the National Institute for Health and Clinical Excellence website [24], and the Trip database [25]. The Medical Observer, the National Guidelines Clearinghouse, and the National Institute for Health and Clinical Excellence websites each contained 1 eligible CPG, whereas the Trip database contained 2 eligible CPGs for this study. In addition, the National Guideline Clearinghouse had a page with links to complementary websites. These links were explored and led to the discovery of 1 eligible guideline via the Guidelines International Network [26]. In total, 6 CPGs were sourced via NDSIS links to other websites following these methods. Next, Google Scholar was searched using the terms *guidelines*, *cannabis*, and *marijuana*. This returned 1290 hits, with titles revealing 6 potentially eligible CPGs. Only 1 of the 6 CPGs was eligible. Both authors agreed on the eligibility/ineligibility of each CPG (see Figure 1).

Figure 1. Selection of Web-based guidelines.



Quality Assessment

All 5 authors read the AGREE II manual and completed the online AGREE II training [19,27]. One author (MMN) selected 4 non-cannabis-related guidelines for pilot testing. Pilot testing allowed all authors to become familiar with the AGREE II assessment procedure and clarify any discrepancies in subjective quality ratings. The AGREE II appraisals were completed independently by 4 authors (the reviewers MWT, SER, JML, and PJG) and then reviewed together with MMN who served as an intermediary. After all reviewers agreed upon a final score for all items for all pilot CPGs, the 4 reviewers independently assessed each of the 7 eligible CPGs using the AGREE II. After review by the intermediary, reviewers were asked to re-evaluate items for which their scores differed by more than 2 points from the other reviewers. The intermediary provided no indication if scores were higher or lower than the other reviewers' scores and did not require reviewers to change their scores.

Agree II

The AGREE II instrument consists of 23 items across 6 domains: (1) scope and purpose, (2) stakeholder involvement, (3) rigor of development, (4) clarity of presentation, (5) applicability, and (6) editorial independence [19]. A 24th item (overall guideline assessment) assesses a reviewer's overall impression of a guideline. All items are rated on a 7-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree). Domain scores range from 0% to 100% and enable scores to be compared across different domains because domains vary in the number of items they contain. Research on the AGREE II demonstrates that its domain scores have acceptable to good internal consistency (alpha range .64 to .89) and interrater reliability (alpha range .63 to .84) when 4 reviewers are used [28]. Importantly, the AGREE II is able to differentiate content designed to be of high and low quality [29]. For the purposes of this study, a domain cut-off score of 65% was used to determine guidelines of moderate to high quality. A cut-off score of 65% was chosen based on prior research identifying that guidelines approved by the Australian Government's National Health and Medical Research Council typically achieve domain scores above 65% [30]. The AGREE II manual advises that domain scores should be interpreted within the context of a project; therefore, quality judgments were based also on inspection of an error bar graph.

Statistical Analysis

First, mean AGREE II item scores were calculated using the 4 reviewers' item scores. Next, domain percentage scores were derived by summing all mean individual AGREE II item scores and standardizing the total as a percentage of the maximum possible score for that domain. Finally, the interrater reliability of the 4 reviewers was assessed using intraclass correlations (ICCs) for each guideline. A 2-way random model for absolute agreement was used. The ICCs were computed before and after arbitration by the intermediary.

Study 2

Procedures

A convenience sample of health care professionals were recruited via Google advertisements restricted to Australia, as well as advertisements on the websites, newsletters, and email list servers of organizations whose members commonly provide substance use counseling. Advertisements specified that we were conducting a 30-minute online survey about cannabis use guidelines and that we were seeking health professionals who were involved in counseling individuals for cannabis use. The advertisements contained a hyperlink to the study information form. The information form specified that the purpose of the survey was to ascertain health professionals' familiarity with guidelines for managing cannabis use and their opinions of them. The form also specified that if participants entered their email address at the end of the survey they would be entered into a draw to win 1 of 10 Aus $100 prizes via PayPal. Before initiating the online survey, participants were required to provide consent by clicking on the following option: “Yes, I have read the information and consent form and I am ready to participate.” Both the information form and survey were stored on the University of New South Wales website using Key Survey Enterprise. At the start of survey, individuals were asked whether or not they had counseled someone for cannabis use in the past 12 months. Only individuals who answered positively were allowed to continue. After 6 months of data collection (January to June 2012), the survey was closed and 10 participants were randomly chosen for the $100 prizes using a random number generator. At this point, data were downloaded from Key Survey Enterprise and stored in an intranet folder that only University of New South Wales study authors can access. Study 2 was approved by the Medical and Community Human Research Ethics Advisory Panel at the University of New South Wales.

Survey

The open survey contained demographic items that assessed participants’ gender, age, country of birth, educational background, profession, and practice area. Additional items assessed experience in counseling individuals who use cannabis and information sources participants used to inform their provision of cannabis use treatment. The remainder of the survey asked specific questions about the 7 CPGs identified during study 1 and used branch logic questioning in order to only ask questions which were relevant to the participant. For example, if a participant was not familiar with a particular CPG, no questions were asked about that guideline and the survey moved on to the next CPG. When a participant reported being familiar with a CPG, they were asked if they had read it and, if so, if they had used it. If participants had not read a CPG after encountering it, they were asked to report if it was because they were too busy, the CPG was too long, the CPG contained things they already knew, or if it was because the CPG conflicted with their theoretical orientation. When participants had read a CPG they were asked to rate the CPG on 9 Likert-scale items from 1 (strongly disagree) to 5 (strongly agree), where 3 represented neutral. Items were presented in the same order for each participant and were mandatory in that participants could not progress unless an item was answered. In addition, participants could only review items for the currently displayed items (ie, there was no “back” button). The usability and functioning of the survey was tested by the first and second authors before its public launch.

Results

Study 1

Clinical Practice Guideline Characteristics

Seven eligible guidelines met inclusion criteria (see Table 1). Two guidelines were specific to cannabis use: Management of Cannabis Use Disorder and Related Issues: A Clinician’s Guide published by the National Cannabis Prevention and Information Centre (NCPIC) [31] and Clinical Practice Guidelines for Management of Cannabis Dependence published by the Indian Psychiatric Society (IPS) [32]. The other CPGs, published by the National Institute for Health and Clinical Excellence (NICE), the American Psychiatric Association (APA), the New South Wales Department of Health, and New Zealand’s National Health Committee (NHC), were related to substance use treatment in general and only included sections specifically related to cannabis use. The New South Wales Department of Health published two guidelines: (1) Drug and Alcohol Psychosocial Interventions Professional Practice Guidelines [33] hereafter referred to as NSWD (New South Wales-Drug), and (2) National Clinical Guidelines for the Management of Drug Use During Pregnancy, Birth and the Early Development Years of the Newborn [34] hereafter referred to as NSWP (New South Wales-Pregnancy). The guidelines were developed in 5 different countries. Guideline length ranged from 12 to 338 pages.

Table 1. Clinical practice guidelines characteristics.

Clinical practice guideline[a]	Date of last update	Country of origin	Number of pages
Management of Cannabis Use Disorder and Related Issues: A Clinician’s Guide (NCPIC) [31]	2009	Australia	128
Clinical Practice Guidelines for Management of Cannabis Dependence (IPS) [32]	2006	India	12
Drug Misuse: Psychosocial Interventions (NICE) [35]	2008	United Kingdom	338
Practice Guideline for the Treatment of Patients with Substance Use Disorders (APA) [36]	2006	United States	276
Drug and Alcohol Psychosocial Interventions Professional Practice Guidelines (NSWD) [33]	2008	Australia	93
National Clinical Guidelines for the Management of Drug Use During Pregnancy, Birth and the Early Development Years of the Newborn (NSW) [34]	2006	Australia	116
Guidelines for Recognising, Assessing and Treating Alcohol and Cannabis Abuse in Primary Care (NHC) [37]	1999	New Zealand	36

[a] NCPIC: National Cannabis Prevention and Information Centre; IPS: Indian Psychiatric Society; NICE: National Institute for Health and Clinical Excellence; APA: American Psychiatric Association; NSW: New South Wales Department of Health; and NHC: National Health Committee.

Interrater Reliability

Before arbitration, the ICCs ranged from 0.80 to 0.94. After the intermediary notified reviewers of scores that differed by more than 2 points from other reviewers, 50 of 672 item scores (7.4%) were changed. These changes led to ICCs between 0.89 and 0.96, demonstrating high interrater reliability.

Agree II

The 3 items that scored the lowest assessed whether the views of the target population had been sought, if the CPG had been externally reviewed by experts, and if the competing interests of the CPG development group had been recorded and addressed (see Table 2). The 3 highest scores were from the scope and purpose domain. These items assessed the quality of descriptions for the overall objective of the CPG, the health question(s) covered by the CPG, and the population for whom the CPG was intended. Across CPGs, average domain scores were 65% or greater in 2 instances: (1) scope and purpose and (2) clarity of presentation. The most variable domain scores across CPGs were for rigor of development (9% to 89%), followed by editorial independence (0% to 77%). These 2 domains also received the lowest mean domain scores, along with applicability.

Table 2. AGREE II mean item scores and domain percentage scores for each guideline.

Item	Guideline[a]							Overall mean score
	NCPIC	IPS	NICE	APA	NSWD	NSWP	NHC	
Scope and purpose, mean item score								
Objective described	5.75	3.50	6.50	6.00	6.50	6.25	6.50	5.86
Health question described	6.00	4.25	6.50	6.25	6.25	6.50	5.50	5.89
Population described	6.00	4.50	6.50	5.75	5.75	6.50	6.25	5.89
Domain score,[b] %	82%	51%	92%	83%	86%	90%	85%	81%
Stakeholder involvement, mean item score								
Relevant professional groups	5.25	2.25	6.50	3.75	5.00	5.75	5.00	4.79
Target population preferences	2.75	1.00	5.50	1.25	1.75	1.75	3.75	2.54
Target users defined	6.75	3.00	6.25	5.75	6.75	6.25	5.50	5.75
Domain score,[b] %	65%	18%	85%	43%	58%	60%	63%	56%
Rigor of development, mean item score								
Systematic search	2.25	1.25	6.75	6.75	2.25	5.50	1.50	3.75
Selection criteria described	3.75	1.50	6.75	6.25	2.25	4.50	4.25	4.18
Strengths/limitations described	5.00	1.00	6.75	6.25	5.50	5.75	2.00	4.61
Formulation methods described	5.25	1.50	6.75	6.00	5.50	3.75	1.75	4.36
Risks/benefits considered	4.75	1.00	5.25	5.00	4.75	5.00	3.00	4.11
Suggestions linked to evidence	5.50	3.50	6.75	6.50	6.25	6.25	4.00	5.54
Externally reviewed by experts	1.00	1.00	5.00	5.00	1.25	1.75	1.25	2.32
Procedure for updates	3.50	1.00	6.50	5.00	4.50	1.75	1.25	3.36
Domain score,[b] %	48%	9%	89%	81%	51%	55%	23%	50%
Clarity of presentation, mean item score								
Specific recommendations	6.25	4.00	6.50	5.50	5.75	5.25	4.50	5.39
Options presented	6.50	3.50	6.50	6.50	6.25	6.25	4.00	5.64
Identifiable recommendations	6.25	4.00	4.50	3.25	6.50	4.75	6.25	5.07
Domain score,[b] %	89%	47%	81%	68%	86%	74%	65%	73%
Applicability, mean item score								
Facilitators/barriers described	4.75	1.25	3.75	4.75	3.75	3.25	3.00	3.50
Advice/tools for implementation	6.50	2.00	6.00	3.25	4.25	6.00	4.00	4.57
Resource implications considered	3.25	1.00	6.75	4.00	3.00	3.00	1.50	3.21
Monitoring criteria presented	4.00	2.00	5.25	4.25	4.00	4.25	3.50	3.89
Domain score,[b] %	60%	9%	74%	51%	46%	52%	33%	46%
Editorial independence, mean item score								
Lack of funding body influence	4.25	1.00	4.50	3.50	3.75	3.50	1.50	3.14
Competing interests addressed	1.25	1.00	6.75	5.25	1.00	1.00	1.00	2.46
Domain score,[b] %	29%	0%	77%	56%	23%	21%	4%	30%
Overall guideline assessment, mean item score								
Overall quality	5.50	2.00	6.00	4.75	4.50	5.25	3.50	4.50

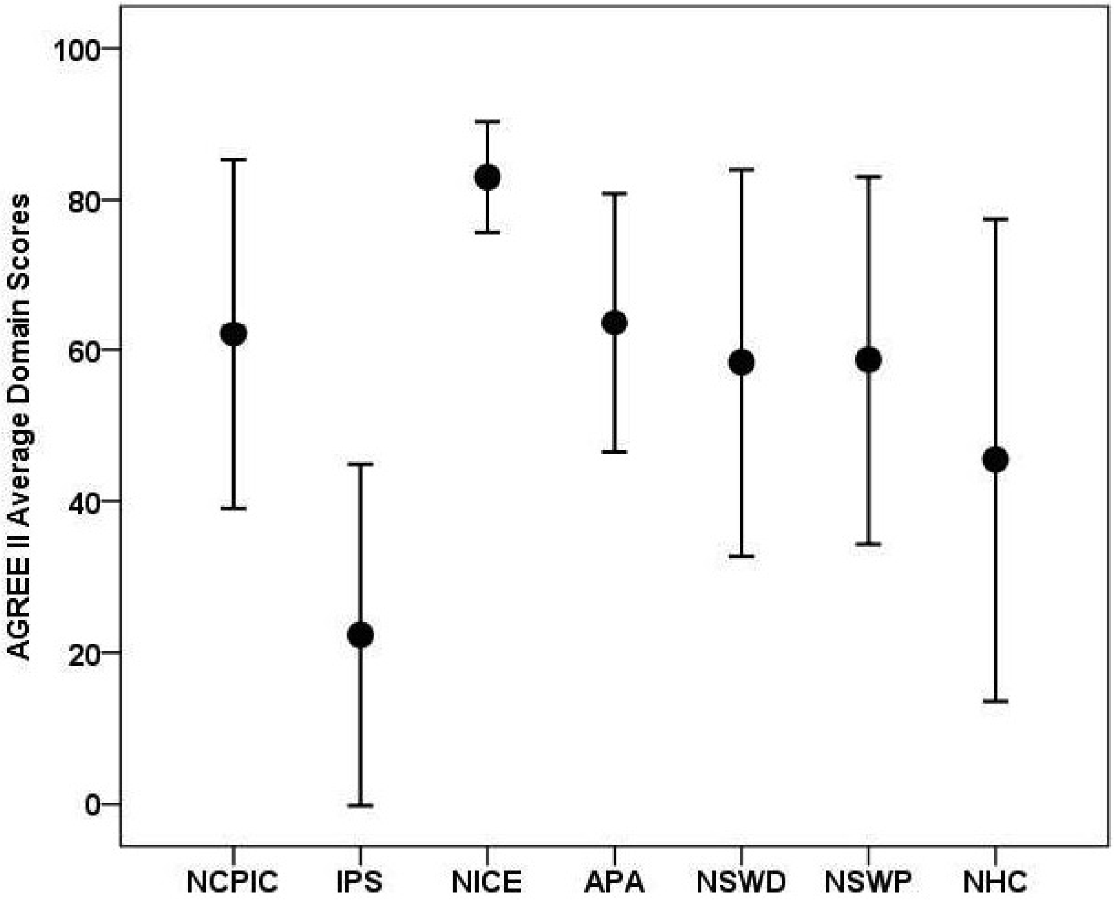
[a] NCPIC: National Cannabis Prevention and Information Centre; IPS: Indian Psychiatric Society; NICE: National Institute for Health and Clinical Excellence; APA: American Psychiatric Association; NSWD: New South Wales-Drug; NSWP: New South Wales-Pregnancy; and NHC: National

Health Committee.

[b] Domain percentage scores were derived by summing all mean individual AGREE II item scores and standardizing the total as a percentage of the maximum possible score for that domain.

The CPGs showed great variability across the domains, ranging from 0% to 92% adherence (Figure 2). The NICE guideline was the most consistent performing CPG and the only CPG to score above 65% in all domains (indicating high quality). This CPG also received the highest scores in all domains, except for clarity of presentation, which was obtained by the NCPIC guideline. The IPS guideline did not achieve over 65% on any domain and achieved the lowest scores across all domains compared to other CPGs (indicating very low quality). Guidelines other than the NICE and the IPS guidelines achieved average domain scores between 46% and 64% (indicating acceptable to low quality).

Figure 2. Mean AGREE II domain scores for the 7 eligible clinical practice guidelines. NCPIC: National Cannabis Prevention and Information Centre; IPS: Indian Psychiatric Society; NICE: National Institute for Health and Clinical Excellence; APA: American Psychiatric Association; NSWD: New South Wales-Drug; NSWP: New South Wales-Pregnancy; and NHC: National Health Committee.



Study 2

Participant Characteristics

A total of 190 individuals provided informed consent to participate in the study; however, only 166 of these individuals reported that they had counseled someone for cannabis use in the past 12 months, meeting the criteria to complete the survey. The average age of these 166 individuals was 45.47 years (SD 12.14). Of these, 64.5% (107/166) were female and 77.7% (129/166) were born in Australia. The next most common country of origin was England (7.2%, 12/166). Educational and professional details for the participants are presented in Table 3. Most participants had received some type of tertiary education, worked for an organization, practiced in a metropolitan area, were a drug and alcohol worker/specialist, and had over 3 years' experience counseling individuals who use cannabis (Table 3). Slightly more of the study sample reported being from regional or remote areas compared to the entire Australian population [38]. Guidelines, websites, colleagues, and workshops were the most frequently identified sources for informing participants' treatment of cannabis use.

Table 3. Educational and professional characteristics of the participants (N = 166).

Characteristics		n (%)
Educational background		
	No higher education degree	4 (2.4%)
	Certificate/diploma/advanced diploma	53 (31.9%)
	Bachelor’s degree	62 (37.3%)
	Master’s degree	34 (20.5%)
	MD/PhD or equivalent	13 (7.8%)
Employment status		
	Employee of organization	150 (90.4%)
	Self-employed	15 (9.0%)
	Unemployed	1 (0.01%)
Practice area		
	Metropolitan	106 (63.9%)
	Rural	54 (32.5%)
	Remote	6 (3.6%)
Profession		
	Drug and alcohol worker/specialist	71 (42.7%)
	Counselor	10 (6.0%)
	Social worker	10 (6.0%)
	Psychologist	32 (19.3%)
	Psychiatrist	2 (1.2%)
	Nurse	24 (14.5%)
	Other	17 (10.2%)
Cannabis counseling experience		
	0-6 months	8 (4.8%)
	6-11 months	12 (7.2%)
	1-3 years	35 (21.1%)
	3-5 years	26 (15.7%)
	Over 5 years	85 (151.2%)
Cannabis use treatment information sources [a]		
	Guidelines	103 (62.0%)
	Websites	96 (57.8%)
	Journal articles	100 (60.2%)
	Books	69 (41.6%)
	Workshops	100 (60.2%)
	Conferences	67 (40.4%)
	Colleagues	99 (59.6%)

[a] Participants were able to choose more than one option, thus, percentages do not sum to 100.

Familiarity with Clinical Practice Guidelines

Participants were most familiar with the NCPIC, NSWD, and NICE guidelines; however, less than half of the study participants (44.6%, 74/166) were aware of the NCPIC guideline, the most frequently encountered CPG (Table 4). Peers/colleagues and websites were the top reasons cited for knowing about all 3 of these CPGs. Professional development workshops also were key in disseminating the NCPIC guideline, as were journal articles for the NICE guideline, and senior professionals for the NSWD guideline. The 3 least frequently encountered guidelines (APA, NSWP, and NHC) also were often discovered via these routes with the addition of education programs.

In most cases, approximately three-fourths of individuals had read the CPGs they had encountered; however, over 90% of individuals had read the NSWD and NSWP guidelines after they heard about them. These 2 CPGs were encountered through senior professionals more so than the other guidelines. The most common reasons acknowledged for not reading a CPG was being too busy (40% to 83% of respondents for all CPGs), believing a CPG was at conflict with one's theoretical orientation (0% to 50% for all CPGs), believing a CPG was too long (0% to 40% for all CPGs), and already knowing the content (0% to 33% for all CPGs). In many cases, after a participant had read a CPG they were likely to use it in their practice. This was most often the case for the NCPIC and APA guidelines. Both of these CPGs were encountered through workshops more so than any other guideline.

Examination of mean scores demonstrates that participants tended to agree or feel neutral toward the quality statements about the selected CPGs (Table 5). Thus, little variability in item scores existed between the CPGs. For 6 of the 9 items, participants scored the NSWP guideline slightly higher. In regards to the 3 other items, participants reported that the NSWD guideline was the easiest to follow, the NCPIC guideline was the most clearly presented, and the NCPIC and NSWD guidelines were the most applicable to their practice. On average, the NHC guideline scored slightly lower across 6 items. In 2 cases, the NICE guideline was rated the lowest. Participants were less supportive of routinely using the NICE guideline and in less agreement that they were easy to follow compared to the other CPGs. Lastly, participants reported that the NCPIC guideline was based on patient preferences the least.

Table 4. Familiarity with clinical practice guidelines (CPGs).

Item	Guideline[a]						
	NCPIC n (%)	IPS n (%)	NICE n (%)	APA n (%)	NSWD n (%)	NSWP n (%)	NHC n (%)
Familiar with the CPG	74 (44.6%)	35 (21.1%)	49 (29.5%)	32 (19.3%)	55 (33.1%)	30 (18.1%)	8 (4.8%)
CPG discovery method [b]							
Education program	7 (10%)	3 (9%)	7 (14%)	6 (19%)	9 (16%)	8 (27%)	3 (38%)
Journal article	6 (8%)	4 (11%)	9 (18%)	5 (16%)	5 (9%)	2 (7%)	1 (13%)
Peers/colleague	26 (35%)	11 (31%)	11 (22%)	12 (38%)	18 (33%)	10 (33%)	2 (25%)
Senior professional	10 (14%)	5 (14%)	8 (16%)	14 (4%)	13 (24%)	7 (23%)	0 (0%)
Mailing list	13 (18%)	2 (6%)	8 (16%)	1 (3%)	7 (13%)	4 (13%)	1 (13%)
Conference	9 (12%)	3 (9%)	6 (12%)	3 (9%)	3 (6%)	3 (10%)	1 (13%)
Workshop	17 (23%)	6 (17%)	4 (8%)	6 (19%)	2 (4%)	1 (3%)	1 (13%)
Website	16 (22%)	14 (40%)	18 (37%)	7 (22%)	17 (31%)	10 (33%)	3 (38%)
Read the CPG[b]	55 (74%)	29 (83%)	37 (76%)	24 (75%)	50 (91%)	28 (93%)	6 (75%)
Used the CPG after reading[c]	55 (100%)	24 (83%)	33 (89%)	23 (96%)	45 (90%)	24 (86%)	5 (83%)

[a] NCPIC: National Cannabis Prevention and Information Centre; IPS: Indian Psychiatric Society; NICE: National Institute for Health and Clinical Excellence; APA: American Psychiatric Association; NSWD: New South Wales-Drug; NSWP: New South Wales-Pregnancy; and NHC: National Health Committee.

[b] Percentages were calculated based on how many people were familiar with that particular guideline and not the total sample.

[c] The denominator for calculating the percentage is equal to the guideline n of Read the CPG.

Table 5. Treatment providers' opinions regarding the clinical practice guidelines.

Item	Guideline,[a] mean (SD)						
	NCPIC	IPS	NICE	APA	NSWD	NSWP	NHC
Should be routinely used	3.70 (0.68)	3.49 (0.61)	3.42 (0.67)	3.44 (0.76)	3.67 (0.82)	3.83 (0.70)	3.50 (0.53)
Easy to follow	3.78 (0.60)	3.63 (0.49)	3.62 (0.57)	3.66 (0.65)	3.87 (0.67)	3.80 (0.61)	3.63 (0.74)
Clear who should use	3.80 (0.72)	3.69 (0.58)	3.60 (0.53)	3.56 (0.67)	3.82 (0.67)	3.90 (0.71)	3.38 (0.52)
Based on patient preferences	3.03 (0.70)	3.14 (0.60)	3.12 (0.56)	3.16 (0.57)	3.24 (0.69)	3.30 (0.84)	3.25 (0.46)
Clearly presented	3.91 (0.58)	3.74 (0.51)	3.62 (0.60)	3.60 (0.71)	3.89 (0.79)	3.80 (0.61)	3.50 (0.53)
Applicable to my practice	3.91 (0.69)	3.77 (0.60)	3.64 (0.60)	3.75 (0.62)	3.91 (0.80)	3.87 (0.82)	3.63 (0.74)
Rigorously developed	3.66 (0.71)	3.69 (0.68)	3.52 (0.54)	3.66 (0.71)	3.60 (0.78)	3.77 (0.63)	3.25 (0.46)
Would recommend	3.88 (0.64)	3.80 (0.68)	3.52 (0.58)	3.63 (0.71)	3.85 (0.78)	4.00 (0.64)	3.50 (0.93)
Overall quality is good	3.95 (0.62)	3.83 (0.62)	3.64 (0.56)	3.72 (0.63)	3.80 (0.68)	3.97 (0.67)	3.63 (0.74)

[a] NCPIC: National Cannabis Prevention and Information Centre; IPS: Indian Psychiatric Society; NICE: National Institute for Health and Clinical Excellence; APA: American Psychiatric Association; NSWD: New South Wales-Drug; NSWP: New South Wales-Pregnancy; and NHC: National Health Committee.

Discussion

Publishing CPGs online is intended to facilitate the dissemination of evidence-based treatment information; however, the provision of these resources through the Internet alone does not guarantee practitioner uptake [13-15]. This caveat combined with the lack of quality control associated with online resources necessitated an evaluation of treatment providers' access to and options of CPGs for managing cannabis use, as well as an evaluation of their scientific soundness. Utilizing 4 trained CPG reviewers, study 1 found a high amount of variability between CPGs for managing cannabis use, whereas treatment providers in study 2 reported much less variability between the CPGs. In addition, these studies identified areas of improvement for guideline developers and a potential dissemination combination that may lead to greater CPG familiarity and implementation.

Clinical Practice Guideline Quality

Based on AGREE II domain scores and examination of an error bar graph, the CPGs fell into 3 broad categories: high quality, acceptable to low quality, and very low quality. The NICE guidelines had the highest overall quality; the NCPIC, APA, NSWD, NHC, and NSWP guidelines were deemed acceptable to low quality; and the IPS guidelines were rated as needing substantial improvement. Inspection of domain scores demonstrated that consistent with prior research, CPGs performed the poorest in the areas of rigor of development, applicability, and editorial independence [8-10]. As such, CPG developers can enhance the quality of revisions to these CPGs by substantially improving reporting in these 3 areas.

Interestingly, findings from studies 1 and 2 were somewhat incongruent. In general, treatment providers assessed during study 2 reported substantially less variability in CPG quality as compared with the reviewers from study 1. All 9 areas of interest examined during study 2 received average scores. Although the clinical significance between mean item scores is likely low, examination of these scores further highlights the quality discrepancies reported by treatment providers and trained reviewers. For example, 3 of the 9 items assessed during study 2 are directly comparable to AGREE II domain scores (rigor of development, clarity of presentation, and applicability). In all of these areas, the trained reviewers rated the IPS guideline the lowest, whereas the treatment providers rated the NHC guideline the lowest. Treatment providers rated the IPS guideline second- to fourth-best in these areas. Examination of study 2 items that were similar to AGREE II items (defining target users, seeking patient preferences, and overall quality) demonstrated a similar discrepancy. In all cases, the IPS guideline was rated the lowest by the trained reviewers, whereas treatment providers reported that the NHC guideline was the poorest in terms of clarity about who should use the guideline and overall quality. Treatment providers also reported that the NCPIC guideline was based less on patient preferences than the other guidelines. The discrepancies in ratings between reviewers and treatment providers indicate that treatment providers may not be able to differentiate between good and poor CPG reporting quality. This finding is important because it may suggest that treatment providers are at risk for adopting CPGs that are not based on the best available evidence.

Although validity testing has demonstrated that the AGREE II is able to differentiate higher quality reporting from lower quality reporting [29], it is possible that well-reported CPGs contain flawed recommendations and poorly reported CPGs contain sound recommendations. A comparison of reports and research protocols for randomized controlled trials conducted by the Radiation Therapy Oncology Group showed that the methodological quality of studies was often substantially better than that reported [39]. For example, allocation concealment and sample size calculations were only reported in 42% and 16% of the reports, but reported in 100% and 76% of the research protocols. If these results are transferable to CPGs, it may mean that the scientific soundness of the poorest performing CPGs according to AGREE II ratings may be substantially better than thought. It is important to note, however, that all research protocols produced by the Radiation Therapy Oncology Group must pass through a rigorous peer review process and be approved through its own committee system and the National Cancer Institute before a randomized controlled trial can progress. Thus, CPGs that do not undergo peer review during development or afterwards may not be better than what AGREE II scores suggest.

Dissemination and Impact

Study 2 demonstrates that the effectiveness of current CPG dissemination methods is suboptimal. Slightly less than half of the study population was familiar with the NCPIC guideline, the most well-known guideline, whereas only a third of the sample had heard of the second most commonly identified guideline (NSWD). Prior research has found that 59% to 98% of substance abuse treatment providers are familiar with motivational and cognitive-behavioral treatment approaches [40-42]. Because these approaches have the most evidence base for treating cannabis use, unless CPGs reach the 49% of providers who do not have preexisting knowledge about these evidence-based approaches, current CPG access rates may not lead to an increase in standards of care. Examination of potential differences in dissemination efforts between the NCPIC guidelines and the other 6 CPGs may suggest methods for improvement because the NCPIC guideline was the most commonly encountered.

Peers/colleagues, websites, and workshops were the most common methods reported for discovery of the NCPIC guidelines. As peers/colleagues and websites were common methods for discovering all identified CPGs, the addition of workshop dissemination may lead to increased CPG familiarity. Previous research suggests that greater adoption of workshop materials is facilitated by greater relevancy of training (eg, information obtained is relevant to the needs of participants' clients) and greater program support (eg, having enough time to implement the materials) [43]. As such, dissemination via workshops may only increase cannabis-related CPG uptake for participants who regularly provide psychosocial treatment for cannabis treatment and who have the time and support of their organization for CPG implementation. In support of this assumption, the NSWD and NSWP guidelines were the most frequently read once encountered, and were heard of more often via senior professionals than the other guidelines. CPG access through senior professionals may be a proxy indicator of organizational support. In addition, the NCPIC and APA guidelines were the most frequently used once read, and these CPGs were accessed via workshops more than the other guidelines. Based on these combined findings, successful dissemination and implementation may be facilitated by the combination of peers/colleagues, senior professionals, workshops, and websites.

To increase the uptake of guideline usage, CPGs should further take into account the needs of the treatment provider. Consistent with previous research on evidence-based treatment and CPG adoption [29,40,43], barriers commonly reported during study 2 for not reading a CPG included a lack of time, CPG length, conflict with theoretical orientation, and already being familiar with the content. Only a lack of time and CPG length can be addressed by guideline developers. Accordingly, finding ways to make CPGs more time efficient while not compromising on quality should be a primary objective of future guideline development. A method for achieving this goal may be for CPG developers to publish two documents online. One document could focus on the content of practice, whereas the other could be reserved for reporting development processes and conflicts of interest.

Strengths and Limitations

The current research has several strengths, including a systematic evaluation of CPGs conducted by multiple reviewers with a high level of consistency among the reviewers. Additionally, the evaluation was conducted using a psychometrically robust assessment tool. Finally, the systematic evaluation study was followed with data from users of the guidelines, enabling us to examine gaps between quality and real-world perceptions of the guidelines. These strengths must be considered in light of study limitations. First, the AGREE II instrument provided an indication of guideline reporting quality, rather than a direct indication of the appropriateness of the recommendations. Previous research cautions that cannabis use information for patients available online is not of a high standard [44]. Therefore, an important follow-up study would involve a content assessment of the identified CPGs. Second, study 2 did not provide a direct comparison of guidelines because this would have required every treatment provider to read and evaluate each CPG. This was not feasible, especially since this study identified that treatment providers did not have enough time to read the CPGs that they had heard of. Third, the type of data obtained through studies 1 and 2 prevented the use of inferential analyses for examining associations between the studies' findings (eg, 4 data points for each AGREE II item because of 4 reviewers and a highly varied sample size for treatment provider opinions based on differential CPG familiarity rates). Lastly, the health provider survey we developed for this study utilized a 5-point response format. This response scale limited the variability of providers' ratings and also prevented direct comparison with the AGREE II.

Conclusions

This research provided the first evaluation of online CPGs that address psychosocial treatments for reducing cannabis use. The findings provide an indication of the reporting quality of CPGs that are freely available to treatment providers, and highlight gaps between the quality of CPGs as assessed by a psychometrically validated assessment tool and treatment provider perceptions. The research also suggests possible methods for increasing the uptake of CPGs among treatment providers.

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Conflicts of Interest

MM Norberg, SE Rooke, and PJ Gates are employed by the National Cannabis Prevention and Information Centre, a publisher of one of the guidelines reviewed in this paper. None of these authors were an author of that guideline.

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Abbreviations

ADCA: Alcohol and Other Drugs Council of Australia
AGREE II: Appraisal of Guidelines for Research and Evaluation
APA: American Psychiatric Association
CPG: clinical practice guideline
ICC: intraclass correlation
IPS: Indian Psychiatric Society
NCPIC: National Cannabis Prevention and Information Centre
NDSIS: National Drugs Sector Information Service
NHC: National Health Committee
NICE: National Institute for Health and Clinical Excellence
NSWD: New South Wales Department of Health (Drug and Alcohol Psychosocial Interventions Professional Practice Guideline)
NSWP: New South Wales Department of Health (National Clinical Guidelines for the Management of Drug Use During Pregnancy, Birth and the Early Development Years of the Newborn guideline)

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Original Paper

How Current Are Leading Evidence-Based Medical Textbooks? An Analytic Survey of Four Online Textbooks

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Abstract

Background: The consistency of treatment recommendations of evidence-based medical textbooks with more recently published evidence has not been investigated to date. Inconsistencies could affect the quality of medical care.

Objective: To determine the frequency with which topics in leading online evidence-based medical textbooks report treatment recommendations consistent with more recently published research evidence.

Methods: Summarized treatment recommendations in 200 clinical topics (ie, disease states) covered in four evidence-based textbooks–UpToDate, Physicians' Information Education Resource (PIER), DynaMed, and Best Practice–were compared with articles identified in an evidence rating service (McMaster Premium Literature Service, PLUS) since the date of the most recent topic updates in each textbook. Textbook treatment recommendations were compared with article results to determine if the articles provided different, new conclusions. From these findings, the proportion of topics which potentially require updating in each textbook was calculated.

Results: 478 clinical topics were assessed for inclusion to find 200 topics that were addressed by all four textbooks. The proportion of topics for which there was 1 or more recently published articles found in PLUS with evidence that differed from the textbooks' treatment recommendations was 23% (95% CI 17-29%) for DynaMed, 52% (95% CI 45-59%) for UpToDate, 55% (95% CI 48-61%) for PIER, and 60% (95% CI 53-66%) for Best Practice (χ^2_3=65.3, P<.001). The time since the last update for each textbook averaged from 170 days (range 131-209) for DynaMed, to 488 days (range 423-554) for PIER (P<.001 across all textbooks).

Conclusions: In online evidence-based textbooks, the proportion of topics with potentially outdated treatment recommendations varies substantially.

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KEYWORDS

databases, bibliographic; medical informatics; evidence-based medicine

Introduction

Online evidence-based textbooks such as UpToDate, Physicians' Information Education Resource (PIER), DynaMed, and Best Practice aim to provide high quality, frequently updated, evidence-based recommendations for clinical practice, enabling clinicians to provide care to their patients, meeting the most recent evidence-based standards [1, 2]. If these goals are achieved, they offer many advantages for supporting clinical decisions, especially in indicating care based on the current best evidence [3]. However, these textbooks often contain topic summaries that have not been recently updated [4-7]. New evidence potentially important to advancing medical practice is published frequently at unpredictable rates, making it necessary for frequent reassessment of management recommendations [5,6]. Lag time between publication of research and its availability in textbooks puts a burden on clinicians, who may provide suboptimal care to patients as a consequence [3].

It is very costly and time consuming for evidence-based textbooks to seek out, appraise, and incorporate new information in a timely manner, using only their own resources [8]. Improved efficiency at lower costs would be an asset to updating such textbooks, and perhaps free-up resources to tackle challenges in integrating evidence-based information into clinical work flow. Tools such as specific and sensitive literature search filters and evidence-based literature appraisal services could help overcome these barriers [9]. Recent studies have assessed the time since updating of individual topics within evidence-based textbooks [4,7,10] but have not attempted to identify individual studies that might affect recommendations for care and thus warrant considering a revision of the most recent textbook version.

The McMaster Premium Literature Service (PLUS) database is a continuously updated, searchable database of primary studies and systematic reviews. Each article from over 120 high quality clinical journals and evidence summary services, such as the AHRQ Technology Assessment Program, is appraised by research staff for methodological quality, and articles that pass basic criteria are assessed by practicing clinicians in the corresponding discipline [1, 9]. Clinical ratings are based on 7-point scales, where clinical relevance ranges from 1 (“not relevant”) to 7 (“directly and highly relevant”), and newsworthiness ranges from 1 (“not of direct clinical interest”) to 7 (“useful information, most practitioners in my discipline definitely don’t know this”). Recently, use of the PLUS database on its own has been shown to identify articles that can be used to update a high proportion of systematic reviews [11].

The primary objective of this investigation was to determine the proportion of topics in UpToDate, PIER, DynaMed, and Best Practice that predated articles in PLUS with findings different from those reported in the topics. We also assessed the number of topics available in each evidence-based textbook compared with the topic coverage in the PLUS database and the recency of updates for these publications.

Methods

Study Design

An analytic survey of 200 clinical topics across four online evidence-based textbooks was performed based on their most recent update to determine how frequent these topics omitted evidence in PLUS that was published since the most recent textbook update. The four textbooks, UpToDate, PIER, DynaMed, and Best Practice, were selected based on their performance in a study which assessed their evidence-based standards of preparation, timeliness of updating, and breadth of topic coverage [4]. These four textbooks have online referencing for treatment recommendations and were available through the McMaster PLUS Federated Search website [12], allowing for simultaneous searching of all textbooks for each topic.

Topic Selection

Articles in the PLUS database are indexed for over 700 topics, 502 of which had at least one corresponding article in the database in June 2011. A randomized sequence for the 502 topics was generated for topic selection. To permit comparisons of the textbooks, topics from the randomized sequence were included if each of the four textbooks had a corresponding chapter or section, and each included treatment recommendations. Searches were conducted using the textbooks’ search engine via a federated search platform [12] that searched the four textbooks simultaneously, using search terms derived from Systematized Nomenclature of Medicine (SNOMed) coding of the topic names for the 200 topics. Topics were excluded if there were more than 5 links to related chapters within a textbook, because it would be difficult to analyze all the relevant pages to this many external links. Topics were assessed for eligibility until our sample size of 200 topics was reached.

Status of Updating for Topics

Corresponding chapters for each topic in each textbook were captured as PDFs at the identical time for a given topic to provide a common baseline capture date for all texts, from July 2011 to November 2011. Any additional chapters linked to specific treatments for the topics of interest (up to 5 links in total) were also captured. It was not feasible to conceal the textbook sources of the PDFs from research staff (RJ, GF, TN) doing assessments; however, the protocol was standardized and outcomes were objective to minimize bias introduced by this lack of blinding.

The date of the most recent article cited for a topic was used as the update time since the textbooks did not consistently specify whether the posted date referred to the last literature search, the date the update was posted, or otherwise.

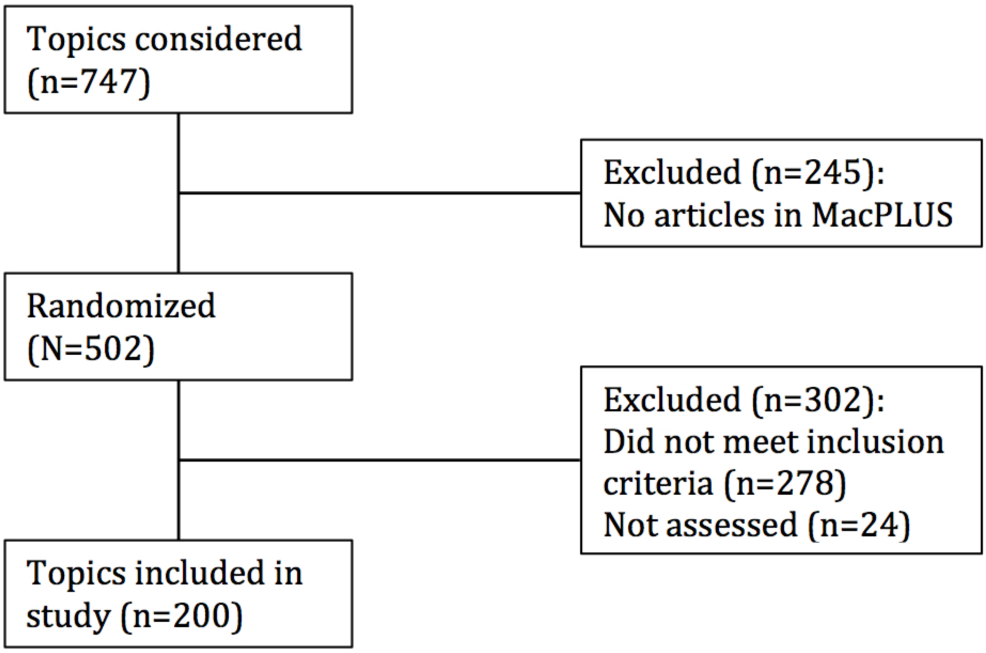
A simultaneous search of the PLUS database was conducted, using the pre-assigned SNOMed indexing terms for each topic, and including only articles that reported randomized trials or systematic reviews of trials relevant to questions about therapy. Data captured included PubMed ID, article title and abstract, and the date the article was posted to PLUS. The PLUS posting date was compared to the last update for each textbook to determine which article was more recent.

The treatments studied in the selected articles were compared to those recommended in the textbooks. If the study findings were qualitatively different from the textbook recommendation, the findings in the article were considered as potential update material for a textbook. For example, if a PLUS article reported a significant effect of nebulized epinephrine for croup and a textbook did not recommend this therapy, the article would be deemed a potential update for this topic. The term potential update was used to acknowledge the fact that clinical recommendations require the consideration of accumulated evidence, patients' circumstances, and other variables such as the quality of the new evidence, in addition to the new evidence itself.

Articles were assessed to determine if the findings of the study showed a benefit, harm, or no effect of the treatment on the clinical outcome reported in the study. This assessment was initially done in duplicate by 2 reviewers (RJ and TN) for 20 topics. The rate of agreement beyond chance (kappa statistic) was 91% (81%-99%). Subsequently, only 1 reviewer assessed each article for the other 180 topics.

The proportion of topics in each textbook with the potential to update was the primary outcome of interest. A topic was in need of an update if there was at least one newer article in PLUS that provided information that differed from the topic's recommendations in the textbook. Practical importance was defined as textbooks which require an update on 15% or more of the topics. The sample size of 200 topics was determined based on this parameter with a 95% confidence interval of ±5%. Chi-squared tests were performed to determine if the proportions of topics needing updates for each textbook were significantly different across the four textbooks. Analysis of variance was used for continuous data comparisons. Stata version 9.2 (StataCorp LP, College Station, TX) was used for statistical analysis.

Figure 1. Flow Diagram of Study Population.



Results

Topic Selection

During topic selection, 478 topics of the 502 were assessed for eligibility. 271 topics were excluded because they were not found in all evidence based textbooks while 7 were excluded because they had more than 5 topic links in a single textbook (Figure 1). Of the excluded topics, a matching chapter was not available in PIER for 87% (241/278), Best Practice for 34% (95/278), DynaMed for 23% (63/278), and UpToDate for 19% (52/278), (χ^2_3=345, *P*<.001 for the differences across textbooks).

Status of Updating for Topics

Overall, 956 articles found in PLUS were more recent than the last update in at least one textbook over all 200 topics. 165 topics of the 200 had at least 1 article for at least 1 textbook that could be a potential update to that topic. All textbooks had >15% of topics with the potential for an update, ranging from 23% (46/200) for DynaMed to 60% (200) for Best Practice (χ^2_3=65.3, *P*<.001, Table 1). The proportion of topics with potential for updates was significantly lower for DynaMed than the other three textbooks, which had statistically similar values (Table 1).

The trend was the same for the mean number of articles available in PLUS since the last textbook update; there were fewer articles accumulating for DynaMed compared with the other textbooks

(Table 1). This is partly explained by the time since the last update. For DynaMed topics, updates occurred on average of 170 days prior to our study, while the other textbooks averaged from 427 to 488 days (Table 1).

Of all evidence-based textbooks, DynaMed missed fewer articles reporting benefit or no effect when the direction of findings available to update (beneficial, harmful, no effect) was investigated (Table 2). For articles reporting harm, there were fewer PLUS articles accruing for DynaMed than Best Practice; no other textbooks showed differences (Table 2).

The clinical relevance and newsworthiness for each article available in PLUS was also investigated, based on the score out of 7 for each category assigned to that article by PLUS raters. For the 406 accruing articles that reported new information on benefit of a treatment for at least 1 textbook, mean clinical relevance scores were 5.51 (95% CI 5.45-5.57; 7-point scale, with 7 high) and mean newsworthiness was 4.98 (4.91-5.04, 7-point scale). Mean clinical relevance scores were ≥ 6 out of 7 for 25% (101/406) of the studies; mean newsworthiness scores were ≥ 6 out of 7 for 9.4% (38/406) of these beneficial studies. For the 27 articles reporting harm, mean clinical relevance was 5.49 (5.24-5.74) and newsworthiness was 5.01 (4.72-5.31). Of the 27 articles reporting harm, 15% (4/27) were rated ≥ 6 for newsworthiness, 26% (7/27) were rated ≥ 6 for clinical relevance.

Table 1. Results for 200 equivalent topics across four evidence-based textbooks.

Variable	Best Practice	DynaMed	PIER	UpToDate
Number of topics with potential for updates	119	46	109	104
Proportion of 200 topics with potential for updates (95% CI)[a]	60% (53%-66%)[b]	23% (17%-29%)	55% (48%-61%) [b]	52% (45%-59%) [b]
Mean (CI) number of articles per topic in PLUS since last update[c]	1.94 (1.46-2.42) [b]	0.48 (0.29-0.67)	1.56 (1.21-1.91) [b]	1.67 (1.25-2.09) [b]
Mean (CI) number of days since last update[c]	435 (392-478) [b]	170 (131-209)	488 (423-554) [b]	427 (360-494) [b]

[a] χ^2_3=65.3, *P*<.001 comparing the four textbooks.

[b] Values sharing a superscript [b] are not significantly different from one another at the *P*=.01 (Bonferroni correction).

[c] One-way ANOVA *P*<.001.

Table 2. Subgroup analysis of articles in PLUS reporting harm, benefit, or no effect.

Variable	Best Practice	DynaMed	PIER	UpToDate
Mean (95% CI) number of new articles reporting benefit per 100 topics[a]	125 (88-161) [b]	31 (19-43)	100 (75-124) [b]	107 (075-138) [b]
Mean (CI) number of new articles reporting harm per 100 topics[a]	14 (8-20)[b]	3 (0-5) [c]	8 (4-12) [bc]	11 (5-16) [bc]
Mean (CI) number of new articles reporting no effect per 100 topics[a]	58 (42-73) [b]	15 (6-24)	50 (35-64) [b]	53 (38-68) [b]

[a] One-way ANOVA *P*=.007 for number of new articles reporting harm and *P*<.001 for other outcomes comparing the textbooks.

[b,c] Values sharing a superscript [b] or [c] are not significantly different from one another at *P*=.01 (Bonferroni correction).

Discussion

We found that topic coverage varied substantially for leading evidence-informed electronic textbooks and generally a high proportion of the 200 common topics had potentially out of date conclusions, missing information from 1 or more recently published studies. PIER had the least topic coverage, while UpToDate, DynaMed, and Best Practice covered more topics, in similar numbers. DynaMed's timeline for updating was the quickest and it had by far the least number of articles that needed to be updated, indicating that quality was not sacrificed for speed.

These findings were similar to a recent study looking at updating systematic reviews [11]. Our sample size included a large number of topics and provided power for our estimate of topics requiring potential updates. Indeed, we found a much higher rate of topics with a potential update than our pre-study expectation of 15%. Although the primary objective was to estimate updating potential within textbooks, some differences across textbooks were apparent.

Evidence-based textbooks are an important source of summary information and care recommendations for practicing clinicians [9]. Keeping these resources updated is a costly and intensive process. The results of this study show that although there is variation in the rate at which the leading textbooks are updated, all of them can benefit from more frequent processing of high quality, clinically relevant, recently published studies. The PLUS database, compared to the latest updates of 200 topics across textbooks, had studies with new, different information related to over half the topics for textbooks, and 23% for DynaMed topics. Some of these more recent articles contained information on benefits of treatment, as well as the potential for harm. This is an underestimate of the potential for PLUS to update textbooks across clinically important topics, as we did not consider studies of diagnosis, prognosis, clinical prediction, quality improvement, or cost-effectiveness, all of which are included in the PLUS database and may affect clinical decisions.

The articles identified as potential updates reporting benefits and harms had a range of scores for clinical relevance and newsworthiness, with most articles rated as “probably” to “definitely” relevant to clinical practice across disciplines, and rated as “useful information” by practicing physicians [13].

Studies have shown that patients often do not receive the best care, or may even receive harmful or unnecessary care, due to difficulties in updating information for practice [10]. Recently published articles about ineffective or potentially harmful treatments should also be included in recommendations, as physicians may not realize there are recent studies that contradict previous evidence. For example, in our study, percutaneous angioplasty for renal artery stenosis was found to be harmful in the ASTRAL trial [14], though the evidence was previously unclear. This trial, published in November 2009, was not cited in PIER, which had been updated for this topic in December 2009 at the time of our study; it has since been incorporated into PIER. At the time of our study, DynaMed, Best Practice, and UpToDate had updated renal artery stenosis to include the ASTRAL trial [14] and recommended against this procedure. Another example, recombinant activated factor VII was found to be harmful in spontaneous intracerebral hemorrhage, but had not yet been included in Best Practice, which was last updated on January 11, 2009, at the time of our study [15]. Therefore, these 2 examples were considered as potential updates from PLUS for textbooks.

It is important to note that no single study is likely to change a clinical recommendation on its own [16,17]. However, articles that we have indicated to be potential updates may tip the balance leading to a recommendation change. That said, creating evidence-based recommendations is a complex process requiring clinical expertise and judgment, and consideration of benefits, harms, costs, and patient values and preferences. For this reason, we are only able to report how many articles might potentially provide updates and cannot be certain that a high quality article from PLUS would impact textbook recommendations and necessitate an update.

The study appraised only online textbooks, each with varying chapter headings and coverage. Comparing the textbooks for currency required finding topics common to all four textbooks, which was challenging. In most instances when a topic was not included in our sample, it was because PIER did not have a comparable chapter or section, making it unlike the other textbooks in terms of breadth of content. Importantly, topics were excluded if they were not included in all textbooks, thus all topics in our study were covered in PIER.

Evidence-based clinical textbooks are in evolution, and we assessed them at only one timepoint, however we compared the updatedness of a large number of topics, allowing us to establish a clear picture of the updating practices of each textbook. We hope that they will continue to improve their coverage and timeliness in considering newly published evidence. All textbooks have access to the PLUS database to facilitate updates, and also use other sources of updates, such as practice guidelines. In this investigation, we looked only at studies published following the most recent textbook updates, and could not discern if the PLUS service is supplementary to other sources of appraised study reports. Redundancy abounds in evidence sources and resources, increasing the costs for publishers, editors, and authors to appraise, organize, and incorporate evidence in a timely fashion, unless ways of reducing redundancy are operationalized.

Future research should investigate best methods of facilitating efficient updates of medical textbooks and uptake of these practice changes by health care professionals. Our study documents that these textbooks have some ways to go in keeping pace with high quality, clinically relevant new evidence. This new evidence has the capacity to impact their clinical recommendations, and potentially the quality of patient care. Follow-up studies to document the progress of these texts in keeping pace with new evidence would be informative.

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Conflicts of Interest

McMaster University has nonexclusive contracts, managed by the Health Information Research Unit, supervised by RBH, with several professional and commercial publishers, to supply newly published studies and systematic reviews that are critically appraised for research methods and assessed for clinical relevance through the McMaster Premium Literature Service (McMaster PLUS). TN and CL are partly paid through these contracts and RBH receives remuneration for supervisory time and royalties. RJ, NLW, GF are not affiliated with McMaster PLUS or any of the textbooks in this study. McMaster PLUS is formally used for updating online textbooks including PIER, DynaMed and Clinical Evidence (which is included in Best Practice). UpToDate also lists Clinical Evidence and ACP Journal Club (which is supported by McMaster PLUS) as resources. The publishers, editors, and staff of these textbooks did not contribute to the funding, design, conduct, analysis, or reporting of this study, which was independently funded.

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Abbreviations

PLUS: McMaster Premium Literature Service
SNOMed: Systematized Nomenclature of Medicine
PIER: Physicians’ Information Education Resource

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Original Paper

Association of eHealth Literacy With Colorectal Cancer Knowledge and Screening Practice Among Internet Users in Japan

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Abstract

Background: In rapidly developing Internet-user societies, eHealth literacy has become important in promoting wellness. Although previous studies have observed that poor health literacy is associated with less knowledge and screening practice of colorectal cancer (CRC), little is known about whether eHealth literacy is associated with these variables.

Objective: The present study examined associations between eHealth literacy, knowledge of CRC, and CRC screening practices.

Methods: Data were analyzed for 2970 Japanese adults (men, 49.9%; mean age ± SD, 39.7 ± 10.9 years) who responded to an Internet-based cross-sectional survey. Knowledge of the definition of CRC, its risk factors and screening practice, previous experience of CRC screening, score on the Japanese version of the eHEALS (J-eHEALS), sociodemographic attributes (sex, age, marital status, educational attainment, and household income level), and frequency of Internet usage were obtained. Sociodemographic attributes and frequency of Internet usage were used as control variables in the multiple regression and logistic regression models.

Results: eHealth literacy was positively associated with CRC knowledge ($\beta = .116$, < .001), when the covariables of both eHealth literacy and CRC knowledge were used in the multiple regression model. Moreover, after controlling for sociodemographic factors, which were significantly associated with eHealth literacy and CRC screening practice, an increase of 1 point in the eHEALS score signified that participants were 1.03 times (95% CI = 1.01–1.05) more likely to undergo CRC screening.

Conclusions: Internet users with high eHealth literacy are more likely to have knowledge and previous screening practice related to CRC compared to those with low eHealth literacy.

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KEYWORDS

eHealth Literacy; Internet; Colorectal Neoplasms; Consumer Health Information; Health Promotion

Introduction

The Internet has become a powerful source of information for health and medicine [1,2]. Approximately 70% of Japanese Internet users seek health information on the Internet, with similar estimates reported from the United States [1,3]. Despite the proliferation of health information on websites, a critical issue has emerged—many websites purporting to provide health information are invalid or difficult to understand for individuals with low health literacy [4-7]. Previous studies have observed that limited health literacy is associated with less knowledge and poor preventive behaviors related to chronic diseases [8-10]. Because of the rapid increase in electronic health information resources, it is important that consumers improve their health literacy, and additional methods need to be developed with regard to health care and its promotion in an electronic world. These electronic health tools provide few benefits for a person's health without "eHealth literacy," which is an individual-level factor [11]. eHealth literacy is an individual-level factor defined as "the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem" [11]. eHealth literacy comprises six core skills or areas of literacy as presented in the original Lily model: (1) traditional literacy and numeracy, (2) health, (3) information, (4) science, (5) media, and (6) computer literacy [11].

Colorectal cancer (CRC) is the third most common cause of cancer death in the Japanese population, although it is largely preventable [12]. Screening tests such as the fecal occult blood test (FOBT) can reduce the morbidity and mortality of CRC [13-15]. Although the Basic Plan to Promote Cancer Control Programs has aimed to increase cancer screening rates to 50% or higher [16], only 27% of Japanese people aged >40 years have undergone CRC screening tests such as FOBT [12]. Considering the high number of Internet users who seek health information in the community, the Internet may be a key channel for disseminating information about CRC to the general population [17-20]. However, because many websites relating to CRC information are linked to commercial goods or private health services [6], consumers who use such websites without adequate eHealth literacy may purchase inappropriate goods or pay for private health services (eg, purchasing weight-loss pills with unfounded merits and paying for unnecessary services) that are actually detrimental to their health. Moreover, although much of the Internet information about CRC has been reported as being too difficult to understand for people with low health literacy [21], little is known about how eHealth literacy is associated with CRC information obtained from the Internet.

Three studies in the US showed that low health literacy was associated with less knowledge and screening practices of CRC [22-24]. In addition, people with low health literacy were less likely to seek or understand the information found about CRC from various information resources [19]. The Internet has notably become an important source of health information in Japan; this is because the Internet has gained in popularity among ordinary people through the widespread use of personal computers and cell phones [3,21,25]. Therefore, it is necessary to determine whether eHealth literacy may be useful to increase society's awareness of CRC. Because eHealth literacy is multidimensional, it is important to begin to understand whether dimensions of eHealth literacy [26], separate and distinct from health literacy, are associated with knowledge and screening practices of CRC. However, little is known about the association between eHealth literacy and knowledge and screening practices of CRC. The present study examined this association between eHealth literacy and the knowledge and screening practices of CRC.

Previous studies of eHealth literacy have focused on particular populations: older people [27], college students [28-30], health care students [28], HIV-positive individuals [31], and parents whose children have life-threatening illnesses [32,33]. These studies used the eHealth Literacy Scale (eHEALS), a simple self-assessment scale for measuring perceived eHealth literacy [27-29,31-33]. The eHEALS was designed to be easy to use and was put through a rigorous testing process to explore the internal consistency, reliability, and validity of the instrument [29]. Vaart et al and Xie used the performance test to measure eHealth literacy [27,34]. Further, Chan et al proposed the methodological framework of eHealth literacy by characterizing complexity of eHealth tasks [35]. However, previous studies have indicated that the eHEALS does not measure all the dimensions of the Lily model of eHealth literacy [26,34]. Moreover, Vaart et al indicated that the validity of the eHEALS was insufficient because of the weak correlation between eHEALS and actual Internet use in searching for health information [34]. However, the eHEALS would appear to be more appropriate for a large-sample Internet-based survey than the performance test. It was believed to be suitable for conducting the Internet-based survey in the present study because of the eHealth literacy needed for Internet users. Therefore, in the present study, eHealth literacy was treated as perceived eHealth literacy because eHEALS was used to assess eHealth literacy [26,27,29].

Methods

Participants

Participants were recruited in 2009 from registrants of a Japanese Internet research service company and asked to answer a cross-sectional Internet-based survey. The research company had approximately 1,150,000 voluntarily registered participants and obtained detailed sociodemographic data (eg, sex, age, marital status, educational attainment, household income level) from each participant at the time of registration. The survey requirement in the present study was to collect data from 3000 men and women aged 20–59 years.

To remove selection bias caused by the proportional differences between gender or age group, the participants were classified by gender and placed into four age groups (20–29, 30–39, 40–49, and 50–59 years), and they were allocated equally to the eight sample groups (for each group, n = 375). Potential respondents (n = 12,435) were randomly and blindly invited from the registered samples in accordance with the set sample size and attributes, and they were invited to participate in the survey via email. The number of potential respondents in each stratified sample group was determined by dividing the quota (n = 375) by the response rate for the corresponding sociodemographic group. This rate was computed from the results of numerous previous surveys conducted by the research company (eg, for potential male respondents aged 40–49 years, the quota was 375/mean response rate of 35% = 1072). Internet-based questionnaires were placed in a protected area of a website, and the potential respondents received a specific URL in their invitation email. Potential respondents could log on to the protected area of the website using their unique log-on

ID and password. After 375 participants in each group had voluntarily signed an online informed consent form, which had been approved by the institutional review board, and completed the sociodemographic data information form, acceptance of further participants was stopped in each group. The response rate of the total sample was 24.1% (3000/12,435). In addition, to remove the influence of CRC diagnosis, 14 participants diagnosed with the condition were excluded from the analyses. The present study received prior approval from the Ethics Committee of the Faculty of Sports Sciences, Waseda University, Japan.

Measurements

Sociodemographic Attributes

The research company provided data on sex, age, marital status, educational attainment, and household income level. These data were collected following the participants' registration with the research company. The participants were asked to select the category that best described their current condition for sex (male, female), age group (20–29, 30–39, 40–49, 50–59), marital status (not married, married), education level (graduate school, college, two-year college, career college, high school, junior high school), and household income (<3 million yen [about US$37,500], 3–5 million yen [about US$37,500−US$62,500], 5–7 million yen [about US$62,500–US$87,500], 7–10 million yen [about US$87,500−US$125,000], and ≥10 million yen [about US$125,000]). Moreover, since few participants answered the questions on graduate school, two-year college, career college, and junior high school, the category groups for education level were divided into the following three categories: ≤ high school graduate (high school and junior high school); two-year college or career college (two-year college and career college); and ≥ college graduate (graduate school and college).

Frequency of Internet Searching

Daily frequency of information searches on the Internet was assessed by the following four response categories: Every day, 4–5 times/week, 2–3 times/week, or ≤1 time/week.

eHealth Literacy

The Japanese version of eHEALS (J-eHEALS) was used to assess eHealth literacy levels of participants [3]. J-eHEALS uses a 5-point Likert scale (ranging from 1, strongly disagree, to 5, strongly agree; score range, 8-40) to measure perceived eHealth literacy for participants. To determine the validity of J-eHEALS, confirmatory factor analysis was conducted using the data from administration of the present survey. This analysis for the eight-item model suggested a good fit for the proposed model (GFI = .988, CFI = .993, RMSEA = .056). In addition, the internal reliability of the test was confirmed using Cronbach alpha coefficient = 0.93 ($P < .01$).

CRC Knowledge Test

Knowledge of CRC was assessed by 20 true/false questions regarding the definition, risk factors, and screening of CRC. This self-administered test was adapted from previous studies of knowledge and attitudes of CRC [36,37]. The true/false instrument score ranged from 0 (low) to 20 (high).

Previous CRC Screening Practice

The participants were asked whether they had ever undergone CRC screening by answering “Yes” or “No”.

Statistical Analyses

Data were analyzed for 2970 adults (response rate: 24.1%) who provided complete information for the study variables. Patients excluded from the data analysis included 16 participants with incomplete information and 14 participants diagnosed with CRC. The *t* test was used to examine the differences in eHEALS score and CRC knowledge score between male and female and between married and unmarried individuals. In addition, the differences in eHEALS score and CRC knowledge score among three or more category groups (age, education level, household income level, and frequency of Internet searching) were examined using one-way ANOVA. Moreover, a chi-square test was employed to evaluate the proportional differences in CRC screening practice for sociodemographic variables and frequency of Internet searching. In accordance with the analytical methodology adopted in previous studies of health literacy and CRC knowledge and practice [23,24,38], the variables of sociodemographic attributes and frequency of Internet searching (which achieve statistical significance in association with CRC knowledge score and CRC screening practice from bivariate analyses) were included in the multiple regression and logistic regression models as covariates. Subsequently, multiple regression analyses adjusted for these covariates were conducted to examine the association between eHealth literacy and CRC knowledge. Moreover, we performed logistic regression analyses adjusted for these covariates to assess the impact of eHealth literacy on CRC screening practice. Additionally, $P < .05$ was considered statistically significant in all analyses. Adjusted ORs and 95% confidence intervals (CI) were calculated for each variable. PASW Statistics 18.0 was used to compute the statistics.

Results

Characteristics of Respondents

Table 1 presents characteristics of the respondents. In the current study, the mean age (SD) of study participants was 39.7 (10.9) years, and 49.9% (n = 1483) of the participants were males. Overall, 60.9% (n = 1809) of the respondents were married, approximately 51.6% (n = 1534) had graduated from college or graduate school, and 23.6% (n = 702) were educated to a level below a high school diploma. Of the respondents, 17.4% (n = 516) had a household income <3 million yen (about US$37,500) and 13.3% (n = 396) earned >10 million yen (about US$125,000). Seventy percent (n = 2086) of respondents used the Internet every day. The mean J-eHEALS score was 23.5 (SD = 6.5). Overall, 58.9% (n = 1748) had high eHealth literacy and 41.1% (n = 1222) of the respondents had a low eHealth literacy level. The mean CRC knowledge test score was 13.8 (SD=2.4). Approximately 59.5% (n = 1766) had a high level of knowledge about CRC, and 19.7% (n = 584) had previously undergone CRC screening.

Association Between eHealth Literacy and CRC Knowledge Adjusted for Covariates

Table 2 presents the differences in eHEALS score and CRC knowledge score with sex and marital status using the *t* test. Also, Table 3 shows the differences in eHEALS score and CRC knowledge score with age group, education level, household income, and frequency of Internet searching using the one-way ANOVA. In bivariate analyses, education level was not statistically significantly related to eHealth literacy (P = .07). Moreover, education level (P = .136) and frequency of Internet searching (P = .08) were not statistically significantly related to CRC knowledge test score. Since sex, age group, marital status, and household income were statistically associated with both eHealth literacy level and CRC knowledge level, these variables were included in the multiple regression model as controlling factors.

Table 4 presents the results of the multiple regression analyses for the association between eHealth literacy and CRC knowledge after controlling for sex, age group, marital status, and household income. The regression model was significant and accounted for 4.6% of the CRC knowledge (R = .221, adjusted R^2 = .046, $P < .001$). When all the controlled variables were entered into the regression model, eHealth literacy was found to be positively associated with CRC knowledge (β = .116, s*tructure coefficient* = .602). In addition, all the controlled variables were significant contributors to the knowledge score of CRC. Moreover, age was a stronger contributor than the other controlled variables.

Association Between eHealth Literacy and CRC Screening Practice Adjusted for Covariates

Table 5 presents the differences of CRC screening practice with sociodemographic characteristics and frequency of Internet searching using the chi-square test. From the sample, the chi-square test indicated that sex (P = .38) and frequency of Internet searching (P = .173) were not related to CRC screening practice. By contrast, participants who had undergone CRC screening were more likely to be older adults ($P < .001$), be married ($P < .001$), have a higher education level (P = .03), and have higher household income ($P < .001$) than reference groups.

Table 6 presents the results of the logistic regression for the association between eHealth literacy and the CRC screening practice after controlling for age, marital status, education level, and household income level. After controlling for these factors, an increase in the eHEALS score by 1 point signified that the subjects of the present study were 1.03 times (95% CI = 1.01–1.05) more likely to undergo CRC screening.

Table 1. Sociodemographic characteristics (numbers and percentages).

Characteristics	n	%
Sex		
Male	1483	49.9
Female	1487	50.1
Age group		
20–29	739	24.9
30–39	746	25.1
40–49	742	25
50–59	743	25
Marital status		
Not married	1161	39.1
Married	1809	60.9
Education level		
≤ High school graduate	702	23.6
2-year college or career college	734	24.7
≥ College graduate	1534	51.6
Household income (yen) [a]		
<3 million	516	17.4
3–5 million	838	28.2
5–7 million	620	20.9
7–10 million	600	20.2
>10 million	396	13.3
Frequency of Internet searching (per week)		
Every day	2086	70.2
4–5 times	374	12.6
2–3 times	248	8.4
≤1 time	262	8.8
eHealth literacy level		
High eHealth literacy (≥24)	1748	58.9
Low eHealth literacy (<24)	1222	41.1
Knowledge of CRC		
High (≤14)	1766	59.5
Low (>14)	1204	40.5
CRC screening		
Yes	584	19.7
No	2386	80.3

[a] $1 = 80yen, in 2011/12.

Table 2. Association of eHealth literacy and knowledge of CRC with sex and marital status (using the *t* test).

Characteristics		eHealth literacy score			CRC knowledge test score		
		Means	SD	*P* values	Means	SD	*P* values
Sex				.002			< .001
	Male	23.15	6.73		13.57	2.46	
	Female	23.87	6.15		14.11	2.27	
Marital status				.016			< .001
	Not married	23.15	6.63		13.48	2.48	
	Married	23.74	6.33		14.06	2.29	

Table 3. Association of eHealth literacy and knowledge of CRC with age, educational level, household income and frequency of Internet searching (using the one-way ANOVA).

Characteristics		eHealth literacy score			CRC knowledge test score		
		Means	SD	*P* values	Means	SD	*P* values
Age group				.01			< .001
	20–29	22.75	6.53		13.30	2.44	
	30–39	23.46	6.38		13.76	2.46	
	40–49	24.06	6.55		14.18	2.30	
	50–59	23.77	6.30		14.10	2.23	
Education level				.07			.136
	≤ High school graduate	23.07	6.43		13.70	2.32	
	2-year college or career college	23.44	6.48		13.95	2.32	
	≥ College graduate	23.74	6.45		13.85	2.44	
Household income (yen) [a]							< .001
	<3 million	23.02	6.54	< .001	13.47	2.39	
	3–5 million	23.09	6.36		13.71	2.40	
	5–7 million	23.30	6.32		13.86	2.37	
	7–10 million	23.85	6.35		14.18	2.31	
	>10 million	24.84	6.73		14.03	2.38	
Frequency of Internet searching (per week)							
	Every day	22.35	6.50	< .001	13.50	2.46	.083
	4–5 times	22.19	6.11		13.96	2.40	
	2–3 times	22.46	6.26		13.78	2.47	
	≤1 time	24.00	6.46		13.88	2.35	

[a] $1 = 80yen, in 2011/12.

Table 4. Multiple regression for Knowledge score of CRC by eHealth literacy and sociodemographic factors.

	B	SE (β)	r_s[a]	r[b]	*P* values
eHealth literacy	.116	.007	.602	.133	< .001
Sex (Male=1, Female=0)	-.103	.087	-.516	-.114	< .001
Age group	.083	.004	.598	.125	< .001
Marital status (Married=1, Not married=0)	.048	.102	.539	.119	.02
Household income	.046	.035	.417	.092	.02

[a] r_s = *structure coefficient.*

[b] r = correlation coefficient.

Table 5. Association of CRC screening practice with sociodemographic characteristics and frequency of Internet searching.

Characteristics		Yes	%	No	%	*P* values
Sex						.38
	Male	282	48.3	1201	50.3	
	Female	302	51.7	1185	49.7	
Age group						< .001
	20–29	12	2.1	727	30.5	
	30–39	55	9.4	691	29.0	
	40–49	221	37.8	521	21.8	
	50–59	296	50.7	447	18.7	
Marital status						< .001
	Not married	107	18.3	1054	44.2	
	Married	477	81.7	1332	55.8	
Education level						.03
	≤ High school graduate	128	21.9	574	24.1	
	2-year college or career college	169	28.9	565	23.7	
	≥ College graduate	287	49.1	1247	52.3	
Household income (yen) [a]						< .001
	<3 million	62	10.6	454	19.0	
	3–5 million	121	20.7	717	30.1	
	5–7 million	107	18.3	513	21.5	
	7–10 million	186	31.8	414	17.4	
	>10 million	108	18.5	288	12.1	
Frequency of Internet searching (per week)						.173
	Every day	411	70.4	1675	70.2	
	4–5 times	61	10.4	313	13.1	
	2–3 times	58	9.9	190	8.0	
	≤1 time	54	9.2	208	8.7	

[a] $1 = 80yen, in 2011/12.

Table 6. Adjusted odds ratios for CRC screening practice by eHealth literacy level.

	Predictor *B*	(SE)	Lower	exp b	Upper	Wald X^2	*P* values
eHealth literacy	.03	.01	1.01	1.03	1.05	11.90	.001
Age group	.10	.01	1.09	1.11	1.12	277.68	< .001
Marital status(Married=1, Not married=0)	.36	.13	1.10	1.43	1.86	7.29	.007
Education level	.04	.06	.92	1.04	1.18	.38	.539
Household income	.08	.04	1.00	1.09	1.18	3.76	.052

Discussion

The present study is the first to examine the association between eHealth literacy and knowledge and screening practice of CRC. The present study found that high eHealth literacy was associated with high knowledge about CRC and CRC screening practice. Considering a great increase in the number of Internet users, the Internet may be an important channel for providing information about CRC screening among the general population [17-21]. Thus, adequate eHealth literacy will become an important factor in improving CRC knowledge and promoting CRC screening practice using the Internet.

The present study found that higher eHealth literacy was associated with higher knowledge and screening practices of CRC even after controlling covariables. These findings are consistent with those observed in the previous studies with respect to associations of health literacy with knowledge and practice about CRC [22-24]. However, these previous studies on health literary indicated that education level was a strong covariate of health literacy [23,24,38], whereas education level was not a statistically significant covariate of eHealth literacy in our study. In contrast, two studies in the United States and Israel about eHealth literacy assessed by eHEALS found that a lower educational level was associated with lower eHealth literacy [33,39]. The use of non-Internet users as participants in previous studies may explain the inconsistencies with the results regarding education level in the present study: registrants of an Internet research service company might have a higher education level than non-registrant Internet users and non-Internet users [3,40]. eHealth literacy is important for Internet users utilizing web-based CRC information since it is estimated that the number of Internet users continues to increase regardless of sociodemographic factors, such as age and education level [3,41]. Therefore, more studies are apparently needed among Internet users to clarify the role of education level and other sociodemographic factors as covariates of eHealth literacy [3,26,33,41].

Since the present study demonstrates the positive association between eHealth literacy and the knowledge about CRC and previous CRC screening practice, both designing the CRC information websites for those with low eHealth literacy levels and developing an intervention for enhancing eHealth literacy might be required strategies in order to improve the knowledge and enhance screening practice of CRC. First, the previous studies found that CRC information websites were often too difficult for American adults with limited literacy to use and understand [6,21]. For one third of Americans with limited health literacy, this may pose a problem in using Internet-based CRC information. Therefore, Friedman et al suggested that health professionals, health informaticians, medical journalists, and web page editors must collaborate to ensure the use of plain language to match the literacy skills of consumers [21]. Also, a Japanese study reported that even the most prominent cancer information website needed to improve its usability and readability to provide cancer information effectively [20]. Thus, the websites of CRC information should be designed to match the low eHealth literacy levels of target populations and incorporate video, graphics, animation, and audio narratives using easy-to-understand language [17,21]. Secondly, an intervention to improve eHealth literacy should be developed in order to use eHealth information effectively to modify health behavior. Recent studies suggested interventions to improve eHealth literacy for older adults and HIV-positive patients with low eHealth literacy [27,31]. These studies found that educational interventions for basic knowledge and skills in using the Internet and evaluating online health information significantly improved eHealth literacy among populations with low eHealth literacy [27,31]. The results of the present cross-sectional Internet-based survey indicate that Internet users with low eHealth literacy have less knowledge about CRC and are less likely to undergo CRC screening. A future intervention study should therefore examine whether improving eHealth literacy through educational programs can enhance knowledge about CRC and promote CRC screening behavior among Internet users with low eHealth literacy.

Future studies should identify subcomponents of eHealth literacy such as specific skills or health literacy among at-risk subgroups, in order to design interventions that improve eHealth literacy in Japan. For example, although people in Japan with higher frequency of Internet searching have high eHealth literacy, young adults who use the Internet more than 30−60 minutes have lower eHealth literacy level than older adults [40]. This suggested that low eHealth literacy of young adults may be influenced by multidimensional literacy of eHealth literacy without computer literacy. However, it is unclear how lower eHealth literacy of young adults might be influenced by subcomponents of eHealth literacy. Moreover, in the previous studies mentioned, it is problematic that eHEALS focuses on only one or two aspects of the Lily Model of eHealth literacy [26,34]. Therefore, future studies need to assess each of the six literacies in the Lily Model to consider the influence of sub-dimensions on eHealth literacy [26].

Limitations

The present investigation has some limitations. First, the analysis was cross-sectional, thereby making determinations of cause and effect not feasible. Second, participants were recruited from one Japanese Internet research service company, and thus the relationships assessed may be biased because of the potentially nonrepresentative nature of this sample as general Japanese Internet users [42]. Also, because the registrants of the research service company were frequent Internet users, the participants of the present study may be skewed toward a high eHealth literacy level. Moreover, since the present study indicated the low effect sizes of the multiple and logistic regressions, the statistical significance from the results of the multivariable analysis in the present study might be an artifact of a large sample size.

Conclusions

Among Japanese adult Internet users, individuals with low eHealth literacy have less knowledge about CRC and are less likely to undergo CRC screening practice. To promote information about CRC screening on the Internet for individuals who need to undergo CRC screening, it is important to improve eHealth literacy among the appropriate populations. In addition, it is essential to design websites containing CRC information specifically for those with low eHealth literacy.

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Conflicts of Interest

None declared.

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Original Paper

Health Outcomes in Patients Using No-Prescription Online Pharmacies to Purchase Prescription Drugs

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Abstract

Background: Many prescription drugs are freely available for purchase on the Internet without a legitimate prescription from a physician.

Objective: This study focused on the motivations for using no-prescription online pharmacies (NPOPs) to purchase prescription drugs rather than using the traditional doctor-patient-pharmacy model. We also studied whether users of NPOP-purchased drugs had poorer health outcomes than those who obtain the same drug through legitimate health care channels.

Methods: We selected tramadol as a representative drug to address our objective because it is widely prescribed as an unscheduled opioid analgesic and can easily be purchased from NPOPs. Using search engine marketing (SEM), we placed advertisements on search result pages stemming from the keyword “tramadol” and related terms and phrases. Participants, who either used the traditional doctor-patient-pharmacy model to obtain tramadol (traditional users, n=349) or purchased it on the Web without a prescription from their local doctor (ie, nontraditional users, n=96), were then asked to complete an online survey.

Results: Respondents in both groups were primarily white, female, and in their mid-forties (nontraditional users) to upper forties (traditional users). Nearly all nontraditional users indicated that their tramadol use was motivated by a need to treat pain (95%, 91/96) that they perceived was not managed appropriately through legitimate health care channels. A majority of nontraditional users (55%, 41/75) indicated they used NPOPs because they did not have access to sufficient doses of tramadol to relieve pain. In addition, 29% (22/75) of nontraditional users indicated that the NPOPs were a far cheaper alternative than seeing a physician, paying for an office visit, and filling a prescription at a local pharmacy, which is often at noninsured rates for those who lack medical insurance (37%, 35/96, of NPOP users). The remainder of participants (16%, 12/96) cited other motivations (eg, anonymity) for using NPOPs. In terms of health outcomes, nontraditional users experienced a significantly ($P<.01$) greater number and severity of adverse events, including life-threatening seizures: 7% (7/96) of nontraditional users reported seizures, while none of the traditional users reported seizures.

Conclusions: Although online pharmacies can offer distinct advantages in terms of convenience and cost, users of these “rogue” pharmacies that offer drugs with no prescription or doctor supervision do so at great risk to their health, as evidenced by much higher rates of adverse events. The most logical explanation for these findings is that the lack of physician oversight of dosage schedules, contraindicated conditions, and concomitant medications, were responsible for the increased intensity and frequency of adverse events in the nontraditional users. Although we only examined tramadol, it is logical to postulate that similar results would be observed with dozens of equally accessible prescription drugs. As such, the geometric growth in the use of online pharmacies around the world should prompt intense medical and regulatory discussion about their role in the provision of medical care.

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KEYWORDS

prescription drugs; health care quality; access; evaluation; health policy; substance-related disorders

Introduction

The Internet has evolved into a source of consumer products that were historically only available in “brick-and-mortar” establishments. Recently, there has been growth in the use of the Internet in medical practice, most prominently in the use of online pharmacies to fill physicians’ prescriptions and mail the drug directly to the patient. These pharmacies serve as an important resource for patients, particularly for those who have limited mobility or accessibility needs [1-5]. Unfortunately, this positive use of modern technology has had an unanticipated outcome: the advent of online pharmacies that provide drugs—such as opioid analgesics, antidepressants, cholesterol-management drugs, and erectile dysfunction medications—without a legitimate prescription from a physician [6-11]. In fact, it has been estimated that in the United States alone, 1 in 6 consumers, or roughly 36 million people, have bought or currently buy prescription medications online without a valid prescription [12].

Initially, as the number of no-prescription online pharmacies (NPOPs) [13] increased exponentially in the late 1990s, there was widespread concern that the Internet would serve as a major source of diversion for prescription drug abusers, since many sites offered controlled substances (such as hydrocodone and oxycodone) for purchase [6,14-15]. After Ryan Haight died from an overdose of hydrocodone, allegedly bought over the Internet without a valid prescription, a law bearing his name was passed in 2008 that made it illegal in the United States for NPOPs to sell controlled substances [16]. No matter the reason, research has shown that the Internet has not evolved into a significant source of prescription drugs for the purpose of drug abuse [17-18].

While controlled substances may not be readily accessible from domestic NPOPs [19], other studies have described the availability of many other types of medication through these outlets. These medications include HIV drugs, benzodiazepines, and cholesterol medications, as well as lifestyle drugs, such as diet pills and erectile dysfunction medications. Unlike controlled substances with the potential for abuse, there are no current laws regulating the sale of these other potentially dangerous prescription medications through NPOPs. The main arguments against taking the easiest step, which would be to simply eliminate all online pharmacies, is that they are difficult to close down [4] and that with appropriate controls they can provide consumers advantages in both cost and accessibility [1-5,20]. In fact, one study demonstrated the efficacy of utilizing an accredited online pharmacy to prescribe Viagra. Patients who used the online pharmacy showed similar numbers of side effects and similar treatment efficacy compared to those receiving Viagra through a local pharmacy. They also provided a more complete medical history [21]. To manage the increased use of online pharmacies, however, more regulations are being proposed, including the Online Pharmacy Safety Act and the development of state-run online pharmacy programs [22,23].

In a major effort to steer consumers toward legitimate online pharmacies that are safe to use and away from rogue online pharmacies that pose a potential threat to consumer safety, the National Association of Boards of Pharmacy developed the Verified Internet Pharmacy Practice Sites (VIPPS) program to accredit online pharmacies based on a number of qualifying criteria [24]. Unfortunately, this accreditation is limited to domestic online pharmacies and, as it only approves online pharmacies that require a valid prescription [24], it does not address the larger issue of people seeking medications through NPOPs outside of a typical doctor-patient-pharmacy relationship.

It should be stressed that no matter what legislative controls are adopted, there is a simple way to bypass these restrictions: move the NPOPs offshore, which is rapidly occurring with little government control [7,25-31]. For example, a report by the World Health Organization (WHO) noted that most countries, particularly India and China, which are major loci for NPOPs, have little or no regulation of online pharmacies [11]. This lack of oversight generates a number of safety concerns for NPOP consumers in distribution, information, and medication-related issues. Distribution issues include damaged packaging that exposes pills to light and moisture, shipments that do not meet manufacturer specifications (such as temperature-controlled or insulated packaging), and the ability of the consumer to reorder as many pills as desired [8-10,32-33]. The lack of proper labeling or safety information is common with NPOP-purchased medications and provides consumers with little to no information on dosage scheduling, dosage administration, or potential side effects [9,32-36]. Finally, the medications themselves could be expired, counterfeit, or cut with other substances. Even genuine drugs purchased from NPOPs could lead to a number of adverse events, including death, if the user is unaware of dangerous drug combinations or contraindicated medical conditions [3,5,32,37].

While the recent focus, appropriately, has been placed on the regulation of online pharmacies, there is very little systematic research outside of case reports on two potentially more important basic issues: (1) why consumers use online pharmacies in the place of legitimate medical channels; and (2) with such a variety of safety concerns, why consumers of drugs purchased from NPOPs have worse health outcomes than those who obtain the same the drugs through legitimate healthcare channels. The study described in this paper was designed to address these issues.

Methods

Selection of Target Drug

Since most online pharmacies offer dozens of drugs for purchase, we needed to narrow the focus to users of a single representative target drug. Tramadol was selected as the representative drug for this study because it is extensively prescribed (the third most frequently used analgesic [38]) and it is one of the most commonly offered authentic drugs from NPOPs with few restrictions on refills or quantity of tablets offered [8,10]. Tramadol has a demonstrated abuse profile [39-41], but its rate of abuse is not as high as other opioids (hence its noncontrolled status in the Controlled Substances Act). Like all drugs, there is also the potential for adverse side effects that can pose serious health risks. For example, tramadol not only has the potential to produce many of the same adverse events as other opioids (eg, constipation and dependence [39]), but also carries a serious risk of potentially fatal grand mal seizures, which are exacerbated by contraindicated medications and medical conditions [42-44]. In a prior report, we documented the ease of obtaining tramadol over the Internet, the authenticity of which was certified by a chemical analysis [8]. The purchase required the completion of a brief questionnaire that served as a medical examination. Subsequently, a virtual prescription was generated and filled by a pharmacy in Canada. The tramadol was received within 24 hours, and numerous phone calls and emails were received almost immediately to refill the prescription (some offers included up to 400 pills in a single order) and have continued on a monthly basis for over three years thus far.

Recruitment

It has been widely documented that recruiting and administering surveys over the Internet is an acceptable and beneficial research methodology [45-46]. While these methods provide quick access to thousands of people, they are not easily used to attract a targeted audience. To circumvent this problem, we developed a recruitment program that directly targeted a population of tramadol users with access to the Internet. We utilized search engine marketing (SEM), which is defined as a “form of Internet marketing that seeks to promote websites by increasing their visibility in search engine result pages through the use of paid placement, contextual advertising and paid inclusion [47].” Using Google AdWords and Yahoo Advertising Solutions for this study, we placed short advertisements (eg, “Do You Use Tramadol?”) in the margins of Google and Yahoo search result pages stemming from keyword searches of the term “tramadol” and related terms and phrases (eg, pain relief, Ultram, and buy tramadol online). Thus, our advertisement only appeared to Internet users who had an interest in tramadol or tramadol-related topics, making our target population more likely to include potential participants (ie, users of tramadol). When users clicked the ad, they were automatically directed to an online consent form and the subsequent survey hosted on an institutional website. Subjects were screened to be 18 years of age, users of tramadol in the past 30 days for any reason, and United States residents. Upon completion of the survey, participants were mailed a $50 Visa Check Card for their time.

Survey Instrument

Since this study represents a preliminary approach into this area of research, no standardized instruments could address all points of inquiry. As such, we developed a descriptive tool centered on our representative drug, in which questions about dosage schedules, adverse events, etc, were specifically related to tramadol. While we developed this descriptive tool to meet the objectives of this pilot study, we hope that the results can provide a basis for a more standardized instrument that can be used to investigate the same objectives for any number of drugs purchased from NPOPs in future studies. Other than demographics, the survey covered a broad variety of topics related specifically to tramadol, including the following: dosage schedule, intended use, comorbidity, legitimate and illegitimate drug use, and adverse events. Participants who listed NPOPs as a source of tramadol were presented with a subset of questions to determine the underlying factors behind their use of online pharmacies.

Data Analysis

A total of 445 tramadol users qualified for and completed this study. Of these participants, 349 indicated that they received tramadol solely through a valid prescription from their local doctor and filled it at a local pharmacy. These participants are referred to as “traditional users.” The other 96 participants are referred to as “nontraditional users.” This group obtained tramadol from an online pharmacy without a valid prescription from their doctor, and included those who were provided a prescription online by a “virtual” physician. We analyzed data using IBM SPSS Statistics Version 20. We used chi-square and logistical regression analyses to test for significant differences between traditional and nontraditional users at a $P<.01$ level.

Results

Demographics

As shown in Table 1, both traditional and nontraditional users were primarily white and female. Traditional users were significantly older than nontraditional users. Looking at various types of health care coverage, 37% (n=35/95) of nontraditional users had no form of insurance, compared to just 16% (n=56/345) of traditional users.

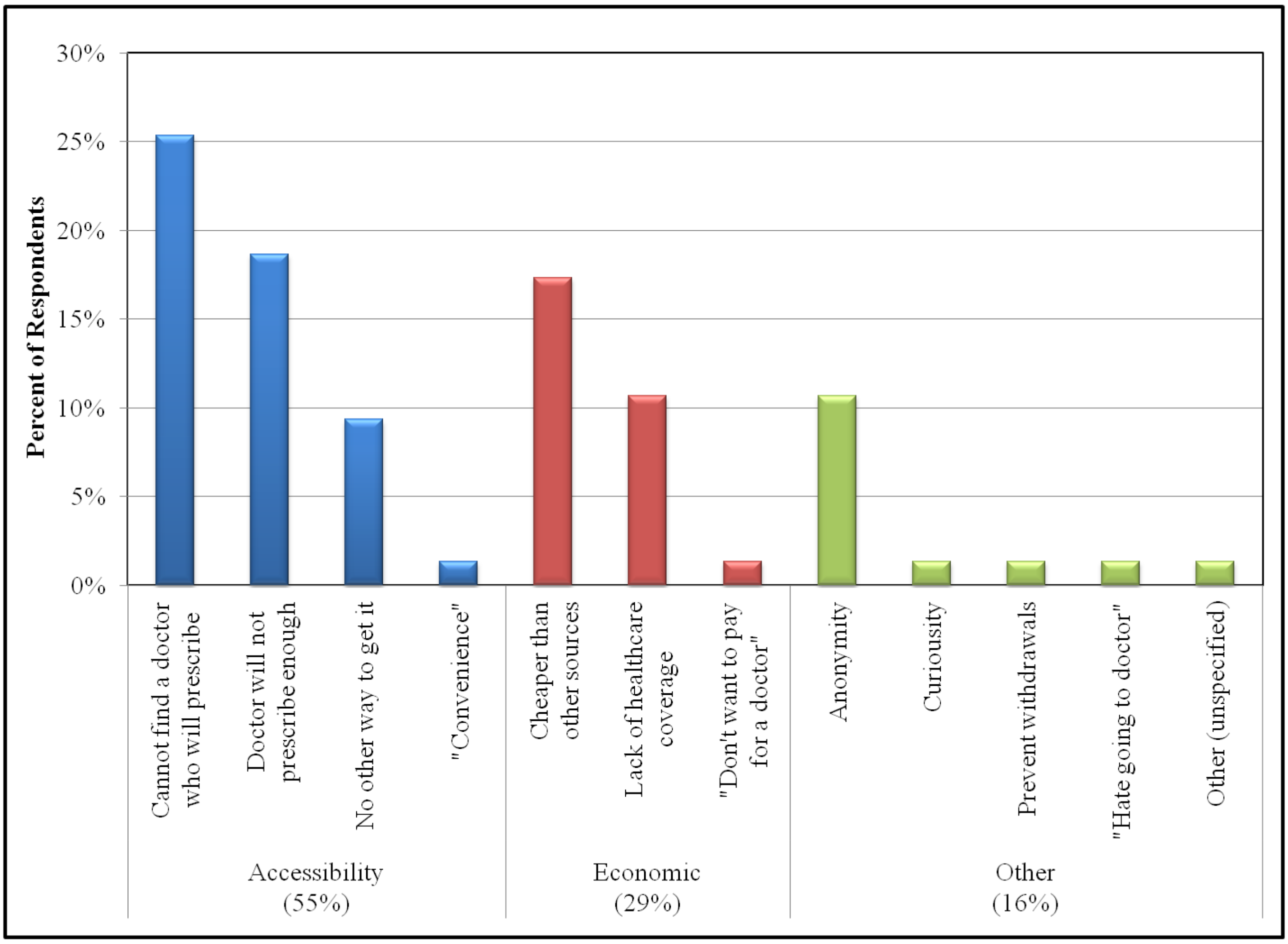
Table 1. Demographics and health information for traditional and nontraditional users.

		Traditional users	Nontraditional users	*P* values
		(n=349)	(n=96)	
Gender, %				
	Female	67.0	57	.08
Ethnicity, %				
	Caucasian	80.2	91	.02
	African American	8.6	3	.07
	Hispanic	4.6	4	.86
	Other	6.6	2	.09
Age in years, mean (SE)		47.2 (0.7)	38.5 (1.2)	<.001
Health care coverage, %				
	Private	36.8	35	.71
	Dependent	10.4	4	.06
	Medicare/Medicaid	25.2	13	.009
	Military	5.5	1	.07
	Other	5.8	11	.11
	None	16.2	37	<.001

Use of NPOPs

We asked nontraditional users what their primary reason was for using online pharmacies in place of other sources (Figure 1): 55% (n=41/75) indicated that they did so for reasons related to accessibility of tramadol (eg, their doctor would not prescribe enough, they could not find a doctor who would prescribe it, or there was no other way to get it), 29% (n=22/75) did so for economic purposes (eg, they had no insurance, their medical plan would not cover it, or it was cheaper than other sources), and 16% (n=12/75) did so for other reasons (eg, anonymity or to prevent withdrawals).

Figure 1. Motivations for using online pharmacies as a source of tramadol reported by nontraditional users (N=96). The values given are the percent of respondents who endorsed a motivation listed or specified a motivation that was not listed (in quotation marks).



Tramadol Use

Table 2 shows that nontraditional users were more likely to take the higher dose (100 mg) traditional users. Nontraditional users were also considerably more likely to use tramadol more frequently (5 or more times per week). All traditional users used tramadol for its indicated purpose (ie, to treat pain), with only 2.3% (n=8/349) additionally using tramadol for its euphorigenic properties. Despite using a source outside of legitimate medical channels, the vast majority of nontraditional users (95%, n=91/96) also cited pain as a reason for using tramadol. Of these, 63% (n=60/96) used tramadol for pain only and 32% (n=31/96) used it for both pain and to get high. Just 5% (n=5/96) of nontraditional users indicated that getting high was the main reason for taking tramadol.

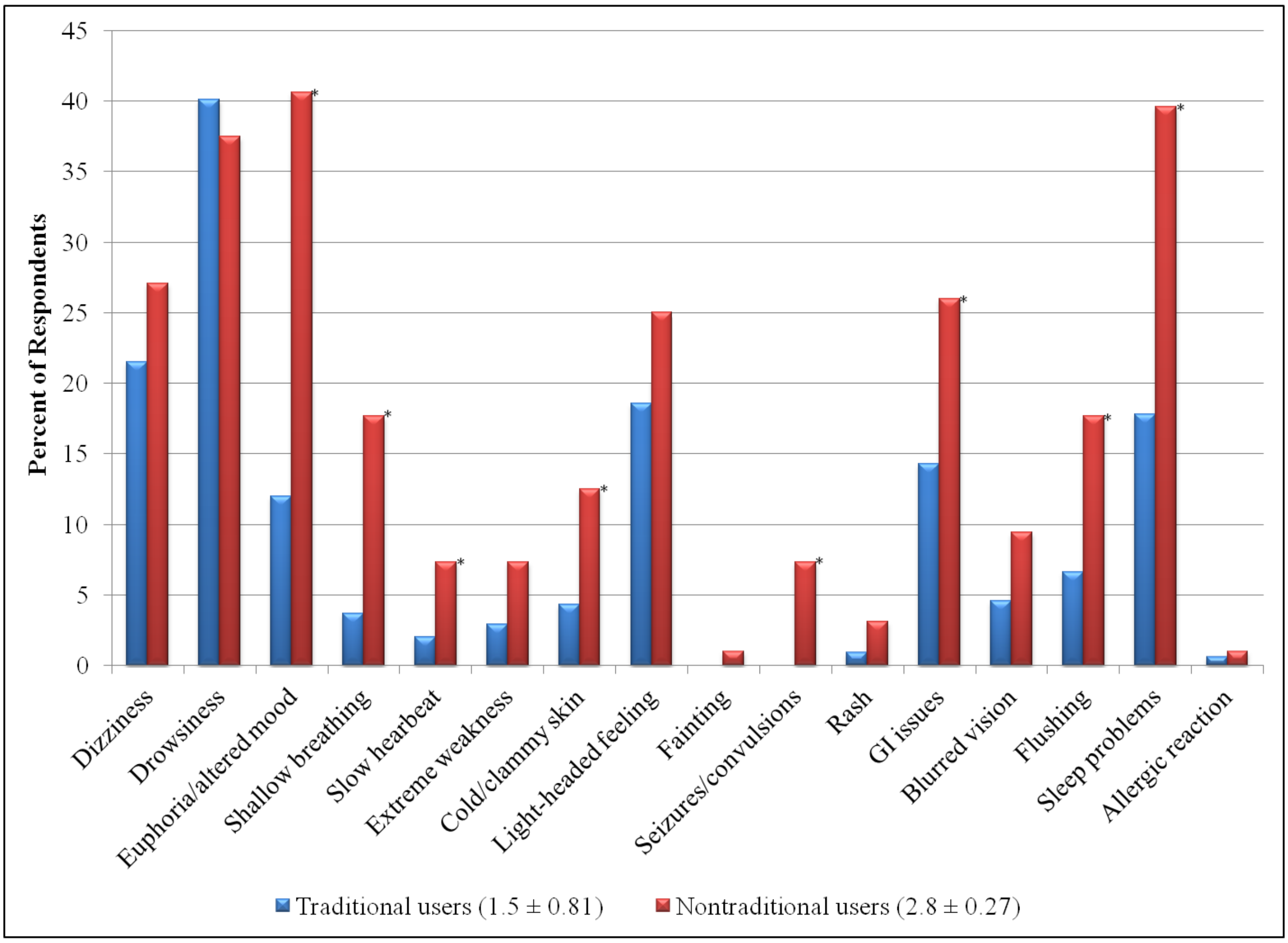
Table 2. Tramadol use among traditional and nontraditional users.

		Traditional users (n=349)	Nontraditional users (n=96)	*P* values
Tramadol dosage, %				
	25 mg	4.9	5	.91
	50 mg	83.7	73	.02
	100 mg	6.2	19	<.001
	150 mg	5.2	3	.39
Tramadol frequency, %				
	1-2 times/week	38.2	26	.03
	3-4 times/week	49.5	29	<.001
	5 or more times/week	12.2	45	<.001
Reasons for using tramadol, %				
	Only to treat pain	97.7	63	<.001
	Both to treat pain and to get high	2.3	32	<.001
	Only to get high	0.0	5	<.001

Adverse Events

Figure 2 shows that we found that the difference in the mean number of adverse events experienced by traditional and nontraditional users was significant (*P*<.001). Nontraditional users experienced a much more severe adverse event profile than traditional users (Figure 2). Euphoria, shallow breathing, slow heartbeat, cold/clammy skin, gastrointestinal issues, flushing, and sleep problems all occurred significantly more frequently in the nontraditional users that in the traditional users. Importantly, seizures, which can have potentially fatal outcomes, had an incidence rate of 7% (n=7/96) among nontraditional users, but were not experienced by a single traditional user.

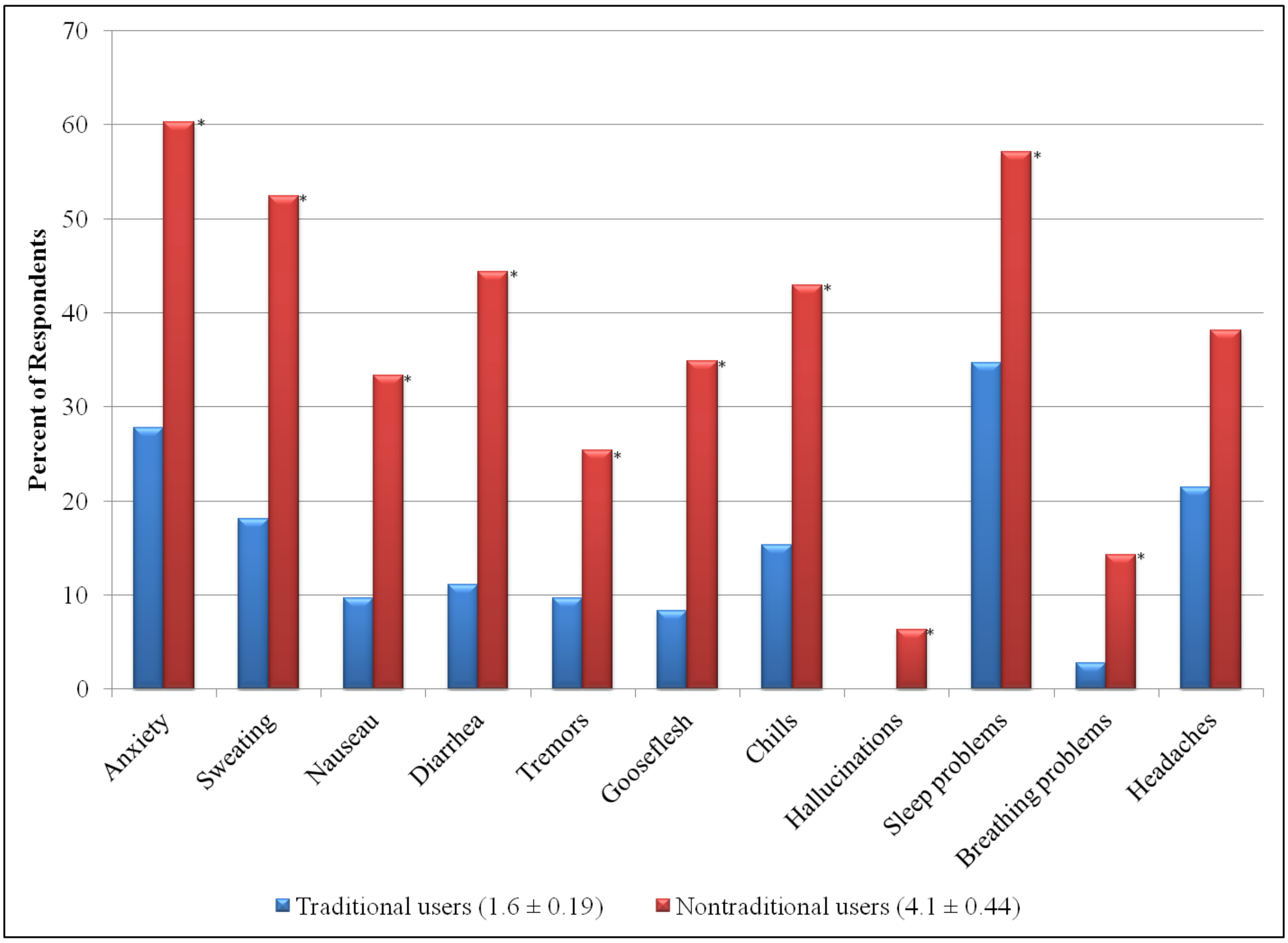
Figure 2. Percent of traditional and nontraditional users who experienced each adverse event while taking tramadol. Asterisks denote a significant difference ($P<.01$) between groups. The legend indicates the mean number of adverse events ± standard error) experienced by both groups.



Physical Dependence

Both groups had high rates of suddenly stopping their use of tramadol, but nontraditional users were significantly more likely to cease use abruptly (traditional users: 41.9%, n=144/344; nontraditional users: 66%, n=61/92; $P<.01$). Upon cessation, nontraditional users experienced more severe withdrawal symptoms than traditional users (see Figure 3). We found that the difference in the mean number of withdrawal symptoms experienced by traditional and nontraditional users was significant ($P<.001$).

Figure 3. Percent of traditional and nontraditional users who experienced each withdrawal symptom as a result of the abrupt cessation of tramadol. Asterisks denote a significant difference (*P*<.01) between groups. In addition , the legend indicates the mean number of withdrawal symptoms ± standard error experienced by both groups.



Discussion

Our data indicate that those who eschew the typical doctor-patient relationship to obtain tramadol through NPOPs do so primarily for reasons related to cost and accessibility and, most importantly, expose themselves to great health risks. We found that nontraditional users who used NPOPs had much higher rates of all recorded adverse events, particularly life-threatening seizures, than traditional users who obtained a prescription for tramadol from their physician. Seizures are quite rare in normal pain patients being treated with tramadol, observed at a rate of less than 1% [48], and they may be related to the dual effect of tramadol on opioid and adrenergic systems in the brain [49-51]. While the precise mechanisms are unknown, seizures are more prevalent in people who take high doses of tramadol [42,52], have predisposing medical conditions (eg, history of head injuries) [53], or take contraindicated medications (eg, tricyclic antidepressants) [54-55]. Physicians are trained to recognize such predisposing factors, but nontraditional users are likely to be unaware of these potential complications, leading to poor health outcomes. Moreover, we found that nontraditional users experienced much more intense opioid withdrawal symptoms when they stopped taking tramadol. The most logical explanation for these findings is that the *lack of physician oversight* in monitoring dosage schedules, contraindicated conditions, and concomitant medications was responsible for the increased intensity and frequency of adverse events in nontraditional users.

Nearly all nontraditional users in our study indicated that their tramadol use was motivated, at least in part, by a need to treat a health condition (eg, pain) that was not otherwise managed through legitimate health care channels. It was this perception of their unmet medical need (ie, inadequate pain management) that drove them to use NPOPs. This finding raises an important question: Why were normal medical channels shunned in favor of an online pharmacy? There appear to be three distinct motivations for using online pharmacies: (1) inability to pay the costs associated with obtaining a legitimate prescription; (2) limited access to a doctor who would prescribe tramadol or prescribe it at doses sufficient to fully relieve pain; and (3) unwillingness, not inability, to use legitimate medical channels.

With regard to economic motivations, 37% (n=35/95 of NPOP users lacked medical insurance coverage and NPOPs are a less expensive alternative to seeing a physician, paying for an office visit, and filling a prescription at a local pharmacy at noninsured rates. Furthermore, many respondents indicated "no other way to get tramadol" as their main reason for using an NPOP, which suggests there were barriers to accessing a physician, such as cost or the patient's distance from a medical facility. By far the most commonly reported motivation for using an NPOP was an issue of accessibility: the absence of a physician who was willing to prescribe tramadol either at all or at levels sufficient to meet a patient's perceived need. There are several possible interpretations of the latter motivation. First, the patient had an unrealistic expectation for "total" pain relief and the physician believed that other drugs would be a suitable alternative to tramadol in providing tolerable pain relief. Second, the physician denied the patient additional tramadol because the doctor incorrectly believed the pain was managed to the extent possible (ie, inadequate pain management). Third, the physician was reluctant to prescribe opioid analgesics, even a weak one such as tramadol, at sufficient levels to adequately relieve pain due to the inherent fear of iatrogenic dependence. At this time, it is unclear which of these was the strongest motivation to use NPOPs, but lack of access to appropriate medical treatment appears to be a major factor. This should not be surprising given the well-documented regional, social, and economic differences in access to medical care in the United States [56-59]. Because of this, there is a large market for the many drugs easily available from online pharmacies, which can best be explained within the context of cost and/or access to appropriate medical care.

While most of the foregoing discussion focused on pain management, 32% (n=31/96) of our population indicated they used an NPOP to buy tramadol for both its euphorigenic and analgesic properties. However, only 5% (n=5/96) reported the Internet as their primary source for tramadol as a drug of abuse. This agrees with a number of studies that show the Internet is not often used as a source of opiates among habitual drug abusers (<5% claim to have obtained their drugs from the Internet [18]). Nevertheless, it needs to be recognized that off-label use to "get high" may serve as one of the motivating factors for the use of NPOPs. In fact, the euphorigenic use of tramadol may explain why a number of respondents indicated "anonymity" as their primary motivator for using NPOPs. It is also possible that some NPOP users, while initially using tramadol for therapeutic purposes, had predisposing factors that led to the development of tramadol misuse or abuse. This euphorigenic use, a health outcome itself, would have led to higher dosages and increased frequency of use, playing a role in the higher rates of adverse events. In a physician-patient relationship, however, a doctor may have recognized predisposing factors for misuse and not prescribed an opioid analgesic or, if already prescribed, recognized the signs of abuse and misuse and switched from tramadol to a less addictive drug.

Although we used tramadol as a prototype in these studies, there is no reason to believe that different results would be observed with dozens of equally accessible prescription drugs obtained through NPOPs that are used without the oversight of a physician. The dangers of overdose and other adverse events with these medications, especially when little to no information about contraindicated medications and medical conditions is included with purchase, have the potential to be more clinically significant with other medications than those we observed with tramadol. As such, the geometric growth in the use of online pharmacies around the world, both legitimate and illegitimate, should prompt intense medical and regulatory discussion about their role, if any, in the provision of medical care.

Currently there are several bills and regulations being discussed to control the use of online pharmacies, some of which ban the use of those located outside of the United States [22,23], but the following two factors need to be considered. First, the passage of online pharmacy regulations that promote verification programs [24], licensure and location disclosures [3], standardized criteria for Internet-based prescriptions [60-61], and a more thorough analysis of the advantages and disadvantages of online health care services (eg, the ability of online pharmacies to detect interactions between medications instantly [5]) may help integrate online pharmacies into health care utilization models. The reality, however, is that regulating these legitimate online pharmacies is likely to have no effect on those using NPOPs. These users have already turned their back on typical medical channels and seem to be able to quickly adapt to any change in access to online pharmacies (eg, shift of NPOPs to foreign countries), and no amount of regulatory oversight would likely change their drug-purchasing behaviors.

Second, so long as a licensed doctor provides a prescription and the pharmacy verifies the legitimacy of the prescription, it would be inappropriate, perhaps unethical, to ban a patient from shopping around to find the most economical and convenient means of filling their prescriptions. Whether this doctor-patient relationship needs to be on a physical basis merits further discussion. Research has shown that email and virtual consultations are just as good, if not better, at capturing patient information necessary for health care decisions [21,62]. However, the old phrase "buyer beware" must be kept in mind, particularly for online pharmacies outside of the United States. Because of aggressive marketing and pricing strategies, as well as the recent shift in patients becoming more involved in their own health care decisions, people using online pharmacies are in danger of unconsciously transforming from patients to consumers, and then back to patients again when they suffer from adverse effects from the use of the drug [13, 63-64]. Patients should be aware of the real possibility that while offshore pharmacies may be cheaper and easier to use, the medications received may not be what was advertised. For this reason, recent US Food and Drug Administration (FDA) and WHO reports have advocated global drug safety, including international cooperation regarding the regulation of online pharmacies [11,31]. Such an effort is badly needed because if one country attempts to ban online pharmacies, most users will simply try a website from another country. Clearly, in addition to regulatory activity, educational efforts are needed to ensure that patients and physicians understand the positive and negative aspects of online pharmacies. Perhaps most importantly, more research is needed to better understand the motivations of people who, despite the availability of legitimate online pharmacies, continue to seek medications using NPOPs.

Limitations

Inherent in this study are all of the limitations typical of epidemiological and survey research, most notably generalizability and veracity of information gathered. With regard to the latter, most studies indicate that the results obtained from self-administered surveys are comparable to those elicited by trained interviewers. In our study, there were no right or wrong answers. There was no incentive or need to lie about any information because respondents were paid for their participation regardless of their answers. In terms of a biased sample, it is true that our subjects might have greater economic status and certainly more computer literacy than the average person, but these users would most likely to be exposed to advertisements touting online pharmacies.

Conclusion

Our data suggest that online pharmacies may have a role in supplying prescribed medications because they are convenient and may charge less than traditional brick-and-mortar pharmacies. However, from a public health perspective, the potential benefits of online medical care need to be balanced against the use of unregulated pharmacies that could sell counterfeit or adulterated drugs and the dangers inherent in self-medication without any physician supervision.

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Conflicts of Interest

None declared.

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Abbreviations

FDA: US Food and Drug Administration
NPOP: no-prescription online pharmacy
SEM: search engine marketing
VIPPS: Verified Internet Pharmacy Practice Sites
WHO: World Health Organization

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Original Paper

To Use or Not to Use – Practitioners’ Perceptions of an Open Web Portal for Young Patients With Diabetes

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Abstract

Background: Health care professionals' attitudes can be a significant factor in their acceptance and efficient use of information technology, so they need to have more knowledge about this resource to enhance their participation.

Objective: We explored practitioners’ perceptions of using an open-access interactive Web portal tailored to young diabetes type 1 patients and their guardians or significant others. The portal offered discussion forums, blog tools, self-care and treatment information, research updates, and news from local practitioners.

Methods: Eighteen professionals who were on pediatric diabetes care teams each wrote an essay on their experience using the portal. For their essays, they were asked to describe two situations, focusing on positive and negative user experiences. The essays were analyzed using qualitative content analysis.

Results: Based on our analysis of the respondents essays, we identified three categories that describe perceptions of the Web portal. The first category - to use or not to use - included the different perspectives of the practioners; those who questioned the benefits of using the Web portal or showed some resistance to using it. The frequency of use among the practitioners varied greatly. Some practitioners never used it, while others used it on a daily basis and regularly promoted it to their patients. Some respondents in this category reflected on the benefits of contributing actively to online dialogues. In the second category - information center for everyone – practitioners embraced the site as a resource for scientifically sound information and advice. As part of their practice, and as a complement to traditional care, practitioners in this category described sending information through the portal to patients and their significant others. Practitioners felt safe recommending the site because they knew that the information provided was generated by other practitioners. They also assumed that their patients benefited from actively using the Web portal at home: peers brought the site to life by exchanging experiences through the discussion forums. In the third category – developing our practice – practitioners reflected upon the types of information that should be given to patients and how to give it (ie, during in-person appointments or through the Web portal). They perceived meeting with various professionals at other hospitals to update information on the portal and develop content policies as constructive teamwork. Practitioners expressed interest in reading patients’ dialogues online to learn more about their views. They also thought about how they could use the portal to adapt more to patients’ needs (eg, creating functions so patients could chat with the diabetes nurses and doctors).

Conclusions: Practitioners expressed positive perceptions toward a tailored open Web portal. They suggested that future benefits could be derived from systems that integrate factual information and online dialogues between practitioners and patients (ie, exchanging information for everyone’s benefit).

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KEYWORDS

Internet; Web 2.0; Health knowledge; childhood chronic disease; health professionals; practice; attitudes; participation; type 1 diabetes; health information; blog; discussion forum

Introduction

Life with pediatric diabetes type 1 can be a more or less daily struggle that involves extensive self-care and a constant interplay between patients and others involved in their care [1]. Coping skills are essential because management of the disease, including insulin injections and self-control of blood glucose, affects everyday life. Most of the treatment is performed by the young patients themselves and their guardians or significant others. Over time, they become their own experts [1], which means that they must keep themselves up to date about treatment, self-care, and scientific findings. They are also guided through the varying phases of the disease trajectory by multi-professional pediatric diabetes teams. For patients to effectively manage their life with diabetes and minimize possible short- or long-term complications, they require guidance and supervision from practitioners [1-4]. Effective physician-patient communication has long been shown to be important in patient satisfaction, treatment adherence, and health outcomes [5-9].

In the context of self-management education, the Internet is a dynamic and promising resource that opens new ways for both medical practitioners and patients to communicate with each other and educate themselves [10-12]. Nevertheless, some practitioners have expressed doubt about introducing the new technology into their practice. Although practitioners may recognize the general benefits, uptake of Web-based technologies has been slow [13]. Studies have identified lack of access, lack of time, and lack of opportunities for training as examples of causal factors preventing practitioners from adopting new technologies [14]. Few practitioners were familiar with the rapidly emerging social networking tools on the Internet and, for some, patient access to electronic information and communication may even have been a source of irritation [10, 12]. To some extent, practitioners' negative attitudes toward new technologies have been related to factors such as age and time since completion of education [14-15].

Other practitioners found that using Web portals in routine care facilitated their work because the sites saved them time and simplified their routines [16-17]. However, for practitioners to benefit from using the Internet in health care, they need to increase their own involvement with and skills in using this technology [18-20]. A recent review indicates that practitioner involvement is a significant factor in patient acceptance and efficiency of Internet use; thus, efforts are needed to enhance practitioners' participation in Web-based technologies [20].

Perception refers to the knowledge gained from a process of coming to know or understand something. This implies the ability to understand inner qualities and relationships. While many studies focus on how patients perceive and use Web portals, little is known about practitioners' perceptions of using such technology for dialogues with and among patients.

We aimed to explore practitioners' perceptions of an open Web portal tailored to young diabetes type 1 patients as well as their guardians, school staff, and significant others.

Methods

Process of Care

In Sweden, children and adolescents with diabetes are treated by hospital-based pediatric diabetes teams that may include nurses and nurse specialists, physicians, dietitians, social workers, and clinical psychologists. These teams educate, advise, and support patients, families, and significant others through the course of a complicated treatment. Typically practitioners meet the young patients, along with their guardians, when patients are hospitalized at onset. Practitioners continue to see their patients every three months or more often as outpatients over many years.

Practitioners and patients usually communicate through regular appointments in the clinic and telephone contact when needed. Local websites of some health care providers include basic patient information and links to other websites. Electronic communication systems are increasingly available, but patient and provider uptake has been slow.

Web Portal

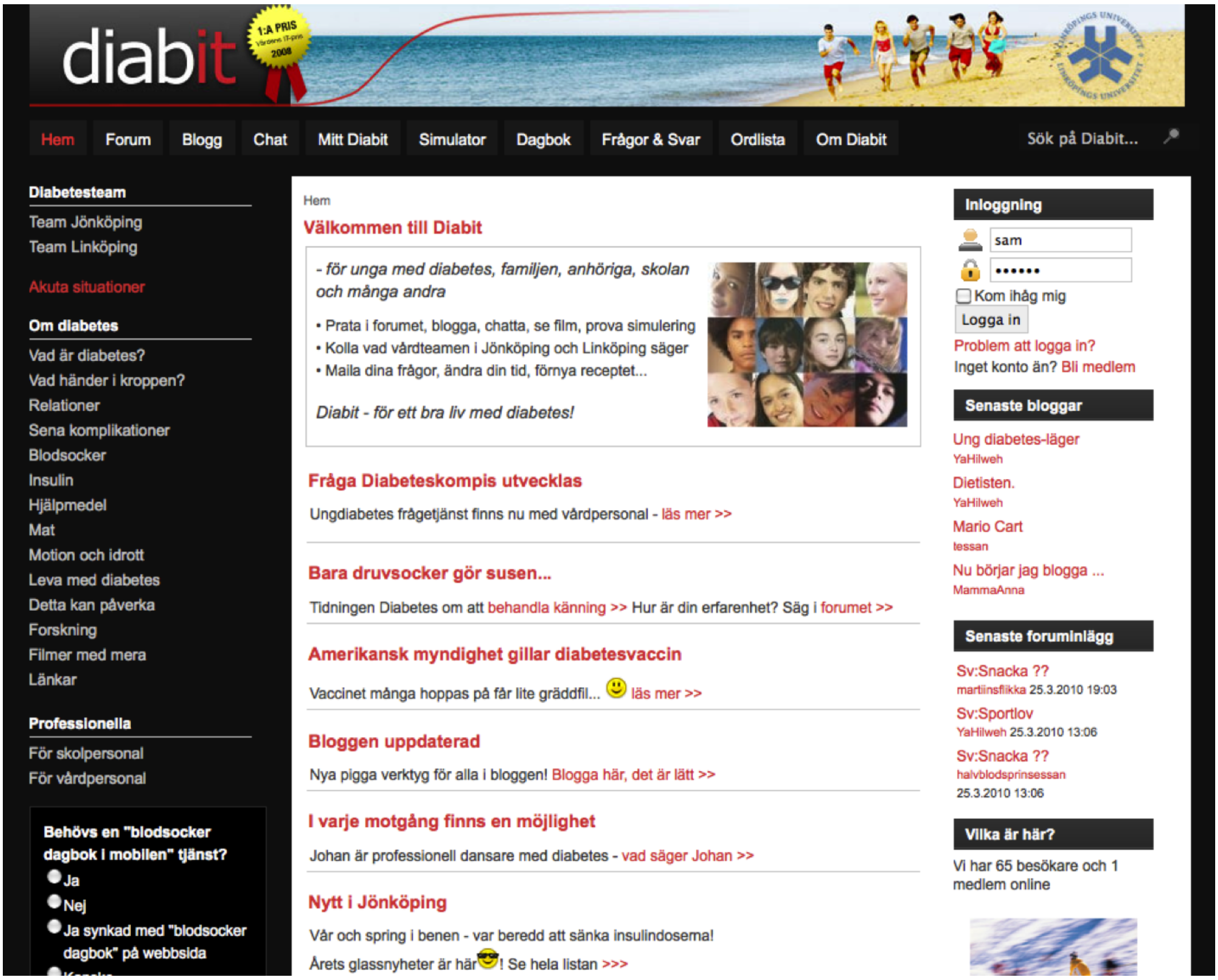
In November 2008 the Diabit LIST research group and two participating pediatric diabetes teams launched an open-access Web portal for young diabetes type 1 patients and guardians, school staff, and significant others. The objective of the portal was to complement traditional treatment by enhancing diabetes-related information for and communication with and among young diabetes type 1 patients. The portal provided access to extensive general, as well as local, information. It also provided peer-mediated information and dialogues through open-access forums and blogs [12, 21]. The medical information provided on the website was generated by experienced practitioners. Both patients and practitioners contributed to the portal as forum moderators.

The portal offered open discussion forums for children, adolescents, and guardians. There were blog tools so anyone could post a blog, and there were also links to the blogs created by patients with diabetes and guardians. It also provided comprehensive self-care and treatment information from practitioners, including advice for specific situations, as well as feeds that supplied research updates and news about devices, products, and activities (Figures 1-4). In addition, a member of each clinical diabetes team managed a local news feed that was integrated in the portal. These information sites included local contact information, staff presentations, and reciprocal services for prescription renewal, booking appointments, and text message exchange between patients with guardians and practitioners. To our knowledge, this portal design remains unique in pediatric care [12, 21].

The portal was gradually developed through a user-centered design process that included iterative sessions conducted over a number of years with groups of patients, guardians, and practitioners [12]. An early interview study found that participating practitioners, regardless of their professional roles, had positive attitudes toward the portal [12].

Local practitioners participated in the portal as part of routine care. After the launch of the open portal, practitioners slowly increased their involvement. Their participation evolved into extra voluntary personal commitments as well; some practitioners edited local news feeds or monitored patient forums. Biannual collaborative group activities included the different professionals updating information on the portal, holding policy discussions, and setting goals for the use and continuous development of the portal.

Figure 1. Screenshot of welcome and news feed page, which includes “About Diabetes,” “Diabetes Teams,” “Latest Blogs,” “Latest Forum Posts,” “Who Is Here?,” “Questions and Answers,” “Word List,” and “Search.” Registration and login were required only for active contribution to portal content (eg, blogs and discussion forums).



Behövs en "blodsocker dagbok i mobilen" tjänst?
○ Ja
○ Nej
○ Ja synkad med "blodsocker dagbok" på webbsida

Välkommen till Diabit

- för unga med diabetes, familjen, anhöriga, skolan och många andra

- Prata i forumet, blogga, chatta, se film, prova simulering
- Kolla vad vårdteamen i Jönköping och Linköping säger
- Maila dina frågor, ändra din tid, förnya receptet...

Diabit - för ett bra liv med diabetes!

Fråga Diabeteskompis utvecklas

Ungdiabetes frågetjänst finns nu med vårdpersonal - läs mer >>

Bara druvsocker gör susen...

Tidningen Diabetes om att behandla känning >> Hur är din erfarenhet? Säg i forumet >>

Amerikansk myndighet gillar diabetesvaccin

Vaccinet många hoppas på får lite gräddfil... läs mer >>

Bloggen uppdaterad

Nya pigga verktyg för alla i bloggen! Blogga här, det är lätt >>

I varje motgång finns en möjlighet

Johan är professionell dansare med diabetes - vad säger Johan >>

Nytt i Jönköping

Vår och spring i benen - var beredd att sänka insulindosema!

Årets glassnyheter är här! Se hela listan >>>

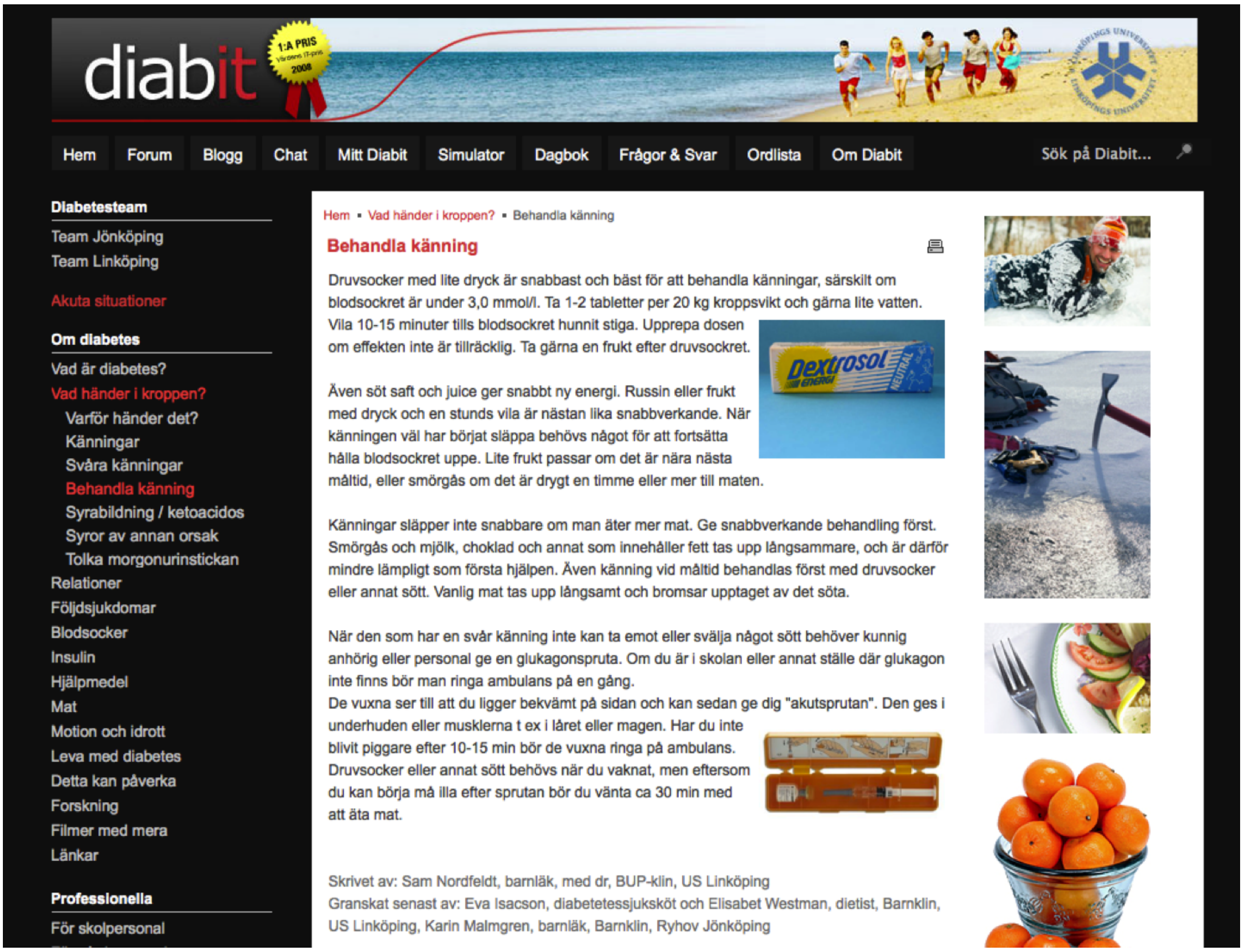
sam
••••••
Problem att logga in?
Inget konto än? Bli medlem

Ung diabetes-läger
YaHilweh
Dietisten.
YaHilweh
Mario Cart
tessan
Nu börjar jag blogga ...
MammaAnna

Sv:Snacka ??
martiinsflikka 25.3.2010 19:03
Sv:Sportlov
YaHilweh 25.3.2010 13:06
Sv:Snacka ??
halvblodsprinsessan
25.3.2010 13:06

Vi har 65 besökare och 1 medlem online

Figure 2. Screenshot of sample fact page: About Diabetes/What happens in the body?/Treating hypos.



Behandla känning

Druvsocker med lite dryck är snabbast och bäst för att behandla känningar, särskilt om blodsockret är under 3,0 mmol/l. Ta 1-2 tabletter per 20 kg kroppsvikt och gärna lite vatten. Vila 10-15 minuter tills blodsockret hunnit stiga. Upprepa dosen om effekten inte är tillräcklig. Ta gärna en frukt efter druvsockret.

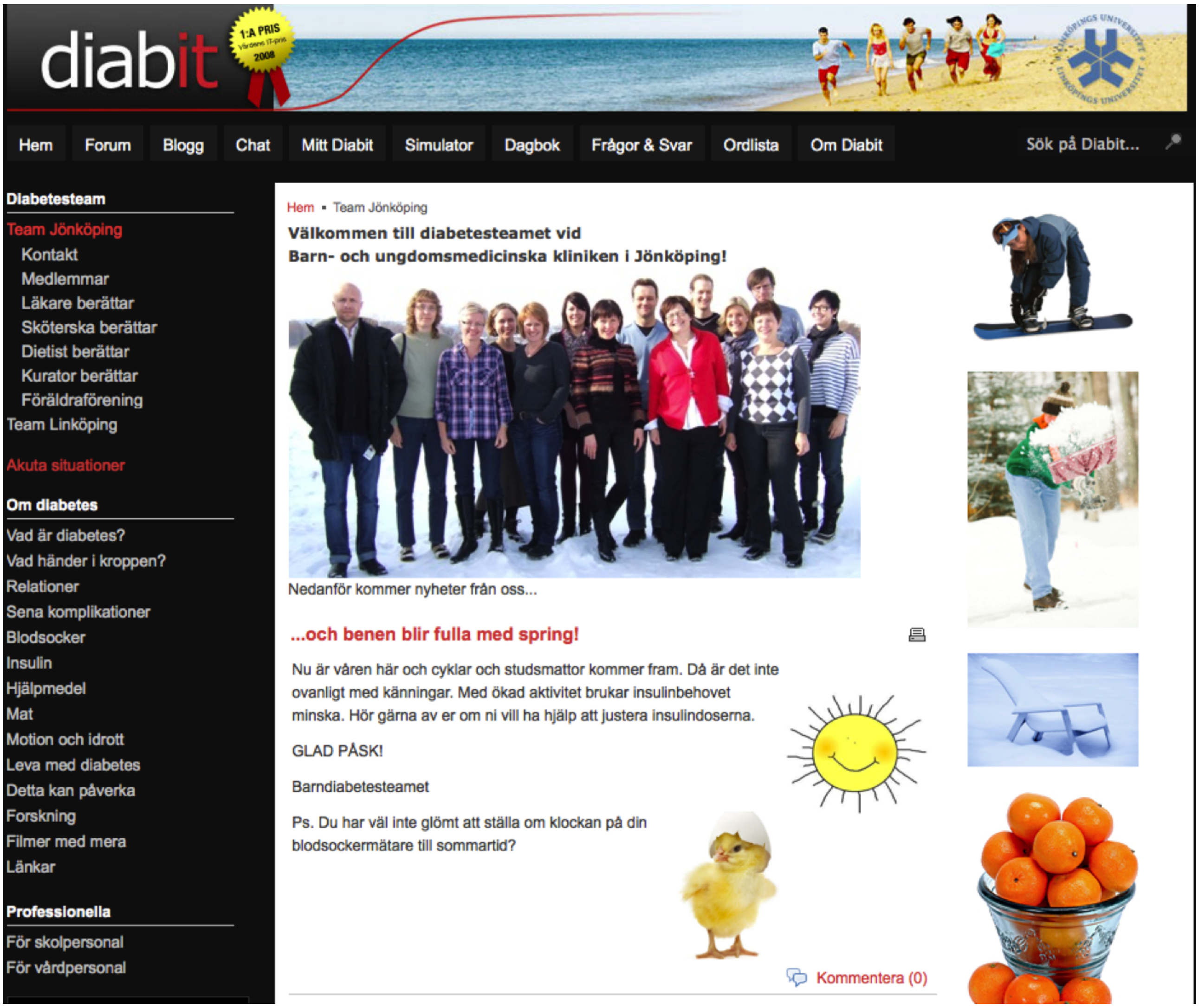
Även söt saft och juice ger snabbt ny energi. Russin eller frukt med dryck och en stunds vila är nästan lika snabbverkande. När känningen väl har börjat släppa behövs något för att fortsätta hålla blodsockret uppe. Lite frukt passar om det är nära nästa måltid, eller smörgås om det är drygt en timme eller mer till maten.

Känningar släpper inte snabbare om man äter mer mat. Ge snabbverkande behandling först. Smörgås och mjölk, choklad och annat som innehåller fett tas upp långsammare, och är därför mindre lämpligt som första hjälpen. Även känning vid måltid behandlas först med druvsocker eller annat sött. Vanlig mat tas upp långsamt och bromsar upptaget av det söta.

När den som har en svår känning inte kan ta emot eller svälja något sött behöver kunnig anhörig eller personal ge en glukagonspruta. Om du är i skolan eller annat ställe där glukagon inte finns bör man ringa ambulans på en gång.
De vuxna ser till att du ligger bekvämt på sidan och kan sedan ge dig "akutsprutan". Den ges i underhuden eller musklerna t ex i låret eller magen. Har du inte blivit piggare efter 10-15 min bör de vuxna ringa på ambulans. Druvsocker eller annat sött behövs när du vaknat, men eftersom du kan börja må illa efter sprutan bör du vänta ca 30 min med att äta mat.

Skrivet av: Sam Nordfeldt, barnläk, med dr, BUP-klin, US Linköping
Granskat senast av: Eva Isacson, diabetetessjuksköt och Elisabet Westman, dietist, Barnklin, US Linköping, Karin Malmgren, barnläk, Barnklin, Ryhov Jönköping

Figure 3. Screenshot of a local diabetes care team’s welcome and news page, menu with contact information, and staff information.



Välkommen till diabetesteamet vid Barn- och ungdomsmedicinska kliniken i Jönköping!

Nedanför kommer nyheter från oss...

...och benen blir fulla med spring!

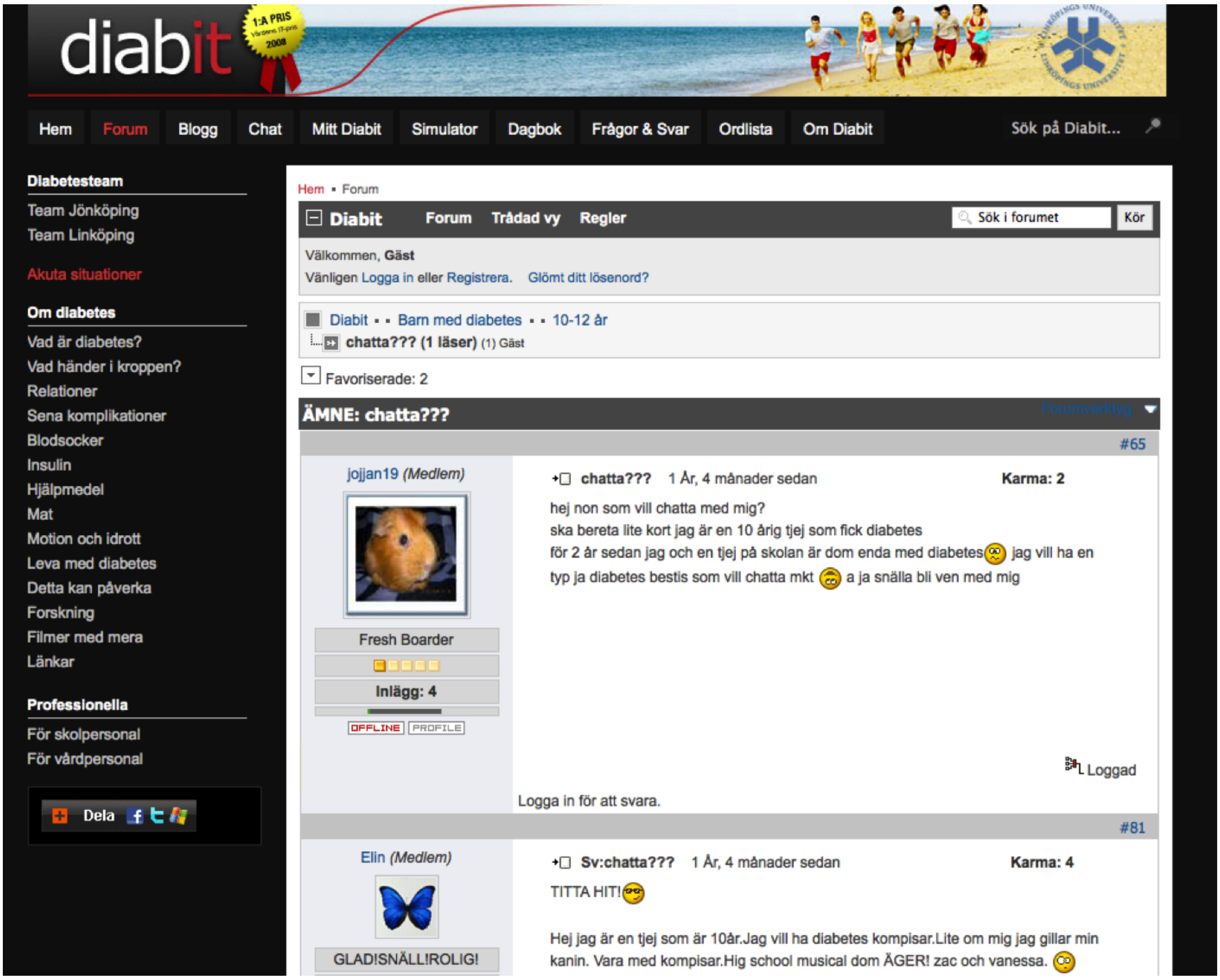
Nu är våren här och cyklar och studsmattor kommer fram. Då är det inte ovanligt med känningar. Med ökad aktivitet brukar insulinbehovet minska. Hör gärna av er om ni vill ha hjälp att justera insulindoserna.

GLAD PÅSK!

Barndiabetesteamet

Ps. Du har väl inte glömt att ställa om klockan på din blodsockermätare till sommartid?

Figure 4. Screenshot of forum posts from patients in the 10-12 years age group.



Välkommen, **Gäst**

Vänligen Logga in eller Registrera. Glömt ditt lösenord?

Diabit • • Barn med diabetes • • 10-12 år

chatta??? (1 läser) (1) Gäst

Favoriserade: 2

ÄMNE: chatta???

#65

jojjan19 *(Medlem)*

chatta??? 1 År, 4 månader sedan **Karma: 2**

hej non som vill chatta med mig?
ska bereta lite kort jag är en 10 årig tjej som fick diabetes
för 2 år sedan jag och en tjej på skolan är dom enda med diabetes jag vill ha en typ ja diabetes bestis som vill chatta mkt a ja snälla bli ven med mig

Inlägg: 4

Logga in för att svara.

#81

Elin *(Medlem)*

Sv:chatta??? 1 År, 4 månader sedan **Karma: 4**

TITTA HIT!

Hej jag är en tjej som är 10år.Jag vill ha diabetes kompisar.Lite om mig jag gillar min kanin. Vara med kompisar.Hig school musical dom ÄGER! zac och vanessa.

GLAD!SNÄLL!ROLIG!

Sample and Data Collection

In May 2010, 24 practitioners were invited by email (with 2 reminders) to write an essay describing their experience using the portal. The invitation letter asked participants to focus on situations that represented positive and negative user experiences. Clarifying questions were provided to help practitioners start their essay writing:

> *(1) Describe a situation when you succeeded in using [the site]. Has [the site] made things easier for you in any way? Are there any advantages in using [the site]? Describe possibilities for using it.*
>
> *(2) Describe a situation when you did not succeed in using [the site]. Has [the site] become an obstacle in some way? Are there any disadvantages in using [the site]? Describe any obstacles in using it.*

Of the 24 practitioners who received the invitation by email, 18 people (members of 2 pediatric diabetes care teams, including doctors, nurses, dietitians, and a social welfare officer) wrote an essay.

Analysis

The 18 essays were analyzed using modern techniques of qualitative content analysis. This method can be applied to transcribed interviews, texts, and narratives, for example [22, 23]. Qualitative content analysis allows the study of both apparent and latent content, which, in turn, allows the tracking of emerging or new perceptions.

Initially, two researchers (SN and CB) independently read and analyzed the essays. Statements with similarities were clustered and summarized into tentative themes based on their emerging contents. The tentative themes with all respective statements were reviewed in detail. Unclear statements were explored with respect to the original context. Before open comparisons, both of them again read all the primary data and the material emerging in the analysis. Through iterative in-depth discussion sessions, a stepwise re-categorization and repeated validation against the complete original essays was performed. A more logical and complete structure consisting of three categories gradually emerged. Any discrepancies were resolved through discussion; no measure of inter-rater reliability was used. Both apparent and latent content was considered important [22].

Results

The results are presented as 3 categories that we identified and interpreted as responses that described situations representing positive and negative user experiences and answered the supporting questions. The category “to use or not to use” was built up from statements related to whether or not respondents found the platform useful in their practice. The second category, "information center for everyone," represents respondents who embraced the portal as a source of scientifically sound information and advice for patients, guardians, and significant others, as well as for other professionals. The final category, "developing our practice," includes respondents that reflected on what information to give through the portal and how to give it, learning more about patients' views, and adapting more to patients' needs.

We include quotations from individual essays within the descriptions below to confirm and illustrate each category .

To Use or Not to Use

The frequency of use among the practitioners varied greatly. Some practitioners never used the Web portal, while others used it on a daily basis and regularly promoted it to their patients. Many respondents stated that they visited the website now and then, just to look around. Many felt it was worthwhile using it in the clinic and recommended it to patients. Some also reflected on the idea of contributing actively to online dialogues themselves.

> *Sometimes I read facts, alone or with patients. I also read blogs, but don't post anything myself.*

There were positive statements concerning the existence, design, and function of the website. Overall, respondents thought that it mostly functioned well. Users considered the design easy to understand. Practitioners found it to be a manageable tool when seeking information. The information was easily accessible to everyone: wherever there was a computer, the information was close by.

> *The advantages are that it is handy if you need to look something up, accessible information, and that it is easy to search.*

The problems that respondents perceived when using the website comprised a range of factors, such as technical problems, lack of time, inadequate computer experience, a lack of commitment, a lack of computer access, and disorganized information.

> *I think that [the site] is very messy; it is not orderly enough and there is almost too much information in one place, which makes it hard to find what I want to read about…*

Information Center for Everyone

Respondents in this category viewed the Web portal as a source of scientifically sound information and advice that is available to several categories of professionals, as well as patients and their significant others. As a complement to traditional care, practitioners described various situations in which they mediated information through the portal to patients and their significant others. Some practitioners demonstrated how to use the website as part of their practice, while others did not.

> *I have never received a "no" when I've asked if I can show the site.*

Some practitioners also assumed that their patients benefited from actively using the website at home: as peers exchange experiences, the site comes alive. Practitioners believed that the portal would help patients and their families learn more at home, enabling them to manage various situations themselves. Answers to questions could be found on the website without patients having to make a call to the pediatric diabetes care team.

> *The big patient benefit is if many patients are there so that they can exchange their different experiences, which makes the site come alive…*

Although the information was targeted to practitioners, patients, and significant others, easy access to the website made it useful for everyone, including new staff, students, school and preschool staff, primary-care and other hospital staff.

> *I recommend [the site] to all patients, parents, and other relatives. I also recommend it for new and old staff. School and preschool staff can visit the site to prepare themselves prior to our visits.*

Practitioners felt safe in recommending the website because they knew that the information was produced by, and the practitioners were part of, a multi-professional community. Provided that all practitioners adhered to the same facts, the information presented on the site would be consistent.

> *What feels safe for me as a part of the nursing staff is that the information they can read here is the information we have provided. We know that we have critically reviewed it together.*

Developing Our Practice

Respondents in this category include those who reflected on what information to give and how to give it (eg, during in-person appointments or through the Web portal). Practitioners perceived updating the information, as well as the content policies, in multi-professional meetings with other hospitals as constructive teamwork.

> *It is useful to have discussions and to hear what other people think concerning diabetes treatment.*

Use of the website increased over time. Over the course of the project, more team members contributed new information and updates to the local editors, and practitioners referred patients to content on the website during clinical visits.

> *For example, they have read about a lecture, tried a recipe, or printed out facts or advice from the site.*

Practitioners expressed interest in adapting their practice to better meet patients' needs, including new services on the Internet. They also indicated they would like to learn more about patients' views by reading dialogues online. Some practitioners found it advantageous to see what questions patients asked and what answers they got.

> *I also follow forums and the blogs without posting anything myself. By doing so I learn how the patients think, which can be useful in working with them.*

Individual respondents also reflected on whether increasing online public exposure to differences between hospitals' policies (eg, differing policies for the use of technical devices) implied difficulties, or if it actually enhanced constructive dialogues.

> *If we collaborate with [another clinic] that is much more generous than we are, with [insulin] pumps for example, it might be more difficult. Or would this become a constructive dialogue? Online, the clinic is a little more public.*

Assuming that they would communicate with patients and their significant others online to an increasing extent, practitioners suggested ways of adapting the site to better meet their patients' needs. Ideas included using more functions on the site that their patients need, referring to preparation sheets before clinical visits, developing prescription and appointment-booking services, providing more frequent updates on food and nutrition, making the site easy to find through search engines, and introducing online chats with nurses and doctors.

> *For example, chatting in the future with the diabetes nurses or the doctors.*

Discussion

The present study demonstrates positive perceptions among health care practitioners regarding the development and use of a Web portal in their practice. Most of the participants wrote in a positive way about the website's existence, design, and function. They pointed out that the site represented scientifically sound information and tips that were useful for several categories of professionals and patients. Although most respondents felt it was worthwhile to use the website in the clinic and recommended that patients should use it, some expressed resistance to using it.

To Use or Not to Use

Use of the Internet as a resource and a means for improving health and health care has attracted considerable attention, but success in adopting these communication technologies depends on the degree of acceptance by its users [24-26]. In light of the important role practitioners play in supporting self-care management, use of a Web portal among patients requires that practitioners actively use it and advocate its use to their patients [21]. We found resistance due to a lack of time, inadequate familiarity with computers, lack of commitment, lack of computer access, and disorganized information on the site. Our findings support previously reported causes for resistance and limited use of new technologies, including little training in computer use in basic education or professional life, a lack of time and opportunities for training, and a lack of access to the technology [14, 19].

The goal of developing health information portals is to produce health benefits for patients with long-term illness. As such, health care practitioners are essential intermediaries of knowledge delivered through these portals. Therefore a process enabling practitioners to develop the skills necessary to participate in portal design and content development is needed. We previously found that participation in portal development could produce a reciprocal willingness to integrate its use into routine care [12]. Hence practitioners are more willing to use and promote health information portals if they perceive that they gain knowledge by developing and using content on the site and thus understand its usefulness. In addition, practitioners will develop new skills and their work will be facilitated due to time-savings and simplified routines [12]. It is possible that the respondents perceived participation in the present study as a meaningful use of already acquired knowledge in a new arena. Clearly, efforts are needed to offer local practitioners a comfortable and time-efficient process for participation.

Information Center for Everyone

Internet use has the potential to improve access to health care by removing barriers associated with physical location and the need for improved communication [25, 27-28]. For instance, the wider implications of certain topics may not become apparent to patients until they have had some time to reflect; once they process the information new questions may arise. It is not unusual for patients to feel frustrated because their needs are not fully met during the course of medical encounters [27]. Therefore, it is not surprising that practitioners viewed the portal in this study as a valuable complement to traditional care. They also perceived it as a source of knowledge for patients and their significant others, as well as for health care professionals (ie, as an information center for everyone). Respondents perceived several advantages to using the Web portal, including providing support for patients to learn more at home, providing easily accessible information, and being useful for a range of people such as school and preschool staff, primary-care practitioners and colleagues in other hospitals, as well new health care staff and students.

The practitioners required that the information given on the portal be trustworthy. In earlier studies, trustworthiness has been described as the absence of commercial interests and up-to-date information, including clear references for the information given [29-30]. In our study, respondents noted that knowing that practitioners and their colleagues were the authors signified a new dimension of trustworthiness. Participation in creating the content on the website made practitioners feel secure in recommending the portal to patients, their guardians, and significant others, as well as referring other professionals (such as preschool and school staff) to the portal. As reported earlier, since the information on the portal was identical to the information provided at the clinic, it was perceived as congruent, familiar, and appropriate for patient use [12]. This appears to be a practitioner-derived dimension of trustworthiness based not only on scientific knowledge and evidence, but also on their participation and collaboration in developing content for the site through multi-professional teamwork.

Developing Our Practice

As use of the Internet leads to a shift in the role of patients from passive recipients to active consumers of health information, practitioners face an increasing demand that they be familiar with a variety of reliable, high-quality sources of online health information and medical websites [31]. The practitioners noted that they needed to collaborate and coordinate information not only between clinics, but also between clinics and the portal. Through this process, practitioners reflected on what information to give and how to give it. Taking advantage of the clinical experience and knowledge of many practitioners to update content on the portal represents a new development in the emerging practices of health portals. Thus our study suggests that practitioners should be involved in developing up-to-date health portal functionality and design solutions, updating information on the site, participating in online dialogues, and advocating the portal to their patients.

Effective care requires focusing attention on both the diseases themselves and patients’ experiences of their illnesses. The disease is what is wrong with the body. Illness is the patient’s personal experience of the disease, such as their thoughts, feelings, and altered behaviours [32]. The portal offers a process for practitioners, patients, and significant others to learn about the disease as well as the illness, particularly through users’ participation in discussions, blogs, and questions and answers posted on the forum. Such new experiences are useful for developing the practitioners’ perspectives on their practice and how they might better adapt to patients’ needs. Hence use of the Internet is not to be seen by patients as a replacement for practitioners and interpersonal meetings, but rather as a complement to traditional care [31]. The Internet offers new knowledge for practitioners, patients, and significant others.

Limitations of the Study

In this study, qualitative methods were used to gain a deeper understanding of the respondents’ perceptions, so it is not possible to make generalizations in a quantitative manner [33]. The essays were a rich source of information even though they were rather short. It is possible that some way of giving respondents a dedicated time for the task would have further expanded the amount of data obtained. We can also speculate that some non-responders (and, perhaps, some responders), felt uncomfortable writing an essay, did not feel very familiar with the portal, or were not particularly motivated or interested in the topic.

Conclusions

The results of this study suggest that there is value in having practitioners continuously involved in developing online content and participating in dialogues with and between patients. The practitioners’ positive perceptions of the portal as a new tool in their practice might be an early indication of a forthcoming change. Their perception of the site’s trustworthiness includes not only scientifically sound information but also their own participation in creating online information to support their patients. Indeed, the findings suggest future benefits from systems that integrate factual information with open dialogues between local practitioners and their patients, or an exchange of information for the benefit of everyone.

Acknowledgments

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Conflicts of Interest

None declared.

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