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Contents

Tutorial

Usability of a Patient Education and Motivation Tool Using Heuristic Evaluation (e47)
Ashish Joshi, Mohit Arora, Liwei Dai, Kathleen Price, Lisa Vizer, Andrew Sears. 3

Original Papers

Health e-Cards as a Means of Encouraging Help Seeking for Depression Among Young Adults: Randomized Controlled Trial (e42)
Daniel Costin, Andrew Mackinnon, Kathleen Griffiths, Philip Batterham, Anthony Bennett, Kylie Bennett, Helen Christensen. 13

Internet Use and Self-Rated Health Among Older People: A National Survey (e49)
Enrique Gracia, Juan Herrero. 27

Disparities by Race and Ethnicity in Cancer Survivor Stories Available on the Web (e50)
Katherine Eddens, Matthew Kreuter, Jennifer Morgan, Kate Beatty, Sina Jasim, Lori Garibay, Donghua Tao, Trent Buskirk, Keri Jupka. 36

Social Media Use in the United States: Implications for Health Communication (e48)
Wen-ying Chou, Yvonne Hunt, Ellen Beckjord, Richard Moser, Bradford Hesse. 47

Age-Sensitive Design of Online Health Information: Comparative Usability Study (e45)
Richard Pak, Margaux Price, Jason Thatcher. 59

Challenges to Using an Electronic Personal Health Record by a Low-Income Elderly Population (e44)
Eung-Hun Kim, Anna Stolyar, William Lober, Anne Herbaugh, Sally Shinstrom, Brenda Zierler, Cheong Soh, Yongmin Kim. 71

Use of Live Interactive Webcasting for an International Postgraduate Module in eHealth: Case Study Evaluation (e46)
Ray Jones, Inocencio Maramba, Maged Boulos, Tara Alexander. 80

An Electronic Clinical Decision Support Tool to Assist Primary Care Providers in Cardiovascular Disease Risk Management: Development and Mixed Methods Evaluation (e51)
David Peiris, Rohina Joshi, Ruth Webster, Patrick Groenestein, Tim Usherwood, Emma Heeley, Fiona Turnbull, Alexandra Lipman, Anushka Patel. 91

Web Usage Data as a Means of Evaluating Public Health Messaging and Outreach (e52)
Hao Tian, Dana Brimmer, Jin-Mann Lin, Abbigail Tumpey, William Reeves. 108

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A Web-Based Nutrition Program Reduces Health Care Costs in Employees With Cardiac Risk Factors: Before and After Cost Analysis (e43)
Naomi Sacks, Howard Cabral, Lewis Kazis, Kelli Jarrett, Delia Vetter, Russell Richmond, Thomas Moore. 121

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Tutorial

Usability of a Patient Education and Motivation Tool Using Heuristic Evaluation

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Abstract

Background: Computer-mediated educational applications can provide a self-paced, interactive environment to deliver educational content to individuals about their health condition. These programs have been used to deliver health-related information about a variety of topics, including breast cancer screening, asthma management, and injury prevention. We have designed the Patient Education and Motivation Tool (PEMT), an interactive computer-based educational program based on behavioral, cognitive, and humanistic learning theories. The tool is designed to educate users and has three key components: screening, learning, and evaluation.

Objective: The objective of this tutorial is to illustrate a heuristic evaluation using a computer-based patient education program (PEMT) as a case study. The aims were to improve the usability of PEMT through heuristic evaluation of the interface; to report the results of these usability evaluations; to make changes based on the findings of the usability experts; and to describe the benefits and limitations of applying usability evaluations to PEMT.

Methods: PEMT was evaluated by three usability experts using Nielsen's usability heuristics while reviewing the interface to produce a list of heuristic violations with severity ratings. The violations were sorted by heuristic and ordered from most to least severe within each heuristic.

Results: A total of 127 violations were identified with a median severity of 3 (range 0 to 4 with 0 = no problem to 4 = catastrophic problem). Results showed 13 violations for visibility (median severity = 2), 38 violations for match between system and real world (median severity = 2), 6 violations for user control and freedom (median severity = 3), 34 violations for consistency and standards (median severity = 2), 11 violations for error severity (median severity = 3), 1 violation for recognition and control (median severity = 3), 7 violations for flexibility and efficiency (median severity = 2), 9 violations for aesthetic and minimalist design (median severity = 2), 4 violations for help users recognize, diagnose, and recover from errors (median severity = 3), and 4 violations for help and documentation (median severity = 4).

Conclusion: We describe the heuristic evaluation method employed to assess the usability of PEMT, a method which uncovers heuristic violations in the interface design in a quick and efficient manner. Bringing together usability experts and health professionals to evaluate a computer-mediated patient education program can help to identify problems in a timely manner. This makes this method particularly well suited to the iterative design process when developing other computer-mediated health education programs. Heuristic evaluations provided a means to assess the user interface of PEMT.

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KEYWORDS

Computers; health; education; usability; heuristic

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Introduction

Computer technology has been widely used for education of both patients and health care professionals. Patient receptivity to computerized education is reported to be high across diverse medical settings and age groups. Computerized patient education has also been shown to increase patient knowledge, but little is reported about the results of findings of usability assessments of computerized patient education programs.

The objective of this case study was to describe the usability of the Patient Education and Motivation Tool (PEMT) through heuristic evaluation of the interface. We report the results of the usability evaluation, make changes based on the findings of the usability experts, and describe the benefits and limitations of applying usability evaluations to PEMT. We used Nielson's 10 usability heuristics [6] to identify potential usability problems, describe severity ratings for each heuristic violation, and use the results to improve the overall usability of PEMT. This paper presents the results of the heuristic evaluation of PEMT, system changes performed based on the evaluation, and planned future research.

Human-Computer Interaction Evaluation

Human factor or usability engineering is a discipline that investigates human/machine interface issues, using a wide array of methodologies [7]. These methodologies vary in terms of research design, complexity, cost, duration, and relevance to operational programs [7]. The two approaches for evaluating the human-computer interaction (HCI) characteristics of a system include inspection methods or user evaluations [5,8]. Inspection methods are based on reviews of a system, often by experts, which can be guided by usability heuristics, user tasks, or other information [5,8,9]. User evaluations measure user task performance in a lab setting [5,8]. Using these methods in system development has been recognized as an important way to ensure the usability of the end product [5,8,9].

Nielson defines heuristic evaluation as a measurement that utilizes heuristics in order to find usability problems [4]. Nielson's method uses a small set of principles, guidelines, or heuristics that are systematically assessed against a target system in order to identify problems and their severity, as well consequences for the user [4,7]. Heuristic evaluation is an effective usability inspection method for discovering the most serious problems with a low investment of resources, while representing a high cost-benefit ratio [10]. During the heuristic evaluation, a group of usability experts examine the user interface design according to a set of usability guidelines [11]. A list of heuristic violations found in the interface design and an assessment of the severity of these problems is generated [11]. The results can be utilized as suggestions for interface refinements. This method requires less time and resources than many other usability engineering methods. Nielsen identified 10 usability heuristics as the basic characteristics of usable interfaces [4]. Research in the past has shown that usability inspection through heuristic evaluation is an effective way to uncover user interface design problems in a broad range of clinical contexts [12]. In a previous study, heuristic evaluation combined with small-scale expert assessment was examined in the context of the design and development of a Web-based telemedicine system [12]. The study found usage difficulties related to HCI problems primarily characterized by a mismatch of the designer model and the content expert model [12]. The heuristic/usage methodology provided an incremental benefit in a variety of design activities [12]. They examined a software user interface with heuristic evaluation, software guidelines, cognitive walkthrough, and usability testing and found that heuristic evaluation by several user interface specialists yielded the highest number of serious problems with the least amount of effort [12]. A single general usability expert familiar with the kind of interface being evaluated can identify about 60% of the problems [7,13]. This method was applied to support the clinical information system during a standard Call for Tender and was found to be an efficient and cost-effective approach to choose an appropriate and useful clinical information system [14]. In another study, Zhang and colleagues applied this method to evaluate patient safety with regard to the use of medical devices [15]. Heuristic evaluation through the identification of usability problems and their severities was found to be a useful, efficient, and low-cost method to evaluate patient safety features of medical devices [15].

Overview of the Patient Education and Motivation Tool (PEMT)

PEMT is an interactive computer-based program that is being designed according to three sets of learning theories [16]: behavioral, cognitive, and humanistic. Two key ideas of behavioral theory are that learning is manifested by a change in behavior and that technology-based instructional materials should be introduced in increments. Cognitive learning theory focuses on providing structured education to individuals along with reinforcement. Humanistic theory predominantly emphasizes the participants' willingness to learn and their ability to be evaluated. The outcome of learning depends upon how the information is presented and how the learner processes that information.

A computer-based educational program provides individuals with a self-paced learning environment and presents educational modules as a series of short messages. The information is provided in various representations, including audio, images, text, and animation with the resulting program being interactive. The system accounts for a variety of literacy levels and learning styles amongst users. Visual learners prefer seeing what they are learning, so pictures and images help them understand ideas and information better than text-based explanations [17]. Auditory learners learn best by hearing things and remember verbal instructions well, preferring someone else read the directions to them while they do the physical work or task [18]. PEMT allows users to toggle the audio on or off based on their preferences. The tool provides users with the opportunity and flexibility to navigate modules relevant to their condition by allowing them to move forward and backward at their own pace. PEMT also provides users with access to extensive information and empowers patients to obtain pertinent information about their condition. We employed usability principles when designing the user interface [19].

PEMT has three key components [20]:

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1. **Screening**: PEMT allows users to enter information about their socio-demographics at their own pace, including age, gender, education, disease severity, and prior disease knowledge through a series of multiple-choice questions. No feedback is given to the individuals during this component.
2. **Learning**: The learning material is broken down into a series of educational messages with relevant audio, images, and animations as appropriate. Individuals can move forward and backward through the messages by clicking next and back buttons. The information on each screen varies in terms of the number of paragraphs, sentences, words, bulleted items, highlights, and animations.
3. **Evaluation**: The evaluation component is a post-learning questionnaire similar to that used during the screening component. Feedback is provided to the users based on their responses. Users giving correct responses receive positive prompts and encouragement while individuals giving incorrect responses are given corrective feedback and reinforcement. The goal of the evaluation component is to track the progress of individual behavior, knowledge, and disease progression over a period of time.

These three key components of PEMT make it a multifaceted tool that can be utilized to screen individuals' demographics, health literacy, prior knowledge, attitudes, behavior, and prior use of technology. The tool has been successfully employed in different clinical settings (including emergency departments and outpatient clinics), for different conditions, including asthma [20] and influenza [21], and across different populations (including children, parents, and caregivers). In our prior study, we implemented PEMT on a touch-screen computer in a pediatric emergency department (ED). Children with asthma and their parents used the asthma education program in the ED. The results showed significant improvement in their knowledge and found PEMT to be highly acceptable [20]. In another study, we implemented PEMT in an ED and in an inner city outpatient pediatric ambulatory center (PAC) to assess and describe changes in the knowledge, attitudes, and practice regarding the influenza vaccine in participants whose children were between 6 months to 5 years of age [21]. The results of the study showed high acceptance of PEMT, and users found PEMT easy to use with no difficulties in navigating from one screen to another [21]. Users could interact with the tool on a desktop, laptop, or tablet PC using a touch screen, keyboard, and/or mouse. The system is available as a local or Web-based application.

PEMT Hardware and Software

PEMT is implemented in an n-tier architecture, using Adobe Flash CS3 for the presentation layer, XML for content management, Microsoft.Net Framework version 2.0 with Visual Basic.Net for program logic and data flow control, and Microsoft SQL Server 2005 for data storage. Educational content elements—including text, images, thumbnails, animations, and audio—and accessibility features—including textual descriptors and closed captions—are organized using multiple XML files. The Adobe Flash layer is used to render educational content and user interface controls dynamically. User interactions with the Adobe Flash layer—including responses to questions and navigational interactions—are captured by the .Net layer and recorded in a relational structure, linked with timestamps and a unique session identifier in the MS SQL Server database. For heuristic evaluations, the software experts used the software on desktop and laptop computers running Windows XP with a minimum configuration of a Pentium 4 processor and 512MB RAM.

Methods

Heuristic evaluation is better if several people conduct the evaluation independent of each other [6]. Jacob Nielsen's heuristics are probably the most used usability heuristics for user interface design [6]. The evaluation is structured in terms of recognized usability principles.

The severity of a usability problem is a combination of three factors:

- The **frequency** with which the problem occurs: Is it common or rare?
- The **impact** of the problem if it occurs: Will it be easy or difficult for the users to overcome?
- The **persistence** of the problem: Is it a one-time problem that users can overcome once they know about it, or will users repeatedly be bothered by the problem?

Three usability experts (LD, KP, and LV) used Nielsen's usability heuristics (Table 1) while reviewing the PEMT user interface and generated a list of heuristic violations. One of the usability experts was a registered nurse with 15 years of clinical and HCI experience and had conducted numerous heuristic evaluation studies (KP). One of the other experts had 12 years of professional experience in usability design and heuristic evaluation (LV), and the third expert was a PhD student in HCI with experience in doing heuristic evaluations for several studies (LD). During the evaluation, the usability experts first reviewed the user interface of PEMT independently and generated a list of heuristic violations. The usability experts then independently rated the severity of each usability violation on the following scale [6]:

0 - I don't agree that this is a usability problem at all

1 - Cosmetic problem only: need not be fixed unless extra time is available on the project

2 - Minor usability problem: fixing this should be given low priority

3 - Major usability problem: important to fix, so should be given high priority

4 - Usability catastrophe: imperative to fix this before product can be released

In rating the problems, persistent issues with major impact on most users received the highest severity rating. The mean severity for each violation was calculated from the individual ratings. The three independent lists were combined together to generate a single list of heuristics violations, their severity ratings, and suggestions for the correction of these violations. The three usability experts (LD, KP, and LV) discussed their individual lists together, and any disagreements in assigning the severity ratings were resolved after mutual discussions. The

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combined list of heuristic violations was then reviewed and changes were made.

Table 1. Nielsen's usability heuristics

Usability Heuristic	Description
1. Visibility of system status	The system should always keep users informed about what is going on, through appropriate feedback within reasonable time.
2. Match between system and real world	The system should speak the users' language, with words, phrases, and concepts familiar to the user, rather than system-oriented terms. Follow real-world conventions, making information appear in a natural and logical order.
3. User control and freedom	Users often choose system functions by mistake and will need a clearly marked "emergency exit" to leave the unwanted state without having to go through an extended dialogue. Support undo and redo.
4. Consistency and standards	Users should not have to wonder whether different words, situations, or actions mean the same thing. Follow platform conventions.
5. Error prevention	Even better than good error messages is a careful design which prevents a problem from occurring in the first place. Either eliminate error-prone conditions or check for them and present users with a confirmation option before they commit to the action.
6. Recognition rather than recall	Minimize the user's memory load by making objects, actions, and options visible. The user should not have to remember information from one part of the dialogue to another. Instructions for use of the system should be visible or easily retrievable whenever appropriate.
7. Flexibility and efficiency of use	Accelerators—unseen by the novice user—may often speed up the interaction for the expert user such that the system can cater to both inexperienced and experienced users. Allow users to tailor frequent actions.
8. Aesthetic and minimalist design	Dialogues should not contain information which is irrelevant or rarely needed. Every extra unit of information in a dialogue competes with the relevant units of information and diminishes their relative visibility.
9. Help users recognize, diagnose, and recover from errors	Express error messages in plain language (no codes), precisely indicate the problem, and constructively suggest a solution.
10. Help and documentation	Even though it is better if the system can be used without documentation, it may be necessary to provide help and documentation. Any such information should be easy to search, be focused on the user's task, list concrete steps to be carried out, and not be too large.

Results

The result of the heuristic evaluation was a combined list of violations with severity ratings. The violations were sorted by heuristic and ordered from most to least severe within each heuristic category. A total of 127 violations were identified with a mean severity of 3 (range 0 - 4). The usability problems pertaining to the system function were organized by individual screens. An excerpt of the evaluation results for the user interface prototype has been presented (Table 2). Sample heuristic violations included a "lack of feedback to the user if they didn't answer a question and tried to proceed to the next screen", and the "inability to exit or obtain help throughout the entire program".

The results of the heuristic evaluation were given to the software development team so that the interface could be revised. The domain expert and the software development team discussed these changes and, based on the severity ratings, changes were prioritized and implemented (Figure 1, Figure 2, Figure 3). In Figure 1, if an option is not selected and the user clicks next to go forward, no feedback is given to the user. No help is provided to assist users during their use of the program, and no exit button is available to leave the program at any time.

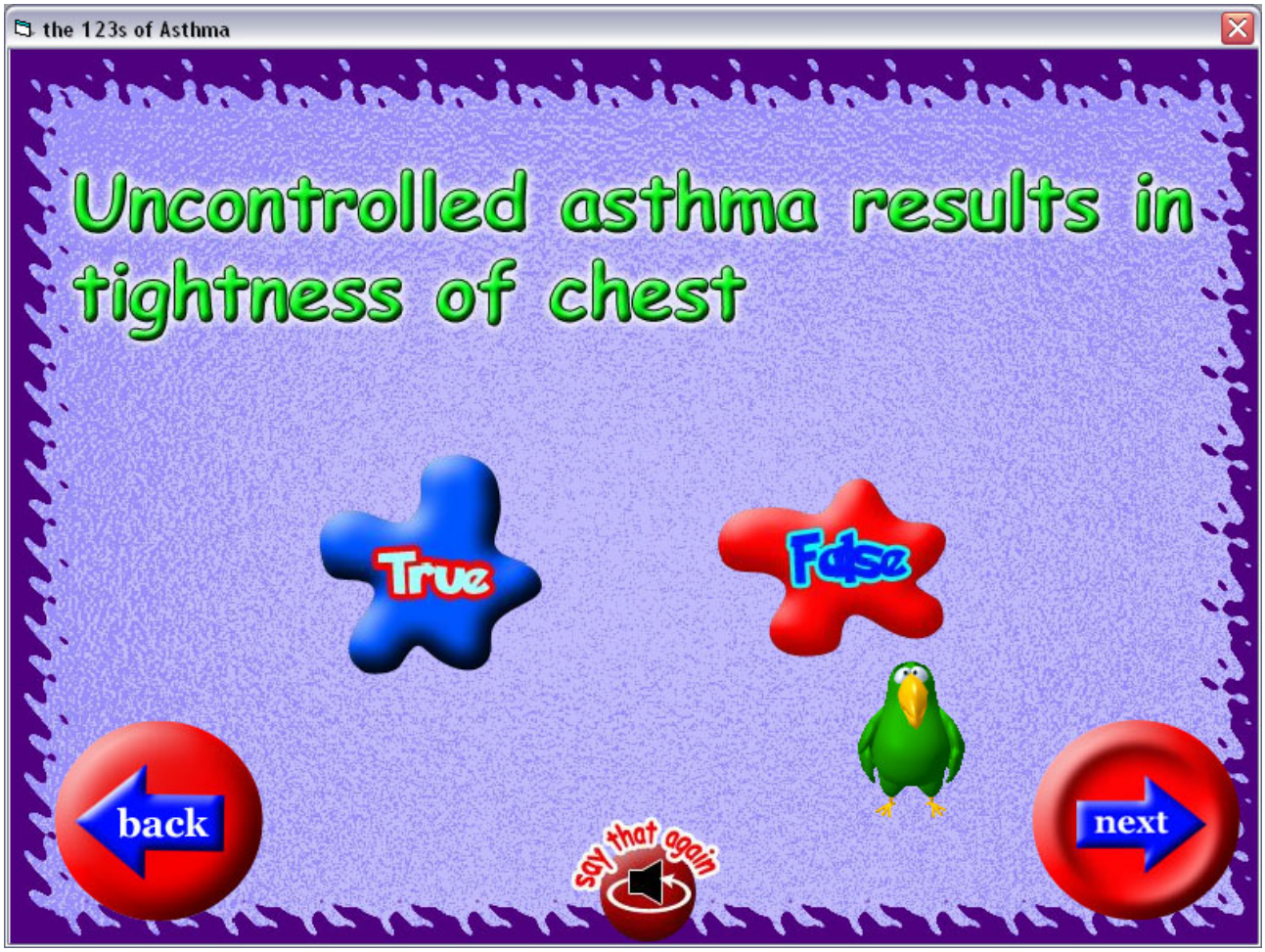
In Figure 2, feedback is provided if no option is selected, and the user is able to exit anytime during the use of the program.

Table 2. Sample heuristic evaluation results

Heuristic violated	Problem Description	Program Section	Severity Rating
Visibility	If you don't answer a question and then try to advance, the system will not let you, but it gives you no feedback on how to proceed.	Screening section	3
User control and freedom	No Exit or Quit present.	Entire program	3
Help and documentation	No Help present.	Entire program	4

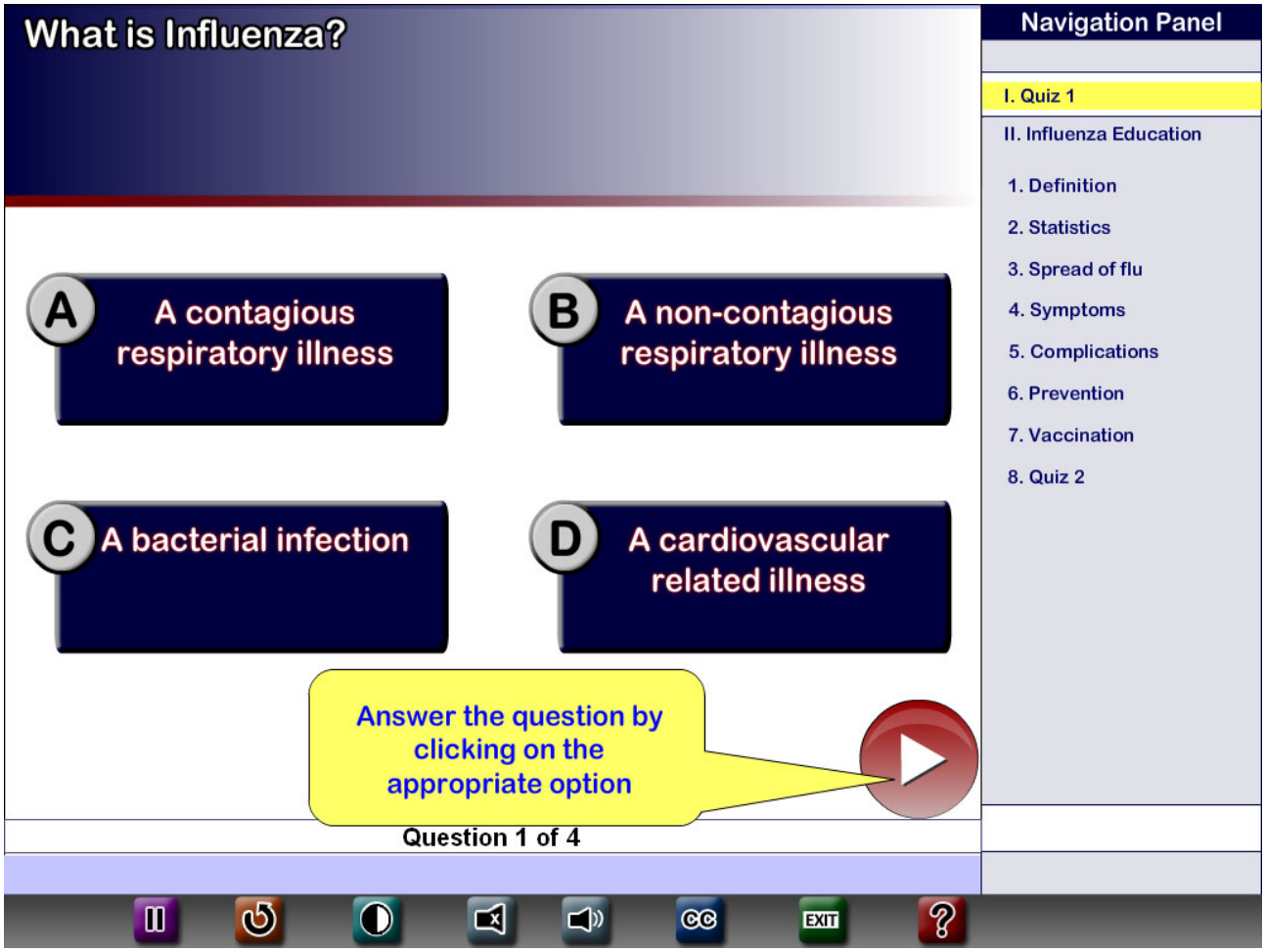
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Figure 1. PEMT Version before heuristic evaluation



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Figure 2. Revised PEMT version after changes were made based on heuristic evaluations



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Figure 3. Help section is provided during the use of the program in the modified version of PEMT

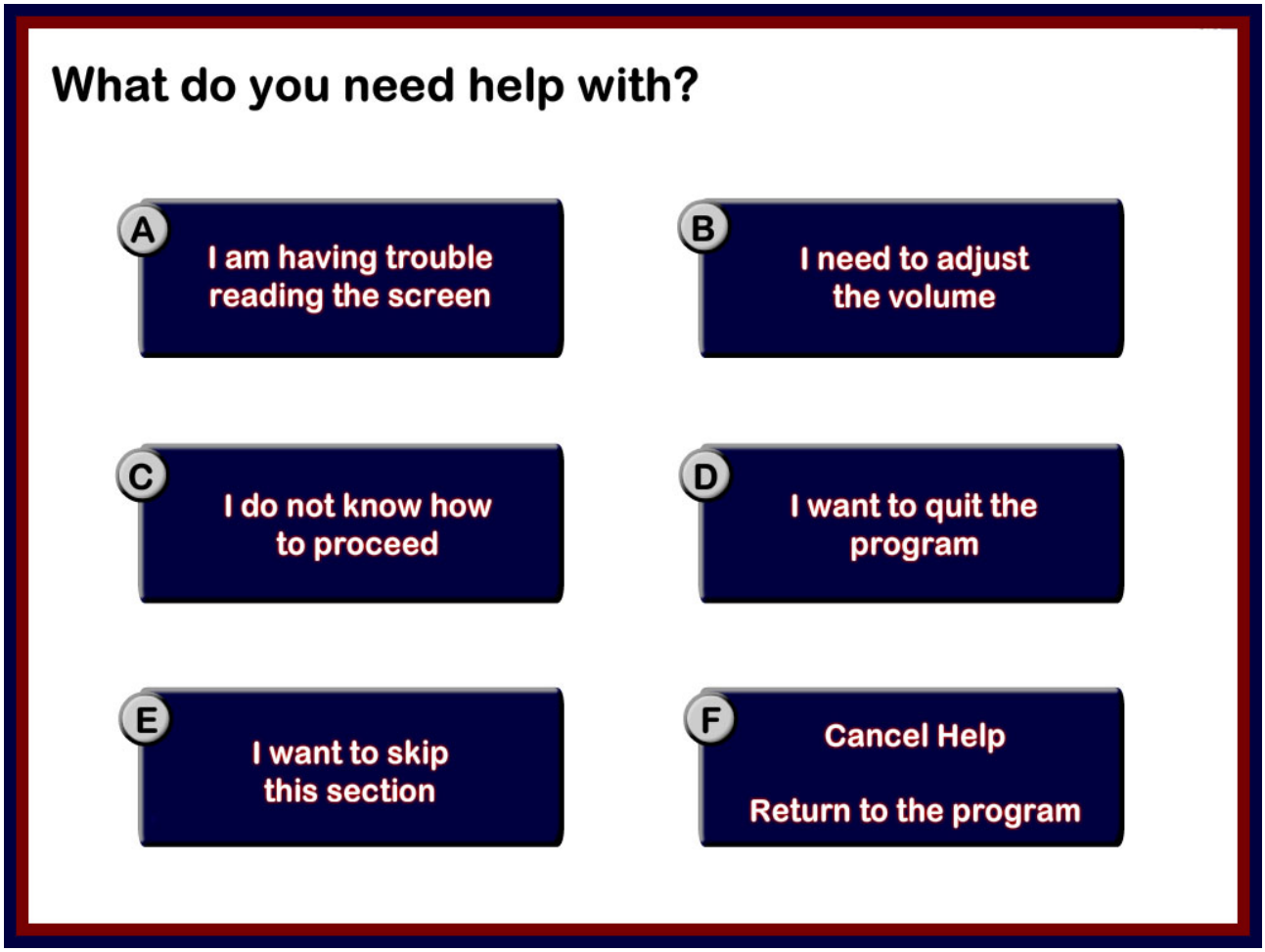


Table 3 shows the average number of violations for visibility, the match between system and real world, user control and freedom, consistency and standards, error prevention, recognition rather than recall, flexibility and efficiency, aesthetic and minimalist design, help users recognize, diagnose, and recover from errors, and help and documentation. Results showed that among the 10 usability heuristics, the match between system and real world (n = 38) and consistency and standards (n = 34) were the two heuristics most frequently violated. These two heuristics accounted for more than half (57%) of all the violations. Two examples of heuristic violations related to the match between system and real world included: 1) lack of clarity in the presentation of the buttons and their functions and 2) a mismatch between the audio and written content. Consistency and standards heuristic violations included: 1) differences in function performed by similar buttons, including the "next" button that was used to display additional content on the same screen instead of to advance screens and 2) inconsistent typesizes and styles used on the same screen.

We found severity ratings predominantly higher for violations of the usability heuristics "Help users recognize, diagnose, and recover from errors" (median rating = 3) and "Help and documentation" (median rating = 4) (Table 3).

For four heuristics, more than 50% of the violations were major violations: "User control and freedom" (n = 4/6; 66.67%), "Error prevention" (n = 6/10; 54.54%), "Recognition rather than recall" (n = 1/1; 100%), and "Help users recognize, diagnose, and recover from errors" (n = 4/4; 100%) (Table 3). The median severity rating per usability heuristic has also been reported (Table 3). This information was used to evaluate the severity of the violations in each category of the usability heuristics and was used as a medium to describe not only the average number of severe violations in each category but also to prioritize changes that can be made to the violations.

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Table 3. Number of violations, average severity rating, and severity category per usability heuristic

Usability heuristic	Median severity rating	Cosmetic	Minor	Major	Catastrophic
Visibility of system status (n = 13)	2		7	6	
Match between system and real world (n = 38)	2	15	17	6	
User control and freedom (n = 6)	3		2	4	
Consistency and standards (n = 34)	2	4	24	6	
Error prevention (n = 11)	3		4	6	1
Recognition rather than recall (n = 1)	3			1	
Flexibility and efficiency of use (n = 7)	2		4	3	
Aesthetic and minimalist design (n = 9)	2	3	6		
Help users recognize, diagnose, and recover from errors (n = 4)	3			4	
Help and documentation (n = 4)	4			1	3

Based on the feedback from the heuristic evaluations, the user interface of PEMT underwent considerable changes. The majority of the changes that required urgent attention were fixed; however, certain changes were particular to the environment in which the system was to be used which, in this case, was an emergency department setting. The changes immediately made to the system included giving users feedback in the form of a text message when they tried to navigate to the next screen without making a choice. Some of the changes that were recommended by the usability experts were not completely adopted in the revised prototype due to specific user roles and the study protocol. Designers and users are faced with different requirements and tend to focus on different sets of issues. A prior study supports the view that it is not surprising to find experts and end users faced with different requirements focusing on different sets of issues [7]. Heuristic evaluation focuses on the interface characteristics mediating between functionality and performance [7].

Discussion

This tutorial illustrates a heuristic evaluation using a computer-based patient education program (PEMT) as a case study. The motivation to conduct this heuristic evaluation was to uncover usability violations in the user interface prototypes of PEMT in an efficient yet effective manner. Our case study illustrates the relevance of the heuristic evaluation for identifying usability problems with computer-based health education programs. We evaluated acceptance of PEMT in the emergency department and the pediatric ambulatory clinic using an attitudinal survey. The results showed that 95% of the users found the program easy to use, 91% found it easy to navigate the program's different screens, 94% found the text easy to read, and 93% liked the colors used on the screen [21]. Overall, the results of this study suggested high acceptance of PEMT [21]. One major weakness in our assessment of heuristic evaluation as a method is that we have no baseline against which to measure our results. Earlier studies suggest that heuristic evaluations detect 40 - 60% of the usability problems an empirical user test would find, and also claim that the types of problems found are roughly comparable [6].

A substantial benefit of heuristic evaluation is that it represents significant savings in time over the duration of a complete empirical user test, both in terms of execution and generation of interface changes for implementation. It has been reported that heuristic evaluations employing 3 - 5 evaluators can identify 60 - 70% of the usability problems in an interface, including many of the major problems, even though it requires less time than other evaluation techniques [21]. The current case study demonstrates the significance and relevance of human factors in designing computer-mediated health education programs, especially with respect to improving the acceptance of these systems.

Heuristic evaluation is a usability inspection method and differs from empirical approaches that rely heavily on user performance data, such as user testing. The study shows the practicality of heuristic evaluation. The results suggest that the application of human-computer interaction design principles to technology-based health education programs can be a quick, relatively efficient way to gather feedback and guidance to improve the interface of a system. The heuristic evaluation results were also a guide during the iterative software development process. The results were presented to the development team, and the recommended changes were implemented. The changes made to the interface were prioritized

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based on the severity ratings, from catastrophic to cosmetic. The immediate changes made to the program included adding a help mechanism, providing feedback to the users based on their actions, and allowing users to exit the system. Therefore, the sorted list of heuristic violations with severity ratings was very helpful for prioritizing the revisions to PEMT. The recommended changes were easily understood, not only by the software development team, but also by domain experts, since the rationale used to make changes to the system was well justified by the heuristics. The benefits of the recommended changes became evident after the revised software demonstrated higher ease of use and greater ease of navigation, while minimizing errors. Thus, providing software designers with practical feedback in a timely fashion represents a distinct advantage that heuristic evaluation possesses which many other usability engineering methods do not.

Over the long term, perhaps the most lasting result of the heuristic evaluation concerns more than the specific system tested, since heuristic evaluation also relates to internal organizational development. Heuristic evaluation was another step in this educational process. The experimenters and evaluators learned to use the method and to incorporate the results into subsequent development. A large number of usability problems were identified with a reasonable expenditure of effort. To ensure the success of education programs, information must be delivered in a way that is accessible to and meaningful to users.

However, there are several limitations of using heuristic evaluation compared to other usability engineering methods. This method relies heavily on the expertise of the usability professionals who conduct the evaluation [5]. These experts may lack domain knowledge and could therefore overlook domain-related usability problems [5]. One way to overcome this obstacle is to employ evaluators, known as double experts, who possess both usability and domain knowledge [5]. In our case study, usability experts, designers, and domain experts worked together on the design and evaluation of the PEMT. It is highly important to have a combination of these experts while evaluating computer-mediated patient education programs in the health care environment, or else there is a risk of producing a mismatch between the system and the real world. Involving professionals with expertise in both computer-mediated education and the health care environment allows for the adjustment of several variables while evaluating the system.

The PEMT user interface was more consistent with Nielsen's usability heuristics after the expert-recommended changes were completed. In our study, we examined the value of heuristic evaluation for improving the usability of PEMT by uncovering heuristic violations in the interface design in a quick, efficient, and cost-effective manner. The ability to identify problems in a timely manner makes this method particularly well suited to the iterative design process. In addition, it is very important that the focus is on users when evaluating the interface design because this can influence the problems identified by the usability experts, as well as how these problems are described and prioritized. The system should speak the user's language, with words, phrases, and concepts familiar to the user, rather than system-oriented terms and information, and these words, phrases, and concepts should appear in a natural and logical order. The "match between system and real world" means that the system should follow real-world conventions as closely as possible, in order to allow the user to understand how to operate the program.

We are currently conducting multiple studies to evaluate the usability of PEMT by combining heuristic evaluation and user testing for other patient education programs.

Conflicts of Interest

None declared.

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Abbreviations

ED: emergency department
HCI: human computer interaction
PAC: pediatric ambulatory center
PEMT: Patient Education and Motivation Tool

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Original Paper

Health e-Cards as a Means of Encouraging Help Seeking for Depression Among Young Adults: Randomized Controlled Trial

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Abstract

Background: There is a need to identify interventions that increase help seeking for depression among young adults.

Objective: The aim was to evaluate a brief depression information intervention employing health e-cards (personalized emails containing links to health information presented on a Web page).

Methods: A randomized controlled trial was carried out with 348 19- to 24-year-olds drawn from the community. Participants were randomized to receive one of three conditions, all of which delivered a short series of health e-cards. Two active conditions involved the delivery of depression information designed to increase help-seeking behavior and intentions and to improve beliefs and knowledge associated with help seeking. A control arm delivered information about general health issues unrelated to depression. The primary outcome was help-seeking behavior. Secondary outcomes were help-seeking intentions; beliefs about the efficacy of depression treatments and help sources; ability to recognize depression; knowledge of the help-seeking process; and depressive symptoms. The study's primary focus was outcomes relating to formal help seeking (consultation with a general practitioner or mental health professional) but also targeted behaviors, intentions, and beliefs relating to informal help seeking.

Results: Relative to the control condition, depression health e-cards were not associated with an increase in formal help-seeking behavior, nor were they associated with improved beliefs about depression treatments; ability to recognize depression; knowledge of the help-seeking process; or depressive symptoms. Depression e-cards were associated with improved beliefs about the overall efficacy of formal help sources ($z = 2.4$, $P = .02$). At post-intervention, participants in all conditions, relative to pre-intervention, were more likely to have higher intentions of seeking help for depression from a formal help source ($t_{641} = 5.8$, $P < .001$) and were more likely to rate interpersonal psychotherapy as being helpful ($z = 2.0$, $P = .047$). Depression e-cards were not associated with any significant changes in informal help-seeking behavior, intentions, or beliefs.

Conclusions: The study found no evidence that providing depression information in the form of brief e-cards encourages help seeking for depression among young adults. Involvement in the study may have been associated with increased help-seeking intentions among participants in all conditions, suggesting that mechanisms other than depression information may increase help seeking.

Trial Registration: International Standard Randomized Controlled Trial Number (ISRCTN): ISRCTN98406912; http://www.controlled-trials.com/ISRCTN98406912/ISRCTN98406912 (Archived by WebCite at http://www.webcitation.org/5k221KiMi)

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KEYWORDS

Depression; mood disorders; young adult; health care seeking behavior; attitude to health; intention; health promotion; randomized controlled trial; electronic mail

Introduction

Depression is a leading contributor to the burden of disease and injury among young adults [1]. Around 6.4% of young Australians aged 18-24 years will be affected by depression each year [1]. Many young adults are unable to recognize the symptoms of depression [2], have limited knowledge about appropriate treatment options [3], and are reluctant to seek help for depression from a general practitioner (GP) or mental health professional [4]. As a consequence, their depression may go unrecognized and untreated. There is a need to develop and evaluate interventions that educate young adults about depression and encourage those experiencing symptoms to consult a health professional.

To date, only three studies have used a randomized controlled trial to investigate depression informational interventions for their effects on help-seeking behavior. Jorm et al [5] provided depressed people in the community with an evidence-based consumer guide to treatments for depression and found that participants who received this guide were no more likely to report subsequently seeking professional help for depression than control group participants who received a short brochure about depression (a rise in help seeking was observed in both groups). A major weakness of this study was the lack of an appropriate comparator—the brochure used in the control condition also provided information about evidence-based treatments for depression. Christensen et al [6] examined the effect of a 6-week intervention involving access to a depression information website and weekly telephone contact from a lay interviewer who directed participants to read particular sections of the website. Relative to an attention control condition (brief weekly telephone contact with a lay interviewer who asked questions about factors that might affect depression, but no access to the website), participants in the website condition were no more likely to report an increase in help seeking from GPs or mental health professionals at 6 months follow-up. A limitation of this study was that participants were recruited to an early intervention trial, so their agreement to participate in the trial might in itself be regarded as an act of help seeking. Finally, in the only randomized controlled trial to have investigated depression information interventions for their effects on help-seeking behavior in young adults, Sharpe et al [7] examined the effect of a 40-minute, classroom-based intervention delivered to university students. They found that the intervention led to more positive attitudes toward seeking psychological help but had no effect on help-seeking behavior compared to an attention placebo condition. A limitation of this study was that participants were not selected on the basis of having elevated levels of psychological distress or depression, so it is difficult to determine whether the failure to modify help-seeking behavior was due to the intervention or low need for help seeking in this sample.

The current study sought to address some of the limitations of these previous studies [5-7] and to add to the evidence about the effectiveness of brief information interventions in increasing help seeking for depression among young adults. Given the convenience and low cost of disseminating public health interventions on the Internet [8] and the popularity of this medium for young people [9], the study employed an Internet intervention. In addition, since it might be anticipated that brief rather than more-extensive Internet interventions would be preferred by young people [10], the intervention employed "health e-cards," an electronic analogue to postcards. A health e-card is a personal email containing a link to depression information presented on a Web page. Previous research has demonstrated that postcards can be an effective means of reducing incidences of self-harm [11], and thus the brief e-cards were considered an appropriate modality in the current context.

Participants were randomized to receive one of three conditions, all of which delivered a short series of health e-cards. Two active conditions (a basic and an enhanced condition) involved the delivery of depression information, and one control arm (control) delivered information about general health issues.

The active conditions were designed to facilitate progression of the process that young people are likely to go through when seeking help for mental health problems. This help seeking process, as conceptualized by Rickwood and colleagues [12], begins with the awareness of symptoms and appraisal of having a problem that may require intervention. The young person must then be able to articulate his or her problem using words that he or she feels comfortable using and that will be understood by others. Finally, sources of help must be available and accessible, and the help seeker must be willing to seek out and disclose information to these sources [12]. The information provided in the active conditions aimed to modify factors that might inhibit progression through this help-seeking process, specifically, the inability to recognize depression [13], negative attitudes toward health professionals and the treatments they provide [14], and lack of knowledge and understanding of where to seek professional help, the services available, how to contact them [15,16], and what to expect at a consultation [12].

To address limitations of previous studies, the control arm provided information about general health issues that were likely to be of relevance to young adults but not related to depression [5]. Furthermore, the trial was presented to participants as a health and well-being trial rather than one that explicitly concerned depression, and the screening and pre-intervention survey included placebo questions relating to general health conditions [6]. Finally, the intervention was delivered to young adults drawn from the community, and the sample was stratified to include individuals experiencing high levels of distress who could be considered in need of help [7].

We hypothesized that, relative to the control group, individuals in the two active conditions would be more likely to seek help for depression from a GP or mental health professional over 3 subsequent weeks. We also hypothesized that participants in the active arms would report a greater willingness to seek

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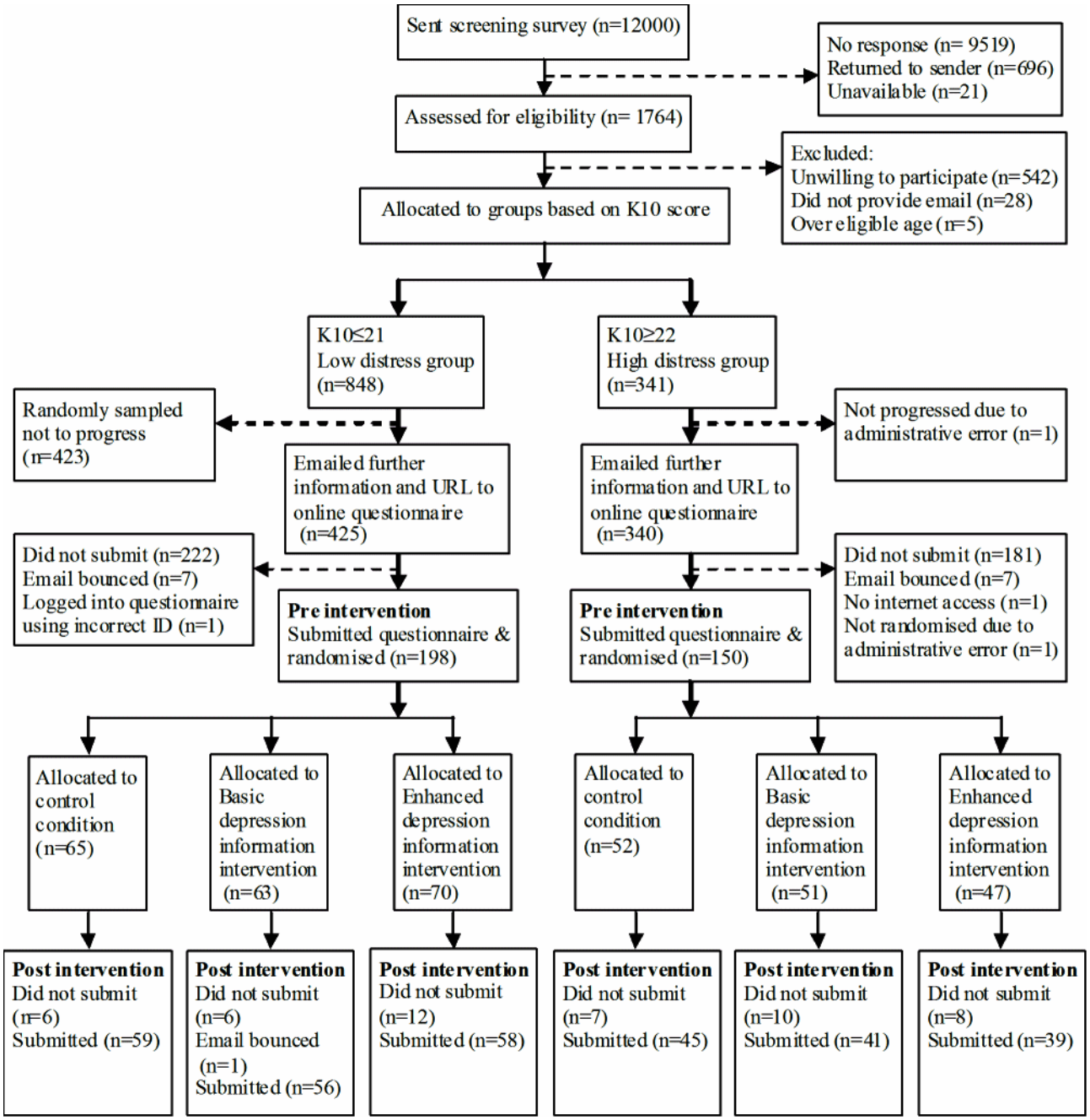
professional help for depression in the future, report more positive beliefs about the efficacy of treatments and health professionals, exhibit improved ability to recognize depressive symptoms, demonstrate improvements in their knowledge of the help-seeking process, and have reduced depressive symptoms. The study's primary focus was outcomes relating to formal help seeking (consultation with a GP or mental health professional), but it also targeted behaviors, intentions, and beliefs relating to informal help seeking (seeking assistance from peers and family).

Methods

Participants and Flow

Figure 1 details the flow of participants through the trial. Participants were recruited by means of a screening questionnaire, posted in March 2007 to 12,000 individuals aged 19 to 23 selected at random from the Australian Electoral Roll. Registration on the electoral roll is compulsory in Australia. The response rate was 14.7% (1764/12000). Respondents were eligible for inclusion in the trial if they indicated a willingness to receive further information about participating in the trial, provided their first name and email address, and fell within the age range of 19-24 years.

Figure 1. Flow of participants



Two strata were formed with the intention to conduct a priori subgroup analyses. The first group consisted of individuals experiencing high levels of distress who could be considered in need of help. The second consisted of individuals

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experiencing lower levels of distress or none at all. Although the second group may not have personally required help, the prevalence of depression is such that there was a high likelihood that individuals in this group might need to recognize and encourage help seeking in a friend (around 18% of young adults report that they would seek help for depression from a friend rather than a health professional [4]).

Eligible respondents scoring 22 or higher on the Kessler Psychological Distress Scale (K10) [17] formed the high distress group, and those scoring 21 or lower formed the low distress group. We anticipated that at least two thirds of eligible respondents would fall into the low distress group. To yield more equal numbers of high and low distress participants in the intervention, we randomly sampled members of the low distress group so that only 50% progressed to the next stage of recruitment, but all members of the high distress group progressed to the next stage. Individuals who progressed were sent further information by email and an URL link to the online pre-intervention questionnaire. The study was approved by the Australian National University Human Research Ethics Committee.

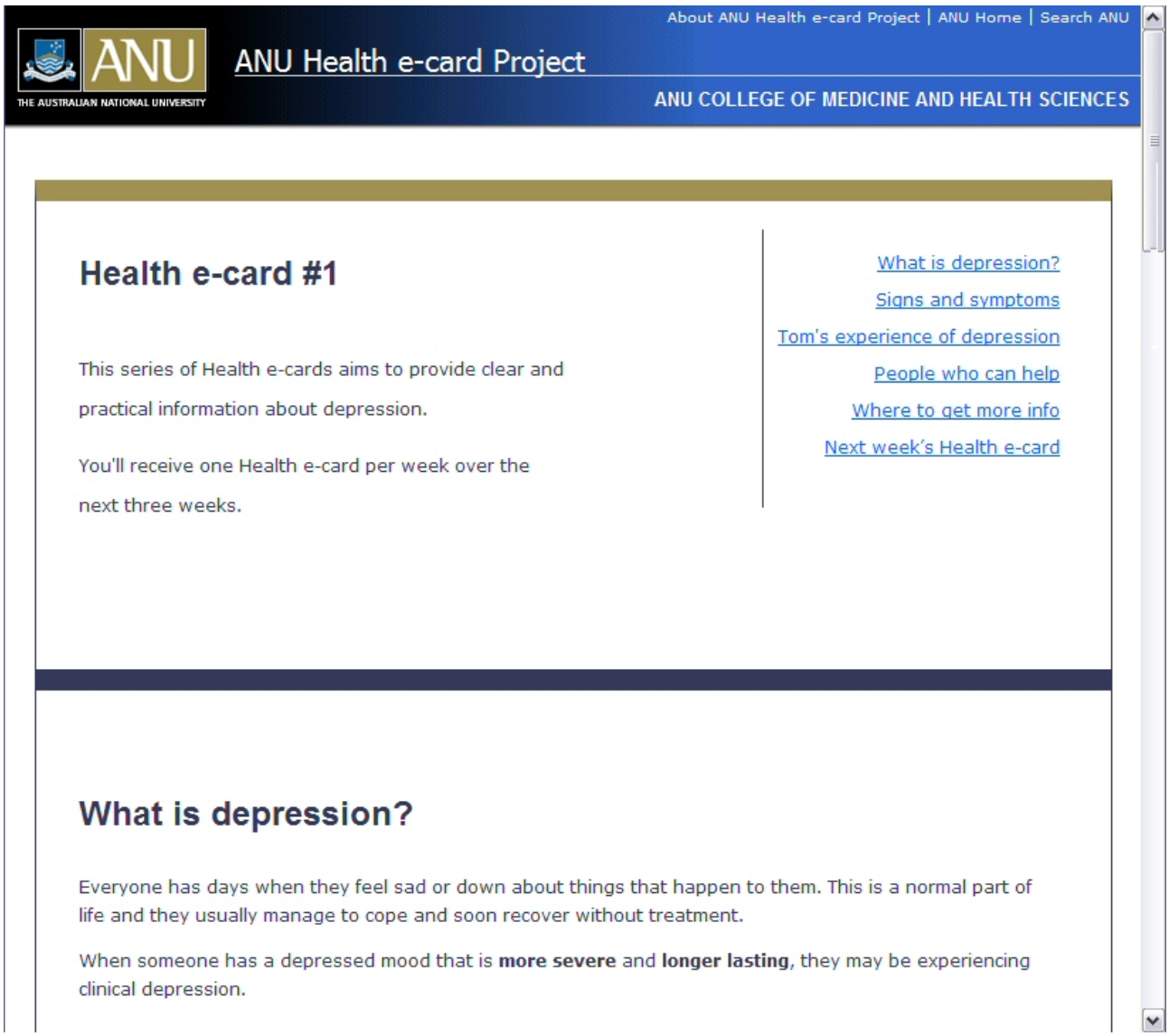
Treatment Allocation

Participants were randomized to conditions after submitting the online pre-intervention questionnaire using block randomization with computer-generated random numbers. Randomization was stratified by sex and pre-intervention score on the Center for Epidemiological Studies Depression Scale (CES-D) [18]. The randomization tables were set up prior to commencement of the study. Randomization was carried out by one of the authors (DC).

Intervention

Individuals started the intervention within 7 days of submitting their pre-intervention questionnaire. The intervention consisted of three personalized emails containing an embedded URL to brief information presented on a Web page. These were described as health e-cards (see Figure 2). Each week for 3 weeks, participants received an automated email from the project coordinator. Emails were personalized with the participant's first name and contained a greeting and directions to click on an URL link to view the brief health information (see Multimedia Appendix). The health e-cards were designed to be read as a series, much like an e-learning program.

Figure 2. Screenshot of a health e-card



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Participants in the basic intervention received depression information health e-cards. The information provided included symptoms of depression, a vignette describing a young man's experience of depression, where to find evidence-based information about depression and its treatment on the Internet, prevalence rates among 18- to 24-year-olds, encouragement to consult with a health professional if feeling depressed, and information about GPs, counselors, clinical psychologists, and psychiatrists, including who they are, treatments they provide, and how to locate them.

Participants in the enhanced intervention also received depression information health e-cards. In addition to the information provided in the basic intervention, these participants also received information on facts about depression and help seeking, what to expect at an initial consultation with each health professional, and practical tips about making contact with health professionals and asking for help. It was anticipated that this additional information would help facilitate movement through the help-seeking process [12] and enhance the effect of depression information in modifying help-seeking behavior [19].

Participants in the control condition received health e-cards containing information on health issues not directly related to depression but still relevant to young adults. These were meningococcal disease, amphetamines, and gamma-hydroxybutyrate (GHB).

The treatments for depression recommended in the basic and enhanced interventions were antidepressants, cognitive behavioral therapy, and interpersonal psychotherapy. These recommendations were based on systematic reviews [20-23]. Information relating to GPs was sourced from Ellis and Smith [24], and information relating to the role and qualifications of different health professionals was sourced from The Australian Psychological Society's website [25]. Information provided in the control condition was reproduced with permission from other health promotion publications [26-29].

Post-Intervention Data Collection

At 3 weeks post-intervention, the automatic email application sent participants a personalized email with an URL link to the post-intervention questionnaire. This email was resent up to three times at 1-week intervals, or until the participant's post-intervention questionnaire was submitted. To our knowledge, there are no data available on the average period of time it takes to complete a visit with a health professional after forming the intention to seek help for depression. We estimated that a period of 3 weeks would be sufficient and would also maximize post-intervention response rates.

Measures

Demographic Information

At screening, data were collected on sex, age, employment status, education, email usage, demographic characteristics based on residential post code, experience seeking help for depression from a GP or mental health professional (General Help Seeking Questionnaire [GHSQ] supplementary questions) [30], current help seeking, and psychological distress (as measured by the K10 [17]).

Primary Outcome Measure: Help-Seeking Behavior

The primary outcome was the proportion of participants who reported at post-intervention that they had sought help for feelings of depression from a formal source (GP or mental health professional) in the past 6 weeks, assessed with the Actual Help Seeking Questionnaire (AHSQ) [12]. Participants were also asked whether they had sought help from an informal help source (friend, partner, or family member).

Secondary Outcome Measures

Secondary outcomes were collected at baseline (screening or pre-intervention) and post-intervention.

Intentions to seek help were assessed using the GHSQ [30]. Respondents were asked, "If you were feeling depressed, how likely is it that you would seek help or advice from the following people during the next six weeks?" They rated, on a 7-point scale (1 = extremely unlikely to 7 = extremely likely), their intentions to seek help from a friend, partner, family member, GP, counselor, clinical psychologist, psychiatrist, or no one. An optional item, "someone else not listed above (please describe who this is)," was also included. Two multi-item scales were created for the analysis using methods described by Deane and Wilson [31]. These were intentions to seek formal help (mean of responses for GP, counselor, clinical psychologist, and psychiatrist) and intentions to seek informal help (mean of responses for friend, partner, and family member). The range of these multi-item scales was therefore 1 to 7, with higher scores representing stronger intentions to seek help.

Beliefs about help seeking were assessed using a modified version of a measure used by Jorm et al [32]. Respondents were asked to rate the helpfulness of various formal help sources (GPs, counselors, clinical psychologists, and psychiatrists), informal help sources (partner, family, and friends), and treatments (antidepressants, cognitive behavioral therapy, interpersonal psychotherapy, and supportive counseling) for a young adult experiencing depression. Responses included "helpful," "harmful," "neither helpful nor harmful," or "don't know." Results were analyzed as the proportion of respondents rating each help source or treatment as "helpful."

Ability to recognize depression was assessed by presenting a vignette describing a 23-year-old male with major depression [32] according to the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (DSM-IV). The character's name and age was changed from Jorm and colleagues' original version to make it more applicable to the participants in this study. Respondents were asked to indicate what (if anything) was wrong with the character by selecting one of 14 responses. The response list included the top 12 responses given by Australian participants in a previous study [33] plus two additional items (bulimia nervosa or meningococcal disease) relating to placebo questions included in the screening survey. A correct response was considered to be one in which the participant endorsed depression.

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Help-seeking knowledge was assessed by asking participants to do the following: "Imagine a good mate or close friend came to you and said that they had been feeling depressed for several weeks and were thinking about going to see a health professional but didn't know much about it, or where to get help." They then rated how much they agreed with each of three statements using a 5-point scale (4 = strongly agree, 3 = agree, 2 = neither agree nor disagree, 1 = disagree, 0 = strongly disagree). The statements were as follows: "I would be able to explain to my friend the type of help or treatment that the following health professionals generally provide for people who have depression," "I would be able to explain to my friend how to locate and contact these health professionals," and "I would be able to explain to my friend what to expect at an initial consultation with these health professionals." The health professionals listed were GPs, counselors, clinical psychologists, and psychiatrists. Ratings for each health professional were cumulated across the three statements to produce four subscores. These were perceived knowledge about seeking help from GPs, counselors, clinical psychologists, and psychiatrists. The range for each subscore was 0-12. A total score was also produced (sum of all items), which ranged from 0-48.

Symptoms of depression were assessed using the CES-D [18]. Higher scores represent greater psychological distress, with scores of 16 or higher usually taken to indicate clinical depression.

To assess the appeal of depression health e-cards, screening survey respondents were asked what type of health information they thought would be most helpful for inclusion in health e-cards aimed at young adults. There were 26 different topics offered, and respondents selected as many items as they wished. Furthermore, at post-intervention, participants were asked to rate the helpfulness of each e-card (very helpful, helpful, neither helpful nor unhelpful, unhelpful, or did not read).

Statistical Methods

Demographic characteristics were compared using one-way analysis of variance (ANOVA) and tests of association (chi-square). Three sets of analyses were conducted: (1) an analysis of differences between the three conditions within the low distress group, (2) an analysis of differences between the three conditions within the high distress group, and (3) an analysis of differences between the high distress group and the low distress group.

Formal help-seeking behavior and informal help-seeking behavior were examined using logistic regression. Predictor variables were condition, distress group, and interaction of condition and distress group. Participants who did not respond to the post-intervention questionnaire were presumed not to have sought help. Ordinal repeated measure outcomes were analyzed using linear mixed models in SPSS 15.0 (SPSS Inc, Chicago, IL, USA), and nominal repeated measure outcomes were analyzed using mixed logit models in Stata 10 (StataCorp LP, College Station, TX, USA). The analyses examined for main effects of condition, wave (pre-intervention vs post-intervention), and distress group; two-way interaction effect of condition and wave; and three-way interaction effect of condition, wave, and distress group. The major significant effect sought was an interaction of condition and wave that would indicate the effect of condition over time in increasing help-seeking intentions, beliefs about help seeking, ability to recognize depression, and help-seeking knowledge and in decreasing symptoms of depression. The interaction between distress group and condition was also of potential interest (whether the intervention was more useful for those with high levels of distress compared to those with low levels of distress). However, the three-way interaction between condition, wave, and distress group was not significantly associated with any of the outcomes, nor was the interaction between distress group and condition. Consequently, the final models included only the main effects and the interaction effect of condition and wave. All effects were tested at the $P < .05$ level.

Power Analysis

Target sample size was determined using GP attendance data previously analyzed by Parslow et al [34] from which a baseline consultation rate of 15% over the 6 weeks of the study was estimated. Consultation rates of between 10% and 20% arising from the invention were deemed possible. To maintain power at 80%, we sought to recruit 80 high distress participants into each arm of the trial. This sample would have comparable power to detect moderate-sized differences (less than .5 standard deviations) between control and active arms for secondary outcomes measured on continuous scales. Accordingly, the same target was set for the low distress group.

Results

The post-intervention response rate was 85.6% (298/348). Demographic characteristics are presented in Table 1. A preliminary analysis of the effect of condition on outcome variables revealed no significant differences between the two active arms (basic and enhanced), so these were combined into a single "depression information" condition for subsequent analyses.

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Table 1. Demographic characteristics[a,b]

	Low Distress Group			High Distress Group		
	Control (n = 65)	Basic (n = 63)	Enhanced (n = 70)	Control (n = 52)	Basic (n = 51)	Enhanced (n = 47)
Age, years, mean (SD)	21.6 (1.6)	21.6 (1.4)	21.3 (1.4)	21.4 (1.5)	21.1 (1.3)	21.4 (1.6)
Sex						
Male	19 (29.2)	16 (25.4)	21 (30.0)	8 (15.4)	11 (21.6)	3 (6.4)
Female[c]	46 (70.8)	47 (74.6)	49 (70.0)	44 (87.6)	40 (78.4)	44 (93.6)
Highest level of education completed						
Less than year 12	1 (1.54)	4 (6.35)	4 (5.71)	5 (9.62)	4 (7.84)	3 (6.38)
Year 12[c]	22 (33.8)	24 (38.1)	23 (32.9)	20 (38.5)	30 (58.8)	25 (53.2)
Year 12+ (certificate I-IV or diploma)	21 (32.3)	15 (23.8)	21 (30.0)	14 (26.9)	12 (23.5)	10 (21.3)
Bachelor degree or higher[c]	21 (32.3)	20 (31.7)	22 (31.4)	13 (25.0)	5 (9.8)	9 (19.1)
Highest current studies						
Not studying[c]	26 (40.0)	20 (31.7)	30 (42.9)	9 (17.3)	12 (23.5)	12 (25.5)
Higher secondary certificate	0 (0.0)	0 (0.0)	0 (0.0)	1 (1.9)	0 (0.0)	1 (2.1)
Certificate I-IV or diploma[c]	7 (10.8)	6 (9.5)	5 (7.1)	9 (17.3)	9 (17.6)	8 (17.0)
Bachelor degree or higher	32 (49.2)	37 (58.7)	34 (48.6)	33 (63.5)	29 (56.9)	26 (55.3)
Employment status						
Employed full-time	28 (43.1)	24 (38.1)	31 (44.3)	21 (40.4)	14 (27.5)	14 (29.8)
Employed part-time/casual	25 (38.5)	27 (42.9)	29 (41.4)	26 (50.0)	29 (56.9)	23 (48.9)
Not currently employed	12 (18.5)	12 (19.0)	10 (14.3)	5 (9.6)	8 (15.7)	10 (21.3)
Demographic rating						
Metropolitan	38 (58.5)	35 (56.5)	38 (55.1)	29 (55.8)	26 (51.0)	20 (42.6)
Provincial	17 (26.2)	17 (27.4)	19 (27.5)	19 (36.5)	16 (31.4)	14 (29.8)
Rural	10 (15.4)	10 (16.1)	12 (17.4)	4 (7.7)	9 (17.6)	13 (27.7)
Previous help-seeking for depression						
Previously[c] sought help	18 (27.7)	14 (22.2)	15 (21.4)	26 (50.0)	29 (56.9)	28 (59.6)
Rated helpfulness of the visits, mean (SD)	2 (0.7)	1.4 (0.9)	2.3 (1.4)	2 (0.9)	2.6 (1.5)	1.9 (0.8)
Currently receiving care for depression from GP or mental health professional[c]	4 (6.2)	1 (1.6)	3 (4.3)	11 (21.2)	12 (23.5)	10 (21.3)
Score on K10, mean (SD)[c]	16.1 (2.7)	15.5 (3.3)	15.6 (2.8)	27.0 (5.0)	26.9 (4.5)	27.3 (4.8)
Score on CES-D, mean (SD)[c]	10.2 (6.2)	10.2 (6.8)	10.0 (9.4)	21.8 (9.3)	22.4(10.0)	22.6 (9.8)
Post-intervention response rates						
Did not submit questionnaire	6 (9.2)	6 (9.7)	12 (17.1)	7 (13.5)	10 (19.6)	8 (17.0)
Completed questionnaire	59 (90.8)	56 (90.3)	58 (82.9)	45 (86.5)	41 (80.4)	39 (83.0)

[a] All values are number (%) unless otherwise indicated.

[b] Not all participants completed all questions.

[c] Significant difference between distress groups (but not between conditions).

Intervention Adherence

The embedded URL links that were emailed to participants ended with a unique identifier. This allowed us to track an individual's adherence to delivered materials by analysing the Web logs for each health e-card site. Of 348 participants, 320 (92%) visited at least one health e-card site, 167 (48%) visited all three sites, 102 (29.3%) visited two sites, 51 (14.7%) visited

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one site, and 28 (8%) visited no sites. Intervention condition had no significant effect on the average number of sites visited by participants in the low distress group ($F_{1,196}$ = .037, P = .85) or the high distress group ($F_{1,148}$ = .097, P = .76).

Primary Outcome: Help-Seeking Behavior

Table 2 presents the percentage of participants in each condition who reported seeking help for depression at post-intervention. Based on a logistic regression model, the interaction between condition and distress group was not significantly associated with help seeking from formal sources (OR = 0.69, χ^2_1 = 0.15, P = .69) or from informal sources (OR = 2.25, χ^2_1 = 2.83, P = .09). Participants in the high distress group were more likely than participants in the low distress group to report help seeking from formal (OR = 6.67, χ^2_1 = 12.97, P < .001) and informal sources (OR = 5.55, χ^2_1 = 34.10, P < .001). There was no effect of the intervention on help seeking from formal (OR = 1.17, χ^2_1 = 0.14, P = .70) or informal (OR = 0.86, χ^2_1 = 0.18, P = .67) sources.

Table 2. Primary outcome: percentage of participants in each condition seeking help from formal and informal sources up to 6 weeks after the intervention

	No.	Help-Seeking Source	
		Formal	Informal
High distress group			
Intervention	80	25.0%	75.0%
Control	45	26.7%	66.7%
Difference (95% CI)		−1.7% (−18.2% to 13.3%)	8.3% (−7.6% to 25.1%)
Low distress group			
Intervention	114	4.4%	25.4%
Control	59	3.4%	39.0%
Difference (95% CI)		−1.0% (−7.0% to 7.5%)	13.5% (−0.8% to 28.1%)

Secondary Outcomes

Changes in secondary outcomes are presented in Table 3 and discussed below.

Help-Seeking Intentions

The interaction between condition and wave was not significantly associated with help-seeking intentions. At post-intervention, participants in both conditions had higher intentions of seeking help for depression from a formal source (t_{641} = 5.8, P < .001). At pre- and post-intervention, the high distress group, relative to the low distress group, had higher informal help-seeking intentions (t_{641} = 5.4, P < .001).

Beliefs About the Efficacy of Formal Help Sources

At post-intervention, individuals in the depression information condition, relative to the control condition, were more likely to rate at least one health professional as helpful (z = 2.4, P = .02). At pre- and post-intervention, individuals in the high distress group, relative to the low distress group, were less likely to rate GPs (z = −2.5, P = .01) and counselors (z = −3.1, P = .002) as helpful.

Beliefs About the Efficacy of Informal Help Sources

The interaction between condition and wave was not significantly associated with beliefs about the efficacy of informal help sources. At pre- and post-intervention, individuals in the high distress group, relative to the low distress group, were less likely to rate friend (z = −2.7, P = .007), partner (z = −3.3, P = .001), family member (z = −2.8, P = .005), or any informal source (z = −2.3, P = .02) as being helpful.

Beliefs About the Efficacy of Treatments

The interaction between condition and wave was not significantly associated with beliefs about the efficacy of treatments. At post-intervention, participants in both conditions were more likely to rate interpersonal psychotherapy as helpful (z = 2.0, P = .047).

Ability to Recognize Depression

The proportion of respondents correctly identifying the vignette as “depression” did not differ across conditions, distress groups, or waves. There was no interaction between condition and wave (z = 0.1, P = .92).

Help-Seeking Knowledge

The interaction between condition and wave was not significantly associated with help-seeking knowledge. At pre- and post-intervention, individuals in the depression information condition, relative to the control condition, indicated that they knew more about seeking help from GPs (t_{641} = −2.3, P = .02). Individuals in the high distress group, relative to the low distress group, indicated that they knew more about seeking help from GPs (t_{641} = −2.2, P = .03), clinical psychologists (t_{641} = −2.0, P = .046), and all health professionals (total score; t_{641} = −2.5, P = .01). Significant effects of wave were found for GPs (t_{641} = −3.1, P = .002), clinical psychologists (t_{641} = −2.8, P = .006), psychiatrists (t_{641} = −3.0, P = .003), and all professionals (t_{641}

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= −3.6, $P < .001$), indicating that participants in both conditions were more knowledgeable at post-intervention about seeking help from these sources.

Symptoms of Depression

Symptoms of depression did not differ between pre- and post-intervention ($t_{641} = 1.6$, $P = .11$). There was no interaction between condition and wave. As expected, individuals in the high distress group, relative to the low distress group, scored higher on the CES-D at both pre- and post-intervention ($t_{641} = −18.6$, $P < .001$). A subanalysis was conducted to determine whether the intervention reduced symptoms of depression among the high distress group. No significant effects or interactions were found.

Appeal of Depression Health e-Cards

Most (1598/1764, 90.6%) of the screening survey respondents selected “depression” when asked what type of health information they thought would be most helpful for inclusion in health e-cards aimed at young adults. Depression was the most frequently endorsed item.

At post-intervention, most participants rated the e-cards as “helpful” or “very helpful:” depression information condition: health e-card 1 (87.6%), health e-card 2 (83.0%), health e-card 3 (85.6%); control condition: health e-card 1 (90.4%), health e-card 2 (92.2%), health e-card 3 (91.0%).

Subsidiary Analysis

Of participants in the high distress group, 22% were already receiving care for depression at baseline, and a high proportion of participants in both groups had previously sought help for depression from a health professional (24% of participants in the low distress group and 53% in the high distress group). To address this, the analysis of help-seeking behavior was repeated twice, first with the exclusion of participants who were receiving treatment for depression at baseline (n = 263), and then with the exclusion of this group as well as participants who had previously sought help for depression (n = 189). The results from both analyses were consistent with the primary analysis in that there was no significant effect of the intervention and the interaction between intervention condition and distress group was not significantly associated with formal or informal help seeking in either subgroup.

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Table 3. Secondary outcomes[a]

	Low Distress Group				High Distress Group			
	Control		Intervention		Control		Intervention	
	Pre (n = 65)	Post (n = 59)	Pre (n = 133)	Post (n = 114)	Pre (n = 52)	Post (n = 45)	Pre (n = 98)	Post (n = 80)
Help-seeking intentions								
Formal help source, mean (SD)[b]	2.82 (1.57)	3.16 (1.42)	2.47 (1.51)	3.40 (1.58)	2.71 (1.53)	3.36 (1.47)	2.43 (1.51)	3.21 (1.68)
Informal help source, mean (SD)[c]	4.86 (1.41)	4.86 (1.60)	4.83 (1.64)	4.79 (1.64)	3.58 (1.52)	4.54 (1.74)	3.98 (1.72)	4.42 (1.55)
Beliefs about formal help sources								
Rated GPs as helpful[c]	43 (66.20)	43 (72.90)	88 (66.20)	90 (78.90)	30 (57.70)	27 (60.00)	50 (51.00)	57 (71.30)
Rated counselors as helpful[c]	54 (83.10)	51 (86.40)	102 (76.70)	101 (88.60)	37 (71.20)	34 (75.60)	61 (62.20)	62 (77.50)
Rated clinical psychologists as helpful	41 (63.10)	41 (95.50)	98 (73.70)	83 (72.80)	36 (69.20)	28 (62.20)	66 (67.30)	62 (77.50)
Rated psychiatrists as helpful	34 (52.30)	35 (59.30)	83 (62.40)	80 (70.20)	28 (53.80)	26 (57.80)	63 (64.30)	56 (70.00)
Rated any formal source as helpful[d]	59 (90.80)	55 (93.20)	119 (89.50)	108 (94.70)	45 (86.50)	36 (80.00)	81 (82.70)	76 (95.00)
Beliefs about informal help sources								
Rated friends as helpful[c]	59 (90.80)	56 (94.90)	110 (82.70)	90 (78.90)	40 (76.90)	32 (71.10)	71 (72.40)	64 (80.00)
Rated partner rated as helpful[c]	59 (90.80)	93 (55.00)	119 (90.20)	95 (83.30)	34 (66.70)	34 (75.60)	73 (74.50)	70 (87.50)
Rated family as helpful[c]	58 (89.20)	48 (81.40)	109 (82.60)	92 (80.70)	34 (66.70)	30 (66.70)	72 (73.50)	61 (76.30)
Rated any informal source as helpful[c]	62 (95.40)	58 (98.30)	130 (97.70)	105 (82.10)	48 (92.30)	40 (88.90)	87 (88.80)	74 (92.50)
Beliefs about treatments								
Rated antidepressants as helpful	34 (52.30)	37 (62.70)	69 (51.90)	60 (52.60)	25 (48.10)	23 (51.10)	53 (54.10)	50 (62.50)
Rated CBT as helpful	36 (55.40)	34 (57.60)	60 (45.10)	64 (56.10)	24 (46.20)	21 (46.70)	44 (44.90)	47 (58.80)
Rated IPT as helpful[b]	27 (41.50)	31 (52.50)	54 (40.60)	63 (55.30)	19 (36.50)	21 (46.70)	40 (40.80)	39 (48.80)
Rated supportive counselling as helpful	56 (86.20)	51 (86.40)	113 (85.00)	101 (88.60)	45 (86.50)	35 (77.80)	86 (87.80)	67 (83.80)
Ability to recognize depression								
Endorsed problem in vignette as depression	63 (96.90)	53 (89.80)	121 (91.00)	101 (88.60)	47 (90.40)	44 (97.80)	91 (92.90)	76 (72.50)
Perceived knowledge of help-seeking process								
All health professionals, mean (SD)[b,c]	27.52 (11.17)	31.07 (10.35)	27.98 (10.71)	32.28 (9.38)	29.21 (11.29)	30.36 (11.21)	31.54 (9.52)	34.14 (8.94)
GPs, mean (SD)[b,c,e]	8.32 (2.98)	9.14 (2.48)	8.58 (2.67)	9.50 (2.05)	8.37 (2.84)	8.84 (2.69)	9.48 (2.40)	9.99 (2.05)

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	Low Distress Group				High Distress Group			
	Control		Intervention		Control		Intervention	
	Pre (n = 65)	Post (n = 59)	Pre (n = 133)	Post (n = 114)	Pre (n = 52)	Post (n = 45)	Pre (n = 98)	Post (n = 80)
Counselors, mean (SD)	7.88 (2.79)	8.75 (2.61)	8.25 (2.73)	8.94 (2.61)	8.46 (2.97)	8.60 (2.57)	9.06 (2.82)	9.29 (2.50)
Clinical psychologists, mean (SD)[b,c]	5.72 (3.46)	6.66 (3.30)	5.92 (3.47)	6.99 (3.29)	6.42 (3.53)	6.73 (3.73)	6.61 (3.46)	7.79 (3.15)
Psychiatrists, mean (SD)[b]	5.60 (3.33)	6.53 (3.36)	5.69 (3.15)	6.85 (3.01)	5.96 (3.25)	6.18 (3.54)	6.39 (3.14)	7.08 (2.88)
Symptoms of depression								
CES-D score, mean (SD)[c]	10.2 (6.22)	9.4 (7.15)	10.09 (8.26)	7.95 (6.79)	21.83 (9.27)	21.56 (10.73)	22.51 (9.87)	22.26 (10.84)

[a] All values are number (%) unless otherwise indicated.

[b] Significant effect of wave.

[c] Significant effect of distress group.

[d] Significant interaction of condition and wave.

[e] Significant effect of condition.

Discussion

This study used a randomized controlled trial to evaluate health e-cards as a means of encouraging help seeking for depression among young adults. We found no significant differences between the two depression information interventions. Neither of these interventions was more effective than a control condition in increasing formal help-seeking behavior or intentions, or in improving beliefs about depression treatments, recognition of depression, knowledge of the help-seeking process, or depressive symptoms, but they were associated with more positive beliefs about formal help sources. At post-intervention, participants in the two active arms and the control condition reported higher intentions of seeking help for depression from a GP or mental health professional, were more likely to rate interpersonal therapy as being helpful, and also reported being more knowledgeable about the help-seeking process. Depression information had no significant effect on informal help-seeking behavior, intentions, or beliefs.

Strengths and Limitations

This study is one of few to have used a randomized controlled trial to evaluate the effectiveness of depression information interventions for increasing help-seeking behavior [5-7] and the first to use an e-card modality for delivering the intervention. The study had several strengths in its design: the inclusion of a group of individuals experiencing high levels of distress who could be considered in need of help, comparison of the depression information intervention to a control condition that did not provide information about depression, presentation of the trial as a health and well-being study rather than a depression study, and the use of Web logs to objectively track individuals' adherence to delivered materials rather than relying on self-report methods.

The principal limitation of the study is that recruitment rates were low. A further limitation is that the recruitment methodology is likely to have selected for participants with a heightened interest in the research topic and willingness to participate (a problem that is pandemic to most public health trials attempting to ascertain participants from a representative community catchment). As a consequence, results may not be generalizable to the whole population of young adults.

Another possible limitation of the study is that the follow-up period of 3 weeks post-intervention may not have been a sufficient amount of time to capture subsequent changes in actual help-seeking behavior. Even if an individual is willing to seek help for depression, other factors such as availability of appropriate help sources can delay help seeking [12]. Ideally, the study would have included a second follow-up questionnaire that assessed outcome changes over a longer period of time (eg, 3 months).

A high proportion of individuals in the high distress group reported at baseline that they were currently receiving care for depression from a GP or mental health professional and/or had previously sought help for depression. This is a potential problem since a help-seeking intervention is unlikely to increase help seeking in those already in treatment or in those already with experience of health services. To address this potential weakness, a subsidiary analysis of help-seeking behavior was conducted with these individuals excluded. The findings remained unchanged with this group removed. The results from this analysis should, however, be interpreted as exploratory due to the low participant numbers and increased risk of type 2 error.

Implications of the Study

The analysis of the effect of condition on help-seeking behavior revealed no significant differences between the basic and enhanced conditions, or between the combined depression information condition and control condition. This may be attributable to the smaller than planned sample, which reduced power. However, the confidence intervals of the nonsignificant

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difference between the depression information intervention and control arms imply the maximum possible effect is unlikely to exceed 13% for formal sources and 25% for informal sources in the high distress group. Given that professional help of some sort is indicated for this group, there is a need to refine and further develop these brief interventions with a view to increasing their potential effectiveness before conducting a larger trial.

An idea for improving the effectiveness of health e-cards would be to modify their content to describe help seeking for mental health problems in general, rather than just depression. In Australia, anxiety disorders are more prevalent among young adults than affective disorders [1], and given this study's use of the K10 as a screening instrument rather than a more specific measure of depression, it is reasonable to assume that some participants in the high distress group might have been experiencing anxiety in addition to, or, rather than, depression. The intervention's focus on depression might have caused these participants to feel that the information and questions about help seeking for depression were not relevant to them, reducing the effectiveness of the e-cards in improving help seeking.

As they stand, the study's findings are consistent with previous randomized controlled trials that have also failed to demonstrate increased help seeking from health professionals following depression information interventions [5-7]. We did, however, find a significant effect of occasion of measurement (post-test versus pre-test) on formal help-seeking *intentions* in all conditions. At post-intervention, participants in both the depression information and control conditions were more likely to report higher intentions of seeking help for depression from a GP or mental health professional. This finding may suggest that the act of making contact with young adults and involving them in an intervention may have been more influential in modifying help-seeking intentions than the informational content provided in the intervention. Although the contact was automated and personalization was minimal, some participants may have felt a connection with the researcher and, as a result, formed more positive attitudes about seeking help from other health professionals in the future. An alternate explanation is that the completion of survey questions about health and well-being led some participants to become more aware of problems they might have been experiencing and influenced their perceived need for help. Participants in both conditions spent a considerable amount of time attending to questions about general health topics and depression. Parslow et al [34] have previously found that participants' use of GP services increased in the 3-month period after participating in a community-based epidemiological health survey. A major limitation to either of these interpretations is the lack of a wait list or nonintervention control. Without these, we can not rule out the possibility that a lapse of time alone yielded greater help-seeking intentions.

Conclusions

There is a need to identify interventions that increase help seeking for depression among young adults. This study failed to find evidence that providing depression information in the form of brief e-cards encourages such help seeking. Further research is required to investigate potential variables that might be critical in facilitating help seeking and in redesigning the content of the e-cards. It may be significant that involvement in the study was associated with increased help-seeking intentions among participants in all conditions. This suggests that mechanisms other than depression information in brief interventions may increase help seeking, but further investigation is required to explore this possibility and identify the nature of such mechanisms.

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Conflicts of Interest

None declared.

Multimedia Appendix

Emails sent to participants in each condition with embedded URLs to health e-card websites

[PDF file (Adobe PDF), 40 KB - jmir_v11i4e42_app1.pdf]

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Abbreviations

AHSQ: Actual Help Seeking Questionnaire
CES-D: Center for Epidemiological Studies Depression Scale
GHSQ: General Help Seeking Questionnaire
GP: general practitioner
K10: Kessler Psychological Distress Scale

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Original Paper

Internet Use and Self-Rated Health Among Older People: A National Survey

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Abstract

Background: Older people are among the segments of the population for which the digital divide is most persistent and are considered to be at risk of losing out on the potential benefits that the information society can provide to their quality of life. Little attention has been paid, however, to relationships between Internet use and actual indicators of health among older people.

Objective: The aim of this study was to examine the association between Internet use and self-rated health among older people and determine whether this association holds independently of socioeconomic position.

Methods: Data were from a survey about the digital divide and quality of life among older people in Spain that was conducted in 2008. The final sample consisted of 709 individuals and was representative of the Spanish adult population in terms of Internet use and sex across two age groups (55-64 and 65-74 years). Multivariate logistic regression analyses were performed to assess the relationship between Internet use and self-rated health.

Results: Results initially showed a significant relationship between Internet use and poor self-rated health (Model 1, OR = 0.32, 95% CI 0.16-0.67, P = .002), suggesting that Internet users have better self-rated health than nonusers. This effect remained significant when other sociodemographic variables were entered into the equation (Model 2, OR = 0.39, 95% CI 0.18-0.83, P = .01; Model 3, OR = 0.41, 95% CI 0.19-0.87, P = .02). However, the significant relationship between Internet use and self-rated health disappeared once social class was considered (Model 4, OR = 0.61, 95% CI 0.27-1.37, P = .23).

Conclusions: This study suggests that the use of the Internet is not a significant determinant of health among older people once the socioeconomic position of individuals is taken into account.

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KEYWORDS

Aged; computers; health; Internet; social class; socioeconomic status

Introduction

Older people are among the segments of the population with lower levels of Internet use—levels that decline sharply with advancing age [1-4]. For example, recent data from Europe indicate that 27% of people over age 54 and only 10% of people over 65 used the Internet, compared to 68% of those 16-24 [5].

The exclusion of older people from the information society is an issue of growing concern. For instance, the European Commission is developing a highly proactive agenda to break the barriers that prevent the older generation from fully embracing the information society and to promote the digital inclusion of older people [6,7]. Behind these efforts lies the idea that access to the information society can have a significant impact on the well-being and quality of life of older people. Access and use of the information society would contribute toward active aging and advancing health into old age by, for example, helping older people overcome isolation and

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loneliness, helping them keep in contact with family and friends by extending social networks, and facilitating the access and use of relevant information and services [3,7,8]. Little scholarly attention has been paid, however, to differences in health among older people who are users or nonusers of the Internet. This is an important issue to be examined given the efforts and investment that are being directed to promote e-inclusion among older people. For example, the European Commission i2010 Initiative on e-Inclusion acknowledges the persistent digital divide among older people, and it proposes to target this group of the population since they are considered at risk of losing out on potential benefits to their quality of life [6]. Efforts such as this should, however, be based on careful research rather than implicit assumptions [9,10].

The available research on the digital divide and health issues has focused mainly on access to health-related information [11-15]. Research has also examined how variables such as health status, age, sex, education, and income influence Internet use for health purposes [16-18]. On the other hand, as Dickinson and Gregor [9] showed in their review, the literature that claims that computer and Internet use has a positive effect on the well-being of older people is based on a few studies that do not support that claim. Most of the studies reviewed by Dickinson and Gregor were "intervention" studies with training programs to use computers and the Internet [19,20]. However, the problem with this research is that the effects of computer use, the effects of training, as well as the effects of the context in which computers are used tend to be confounded. Similar problems can be found in more recent studies that claim that Internet training and use contribute to older adults' well-being [21]. As Dickinson and Gregor noted [9], the improvements reported in these studies may be attributable to the training programs and the social interaction with other learners rather than to computer and Internet use. Other studies reviewed by Dickinson and Gregor, both correlational [22] and qualitative [23], suffered from important limitations (ie, misattribution of causality and inappropriate generalization of results) that question their claims that computer use improves the well-being of older adults. For example, the association reported in some studies between Internet use and health among older people does not indicate the direction of this relationship (ie, people who use the Internet may be healthier, but it is also possible that healthier people are more likely to use the Internet). More recent studies also suffer from selection bias that makes the generalization of results difficult [17,24].

Clearly, more research is needed to explore the relationship between the digital divide and actual indicators of health among older people. The research question we posit is, therefore, whether the digital divide can be considered as a significant determinant of health among older people.The digital divide has often been defined as the split between the "haves" and "have-nots" (or between users and nonusers of new media) [25-27]. This definition has been expanded, however, to include the various dimensions along which inequalities in the digital age may occur [25-28]. Thus, DiMaggio et al [29] refer to the digital divide as the "inequalities in access to the Internet, extent of use, knowledge of search strategies, quality of technical connections and social support, ability to evaluate the quality of information, and diversity of uses" (p. 310). For our purposes, we define the digital divide among older people in terms of Internet users and nonusers.

To our knowledge, this is the first study examining relationships between Internet use and self-rated health among older people using representative samples of Internet users and nonusers from the general population. In this paper we will examine whether Internet use among older people is associated with self-rated health and whether this association holds beyond the socioeconomic position of individuals (ie, the "social divide"), a major social determinant of health [30-37]. It has been suggested that, in addition to age, income and education are two of the most important barriers to Internet use [38-41]. Thus, the inequalities associated with the socioeconomic position of individuals in society are also related to the digital divide [16]. It is possible, therefore, that potential relationships between Internet use and health might be reflecting the relationship between socioeconomic position (a major determinant of access and use of the Internet) and health rather than reflecting benefits of Internet use by itself [3]. This being the case, the relationship between the digital divide and health among older people would be just a reflection of already existing socioeconomic inequalities in health, that is, a reflection of the relationship between the social divide and health.

To disentangle these relationships, we analyzed the association between Internet use and self-rated health, comparing users and nonusers of the Internet between 55 and 74 years of age, taking into account the socioeconomic position of individuals as well as other potential sociodemographic correlates of health: sex, age, marital status, and area of residence.

Methods

Study Sample

We used data from a survey about the digital divide and quality of life among older people in Spain conducted in 2008. In Spain, the National Statistics Institute has calculated that, in 2008, there were 1,226,000 Internet users between 55 and 64 years and that this number decreases sharply to 302,000 users between 65 and 74 years [42]. In percentages, 24.4% and 7.9% of people 55-64 and 65-74 years, respectively, had used Internet in the last 3 months. This is 17.3% of the Spanish population between 55 and 74 years. To ensure adequate statistical inference was possible, Internet users were oversampled in the original survey. To do so, the survey takes advantage of two sampling methods to locate eligible participants. Internet nonusers 55-74 years were contacted via random digit dialing and screened about their use of the Internet in the last 3 months. Eligible participants (those not having used the Internet in the last 3 months or more) were interviewed about their health status using computer-assisted telephone interviewing. Response rate for eligible participants (55-74 years) was 60%.

Internet users were sampled from an online research panel of more than 50,000 Spanish Internet users. The recruitment of panel members is based on sociodemographic variables as well as Internet behavior, leading to a high rate of representation of the population of Spanish Internet users. This panel is

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maintained only for research purposes, with constant recruitment of new members. To exert a tight control of potential sampling bias, eligible participants were selected and invited to participate in the study (targeted advertising), applying quotas of sex, age, size of locality, and education level to match official data [42]. A link to a website containing the online questionnaire and a random identification code were sent to eligible participants by email. The online questionnaire was identical to the telephone interview. This recruiting technique, known as invited participation, allows the researcher to verify that each participant is engaged in the study on one occasion only, and, when combined with targeted advertising, control over sampling is maximized [43,44]. Online participants were given small incentives for completing the questionnaire; no incentive was given to telephone interview participants. Average time to complete the questionnaire was 9 minutes. Once the questionnaire was completed, participants no longer had access to the online survey. Only completed questionnaires were included in the dataset. The response rate, calculated as the ratio between completed questionnaires and emails sent, was 50%. The final sample of Internet users showed only very small deviations from the target population. Small corrections were made in this sample to represent the population of Internet users. For example, 49.6% of those sampled lived in a big city (or surroundings), while the figure in the target population was 49%. For sex, we surveyed 68.4% of men compared to a target of 70%. In all of the remaining categories, the deviations were also very small. According to our data, it seemed that Internet users were self-selected almost completely at random.

The final sample consisted of 709 Spanish individuals between 55 and 74 years and was finally balanced to represent the Spanish population 55-74 years in terms of Internet use and sex across two age groups (55-64 and 65-74 years). Sampling error was ± 3.7% for a 95% confidence interval.

Outcome Variable

Subjects were asked to rate their health in general on a 5-point scale, ranging from “very good” to “very bad.” We used the categories that fell below “good” health as an indicator for self-rated poor health. This single-item measure of self-rated health is an extensively used measure of health with strong relations with outcomes such as mortality, morbidity, and physical and mental health status across groups with different sociodemographic characteristics, and it has been considered as a valid measure of health [45-48].

Predictors

Internet use refers to Internet user status (coded as 1 = nonuser, 2 = user) rather than the type of Internet use (ie, frequency). We assigned the status of “user” to those participants who had been connected at least once in the last 3 months. All the remaining participants were considered nonusers. Sex was coded as 1 = male, 2 = female. Age was coded into two groups: 1 = 55-64 years, 2 = 65-74 years. Marital status was coded as 1 = never married, 2 = married/living with partner, 3 = separated/divorced, 4 = widowed. Area of residence was coded as 1 = a country village or farm in the countryside, 2 = a town or small city, and 3 = a big city or the suburbs or outskirts of a big city. These last two were treated as categorical variables in the analyses.

To measure the socioeconomic position of participants, we used an indicator of social class that derives from the cross-classification of occupation and educational attainment of the head of family (main income earner). This cross-classification is a standard for media studies in Spain and provides five different social classes (high, medium-high, medium, medium-low, and low) by combining head of family education level and occupation (or last occupation) [49]. Given that education level and occupation were used for the computation of social class, this information was not used separately in the statistical analysis, to avoid multicollinearity.

Analytical Strategy

For the analysis of the data, we used multivariate binomial logistic regression to estimate the odds ratios of being in the self-rated poor health category. We estimated four regression equations (models) in a nested fashion. The first equation (Model 1) tested whether there was any association between Internet use and health. Model 2 adds sociodemographic covariates (sex, age, and marital status) to equation 1. In Model 3, we included area of residence. Finally, in Model 4, we included social class as a covariate to estimate the effect of Internet use on health, controlling for socioeconomic effects. Odds ratios, 95% confidence intervals, deviation statistics, and chi-square values were calculated for each model.

Results

Table 1 presents descriptive statistics of the study participants.

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Table 1. Descriptive statistics of study participants

Variable	No.	%
Sex		
Female	370	52.2
Age		
65-74 years	307	43.3
Marital status		
Never married	22	3.2
Married/living with partner	564	79.6
Separated/divorced	47	6.6
Widowed	76	10.6
Area of residence		
Country village or farm	296	41.8
Town or small city	145	20.4
Big city or surroundings	268	37.8
Social class		
High	57	8.1
Medium-high	65	9.2
Medium	186	26.3
Medium-low	251	35.5
Low	149	21.0
Internet use		
User	123	17.3
Self-rated health		
Poor	119	16.8

Table 2 summarizes the covariates of self-rated poor health from the four binomial logistic regressions models.

Results for Model 1 show that Internet users have statistically significant lower odds of being in the poor health category as compared to nonusers. This result remained for Model 2 and Model 3 as well, indicating that the effect of Internet use on health was still present after taking into account sex, age, marital status (Model 2), and area of residence (Model 3). In the specific case of marital status, we further checked if the small size of the "never married" category was affecting the results. Results remained the same whether we collapsed marital status into married vs other, or any other combination.

The inclusion of social class as a continuous covariate in Model 4, however, removed the statistical significance of the influence of Internet use on health that was observed in previous models (OR = 0.61, P = .23).

The only remaining significant covariate in Model 4 other than socioeconomic position was sex, indicating that women have 1.90 greater odds of being in the poor health category than men (P = .004), after adjusting for all other covariates of the study.

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Table 2. Covariates of self-rated poor health from four binomial logistic regressions models

	Model 1	Model 2	Model 3	Model 4
	OR (95% CI), *P*	OR (95% CI), *P*	OR (95% CI), *P*	OR (95% CI), *P*
Internet user status				
Nonuser	1	1	1	1
User	0.32 (0.16-0.67), .002	0.39 (0.18-0.83), .01	0.41 (0.19-0.87), .02	0.61 (0.27-1.37), .23
Sex				
Male		1	1	1
Female		1.87 (1.22-2.89), .004	1.89 (1.23-2.91), .004	1.90 (1.23-2.92), .004
Age				
55-64 years		1	1	1
> 64 years		0.99 (0.65-1.45), .99	0.97 (0.64-1.47), .88	0.95 (0.63-1.45), .82
Marital status				
Never married		1	1	1
Married/living with partner		1.53 (0.41-5.74), .52	1.45 (0.39-5.46), .58	1.43 (0.38-5.42), .60
Separated/divorced		0.64 (0.23-3.32), .59	0.65 (0.12-3.38), .61	0.62 (0.26-3.27), .57
Widowed		0.69 (0.16-3.03), .62	0.66 (0.15-2.91), .58	0.61 (0.14-2.73), .52
Area of residence				
Country village or farm			1	1
Town or small city			0.72 (0.40-1.32), .29	0.82 (0.45-1.51), .53
Big city or surroundings			1.02 (0.66-1.60), .90	1.14 (0.73-1.80), .57
Social class				0.74 (0.59-0.92), .008
Constant	0.23, < .001	0.12, .002	0.13, .004	0.24, .05
χ^2 (df)	12.17 (1), < .001	25.84 (6), < .001	27.31 (8), < .001	34.82 (9), < .001
Model deviation[a]	630.02	616.35	614.89	607.37

[a] Model deviation is measured as −2 log likelihood.

Discussion

This paper presents analyses from cross-sectional data exploring the potential association between Internet use and self-rated health among older people. Results initially showed a significant relationship between Internet use and self-rated health (Model 1), suggesting that Internet users have better self-rated health than nonusers. This effect remained when other sociodemographic variables (sex, age, marital status, and area of residence) were entered into the equation (Models 2 and 3). However, the significant relationship between Internet use and self-rated health disappeared once social class was considered (Model 4). Overall, these results suggest that there is no evidence supporting the idea that use of the Internet has a significant relationship with health for the older population once the socioeconomic position of individuals is taken into account.

The analysis of Internet users aged 55-74 years in relation to health issues is a strength of the study. Traditionally, little attention has been paid to Internet users in this age group. For instance, in Spain, little is known about this segment of the population beyond the fact that they constitute a rather small group. It has been suggested that access to and participation in the information society among older people will promote positive outcomes in health and well-being [3,6-9]. From this viewpoint, the digital divide would be a significant determinant of health for older people. And it appears to be so when the social position of individuals is ignored. Our results suggest, however, that the digital divide is not a source of health inequalities beyond already-existing socioeconomic inequalities of health. Therefore, the apparent relationship between the digital divide and health among older people appears to be a reflection of existing social inequalities in health. In other terms, Internet users can be healthier provided that they are wealthier. In this regard, our study further illustrates the association between socioeconomic position and heath indicators [30-37]. The socioeconomic gradient in health is a well-established finding in the literature that, even though it declines with age [45,46], extends to older people [34,47,50]. Furthermore, this socioeconomic gradient in health is observed regardless of whether socioeconomic status is measured by occupation, education, or income [35,37,47]. Our results also revealed gender differences in self-rated health that are in line with other studies reporting higher proportions of women rating their health as poor [33,50-54].

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Limitations

The study has several limitations. First, we examined self-rated health (ie, perceptions of health in general) and did not include specific measures of mental health. Future research would benefit from including specific measures of physical and mental health. Second, recent research has shown how self-rated health responses, our outcome variable, might be biased in certain sociodemographic groups. For instance, Delpierre et al [32] have shown that the impact of health problems on self-rated health is stronger among better-educated individuals. This phenomenon could lead to an underestimate of the health inequalities across socioeconomic groups. In our study, social class behaved as a key determinant of health among Internet users and nonusers, and, according to Delpierre et al, we cannot be sure about the real difference in health. Future research focusing on other measures of health is clearly needed. Third, random sampling of Internet users was done according to official data about people 55-74 years who used the Internet in the last 3 months. This is a broad definition of an Internet user that might have an effect on the results of the study. Finally, some caution must be taken in generalizing our results. Our data refer to cohorts of older people (individuals born between 1934 and 1953) with relatively small exposure to the Internet and other tools of the information society. It remains to be seen whether, for future cohorts of older people with greater exposure to the information society, the digital divide becomes a significant source of health inequalities. This is certainly an issue that deserves further research and consideration. In this context, future studies should also examine whether, among Internet users, those in higher socioeconomic groups would achieve better health outcomes through better information use and better use of the Internet.

Conclusions

In conclusion, results from this paper suggest that beyond the social divide, the digital divide does not add another source of health inequalities for older people. Older people are among the groups most excluded from the information society. Reducing the digital divide among older people has become a target for many policy initiatives since it is believed that the information society will provide benefits for the well-being of older people [9,10]. However, as the digital divide is also an expression of social inequalities, policies and initiatives aiming to reduce the digital divide, without reducing the social divide, may contribute to existing socioeconomic inequalities and may benefit those already advantaged.

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Conflicts of Interest

None declared.

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Original Paper

Disparities by Race and Ethnicity in Cancer Survivor Stories Available on the Web

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Abstract

Background: The rapid growth of eHealth could have the unintended effect of deepening health disparities between population subgroups. Most concerns to date have focused on population differences in access to technology, but differences may also exist in the appropriateness of online health content for diverse populations.

Objective: This paper reports findings from the first descriptive study of online cancer survivor stories by race and ethnicity of the survivor.

Methods: Using the five highest-rated Internet search engines and a set of search terms that a layperson would use to find cancer survivor stories online, we identified 3738 distinct sites. Of these, 106 met study criteria and contained 7995 total stories, including 1670 with an accompanying photo or video image of the survivor. Characteristics of both websites and survivor stories were coded.

Results: All racial minority groups combined accounted for 9.8% of online cancer survivor stories, despite making up at least 16.3% of prevalent cancer cases. Also notably underrepresented were stories from people of Hispanic ethnicity (4.1%), men (35.7%), survivors of colon cancer (3.5%), and older adults.

Conclusions: Because racial/ethnic minority cancer survivors are underrepresented in survivor stories available online, it is unlikely that this eHealth resource in its current form will help eliminate the disproportionate burden of cancer experienced by these groups.

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KEYWORDS

Cancer; health disparities; survivorship; African American; Hispanic; online

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Introduction

The benefits of eHealth information and services for patients and the public are well documented and numerous [1-8]. It is possible, however, that the growth of eHealth could have the unintended effect of deepening disparities in health status between population subgroups [9]. Most concerns in this regard have focused on population differences in access to technology, or the so-called "digital divide" [10]. More recently, research has focused on the availability of information over the Internet, or "infodemiology" [11,12]. But differences also exist in the *appropriateness* of health content available online for diverse population subgroups [13]. This issue has received much less attention in eHealth research and infodemiology and is the focus of the present study.

Specifically, the study explores the availability of online cancer survivor stories by race and ethnicity of the survivor. In the United States, cancer disproportionately affects African Americans, who are more likely than other groups to be diagnosed with cancer at a later stage of disease, who receive substandard cancer care once diagnosed, and who have lower 5-year survival rates and higher cancer death rates [14,15]. Similarly, Hispanic women have disproportionately high rates of cervical cancer, while Asian Americans and Pacific Islanders have higher rates of stomach and liver cancer [16]. Population-specific eHealth information and resources, such as online stories from cancer survivors representing these groups, might help address these disparities.

Survivors' stories can model coping skills, provide perspective, and share valuable information and resources. An estimated 2.3 million persons with cancer are online [17], and use of information sharing and support sites, precisely where survivor stories are commonly available, is widespread [18-20]. Survivors' direct experience and demonstrated success living with cancer makes them especially attractive and credible as messengers of cancer information [21], and studies have found psychological benefits for both the survivor and the recipient from sharing stories [22-24].

Race and ethnicity of a human information source are important factors in enhancing the effectiveness of communication, and specifically health communication, for members of minority populations. From a communication standpoint, the impact of information is generally enhanced when the recipient perceives the messenger as being similar to him- or herself. Similarity based on race, ethnicity, or other demographic characteristics can enhance receivers' liking of an information source [25] and trust in the source [26], and it can lead to inferences of attitudinal similarity that in turn increase respect and perceived attractiveness of the source [27]. Advertising research shows that viewer responses to ads are more favorable when the models or actors in the ads are of the same race or ethnicity as the viewers [28,29]; this is especially true in minority groups like African Americans and Hispanics [30], and the effect is greatest among viewers who identify strongly with their racial/ethnic group [31,32].

These findings are reinforced by cancer control research showing that videos using race- and gender-concordant messengers can increase use of cervical cancer screening [33] and identification with a quit smoking role model [34] among minority women. In the specific case of cancer survivor stories, a recent study among African American women found that by far the strongest predictor of becoming engaged in a cancer survivor's videotaped story and having positive reactions to the story was the extent to which participants saw themselves as similar to the survivor [21], including both attitudinal and demographic dimensions of similarity.

Finally, the importance of messenger characteristics is heightened when information is delivered via visual stimuli such as television, videos, and, increasingly, Web-based content. Studies show that compared to other media (eg, print, audio), video elicits more thoughts about and positive perceptions of a messenger [35,36], is better able to carry nonverbal messages [37], and is especially effective with messengers who are likable [38] or trustworthy [39,40]. In a meta-analysis of studies exploring source effects on persuasion, the size of such effects in visual media was exceeded only by face-to-face communication [41]. In short, the effects of race and ethnicity of a messenger will be greatest when these characteristics are apparent to audience members.

In summary, because survivor stories contain unique and valuable information, they may be especially useful to members of minority groups who suffer a disproportionate burden of cancer. Research from communication and persuasion suggests that audience members for such information are more likely to identify with and trust the survivor and act in accordance with the survivor's story if they are of the same race or ethnicity. Thus, if stories from racially and ethnically diverse survivors were available online, we would generally expect that people exposed to these stories could find potential role models that were similar to them and who they trusted and liked, which would increase the probability that the information provided by the survivor was adopted and used.

This paper reports findings from the first descriptive study to document the availability of online cancer survivor stories by race and ethnicity of the survivor and to compare the results to expected population proportions and to cancer burden by race and ethnicity. As the number of online survivor stories grows and evidence of their benefits builds, it is important for assuring population health and achieving health equity that the diversity of survivors represented in these stories matches that of potential users.

Methods

Sampling

ComScore's qSearch data were used to identify the five highest-ranked search engines at the time of data collection (October, 2007). ComScore is a global Internet information provider that maintains databases on real-time use of the Internet and consumer behavior in the Internet, and its qSearch tool measures all search activity on the Internet, including major search engines, private sites such as MySpace, vertical searches on sites such as Amazon or eBay, local searches for maps or directions, cross-channel searches such as searching the Web,

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maps and images for the same term, and more [42]. It is a comprehensive tool measuring the search universe, and it has been applied previously in scientific research [43]. The five top-ranked search engines were Google, Yahoo, Microsoft Sites (including MSN/Windows Live), Time Warner Networks (including AOL), and Ask Networks (including Ask.com) [42].

A subgroup of the study team generated a list of search terms that a layperson might use to search for online cancer survivor stories. This group included four family members of cancer patients, representatives of three different racial or ethnic groups, and an information science specialist with expertise in Web searching. The list took into consideration synonyms and word variations. A pilot search with each term was conducted, and the final six search phrases were selected because they yielded the largest number of relevant hits. The six search phrases used in the study were the following: "cancer survivor stor," "cancer stor," "cancer patient stor," "cancer testimonial," "sharing cancer stor," and "cancer experience." Boolean operator "OR" was used to perform the union of the six phrases. For cancers not identified by the word "cancer," such as leukemia, lymphoma, and melanoma, we replaced the word "cancer" in the six search phrases with each of these, resulting in 18 total search phrases for online stories of survivors diagnosed with leukemia, lymphoma, and melanoma. We chose these three cancers because they may have been missed in our search and are also prevalent in the United States [44]. While searching "stor" in Google, AOL, and Ask.com can yield results with both "story" and "stories," Yahoo and MSN/Windows Live do not accept the truncation search. Therefore, the words "story" and "stories" replaced "stor" in these search engines and resulted in doubling the total number of search phrases for these search engines. Summing all permutations of the original search terms, Google, AOL, and Ask.com had 24 distinct search phrases, while Yahoo and MSN/Windows Live had 48.

The search was performed from October 15 to October 30, 2007. Excluding sponsored links, the URLs of all websites were recorded until duplicates or irrelevant results dominated the search hits list, which resulted in 1420 websites identified from Google, 1055 from Yahoo, 1039 from MSN/Windows Live, 1055 from AOL, and 1053 from Ask.com. After removing exact duplicates, 3738 distinct websites were identified.

Eligibility

To be included in the study, a website had to (1) contain cancer survivor stories in text, audio, or video form with an accompanying photo or video of the survivor; and (2) identify (or imply) presentation and/or sharing of stories as a purpose of the site. This latter criterion excluded personal blogs, news stories, and websites ending in a "PDF" extension, as these were usually reports. Websites hosted outside the United States were also excluded due to differences in cancer prevalence, racial/ethnic composition of the population, and use of different search engines. A total of 106 websites met these eligibility criteria.

Coding

While many of the websites included stories without photos or video, we coded only those stories accompanied by a photo or video in which the survivor or storyteller was represented. Uncoded types of stories included those with text only, links to personal blogs, and stories entered on forums. On the 106 websites, there were 7995 stories total, of which 1670 (20.9%) had an accompanying photo or video image of the survivor.

Characteristics of websites and survivor stories were coded over a 2-month period from November 2007 to January 2008. Members of the research team who received formal training, rehearsal, and evaluative feedback completed all coding, adhering to specific operational definitions and coding instructions. The research team coded every cancer survivor story. In rare instances when a member of the research team had difficulty coding race or ethnicity, another trained coder was consulted and consensus reached.

Measures

Website Characteristics

For each website, we counted the number of all human images and human images of minorities appearing on the website's home page and (where applicable and different) on the home page for survivor stories. When minority images were present, they were coded using racial and ethnic categories from the 2000 US Census. Cancer site was coded as both a broad categorical type (a particular cancer, a set of related cancers, or general/all cancer) and by specific cancer (eg, lung cancer, breast cancer). Web address extension (.com, .edu, .org, etc) and the ability to post or share a story were also captured. The sponsoring organization of each website was recorded. Additionally, the total number of stories that were available on the website was recorded.

Survivor Characteristics

Survivor stories were coded for type of storyteller (cancer survivor, family member or friend of the survivor, or third person narrator such as the website editor or a journalist), survivor age at diagnosis, gender (when available in the story or discernible from an image), and survivor race and ethnicity (from story or images, using racial and ethnic categories from the 2000 US Census).

Form of Communication

Form of communication was recorded, including how the story content was presented (text or audio) and the type of image present (still image, video image, or link to photo). Both text and video stories could have accompanying audio tracks. Each image was coded for quality (professional photo/video vs a personal photo/video).

Cancer Type

Type of cancer, year of diagnosis, cancer stage, survival status, and years survived were also obtained, when available, from the content of the story. When information from story content or images was insufficient to make a definitive coding judgment for any measure, coders indicated so.

Statistical Analyses

Descriptive statistics are provided to characterize survivor stories and websites. All stories and websites are included in the analysis.

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Results

Website Characteristics

Characteristics of websites are summarized in Table 1. Of the 106 websites included in the final sample, 56 (52.8%) were hosted by nonprofit organizations (".org"), 7 (6.6%) by educational institutions (".edu"), and the remaining by for-profit companies, with Web extensions including ".com," ".html," and ".net." Sixty-four of the 106 websites addressed cancer in general (60.4%), while the remainder focused on a specific type of cancer (n = 34, 32.1%) or a set of related cancers, such as leukemia and lymphoma or brain and other nervous system cancers (n = 8, 7.5%). The number of stories per website ranged from 1 to 232, with a mean of 16.5 (SD 32.2).

Survivor Characteristics

Most stories were told by survivors (n = 1052, 63%), with the remainder told by a third person narrator (n = 390, 23.4%) or a family member or friend (n = 206, 12.3%). Most stories were told by women (n = 1073, 64.3%). When age was reported (n = 1008, 60.4% of stories), the mean age at diagnosis was 35 years. Characteristics of stories are summarized in Table 2.

Form of Communication

Stories could be presented in more than one form. Nearly all stories were told through written text (n = 1643, 99.2%), with some told through audio (n = 337, 20.2%) and/or video (n = 264, 15.8%). Most stories were accompanied by a still photo (n = 1643, 98.4%), and half of these photos (n = 936, 56.0%) were professional grade.

Cancer Type

One in four stories (n = 440, 26.3%) addressed breast cancer, followed by leukemia (n = 282, 16.9%), lymphoma (n = 165, 9.9%), prostate cancer (n = 142, 8.5%), and skin cancer, including melanoma, basal cell carcinoma, and squamous cell carcinoma (n = 69, 4.1%). Among stories that reported cancer stage at diagnosis (n = 318, 19.0%), later stages were most represented, with stage 4 diagnoses being most common (n = 88/318, 27.7%), followed by stage 3 (n = 85/318, 26.7%), stage 1 (n = 82/318, 25.8%), stage 2 (n = 57/318, 17.9%), and stage 0, (n = 6/318, 1.9%).

Table 1. Characteristics of websites containing cancer survivor stories (n = 106)

Characteristic	Percent[a]
Type of cancer website	
General cancer (n = 64)	60.4
Single cancer (n = 34)	32.1
Set of related cancers (n = 8)	7.5
Searching and sharing capabilities	
Users can post or share a story (n = 43)	40.6
Users can search library of stories with a search box (n = 11)	10.4
Images	
Images of racial/ethnic minorities on main landing page (n = 1501)	14.1
Images of racial/ethnic minorities on home page for stories (n = 1055)	14.6
Web address extension	
.org (n = 56)	52.8
.com (n = 37)	34.9
.edu (n = 7)	6.6
.htm(l) (n = 4)	3.7
.net (n = 2)	1.9
Number of stories, mean (SD)	16.5 (32.2)

[a] Values are percentages unless otherwise noted.

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Table 2. Characteristics of cancer survivor stories (n = 1670)

	Percent[a]				
Characteristic	Overall	White	Black	Asian[b]	Hispanic
Survivor/storyteller					
Primary storyteller					
Survivor (n = 1052)	63.0	62.8	68.0	61.3	61.8
Third person narrator (n = 390)	23.4	23.0	26.8	25.8	22.1
Family, friend, or caregiver (n = 206)	12.3	12.8	3.1	12.9	13.2
Could not be determined (n = 22)	1.3	1.3	2.1	0	2.9
Gender of survivor					
Female (n = 1073)	64.3	63.8	72.2	64.5	69.1
Male (n = 597)	35.7	36.2	27.8	35.5	30.9
Other characteristics					
Age in years at first cancer diagnosis (n = 1008), mean (SD)	35.0 (19.2)	35.1 (19.2)	38.0 (18.0)	29.0 (19.6)	35.4 (20.4)
Survivor living at time of story (n = 1670)	93.1	92.9	94.8	93.5	91.2
Form of communication					
Story content					
Text only (n = 1332)	79.8	80.4	82.5	64.5	79.4
Text and audio (n = 324)	19.4	18.8	17.5	35.5	20.6
Audio only (n = 13)	0.8	0.9	0	0	0
Type of image present					
Still image only (n = 1330)	79.6	79.9	81.4	75.8	88.2
Still image, video image, and link to photo (n = 172)	10.3	9.6	13.4	17.7	5.9
Still image and link to photo (n = 75)	4.5	4.7	1.0	1.6	2.9
Still image and video image (n = 66)	4.0	4.0	3.1	4.8	1.5
Video image only (n = 21)	1.3	1.3	1.0	0	0
Video image and link to photo (n = 5)	0.3	0.3	0	0	1.5
Link to photo only (n = 1)	0.1	0	0	0	0
Image quality					
Professional (n = 936)	56.0	55.9	57.7	53.2	45.6
Lay (n = 703)	42.1	42.2	41.2	46.8	48.5
Could not be determined (n = 31)	1.9	1.9	1.0	0	5.9
Cancer type and stage					
Most common cancer types[c]					
Breast (n = 440)	26.3	25.3	44.3	25.8	36.8
Leukemia (n = 282)	16.9	17.0	8.2	25.8	11.8
Lymphoma (n = 165)	9.9	9.7	8.2	17.7	8.8
Prostate (n = 142)	8.5	8.5	13.4	1.6	7.4
Skin (n = 69)	4.1	4.5	1.0	0	4.4
Brain and other nervous system (n = 66)	4.0	4.1	2.1	1.6	2.9
Ovary (n = 59)	3.5	3.7	1.0	1.6	1.5
Colon (n = 58)	3.5	3.4	3.1	6.5	2.9

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Characteristic	Percent[a]				
	Overall	White	Black	Asian[b]	Hispanic
Other (n = 363)	21.7	22.4	15.6	16.2	20.6
Unknown (n = 26)	1.6	1.4	3.1	3.2	2.9
Stage at diagnosis (when reported; n = 318)					
Stage 0 (n = 6)	1.9	1.7	14.3	0	0
Stage 1 (n = 82)	25.8	27.0	14.3	0	38.9
Stage 2 (n = 57)	17.9	17.7	14.3	22.2	11.1
Stage 3 (n = 85)	26.7	26.7	28.6	22.2	22.2
Stage 4 (n = 88)	27.7	27.0	28.6	55.6	27.8
Race/ethnicity of survivors					
Race					
White or White American (n = 1503)	90.0	-	-	-	-
Black or African American (n = 97)	5.8	-	-	-	-
Asian/Native Hawaiian/Other Pacific Islander (n = 62)	3.7	-	-	-	-
American Indian and Alaskan Native (n = 5)	0.3	-	-	-	-
Could not be determined (n = 3)	0.2	-	-	-	-
Ethnicity[d]					
Not Hispanic or Latino (n = 1524)	91.3	93.7	82.5	51.6	-
Hispanic or Latino (n = 68)	4.1	3.5	14.4	1.6	-
Could not be determined (n = 78)	4.7	2.8	3.1	46.8	-

[a] Values are percentages unless otherwise noted.

[b] Asian/Native Hawaiian/Other Pacific Islander.

[c] $P < .01$.

[d] $P < .001$.

Differences by Race/Ethnicity

A large majority of stories in our sample (n = 1503, 90%) were told by whites. Among minority groups, blacks or African Americans were represented in 5.8% of stories (n = 97), Asians (including Native Hawaiian and Other Pacific Islanders) in 3.7% of stories (n = 62), and American Indian and Alaskan Natives in 0.3% of stories (n = 5). Race could not be determined in 0.2% of stories (n = 3). For ethnicity, most stories were from non-Hispanic or non-Latino survivors (n = 1524, 91.3%); 4.1% of survivors were identified as Hispanic or Latino (n = 68). In 4.7% of stories, the survivor's ethnicity could not be determined (n = 78).

Most story characteristics did not differ across race or ethnicity. There was a significant difference in cancer type between races represented; however, with 33.3% of cells having counts less than five, the test statistic may not be valid.

Discussion

Minority cancer survivors are underrepresented in survivor stories currently available online. African Americans make up 12.4% of the US population [45], account for 8.6% of prevalent cancer cases (limited duration prevalence, 0 to < 15 years since diagnosis [46]), and have higher overall cancer mortality rates than all other racial or ethnic groups [47], but, in this study, they accounted for just 5.8% of online survivor stories (n = 97). Similarly, persons of Hispanic origin account for 15.1% of the US population and 5.3% of prevalent cancer cases [46], yet make up just 4.1% of online survivor stories (n = 68). While reliable prevalence data are not available for all racial and ethnic minority groups, Asian/Pacific Islanders are properly represented in online survivor stories in this study, with 2.4% of prevalent cancer cases [46] and 3.7% of stories (n = 62).

A combination of differences in online access and patterns of eHealth usage across racial and ethnic groups likely explains at least part of this disparity. While socioeconomic status remains an important determinant of Internet access via personal computer [48], minorities are less likely than whites to have such access even in the lowest income groups [49-51]. Among those who have online access, studies suggest that minority group members are less likely to participate in online cancer support groups [52] or use the Internet for obtaining health information [53]. If exposure to and use of such stories are indeed less common among minority cancer survivors, we would generally expect these groups to have lower rates of story

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sharing as well, at least on websites where survivors could post their own stories. For example, while some of the websites in the study allowed users to post their personal stories, this would only happen among those who could and did access the site.

But on most websites in the study sample, the collection of available stories was set by the host and was not open to posting from users. On some websites, we found a large discrepancy between the level of racial and ethnic diversity represented on the home page and the comparative lack thereof in the actual collection of stories (overall, the two rates were comparable: 14.1% vs 13.7%, respectively). One interpretation of these cases is that website hosts recognize the value of offering stories from a diverse set of survivors (and thus give their site the outward appearance of diversity), but find it more difficult to identify minority survivors and/or collect their stories for sharing. To more consistently deliver on the promise and appearance of diversity suggested by websites' home pages, hosts will likely need to take purposeful steps and consider different approaches to their story collection process. For example, access to racial and ethnic minority survivors might be increased by establishing partnerships with cancer care organizations serving these groups.

The disproportionate number of stories from young cancer survivors was unexpected and striking, even given the study's methods. While cancer affects people of all ages, it is predominantly an older person's disease. Yet the mean age of survivors who shared their stories was only 35, which is a full three decades younger than the median age at diagnosis for all cancers combined [47]. While a primary goal of this study was to determine whether race- and ethnicity-concordant survivor stories were available to minority cancer patients, this finding suggests that an even greater age gap may exist between those with cancer and those survivors whose stories are available online. Because sharing one's story online with accompanying photos or video requires some degree of computer savvy (which studies have shown is currently inversely related to age [50]), this finding is not altogether surprising. It is possible, for example, that this study's requirement of stories including a visual image of the survivor disproportionately excluded older survivors. It is also possible that those survivors whose stories did not disclose age at diagnosis (662/1670, or 39.6% in this sample) were older. Anecdotal information supports this latter explanation: we observed that in many stories from cancer survivors who were diagnosed at a young age, their age at diagnosis was highlighted as a kind of warning (eg, "I was only 28, I never thought this could happen to me"). Framing a story in this way would be less likely among older adults. While these two factors may account for some portion of the differences found, we think it is unlikely that they would entirely negate the finding, given the magnitude of the difference.

The finding that certain groups were underrepresented in survivor stories could also reflect the target audiences of the websites coded. Of the 106 websites, 39 were targeted at a specific survivor audience (eg, young adults or survivors of a specific cancer), and 42 were aimed at providing testimonials for a particular center, treatment, or product. Ten of the sites were targeted toward women, but only three were aimed at an audience of men. Perhaps most telling is that four sites were aimed specifically at younger adults, while none appear to be aimed at older adults, and none were specifically directed toward a minority group.

Limitations

As this discussion has already identified, there are limitations to the study. Cancer survivor stories that did not include pictures of the survivor were not part of the sample. While this was necessary to achieve the study aim (ie, to identify race and ethnicity of survivors whose stories are available online), it's possible that stories with and without pictures varied in other ways not intended in the study. If minority survivors were less likely than other survivors to provide a picture with their story, the study findings would underestimate the proportion of such stories. We have no indication whether survivor stories with and without pictures varied systematically by race or ethnicity. However, from a practical standpoint, unless story content explicitly mentioned the survivor's race or ethnicity, this information would not be available to an online information seeker who might value it. Thus, while any real differences might be of interest for academic purposes, they would be largely irrelevant to those consuming the stories.

We also acknowledge that making judgments of a survivor's race and ethnicity from online photos was sometimes challenging and, like any coding, subject to misclassification. In cases when multiple coders could not determine or agree upon a survivor's race or ethnicity, it was classified as such. But because there were so few cases where race and ethnicity could not be determined (3/1670, 0.2% for race; 78/1670, 4.7% for ethnicity), it is improbable that misclassification bias alone would account for the pattern of findings in the study, even if every survivor whose race or ethnicity could not be classified was in fact a minority group member. Finally, it is possible, but we think highly unlikely, that stories from minority survivors exist in proportionally greater numbers under different search terms than those used in the study.

Thirty-two percent of the stories (534/1670) were hosted by four large not-for-profit organizations promoting patient advocacy and research. Each of these organizations has a public face that may draw more survivors from a variety of racial/ethnic backgrounds and age groups. Another 14.7% of stories (246/1670) were on websites of prominent cancer research and treatment centers. Some websites and organizations are doing a better job than others in recruiting minority cancer survivors to share their stories of survival. Organizations providing this service can learn from the websites that have collected libraries of stories from diverse populations. We also recognize that three of the four primary cancers represented in these stories (breast, leukemia, and lymphoma) do not occur disproportionately in minorities, and, therefore, it may not be surprising that we did not find a larger proportion of stories from minorities.

Besides increasing the proportion of survivor stories from minorities, older adults, and men, the study findings also suggest that websites providing cancer survivor stories might enhance their offering in at least three other ways. First, our research team learned that finding survivor stories online was often challenging and time consuming, requiring study team members to search through a lot of other cancer content to find stories. Stories were seldom available from a single location on a

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website, and the location of stories varied greatly from site to site.

Second, we observed that few sites (11/106, 10.4%) offered users a means of searching available cancer survivor stories, and less than half (43/106, 40.6%) allowed users to share or post a story.

Third, although we found stories from survivors of a wide range of cancers, there were clear gaps in the distribution of cancers represented. For example, only 58/1670 (3.5%) of stories were from colon cancer survivors, despite colon cancer being the third leading cause of cancer death in United States [54]. In addition, stories from lung and bronchus cancer survivors, the leading cause of cancer death in the United States for both men and women, represented only 1.6% of stories in this sample (n = 27). It may be that those with lung and bronchus cancer do not live very long and therefore don't contribute to survivor stories on the Internet. We did find that when stage at diagnosis was reported, most of the survivors (173 of 318, 54.4%) were diagnosed with stage 3 or 4 cancers. Websites that select stories to post may choose stories from long-term survivors and from survivors who have overcome greater odds. Making improvements in these areas would enhance the accessibility and benefit of stories to users, as would developing technology tools that facilitate story sharing.

Future Implications

The study also raises new questions and identifies promising avenues for future inquiry. An important next step may be determining the relative importance of technological (eg, online access, digital camera ownership, computer skills), psychological (eg, interest and willingness), and organizational (eg, website policies) factors in explaining the dearth of online survivor stories from minorities, older adults, and men. Intervention and audience research studies among cancer survivors might explore strategies to raise awareness of, interest in, and motivation to share online stories. Such work would be especially valuable when conducted among groups that were underrepresented in the online collections of stories in the current study (eg, racial and ethnic minorities, older adults, men, those with certain types of cancer). Usability research could test alternative Web designs and functionality to optimize ease and efficiency of use for sharing and accessing survivor stories.

We know from previous research that when characteristics of survivors match those of the reader or viewer, the information provided by the survivor will be more engaging, enhance information recall, and stimulate more thoughts about the story [21]. While these are important communication outcomes, they are several steps removed from the kinds of prevention, screening, or treatment adherence behaviors that would actually reduce cancer disparities. Still, matching the race/ethnicity of survivor stories to a viewer would seem to be an important and achievable first step toward these higher order outcomes.

Although there are currently no published studies reporting numbers of minority survivors seeking online survivor stories, there is considerable evidence that minority groups want and need better health information and often turn to the Internet to find it. The Internet is an important source of health information for African Americans and other minority groups, including patients diagnosed with cancer [55,56,58,59]. Yet cancer survivors as a group—including African Americans and Hispanics—are more likely than healthy adults to report wanting more information, having difficulty finding desired information, feeling frustrated during their search for information, and finding the information too hard to understand [57]. Because of differences in access to and use of the Internet in minority populations, changing the mix of stories alone won't be enough to make an impact on cancer disparities. Changes in policy that would improve access to the Internet are also needed in addition to a better mix of survivor stories.

Conclusions

This study provides the first descriptive summary of online cancer survivor stories and identifies some important gaps in currently available offerings. There is a risk that the benefits these stories can confer to users might be unequally distributed across the population due to a lack of stories from members of certain groups. The fact that several of these underrepresented groups also bear a disproportionate burden of cancer suggests that the collection of survivor stories available online today is unlikely to help eliminate disparities in cancer.

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Conflicts of Interest

None declared.

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Original Paper

Social Media Use in the United States: Implications for Health Communication

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Abstract

Background: Given the rapid changes in the communication landscape brought about by participative Internet use and social media, it is important to develop a better understanding of these technologies and their impact on health communication. The first step in this effort is to identify the characteristics of current social media users. Up-to-date reporting of current social media use will help monitor the growth of social media and inform health promotion/communication efforts aiming to effectively utilize social media.

Objective: The purpose of the study is to identify the sociodemographic and health-related factors associated with current adult social media users in the United States.

Methods: Data came from the 2007 iteration of the Health Information National Trends Study (HINTS, N = 7674). HINTS is a nationally representative cross-sectional survey on health-related communication trends and practices. Survey respondents who reported having accessed the Internet (N = 5078) were asked whether, over the past year, they had (1) participated in an online support group, (2) written in a blog, (3) visited a social networking site. Bivariate and multivariate logistic regression analyses were conducted to identify predictors of each type of social media use.

Results: Approximately 69% of US adults reported having access to the Internet in 2007. Among Internet users, 5% participated in an online support group, 7% reported blogging, and 23% used a social networking site. Multivariate analysis found that younger age was the only significant predictor of blogging and social networking site participation; a statistically significant linear relationship was observed, with younger categories reporting more frequent use. Younger age, poorer subjective health, and a personal cancer experience predicted support group participation. In general, social media are penetrating the US population independent of education, race/ethnicity, or health care access.

Conclusions: Recent growth of social media is not uniformly distributed across age groups; therefore, health communication programs utilizing social media must first consider the age of the targeted population to help ensure that messages reach the intended audience. While racial/ethnic and health status–related disparities exist in Internet access, among those with Internet access, these characteristics do not affect social media use. This finding suggests that the new technologies, represented by social media, may be changing the communication pattern throughout the United States.

(J Med Internet Res 2009;11(4):e48) doi:10.2196/jmir.1249

KEYWORDS

Internet; social media; social networking; demography; population surveillance; eHealth, new technologies; health communication

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Introduction

From 2005 to 2009, participation in social networking sites more than quadrupled [1]. In the health communication community, there is a widespread assumption that recent advances in Internet technologies (Web 2.0), particularly the participative Internet (known as social media), have transformed the pattern of communication, including health-related communications [2]. For example, social scientists observed that social media have increased individuals' connectivity and enabled users' direct participation. This observation is believed to have direct implications for health communication programs, prompting efforts to identify new opportunities of using social media to impact population health [3-6]. While these observations on the impact of social media are important in public health, little of the research in this area has been based on large-scale population data, partly due to the rapidity of technological changes. The key questions that remain unanswered include the following: (1) What is the true reach and impact of social media among the current US population? (2) What are the user characteristics of the different types of social media currently being used? Although market research has previously reported on the overall prevalence of Internet and social media use, with the exception of online support group use, user characteristics of social media have not been comprehensively examined using a nationally representative population sample [7]. Developing an empirically based understanding of these behaviors and their implications has become a key priority in current health communication research.

Given that key aims of social media research are to monitor its growth and to inform health promotion efforts aiming to utilize new communication technologies, it is important to explore the relationship between social media use and health-related factors. Current research on the relationship between social media and health has produced conflicting results. On the one hand, studies have found that social media may bear health-enhancing potential through several mechanisms. First, the Internet-based social networks may increase perceived social support and interconnectivity among individuals [8,9]. Second, with the increase of user-generated content, information sharing is seen as more democratic and patient controlled, enabling users to exchange health-related information that they need and therefore making the information more patient/consumer-centered [10]. Third, in recent times, public health programs have demonstrated success in adapting social media as a communication platform for health promotion efforts such as smoking cessation and dietary interventions, increasing their reach through cyberspace [3,4,6,11-13].

Yet, indirect and sometimes unintended negative health impacts of social media have also been identified. First, the participatory nature of social media entails an open forum for information exchange, therefore increasing the possibility of wide dissemination of noncredible, and potentially erroneous, health information [14,15]. Second, health scientists exploring the issue of the digital divide have found evidence of a double divide. Specifically, those without Internet access (a large portion of whom may be without adequate health care access) are prevented from gaining health information available on the Internet [16-20]. In sum, given the direct and indirect health impacts and the wide range of and divergent results, the current study will offer an opportunity to disentangle aspects of the complex relationship between social media use and health-related factors.

The most recent iteration of the Health Information National Trends Survey (HINTS 2007) is an ideal data source to provide an in-depth examination of the prevalence and user characteristics of social media. This nationally representative survey is uniquely positioned to study social media because this new iteration contains specific follow-up questions for all Internet users, allowing us to separately estimate and compare the use of different types of social media. Another distinct advantage of the HINTS 2007 is its inclusion of many health-related questions, enabling us to comprehensively examine the association between social media use and several important health proxies. Our primary research aims are to (1) report on the prevalence of three forms of social media use in 2007: online support group participation, blogging, and social networking site participation; and (2) identify the sociodemographic and health-related predictors of the use of these three forms of social media.

Methods

Data Source

The data for this study were drawn from HINTS 2007, developed by the National Cancer Institute in 2007 with data collected from January 2008 through May 2008. Publicly accessible on the Internet, the HINTS is a biennial national survey of the US civilian noninstitutionalized adult population designed to assess the American public's use of health- and cancer-related information and to assess other cancer-related knowledge, attitudes, and behaviors. The survey's primary goal is to inform social scientists and program planners about current health communication usage across populations and to assist in developing effective health communication strategies in an age of rapid communication changes. Comprehensive reports on the conceptual framework and sample design of HINTS are published elsewhere [21,22]. Note that while the conceptual framework and most survey content remained consistent across the three iterations of HINTS (2003, 2005, and 2007), the newest iteration (HINTS 2007) contains some changes. Detailed information about HINTS 2007 scope and methodology can be found in a comprehensive report [23]. Specifically, in addition to the inclusion of new survey items (such as items concerning blogging and social networking site participation), a new sampling method was adopted for HINTS 2007 to increase response rates and reduce bias. Two modes were used for data collection: (1) a random digit dial telephone survey, using a computer-assisted telephone interview, of representative samples of US households with land-line telephones (N = 4092); and (2) a pencil-and-paper questionnaire mailed to representative US postal addresses that oversampled for minorities (N = 3582). The use of the dual sampling frames was a response to the recent dramatic decrease in telephone survey response rates and is a method currently being utilized by other government agencies. Response rates were 24% for the random digit dial survey and

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31% for the mail survey. Complete surveys were obtained from 7674 adults. Only Internet users (N = 5078; approximately 68% of the population) were asked about social media use, and they form the sample for the current study.

HINTS contained both final sample weights that helped obtain population-level estimates and a set of 50 replicate sampling weights to obtain the correct standard errors; both of these were included in the present analysis. Detailed descriptions of how the sample and replicate weights were calculated can be found in the HINTS 2007 Final Report [23].

Study Variables

We selected the following sociodemographic variables to be included in the study: age, gender, education, and race/ethnicity. Age was categorized into six groups: 18-24, 25-34, 35-44, 45-54, 55-64, 65 and above. Education was categorized as high school degree or less, some college, or college graduate. Race/ethnicity was coded into one of the following four categories: non-Hispanic white, non-Hispanic black (black/African American), Hispanic, and non-Hispanic other.

In addition to the sociodemographic variables, three health-related variables were examined. The first is self-described health status, including overall health and distress level(measured by a summed score of six-item assessment of depressive symptoms borrowed from the National Health Interview Survey, 1997, Adult Core Questionnaire [24]). The second is the respondent's cancer experience, coded into three categories: (1) having had a personal diagnosis of cancer, (2) having had a family member diagnosed with cancer, or (3) having had no personal experience or family member with cancer. Note that the categories are mutually exclusive: individuals with a personal diagnosis of cancer are automatically categorized as (1) regardless of their status in (2). The final health-related variable is health care access, measured by whether the respondent reports having a regular health care provider or not.

Internet status was measured by response to the following question: "Do you ever go on-line to access the Internet or World Wide Web, or to send and receive an email?" Among Internet users, social media use was assessed by responses to the following three questions: "In the past 12 months, have you done the following while using the Internet: (1) participated in an on-line support group for people with a similar health or medical issue? (2) wrote in an online diary or blog? (3) visited a social networking site, such as 'My Space' or 'Second Life'?"

Data Analysis

To accommodate the complex sampling design of HINTS, analyses were conducted using SUDAAN, version 10 (Research Triangle Institute, Research Triangle Park, NC, USA). Missing data (with responses of "refuse" or "don't know") were recoded as missing for all analyses. Bivariate analyses (chi-square) were conducted to estimate the prevalence of social media use and associations between study variables and each of the three types of social media. To address potential differences in responses due to the dual frames of the 2007 survey, we tested for potential mode differences and found no differential responses by mode to any of the social media use outcomes of interests; thus, a combined sample was used for subsequent analysis.

Separate multivariate logistic regression models were conducted to estimate the odds of writing a blog, participating in an online support group, and participating in a social networking site, while including a set of demographic and health-related predictors. Finally, given the overwhelmingly significant contribution of age in all three models, each outcome was tested using age-stratified analyses by running separate models within each of the three age categories of 18-34, 35-54, and 55 and above.

Results

Sample Characteristics

In 2007, approximately 69% of the US population reported having access to the Internet. This estimate is consistent with other prevalence estimates of Internet use in the same period [1]. Table 1 displays the weighted sample characteristics of non-Internet users and Internet users.

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Table 1. Weighted sample characteristics: proportion of non-Internet and Internet users in each category

Characteristic	Non-Internet Users (N = 2566, 31.46%)	Internet Users (N = 5078, 68.54%)
Age	*P* < .001	
18-24	15.2%	84.8%
25-34	23.0%	77.0%
35-44	21.7%	78.3%
45-54	28.9%	71.1%
55-64	33.0%	67.0%
65+	66.4%	33.6%
Gender	*P* = .003	
Male	33.6%	66.4%
Female	29.5%	70.6%
Education	*P* < .001	
High school or less	50.5%	49.5%
Some college	17.1%	82.9%
College graduate	9.0%	91.0%
Race/ethnicity	*P* < .001	
Non-Hispanic white	25.0%	75.2%
Hispanic	50.7%	49.3%
Black/African American	43.3%	56.8%
Other[a]	25.8%	74.2%
General health	*P* < .001	
Excellent, very good, or good	26.7%	73.3%
Fair or poor	51.4%	48.6%
Psychological distress	*P* < .001	
Yes	43.4%	56.6%
No	28.4%	71.6%
Cancer experience	*P* < .001	
No personal experience with cancer	36.7%	63.3%
Had family with cancer	26.3%	73.7%
Cancer survivor	43.1%	56.9%
Have regular health care provider	*P* < .001	
Yes	29.1%	70.9%
No	35.7%	64.3%

[a] Other includes American Indian, Asian American, Pacific Islander, Native Hawaiian, Alaskan Native, and multiple races mentioned.

Bivariate analyses revealed a number of significant differences between Internet users and non-Internet users. Consistent with prior results, non-Internet users were more likely to be ethnic minorities, older, less educated, less healthy, more distressed, and to report a history of a cancer diagnosis.

Further, as Table 2 below shows, among Internet users, approximately 27% reported using at least one form of social media. We used chi-square tests to compare those who reported using social media (as defined by individuals who responded "yes" to at least one of the three questions on social media) to Internet users who reported not using social media.

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Table 2. Weighted sample characteristics of Internet users (N = 5078, 68.54% of US population) who use and do not use social media

Characteristic	Don't Use Social Media (N = 3660, 72.65%)	Use Social Media (N = 1378, 27.35%)
Age[a]	*P* < .001	
18-24	23.7%	76.4%
25-34	42.7%	57.3%
35-44	64.6%	35.5%
45-54	77.6%	22.4%
55-64	86.8%	13.1%
65+	92.0%	8.00%
Gender	*P* = .25	
Male	60.2%	39.8%
Female	62.6%	37.4%
Education[a]	*P* = .02	
High school or less	62.1%	37.9%
Some college	58.7%	41.3%
College graduate	65.3%	34.7%
Race/ethnicity[a]	*P* < .001	
Non-Hispanic White	64.9%	35.2%
Hispanic	56.4%	43.6%
Black/African American	53.4%	46.6%
Other[b]	49.7%	50.3%
General health	*P* = .27	
Excellent, very good, or good	62.5%	37.5%
Fair or poor	58.3%	41.7%
Psychological distress[a]	*P* = .02	
Yes	49.1%	50.9%
No	62.7%	37.3%
Cancer experience [a]	*P* < .001	
No personal experience with cancer	61.3%	38.7%
Had family with cancer	60.7%	39.3%
Cancer survivor	81.6%	18.4%
Have regular health care provider[a]	*P* < .001	
Yes	65.4%	34.7%
No	52.4%	47.6%

[a] Variables that are significantly associated with social media use at *P* < .05 level.

[b] Other includes American Indian, Asian American, Pacific Islander, Native Hawaiian, Alaskan Native, and multiple races mentioned.

Among Internet users, use of social media was not uniformly distributed across the age strata. The largest proportion of social media use occurred among Internet users between the ages of 18 and 24 (65%) and decreased thereafter with each subsequent age group. In addition, patterns of social media use varied by race. Non-white Americans who accessed the Internet were more likely to use social media than white Americans.

The potentially different user characteristics among different types of social media prompted separate analyses by each type of media. Table 3 summarizes the bivariate associations between each type of social media (not mutually exclusive) and the study variables.

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Table 3. Bivariate associations between three types of social media use and study variables: weighted results

Characteristic	Online Support Group Users (N = 232)	Bloggers (N = 356)	Social Networking Site Users (N = 1159)
Percent of Internet users	4.6%	7.1%	23.0%
Age[a]	*P* < .001	*P* < .001	*P* < .001
18-24	1.4%	21.3%	74.0%
25-34	7.8%	16.3%	52.1%
35-44	6.7%	8.2%	30.4%
45-54	5.3%	4.7%	17.5%
55-64	3.6%	3.2%	9.2%
65+	2.0%	1.3%	5.5%
Gender	*P* = .06	*P* = .34	*P* = .13
Male	4.0%	9.3%	35.9%
Female	5.9%	10.6%	32.7%
Education[a]	*P* = .02	*P* = .12	*P* = .005
High school or less	3.5%	8.4%	35.4%
Some college	6.7%	12.0%	36.8%
College graduate	4.2%	8.8%	29.7%
Race/ethnicity [a]	*P* = .81	*P* = .43	*P* < .001
Non-Hispanic white	5.0%	8.9%	31.2%
Hispanic	3.5%	9.1%	41.3%
Black/African American	5.2%	12.9%	42.8%
Other[b]	4.9%	12.9%	44.7%
General health[a]	*P* = .003	*P* = .82	*P* = .70
Excellent, very good, or good	4.1%	9.7%	33.8%
Fair or poor	10.8%	10.2%	35.2%
Psychological distress[a]	*P* = .01	*P* = .45	*P* = .06
Yes	15.7%	13.5%	44.6%
No	4.2%	9.6%	33.4%
Cancer experience[a]	*P* < .001	*P* < .001	*P* < .001
No personal experience with cancer	2.6%	8.1%	36.5%
Have family with cancer	5.4%	11.0%	35.0%
Cancer survivor	8.1%	3.5%	10.2%
Have regular health care provider [a]	*P* = .83	*P* = .02	*P* < .001
Yes	5.1%	8.6%	30.2%
No	4.7%	13.3%	43.7%

[a] Variables that are significantly associated with one or more of the social media variables at *P* < .05 level.

[b] Other includes American Indian, Asian American, Pacific Islander, Native Hawaiian, Alaskan Native, and multiple races mentioned.

Among the three forms of social media included in the survey, social networking received the most utilization (23% of Internet users), followed by blogging (7% of Internet users) and, finally, participation in online support groups (5% of Internet users).

Blogging and social networking site participation showed the expected inverse linear relationship with age (ie, increased use across decreasing age strata). Partially because of the younger age, users tend to not have personal experience with cancer and not have a regular health care provider. The user characteristic profile of online support group participation was distinct from

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the other two forms of social media. Use of online support groups was rarely seen in the youngest age group (18-24) and was uniquely associated with several health-related factors, including rating general health as poor and reporting psychological distress. In contrast, blogging and social networking site participation were not associated with measures of self-reported health status. Finally, we found an unexpected education and racial/ethnic breakdown among social networking site users: less-educated individuals and racial/ethnic minorities were more likely to use this form of social media. However, these differences disappeared in subsequent regression analyses (below), suggesting that the differences observed here are likely explained by age.

Multivariate Analyses

The three separate multivariate regressions estimated the odds of using a particular form of social media in HINTS 2007. Given that gender was not associated with social media use at the bivariate level, we dropped it from the regression models. Table 4 displays the results of the analysis.

Among Internet users, online support group participation was predicted by age, education, as well as several health-related factors. Compared with people 65 and over, those aged 25-44 were three to five times more likely to use support groups. Compared with college graduates, those with some college were more likely to use support groups. Moreover, consistent with the bivariate-level observations, those who regarded themselves as less healthy, more distressed, and who had a personal cancer experience were more likely to have used online support groups, confirming that health status is an important determinant of support group participation.

In contrast to the model for support group participation, age emerged as the only significant predictor in the models of blogging and social networking site participation. A statistically significant linear effect of age on the two outcome variables was observed ($P < .001$). Among individuals aged 55 and below, we observed a strong linear age effect, with each decreasing age stratum, in the odds of blogging. Participation in social networking sites shared similar user characteristics, except the odds ratios were even larger, with the age effect encompassing every age stratum. In addition, among Internet users, African Americans were more likely than non-Hispanic whites to use a social networking site (OR = 1.51, 95% CI 1.01-2.24).

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Table 4. Multivariate logistic regressions of three types of social media use among Internet users

Characteristic	Odds of Participating in an Online Support Group		Odds of Writing in a Blog		Odds of Using a Social Networking Site	
	OR (95% CI)	*P*	OR (95% CI)	*P*	OR (95% CI)	*P*
Age		< .001		< .001		< .001
18-24	0.98 (0.28-3.45)	.98	19.11 (7.60-48.06)	< .001	47.85 (27.92-82.00)	< .001
25-34	4.97 (2.30-10.75)	< .001	13.12 (5.53-31.13)	< .001	17.62 (10.56-29.42)	< .001
35-44	3.64 (1.87-7.08)	< .001	6.71 (2.80-16.06)	< .001	6.97 (4.57-10.64)	< .001
45-54	3.16 (1.59-6.28)	.002	3.31 (1.31-8.39)	.01	3.41 (2.23-5.20)	< .001
55-64	1.76 (0.78-3.93)	.17	1.96 (0.77-4.99)	.15	1.62 (1.04-2.52)	.03
65+	1.00		1.00		1.00	
Education		.01		.07		.48
High school or less	0.83 (0.48-1.43)	.49	0.73 (0.52-1.03)	.07	0.85 (0.65-1.11)	.23
Some college	1.58 (1.06-2.36)	.02	1.11 (0.77-1.60)	.56	0.96 (0.74-1.23)	.73
College graduate	1.00		1.00		1.00	
Race/ethnicity		.92		.47		.13
Non-Hispanic white	1.00		1.00		1.00	
Hispanic	0.75 (0.30-1.92)	.55	0.78 (0.37-1.65)	.51	0.83 (0.53-1.31)	.42
Black/African American	0.99 (0.48-2.08)	.98	1.58 (0.85-2.95)	.14	1.51 (1.01-2.24)	.04
Other[a]	1.08 (0.46-2.56)	.86	1.31 (0.63-2.75)	.46	1.36 (0.82-2.27)	.23
General health						
Excellent, very good, or good	1.00		1.00		1.00	
Fair or poor	2.25 (1.31-3.87)	.004	1.01 (0.53-1.93)	.97	1.09 (0.77-1.55)	.63
Psychological distress						
Yes	3.28 (1.59-6.77)	.001	1.45 (0.53-3.96)	.46	1.49 (0.88-2.52)	.14
No	1.00		1.00		1.00	
Cancer experience		.002		.15		.02
No personal experience with cancer	1.00		1.00		1.00	
Have family with cancer	2.11 (1.24-3.58)	.007	1.53 (0.99-2.38)	.06	1.12 (0.85-1.48)	.41
Cancer survivor	4.20 (1.98-8.92)	< .001	1.24 (0.56-2.74)	.60	0.63 (0.40-1.01)	.06

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Characteristic	Odds of Participating in an Online Support Group		Odds of Writing in a Blog		Odds of Using a Social Networking Site	
	OR (95% CI)	*P*	OR (95% CI)	*P*	OR (95% CI)	*P*
Have regular health care provider						
Yes	1.05 (0.58-1.90)	.87	0.99 (0.63-1.58)	.97	1.13 (0.85-1.52)	.39
No	1.00		1.00		1.00	

[a] Other includes American Indian, Asian American, Pacific Islander, Native Hawaiian, Alaskan Native, and multiple races mentioned.

Age-Stratified Multivariate Analyses

Given the central role of age in predicting social media use, and the significant interactions found between age and race/ethnicity, we conducted age-stratified logistic regressions to see whether adjusting for specific age strata would illuminate other important variables associated with social media use. Age was stratified into three categories for multivariate logistic regression models: 18-34 (younger group), 35-54 (middle-age group), 55 and older (older group). In general, the stratified models confirmed age to be the single most important predictor of social media use. Significant predictors within each type are summarized below. Note that all results reported are significant at $P < .05$.

Online Support Group

In the youngest group, higher education (OR = 6.33, 95% CI 2.10-19.10) and higher distress level (OR = 5.56, 95% CI 1.65-18.76) explained the outcome. Among the middle-age group, female gender (OR = 2.04, 95% CI 1.20-3.46) and higher education (OR = 2.13, 95% CI 1.21-5.12) were significant predictors. In the oldest group, poorer self-reported health (OR = 3.39, 95% CI 1.38-8.34) explained support group use.

Blogging

In all three age categories, the age-stratified models found no significant predictors of blogging.

Social Networking Sites

In the middle-age group, having no personal experience with cancer predicted social networking site participation (OR = 0.39, 95% CI 0.18-0.86). For the oldest group, male gender was the sole predictor of social networking site use (OR = 1.87, 95% CI 1.28-2.71).

Discussion

The current study examined sociodemographic and health-related predictors of the use of three forms of social media in an effort to better understand who is accessing and being reached through these emerging communication channels. The results showed that these three forms of social media have distinctly different use patterns and user characteristics, hence different health communication implications. Among the three forms of social media considered in this study, social networking sites by far attract the most users, making them an obvious target for maximizing the reach and impact of health communication and eHealth interventions. Furthermore, with increasing prevalence of personal wireless devices, communication scientists unanimously anticipate the popularity of social networking applications to continue to grow worldwide [2,25-27]. Compared to social networking sites, a much smaller percentage of Internet users reported writing in a blog, suggesting a lower prevalence of blogging. However, reading and commenting on a blog may have been a more reliable measure of blogosphere penetration due to its lower intensity than actively keeping a blog. Moreover, the blogosphere presents a tremendous opportunity for health communication. Particularly so, because bloggers have been observed to act as important communication stakeholders—not only are they information disseminators, but they play a crucial role in directing Internet traffic through opinions and hyperlinks [28].

Online support group participation was the only survey item included in the present study that was assessed throughout the three iterations of HINTS, and the weighted prevalence estimates suggest a minor increase: in 2003 and 2005, 3.9% of Internet users had participated in online support groups compared to 4.6% in 2007. User characteristics of support groups differed from blogging and social networking site participation, suggesting that online support group participation is driven by health status. This disease-focused medium may be gradually replaced by more interactive, patient-directed social networking sites and blogs, such as CaringBridge and Patientslikeme. These forms of social media have the potential to serve the social support and empowerment functions previously identified for online support groups [29].

Apart from the patterns described above, the results of the study underscore the extent to which age determines who among US adult Internet users are engaging with social media. In this nationally representative sample, age emerged as the single strongest predictor of both social networking and blogging. In light of these findings, it seems reasonable to conclude that health communication efforts utilizing social media will have the broadest reach and impact when the target population is the younger generation. The relatively low penetration in the older population of 55 and older suggests that it is not yet an opportune time to utilize social media in communication with this age group. While this is true currently, we predict a continuing increase in utilization across all generations and groups in the next few years, and it remains a key health communication priority to continue tracking the sociodemographic trends of social media use to be sure that health communicators leverage these dissemination channels most effectively. Finally, for cancer communication efforts, this study found a high prevalence of Internet and social media use among individuals with family members who have/had cancer (see Table 1 and Table 2), suggesting the potential effectiveness

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of social media cancer communication efforts targeting "secondary audiences," that is, caregivers, family, and friends of cancer patients.

A key finding of this study offers new and important implications for health communication in this digital age: among Internet users, social media are found to penetrate the population regardless of education, race/ethnicity, or health care access. In particular, the multivariate analyses showed that having access to a regular health care provider did not predict social media use, suggesting that its significance in the bivariate analyses was primarily due to the effect of age. Specifically, younger individuals are less likely to have a regular health care provider. Considering implications of health communication efforts, the results of this study suggest that in the future, social media promise to be a way to reach the target population regardless of socioeconomic and health-related characteristics. If we can enable broader and more equitable Internet access (eg, increasing broadband access or wireless mobile access), thus reducing the digital divide, the potential for impacting the health and health behavior of the general US population through social media is tremendous. Furthermore, the results showed social networking sites are being utilized by African Americans at a higher rate than by non-Hispanic whites. Given the continuing increase in Internet penetration, these findings suggest a potential systematic shift in the communication pattern that transcends the traditional digital divide. Future studies should continue to examine the impact of changing technologies on patterns of health disparities. On the practice side of health communication, social media outlets may represent an excellent opportunity to reach traditionally underserved members of the population.

Limitations

The nature of self-report and the current low survey response rates present two major challenges to the generalizability of the results. First, the accuracy of self-reports of specific Internet usage may be affected by recall bias and respondents' comprehension of survey items. In spite of this issue, this study's prevalence estimates on Internet and social media penetration are in agreement with the published literature and are the first to be drawn from a nationally representative sample. One aspect to note is that compared to market surveys such as the Pew and Manhattan Research reports, the HINTS estimates are generally more conservative. This is in part attributable to the higher sampling precision mandated for federal surveys. Second, low response rate being a challenge facing all current survey research, HINTS 2007 attempted to boost response rates and extend coverage (especially to cell phone–only households) by adapting a dual sampling frame. As a result, the addition of the mail survey helped remedy the low response rate, to increase the generalizability of the data.

An additional limitation concerns the instrumentation and questions related to blogging and social networking site participation: since neither question asked specifically about health-related use of these technologies, we cannot precisely estimate the prevalence of health-related social media use using HINTS data. Given the growing role of social media in health, future iterations of HINTS may specifically capture health-related social media use [10]. As well, the question on blogging does not capture individuals who view and comment on blogs and thus may underestimate the degree to which the American public is engaged with this activity.

Finally, with new technologies and social media continuing to evolve rapidly, these data, despite being the most updated national survey data available, may not have been able to capture some emerging social media forms (eg, Twitter and Wikipedia) and rapid changes brought on by the increasing use of personal wireless devices [27]. In order to track the public's use of new media, future research should track different age groups' social media adoption while identifying new forms of social media. Given that the younger age groups are likely to continue their use of social media, we would expect to see a persistent increase across the middle-age population in the near future.

Conclusions

With the goal to develop a better understanding of social media use in the current US population, we have reported on the prevalence and user characteristics of three types of social media using the 2007 HINTS survey. While observations and theories about communication changes brought about by new technologies abound, little is supported by empirical evidence based on nationally representative data. The findings of this study contribute to the knowledge base to inform future programs aiming to utilize social media.

As we have seen, forms of social media present different opportunities for health communication efforts. In particular, social networking sites attract the largest portion of Internet users and are likely to continue to grow, making them an obvious target for maximizing the reach and impact of health communication and eHealth interventions. In addition, recent growth of social media is not uniformly distributed across age groups. New health communication programs aiming to utilize social media must first consider the age of the targeted population. The data also prompt a rethinking of the connection between technologies and health disparities since the findings point to the fact that social media are penetrating individuals of different demographics at the same rate. Opportunities for narrowing the health disparities gap exist through effective use of social media as communication and health promotion platforms. These media will not enable targeted communication messages but may have the capacity to reach a wider audience than traditional media have been able to reach.

Finally, while surveillance research such as the present project is useful for determining the reach of social media, it is less useful for assessing the impact of participation in social media use on health. To assess the multiple levels of social media impact on health, future studies need to bring in diverse disciplines and methods, including intervention studies, longitudinal cohort studies, as well as ethnographic/qualitative observations to examine the effect of the social media–driven changing communication patterns on health.

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Conflicts of Interest

None declared.

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Abbreviations

HINTS: Health Information National Trends Survey

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Original Paper

Age-Sensitive Design of Online Health Information: Comparative Usability Study

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Abstract

Background: Older adults' health maintenance may be enhanced by having access to online health information. However, usability issues may prevent older adults from easily accessing such information. Prior research has shown that aging is associated with a unique pattern of cognitive changes, and knowledge of these changes may be used in the design of health websites for older adults.

Objective: The goal of the current study was to examine whether older adults use of a health information website was affected by an alternative information architecture and access interface (hierarchical versus tag-based).

Methods: Fifty younger adults (aged 18-23) and 50 older adults (aged 60-80) navigated a health information website, which was organized hierarchically or used tags/keywords, to find answers to health-related questions while their performance was tracked. We hypothesized that older adults would perform better in the tag-based health information website because it placed greater demands on abilities that remain intact with aging (verbal ability and vocabulary).

Results: The pattern of age-related differences in computer use was consistent with prior research with older adults. We found that older adults had been using computers for less time ($F_{1,98}$= 10.6, P= .002) and used them less often ($F_{1,98}$= 11.3, P= .001) than younger adults. Also consistent with the cognitive aging literature, younger adults had greater spatial visualization and orientation abilities ($F_{1,98}$= 34.6, P< .001 and $F_{1,98}$= 6.8, P= .01) and a larger memory span ($F_{1,98}$= 5.7, P= .02) than older adults, but older adults had greater vocabulary ($F_{1,98}$= 11.4, P= .001). Older adults also took significantly more medications than younger adults ($F_{1,98}$= 57.7, P< .001). In the information search task, older adults performed worse than younger adults ($F_{1,96}$= 18.0, P< .001). However, there was a significant age × condition interaction indicating that while younger adults outperformed older adults in the hierarchical condition ($F_{1,96}$= 25.2, P< .001), there were no significant age-related differences in the tag-based condition, indicating that older adults performed as well as younger adults in this condition.

Conclusions: Access to online health information is increasing in popularity and can lead to a more informed health consumer. However, usability barriers may differentially affect older adults. The results of the current study suggest that the design of health information websites that take into account age-related changes in cognition can enhance older adults' access to such information.

(J Med Internet Res 2009;11(4):e45) doi:10.2196/jmir.1220

KEYWORDS

Internet; information organization; aging; health-related websites

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Introduction

According to a recent Pew report on Internet usage, up to 80% of American Internet users have accessed health information on the Internet, with 64% of Americans searching for information about a specific disease and 51% searching for treatments [1]. The ease with which health consumers can access high-quality, doctor-reviewed medical information has the potential to allow patients to take more control of their health outcomes. The same Pew report shows mostly positive perceived outcomes with this ease of information access, such as feeling relieved or comforted by the information found (56%) and, more importantly, feeling confident about raising questions to the doctor after searching the Internet (56%).

However, the wealth of available information may be a curse to some health consumers: 25% of consumers who have searched for health information on the Internet felt overwhelmed by the amount of information available [1]. In addition, some sources of online health information may be of higher quality than others [2]. The issue of quality and reliability of information is problematic for interpretation when combined with health consumers' potential lack of knowledge on health topics. Despite these downsides, access to information does seem to lead to better-perceived outcomes, such as increased confidence in patients' perception of their health care decision-making ability [1].

Abilities, Aging, and Internet Use

The current study examined older adults' ability to easily access online health information. Specifically, we were interested in understanding whether interface design influenced successful access and usage of online health information sources by older adults (those age 60 and over). As a group, older adults are less active users of the Internet and Web services when compared to other age groups [3]. In addition, older adults are also more likely to suffer from various health conditions [4] and take more medications [5]. Access to quality health information might be especially beneficial to older adults' maintenance of their more complicated health situations [6]. Being better informed may allow them to ask more questions of their health care providers or to alleviate their concerns due to lack of information.

There are a myriad of reasons why older adults are less active users of the Web. One reason is that getting older is associated with cognitive changes that make using the Web and computers in general more challenging [7-9]. Using the Internet, and more specifically navigating online information sources, places particularly heavy demands on "fluid abilities" [9]. Fluid cognitive abilities, for example working memory (the ability to hold contents in memory while attending to other things) and spatial abilities (creating and manipulating mental representations such as maps), allow us to think and act in situations that are novel[9]. Fluid abilities can be described as the means or process that allows us to learn and adapt in novel situations. When we browse or navigate a website, our performance depends on our ability to keep track of where we were in the system (working memory) and our ability to create abstract maps or models of the system (spatial abilities) [10]. As these abilities decline with age, performance on tasks that depend heavily on these abilities suffers.

However, increasing age is also associated with an increase in "crystallized intelligence" [11]. Crystallized intelligence is the nonspecific, accumulated knowledge that one gains from a lifetime of education and experience. It is the product of formal education and life experience. It is commonly measured in the laboratory with tests of vocabulary or general knowledge. In a prior study, Pak and Price [12] examined age-related changes in cognition and designed a Web interface that was adjusted for older users' cognitive abilities. When websites were designed around keywords, or tags, instead of in a hierarchy (or folders), older users were more efficient at finding information online. In that study, younger and older users browsed a fictional travel information website to answer a series of specific questions (eg, "Where do you mail your passport application?"). Pak and Price theorized that the older adults' advantage was due in part to their greater facility with general vocabulary and verbal ability and the interface's reduced demands on age-sensitive spatial abilities. In their analysis, the tag-based interface placed greater demands on knowledge of vocabulary, which is an ability that grows with age; that is, the cognitive requirements of navigating in a tag-based system (compared to navigating a hierarchy) seemed to have been especially dependent on good verbal and vocabulary abilities. In many studies, including our prior study, older adults routinely outperformed younger adults on tests of vocabulary and verbal knowledge [7].

Overview of the Study

In Pak and Price's study [12], the travel domain was chosen to equate the amount of knowledge between younger and older adults. Prior research had shown that younger and older users did not differ in their knowledge and experience with such information [13]. However, the findings from our prior study needed replication, especially in a domain that may be more applicable to older adults: online health information. In the current study, we examined whether older adults' navigation of a health information website would improve in a tag-based interface. There currently exists a large body of literature related to aging and usability issues on the Web (see [14] for an extensive review). However, there is far too little work on translation of this basic research into design and testing of design recommendations to improve Web usability for older adults.

Methods

Participants

The younger adults recruited for the study were college students, while the older adults were community-dwelling, independent-living adults recruited through newspaper advertisements. Younger adults participated for course credit or US$7/hour, whereas the older adults participated in exchange for US$7/hour.

Participants were asked about their computer experience, including length of computer experience and frequency of use. To indirectly measure experience or exposure to health-related information, participants also reported the amount of prescription medications they were taking at the time of the

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study. We also had participants fill out a more direct measure of health literacy, the Short Test of Functional Health Literacy in Adults (STOFHLA [15]). Finally, several ability measures were included to compare our sample of participants to typical samples used in age studies. They were a measure of general vocabulary knowledge (Shipley vocabulary test [16]), a measure of working memory (reverse digit span [17]), two measures of spatial ability (paper folding and cube comparison [18]), and finally a measure a perceptual speed (digit symbol substitution [19]).

Web Interfaces

To create the interfaces, we first copied content from various health-related websites. The majority of information was taken from the National Institutes of Health website NIHSeniorHealth [20]. A total of 122 Web pages were captured, and the pages' appearance was standardized (eg, same font, size, colors). These Web pages were organized using one of two information architectural schemes: tag/keyword-based or hierarchical (folders). To create these information architectures, we first grouped the 122 pages into a hierarchical system. This was done by having undergraduate students carry out a card-sorting procedure. In the procedure, students placed each page into an organizational hierarchy that made sense to them. Afterwards, they named these groupings. The results of several sessions of card sorting were merged to create the hierarchical condition that consisted of 10 top-level categories (bone and joint, cardiovascular diseases, depression, diabetes, dry mouth, hearing and vision, lung diseases, medications, skin cancer, and talking to your doctor). This same methodology was used by Pak and Price [12]. The tag-based system was created directly from the hierarchy. For example, if a page on gout treatment was organized in the hierarchical condition as Bone & Joint > Arthritis > Gout > Treatment, it was assigned the keywords "bone & joint," "arthritis," "gout," and "treatment." Our rationale for such a label assignment system was our overriding concern to keep the label names as constant as possible across both conditions. We did not want to inadvertently present more or better information in one condition over another.

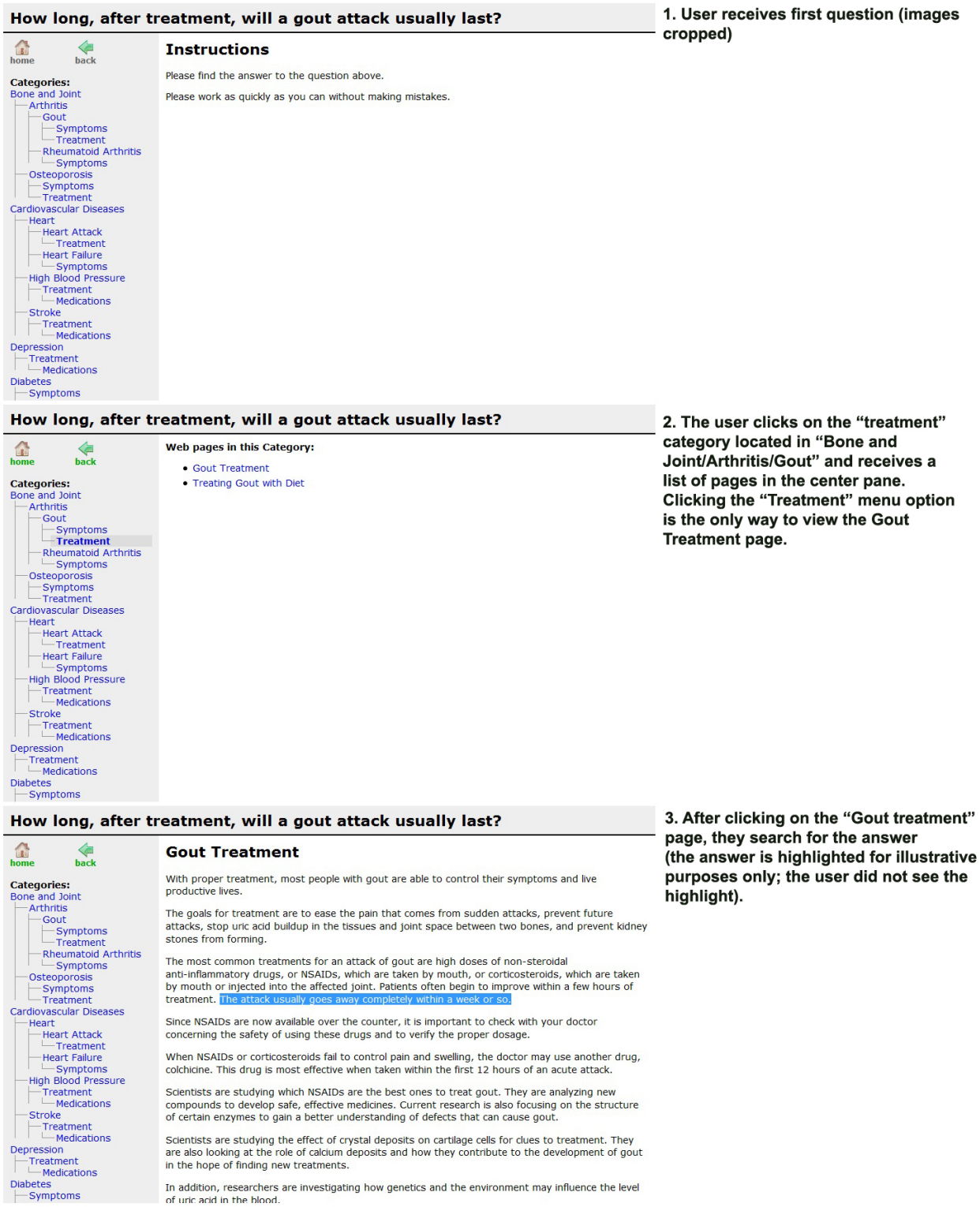
The main difference between the two conditions (aside from the visual difference; the hierarchical condition was visually longer) was that Web pages were only accessible in the hierarchical condition if the participant reached the single category in which it resided (ie, they had to reach the exact "folder" or "subfolder" that held the desired page). However, in the tag-based condition, Web pages could be accessed by selecting any label that was associated with the page. Figure 1 and Figure 2 show the access interfaces for the hierarchical and tag-based conditions, respectively. They illustrate the task flow for a user answering a question about gout. In both conditions, users were presented with the question at the top of the screen, the navigation interface (hierarchical or tag-based) on the left side, and the information pane on the right side.

Hierarchical organization is typically how information is organized on the Web (eg, NIHSeniorHealth). A sample hierarchical organization in our example would be the pages related to "gout" organized within the "arthritis" folder, which is within the "bones & joint" folder. The hierarchical organization is identical to how one might organize files on a computer using nested folders.

In the tag-based organizational scheme, Web pages were each labeled with keywords and the interface presented these keywords to the user. For example, if the user clicked on the gout keyword, all pages that were pre-assigned that keyword appeared (eg, a page on gout prevention, definition of gout). This is similar to how photographs are organized on the photo-sharing website Flickr.com. However, the important difference was that in our website the tags were pre-assigned by the experimenters, while on other websites tags are user generated.

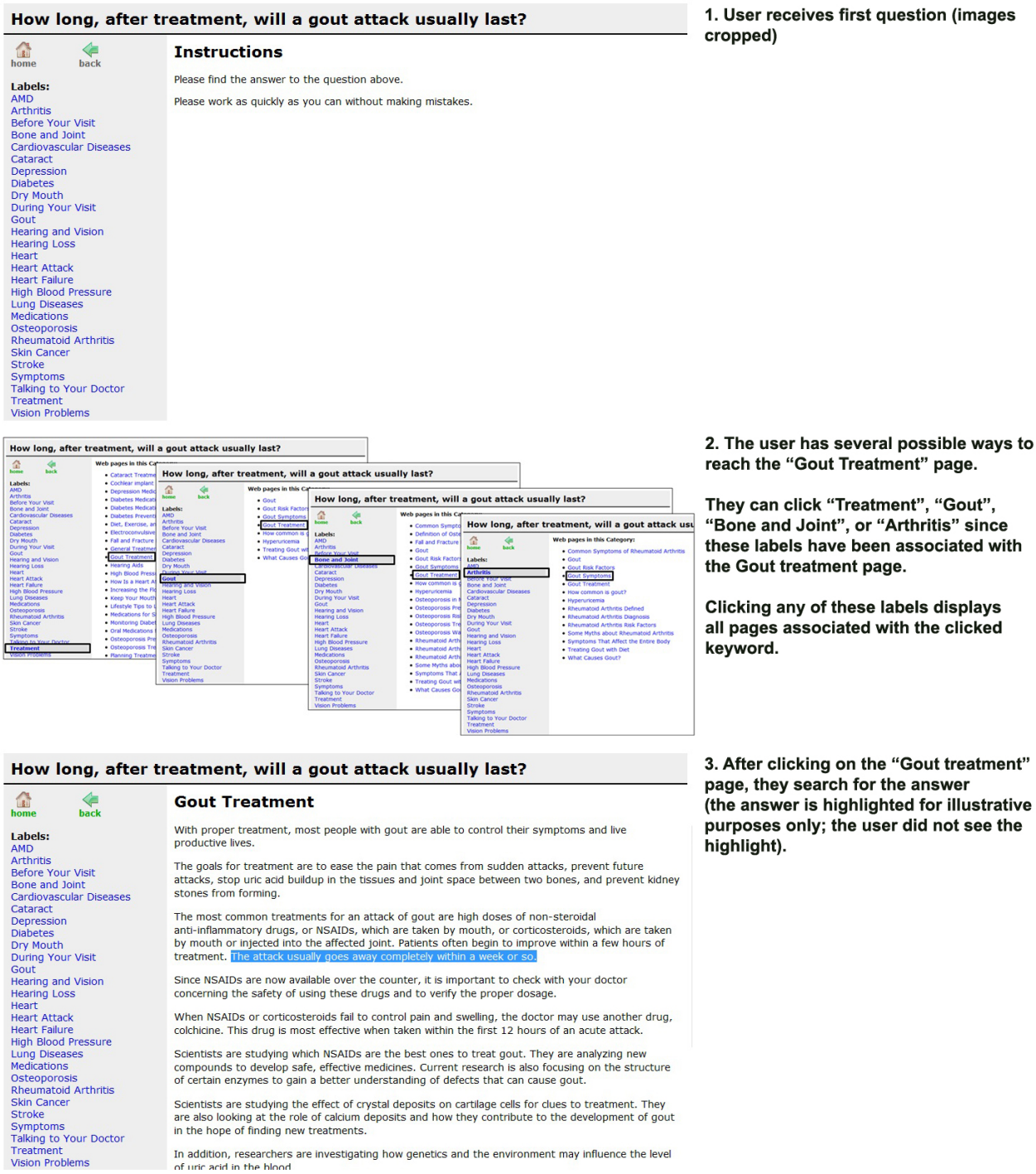
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Figure 1. Task flow for a user in the hierarchical interface condition



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Figure 2. Task flow for a user in the tag-based interface condition



Experimental Task

Participants were asked to answer health-related questions by searching the health information site that we provided. An example question was, "What is considered normal blood pressure?" Half of the participants searched the hierarchically organized site, while the other half searched the tag-based site. When they found the answer on a specific Web page, they clicked the answer text on the page and the application presented feedback as to the correctness of the answer. A total of 25 questions were presented. The Web application was programmed in the PHP scripting language and ran on a local Web server. The application recorded the name of each visited Web page, how much time was spent on each page, and the number of times participants clicked the back button.

Study Design and Procedure

The study was a 2 (age group: young, old) × 2 (organizational scheme: hierarchical or tag-based) factorial with age group as a grouping variable and organizational scheme as a between-group variable. Sessions were assigned to each condition and tested in a computer lab in groups of three to four people so that all participants in a session were assigned to either a hierarchical condition or a tag-based condition. The dependent variables were task completion time, errors, and mouse clicks.

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Participants first filled out paperwork (eg, consent form, demographics, abilities tests) and then moved to the computer to start the information search task. Participants as a group were first guided by the experimenter through two example questions. During the example questions, participants got acquainted with the interface, and any questions were answered. After this practice session, participants were instructed to complete the search tasks as quickly but as accurately as possible and were left to complete the task on their own. These instructions were reiterated by the computer after every trial.

Statistical Analyses

The three dependent measures of performance (task time, clicks, and errors) were subjected to a multivariate analysis of variance (MANOVA) with condition and age group as between-subject factors. In addition to an analysis of the individual dependent measures, a composite variable with the three dependent measures was created. The benefits of creating a composite are increased stability of measurement. A composite performance variable incorporating task completion time, error rate, and number of steps was created for analysis. Each dependent variable was normalized (zscore transformed), and these individual zscores were averaged to create a unit-less composite performance variable that ranged from 1 (worst performance) to −1 (best performance). The analysis of composite variables in usability evaluation has been suggested by researchers as a way to increase stability of measurement [19] and ease interpretation [19,21]. This composite performance measure was subjected to a 2 × 2 analysis of variance (ANOVA).

Results

Participant Characteristics

Fifty younger adults (29 female) ranging in age from 18 to 23 (mean = 19.5, SD = 1.7) and 50 older adults (27 female) ranging in age from 60 to 80 (mean = 70.6, SD = 5.6) participated in the study.

There were significant age group differences in total length of computer experience and frequency of use, with younger adults using computers for a longer period of time than older adults ($F_{1,98}$= 10.6, P = .002, η_p^2= .10) and more frequently ($F_{1,96}$= 11.3, P = .001, η_p^2= .1). Older adults reported taking significantly more prescriptions than younger adults ($F_{1,98}$= 57.7, P < .001, η_p^2= .37). According to the STOFHLA, there were no age group differences in health literacy. Older adults typically outperform younger adults on tests of vocabulary, and this was the case in our sample, with the older adults outperforming the younger adults ($F_{1, 98}$= 11.4, P= .001, η_p^2= .11). Younger adults, however, outperformed the older adults in the fluid ability measures (memory span $F_{1,98}$= 5.7, P= .02, η_p^2= .06; spatial visualization $F_{1,98}$= 34.6, P< .001, η_p^2= .27; spatial orientation $F_{1,98}$= 6.8, P= .01, η_p^2= .07; and perceptual speed $F_{1,98}$= 70.2, P< .001, η_p^2= .42), which is consistent with the general literature on aging and cognition [7].

General participant characteristics are presented in Table 1.

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Table 1. Younger and older user characteristics by condition

	Age Group P[a]	Younger Users					Older Users				
		Hierarchical		Tag-Based		t[b]	Hierarchical		Tag-Based		t[b]
		Mean	SD	Mean	SD		Mean	SD	Mean	SD	
Age (years)		19.4	1.7	19.6	1.8	0.4	70.6	5.8	69.4	5.5	−0.8
Length of computer use[c]	.002	5.0	0.0	5.0	0.2	−1.0	4.5	1.2	4.5	0.9	0.1
Frequency of computer use[d]	.001	5.9	1.0	5.6	1.0	−1.1	5.0	1.4	4.8	1.6	−0.5
Number of medications taken[e]	< .001	0.9	1.2	1.0	1.4	0.3	4.1	2.8	5.2	3.5	1.2
Health literacy[f]	.12	35.2	1.1	35.5	0.7	1.2	34.6	2.6	35.1	1.3	0.9
Vocabulary[g]	.001	30.2	3.2	27.2	5.9	−2.2	37.6	20.4	34.6	4.6	−0.7
Memory span[h]	.02	10.6	2.0	9.8	2.9	−1.1	8.3	3.0	9.5	2.6	1.5
Spatial visualization[i]	< .001	5.8	2.1	6.0	2.0	0.4	3.5	1.6	4.2	1.4	1.6
Spatial orientation[j]	.01	9.8	3.2	10.9	4.0	1.1	8.6	2.8	8.8	2.5	0.2
Perceptual speed[k]	< .000	66.7	10.3	66.0	9.9	−0.3	49.1	10.8	50.3	8.6	0.4

[a]One-way ANOVA.

[b]$t$tests showed no significant condition differences (within each age group) at $P<.001$ (stricter Pcriterion used to compensate for inflated degrees of freedom due to multiple comparisons).

[c] Total length of computer experience on a scale of 1 (less than 6 months) to 5 (greater than 5 years).

[d] Frequency of computer use on a scale of 1 (once every few months) to 7 (daily, most of the day).

[e] Prescription medications only.

[f] Test of health literacy composite score (STOFHLA) [15]; higher equals better health literacy.

[g] Shipley vocabulary score; higher is better [16].

[h] Reverse digit span [17].

[i] Paper folding test [18].

[j] Cube comparison test [18].

[k]Digit symbol substitution (number correct [19]).

Performance

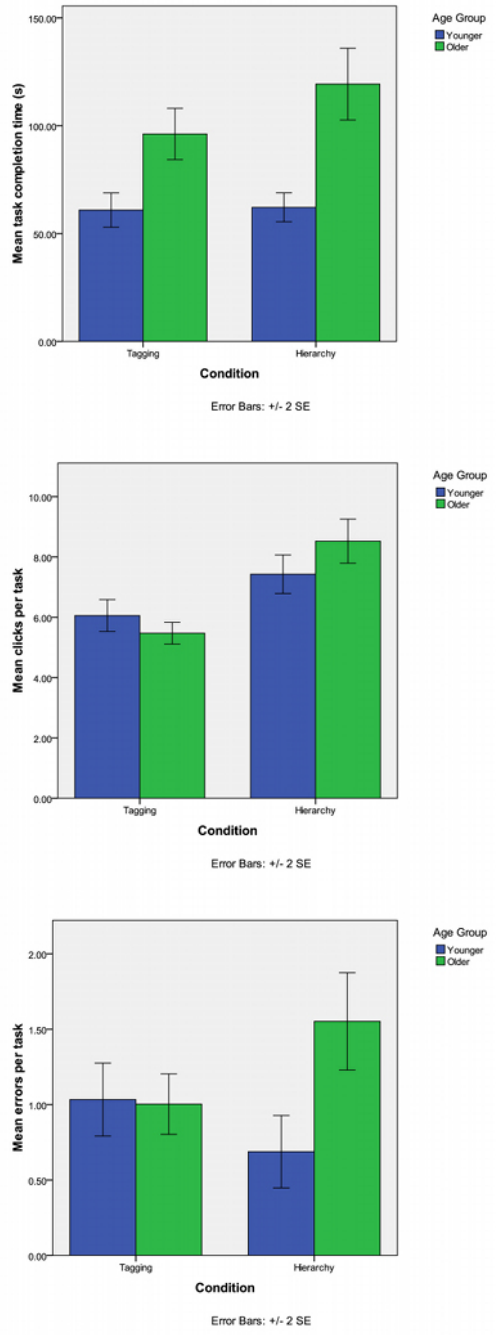
Performance (mean task completion times, mean number of mouse clicks to completion, and mean errors per task) is shown in Table 2 and illustrated in Figure 3.

Table 2. Measures of performance as a function of condition and age group

	Younger Users		Older Users	
	Mean	SD	Mean	SD
Mean task completion time (s)				
Tag-based	60.90	19.86	96.17	29.70
Hierarchy	62.16	16.78	119.31	41.62
Mean clicks per task				
Tag-based	6.06	1.32	5.47	.91
Hierarchy	7.43	1.60	8.52	1.83
Mean errors per task				
Tag-based	1.00	.50	1.02	.55
Hierarchy	1.55	.81	1.12	.83

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Figure 3. Time, errors, and clicks as a function of condition and age group (error bars represent standard error)



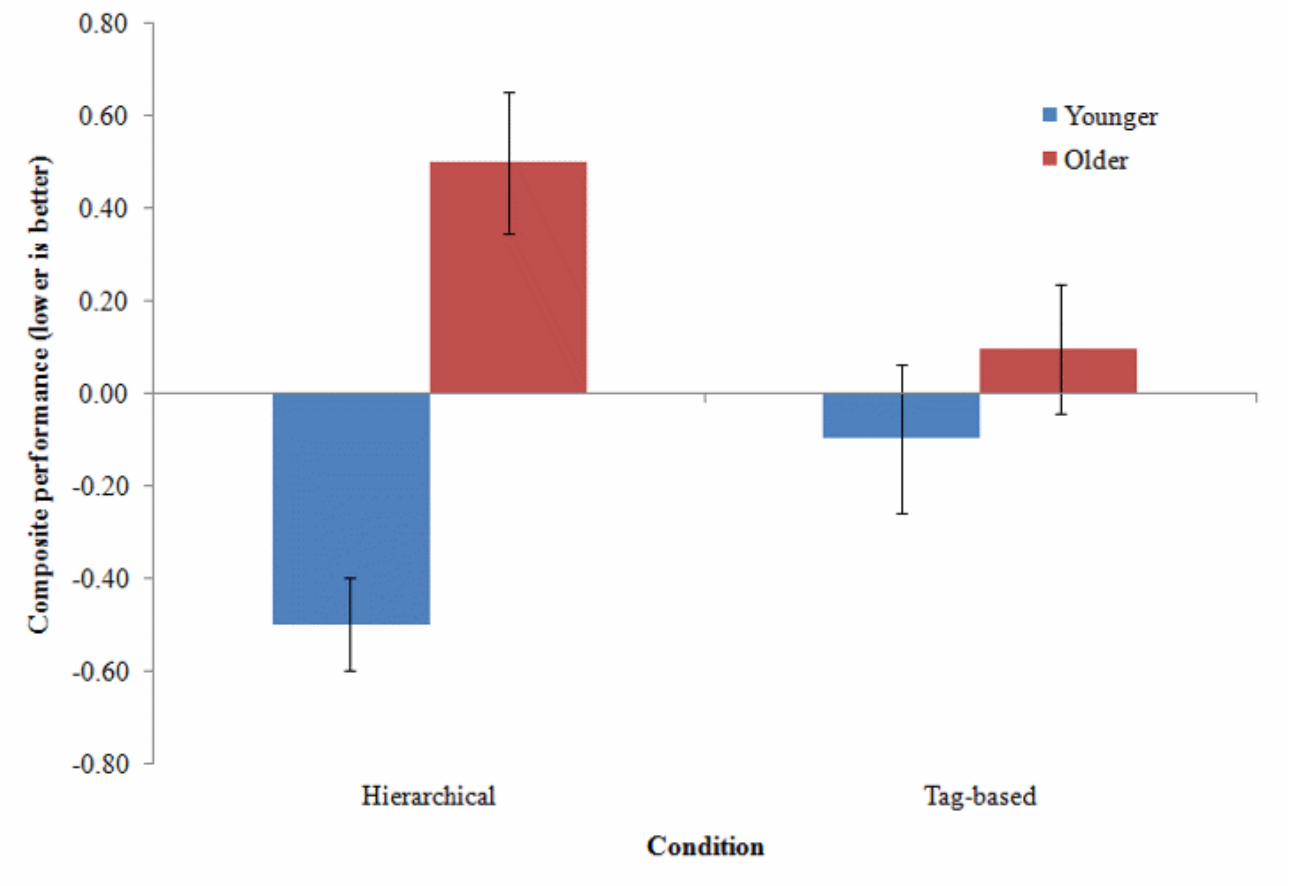
The results of the analysis of dependent measures showed significant overall main effects of condition and age group ($F_{1,94}$= 23.8,P< .001, η_p^2= .43, $F_{1,94}$= 29.5, P< .001, η_p^2= .48, respectively), and the interaction was significant ($F_{1,94}$= 4.7, P< .001, η_p^2= .13), so the main effects were not followed up. Follow-up analysis revealed that the significant interaction was due to a significant interaction in mean clicks ($F_{1,96}$= 8.4, P< .001, η_p^2= .04) and mean errors ($F_{1,96}$= 12.29, P< .001, η_p^2= .11). The interaction in mean task time was not significant (P= .06). The source of the interaction in mean clicks and errors was not significant age difference in clicks or errors in the tag condition but in the taxonomy (hierarchical) condition: older adults made more clicks than younger adults. These interactions are illustrated in Figure 3. These results conceptually replicate the earlier results [12] that showed that navigation through a website can be improved if the organization is organized around keywords, not a hierarchy.

The analysis of the composite measure of performance showed that the main effect of age group was significant ($F_{1,96}$= 18.0, P <.001, η_p^2= .16), indicating that older adults in general performed worse than younger adults. There was no significant main effect of condition; however, the age group × condition interaction was significant ($F_{1,96}$= 8.1, P = .005, η_p^2= .08), indicating that condition (hierarchical vs tag-based) differentially affected each age group. Post hoc analyses (Bonferonni method) revealed that the source of this interaction was the hierarchical condition. Younger adults significantly outperformed older adults in the information search task when using the hierarchical

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condition ($F_{1,96}$= 25.2, P <.001, η_p^2= .21). However, in the tag-based condition, there were no significant performance differences between the younger and older adults in the information search task. This replicates our earlier findings that a tag-based system that relies on the generation and recognition of keywords may benefit older adults' information-finding performance. The interaction is represented in Figure 4.

Figure 4. Performance as a function of condition and age group (error bars represent standard error)



The current finding that older users' performance searching for medical information through a tag-based system was better than through a hierarchically organized system replicates our earlier findings examining travel information. However, we also wanted to examine how pre-existing domain knowledge or experience with health and medical information might be related to performance in each of the two organizational schemes. Table 3 shows the correlations between performance, number of medications, and experience measures (computer experience and health/medical experience).

In the hierarchically organized condition, performance was significantly correlated with age (older adults performed worse than younger adults), the number of medications currently taken (increased number of medications was associated with worse performance), and health literacy (those with greater health literacy performed better). It is somewhat intuitive that health literacy (STOFHLA) was associated with better performance in the information search task, but it is puzzling that performance was not correlated with number of medications taken. We initially assumed that number of medications could be used as an indirect indicator of health knowledge, with the assumption that people who took more medications would have a greater amount of health knowledge because of their need to manage and understand their medication regimen. However, the correlation between STOFHLA and number of medications was not significant. One possibility could be that number of medications taken is a better indicator of overall cognitive and physical health status (with those taking more medications having worse health and thus cognitive status), and not knowledge.

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Table 3. Correlations between health literacy and knowledge and performance in hierarchical and tag-based conditions

Hierarchical Condition					
		1	2	3	4
1	Age	-			
2	Number of medications	**0.6**	-		
3	STOFHLA[a]	−0.2	0.0	-	
4	Composite performance[b]	**0.6**	**0.3**	**−0.5**	-
Tag-Based Condition					
		1	2	3	4
1	Age	-			
2	Number of medications	**0.6**	-		
3	STOFHLA[a]	−0.2	−0.1	-	
4	Composite performance[b]	0.2	−0.1	−0.1	-

[a] Health literacy; higher is better.

[b] Composite performance was reverse coded (lower is better).

[c]Boldface indicates significant correlations at $P < .05$.

In contrast, the pattern of correlations in the tag-based system show that performance was not significantly associated with age, number of medications, or health knowledge. These results are consistent with those of Pak and Price [12], which showed that age was not a significant predictor of performance in the tag-based condition but did predict significant variance in the hierarchical condition. The implication is that hierarchical systems are sensitive to age (and thus age-related differences in abilities and knowledge), while tag-based systems are not.

Discussion

The online health information consumer ranges widely in age, experience with computers, and health status [1,22]. It is thus critical to examine usability issues that assure people with varying backgrounds can successfully access online health information. The goal of the current study was to determine whether older adults' health information search and retrieval performance could be improved with relatively modest interface usability changes based on the cognitive aging literature. Earlier work showed that when older adults searched through a tag-based website, their performance was relatively better than when they searched through a hierarchically organized website. The basis for improvement was theorized to be that tag-based interfaces, compared to hierarchical organizations, shift cognitive demands from spatial abilities (ie, knowing where you are) to verbal/vocabulary abilities (knowing keywords).

The results from the current study show that with a restructuring of the information architecture and the access interface (from a hierarchical organization to one based on keywords or tags), older adults are able to improve their information search and retrieval performance. This was presumably the result of a change in the ability demands of each system, with the tag-based system placing less stringent demands on older adults' cognition than the hierarchical system. This study represents the first replication of our earlier results, but with a topical domain that may be especially relevant to older adults: online health information.

While older adults' performance was improved in a tag-based interface, younger adults' performance was worse in the tag-based system. This may be due to the simultaneous reduced spatial ability demands and increased verbal/knowledge demands from the tag-based interface coupled with younger adults' relative lack of verbal abilities (compared to older adults). This suggests the possibility that, for optimal performance, online health information providers may need to provide age-specific interfaces for their users. However, it also stresses the need for further research into interfaces that can combine the beneficial aspects of tag-based and hierarchical interfaces useful for people of all ages. One such novel interface, faceted navigation, is being used on some websites and may be the bridge between hierarchical interfaces and pure tag-based interfaces [23]. In facetted navigation systems, users progressively narrow search results by selecting facets, or dimensions, of information. For example, a free-text search of diabetes from a health information site might return several thousand results. In a facetted navigation system, the user could then focus on facets of those results (eg, only news articles, or peer-reviewed research) by selecting keywords. The user experience is similar to tag-based interfaces, but the difference is that the presentation of tags can be hierarchical.

Limitations

One limitation of this research is that online medical information websites or portals may only be one of several possible destinations for health consumers [1,24]. For example, information searchers may turn to generic search engines (eg, Google, Yahoo), which brings unique usability problems [24,25]. In a usability study of Web-based health information, Eysenbach and Köhler found that older users exhibited suboptimal search engine use such as viewing only the initial search results page (when more were available) [24]. Another

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limitation is related to the design of the materials. Because of our desire to keep the hierarchy and tag-based conditions as conceptually consistent as possible, the hierarchy (presented on the left-hand side) was slightly visually taller than the tag-based condition. However, we believe that this difference was minor and is unlikely to, by itself, explain the observed effects. For example, it could be the case that the longer hierarchy (and concomitant increase in visual clutter) may explain older adults performing more poorly in the hierarchical condition compared to the tag-based condition. However, the clutter explanation does not explain why younger adults performed relatively better in the presence of the hierarchical condition compared to tag-based—they would also be subject to clutter effects.

Conclusions

The current research was an attempt to add evidence-based knowledge to the problem of older adult information searching on the Web. There is now nearly a critical mass of literature on age-related changes as they may relate to the use of Web resources [14], but much work is necessary to translate this basic knowledge of age differences into specific design recommendations and recommendations for older adults.

Acknowledgments

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Conflicts of Interest

None declared.

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Abbreviations

STOFHLA: Short Test of Functional Health Literacy in Adults

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Original Paper

Challenges to Using an Electronic Personal Health Record by a Low-Income Elderly Population

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Abstract

Background: Electronic personal health records (PHRs) are increasingly recognized and used as a tool to address various challenges stemming from the scattered and incompatible personal health information that exists in the contemporary US health care system. Although activity around PHR development and deployment has increased in recent years, little has been reported regarding the use and utility of PHRs among low-income and/or elderly populations.

Objective: The aim was to assess the use and utility of PHRs in a low-income, elderly population.

Methods: We deployed a Web-based, institution-neutral PHR system, the Personal Health Information Management System (PHIMS), in a federally funded housing facility for low-income and elderly residents. We assessed use and user satisfaction through system logs, questionnaire surveys, and user group meetings.

Results: Over the 33-month study period, 70 residents participated; this number was reduced to 44 by the end of the study. Although the PHIMS was available for free and personal assistance and computers with Internet connection were provided without any cost to residents, only 13% (44/330) of the eligible residents used the system, and system usage was limited. Almost one half of the users (47%, 33/70) used the PHIMS only on a single day. Use was also highly correlated with the availability of in-person assistance; 77% of user activities occurred while the assistance was available. Residents' ability to use the PHR system was limited by poor computer and Internet skills, technophobia, low health literacy, and limited physical/cognitive abilities. Among the 44 PHIMS users, 14 (32%) responded to the questionnaire. In this selected subgroup of survey participants, the majority (82%, 9/11) used the PHIMS three times or more and reported that it improved the quality of overall health care they received.

Conclusions: Our findings suggest that those who can benefit the most from a PHR system may be the least able to use it. Disparities in access to and use of computers, the Internet, and PHRs may exacerbate health care inequality in the future.

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KEYWORDS

Personal health record (PHR); personally controlled health record (PCHR); elderly populations; low-income populations; Web-based; Internet

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Introduction

Health care systems around the world are facing various challenges. In the United States in particular, the health care system is considered expensive, fragmented, unsafe, and unequal [1], although many innovations in medical diagnosis and treatment have been pioneered and made clinically available [2]. Over the past several years, health information technologies, such as electronic health records (EHRs) and personal health records (PHRs), have emerged and have been promoted by experts, industry, and government as an effective tool to address the inefficiencies and disadvantages of the current health care system [3-12]. The EHR and PHR systems hold the promise of improving the quality of health care services by improving communication within and across the health care system, reducing medical errors and waste of health care resources, and simplifying the complexity inherent in redundant information from fragmented sources.

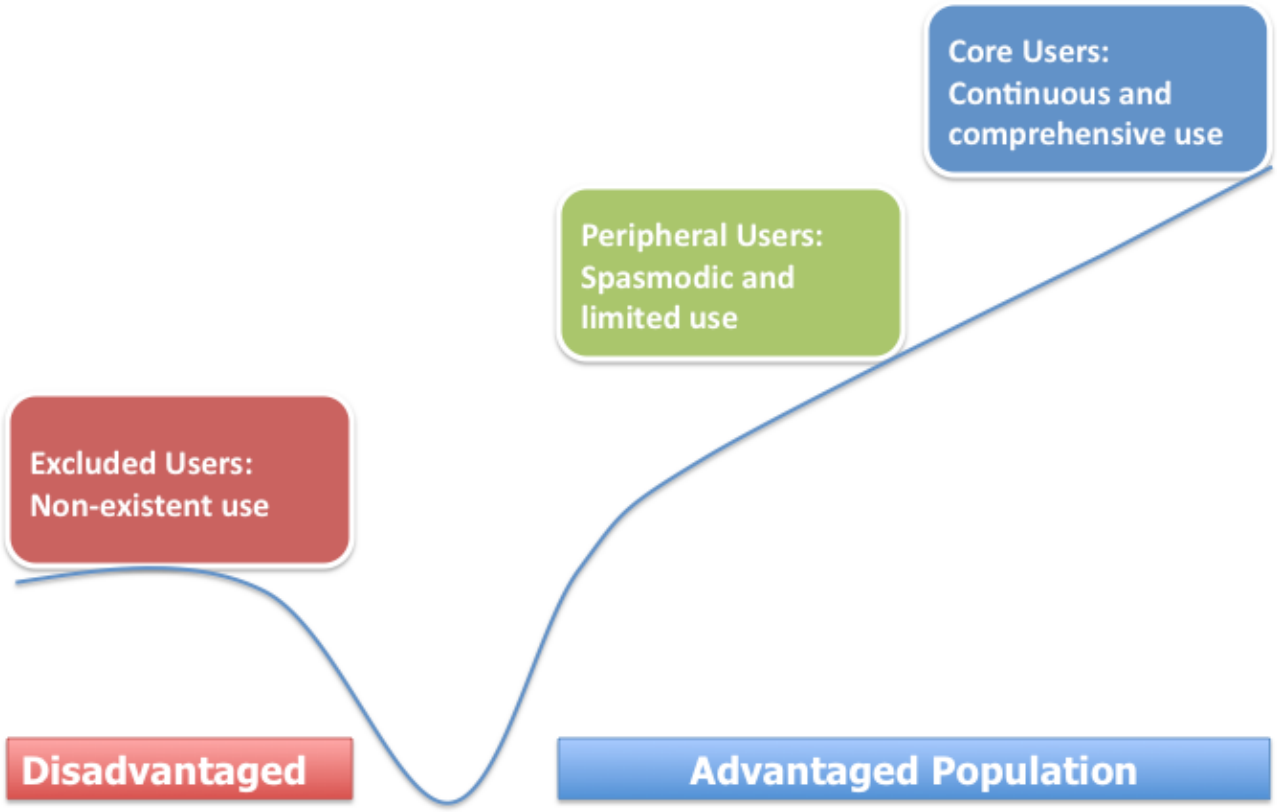
The EHR refers to a computerized health history of an individual that can be viewed as a collection of electronic medical records and other health-related information to be used and viewed primarily by care providers [5,13]. On the other hand, the predominant model of PHRs is an electronic repository of personal health information to be managed and accessed by patients and others authorized by patients [5,6]. Although the EHR and PHR have different end-user groups, they contain similar information. Ideally, they should be interoperable. In the past few years, adoption of EHRs has been encouraged, whereas PHRs have not received the same level of attention. However, as Tang and Lansky [14] and Ball et al [15] discussed, the EHR alone may lack the ability to sufficiently motivate and engage patients to take a more active role in managing their own health, a condition found critical for improving care quality and efficiency [16]. Therefore, PHRs have been recognized as a means of patient engagement. An EHR-coupled PHR, which is often referred as a patient-accessible EHR [13] or tethered PHR [5], has been increasingly offered in the United States to patients as an institution-specific (limited to a certain organization) Internet portal by some large health care organizations (eg, Kaiser Permanente, Veterans Health Administration, Group Health Cooperative, CareGroup Health Care System, and Palo Alto Medical Foundation).

Enabled by information and communication technology (ICT) and spurred by trends of moving toward patient-centered care, the public interest in accessing and managing personal health information has been growing [17]. Relatively new applications, such as Microsoft HealthVault and Google Health, make a stand-alone PHR available to anyone with Internet access. In spite of the widespread interest and availability of PHRs, their use and utility among the primary users (ie, patients themselves) is not well documented or analyzed [18,19]. Particularly, little work has been done for the elderly and low-income population. Due to the high incidence and prevalence of chronic conditions that generally require frequent monitoring and interventions, elderly people would benefit more because the PHR system could enable more coordinated and cost-effective communication and health care delivery.

Compared with younger and/or more affluent counterparts, the elderly with low income are likely to be disadvantaged in using PHRs due to the disparities in accessing and using ICT, referred as the “digital divide.” The digital divide is defined as the gap that exists between individuals, groups, or communities in terms of the availability of ICT and the ability to use these technologies effectively [20]. Although the availability of Internet access has been steadily increasing, only 40% of low-income families (those with less than US$20,000 household income) have Internet access compared to 73% of the overall US population according to a survey conducted in 2008 [21]. The survey also found that although Internet use among adults aged 50 or older has shown the highest growth rates, only 35% of this population have Internet access. Therefore, the low-income elderly are more likely to be on the underprivileged side of the digital divide, and many would be classified as excluded users based on Murdock’s categorization as illustrated in Figure 1 [22]. This divide was observed in a study using a tethered PHR: healthier, socioeconomically advantaged, health-minded, and younger individuals were more likely to use the portal [23]. Hsu et al [24] also found the widening divide over time (from 1999 to 2002) in the adoption of PHRs and related applications between the low socioeconomic group and its counterpart.

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Figure 1. Digital divide (model adopted from Murdock [22]: three groups of ICT users were described in terms of levels of access and use; blue line represents the conceptual valley and barriers of the digital divide)



In this paper, we present a 33-month study of an institution-neutral, "stand-alone" PHR used by low-income elderly residents living in a subsidized housing facility. This PHR system, the Personal Health Information Management System (PHIMS), allowed users to enter and manage their health information with the help of student nurses. In this paper, we present the results of this exploratory study, the utility and use of PHIMS in this socioeconomically disadvantaged population, and user satisfaction.

Methods

The PHIMS is an institution-neutral (not bound to any organization), individually controlled, Web-based repository of personal health information [25]. It allows users to enter, update, or delete structured information in nine different categorizes. Each category has multiple information elements. For example, under medications, one can record dosage, effectiveness, prescribing doctor's name, and reasons for taking/stopping each medication. Many categories have free-text boxes where any additional information a user wants to record can be entered. Some of these text boxes are used to enter questions or topics a user wishes to discuss with providers. The PHIMS provides summary pages that list all the information a user has entered into the system. He or she can share a hardcopy and/or electronic copy with health care providers or family members.

The PHIMS was deployed in a housing complex located in Everett, WA, USA, which serves approximately 500 households. Most residents have a household income below 100% of the federal poverty line, although the eligibility for residency is below 250%. The majority of residents in the complex are the elderly (ie, age 65 or over), who have a high prevalence of multiple chronic illnesses. The PHIMS was initially deployed in December 2004 in one apartment that serves approximately 180 residents. In May 2006, a second location with around 150 residents was added. Socioeconomic status and ages of the residents in the second location were similar to those in the first apartment, except that about 30% (45/150) of them were immigrants whose primary language was Russian.

The PHIMS was made available to all adult residents (most residents were adults) from December 2004 (May 2006 for the second location) to August 2007. In 2004, approximately 80% (145/180) of residents did not have Internet access. Consequently, a computer room equipped with six PCs with a broadband Internet connection and a printer was set up for the residents. When the deployment was expanded in 2006, the second location already had a computer room with four Internet-linked PCs and two printers. Two graduate nursing students visited the complex once a week (mostly Thursdays from 10:00 am to 2:00 pm) to help the residents create and manage (enter, update, delete, or print) their personal health information. One housing staff member (social worker) occasionally helped the residents as well. For Russian-speaking residents, an interpreter service was also made available.

We conducted various informational sessions to explain what the PHIMS was and to demonstrate how to use it [25,26]. The study was approved by the Institutional Review Board at the University of Washington. All participating residents (PHIMS users) accepted the terms of the online consent form.

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System usage (ie, user activities), such as information updates and retrievals, was analyzed from the system logs. The logs recorded the details of user activities, including accessed information category, activity type (eg, enter, update, or delete), and the date, time, and duration of each access.

In August 2007, a (paper) questionnaire was administered to the users of the system to assess overall satisfaction with PHIMS and obtain self-reported comments on their experience.

The questionnaire responses and the system logs were analyzed using MATLAB with Statistics Toolbox (The Mathworks, Inc, Natick, MA, USA). Exploratory descriptive statistics were mostly used to analyze the questionnaire responses and the frequencies and patterns of user activities.

Results

Participation

A total of 70 residents participated in the study. Table 1 describes the age and gender distribution of the PHIMS users. The average age of participants was 63.1 years (SD = 15.4 years), which was not significantly different (P = .23, Student unpaired t_{298} test) from all the residents in the housing complex (mean = 65.8, SD = 15.7 years). Of the 70 participants, 44 (63%) were older than 60 years, and 71% (50/68) were female. The gender of PHIMS users was not significantly different from the resident population (P = .27, Fisher exact test). All participants indicated that their primary language was English.

Table 1. Age and gender distribution of PHIMS users (N = 70)

	Number (%)
Age (years)	
21-30	2 (2.9)
31-40	2 (2.9)
41-50	8 (11.4)
51-60	14 (20.0)
61-70	27 (38.6)
71-80	5 (7.1)
81-90	7 (10.0)
91-100	5 (7.1)
Gender	
Male	18 (25.7)
Female	50 (71.4)
Not disclosed	2 (2.9)

System Usage

Three users used the PHIMS for 25, 21, and 17 days each. On the other hand, 33/70 participants (47%) used the PHIMS only on a single day during the study period, as shown in Table 2. If we limit the users to those who had at least 12 months to use the PHIMS (n = 53), more than half (51%, 27/53) accessed the system only one day during their first-year PHIMS use.

The system was most frequently used on Thursdays (67%, 5387/8008), followed by Fridays (14%, 1098/8008), which coincided with the onsite availability of graduate nursing students. Most (77%, 6174/8008) of the system use happened while assistance from graduate nursing students or housing staff was available to the residents. On the other hand, 8% (677/8008) of user activities occurred during off hours when the students or staff were not available (from 5:00 pm to 8:00 am weekdays and weekends).

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Table 2. Number of discrete days of PHIMS use during the study period for all users (N = 70) and during the first 12 months (N = 53)

Number of Days Used	All Users, No. (%)	Users for the First 12 Months, No. (%)
1	33 (47.1)	27 (50.9)
2	17 (24.3)	11 (20.8)
3	6 (8.6)	3 (5.7)
4	3 (4.3)	4 (7.5)
5	5 (7.1)	4 (7.5)
6+	6 (8.6)[a]	4 (7.5)[b]

[a]6, 9, 17, 21, and 25 discrete days of use.

[b]8, 10, 16, and 17 discrete days of use.

Survey Responses

In August 2007, only 44/70 PHIMS users were still living in the housing complex. Some had moved out of the building due to changes in their financial status and other reasons, and some had passed away during the study period. Among the 44 PHIMS users, 14 (32%) responded to the questionnaire. A total of 79% (11/14) of the survey respondents said that they entered health information by themselves at least once. Except the three respondents who had used the PHIMS for less than 6 months, 82% (9/11) used the PHIMS three times or more. The average age of the survey participants was 65.5 years (SD = 9.8 years).

Textbox 1 shows a summary of survey responses. Most respondents (12/13, 92%) were satisfied with the PHIMS. All shared their PHIMS records with care providers, family members, and/or friends; 93% (13/14) shared their records with their primary care providers and/or specialists. All the respondents judged that with the PHIMS they were able to provide more health information to the providers. Most respondents (10/11, 91%) found that the PHIMS made their face-to-face meetings with providers efficient and felt more prepared for emergencies and in control of coordinating their care.

Textbox 1. Summary of survey responses (95% confidence intervals are calculated based on the adjusted Wald method)

- 14/14 (100%; 95% CI = 80.9-100) shared their PHIMS record with
  - primary care provider and/or specialist: 13 (92.9%; 95% CI = 66.5-100)
  - family member: 6 (42.9%; 95% CI = 21.3-67.5)
  - friends: 1 (7.1%; 95% CI = 0-33.5)
- 12/12 (100%; 95% CI = 78.4-100) felt that they were able to provide more health information to their health care provider with PHIMS
- 11/12 (91.7%; 95% CI = 62.5-100) felt that they were more prepared for medical emergencies with PHIMS
- 10/11 (90.9%; 95% CI = 60.1-100) indicated that their face-to-face meeting time with their health care provider was used more efficiently with PHIMS
- 9/11 (81.8%; 95% CI = 51.2-96.0) indicated that PHIMS improved the quality of overall health care they received
- 12/13 (92.3%; 95% CI = 64.6-100) were overall satisfied with the PHIMS system

Discussion

To our knowledge, this is the first study on stand-alone PHR use involving a homogeneous group of subjects living in a low-income housing facility where the majority of residents were elderly.

Principal Findings

The results from this study underscore challenges in the deployment and widespread adoption of PHRs by socioeconomically disadvantaged populations. Since all the residents were low income and the majority were elderly, most residents belonged to the disadvantaged group in Figure 1. The digital divide includes a technical divide based on the availability of ICT infrastructure, hardware, and software and a social divide resulting from the skills required to manipulate and utilize technical resources [27]. To help the residents overcome these technical and social divides in PHIMS use, PCs, Internet connection, and assistance from nursing students and housing staff were made available free of charge. In spite of this support, the participation rate in using the PHIMS was not much different from previous studies with tethered PHRs that reported a participation rate from 9.3% to 25% with the general population [23,24,28,29]. During our study period of 33 months, the PHIMS attracted 70 users, and in August 2007, 44 still lived in the residence, about 13% (44/330) of the eligible residents. If only residents whose primary language was English are counted, the PHIMS user group is approximately 15% of the eligible residents (44/285).

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Compared with the study by Hsu et al [24], who reported 5.3% of people between 50 and 74 years and 2.8% living in a low socioeconomic neighborhood using PHRs without any help, the PHIMS participation rate of 13% indicates that the infrastructure and assistance helped some residents overcome an initial barrier and fear toward using the PHIMS. If the resources and support had not been provided, participation rates would have been lower. In fact, we found that only 8.6% (6/70) of the participants and 1.5% of the eligible residents (5/330 in August 2007) were able to use PHIMS independently without any assistance. Not surprisingly, this group of independent users were the most frequent PHIMS users. If the PHIMS users were an unbiased sample of the residents, the independent users could account for 8.6% of the residents. However, the PHIMS users were self-selected and a biased sample. Thus, the proportion of independent users among the elderly with low income is closer to 1.5% than to 8.6%.

Overall, system usage was limited. Almost one half of the users used the PHIMS only on a single day. In addition, user activities highly correlated with the availability of assistance. Nearly 80% of the user activities occurred during the time when the graduate nursing students and/or housing staff were present on site. The graduate nursing students provided assistance to the residents for only about 4 hours per week during the academic quarters. However, 63% of the total user activities (5035/8008) coincided with their on-site availability. This high dependency was mainly due to the limited physical and cognitive abilities and technophobia (ie, computer anxiety) of the residents, as we had found in an earlier study [26]. While some residents were enthusiastic about using the PHIMS, others expressed fear over computers and the Internet. Among the PHIMS users, 58% had computer anxiety and were initially afraid of using a computer [26]. Therefore, they needed emotional support to overcome their fear. Low health literacy (29% in [26]) was also an important factor that limited PHIMS use. Some users (at least 5 among 13 survey respondents) who said that they could use the PHIMS by themselves commented that they preferred to use it with a nursing student who could not only help in updating records but also provide explanations for them to understand their health information. Both language and culture were formidable barriers in the digital divide, as Keniston [30] identified. None of the Russian-speaking residents used the PHIMS even though interpreter services were made available to them and many had previously expressed interest during information sessions.

In spite of the fact that the participation rate was low and PHIMS use was infrequent, those users who participated in the survey found PHIMS beneficial. Particularly, the respondents who had shared their PHIMS information with their care providers felt very positive about PHIMS and noted the system's usefulness. With a printout of their PHIMS summary, they were able to provide health information to providers accurately and quickly, leading to better communication with their care providers. This result is consistent with various studies on the impact on patient-provider relationships and communication of using Web-based, provider-supplied health information systems [31-36].

Limitations

Potential biases in survey responses should be noted. More than half (57%, 8/14) of survey participants said that they were able to use and update the PHIMS on their own most or all the time, whereas only 3/14 (21%) said that they never used or updated the PHIMS by themselves. This self-use rate is quite different from our earlier study, where almost 80% of participants needed assistance to use and update the PHIMS and more than 60% had low computer literacy [26]. Thus, survey respondents in the current study were more computer literate and self-sufficient users than those users who did not participate in the survey. In addition, 82% (9/11) of survey participants who used the PHIMS for 6 months or more used it three times or more, whereas almost half of users used the PHIMS only once. Therefore, the survey respondents were those who were more active users of the PHIMS, and their responses might have not represented those PHIMS users who have only used the system once. However, we were able to clearly observe that at least a fraction of the population in the study was able to receive the benefits of the PHIMS and reported improvements in their perceived quality of care.

Another aspect to be noted is that the PHIMS is an institutional-neutral, untethered (stand-alone) PHR. It contains only self-reported data, the majority of which were entered with the assistance from graduate nursing students. In tethered, provider-supplied PHRs, the majority of personal health information can be added from multiple existing sources, including the provider's information systems. Therefore, the adoption rate, utility, and use frequency of specific features with tethered PHRs could be somewhat different from those observed in our study, although we found some similarities as well. In our earlier study [25], we found that the medication information was the most frequently used and updated category in the PHIMS, which is similar to the use of tethered PHRs [9,23]. On the contrary, the lab test was one of the least frequently used information categories in the PHIMS, whereas in tethered PHRs, the lab test was one of the most popular features. This may be due to the fact that in a tethered PHR users check lab test results made available by their provider, whereas in a self-entry PHR users enter test results they have received. Because of the reduced workload in managing personal health information, related to not having to enter data into their record themselves, tethered PHRs might be more easily adopted than untethered PHRs. However, even tethered PHRs may not be able to address root causes that limit the use of PHRs, such as age-related reduced physical and cognitive abilities of the low-income elderly. Thus, we believe that the low-income elderly would face similar challenges found in this study whether using a tethered or untethered PHR.

Concluding Remarks

In the last several years, momentum has been building toward widespread deployment of health information technology in the United States. Earlier studies on PHRs demonstrated their usefulness in improving the quality of care for patients with chronic illnesses [37], in controlling costs [3], and in reducing health care disparities [38-40]. The accelerated efforts from ICT and health care companies and their partnerships will likely

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substantially increase the availability and usability of PHRs. Furthermore, US government incentives and support as well as broad-based health care reform initiatives now being discussed will facilitate PHR deployment and use by patients and care providers.

It is widely believed that the elderly would benefit more from PHR use than would younger populations [17,41]. However, our findings suggest that the majority of the low-income elderly would not be in a position to benefit from PHRs due to poor technical skills, technophobia, low health literacy and limited physical/cognitive abilities, leaving only a small fraction who can take advantage of PHRs to the full extent. As a result, PHRs may mainly serve self-proficient, advantaged individuals, which could result in further widening of the inequality in health care. As the next-generation elderly population will be more computer literate than the current generation, PHR use among the elderly will increase in the future. However, their low or reduced physical/cognitive abilities due to aging and low health literacy would limit the PHR use. Therefore, many of the underprivileged in the digital divide would be left behind in receiving the benefits that are enabled by ever-advancing PHR systems and their clinical applications, potentially exacerbating the health care inequality.

Conflicts of Interest

None declared.

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Abbreviations

EHR: electronic health record
ICT: information and communication technology
PC: personal computer
PHIMS: Personal Health Information Management System
PHR: personal health record

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Original Paper

Use of Live Interactive Webcasting for an International Postgraduate Module in eHealth: Case Study Evaluation

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Abstract

Background: Producing "traditional" e-learning can be time consuming, and in a topic such as eHealth, it may have a short shelf-life. Students sometimes report feeling isolated and lacking in motivation. Synchronous methods can play an important part in any blended approach to learning.

Objective: The aim was to develop, deliver, and evaluate an international postgraduate module in eHealth using live interactive webcasting.

Methods: We developed a hybrid solution for live interactive webcasting using a scan converter, mixer, and digitizer, and video server to embed a presenter-controlled talking head or copy of the presenter's computer screen (normally a PowerPoint slide) in a student chat room. We recruited 16 students from six countries and ran weekly 2.5-hour live sessions for 10 weeks. The content included the use of computers by patients, patient access to records, different forms of e-learning for patients and professionals, research methods in eHealth, geographic information systems, and telehealth. All sessions were recorded—presentations as video files and the student interaction as text files. Students were sent an email questionnaire of mostly open questions seeking their views of this form of learning. Responses were collated and anonymized by a colleague who was not part of the teaching team.

Results: Sessions were generally very interactive, with most students participating actively in breakout or full-class discussions. In a typical 2.5-hour session, students posted about 50 messages each. Two students did not complete all sessions; one withdrew from the pressure of work after session 6, and one from illness after session 7. Fourteen of the 16 responded to the feedback questionnaire. Most students (12/14) found the module useful or very useful, and all would recommend the module to others. All liked the method of delivery, in particular the interactivity, the variety of students, and the "closeness" of the group. Most (11/14) felt "connected" with the other students on the course. Many students (11/14) had previous experience with asynchronous e-learning, two as teachers; 12/14 students suggested advantages of synchronous methods, mostly associated with the interaction and feedback from teachers and peers.

Conclusions: This model of synchronous e-learning based on interactive live webcasting was a successful method of delivering an international postgraduate module. Students found it engaging over a 10-week course. Although this is a small study, given that synchronous methods such as interactive webcasting are a much easier transition for lecturers used to face-to-face teaching than are asynchronous methods, they should be considered as part of the blend of e-learning methods. Further research and development is needed on interfaces and methods that are robust and accessible, on the most appropriate blend of synchronous and asynchronous work for different student groups, and on learning outcomes and effectiveness.

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KEYWORDS

Webcasting; synchronous e-learning; eHealth

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Introduction

To date, most e-learning has tended to be asynchronous through Internet access to websites and other interactive materials, which are used by students in their own time. With the development of new technologies, however, there is potential for the development of interactive, participatory, synchronous methods of e-learning [1]. Webcasting is one such method that also offers students the ability to participate in real-time discussion with each other and with the presenting lecturer, from any Internet-connected computer that plays sound.

DiMaria-Ghalili and Ostrow were among the first to use webcasting routinely. They changed from interactive TV to webcasting in the spring of 2003 to deliver distance learning for graduate nurses in rural West Virginia, USA [2,3]. Although some of their students were still using dial-up connections to the Internet, the method was acceptable and thought to be more interactive than interactive TV. A number of centers have used or experimented with either live streaming [4] or filmed lectures [5], but these have generally not included any synchronous interactivity. Others have used Web conferencing with video connection from all participants [6], which is more suitable for peer-to-peer meetings than for student education. Webcasting has been used nationally in continuing education in pathology [7] and nursing [8] but sometimes fails to become routine practice [9]. Some found problems with webcasting because of the lack of interpersonal interaction [10]. However, Reynolds et al reported successful trials of webcasting in dental undergraduate and postgraduate education [11]; for example, they found that students preferred webcasting to traditional lectures because of active and nonthreatening participation. We developed interactive webcasting that combined a live video stream with chat room interactivity [12] and had used this extensively for open "webinars" and occasional lectures, but not for a complete module.

The aim of the present study was to develop, deliver, and evaluate an international postgraduate module in eHealth using live interactive webcasting.

Methods

Participants

We advertised the module (cost £220) on the University of Plymouth website and via various email discussion lists. Eleven paying students applied and were accepted to the module. In addition, we invited five (three full time, two part time) of our "distance" PhD students who had an interest in eHealth. Students came from a wide range of backgrounds and posts: academics in health or medicine (2), health service public health (1), diagnostic imaging technologist (1), clinical governance (1), health visiting (ie, home nursing) (1), private sector health informatics (2), complementary cancer care information department (1), computing science student (1), head of hospital IT department (1), librarian (2), journalist (1) working in NHS (National Health Service in England), and health services research (2). The 16 students came from six countries: Malaysia (1), Mauritius (1), Saudi Arabia (1), England (10), St Vincent and Grenadines (1), and Canada (2). There were 11 male and five female students, with an age range of about 24-50 years.

Module

We ran 2.5-hour live sessions (UK time 2:00-4:30 pm) weekly for 10 weeks from October to December 2008. Although the module was available as part of a masters program, on this first occasion, all students took the module as a "stand-alone" continuing professional development. The content included the use of computers by patients, patient access to records, different forms of e-learning for patients and professionals, research methods in eHealth, geographic information systems, and telehealth. One session was a student-defined session in which students, either singly or in groups, prepared their own presentations. These were given via the video window with discussion, as usual, through the chat room.

Webcasting System

Coming from a background of using interactive satellite TV [13], we developed a hybrid solution for live interactive webcasting using a scan converter that converted the PC signal (PowerPoint) to an analogue signal, where it was mixed by the presenter with the camera signal. The combined signal was digitized and sent via a video server to a Web page where it was embedded in a student "chat room" (Figure 1) developed using open source software. We used this webcasting system with access via a module portal. Table 1 shows the main features of this approach. All sessions were recorded: presentations were recorded as video files (see Multimedia Appendix 1) and student interaction was recorded as text files (see Multimedia Appendix 2). Handouts prior to sessions and recordings after sessions were posted as blogs on the module portal. The possibility existed for students to post their own blogs to the portal.

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Figure 1. An anonymized mockup of a webcast (cartoon heads replace real photos of participants, and “PersonA” to “PersonD” replace real names)

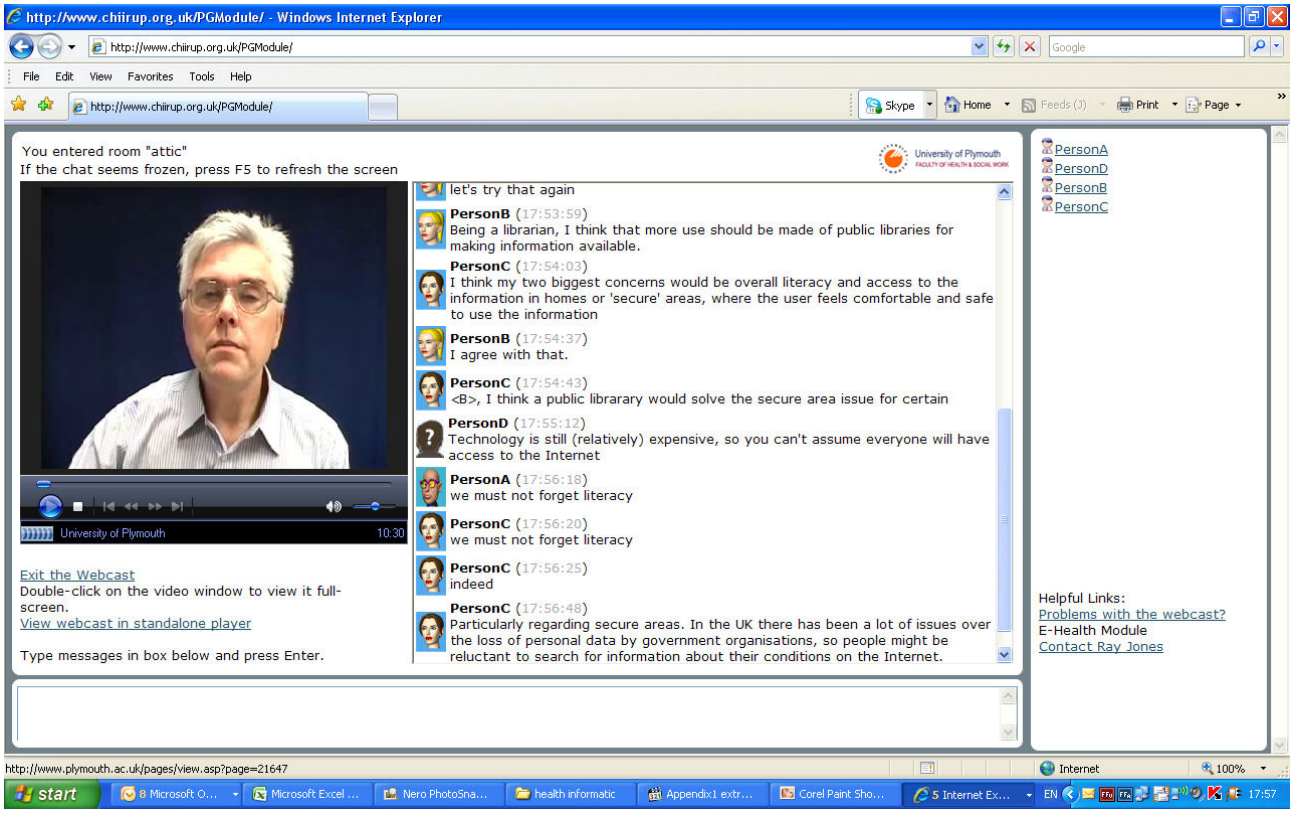


Table 1. Features of our webcasting

Live Interactive Webcasting Feature	Comment
Webcast audience is online only	We do not stream live lectures since we believe that the online audience will feel excluded. Unless the presenter concentrates fully on the distance audience, they are unlikely to achieve suitable interaction.
Live quality video showing talking head of presenter	By using a video server and good quality cameras, we achieve high-quality video and sound (rather than the familiar poor-quality video from low-end webcams). This was important for delivery but is a trade-off with the need to deliver from a mini-studio and the introduction of a 30-second delay for the video signal to reach the students (while typed chat remains instantaneous).
Live PowerPoint or presentation display	The presenter could fade between the talking head and PowerPoint using a desktop joy-stick.
List of people participating can be seen by presenter and participants	It is important for the presenter and participants to know who else is there and, if in groups, the composition of the groups.
Photo of participants can be seen by other participants	A photo of each student (avatar in the terminology of this software) was shown against their comments.
Participants can comment in real time by typing in chat room (text chat)	Participants did not use audio or video input. See results for student views on this design aspect.
Participants can be divided into breakout rooms for discussion	Participants can create a chat room on the fly simply by changing rooms. We typically used three or four rooms (attic, cellar, hall, kitchen), dividing participants by their birthday month or student name.
Recording of talking head, PowerPoint presentation, and participant discussion	Recordings of video, presentation, and chat room transcripts were made available on the module portal.

Evaluation

One week after the module was completed, students were sent an email questionnaire (see Multimedia Appendix 3) that included a mix of closed and open questions seeking their views on this form of learning. The email questionnaire was divided into six sections:

A. Overall (five open and one closed question)

B. Method of delivery: with subsections on breakout groups, pace, screen layout, audio vs text, robustness and technical difficulty, connectivity with other students, downloads, portal, video window, presentation style, overall delivery method (13 open and three closed questions)

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C. Content (three open questions)

D. Assessment (five open and one closed question)

E. Future and other possibilities (three open questions)

F. Marketing and promotion (four open questions)

Several reminders were sent over the next few weeks. The data generated by the survey were placed into a chart for each individual by a colleague (TA) who was not part of the teaching team (RJ, MKB, IM).

For closed questions and open questions that generated a limited range of answers, responses were noted and counted. For example, for question A3 ("Would you recommend the module to others amongst your colleagues? If so which job functions or roles?"), all respondents noted groups to whom they would recommend the module, so we concluded that all said yes. We classified their answers into five groups (see Multimedia Appendix 4).

For open questions that generated a narrative response, we used generic qualitative analysis [13,14]. Using an iterative process in order to generate themes, starting with the first question, comments were clustered under the corresponding question and then read through for themes (see Multimedia Appendix 4). Where there were multiple themes, items were tallied and the quotation that best represented the theme was selected. If a participant's response seemed unclear, the researcher went back to the participant's own data set to verify and clarify the information. In order to check for researcher bias, the researcher looked for conflicting data and noted those quotations. Unusual comments not related to a theme were not incorporated but were retained for team discussion. As one example, question A6 was about overall value for money and referred to the possible use of more asynchronous materials. This prompted some to comment on synchronous vs asynchronous methods, which we asked a specific question about in B2, so some A6 comments were therefore combined with others from B2. Triangulation was used in order to confirm the results. TA reviewed the anonymized results with the teaching team to compare with feedback received from participants over the course of the semester. The final data were then shared with participants to verify that their information was correctly represented.

Results

Response Rate to Email Questionnaire

The majority of students (14/16) responded to the request for feedback, most of them in some depth. The average length of email response was 1619 words (range 1144-2244 words), of which the questions comprised 955 words. That fact that students were prepared to respond to this degree suggests that a good degree of "connection" with the course and teaching team had been built over the 10 weeks.

Overall Satisfaction With the Course

There were 12/14 students who found the module useful or very useful, and two who were undecided or had no opinion. However, all 14 would recommend the module to others among their colleagues. All liked the method of delivery and would be interested in taking other modules using this same method (Table 2). Some students mentioned features that they particularly liked: the variety of other students' backgrounds (n = 3), the interactivity (n = 7), and the "closeness" of the group (n = 7).

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Table 2. Sample quotations from participants

Aspect of Course	Quotation
Overall satisfaction with the course	"It made it easy to fit the course in around my day job."
	"I very much liked the live webcasting as it is interactive and facilitates discussion and debates among the participants."
Value for money and group size	"The size of the group matters. If it was large, then some members taking part would be silent. This could possibly be overcome by breaking the group into smaller discussion groups and sticking with the same breakout groups across all sessions."
Connectivity with other students	
Positive	"Surprisingly felt more connected than I thought I would, I think for two main reasons:
	- [I had] the ability to associate thoughts and questions through the text chats with specific individuals (this would be lost if audio interaction was adopted instead)
	- The group activities split us up into smaller groups, which were more manageable and interactive.
	I felt connected and respected. The pace was set by the presenters—they greeted everyone as if they were equally important and welcomed."
Negative	"There were times in the chat rooms when I felt very isolated; the others were chatting and my comment/query was missed in the exchange. Sometimes this led me to think that my input was not valid/valued."
Suggestions for change	"Would it be possible to have information about people closer at hand (ie, when someone has commented, it's hard to remember who they are, where they are from, and what they do)?"
Connection and physical environment of participation	
Positive (for at home)	"I was able to concentrate better, had the liberty to move around (to take water or go to toilet) and to eat without disturbing the cohorts; if I didn't understand any concept and if I was not convinced by explanation by the tutors, I had the chance to surf the net for clarifications."
Negative (for at work)	"Sometimes not having somewhere to be 'physically' made it more difficult to take time out of everyday work to attend. I'd be sitting at my computer with headphones on but still very much 'at work' (ie, people in my office chatting and occasionally talking to me)—I think in a classroom situation it is perhaps easier to focus. A note to all participants to buy themselves a good pair of earphones if they are planning to listen whilst at work (ie, if they have a shared office) would be very helpful."
Use of more asynchronous materials such as recorded webcasts from the year before	"I think [the] risk of asynchronous [materials is that the experience] becomes less engaging—like watching a TV program rather than discussing thoughts [and] ideas with students in real time."
	"I like the fact that the course uses real-time interaction. The real-time, two-way communication provided by the chat room is very important to the course delivery."
Interface	"I discovered that you could send 'a secret message'—this was excellent, and I have had excellent 1:1 conversations with some of my colleagues."
	"This [session where we used a slide share] worked quite well, although it reduced the space available for the chat window. If you can find a way of accommodating all three things, that'd be ideal, but on balance I think a large chat area is more important than providing access to the slides from within the Web application."
Audio vs text input	"Would have liked to have [the] ability to talk sometimes (although not very often, surprisingly)."
	"The advantage of text is that we could all speak simultaneously; text was also instantaneous. Bearing in mind that some participants were at the other side of the world, I am sure that there would be problems with audio feeds. Text works. We are all, increasingly, becoming used to typing/texting, and it is a comfortable medium. However, English may not be the first language for all."
	"I do like audio, but then you need a 'hand raising' tool too, like in e-class."

Value for Money and Group Size

All but one student thought that the course was worth the £220 fee; one students that the current fee level and number of students was not economic for the university and asked for their views about increasing the cost to £400; opinion was divided, and one student suggested smaller incremental increases to test the level of fee. When asked about increasing the class size, some students (n = 6) said no to larger groups, one noting that it might inhibit contribution. Another suggested that this could be overcome by the use of breakout groups (see Table 2).

Connectivity With Other Students

Most students (n = 11) felt connected with the other students in the course. One suggested improving connectivity by using the same combination of students in the breakout rooms more often. There was, however, room for improvement in the facilitation of chat rooms and in providing other prompts and information to enable connection between participants (see Table 2.)

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Volume of Chat

Multimedia Appendix 2 gives an anonymized extract of a chat transcript. To illustrate the volume of chats, we will use session 5 as a typical session. A total of 14/16 students took some part in the discussion (two were unavailable). One student had Internet connection problems and only posted three messages and then took no further part. In total, there were 756 comments posted, including 108 by two members of the teaching team (RJ, IM). The 13 students who participated in the whole session posted an average of 48 messages (range 14-124) during the 2.5-hour session.

Connection and Physical Environment of Participation

During the course of the module, some students had hardware connection problems; in particular, two or three connecting from NHS sites often found it more convenient to go home for the session. A few students mentioned bandwidth-related problems in the questionnaire. Home appeared the best place to study, with no interruptions from work colleagues and the ability to "be comfortable" (see Table 2).

Use of More Asynchronous Materials Such as Recorded Webcasts From the Year Before

Students were asked if re-use of recorded materials from one year to the next would affect the course. Some students commented that use of more asynchronous material would be fine as long as there was still some sort of group facilitation and follow-up discussion, but others did not want asynchronous materials.

Synchronous Compared to Asynchronous Methods

Some students had previous experience of asynchronous e-learning (11/14), two as teachers. Most students (12/14) suggested advantages of synchronous methods, mostly associated with the interaction and feedback from teachers and peers. Although the disadvantage of the time zone differences was noted, nine students thought that the timing of the module (2:00-4:30 pm UK time) was convenient and three students, not so convenient. One noted issues around unreliability of the synchronous technology. Another suggested that with asynchronous methods more in-depth answers can be given, but some noted that asynchronous was more impersonal and less engaging.

The advantage of interaction with other students and the lecturers was supported by comments about individual sessions. Two or three sessions that gave the students less opportunity to interact were reviewed less favourably and suggestions were made to change them: "They could have been broken into two sessions each. I didn't get enough time to reflect on the teaching and hence was not able to contribute anything for the discussions."

When asked about breakout groups, students thought the balance was about right, apart from the two to three sessions in which they thought that there were too few opportunities for discussion. Various comments suggested that it was important for the presenter to facilitate breakout group discussions. One student said, "I guess that this is challenging for the teacher—knowing how long to allocate for the session and being flexible enough/savvy [enough] to facilitate longer sessions where discussion is animated and cut short those where the level of discussion is clearly non-existent!"

Another student noted the problem of multiple streams of thought in chat rooms. We addressed this by using breakout rooms, but the presenters' decisions of when to use breakout rooms, how many, and which participants to have in each room were critical in making this work.

Improving Communications and the Interface

Although most students thought that there was a lot of interaction and that this was the best part of the course, useful comments were made on how the course could be further improved, such as through one-to-one chat. The importance of the interactivity and space available for chatting were always rated highly (see Table 2).

One student wondered if the interface could be changed on the presenter's side so that occurrences of presenter error, such as talking while the sound was turned off, could be reduced.

Students were asked if they would prefer audio to text input. More preferred text, the advantage being that all participants can contribute simultaneously and that there may be problems with audio feeds. But still, some would like audio (see Table 2).

One student noted a specific problem with the chat room: "When attempting to scroll up to find something someone previously wrote, [the] cursor would immediately jump back down to the bottom as soon as someone [wrote] something new (so [it was] difficult to scroll through [the] history)." Two commented on the copyright-free music that we used when students were working on their own or perhaps in groups. One said, "I liked the music"; another stated, "The music was ghastly but very necessary as it was an easy way of knowing that the link was active."

Students generally thought that the way we used the video window was acceptable. Comments included the following: "The fading back and forth was very effective when used. It not only gave a bit of a feeling of 'interactivity' but also broke up the slideshow nicely (great for people with shorter attention spans and a million thoughts a minute like myself!)" Another student said, "Nice to see [a] real face now and then rather than disembodied slides/voice." But having the PowerPoint slides to download was also seen as useful: "I liked the simplicity of the slides onscreen, but having the presentation available as well meant that the complicated ones weren't lost as they could be studied after or on printout or in a different window. Our choice."

Module Portal

All but one student used the portal to download materials. Nine downloaded both papers (extra reading) and the presentations; four downloaded the papers only. The portal was never used by students to post items. Comments suggested that it was not easy to use for that purpose or had not been sufficiently explained; one student said, "I would have liked to be able to share resources with other students, eg, useful websites found

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following the sessions." Another said, "I still haven't worked out how to use the blog."

Module Content

Students were asked about adding or subtracting from the module content. Various suggestions were made as to additional content: two suggested including eHealth education, two, behavioral theories, and three, patient information systems. If a session had to be dropped, six students would have cut session 4 (on 3D virtual worlds), but three students thought this to be the most relevant session. Votes for other sessions were spread fairly evenly, but some commented that they would not want to see the number of sessions reduced. However, to achieve more interactivity in all sessions, we will probably need to reduce the density of topics by dropping one.

Assessment

Only five of the 16 students took the assessment, the others opting for "attendance only." All were invited to comment on the amount of assessment (a 3-hour exam in the last of the 10 weeks and one coursework essay to be handed in 6 weeks later). Four students thought that the assessment was about right, three thought it was too heavy, and the others did not comment. Six thought that the timing was okay, and three thought the exam should be later. No one felt that there should be any concerns about the open book and distance nature of the exam.

Marketing

Six students heard about the course from individual emails, two found it on a Google search, four heard about it from email distribution lists (two from Patient Information Forum [PIF] Aware), one from consumer-health informatics list on jiscmail, one from Afro-nets, one from NHS Connecting for Health "Health Informatics" eSpace community, and one from the Plymouth University website. Students recommended a number of sites where the module could be advertised.

Discussion

The use of e-learning in the health professions is expanding rapidly [16]. Traditionally, e-learning has been asynchronous, but the development of learning objects can be very time consuming and not within the skill set of many academic staff. Various initiatives are underway to develop shared e-learning resources (eg, [17]), but there is a growing body of research exploring how student-student or staff-student communication (either synchronous or asynchronous) can be used in addition to, or instead of, fixed learning objects [18,19]. For example, Baecker et al have developed methods (ePresence [20,21]) that support real-time video and voice and video conferencing for a few participants, while streaming an event to many others. Methods such as these seem particularly relevant in situations such as eHealth where the academic content changes rapidly and investment in learning objects has a short shelf-life.

We have tested a novel method for delivery of a postgraduate module. As such, our evaluation was limited to a first-level study [22] in which we assessed the feasibility and the reaction of our participants. Although we cannot draw any solid conclusions from just one case study with 16 participants, we found that the use of interactive live webcasting was successful for a 10-week international course in eHealth.

This was the first time we have run this module, and the methods of delivery are novel. By definition, therefore, our participants were early adopters and so may not be typical of later recruits. Nevertheless, students from Malaysia through to mid-Canada, from a variety of backgrounds, were able to participate in a 2.5-hour online session once a week. Live presentations in which the presenter was seen and heard in a (good quality) video window fading between a talking head and PowerPoint slide worked well. Participants particularly found the discussions (by typed chat) in smaller breakout groups an important and successful element of the delivery. This agrees with our own studies with nursing and midwifery students [15,16] who knew each other from face-to-face teaching and with Reynolds et al's trials with dental students [11]. Most of our students had experience with asynchronous e-learning and found the interactivity of this synchronous method engaging.

There were, of course, some teething problems with our webcasting, with probably the most important being limited bandwidth in NHS sites. Others who have used webcasting have had problems with connection speed, bandwidth, and server access [8,10]. Others have pointed to the need for students and staff to receive training in how the technology works [6,8]. We agree that there is a need for some staff training, but with an emphasis on how to use the technology effectively for teaching and learning rather than on how the technology works per se.

Of the 16 students who started the module, only two dropped out: one missed the last four sessions because of NHS workload, and one missed the last two sessions because of illness. Participating from home offered other advantages for some students, by having fewer interruptions or distractions.

Students participated in this synchronous international module at times ranging from 9-12 pm (Malaysia), through 2-5 pm (United Kingdom), and 7-10 am (Alberta, Canada). Most students said that they found the timing convenient, but clearly this is a selected group who chose to take the course. Given sufficient students worldwide wishing to participate in a synchronous module, it should be possible to run it at different times of the day to suit different time zones and lifestyles, although participation from Australia and New Zealand in a European module is unlikely.

E-learning based on webcasting, such as we have used, is also a much easier transition for lecturers used to face-to-face teaching, and it allows on-the-fly content tailoring guided by audience needs as one would do in a conventional lecture. Given the positive responses of our students over a 10-week course, it would appear a useful way forward. More traditional asynchronous e-learning, of course, should form part of a blend of methods. Within the structure of our webcast sessions, we were able to ask students to spend some time looking at some reusable learning objects or previously recorded webcasts. We hope also to re-use some of the recorded webcasts in subsequent years and that creating a bank of learning materials from the live webcasts will produce a useful learning resource. The research questions then center on the most cost-effective blend of synchronous and asynchronous methods.

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We used an in-house developed system [12], combining TV methods with open source software. The equipment for our webcasting mini-studio cost about £8000 2 years ago. Costs of alternative hardware may now cost less, but this approach requires that the presenter be located in a studio. There are now a variety of solutions (Table 3) on offer that may be able to deliver the same or better functionality, including webcasting from any desktop. Our own university is currently trialing MS Communicator, while our attached medical school is trialing Wimba.

Table 3. Examples of current interactive webcasting and Web conferencing solutions for e-learning

Webcasting or Web Conferencing Solution	URL
ePresence	http://epresence.tv/
Elluminate	http://www.elluminate.com/
Dimdim	http://www.dimdim.com/
Yugma	https://www.yugma.com/
Openmeetings	http://code.google.com/p/openmeetings/
Vyew	http://vyew.com/
iVocalize	https://www.ivocalize.com/
Qwaq	http://www.qwaq.com/
Adobe Connect	http://www.adobe.com/products/acrobatconnect/
Wimba	http://www.wimba.com/products/wimba_collaboration_suite/
MS Communicator	http://office.microsoft.com/en-us/communicator/FX101729051033.aspx
Mogulus ProCaster	http://www.procaster.com/video

There are various research questions related to the use of webcasting that remain:

1. What proportion of potential learners are able to participate in webcasting? For example, we had some problems with students accessing from UK health service sites, which apparently had low bandwidth availability. Are there other methods that can overcome this, or is the solution to find alternative learning sites?

2. What is the best blend of synchronous and asynchronous methods in different learning situations? Further work is needed to explore the cost-effectiveness of different proportions of live or asynchronous contact vs individual learning, and how this varies by learner groups or environments.

3. How do these synchronous methods compare with asynchronous methods, for example, through the use of recorded videos and an asynchronous discussion? Is the quality of participant discussion significantly better if participants have more time to reflect on their answers?

4. Does webcasting need a talking head and shared computer screen both permanently on? In our webcasting, the presenter could “mix” the camera shot with PowerPoint (ie, decide which was to be seen by the students). Some students commented that this works well. But using an embedded Slideshare presentation and having the talking head always present (as used by Reynolds [11]) is another option in which the slides are clearer. Most commercial packages use that method.

5. Which works best, voice or text chat? This small study and our other studies [23,24] suggest that text chat works well, but some students suggested, and most commercial packages include, the use of voice.

6. How much training or support do lecturers, new to webcasting or similar methods, require? We support the views of others who have noted that technical success is not always followed by organizational adoption of the technology [10]. Yagi et al [7] used webcasting in a large geographically dispersed pathology department and concluded that successful webcasting depends on the creation of a faculty steering committee to control resources and manage growth, the availability of support for technical staff, and embedding the service as part of the core departmental information technology infrastructure. These requirements have currently been met at our university. The module described in this paper ran again starting in September 2009. Webcasting has been adopted for a range of undergraduate [23,24] and postgraduate modules (Heather Skirton, personal communication 3/4/2009), and we have been able to issue some presenter guidelines (Multimedia Appendix 5) to support wider use. However, organizations new to these methods will need to appraise the costs and benefits of such developments.

7. How many students can be engaged in an interactive webcast while keeping it a good experience for the students? Making postgraduate modules cost-effective is a continuing challenge. With our own module, we will aim to recruit more students but to use breakout groups to keep them in the same tutorial group throughout. This will be challenging for the presenters, but we aim to involve other members of staff who are new to eHealth but who are experienced facilitators so that our students have breakout room support while the staff member has a professional development opportunity.

8. Should live webcasting be used to complement live lectures? In the past, we have had TV assistance to webcast live lectures [25], and Baecker et al [20,21], among others, have reported successful use of that approach. Our own view is that this disadvantages the distant webcast audience, who feel like flies

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on the wall rather than full participants. However, further work into the advantages and disadvantages may be worthwhile.

9. How well are learning outcomes achieved using webcasting compared to other methods?

In conclusion, this model of synchronous e-learning based on interactive live webcasting was a successful method of delivering an international postgraduate module. Students found it engaging over a 10-week course. Although this is a small study, given that synchronous methods such as interactive webcasting are a much easier transition for lecturers used to face-to-face teaching than asynchronous methods, they should be considered as part of the blend of e-learning methods. Further research and development is needed on interfaces and methods which are robust and accessible, and on the most appropriate blend of synchronous and asynchronous work for different student groups.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Extract of recorded session (video file)

[Flash video (Adobe FLV), 51,683 KB - jmir_v11i4e46_app1.flv]

Multimedia Appendix 2

Extract of chat room conversation (Excel file)

[XLS file (Microsoft Excel), 26 KB - jmir_v11i4e46_app2.xls]

Multimedia Appendix 3

Email questionnaire

[PDF file (Adobe PDF), 60 KB - jmir_v11i4e46_app3.doc]

Multimedia Appendix 4

Illustrative extracts from the collated responses

[PDF file (Adobe PDF), 40 KB - jmir_v11i4e46_app4.pdf]

Multimedia Appendix 5

Guidelines for presenters using our webcasting (PowerPoint file)

[PPT file (Microsoft Powerpoint File), 1,066 KB - jmir_v11i4e46_app5.ppt]

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Abbreviations

NHS: National Health Service in England
TV: television

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Original Paper

An Electronic Clinical Decision Support Tool to Assist Primary Care Providers in Cardiovascular Disease Risk Management: Development and Mixed Methods Evaluation

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Abstract

Background: Challenges remain in translating the well-established evidence for management of cardiovascular disease (CVD) risk into clinical practice. Although electronic clinical decision support (CDS) systems are known to improve practitioner performance, their development in Australian primary health care settings is limited.

Objectives: Study aims were to (1) develop a valid CDS tool that assists Australian general practitioners (GPs) in global CVD risk management, and (2) preliminarily evaluate its acceptability to GPs as a point-of-care resource for both general and underserved populations.

Methods: CVD risk estimation (based on Framingham algorithms) and risk-based management advice (using recommendations from six Australian guidelines) were programmed into a software package. Tool validation: Data from 137 patients attending a physician's clinic were analyzed to compare the tool's risk scores with those obtained from an independently programmed algorithm in a separate statistics package. The tool's management advice was compared with a physician's recommendations based on a manual review of the guidelines. Field test: The tool was then tested with 21 GPs from eight general practices and three Aboriginal Medical Services. Customized CDS-based recommendations were generated for 200 routinely attending patients (33% Aboriginal) using information extracted from the health record by a research assistant. GPs reviewed these recommendations during each consultation. Changes in CVD risk factor measurement and management were recorded. In-depth interviews with GPs were conducted.

Results: Validation testing: The tool's risk assessment algorithm correlated very highly with the independently programmed version in the separate statistics package (intraclass correlation coefficient 0.999). For management advice, there were only two cases of disagreement between the tool and the physician. Field test: GPs found 77% (153/200) of patient outputs easy to understand and agreed with screening and prescribing recommendations in 72% and 64% of outputs, respectively; 26% of patients had their CVD risk factor history updated; 73% had at least one CVD risk factor measured or tests ordered. For people assessed at high CVD risk (n = 82), 10% and 9%, respectively, had lipid-lowering and BP-lowering medications commenced or dose adjustments made, while 7% newly commenced anti-platelet medications. Three key qualitative findings emerged: (1) GPs found the tool enabled a systematic approach to care; (2) the tool greatly influenced CVD risk communication; (3) successful implementation into routine care would require integration with practice software, minimal data entry, regular revision with updated guidelines, and a self-auditing feature. There were no substantive differences in study findings for Aboriginal Medical Services GPs, and the tool was generally considered appropriate for use with Aboriginal patients.

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Conclusion: A fully-integrated, self-populating, and potentially Internet-based CDS tool could contribute to improved global CVD risk management in Australian primary health care. The findings from this study will inform a large-scale trial intervention.

(J Med Internet Res 2009;11(4):e51) doi:10.2196/jmir.1258

KEYWORDS

Decision support systems; clinical; cardiovascular diseases; physicians, family; Aborigines, Australian

Introduction

Cardiovascular disease (CVD) accounts for 18% of the total disease burden and 11.2% of health system expenditure in Australia [1]. Australian Aboriginal peoples experience around five times greater CVD burden than other Australians [2]. Despite recent gains, CVD remains Australia's biggest killer, accounting for 46,134 deaths and disability in around 1.4 million Australians in 2005 [1]. Although effective preventive therapies are available for people at high risk of a first and subsequent CVD event [3-7], substantial challenges remain in translating this evidence into clinical practice. Our recent studies of CVD risk management in mainstream Australian general practice and indigenous health service settings found around half of routinely attending adults lacked sufficient information to comprehensively screen for CVD risk. For those identified at high CVD risk, only a minority (31% in mainstream general practice settings and 40% in indigenous health services) were prescribed guideline-indicated medications [8,9].

The reasons for suboptimal implementation of clinical guidelines include complex and multiple barriers at the health system, doctor, and patient level [10]. For a time-constrained general practitioner (GP), consolidating numerous guidelines to make clinical decisions is challenging. This is particularly true for CVD, where overall or absolute risk assessment is recommended and simultaneous management of multiple risk factors is required. Despite guideline endorsement of the absolute risk-based approach, few Australian GPs use cardiovascular risk assessment tools to guide management [11,12].

Clinical decisions support (CDS)—in Australia also commonly called electronic decision support (EDS)—is one of the most promising interventions to improve uptake of guideline-based recommendations in clinical practice. In two systematic reviews on the effectiveness of CDS, around two-thirds of studies demonstrated improvement in practitioner performance [13,14]. Key features of successful interventions included instantaneous output generation for use at the point-of-care, minimal data entry, provision of automatic prompting for GPs, and a requirement that GPs actively respond to recommendations.

A number of controlled evaluations of CDS systems that are integrated with electronic medical records (EMRs) have been conducted in the areas of CVD risk and diabetes [15-19]. They have shown variable improvements in risk factor screening/documentation and overall processes of care. Beyond trial settings, several countries have successfully implemented large-scale CDS systems for CVD risk in primary care settings. In the United Kingdom, an electronic CVD risk assessment (but not decision support) package is being integrated into one of the most commonly used GP software systems [20]. In the United States, the ATHENA decision support system is able to be integrated with a variety of primary care software platforms to promote guideline-based management of blood pressure (BP) [21]. In New Zealand (NZ), an Internet-based CVD risk management system based on the New Zealand Guidelines Group recommendations [22] has been fully integrated into the country's most popular medical software platform EMR. This system has demonstrated improvements in uptake of CVD risk assessments [23]. Although there have been attempts in Australia to consolidate evidence about CVD management into a point-of-care paper chart tool [24], GPs would prefer decision support in an electronic format [12].

Here we outline our methods for the development of a CDS tool and present the findings of a preliminary evaluation of its use in primary care settings. This forms the first stage of a broader research and development program that will lead to the implementation and controlled evaluation of a tool that is fully integrated into Australian primary care software systems.

Methods

Development of the CDS Tool

For risk assessment, an algorithm was written based on the 1991 Framingham risk equation to predict 5-year risk of a first CVD event (coronary heart disease, stroke, congestive heart failure, peripheral vascular disease) [25]. Recognizing that this equation might underestimate risk for certain clinical conditions and for specific ethnic groups, adjustments were made using recommendations from the New Zealand Guidelines Group and guidelines from the 2004 National Heart Foundation (NHF) of Australia [26,27]. The risk factor variables and adjustments are summarized in Textbox 1.

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Textbox 1. Framingham risk equation variables and adjustments used for calculation of 5-year CVD risk in the CDS tool

Framingham risk factor variables:

- Age
- Sex
- Smoking status
- Blood pressure (BP)
- Total and high-density lipoprotein cholesterol levels
- Presence of diabetes
- Presence of left ventricular hypertrophy

5% increase to the baseline risk score is made once only if any of the following are present:

- History of premature CVD in a first-degree relative
- Body mass index ≥ 30 kg/m^2
- Total cholesterol > 8 mmol/L
- Systolic BP > 170 mmHg
- Diastolic BP > 100 mmHg
- Diabetes duration > 10 years
- Glycosylated hemoglobin (HbA1C) > 8% for the last 12 months
- High-risk ethnic background (Aboriginal, Torres Strait Islander, Maori, Pacific peoples, South Asian)

Age ≥ 75 years and calculated 5-year risk < 15%, then risk is adjusted to 15%

If the following high-risk conditions are present and calculated 5-year risk is < 20%, then risk is adjusted to 20%:

- Established CVD (coronary artery disease, ischemic cerebrovascular disease, peripheral vascular disease)
- Left ventricular hypertrophy
- Genetic dyslipidemias
- Diabetes and chronic kidney disease (estimated glomerular filtration rate [eGFR] < 60 mL/min/1.73 m^2)
- Proteinuria (defined as either albumin to creatinine ratio ≥ 30 mg/mmol or proteinuria > 1 g/day)

To define the risk management outputs of the tool, pharmacological treatment recommendations from six Australian CVD-related guidelines current in 2007 were consolidated into a single algorithm [26,28-31]. The thresholds and treatment targets for BP, lipid, and anti-platelet management are summarized in Textbox 2.

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Textbox 2. Indications and target levels for CVD medication management programmed into the CDS tool

1. **Anti-platelet medication indications:**
   - Established coronary heart disease
   - Diabetes
   - Ischemic cerebrovascular disease
2. **BP medication**
   - **Indications for commencing treatment:**
     - BP > 125/75 mmHg for the following:
       - Diabetes and proteinuria (defined as either albumin to creatinine ratio > 30 mg/mmol or proteinuria > 1 g/day)
       - Diabetes and chronic kidney disease (defined as eGFR < 60 mL/min/1.73 m^2)
     - BP > 130/80 mmHg for all others with diabetes or isolated proteinuria
     - BP > 140/90 mmHg and any one of the following:
       - Established CVD
       - Chronic kidney disease (eGFR < 60 mL/min/1.73 m^2)
       - Aboriginal, Torres Strait Islander, Pacific Islander, Maori, South Asian background
       - Adjusted 5-year CVD risk > 10% (assuming lifestyle advice given for 3-6 months)
     - BP > 150/95 mmHg and adjusted 5-year CVD risk < 10% (assuming lifestyle advice given for 3-6 months)
   - **Target treatment levels:**
     - - BP < 125/75 mmHg for those with diabetes and proteinuria
       - BP < 130/85 mmHg for:
         - All others with diabetes
         - Chronic kidney disease
         - Isolated proteinuria
         - Age < 65 years
       - < 140/90 mmHg for all others
3. **Lipid medication**
   1. **Indications for commencing treatment:**
      - Established CVD at any level
      - Genetic lipid disorders at any level
      - Diabetes and serum triglycerides > 2 mmol/L
      - Low-density lipoprotein cholesterol > 2.5 mmol/L and any of the following:
        - Diabetes
        - Aboriginal or Torres Strait Islander
        - Adjusted 5-year CVD risk > 15%
   2. **Target treatment levels:**
      - Low-density lipoprotein cholesterol < 2.5 mmol/L

The risk assessment and management algorithms were programmed into a stand-alone software package (Igor Pro 6, WaveMetrics Inc, Portland, OR, USA) that produced a single-page output. If there was complete risk factor information available, a risk score was generated and plotted along a color spectrum bar and treatment recommendations were provided.

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If information required for absolute risk assessment was absent, the output identified the variables missing and the color bar was changed to greyscale. Because many Australian guidelines are not exclusively risk based, some treatment recommendations could still be made despite incomplete risk factor information. Examples of these two types of output are shown in Figure 1 and Figure 2.

Figure 1. Sample CDS output with complete information and color bar

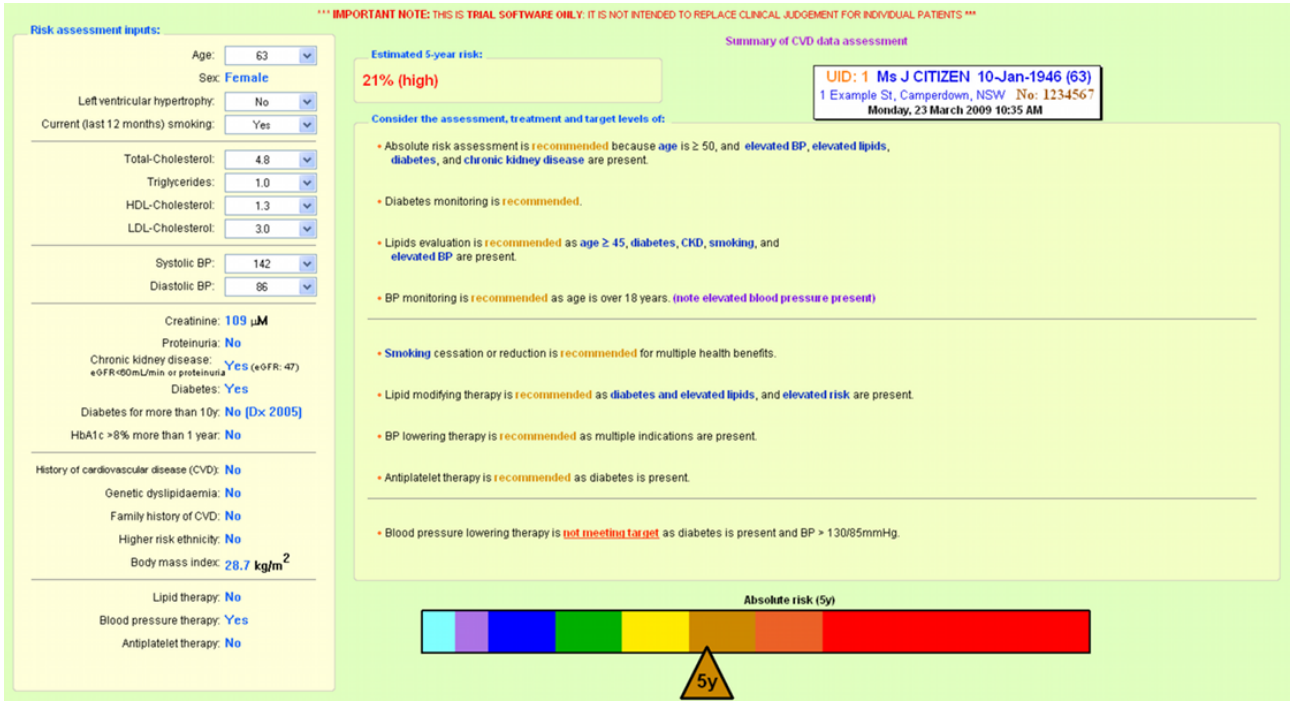


Figure 2. Sample CDS output with incomplete information and greyscale bar



Validation Testing of the Tool

De-identified data from all consecutive patients with complete risk factor information attending a specialist vascular clinic over a 3-month period (May to August 2008, n = 137) were entered into the tool by a trained research assistant to generate CDS outputs. The validity of these outputs was assessed in two parts. First, a researcher who was not involved with the algorithm development programmed the Framingham risk equation and adjustments into a second statistical software package, STATA version 9.2 (Stata Corporation, College Station, TX, USA). Correlation between risk scores generated from the CDS tool and the STATA program were assessed. Second, an experienced physician, blinded to the CDS tool management

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recommendations, reviewed the risk assessment data for each patient. She then performed a manual review of the guidelines and assessed whether anti-platelet, BP-lowering, and lipid-lowering medications were indicated or whether targets were being met for those patients already prescribed BP-lowering and lipid-lowering drugs. Agreement between the CDS tool and the physician's recommendations was assessed.

Field Testing in Primary Health Care

The tool was field tested in two different Australian primary health care settings: eight teaching general practices in Sydney and three Aboriginal Medical Services (AMSs) in New South Wales. Sampling was purposive and sought GPs interested in research and training who might critically appraise the tool and provide recommendations for its future development. A diversity sample in terms of GP age, gender, and size of practice was sought. Consecutive, routinely attending patients (Aboriginal ≥ 35 years, non-Aboriginal ≥ 45 years) were invited from the waiting room to participate. The patient age range is based on Australian guideline recommendations for absolute risk assessment screening [32]. Each GP had outputs generated for around 10 patients. This number was considered sufficient to allow (1) adequate exposure to a variety of tool outputs, (2) an appreciation of the tool's application in a typical working day, and (3) minimal administrative burden to the GP or the practice. Figure 3 provides a schema for how the study was conducted. Because the pilot version of the tool was built using stand-alone software, it lacked the ability to pre-populate with demographic and clinical data already existing in the EMR. Thus, the key role of the research assistant was to act as a proxy for this pre-populating feature by accessing the relevant risk factor information from the patient's EMR. In essence, this simulated the situation that might occur if the tool was built into the GP's practice software system. The resultant output was given to GPs prior to the consultation for review with their patients.

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Figure 3. Study schema

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Evaluation and Analyses

A mixed methods evaluation was conducted following the methods outlined by Tashakkori and Teddlie [33]. Specifically, the quantitative and qualitative components were equally weighted and combined simultaneously to obtain an understanding of the effectiveness (quantitative), acceptability (quantitative and qualitative), and feasibility (qualitative) of a CDS tool for CVD risk management in primary care settings.

At the end of each consultation, GPs completed a short survey on their attitudes about the tool and management provided. At study completion, GPs completed a second survey on their practice characteristics. This survey adapted some questions from a previously published instrument [34]. GPs then participated in an in-depth interview evaluation. Interviews were semistructured and conducted by a GP researcher who had a practical working knowledge of the tool in clinical settings. Interviews covered three domains: (1) general attitudes about the tool and its impact on the consultation; (2) a review of specific tool outputs; (3) recommendations for future tool development. Full details of the survey instruments and interview guide are provided in Multimedia Appendix 1-3.

Descriptive statistics and quantitative analyses were conducted using SAS version 9.1 (SAS Institute Inc, Cary, NC, USA). Management decisions were assessed as to whether GPs acted on recommendations from the tool output. Interview recordings were professionally transcribed, and thematic content analysis was performed drawing on the methods outlined by Patton [35]. Interview transcripts were initially reviewed in their entirety to become familiar with the data. They were then open coded to core thematic categories and these analyses were conducted contemporaneously with data collection. At the end of study, the investigator team met on several occasions to determine how these open-coded categories would be relationally grouped to determine the final major themes. NVivo 8 (QSR International, Melbourne, Victoria, Australia) was used to help organize the data through this analysis process.

The study was approved by both the Sydney South West Area Health Service and Aboriginal Health and Medical Research Council ethics committees. Patients and GPs gave written informed consent to participate in the study. Signed agreements were obtained from the three participating AMSs.

Results

Validation of the Tool

The tool's risk assessment algorithm showed near perfect correlation with the independently programmed algorithm used in STATA (intraclass correlation coefficient 0.999). The variation was wholly explained by different rounding methods used in each software program. For prescribing recommendations, agreement between the tool and the physician's recommendations for initiation of anti-platelet and lipid treatment was 100%. Agreement on meeting guideline targets for those already prescribed BP- and lipid-lowering treatments was also 100%. Agreement on initiation of BP treatment was 97% (kappa 0.95). In both cases of disagreement, the BP was < 125/75 mmHg and the physician judged that treatment was not indicated, while the tool recommended that treatment could not be determined due to missing information on proteinuria.

Field Testing – Quantitative Evaluation

Twenty-one GPs participated in the study. Practices varied greatly in size, ranging from a solo GP practice with minimal administrative support to a large practice with 23 GPs and 15 nurses. Table 1 outlines GP characteristics and their use of electronic practice management features. Table 2 shows the risk factor characteristics of the patient population by Aboriginal status and prescribing rates of preventive CVD medications.

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Table 1. Characteristics of the 21 participating GPs

	No.	%
Male	12	57
Age group (years)		
20-29	1	5
30-39	3	14
40-49	11	52
50+	6	29
Postgraduate qualifications		
Fellowship of the Royal Australian College of GPs	15	71
Diploma (eg, obstetrics, child health)	11	52
Master (eg, public health)	4	19
Participate in research sometimes or often	19	90
Use of Internet at least once daily	19	90
Electronic practice software features always used		
Medication prescribing	20	95
Automated pathology results downloaded	19	90
Online billing	14	67
Electronic patient recalls	13	62
Scanning of paper documents	12	57
Electronic care plans	12	57
Disease registers	7	33
Frequency of performing cardiovascular risk assessments for Aboriginal 35+ years, non-Aboriginal 45+ years		
Never	3	14
Less than 50% of the time	16	76
Greater than 50% of the time	2	10
Preferred method of assessing risk		
New Zealand guidelines color charts	15	71
Calculators within medical software	2	10
Other methods (eg, downloaded calculator)	1	5
Risk assessment never performed	3	14

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Table 2. Baseline risk assessment characteristics of 200 patients attending their GP[a]

	Non-Aboriginal (n = 134)	Aboriginal (n = 66)	Total (n = 200)
Age in years (mean ± SD)	51.5 ± 29.8	50.1 ± 10.62	51.1 ± 25.1
Female	79 (59%)	45 (68%)	124 (62%)
Recorded diabetes	37 (28%)	30 (46%)	68 (34%)
Current smoker[b]	36 (27%)	33 (50%)	69 (35%)
5-year adjusted CVD risk			
Low risk (< 10%)	28 (21%)	16 (24%)	44 (22%)
Moderate risk (10-15%)	12 (9%)	9 (14%)	21 (11%)
High risk (> 15%), excluding established CVD	28 (21%)	11 (17%)	39 (20%)
Established CVD	30 (22%)	13 (20%)	43 (22%)
Unable to estimate risk due to missing information	36 (27%)	17 (26%)	53 (27%)
Medication prescribed			
Lipid-lowering	67 (50%)	31 (47%)	98 (49%)
Anti-platelet	50 (37%)	20 (30%)	70 (35%)
BP-lowering	85 (63%)	37 (56%)	122 (61%)

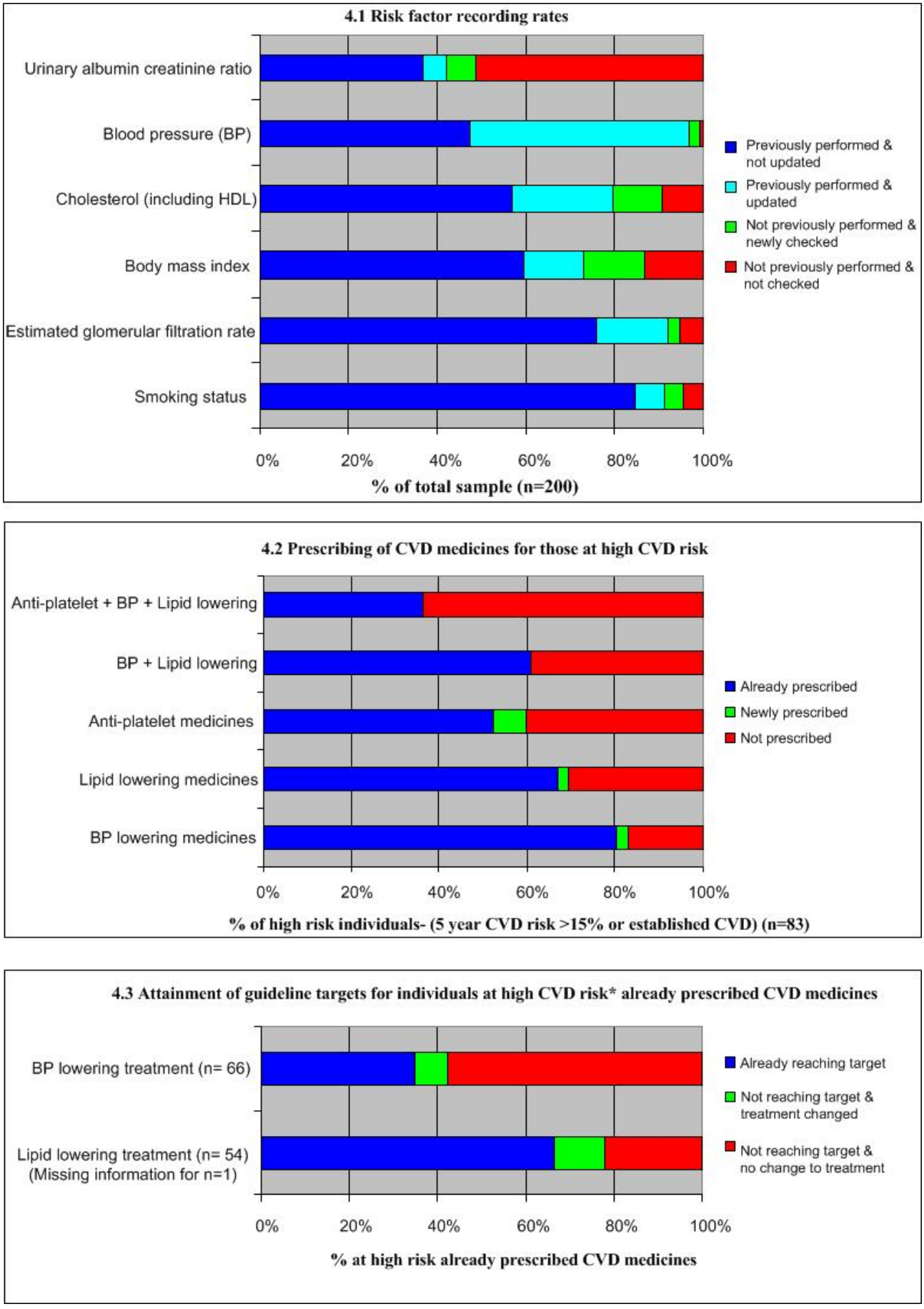
[a] Reported as no. (%) unless otherwise indicated. Percentages may not add to 100% due to rounding.

[b] Current smoker or quit within past 12 months.

For the 200 CDS outputs generated for review, GPs agreed or strongly agreed that the output was easy to understand (77% of outputs), that screening and prescribing recommendations were appropriate (72% and 64% of outputs, respectively), and that recommendations on treatment targets were appropriate (70% of outputs). Fifty-two (26%) patient records were updated with CVD-related information, most commonly family history, past history of CVD, and smoking status. Figure 4 highlights the changes in risk factor screening and management following the consultation. Ninety-five (48%) patients received changes to their management, of whom 49 (52%) received lifestyle advice on CVD risk factors. For people assessed at high CVD risk (n = 82), 10% and 9%, respectively, had lipid-lowering and BP-lowering medications commenced or dose adjustments made, while 7% newly commenced anti-platelet therapy.

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Figure 4. CVD management practices before and after a consultation involving the CDS tool



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Field Testing – Qualitative Evaluation

All GPs participated in the interview evaluation, with interviews ranging from approximately 30 to 60 minutes duration. One interview was conducted with a pair of participants, two interviews were conducted over the telephone, and the remainder were individual face-to-face interviews. Three major themes arose from the interview content analysis that will be reported here. A fourth substantive theme was identified that related to how tools are used in general practice and the role of evidence-based medicine in decision making. As this issue extends beyond factors related to the CDS tool and was not a specific objective of the study, an in-depth analysis of this theme will be conducted separately.

Theme 1: Systematic Provision of Care

Most GPs felt that the tool was effective in providing comprehensive support in CVD risk management, both at the point-of-care and as an adjunct to reviewing their clinical performance.

> *Oh well it does help, because it's your data there...and you look at it and you think "Oh gee, that's not there. I haven't put that in" or "Well yeah, they are not to target there".... So it's just a reminder that you might think you're doing okay, but there's nothing like seeing the actual figures to make you realize that "Okay, there's room for improvement here."* [Interview 7: Male GP over 60 years]

> *I think it was quite a good thing because you would finish the consultation about whatever that was about and then you'd almost have a separate time set for looking at cardiovascular risk.... Otherwise, I would think about doing it through the consultation, but you just seem to forget and then you would think "Oh damn it, I should have done that." So having that piece of paper there gave you that conversation: "Well now we've finished everything, let's look at this."* [Interview 12: Male GP 40-49 years]

> *I think it's useful to us.... It's basically like a mini audit. So anything that makes you look a little bit deeper at the person sitting in front of you is always worthwhile....* [Interview 19: Male AMS GP 40-49 years]

Importantly, however, recommendations based on single risk factor readings, out-of-date, or even false readings undermined the full benefit of such a tool. GPs sought clarification on the underlying assumptions in how risk was calculated and management recommendations were made. For the few GPs who were dissatisfied with the tool's recommendations, these issues accounted for much of that dissatisfaction.

> *It gives information which, as it's blandly presented, you go, "How did you get that?..." I got a couple of people where I got a 20% number and you go, "Oh that's madness, that's not you," and often because it's based on single digit information…like a single blood pressure.* [Interview 11: Male GP 50-59 years]

> *The other issue I have with this data which came up is it uses the last available input.... I think what would be really good is something that came up and said, "This is the risk, but we've used data that's three years out of date.... You need to be doing it again."... just a reminder to say, "Ah, I should be thinking about that for everyone." I think that would be really useful.* [Interview 17: Female AMS GP 20-29 years]

GPs further highlighted the need for ongoing revision as guidelines are updated.

> *We're used to every month getting a download of the new drug file, the new program data…with therapeutic guidelines.... There's a little button that says, this is emerging guidelines or these are the things that have just been incorporated within it.... You don't really want to be working on guidelines that are too old....* [Interview 11: Male GP 50-59 years]

Theme 2: Risk Communication

Despite only brief exposure to the tool, many GPs commented on its role in risk communication. The synthesis of multiple risk factor information onto a single page appeared to promote a beneficial dialogue with patients. The need for an evaluation from the patient perspective was highlighted.

> *I think the biggest impact is that it changed the way I talked about what I was doing with patients, in that it made it a much more slick, neat package to describe the normal screening that you do for risk management. And so I felt it was easier to deliver some description of where they're at now. And from their point of view, I mean it's hard to know, but they seemed to understand that it was a multifactorial thing, rather than just being one of those single disease problems.... The thing that I don't really know, that I guess would be useful, is what they think when they walk out the door, what they actually understand of what I've said.* [Interview 2: Female AMS GP 40-49 years]

Most noteworthy was the prominence of the color bar (see Figure 1) in promoting discussions about risk management.

> *I like this one [referring to the color bar].... I mean, everyone knows that red means danger, so if they're heading towards this one, it's a lot more visual, the impact....* [Interview 15: Female AMS GP 30-39 years]

> *I could see the potential for using it to discuss with the patient.... I like the fact that it had that nice bar with the color gradations because my other previous use of trying to describe risk has been using that one from the New Zealand calculator, and it's very complicated. It's too complicated. And I find it really, you know, very pretty, but difficult for the patient to really get much sense out of. So I liked that single bar. I thought that was much more useful for people.* [Interview 9: Female GP 50-59 years]

> *Yeah, and even the colored diagram is really helpful in seeing and being able to say, "…Look, this is going into orange – this says high in red." And there's*

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> *almost an emotional response to the colors that come back there that is actually really useful compared to me saying, "Look, people with diabetes have heart attacks and strokes."* [Interview 4: Male AMS GP 30-39 years]

Additionally, some GPs considered that interactively changing the risk factor profile and resulting risk score (including color category) would facilitate conversations about the relative contributions of individual risk factors to overall risk.

> *I could think on the absolute risk bar, if you've got an arrow for where they sit now, potentially you could have an arrow for if you were to modify what was modifiable and where could you get.... "You [the patient] could ultimately work your way down to here," and it might be a way of saying, "Well, there is the gap," and that might be helpful as a motivator.* [Interview 8: Male GP 30-39 years]

> *So that gets me thinking about talking to the patient about the relative merits of putting them on drugs compared to smoking, and I think as an interactive thing I could bring up this thing and change her smoking or change her BMI...and say, "This is a much simpler way of dramatically changing your absolute risk."* [Interview 16: Male AMS GP 50-59 years]

Theme 3: Challenges for Implementation in Routine Care

While GPs felt that it was appropriate and feasible to incorporate CVD risk management into routine care, the time pressures in doing so were highlighted. A major potential constraint identified would be the time required for data entry. A common view expressed was that a tool integrated with practice software would need to be pre-populated with as much risk factor information as possible.

> *I think it depends on the patient. The ones where I think it takes most time are those where it's not been brought up and it turns out that the risk is high. So where you feel the stakes are higher...and it's not really been on your radar and it's certainly not been on the patient's radar. There aren't that many of those. For most of the patients where the risk is high, you're already aware that their risk is high.... In that context, it isn't that much extra work....* [Interview 4: Male AMS GP 30-39 years]

> *I'm not sure how you can do it, because some are from pathology reports coming back, some things you have to measure, and then some people don't put it in the right boxes. They just type in. So if you don't put it in the right place, then the software won't be able to pick it up. If I have to go enter [data] into this thing, then I'm pretty sure very few people are going to do it...just like the New Zealand one.... But, if you could extract it automatically, or maybe I fill in the occasional one...then that's fine.* [Interview 10: Male GP 50-59 years]

> *One of my rules in general practice is "every 30 seconds counts," so if it becomes something that slows the program down, if it becomes something that blocks your progress on doing what you want to do...they're the things that would make it less usable...rather than becoming distracted by this thing because you are stuck with closing boxes and pop-ups and forced to put data in.... What I like about this [the CDS tool], it pulls information together for you so you don't have to look through 7, 8 different places....* [Interview 11: Male GP 50-59 years]

This was considered particularly germane to GPs who are less comfortable with EMR use and where information may not be stored in an extractable format.

> *Less-computer-literate doctors will find it less useful because they don't have the information there.... So, if people put garbage in, you will get garbage out, and I don't think that is going to change..... I can't imagine a paper file doctor wanting to use the tool in the first place. So I think your target is only likely to be people who are more computer savvy.* [Interview 8: Male GP 30-39 years]

Some GPs advised of the need for a more graphically oriented layout and innovative prompting mechanisms that avoid contributing to the already congested number of "pop-up" prompts present in their systems. Additionally, some GPs felt that the screening (as opposed to management) recommendations offered little additional value and, in their time-poor context, may distract from the recommendations about indicated preventive therapies.

> *I find it all too wordy.... I can't read those words while I'm sitting there with a patient. I still have to sit there and think, "What does that sentence actually mean?..." So, it needs to be very graphic, where it says the same thing to you graphically.* [Interview 2: Female AMS GP 40-49 years]

> *[The tool was] almost too busy.... I've only got a minute to glance at it.... People normally wait about four, six weeks to come and see me, and so they've got a lot of stuff they want to see me about.... I don't need to know that lipids evaluation is recommended for those aged over 50. What you want is the real necessary stuff...those first four things (the screening recommendations) actually weren't necessary.... You've got 15 minutes at most and...if you don't have that information in the first two lines, people won't read it.* [Interview 14: Female GP 40-49 years]

Discussion

This preliminary evaluation demonstrates that a valid decision support tool for CVD risk management can be successfully developed and that such a tool was favorably received by GPs working in two distinct primary health care settings. The baseline prescribing patterns of CVD medications to high-risk individuals were broadly similar to those reported in our previous Australian audit studies [8,9]. The improvements in risk factor screening and the intensification of existing therapies were promising signs of the tool's ability to promote absolute risk-based care. It was also encouraging that despite, or perhaps

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because of, the high rates of Aboriginal CVD disease burden, the tool was viewed positively by AMS care providers. A large-scale controlled evaluation would clearly be needed to substantiate these preliminary study findings.

The evaluation identified key aspects of both the tool's scientific design and functionality that are likely to be crucial for successful wider implementation. Our findings support the systematic review evidence that CDS tool features associated with improved performance include factors such as integration with routine workflow, provision of automated decision support, and provision of recommendations rather than simply assessments [14]. Perhaps the most fundamental finding from this study is that CDS tools need to be effectively incorporated into routine care and avoid being viewed as an optional, additional burden to the workload. Integration within existing medical software systems and maximal use of information contained in other parts of the EMR would reduce data entry and increase the tool's use. Although the uptake of EMRs in the Australian primary care system is widespread for prescribing medications and pathology services, their routine use for other purposes is more variable [36]. This poses both challenges and opportunities for CDS tools. In this pilot, the research assistant accessed health information from disparate parts of the EMR, including free-text information. The ability to automatically "push" data into a CDS tool and limit burdensome data entry is dependent on the extent to which information exists in an extractable format. If the amount of extractable information is scant, this could pose a major barrier to use of CDS tools. The tool itself, however, can be utilized as a strategy to overcome this problem. If the information that is entered directly into the tool can be "pulled" back into the appropriate parts of the EMR, then there is a dual purpose being served—that of performing a clinically relevant task at the point-of-care and a data cleaning process. In practical terms, this would mean that the CDS output would either be automatically generated based on existing data or prompt the practitioner for any missing data. This missing data could then be entered directly into the tool and written back to the appropriate part of the health record, avoiding the need for double data entry. This makes future risk assessments easier to perform, affords extraction of more reliable data for auditing and quality improvement purposes, and supports the use of shared electronic health records across multiple service providers. Full EMR integration is also a key consideration in supporting other components of chronic disease management such as chronic care plans, well person's health assessments, and audit cycles of care (all of which attract Australian government–funded rebates). This could ensure that the tool facilitates existing care, rather than competes with it.

The NZ Web-based decision support system for CVD risk has been purposefully designed to be "agnostic" to the EMR environment and is capable of pushing and pulling data with a variety of commercial products. As a centrally deployed system, there is also a mechanism for rapid implementation of updates as subsequent guidelines evolve (already a priority issue in Australia given that three new CVD-related guidelines have been released since initial programming of this tool). In order to meet these specification requirements in the Australian context, adequate resourcing and a close collaboration between researchers and EMR vendors are needed. The Medical Software Industry of Australia, which is the peak representative body for all EMR providers, the Australian Health Information Council, and the Australian government's National E-Health Transition Authority are key stakeholders that can assist with establishing industry standards on CDS tools. Furthermore, endorsement of these tools by the peak national bodies responsible for generating and disseminating guidelines could further increase GP confidence in their validity.

An important consideration for future development of the tool is to more fully understand its impact on communication of CVD risk between care provider and patient. This study confirms previous findings that GPs use these tools to facilitate the provider–patient interaction [12]. Of particular note was the role of the color spectrum bar in communicating risk information and the desire to interactively change this based on different risk scenarios. While this tool examined decision support for the care provider, further work examining how best to provide decision support for the patient is needed. This includes identifying acceptable formats for conveying risk information, evaluating the impact of decision support on health care interactions, and exploring its potential for use outside the clinical consultation (eg, self-management programs and personal eHealth records).

Limitations

A limitation of this preliminary evaluation was that changes in care provider practices were based on a single consultation, reducing the ability to assess the potential impact of the CDS tool over time. A second potential limitation was the sampling method. Rather than seek a representative sample, we sought GPs who might actively contribute to the future development of the tool. AMSs were considered important settings to assess whether the tool was acceptable for use in a population with high levels of health disadvantage. Despite this purposive sampling, the types of medical software used, the electronic features used within those software systems, and the rates of performing absolute risk assessments were broadly similar to those reported in the Australian literature [12,36].

Future Implications

The implications of a CDS tool for CVD risk management extend well beyond being a point-of-care clinical resource. Data from UK CVD risk programs have allowed for the generation of population-specific risk prediction equations that outperform Framingham-based algorithms [20]. The NZ decision support system, combined with linkage to mortality and hospital databases, is similarly allowing for rapid advances in CVD risk factor epidemiology. The combination of a centrally managed Internet-based system with local management of program specifics by primary health organizations allows for a "ground up" approach to incorporating population health aspects into such systems. Along with epidemiological advances, both the UK and NZ systems allow for the use of large-scale primary care data to monitor health system performance. In Australia, such systems will play an integral role in the broader eHealth strategies being proposed to reform the health care system [37-39]. Performance measures in CVD risk management are integral to the UK Quality and Outcomes Framework and are

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allowing for large-scale analyses of regional variation and progress in reducing health inequalities [40]. In Australia, this is especially pertinent to addressing Aboriginal health inequities where specific indicators for the measurement and reduction of CVD risk are proposed [41]. Awareness of these broader issues and incorporation of the major study findings into the next phase of the project will provide a strong foundation to develop, implement, and evaluate an integrated CVD risk management system in Australian primary health care.

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Conflicts of Interest

None to declare

Multimedia Appendix 1

GP questionnaire completed at the end of each patient consultation

[PDF file (Adobe PDF), 40 KB - jmir_v11i4e51_app1.pdf]

Multimedia Appendix 2

GP questionnaire completed at the end of the study

[PDF file (Adobe PDF), 402 KB - jmir_v11i4e51_app2.pdf]

Multimedia Appendix 3

GP interview guide

[PDF file (Adobe PDF), 30 KB - jmir_v11i4e51_app3.pdf]

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Abbreviations

AMS: Aboriginal Medical Service
BP: blood pressure
CDS: clinical decision support
CVD: cardiovascular diseaseeGFR: estimated glomerular filtration rate
EMR: electronic medical record
GP: general practitioner
NZ: New Zealand

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Original Paper

Web Usage Data as a Means of Evaluating Public Health Messaging and Outreach

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Abstract

Background: The Internet is increasingly utilized by researchers, health care providers, and the public to seek medical information. The Internet also provides a powerful tool for public health messaging. Understanding the needs of the intended audience and how they use websites is critical for website developers to provide better services to the intended users.

Objective: The aim of the study was to examine the utilization of the chronic fatigue syndrome (CFS) website at the Centers for Disease Control and Prevention (CDC). We evaluated (1) CFS website utilization, (2) outcomes of a CDC CFS public awareness campaign, and (3) user behavior related to public awareness campaign materials and CFS continuing medical education courses.

Methods: To describe and evaluate Web utilization, we collected Web usage data over an 18-month period and extracted page views, visits, referring domains, and geographic locations. We used page views as the primary measure for the CFS awareness outreach effort. We utilized market basket analysis and Markov chain model techniques to describe user behavior related to utilization of campaign materials and continuing medical education courses.

Results: The CDC CFS website received 3,647,736 views from more than 50 countries over the 18-month period and was the 33rd most popular CDC website. States with formal CFS programs had higher visiting density, such as Washington, DC; Georgia; and New Jersey. Most visits (71%) were from Web search engines, with 16% from non-search-engine sites and 12% from visitors who had bookmarked the site. The public awareness campaign was associated with a sharp increase and subsequent quick drop in Web traffic. Following the campaign, user interest shifted from information targeting consumer basic knowledge to information for health care professionals. The market basket analysis showed that visitors preferred the 60-second radio clip public service announcement over the 30-second one. Markov chain model results revealed that most visitors took the online continuing education courses in sequential order and were less likely to drop out after they reached the Introduction pages of the courses.

Conclusions: The utilization of the CFS website reflects a high level of interest in the illness by visitors to the site. The high utilization shows the website to be an important online resource for people seeking basic information about CFS and for those looking for professional health care and research information. Public health programs should consider analytic methods to further public health by understanding the characteristics of those seeking information and by evaluating the outcomes of public health campaigns. The website was an effective means to provide health information about CFS and serves as an important public health tool for community outreach.

(J Med Internet Res 2009;11(4):e52) doi:10.2196/jmir.1278

KEYWORDS

Internet: Web usage mining; chronic fatigue syndrome; public health campaigns; market basket analysis; Markov chain model; continuing medical education

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Introduction

In our fast-paced culture, the Internet has become a common public resource for medical information [1-4]. Survey results from the Pew Internet & American Life Project found that 80% of Internet users looked online for information on health topics [5]. Clinicians also use the Internet to search current information and communicate with patients [6]. In addition to providing information sought by patients and health care providers, the Internet provides a mass medium for health campaigns to generate consumer awareness and influence health behaviors [7].

Optimal use of the Internet for public health messaging requires an understanding of user characteristics, needs, and interests. Websites function as bidirectional communication channels, whereby Web content is the message sent to users and Web usage data from interactions between users and the website represents the visitor feedback. Web usage data reflects users' contextual interests, geographic locations, and navigation patterns; appropriate analysis provides insight to better understand and serve users' needs [8,9]. Both the public and private sector have utilized Web usage data to personalize sites, improve website quality, gather business intelligence, and enhance website design based on navigation patterns [9-12].

Chronic fatigue syndrome (CFS) is a debilitating illness of unknown etiology characterized by multiple unexplained symptoms including fatigue [13-15]. CFS affects between 4 and 7 million Americans [16]. A quarter of those with CFS are unemployed or receive disability, and the average family in which a member suffers from the illness foregoes about US$20,000 annually in earnings and wages [17]. In spite of this burden, only half of those with CFS have consulted a physician, and fewer than 20% have been appropriately diagnosed [18-20]. Providing credible evidence-based information concerning CFS to health care providers, patients, and their families has obvious public health significance. In this study, we evaluated the usage of the CDC's CFS website and focused on three objectives: (1) CFS website utilization, (2) outcomes of a CDC CFS public awareness campaign, and (3) user behavior related to public awareness campaign materials and CFS continuing medical education (CME) courses.

Methods

The CFS website was launched in June 1996 to provide current evidence-based information about CFS. Since May 2005, CDC websites have used the Omniture Web tracking system (Omniture Inc, Orem, UT, USA). The CDC maintains approximately 300 topic-specific websites. Due to privacy policies, CDC websites do not utilize persistent cookies and cannot collect personal identifiers.

Data Collection

We based our analysis on website usage data collected over 18 months between June 11, 2006, and December 8, 2007. We selected this time period because the re-designed website was launched on June 11, 2006. The site included four topic segments:

1. "Information for Patients and Caregivers" – basic facts, symptoms, risk factors, diagnosis, treatment options, information for communicating with doctors, and brochures
2. "Information for Healthcare Professionals" – symptoms, diagnosis, treatment options and management plans, toolkits, and brochures
3. "News and Highlights" – new publications, information on the CDC's CFS public health research program, and an annotated bibliography of peer-reviewed publications
4. "CFS Public Awareness Campaign" – brochures, a photo exhibit, two radio public service announcements (PSAs; 30 and 60 seconds), and a video PSA (30 seconds)

In January 2008, two online CME courses were added to the site: (1) CFS: Diagnosis and Management, for physicians, nurses, and physician assistants, and (2) CFS: A Primer for Allied Health Professionals (see the Multimedia Appendix).

Raw Web usage data were collected and preprocessed by Omniture and then exported in formats of various Web traffic and path reports through SiteCatalyst (Omniture Inc, Orem, UT, USA). We developed a Java program to further process SiteCatalyst reports for specific analyses. Our current analyses excluded visits from CDC computers (ie, CDC staff accessing the site from within the CDC firewall). We also identified and eliminated noisy data in navigation path reports (eg, access by Web crawlers).

Web Utilization

We used the following information to measure CFS website utilization.

Page View

A page view is a view of a full Web page document, which occurred when a visitor opened or reloaded a Web page. Page views to one of the four topic Web pages or an individual page reflected traffic patterns over specific time periods. We defined total page views as the number of times a Web page was viewed in a given period.

Visit

A visit is an interaction between a visitor and the website, which occurred when a visitor opened and navigated around the website. In this study, a visit persisted until 30 minutes of inactivity or 12 hours of continuous activity. A single visit could include multiple page views.

Geo-Location

Geo-locations are locations in the United States from which visitors accessed the website. We categorized all locations by state. As in other Web usage studies, we excluded AOL (America Online) users from geo-location analysis because their physical geographic positions could not be correctly located by current Web tracking techniques; however, they were included in all other analyses in this study.

Visiting Density

The visiting density is the number of page views per Internet population. We estimated the Internet population of each state based on census data [21,22] and calculated state-specific visiting density as follows:

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Referring Domain

The referring domain is the base domain (without the query string or subdirectories) of the website address that referred a visitor to the CFS website.

We also used views to the publication Web pages to evaluate the utilization of publications on the CFS website.

Web Traffic Associated With CFS Public Awareness Campaign

On November 6, 2006, the CDC launched a national CFS public awareness campaign with the purpose of educating the public and health care professionals about CFS. The campaign was launched at the National Press Club in Washington, DC and consisted of TV and radio PSAs, press releases, and a traveling public photo exhibit. A major specific aim (and outcome measure) was to encourage utilization of the CFS website. We analyzed the Web usage data around the campaign to describe its impact on Web traffic to the CFS website. We selected three time periods: (1) pre-campaign (5 weeks before campaign: September 17 to October 21, 2006), (2) launch of the campaign (3 weeks around the campaign launch: October 29 to November 18, 2006), and (3) post-campaign (5 weeks after the campaign: November 26 to December 30, 2006). We examined outcomes of the CFS public awareness campaign by analyzing the number of visits to the website and user interests.

User Behavior Related to CFS Public Awareness Campaign and Online CME Courses

The key to understanding user behavior is to analyze the navigation path, which is the sequence of Web pages a user clicks through while visiting a website. Due to the simple structure of the CFS website, we did not conduct a cluster analysis. Instead, we used a market basket analysis (also known as association rule mining) to inspect the user preference for five different types of media used in the CFS awareness campaign: brochures (in PDF format), a photo exhibit, 30- and 60-second radio PSA clips, and a 30-second video PSA clip. To evaluate user behavior of the two online CME courses, we built a Markov chain model from the navigation paths.

Market Basket Analysis

Market basket analysis [23] is a common mathematical technique used by marketing professionals to reveal association rules between individual products or product groups. It has been widely used in retail business to find the relationships between sets of products (ie, purchases) to understand the shopping behavior of customers. The analysis assumes that if you buy certain items in a store, you are more or less likely to buy another type of item. A typical association rule consists of an antecedent and a consequent, which are two disjoint item sets. It is usually measured by the confidence of a rule (scaled from 0% to 100%), which is defined as the ratio of the number of transactions including all items in both antecedent and consequent sets to the number of transactions including only items in the antecedent. An example of such a rule is that 95% (confidence of the association rule) of customers who purchased milk (antecedent) also bought some bread (consequent). The information obtained from such analysis can be used in forming marketing strategies, improving store design for cross-selling, determining promotion and discount plans, and so on.

In this study, we applied market basket analysis to find the visiting associations (ie, association rules), which are the likelihoods of certain pages being viewed together by a visitor. We defined a high association as a confidence rule value of 80% or above. Since we focused only on a small basket of items (ie, less than 10 Web pages), the computation efficiency and excessive irrelevant rules were not issues. We collected navigation paths from the 5 weeks before the campaign launch (September 17 to October 21, 2006) and a 5-week period after the launch (November 26 to December 30, 2006). We transformed navigation paths into “purchasing transactions” consisting of “purchased items” (Web pages with different CFS awareness media types) from a “store” (the CFS website). Each “transaction” made by a “customer” is equivalent to a single navigation path from a visitor. We developed a Java program to implement market basket analysis to describe co-occurrence relationships among usage of different online messaging media types.

Markov Chains

A Markov chain is a stochastic process with Markov property [24]. It has been used to model navigation behaviors on websites to predict the next link that a user will click [25], and the chain is defined by a set of states and a set of transitions (ie, the changes of state) between them. Each transition is associated with a probability indicating the likelihood of a transition occurring. In a first-order Markov chain model, the future state depends only on the present state and is independent of past states. In this study, we used a first-order Markov chain model to represent visitors’ navigation information for the two online CME courses and analyze the transition probabilities of the next Web page that a visitor would visit according to what pages they were on. Although this simple Markov chain model ignored the past Web pages viewed by users and calculated the transition probabilities only based on the present Web page, it provided us general navigation patterns. Both of the CME courses consisted of eight components (Syllabus, Introduction, three content-related Chapters, Appendix, Case Study, and References). Each component may contain one Web page (eg, Syllabus and Introduction) or several Web pages (eg, content-related Chapters). We identified and extracted the navigation paths to the courses and used them to build a Markov chain model, whose states and transition probability were defined as follows:



The states in the model included the eight components of each course plus three additional states, *start*, *exit*, and *CME homepage*. The *start* and *exit* states did not correspond to any particular Web page, which only indicated the starting and ending of a visit. By introducing the *exit* state, we defined the dropout probability of a state as the transition probability from

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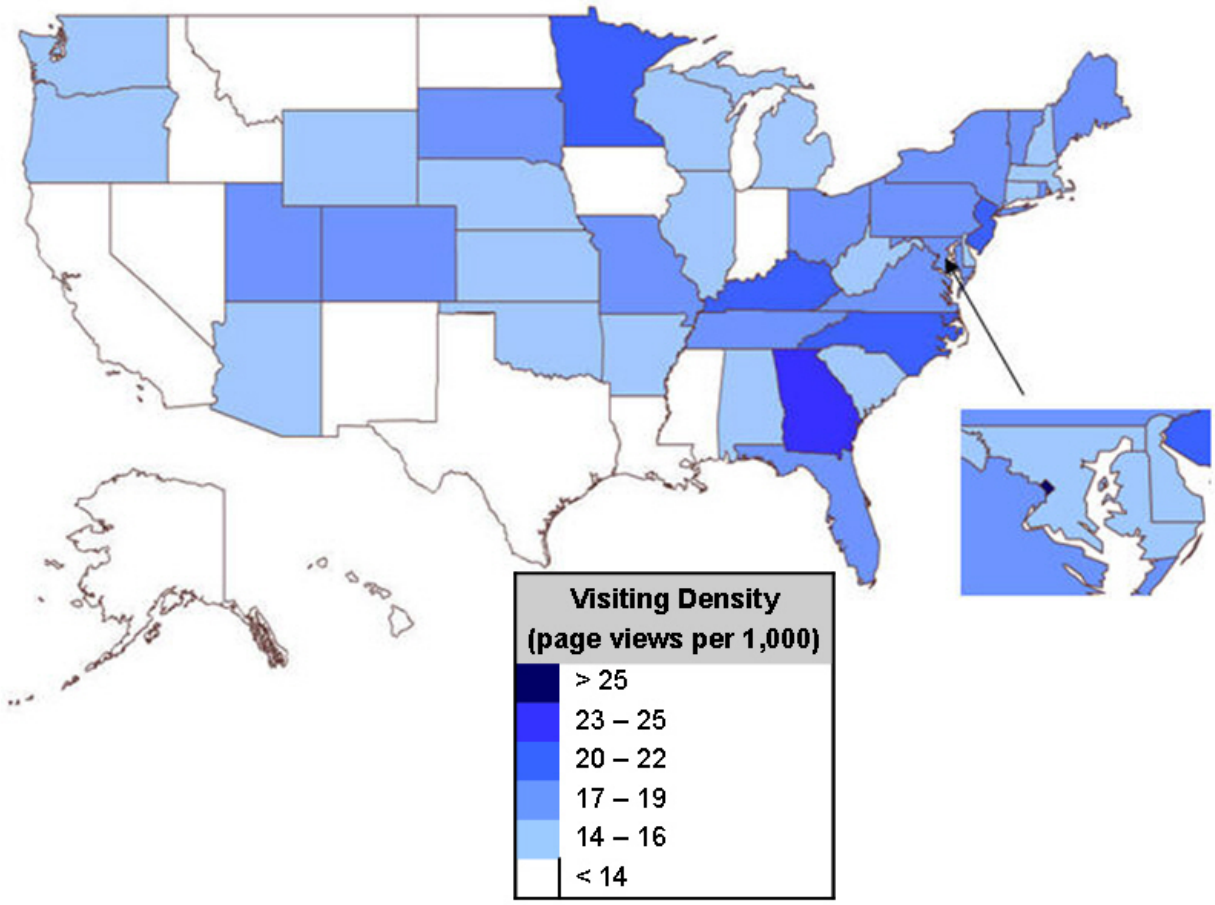
this state to *exit* state. *CME homepage* state corresponded to the home Web page of the continuing education portal for the two courses. In other words, we defined "state" as a Web page or group of pages a person views. For example, a visitor could view the Introduction page to a CME course, and this would be considered a state. A transition occurred when a visitor moved from one state to another state (ie, moving from one component within a CME course to another component). The key information in the model is the probability of a transition.

Results

Web Utilization

Between June 11, 2006, and December 8, 2007, the CFS website received 843,567 visits, resulting in 3,647,736 page views. During this time period, the CFS website ranked 33rd and was in the top quarter of viewed websites at the CDC. Geographic distribution of page views reflected distribution of the 2007 US population; most visits came from California, Texas, New York, Florida, and Pennsylvania. Of note, 20% of page views came from more than 50 foreign countries. To determine geographic specific interest in CFS, we calculated views per Internet population or state-specific visiting density (Figure 1). Washington, DC had the highest visiting density (111 page views per 1000), followed by Georgia (25 page views per 1000), North Carolina (21 page views per 1000), New Jersey (21 page views per 1000), and Minnesota (20 page views per 1000).

Figure 1. Visiting density of the CFS website



User interest in the four topic segments of the CFS website are shown by aggregating the page views of individual Web pages into topic segments (Table 1). "Information for Patients and Caregivers" had the greatest number of page views (57%), followed by "Information for Healthcare Professionals" (31%), "News and Highlights" (8%), and the "Awareness Campaign" (4%).

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Table 1. CFS website page views by topic segment

Topic Segment (with top three pages)	No.	%[a]
Information for patients and caregivers	**1,432,512**	**57**
CFS basic facts	360,983	14
CFS treatment options	188,852	8
CFS symptoms	127,569	5
Information for health care professionals	**774,404**	**31**
CFS diagnostic symptoms	319,544	13
CFS toolkit: fact sheets	114,443	5
CFS treatment	101,008	4
News and highlights	**205,504**	**8**
CFS research: new knowledge and publications	54,910	2
CFS publications: new	21,246	1
CFS news and highlights	21,124	1
Awareness campaign	**92,412**	**4**
Brochures	36,360	2
Topic segment home page	26,381	1
Public service announcements	9,056	< 1

[a] Page views to the CFS home page were excluded, resulting in 2,504,832 page views.

Over the 18-month period, the publication section on the CFS website received a total of 199,690 page views. The most frequently viewed page in this section was “New Publications” (76,949 page views), and the top five most frequently viewed papers on the CFS website were accessed 5158, 4709, 4636, 2872, and 2850 times, respectively.

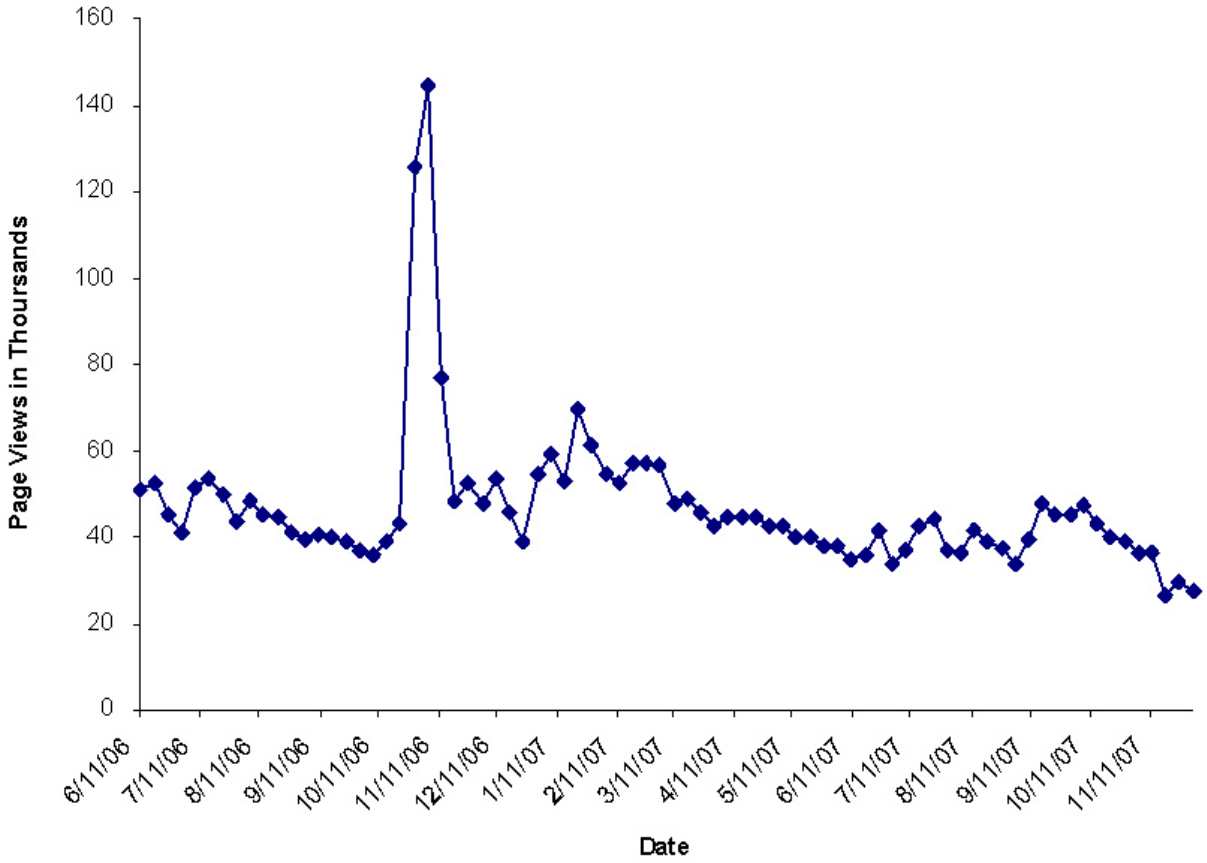
We also assessed how individuals were referred to the website. Among 962,490 visiting instances, 71% (687,316) were referred by Web search engines, 16% (156,142) by non-search-engine websites, and 12% (119,027) directly by bookmarked/typed uniform resource locators (URLs). Among the search engines, Google contributed to 73% of referrals, compared to Yahoo’s 13% and MSN’s 9%.

CFS Public Awareness Campaign

After the campaign was launched, the average weekly visits increased more than one and a half times for a 3-week period (from 9594 to 24,977 visits/week) and then dropped to 11,060 visits/week during the 5 weeks post-campaign (Figure 2).

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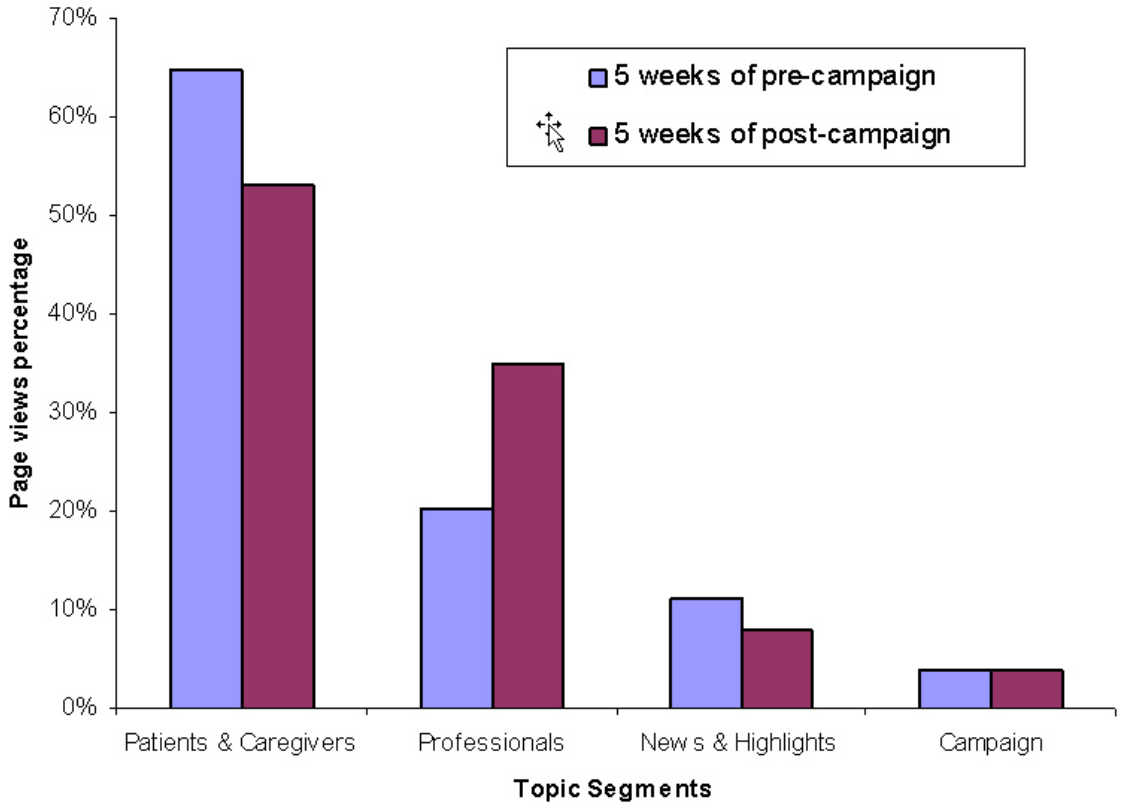
Figure 2. CFS website traffic pattern



In addition to the change in Web traffic volume, the proportion of page views to the four topic segments also changed following launch of the campaign (Figure 3). Although the percentage of page views to the topic segment "Information for Patients and Caregivers" remained the highest, it decreased from 65% to 53%, whereas the percentage of page views to "Information for Healthcare Professionals" increased from 20% before the campaign to 35% after the campaign.

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Figure 3. Topic segments and the CFS awareness campaign (y-axis value is the percentage of page views to a topic segment over the total page views to the website; page views to the home page are excluded)

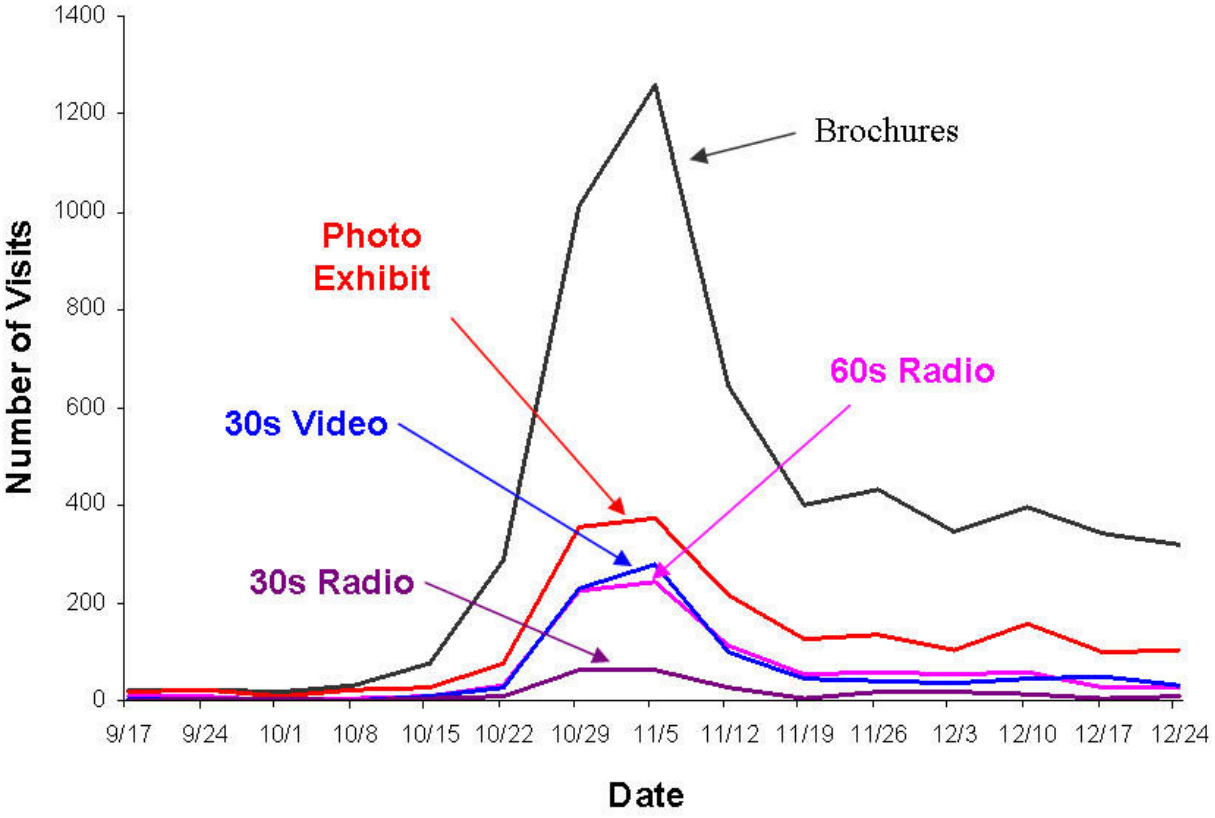


User Behavior for CFS Campaign Materials and CME Courses

Figure 4 depicts visitors' preferences for the different types of CFS campaign materials. The spike indicates the time period of the campaign launch. After the campaign launch, the brochure was the most frequently viewed campaign media type followed by the photo exhibit. The 60-second radio clip and 30-second video clip had approximately an equal number of visits, whereas the 30-second radio clip was the least viewed type of media.

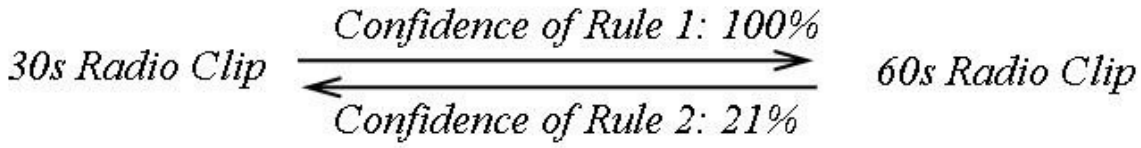
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Figure 4. Usage of the different CFS campaign materials



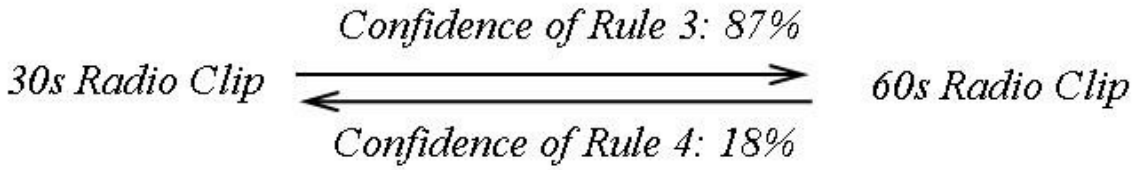
Market basket analysis results indicated users' preference for the 60-second radio clip over the 30-second radio clip (Figure 5 and Figure 6) as found in the 5 weeks prior to launch and post-campaign. The association rules between other types of campaign materials such as brochures vs photo exhibit, brochures vs video, video vs 60-second radio clip, etc, all had low confidence values ranging from 1 to 65, well below the cutoff of 80.

Figure 5. Association Rules 1 and 2



Association Rule 1 shows that in the 5 weeks before the campaign launch, 100% of visitors who viewed the 30-second PSA radio clip page also viewed the 60-second PSA radio clip page, compared to 21% of visitors who viewed the 60-second PSA radio clip page and then also viewed the 30-second PSA radio clip page (Association Rule 2).

Figure 6. Association Rules 3 and 4



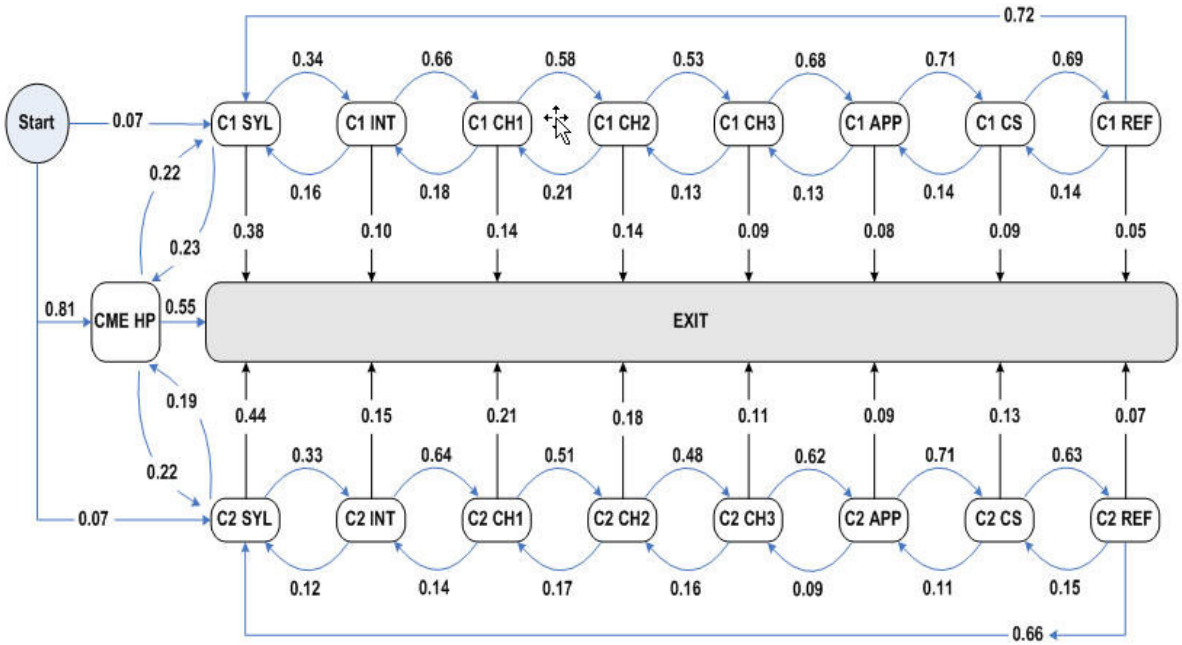
In the 5 weeks after the campaign launch, 87% of visitors who viewed the 30-second PSA radio clip page also viewed the 60-second PSA radio clip page (Association Rule 3), vs 18% of visitors who viewed the 60-second PSA radio clip page and

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then viewed the 30-second PSA radio clip page (Association Rule 4).Thus, overwhelmingly, visitors who viewed the 30-second PSA radio clip page also viewed the 60-second PSA radio clip page, yet only a small proportion of visitors who viewed the 60-second radio clip (21%) checked the 30-second radio clip as well (18%).

From January 1 to August 31, 2008, there were 43,428 page views to the online CFS CME courses (Multimedia Appendix: i. Continuing Education Portal). From these page views, 8070 navigation paths were identified and used to build the Markov chain model (Figure 7).

Figure 7. Markov chain model of online CFS CME courses (ovals represent the states and arrows represent the transitions; the number next to each arrow is the transition probability; transition probabilities less than 0.05 are not shown; C1: CFS – A Primer for Allied Health Professional; C2: CFS – Diagnosis and Management)



For all visits (n = 8070), 46% (3737) viewed the home page and then exited. The Diagnosis and Management CME course received 2451 (30%) visits and the A Primer for Allied Health Professional course, 2298 (28%). Only 5% (407) viewed the content from both courses. The user visiting patterns identified by the Markov chain model matched the Web structure of the two courses very well. All transitions between two course components could match to either a “next page” or “previous page” button on the Web pages, indicating that users followed the courses in sequential order. Although users could directly access any component from anywhere in the course through the left navigation panel on each page, the probabilities of these skip patterns or short-cut transitions were shown to be not greater than 0.05 in the Markov chain model. The Markov chain model also found that the dropout probabilities from the CME home page and Syllabus pages were much higher than those from other course components. The CME home page was the most common entrance (0.81) and exit (0.55) to the CME courses. The transition probabilities from the CME home page to the Syllabus pages of the two courses were the same (0.22). It is to some extent unexpected that the dropout probabilities on the Syllabus pages were high (0.38/0.44). Based on the structure of the Syllabus Web pages, it is possible that this high dropout rate reflects the fact that the hyperlink to the Introduction page is at the bottom of the page and is not highlighted, in addition to the excessive length of these pages (> 120 lines).

Discussion

The high utilization rate of the CDC CFS website indicates the magnitude of interest in CFS and reflects the website’s importance as an online resource for investigators, health care providers, patients, and caregivers around the world. Over 6000 page views to the website occurred each day, with over 840,000 visits over an 18-month period.

Analysis of geographic-specific CFS website utilization provided important information. Simply tabulating geographic distribution of website use by state is misleading since this merely reflects the US population. Visiting density is a better index that indicates the likelihood of individuals visiting the site based on the Internet population. Washington, DC and Georgia had the highest visiting densities and are home to the US Department of Health and Human Services and the CDC. North Carolina is the headquarters for the Chronic Fatigue and Immune Dysfunction Syndrome Association of America, a large patient advocacy group and CDC’s contractor managing the public awareness campaign. New Jersey is home to the University of Medicine & Dentistry of New Jersey, sponsoring one of the largest and highly respected CFS research programs, and to the New Jersey Chronic Fatigue Syndrome Association, an active patient advocacy group. Finally, the Mayo Clinic Hospital, which has a CFS clinical program, is located in Minnesota, the state with the fifth highest visiting density.

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Visiting density indicates the potential importance of CFS research institutions in directing visitors to the CDC CFS website.

Analysis of referral sources to the website also revealed important information. Not surprisingly, the Google search engine sent most visitors to the CFS website, followed by Yahoo and MSN. Twelve percent of visitors bookmarked the CFS Web address. It would be of interest to determine what proportion stemmed from patient advocacy groups or persons conducting CFS research.

The website contains a section with all publications from the CDC CFS public health research program and receives a considerable amount of views compared to online journals. For example, our five most popular publications were viewed between 5158 and 2850 times. This is similar to the top 10 most-viewed articles published in 2008 by BMC Genomics, which were accessed between 8066 and 2880 times.

Evaluation of website use also provides quantitative data concerning the effectiveness of messaging in public health campaigns and their sustainability. The sharp spike in Web visits in early November 2006 revealed a boost in campaign exposure related to a half day Department of Health and Human Services event at the National Press Club to kick off the CFS public awareness campaign. However, the spike decreased after 3 weeks and ultimately reverted to levels before the campaign. The timeline illustrates that a campaign booster inserted 2 to 3 months after the launch may be appropriate to sustain interest. Many campaigns initiate a boost 6 to 12 months after the initial launch, and, based on our results, this timeframe may delay potential sustainability benefits in terms of website utilization.

Web usage data provide valuable information concerning how websites can attract more visitors. The most-viewed Web pages represent the users' interests and should be easy to access and frequently updated, and this should take into account shifts in interest. Comparing the 5 weeks before and 5 weeks after launch of the campaign, the "Information for Healthcare Professionals" segment showed the greatest percentage increase in page views (15% increase), and the "Information for Patients and Caregivers" section had the greatest percentage decrease in views (12% decrease). While we cannot identify the audience looking at these sections, one possible explanation is that return visitors started looking at CFS professional information rather than just the information for patients. Alternatively, there could have been an increase in new visitors looking for professional health care information. Regardless of which segment a visitor accessed, we found that the CDC CFS website was most frequently visited by individuals seeking basic facts, treatment options, symptoms, and publications.

When we examined user behavior regarding the campaign materials, the brochure was the most popular media type among visitors and consistently sustained a higher level of page visits than all other campaign materials. All brochures on the website are designed to be printed, and this may help to explain why people preferred the brochure—it is a tool that visitors can take with them. The longer radio clip (60 seconds) performed much better than the shorter one (30-second radio or video clip). The market basket analysis showed that none of the visitors listened to the 30-second radio clip without checking out the 60-second radio clip during the 5 weeks after the clips were put on the Internet, while the majority of visitors to the 60-second radio clip did not access the 30-second radio clip. This suggests the public's preference for a longer media clip in terms of CFS information, perhaps because the shorter radio clip did not provide enough information. Public health campaigns using the Internet may want to consider utilizing market basket analysis techniques to improve campaign evaluations and sustainability efforts as these analyses help to determine which components are actually viewed by the public or target audience. For example, the cost-effectiveness implication from this study is that campaign planners may want to consider not running both 30-second and 60-second radio PSAs during the same campaign time period. Instead, organizers may want to start with the 60-second spot and present the 30-second advertisement in a campaign booster. In addition, one could run market basket analyses on a more frequent basis (ie, every 2 months) to monitor the usage-association changes among campaign materials or Web pages in order to improve the campaign sustainability.

The match between the user visiting pattern in the Markov chain model and the Web structure of the two CME courses reflects the fact that the users took the courses in the sequential order recommended by the website. The two courses are designed for different audiences, and Markov chain model results show that only 5% of visitors visited each course in the same visit, indicating that each of the courses is serving a different population. The Web traffic volume and navigation patterns to them are very similar for both courses. The high dropout probabilities for the CME home page and two Syllabus pages imply that visitors were less likely to leave the course after they reached the Introduction pages. In other words, persons who do start the course are likely to finish it.

As shown by the Markov chain model results, factors were identified that may affect sustainability of visits to a website. Public health websites may want to apply the Markov chain analysis to all content on a website to identify the main exit points and therefore improve Web structure and content. When visitors stay longer on a site, it increases the probability of exposure to information.

Limitations

This study has several limitations. The CDC website allows only session cookies, not persistent cookies; therefore, we cannot get the accurate number of new/unique visitors to provide more insightful information than the number of visits/page views. Theoretically, one individual could access the website frequently, but results of both the geographic pages views and visiting density analysis reduce the likelihood of this possibility. AOL users were excluded in the geographic distribution analysis given the technical issues of identifying their geographic locations. Despite this, the number of page views from AOL users accounted for only 4% of total page views to the website, and exclusion of this data should likely not have a significant impact.

The user behavior analysis in this study focuses on only a particular group of Web pages such as campaign media pages

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and CME courses, and user navigation analysis of the campaign materials was limited to 5 weeks pre- and post-campaign launch, which did not allow for tracking user behavior over the 18-month period. However, the decision to analyze time periods was determined a priori and centered on the campaign launch dates, which allows for a more accurate and narrow timeframe of comparison. The CDC CFS website has a simple hierarchical Web structure, with most content at levels 3 and 4. Conducting a broad range of behavior analyses on data collected from such a simple website may cover or hide the issues that we found in this study through a more topic-focused behavior analysis. However, defining an appropriate level for the comprehensive market basket and Markov chain analyses of the whole website will be of interest to all public health website managers.

Future Research

All CDC websites are periodically updated to reflect current developments in the Internet as well as content information. Currently, the CDC CFS website is undergoing an upgrade with a new template, and findings from this study will provide valuable information to the reconstruction of the new site. Once the new website has been completed, market basket and Markov chain analyses will be conducted to compare the results of the two different Web designs. We hypothesize that a better understanding of the impacts of different public health Web structures can be obtained. We also plan to apply navigation pattern analysis to the entire website. The interaction analysis can also be enhanced by increasing the order of the Markov chain model. As a result, the transition probability will be determined by a certain number of past states, rather than just the present state.

Conclusion

This study shows that the CFS website is an important online resource for the public regarding CFS, especially the topics of basic facts, symptoms, and treatments. The popularity of CFS publications on the website to some extent reflects the significant position of public health agencies in the field of CFS research. The market basket analysis, a traditional analytic technique in retail business, was applied to this public health website and showed utility in identifying user preferences for different online public health messaging formats. Markov chain analysis confirmed that visitors completed the CME courses in sequential order. In summary, the CFS website is an effective way of providing CFS health education and information and serves an important tool in public health outreach.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix

Screenshots of some CDC CFS Web pages

[PDF file (Adobe PDF),3373 KB - jmir_v11i4e52_app1.pdf]

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Abbreviations

AOL: America Online
CDC: Centers for Disease Control and Prevention
CFS: chronic fatigue syndrome
CME: continuing medical education
PSA: public service announcement

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Original Paper

A Web-Based Nutrition Program Reduces Health Care Costs in Employees With Cardiac Risk Factors: Before and After Cost Analysis

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Abstract

Background: Rising health insurance premiums represent a rapidly increasing burden on employer-sponsors of health insurance and their employees. Some employers have become proactive in managing health care costs by providing tools to encourage employees to directly manage their health and prevent disease. One example of such a tool is DASH for Health, an Internet-based nutrition and exercise behavior modification program. This program was offered as a free, opt-in benefit to US-based employees of the EMC Corporation.

Objective: The aim was to determine whether an employer-sponsored, Internet-based diet and exercise program has an effect on health care costs.

Methods: There were 15,237 total employees and spouses who were included in our analyses, of whom 1967 enrolled in the DASH for Health program (DASH participants). Using a retrospective, quasi-experimental design, study year health care costs among DASH participants and non-participants were compared, controlling for baseline year costs, risk, and demographic variables. The relationship between how often a subject visited the DASH website and health care costs also was examined. These relationships were examined among all study subjects and among a subgroup of 735 subjects with cardiovascular conditions (diabetes, hypertension, hyperlipidemia). Multiple linear regression analysis examined the relationship of program use to health care costs, comparing study year costs among DASH participants and non-participants and then examining the effects of increased website use on health care costs. Analyses were repeated among the cardiovascular condition subgroups.

Results: Overall, program use was not associated with changes in health care costs. However, among the cardiovascular risk study subjects, health care costs were US$827 lower, on average, during the study year ($P = .05$; $t_{729} = 1.95$). Among 1028 program users, increased website use was significantly associated with lower health care costs among those who visited the website at least nine times during the study year (US$14 decrease per visit; $P = .04$; $t_{1022} = 2.05$), with annual savings highest among 80 program users with targeted conditions (US$55 decrease per visit; $P < .001$; $t_{74} = 2.71$).

Conclusions: An employer-sponsored, Internet-based diet and exercise program shows promise as a low-cost benefit that contributes to lower health care costs among persons at higher risk for above-average health care costs and utilization.

(J Med Internet Res 2009;11(4):e43) doi:10.2196/jmir.1263

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KEYWORDS

Employer health costs; disease management; health promotion; wellness programs; costs and cost analysis

Introduction

Health insurance premiums have risen faster than inflation for the past 10 years, placing an increasing burden on employer-sponsors of health insurance and their employees [1,2]. Some employers have become proactive in managing health costs, providing tools that encourage employees to directly manage their health and prevent disease [3]. Examples include smoking cessation and stress management programs, gym and health club memberships, and formal disease management programs, many of which are popular with employees and improve employee satisfaction. But there is very little evidence that any of these initiatives actually reduce health care costs [4].

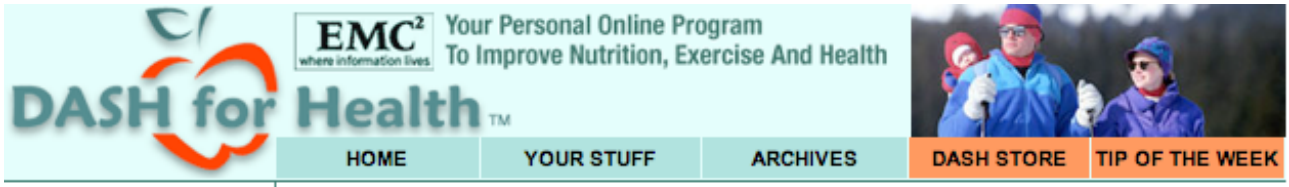
Recent reviews of employer health promotion programs show some success in improving employee health and productivity, but show mixed results as to whether or not these programs have an impact on health care costs [5]. Employers commonly offer nutrition education programs [6,7], but there is little evidence that such programs alter eating behaviors or change health care costs. Yet rapidly rising rates of overweight and obesity can contribute to a number of high-cost chronic diseases (eg, diabetes, hypertension, heart disease), increasing the likelihood that health care costs for these already highly prevalent and expensive conditions will increase dramatically in the future.

To address the issue of poor nutrition and the diseases associated with it, we designed an Internet-based nutrition and exercise behavior modification program called DASH for Health. Our program was based on the National Heart Lung and Blood Institute (NHLBI) DASH diet, which was originally developed to lower blood pressure and which has been demonstrated in randomized controlled trials to lower blood pressure and cholesterol levels and heighten insulin sensitivity [8-12]. We developed the Web-based DASH for Health program in collaboration with EMC Corporation, a Massachusetts-based global information infrastructure company. The program was offered as a free employee benefit to US-based EMC employees and their family members, who could opt-in to the program and were free to use the program however intensely they chose. Employees and their spouses were eligible to enroll in the program at the beginning of the calendar year in which it was offered. During the first year this program was offered at EMC Corporation (the same year that the health costs reported in this paper were collected), enrollees in the program were found to have significantly lost weight, lowered their blood pressure, and improved their healthy eating habits [11]. Examples of articles provided on the DASH for Health website are shown in Figure 1 and Figure 2.

To determine whether an Internet-based behavior modification program like DASH for Health has any effect on health care costs, we analyzed the costs for EMC employees and their spouses during the 12 months preceding the initial launch of the DASH for Health program and during the 12 months following the launch. The baseline year was the 12 months immediately preceding the initial launch of the program, and the study year was the 12 months immediately following the launch. We compared health care costs of those who participated in the DASH for Health program with those of nonparticipants. We analyzed costs for all study subjects and then performed a more focused analysis on employees and spouses with medical conditions (hypertension, hyperlipidemia, and/or diabetes) targeted by the DASH program.

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Figure 1. Example of article provided on the DASH for Health website



HEALTH CALCULATORS
FAQ'S
SEND US A QUESTION
SEND US A RECIPE
ABOUT THE PROGRAM
LINKS TO DASH
ABOUT US
RECIPES
HEALTH LINK
LOG OUT

SEARCH

ENTER YOUR FOOD
Date: 08/10/2009
Today's Weight:
Today's Blood Pressure: /
SUBMIT

CREAM OR MILK IN YOUR COFFEE?

What you add to your cup of coffee can make a big difference in the calories and fat you consume on a daily, monthly, and even yearly basis. It all adds up! National chains are starting to recognize that, too, and are offering lower-fat options for their customers. Starbucks, for example, now offers 2% milk, a much lighter version that still satisfies those customers that want a creamy cup.

Read on to learn more about how the way you dress your java and why it counts:

Think of it in terms of butter. Did you know that when you add cream, light cream, or even half and half to your coffee, you're effectively adding butter? That's right, the fat in cream is the same as the fat in butter. These coffee "creamers" have much more fat than even whole milk, 2% milk, and milk with less fat. But, you say, how much different can it make?? A LOT.

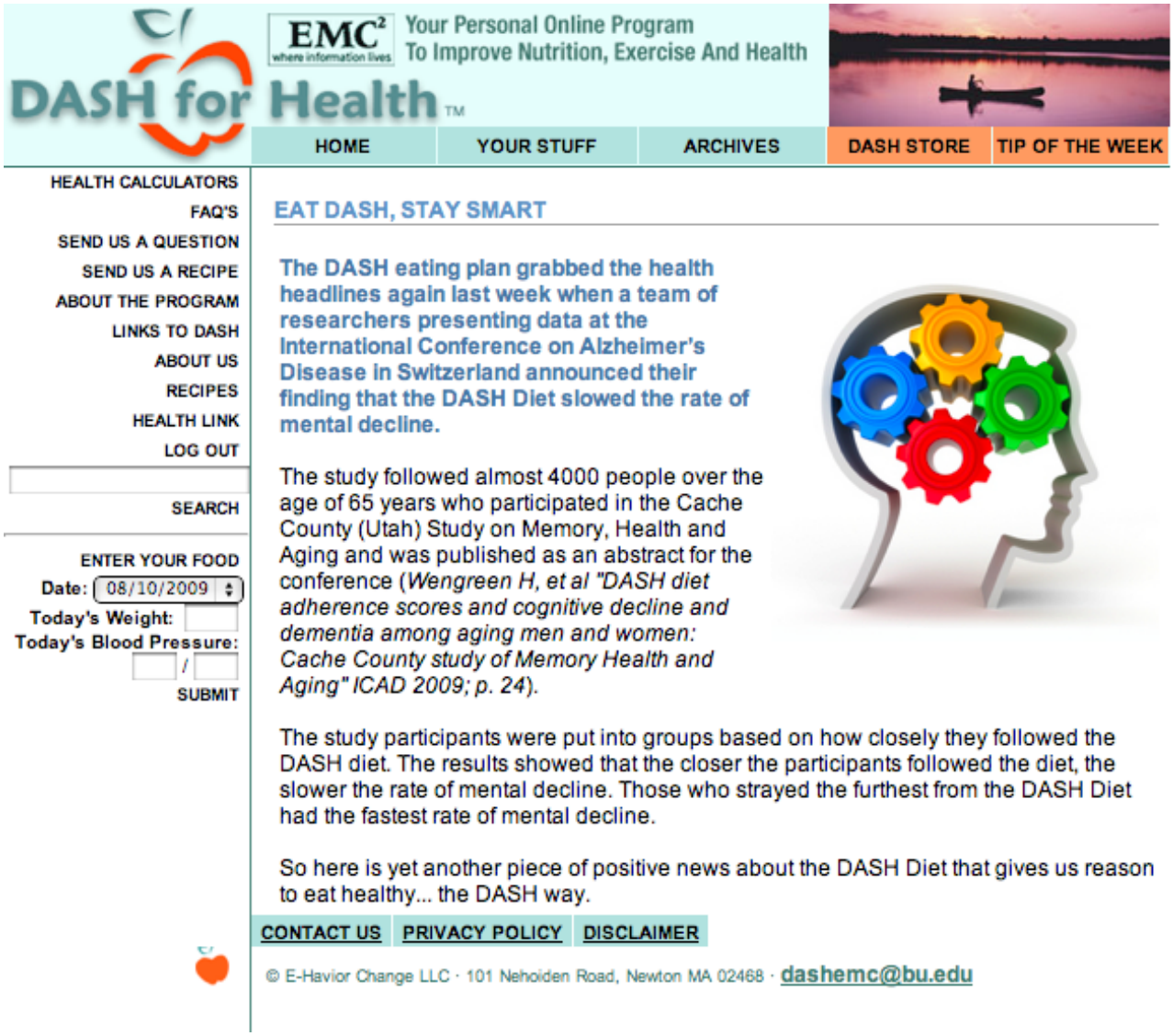
If you add cream or half-and-half to your coffee, most people add around 4 ounces to each "large" cup (about 16 ounces; equivalent to a Grande at Starbucks or a Medium at Dunkin Donuts). Check the table below to see how much BUTTER and how many calories you are adding EACH MONTH if you drink just one large coffee with milk or cream per day.



4 oz. per day serving	Sticks of butter per month	Calories per month
Light Cream	7.6 sticks	7,100
Half and Half	4.6 sticks	4,700
Whole Milk	1.3 sticks	2,400
2% milk	0.4 sticks	1,830

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Figure 2. Example of article provided on the DASH for Health website



Methods

Study Setting

The DASH for Health website was developed by a team at Boston University School of Medicine (BUSM). The website provides tools for enrollees to record and follow their body weight, blood pressure, eating habits, and exercise habits as well as providing a variety of healthy recipes based on the DASH diet. These tools include easy-to-use entry fields for entering weight, blood pressure, 24-hour food recall, and exercise habits. Although enrollees were encouraged to use these data "progress reports" as a means of encouraging their adherence to the program, there were no requirements or set expectations of how often enrollees would enter their own data. The website also provides two new articles each week on improving nutritional habits (based on the DASH diet) or healthy exercise. Everyone who enrolls in the program gets a reminder email each time a new article is posted on the website. The website is hosted at SignalZ Corporation (Montpelier, VT, USA). Self-reported data on demographics (age, gender, and employee/dependent status) and website visits during each year were collected by SignalZ and transferred to the research team at BUSM. Because enrollees had to enter the site using their username and password, standard website monitoring software was used to track how many times a particular enrollee visited the site. We define a "visit" as a unique instance of an enrollee logging on to the site.

When the program was about to launch, EMC Corporation informed employees that DASH for Health would be available at no cost to them and their adult household members. EMC had no other role in the program. EMC management had no access to the identities of the subjects or to their medical data. Once the program began, the employer took no role in encouraging website usage. The announcing emails from EMC leadership clearly stated that the employer would not know any enrollee's individual data or the identities of people who did and did not enroll.

EMC's clinical data warehouse, Ingenix, provided demographic and medical and pharmacy cost data for employees and their adult dependents. These data included date of birth, gender, and employee status. D2Hawkeye, a medical analytics firm specializing in data warehousing and health claims analysis, provided data cleansing services and summarized study subjects'

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demographic information, condition specific diagnoses, and total health care costs. D2Hawkeye calculated a risk adjustment factor for each study subject, using a proprietary methodology that combines diagnostic, procedural, and pharmacy information in health claims data with pattern recognition and times series analysis. The risk index provides a single representation of an individual's disease burden and has been shown to correctly distinguish high-cost and low-cost persons 77% of the time. Additionally, the likelihood that an individual will be in a high-cost group increases as the risk index value increases. We used an extension of the risk index, the adjusted risk index (ARI), which incorporates assessments of gaps in care (medical or pharmaceutical) for various conditions [13].

We used individual subject-level linkages to merge data on DASH for Health participants' website visit frequency with health care cost data and other variables. A subset of study subjects was identified with evidence of diabetes, hypertension, or hyperlipidemia, conditions that could be expected to benefit from the improved dietary behaviors that are encouraged by the DASH for Health program. This subset is referred to as the cardiovascular (CV) risk group. Data were managed and analyzed using SAS, version 9.1.3 (SAS Institute Inc, Cary, NC, USA). Approval for this study was obtained from the Boston University Institutional Review Board.

Study subjects with missing data for key fields such as age, employee status, or gender were excluded, as were DASH participants with no matching entries in the health care cost files. These enrollees were either not covered by the EMC insurance plan or were not affiliated with EMC at the end of the study period. The study was limited to study subjects with health care costs in both study years to ensure that those with bad claims data reported as negative or zero amounts were excluded from the analysis and to increase the likelihood that the analysis was restricted to those with primary insurance coverage through EMC. Information on job classification was not included since baseline year health care costs and risk assessment are proximal for our analysis.

The total number of EMC employees and their spouses was 29,675, of which approximately 75% (n = 22,354) were reported to have received health coverage through EMC and had health care costs in the baseline or study year. Sixty-eight percent (n = 15,237) of these subjects had costs in both years. Additionally, 3797 EMC employees or spouses enrolled in the DASH for Health program and used the DASH program website at least once in the study year (DASH participants). Seventy-three percent (n = 2756) of these DASH participants were found in the health claims summary file, and 71% (n = 1967) of these 2756 had health care costs in both years. The final study sample (N = 15,237, DASH = 1967, non-DASH = 13,270) also reflected the restrictions described above.

Analysis

In univariate analyses to describe our sample, we generated means and standard deviations for continuous variables and counts with percentages for categorical variables. We used bivariate analyses to examine the relationships among demographic, annual health care cost, and website usage data for 15,237 study subjects over the 2-year baseline and study year period. In these analyses, we employed chi-square tests for analyses of categorical data and two-sample *t* tests for comparisons of continuous by categorical variables. Multiple linear regression analysis examined the relationship of DASH program enrollment with study year health care costs, controlling for other salient factors. To control for potential bias of self-selection of the DASH participants, we used a logistic regression model to construct a propensity score that represented the likelihood of participation in the DASH program. Studies that use observational data, as ours does, are subject to bias because the "treatment" and "control groups" are not randomly assigned and may differ in ways that affect the outcome of interest. A propensity score, which represents the conditional probability of receiving a given treatment, given a vector of measured covariates, is frequently used in such studies to adjust for differences in the observed characteristics between the treatment and the control groups. Our use of logistic regression is one of several recommended approaches for determining the propensity score [14].

All available study variables were included in the propensity score model (baseline year risk index and ARI, baseline year costs, age, gender, and employee status). We then used a linear regression model to compare study year costs among DASH and non-DASH participants, controlling for age, gender, ARI, baseline year costs, and likelihood of DASH participation (propensity score). In this model, study year total health care costs was the dependent (outcome) variable; independent (predictor) variables were DASH participation, age, gender, employee status, baseline year ARI, and baseline year total health care costs. Next, because stronger effects of an intervention are often observed in the most compliant or frequent participants, we examined whether more frequent use of the website than is typical is more strongly associated with reduced costs among DASH participants than across the full range of website use overall. For this, we used a similar linear regression analysis to evaluate the relationship of website usage intensity at or above the median to health care costs in the study year. Study year total health care costs was the dependent variable; independent variables were number of website visits, age, gender, employee status, baseline year ARI, and baseline year total health care costs. We repeated these analyses using the 735 DASH CV risk group and non-DASH CV risk group study subjects who showed evidence in both study years of diabetes, hyperlipidemia, or hypertension.

To address the skewed distribution of the cost data, baseline and study year costs in all analyses were top-coded at US$25,000, which represents the 99th percentile of annual health care costs in our study population. Website usage was top-coded at 75 website visits to address skewness. The analyses were repeated using trimming to remove high-cost outliers, using the entire study population and using top-coding at other thresholds. As top-coding is recommended for reducing the effects of high-cost outliers on model results while retaining useable observations, we report results of those analyses here. Our choice of US$25,000, or the 99th percentile, is also consistent with others [15-17].

As part of model development, we added interaction terms as covariates and conducted additional analyses where we limited

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study subjects to employees, males, and male employees, reflecting the larger number of employees and males in the study group. To account for nonlinear effects of DASH participation and website use intensity, we grouped study year costs into quartiles; we also grouped website visits and study year costs into quartiles. There were no differences suggesting that the interaction terms, study population restrictions or groupings should be included in the final model as none of these modifications affected the results. We repeated the analyses we report here using square root and log transformations for all cost variables because of their good performance with heteroscedastic health care cost data [18]. Our results based on the transformed data were similar to those observed using the untransformed data. Thus, to allow for ease of interpretation, we present results here for the untransformed data.

Results

All Study Subjects

Demographic, ARI, and baseline medical and pharmacy cost information were gathered for all study subjects (N = 15,237) and for the subgroup of subjects with CV risk conditions (N = 735). These measures were also examined for DASH (N = 1967) and non-DASH (N = 13,270) participants overall and in the CV risk group (DASH: N = 134; non-DASH: N = 601). These results are shown in Table 1.

Table 1. Baseline characteristics of DASH and non-DASH participants

	All Study Subjects			CV Risk Subgroup[a]		
	Total (N = 15,237)	DASH Participants (N = 1967)	Non-DASH Participants (N = 13,270)	Total (N = 735)	DASH Participants (N = 134)	Non-DASH Participants (N = 601)
Cost baseline year (US$)						
mean (SD)	2684 (7164)	2181 (4351)	2758 (7489)	5663 (10,089)	4239 (6335)	5980 (10,727)
P25/P50/P75[b]	327/934/2612	345/933/2224	324/935/2563	1401/2772/5783	1002/2028/4527	1490/2849/6020
Cost DASH year (US$)						
mean (SD)	2814 (7835)	2413 (4315)	2879 (8228)	5929 (13,611)	3425 (3667)	6487 (14,897)
P25/P50/P75	358/1006/2621	442/1145/2700	347/981/2607	1394/2681/5755	1146/2318/4222	1467/2848/6152
Baseline year ARI						
mean (SD)	3.70 (6.80)	3.52 (6.04)	3.72 (6.91)	12.14 (13.70)	10.10 (9.73)	12.59 (14.41)
P25/P50/P75	1/1/3	1/1/3	1/1/3	3/7/16	2/6/14	3/8/17
Age (years)						
mean (SD)	40.2 (9.2)	40.7 (9.1)	40.1 (9.2)	47.5 (8.54)	46.1 (8.28)	47.8 (8.57)
P25/P50/P75	33/40/46	34/41/47	33/40/46	42/49/54	41/47/52	42/49/54
Gender, % (no.)						
Male	46 (7041)	56 (1116)	45 (5925)	65 (476)	73 (98)	63 (378)
Female	54 (8196)	44 (851)	55 (7345)	35 (259)	27 (36)	37 (223)
Enrollment status, % (no.)						
Employee	55 (8384)	84 (1659)	51 (6725)	64 (469)	85 (114)	59 (355)
Spouse	45 (6853)	16 (308)	45 (6853)	36 (266)	15 (20)	41 (246)
Website visits						
mean (SD)	N/A[c]	12.0 (17.0)	N/A	N/A	16.9 (26.3)	N/A
P25/P50/P75	N/A	3/9/12	N/A	N/A	3/9/17	N/A

[a] CV risk group subjects show evidence of hyperlipidemia, hypertension, and/or diabetes in both years.

[b] P25/P50/P75 equals 25th, 50th, and 75th percentiles.

[c]Not available.

Among the 15,237 study subjects, 55% (n = 8384) were employees, while 45% (n = 6853) were spouses. The overall study sample was 46% male (n = 7041), with an average age of 40.2 years. Average total baseline year health care costs were US$2684. A slightly higher proportion of the DASH participants was male, compared to the non-DASH participants (56% vs 45%). The average age of the DASH participants was 40.7 years, slightly higher than the non-DASH participants (40.1 years). DASH participants were mostly employees (84%; n = 1659). DASH participants had a mean ARI of 3.52, which was slightly lower than the mean ARI for the non-DASH participants (3.72). Average total costs among DASH participants in the baseline

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year were lower than among the non-DASH participants (US$2181 vs US$2758).

Table 1 also shows demographic, ARI, and baseline year health care costs for the DASH and non-DASH CV risk groups. This subgroup was 65% male (n = 476) and 64% employees (n = 469), with an average age of 47.5 years, older than the overall study sample. The mean baseline year ARI of 12.14 (DASH: 10.10, non-DASH: 12.59) was also higher than in the general study sample, as were mean total baseline health care costs (overall: US$5663; DASH participants: US$4239, non-DASH: US$5980).

Table 2. Predictors of costs in DASH year: DASH vs non-DASH (overall and CV risk group)[a]

	All Study Subjects (N = 15,237)		CV Risk Group (n = 735)	
	Difference in Mean Study Year Cost[b] (SE)	*P* (*t*[c])	Difference in Mean Study Year Cost[b] (SE)	*P* (*t*[c])
DASH use vs non-use[d]	$85.14 ($90.83)	.35 (0.94)	−$826.95 ($424.81)	.05 (1.95)
Age	$8.18 ($3.31)	.01 (2.47)	$50.40 ($25.85)	.05 (1.95)
Male vs female	−$453.05 ($156.98)	.004 (2.89)	$88.90 ($645.85)	.89 (0.14)
Employee vs non-employee	−$136.45 ($370.54)	.72 (0.37)	−$2862.85 ($1564.49)	.07 (1.83)
Baseline year ARI[e]	$123.46 ($5.92)	< .001 (20.85)	$133.69 ($17.61)	< .001 (7.59)
Baseline year cost[f]	$0.29 ($0.01)	< .001 (29.00)	$0.34 ($0.04)	< .001 (8.50)

[a] Baseline and study year costs top-coded at US$25,000; study year website visits top-coded at 75; probability of DASH participation included as model covariate (not shown).

[b] For age, ARI, baseline year cost: difference in mean study year costs per unit difference; unit is one year (age), one integer (ARI), one US dollar (baseline year cost).

[c] Degrees of freedom = n − 6.

[d] DASH participants' health care costs were, on average, US$85 higher than those of nonparticipants, although this result was not statistically significant.

[e] Higher baseline year ARI increases were associated with higher study year costs. On average, study year costs increased US$123 with each additional unit increase in the baseline year ARI. A unit refers to an integer; as an example, an ARI of 10 is one unit greater than an ARI of 9.

[f] Higher baseline year health care costs were associated with higher study year costs. On average, study year costs were US$0.29 higher for each additional dollar in baseline year cost.

The results of the linear regression analysis of study year costs for DASH vs non-DASH in the full sample are shown in Table 2. Among all study subjects, DASH participation was associated with increased health care costs, although this result was not statistically significant (difference in mean costs, DASH vs non-DASH = US$85.14; $P = .35$). Model covariates associated with significantly higher study year costs were older age ($P = .01$), being female ($P = .004$), higher baseline ARI ($P < .001$), and higher baseline year costs ($P < .001$).

Results of the linear regression analysis of study year costs for DASH and non-DASH CV risk group study subjects are also shown in Table 2. DASH CV risk group members' study year health care costs were US$827 lower, on average, than those of the non-DASH CV risk group members ($P = .05$). Higher baseline year ARI was significantly associated with higher study year costs, with each additional unit of risk associated with an increase, on average, of US$134 ($P < .001$). Each additional dollar in baseline year costs was associated with an additional US$0.34, on average, in study year costs ($P < .001$).

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Table 3. Cost in DASH year as a function of intensity of website use, adjusting for covariates[a]

	All DASH Participants (n = 1967)		CV Risk Group (n = 134)	
	Difference in Mean Study Year Cost[b] (SE)	*P* (*t*[c])	Difference in Mean Study Year Cost[b] (SE)	*P* (*t*[c])
Change in costs per website visit[d]	−$6.66 ($5.34)	.21 (1.25)	−$28.45 ($14.61)	.054 (1.95)
Age[e]	$34.07($8.05)	< .001 (4.23)	$17.50 ($31.57)	.58 (0.55)
Male vs female	−$458.43 ($161.07)	.005 (2.85)	−$1121.62 ($686.75)	.11 (1.63)
Employee vs non-employee	$66.82 ($215.01)	.76 (0.31)	−$39.67 ($861.64)	.96 (0.05)
Baseline year ARI[f]	$60.24 ($16.74)	< .001 (3.60)	$54.48 ($36.69)	.14 (1.48)
Baseline year cost[g]	$0.30 ($0.03)	< .001 (10.00)	$0.34 ($0.07)	< .001 (4.86)
	DASH Participants Website Use at or Above Median[h] (n = 1028)		CV Risk Group Website Use at or Above Median[h] (n = 80)	
	Difference in Mean Study Year Cost[b] (SE)	*P* (t[d])	Difference in Mean Study Year Cost[b] (SE)	*P* (t[d])
Change in costs per website visit	−$14.26 ($6.97)	.04 (2.05)	−$54.61 ($20.16)	.01 (2.71)
Age	$49.22 ($11.87)	< .001 (4.15)	$18.69 ($47.47)	.70 (0.39)
Male vs female	−$444.33 ($230.67)	.05 (1.93)	−$1855.55 ($940.40)	.05 (1.97)
Employee vs non-employee	$141.08 ($301.12)	.64 (0.47)	$757.00 ($1286.59)	.56 (0.59)
Baseline year ARI	$109.73 ($26.49)	< .001 (4.14)	$98.59 ($55.97)	.08 (1.76)
Baseline year cost	$0.24 ($0.04)	< .001 (6.00)	$0.25 ($0.12)	.04 (2.08)

[a] Baseline and study year costs top-coded at US$25,000; study year website visits top-coded at 75.

[b] For number of website visits, age, ARI, baseline year costs: difference in mean study year costs per unit difference; unit is one year (age), one integer (ARI), one US dollar (baseline year cost).

[c] Degrees of freedom = n − 6.

[d] Among all DASH participants, each additional website visit was associated, on average, with a US$6.66 decrease in study year health care cost. This result was not statistically significant. Among CV risk group DASH participants, each additional website visit was associated with a US$28 decrease in study year cost; this result was not statistically significant at the $P < .05$ level. Among DASH participants who visited the website at least the median number of times during the study year (nine visits), each additional visit was associated with a US$14 study year cost decrease. Among CV risk group DASH participants who visited the website at least the median number of times for the CV risk group (also nine visits), each additional visit was associated with a US$55 decrease in study year cost.

[e]Among all DASH participants, each additional year of age was associated with US$34, on average, higher study year health care cost. Among DASH participants who visited the website nine or more times during the study year, each additional year of age was associated with US$49 higher study year health care cost. Among CV risk group DASH participants, the relationship of age to study year health care costs was not statistically significant at the $P < .05$ level.

[f]Among all DASH participants, each additional increment in baseline year ARI was associated with US$60 higher study year health care cost.

[g] Each additional dollar in baseline year costs was associated with increased study year health care costs as follows: US$0.30 among all DASH participants; US$0.34 among CV risk group DASH participants; US$0.24 among DASH participants who visited the website at least nine times; US$0.25 among CV risk group DASH participants who visited the website at least nine times.

[h] Median website usage for all DASH and CV risk group DASHparticipants: nine visits.

Results of the analyses of intensity of website usage and study year costs are shown in Table 3. Among 1967 DASH participants, each additional website visit was associated with almost a US$7 decrease in study year health care costs, but this result was not statistically significant ($P = .21$). Among participants whose website usage was at or above the nine-visit study year median (n = 1028), each additional website visit was associated with a US$14 decrease in health care costs on average ($P = .04$).

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Figure 3. CV risk group change in unadjusted total costs from baseline to DASH study year in DASH participants vs nonparticipants

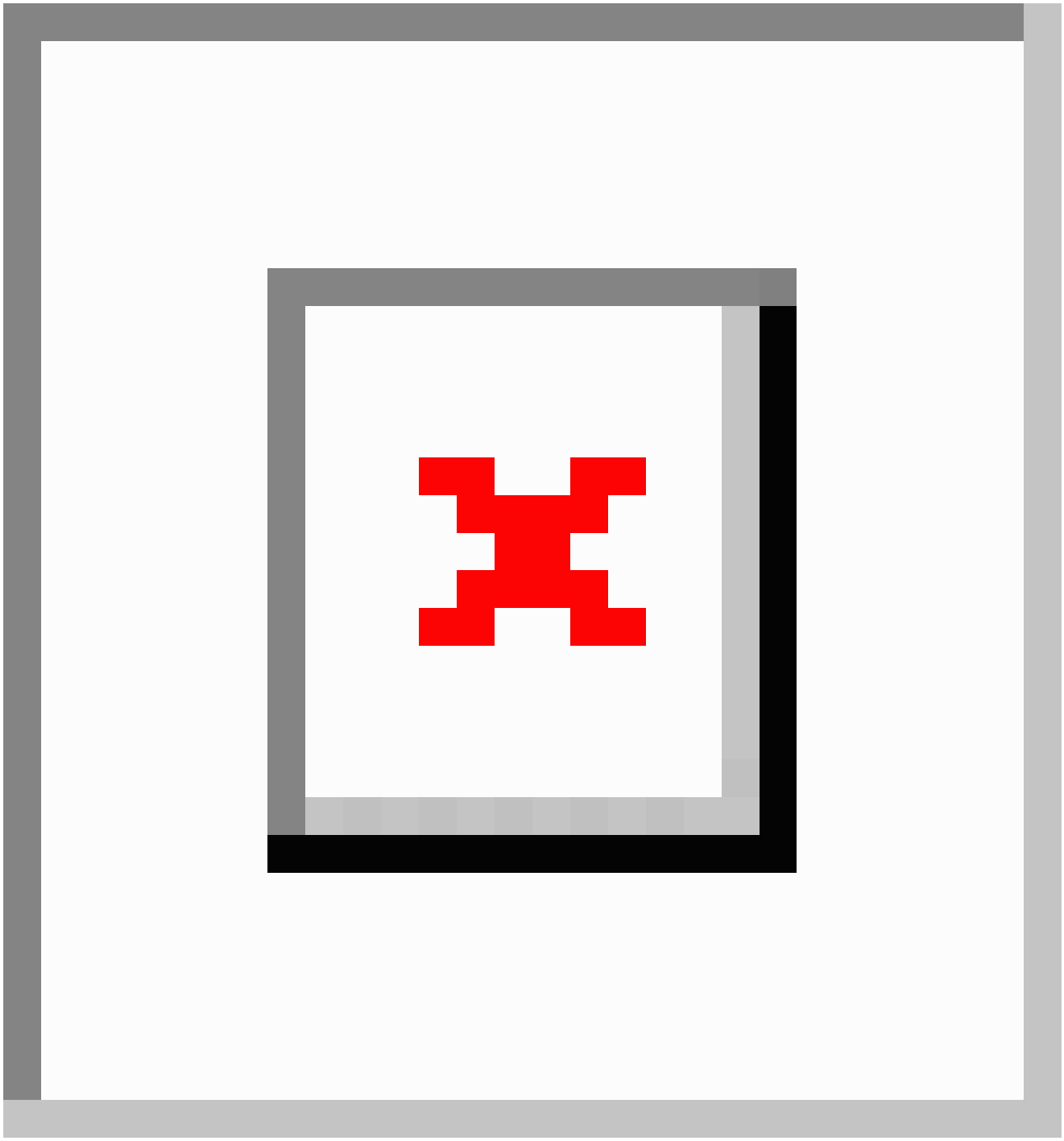


Figure 3 compares the change in crude study year costs, relative to baseline year costs, among DASH participants versus nonparticipants in the CV risk group. Among DASH CV risk group participants, study year health care costs were US$814 lower than baseline year costs. Among DASH nonparticipants, study year costs were US$507 higher than baseline year costs. These results are not adjusted to control for age, gender, employee status, or baseline ARI.

Results of the analysis of website use intensity in the DASH CV risk group are also shown in Table 3. Among the 134 DASH CV risk group members, each additional website visit was associated with a decrease of approximately US$28 in health care costs (P = .05). Among those who used the website at least the median number of nine times during the year (n = 80), each additional visit was associated with a US$55 decrease in study year costs (P = .01).

Discussion

We did not find DASH participation to be associated with lower health care costs in the overall study sample. With an average age of 40 years, an average ARI of 3.7, and minimal health services utilization, this study sample is relatively young and healthy. The significance of higher baseline year risk and costs, female gender, and increasing age as predictors of study year costs is consistent with a relatively young, commercially insured population. Improvements in diet and exercise habits would not

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be expected to address the highest expenditures in this group—pregnancy and childbirth, depression, and back pain.

We found suggestive evidence that DASH program use was associated with decreased health care spending among study subjects with CV risk. Within the DASH CV risk group, participants' study year health care costs were US$827 lower than for the DASH nonparticipants. Although this result only achieved a significance level of $P = .05$, the reduction in mean costs from DASH participation (US$827), which was nearly twice the standard deviation (US$425), indicates that the effect size is quite large; the model R-square, 39%, is also noteworthy. Improvements in diet and exercise would be expected to address health care expenditures among study subjects with hyperlipidemia, hypertension, or diabetes. This subgroup is older (average age 47 years) and less healthy, with a baseline year ARI more than three times that of the general study sample.

We also found evidence suggestive of a dose-response relationship. Among DASH participants who visited the website at least nine times during the study year, each additional visit was associated with lower study year costs overall ($P = .04$) and in the DASH CV risk group ($P = .01$). Evidence of this dose-response was strongest among the DASH participants in the CV risk group, where each additional website visit was associated with a US$55 decrease in study year health care costs ($P = .01$).

The DASH CV risk group participants' baseline ARI (10.10) suggests that they may be less sick than the non-DASH CV risk group (baseline ARI = 12.59). However, the DASH CV risk group, with conditions targeted by the DASH program, was the only subgroup that showed a decrease in health spending. Health care costs among DASH enrollees decreased 24% between the baseline (US$4239) and study years (US$3425) in the DASH CV risk group. By contrast, health spending increased US$507 (8%) in the non-DASH CV risk group and approximately US$130 per person (4.8%) across the general study sample.

We also found evidence of selective enrollment in the DASH program by study subjects with hypertension, hyperlipidemia, and diabetes. Despite being offered as a benefit to all employees and their dependents, participation in DASH for Health was proportionally higher (18%) among individuals with CV risk conditions (ie, those who might benefit most from nutrition improvement) than it was among individuals without those conditions, of whom 13% signed up for the DASH program ($P < .001$). For employers interested in offering benefit programs equally to all employees rather than targeting a selected subset of the employee population, this finding provides evidence that the DASH for Health program benefits the subset of the employee population whose health risks are of concern and whose health status is targeted by the program.

Our results expand on the already-published reports that Internet-based programs can have positive effects on clinical parameters such as weight and blood pressure [11,19-22] and contribute to our understanding of the effects of nutrition, weight management, and exercise programs on health care costs in targeted populations [23-26], including workplace populations [3,27-32]. Several recent studies indicate that workplace-sponsored, Web-based programs can lead to these improvements in clinical parameters [11,33-36]. Our focus on the effects of an employer-sponsored, Web-based diet and exercise program on health care costs also expands our understanding of the effects of employer benefits that encourage employees to better manage their health status and contain health care costs. Hsu et al [37] observed significant increases in nonpharmaceutical health care expenses over a short time period among persons with chronic conditions who reduced their prescription medication use in response to increased cost sharing in benefit design. By contrast, regular use of the DASH for Health program may encourage health behavior changes that result in cost savings among persons with chronic conditions in a similarly short time frame. The benefits of DASH participation among healthier, younger enrollees may be evident over a longer time period than the year evaluated for this study. Employers, particularly those who are self-insured, may be interested in both short- and long-term employee costs and health status and choose to invest in health status improvements that will show benefits over the long term [38-40].

Limitations

A number of study limitations should be noted. Our analysis used observational data and is vulnerable to selection effects, which represent the largest threat to validity in observational studies. Our use of a control group and a pre-test, coupled with our use of a propensity score, are standard mechanisms for addressing selection bias in quasi-experimental study designs. However, our model would not control for the possibility that study subjects who were motivated to manage their CV risk conditions were more likely to enroll in DASH for Health and would visit the website more often. However, it is unlikely that our finding that even moderate use of the DASH for Health program is associated with lower health care costs is attributable to motivation and not to participation in the program. This finding is consistent with clinically oriented studies of the DASH diet program indicating that the DASH diet is associated with improved blood pressure, lower cholesterol levels, and increased insulin sensitivity. Such clinical improvements would be expected to be associated with lower health care costs.

Several other limitations should be noted. First, the study sample was limited to persons with health care costs in both years. The proportion of study subjects with costs in only one year (costs in baseline year only: 90%; costs in study year only: 79%) is consistent with the national Medical Expenditure and Panel Survey (MEPS) data indicating that 11% of commercially insured persons do not use health services in a given year. D2Hawkeye received and cleaned the source claims data and reported that the proportion of study subjects with zero costs was higher than expected. Because the data could not be sent back to the data warehouse for review, we chose to restrict the study to persons with costs in both years. In analyses with all study subjects, including those with no costs in either or both years, costs for all DASH participants were significantly lower than for non-DASH participants, and the cost savings were higher among DASH participants with CV risk conditions. (Results available on request.) Restricting study subjects to those with costs understates the effects of the DASH program on costs. Second, our analysis compares study subjects who visited the DASH website at least once with those who did not

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visit it at all. However, subjects who visited the website once during the study year would not be expected to benefit from the nutrition and exercise education that the DASH for Health website program offers. Our finding of a dose-response effect would be strengthened by the inclusion of subjects who signed up for the program but never visited the website. From the perspective of benefit design, this effect would be more useful for guiding planning or coaching efforts. Third, our propensity score is based only on available data and therefore may not completely address potential selection bias. It is possible that DASH participants with CV risk conditions would have had decreased health care costs without participation in DASH. However, the clinically observable effects of the DASH diet on CV risk conditions make this result less likely. Fourth, our results are based on all health care costs for all conditions. Costs for conditions targeted by the DASH diet cannot be distinguished from costs for medical conditions that are not likely to benefit from improved diet, such as pregnancy and childbirth and back pain. However, the dose-response effect among participants who use the DASH website more often and the increasing significance of additional website usage in the DASH CV risk group suggest that participation in the DASH program is related to decreases in health care costs among persons at higher risk for health care expenses. We performed additional analyses of the effects of DASH participation on study year costs for subjects with different baseline year risk levels. Based on the regression model, at higher levels of baseline year risk, DASH participants had significantly lower study year costs than nonparticipants. (Results available on request.) These results are of particular interest given that higher levels of baseline year risk are predictive of higher costs [13]. Finally, study year costs include health care costs incurred during the initial enrollment period. The effects of DASH for Health program participation would not expected to be evident during the initial launch of the program or during the first few months of the year. However, this limitation suggests that our study results understate the effects of DASH for Health program participation since they include this initial time frame.

Our focus on short-term cost savings does not examine whether these savings are offset by increases in other costs [40]. Although the DASH for Health program is relatively inexpensive, further study to evaluate its cost-effectiveness as a corporate benefit would be beneficial. Finally, the study sample was limited to employees at one technology firm and their dependents. Our study results may not be generalizable to persons without employer-based insurance or to adults who are less comfortable using the Internet for information about diet, exercise, and health management. Research into the effectiveness of DASH for Healthin other populations is warranted.

Conclusions

Use of an Internet-based program that targets changes in diet and exercise to reduce weight, cholesterol, and blood pressure shows evidence of reducing short-term health care costs among persons at high risk for health care expenditures with conditions targeted by the diet. Offering access to a website with diet and exercise information appears to have promise as a low-cost, employer-sponsored benefit that contributes to lower health care costs among persons at higher risk for above-average health costs and utilization.

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Conflicts of Interest

Dr. Moore is Chairman of E-Havior Change, LLC, which owns the copyright to the DASH for Health™ program.

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Abbreviations

ARI: adjusted risk index
BUSM: Boston University School of Medicine
CV: cardiovascular
DASH: Dietary Approaches to Stop Hypertension

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