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Tutorial

Adding an Online Community to an Internet-Mediated Walking Program. Part 2: Strategies for Encouraging Community Participation

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Abstract

Starting a new online community with a limited number of members who have not self-selected for participation in the community is challenging. The space must appear active to lure visitors to return; when the pool of participants is small, a large fraction must be converted from lurkers to contributors, and contributors must receive responses quickly to encourage continued participation. We report on strategies for overcoming these challenges and our experience implementing them within an online community add-on to an existing Internet-mediated walking program. Concentrated study recruitment increased the effective membership size. Having few conversation spaces rather than many specialized ones, staff seeding of the forums before members were invited to visit, and staff posting of new topics when there were conversation lulls, all helped to make the forums appear active. In retrospect, using even fewer separate spaces and displaying a flat rather than nested reply structure would have made the forums appear even more active. Contests with small prizes around participation in the forums and around meeting walking goals generated a lot of discussion; a contest for first-time posters was especially effective at moving lurkers to post. Staff efforts to elicit participation by asking questions had mixed success. Staff replies to posts that had not received member replies created a feeling of responsiveness despite limited membership.

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KEYWORDS

Social support; online community; Internet; adherence; retention; exercise; health; forums; on demand; support

Introduction

Starting a new online community with a limited number of members who have not self-selected for participation in the community is challenging. This paper reports on design, management, and moderation strategies for overcoming these challenges and our experience implementing them within an online community add-on to an existing Internet-mediated walking program.

Online communities are everywhere on the Internet. People who share an interest in a hobby, a product, a political cause, or a celebrity join in conversation [1]. Those who share a problem or a solution to a problem find each other on the Internet as well. In health-support communities, people share disease-specific information as well as provide support and encouragement [2-7]. Yahoo! Groups, just one of many available platforms, claims to host millions of groups.

While there are many success stories, there are even more that have failed to take off. For example, Butler found that a third of public hobby and work mailing lists had no traffic over a 4-month period even after significant screening to eliminate nonfunctioning lists [8]. Efforts to test the impact of online communities on participants are a particularly risky research enterprise if they require generating a new community. For example, smokefree.gov, an online tobacco cessation program, attempted to add an online community for some of its users but was unable to garner enough activity in the community during the trial period to determine whether such a community, if it were active, would help users quit smoking [9]. Presumably, many more failed attempts to create online communities in research settings go unreported.

It is especially difficult to create a new online community as a support to some other program or activity that has a limited pool of potential members who have not self-selected for online community participation. Such settings include communities of practice within small organizations, discussion forums associated with courses, and medical interventions where only participants in the research study are eligible to participate in the online community. In some settings, such as courses and medical interventions, a limited duration for the community or for individual participation in it (16 weeks from joining in our case) may pose an additional challenge by reducing the opportunity for interpersonal bonds to form, requiring a greater dependence on commitment to the group or the activity as a whole to motivate participation [10].

Not everyone who visits a Web-based community or becomes aware of an email list will participate at all, even as a lurker. In arenas such as consumer product support, where every customer is a potential member, simply getting enough visitors can be enough to kick-start active discussion. One provider of product-support communities estimates that in any given month, 10% of visitors to a product website will follow a prominent link to discussion forums, and 10% of these will post [11]. Thus, 5000 monthly visitors to a product website could be expected to yield 50 posters, which would be sufficient to generate active forums if a few of the posters were to become regular contributors. Nonnecke and Preece found that just less than half of subscribers to health-related email lists lurked without posting, and more than 80% of subscribers to software support email lists did so [12]. As they point out, this is not necessarily a problem, since lurkers gain value from reading, and posters may gain value from having an audience. When the pool of eligible participants is much smaller, however, it is necessary to attract a larger percentage to post to create enough content to keep people coming back.

Once people post, the reaction they get can help decide their continued participation. Previous studies have shown that first-time posters who receive a response are more likely to post again [13] or to post sooner [14]. In the largely technical community Slashdot.org, the valence of the reaction did not seem to have an effect; continued participation depended merely on whether the poster received a response at all. In a health-support community, however, it seems likely that responses that provide requested information and are emotionally supportive will be more effective at encouraging additional contributions.

In all, 3 major challenges arise, then, in building a new online community, especially with a limited pool of potential members and a limited time horizon. The first is to present the appearance of an active space that has interesting content and people with whom to interact so that visiting members will want to keep coming back. The second is to convert members from lurkers to posters. The third is to ensure that posters receive appropriate responses.

Implementing an online community involves a variety of strategic design choices about software configuration, about activities and conversation topics to introduce, and about types and quantity of staff participation. These strategic choices can have a big impact on the success or failure of an online community. Prior research has investigated design choices and behavior in mature communities [5,15-25]. Researchers developing new ways for people to interact have conducted empirical assessments by forming new user communities, but their reporting has not focused on the process of starting the new communities [26-28].

Stepping Up to Health (SUH) is an Internet-mediated walking program designed to collect walking data and return feedback to the user to produce a gradual increase in walking. Participants receive a pedometer to record step counts, which they upload periodically over the Internet. The main page of the website features a graph displaying step counts against goals as well as some textual feedback about walking progress, tailored motivational messages, and tips about walking. In this iteration of SUH interventions, some participants also received access to an online community through the SUH website.

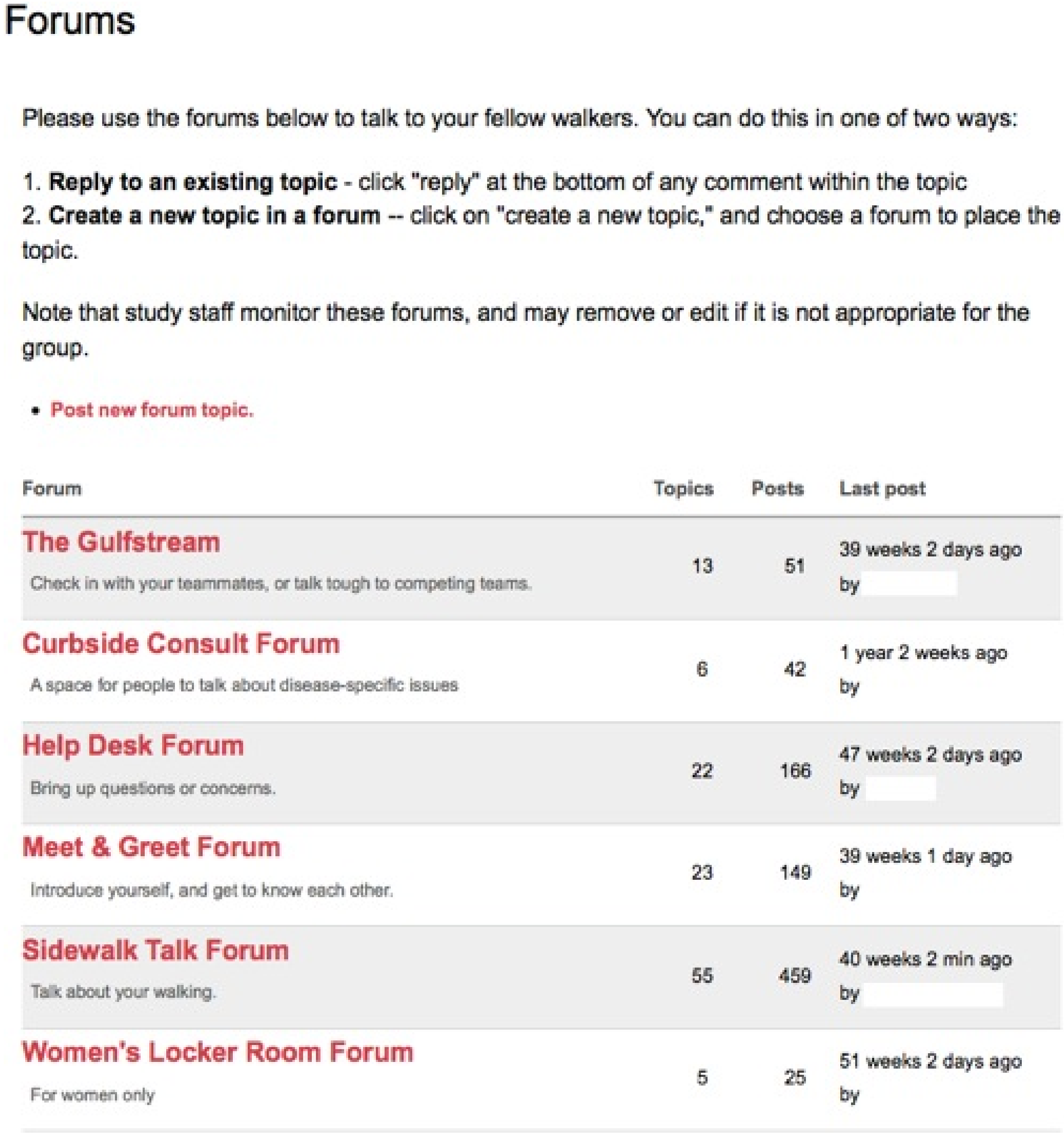
The online community was successful at encouraging retention in the program (21% vs 34% dropout rate). Participants in both arms increased their walking significantly, with no difference between the arms. The companion paper, Part 1, gives more details on the aforementioned results [29]. While in Part 1 we examine differences in outcome between community members and nonmembers, as well as explore potential mechanisms for differences, here in Part 2 we report on the choices made when adding discussion forums to an SUH intervention and reflect on their impacts on member participation in the forums.

The Community

The online community component added to Stepping Up to Health was implemented using the forums module of Drupal, an open-source content management system. Only the 254 intervention participants randomized to the online community arm were able to access the forums. We will refer to these participants as the *members* of the community even though not all of them chose to participate in the community itself. Members could see a link labeled “Talk to other participants” in the left sidebar menu, which took them to a page showing the available topical forums (see Figure 1). In addition, members could scroll down the initial log-in page to see teasers for the

5 most recently active post titles in the online forums. Members could also fill out profiles and read each other's profiles.

Figure 1. Available forums in the online community



Forums

Please use the forums below to talk to your fellow walkers. You can do this in one of two ways:

1. **Reply to an existing topic** - click "reply" at the bottom of any comment within the topic
2. **Create a new topic in a forum** -- click on "create a new topic," and choose a forum to place the topic.

Note that study staff monitor these forums, and may remove or edit if it is not appropriate for the group.

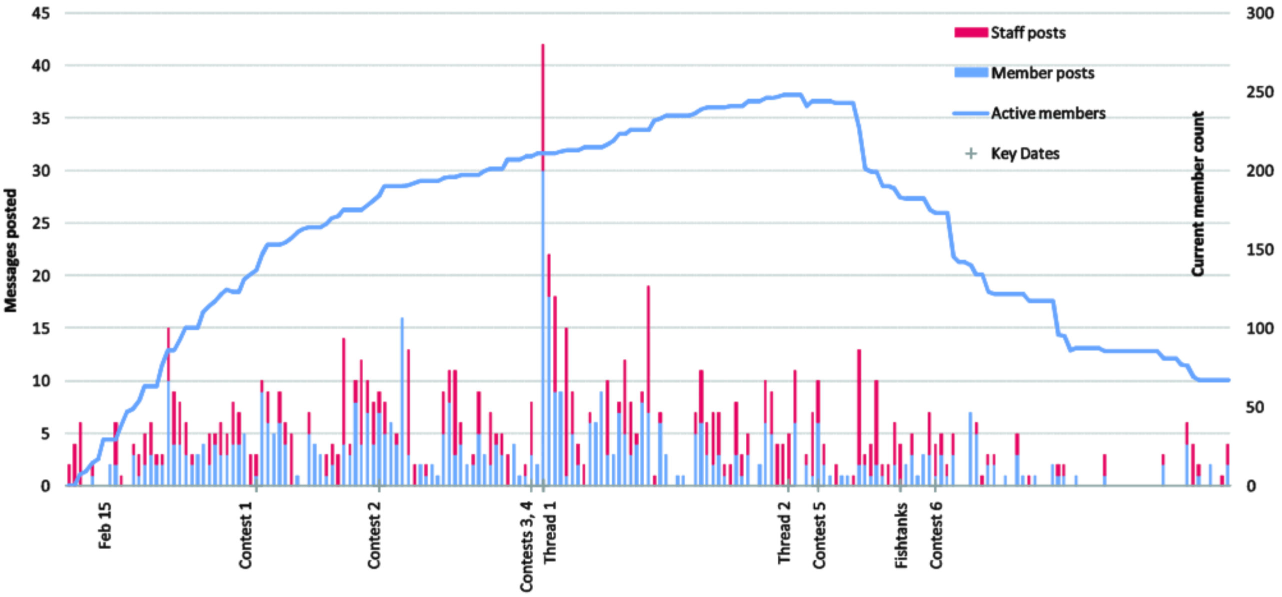
- Post new forum topic.

Forum	Topics	Posts	Last post
The Gulfstream Check in with your teammates, or talk tough to competing teams.	13	51	39 weeks 2 days ago by [redacted]
Curbside Consult Forum A space for people to talk about disease-specific issues	6	42	1 year 2 weeks ago by
Help Desk Forum Bring up questions or concerns.	22	166	47 weeks 2 days ago by [redacted]
Meet & Greet Forum Introduce yourself, and get to know each other.	23	149	39 weeks 1 day ago by
Sidewalk Talk Forum Talk about your walking.	55	459	40 weeks 2 min ago by [redacted]
Women's Locker Room Forum For women only	5	25	51 weeks 2 days ago by

Posting

As shown in Figure 2, after an initial start-up period and until members who had completed the program started losing access to the forums, on most days there were 3 to 10 posts. Participants posted 56% (524) of the 929 total forum messages, with staff posting the rest. Of the 254 people assigned to the online community arm, 114 (45%) posted at least once, 22 (9%) posted more than 5 times, 12 (5%) posted more than 10 times, and 1 member posted more than 50 times. Those who posted averaged 5 posts per person (median 2).

Figure 2. Timeline of interventions and participation



Viewing

Participation in an online community can be passive as well. Of all 254 members, 52 (20%) were lurkers, defined as never posting but viewing an average of at least 1 forum page per week (16 pages over the course of the study). Members viewed pages in the online community at varying frequencies, with a median of 24 views; 4 members viewed more than 1000 pages. Those who viewed more pages posted more messages (Poisson regression, $r = 0.65$, $P < .001$). Of all members, 5% (12/254) never viewed a forum page.

Content

No malicious or inappropriate posts appeared on the site. The most popular topics were discussions on walking motivation and strategies, physical health, and study procedures. Table 1 contains a detailed breakdown of post content.

Table 1. Post content, all posts

Category	Percent of All Posts (929)
Strategies/motivation	58.1
Physical health	15.9
Study procedures	11.8
Diet/nutrition	11.1
Other	10.4
Pedometer	10.0
Website	6.5
Mental health	5.7
Teams	5.7
Introductions	4.3

As with other online health communities, posts offered a mix of information and emotional support [5], and some members took inspiration from others’ successes.

Examples of member posts on motivation and strategies include:

> *In the past, I looked for the closest parking spot; now I find the farthest and it helps to add steps for the winter walks.*
>
> *…Because of the weather for now my walking is daily steps plus getting on the treadmill in the evening. I’m hoping that once the weather gets a little less muddy I am going to go out and explore my woods. I agree it helps to have a partner to motivate you. I used to have a friend who lived close to me and we would walk a few times a week. Now we are too far apart for that to be convenient.*

The following is an example of a post that broaches physical health issues:

> *My feet and back had been “uncomfortable” after lots of walking. I hesitate to say hurting, but more like tired and sore. Then I realized how old and probably broken-down my tennis shoes were and after buying new tennis shoes specifically for walking and*

> *new inserts that provide arch support, I've found it a pleasure to walk again.*

Participants congratulated and encouraged each other in some posts:

> *Congrats on your loss of 6 lbs in 5 weeks! Do you have any tips? I seem to want to eat more, not less. I've only been maintaining at best.*
>
> *Congrats on completing a full week and keep up the great work.*
>
> *I know I have only one full week of completion on my record as well. I allow myself one day a week to not worry about the daily goal. I do, like you, make sure to keep my daily average above the goal, ie, I make up the steps during the week. As a matter of fact I just had my largest one-day total tonight…*

Some posts showed explicit evidence that members took inspiration from each other:

> *There I was on Saturday night sitting around and came across your messages on 100K. I realized I was in reach, so I grabbed my walking poles and left the house at 9pm Saturday just to say I could do it. Thanks again.*

Some interpersonal bonds were formed, as evidenced by posts that announced and acknowledged the impending departures of certain members. For example, a new topic and the first reply:

> *I've completed my 16-week participation in the study, and I've been informed by the staff my account will be deleted this weekend. Therefore this will be my last opportunity to log in to the site and post a message. I'm going to use this opportunity to say farewell to all my friends here. To those of you who have walked along with me for weeks and will be completing participation yourselves soon, my best wishes to you for continuing success walking…*
>
> *Good luck with keeping up with your walking with your new lifestyle! You are a great motivator and will be missed. Just think for a minute that walkers are reading your posts, getting motivated, and just taking it all in. You have accomplished a lot and should be very proud of yourself!*

Design Choices and Their Impacts

While the online community effectively provided information and support, its success was not entirely organic. Staff authored 44% (405/929) of all posts and made numerous strategic choices regarding the design and management of the community. We present those choices, describe their effects, and make suggestions for future community designers. The narrative is organized around the 3 challenges that the design and management strategies were intended to address: presenting the appearance of activity, motivating lurkers to post, and assuring responsiveness.

Presenting the Appearance of Activity

The appearance of inactivity can create a self-fulfilling prophecy. If a member checks the forums and finds nothing new and interesting, he or she might form an expectation that nothing much happens in the forum and not bother to check it again. One vendor offered a rule of thumb: a forum needs 5 to 10 messages per day to feel active enough to spur ongoing use [11].

Concentrated Recruitment

Our first strategy for presenting the appearance of recent activity was simply to maximize the number of members who could potentially be active. As described in the companion paper, to create a more active community, the randomized trial employed an imbalanced design with more people in the online community arm. In addition, we tried to concentrate recruitment into the study to create as much overlap as possible in participants' 16-week participation windows. This required a novel recruitment strategy for the intervention. We abandoned traditional clinical trial recruitment practices, such as fliers in hospitals, clinics, and public places, which have low yield. Instead, we pulled a list of potentially eligible patients from the clinical data warehouse of a large medical system and mailed targeted recruitment letters to these individuals. For a detailed report of recruitment results, see Part 1. We also moved screening and enrollment to the Internet; without the need for face-to-face encounters with staff (though often with significant phone and email support), we were able to process participants in larger waves.

Even with these efforts, it was not possible to synchronize the start—and thus the end—dates of members fully. Participants took varying amounts of time to complete the prerandomization requirements: medical clearance, online survey, and uploading baseline step-count data. Once participants had completed all the preliminaries, we were worried that making them wait before starting the walking intervention and the online community participation would demotivate them.

Finally, we did not have sufficient staff to handle intake of all participants simultaneously, even with a largely automated process, so we sent out invitation letters in waves. Thus, we still had staggered start dates. The line graph in Figure 2 shows the number of members who had access to the forums during the period of the study. Not surprisingly, as shown in the blue bar graphs in Figure 2 (member posts), the greatest participation in the forums also coincided with the period in which the greatest number of members had access to them.

Few Separate Forums

Before the experiment, it was easy to imagine many different things that members might want to discuss. It was tempting to create a separate forum for each category of topic, both to suggest the different kinds of topics to members and to allow them to navigate to just the ones they found interesting. For example, we wanted to provide a place where people could discuss technical support questions with respect to the pedometer or uploading functions without intruding on discussions about motivations for walking. Because there are gender-specific barriers to exercise, we also wanted to provide separate single-sex forums where men could interact with men and women with women.

We anticipated, however, that we would not have enough conversation to keep lots of different forums populated with new content. Thus, we limited the initial set of forums that anyone would see to 5. Figure 1 shows the initial 5 forums that were visible to women plus "The Gulfstream," which we added later for team competitions, described below. Men saw "Men's Locker Room" instead of "Women's Locker Room." In retrospect, we probably should have been ruthless in limiting the number of forums. The Men's Locker Room had only 7 threads, the Women's Locker Room, 5, and Curbside Consult had only 6. Visitors to any of these specific forums would have found no recent conversation in them. Having just a single forum might have been the most effective way to avoid the possibility of members encountering dead zones with no recent activity.

Flat Versus Nested Display of Conversations

There are two common display formats for online discussions. The first, known as a "flat structure," displays comments in chronological order, with either newest or oldest first. Flat comments are common in blogging packages and online newspapers and magazines. While comments follow a particular story or post, in a flat structure the display does not indicate which comments are replies to others, so writers sometimes name the author or otherwise describe the comment to which they replied. The second format, known as "threaded" or "nested," is more often used in discussion forums. Replies usually have an indent or other visual marker to set them apart from new comments. Each comment has a reply option, and writers choose the appropriate place to insert their messages, possibly in the middle of the displayed page.

Since we envisioned our online community features as discussion forums, we used the threaded display. One drawback of this structure, however, is that since the newest messages may be in the middle of a conversation thread, it is possible for a discussion to look stale to a first-time visitor even if it is not. Moreover, some of our users were not very familiar with discussion forums and did not realize that it mattered which button labeled "reply" they clicked on, and so some messages appeared indented under other posts they were not in fact replying to, which made it confusing for readers. Finally, unlike some discussion boards, ours contained no demarcation of posts unread by a specific user, so members could not hunt for replies to their posts without remembering where they had posted and then navigating back to them. We suggest that other designers of online communities for people who are not already experienced forum users would do better to select a flat display rather than threaded and possibly use software that allows for an individualized notification scheme.

Initial Forum Seeding and Restarting Conversations

Staff seeded the forums with initial content so that the first members to visit would encounter a nonempty space. As shown in Figure 1, members could see how recently content had been posted to each forum. To convey the sense of a lively space, we delayed adding the staff-seeded content until the week when the first members received access to the online community.

Overall, we seeded 12 posts into the forums before members arrived. Of the seeded posts, 8 contained staff introductions, and 1 post introduced each of the other initial forums. Of the initial posts, 7—4 of the personal introductions and 3 of the forum introductions—explicitly asked questions or invited members to post information.

To convey on any member visit the impression of recent conversation, staff monitored the forums and started new discussion topics whenever there was a lull. Staff started 75 of the 133 total topics in the forums.

Encouraging Posting

A second challenge in a forum that has only a few members is to coax as many as possible to post rather than just reading. We made 3 design choices aimed to increase member posting: questions, posting contests, and walking contests.

Questions

First, many of the staff-initiated threads and staff responses to member posts employed the rhetorical ploy of asking questions. When answering a member's question, the staff member would also ask the member a follow-on question or encourage additional responses from other participants. For example (emphasis added):

> *I know when I get home from work, my first instinct is to veg out or do things around the house. It helps me if I make plans with a friend to go exercise.* ***Do you have anyone, in your household or outside it, who might want to make a walking date with you?***
>
> *…[Information about preventing blisters and shopping for shoes, responding to a member concern with blisters]… I hope some of this information helps. Let us know what works and what does not work for you.* ***I'm guessing that there are others who are in the Stepping Up to Health program who have experienced blisters also. We can learn [from] each other in the forums.***

Staff reported that they sometimes felt they had overused this rhetorical ploy. Results were somewhat mixed. Of 39 staff responses that posed a question back to the original poster, only 12 elicited a response from the original poster, and 6 elicited a response from someone else. Staff responses that explicitly solicited replies from the whole community were somewhat more effective: Of 19 such messages, 5 elicited a response from the original poster, and 10 elicited a response from someone else.

Initial posts that asked questions as a way to generate conversation were more effective. Some introduced topics that many people could relate to and contribute to, such as vacation plans or the following post on coping with mosquitoes, which generated 14 responses.

> *I'm very happy that it's summer, but I've heard a lot of complaints from coworkers about the ravenous mosquitoes…that appear around dusk as well as the clouds of gnats that seem to appear late afternoon everyday. These little friends can really take the enjoyment out of an evening bike ride or walk. Does anyone have some good suggestions on how [to]*

> *overcome this natural obstacle to a relaxing evening walk?*
>
> *Bugged out…*

Another successful conversation starter was a personally revealing anecdote accompanied by a request for suggestions. Personal revelations are known to increase interpersonal attraction in laboratory settings [30]. The role reversal of having someone who usually provides support instead asking for it can also serve as an icebreaker.

> *My baby sister graduates this weekend! Because I love my little sister, and I'm very proud of her, I'm going to her graduation. But in making the plans I realized something—it's really going to mess with my exercise schedule. Anyone else having this problem? Time sitting in the car, time sitting at the graduation, time sitting in restaurants…Plus switching my gym time around so I could add a whole bunch of graduation stuff to my weekend will leave me at least one planned workout short this week. Anyone have ideas for how to get some walking in at times like these?*

Members responded by completing the role reversal, not only providing tips, but also suggesting that she rethink whether she was getting too obsessive about her exercise. The thread generated 16 comments in all. Moreover, members asked questions of their own in response, as well as giving advice to the staff moderator. A sampling of 2 of the member responses follows:

> *I guess when I read that I could totally relate and that is why I am hoping you are not offended when I say it sounds a bit obsessive. I just said to my friend today that... "My husband wants to meet me for lunch today, but if I do that I won't get my walk in." I guess I am answering your post with another question…[Do you think activity] begins to feel not so much like something just to do, but something you have to do? I have been struggling with that as I would like to lose some weight but I am feeling a bit deprived of the "carefree-ness" of not paying attention to everything I eat and how much I walk.*
>
> *So I wonder, [name redacted], if the question you are really asking is not "is it OK to skip this walk so I can see my baby sister graduate [?]" but "have I reached that state of confidence and balance that tells me I'm in control, so I won't worry about swapping my sister's graduation for a walk?" We all have to get from counting steps to counting on ourselves somehow. How do we get there from here?*

Posting Contests

A second strategy for increasing member posting was contests. The contests were time-limited, and all but 1 of the 6 centered on posting.

The first contest came about a month after the forum opening with more than 100 members able to access the forums and promised members who posted that day or the next that their post would be entered into a "staff favorite" judging. The winner would receive an unspecified prize in the mail. The contest announcement produced 42 responses.

The prize for the first contest was a water bottle. Small monetary rewards can have a demotivating effect [31], but the low-cost prizes were a hit. The staff picked 2 winners, and both posted about their prizes without revealing what they were.

> *I wanted to let you know the award package arrived in the mail on Friday without having been broken, flattened, eaten, stained, spindled, or creased by the postal service…Everyone will just have to trust me that they will want to win. Anyway, my thanks to the staff for selecting my posting as one of the winners. That won't stop me from trying to do better in the next contest (if there is one) either.*

The second contest, specifically intended to get lurkers to unveil themselves, took place about 3 weeks after the first. Anyone posting for the first time within this 5-day window was eligible for a prize drawing. The thread generated 26 responses.

The next contest, about a month after the second, invited members to post a favorite healthy snack idea. In all, 45 members posted snack ideas on the thread and again were eligible for a single-winner drawing. Staff compiled and grouped the snacks in a new thread that received only 1 reply.

The final posting competitions took place 6 and 9 weeks later, respectively. Both occurred as participants were exiting the forums, and both were repeats of previous contests: the "staff favorite" and the "first-time poster." Table 2 shows each forum event, including contests, and the number of replies generated.

Table 2. Index of staff interventions

Date	Event Type	Event	Number of Replies Generated
Mar 12	Posting contest	Contest 1: Staff favorite	42
Apr 2	Posting contest	Contest 2: Virgin poster	26
Apr 29	Posting contest	Contest 3: Healthy snacks	46
Apr 29	Walking contest (individual goals)	Contest 4: Meet own walking goal 5 of 7 days	37
May 1	Seeding thread	Thread 1: Role reversal, with advice and support to staff	16
Jun 12	Seeding thread	Thread 2: Mosquitoes	14
Jun 17	Posting contest	Contest 5: Virgin poster	9
Jul 1	New feature announced	Fish tanks introduced	9
Jul 7	Walking contest	Team competition announced	2
Jul 7	Posting contest	Contest 6: Staff favorite	4

Walking Contests

A third strategy was to create common experiences in the walking program that became foci for conversation in the online community. Staff announced a contest to meet one’s personal walking goals 5 out of 7 days in a particular week. Rather than draw from a hat, the staff sent an “I (heart) walking” bumper sticker to each person who met the criteria. The contest thread generated 37 replies.

In a similar vein, toward the end of the intervention on July 1, 2008, we introduced an element of team camaraderie and interteam competition. The earliest participants had already completed their 16 weeks in the program and no longer had access to the forums. We assigned remaining members to 10-person teams and added a new forum just for discussion of team competitions. Drawing on the Tamagotchi-like idea of feeding a pet fish through one’s exercise that had proved effective in a different walking intervention [32], we showed a graphic of a fish tank. Each fish represented a particular member, and a fish’s visible health (color, movement) represented the member’s walking progress. We announced the competition a week later, with T-shirt prizes to members of the team that collectively met the highest percentage of their members’ goals.

While some of the features of the team assignment and fish tank display received mixed reviews from participants, they did generate a flurry of messages trying to generate team spirit. The following exchange was typical:

> *I am alive and well!! Lost my pedometer but I am back now! Getting some color. Let’s go for a swim!*
>
> *Hey [name redacted]. Glad to have you back and in color! Wish we could help a few of those grey fish in our tank! But I’m happy for you! Swim on!*

Responsiveness

Newcomers to online communities who receive a reply to their first post are more likely to post again [13,14] or to post sooner [33]. More generally, we thought that the forums would feel more responsive and thus invite more participation if all posts received responses. Our strategy to achieve responsiveness was to have staff reply whenever members did not.

Staff logged into the forums most days, looked for posts that had not received responses, and responded to them. Overall, all but 3 of the 58 member-initiated threads received replies, either from other members or from staff. The 2 threads that did not receive replies were a post addressed solely to team members in the team walking contest and a staff oversight. The median time to first reply was 11.2 hours, and 46 out of the 58 threads received a reply within 24 hours.

Staff also made an effort to respond to member posts that did not start threads except for those that were simple offers of support or encouragement. Of the 466 member comments that did not start new threads, 12% received replies from other members, and 36% received replies from staff, with a median time to first reply of 19.3 hours for those that did receive a reply.

Staff responses, like member posts in health forums more generally, included 1 or more of 3 different kinds of content. Of these, 1 type provided information and advice, such as:

> *To avoid unhealthy heat and UV ray exposure, I would encourage outdoor walkers to get their outdoor activity in before 10am and avoid strenuous activity until after 4pm. If the temperature is hot and the humidity is high, be sure to bring along some ice-cold water in a water bottle and wear lightweight clothes and appropriate sunscreen. If you can choose your outdoor walking routes, why not select routes that are shady and take you by pleasant gardens, wild flowers, and other scenic summer foliage?*

Another category of content was emotional support, including encouragement, reassurance, or thanks to the poster. The supportive response could be either related to the physical activity intervention or to participation in the forums. For example:

> *Wow! I love that idea. That is an excellent idea as a reward for finding a way to fit walking into your day.*

> *Congratulations on doing so well with your walking goals, and thank you for sharing your progress with everyone within the forums…*

A third category of content was reflections and anecdotes about the staff member's own barriers or approaches to physical activity. Such posts validated members' struggles, and we expect that they were perceived as emotionally supportive even when they did not directly provide any suggestions or encouragement. Following are 2 examples of such posts:

> *My family just got a new puppy…He is a handful and chews up everything in the house but he definitely gets us out of the house more often and he definitely helps me keep my step counts up. And he is pretty much always up for another walk if you need a walking buddy...*
>
> *Not being very active when working is a problem I face a lot. Here are some of the strategies I use to get a little more active…*

Discussion

We made two design decisions that helped to concentrate activity so that visiting members did not find an empty space. First, we altered our recruitment methods to ensure that as many people as possible would have simultaneous access to the online community. The first burst of posting (10 messages in 1 day) came after 2 weeks following a burst of 23 new members in 2 days, which brought the total membership to 86. This suggests that even more concentration of entry into the community probably would have helped it to take off faster. Second, we limited the number of initial forums to 5 to make it less likely that members would encounter forums without recent activity. Deciding which 5 to include was a difficult process that required jettisoning personal favorites of some staff. In retrospect, we probably would have done better simply to group all of the conversation into a single forum so that members would not need to navigate to multiple pages to find all the new posts.

We employed several seed-and-feed tactics to elicit more participation from members than they might have contributed organically. We seeded the forums with initial content to lower the burden of coming up with a topic for first-time visitors. This seemed to be less successful than we had hoped, however, as the members made only 16 posts in the first 2 weeks in response to those seed messages. We posted new threads whenever we sensed a lull in the conversation. We went out of our way to make sure that any member posts where a reply was appropriate received one. We employed the rhetorical tactic of asking questions in our responses, though that met with mixed success. We also employed a rhetorical tactic of having the staff relate personal anecdotes, which often elicited replies from members and, on rereading the forums after the study, seems to have created a warm, personal feeling that may have set a positive tone for member interactions.

Staff did not separately track their time devoted to 405 posts worth of seeding and feeding, but we offer a rough estimate. We estimate 1 hour of staff time to compose each of the 75 messages that started threads, including some that were carefully crafted in multi-person staff meetings. We estimate 15 minutes to compose each of 330 staff response messages, averaged over those that were short and those that were longer and required research. Finally, we estimate 10 minutes of staff reading time for each of the 524 member messages, since multiple staff followed the posts in the forums. The total is just under 245 staff hours, or the equivalent of about 6 weeks full-time for 1 staff member. While it was a significant effort, it was, for example, probably smaller than the amount of effort that went into designing, implementing, and testing the additional online community features that were added to the original SUH walking intervention. In many situations, this level of staff involvement would be reasonable.

One danger in providing staff contributions to make up for those that members might provide in larger communities is that staff content may drive out contribution of the members who are present. We do not have a way to estimate the extent to which such undesirable substitution occurred.

The occasional contests, with unspecified token prizes, were the most effective single intervention at producing participation. The 4 most popular threads were all prize threads. The most popular of these started a new topic that was of great interest to the participants (walking and snacking), but even the contests for first-time posts and for unspecified good posts on any topic were effective at eliciting participation. The contests were largely noncompetitive in nature, since there was no visible means of comparing anyone's performance with others' with the exception of the "meet your goal 5/7 days" contest, where some members offered "I made it" posts, and others seemed to be discouraged by not making it. We recommend that other online community managers consider the use of contests as a low-cost and effective way to generate participation, especially contests that reward participation over performance.

Finally, we found that team competition in the underlying activity (walking) tended to generate "go team" messages in the forums. Our team competition came late in the study, when many members had already completed the 16-week program and thus no longer had access to the online community. In addition, our implementation was imperfect. Even so, more than 5% of all the posts in the forums for the entire length of the study were about the team competition and the team fish tank visualization. Team competitions may not be available as a design option for all online community managers, since there may be no underlying activity on which teams can compete. Moreover, managers should employ them with caution, as some people may have a negative reaction to competition even though many others will not.

Conclusion

Our major conclusion is that with enough careful design and staff effort, it is possible to create an online community on demand that is sufficiently active to retain participants, even with a small number of temporary members. A number of design choices are available that will increase the density and timeliness of participation. Seeding-and-feeding tactics can substitute staff participation for what a larger number of members might provide naturally and elicit more participation from the members who are there. The most effective single tactic we found was contests with small prizes for posting in the forums.

We have reported on a single case study. We have attempted to document and reflect on the design decisions we made. They are not, however, sufficiently transferable and actionable to guarantee that the results can be reproduced in other settings, especially given that the effects of individual members of online communities may have large effects on community outcomes.

While a more scientific test of the effectiveness of different community designs and management tactics would come from controlled experimentation, it would be prohibitively expensive to start a large number of new online communities. Moreover, in most settings, if there are enough people to form many online communities, the network effects would make it even more effective to form a single, larger community. Thus, case studies, with careful documentation of design choices and management tactics and their apparent impacts, are likely to be the best way to accumulate knowledge about how to start online communities. We hope to see many more such case studies of the formation of new communities.

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Conflicts of Interest

None declared

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Abbreviations

SUH: Stepping Up to Health

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Original Paper

Effectiveness of a Web-based Intervention for Problem Drinkers and Reasons for Dropout: Randomized Controlled Trial

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Abstract

Background: Online self-help interventions for problem drinkers show promising results, but the effectiveness of online therapy with active involvement of a therapist via the Internet only has not been examined.

Objective: The objective of our study was to evaluate an e-therapy program with active therapeutic involvement for problem drinkers, with the hypotheses that e-therapy would (1) reduce weekly alcohol consumption, and (2) improve health status. Reasons for dropout were also systematically investigated.

Method: In an open randomized controlled trial, Dutch-speaking problem drinkers in the general population were randomly assigned (in blocks of 8, according to a computer-generated random list) to the 3-month e-therapy program (n = 78) or the waiting list control group (n = 78). The e-therapy program consisted of a structured 2-part online treatment program in which the participant and the therapist communicated asynchronously, via the Internet only. Participants in the waiting list control group received “no-reply” email messages once every 2 weeks. The primary outcome measures were (1) the difference in the score on weekly alcohol consumption, and (2) the proportion of participants drinking under the problem drinking limit. Intention-to-treat analyses were performed using multiple imputations to deal with loss to follow-up. A dropout questionnaire was sent to anyone who did not complete the 3-month assessment. Reasons for dropout were independently assessed by the first and third author.

Results: Of the 156 individuals who were randomly assigned, 102 (65%) completed assessment at 3 months. In the intention-to-treat analyses, the e-therapy group (n = 78) showed a significantly greater decrease in alcohol consumption than those in the control group (n = 78) at 3 months. The e-therapy group decreased their mean weekly alcohol consumption by 28.8 units compared with 3.1 units in the control group, a difference in means of 25.6 units on a weekly basis (95% confidence interval 15.69-35.80, $P < .001$). The between-group effect size (pooled SD) was large (d = 1.21). The results also showed that 68% (53/78) of the e-therapy group was drinking less than 15 (females) or 22 (males) units a week, compared with 15% (12/78) in the control group (OR 12.0, number needed to treat 1.9, $P < .001$). Dropout analysis showed that the main reasons for dropouts (n = 54) were personal reasons unrelated to the e-therapy program, discomfort with the treatment protocol, and satisfaction with the positive results achieved.

Conclusions: E-therapy for problem drinking is an effective intervention that can be delivered to a large population who otherwise do not seek help for their drinking problem. Insight into reasons for dropout can help improve e-therapy programs to decrease the number of dropouts. Additional research is needed to directly compare the effectiveness of the e-therapy program with a face-to-face treatment program.

Trial registration: ISRCTN39104853; http://controlled-trials.com/ISRCTN39104853/ISRCTN39104853 (Archived by WebCite at http://www.webcitation.org/5uX1R5xfW)

(J Med Internet Res 2010;12(4):e68) doi:10.2196/jmir.1642

KEYWORDS

E-therapy; Internet; Online treatment; Alcohol abuse; Substance abuse; web-based; dropout; randomized controlled trial

Introduction

Problem drinking is a highly prevalent public health issue, with serious consequences in terms of morbidity and mortality [1], and associated economic costs [2] and social problems [3]. However, most problem drinkers will never seek treatment [4]. In the United States, only 16% of people with an alcohol-abuse disorder had received treatment in 2001 [5], and in the Netherlands, only 10% of the problem drinkers received professional help in 2006 [6]. Furthermore, people often seek help only at a late stage; usually after 10 or more years of alcohol abuse or dependence [7]. Therefore, improved access to therapy for problem drinkers is needed [8-10]. The Internet offers a novel opportunity to reach a larger and more diverse segment of the population of problem drinkers [11,12] and improves the availability of alcohol treatment services. Online treatment programs are distinguishable by the intensity of the therapist involvement. Andersson and colleagues [13] distinguished the different forms of Internet interventions in a clear manner: (1) fully self-administered therapy or pure self-help, (2) predominately self-help (ie, therapist assesses and provides initial rationale, and teaches how to use the self-help tool), (3) minimal-contact therapy (ie, active involvement of a therapist, but to a lesser degree than in traditional therapy, eg, using email), and (4) predominantly therapist-administered therapy (ie, regular contact with therapist for a number of sessions, but in conjunction with self-help material). A meta-analysis of 12 randomized controlled trials (RCTs) of Internet-based cognitive behavioral therapy programs for depression and anxiety showed that Internet-based interventions are effective; especially those with therapist involvement [14].

RCTs of Internet interventions for problem drinking are available, and they show promising results [15-23]. However, all of these online alcohol interventions are fully self-help interventions without therapist involvement. The effectiveness of predominantly therapist-administered online therapy for problem drinkers solely via the Internet has not yet been examined in a RCT. It is expected that active therapeutic involvement will lead to greater treatment effects compared with self-help. In addition, we expect to reach another group of people, who prefer intensive personal therapist contact instead of dealing with their problem themselves.

This report describes the main findings from a RCT in which participants were randomly assigned to the 3-month therapist-involved e-therapy program or to the waiting list control group. Because of poor adherence and high dropout rates in e-health interventions [24-26], and a low completion rate (173/527, 33%) in our pilot study [27], we decided to systematically investigate the reasons for dropout as part of our RCT study as well. Insight into those reasons may identify factors that are responsible for dropout, and online treatment programs can consequently be improved to reduce the number of participants ending treatment prematurely. Based on the prior results of our uncontrolled observations, where we found a significant decrease in alcohol consumption and alcohol-related health complaints [27], we tested the hypothesis that e-therapy would (1) reduce weekly alcohol consumption, and (2) improve health status. To our knowledge this is the first RCT that evaluates the effectiveness and reasons for dropout of an e-therapy program for problem drinking with active therapeutic involvement.

Methods

Study design and participants

We undertook an open RCT, with recruitment taking place between October and December 2008. To be included in the trial, participants had to be Dutch-speaking problem drinkers in the general population aged 18 years or more. Problem drinking was defined as drinking currently at least 15 units (of 10 g of ethanol) a week for females and 22 units for males, with a maximum of 67 units a week for females and 99 units for males. This was based on the mean weekly alcohol consumption in the pilot study, added with 1.5 SD. We excluded participants treated for problem drinking in the preceding year and participants with psychiatric treatment in the past 6 months or those currently having a psychiatric disorder.

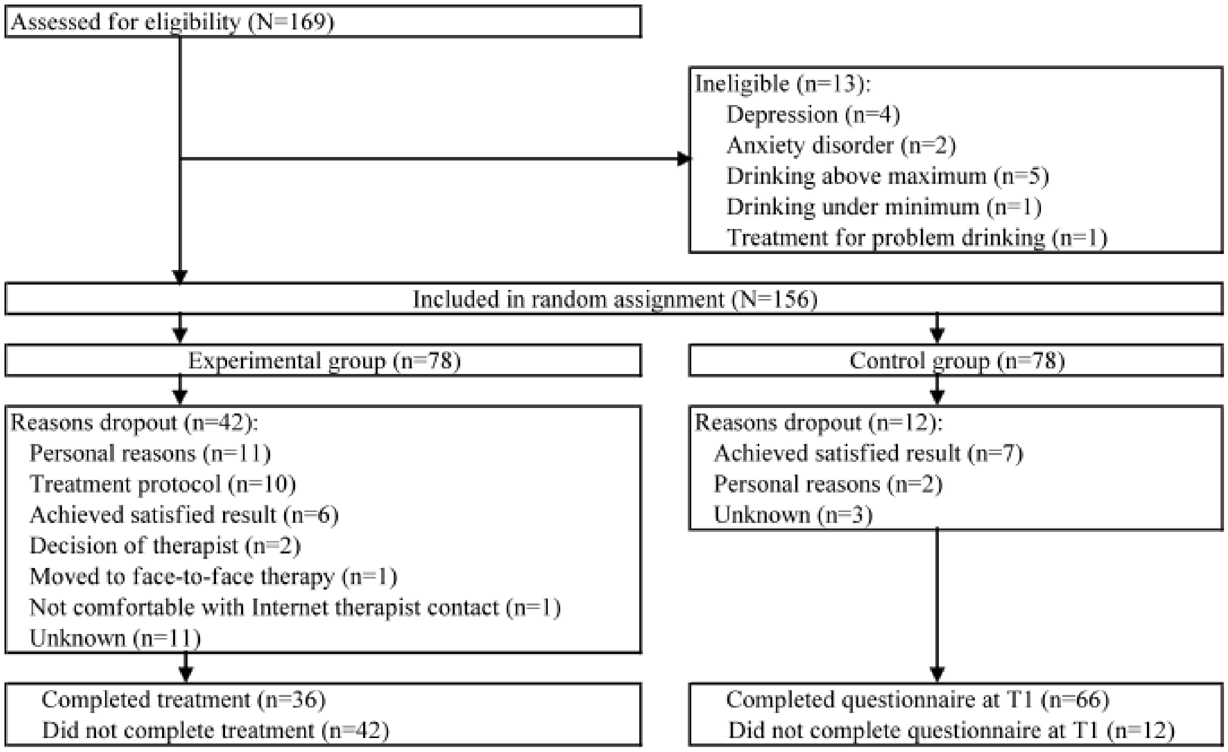
Participants were recruited through an advertisement on the website’s homepage (http://www.alcoholdebaas.nl), through media attention on national television, and by responding to 500 expressions of interest that had been emailed to the website. Participants were referred to a research website for additional information about the study and encouraged to screen themselves on the inclusion criteria. A total of 169 participants deemed themselves eligible, provided online informed consent, and completed the baseline questionnaire. Participants received the e-therapy intervention free of charge. We did not provide any kind of incentive for study participation. The study protocol was approved by the independent medical ethics board METiGG (ref. no. NL20742.097.07) and registered at http://www.controlled-trials.com (ISRCTN39104853).

Procedure

As shown in the flow chart (Figure 1), 156 of the 169 participants screened were subsequently determined to be eligible for the study and were randomly assigned to either the e-therapy treatment group or to the waiting list control group. Participants were randomly assigned in blocks of 8, according to a computer-generated random list (based on a random generator and algorithm, Microsoft .NET Framework version 3, Microsoft, Bellevue, WA, USA), implemented by a technician who was not involved in the recruitment process. Block randomization ensures group numbers are evenly balanced at the end of each block. Because of the limited availability of the therapists, we needed to keep the numbers in both groups very close at all times. Participants were automatically allocated by computer.

Every e-therapy participant was assigned to a personal therapist for the duration of the study. The 12 experienced therapists were all qualified social workers with higher vocational education, who had received special training in the technical aspects and content of the e-therapy program, with special focus on motivational writing skills. Therapists could obtain expert advice from the multidisciplinary team, consisting of treatment staff, an addiction medicine specialist, a psychologist, and 2 supervisors. Both supervisors regularly checked the therapists' files for fidelity to treatment protocols. Participants were allocated on a sequential basis to the next available therapist. The mean total time spent on each participant was approximately 1.5 hours per week.

Figure 1. CONSORT diagram: flow of participants through the study protocol.

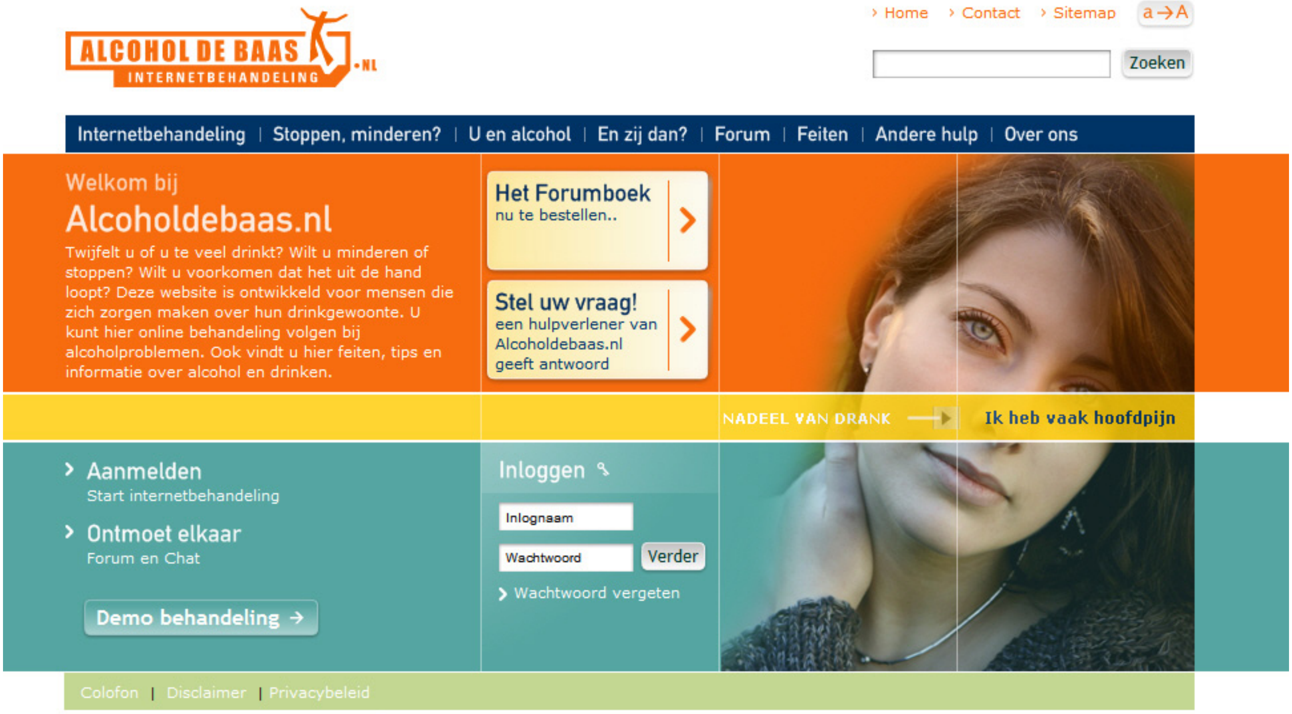


T1 = 3-months' follow-up for control group

Interventions

The e-therapy program could be accessed via the homepage (Figure 2) and consisted of a structured 2-part online treatment program in which the participant and the therapist communicated asynchronously, via the Internet only. Participants accessed the e-therapy program in their personal environment. Participant and therapist were in separate or remote locations; the interaction occurred with a time delay between the responses. The aim of the e-therapy program was to reduce or stop the participant's alcohol intake. The method underlying the program was based on the principles of cognitive behavior therapy [28] and motivational interviewing [29]. All communication between therapists and participants took place through a Web-based application (Figure 3), as described previously [27].

Figure 2. Homepage of http://www.alcoholdebaas.nl



Welkom bij
Alcoholdebaas.nl

Twijfelt u of u te veel drinkt? Wilt u minderen of stoppen? Wilt u voorkomen dat het uit de hand loopt? Deze website is ontwikkeld voor mensen die zich zorgen maken over hun drinkgewoonte. U kunt hier online behandeling volgen bij alcoholproblemen. Ook vindt u hier feiten, tips en informatie over alcohol en drinken.

Figure 3. Participant's personal record

Onderwerp	Datum
psycho-educatie	08-10-2008 10:25
Testbericht voor testcliÞent	03-10-2008 11:28
Huisarts	17-09-2008 12:59
Dat verdient een bloemtje	17-09-2008 12:55
testberichtje	17-09-2008 10:25

Omdat je hebt aangegeven nogal last te hebben van maagklachten, wil ik je adviseren om een bezoek te brengen aan je huisarts. Het is verstandig om een algemeen lichamelijk onderzoek te laten doen door je huisarts. Zeker als je daar al een tijd niet meer geweest bent, is het goed om dit te doen.

Hieronder vind je een brief die je hierbij kan helpen. Je kunt de brief downloaden, printen en meenemen naar de afspraak bij je huisarts. In de brief staat dat je deelneemt aan de internetbehandeling Alcoholdebaas.nl, en wat dit inhoudt. De brief bevat verder algemene informatie, o.a. over medicatie, en een checklist met mogelijke klachten bij overmatig drinken. Deze is voor je arts bedoeld. Het eerste blad van de checklist kun je eventueel zelf alvast invullen.

Part 1 of the program consisted of 2 assessments and 4 assignments, with the accompanying communication focusing on the analysis of the participants' drinking habits. Part 1 covered the following core concepts: (1) exploring advantages and disadvantages of alcohol use, (2+3) understanding drinking patterns through completion of a daily drinking diary and descriptions of the craving moments, and (4) identifying risky drinking situations. The therapist helped the participant at every step in the program; he or she explained the assignments and provided feedback. The therapist always responded within 3 days. Messages were always personalized, although therapists used preprogrammed text parts for the analogous parts, such as the explanation of an assignment. The therapist and participant could not move on to the next assignment until they completed the previous one. We chose a linear model, also called tunnel IA design, as the therapy program is most effective with a specific ordering of treatment steps, and this model is also useful in working with homework assignments and tailored feedback [30]. The therapist provided contact details of the institution that participants could reach 24 hours a day in case of crisis situations. At the end of part 1, personalized advice was given and the participant could choose whether to continue with treatment in part 2 or to stop. The multidisciplinary team evaluated every participant's record and gave advice to the therapist for the further treatment stages in part 2.

Part 2 focused on behavioral change and included 5 central concepts: (1) setting a drinking goal, which could be abstinence or moderate drinking, (2) formulating helpful and nonhelpful thoughts, (3) considering helpful behaviors for moments of craving, (4) identifying the moment of the decision to drink alcohol, and (5) formulating an action plan for maintaining the new drinking behavior and for preventing relapse. The mean duration of the total e-therapy program was 3 months, with 1 or 2 therapist contacts per week and daily self-registration during the whole program. Besides registration, the participant usually responded every 3 or 4 days. If there was no response from the participant, the therapist contacted the participant 3 times during the following 2 weeks. If there was still no response, the participant received a message that his or her record would be closed after 2 weeks. The posttreatment questionnaire was sent to the participant's personal data record.

Participants in the waiting list control group received "no-reply" email messages once every 2 weeks during the waiting period of 3 months to keep them involved in the study. The messages contained alcohol-related information, psychoeducational material, motivational messages, and references to the information website and the forum for online contact with fellow sufferers. Participants knew that they were assigned to the control group and that they could start the e-therapy intervention after they completed the assessment at 3 months.

Outcome measures

All data were collected online. Participants completed online self-report questionnaires at baseline and at 3-months' follow-up (control group) or at posttreatment, which was at approximately 3 months (e-therapy group). Weekly alcohol consumption was assessed by a 7-day retrospective drinking diary [31]. Type and severity of substance dependence was assessed by the Substance Abuse Module of the Composite International Diagnostic Interview [32]. The General Health Questionnaire (GHQ-28) and the Maudsley Addiction Profile, Health Symptom Scale (MAP-HSS) were used to assess health status [33,34]. The 21-item Depression Anxiety Stress Scale (DASS-21) was used to measure the 3 related negative emotional states of depression, anxiety, and stress [35]. Quality of life was measured with the EuroQol-5D (EQ-5D) [36] and initial treatment motivation with the TCU Motivation for Treatment (MfT) scale [37]. To determine the reasons for dropout, we sent an email to all dropouts with a link to an additional online questionnaire consisting mainly of open questions. If participants did not complete this questionnaire, they were contacted by telephone to remind them to complete the questionnaire online or to administer it by phone immediately. Dropout was defined as anyone who did not complete the 3-month assessment. Dropouts in the e-therapy group did not complete all 12 treatment sessions: 9 assignments and 3 assessments. Because of the design of the e-therapy program it was impossible for participants to skip parts of the intervention; therefore, adherence corresponds to the moment of dropout.

The primary outcome measures were (1) the difference in the score on weekly alcohol consumption, and (2) the proportion of participants drinking under the problem drinking limit. Secondary outcomes were difference scores on health status (GHQ-28 and MAP-HSS), DASS-21 scores, and quality-of-life ratings (EQ-5D).

Sample size and statistical analysis

Based on the results of our explorative study, we anticipated a 50% reduction of mean weekly alcohol consumption in the experimental group and 25% in the control group. To detect a difference of 25% with an alpha of .05 and a power of 80%, 45 participants were required in each group. To allow for dropouts, our target sample size was 75 participants in each group.

We used chi-square and *t* tests for demographic data and pretreatment characteristics to assess whether randomization resulted in 2 comparable groups at baseline and whether any differential loss to follow-up had occurred. We performed intention-to-treat analysis using multiple imputations (SPSS version 17.0, SPSS Inc, Chicago, IL, USA) to deal with loss to follow-up. We used 5 imputed data sets, and group was used as predictor in the imputation equation. We used *t* tests to assess the differences between pre- and posttreatment measures. Between-group effect sizes were calculated based on the pooled standard deviation, Cohen d. Effect sizes of .80 were considered to be large [38].

Reasons for dropout were independently assessed by the first and third author. If the 2 authors did not agree, the topic was discussed to reach agreement. If necessary, the second author was consulted to arbitrate.

Results

Participant characteristics

Table 1 presents baseline characteristics of the 156 participants who were included in the trial. Of these, 54% were women, 58% had a higher education level, and 82% were employed; age ranged from 22 to 66 years, with a mean of 45.3 years. A total of 127 participants reported alcohol dependence (81%). The majority (134/156, 86%) had never received professional help for their drinking problem. The mean weekly alcohol consumption was 41.9 standard units a week: 49.8 for men and 35.2 for women. Participants used a considerable amount of medication for somatic complaints, but no medication that interfered with the treatment program, with the exception of one person using anticraving medication.

Chi-square analysis indicated that there was a significant difference between the groups on prior alcohol treatment; the experimental group had received more alcohol addiction treatment than the control group (24% vs 4%, $X^2_1 = 13.5$, $P < .001$). There were no other significant differences in treatment condition in any of the variables presented in Table 1.

Table 1. Baseline characteristics of test populations

Variable	E-therapy Group (n = 78)		Control Group (n = 78)		Total (N = 156)		Analysis		
	n	%	n	%	n	%	X^2	df	*P*
Female	42	54	42	54	84	53.8	0.0	1	1.00
Higher education	42	54	48	62	90	57.7	0.9	1	.33
Employed	65	83	63	81	128	82.1	0.2	1	.68
DSM-IV [a] diagnoses							1.1	2	.56
Alcohol dependence	65	83	62	79	127	81.4			
Alcohol abuse	6	8	10	13	16	10.3			
No dependence or abuse	7	9	6	8	13	8.3			
Prior alcohol treatment	19	24	3	4	22	14.1	13.5	1	<.001
Problem drinking [b]	78	100	78	100	156	100	0.00	1	1.00
	Mean	SD	Mean	SD	Mean	SD	*t*	df	*P*
Age (years)	46.7	9.7	43.9	9.7	45.3	9.8	1.8	1,154	.08
Weekly alcohol consumption									
Males	47.6	21.3	51.9	16.7	49.8	19.1	-1.0	1,70	.34
Females	36.3	13.0	34.1	14.5	35.2	13.7	0.7	1,82	.46
GHQ-28 score [c]	53.6	12.1	55.6	11.7	54.6	11.9	-1.1	1,154	.28
MAP-HSS score (0-40) [d]	20.3	6.6	20.0	5.3	20.2	6.0	0.3	1,148	.76
DASS-21 total score [e]	27.5	20.0	28.4	14.7	27.9	17.5	-0.3	1,154	.75
MfT subscales [f]									
Recognition of General Problems	3.6	0.8	3.5	0.6	3.5	0.7	0.6	1,145	.58
Recognition of Specific Problems	2.2	0.7	2.2	0.5	2.2	0.6	-0.2	1,143	.86
Desire for Help	3.9	0.7	3.9	0.6	3.9	0.7	0.5	1,154	.63
Treatment Readiness	4.1	0.5	4.0	0.4	4.1	0.5	0.8	1,154	.45
EQ VAS [g]	60.2	22.3	59.7	21.8	59.9	22.0	0.1	1,154	.90

[a] Diagnostic and Statistical Manual of Mental Disorders, 4th revision

[b] Drinking >21 (male) or >14 (female) units mean per week

[c] General Health Questionnaire

[d] Maudsley Addiction Profile, Health Symptom Scale

[e] Depression Anxiety Stress Scale

[f] TCU Motivation for Treatment scale

[g] EuroQol-5D visual analog scale

Loss to follow-up

Of the 156 individuals who were randomly assigned, 102 (65%) completed assessment at 3 months (Figure 1). Loss to follow-up at 3 months was higher in the e-therapy group (42/78, 54%) than in the control group (12/78, 15%, $X^2_1 = 25.5$, $P < .001$). Completers and noncompleters in the e-therapy condition differed in 1 variable at baseline: the mean score on the Treatment Readiness subscale of the MfT was higher for completers (mean = 4.23) than for noncompleters (mean = 3.98, $F_{1,76} = 5.89$, $P = .02$). In the control condition the groups differed in 2 variables: more noncompleters were male (92% vs 38%,

X^2_1 = 11.82, $P < .001$) and fewer of them had a diagnosis of alcohol dependence (58% vs 83%, X^2_1 = 3.89, $P = .04$).

Outcome

Participants allocated to the e-therapy group showed a greater decrease in alcohol consumption than those in the control group at 3 months (Table 2). The e-therapy group significantly decreased their mean weekly alcohol consumption by 28.8 units compared with 3.1 units in the control group, a difference in means of 25.6 units on a weekly basis (95% confidence interval [CI] 15.69-35.80; $P < .001$). The between-group effect size (pooled SD) was large (d = 1.21). Additional analyses showed no effect modification and confounding for gender and prior alcohol treatment (data not shown).

Table 2. Difference scores by treatment condition at 3 months

	E-therapy (n = 78)		Control (n = 78)		Analysis			
Measure	Mean	SD	Mean	SD	95% CI		*P*	Effect size
Weekly alcohol consumption	28.8	21.3	3.1	21.2	25.65 (15.69-35.80)		<.001	1.21
MAP-HSS score (0-40) [a]	5.2	5.2	0.9	3.7	4.27 (2.37-6.17)		<.001	0.96
GHQ-28 score [b]	12.8	12.0	4.3	10.4	8.46 (3.82-13.09)		<.005	0.76
DASS-21 total score [c]	16.3	19.4	2.2	15.6	14.13 (7.96-20.29)		<.001	0.81
EQ VAS [d]	-10.6	29.4	-2.7	25.6	-7.95 (-16.69 to 0.79)		0.08	-0.29
	n	% success	n	% success	OR	NNT [e]	*P*	
Drinking within guidelines	78	68%	78	15%	12.04	1.9	<.001	

[a] Maudsley Addiction Profile, Health Symptom Scale

[b] General Health Questionnaire

[c] Depression Anxiety Stress Scale

[d] EuroQol-5D visual analog scale

[e] Number needed to treat

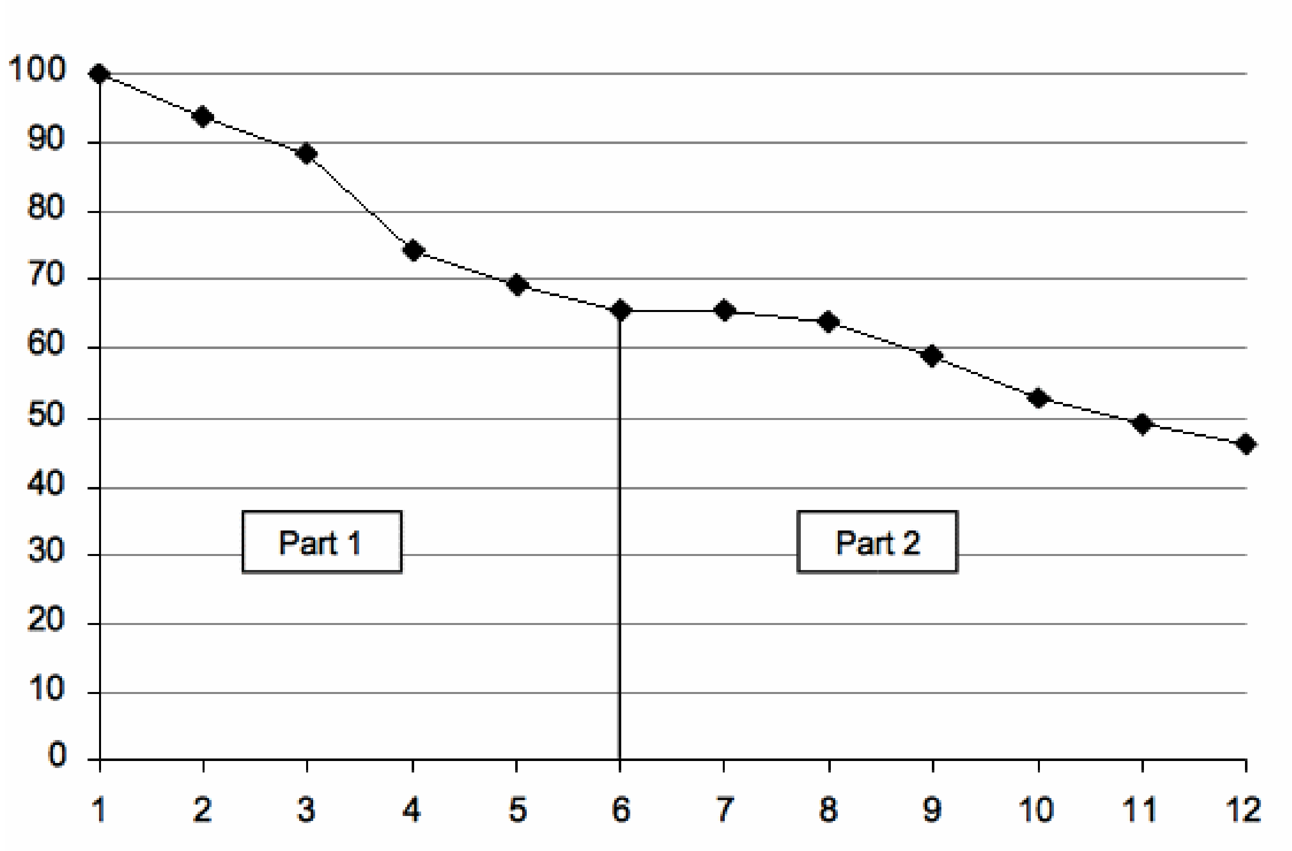
The clinical significance of the e-therapy program was assessed using the number of participants with alcohol consumption under the problem drinking limit at 3 months. The results showed that 68% of the e-therapy group was drinking less than 15 (females) or 22 (males) units a week, compared with 15% in the control group (OR 12.0, number needed to treat 1.9, $P <$ .001).

The secondary outcome data showed that participants in the e-therapy group scored significantly better on the MAP-HSS (95% CI 2.37-6.17, $P < .001$), GHQ-28 (95% CI 3.82-13.09, P < .005), and DASS-21 (95% CI 7.96-20.29, $P < .001$), but not on the EQ-5D (Table 2).

Compliance

In the e-therapy group, the mean number of sessions completed was 8.3 (SD 4.2) out of 12. Participants completed the modules in the order that they were presented. Treatment completers (36/78, 46%) completed all 12 assignments and dropouts (n = 42) completed a mean of 5.1 (SD 3.2) assignments. The dropout rate was higher in part 1 (36%) than in part 2 (19%). Figure 4 shows the attrition curve for the e-therapy group. The mean duration of treatment completion was 16.6 weeks and the mean waiting time of the control group was 14.2 weeks.

Figure 4. Attrition curve e-therapy group: proportion participants by number of assignments



Reasons for dropout

A substantial number of participants in the e-therapy group (n = 42) and in the control group (n = 12) did not complete postassessment. We were not able to contact 14 participants, because of nonresponse or an invalid phone number. However, we could establish that in the e-therapy group 11 participants dropped out because of personal reasons unrelated to the e-therapy program or the study (eg, ill family member), 10 because they were not comfortable with the treatment protocol (eg, too intensive), and 6 because they were satisfied with the positive results being achieved (eg, “I have been sufficiently helped”). Additionally, 1 person was not comfortable with the Internet therapist contact, 1 participant moved on to face-to-face treatment, and the therapist decided to terminate the e-therapy on 2 occasions, 1 because of insufficient information and the other due to an inability to set a realistic drinking goal. In the control group, 7 participants quit because they were satisfied with the results achieved and 2 for personal reasons.

Discussion

Main results

Participants who received the therapist-supported e-therapy program reported substantially greater gains than those who received no-reply email messages. At the end of treatment, 7 out of 10 participants in the e-therapy group achieved drinking behavior within the guidelines for low-risk drinking. The e-therapy group also showed greater improvement than the control group on general health and depression symptoms. Besides the outcome measures, this study also gained insight into the reasons for dropout; the main reasons for dropping out of the e-therapy program were personal reasons unrelated to the program, the protocol or content of the e-therapy program, and satisfaction with the positive results that had been achieved.

E-therapy with active therapeutic involvement

This is, to our knowledge, the first RCT evaluating an online treatment program with active therapeutic involvement for problem drinking solely via the Internet. The results of the present study replicate the results of our uncontrolled observations [27]. The effect sizes in this study are quite large compared with effects found for other Web-based interventions designed to decrease alcohol consumption [15,25]. A possible explanation might be the active therapeutic involvement in the present intervention, which replicates earlier findings from Spek et al [14] that active therapeutic involvement seems to be especially effective. It also seems reasonable that the large effects are a result of the key ingredients of the e-therapy program: the therapy itself was intensive; the therapists were experienced, were well educated, and had special training and good supervision throughout the trial; and the recruitment process involves a certain amount of motivation and readiness to change. Further research is needed to identify the effective elements of the e-therapy program and the optimal amount of therapeutic contact needed.

Although around 80% of participants were deemed to be dependent drinkers by Diagnostic and Statistical Manual of Mental Disorders, 4th revision (DSM-IV), it may be that the severity of dependence was actually quite low, as a high proportion of the participants were employed and well educated.

E-therapy attracts participants who are otherwise unlikely to use regular face-to-face treatment facilities or self-help programs. A study by Postel et al [12] showed that e-therapy reaches more women, higher-educated people, and employed people, groups that are underrepresented in regular face-to-face therapy. One of the perceived advantages of e-therapy over a face-to-face treatment is its anonymity. Participants no longer need to stay away from treatment because of shame, fear of stigmatization, or another high barrier to professional help. Furthermore, e-therapy helps participants in their own environment at a time of their own choosing; they no longer need to visit the therapists' office for scheduled weekly visits, which makes e-therapy more easily accessible and convenient. This is also the reason for choosing asynchronous communication instead of chat; using chat these advantages would no longer exist. An advantage of active therapeutic involvement over self-help is the added value of personal contact with the professional therapist. Although (tailored) screening or self-help interventions have proven to be successful [10,16-18,39], some participants prefer having contact with a professional therapist. Based on the findings of online treatment for depression and anxiety [14], online treatment with therapist involvement might also be more effective than online self-help for alcohol problems.

Dropout

The dropout rate in this study was substantial (54/156, 35%). E-therapy dropouts showed less readiness for treatment. It is important to note that there were more dropouts in the e-therapy group (42/78, 54%) than in the control group (12/78, 15%), which suggests that actively working on behavioral change causes more resistance and fear than waiting for change. This corresponds to our experiences in regular addiction health care practice, where we see that as patients embark on changing their addictive behavior, it is the fear that dominates. On the other hand, the intention to change your alcohol consumption in the near future is ego syntonic. This might explain the differences in dropout rate between the 2 groups, and this may also be the reason for the overall high dropout rate in addiction treatment interventions.

Although e-therapy is suitable for a broad range of participants, it probably will not be the best alternative for each problem drinker. Some problem drinkers prefer real-life contact with their therapist, and for some participants another form of treatment is recommended because of their specific situation.

The main reasons for dropout in our study are in line with earlier findings on potential factors for attrition as described in the law of attrition by Eysenbach [26]. Personal reasons unrelated to the e-therapy program fall under “external events,” and not being comfortable with the treatment protocol falls under “workload and time required.” However, satisfaction with the positive results being achieved seems to be a new factor, not yet covered in the law of attrition. Eysenbach describes “tangible and intangible observable advantages in completing the trial or continuing to use it” as a potential factor, which refers to advantages when completing the trial or intervention. In our study, participants mentioned a different thing: since they already achieved their treatment goal during the intervention, they decided that completing the trial or continuing to use the intervention would not lead to additional advantages. It seems that some of the e-therapy participants who did not complete the entire program received what they considered to be enough therapy. It would be interesting to confirm this hypothesis, although we realize that it is difficult to obtain data from dropouts. Instead of sending a separate dropout questionnaire, the participants' situation could be monitored more closely by using interim questionnaires to measure more frequently during the study. Another possibility is to develop the daily registration tool (eg, drinking diary) in a way that data can easily be transported for research purposes.

Methodological considerations

Despite randomization, a substantially higher proportion of participants in the e-therapy group than in the control group received prior alcohol treatment. Therefore, part of the reduction in alcohol consumption might be explained by this baseline difference. Prior alcohol treatment has been shown to have predictive power with regard to treatment outcome; however, other studies have shown the reverse [40]. Although the large differences between both groups already suggested that prior treatment would play no meaningful role in our study, we performed additional analyses and revealed that prior alcohol treatment had no significant effect on treatment outcome.

Although high dropout rates seem to be characteristic of online interventions [24], this highlights a weakness in our study; especially as we were not able to acquire posttest data from the dropouts as a consequence of the technical procedures of the e-therapy program. We therefore could contact dropouts only by a dropout questionnaire sent separately by email. In future studies, procedures will be changed to ensure that posttreatment assessment can be completed, independent of treatment completion.

We consider the formal investigation of the reasons for dropout to be a strength of our study, as only 1 previous study has formally examined the reasons for dropout [24,41]. This study from Lange and colleagues studied online therapy for posttraumatic stress disorder and showed that the 2 reasons for quitting were technical problems and the form and content of the therapy [41]. As their study was conducted in 2003, and computer and Internet technology has significantly improved since then, it could be expected that technical aspects would no longer one of the main problems. In line with Lange and colleagues, we also found that dissatisfaction with the form or content of the e-therapy program is a reason for dropout. In addition to their findings, we also found that personal reasons and satisfaction with the results achieved were reasons for dropout. Contrary to our expectations, our results show that quitting the e-therapy program prematurely does not automatically mean that the participant has relapsed. Satisfaction with the results being achieved for 7 participants in the control group suggests that receiving informational email messages can be very helpful for some participants. This is most likely true for the group with less serious alcohol problems, as fewer dropouts in the control group had a diagnosis of alcohol dependence. Based on the information on dropout, the e-therapy program can be improved to decrease the number of participants dropping out.

We expect to be able to generalize the 3-month findings of our study to the general population of e-therapy clients, as our sample was comprehensively representative. We kept the exclusion criteria to a minimum, and therefore reached a population of problem drinkers that shows many similarities with participants in the daily practice open-access intervention of the e-therapy program.

We can only report short-term effects of the e-therapy intervention. It was not possible to compare group outcomes at 6 months because of a prior decision to permit the waiting list controls to receive e-therapy after 3 months; this was done for ethical reasons. We know that this is a serious study limitation, as it is important to know the longer-term effects of alcohol treatment programs. A study from Riper and colleagues [42] showed that the beneficial effect of their online alcohol self-help intervention had disappeared at 12 months.

Future directions and implications

Until recently, the e-therapy program had been available only in Dutch. However since February 2010, the e-therapy program is also available in English (http://www.lookatyourdrinking.com). This greatly expands the implementation of this e-therapy program, and offers the possibility to reach a larger population of problem drinkers and to conduct cross-cultural research. Although the Dutch version of the e-therapy program is fully reimbursed by the health insurance companies and therefore free of charge for participants, the English version unfortunately is not yet. English participants have to pay for the treatment program themselves.

Insight into the reasons for dropout offers possibilities for the improvement of online treatment programs. For example, more therapist attention for participants’ satisfaction will possibly result in more treatment terminations in good consultation. Sending an email alert to participants when they receive a new message from their therapist can easily eliminate part of the dissatisfaction. At this moment, the challenge of e-therapy programs no longer seems to be its effectiveness but keeping participants involved till the end of the treatment program.

In summary, it appears that, because many problem drinkers do not receive any kind of treatment, these initial results point to a meaningful way to deliver easily accessible and effective alcohol treatment to a larger population, members of which do not otherwise seek or receive help for their drinking problem. Additional research is needed to gain more insight into reasons for dropout and to directly compare the effectiveness of the e-therapy program with a face-to-face treatment program. We plan to conduct secondary analysis after treatment completion in both groups. We will then merge the experimental and control groups to explore whether e-therapy might work more effectively for some people than for others.

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Conflicts of Interest

None declared

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Abbreviations

CI: confidence interval
DASS-21: Depression Anxiety Stress Scale
DSM-IV: Diagnostic and Statistical Manual of Mental Disorders, 4th revision
EQ-5D: EuroQol-5D
GHQ-28: General Health Questionnaire
MAP-HSS: Maudsley Addiction Profile, Health Symptom Scale
MfT: TCU Motivation for Treatment scale
RCT: randomized controlled trial

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Original Paper

Engagement and Retention: Measuring Breadth and Depth of Participant Use of an Online Intervention

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Abstract

Background: The Internet provides us with tools (user metrics or paradata) to evaluate how users interact with online interventions. Analysis of these paradata can lead to design improvements.

Objective: The objective was to explore the qualities of online participant engagement in an online intervention. We analyzed the paradata in a randomized controlled trial of alternative versions of an online intervention designed to promote consumption of fruit and vegetables.

Methods: Volunteers were randomized to 1 of 3 study arms involving several online sessions. We created 2 indirect measures of breadth and depth to measure different dimensions and dynamics of program engagement based on factor analysis of paradata measures of Web pages visited and time spent online with the intervention materials. Multiple regression was used to assess influence of engagement on retention and change in dietary intake.

Results: Baseline surveys were completed by 2513 enrolled participants. Of these, 86.3% (n = 2168) completed the follow-up surveys at 3 months, 79.6% (n = 2027) at 6 months, and 79.4% (n = 1995) at 12 months. The 2 tailored intervention arms exhibited significantly more engagement than the untailored arm ($P < .01$). Breadth and depth measures of engagement were significantly associated with completion of follow-up surveys (odds ratios [OR] = 4.11 and 2.12, respectively, both P values < .001). The breadth measure of engagement was also significantly positively associated with a key study outcome, the mean increase in fruit and vegetable consumption ($P < .001$).

Conclusions: By exploring participants' exposures to online interventions, paradata are valuable in explaining the effects of tailoring in increasing participant engagement in the intervention. Controlling for intervention arm, greater engagement is also associated with retention of participants and positive change in a key outcome of the intervention, dietary change. This paper demonstrates the utility of paradata capture and analysis for evaluating online health interventions.

Trial Registration: NCT00169312; http://clinicaltrials.gov/ct2/show/NCT00169312 (Archived by WebCite at http://www.webcitation.org/5u8sSr0Ty)

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KEYWORDS

Methodological studies; Internet; process metrics; tailored intervention

Introduction

The major advantages of online interventions lie in their ability to reach large numbers of potential clients with very complex individually tailored designs and with relatively low cost [1,2]. One of the disadvantages of online interventions is the lack of "stickiness"—the ability to attract and retain Internet visitors—relative to other modes of contact [3,4]. Providing people access to a website is no guarantee that they will use it. A key concern is with lack of engagement [5] in online interventions, leading to dropout from the study and loss to follow-up or to dampening of the treatment effect [6-8]. However, unlike other media for health interventions (especially those not involving direct human contact), logs of access and use of online interventions can give researchers insight into what people are doing and when they are doing it. Such interventions provide tools to learn more about participant engagement and, further, how that relates to retention and intervention outcomes. This information can be used to understand the dynamics of engagement and can lead to design changes to improve the retention and engagement of online health behavior interventions.

This paper focuses on what is variously called dosage [9], exposure [10,11], adherence [12], or engagement [5]. As Danaher et al [11] note, "a key ingredient in determining the impact of any Web-based behavior change program is the extent to which participants are exposed to the program." We use the paradata from an online intervention to explore the level of engagement and factors associated with user engagement in the intervention. Paradata are auxiliary data that capture details about the *process* of interaction with the online intervention [13]. Some paradata are captured as a matter of course when users connect to a website. These user metrics contain information on the user's browser, connection speed, and other details about user behaviors. Other types of paradata must be captured as an explicit part of the design of the site, using a variety of tools such as cookies, Web bugs, and session identifiers. These can include information on which pages are visited, when and how often, and for how long. This kind of information can provide insight into what people are spending time on and, more importantly, what they are ignoring and missing. Paradata are widely used in Web survey settings to learn more about respondent behavior [14-18], but have not been widely used in online health interventions, with some exceptions [6,11,19].

The goal of this paper was to use paradata to explore engagement in a randomized controlled trial (RCT) of an online intervention with several different arms. Specifically, we examined both breadth and depth of engagement defined in new measures built from paradata. We then explored how engagement was related to retention in the study, as measured by completion of the follow-up surveys. Finally, we addressed the relationship between engagement and key outcomes of the trial. Our expectation was that tailored interventions would result in greater engagement in the online material, leading to lower attrition in the intervention and improved outcomes. This paper provides a starting point to identify areas where online intervention design improvements may be required and, ultimately, may give us clues as to why a particular intervention may be more or less successful.

Methods

Data for this study came from the Making Effective Nutritional Choices for Cancer Prevention (MENU) study (Trial Registration: ClinicalTrials.gov NCT00169312), a randomized trial conducted in conjunction with the Cancer Research Network (CRN). The CRN is a consortium of 14 research organizations affiliated with nonprofit integrated health care delivery systems and the National Cancer Institute (NCI) [20,21]. The MENU study tested a randomized longitudinal intervention utilizing an interactive website to promote greater intake of fruit and vegetables [22]. In total, 5 of the CRN affiliated health care delivery systems in their headquarter cities—Group Health Cooperative in Seattle, Kaiser Permanente Colorado in Denver, HealthPartners in Minneapolis, Henry Ford Health System in Detroit, and Kaiser Permanente Georgia in Atlanta—collaborated with the University of Michigan's Center for Health Communications Research, which provided Web design and support for the MENU study. The online intervention offered 4 core education sessions phased over a 4-month period with 4 assessment surveys at baseline, 3-, 6-, and 12-months post enrollment. Sessions included motivation support, information, and "how to" behavioral strategies, and offered supplemental "special features," a bank of 300 fruit and vegetable-based recipes, plus food preparation videos. All enrollment processes and assessment surveys were completed online. Participants were enrolled between September 2005 and March 2006. All protocols were approved by the institutional review boards of the participating institutions.

Participants

Study subjects, aged 21 to 65 years, were randomly selected and recruited from the administrative databases of the 5 participating health care systems. Selection was limited to those members who had at least one-year enrollment in the respective health plan and had no record (according to diagnostic codes) of existing health conditions that might be negatively affected by increasing dietary fruit and vegetables. Equal numbers of men and women were selected, and 3 sites over-sampled minority racial/ethnic groups (African American or Hispanic) to enhance diversity in enrollment. Access to the Internet for personal use and use of a working email account, assessed during the study's online eligibility survey, was also required for enrollment.

Of the 28,460 members mailed invitations to participate in the study, 4270 (15%) visited the website and 2540 (8.9% of those invited or 59.5% of those visiting the website) enrolled. Analysis following the 12-month survey identified 27 participants who reported inconsistencies in birth date and gender, suggesting different people may have completed the follow-up surveys. These cases were dropped from all analyses, leaving a final count of 2513 participants for analysis (Table 1). Further information on the enrollees is provided in Stopponi et al [23]. Of the 2513 enrollees, the average age was 46.3 years, 69% were women, 66% were white or other non-Hispanic, 24% were African American, and 8% were Hispanic; 51% of enrollees had a college education or higher.

Recruitment Procedures

Participants were recruited with a single mailed invitation letter using health system stationery. The letter described eligibility criteria and included the Web address and a unique sign-on code which could be used to access more information about the study online. Also included were a US $2 bill preenrollment incentive and the promise of US $20 for completing each of the 3 follow-up surveys during the 12-month follow-up period [24]. After logging in online, individuals were asked for permission to proceed through the eligibility screening questions (9 to 12 questions, depending on personal tailoring). If eligible, individuals were given information about the study (the information was displayed and distributed across 8 consecutive Web pages) and were asked to provide informed consent. Those who consented were asked to provide their personal contact information (ie, phone, email, and mailing address). Email addresses were verified, and consenting individuals were asked to complete the first (baseline) survey after which they were randomized to a study arm. Participants were encouraged to complete the enrollment process in one sitting but could complete it in more than one session if necessary.

Intervention

Enrollees were randomized to 3 experimental arms receiving Web sessions that were (1) untailored, (2) tailored, or (3) tailored with email support which utilized a human online behavioral intervention (HOBI) consisting of behavior change counseling. Randomization was assigned by study site, gender, and stage of change with eating fruit and vegetables. Tailored Web sessions were based on health risk information and motivations for change obtained from baseline or 3-month post surveys. All materials were provided in English only.

An initial online welcome letter showed the participant's current status of reported fruit and vegetable servings compared with recommended intakes [25] and explained the sequence of the 4 core Web sessions. Web sessions were similar in design and educational content, which was focused on nutritional information and cognitive and behavioral support to eat more fruits and vegetables. The welcome session was available immediately following the baseline assessment, and subsequent intervention sessions were made available at 1-, 3-, 13-, and 15-weeks postenrollment. An automated process sent emails when new content was available for review. All materials were available, once presented, through the end of the 12-month study period.

The MENU tailored Web program included content and suggestions matched to each person's gender, needs, characteristics, dietary preferences, and interests. Behavioral sessions were tailored to each person's stage of change and were designed to increase participants' motivation and self-efficacy for buying, preparing, and eating fruits and vegetables. Tailored web sessions also contained tailored video and audio files designed to reinforce behavioral advice featuring videos of food preparation by Graham Kerr, a well-known, health-conscious chef. Additionally, persons in the tailored arms were able to access an expert-tailored menu, which was generated based on their fruit and vegetable preferences, dietary restrictions, and other preferences.

In addition to the tailored program, participants in Arm 3 were offered corresponding email counseling support sessions. Each counseling session was initiated by a study counselor within a week after each Web session was first visited. Counselors provided additional support for dietary change, following the therapeutic principles outlined in motivational interviewing [26,27]. Counselors responded to any request for strategies or for nutrition information with a referral to the MENU website. A maximum of 4 unique email discussions corresponding to each of the 4 Web sessions were initiated by the counselor when the sessions were accessed. Each email discussion was limited to 4 "back and forth" exchanges.

Special Features

In addition to the sessions, participants could access "special features," which were short, optional, and individually accessed clusters of Web pages that appeared periodically on the intervention website and which presented tips and other additional information in a pop-up window. Like sessions, notice of each feature's availability was automatically delivered a fixed number of days after enrollment. Examples of special features included recipes developed by Graham Kerr, a dietary intake goal-setting tool, tips for eating out, food safety and storage, fun with fruit and vegetables, and nutritional similarities of fresh, frozen, and canned foods (for details, see [22]). Participants reporting children in their household received a special feature on encouraging kids to eat fruit and vegetables, while those reporting no children were given a special feature on preparing quick and healthy foods. A total of 17 unique special features were offered, but only 16 were available for any one participant since one was tailored to parental status. Once available and accessed, special features could be revisited. We tracked the total number of times, if any, that participants accessed each special feature.

Data Collection Procedures

The Web protocol for all data collection surveys was similar. Participants were asked to report fruit and vegetable intake at baseline, 3, 6 and 12 months, using one or both of two fruit and vegetables screeners. The first, used at baseline and 12 months, is based on a 16-item measure of fruit and vegetable servings, adapted from the NCI 19-item fruit and vegetable food frequency questionnaire [28]. The second, used at all 4 assessment time points, is based on a 2-item measure assessing total servings of fruit and vegetables on a typical day [29]. Also included in the baseline survey were questions about intrinsic and extrinsic motivations, barriers to eating fruit and vegetables, and confidence about making dietary changes. Intrinsic and extrinsic motivation for eating fruit and vegetables were assessed using a 14-item subset of the Treatment Self-Regulation Questionnaire (TSRQ) measure developed by Williams and Deci [30] and modified to apply to fruit and vegetable intake by Resnicow et al [31]. Living status and demographics were also assessed.

Table 1. Baseline description of the enrolled subjects by study arm

Variable	Total (n = 2513)	Study Arm Arm 1 Control (n = 836)	Arm 2 Tailored (n = 839)	Arm 3 Tailored + HOBI (n = 838)
Age (years), mean (SD) median	46.3 (10.8) 48.0	46.1 (10.6) 47.0	46.5 (10.8) 48.0	46.4 (10.9) 47.0
Female, n, %	1729 (69)	576 (69)	577 (69)	576 (69)
African American, n, %	585 (24)	192 (23)	196 (24)	197 (24)
Hispanic, n, %	192 (8)	69 (8)	66 (8)	57 (7)
Married/with partner, n, %	1805 (72)	595 (72)	602 (72)	609 (73)
High school education or less, n, %	217 (9)	76 (9)	70 (8)	71 (9)
Associate or some college, n, %	1023 (41)	334 (40)	352 (42)	337 (40)
College degree, n, %	659 (26)	219 (26)	232 (28)	208 (25)
Post bachelor’s education, n, %	607 (24)	205 (25)	183 (22)	219 (26)
Fruit consumption, stage of change				
Precontemplator stage, n, %	49 (2)	17 (2)	14 (2)	18 (2)
Contemplator stage, n, %	1247 (50)	412 (49)	421 (50)	414 (49)
Preparation stage, n, %	511 (20)	164 (20)	175 (21)	172 (21)
Action stage, n, %	170 (7)	54 (6)	61 (7)	55 (7)
Maintenance stage, n, %	533 (21)	189 (23)	166 (20)	178 (21)
Vegetable consumption, stage of change				
Precontemplator stage, n, %	40 (2)	11 (1)	17 (2)	12 (1)
Contemplator stage, n, %	1547 (62)	519 (62)	523 (62)	505 (60)
Preparation stage, n, %	389 (15)	128 (15)	124 (15)	137 (16)
Action stage, n, %	104 (4)	35 (4)	35 (4)	34 (4)
Maintenance stage (%)	430 (17)	143 (17)	138 (16)	149 (18)
Fruits and vegetables/day, 16-item measure of servings: mean[a] (SD) median	4.4 (2.8) 3.8	4.6 (3.0) 3.9	4.2 (2.7) 3.6	4.5 (2.7) 4.0
Fruits and vegetables/day, 2-item measure of servings: mean (SD) median	3.3 (1.58) 3.0	3.3 (1.57) 3.0	3.2 (1.57) 3.0	3.4 (1.59) 3.0

[a] Using the Kruskal-Wallis test, the means by arms were statistically significantly different at $P = .049$.

Measures

Outcome Measures

We examined the role of engagement in minimizing attrition or maximizing retention in the study. We defined retention as completion of the follow-up surveys at 3-, 6-, and 12-months after baseline.

We also examined two key substantive outcomes measured as change in mean fruit and vegetable consumption from baseline to 12-month follow-up. In both cases, a positive score indicated an increase in consumption. The 2 measures were correlated ($r = .60$), with the shorter 2-item measure having had a higher 12-month completion rate.

The baseline survey included 70 questions and took an average of 25 minutes to complete. The 3-month follow-up survey included 32 questions, taking an average of 13 minutes to complete; the 6-month survey included 30 questions, taking an average of 13 minutes to complete; and the 12-month survey included 80 questions, taking an average of 29 minutes to complete. A reminder letter was mailed to all enrollees a week prior to each survey due date, and an email reminder was sent to all enrollees on each survey due date. A series of 5 automated reminder emails were sent to anyone who had not completed the survey every 3 or 4 days after the due date. For the 3-month survey, phone call reminders were initiated in the final 5 days of the online completion "window" during which callers offered enrollees reminders to do the survey and the opportunity to complete the survey by phone. Nearly all of the assessments (> 96%) were completed online. Overall, 86.3% of baseline participants completed assessments at 3 months, 79.6% at 6 months, and 79.4% at 12 months with no significant differences by intervention arm.

Paradata Measures

The engagement measures were obtained using server-side paradata. For confidentiality reasons we did not embed JavaScript code in the Web pages to capture client-side paradata [17]. We used the time stamps from the following 5 primary actions: (1) logging in to the website; (2) initiation of any of the 4 online surveys; (3) completion of any of the online surveys; (4) loading the first page of any of the 4 core Web sessions; and (5) loading the first page of any 1 of the 17 special features. The website automatically logged out the participant after 30 minutes if there was no new participant-generated activity. If logged out, the participant would need to repeat the log-in process, generating another log-in event.

Total Sessions

The MENU program consisted of 4 sessions, each made available at different time points: 3 days after baseline, 21 days after baseline, 3 days after the 3-month survey, and 21 days after the 3-month survey. Once new content was available, the user was automatically presented with the current new session at log-in. A bank of nearly 300 recipes and a goal-setting feature were available as optional elements throughout the study. All previous sessions remained available in a navigation bar at the top of the Web page. Participants could thus view up to 4 unique informational sessions by the end of the intervention program; however, the total count of sessions accessed could be higher if a session was viewed more than once.

Unique Sessions

The measure "unique sessions" was simply a count of the number of offered informational Web sessions visited at least once, with the maximum being 4.

Time Online

To approximate the total time spent interacting with the website over the course of the study, we attributed the elapsed time between 2 time-stamped events to the action that generated the first of the events. These elapsed times were then accumulated across the various actions to give total elapsed times for each type of action done on the website. These accumulated times may have been slightly lower than the time actually spent on the site since we did not capture how long the participant spent reading the previously accessed Web session or special feature.

Engagement

We focused on the 4 measures of engagement captured through the website paradata and described above: total session accesses, unique session accesses, total special feature accesses, and total time on the website (excluding time spent completing the surveys) (see Table 2). Given that all 4 measures are related, we sought to create more parsimonious summary measures of engagement. The 4 measures were subjected to a principal components analysis (PCA). The first 2 principal components accounted for 90% of the total variation in program usage between study participants, with the first accounting for 73% and the second for 17% of the total variation. Based on this, the following 2 summary measures were created:

- BREADTH is a summary measure of access to all activity on the website. It is composed of the sum of the 4 measures in Table 2, standardized by dividing by their standard deviations to compensate for the differences in scales. BREADTH approximates the first principal component from the PCA.
- DEPTH is a summary measure of how deeply individuals engaged in the online material, for a given level of overall Web activity. NON_SURVEY_MINS (total minutes spent excluding survey completion) and SF_TOT (total number of special feature accesses) loaded positively on the second principal component, while SESS_UNIQ (number of unique session accesses) loaded negatively, with the loading of SESS_TOT (total number of session accesses) close to 0. The measure of DEPTH is thus obtained as the sum of the average (standardized) total of accessed special feature sessions (SF_TOT) and standardized nonsurvey minutes spent online (NON_SURVEY_MINS), minus twice the total number (standardized) of unique sessions accessed (SESS_UNIQ). The more special features a person accessed, and the longer they spent on the website relative to the number of different sessions they saw, the higher the value of DEPTH. DEPTH approximates the second component from the PCA.

Using the factor loadings from the PCA yielded similar results to those using the methods described above. The measures of BREADTH and DEPTH were again standardized (mean 0, SD 1) for further analyses. The two measures were slightly positively correlated, $r = .12$. Based on the PCA, we named these 2 measures to indicate that they measured different aspects of engagement.

In the multivariate models, we controlled for a number of additional variables measured at baseline. Fruit and vegetable consumption was based on the sum of 2 single measures and collapsed into low (less than 2 servings per day), medium (2 to 4 servings per day), and high (5 or more servings per day) consumption.

Statistical Analysis

We focused on several outcomes of interest. First, utilizing our 2 newly derived indicators of the depth and breadth of engagement based on PCA, we explored the correlates of these engagement indicators from the baseline survey, using ordinary least squares (OLS) regression. Next, we examined completion of the follow-up surveys using both the baseline measures and the 2 new engagement indicators as predictors. These analyses used generalized estimating equations (GEE), reflecting the within-subject correlation across outcomes. A likelihood ratio chi-square was used to test whether the addition of the 2 engagement indicators improved the model fit. Finally, we examined 2 key outcome measures (fruit and vegetable consumption at 12 months) to explore how engagement may mediate the effect of the intervention on outcomes. The models again used OLS regression. Statistical analyses were done using SAS 9.1.3(SAS Institute Inc, Cary, NC, USA).

Results

The 4 component indicators of engagement are presented in Table 2. On average, participants visited the sessions a total of 10.6 times across the course of the intervention; no differences were identified by study arm. In terms of unique sessions, not all sessions were seen by all participants, with an average of 3.1 sessions visited, overall. Of all participants, 5.1% (128/2513) of participants did not visit any of the 4 sessions. Just over half (1410/2513, 56.1%) visited all 4 unique sessions; this did not vary by intervention arm. Similarly, on average, participants visited special features an average of 11.1 times, with 13.7% (344/2513) not visiting special features at all.

Table 2. Descriptive statistics on component engagement measures (n=2513)

Variable	Mean	SD	Median
Total session accesses (SESS_TOT)	10.64	7.14	9
Unique session accesses (SESS_UNIQ)	3.14	1.20	4
Total special feature accesses (SF_TOT)	11.13	10.79	8
Total time excluding survey completion (NON_SURVEY_MINS)	42.16	42.93	29.55

The mean number of special feature accesses (8.3 for arm 1, 10.2 for arm 2, 10.3 for arm 3) and mean total minutes devoted to the intervention website (32.3 for arm 1, 44.1 for arm 2, 46.7 for arm 3) differed significantly by arm ($F_{2,2512} = 9.57$, $P < .001$ and $F_{2,2512} = 27.04$, $P < .001$, respectively). Levels of engagement with accessing special features and time spent on the Web intervention were lower in the untailored arm for both measures, with higher and nearly equivalent levels observed when comparing the 2 tailored arms.

Correlates of Engagement

We regressed the standardized measures of depth and breadth, in turn, on a series of sociodemographic and related behavioral variables at baseline, using OLS regression (SAS 9.1.3 PROC GLM, SAS Institute Inc, Cary, NC, USA). These models are presented in Table 3.

Table 3. Models of standardized breadth and depth regressed on common demographic/baseline variables

Predictors	Breadth		Depth	
	Coefficient	(SE)	Coefficient	(SE)
Arm				
Arm 1: Untailored	---	---	---	---
Arm 2: Tailored	0.114 [b]	(0.047)	0.234 [b]	(0.049)
Arm 3: Tailored with HOBI	0.141 [b]	(0.047)	0.305 [b]	(0.049)
Female versus male	0.407 [b]	(0.044)	0.087	(0.046)
Age				
< 29	-0.475 [b]	(0.101)	-0.428 [b]	(0.104)
29-38	-0.437 [b]	(0.081)	-0.315 [b]	(0.084)
39-48	-0.230 [b]	(0.074)	-0.262 [b]	(0.077)
49-58	-0.047	(0.068)	-0.182 [b]	(0.070)
59+	---	---	---	---
Race				
White	---	---	---	---
Black	-0.045	(0.050)	0.098	(0.052)
Other	-0.034	(0.071)	-0.110	(0.073)
Hispanic versus non Hispanic	-0.127	(0.086)	0.094	(0.088)
Education				
High school or less[c]	---	---	---	---
Some college	0.110	(0.059)	-0.150 [a]	(0.061)
College graduate	0.106	(0.063)	-0.137 [a]	(0.065)
Postgraduate	-0.026	(0.064)	-0.265 [b]	(0.067)
One or more children in home versus none	-0.167 [b]	(0.046)	-0.062	(0.047)
Marital status				
Never married	---	---	---	---
Formerly married	-0.048	(0.079)	0.007	(0.082)
Married/living with partner	-0.015	(0.066)	0.071	(0.068)
Self-reported health				
Poor to good	-0.050	(0.042)	0.063	(0.044)
Very good to excellent	---	---	---	---
Fruit and vegetable consumption				
Low	-0.047	(0.063)	0.101	(0.065)
Medium	---	---	---	---
High	0.031	(0.052)	-0.054	(0.054)
Comfort using Internet				
Low	-0.126 [a]	(0.057)	-0.071	(0.059)
Medium	---	---	---	---
High	-0.078	(0.048)	-0.069	(0.050)
Motivation to eat more fruit				

Predictors	Breadth		Depth	
	Coefficient	(SE)	Coefficient	(SE)
Low	-0.126 [a]	(0.057)	0.018	(0.056)
Medium	---	---	---	---
High	-0.078	(0.063)	0.015	(0.060)
Motivation to eat more vegetables				
Low	0.021	(0.054)	-0.027	(0.056)
Medium	---	---	---	---
High	-0.074	(0.058)	-0.023	(0.060)
Physical activity level				
Inactive	0.197 [a]	(0.094)	0.182	(0.098)
Low activity	0.163 [a]	(0.066)	0.047	(0.068)
Somewhat active	0.100	(0.059)	0.065	(0.061)
Very active	---	---	---	---
Motivation				
Intrinsic motivation[d]	0.074 [b]	(0.021)	0.026	(0.026)
Extrinsic motivation[e]	-0.047 [b]	(0.014)	-0.017	(0.014)
Model fit				
Constant	-0.287	(0.195)	-0.259	0.202
Observations	2461		2461	
R^2	.108		.053	

[a] $P < .05$

[b] $P < .01$

[c] Category includes those with vocational or technical training.

[d] Intrinsic motivation measures personal importance or internal drive to do a behavior. Examples are: “I have a strong value for eating healthy” and “I want to take responsibility for my own health.”

[e] Extrinsic motivation measures perceived outside influences on behavior. Examples are: “Others would be upset with me if I didn’t (eat more fruits and vegetables)” and “It is easier to do what I am told.”

Together these baseline measures explained a modest proportion of variation in the breadth ($R2$ = .108) and depth ($R2$ = .053) of engagement in the online materials. In terms of experimental conditions, those exposed to either of the 2 tailored conditions exhibited significantly more overall online activity than those exposed to the untailored materials. Women had significantly higher levels of breadth (exposure to a variety of items in the intervention) than men, but depth (more time dedicated to the intervention materials) did not differ by gender. Age was significantly associated with both engagement measures, with lower levels of engagement exhibited by younger participants. Race and ethnicity were not associated with differences in engagement. Education was significantly associated with the depth measure, with lower engagement (eg, less time online, fewer special feature accesses) by those with higher levels of education. The presence of children in the home was negatively associated with breadth of engagement but not with depth, and marital status showed no association with either breadth or depth.

Few of the baseline measures showed significant associations with the measures of engagement in the program. Low comfort using the Internet was significantly related to lower breadth, or amount of the website seen. Those with low motivation to eat fruit upon enrollment exhibited slightly lower breadth of engagement, but those who were less physically active showed higher levels. Intrinsic motivation was positively associated with depth, while extrinsic motivation was negatively associated with depth.

Predictors of Survey Completion

In the second step, we used the standardized breadth and depth measures of engagement along with all of the baseline measures included in Table 2 to predict completion of the follow-up surveys at 3-, 6-, and 12-months after baseline. Our expectation was that those who were less engaged in the online material would be less likely to complete the follow-up surveys.

We used a generalized estimating equation (GEE) in SAS 9.1.3 PROC GENMOD to model survey completion, reflecting the within-subject correlation across outcomes [32]. The odds ratios and 95% confidence intervals for survey completion are presented in Table 4.

Table 4. Model of survey completion at 3-, 6-, and 12-months

Predictors	Odds Ratio	95% Confidence Interval
Follow-up survey		
3-month	1.0	
6-month	0.48 [b]	(0.42-0.56)
12-month	0.48 [b]	(0.41-0.55)
Arm		
Arm 1: Untailored	1.0	
Arm 2: Tailored	0.82	(0.64-1.06)
Arm 3: Tailored with HOBI	0.79	(0.61-1.02)
Female versus male	1.07	(0.85-1.35)
Age		
< 29	1.06	(0.63-1.81)
29-38	1.1	(0.71-1.69)
39-48	1.03	(0.70-1.54)
49-58	0.92	(0.63-1.34)
59+	1.0	
Race		
White	1.0	
Black	0.85	(0.66-1.09)
Other	0.82	(0.57-1.17)
Hispanic	0.63 [a]	(0.41-0.97)
Education		
High school or less	1.0	
Some college	0.86	(0.64-1.15)
College graduate	1.02	(0.74-1.41)
Postgraduate	1.32	(0.94-1.85)
One or more children in home versus none	1.00	(0.79-1.27)
Marital status		
Married	1.0	
Formerly married	0.99	(0.66-1.50)
Never married	1.24	(0.87-1.77)
Self-reported health		
Poor to good	0.77 [a]	(0.62-0.96)
Very good to excellent	1.0	
Fruit and vegetable consumption		
Low	0.77	(0.58-1.04)
Medium	1.00	
High	1.00	(0.74-1.34)
Comfort using Internet		
Low	0.97	(0.72-1.30)
Medium	1.0	
High	1.06	(0.82-1.36)

Predictors	Odds Ratio	95% Confidence Interval
Motivation to eat more fruit		
Low	0.97	(0.73-1.29)
Medium	1.0	
High	1.17	(0.86-1.59)
Motivation to eat more vegetables		
Low	1.29	(0.96-1.73)
Medium	1.0	
High	0.73 [a]	(0.54-0.99)
Activity level		
Inactive	0.68	(0.43-1.09)
Low activity	0.89	(0.62-1.29)
Somewhat active	0.91	(0.65-1.26)
Very active	1.0	
Motivation		
Intrinsic motivation (see Table 3)	0.98	(0.86-1.12)
Extrinsic motivation (see Table 3)	0.96	(0.90-1.03)
Breadth	4.11 [b]	(3.61-4.69)
Depth	2.12 [b]	(1.89-2.38)
Constant	22.55 [b]	(7.95-63.92)
Model fit		
Observations	7383	
Max-rescaled *R2*	.32	

[a] $P < .05$

[b] $P < .01$

From the model, we can see a significant drop-off in completion from the 3-month follow-up to the 6-month follow-up, but not from the 6-month to the 12-month. What is striking from Table 4 is that few of the baseline measures—with the exception of Hispanic origin and motivation to eat more vegetables—are predictive of survey completion following the start of the intervention.

However, our main focus was on the role of the 2 engagement measures. Both were significantly and strongly associated with survey completion. The likelihood ratio (LR) chi-square test of the addition of these two variables to the model was significant (LR $\chi^2_2 = 1005.8$, $P < .001$). The Nagelkerke [33] adjusted generalized coefficient of determination (or max-rescaled *R2*), which is analogous to the multiple *R2* in linear regression, increased from .05 from the model without these two variables to .32 for the model including BREADTH and DEPTH. Thus, the level of engagement in the online materials was highly associated with completion of the follow-up surveys or attrition in the study.

Predictors of the Key Outcomes

Finally we added BREADTH and DEPTH to a model regressing 2 key fruit and vegetable intake outcome variables on the baseline measures included in the models in Table 4 to examine whether the measures of engagement added to the explanation of the study outcomes. Given that our focus was on the role of engagement, we do not present the full models. In the 2 regression models predicting change in fruit and vegetable consumption, the engagement measures added significantly to the explained variance ($F_{2,1722} = 22.08$ for the 16-item measure and $F_{2,1945} = 29.9$ for the 2-item measure). Examining the individual coefficients, BREADTH was statistically significant ($P < .001$) in both models, while DEPTH failed to reach significance ($P = .83$ and $P = .92$ respectively), although both coefficients were in the expected direction. We tested the interactions of the engagement measures with study arm for both outcomes, and none of them was statistically significant. We thus found a main effect of engagement (specifically, BREADTH) on change in fruit and vegetable consumption, with greater breadth of engagement associated with greater (positive) change in fruit and vegetable consumption.

Discussion

This paper focused on the use of paradata to measure the process of engagement in an online intervention aimed at increasing fruit and vegetable consumption. These data, collected throughout delivery of these online materials, reveal what pages of informational sessions are visited and the frequency and duration of the visit, but they do not reveal *why* a participant may find a particular element of the online content engaging. Paradata are thus indirect measures of engagement. We learned several things from the analysis of paradata.

Principal Results

First, those in the 2 tailored intervention arms showed higher levels of engagement—as indicated by the 2 composite measures, BREADTH and DEPTH of engagement—than those in the untailored arm. This suggests that the tailoring is responsible for participants' increased use of the program materials. Variation in engagement by demographic characteristics may indicate groups' differing levels of interest in the program or online materials. Whether this is a reaction to the intervention content or a reflection of preexisting differences in interest that were not captured by our baseline measures is unclear.

Second, the engagement indicators were significant correlates of attrition from the intervention. This suggests that the more participants are engaged with the online materials, the more likely they are to complete the follow-up surveys. This is a key finding, as discovering mechanisms that promote collection of more complete outcome measures is essential to research studies.

Finally, engagement was also significantly associated with the key behavioral outcomes of the study: changes in fruit and vegetable consumption. Those who spent more time on the website, who visited a greater number of pages, and who visited the site more often, as captured by the composite measure of breadth of engagement, showed significantly greater gains in fruit and vegetable consumption from baseline to 12-month follow-up than did those who exhibited less engagement. This finding provides further empirical evidence that "dose matters" in Web-based interventions. [9]

Strengths and Limitations

Key strengths include the large number of participants and the racial/ethnically diverse sample of relatively healthy adults from 5 geographic regions, providing a large number for analyses by subgroup. The relatively high response rates for the follow-up surveys permitted analysis of baseline and process variables to understand change in eating behaviors. Paradata measures were collected with date and time stamps over the 12-month study duration, which permitted the creation of duration and frequency variables and quantified the time lapse between website visits.

Limitations include the requirement that participation eligibility include both access to the Internet and an active email account, so findings may not generalize to all Internet users. We also were limited in the detail of the paradata we collected, as we were limited in measuring interruptions or distraction time during a Web encounter. This may have influenced our ability to distinguish between "sessions" and "visits" and did not provide details on what participants did within website sessions. Further, the incentives paid for participation, which were equivalent across intervention arms, and the effort taken to retain participants, relying mainly on automated email and single mailed reminders, may limit generalizability to other online interventions regarding the levels of engagement.

This paper demonstrates the usefulness of paradata in providing insight into the process by which an online intervention may affect outcomes. Such data are useful in identifying the "active ingredients" in a tailored intervention, that is, what works and what does not. Paradata could also be used to improve the design of online health interventions and websites, whether tailored or not, by identifying such components as which features visitors use, what pages they visit and revisit, and how long they spend on various parts of the site. This information could be used, in combination with other methods such as debriefing questionnaires or usability tests, to identify areas for program improvement, either in content or in navigation. We used a limited set of paradata captured in this online intervention. It is relatively easy to embed richer measures in health websites to provide more insight into what users are doing when they visit such sites. As online interventions increase in utilization and extend accessibility to various populations, we urge the collection and reporting of analysis of expanded paradata measures to improve the design and effectiveness of online health interventions.

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Conflicts of Interest

None declared

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Abbreviations

CRN: Cancer Research Network
GEE: generalized estimating equations
HOBI: human online behavioral intervention
LR: likelihood ratio
MENU: Making Effective Nutritional Choices for Cancer Prevention study
NCI: National Cancer Institute
NON_SURVEY_MINS: total time excluding survey completion
OLS: ordinary least squares regression
PCA: principal components analysis
RCT: randomized controlled trial
SESS_TOT: total session accesses
SESS_UNIQ: unique session accesses
SF_TOT: total special features accesses
TSRQ: Treatment Self-Regulation Questionnaire

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Original Paper

The Potential of Web-based Interventions for Heart Disease Self-Management: A Mixed Methods Investigation

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Abstract

Background: Existing initiatives to support patient self-management of heart disease do not appear to be reaching patients most in need. Providing self-management programs over the Internet (web-based interventions) might help reduce health disparities by reaching a greater number of patients. However, it is unclear whether they can achieve this goal and whether their effectiveness might be limited by the digital divide.

Objective: To explore the effectiveness of a web-based intervention in decreasing inequalities in access to self-management support in patients with coronary heart disease (CHD).

Methods: Quantitative and qualitative methods were used to explore use made of a web-based intervention over a period of 9 months. Patients with CHD, with or without home Internet access or previous experience using the Internet, were recruited from primary care centers in diverse socioeconomic and ethnic areas of North London, UK. Patients without home Internet were supported in using the intervention at public Internet services.

Results: Only 10.6% of eligible patients chose to participate (N=168). Participants were predominantly Caucasian well-educated men, with greater proportions of male and younger CHD patients among participants than were registered at participating primary care practices. Most had been diagnosed with CHD a number of years prior to the study. Relatively few had been newly diagnosed or had experienced a cardiac event in the previous 5 years. Most had home Internet access and prior experience using the Internet. A greater use of the intervention was observed in older participants (for each 5-year age increase, OR 1.25 for no, low or high intervention use, 95% CI, 1.06-1.47) and in those that had home Internet access and prior Internet experience (OR 3.74, 95% CI, 1.52-9.22). Less use was observed in participants that had not recently experienced a cardiac event or diagnosis (≥ 5 years since cardiac event or diagnosis; OR 0.69, 95% CI, 0.50-0.95). Gender and level of education were not statistically related to level of use of the intervention. Data suggest that a recent cardiac event or diagnosis increased the need for information and advice in participants. However, participants that had been diagnosed several years ago showed little need for information and support.

The inconvenience of public Internet access was a barrier for participants without home Internet access. The use of the intervention by participants with little or no Internet experience was limited by a lack of confidence with computers and discomfort with asking for assistance. It was also influenced by the level of participant need for information and by their perception of the intervention.

Conclusions: The availability of a web-based intervention, with support for use at home or through public Internet services, did not result in a large number or all types of patients with CHD using the intervention for self-management support. The effectiveness of web-based interventions for patients with chronic diseases remains a significant challenge.

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KEYWORDS

Internet; Coronary disease; Heart diseases; Primary health care; Self care; Selective enrolment; Digital divide; Healthcare disparities

Introduction

Support for patient self-management is central to healthcare strategies for managing patients with chronic diseases [1,2]. For patients with heart disease, self-management education is usually provided as a component of a cardiac rehabilitation program [3] or through more generic chronic disease initiatives such as the Chronic Disease Self-Management Program (CDSMP) in the USA [4] and the Expert Patients Programme (EPP) in the UK [5]. However, low enrolment is a problem for these programs, and concerns have been raised over whether they are reaching those most in need [6,7]. For example, fewer than 30% of eligible patients enroll in cardiac rehabilitation programs [6] and initial evaluations of the EPP found that 75% of programs experienced recruitment difficulties [8] and enrolled predominantly highly educated participants [8-10]. The CDSMP and EPP programs have a predominance of Caucasian and female participants [8,10], whereas cardiac rehabilitation programs have a disproportionately high number of younger male participants [9].

Reducing healthcare disparities is a major health policy goal in many countries [11,12]. It has been suggested that delivering self-management interventions over the Internet (web-based interventions) may reduce disparities in access to these programs by overcoming many of the practical barriers that hinder attendance to programs that use a one-on-one approach [13,14]. Web-based interventions also have the potential to overcome educational barriers by presenting complex information in a more easily accessible manner, for example, through animations or video. Systematic review evidence suggests that web-based interventions can achieve health benefits in patients with chronic diseases [15], and qualitative research suggests that patients see the potential of web-based interventions for meeting their information and support needs [16].

However, while access to the Internet increases on a yearly basis; it is not equally accessible [17-22]. Although 70% of the general population in the UK had home Internet access in 2009 [17,19], access was much lower in less advantaged populations: 38% among those with the lowest annual income (< £12,500 per year, equivalent to US$ 20,000, €13,800), and 49% among those with only basic education [19]. Relatively low Internet use (41%) has also been found among people with health problems or disabilities [19], in older individuals (30% of those ≥65), and among women [17]. Similar disparities exist in the US [12,16], Canada, and other countries [17].

Despite the relative lack of access to the Internet amongst disadvantaged groups, individuals in these groups seem to make relatively high use of the Internet for their health information needs. Women, and individuals with chronic diseases in particular, use the Internet to obtain health information [23-25]. Those in poorer health and in lower income brackets are more likely to use health-focused online support groups [23]. Individuals with chronic diseases and those in older age groups use the Internet for social networking and for obtaining health information as much as those without health problems and those in younger age groups, respectively [24,25]. Increasing use of the Internet for obtaining health information has been observed in patients with heart disease [26].

As a result, there is uncertainty as to whether the lack of equity in Internet access (the digital divide) results in increased health disparities [27-28], or whether other factors such as enhanced comprehension and greater use by relevant groups can increase the equity in the use of web-based self-management programs.

To date, most evaluations of web-based interventions for patient self-management have been limited to patients that already have Internet access. Studies that attempted to be more inclusive provided computers and home Internet access to participants for the duration of their studies [29,30]. They showed increased benefits to participants and, as a result, provide further support for the potential value of these types of interventions in patients previously without Internet access. However, this approach is costly and unlikely feasible outside of a research setting.

An alternative approach is to encourage access to web-based interventions at public Internet facilities. This is possible in the UK due to government investment in the provision of free public Internet access, support, and training aimed specifically at overcoming the digital divide [31]. However, whether public Internet access facilitates the use of online self-management support by individuals with chronic diseases remains unclear.

The objective of this study was to explore the potential of a web-based intervention for reaching a large number of patients, including those in disadvantaged groups, by examining: (1) the participation level in a study evaluating a web-based intervention for coronary heart disease (CHD), and (2) the level of use of the intervention by the participants. The study aimed to be inclusive by recruiting participants from primary care centers that offer services to diverse ethnical and socioeconomic communities, and by providing support to patients that had no prior Internet experience or home Internet access.

Methods

Design

This prospective cohort study examined the level of use of a web-based intervention by primary care patients with CHD over a 9-month period. The study used both quantitative and qualitative methods. The methods were designed to complement each other by examining the topic from two perspectives: the statistical investigation of the level of use of the intervention and exploration of individual patient experiences of the intervention. Ethics and research governance approval were obtained from the Camden and Islington Local Research Ethics Committee and the appropriate primary care trusts.

Recruitment

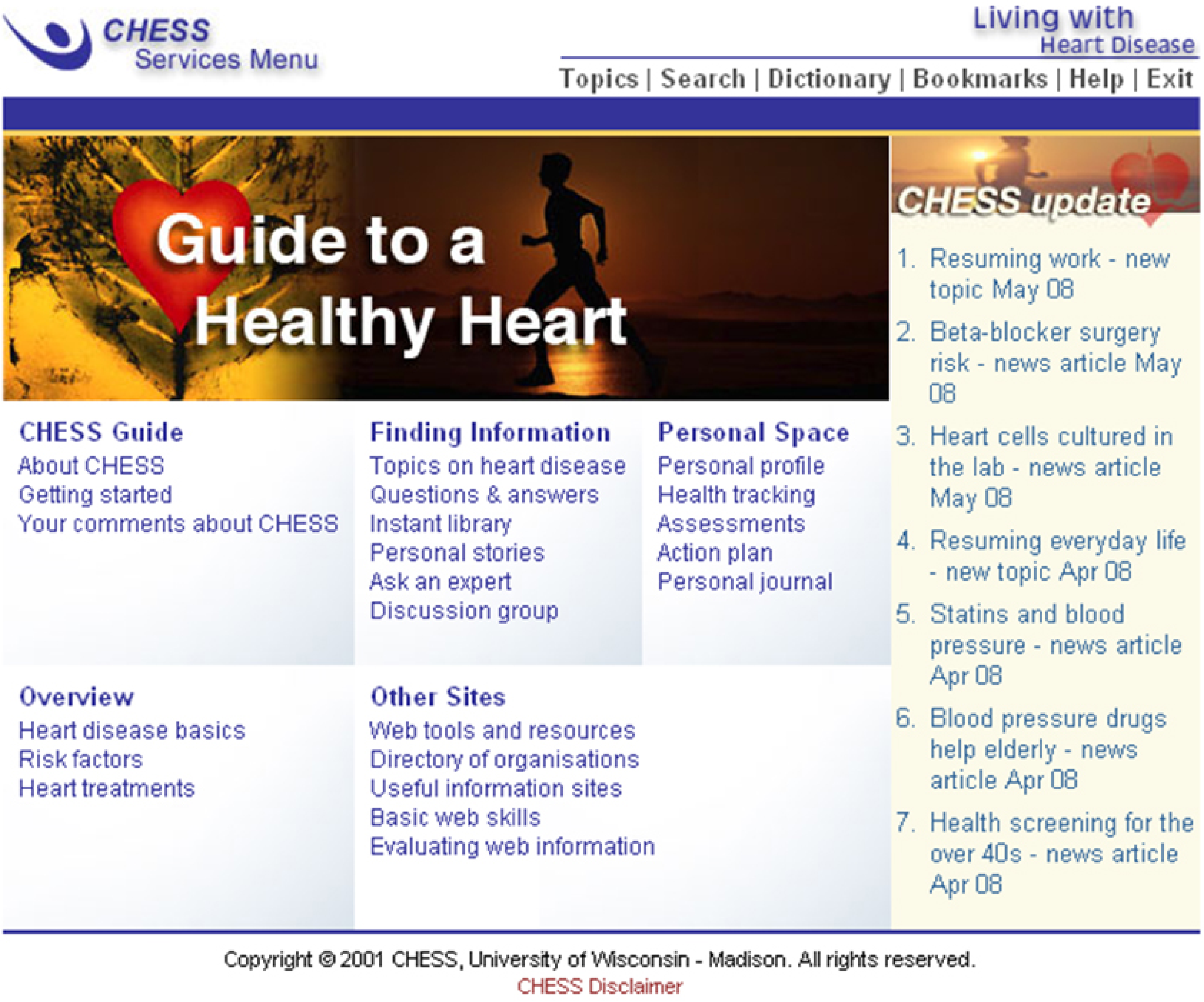
General practices in the UK maintain accurate and up-to-date registers of patients with long-term conditions, including CHD. One hundred sixty-eight (N=168) patients on the CHD registers of 10 primary care centers in North London, UK, were recruited for this study. The centers were selected based on the diversity of the communities they serve and the research interests of their general practitioners (GPs). All centers served populations that ranked in the most deprived quintile of the UK population, based on Townsend deprivation scores [32]. These scores are a summary measure of relative material deprivation within small populations based on 4 indicators from Census data: unemployment, overcrowding, lack of owner occupied accommodation, and lack of car ownership. Positive scores indicate a higher rate of material deprivation and negative scores represent the opposite [33]. Recruitment was as inclusive as possible and based on the following criteria. Inclusion criteria included patients with a diagnosis of CHD registered at a participating North London general practice, and patients who were willing to visit a local public Internet service or had Internet access at home. Exclusion from the study were: patients who were terminally ill (< 9-month life expectancy); patients unable to provide informed consent due to mental impairment; patients unable to speak English well enough to consult without an interpreter; and patients unable to use a computer due to visual, hearing, or motor impairment.

Physicians at the participating centers screened patients from the CHD register and excluded patients based on the exclusion criteria. Eligible CHD patients were sent a written invitation to participate in the study. Recruitment materials specified that participants with no previous computer or Internet experience and/or without home Internet access were welcome to participate. Housebound patients with home Internet access were included but those without were excluded.

Web-based Intervention

The Comprehensive Health Enhancement and Social Support (CHESS) Living with Heart Disease web-based intervention used in this study provided interactive information, behavior change support, and peer and expert support components. It was designed by the CHESS Team at the University of Wisconsin [34] and was further developed for this study [35]. Figure 1 shows a screenshot of the final intervention.

Figure 1. Screen shot of the home page (services menu) of the CHESS Living with Heart Disease web-based intervention used in this study.



CHESS
Services Menu

Living with
Heart Disease

Topics | Search | Dictionary | Bookmarks | Help | Exit

Guide to a Healthy Heart

CHESS Guide
About CHESS
Getting started
Your comments about CHESS

Finding Information
Topics on heart disease
Questions & answers
Instant library
Personal stories
Ask an expert
Discussion group

Personal Space
Personal profile
Health tracking
Assessments
Action plan
Personal journal

Overview
Heart disease basics
Risk factors
Heart treatments

Other Sites
Web tools and resources
Directory of organisations
Useful information sites
Basic web skills
Evaluating web information

CHESS update

1. Resuming work - new topic May 08
2. Beta-blocker surgery risk - news article May 08
3. Heart cells cultured in the lab - news article May 08
4. Resuming everyday life - new topic Apr 08
5. Statins and blood pressure - news article Apr 08
6. Blood pressure drugs help elderly - news article Apr 08
7. Health screening for the over 40s - news article Apr 08

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To help overcome the digital divide, participants received individual training in how to use the intervention and were provided information on local, free, or low-cost public Internet services and training courses. Training was tailored to each participant's level of Internet experience. Training of patients without home Internet access was conducted at a local public Internet service (eg, library, Internet café, community centre). This included a booklet for each participant to record login details, contact details for assistance, a summary of the intervention services, and details of local Internet services and courses. Participants were encouraged to contact the research team for further training when necessary and were offered further training if they had not used the intervention within a month of initial training.

Data Collection

Quantitative Data

Participants completed a questionnaire that provided demographic details, CHD history, and information about their Internet experience and accessibility to the Internet. Clinical information was cross-referenced with GP records for participants that consented (N=160, 95%). Consent to this aspect of the study was optional due to ethical requirements. Participants also completed standard validated questionnaires including illness perception [36], perceived social support [37], and emotional status [38]. The intervention was programmed to automatically record frequency of logins and pages viewed by the individual users. Based on this data, overall level of intervention use and use of different intervention components were calculated for each participant.

The 10 participating GP practices provided limited demographic summary data from their CHD registers that allowed a limited comparison between the study sample and the general CHD population. Data and reports from UK population surveys were used to evaluate the representativeness of the study sample, based on level of education and level of Internet access [17,19,39].

Participant Interviews

Individual semi-structured interviews, typically lasting 20 to 40 minutes, were conducted with a subsample of participants (n=19). Each participant was given the opportunity to volunteer for interview in a questionnaire completed at the end of the 9-month period of Internet access to the intervention. Participants with a range of demographic characteristics, prior Internet experience, and level of use of the intervention were selected for interview. Characteristics of the subsample of participants who were interviewed are shown in Table 1. Sampling continued until no new themes emerged from interviews.

Interviews consisted of general and follow-up questions that were developed following discussion with clinicians, a medical sociologist, and user representatives, with the intent of exploring each participant's perceptions, level of use of the intervention, and personal experience of the intervention. Discussion of factors influencing the use of the intervention was also initiated by more focused questions about whether participants had used the intervention as much as they expected to, when they were most likely to use it, and when had they found it useful or helpful.

Interviews were conducted in person by one researcher (CK) and recorded. Brief notes were made after each interview to record contextual information. Interviews were conducted in small batches of 3 to 4 at a time to allow an iterative process of data collection and analysis, as per good practice guidelines for qualitative analysis [40].

Analysis

Statistical

Data on level of intervention use were highly skewed. As a result, the total number of intervention web pages viewed by each participant was converted into three categories of use (no, low, and high). No included those that made zero page requests. Those that made at least one page request were assigned to low- and high-use categories by median split. Multivariable analyses was performed using a proportional odds model to examine predictors of level of intervention use. Analysis was performed using SPSS® software, version 15 (SPSS UK Ltd. Surrey, UK) [41].

To ensure sufficient power of analysis, the number of predictors selected for inclusion was limited to 10. Predictors were selected based on a priori observed correlation and statistical grounds. Age, gender, level of education, availability of home Internet access, and level of Internet experience were selected a priori because of their importance as factors in the digital divide. Availability of home Internet access and level of Internet experience were combined into one variable to avoid multicollinearity in the regression model. Clinical variables (eg, time since most recent cardiac event or diagnosis) and other predictors (perception of illness identity, depression, and perceived social support) were selected on the basis of sufficient variation in scores, correlation with intervention use, and relatively low correlation with other predictors.

Qualitative

Thematic analysis of interview transcripts was performed concurrently with data collection. This allowed for later interviews to define, extend, and clarify emerging themes. It also helped determine when no new themes were emerging and, as a result, additional interviews were no longer required.

Three members of the research team (CK, EM, FS) discussed the interview notes and transcripts before emerging themes were presented to a multidisciplinary project steering group for their feedback. Qualitative analysis was performed using Atlas.ti software, version 5 (Chicago, IL, USA) [42].

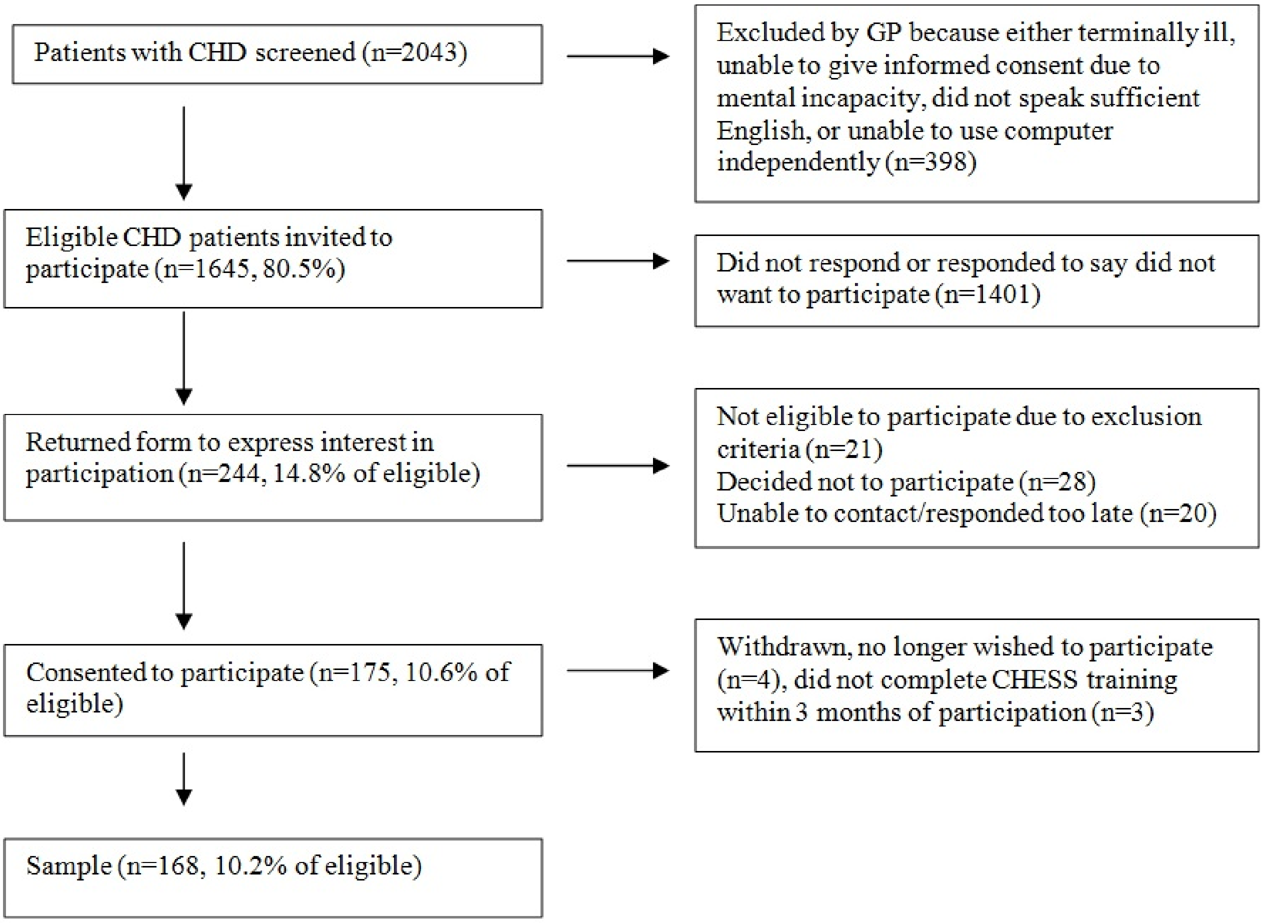
Results

Participants

Sample Recruitment

Although more than 80% of patients with CHD registered at participating centers were eligible (N=1645), only about 10% of them chose to participate (N=168), as observed in Figure 2.

Figure 2. Sample recruitment



Sample Characteristics

Patients with CHD that participated in the study were predominantly male, well educated, and Caucasian (Table 1). Close to 50% of participants had been diagnosed with CHD more than 10 years prior to the study, and very few had been diagnosed with CHD for the first time in the preceding 2 years. A greater proportion of participants had experienced a cardiac event (MI, surgical intervention, emergency hospitalization, or additional CHD diagnosis (eg, heart failure)) in the preceding 2 years. However, almost 40% of participants had not experienced a cardiac event or CHD diagnosis in the previous 5 years. Most participants had home Internet access (80%) and/or were experienced Internet users (60%) (Table 1).

Men were overrepresented in the sample, since more than 80% of participants were male compared to fewer than 65% of patients with CHD from the participating centers. The sample contained a wide spread of ages, with a mean age of 66.8 years (SD=10.1). Compared to the data for patients with CHD registered at the centers, study participants were relatively young and patients over 75 years-of-age were underrepresented (Figure 3).

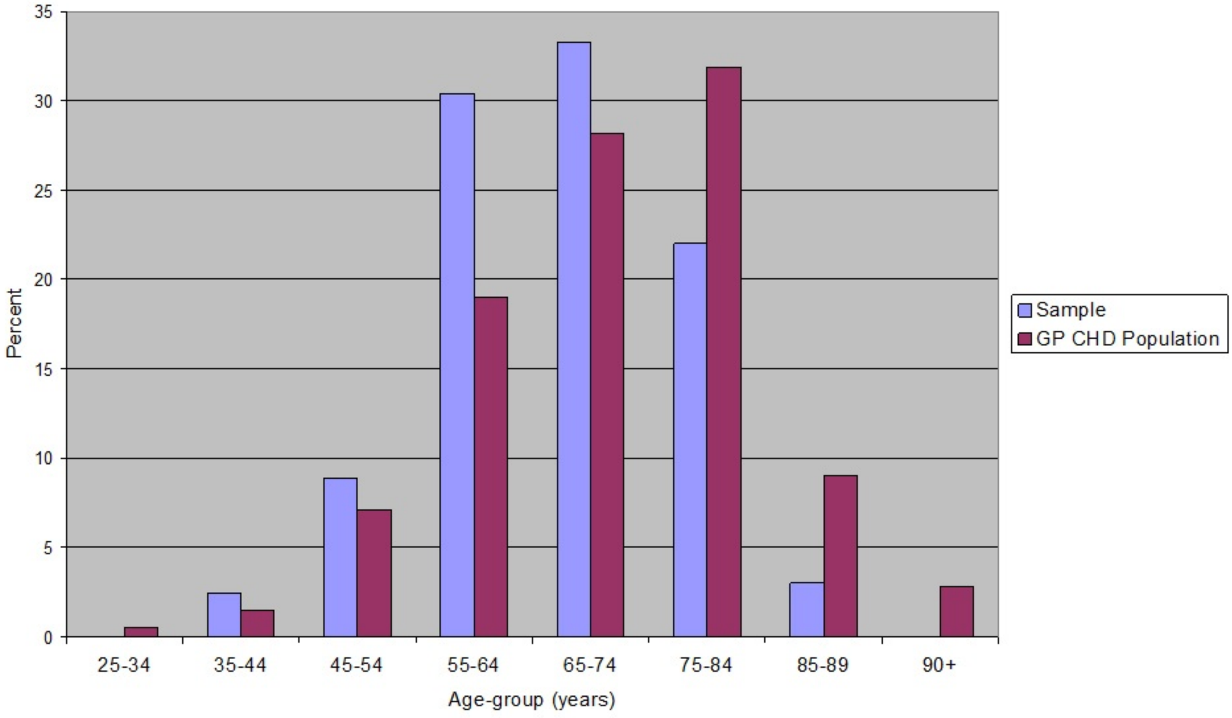
Compared to UK population surveys, the number of participants with advanced levels of education, home Internet access and experience using the Internet was high. In the 2005 Health Survey for England, fewer than 8% of respondents with heart attack or angina had an advanced level of education [39] compared to 45% of participants in this study. The proportion of participants (80%) in this study that had home Internet access and/or some prior experience with using the Internet was much higher than the 41% of patients with a disability or chronic health problem that reported Internet access or Internet use in a recent population survey [19]. The proportion was also much higher than that shown in adults over 65 years-of-age that reported having used the Internet (30%) [17].

Table 1. Sample characteristics

		Sample (N = 168)	Interview subsample (n = 19)
Age (years)	Mean (standard deviation)	66.8 (10.1)	71.0 (8.8)
	Range	38-87	53-82
Gender	Male	137 (81.5%)	13
	Female	31 (18.5%)	6
Employment	Employed (full or part-time)	31 (18.5%)	1
	Self-employed	34 (20.2%)	1
	Full-time care	6 (3.6%)	2
	Retired	80 (47.6%)	12
	Unemployed or not working for other reasons	16 (9.5%)	3
	Not disclosed	1 (0.6%)	0
Level of education	School leaver (no further/higher qualifications)	57 (33.9%)	9
	A levels or vocational equivalent	32 (19.0%)	4
	Degree or equivalent	76 (45.2%)	6
	Not disclosed	3 (1.8%)	0
Ethnic group	White (British, Irish, other)	141 (83.9%)	14
	Black (British Caribbean, African, other)	9 (5.4%)	2
	Asian (British Indian, Pakistani, Bangladeshi, other)	14 (8.3%)	3
	Other (Chinese, other)	4 (2.4%)	0
Heart disease	Angina only	57 (33.9%)	9
	MI only	38 (22.6%)	4
	Both	46 (27.4%)	4
	Other CHD (diagnosed without angina or MI)	27 (16.1%)	2
Comorbidities	Cardiovascular comorbidity only (including diabetes, stroke)	26 (15.5%)	2
	Non-cardiovascular comorbidity only (eg, arthritis)	49 (29.1%)	3
	Both cardiovascular and other comorbidities	42 (25.0%)	8
	No comorbidity	51 (30.4%)	6
Time since earliest CHD diagnosis (years)	Mean (standard deviation)	10.6 (7.3)	9.8 (6.5)
	Range	0-35	1–22
	Diagnosed in the last year	2 (1.2%)	0
	Diagnosed 1-2 years ago	22 (13.1%)	4
	Diagnosed 3-5 years ago	28 (16.7%)	2
	Diagnosed 6-10 years ago	37 (22.0%)	3
	Diagnosed >10 years ago	77 (45.8%)	9
	Earliest CHD diagnosis given as rheumatic fever in childhood	2 (1.2%)	1

		Sample (N = 168)	Interview subsample (n = 19)
Time since most recent cardiac event (years)	Range	0-21	0–15
	Mean (standard deviation)	5.4 (4.9)	3.7 (3.6)
	Cardiac event in the last year	21 (12.5%)	1
	Most recent cardiac event 1-2 years ago	44 (26.2%)	8
	Most recent cardiac event 3-5 years ago	42 (25.0%)	7
	Most recent cardiac event 6-10 years ago	32 (19.0%)	2
	Most recent cardiac event >10 years ago	29 (17.3%)	1
Home Internet access	No	34 (20.2%)	6
	Yes	134 (79.8%)	13
Level of Internet experience	None	35 (20.8%)	6
	Basic (used a few times but not often)	32 (19.1%)	5
	Experienced or expert (regular Internet use)	101 (60.1%)	8

Figure 3. Age distributions of sample and CHD patients registered at participating practices.



Use of the Intervention

The intervention was used at least once by 77% (129/168) of the participants. However, participants varied greatly as to the frequency of using the intervention during the 9-month period (logins: range, 0-149; 10th-90th percentile, 9-23).

Median use over 9 months among participants that made at least some use of the intervention was 4 logins or viewing 148 pages of the intervention. Table 2 shows the characteristics of participants categorized as making no, low- and high-use of the intervention over 9 months (viewing 0 pages, ≤148, or >148 pages, respectively).

Table 2. Characteristics of participants by level of intervention use

Participant characteristics N = 168		Level of overall intervention use		
		No use: zero intervention web-pages viewed (n = 39)	Low use: ≤148 intervention web-pages viewed (n = 66)	High use: >148 intervention web-pages viewed (n = 63)
Age (years)	Mean (SD)	66.3 (9.6)	65.0 (9.7)	69 (10.6)
Gender	Male (n=137)	31 (23%)	55 (40%)	51 (37%)
	Female (n=31)	8 (26%)	11 (36%)	112 (38%)
Level of education[a]	School drop-out (n=57)	11 (19%)	22 (39%)	24 (42%)
	A levels or equivalent (n=32)	5 (16%)	16 (50%)	11 (34%)
	Degree or equivalent (n=76)	22 (29%)	27 (35.5%)	27 (35.5%)
Time since most recent cardiac event or diagnosis (years)	Mean (SD)	5.6 (4.6)	6.3 (4.9)	4.2 (5.0)
Level of Internet experience and home access	Basic or no experience, without home access (n=31)	11 (35.5%)	11 (35.5%)	9 (29%)
	Basic or no experience with home access (n=36)	6 (17%)	17 (47%)	13 (36%)
	Experienced or expert, most with home access (n=101)	22 (21%)	38 (38%)	41 (41%)

[a] n=3, level of education not disclosed

Factors Influencing Use of the Intervention

Proportional odds regression analyses of all complete cases of data (N=161) found that participants that were older, had more recently experienced a cardiac event or diagnosis, had home Internet access and experience using the Internet, were more likely to make some or high use of the intervention (Table 3). Gender and level of education did not predict levels of overall intervention use. Qualitative analysis confirmed the importance of several significant predictors of intervention use. Content and illustrative quotes from these themes suggest how these factors influenced intervention use and are presented below.

Table 3. Results of ordinal regression analyses predicting overall level of intervention use (no use, low use or high use)

Baseline predictors	Multivariable analysis	
	Odds ratio (95% confidence interval)	*P*-value
Age	1.25[a] (1.06-1.47)	.01
Time since most recent cardiac event or diagnosis	0.69[a] (0.50-0.95)	.03
Internet experience and availability of home access		
Basic or no experience, without home access	1.00 Reference category	.01
Basic or no experience, with home access	2.85 (1.02-7.93)	
Experienced or expert, most with home access	3.74 (1.52-9.22)	
Perception of illness identity (symptoms experienced)	1.13 (0.99-1.29)	.07
Depression	1.06 (0.94-1.19)	.31
Level of education		
School leaver	1.00 Reference category	.10
A levels	1.40 (0.55-3.56)	
Degree	0.61 (0.29-1.28)	
Gender		
Female	1.00 Reference category	.36
Male	1.44 (0.66-3.15)	
Perceived social support (information and emotional)	0.85 (0.62-1.18)	.33
Model Fit (compared to intercept only)	.002	

[a] Odds ratio calculated for 5-year increase

Time Since Most Recent Cardiac Event or Diagnosis

The length of time since receiving a diagnosis of CHD or experiencing a cardiac event was related to participant level of need for CHD information, advice, or support. Many participants believed that they were well informed about heart disease, and this seems to have reduced their need for further assistance.

> *P0101: "I felt that I'd gone well past that stage because I've had my heart problem for 17 years. And as I said before, before CHESS came along I was already reasonably informed about most of the problems that would help me in my problem, how to deal with it.* [82-year-old male, experienced Internet user]

They also had few questions or concerns about their disease, because they were not currently experiencing problems and generally reported feeling well and able to carry on their normal lives.

> *P0110: "I'm glad that you are doing this because it possibly could have helped me but I suppose I'm fortunate that I haven't got a problem and therefore I didn't need any."* [79-year-old male, basic Internet experience]

Participants experiencing recent heart disease complications reported use of the web-based intervention program to obtain new information and advice.

> *P0112: "one serious problem and one piece of information I needed to know came up as a result of my heart problems and I just, at that time, could not find the answer and CHESS… gave me the answer…it's been very useful to tell me what was going on after my situation changed"* [64-year-old male, experienced Internet user]

Home Internet Access

The convenience of using the web-based intervention at home was particularly appreciated.

> *P0121: "Well yes I could go up and have a look at it, you see, it was great, great just to press a couple of buttons and you're there… I could go upstairs any time and look to see if I could find the answer up there."* [79-year-old female, experienced Internet user]

With a couple of notable exceptions, those without home Internet access reported that lack of home Internet availability was a barrier to intervention use.

> *P0320: "… just the effort of getting out, going to the library and doing it, I know I would have done better with one [at home] because often I felt like doing that sort of in the evening… I didn't like the forward planning, I'd have liked of just sort of get out the old computer, put it down and do it when I felt like it"* [81-year-old female, no previous Internet experience]

Two participants that did make high use of the intervention at local public Internet services reported having unlimited and free access to the Internet, and in one case, extensive technical support from staff. They reported added benefits to accessing the intervention away from home, such as getting uninterrupted time away from a busy home environment or because of the physical activity required to leave the house.

Prior Internet Experience

Generally, lack of confidence using computers hampered use of the intervention by many participants with little or no Internet experience. Participants with little Internet experience were likely to forget how to use the intervention and felt uncomfortable asking for help.

> *P0110: "I didn't think I would use it a lot because… I get frustrated if the machine doesn't immediately do what I want it to do and then I have to call my wife in and we have to sit there together."* [79-year-old male, basic Internet experience]

Participants were aware that family members and library or research staff could provide assistance, but felt embarrassed to reveal their lack of computer skills or that they had forgotten previous instructions.

> *P0308: "You did volunteer to help me and I was embarrassed"* [53-year-old male, no previous Internet experience]
>
> *P0320: "they were very helpful in the library I might say, but it was a little bit embarrassing admitting to your inadequacies"* [81-year-old female, no previous Internet experience]

Qualitative analysis also identified themes related to participant use of the intervention that add to, rather than explain the quantitative results. These included other themes related to participant need for information and support and their perceptions of the intervention.

The participants' perceived need for help with CHD was related to more than the length of time since their diagnosis of CHD or cardiac event. Their perceived need was also related to their perceptions of CHD, to the inadequacy of existing sources of information and support, and to competing priorities. There was a strong connection between participants' perceived need for help with CHD and their use of the web-based intervention.

Participant Levels of Need and Perceptions of their CHD

Many felt their CHD was not as severe as in other patients. This view was often based on whether or not they had experienced a heart attack.

> *P0110: "Well very fortunately none of the problems that other people have with heart problems. I haven't, I didn't have a heart attack, I had a bypass."* [79-year-old male, basic Internet experience]

Others judged the severity of their condition by whether they were currently experiencing any symptoms of CHD.

> *P0802: "… symptoms wise I do not have any heart problem… I had [a] heart attack… and so there's obviously, its effect is there within me in some way, but it does not affect my daily life and I do not have any pain"* [79-year-old male, experienced Internet user]

In addition, symptoms were often not perceived as problematic because they quickly resolved or were attributed to other causes (eg, other health condition, the weather, age).

Levels of Need and Adequacy of Existing Sources of Information and Support

Views on this differed greatly between participants and focused on the level of access to health professionals with sufficient time and expertise. Several participants felt they had good access to trusted health professionals and had no need to seek additional information.

> *P0608: "I'm not shy in coming forward… I ask him you know … always go to the specialist and that's it. If I don't get the right answer I go and ask another one…* [66-year-old male, experienced Internet user]

Others had no desire to question the advice they received from health professionals.

> *P0110: "… why sort of double check something that somebody tells you… whom you trust… if your website or your answers would have been the same as ours well that confirms it, but I didn't feel I was in need of confirmation."* [79-year-old male, basic Internet experience]

However, some participants felt that their health professionals had insufficient time to address their queries and concerns. For them, the intervention played an important role in dealing with this issue.

> *P0101: "… the cardiologist and GP, I only get very limited information from them. Mainly from the cardiologist but the amount of information he can give me in the time that he can devote to me is very limited and just… highlights points… which often I want to know more about"* [82-year-old male, experienced Internet user]

Levels of Need and Competing Priorities

Intervention use was greatly affected by events in other areas of the participants' lives. Those that felt little need for heart disease information and support were often busy with other priorities and had little time to use the intervention.

> *P0110: "My wife and I fortunately lead a very busy life and we travel quite a lot still and so there's rarely a time when I sort of sit at my desk and say now what can I do …when I prioritize things I have to do, there isn't a great deal of time left…"* [79-year-old male, basic Internet experience]

For others, concurrent health problems were more of a concern than their heart disease, so those took priority. This was particularly true when participants experienced frequent symptoms from concurrent conditions or when those conditions required daily management.

Perceptions of the Intervention

Perceptions of the intervention varied greatly between participants. In general, participants that held positive views of the intervention used it, although some with a low need for information and support or low confidence in using computers, made little use of the intervention, despite viewing it positively. Perceptions were based on comparisons with other sources of information, advice, and support. In general, the intervention was favorably compared to other websites because it provided quicker access to relevant information.

> *P0101: "It was a quick source for the information whereas previously I had to go over other websites or publications to get the information. This helped to centralize that I can go to the CHESS site, it would lead me to other links."* [82-year-old male, experienced Internet user]

The intervention was also perceived as more relevant than newspapers because it provided more information and was easier to understand.

> *P0121: "…it was giving me information that I wouldn't have had otherwise… you wouldn't read those sort of things in the paper… probably the information wouldn't be there… you get maybe a page of it in the paper, but just little bits…"* [79-year-old female, experienced Internet user]

However, newspapers and books were preferred by participants that only wanted brief information or that had little confidence in using computers.

> *P0320: "I suppose I just didn't get the facility in using a computer that I would have liked, the way I could using books… which I'm very familiar with of course.*
>
> *R: So by comparison it was*
>
> *P0320: It was hard work…"* [81-year-old female, no previous Internet experience]

Some participants preferred the intervention to contact with health professionals because it was easier to access and without time constraints.

> *P0121: "… it's very difficult because if I want to ask my doctor a question… I have to go through the receptionist …and I might not speak to my own doctor, so the doctor I speak to doesn't really know me, and I think that's very off-putting. Whereas if I can go get what I want from upstairs with no problem at all… just switching the computer on, then that's great… I'd much rather do that"* [79-year-old female, no previous Internet experience]

However, participants were most critical of the intervention when they compared it to seeking or receiving information and support during a one-on-one discussion. As a result, the intervention was perceived as more difficult, less personal, and less effective as a means of communication.

> *P0906: "I would rather go out and meet somebody and talk to them like this because I think… you can't convey a lot of that over a forum"* [72-year-old male, no previous Internet experience]

Discussion

Main Results

Despite an inclusive design, only a small proportion of eligible patients with CHD participated in the study (N=168, 10.6%). There was a greater proportion of participants that were younger and male compared to the general CHD population. Participants were predominantly Caucasian and had a higher level of education. Most had been previously diagnosed with CHD a number of years ago with no recent cardiac event or CHD complication. Most had home Internet access and prior Internet experience.

Statistical and qualitative analyses showed that time since the most recent CHD diagnosis or cardiac event, access to home Internet, and prior Internet experience were important factors in whether participants used the intervention. Qualitative data provided explanations for how and why these factors influenced use or lack of use of the intervention. A recent cardiac event or complication seemed to increase use of the intervention, due to an increased need of the participant for information and advice on CHD. However, this finding has to be interpreted within the context of few patients with a recent cardiac event or recently diagnosed with CHD choosing to participate in the study. Participants with no history of a recent cardiac event or complication reported little need for self-management support.

Other qualitative findings placed the effect of time since diagnosis with participant perceptions of their heart disease, the adequacy of existing sources of support, and competing priorities in determining need for self-management support and intervention use.

The convenience of accessing the intervention at home encouraged use, whereas lack of home Internet access was a barrier to intervention use. Participants with little or no Internet experience showed a lack of confidence in using computers in general and felt uncomfortable seeking help, even when it was available. Interview data also suggest that participant perception of the intervention, specifically when compared to other sources of information, advice, and support, interacted with their level of need and confidence with computers to influence their use of the intervention. Gender and level of education did not significantly predict level of intervention use. Older participants made greater use of the intervention compared to younger participants.

Comparisons to Previous Studies

A low rate of participation and a high proportion of Caucasian well-educated patients mirror the problems found in generic self-management programs [7,8,10]. Contrary to these programs and patterns of internet use for health information [23,25], participants in this study were predominantly male. However, this has been shown to be common in secondary prevention interventions for CHD [6,9]. Gender bias in participation rates could be the result of the low appeal of the intervention or increased barriers to participation among women, rather than the high appeal of the intervention to men. Overall, these results suggest that the study was not successful in reaching individuals most in need. Moreover, participant clinical features and qualitative data suggest that participants' CHD was relatively unproblematic.

Key factors in the digital divide (gender, age, and education) did not appear to affect participant level of use of the intervention. In fact, it was observed that older participants were more likely to make use of the intervention. This is a counterintuitive finding and should be interpreted with caution, since older participants were not well represented in the sample. Sample characteristics suggest that the older participants in this study might not be representative of older CHD patients in general. Qualitative findings did not provide a clear explanation for the effect of age on intervention use, although increased free time among retired participants might be a factor. In general, these findings support those of similar studies on the use of the Internet for obtaining health information [43,44], and suggest that, when participants are provided Internet access, disparities associated with the digital divide are likely to disappear.

However, ease of access to public Internet services did not encourage many of the CHD patients without home Internet access to participate in the study. Moreover, lack of home Internet access and prior Internet experience were significant predictors of lower use of the intervention. This appeared to be due to the inconvenience of public Internet access, lack of confidence with computers, and discomfort in asking for assistance. This suggests that factors other than ease of access or availability of public Internet services are required to overcome the digital divide. Barriers and aids to Internet use, beyond issues of access, have been explored in a recent small-scale study [45]. Investigators provided computer novices from low socioeconomic groups with free home computer systems, broadband Internet access, monthly computer training courses, and technical support for a year. Regular training and technical support, in addition to social support from other participants, facilitated general computer and Internet use beyond the availability of home Internet access [45]. However, the feasibility of such an approach on a larger scale outside the research setting remains an issue.

Strengths and Limitations

The strengths of this study are its inclusive and mixed methods design. The study design included recruitment of participants from diverse socioeconomic and ethnic backgrounds that were offered a self-management intervention made available to them through public and home Internet access. Mixed quantitative and qualitative methods enabled the authors to both quantify and explain the factors influencing the use of the intervention. Another strength of the study was the web-based intervention used: it was designed by the experienced CHESS team and further developed to meet the particular needs of UK patients.

However, one limitation to the study was a lack of information about the large number of patients that were eligible to participate but chose not to. Access to this information was restricted for ethical reasons, based on their lack of consent. Comparison of participant data with general data from CHD registers and UK population surveys provides certain general conclusions about those that chose not to participate. However, the specific reasons behind their decision not to participate are unknown. Recruitment following a single written invitation to participate was ethically appropriate but might have played a role in the limited number of participants. The recruitment strategy might have been more successful in enrolling patients without home Internet or prior experience through the use of a more personal approach. Conclusions about the relationship between age, gender, level of education, date of recent cardiac event, CHD diagnosis or complication, and use of the intervention are limited by the lack of representation of these characteristics in the study sample.

Conclusions

Despite an inclusive recruitment strategy, participants in this study seemed to have a higher level of education, better access to and experience of the Internet, and might have had fewer problems with their condition compared to that observed in the general CHD population. Predictors of use of the intervention by those who participated underlined participants' relatively low need for information, advice, and support; the availability of home Internet access; and the level of experience using the Internet. This study suggests that availability of public Internet access is unlikely to be sufficient to help individuals overcome the digital divide. Equitable access to Internet services remains a significant challenge that could limit the potential of web-based interventions for overcoming health disparities through the use of self-management programs by chronically ill patients.

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Conflicts of Interest

None declared

Authors' Contributions

CK contributed to the study design, intervention development and maintenance, collected all data, led on analysing and interpreting the data and drafted the manuscript. EM contributed to the study design, intervention development and maintenance, analysing and interpreting the data, and helped to draft the manuscript. LN and RM contributed to the study design, analysing and interpreting the data, and helped to draft the manuscript. CB and FS contributed to analysing and interpreting the data and helped to draft the manuscript. DP contributed to the study design, intervention development and maintenance, helped to interpret the data and draft the manuscript. RP contributed to intervention maintenance, helped to interpret the data and draft the manuscript. IT provided user input into intervention development, helped to interpret the data and draft the manuscript. KJ provided user input to interpret the data and helped draft the manuscript. IN contributed to the study design, helped to interpret the data and draft the manuscript. All authors read and approved the final manuscript.

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Original Paper

Evaluation of a Web-based Intervention Providing Tailored Advice for Self-management of Minor Respiratory Symptoms: Exploratory Randomized Controlled Trial

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Abstract

Background: There has been relatively little research on the role of web-based support for self-care in the management of minor, acute symptoms, in contrast to the wealth of recent research into Internet interventions to support self-management of long-term conditions.

Objective: This study was designed as an evaluation of the usage and effects of the “Internet Doctor” website providing tailored advice on self-management of minor respiratory symptoms (eg, cough, sore throat, fever, runny nose), in preparation for a definitive trial of clinical effectiveness. The first aim was to evaluate the effects of using the Internet Doctor webpages on patient enablement and use of health services, to test whether the tailored, theory-based advice provided by the Internet Doctor was superior to providing a static webpage providing the best existing patient information (the control condition). The second aim was to gain an understanding of the processes that might mediate any change in intentions to consult the doctor, by comparing changes in relevant beliefs and illness perceptions in the intervention and control groups, and by analyzing usage of the Internet Doctor webpages and predictors of intention change.

Methods: Participants (N = 714) completed baseline measures of beliefs about their symptoms and self-care online, and were then automatically randomized to the Internet Doctor or control group. These measures were completed again by 332 participants after 48 hours. Four weeks later, 214 participants completed measures of enablement and health service use.

Results: The Internet Doctor resulted in higher levels of satisfaction than the control information (mean 6.58 and 5.86, respectively; $P = .002$) and resulted in higher levels of enablement a month later (median 3 and 2, respectively; $P = .03$). Understanding of illness improved in the 48 hours following use of the Internet Doctor webpages, whereas it did not improve in the control group (mean change from baseline 0.21 and -0.06, respectively, $P = .05$). Decline in intentions to consult the doctor between baseline and follow-up was predicted by age (beta = .10, $P= .003$), believing before accessing the website that consultation was necessary for recovery (beta = .19, $P < .001$), poor understanding of illness (beta = .11, $P = .004$), emotional reactions to illness (beta = .15, $P <.001$), and use of the Diagnostic section of the Internet Doctor website (beta = .09, $P = .007$).

Conclusions: Our findings provide initial evidence that tailored web-based advice could help patients self-manage minor symptoms to a greater extent. These findings constitute a sound foundation and rationale for future research. In particular, our study provides the evidence required to justify carrying out much larger trials in representative population samples comparing tailored web-based advice with routine care, to obtain a definitive evaluation of the impact on self-management and health service use.

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KEYWORDS

Internet; self-care; consumer health information; communication; common cold; influenza

Introduction

There has been relatively little research on the role that web-based support for self-management might play in the management of minor, acute symptoms, in contrast to the wealth of recent research into Internet interventions to support self-management of long-term conditions. It is well known that patients already self-care for the vast majority of minor symptoms, making their own decisions about whether and how to manage symptoms themselves (eg, using over-the-counter remedies) or whether to seek medical advice [1]. Nevertheless, over half the population in the United Kingdom consult their doctor each year for a minor symptom, and acute respiratory symptoms (eg, cough, sore throat) are the most common cause of consultation [2,3]. Only a tiny minority of the general public use the Internet for routine health care activities such as contacting their own doctor [4].

There are compelling reasons for finding ways to use the Internet to support patients to self-manage minor symptoms. Most people say that they would find it convenient and empowering to be given enough information to be able to self-manage without seeing their doctor [5-7]. Policy makers and clinicians are concerned that unnecessary consultations are an inefficient use of scarce health care resources [8,9]. However, there are also significant barriers to using the Internet for self-care. Both patients and doctors are concerned about the quality of information provided, and whether patients have the necessary skills and confidence to evaluate and manage their symptoms [3,10-12].

Prior to the advent of mass Internet access, patient education about self-management of minor symptoms was attempted by means of booklets and other media with some degree of success [13-16], although effects on consultation rates were typically very modest. A plausible advantage of using the Internet as a means of providing advice about self-management is that it can be tailored to symptoms, and should therefore be, and be perceived as, more personally relevant and hence accurate [17]. Qualitative evaluations of websites that provide tailored information for self-diagnosis and self-management of symptoms [18,19] suggest that they are seen as a useful complement to medical advice, but that it can be difficult to provide patients with advice that is sufficiently personalized, accessible, and detailed to replace consultation. However, the assumption that tailoring advice to the individual's symptoms will improve patient satisfaction and outcomes has not yet been experimentally tested in the context of web-based advice for self-management of common symptoms.

Previous studies of providing information on self-management of symptoms have been largely pragmatic, focusing simply on whether providing educational materials leads to better outcomes than routine care. For example, an observational study of providing a student population with online digital triage advice on whether they needed to seek medical care for minor symptoms was able to demonstrate satisfactory uptake and excellent concordance between the online advice and clinical diagnoses [20]. However, if Internet-delivered care is to become a widely accepted and well-integrated part of efficient routine health care, then we need to understand better how and why it might be welcomed and used effectively [14]. Theory-based psychological explanations of how people decide whether they can self-manage symptoms may help us to understand how interventions can be designed to better support self-care.

According to the Social Cognitive Theory, performance of any behavior is typically predicted by confidence that one can carry out the behavior successfully (self-efficacy) and beliefs about the likely consequences ("outcome expectancies") [21-23]. Thus, advice on how to self-manage symptoms and evidence that the advice has worked for others should improve confidence in the ability to self-care, while reassurance that symptoms are not indicative of serious illness requiring medical care should reduce beliefs that consultation is necessary for recovery. In addition, the Common Sense Model of Self-regulation of health and illness [24] highlights perceptions of illness that are likely to affect self-management of symptoms, such as whether the symptoms cause emotional reactions or are not well understood [25]; providing information about these aspects of symptoms may provide reassurance and reduce the need to consult the doctor. Finally, the Theory of Planned Behavior [26] proposes that the effects of beliefs on behavior are mediated by conscious intentions. A small observational study confirmed that intention to comply with the advice provided by a web-based system providing tailored advice for common symptoms was a strong predictor of reported compliance with the advice 3 months later [27].

This study forms part of a program of research into how theory and evidence can be used to design an intervention that will help patients to self-manage minor respiratory symptoms without seeking medical help. In accordance with best practice in the development of complex interventions [28], it was designed as an exploratory or phase 2 randomized controlled trial (RCT) that would provide an initial evaluation of the usage and effects of the "Internet Doctor" website. The first aim of the study was to evaluate the effects of using the Internet Doctor webpages on the target outcomes for the main trial, namely patient "enablement" [29] (ie, perceived ability to self-manage health and illness) and use of health services (ie, contacting the doctor or other health care services). The control condition was a webpage consisting of advice previously shown to be effective in reducing consultations and improving patient confidence to self-care [9]. This design provides a direct test of whether tailored, theory-based advice is more effective than the best existing information and advice. The second aim was to gain an understanding of the processes that might mediate any change in intentions to consult the doctor, by comparing changes in consultation intentions and in relevant beliefs and illness perceptions in the intervention and control groups, and levels of satisfaction with the website advice. The third aim was to examine whether outcomes were predicted, as expected, by beliefs about self-care and illness perceptions, and use of our theory-based advice. This was addressed by analyzing usage of the Internet Doctor webpages and predictors of change in consultation intentions.

Methods

Design and Procedure

This study was designed as an exploratory or phase-2 RCT [28] in preparation for a definitive trial of clinical effectiveness. As such, it has some but not all the characteristics required for a definitive trial. Participants were automatically assigned to the intervention and control groups and were blind to group assignment. However, the trial was not registered, and no sample size calculation was possible or necessary, since an aim of the study was to provide data from which required sample size for a definitive trial could be calculated and the study was not powered as a definitive test of intervention effects. Moreover, our participants were online volunteers with unknown characteristics who could not be followed up rigorously, which precluded meaningful intention-to-treat analysis, whereas a definitive trial would require a clinical sample with known baseline characteristics that could be followed up comprehensively and objectively through their medical records.

The study was approved by the ethics committee of the School of Psychology, University of Southampton. Participants were recruited between October 2009 and March 2010 (the UK winter respiratory infection season) by advertisements providing the website uniform resource locator for the intervention and inviting adults with cold or flu symptoms to try out the website. We specifically targeted university students, as our own qualitative research [30] had suggested that young people with little experience of self-managing minor symptoms on their own were more likely to need and benefit from advice. Advertisements were sent by email to students in 55 university departments in the United Kingdom, distributed as posters and flyers around three university campuses, and placed on websites and at other public locations. Participants who logged onto the website first gave informed consent online (to give their views on one of two versions of self-management advice) and completed the baseline questionnaire. They were then automatically randomized to the intervention (Internet Doctor) or control group by the web-based software, but were not informed which group they were in. The control group was provided with precisely the same advice as that given in the previous successful trial of booklet-based self-care information [9], delivered as a static webpage. The intervention webpages are described below.

Participants were sent an automatic email invitation to complete the intermediate follow-up 48 hours after accessing the intervention, and an invitation to complete the final follow-up after 4 weeks. An incentive (being entered into a prize draw for £100) was offered for completion of the follow-up measures, and nonrespondents received up to two additional reminders to complete the follow-up.

The Internet Doctor Intervention

The intervention was a fully automated digital triage system that provided tailored computer-generated advice. Participants were presented with a homepage (Figure 1) explaining what the site offered, with links to details about the medical expert on the team (PL) and the medical evidence the advice was based on. From this homepage participants could choose to access Diagnostic pages, Treatment pages providing self-management information, or Common Questions (see Multimedia Appendix 1 for illustrative screenshots of all of these sections).

Figure 1. Homepage of the Internet Doctor website

http://www.internetdr.org.uk?thiz=pc2

Your Personal Internet Doctor For:

Flu-related symptoms and infections (including swine flu)

You can also consult the Internet Doctor for:

- Cough, chest infections
- Sore throat, tonsillitis
- Runny/stuffy nose, sinusitis
- Fever, feeling achy and unwell

Professor Paul Little, a GP who is an international expert on caring for these infections has led the team who prepared the advice on this website.

You can check your own symptoms or someone else's symptoms and get free personal advice by viewing these sections:

Find out if your symptoms are serious and get personalised symptom advice

Find out how to make yourself feel better

Get answers to common questions about colds and flu

Welcome Video:

Meet the team behind the Internet Doctor

Study information

Our aim is to give you all the information you could get from seeing your doctor, but with the added advantage that:

- You don't have to travel to the surgery and sit there waiting for your appointment with other unwell people!
- You can consult the Internet Doctor whenever you like

The Diagnostic pages first asked a series of questions about the participant's symptoms; participants completed these pages for one symptom at a time, and could choose from cough, sore throat, fever, and runny/stuffy nose. Then a complex algorithm provided appropriate tailored advice on whether they needed to contact health services for that symptom (see Table 1). There were options to click on the answers to further questions about their symptoms and possible diagnoses. Participants who selected the Treatment pages could then choose between information about natural remedies or over-the-counter medication for symptoms, and advice on how to boost their immune system. The Common Questions section addressed common concerns and misconceptions about symptoms and treatment.

Table 1. Varieties of advice provided by the Internet Doctor[a]

Advice type	Symptom reports prompting this advice
Contact NHS Direct[b] immediately and then your doctor (gives list of symptoms reported that led to this advice)	Symptoms indicating a serious, acute condition (eg, meningitis or septicemia)
You should contact NHS Direct (gives list of symptoms reported that led to this advice)	Symptoms lasting and/or moderately severe (eg, fever ≥38.5^{o} for ≥3 days, cough for ≥4 weeks, breathing getting worse) OR less severe symptoms together with other risk factors (eg, older age, chronic conditions, immune system suppression)
Your symptoms are not a sign of serious illness and you do not need to contact the doctor at present (gives reassuring explanation of symptoms and advises to reconsult website if symptoms persist or worsen)	Symptoms acute and not severe or worsening

[a] Screenshots illustrating each advice type are given in Multimedia Appendix 1.

[b] NHS Direct is a national telecare triage system providing 24-hour telephone support. We advised contacting NHS Direct in the first instance, as this service offers instant personal triage regarding appropriate next steps (eg, call ambulance, see doctor next day, etc).

The intervention was created by the research team using the LifeGuide software [31]. To ensure that the advice was safe and medically appropriate, we drew on the latest evidence-based medicine (eg, Cochrane systematic reviews, UK National Institute for Health and Clinical Excellence guidelines) and the clinical expertise of members of the research team. The content of the information provided was also informed by psychological theory. Drawing on Bandura's Social Cognitive Theory [32], we sought to increase confidence to self-care (self-efficacy) by providing in-depth information to enhance skills and perceived capabilities for managing symptoms (particularly in the Treatment pages), and provided "vicarious learning" information about successful coping experiences of others who had used these self-care methods (eg, in clinical trials). In the Diagnostic pages we provided information on each aspect of symptoms identified by Leventhal's model [33] as important to self-regulation of illness–that is, identity (characteristic symptomatology), cause, timeline, consequences, and possibilities for control or cure.

Measures

Table 2 summarizes the measures used in this study, providing the full wording for items constructed for this study, and giving the reliability of multiple item scales.

Table 2. Final and intermediate outcome measures

Time point/target construct	Scale/item[a]	alpha[b]
Final (4-week) follow-up		
Enablement	*Patient Enablement Instrument* [29]	
Health Services Use	Three items asking whether since using the website the respondent had contacted (1) their general practitioner (or other practice staff), (2) NHS Direct or the National Pandemic Flu Service[c], or (3) any other health care services (eg, accident and emergency)	
Intermediate (48-hour) follow-up		
Satisfaction	Three items assessing satisfaction with and trust in the website advice (see Table 3)	.89
Baseline and intermediate (48-hour) follow-up		
Intentions	*Intentions to consult*	.97
	I plan to go to see a doctor for my symptoms	
	I intend to go to a doctor for my symptoms	
Self-efficacy	*Confidence to self-care*	.94
	I know what to do about my symptoms	
	I can care for my symptoms myself	
	I can cope with my symptoms without going to a doctor	
Outcome expectancies	*Consultation necessity beliefs*	.92
	I will get better more quickly if I go to see a doctor	
	Seeing a doctor will help me to recover	
	My illness may get worse if I do not see a doctor	
	I could become very ill if I do not see a doctor	
Illness perceptions	*Poor understanding of illness* ("coherence" subscale of Illness Perceptions Questionnaire - Revised [25])	.95
	Emotional reactions to illness (emotional representations' subscale of Illness Perceptions Questionnaire – Revised [25])	.91

[a] Full wording of items is provided for measures newly constructed for this study.

[b] Cronbach alpha coefficient is provided for scales newly constructed for this study.

[c] Data were collected during a period in which government advice was to contact the National Pandemic Flu Service for flu symptoms.

We assessed the primary outcomes at final (4-week) follow-up by two measures. The Patient Enablement Instrument [29] was used to measure confidence to self-manage illness; the stem was modified so that instead of asking respondents to indicate how they felt "As a result of your consultation," they were asked to indicate how they felt "Compared with before you read the Internet Doctor webpages." Health services usage was assessed by 3 items asking whether the respondent had contacted their general practitioner, telecare (NHS Direct), or other health care services for the symptoms they had used the website for.

Predictors and intermediate outcomes were measured by scales assessing beliefs theoretically likely to predict consultation, and that the Internet Doctor was intended to influence, namely *intentions to consult* a doctor, *confidence to self-care* (ie, self-efficacy for self-management), and *consultation necessity beliefs* (ie, outcome expectancies that the illness might get worse or last longer unless the respondent consulted a doctor). Relevant illness perceptions, comprising *poor understanding of illness* and *emotional reactions to illness*, were assessed by subscales from the Revised Illness Perception Questionnaire [25], omitting the reversed items due to an unreliable pattern of responses to these items. For ease of responding, all scales were constructed from items scored from 0 (strongly disagree) to 10 (strongly agree). At baseline, additional questions recorded age, gender, and education. At the first follow-up, three additional items (see Table 3) were used as a scale measuring website satisfaction.

Analysis

Numbers of participants completing study measures and phases varied, and so precise numbers are given for each analysis. Since many variables were somewhat skewed toward low concern about symptoms, we used conservative nonparametric tests to compare groups on the final outcome variables. We used a 2-tailed Kruskal-Wallis test for between-group comparisons in patient enablement scores, and a 2-tailed chi square test to compare numbers contacting health services.

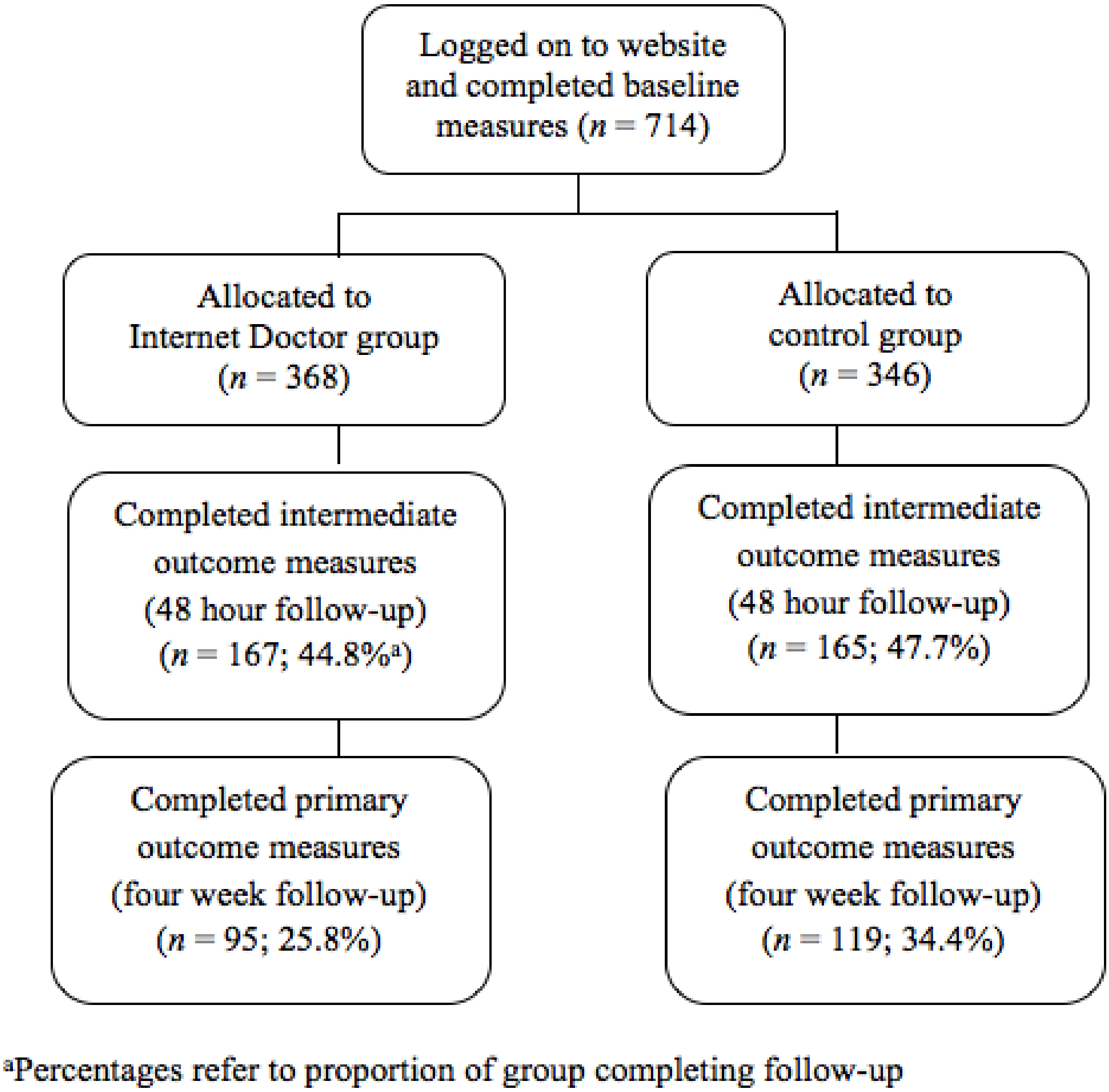
Parametric analyses were used for the secondary analyses, as there are no satisfactory nonparametric tests for time-by-group interactions and analysis of variance (ANOVA) is robust to violations of the assumption that variables are normally distributed, unless sample sizes are small [34]. To examine change in intentions and proposed mediating variables, 2 × 2 factorial ANOVAs were carried out to test for main effects of change over time, between-group differences, and interactions between group and change. The web satisfaction items were normally distributed and so groups were compared using independent *t* tests. Independent *t* tests were also used to compare the baseline scores of those who did and did not drop out before the first follow-up.

Hierarchical linear regression was employed to examine predictors of change in intentions, pooling data across both groups. To identify bivariate predictors of change in intentions, separate regressions of each baseline and website usage predictor were carried out with intentions at follow-up as the dependent variable, controlling for baseline intentions. We then carried out a multiple regression to determine whether (1) psychological variables predicted change in intentions after controlling for relevant demographic variables, and (2) use of the Diagnostic Webpages predicted change in intentions after controlling for relevant demographic and psychological variables (ie, those with a significant bivariate relationship to change in intentions). For this regression, after controlling for baseline intentions in step 1, age was entered in step 2 (dichotomized into aged under or over 25 because of a marked skew). In step 3 we entered consultation necessity beliefs (since theory predicts these should be directly related to intentions) and in step 4 we entered illness perceptions (poor understanding of illness and emotional reactions). Finally, in step 5 we entered use of the Diagnostic Webpages. We inspected the residuals from the final regression equation to confirm that they were normally distributed.

Results

Baseline measures were completed by 714 people; 368 (51.5%) were randomized to the Internet Doctor website and the remainder to the static website control (see Figure 2 for flow through the study). There were 198 (27.7%) men and 516 (72.3%) women with an age range of 18 to 79, but most (440/709, 62.1%) were aged under 25. The vast majority (651, 91.2%) were completing or had completed a university degree.

Figure 2. Flow of participants through the trial. ^{a}Percentages refer to proportion of group completing follow-up



Comparison of Internet Doctor and Control Groups on Primary Outcomes at 4-Week Follow-up

Of the 214 people who completed the measures of the target outcomes at the final (4-week) follow-up, 95 (44.4%) had been assigned to the Internet Doctor group. The median patient enablement score was significantly greater in the Internet Doctor group than in the control group (median score of 3 vs 2, with an interquartile range of 0 to 5 for the whole sample, $P = .03$). Of the people in the Internet Doctor group, 11 (11.6%) had consulted their doctor or used other health care services (mainly NHS Direct) for their symptoms, compared with a substantially greater proportion (21; 17.6%) in the control group, although this difference did not approach significance in this small sample ($P = .22$).

Comparison of Internet Doctor and Control Groups on Intermediate Outcomes at 48-Hour Follow-up

Of the 332 (46.5%) people who completed the intermediate outcomes at first follow-up, 167 (50.3%) were in the Internet Doctor group. The Internet Doctor group rated the website more positively than the control group did on all satisfaction measures (see Table 3). Comparison of those who did and did not complete the first follow-up showed that those who dropped out had significantly more negative beliefs about self-management of symptoms ($P < .01$ for all measures).

Table 3. Satisfaction with web-delivered advice in the Internet Doctor and control groups (n = 332)

Scale/item	Mean (SD) for each group		*P*
	Internet Doctor	Control	
Total scale (summed items divided by 3)	6.58 (1.96)	5.86 (2.27)	.002
The website gave me all the advice I needed	6.40 (2.05)	5.63 (2.51)	.002
The website was helpful to me	6.41 (2.17)	5.72 (2.51)	.007
I felt I could trust the website	6.91 (2.21)	6.25 (2.54)	.01

Intentions to consult the doctor declined between baseline and the intermediate (48-hour) follow-up; although the decline was greater in the Internet Doctor group this difference did not reach significance (see Table 4). Consultation necessity beliefs and emotional reactions to illness declined at follow-up to a similar extent in both groups. Poor understanding of illness declined in the Internet Doctor group but slightly increased in the control group, resulting in a just significant interaction between time and group effects. Self-confidence to self-care remained stable, similar and high in both groups at both time points.

Table 4. Intentions and attitudes at baseline and intermediate follow-up (n = 332)

	Internet Doctor group means (SD)		Control group means (SD)		*P* [a]	*P* [b]	*P* [c]
Scale	Baseline	Follow-up	Baseline	Follow-up	Time	Group	Interaction
Intention to consult doctor	2.00 (2.57)	1.66 (2.32)	1.88 (2.57)	1.82 (2.45)	.03	.93	.11
Consultation necessity beliefs	2.54 (2.25)	2.29 (2.37)	2.38 (2.23)	2.03 (2.37)	.01	.62	.61
Confidence to self-care	7.75 (2.00)	7.69 (2.08)	7.78 (1.97)	7.80 (2.01)	.84	.73	.62
Poor understanding of illness	1.86 (2.13)	1.65 (1.92)	1.64 (2.05)	1.70 (2.07)	.29	.70	.05
Emotional reactions to illness	2.36 (2.14)	2.03 (2.21)	2.40 (2.42)	2.17 (2.30)	<.001	.70	.53

[a] Significance of main effect for time, ie, change from baseline to follow-up

[b] Significance of main effect for between-group difference

[c] Significance of interaction between time and group effects, ie, group difference in change from baseline

Understanding Website Usage and its Relationship to Outcomes

The mean duration of website usage in the Internet Doctor group was 454 seconds (around 8 minutes), with a range from 24 seconds to over 52 minutes. Of the 368 people randomized to the website, 280 (76.1%) looked through the pages. Just over half (196; 53.3%) entered the Diagnostic section, a similar proportion (203; 55.2%) looked at the Treatment section, and over a quarter (104; 28.3%) looked at the Common Questions. Examination of the numbers of participants using each individual webpage revealed very diffuse usage, with virtually every page being used by at least some participants. Advice was provided for 146 symptoms, comprising runny nose in 57 (39.0%) cases, cough in 50 (34.2%) cases, sore throat in 29 (19.9%) cases, and fever in 10 (6.8%) cases. In 30.8% (45) of these cases the advice given was to contact health services.

Twenty-one people advised to contact health services completed the intermediate follow-up. There was no difference in satisfaction levels between those who were and those who were not advised to contact health services (mean 6.79, SD 2.03 and mean 6.18, SD 2.15, respectively; *P* = .21). However, intention to consult the doctor actually declined more in those advised to contact health services (*P* = .02). This was because those advised to contact health services had a higher level of intention to consult the doctor at baseline than those not advised to contact health services (mean 2.83, SD 2.98 and mean 1.88, SD 2.53, respectively), whereas at follow-up intentions were similar in both groups (mean 1.83, SD 2.59 and mean 1.73, SD 2.37, respectively).

Regression analysis (see Table 5) confirmed that reduction in intentions to consult across both groups was predicted by all the baseline measures of cognitions and illness perceptions, except for confidence to self-care. Being under 25 predicted a reduction in intentions to consult, but there were no gender differences. Use of the Diagnostic section predicted reduction in intentions, but the effect of use of the Treatment section did not quite reach significance. After controlling for the effects of age, both consultation necessity beliefs and emotional reactions to illness continued to predict reduction in intentions. After controlling for all these variables, use of the Diagnostic section remained a significant predictor of reduction in intentions to consult.

Table 5. Baseline and website usage predictors of intentions to consult the doctor at intermediate follow-up, controlling for intentions at baseline

Variables	Bivariate regressions[a]		Hierarchical regression[b]	
	Beta	*P*	Final beta	*P*
Baseline intentions	.78	<.001	.617	<.001
Age less than 25	.10	.003	.07	.04
Gender	.01	.79	-	-
Consultation necessity beliefs	.19	<.001	.13	.01
Confidence to self-care	-.04	.30	-	-
Poor understanding of illness	.11	.004	.05	.18
Emotional reactions to illness	.15	<.001	.11	.01
Diagnostic section used	.09	.007	.08	.02
Treatment section used	.06	.07	-	-

[a] Intention to consult the doctor entered in step 1, then contribution of each variable examined independently.

[b] Intention to consult the doctor entered in step 1, then variables entered in order shown, omitting those with nonsignificant bivariate relationships to intention change (see Method for details and rationale). Beta weights shown are for the last step of the equation.

Discussion

The findings from this study suggest that tailored website advice may prove superior to simply providing written information about self-care. The Internet Doctor advice was rated as more helpful and trustworthy than the control information and resulted in higher levels of patient enablement a month later. Understanding of illness improved in the 48 hours following use of the Internet Doctor webpages, whereas there was no improvement in understanding of illness in the control group.

The shift toward weaker intentions to consult the doctor after using the website was more marked for the student-aged participants, consistent with our expectation that providing advice on self-care (in both groups) would have more influence on the intentions of those with less experience of independent self-care. As expected, reduction in intentions to consult was also predicted by prior beliefs that consultation was necessary to achieve recovery, poor understanding of illness, and greater emotional reactions to illness. This finding confirms that providing advice is likely to have most influence on the consultation rates of those who are most puzzled and distressed by their symptoms, and concerned that they may not recover without medical help. This profile matches that of patients who are more likely to consult [1, 33,35], suggesting that the advice is proving relevant to this target population.

Use of the Diagnostic section of the Internet Doctor website predicted a reduction in the strength of intentions to consult, whereas use of the Treatment section did not. This finding is not entirely surprising, since only the Diagnostic section provided specific advice about whether medical help was necessary. However, an unexpected finding was that confidence to self-care was unrelated to change in intentions to consult. Since confidence that one can carry out a behavior successfully (self-efficacy) is usually a strong predictor of behavior [21], one might expect confidence in self-care to reduce the perceived need for, and therefore intention to seek, medical help. The finding that in this case self-efficacy did not predict intentions to consult may explain why use of the Treatment section was also unrelated to consultation intentions, since this section was intended primarily to increase confidence in self-care. However, it appears that consultation is motivated more by concern about serious illness requiring medical care rather than by the desire for advice on how to relieve symptoms. Indeed, both groups already had high and stable levels of confidence in their ability to cope with these common, minor symptoms. This ceiling effect may also explain why the intervention did not produce increases in the already high levels of self-efficacy, whereas web-based interventions for more serious mental and physical conditions have been shown to increase self-efficacy [32].

Only a minority of people were advised to contact health services, a much smaller proportion than in previous studies of triage for minor symptoms [20,36]. The low rate of advice to use health services could be due to our sample of young, healthy people, who were consulting mainly for minor symptoms, but could also reflect a triage system that had a slightly higher severity threshold for recommending contacting health services. The relatively low numbers of people the system advised to contact health services is compatible with the finding that participants using the Diagnostic section were less likely to intend to consult. However, an unpredicted finding was that intentions to consult the doctor actually declined more in those who were advised to contact health services. This might simply be because they had more severe symptoms at baseline, which then abated during the 48 hours before follow-up. Since advice to contact health services was accompanied by an explanation of which symptoms were of concern, an alternative possibility is that participants used this information to monitor these symptoms for improvement after using the Internet Doctor.

Strengths and Limitations of the Study

This study had a number of strengths as a direct test of the effects of tailored advice in the context of self-management of minor symptoms: in particular, a direct comparison with the best existing nontailored patient information, and detailed analysis of reliable, theory-based measures of relevant beliefs and perceptions. However, the findings cannot be considered definitive. The sample size was too small to reliably detect group differences in consultation rates, and reported consultation rates were not objectively verified. Future research should evaluate the effects on recorded consultations in a much larger sample, following all the usual conventions for a full trial.

While our study design provided a strong test of the efficacy of tailoring information, it did not permit evaluation of the effectiveness of the website for reducing consultation rates, since the control group was given nontailored advice that was previously shown to be effective in reducing consultation rates. It is encouraging that a reduction in intentions to consult, consultation necessity beliefs, and emotional reactions was seen in both groups after using the website. However, a further trial is needed, including comparison with a control group who are not given access to any triage advice, in order to determine to what extent reductions in consultations intentions are due to receiving web-based advice.

There was substantial dropout before follow-up, which is a common problem in internet studies with volunteer samples [37-39]. Those who dropped out had less confidence to self-manage their symptoms, suggesting that the reductions in concern about symptoms seen in those who were followed up might not have been observed in those who dropped out. Overall satisfaction levels even in those who completed the study were only mildly positive; findings from a qualitative study of responses to the Internet Doctor [40] suggest that this may be because the somewhat restricted computer-tailored advice is often perceived as inferior to the detailed personal advice that a health professional can provide. Further research and development is required in order to try to determine whether it is possible to achieve higher levels of satisfaction, and whether these might attenuate attrition [39]. This is particularly important, as our sample is likely to have had more positive attitudes toward web-based advice than might be found in the general population. In addition to being volunteers, our sample mainly comprised students, and web-based advice may prove less appealing and effective in older and less well-educated populations, since they tend to have lower levels of self-efficacy both for web usage and for self-management of health [10,41]. In addition, women were substantially overrepresented in our sample (although the proportion was similar to the take-up observed in an observational study of providing digital triage for a student population [20]). There is evidence that women tend to have a more positive attitude than men toward self-management of health [42]. For these reasons, future research should be carried out in a more representative population sample.

Conclusions

Our findings provide initial evidence that tailored web-based advice could help patients self-manage minor symptoms to a greater extent. Effect sizes on consultation rates were modest, which is consistent with previous research suggesting that often information may be obtained from the Internet in order to supplement rather than replace consultations with doctors [12,41,43]. Nevertheless, if replicated, these effect sizes would be potentially very valuable if the intervention were rolled out widely. Consequently, these findings constitute a sound foundation and rationale for future research. In particular, our study provides the evidence required to justify carrying out much larger trials in representative population samples comparing tailored web-based advice with routine care, in order to obtain a definitive evaluation of the effects on self-management and health service use.

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Conflicts of Interest

None declared

Multimedia Appendix

Illustrative screen shots of the Internet Doctor

[PPT file (Microsoft Powerpoint File), 1214 KB - jmir_v12i4e66_app1.ppt]

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Abbreviations

ANOVA: analysis of variance
RCT: randomized controlled trial

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Original Paper

An Online Community Improves Adherence in an Internet-Mediated Walking Program. Part 1: Results of a Randomized Controlled Trial

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Abstract

Background: Approximately half of American adults do not meet recommended physical activity guidelines. Face-to-face lifestyle interventions improve health outcomes but are unlikely to yield population-level improvements because they can be difficult to disseminate, expensive to maintain, and inconvenient for the recipient. In contrast, Internet-based behavior change interventions can be disseminated widely at a lower cost. However, the impact of some Internet-mediated programs is limited by high attrition rates. Online communities that allow participants to communicate with each other by posting and reading messages may decrease participant attrition.

Objective: Our objective was to measure the impact of adding online community features to an Internet-mediated walking program on participant attrition and average daily step counts.

Methods: This randomized controlled trial included sedentary, ambulatory adults who used email regularly and had at least 1 of the following: overweight (body mass index [BMI] ≥ 25), type 2 diabetes, or coronary artery disease. All participants (n = 324) wore enhanced pedometers throughout the 16-week intervention and uploaded step-count data to the study server. Participants could log in to the study website to view graphs of their walking progress, individually-tailored motivational messages, and weekly calculated goals. Participants were randomized to 1 of 2 versions of a Web-based walking program. Those randomized to the "online community" arm could post and read messages with other participants while those randomized to the "no online community" arm could not read or post messages. The main outcome measures were participant attrition and average daily step counts over 16 weeks. Multiple regression analyses assessed the effect of the online community access controlling for age, sex, disease status, BMI, and baseline step counts.

Results: Both arms significantly increased their average daily steps between baseline and the end of the intervention period, but there were no significant differences in increase in step counts between arms using either intention-to-treat or completers analysis. In the intention-to-treat analysis, the average step count increase across both arms was 1888 ± 2400 steps. The percentage of completers was 13% higher in the online community arm than the no online community arm (online community arm, 79%, no online community arm, 66%, $P = .02$). In addition, online community arm participants remained engaged in the program longer than no online community arm participants (hazard ratio = 0.47, 95% CI = 0.25 - 0.90, $P = .02$). Participants with lower baseline social support posted more messages to the online community ($P < .001$) and viewed more posts ($P < .001$) than participants with higher baseline social support.

Conclusion: Adding online community features to an Internet-mediated walking program did not increase average daily step counts but did reduce participant attrition. Participants with low baseline social support used the online community features more than those with high baseline social support. Thus, online communities may be a promising approach to reducing attrition from online health behavior change interventions, particularly in populations with low social support.

Trial Registration: NCT00729040; http://clinicaltrials.gov/ct2/show/NCT00729040 (Archived by WebCite at http://www.webcitation.org/5v1VH3n0A)

(J Med Internet Res 2010;12(4):e71) doi:10.2196/jmir.1338

KEYWORDS

Internet; walking; social support; chronic disease management; adherence; attrition; retention; engagement; online community; exercise

Introduction

Intensive and expensive interventions targeting diet and exercise can reduce the risk of developing chronic conditions such as diabetes and cardiovascular disease [1]. The major challenge that remains is to find a way to deliver lifestyle interventions to more people and at a lower cost. Individuals, health systems, and insurance providers are turning to automated lifestyle interventions as a way to control costs and improve health outcomes. Automated lifestyle interventions assist users with diet and exercise logging, goal setting, feedback, and motivational messages. In addition to being lower cost than interventions delivered by a trained provider, automated interventions can be more convenient for the user in that they do not require frequent travel to a facility or scheduled synchronous sessions. Unfortunately, many of the automated lifestyle interventions that have been tested suffer from high dropout rates [2] and limited effectiveness.

Online communities are groups of users that interact by posting and reading messages on a group message board on the Internet. Online communities have the potential to improve both participant retention and the effectiveness of automated lifestyle interventions [3]. An active online community might contain user posted stories about overcoming barriers, empathic messages of support for those who are struggling, and celebrations of success. Such user interaction, if successful, could leverage social support, positive social modeling, and dynamic content to keep users engaged in the program and to support behavior change.

Unfortunately, previous studies examining the impact of online communities on Internet-mediated lifestyle interventions have been disappointing. In a review of 38 studies of online communities in Internet-mediated health interventions by Eysenbach et al, there was little evidence found of a positive impact of online communities on behavioral outcomes or program retention [4]. One of the major issues limiting the effectiveness of online communities is that it is difficult to create and sustain a vibrant and active online community. In a recent review of online health interventions, Bennet and Glasgow state that "despite our best efforts, forums, message boards, and chat rooms are rarely used in Internet interventions" [5].

The primary goal of this trial was to measure the impact on program retention and behavior change of adding an online community to an automated lifestyle change intervention. We added an online community to an automated Internet-mediated walking program that has been shown in previous studies to increase walking by approximately 1 mile per day among participants [6]. The hypothesis was that participants with access to online community features would increase step counts more and would remain engaged in the program longer than those without online community access.

The online community in this study was designed using strategies and features to encourage participant engagement and to increase the chances that the online community conversation would be active enough to have a measurable impact on users. The focus of this manuscript is to report the main outcomes from the randomized controlled trial. A second manuscript in this issue details the strategies used to create the online community [7].

Methods

Study Design

In this 2-arm randomized controlled trial, participants in both the intervention and control arms were enrolled in Stepping Up to Health (SUH), an Internet-mediated walking program. Participants in both arms were given a user name and password that allowed them to access a personalized intervention webpage. Intervention-arm participants in the “online community” arm had access to online community features embedded in their intervention webpage. In contrast, control participants allocated to the ”no online community” arm could not read or post messages to other control-arm participants.

Recruitment

A list was obtained of all patients who received treatment from a University of Michigan Health System provider within the previous 6 months with at least 1 of the following: body mass index (BMI) ≥ 25, type 2 diabetes, or coronary artery disease. Individuals diagnosed with quadriplegia or paraplegia or as having been pregnant within the previous year were excluded. Using a computerized process [8], a random subsample of the list received an invitation letter (Multimedia Appendix 1) for study participation. The letter included a brief description of the study, key eligibility criteria, and a website address for more information. Individuals who heard about the study by word-of-mouth were referred to the study website for detailed study information and eligibility screening.

Eligibility Screening and Consent

Interested individuals were instructed to go to the study website where they completed an automated eligibility (Multimedia Appendix 2) and consent (Multimedia Appendix 3) process online. Participants were eligible if they were over 18 years of age and had at least one of the following: BMI ≥ 25, type 2 diabetes, or coronary artery disease. To be eligible, participants had to have access to an Internet-connected computer with Windows XP or Vista operating system, a valid email address, and use email at least once per week. Additionally, participants had to be sedentary, which was defined as less than 150 minutes per week of moderate physical activity [9]. Participants were required to have access to a treating physician who could provide medical clearance. Individuals were not eligible if they were pregnant, could not walk a block on their own, or could not make their own medicolegal decisions.

After providing consent, participants received a mailed packet containing a pedometer, an upload cable for the pedometer, pedometer instructions, study team contact information, and a medical clearance form (Multimedia Appendix 4) for the participant's physician to complete and return.

Baseline Data Collection

Baseline data collection had 2 components: survey data and pedometer data. Participants completed a detailed online survey (Multimedia Appendix 5) including questions about demographics, health history, motivations, and barriers for walking, knowledge and attitudes about diabetes, heart disease and obesity, and comfort with computers.

Step counts were assessed using an Omron HJ-720-ITC pedometer that contains a dual-axial accelerometer, an embedded USB port, and enough memory to store 42 days of step-count data. These pedometers are valid and reliable [10] and accurate to ± 4% of observed steps [11]. During the baseline period, pedometer displays were covered by a sticker. Participants wore the pedometer for 7 days without removing the sticker and then uploaded their step-count data.

Randomization

Once participants completed baseline data collection and submitted a signed medical clearance form, an automated randomization algorithm [12] assigned them to either the control or the intervention arm with unequal probability (a ratio of 1:5). The randomization of more individuals to the intervention arm was intentional to ensure a large participant pool to sustain online community dialogue. This type of unequal randomization has been used in previous studies, often for ethical reasons [13]. Such unequal designs retain all of the benefits of a balanced randomized controlled trial with respect to controlling for potential confounding and do not introduce statistical bias. Total sample size was increased to counteract the decrement to statistical power resulting from unequal randomization (see "Sample Size Calculation" section for details).

Once randomized, participants received automated email messages informing them of their initial step-count goals and instructing them to remove the stickers from their pedometers. Participants then gained full access to their personalized intervention page based on their arm assignment.

Intervention

The intervention website was implemented in Drupal [14], an open-source content management system with online community features. Figure 1 is a sample screen shot of a personalized SUH home page. The SUH intervention includes 4 intervention components described in detail in a previously published manuscript: uploading pedometers, step-count feedback, individually assigned and gradually incrementing step-count goals, and individually tailored motivational messages [6]. Participants were instructed to wear their pedometers every day while awake and to log in at least once a week to view tailored messages and updated goals.

Figure 1. Screenshot of website

Your walking goal for today is **800 steps.**

Report an illness or injury

Adrienne

Your progress

For the week of May 25, 2008 to May 31, 2008, you met your walking goal of 2700 steps on 4 of 7 days. Your average daily step count for the week was 4842 steps.

Click on a day in the calendar to view that week. Click on a bar in the graph to see the day's detail.

- Michelle Draska, New Study Staff -- Meet & Greet Forum
- What happened to my fish tank? -- The Gulfstream
- passing the walking time-ideas? -- Sidewalk Talk Forum
- saying hello at the end of week 13 -- Meet & Greet Forum
- Walking groups or buddies -- Sidewalk Talk Forum

Theoretical Framework

The key behavior change theories that support our current hypotheses are Bandura's social-cognitive theory and social influence theories including social learning theory [15]. There are 3 possible mechanisms by which participation in an online community might impact program attrition and step counts.

Mechanism 1: Increased Social Support

Social support, defined as the structure and quality of social relationships, can improve health outcomes by improving adherence to healthy behaviors [16] and by impacting emotions and mood [17-19].

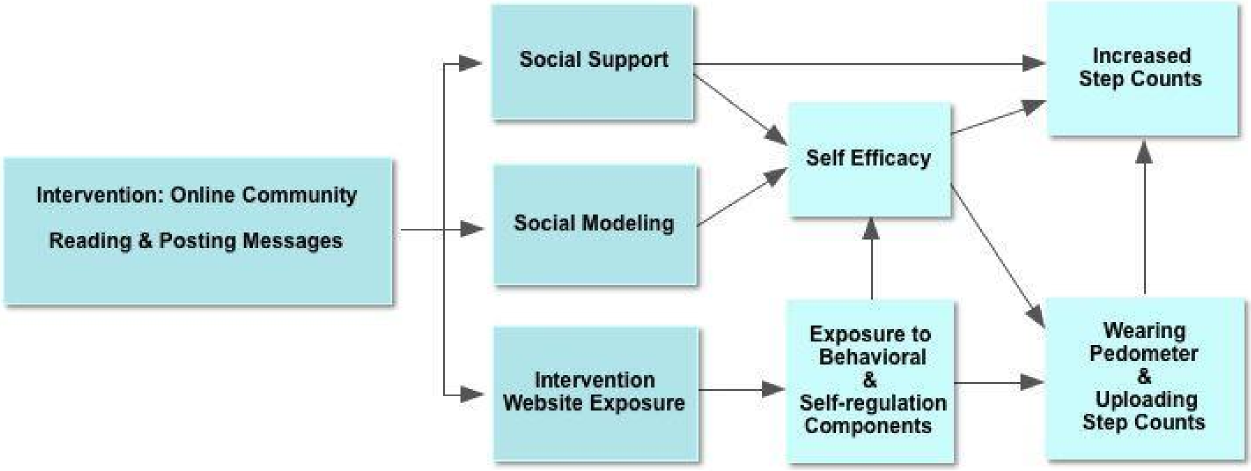
Mechanism 2: Social Modeling

The experiences of others, including the barriers they have overcome and the successes they have achieved, can serve as inspirational models. Reading the posts of others enables vicarious learning [20].

Mechanism 3: Increased Intervention Website Exposure

Online communities can provide engaging and dynamic content that increase return visits and encourage use of nononline community components including self-regulation components such as goal setting, feedback, and tailored motivational messages.

Figure 2. Conceptual model



The online community design followed principles and practices developed by online community experts. Consistent with our theoretical model, content in the online community was focused on providing social support, encouraging social modeling of successes, and facilitating use of noncommunity components of the intervention. To promote sociability, participants were encouraged to post self-introductions, and research staff posted their own self-introductions. In addition, research staff posted open-ended questions encouraging participants to post messages modeling self-regulation strategies such as overcoming barriers and describing successes. Posts about pedometers, goals, and graphs encouraged participants to pay attention to the nononline community components of the intervention. To generate more activity, contests were run with small rewards such as water bottles or bumper stickers for posting content. Because researchers have found that people who get responses, especially to initial posts, are more likely to continue posting, research staff made an effort to post responses, usually within 24 hours, to all participant posts [21-23]. All posts by staff were identified as such. Part 2 of this manuscript provides more details about strategies used to stimulate the online community [7].

Postintervention Assessment

At the end of the 16-week intervention period, participants completed a postintervention online survey, performed a final pedometer upload, and received a US $25 honorarium plus a free 1-year subscription to a commercial Internet-mediated walking program [24].

Objective Measures

Change in Average Daily Step Counts

Change in average daily step counts was calculated by subtracting average end-of-study step counts from average baseline step counts using uploaded pedometer data. Days during which the pedometer was not worn (less than 100 steps recorded during the day or less than 8 hours of wear time as assessed by the pedometers activity flag) were considered not valid and were not included in averages. At least 5 of 7 consecutive days of valid baseline data were required for randomization. At least 20 of 30 days of valid pedometer data were required to calculate the average step count at the end of intervention period.

Percent of Valid Days of Pedometer Data

The percent of valid days of uploaded pedometer data was calculated by dividing the number of valid days of uploaded pedometer data by 112 days (16 weeks).

Online Community Use

Each click by a user on a website hyperlink generated a time-stamped record. Each instance of clicking a link that led to a section or subsection of the online community and its features counted as a “view.” Each instance in which a participant composed a new post or replied to an existing message on the online community counted as a “post.”

Intervention Completers

Participants who uploaded at least 20 valid days of pedometer data during the final month of the 4-month intervention were considered “completers” for the completers and attrition analysis.

Subjective Measures

Participants responded to a series of lengthy surveys (Multimedia Appendices 5 through 8). The majority of the survey responses were used only to inform the tailored messaging algorithms (Multimedia Appendices 9 through 16). Self-reported responses to online survey items about age, sex, race, height, weight, Internet proficiency, previous pedometer use, and previous use of social media were also used to describe the study sample and to control for potential confounding in multiple regression. In addition, 2 single-item, unvalidated measures were used as predictors or outcomes in secondary analyses, 1 on social support and 1 on motivation for walking. Social support was measured in the baseline survey with the question, “Do you currently get support from your family and friends in getting enough physical activity?” Additionally, in a brief survey at the end of the intervention period, participants with online community support responded to the question, “Did the ability to talk to or read posts from other participants motivate you to walk more?”

Statistical Analysis

Sample Size Calculation

In calculating sample size, 2 goals were considered. First, as in a traditional sample size calculation, the sample size was calculated to provide adequate power based on the variance and clinically significant difference of the outcome. The minimum clinically significant increase in average daily step counts was estimated at 1000 steps. If an individual walks with moderate intensity at 3 miles per hour, an increase of 1000 steps is equivalent to approximately 10 minutes of walking per day. A previous study using the SUH intervention revealed a step count standard deviation of 2000 steps [6]. If statistical power had been the only goal in determining sample size, the sample required in each arm would have been 63 for a total sample of 126. However, we also desired a sufficient number of participants in the online community arm to sustain an active online community. To this aim, we increased the total sample size and changed the randomization ratio to yield the appropriate sample size for adequate power with an unequal design. We then increased this estimated sample size by 25% to allow for attrition, and our final total targeted sample size was 300 participants.

Analysis

Univariate statistics summarized baseline characteristics and process and outcome variables. Means and standard deviations were reported for continuous variables with a normal distribution, and percentages were reported for categorical variables. Within-arm comparisons between baseline and endpoint physical activity levels used paired *t* tests. For all other results, multiple regression models controlled for the continuous variables, age and BMI, and for the dichotomous variables, sex, type 2 diabetes, and coronary artery disease. All regressions were also adjusted for average baseline step count (a continuous variable) except when the dependent variable was average baseline step count. Regression assumptions were tested and regressions were performed with and without influential outliers to ensure validity. For intention-to-treat analyses, all individuals who were randomized were included in the analysis and baseline values were carried forward for those who did not complete the program. Completers analyses only included individuals who completed the program, uploading at least 20 valid days of pedometer data during the final month of the program.

Linear regression analysis was used with normally distributed, continuous dependent variables including total steps, change in total steps, and valid days uploaded. Logistic regression analysis was used to estimate the effect of online community access on attrition rate and walking motivation. Likert scales were dichotomized for analysis. Poisson regressions compared website variables indicating counts of messages posted and posts viewed and compared the frequency of total, serious, and minor adverse events.

A mixed-model regression compared the rate of step-count increase between arms. A time-to-event analysis compared time to last pedometer upload between arms, with an unadjusted log-rank test for equality of survivor functions and a Cox regression model controlling for confounders with a Breslow methods for ties. Those individuals whose last upload was after 102 days were right censored. STATA 10.1 (StataCorp, College Station, TX, USA) was used for sample size calculations and statistical analyses.

Human Subjects

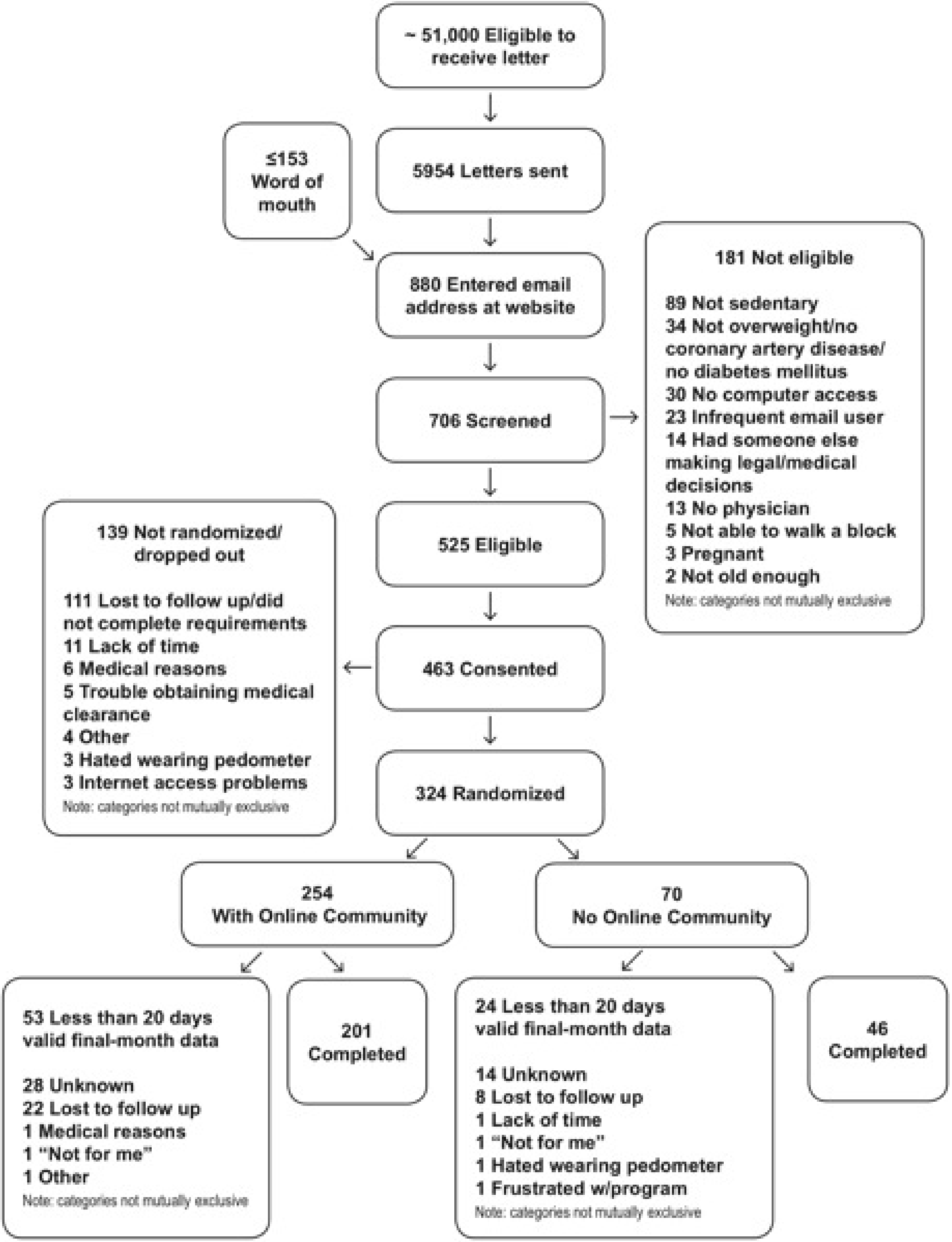
The University of Michigan Institutional Review Board approved the study with a waiver of documentation of written consent (IRBMED HUM00012230). All participants gave online consent.

Results

Recruitment

A total of 5954 potentially eligible patients received invitation letters. Of those, 706 completed online eligibility screening, and 525 were eligible to participate. A total of 324 individuals completed baseline enrollment procedures (online community arm = 254, no online community arm = 70). See Figure 3 for more details.

Figure 3. Recruitment flow sheet



Baseline Characteristics

Participant ages ranged from 24 to 82 years (mean age 52.0 ± 11.4). Two-thirds of participants were women and the majority of participants were white (Table 1). Baseline step counts were significantly higher in the online community arm than the no online community arm. This difference was due to chance alone, as a computer algorithm assigned participants randomly to arms with no research staff input (Table 2).

Table 1. Baseline demographics and characteristics by arm[a]

	Both Arms	No Online Community Arm	With Online Community Arm
N	324	70	254
Mean age (SD)	52.0 (11.4)	53.3 (11.8)	51.7 (11.3)
Gender			
Male, %	35%	34%	36%
Female, %	65%	66%	64%
Hispanic, %	2%	1%	2%
Race			
White, %	86%	80%	87%
Black, %	6%	6%	6%
Asian, %	3%	6%	3%
American Indian, %	1%	1%	0%
Other, %	2%	4%	1%
Body Mass Index			
Mean BMI (SD)	33.2 (6.2)	33.4 (5.8)	33.1 (6.3)
BMI ≥ 25, %	99%	99%	99%
BMI ≥ 30, %	62%	67%	60%
Coronary artery disease, %	12%	13%	12%
Type 2 diabetes, %	20%	26%	19%
Used pedometer previously, %	43%	41%	44%
Internet proficiency			
Limited, %	2.8%	2.9%	2.8%
Basic, %	8.8%	8.8%	8.8%
Moderate, %	33.1%	33.8%	32.9%
Advanced, %	41.0%	44.1%	39.8%
Expert, %	14.5%	10.3%	15.7%
Use social media at least weekly			
Forums, %	19.0%	18.3%	19.1%
Listservs, %	22.6%	25.0%	21.9%
Chat rooms, %	8.3%	8.3%	8.3%
Blogs, %	11.5%	6.7%	12.8%

[a] No significant difference between arms.

Online Community Use

Consistent with our theoretical model, content in the online community provided social support, encouraged social modeling of successes, and facilitated use of noncommunity components of the intervention. In introductions and elsewhere, many users described personal challenges that made it difficult for them to exercise. This gave participants in the online community arm an opportunity to respond with empathy, encouragement, and informational social support. Both staff and participants referred frequently to nononline community intervention components in posts. Within the online community arm, the online community was active with 65% (165/254) of participants using the online community, either as posters or “lurkers” (ie, readers who did not post).

Average Daily Step Counts

Table 2 shows arm and total sample baseline step counts, final step counts, and absolute change in average daily step counts using both intention-to-treat and completers analysis. Both arms significantly increased their average daily steps between baseline and the end of the intervention period, but there were no significant differences between arms using either intention-to-treat or completers analysis. For the entire sample (n = 324), participants increased their average daily steps by 1888 steps per day in the intention-to-treat analysis ($P < .001$), which approximates to 1 mile per day. Among those who completed the intervention, the average step-count increase was 2477 steps per day ($P < .001$) or about 1.25 miles per day. See Figure 4 for average step-count change by week. The rate of increase in step counts did not differ by arm ($P = .82$).

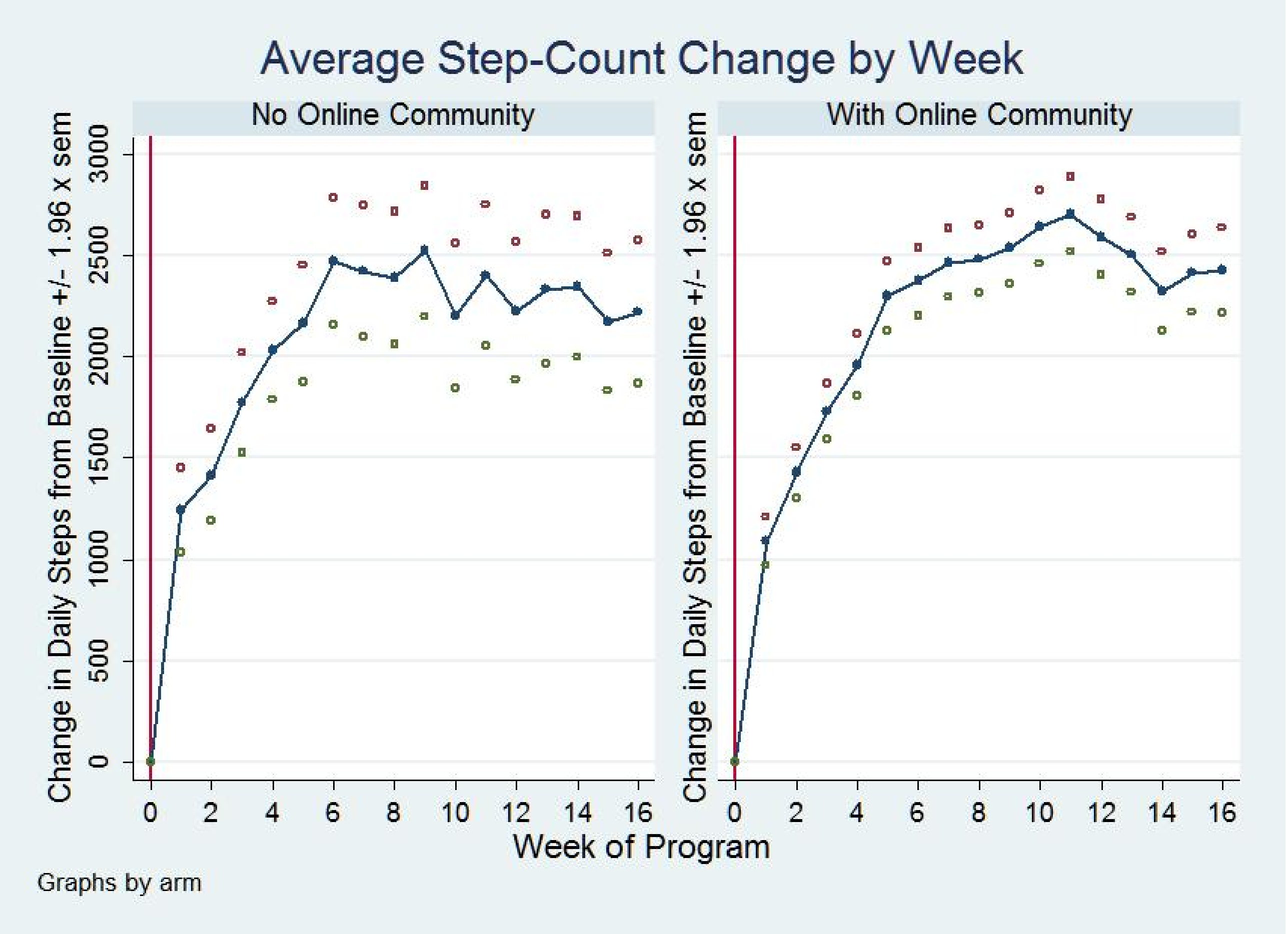
Table 2. Step-count measures by arm

	Both Arms n = 324	No Online Community Arm n = 70	With Online Community Arm n = 254	Between-Arm Comparison *P* value[a]
Total steps, intention-to-treat				
Baseline, mean (SD)	4441 (2000)	3859 (1586)	4601 (2074)	.01
Final, mean (SD)	6329 (3066)	5438 (2667)	6575 (3127)	.20
Change, mean (SD)	1888 (2400)	1579 (2137)	1974 (2464)	.20
P value (SEM)[b], intention-to-treat	< .001 (133)	< .001 (255)	< .001 (155)	
Completers, n (% of participants randomized to arm)	247 (76%)	46 (66%)	201 (79%)	
Total steps, completers				
Baseline, mean (SD)	4468 (1884)	4018 (1621)	4571 (1927)	.10
Final, mean (SD)	6945 (3006)	6421 (2623)	7065 (3081)	.97
Change, mean (SD)	2477 (2469)	2402 (2232)	2494 (2525)	.97
P value (SEM)[b]	< .001 (157)	< .001 (329)	< .001 (178)	

[a] *P* values for parameter estimate of arm in linear regression adjusting for age, sex, coronary artery disease, type 2 diabetes, BMI, and baseline steps (except where baseline steps was the outcome).

[b] Pre-post paired *t* tests, not adjusted for confounders

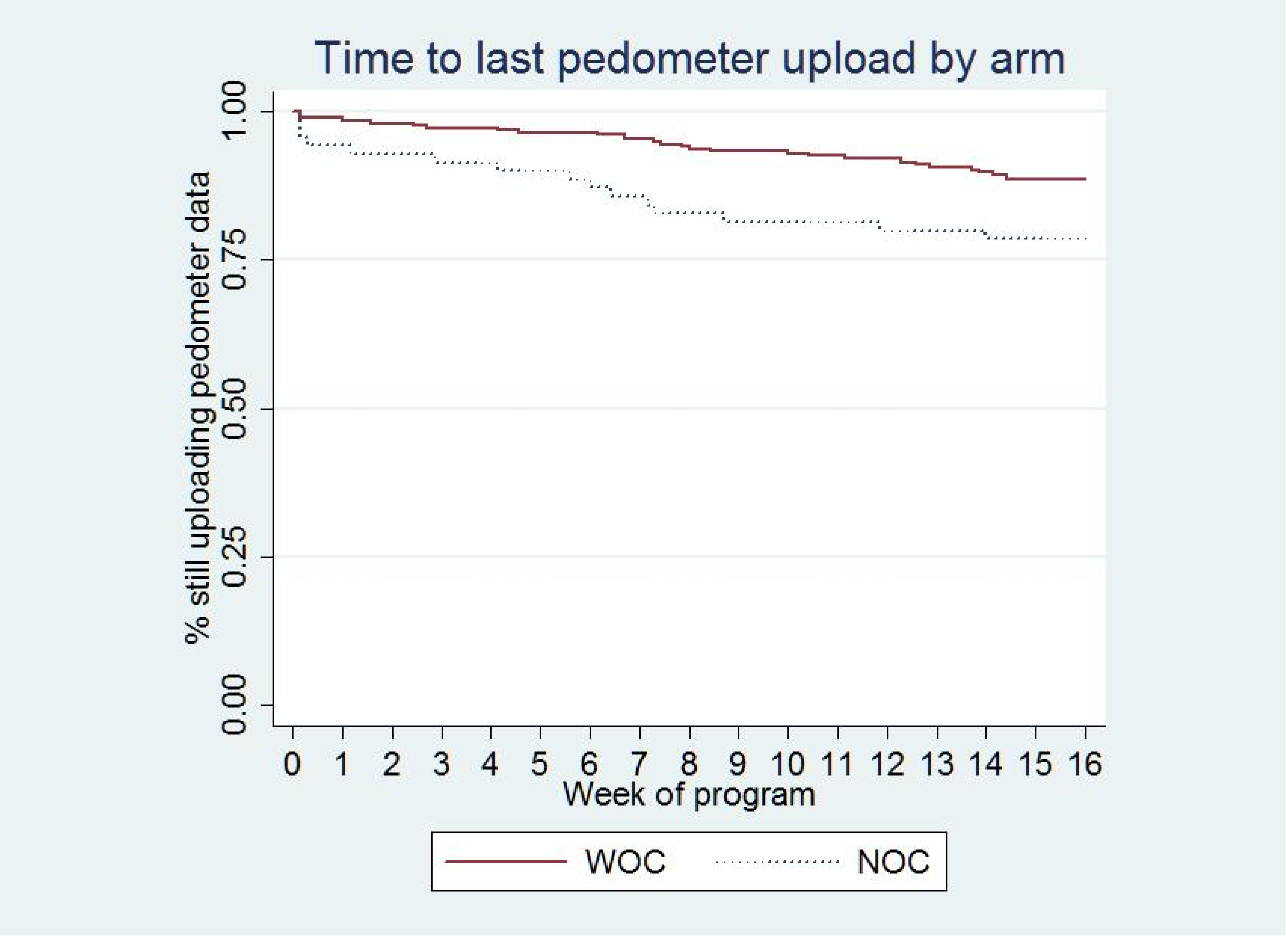
Figure 4. Average step-count change by week



Program Engagement and Attrition

The online community arm uploaded valid pedometer data on more days than the no online community arm (online community, 87% of days, no online community, 75% of days, *P* = .001). In addition, the online community arm was more likely to upload valid final-month data; percentage of completers was 13% higher in the online community arm than the no online community arm (online community, 79%, no online community, 66%, *P* = .02). Time to last pedometer upload was earlier in the no online community arm indicating that those in the no online community arm dropped out earlier than those in the online community arm (hazard ratio = 0.47, *95%* confidence interval [CI] = 0.25 - 0.90, *P* = .02). Figure 5 charts the weekly percentage of participants who were still uploading data.

Figure 5. Time-to-event analysis



Social Support

There was no difference between arms in baseline and postintervention perceived social support. Online community arm participants who reported lower baseline social support posted more messages to the online community (incidence-rate ratio = .65, 95% CI = 0.54 - 0.78, *P* < .001,) and viewed more posts (incidence-rate ratio = .50, 95% CI = 0.49 - 0.52, *P* < .001) than participants with higher baseline social support. Participants in both arms who reported having social support at the end of the study were more likely to increase their step counts (*P* = .01).

Intervention Website Exposure

The online community arm had more home pages hits than the no online community arm with intention-to-treat analysis (*P* = .02) but not with completers analysis. Online community and no online community participants did not differ in views of tailored messages.

Effect of Online Community Use on Walking

Online community participants who posted more showed a larger increase in step counts (additional 62 steps per day for each message posted, *P* = .03). Additionally, online community participants with more pages viewed had larger increases in step counts (additional 2.3 steps per day per page view, *P* < .001). More posts written and pages viewed correlated with greater reported motivation to increase walking (odds ratio [OR] = 1.15, 95% CI = 1.06 - 1.24, *P* = .001, and OR = 1.005, 95% CI = 1.002 - 1.007, *P* < .001 respectively).

Adverse Events

There was no difference between arms in the number of related total, serious, or minor adverse events. There were no adverse events associated with online community use. There were 7 serious adverse events related to the intervention including a slip and fall on ice during a walk resulting in a broken leg, 1 hypoglycemic event with a fall, and 5 adverse events related to cardiac symptoms. Minor musculoskeletal injuries were common with 2.5% (8/324) of participants experiencing plantar fasciitis.

Discussion

Summary of Principal Results

Access to an online community focused on enhancing social support, social modeling, and self-regulation strategies increased participant retention in an Internet-mediated walking intervention. This study is one of the first to document the benefit of an online community using a randomized controlled trial design. The results presented here strengthen the evidence supporting the use of online communities as a tool for reducing attrition. In contrast, online community access did not change average daily step counts among those who remained in the program. Step-count increases between arms of completers were nearly identical.

While this study was designed to document the overall effect of the online community on program retention and step counts, some secondary quantitative analyses support the mechanisms hypothesized in the conceptual model. First, those who reported lower baseline social support used the online community more frequently both for posting and for reading posts by others. Viewing posts was also correlated with higher increases in step counts. These findings support the hypothesized social support and social modeling mechanisms. The survival curves in Figure 5 suggest that some but not all of the improved retention seen in the online community arm was evident during the first week of participation. This early effect was more likely due to social modeling than to social support as it takes time to build supportive relationships. Posts from participants that modeled overcoming barriers, described personal successes, and gave generic encouragement were available to those in the online community arm from the first time they logged in to the site. Additionally, those in the online community arm used the self-regulation components of the intervention more often than those in the no online community arm. For example, online community arm participants wore their pedometers on more days and uploaded valid pedometer data for more days than no online community participants.

Study Strengths

There were a number of unique aspects to this study that strengthened the results. First, this study was innovative in that it tested the effect of a single component (online community support) in a randomized controlled trial, the gold standard to determine causality between an intervention and outcome. Randomization minimizes the potential for influence from both measured and unmeasured confounders. The few studies that have assessed the impact of online communities have generally used observational rather than experimental study designs [4]. The effect of online communities detected in such observational studies may be entirely due to confounding constructs such as baseline participant motivation or self-regulation skills. Individuals with baseline traits that favor successful behavior change may be more likely to use online community resources. Additionally, we found support for the hypothesis that online community access would increase exposure to nononline community intervention components such as self-regulation tools. For example, online community participants wore their pedometers on more days and uploaded valid pedometer data for more days than no online community participants.

In addition to randomization, objective measures of outcomes also strengthened the study results. Both walking and program retention outcomes were measured objectively using uploaded pedometer data and electronic logging of participant interaction with the website rather than less reliable subjective reports of retention or behavior changes. Also, the entire intervention as well as all participant recruitment and enrollment procedures were automated and were delivered remotely with no face-to-face interaction between study participants and research staff. This emphasis on automation means that the intervention could be scaled up to a large volume of users with few modifications. Additionally, inclusion criteria were intentionally broad including a large percentage of adults who could benefit from increasing their physical activity. This increases the potential reach of the intervention and strengthens the generalizability of the study results.

Comparison With Existing Literature

The significant increase in participant retention found in this study contrasts with previously published literature showing no benefit or possible harm from online communities. For example, Glasgow et al found that adding an online community to an information-focused, Internet-based intervention for diabetes self-management did not significantly improve any of the behavioral, biological, or psychosocial outcomes after 10 months compared with the information-only control group [25]. Some studies raise concerns about possible negative effects of online communities. Negative social modeling by online community participants may encourage participants to initiate or continue unhealthy behaviors or negative coping strategies. For example, Takahashi et al studied a peer-support group for depression and found that interactions with individuals who were depressed or had negative perceptions of the online community could trigger depressive states [26].

Consistent with the current findings, a few well-designed randomized controlled trials have shown positive results for Internet-based health behavior interventions. In one study, 580 participants with chronic low-back pain were randomized to an email discussion group or a no email discussion control group. Those randomized to the email discussion intervention group had significant improvements in pain, disability, role function, and health distress compared with the control group [27]. Notably, the email discussion list was active with over 2000 posted messages during the year-long intervention. In fact, this high level of activity may have been detrimental to continued participation; approximately 20% of the intervention-arm participants dropped out specifically because of the high email volume during the first month. In addition to the online community, participants in the intervention arm also received a book and videotape with information about chronic low-back pain, and these confounders may have impacted the improved outcomes. However, the high email volume suggests that the email exchanges played a significant role in improving outcomes.

Previous online community studies have also been limited by low community use. In one of the few trials to specifically examine the impact of an online community, Stoddard et al randomized participants to an online smoking cessation intervention with or without an online community. Of the 684 individuals randomized to the online community intervention, only 81 participants viewed or posted a message [28]. In another randomized study, McKay et al examined the effect of online community features on physical activity among patients with diabetes. Participants randomized to the intervention arm (n = 38) posted only a total of 42 messages during the 8-week intervention. Compared with the control group, participants with online community access had a small and nonsignificant increase in physical activity [29].

A large observational study of a smoking cessation website showed that only 24% of the 607 participants posted messages to the online community, and those who posted had higher quit rates than those who did not post. However, after controlling for use of other online features including interactive quitting tools and one-to-one messaging, the association between posting and increased quit rates was no longer significant. This suggests that the association between online community posting and smoking cessation was not causal and may have been confounded by exposure to other website components or by baseline commitment to quitting [30]. Collectively, these studies reinforce the concern that low online community use is a common problem in automated health behavior change interventions and that low use may weaken the effect of online communities on retention and behavior change outcomes.

Study Limitations

There are a number of study limitations to consider when interpreting this study. First, by chance and despite randomization, participants in the online community arm were more active at baseline than those in the no online community arm. This difference required control for baseline step counts in all analyses. This was accomplished by using change in step counts as the outcome rather than absolute step counts. Additionally, baseline step counts were included as a potential confounder in all between-arm multiple regression analyses. For future studies, a better approach would use stratified randomization to ensure equitable allocation of higher and lower baseline step-count participants into the two arms.

A second limitation is that the techniques used to stimulate online community involvement required significant research staff contributions to online community content. Such manipulations were necessary to test the effectiveness of an active online community. However, the staff-provided content may differ from spontaneous participant content, so these results might not be generalizable. Size does matter in an online community. Larger online communities tend to have more active interactions and tend to attract and retain more users. Increasing the size of the online community by randomizing more people to the online community arm than to the control arm was another strategy used to insure active and engaging interaction between participants. Studies of large, organic, and preexisting online communities may require less manipulation by research staff to sustain an active conversation, but such studies are difficult to randomize.

A third limitation is that the intervention lasted only 4 months and may not predict attrition and intervention adherence over longer periods. Additionally, there is no information about physical activity level during periods in which the pedometer was not worn. Participants may have been less active on days when they did not wear the pedometer, and this would artificially inflate the calculated average step counts. Because those in the no online community arm uploaded fewer days of valid pedometer data than those in the online community arm, this would bias the results in favor of the no online community arm.

Finally, the association between social support and online community use must be interpreted with caution. The measure of baseline social support was a single-item survey question designed to provide data to a message-tailoring algorithm rather than to precisely measure social support. However, using well-validated measures, previous investigators have established the connection between perceived social support and online community use. Barrera et al randomized participants with diabetes to 1 of 4 conditions: (1) a diabetes information only control, (2) a personal self-management coach, (3) an online community only, or (4) a combination of the personal self-management coach and the online community. Results showed that the online community alone or in combination with the personal self-management coach significantly increased perceived social support compared with the control group [31]. Social support may be a critical component to the success of online interventions, but whether this support actually mediates the relationship between online community use and program engagement remains to be determined. The online communities created in the Barrerra et al study as well as our study were created specifically for the study interventions. An alternative approach may be to create Internet-based health interventions that leverage preexisting friendships and online community affiliations. Building on existing social ties may increase intervention efficacy and is a worthy approach for future studies.

The current study is one in a series that examines the effects of specific components of an Internet-mediated walking program. Previous studies examined components related to participant safety, goal setting options, and group competition on intervention outcomes [6,32,33]. By examining specific components of complex programs, we hope to develop an evidence base that will guide the development of future interventions.

Conclusions

Adding online community features to an Internet-mediated walking program did not increase participant step count but did reduce attrition. Participants with low baseline social support for physical activity used the online community features more than participants with high baseline social support. Thus, online communities may be one solution to attrition from online health behavior change interventions, particularly in populations with low perceived social support for health behavior change. However, the design and implementation of active online communities is a considerable challenge. Part 2 of this manuscript describes some of the design choices and costs involved in implementing an online community [7].

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Conflicts of Interest

None declared

Multimedia Appendix 1

Invitation letter

[PDF file (Adobe PDF File), 83 KB - jmir_v12i4e71_app1.pdf]

Multimedia Appendix 2

Eligibility screening

[PDF file (Adobe PDF File), 57 KB - jmir_v12i4e71_app2.pdf]

Multimedia Appendix 3

Informed consent document

[PDF file (Adobe PDF File), 279 KB - jmir_v12i4e71_app3.pdf]

Multimedia Appendix 4

Medical clearance form

[PDF file (Adobe PDF File), 108 KB - jmir_v12i4e71_app4.pdf]

Multimedia Appendix 5

Presurvey (baseline survey)

[PDF file (Adobe PDF File), 302 KB - jmir_v12i4e71_app5.pdf]

Multimedia Appendix 6

Week two survey

[PDF file (Adobe PDF File), 169 KB - jmir_v12i4e71_app6.pdf]

Multimedia Appendix 7

Postsurvey 1

[PDF ile (Adobe PDF File), 81 KB - jmir_v12i4e71_app7.pdf]

Multimedia Appendix 8

Postsurvey 2

[PDF file (Adobe PDF File), 295 KB - jmir_v12i4e71_app8.pdf]

Multimedia Appendix 9

Tailored content for session 1

[HTML file (HTML Document), 49 KB - jmir_v12i4e71_app9.html]

Multimedia Appendix 10

Tailored content for session 2

[HTML file (HTML Document), 29 KB - jmir_v12i4e71_app10.html]

Multimedia Appendix 11

Tailored content for session 3

[HTML file (HTML Document), 33 KB - jmir_v12i4e71_app11.html]

Multimedia Appendix 12

Tailored content for session 4

[HTML file (HTML Document), 28 KB - jmir_v12i4e71_app12.html]

Multimedia Appendix 13

Tailored content for session 5

[HTML file (HTML Document), 24 KB - jmir_v12i4e71_app13.html]

Multimedia Appendix 14

Tailored content for session 6

[HTML file (HTML Document), 98 KB - jmir_v12i4e71_app14.html]

Multimedia Appendix 15

Tailored content for session 7

[HTML file (HTML Document), 4 KB - jmir_v12i4e71_app15.html]

Multimedia Appendix 16

Tailored content for barriers

[HTML file (HTML Document), 72 KB - jmir_v12i4e71_app16.html]

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Abbreviations

BMI: body mass index
SUH: Stepping Up to Health
VA: Veterans Affairs

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Original Paper

Attitudes of Heart Failure Patients and Health care Providers towards Mobile Phone-Based Remote Monitoring

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Abstract

Background: Mobile phone-based remote patient monitoring systems have been proposed for heart failure management because they are relatively inexpensive and enable patients to be monitored anywhere. However, little is known about whether patients and their health care providers are willing and able to use this technology.

Objective: The objective of our study was to assess the attitudes of heart failure patients and their health care providers from a heart function clinic in a large urban teaching hospital toward the use of mobile phone-based remote monitoring.

Methods: A questionnaire regarding attitudes toward home monitoring and technology was administered to 100 heart failure patients (94/100 returned a completed questionnaire). Semi-structured interviews were also conducted with 20 heart failure patients and 16 clinicians to determine the perceived benefits and barriers to using mobile phone-based remote monitoring, as well as their willingness and ability to use the technology.

Results: The survey results indicated that the patients were very comfortable using mobile phones (mean rating 4.5, SD 0.6, on a five-point Likert scale), even more so than with using computers (mean 4.1, SD 1.1). The difference in comfort level between mobile phones and computers was statistically significant ($P < .001$). Patients were also confident in using mobile phones to view health information (mean 4.4, SD 0.9). Patients and clinicians were willing to use the system as long as several conditions were met, including providing a system that was easy to use with clear tangible benefits, maintaining good patient-provider communication, and not increasing clinical workload. Clinicians cited several barriers to implementation of such a system, including lack of remuneration for telephone interactions with patients and medicolegal implications.

Conclusions: Patients and clinicians want to use mobile phone-based remote monitoring and believe that they would be able to use the technology. However, they have several reservations, such as potential increased clinical workload, medicolegal issues, and difficulty of use for some patients due to lack of visual acuity or manual dexterity.

(J Med Internet Res 2010;12(4):e55) doi:10.2196/jmir.1627

KEYWORDS

cellular phone; heart failure; telemedicine; patient monitoring; attitude

Introduction

Effective tools to help manage chronic conditions such as heart failure are required if limited health care resources are expected to meet the growing demand [1-5]. Recent studies have found that remote monitoring may be an effective strategy for improving heart failure health outcomes and reducing costs by providing real-time physiological information to health care providers and increasing self-care [6-14]. Mobile phone-based remote monitoring systems are being proposed because mobile phones have considerable computational power while being relatively inexpensive compared to dedicated remote monitoring hardware [15-17]. These systems also have the added benefit of being portable, enabling patients to be monitored anywhere that has mobile phone reception.

Prior to implementing mobile phone-based remote monitoring systems for heart failure management, the willingness and readiness of heart failure patients and their health care providers to use this technology should be determined. A few studies have investigated the perceptions of different patient populations regarding mobile phone-based remote monitoring, such as for asthmatic and hypertensive patients [18-20]. However, heart failure remote monitoring has additional challenges. Heart failure management requires several different parameters to be monitored, resulting in greater complexity, and a delayed response to a worsening heart failure condition could have critical consequences. Furthermore, the average heart failure patient is often older than patients with other chronic illnesses, which could result in them being less willing and able to use certain technologies.

The objective of this mixed methods study was to assess the attitudes of heart failure patients and their health care providers from a heart function clinic in a large urban teaching hospital toward the use of mobile phone-based remote monitoring.

Methods

Participants and Recruitment

Study participants (patients and clinicians) were recruited from the Heart Function Clinic at the University Health Network, Toronto, Canada. Eligible patient participants for both the interviews and questionnaires were outpatients diagnosed with heart failure. Other eligibility criteria included being older than 18 years, being able to speak and read in English, not being on the heart transplantation list, and being expected to survive more than 1 year. During their usual heart function clinic visit, all patients who met the inclusion criteria were asked by their cardiologist if they were willing to speak to the study coordinator regarding participating in the study. All patients who were approached for the interviews agreed to participate, and about 12 out of 112 patients approached to participate in the survey declined (11%). See Table 1 for demographic/clinical characteristics of the patient participants.

Clinician participants were physicians and nurse practitioners associated with the Heart Function Clinic. Clinicians were sent an email asking them to respond if they would like to participate in the study. All clinicians who were emailed agreed to be interviewed. The clinicians included 5 staff cardiologists, 5 nurse practitioners, and 6 clinical fellows.

Study Setting and Design

We asked 100 heart failure patients to complete and mail back a questionnaire that included questions on their perceptions of remote monitoring and their comfort with using mobile phones and computers. The questionnaires were administered between September 2009 and February 2010. The participants were asked to rate each of the 8 questions using a five-point Likert scale (Table 2). The estimated time to complete the questions was approximately 5 minutes. If patients did not return the questionnaire within 2 weeks, they were called to remind them to do so. Those who still did not return the questionnaire were called once again after another 2 weeks. The final response rate was 94 out of 100 administered questionnaires (94%).

Individual face-to-face semistructured interviews were also conducted with 20 heart failure patients (different patients from those surveyed) and 16 heart failure clinicians to elicit their attitudes toward mobile phone-based remote patient monitoring. Informal caregivers (eg, parents or children of the patients) were also present at the patient interviews, approximately a fifth of the time, and were encouraged to offer their opinions. The interviews were conducted between April 2008 and February 2009. The interviews were recorded and later transcribed. Each interview lasted between 30 and 60 minutes. The transcripts were analyzed using a conventional content analysis approach [21]. Two researchers (ES and CM) analyzed the transcripts independently and coded the transcripts with the software program NVivo version 7 (QSR International, Doncaster, Victoria, Australia). The researchers then discussed the themes and issues that emerged until a consensus was reached.

The study was approved by the University Health Network and University of Toronto Research Ethics Boards.

Description of a Mobile Phone-Based Remote Monitoring System

A description of a mobile phone-based remote monitoring system was provided to all study participants prior to eliciting any feedback. Patients were also walked through a prototype system, demonstrating the steps that they would have to take for the proposed remote monitoring. (See Multimedia Appendix 1 for the description and instructions for using the proposed monitoring system.) The described system included a wireless (Bluetooth-enabled) weight scale, blood pressure monitor, and single-lead electrocardiogram (ECG) recorder that automatically transmitted the data to a mobile phone. Patients were expected to take their weight and blood pressure (pulse would be included with the blood pressure measurement) every morning and an ECG recording weekly. They were also asked to record their symptoms each morning by answering symptom questions by pressing 1 for no and 2 for yes on the mobile phone keypad. The mobile phone automatically transferred the data to computer servers for analysis using third-generation (3G) technology. Depending on the readings, an alert message could be generated and sent to the patient’s mobile phone. When an alert was generated, an email was also sent to a cardiologist’s mobile phone with all relevant patient information. Both patients and clinicians were able to view all historical data and alerts on a secure password-protected website.

Results

Survey Results

Table 1 summarizes the demographic and clinical characteristics of the patients who completed and returned the questionnaire. The demographics of the participants are representative of the patient population who attend the University Health Network Heart Function Clinic.

Table 2 summarizes the results from the survey. The patients indicated that they thought it was important to monitor their weight and blood pressure. They were slightly more comfortable using a mobile phone than a computer ($P < .001$, 2-tailed paired Student t test, $t_{89} = 4.13$), but rated the comfort level high for both. Most patients could easily access a computer. Patients rated their confidence in looking up health information on a mobile phone and computer equally high. Patients indicated moderately high confidence that their privacy would be secure if their health information was accessible by a computer.

Table 1. Demographic and clinical characteristics of patient participants who returned a completed survey (missing values account for totals less than 94)

Variable		Response, N=94
Mean age, years (SD)		54.6 (13.4)
Gender	Male	74 (79%)
	Female	20 (21%)
Ethnicity	Caucasian	71 (76%)
	African Canadian	7 (8%)
	Southeast Asian	4 (4%)
	Chinese	4 (4%)
	Other	7 (8%)
Marital status	Married	62 (67 %)
	Never married	17 (18%)
	Divorced	10 (11%)
	Widowed	4 (4%)
Highest education achieved	Less than high school	7 (8%)
	High school	25 (27%)
	Trade or technical training	16 (17%)
	College/university undergraduate	37 (40 %)
	Postgraduate	8 (9%)
Income	< $15,000	20 (21%)
	$15,000 - $29,999	17 (18%)
	$30,000 - $49,999	17 (18%)
	$50,000 - $74,999	14 (15%)
	> $75,000	14 (15%)
	Preferred not to answer	12 (13%)
Employment	Full-time	27 (29%)
	Part-time	4 (4%)
	Disabled	37 (40 %)
	Retired	15 (16%)
	Unemployed	11 (12%)
New York Heart Association class	II	40 (43%)
	II/III	12 (13%)
	III	38 (40%)
	IV	4 (4%)
Mean left ventricular ejection fraction (SD)		26.8 (8.6)
Mean length of heart failure, years (SD)		6.3 (6.7)
Primary cause of heart failure	Ischemic	32 (34%)
	Idiopathic	47 (50%)
	Other	15 (16%)

Table 2. Mean responses to survey questions (1: Strongly Disagree, 2: Disagree, 3: Neither Agree or Disagree, 4: Agree, 5: Strongly Agree)

Survey Question	Mean Response (SD)
I need to weigh myself every day at home.	4.5 (0.8)
It is important to take my blood pressure at home as often as my doctor says I should.	4.3 (0.9)
I am confident that my privacy would be secure if my health information was accessible by a computer.	3.9 (1.2)
I feel comfortable using a mobile phone.	4.5 (0.6)
I feel confident that I could use a mobile phone to look up my health information if shown how to do it.	4.4 (0.9)
I feel comfortable using a computer.	4.1 (1.1)
I feel confident that I could use a computer to look up my health information if shown how to do it.	4.4 (0.9)
It is easy for me to get access to a computer at home.	4.4 (1.1)

Interview Results

Heart failure patients and their health care providers perceived numerous benefits and barriers to using mobile phone-based remote monitoring. Table 3 summarizes the benefits and Table 4, the barriers. The willingness and readiness of the patients and clinicians to use a mobile phone-based remote monitoring system are presented separately below, and are partially informed by the perceived benefits and barriers.

Willingness to Use Mobile Phone-Based Remote Monitoring

Most patients perceived that monitoring their weight and blood pressure was important to help manage their heart failure condition. Several interviewed patients volunteered without prompting to use the monitoring system whenever it was made available. Interviewed patients stated that they would be willing to try using the proposed remote monitoring system under the following conditions and caveats:

First, the monitoring system should be an adjunct to their relationship with their clinician at the heart function clinic. It should not be a replacement.

Second, patients would adhere to taking daily measurements long-term if they perceived clear tangible benefits from using it. The patients also stated that they would monitor their weight, blood pressure, and other factors more closely if their heart condition ever worsened.

Third, the system should be as easy to use as possible. They also requested appropriate training and a way to get technical support if they needed it.

Fourth, some patients questioned the necessity of monitoring their blood pressure daily. Some patients did not believe that they needed to take their blood pressure daily because their blood pressure in the past had been stable.

The clinicians thought that the proposed remote monitoring system could help them manage their patients' condition by providing timely alerts to worsening health and additional information about their patients that they would otherwise not have. They also believed that the monitoring system could improve their patients' self-care. All interviewed clinicians were willing to try using the monitoring system under the following conditions and caveats:

First, the system should not result in a significant increase in workload for them. The clinicians stated that they did not have further capacity to take on duties that would add to their already busy schedule. In particular, they were concerned about managing the alerts during off-hours (during nights, week-ends, and vacation). The clinicians suggested that a nurse practitioner be assigned to initially respond to the alerts and to contact the cardiologists as necessary.

The medicolegal implications of using the monitoring system needed to be determined. Clinicians were concerned that they would be legally liable if they did not respond to an alert immediately and the patient's health worsened as a result. Clinicians recommended that a method was necessary to document their actions from the alerts for medicolegal purposes.

The patient alerts and instructions needed to be appropriate and safe. Clinicians were concerned that the alerting algorithm would generate inappropriate alerts and instructions to the patient. Some suggested that a health care provider should vet each alert before it was sent to the patient.

Ability to Use Mobile Phone-Based Remote Monitoring

Patients generally thought that they would be able to use the proposed monitoring system. Many of them already practiced some form of self-monitoring, including weighing themselves in the morning and taking their blood pressure periodically with their own home blood pressure monitor. All patients who owned home blood pressure monitors and weight scales thought they were easy to use. In addition, some patients had access to a computer and many already owned a mobile phone. Several of the patients who were not accustomed to the technology stated that they would be able to receive help from family members (eg, their spouses and children).

Both the interviewed patients and clinicians thought that older and less technologically savvy patients could have trouble operating the mobile phone. In particular, they thought that the small buttons and font on the mobile phone could cause difficulty to some patients. However, none of the interviewed patients thought that they themselves would have significant problems using the equipment.

The interviewed clinicians did not have concerns on their ability to use the system but instead cited barriers related to the readiness of the clinic and the health care system to support the use of remote monitoring. For example, additional human resources would be required at the clinic, such as a nurse practitioner, to respond to the alerts at all times. Another concern was that there was no method of remuneration for phone interactions with their patients.

Table 3. Perceived benefits by patients and clinicians (quotes in italics)

Benefit	From Patient Interviews	From Clinician Interviews
Clinical care improvement	Clinicians would be able to view their patients' health data easily and quickly. The alerts sent to the physicians would enable them to provide their patients with immediate feedback.	Clinicians would be able to monitor their patients closely and would be provided with more information than they previously had to base their clinical decisions on. The information would be particularly useful for medication titration, and could help with false high blood pressure seen in clinic (ie, white coat syndrome). The alerts would be beneficial to inform them when their patients needed their help the most.
	The fact that it goes to a hospital and to a team of professionals that could give me feedback about where I am in my health and to be able to direct me to stay on track and that all this technology is grouped together in order to help me that way. I think that's star quality treatment.	
Self-care improvement	The system would improve the patient's understanding of how lifestyle choices would affect their health and would help them keep track of their health ("body awareness"). The system would also help them get into a routine and inform them when they are not at their ideal target range for their weight and blood pressure.	Clinicians thought the system would help reinforce the instructions that were given to their patients in clinic (eg, following reduced salt and fluid intake).
	It gives you a vision of how things are going...it's probably easier for you to make slight adjustments also to your eating habits and that will allow you to better treat your health, better treat your symptoms.	*We throw a lot of information at them and they probably don't get half of it and they can come home and this is a bit of a security blanket.*
Increased reassurance/ accountability	Patients and their caregivers would feel reassured that their doctors would be watching over them. They also thought they would feel a sense of accountability because they would be closely watched, which would have a positive effect of keeping them adherent to their self-care regimen, including diet and exercise.	Not mentioned in the interviews.
	You learn about your foods and your exercise, smoking, drinking and all that stuff, but this would kind of give you motivation to stay within say a weight range all the time and it's almost like a trainer.	
Reduced clinic visits	The number of times they would have to visit the clinic would be reduced. Many patients stated that they traveled far distances to get to their scheduled clinic visits, which was inconvenient for themselves and their family members.	Clinic visits by some patients could be reduced if they were closely monitored at home.
Ability to monitor even if they were away from home	Patients would be able to bring it with them on vacation (eg, Florida) and to their cottage.	Not mentioned in the interviews.
	It's not ready of course but I'm leaving for Florida in a couple of days or so, well, for the month of March. I could take it with me if I was on the system.	

Table 4. Perceived barriers by patients and clinicians (quotes in italics)

Barrier	From Patient Interviews	From Clinician Interviews
System not suitable for all patients	Patients with poor vision could have trouble reading the mobile phone screen, and patients with inadequate manual dexterity could have problems entering information on the mobile phone keypad. However, none of the interviewed patients thought they themselves would have these problems. Patients also had concerns of getting used to the technology, but they thought they would be able to learn to use it with technical support and training. Some patients stated that their family members could help them use the technology.	Clinicians echoed the concerns expressed by the patients that some would have difficulty using the proposed monitoring system. In addition, they were concerned that patients predisposed to anxiety might not be suitable to use it.
		You never want to overload people because not everybody is a real techy kind of person and you're dealing with an older population that's not really inclined. A lot of these patients are going be intimidated at first, you know, and will just need some gentle training but I have no doubt that you can train people to do this because we've trained them to take transplant medications.
Clinical workflow challenges	Clinicians responding to the alerts could be “overburdened”, especially if time was not specifically allocated for managing the alerts.	Clinicians are too busy to respond to the alerts. They were concerned about managing the alerts 24/7, including when they were away on vacation. The most common suggestion was to have a nurse practitioner respond to the alerts. They also commented that there should be a way to financially reimburse physicians for calling patients.
	I think they would just get bombarded by calls every time you had a symptom.	
Medicolegal issues	Not mentioned in the interviews.	There could be legal implications if clinicians did not respond to an alert immediately and the patient’s health further deteriorated. They thought that a method to document their actions would be necessary for medicolegal reasons.
Inappropriate automated instructions	The system might instruct them to go to the emergency department (ED) unnecessarily, which would contribute to the backlog in the ED. They were also concerned about the anxiety that unnecessarily urgent alert messages could cause.	The automatically generated instructions and alerts sent to the patients could be inappropriate. Some clinicians suggested that a clinician should vet each alert before the alert is sent to the patient.
Security/ privacy	In general, patients did not have major security concerns about using the monitoring system as long as reasonable measures were taken to protect the confidentiality of their information.	The patient information must be secure, and appropriate technological measures must be taken to ensure patient confidentiality.

Discussion

Willingness to Use Mobile Phone-Based Remote Monitoring

Heart failure patients and their health care providers perceived a large opportunity for remote monitoring to increase self-care and improve clinical care. Patients thought that remote monitoring would provide a sense of reassurance. This feeling of reassurance was also found in a previous trial investigating remote monitoring of patients with implantable cardioverter-defibrillators for cardiac resynchronization therapy [22]. However, patients did not want remote monitoring to result in a decrease in communication with health care providers, and thought that they would continue remote monitoring only if there were clear and tangible benefits to their doing so. These findings were supported by a study investigating the views of patients with type 2 diabetes on self-monitoring of blood glucose [23]. It found that self-monitoring decreased over time largely because patients did not know how to interpret and act on the blood glucose readings and they perceived a lack of interest by their clinicians in their readings.

Our findings had similarities to the results from studies examining the attitudes of patients and health care providers on using mobile phone-based remote monitoring with other patient populations. A study of the acceptability of mobile phone-based remote monitoring of hypertensive patients found that the patients and clinicians were willing to try using the technology because they perceived that it would encourage self-care through improved medication and lifestyle behavior adherence, and that it would help detect health deterioration earlier than without its use. The study found that clinicians were concerned about the increase in workload and the need to respond immediately to the continuous incoming blood pressure information [18]. Studies with asthma patients also found high levels of acceptability in using mobile phone-based remote monitoring [19, 20]. The perceived benefits included identifying poor control of the asthma condition quickly and reducing the need for face-to-face consultations. Both patients and clinicians cited increased clinical workload and implementation costs as concerns.

Ability to Use Mobile Phone-Based Remote Monitoring

The survey data indicated that patients were comfortable using mobile phones and computers, and were confident that they could learn to look up health information on both mobile phones and computers. In addition, many patients already use home medical devices, such as weight scales and blood pressure monitors. The perceived readiness of the patients to use mobile phone-based remote monitoring technology is in contrast to the findings of a study with asthma patients [20]. The asthma study had a low survey response rate by the clinicians and patients, and had a high rate of return of uncompleted questionnaires that stated there was a lack of perceived relevance. The researchers concluded that mobile phone-based remote monitoring was not of interest to the majority of the participants, and remained an interest only to early adopters of technology.

It is possible that the increased ubiquity of mobile phones between the study of Pinnock and colleagues in 2005 and our study in 2010 is partly responsible for this difference. Our study participants rated their comfort of using a mobile phone higher than using a computer, a difference that was found to be statistically significant ($P < .001$). A wireless market study report found that, in 2006, mobile phone ownership was much higher for younger Canadians than those 55 years or older, but that the usage among older Canadians had grown more between 1997 and 2006 [24]. A systematic review of studies investigating mobile phone voice and text messaging interventions for health care found improvements in outcomes of care and processes of care, and suggested a “trend toward a digital divide in the reverse” [25].

Undoubtedly, the use of mobile phone-based remote monitoring is not suited for all heart failure patients, as acknowledged by both the interviewed patients and the clinicians. For example, patients with poor manual dexterity or vision and those who are predisposed to high anxiety may not be suitable candidates for the use of this technology. However, all 20 of the interviewed patients thought that they themselves would be able to use the proposed technology. This was similar to the finding in a trial of mobile phone remote monitoring of asthma patients, where the interviewed patients hypothesized that patients less comfortable with mobile phones might have greater difficulty using the equipment, but none of the patients inexperienced with mobile phones actually reported problems [19]. Future investigation is warranted into whether the perception of the percentage of patients who would be unable to use mobile phone-based remote monitoring is higher than in reality.

A factor that could influence the ability of patients to successfully use a mobile phone-based monitoring system is its design. A user-centric design process to develop a simple and easy-to-use system could significantly increase the number of patients who could successfully use the technology. The interviewed patients stressed the importance of developing a system that is robust and as easy to use as possible, and that technical support will be required. Studies have shown that weaknesses in telemedicine implementations are largely attributed to technical problems [19, 26]. Another factor to success is the availability of informal caregivers to help. Many of the patients stated that they had spouses and children who were much more technologically savvy than they were and that these relatives could help the patients use the monitoring system.

Limitations

Participants in this study were recruited from a single heart function clinic. This particular clinic treats a higher proportion of severely ill patients compared to other heart function clinics. Patients attending this clinic include young heart failure patients (eg, in their 20s). The average age of the heart failure patients attending the clinic is approximately 54 years (SD 15 years), which is consistent with the participants in this study. Therefore, it is possible that the study participants might be slightly more comfortable than the average heart failure patient with using technology. Another limitation is that the patients who agreed to participate in the study may have been biased to have a more positive attitude toward remote monitoring. However, the participation refusal rate was very low, which suggests that the bias was minimal. Finally, the mobile phone-based remote monitoring system that was proposed to the participants had functionality that was beyond what is available in current best practice. A description of the functionality of currently available systems may have elicited less positive responses.

Conclusions

The heart failure patients participating in this study were confident in their ability to use a mobile phone-based remote monitoring system, largely because mobile phones are becoming increasingly pervasive even among older individuals. The patients and clinicians were willing to use a mobile phone-based remote monitoring system because they perceived many benefits, including providing patients with immediate feedback at the earliest sign of deteriorating health. However, both groups cited several caveats to their willingness to use such a system. The monitoring system would have to be easy to use, the benefits to using the system must be evident and tangible, patient information must be secure, and any automated instructions or feedback to the patient must be trusted. Reservations by the clinicians regarding using the system included increased clinical workload and medicolegal issues. If the concerns voiced by the patients and clinicians are first addressed, mobile phone-based remote monitoring could be a relatively inexpensive and convenient tool to improve heart failure management.

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Conflicts of Interest

None declared

Multimedia Appendix

Description provided to study participants of the proposed mobile phone-based heart failure remote monitoring system.

[PDF file (Adobe PDF), 90 KB - jmir_v12i4e55_app1.pdf]

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Original Paper

Consumers' Perceptions About and Use of the Internet for Personal Health Records and Health Information Exchange: Analysis of the 2007 Health Information National Trends Survey

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Abstract

Background: Personal health records (PHRs) and the sharing of health information through health information exchange (HIE) have been advocated as key new components in the effective delivery of modern health care. It is important to understand consumer attitudes toward utilization of PHRs and HIE to evaluate the public's willingness to adopt these new health care tools.

Objective: The purpose of this study was to examine consumer attitudes toward PHRs and their health care providers' use of HIE, as well as to evaluate consumer use of the Internet for tracking PHRs.

Methods: Analysis of data from the 2007 iteration of the Health Information National Trends Study (HINTS, N=7674) was conducted using multivariate logistic regression to identify predictors of consumer (1) appraisal of PHRs, (2) appraisal of health care provider use of HIE, and (3) use of the Internet for tracking PHRs.

Results: : Approximately 86% of US adults rated electronic access to their PHRs as important. However, only 9% of them used the Internet for tracking PHRs. Those who rated electronic access to their PHRs as important were more likely to be Hispanic (odds ratio [OR] = 1.34, 95% confidence interval [CI] 1.04 - 1.72) and Internet users (OR = 1.27, 95% CI = 1.02 - 1.57) and less likely to be age 65 and above (OR = 0.50, 95% CI = 0.38 - 0.67) or individuals whose doctors always ensured their understanding of their health (OR = 0.62, 95% CI = 0.49 – 0.78). Those who rated HIE as important were more likely to be 45 to 54 years of age (OR = 1.46, 95% CI = 1.03 - 2.08), 55 to 64 years of age (OR = 1.83, 95% CI = 1.32 - 2.53), or 65 and above (OR = 1.76, 95% CI = 1.27 - 2.43) and less likely to be women (OR = 0.80, 95% CI = 0.68 - 0.95) or individuals who perceive their health information as not safely guarded by their doctors (OR = 0.53, 95% CI = 0.40 - 0.69). Among Internet users, those who used the Internet to track their PHRs were more likely to be college graduates (OR = 1.84, 95% = 1.32 - 2.59) or to have completed some college courses (OR = 1.46, 95% CI = 1.02 - 2.11), to be Hispanic (OR = 1.92, 95% CI = 1.23 - 2.98), or to be individuals with health care provider access (OR = 1.90, 95% CI = 1.21 - 2.97). Women were less likely to use the Internet for tracking PHRs than men (OR = 0.78, 95% CI = 0.61 - 1.00).

Conclusions: Despite widespread positive appraisal of electronic access to PHRs as important, Internet use for tracking PHRs remains uncommon. To promote PHR adoption, the digital divide associated with the gap in health literacy must be improved, and cultural issues and the doctor-patient relationship need to be studied. Further work also needs to address consumer concerns regarding the security of HIE.

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KEYWORDS

Internet; personal health records; health information exchange; consumer perceptions and utilization; demography; health care surveys; health communication trend

Introduction

The Institute of Medicine’s 2001 landmark report, Crossing the Quality Chasm, notes that “the advent of the Internet and the World Wide Web has placed us on the threshold of a change that is reshaping virtually all aspects of society, including health care delivery” [1]. The report recommended that “access to care should be provided over the Internet, by telephone, and by other means in addition to in person visits.” In 2005, the Pew Internet and American Life Project survey found that one fifth of Americans who used the Internet reported that the Internet had greatly improved the way that they received information about health care [2]. They also found that 17 million Americans reported that the Internet played a crucial or important role as they helped another person cope with a major illness [2]. According to an analysis of data from the 2003 Health Information National Trends Survey, there were substantial differences between where people preferred to obtain cancer-related information (half preferred to go to health care professionals) and where they actually got this information; consumers actually used the Internet to access health information far more often than getting information from their doctors [3].

Personal health records (PHRs), one of the emerging health informatics technologies, provide powerful and transformative potential for enhancing the delivery of health care. PHRs are electronic applications that consumers can use to enter and exchange their own health data and to access information from their medical records and other resources [4]. Some of these approaches are “tethered” applications to a given institution and largely focus on insuring patient access to data collected in the course of clinical care (eg, PatCIS [5] and PatientSite [6]). Tethered PHRs’ application components continue to expand to include features such as clinical communication capabilities, disease management tools, decision support systems, and patient annotation capabilities, with great potential to advance patient engagement and activate the patient in knowledge-based collaborations with clinicians, resulting in a transformation of the patient-provider relationship and patient-centered care [4,7-10]. “Untethered” PHRs are freestanding repositories into which an individual can document various health behavior observations regarding diet, exercise, smoking, and other lifestyle changes (eg, WebMD, www.webmd.com). It is advocated that many untethered applications will perform these functions superiorly to some tethered PHRs and can be useful supplements to them [11]. Research consistently shows that consumers have growing and significant interest in using PHRs due to employers demanding PHRs to be included in health plans, health care reforms identifying PHRs as solutions, and the market entry of Google and Microsoft into the promotion of PHRs. However, actual utilization of PHRs technologies is still low [12]. More than 60% of people participating in a Deloitte 2008 Survey of Health Consumers reported that they wished they had online access to their medical records [13]. Another public survey administered by the Markle Foundation found that 89% of the survey respondents reported that they would like to review their medical records if they could, and 65% were interested in accessing their own PHRs online [14]. In 2008, a national survey reported that 79% of US consumers agreed that using electronic PHRs could provide significant benefits in managing their health and heath care services [15]. However, only 2.7% of adults have an online PHRs, and 80% of those who have accessed their online PHRs considered it to be valuable [15]. In sum, trends in consumer survey research suggest growing interest in using electronic PHRs but also reflect limited access to them.

Sharing appropriate patient information electronically among different parties and the ability to access medical records online have been cited as high priorities for encouraging health care technology investment and facilitating health care reform [16,17]. Health information exchange (HIE) benefits include providing real-time decision support to clinicians and patients, making critical clinical information available, and reducing unnecessary testing [18,19]. Models also suggest that HIE will have substantial financial benefits [20]. However, issues of patient privacy and data security have often been raised because HIE involves electronically exchanging patient-identified health information across separate entities that might have potential threats to the confidentiality of the information [21,22]. From the patient's perspective, confidentiality is essential to the patient–physician relationship [21,22]. Patients need to be assured that only information crucial to their correct treatment will be disclosed to providers who have bona fide needs for this information. One recent study reported that patients were enthusiastic about HIE, recognizing its capacity to improve the quality and safety of health care despite concerns about the privacy of their health information [23]. Educational materials and thoughtful consenting processes were identified as critical facilitators for patients’ HIE participation and engagement [23]. Another study conducted with primary care patients found that many patients were unwilling to have their personal information distributed other than for the purposes of their clinical care and that they would like to be consulted before their information is released [24]. The high level of interest, as well as concerns, about HIE suggest that more attention should be directed toward achieving a better understanding of consumers’ attitudes and willingness to engage in health information exchange.

The most recent iteration of the Health Information National Trends Survey (HINTS 2007) is an ideal data source for examining the perceptions, prevalence, and user characteristics of Internet applications for PHRs and HIE for US consumers. The HINTS 2007 nationally representative survey contains specific questions with regard to individual attitudes toward using the Internet for personal health information electronic access and exchange. Since HINTS 2007 also includes many demographic and health-related questions, it also allows examination of the association between these primary interest questions and other domains. This study’s specific aims were to identify (1) the sociodemographic and health-related predictors of consumer perceptions about the importance of PHRs and HIE and (2) the prevalence and predictors of use of the Internet for tracking personal health information.

Methods

Data Source

This study used data from the publicly accessible 2007 HINTS developed by the National Cancer Institute, a biennial national probability survey of US civilian noninstitutionalized adults. HINTS collects representative data regularly (the 3 iterations were in 2003, 2005, and 2007) to assess the US public's use of health-related and cancer-related information and perception, knowledge, and behaviors. The primary goal of the HINTS program is to provide updates on health communication usage, trends, and practices across the US population. Information about the HINTS survey conceptual framework and methodology are available elsewhere [25,26]. The 2007 HINTS contains some changes with regard to new survey items (such as items addressing concepts of PHRs and HIE) and a new sampling method to increase response rates and reduce bias [27]. For data collection, 2 formats were used: (1) a random digit dial (RDD) telephone survey with a computer-assisted telephone interview of representative samples of US households with landline telephones (n = 4092) and (2) a pencil-and-paper questionnaire mailed to representative samples of US postal addresses oversampled for minorities (n = 3582). The application of the dual sampling frames was an alternative solution for a recent dramatic decrease in telephone survey response rates and is an effective method currently being employed by other government agencies.

A total of 7674 adults participated in the survey. All participants were asked about their attitudes toward "accessing their medical information electronically" (our question for PHRs importance) and "their health care providers sharing medical information electronically" (our question for HIE importance). Only those 5078 survey participants who had access to the Internet were asked about their "use of the Internet for tracking personal health records" (our question for PHRs use). In the present analysis, we included both final sample weights and replicate weights to obtain population-level estimates with the correct standard errors [27].

Study Variables

Data for each variable were grouped into categories consistently with other research using HINTS data [28-30].

Sociodemographic Variables

Age, gender, education, and race/ethnicity were included in the analysis. Age was categorized into 6 groups: 18 to 24, 25 to 34, 35 to 44, 45 to 54, 55 to 64, and 65 and above. Educational level was categorized as high school degree or less, some college, or college graduate. Race and ethnicity was categorized into 4 categories: non-Hispanic white, non-Hispanic black (African American), Hispanic, and non-Hispanic other. Non-Hispanic other included American Indian, Asian American, Pacific Islander, Native Hawaiian, and Alaskan Native.

Health-Related Variables

In all, 3 health-related variables were included. The first was self-identified overall health status, recoded into 2 categories: (1) excellent, very good, or good, and (2) fair or poor. The second was the respondent's cancer experience with 3 mutually exclusive categories: (1) having had a personal diagnosis of cancer (regardless of whether or not a family member had been diagnosed with cancer), (2) having had a family member diagnosed with cancer, or (3) having had no personal experience or family member with cancer. We also included a health care access variable, indicated by whether the respondent reported having a regular health care provider or not (yes or no response).

Internet Access Variable

The question "Do you ever go online to access the Internet or World Wide Web or to send and receive an email?" was used to measure the Internet status of the respondents (yes or no response).

Perceived Deficits in Health Care Provider Variable

With respect to individuals' perceptions of their information comprehended by their providers, we used the question: "How often did they (health care providers) make sure you understood the things you needed to do to take care of your health?" The responses to this question were recoded to 2 categories: (1) always/usually and (2) sometimes/never.

Personal Health Information Security Variable

Individuals' perceptions for the security level of personal health information were measured by the responses to the statement: "In general, I think that the information I give doctors is safely guarded" (agree or disagree response).

Outcome Variables: Personal Health Records Perception and Use Variables

Individual importance attitude toward accessing personal electronic medical records was measured by the following question: "How important would it be for you to get your own medical information electronically?" Responses to this question were recorded on a 3-point scale of importance that denoted (1) very important, (2) somewhat important, and (3) not at all important. Use of the Internet for tracking personal health records was assessed by responses to the following question: "In the past 12 months, have you done the following while using the Internet: Kept track of personal health information, such as care received, test results, or upcoming medical appointments?" (Respondents were asked to give a yes or no response.)

Outcome Variable: Health Information Exchange Perception Variable

The importance that individuals placed on health information exchange among providers was assessed by the question: "How important is it to you that your health care providers are able to share your medical information with each other electronically?" Responses to this question were recorded on a 3-point scale of importance that denoted (1) very important, (2) somewhat important, and (3) not at all important.

Data Analysis

Analyses were done using Stata 10.0 (College Station, Texas, USA) package to accommodate the sampling design of HINTS. Any responses of “refused” or “don’t know” were treated as missing values for all analyses. Unknowns were removed from the denominators when calculating percents. We examined 3 outcome variables: (1) How important would it be for you to get your own medical information electronically? (2) How important is it to you that your health care providers are able to share your medical information with each other electronically? (3) In the past 12 months, have you kept track of personal health information, such as care received, test results, or upcoming medical appointments while using the Internet? The data sampling mode effect was tested against all 3 outcome variables. The 2 PHR outcome variables were significantly different between mail and telephone survey samples. To be consistent, mode effect was adjusted for all analyses. All point estimations were adjusted by the final sample weights and the jackknife method was used for the standard error estimations with 100 replicate weights incorporated. Descriptive statistics were calculated for all variables. A separate bivariate analysis was conducted to estimate the proportion in each responsive category of the study variables between Internet users and Internet nonusers. Logistic regression analyses were used to answer the research questions of whether selected sociodemographic and health domain variables predict the individual’s perception for PHRs and HIE, as well as the user behavior of tracking personal health information on the Internet.

Results

Characteristics of the Sample Population

In 2007, approximately 69% of the US population reported that they used the Internet. The findings showed that Internet users were more likely to be younger, healthier, non-Hispanic white, with some college education and without a history of cancer diagnosis. (The weighted sample sociodemographic and study variables are summarized between Internet users and Internet nonusers in Table 1). Approximately half of the overall sample perceived the PHRs and HIE as “very important.” Of the Internet users, approximately 15% (772/5078) reported using the Internet to track their personal health information.

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

Characteristic	Internet Users (Total n = 5078, 68.7%)		Internet Nonusers (Total n = 2566, 31.3%)		
	n	Weighted Percent[a]	n	Weighted Percent[a]	*P* Value
Age					.001
18-24	303	16.2	51	6.1	
25-34	629	19.7	130	13.1	
35-44	913	22.0	189	13.9	
45-54	1213	19.9	357	17.6	
55-64	1137	13.7	464	14.5	
65+	860	8.4	1344	34.9	
Gender					.001
Male	1934	47.1	1028	51.9	
Female	3141	52.9	1533	48.1	
Education					< .001
High school or less	1014	27.8	1460	70.7	
Some colleague	1608	39.8	576	22.2	
Colleague graduate	2309	32.4	323	7.1	
Race/ethnicity					< .001
Non-Hispanic white	3868	74.5	1561	57.3	
Hispanic	324	9.4	295	21.1	
Black/African American	381	9.5	302	15.8	
Other	283	6.7	140	5.8	
General health					< .001
Excellent, very good, or good	4383	88.4	1736	72.4	
Fair or poor	545	11.6	622	27.6	
Cancer experience					< .001
No personal experience with cancer	1262	29.5	872	40.0	
Have family with cancer	3235	64.7	1277	50.6	
Cancer survivor	581	5.8	417	9.4	
Have regular health care provider					< .001
No	1008	29.1	627	35.1	
Yes	4035	70.9	1890	64.9	
How often did they (health care providers) make sure you understood the things you needed to do to take care of your health?					.77
Sometimes/never	496	12.9	270	13.3	
Always/usually	4024	87.1	1885	86.7	
In general, I think that the information I give doctors is safely guarded.					.23
Agree	4370	87.5	2190	89.1	
Disagree	613	12.5	259	10.9	
How important would it be for you to get your own medical information electronically?					< .001
Very important	2579	46.6	1007	53.6	
Somewhat important	1767	32.7	762	35.2	
Not at all important	641	20.7	605	11.2	

Characteristic	Internet Users (Total n = 5078, 68.7%)		Internet Nonusers (Total n = 2566, 31.3%)		
	n	Weighted Percent[a]	n	Weighted Percent[a]	*P* Value
How important is it to you that your healthcare providers are able to share your medical information with each other electronically?					.04
Very important	2564	47.2	1304	52.0	
Somewhat important	1905	42.0	834	37.4	
Not at all important	492	10.8	243	10.6	
In the past 12 months, have you done the following while using the Internet: Kept track of personal health information such as care received, test results, or upcoming medical appointments[b]?			Not applicable	Not applicable	Not applicable
Yes	772	13.8			
No	4271	86.2			

[a] Results were weighted to be representative of the adult population of Internet users residing in the United States. Mail and RDD sample were separately weighted due to different survey mode effect. All analyses were adjusted by survey mode effect.

[b] The use of the Internet for tracking personal health information was only asked of Internet users.

[c] *P* values associated with Wald statistics

Multivariate Analyses

Odds of Importance of Accessing Personal Health Records Electronically

Age, racial ethnicity, Internet access, and perceived deficits in information comprehended by health care providers emerged as the significant predictors in the model of perceived importance for accessing personal health records electronically. Individuals aged 65 and above were about half as likely as those aged from 18 to 24 to value the importance of accessing personal health records electronically (odds ratio [OR] = 0.50, 95% confidence interval [CI] = 0.38 - 0.67). Members of the Hispanic population were more likely than non-Hispanic white respondents to value the concept of electronic personal health records (OR = 1.34, 95% CI = 1.04 -1.72). Compared with those who did not have Internet access, Internet users were more likely to positively appraise the importance of accessible electronic personal health records (OR = 1.27, 95% CI = 1.02 - 1.57). Those who reported deficits in information comprehended by their health care provider were more likely than those who reported that their doctors always ensured their understanding of their health to rate accessing personal health records electronically as important (OR = 0.62, 95% CI = 0.49 - 0.78).

Odds of Importance of Personal Health Information Exchange Among Health Care Providers

Our analysis showed that age, gender, and perception of personal health data security predicted who was more likely to value the importance of health information exchange among providers. Adults aged 45 to 54, 55 to 64, and 65 and above were more likely than those aged 18 to 24 to rate the use of health information exchange as important, while the age group 55 to 64 reported the highest importance of HIE (OR = 1.83, 95% CI = 1.32 - 2.53). Females were less likely than males to perceive the importance of their health care providers sharing personal health records electronically (OR = 0.80, 95% CI = 0.68 - 0.95). Respondents who perceived their health information was not safely guarded by their doctors were about half as likely to value the importance of health information exchange among providers as those who believed their personal information was secured (OR = 0.53, 95% CI = 0.40 - 0.69).

Table 2. Multivariate ordinal logistic regression of predictors of perceived importance for accessing electronic personal health records (n = 7383) and health care provider sharing personal health information electronically (n = 7366)[a]

Characteristic	Odds of Importance of Accessing Personal Health Information Electronically		Odds of Importance for Health Care Providers Sharing Personal Health Information With Each Other Electronically	
	OR (95% CI)	*P* Value[b]	OR (95% CI)	*P* Value[b]
Age		< .001		< .001
18-24	1.00		1.00	
25-34	0.90 (0.63 - 1.28)	.55	1.03 (0.73 - 1.44)	.88
35-44	1.03 (0.74 - 1.44)	.84	1.39 (0.97 - 1.98)	.07
45-54	0.90 (0.66 - 1.22)	.48	1.46 (1.03 - 2.08)	.03
55-64	0.89 (0.64 - 1.23)	.47	1.83 (1.32 - 2.53)	< .001
65+	0.50 (0.38 - 0.67)	< .001	1.76 (1.27 - 2.43)	< .001
Gender		.45		.01
Male	1.00		1.00	
Female	0.94 (0.81 - 1.1)	.45	0.80 (0.68 - 0.95)	.01
Education		.86		.66
High school or less	1.00		1.00	
Some colleague	1.06 (0.87 - 1.29)	.59	0.91 (0.75 - 1.12)	.37
Colleague graduate	1.03 (0.82 - 1.29)	.78	0.96 (0.79 - 1.16)	.67
Race/ethnicity		.10		.78
Non-Hispanic white	1.00		1.00	
Hispanic	1.34 (1.04 - 1.72)	.03	1.04 (0.77 - 1.42)	.80
Black/African American	1.23 (0.92 - 1.64)	.16	0.89 (0.68 - 1.16)	.38
Other	1.10 (0.76 - 1.58)	.61	0.89 (0.58 - 1.35)	.58
General health		.51		.62
Excellent, very good, or good	1.00		1.00	
Fair or poor	1.08 (0.86 - 1.36)	.51	1.07 (0.82 - 1.40)	.62
Cancer experience		.43		.46
No personal experience with cancer	1.00		1.00	
Have family with cancer	0.90 (0.76 - 1.06)	.21	1.11 (0.92 - 1.34)	.28
Cancer survivor	0.92 (0.74 - 1.13)	.42	1.15 (0.90 - 1.46)	.25
Have regular health care provider		.21		.44
No	1.00		1.00	
Yes	0.88 (0.71 - 1.08)	.21	1.10 (0.87 - 1.38)	.44
Internet access		.03		.29
No	1.00		1.00	
Yes	1.27 (1.02 - 1.57)	.03	0.89 (0.73 - 1.10)	.29
How often did they (health care providers) make sure you understood the things you needed to do to take care of your health?		< .001		.64

Characteristic	Odds of Importance of Accessing Personal Health Information Electronically		Odds of Importance for Health Care Providers Sharing Personal Health Information With Each Other Electronically	
	OR (95% CI)	*P* Value[b]	OR (95% CI)	*P* Value[b]
Sometimes/never	1.00		1.00	
Always/usually	0.62 (0.49 - 0.78)	< .001	1.05 (0.86 - 1.28)	.64
In general, I think that the information I give doctors is safely guarded.		.88		< .001
Agree	1.00		1.00	
Disagree	0.98 (0.73 - 1.31)	.88	0.53 (0.40 - 0.69)	< .001

[a] Results were weighted to be representative of the adult population residing in the United States. All analyses were adjusted by survey mode effect.

[b] *P* values associated with Wald statistics

Odds of Use of Internet for Tracking Personal Health Information

Among Internet users, use of the Internet for tracking personal health information was predicted by gender, race, educational level, and access to a regular health care provider. Females were less likely than males to use the Internet for tracking personal health information (OR = 0.78, 95% CI = 0.61 - 1.00). Those with educational levels more extensive than a high school degree were more likely than those with only a high school degree or less to use the Internet for tracking personal health information (OR = 1.46, 95% CI = 1.02 - 2.11 for those who had some college education compared with those who had high school education or less, and OR = 1.84, 95% CI = 1.32 - 2.58, for college graduates compared with those who had high school education or less). Compared with non-Hispanic white respondents, Hispanic population members were almost twice as likely to use the Internet for tracking personal health information (OR = 1.92, 95% CI = 1.23 - 2.98). Respondents with a regular health care provider were almost twice as likely as those without a regular health care provider to use the Internet for tracking personal health information (OR = 1.90, 95% CI = 1.21 - 2.97).

Table 3. Multivariate logistic regression of use of Internet for tracking personal health information among Internet users (n = 5078)[a]

Characteristic	Odds of Using the Internet for Personal Health Information	
	OR (95% CI)	P [b]
Age		.35
18-24	1.00	
25-34	0.91 (0.49 - 1.67)	.75
35-44	0.84 (0.46 - 1.53)	.56
45-54	0.91 (0.51 - 1.62)	.74
55-64	0.96 (0.53 - 1.74)	.88
65+	1.28 (0.68 - 2.4)	.44
Gender		.05
Male	1.00	
Female	0.78 (0.61 - 1.00)	.05
Education		.002
High school or less	1.00	
Some college	1.46 (1.02 - 2.11)	.04
College graduate	1.84 (1.32 - 2.58)	< .001
Race/ethnicity		.04
Non-Hispanic white	1.00	
Hispanic	1.92 (1.23 - 2.98)	< .001
Black/African American	1.21 (0.76 - 1.92)	.43
Other	1.36 (0.8 - 2.33)	.25
General health		.26
Excellent, very good, or good	1.00	
Fair or poor	1.25 (0.85 - 1.83)	.26
Cancer experience		.40
No personal experience with cancer	1.00	
Have family with cancer	0.87 (0.64 - 1.18)	.38
Cancer survivor	1.04 (0.69 - 1.58)	.85
Have regular health care provider		.01
No	1.00	
Yes	1.90 (1.21 - 2.97)	.01
How often did they (health care providers) make sure you understood the things you needed to do to take care of your health?		.12
Sometimes/never	1.00	
Always/usually	0.73 (0.49 - 1.09)	.12
In general, I think that the information I give doctors is safely guarded.		.82
Agree	1.00	
Disagree	0.95 (0.59 - 1.51)	.82

[a] Results are weighted to be representative of the adult population of Internet users residing in the United States. All analyses were adjusted by survey mode effect.

[b] *P* values associated with adjusted Wald statistics

Discussion

This study examined consumers' attitudes toward accessing personal health records electronically and their health providers' health information exchange ability, as well as the prevalence of using the Internet for tracking personal health information to better understand who would value these concepts and who is currently accessing the emerging PHR technologies. The results showed widespread positive appraisal of electronic access to PHRs, which was predicted by younger age, Hispanic ethnicity, Internet access, and perceived deficits in health care provider. The characteristics of older age, male gender, and the belief in personal health information security predicted positive appraisals of health information exchange. Use of the Internet for tracking personal health information was uncommon and was predicted by the following demographic characteristics: male gender, Hispanic ethnicity, higher educational level, and access to a regular health care provider.

The Importance of Electronic Personal Health Records

Age Difference in the Perception of the Importance of PHRs

According to our findings, older adults were less likely than younger adults to value the importance of PHRs. Other studies also found that those aged 65 and over reported placing less value in Internet health information than those younger than age 65 and that those aged 65 and over would be less likely to use the Internet to find health information [31]. As the adoption rate of Internet and broadband use has continued to grow among senior citizens [32] and health problems tend to increase with age, future research needs to examine factors such as improving computer self-efficacy [33] and addressing design issues [34] that promote senior citizens' value of and intention to use PHRs, which will impact on their chronic care management.

Perception of PHRs Among Hispanic Population Members

Members of the Hispanic population more highly valued the concept of electronically accessible medical records than non-Hispanic white respondents in our overall sample. Studies have shown that Hispanic individuals are interested in using the Internet for health information [35], but they are less likely than whites to have access and to use the Internet. Income and education levels do not fully explain the gap in Hispanic individual's use of the Internet [36]. Cultural factors are more likely to influence perceptions of use of the Internet for health information [37,38]. As technologies evolve, we need to evaluate how cultural factors impact on the design, adoption, and dissemination of PHR applications among different ethnical groups.

Internet Access and Perception and Use of PHRs

Almost 46.7% (3586/7674) of the respondents surveyed reported that it was very important to have access to their medical records electronically (32.9% also reported that this was "somewhat important"). In particular, Internet users were more likely than Internet nonusers to report the importance of tracking their personal health information online. However, only 15% of the Internet users had used the Internet for tracking their personal health information in 2007. Our finding is consistent with previous consumer survey research that showed that despite high enthusiasm among consumers for PHRs, the actual uptake of PHRs has been relatively slow [39]. PHR technologies have become increasingly popular among consumers, clinicians, policy makers, and purchasers, and many vendors and health care providers already have the tools available to offer PHRs to their customers [40]. While the uptake of PHRs has been slow, a growing number of patients actively use this emerging technology [41]. We need to continue evaluating barriers to the adoption of PHRs.

Perceived Deficits in Information Comprehended by Health Care Providers Positively Associated With Perceived Importance of Personal Health Records

Interestingly, our results showed that respondents who reported a lack of attention from their health care providers to ensure their understanding and comprehension of their personal health were more likely to value the importance of accessing their medical records electronically. This suggests the possibility of these consumers perceiving PHRs as a compensating tool for gathering their personal health information they are not receiving from their doctors. In a related finding, Zickmund et al [42] in studying a diabetes patient portal with online information, laboratory results, and secured messaging, found that patients' interest in the portal was linked to dissatisfaction with their doctor-patient relationship. Individuals may be more willing to reach out for alternative modes of computer-mediated information and communication if they have a dissatisfying relationship with their providers. To fully understand the potential of PHRs for providing consumers with relevant health information, further studies are needed to determine changes in both patients' and providers' attitudes regarding the use of PHRs and the impact of PHR use on the doctor-patient relationship.

The Importance of Health Information Exchange

Age Difference in Perceptions of the Importance of HIE

Respondents in the youngest group studied (aged 18 to 24) in the sample were less likely to value the importance of HIE compared with respondents who were aged 35 and above. The discrepancy in perceptions of HIE importance between younger and older generations might reflect the difference in experience interacting within the health care system. Since younger consumers are generally healthier than older consumers, younger consumers tend to have fewer concerns about their personal health histories and have less frequent interactions within the health care system. The meaning of HIE is likely to be much different for younger consumers than for members of older generations who potentially have more experience with illness and health care providers due to the aging process.

Gender Difference in Perceptions of the Importance of HIE

Men were more likely than women in this survey to positively appraise the importance of HIE in 2007. This finding may suggest greater comfort with using information technologies and interacting with health care providers among men, although previous research has suggested that women generally have greater concern for health issues and actively seek health information more often than men [30]. The general importance afforded to HIE by men, however, suggests an opportunity to expand HIE programs and services for men.

Consumer Concerns About HIE Security

It is argued that building privacy and security protection into HIE systems will bolster the public trust and confidence that are critical to the rapid adoption of HIE and to the realization of its benefits [43]. Not surprisingly, our analysis revealed that consumers' attitudes toward HIE were significantly influenced by the perceived level of security of their personal health information managed by their providers. The security and privacy issue has been recognized as a significant barrier to electronic HIE, which requires the implementation and establishment of national privacy principles, trusted network design characteristics, and oversight and accountability mechanisms [43]. To fully engage consumers in health information technology innovations, it may be wise to use health literacy principles to develop simple but clear patient consent and educational materials explaining privacy and security precautions [44]. Recently, the Consumer Education and Engagement Collaborative was formed to develop a series of coordinated, state-specific projects to educate consumers about privacy and security to make them fully aware of current information-sharing practices and policy discussions [45]. Future initiatives must be designed to build awareness and trust for new health information technologies within society to facilitate HIE adoption and to influence its use in health care. We also need to carefully design policies relating to patient consent without placing an undue burden on health care professionals [46].

The Use of the Internet for Tracking Personal Health Information

Higher Use of PHRs Among Hispanic Population Members

It is interesting to note in our findings that members of the Hispanic population who had Internet access were more likely to use the Internet for tracking personal health information than non-Hispanic white respondents after adjusting for age, educational level, and so on. Although Hispanic individuals and members of other minority groups are substantially less likely to have a home computer and use the Internet than non-Hispanic whites [47], there is strong evidence that eHealth systems will be used extensively with a positive impact on underserved minority populations who have access to such technology [48].

Health Literacy Impacts on the Adoption and Use of PHRs

Our finding in this study suggests that PHR use is generally associated with higher educational levels among all Internet users. Kaiser Permanente's PHR study also reported that their PHR registration was associated with higher educational levels [49]. As the adoption rate of Internet and broadband has continued to grow among those with less than a high school education [50], patients with limited health literacy may not be able to easily understand the information available on PHRs, thus limiting the benefit from such health communication tools [51]. To provide optimal benefits to the patient, PHRs must present data, information, terminology, and accompanying tools in ways that allow the patient to understand and to act on the information learned [4]. Thus, PHR development should focus on meeting patients' health information preferences and capabilities. Integrating patient-centered testing throughout PHR development is essential to ensure the readability and usability of PHRs. Early assessment, testing, and prompt initiation of training to address literacy issues is critical to ensure successful PHR adoption [52]. Computer skills and technological literacy is another related yet critical concern that needs to be addressed. Whether individuals are technology savvy enough to update personal records and interact with health information systems may also impede adoption of PHRs.

Gender Difference in the Prevalence of Use of PHRs

To our surprise, our findings revealed that men who were online were more likely to use the Internet for tracking personal health information compared with women who were online. In contrast to our findings, past Internet research indicated that women were more likely than men to search for health information [30], use online patient provider communication [53], and use online support groups or health-based chat rooms [54]. Similar findings of gender differences in online health searching were also reported by the Pew Internet and American Life Project [55]. However, other studies also showed that men tend to use the Internet for instructional support while women tend to use the Internet to seek emotional support [56].

Health Care Provider Access Associated With PHR Use

The association between having access to a health provider and PHR use was also observed, suggesting that Internet users with a regular provider were more likely to use PHRs. The result is consistent with findings that individuals with a regular primary care provider are more likely to use eHealth services than those who do not have a regular primary care provider [57]. It is likely that HINTS respondents with a regular health care provider were more likely to be health conscious, and health consciousness has been shown to influence preventive health care behaviors [58] and online health information-seeking behaviors [59].

Cancer and Health Status With Relation to PHRs

We found that neither cancer history nor general health status were associated with PHR use. Previous eHealth studies have shown that Internet users with more medical needs tend to use eHealth services more frequently [53]. However, HINTS survey respondents who reported that they had been diagnosed with cancer could currently be in remission and may not have been actively coping with the disease. Therefore, we might not accurately distinguish healthy versus less healthy respondents in our analysis [28]. Also, eHealth interventions have been identified as most valuable for individuals with chronic conditions [60,61]. Pew project research has suggested that individuals with chronic disease who have Internet access are more likely to search for health information online than those without a chronic condition [62]. Access to appropriate health information is a key support function for cancer patients. PHRs and related eHealth services provide an effective mechanism of patient access, which is consistent with the increasing preference of cancer patients for personalized information according to their medical records [63]. Future research is needed to further investigate the potential of PHR use for cancer patients.

Limitations

The HINTS survey question asked only about use of the Internet for tracking personal health information, such as care received, test results, or upcoming medical appointments. However, people may use the Internet for many health purposes (such as documenting drug prescriptions with applications like GoogleHealth or to view insurance claim data with the use of subscriber portals provided by insurance companies), which is consistent with the concept of PHRs but may not have been identified by survey respondents as “use the Internet for tracking personal health information.” Thus, we might underestimate the prevalence of Internet use for PHRs. HINTS data were based on self-report with potential bias due to social desirability, which may challenge the generalizability of the results. In addition, the HINTS survey does not allow for further examinations of barriers to the use of PHRs or the perceived benefits for those who use these tools. Many PHRs also include unique functionality that allows patients to send secured messages to their providers. Research examining online doctor-patient communication using the HINTS data has been reported elsewhere [53].

Due to item wording, we can only discuss our results with regard to HIE as a way for “health care providers to share medical information with each other electronically” and cannot characterize the HIE mechanisms in different formats (ie, consumers who exchange their personal information with providers) that could potentially affect our findings concerning consumers’ perceived value of HIE. We were limited to examination of the use of PHRs rather than HIE with the survey instrument. People may be engaging in HIE through their health care providers in ways that were not reported in the survey. Further examination of consumer participation in HIE would provide new insights into the use of the Internet for exchanging personal health data.

To improve the delivery of health care we need to continue to assess consumers’ and health care providers’ perspectives on barriers and benefits related to using the Internet for PHRs and HIE as health information technologies evolve rapidly as part of clinical practice.

Conclusions

Personal health records and health information exchange are critical tools for reengineering our health care system. Significant future research is needed to understand the adoption of PHRs and HIE as integrated tools that improve patient-centered care and care coordination and to identify the barriers and impact of their use on patients, providers, organizations, and health care systems across clinical, financial, and behavioral outcomes.

Although current dissemination of PHRs and HIE into clinical care is limited, the advocacy of stakeholder groups, demand from patients, and strong push for health care reform are likely to accelerate the adoption of these important technologies. However, just making the technologies accessible and available is not sufficient. In 2009, the Health Information Technology for Economic and Clinical Health (HITECH) Act authorized incentive payments through the Center of Medicare and Medicaid Services to clinicians and hospitals when they demonstrate meaningful use of certified electronic health records privately and securely. The proposed definition of meaningful use includes ways not only for health care providers to store and retrieve patient medical information but also for patients and families to gain access to their medical records and thus engage more fully and collaboratively in their care [64,65.] Health care agencies and research communities need to ensure the readability and usability of PHR tools to meet the needs of diverse populations with varying levels of health and computer literacy [40,66]. Supporting the patient’s transitions between care settings or personnel is also part of the meaningful use objectives. Attention must be given to critical issues inherent to the use of HIE, including security, privacy, and confidentiality. Clear information and policies about data management and transaction and security and privacy issues need to be rigorously defined and disseminated to sustain consumer trust.

In sum, we need to continue addressing policies and establish architectures at both state and federal levels that support the development and implementation of PHRs and HIE and that account for both consumer and health care provider needs and preferences. Critical issues with regard to system usability and interoperability, health literacy and cultural issues, data security, and health care costs need to be addressed for maximizing the wide dissemination of PHRs and HIE.

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Conflicts of Interest

None declared

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Abbreviations

HIE: health information exchange
HINTS: Health Information National Trends Study
HITECH: Health Information Technology for Economic and Clinical Health
PHRs: personal health records
RDD: random digit dial

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Original Paper

The Influence of Response Mode on Study Results: Offering Cigarette Smokers a Choice of Postal or Online Completion of a Survey

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Abstract

Background: It is unclear whether offering online data collection to study participants affects compliance or produces bias.

Objective: To compare response rates, baseline characteristics, test-retest reliability, and outcomes between cigarette smokers who chose to complete a survey by mail versus those who chose to complete it online.

Methods: We surveyed cigarette smokers who intended to stop smoking within the next 30 days to determine barriers to calling a smoking quit line. Participants were offered the choice of completing a paper version of the survey sent through the mail or an online version at a password-protected website. Participants were called 2 months later to determine if they had made a quit attempt and/or called a smoking quit line since the baseline survey. We compared characteristics and outcomes among those who chose postal versus online completion. We measured test-retest reliability of the baseline survey by resurveying a semirandom sample of participants within 10 days of the original survey.

Results: Of 697 eligible respondents to newspaper ads in 12 US cities, 438 (63%) chose to receive a mailed paper survey and 259 (37%) chose an Internet survey. Survey return rates were the same for the 2 modes (92% versus 92%, $P = .82$). Online respondents were younger (mean of 46 versus 51 years old for postal, $P < .001$), more likely to be white (76% versus 62%, $P < .001$), less likely to be African American (18% versus 30%, $P < .001$), more highly educated (34% college graduate versus 23%, $P < .001$), more likely to intend to stop smoking in the next 30 days (47% definitely versus 30%, $P < .001$), and more likely to have heard of a smoking quit line (51% versus 40%, $P = .008$). Participants did not differ on gender (54% female for online versus 55% for postal, $P = .72$) or cigarettes smoked per day (mean of 19 versus 21, $P = .30$). Online respondents had slightly fewer missing items on the 79-item survey (mean of 1.7% missing versus 2.3%, $P = .02$). Loss to follow-up at 2 months was similar (16% for online and 15% for postal, $P = .74$). There was no significant difference between online and postal respondents in having called a smoking quit line during the 2-month follow-up period (20% versus 24%, $P = .22$) or in having made a quit attempt (76% versus 79%, $P = .41$).

Conclusions: Cigarette smokers who chose to complete a survey using the Internet differed in several ways from those who chose mailed surveys. However, more importantly, online and postal responses produced similar outcomes.

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KEYWORDS

Internet; mail; questionnaires; smoking

Introduction

Since the origin of the World Wide Web, its potential for use in research studies has been recognized. One use is to collect information from study participants [1]. This method can be less expensive and produce data sooner with fewer errors. However, due to nonuniversal Internet access and dissimilarity in the physical nature of how data are collected from the World Wide Web as compared to more traditional methods, there are concerns about potential systematic differences in data collected by these methods [2,3].

A number of randomized and nonrandomized studies have compared postal and online responses regarding alcohol and drug use, particularly among college students [4-9]. Few such studies have been conducted among cigarette smokers in particular [10,11], with none having examined the effect of giving these respondents a choice of survey mode.

We conducted a prospective study among cigarette smokers who intended to quit smoking to identify barriers to calling a toll-free quit smoking phone line [12]. In this study, participants chose to complete a survey using either a paper questionnaire returned by mail or an online survey accessed at a secure website. The primary aim of the current analysis was to determine if study outcomes differed for cigarette smokers who chose different data collection methods. If they did differ, this could be an indication of potential selection or information bias. Secondary outcomes were to compare participant characteristics and test-retest reliability of those who chose paper or online questionnaires.

Methods

Sample

Potential participants were recruited in 2007 using newspaper advertisements in 12 US cities in 8 states. The advertisement was as follows:

> *Daily cigarette smokers who plan to quit smoking wanted for University of Vermont research study. This study does not offer treatment. Compensation for completing mailed or online survey about quit smoking services and one brief follow-up phone call. If interested, call 1-800-[xxx-xxxx] (toll-free).*

Screening for eligibility was obtained over the phone. Eligible participants were at least 18 years of age, fluent in English, smoked at least 5 cigarettes daily, intended to quit in the next 30 days, and had not called a smoking quit line in the past 30 days. Verbal informed consent was obtained from all participants during the screening phone call after the participant had been determined to be eligible. The consent statement included that the study was funded by the National Institutes of Health, and stated that the study:

> *…involves filling out a 20-minute mailed or online survey about your cigarette smoking and your thoughts about services that might help you quit, and then completing a 5-minute interview by telephone about two months later. We will reimburse you [US] $35 for the survey and [US] $25 for the telephone interview. You may or may not be asked to fill out the 20-minute survey a second time. If you are asked to do that, you will be reimbursed an additional [US] $35.*

The statement also indicated that all information would be confidential, participation was voluntary, and the participant could refuse at any time. Participants were provided with the name, phone number, and email address of the principal investigator (author JRH). Confidential data were stored on a password-protected computer with access limited to study personnel. The study was approved by the University of Vermont Institutional Review Board. All study personnel were required to complete a tutorial from the University of Vermont Institutional Review Board on the protection of human subjects in research.

Instruments

At the conclusion of the initial phone call, participants were given a choice of completing a baseline survey via returning a mailed paper version in a prepaid envelope or accessing an online version using a password protected website. Participants were asked, “Would you prefer that we mailed you the survey through regular mail with a stamped return envelope or would you rather complete the survey online?”

The baseline survey asked demographic and smoking information and an additional 53 items specifically targeting barriers to calling a smoking quit line (eg, “I might not call the quit line because I’m sure I can quit on my own,” with response choices: 1 = not at all true for me; 2 = somewhat true for me; 3 = mostly true for me; 4 = completely true for me). The only previously validated items on the survey were a subset of questions from the Fagerstrom Test for Nicotine Dependence [13]. The survey contained a total of 79 items, formatted with contrasting shading for every other item so that respondents could distinguish them easily. The printed version was 6 pages long.

The Web version of the questionnaire was formatted to look the same as the paper version. To avoid rapid online responses, there were no more than 5 items per screen, giving a total of 16 screens. For consistency with the paper survey, online respondents could skip items and could go back to review responses before submitting the survey. All submitted questionnaires were included in the analysis even if items were missing, but questionnaires terminated before submission were not included. Multiple submissions by the same subject were not allowed—each respondent who chose to complete the survey online received a password that could only be used for one submission.

The online system was tested in 2 pilot studies that were conducted to construct the 53 items concerning barriers to calling a smoking quit line, and the final online questionnaire was completed multiple times by members of the research team before any participants were enrolled.

Because of concern of respondent fatigue, 10 versions of the baseline survey were used, with the 53 items concerning barriers in a different order for each. No significant differences in the means or variances of the items were found, so the 10 versions were pooled for the analysis.

A follow-up telephone survey 2 months later asked whether participants had called a quit line or had made a quit attempt since completing the baseline survey. Test-retest reliability of the baseline survey was assessed by requesting a semirandom sample of the postal and online respondents to repeat the survey 10 days after original completion.

Statistical Analysis

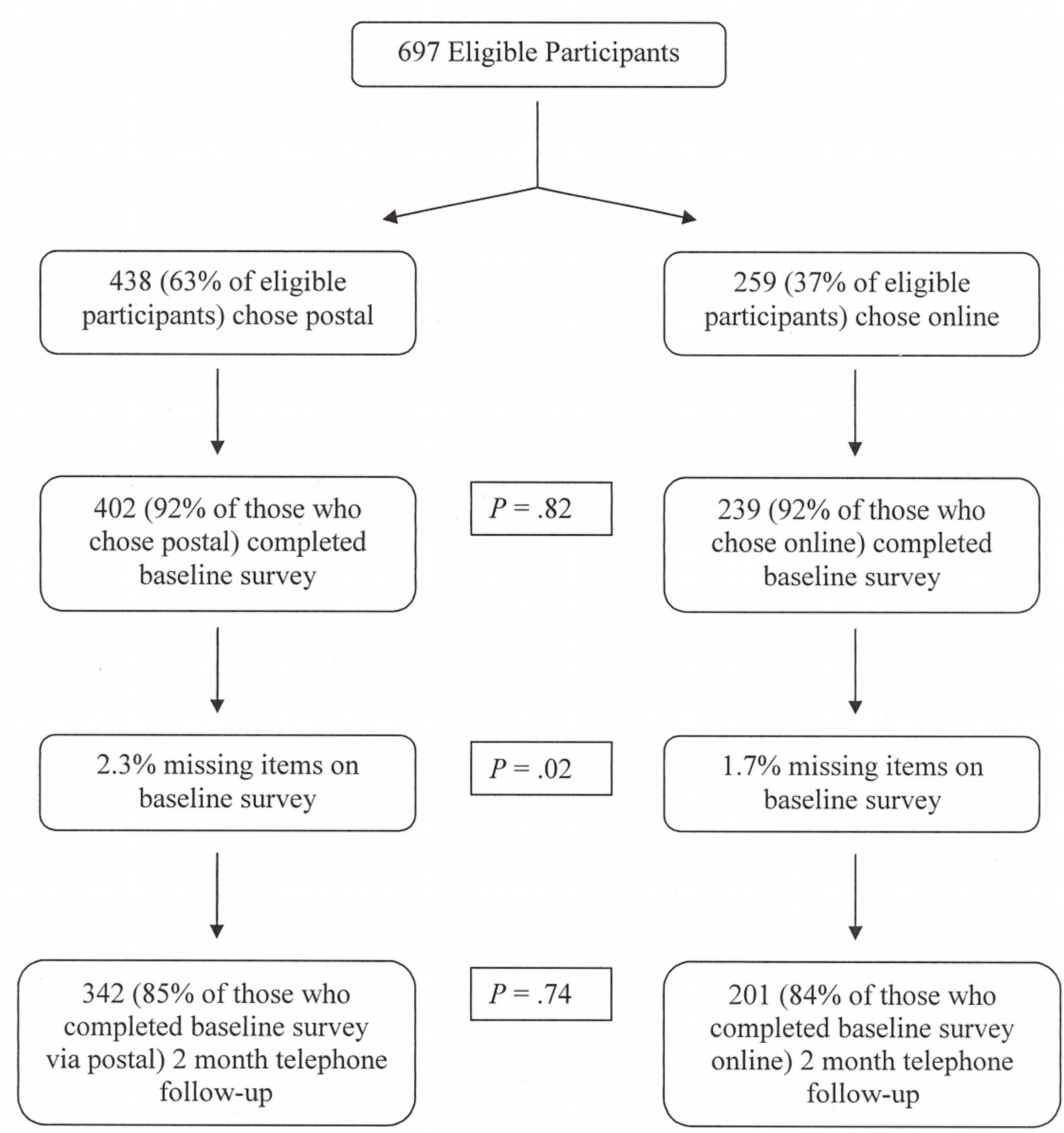
Postal and online respondents were compared using chi-square tests for categorical variables and the Wilcoxon rank sum test for continuous variables. A nonparametric approach was used for comparing continuous variables due to the nonnormal distribution of several of the variables. Test-retest reliability was measured by computing intraclass correlation coefficients for consistency using a two-way random-effects model [14], which measures repeatability of responses. Differences in 2-month results (incidence of calling a quit line or making a quit attempt) were compared using chi-square tests for bivariate analyses and logistic regression to control for baseline differences in respondents. Analyses were conducted using SAS 9.1 (SAS Institute Inc, Cary, NC, USA) except for reliability, for which SPSS 15.0 (SPSS Inc, Chicago, IL, USA) was used.

Results

Results pertaining to barriers to calling a smoking quit line have previously been reported [12]. Overall, 1527 people called in response to the newspaper advertisements and were screened. Of these, 789 (52%) were ineligible, with most (691/789, 88%) excluded because they did not answer “probably” or “definitely” to the question “Are you planning to quit smoking cigarettes in the next 30 days?” An additional 41 callers did not give verbal consent, leaving 697 recipients of the baseline survey.

Of the 697 participants, 438 (63%) chose to complete the baseline survey using mail (Figure 1). Surveys were returned by an equal percentage of those who chose mail and those who chose Internet ($\chi^2_1 = 0.1$, $P = .82$). There were significantly more missing items on the paper survey but the difference was very small ($\chi^2_1 = 5.7$, $P = .02$). Of those who completed the baseline survey, a similar proportion of postal and online respondents completed the 2-month follow-up phone survey ($\chi^2_1 = 0.1$, $P = .74$).

Figure 1. Choice of response mode, response rates, and rates of missing items



Comparisons of baseline characteristics and responses are shown in Table 1. There was no difference in gender for postal versus online completers. Online respondents were significantly younger and more educated. African Americans were more likely to use a paper form, while a higher percentage of whites chose online. (There are separate *P* values for each ethnic group because respondents could choose more than one ethnic group.)

The number of cigarettes smoked per day was similar. Online respondents were more likely to definitely intend to stop smoking in the next 30 days and were more likely to have heard of a smoking quit line but were equally likely to have called a quit line in the past. Importantly, the mean scores on the 53 barriers items (the major independent variable) were the same.

Table 1. Comparison of postal and online responses on baseline survey

			Test Statistic (χ2)		
	Postal	Online	df	χ2	*P* value
Total n	402	239			
Age in years, mean (SD)	51 (12)	46 (13)	1	28.5	< .001
Female gender, n (%)	222 (55%)	128 (54%)	1	0.1	.72
Highest level of education					
≤ High school, n (%)	154 (38%)	43 (18%)	2	30.0	< .001
Some college, n (%)	153 (38%)	114 (48%)			
College degree, n (%)	94 (23%)	82 (34%)			
Ethnicity					
Hispanic, n (%)	33 (8%)	15 (6%)	1	1.0	.32
African American, n (%)	120 (30%)	43 (18%)	1	11.2	< .001
White, n (%)	249 (62%)	181 (76%)	1	12.6	< .001
Other, n (%)	45 (11%)	18 (8%)	1	2.3	.13
Cigarettes per day, mean (SD)	21 (12)	19 (10)	1	1.1	.30
Do you intend to stop smoking in the next 30 days?					
Definitely not, n (%)	0 (0%)	0 (0%)	3	21.8	< .001
Probably not, n (%)	22 (6%)	7 (3%)			
Possibly, n (%)	149 (37%)	59 (25%)			
Probably, n (%)	110 (28%)	61 (26%)			
Definitely, n (%)	119 (30%)	112 (47%)			
How confident are you that you can stop in next 30 days?					
Not at all confident, n (%)	56 (14%)	26 (11%)	4	9.6	.05
Slightly confident, n (%)	184 (46%)	91 (38%)			
Confident, n (%)	101 (25%)	70 (29%)			
Very confident, n (%)	46 (11%)	32 (13%)			
Extremely confident, n (%)	15 (4%)	19 (8%)			
Have you ever heard of a smoking quit line? Yes, n (%)	162 (40%)	122 (51%)	1	7.0	.008
Have you ever called a smoking quit line? Yes, n (%)	35 (9%)	16 (7%)	1	0.8	.36
Mean of 53 barriers items, each on scale of 1 to 4 (1=not at all true for me, 4=completely true for me), mean (SD)	1.6 (0.5)	1.6 (0.4)	1	0.03	.87

Table 2. Comparison of postal and online baseline respondents at 2-month telephone survey

			Test Statistic (χ2)		
	Postal	Online	df	χ2	*P* value
Total n	342	201			
Called smoking quit line, n (%)	82 (24%)	39 (20%)	1	1.5	.22
Made quit attempt, n (%)	270 (79%)	153 (76%)	1	0.7	.41

To measure test-retest reliability, the baseline survey was repeated by 55 (74%) of 74 postal and 27 (63%) of 43 online participants invited to retake the survey. The intraclass correlation coefficient was .76 (95% confidence interval [CI] .61-.85) for postal and .90 (95% CI .80-.95) for online.

At 2-month follow-up, slightly more postal respondents had called a smoking quit line and had made a quit attempt, but these differences were not statistically significant (Table 2). Since true differences could be masked by confounding due to baseline differences, these comparisons were repeated using logistic regression to adjust for age, education, and ethnicity.

The adjusted results were essentially the same as the bivariate findings shown in Table 2.

Discussion

Our major finding is that although online participants varied in some ways from postal participants, these differences did not appear to affect the study results. Response rates, missing data, reliability, and follow-up rates were at least as good for online participants as for postal participants, and outcomes at 2 months were similar for the 2 groups.

Study participants who chose to complete the baseline survey online were, on average, younger, better educated, less likely to be African American, and more likely to be white. Given the demographics of Internet use [15], these differences are not surprising. We also found those who chose Internet were more likely to intend to quit, although actual quitting was not greater in this group. An analysis of a nationally representative sample found similar results for age, education, ethnicity, and gender for smokers who do and do not use the Internet and also found that smokers who use the Internet were more likely to report planning to quit smoking [16]. In a comparison of postal, Internet, and telephone respondents to the Behavioral Risk Factor Surveillance System, which asks about smoking and other risk behaviors, there were no differences in gender and ethnic distribution for Internet respondents [4]. A survey of alcohol use among college students found no ethnic differences in online and postal respondents, but found online respondents to be younger and more likely to be male [7]. However, these differences may be because the option of completing the survey via mail was only offered to nonrespondents of the Internet invitation. Another study that used this design found online respondents to have higher mean education and income than postal respondents [17], which could be due to better computer access for those with higher education and income or could be because of higher education of first responders in general.

We did not find a difference in response rates between the online and Internet groups. Response rates might be expected to be higher for online participants due to the more immediate receipt of the survey, but could be expected to be lower because of the lack of a physical reminder of the survey (eg, paper survey sitting on the kitchen counter) and because the email with the password and website could be deleted as potential spam. Past studies have had mixed results, with some having lower Internet response rates [18-22], some with no difference [9,23,24], and some with higher Internet response rates [5,6,25]. These studies differed from ours in that participants were randomized to condition rather than given a choice, which would affect comparability of response rates.

Meta-analyses comparing Web and postal response rates find overall lower response rates for Web surveys [26,27], but at least some of the studies included in these meta-analyses recruited subjects at websites or through the mail, rather than recruiting all subjects using the same method as in our study.

In our study, the high response rates for both groups may be due to (1) participants who were motivated enough to call in response to a newspaper advertisement and/or (2) financial incentives for completing the survey. Both monetary and nonmonetary incentives have been found to substantially increase response rates [28].

Test-retest reliability of the survey was at least as good for online participants and perhaps better. If it was truly better, this could be due to the differing characteristics of the respondents (eg, education). Other studies have found high reliability for Internet questionnaires completed by smokers, with no apparent systematic differences from other modes [10,11] and other populations [8,19,23,29-38]. Im et al [39] found higher reliability and convergent validity for postal as compared with online completion of the Midlife Women’s Symptom Index; however, they concluded that reliability and validity were sufficiently high for both formats.

Responses on the survey may have been influenced by social desirability bias, where participants may have overreported factors such as desire to quit smoking. Whether such bias differentially affects online versus postal responses is unclear. Our finding of higher baseline intentions to stop smoking and confidence in ability to stop in online respondents could be due to higher social desirability bias in this group or could be due to demographic differences between the groups. Randomized studies of alcohol use [8] and illicit drug use [5] did not find differences in reporting of these behaviors for different modes of survey completion.

Our finding of low rates of missing data for both survey modes agrees with the results of Smith et al [40], who found a mean number of missing items of 1.7% for both online and postal respondents. Their study was similar to ours, with participants choosing to return the survey online or through the mail. In a survey of college students on alcohol and other drug use [6], surveys returned via Internet and mail both had 2.6% missing data rates. Surveying pediatricians, McMahon et al [41] found significantly fewer missing items for surveys returned via email as compared with mail or fax, but the mean number of missing items was low for all three modes (0.4%, 2.1%, and 2.8%, respectively). Im et al [39] observed similar findings surveying women aged 40 to 60 years, with 1.3% of items missing for Internet completion and 2.6% missing for mailed surveys.

A limitation of our study is that participants were not randomized, but self-selected survey mode. Many prior studies have randomized respondents to complete surveys by paper or online [5,6,8,18,19,21-25,29,38,42] or have used a within-subject design where each participant filled out both paper and online forms [10,11,29-32,37]. These approaches have the advantage that any observed differences are likely due to mode of completion. Although a randomized design would have been possible for this study, our intent was to compare the characteristics of those who chose to use Internet with those who chose mail, since this is the design used for many studies that include an Internet option. Our observational design allowed examination of the actual circumstances under which such Internet surveys are implemented, which increases external validity.

Our external validity may be decreased, however, by using a volunteer sample recruited from newspaper advertisements. Compared with all current daily smokers in the United States

[43], our respondents were somewhat older (mean of 49 years versus 42 years), more likely to be female (55% versus 46%), better educated (69% with education beyond high school versus 39%), more likely to be African American (25% versus 11%), and smoked more (mean of 20 cigarettes per day versus 16). Some of these differences may be due to recruitment methods, and some may be due to the eligibility requirements of the study (eg, smoke at least 5 cigarettes per day and intend to quit in the next 30 days).

Offering participants a choice of postal or online completion of a survey can gain some of the advantages of Internet use in research while avoiding some of the disadvantages. Internet surveys are generally less expensive than mail, have faster response times, and have the potential for more valid data by automated skip patterns and checks for illogical values [2,3]. However, recruiting participants via the Internet can suffer from low response rates and questions about who is missed due to lack of Internet access [2]. These are not issues when participants are recruited using traditional methods but given a choice of response mode.

A number of studies have reported consistency in research results across online and postal response formats in spite of differences in respondent characteristics [3]. We have extended this finding to a sample of cigarette smokers. In summary, we found that offering online and mail versions of a survey allowed participants to choose whichever was most convenient without having a negative impact on the study data.

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Conflicts of Interest

In the last 3 years, Dr Hughes has received research grants from the National Institute on Health and Pfizer Pharmaceuticals and accepted honoraria or consulting fees from Abbot Pharmaceuticals, Academy for Educational Development, Acrux DDS, Aradigm, American Academy of Addiction Psychiatry, Atrium, Cambridge Consulting, Celtic Pharmaceuticals, Cline, Davis and Mann, Constella Condition, Concepts in Medicine, Consultants in Behavior Change, Cowen Inc, Cygnus, Edelman PR, EPI-Q, Evotec, Exchange Limited, Fagerstrom Consulting, Free and Clear, Health Learning Systems, Healthwise, Insyght, Invivodata, Johns Hopkins University, J Reckner, Maine Medical Center, McNeil Pharmaceuticals, Nabi Pharmaceuticals, Novartis Pharmaceuticals, Oglivy Health PR, Pfizer Pharmaceuticals, Pinney Associates, Reuters, Shire Health London, Temple University of Health Sciences, United Biosource, University of Arkansas, University of Auckland, University of Cantabria, University of Greifswald, University of Kentucky, US National Institutes of Health, Xenova and ZS Associates. All other authors have nothing to declare.

Authors' Contributions

Dr. Callas contributed to the design of the study, analyzed the data, intepreted the results, and wrote the first draft of the paper. Dr. Solomon, Dr. Hughes, and Ms. Livingston contributed to the design of the study, interpretation of the results, and editing of the paper.

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Original Paper

The Establishment of an Ethical Guideline for Genetic Testing Through Citizen Consensus via the Internet in Taiwan

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Abstract

Background: With the rapid advance of genetics, the application of genetic testing has become increasingly popular. Test results have had a tremendous impact on individuals who receive the test and his or her family. The ethical, legal, and social implications (ELSI) of genetic testing cannot be overlooked. The Internet is a potential tool for public engagement.

Objectives: This study aimed at establishing ethical guidelines for genetic testing in Taiwan through a participatory citizen consensus approach via the Internet.

Methods: The research method used was a citizen consensus conference modified by an Internet application and the Delphi technique. The citizen consensus conference is one of the public participation mechanisms. The draft ethical guidelines for genetic testing were written by an expert panel of 10. The Delphi technique was applied to a citizen panel recruited via the Internet until a consensus was reached. Our research population was restricted to people who had Internet access.

Results: Included in the citizen panel were 100 individuals. A total of 3 individuals dropped out of the process. The citizen panel was exposed to the issues through Internet learning and sharing. In all, 3 rounds of anonymous questionnaires were administered before a consensus was reached in terms of importance and feasibility. The result was ethical guidelines composed of 4 categories and 25 items. The 4 categories encompassed decision making (6 items), management of tissue samples (5 items), release of results (8 items), and information flow (6 items). On a scale of 1 to 10, the average (SD) importance score for the decision-making category was 9.41 (SD 0.58); for the management of tissue samples category, the average score was 9.62 (SD 0.49); for the release of results category, the average score was 9.34 (SD= 0.59); and for the information flow category, the average score was 9.6 (SD = 0.43). Exploratory analyses indicated that participants with higher education tended to attribute more importance to these guidelines.

Conclusions: The resulting recommended ethical guidelines had 4 categories and 25 items. We hope through the implementation of these guidelines that mutual trust can be established between health care profession and the general public with respect to genetic tests.

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KEYWORDS

Ethics; genetic testing; Internet; public participation; public engagement; participatory medicine

Introduction

A genetic test is defined as the analysis of human DNA, RNA, chromosomes, proteins, and certain metabolites in order to detect heritable disease-related genotypes, mutations, phenotypes, or karyotypes for clinical purposes [1]. Every year, 4 million genetic tests are performed in the United States; many of these tests have been commercialized in England [2]. Genetic testing has been conducted for various purposes such as the prediction of hereditary disease, diagnosis and treatment, disease prevention, health promotion, and newborn screening. It is foreseeable that the frequency of genetic testing will continue to grow rapidly in the future.

Nonetheless, the ethical, legal, and social implications (ELSI) of genetic testing cannot be overlooked. The test results often have a tremendous impact on the lives of the individuals who receive the test and his or her family. As such, the 1998 World Health Organization's Proposed International Guidelines on Ethical Issues in Medical Genetics and Provisions of Genetic Services recommended that:

> *Every genetic test should be offered in such a way that individuals and families are free to refuse or accept according to their wishes and moral beliefs. All testing should be preceded by adequate information about the purpose and possible outcomes of the test and potential choices that might arise. Children should only be tested when it is for the purpose of better medical care [1].*

More importantly, genetic testing is not only an issue of individual choice, but also of social choice. Health care professionals should conduct such testing in compliance with social norms so as to avoid the potential chaos that genetic testing is capable of creating.

Various ethical, legal, and social issues have been raised in the past regarding genetic testing. For instance, in 2008 the American College of Obstetricians and Gynecologists (ACOG) issued a committee opinion on ethical issues in genetic testing that included informed consent, prenatal genetic testing, genetic data and the family, genetic data and insurers and employers, genetics and assisted reproductive technology, in addition to other topics. The more contentious issues included confidentiality, privacy, the right of minors, the balance between the rights of individuals and their families, and potential discrimination by employers or insurers [3-8].

Due to the clear need of guidance in translating genetic discoveries into clinical care, guidelines in this regard have been developed throughout the world [9]. There have been fewer such efforts in Asia. The most notable are the guidelines for genetic testing published in Japan by 10 societies concerned with issues in genetic medicine [10]. There are no such guidelines in Taiwan at present; therefore, the purpose of this research was to establish ethical guidelines for genetic testing in Taiwan through a citizen consensus approach via the Internet.

Most professional ethical guidelines have been written entirely within the profession. The use of expert focus groups is one of the commonly applied methods for developing ethical guidelines [11]. However, it has been vigorously asserted that authors of ethical guidelines and the manner of their compilation will determine whether the guidelines themselves are ethical [12]. Meeting the needs of the public is an important aspect of genetic testing and can be decided by the public. Although ethical guidelines for genetic testing are the conduct guidelines for health care professionals, allowing citizen participation in the formulation process gathers more public voices and facilitates meeting society's expectations.

Engaging citizens in policy making has attracted much attention in recent years. Public participation, public engagement, or public involvement refer to interactions between the public and decision-making bodies, and the guiding principles for these activities are transparency and openness, which ensure that decisions are made based on the best available evidence [13].

For instance, member countries of the Organization for Economic Cooperation and Development (OECD) also strengthen their relations with citizens in order to improve the quality of policy [14]. As stated in a policy brief produced by the OECD [14], in addition to the necessity of having adequate information and consultation, active participation of citizens helps generate policy options. A citizen consensus conference is cited as one of the tools that can facilitate active participation. The OECD report also recognized information and communication technology (ICT) as a powerful tool to engage citizens.

There are 3 classes of public engagement based on the flow of information between participants and sponsors: public communication, public consultation, and public participation [15]. In public communication, information is conveyed from sponsors of the initiatives to the public; in public consultation, information is conveyed from the public to the sponsors; while in public participation, information is exchanged between the public and the sponsors. Public engagement is enacted through a variety of structured mechanisms that are many in number but generally poorly defined [15]. What works best when is a major concern.

Methods

The research method we applied was the citizen consensus conference modified by Internet application and Delphi technique.

Originating in Denmark, the citizen consensus conference is a method of public opinion extraction that gives ordinary citizens opportunities to make their voices heard in technology policy debates [16]. This kind of conference provides lay citizens with sufficient information to deliberate public polices. Citizen consensus conferences are touted as being able to increase an ordinary citizen's opportunities to participate in public affairs, and the policy dialogue process provides ordinary citizens with ample information to participate in public discussions and debates [17]. The steps include (1) issue framing, (2) organizing the steering committee, (3) choosing the lay panel, (4) preparatory meetings, (5) formulating questions and choosing the expert panel, (6) conducting the public forum, and (7) writing the lay panel consensus statement [16]. The process itself is lengthy and time consuming. With the widespread application of the Internet, and in light of the recommendation from the OECD, we sought to modify the processes in this research via the use of Internet communication.

According to a typology developed by Rowe [15], there are a total of 3 classes (public communication, public consultation and public participation) and 13 types of public engagement mechanisms. The citizen consensus conference, classified as participation type 1, focuses more on laypersons than experts [15]. This type of mechanism is characterized by the controlled selection of participants, facilitated group discussion, unconstrained participant responses, and flexible information input from sponsors in the form of experts available for questioning [15]. Since the aim was to have the guidelines decided by the public, and our research team has had past experiences with the same mechanism in a face-to-face fashion [18], a citizen consensus conference modified with Internet application therefore became the mechanism of choice.

This research was divided into 3 phases, each of which is described in more detail below. In the first phase, we used the Internet to recruit citizens to join the research. We recruited and randomly sampled volunteers and obtained written consent from the final list of participants. The next phase was to invite the citizen panel to participate in Internet learning, sharing, and discussion. Written background material was distributed to the participants via email. Participants could engage in exchanges and discussions through the group email list where our expert panel also participated via group emailing. Meanwhile, we drafted ethical guidelines for genetic testing and invited an expert panel of 10 to review content validity. The third phase was to apply the Delphi technique to the citizen panel until a consensus was reached in terms of importance and feasibility of items contained in the guidelines.

By posting Internet announcements to recruit the lay panel, our research population sample was restricted to people who had Internet access. The announcement was posted for 1 month in popular local Internet portals such as Yam and Kijiji, as well as on websites of some universities and community colleges. The inclusion criteria were age greater than 20 years and an interest in the ethics of genetic testing. In total, 119 persons volunteered. Of the 119 in the preliminary sample, 47 had health care professional backgrounds, and 72 did not. After random sampling in a ratio of 4 to 6, the final panel included 40 people who had a health care background and 60 who did not.

The research questionnaire used in the Delphi processes was based on ethical guidelines drafted by the steering committee, which was composed of the principal investigator (PI) and the coinvestigators. The committee invited 10 experts (2 biomedical scientists, 2 clinical doctors, 2 ethics scholars, 2 lawyers, and 2 representatives from the biotechnology industry) to review the questionnaire. Each item's content validity index (CVI) of .8 in terms of importance was preserved. Our first draft had 4 categories and 28 items; after the expert panel's review, 4 categories and 21 items were retained in the questionnaire. Each item was scored on a scale of 1 to 10 in terms of importance and feasibility, with higher scores indicating higher levels of importance and feasibility.

The technique we applied is, in effect, a Delphi technique modified by the application of the Internet. The Delphi technique is one of the nominal group techniques that use questionnaires to build consensus. Conventionally, questionnaire surveys can only be completed by pen and paper, but these can now be conducted through the Internet. Administration of Web questionnaires has been reported in the literature to have the same reliability [19] as mailed pen and paper questionnaires but to have varied response rates [20]. The advantages of Web-based questionnaire administration are time and cost savings, while the main disadvantage is that response rates depend on the level of Internet readiness of the target population [20]. However, since our lay panel volunteered via the Internet before we started posting the questionnaires, a low response rate and lack of Internet readiness were not major concerns for our study.

In terms of data analyses, we applied CVI to determine expert content validity. Internal consistency calculations were used in the Delphi stage to determine whether a consensus had been reached. All other analyses were descriptive and exploratory in nature. The PI of this study was deemed responsible for the storage and confidentiality of the database.

Results

In total, 3 persons dropped out of the lay panel during the process. From Table 1, we can see the composition of the initial citizen panel was 43% (42/97) male and 57% (55/97) female, with the largest age group consisting of 26 to 30 year olds (47/97 or 48%) and the second largest group consisting of 21 to 25 year olds (43/97 or 44%). In terms of education level, 57% (55/97) had or were currently engaged in a college education, while 43% (42/97) had or were engaged in a graduate education. Of note, most respondents (63/97 or 65%) declared having no religion. In terms of geographic distribution, although the respondents were scattered among 16 administrative areas, 60% (58/97) were residents from the capital area, that is, Taipei city and Taipei county.

Table 1. Descriptive statistics of the citizen panel

Characteristics of the Citizen Panel	Number	Percentage
Gender		
Male	42	43.3
Female	55	56.7
Age group		
21-25	43	44.3
26-30	47	48.5
31-35	5	5.2
46-50	1	1.0
51-55	1	1.0
Education		
Junior college degree	9	9.3
College student	27	28
Bachelor’s degree	19	20
Graduate student	24	25
Master’s degree	14	14
Doctoral candidate	4	4
Religion		
None	63	65
Buddhism	14	14.4
Taoism	18	18.6
Christianity	2	2.1
Residency		
Taipei city	29	30
Taipei county	29	30
Others	39	40
Employment		
Military and police	1	1
Civil service	4	4
Teacher	6	7
Industry and business	16	16.5
Freelance	16	16.5
Students	44	45
Housekeeping and unemployed	2	2
Part-time	8	8
Seniority in the workforce		
No work experience	33	34
Less than 1 year	18	19
1-3 years	28	29
4-6 years	10	10
7-9 years	2	2
More than 10 years	6	6
Have you or your family members ever received genetic testing?		

Characteristics of the Citizen Panel	Number	Percentage
Yes	9	9
No	88	91
Have you ever heard of genetic testing?		
Yes	62	64
No	35	36

Table 2. The categorization of the draft ethical guidelines

Category (Number of Items)	Importance Score[a] Average (SD)
1. Decision making in genetic testing (6)	9.41 (0.58)
2. Management of tissue samples in genetic testing (5)	9.62 (0.49)
3. Release of results in genetic testing (8)	9.34 (0.59)
4. Information flow in genetic testing (6)	9.60 (0.43)
Total (25)	9.48 (0.46)

[a] The scale ranged from 1 to 10, with higher scores corresponding to greater importance.

In the Delphi stage, 3 rounds of anonymous questionnaires were conducted prior to consensus in terms of importance and feasibility, which achieved an internal consistency of Cronbach alpha .93. In the final stage, the ethical guidelines included 4 categories and 25 items. The 4 categories were: decision making, management of tissue samples, release of results, and information flow. The importance scores of each item ranged from 9.34 to 9.62 on average for these 4 categories (Table 2).

The decision-making category included 6 items that dealt primarily with autonomy and informed written consent. The management of tissue sample categories included 5 items that encompassed the scope of use, storage security, timing of destruction, and research problems. The release of the results category included 8 items and dealt with privacy issues, such as whether and how family members should be informed of test results. The information flow category included 6 items, primarily centered on confidentiality issues that emphasized how test results should be kept confidential from insurance companies, third persons, and employers. All categories and items within each category are presented in Table 3.

Table 3. The final Delphi results of the draft ethical guidelines

Category and Item	Importance Score Average (SD)	Feasibility Score Average (SD)
1. Decision making in genetic testing		
1.1 The examinee has the right to decide whether he or she will undergo genetic testing. If the examinee is legally incompetent, the decision will be made by his or her legal guardian.	9.12 (0.80)	8.83 (0.97)
1.2 Written consent should be obtained from the examinee or the legal guardian before conducting the genetic test.	9.52 (0.62)	9.16 (0.87)
1.3 Before signing the consent form, the examiner should give detailed explanation regarding testing alternatives.	9.35 (1.15)	8.76 (1.00)
1.4 Before signing the consent form, the examiner should give a detailed explanation regarding the items of the test, purposes, processes, management of tissue samples, control of information flow of test results, potential hazards, etc.	9.60 (0.69)	8.85 (1.12)
1.5 Before signing the consent form, the examiner should give a detailed explanation regarding the impact if test results are disclosed to other people.	9.47 (0.74)	8.54 (1.19)
1.6 Before signing the consent form, the examiner should give a detailed explanation to the examinee regarding how the test items will influence the examinee him or herself and his or her family.	9.44 (0.81)	8.73 (1.09)
2. Management of tissue samples in genetic testing		
2.1 The tissue samples can only be tested on the consented items and cannot be used for other purposes without the examinee’s or the legal guardian’s consent.	9.68 (0.55)	8.45 (1.18)
2.2 Both before and after the testing, all tissue samples should be stored anonymously and with high security.	9.71 (0.56)	8.64 (1.13)
2.3 The scope of tissue sample use should be agreed upon by the examinee and included in the written consent.	9.66 (0.60)	8.82 (1.09)
2.4 When other research institutes or researchers need to use tissue samples for research purposes, separate written consents should be obtained.	9.60 (0.69)	8.52 (1.24)
2.5 Whether the tissue samples will be destroyed or stored after testing should be clearly stated in the consent form.	9.47 (0.74)	8.80 (0.98)
3. Release of results in genetic testing		
3.1 Test results can only be released to the examinee or the legal guardian.	9.51 (0.85)	8.46 (1.27)
3.2 Test results can never be disclosed to other people without the consent of the examinee or the legal guardian.	9.69 (0.57)	8.53 (1.41)
3.3 Physicians have the obligation to fully inform the examinee or legal guardian of the test results and their implications.	9.62 (0.59)	8.87 (0.88)
3.4 When physicians inform the examinee or the legal guardian of the test results and implications, they also must inform him or her about the impact on his or her family.	9.13 (0.89)	8.39 (1.11)
3.5 The examinee or legal guardian has the right to decide whether the family member who might be affected by the test results will be informed.	8.89 (1.04)	8.12 (1.45)
3.6 Physicians and genetic counselors should encourage the examinee or legal guardian to disclose relevant information to affected family members.	8.88 (1.32)	8.18 (1.52)
3.7 Health care professionals should not out of their own initiative inform family members or any third person of the test results. The decision to disclose can only be made after consulting the examinee.	9.40 (0.74)	8.66 (1.24)
3.8 Only authorized health care professionals can access the test results. Laboratory technicians can only work on deidentified tissue samples and reports.	9.55 (0.60)	8.82 (1.10)
4. Information flow in genetic testing		
4.1 Health care professionals should keep relevant information confidential.	9.81 (0.40)	8.69 (1.20)
4.2 The examiner should sign a contract with the examinee before testing to assure confidentiality.	9.55 (0.62)	8.89 (1.08)
4.3 Test results should be kept confidential from insurance companies or the like.	9.60 (0.59)	8.28 (1.48)
4.4 Test results should be kept absolutely confidential from irrelevant third persons.	9.69 (0.53)	8.65 (1.23)
4.5 When insurance companies or organizations of a similar nature require the insured to receive genetic testing, the insured’s consent has to be obtained in advance.	9.64 (0.72)	8.61 (1.26)
4.6 Employers shall not require their employees to receive genetic testing.	9.31 (0.87)	8.10 (1.57)

Whether personal characteristics affected the responses of the lay panel was further explored. In terms of importance scoring, only the variable of education had a significant influence on all 4 categories according to ANOVA. Post hoc Scheffe’s analyses indicated that the average scores of graduate students were significantly higher than those of college students in the categories of decision making (*P* = .047), release of results (*P* = .02), and information flow (*P* = .02), whereas in the management of tissue samples category, the average scores of educational groups in descending order were: doctoral students, people with a master degree, graduate students, and college students (*P* = .02). The results implied that participants with higher education tended to attribute more importance to these guidelines.

Discussion

Principal Results

With the rapid advance of genetics, the application of genetic testing has become increasingly popular. The concept of genetic exceptionalism has been advanced by many ethicists, arguing that genetics should be subject to a more rigorous process of scrutiny due to the following reasons: (1) the results of genetic testing subject perfectly healthy individuals to discrimination due to potential future illnesses, (2) the uncertainties of genomic application including genetic testing and genetic treatment are still ominous, (3) there are consequences not only for the individuals who test, but also for family members [21].

Most scholars agree that, although it is imperative to respect autonomy and privacy in conducting genetic testing, health care professionals must also inform the examinee that it is his or her moral obligation to inform family members regarding hereditary risks [4-8]. During our research process, we found that some ethicists contended that certain genetic tests required decision-making and sharing of information, that is, the undertaking of certain genetic tests need the approval of close family members of the same blood line, and the results of all relevant family members should be disclosed. Nonetheless, it appears from our tentative research results embodied in the draft guidelines that most Taiwanese are in favor of individual autonomy. This conflicting opinion is also reflected by the low degree of consensus in 2 of the items contained in our guidelines (items 3.5 and 3.6) compared with the other items. Item 3.5 says that the examinee or legal guardian of the examinee has the right to decide whether the family member who might be affected by the test results will be informed. And item 3.6 requires physicians and genetic counselors to encourage the examinee or the legal guardian of the examinee to disclose relevant information to the affected family members.

Because a breach of confidentiality in genetic information might affect family relations, employment, insurance, paternity law suits, and so on, and might further lead to stigmatization and discrimination, high standards of security must be established to ensure confidentiality [3,7]. As a result, the guidelines resulting from our Delphi process also emphasized the importance of confidentiality and the restriction on information flow. Items 4.3 and 4.4 stress that test results should be kept confidential from insurance companies and irrelevant third persons. Item 4.5 states that when an insurer requires an individual to receive genetic testing as a condition of obtaining insurance, the individuals consent must be obtained in advance. Item 4.6 forbids employers from requesting that their employees receive genetic testing.

Another interesting phenomenon worth noting is that feasibility score averages tended to be lower than those of importance scores for the same item (Table 3). That is, although the statement was deemed important, the respondents were less confident regarding whether it could be executed in real life as written. As such, the establishment of mutual trust relating to genetic testing between health care professionals and the general public is vital for its conduct.

Furthermore, the lowest feasibility score was for item 4.6, which stated that employers be prohibited from subjecting their employees to genetic testing. This item clearly shows a lack of confidence in employers and reflects a worry that employers are unstoppable and will eventually control their employees through genetic testing in some way.

Another finding worth noting is that our lay panel inserted a contractual requirement for the health care industry. Item 4.2 states that the examiner should sign a contract with the examinee before testing to assure confidentiality. Under most health care circumstances, patients or recipients of care are requested to sign consent forms. Although the responsibilities of the physicians and caregivers are also specified in the consent forms, most people felt that their consent was sought merely to protect the health care professionals rather than themselves. In short, the requirement for informed consent was not deemed reciprocal by the general public. Therefore, it is natural for laypersons to think that they are entitled to written contracts from examiners to ensure that examiners fulfill their obligations, underlining the importance of the citizen consensus conference in giving voice to the general public.

Many countries have applied the techniques of the citizen consensus conference to explore public issues including Argentina, Australia, Austria, Japan, Netherlands, New Zealand, Canada, Denmark, France, German, Israel, Norway, Korea, Switzerland, the United Kingdom, and the United States as well as others [22]. Citizen consensus conferences in these countries have covered a wide variety of issues. For instance, in Denmark, discussions topics have included gene technology in industry and agriculture, human genome mapping, transgenic animals, infertility, gene therapy, genetically modified foods, testing our genes, and others [22]. Other countries have applied the same consensus mechanisms to similar topics, with gene-related topics frequently being among the topics of such discussions around the world.

Our research group adopted the same techniques to help with the revision of the code of ethics for nurses in Taiwan in 2005 and 2006 [18]. Although we found this method useful, it was quite time consuming for lay panelists and therefore limiting in its widespread application. By modifying the guidelines with the help of the Internet and the Delphi technique, we were able to recruit a larger citizen panel to participate in the development of ethical guidelines for genetic testing. The downside was that the Internet and the larger panel size might have deterred effective communication among participants. Instances of face-to-face citizen consensus conferences, however, do not necessarily guarantee effective communication and decision making. In addition, the relatively small number of citizens who could physically participate in the consensus conference has been criticized as being unrepresentative of real-life consensus. In contrast, group emailing can increase the speed of group discussions and applications of the Delphi technique and can facilitate decision making if we wish to involve more citizens in the process.

Citizen consensus conferences need to have ample participation from the lay panel. As a result, for the modified Delphi technique to work for a citizen consensus conference, a good response rate to the questionnaires is very important. Internet technology has been reported to have the potential to decrease the time and cost in conducting a health care survey and increase response rates [20]. Although conducting health surveys using the Internet has not always resulted in a good response rate [20], the low dropout in our study was an example of how Internet-based studies could actually work better than traditional forms of data collection using surveys or questionnaires.

Limitations

The composition of our citizen panel tended to be young urban students. This phenomenon was caused by our reliance on the Internet in this study because such students are more technology savvy and broadband services are more ubiquitous near city centers. Although this phenomenon limits the generalizability of our research results, the fact that the younger well-educated generation will ultimately provide the opinion leaders of the future suggests that our draft guidelines will likely be relevant for some time to come.

Another drawback is that we had a high percentage of health care professionals in the lay panel who were knowledgeable about genetic testing. Therefore, the composition of the lay panel was not representative of society. This difficulty arose due to the high percentage of respondents having medical backgrounds. It is reasonable to assume that those with medical backgrounds would be more interested in this issue than those without. Regardless, the common sense of health care professionals is important for forging societal consensus.

On the other hand, these limits to generalizability could have been caused by our advertising and recruiting strategy. Due to the limitation of funding, we relied solely on free Internet portals. If our recruitment announcements could have been placed in major commercial portals, such as Yahoo and Google, we might have been able to gather a more varied population of volunteers as potential participants.

Despite the growing interest in public participation, the real effectiveness of participation remains difficult to ascertain. The main difficulty comes from how to define effectiveness and how to make it operational [23]. In the instance of consensus conference exercises, most evaluations from the past have only indicated that such consensus conferences were effective because of continuing application and wide audiences, which is not strong proof that they have been effective. It has been argued that rigorous evaluations using social science methodologies should be an important part of public-participation exercises. There are also attempts to establish a research agenda for evaluating public participation exercises [23]. The fact that our study did not evaluate the effectiveness of the exercise itself remains a major limitation of its generalizability.

No doubt, the sample size of this study is inadequate to draw definitive conclusions about the sensitive issue at hand. This study was merely an attempt to forge some consensus in genetic testing through Internet public participation. Whether a larger number of participants would add strength to this policy making exercise remains to be seen. From the experience gained by conducting this study, we found that a sample size of 100 participants was fairly difficult to manage. For a citizen consensus conference to operate efficiently and effectively, researchers need to communicate with the participants constantly throughout the process. As the group gets larger, even with the help of information and communication technology, it becomes harder and harder to keep tract of the participants and make sure they keep their commitments. Other mechanisms need to be added if a broader participation is desired. There is no way in a democracy that citizen consensus conferences can replace all other policy-making mechanisms, such as referendums.

Conclusions

The ethical, legal, and social impact of genetic testing cannot be overlooked. Test results not only have a tremendous impact on the life of the individuals who receive the test, but also impact his or her family. This research helped to establish ethical guidelines for genetic testing using public participation via the Internet. The recommended ethical guidelines had 4 categories and 25 items; the 4 categories encompassed decision making, management of tissue samples, release of results, and information flow. We hope, through the implementation of these guidelines, mutual trust can be established between the health care professionals and the general public with respect to the application of genetic tests.

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Conflicts of Interest

None declared

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Abbreviations

ACOG: American College of Obstetricians and Gynecologists
CVI: content validity index
ELSI: ethical, legal, and social implications
OECD: Organization for Economic Cooperation and Development
PI: principal investigator

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Original Paper

Dropout, Nonusage Attrition, and Pretreatment Predictors of Nonusage Attrition in a Commercial Web-Based Weight Loss Program

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Abstract

Background: An understanding of the factors that predict retention and website use are critical to the development of effective Web-based weight loss interventions. However, poor retention (dropout attrition) and website utilization (nonusage attrition) are major inhibitors to the effectiveness of Web-based programs.

Objective: The study aimed to (1) describe the prevalence of dropout and nonusage attrition and (2) examine pretreatment predictors of nonusage attrition in a cohort of commercial Web-based weight loss program participants.

Methods: Participants enrolled in the online program, The Biggest Loser Club, Australia, from August 15, 2007, to May 31, 2008. Only those who subscribed for 12 or 52 weeks were included in this study. All data were collected by the program proprietors, SP Health Co Pty Ltd (Sydney, Australia), and provided in "deidentified" form. Data collected included responses to a pretreatment survey (sociodemographic and behavioral characteristics), subscription history (date of enrollment and subscription end), and website use (log-ins, food and exercise diary entries, weigh-ins, and forum posts). Participants were classified as a member of the program at 12 or 52 weeks if they held an active subscription plan at that point in time. Participants were classified as nonusers at 12 or 52 weeks if they had stopped using all of the website features and had not returned. Predictors of nonusage attrition were explored using Cox proportional hazards regression analysis.

Results: Of the 9599 eligible participants, 6943 (72%) subscribed to the program for 12 weeks, and 2656 (28%) subscribed for 52 weeks. Of all participants, 31% (2975/9599) were classified as overweight, 61% (5866/9599) were classified as obese, 86% (8279/9599) were female, and participants' mean (SD) age was 35.7 (9.5) years. The 12 week and 52 week subscribers' retention rates were 97% and 77% respectively. Of 12 week subscribers, 35% were classified as program "users" after 12 weeks, and 30% of 52 week subscribers were classified as "users" after 52 weeks. Significant predictors of nonusage attrition among 12 week subscribers included age (hazard ratio for 45 to 55 years of age = 0.83, 95% confidence interval [CI] 0.73 - 0.93, P = .001; hazard ratio for 55 to 65 years of age = 0.80, 95% CI 0.66 - 0.99, P = .04), exercise level (hazard ratio = 0.76, 95% CI 0.72 - 0.81, P < .001), emotional eating (hazard ratio = 1.11, 95% CI 1.04 - 1.18, P = .001), eating breakfast (hazard ratio = 0.88, 95% CI 0.82 - 0.95, P = .001), and skipping meals (hazard ratio = 1.12, 95% CI 1.04 -1.19, P = .001). For 52 week subscribers, eating breakfast (hazard ratio = 0.88, 95% CI 0.79 - 0.99, P = .04) and not drinking tea or coffee with sugar (hazard ratio = 1.23, 95% CI 1.11 - 1.37, P < .001) were the pretreatment characteristics that significantly decreased risk of nonusage attrition.

Conclusions: The findings demonstrate a high prevalence of nonusage attrition among a cohort of commercial Web-based weight loss program participants. Several sociodemographic and behavioral factors were shown to independently predict nonusage attrition.

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KEYWORDS

Weight loss; Internet; commercial sector; retention

Introduction

Public health interventions delivered via the Internet are becoming increasingly popular, and evidence to support their ability to achieve health-related behavior change and positive health outcomes is growing [1]. However, there is a need for Internet-delivered health and lifestyle interventions to minimize attrition and boost utilization rates in order to improve effectiveness [2-4]. A recent systematic review of Web-based weight loss interventions found that these interventions have the potential to achieve significant weight loss; however, they can also suffer from high dropout and poor utilization [5].

Retention rates published to date for Web-based weight loss programs range from 20% to 100%, with the majority less than 80% [5]. There may be an association between increased numbers of tasks prescribed or degree of participation required in Web-based interventions with lower retention rates. For example, studies comparing participants in Web-based weight loss interventions with control groups almost universally report higher retention among the control groups [6-12]. Furthermore, in some studies, where Web-based weight loss interventions are compared with Web-based interventions with a greater number of features, higher retentions rates are often found in the Web-based interventions with fewer features [13-16].

The majority of Web-based weight loss interventions report low website usage and experience a steady drop in usage over time [2]. Many participants also do not achieve the level of use prescribed by the program [2,17-19]. It appears, however, that the addition of evidence-based components to Web-based interventions such as behavioral therapy, human counseling, or motivational interviewing may result in greater website use compared with Web-based interventions that provide basic education or information only [14-16,20]. For example, studies have demonstrated significantly higher numbers of log-ins [14-16,20] as well as more self-monitoring occasions and higher attendance in online meetings [14] with the addition of these evidence-based components. Recent systematic reviews of Web-based weight loss interventions have also acknowledged the inverse relationship between website use and weight loss [4,18]. Therefore, the ability of Web-based interventions to maximize utilization and retain participants is a crucial component of efforts to enhance effectiveness.

As participants can potentially fail to drop out of Web-based interventions but stop using the website, Eysenbach [4] has suggested that exploration of attrition rates should include dropout attrition rates (ie, participants who do not complete the study/program) and nonusage attrition rates (ie, participants who stop using the website). Such knowledge is required to improve our understanding of how participants use Web-based programs. Eysenbach [4] has also highlighted the importance of exploring predictors of attrition in Web-based programs. Previous research has investigated pretreatment predictors of dropout attrition from weight loss interventions and demonstrated key sociodemographic characteristics (education level [21], employment status [21,22], age [23,24], gender [25]) and behavioral factors (number of previous weight loss attempts [21,26,27], dietary intake [26], emotional status [27,28], binge eating [28], and weight loss expectations [26]) that were predictive of dropout attrition. However, no consistent patterns of pretreatment predictors of nonusage attrition from Web-based weight loss interventions have been identified to date. Potential predictors include gender [13,29], age [13,29,30], motivation [13], body mass index [30], physical activity [30], and fruit and vegetable consumption [30].

To date, studies investigating Web-based weight loss programs have predominantly been randomized controlled trials (RCTs). However, RCTs could potentially overestimate or underestimate participant attrition and website use due to the inherent characteristics of volunteers and study rigor (eg, motivated participants, additional assessment sessions, subject retention strategies, greater accountability, and contact with study staff). Therefore, RCTs may not represent attrition or website usage in the “real world.” Studies that follow real-world participants of Web-based weight loss programs are, therefore, needed to ascertain true dropout and nonusage attrition rates in order to enhance program effectiveness.

Therefore, the first aim of this study was to describe in a large cohort of real-world users of a commercial Web-based weight loss program, the prevalence of dropout and nonusage attrition. The second aim was to determine which pretreatment sociodemographic and behavioral characteristics predict nonusage attrition.

Methods

Participants and Design

Participants were adults 18 to 75 years of age who enrolled in a commercial Web-based weight loss program from August 15, 2007, through May 31, 2008, and paid a subscription to access the program. A self-reported body mass index (BMI) of greater than or equal to 22 kg/m^2 was required to enroll in the program. Only participants who subscribed for 12 or 52 weeks were included in this study, as they are the most predominant subscription lengths. Participants who did not pay for their initial subscription (eg, free promotional program trials) were excluded. Data related to free or nonconsecutive memberships (≥ 7 days apart) were also not included in the analysis. Membership status and website use were tracked for the duration of the subscription.

The Commercial Web-Based Weight Loss Program

SP Health Co Pty Ltd (Sydney, Australia) developed the Web-based weight loss platform that is commercially available as The Biggest Loser Club. In summary, the online program incorporates key evidence-based weight management strategies and aligns with key elements of social cognitive theory [31] including self-management, social support, self-efficacy, outcome expectations and expectancies, and perceived barriers/facilitators. The key features of the program include goal setting (goal weight, daily calorie goal, and weekly exercise goals), self-monitoring of weight via weekly weigh-ins, as well as food and exercise using an online diary, educational material provided by weekly email, and an online discussion *forum*. Participants who enroll in the program purchase a specific subscription plan. The subscription plans are of 4, 12, 16, or 52 week's duration and are either paid for prospectively at enrollment or by monthly installments. In 2007–2008 the cost of the program ranged from A$16.50 to A$79.95 per month. The cost per month to the participant was lower if they subscribed for longer and/or paid up front. Participants were predominantly recruited via marketing of the program through a reality television program, *The Biggest Loser, Australia*.

Data Collection

The proprietors of program, SP Health Co, store all data entered by participants accessing the program website. Data stored include responses to an enrollment survey, subscription plans held, and use of a number of the website features (log-ins, online food and activity diary entries, weigh-ins, and posts to the discussion forum). SP Health Co extracted stored data in "deidentifiable" form for up to 52 weeks from enrollment for all participants who met the inclusion criteria. Ethics approval for the study was obtained from the University of Newcastle Human Research Ethics Committee.

Pretreatment Characteristics

Participants' pretreatment characteristics were captured from the enrollment survey. Participants' self-reported height and weight were used to calculate BMI (weight in kilograms divided by height in meters squared), which was categorized as healthy, overweight, or obese using the World Health Organization's BMI classification [32]. Reported postcodes were assigned an Index of Relative of Socioeconomic Advantage and Disadvantage (IRSAD) decile (ranked from 1 = disadvantaged to 10 = advantaged) as an indicator of socioeconomic status [33]. The remoteness of the area in which participants lived was classified according to the Accessibility/Remoteness Index of Australia (ARIA) of their postcode [34]. Participants' reasons for wanting to achieve weight loss were grouped as health-related reasons (eg, doctor recommended or health scare) and reasons not related to health (eg, to look good or to enhance one's love life), and participants were categorized as having 1 or more health-related reasons or no health-related reasons for wanting to lose weight. Participants also selected their reasons for eating (to ease emotional upset, for the joy of it, to reduce stress, and out of boredom), whether they had eating habits associated with weight gain (frying foods, using butter in cooking, drinking full sugar soft drinks, skipping meals, drinking tea or coffee with sugar, not eating breakfast, not using low fat products, keeping snack foods in the house, and not drinking 6 or more glasses of water a day) and the number of days they exercised per week. Age and gender were also captured from the enrollment survey.

Website Use

Website use was assessed by summing available usage data. Participants were classified as having used the website on any given day if they logged in, made an entry in the diary, posted to the forum, and/or weighed in. The total number of days per 4 week period each participant "used" the website was calculated and categorized as 0 days, 1 to 3 days, 4 to 7 days, 8 to 15 days and 16 or more days. All website use variables were calculated from enrollment to 12 and 52 weeks for the 12- and 52 week subscribers respectively.

Dropout Attrition

The date a participant enrolled in program and the date membership ceased were used to calculate the number of days each participant was a member of the program (ie, duration of membership). The date membership ceased was the end date of the participant's subscription plan unless there were special circumstances that prevented the participant from completing the subscription (eg, pregnancy or financial constraints). Participants were classified as members of the program at 12 or 52 weeks if they held an active subscription plan at that point in time (≥ 78 days for 12 week subscriptions and ≥ 359 days for 52 week subscriptions). Otherwise they were classified as a dropout.

Nonusage Attrition

Nonusage attrition was only considered for participants who completed their subscription (ie, they did not drop out). Participants were classified as a nonuser at 12 or 52 weeks if they stopped using the website features (ie, no log-ins, food/activity diary entries, weigh-ins, or posts to the discussion forum). The week a participant was classified as a nonuser was the week he or she ceased using the website and did not return.

Data Analysis

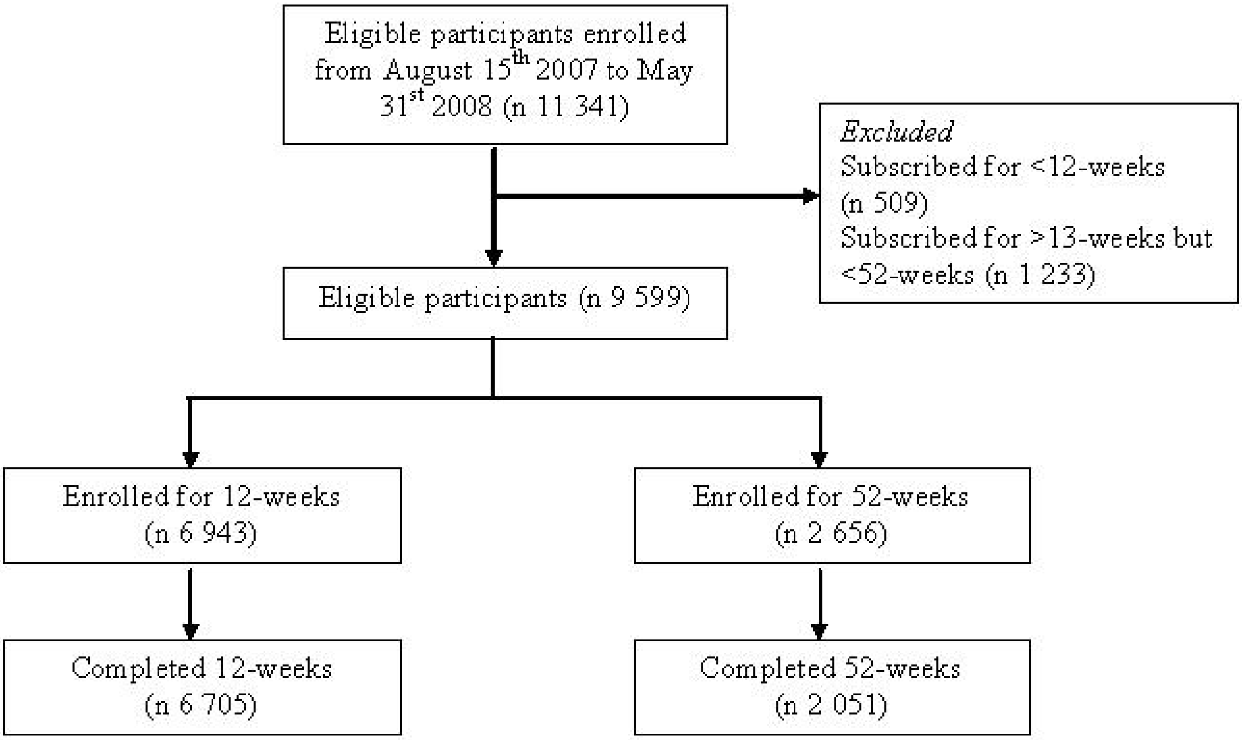
Data analysis was undertaken using Stata 11 IC (StataCorp LP, College Station, USA). Participant pretreatment characteristics were described as means (SD) for continuous variables and percentage for categorical variables. Subscription length (12 and 52 weeks) group differences were tested using independent *t* tests for continuous variables and chi-square tests for categorical variables. Participants' pretreatment characteristics were investigated as predictors of nonusage attrition for 12- and 52 week subscribers using Cox proportional hazards regression analyses. The time variable was the duration of usage (in weeks), and nonusage was considered a failure. Univariate analyses were conducted on all pretreatment predictor variables of interest and those with $P < .2$ were included in a stepwise regression analysis to find the most parsimonious model. The proportional hazards assumption was tested for each model using the Schoenfeld residuals. The significance level was set at alpha = .05.

Results

Pretreatment Characteristics and Website Use

Of the 11,341 participants who enrolled in the commercial Web-based weight loss program between August 15, 2007, and May 31, 2008, 9599 were eligible for inclusion in the study, and 1742 were excluded (Figure 1). In all, 72% (6943/9599) of eligible participants subscribed to the program for 12 weeks, and 2656 subscribed for 52 weeks.

Figure 1. Participant flow



The characteristics of the eligible participants are outlined in Table 1. In summary, 31% (2975/9599) of participants were overweight, 61% (5866/9599) were obese, and 86% (8279/9599) were female. The mean (SD) age of participants was 35.7 (9.5) years, 85% (8022/9455) of participants were of moderate-to-high socioeconomic status (ie, scored between 5 and 10 on IRSAD), and 75% (7125/9456) were from major cities in Australia. The majority of the group reported some healthy eating habits such as eating breakfast (7052/9599 or 74%) and using low fat products (6269/9599 or 65%), but many (5098/9599 or 53%) also reported poor eating habits such as skipping meals. Most participants reported inadequate levels of physical activity at enrollment, with 51% (4875/9569) exercising less than 2 days per week.

Table 1. Pretreatment characteristics

Descriptor	Total	12 Weeks	52 Weeks	*P* Value
	n = 9599	n = 6943	n = 2656	
Age (years)				
Mean (SD)	35.7 (9.5)	35.3 (9.4)	36.7 (9.6)	< .001
18 to 25 years, %	12.8	13.5	10.8	< .001
25 to 35 years, %	37.4	38.6	34.5	
35 to 45 years, %	33.2	32.3	35.6	
45 to 55 years, %	13.2	12.6	14.7	
55 to 65 years, %	3.1	2.8	4.0	
65 to 75 years, %	0.4	0.4	0.4	
Female (%)	86.3	86.5	85.7	.30
BMI (kg/m 2)				
Mean (SD)	32.9 (6.7)	31.8 (6.1)	35.8 (7.1)	< .001
Healthy weight, %	7.9	9.7	3.1	< .001
Overweight, %	31.0	35.7	18.7	
Obese, %	61.1	54.6	78.2	
Socioeconomic status (IRSAD decile) [a]				
1-2, %	5.8	4.9	8.0	< .001
3-4, %	9.4	9.1	10.3	
5-6, %	18.2	17.4	20.2	
7-8, %	29.3	29.5	28.7	
9-10, %	37.4	39.1	32.8	
Remoteness (ARIA) b				
Major city, %	75.4	76.4	72.7	.001
Regional, %	23.2	22.3	25.8	
Remote, %	1.4	1.3	1.6	
Days of planned exercise [c]				
0-1 days, %	51.0	50.6	51.8	< .001
2 or more days, %	49.0	49.4	48.2	
Eating habits				
Fry foods, %	37.9	36.4	42.4	< .001
Use butter in cooking, %	36.1	35.4	38.2	.01
Drink full sugar soft drinks, %	29.4	28.2	32.6	< .001
Skip meals, %	53.1	51.3	58.0	< .001
Drink tea or coffee with sugar, %	43.7	44.4	41.9	.03
Eat breakfast, %	73.5	74.7	70.3	< .001
Use low fat products, %	65.3	66.3	62.7	.001
Keep snack foods in the house, %	59.8	58.9	62.1	.004
Drink 6+ glasses of water a day, %	40.7	41.2	39.4	.10
Reason for eating				
To ease emotional upset, %	56.0	55.0	58.7	.001
For the joy of it, %	55.9	53.4	56.9	.002

Descriptor	Total	12 Weeks	52 Weeks	*P* Value
To reduce stress, %	44.6	44.0	46.1	.07
Out of boredom, %	78.6	78.9	77.9	.26
One or more health-related reasons for weight loss, %	54.7	53.2	58.9	< .001

[a] Total n = 9455; at 12 weeks n = 6841; and at 52 weeks, n = 2614

[b] Total n = 9456; at 12 weeks, n = 6842; and at 52 weeks, n = 2614

[c] Total n = 9569; at 12 weeks, n = 6923; and at 52 weeks, n = 2646

Statistically significant differences in pretreatment characteristics of 12- and 52 week subscribers were evident, with the mean (SD) age of participants who subscribed for 52 weeks being significantly greater (35.8 [7.1] years of age vs 31.8 [6.1] years of age), having a higher mean (SD) BMI (36.7 [9.6] vs 35.3 [9.4]), being of lower socioeconomic status (82% vs 86% with an ISRAD of 5 to 10), and a lower proportion residing in major cities of Australia (73% vs 76%) when compared with 12 week subscribers. A significantly higher proportion of 52 week subscribers reported poor eating habits (eg, frying foods or drinking full sugar soft drinks), exercising less than 2 days per week, eating for emotional reasons or for the joy of it, and having health-related reasons for wanting to lose weight.

Figures 2 describe overall website use. For both 12- and 52 week subscribers, the highest proportion of participants used the website on 16 days or more during weeks 1 to 4 of the program. During weeks 5 to 8 and weeks 9 to 12, the highest proportion of 12 week subscribers did not use the website. However, of the participants who did use the website, most used it 1 to 3 days during each 4 week period. For 52 week subscribers, the highest proportion of participants used the program on 1 to 3 days from weeks 5 to 8. After this time (ie, weeks 9 to 52) the highest proportion of participants never used the website, and the second highest proportion used the website 1 to 3 days in each 4 week period.

Figure 2. Website use from enrollment to 12 weeks among 12 week subscribers

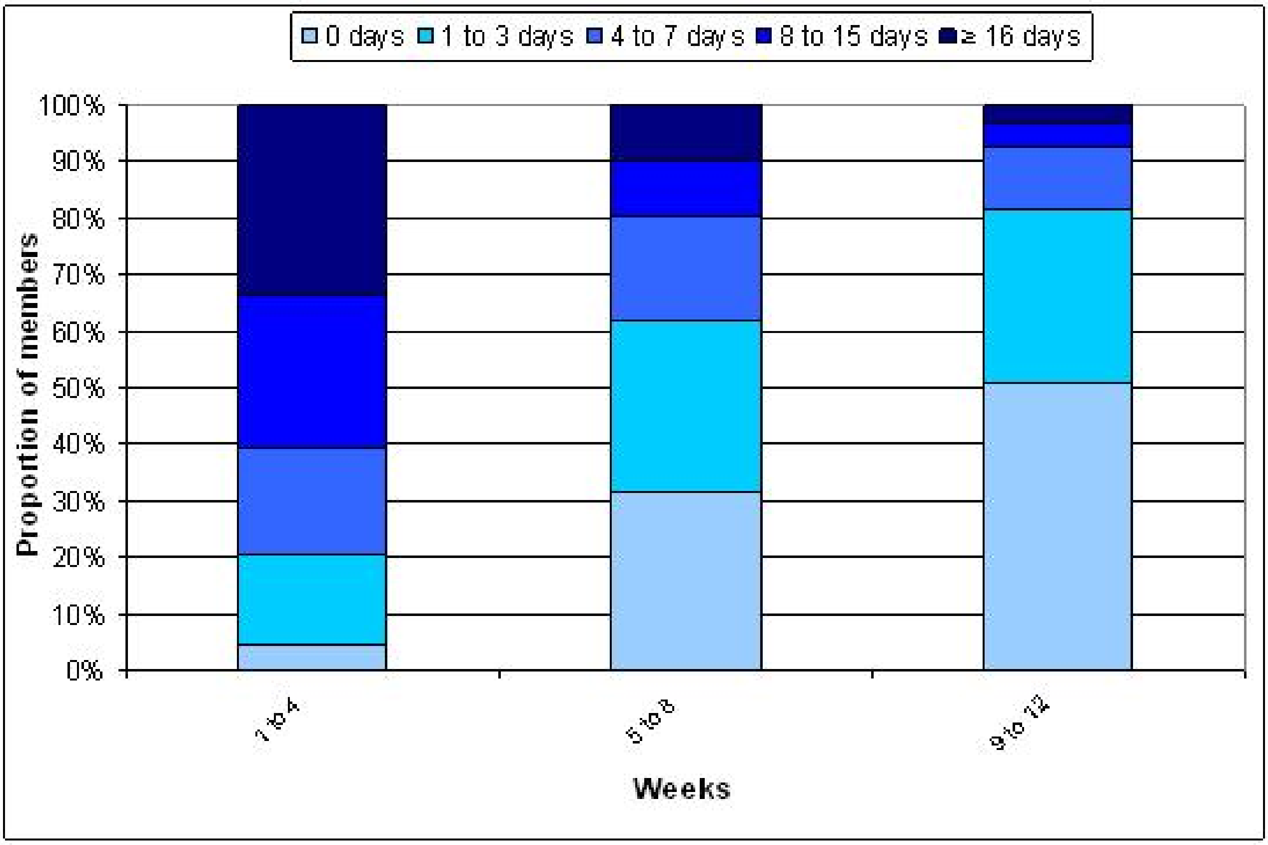
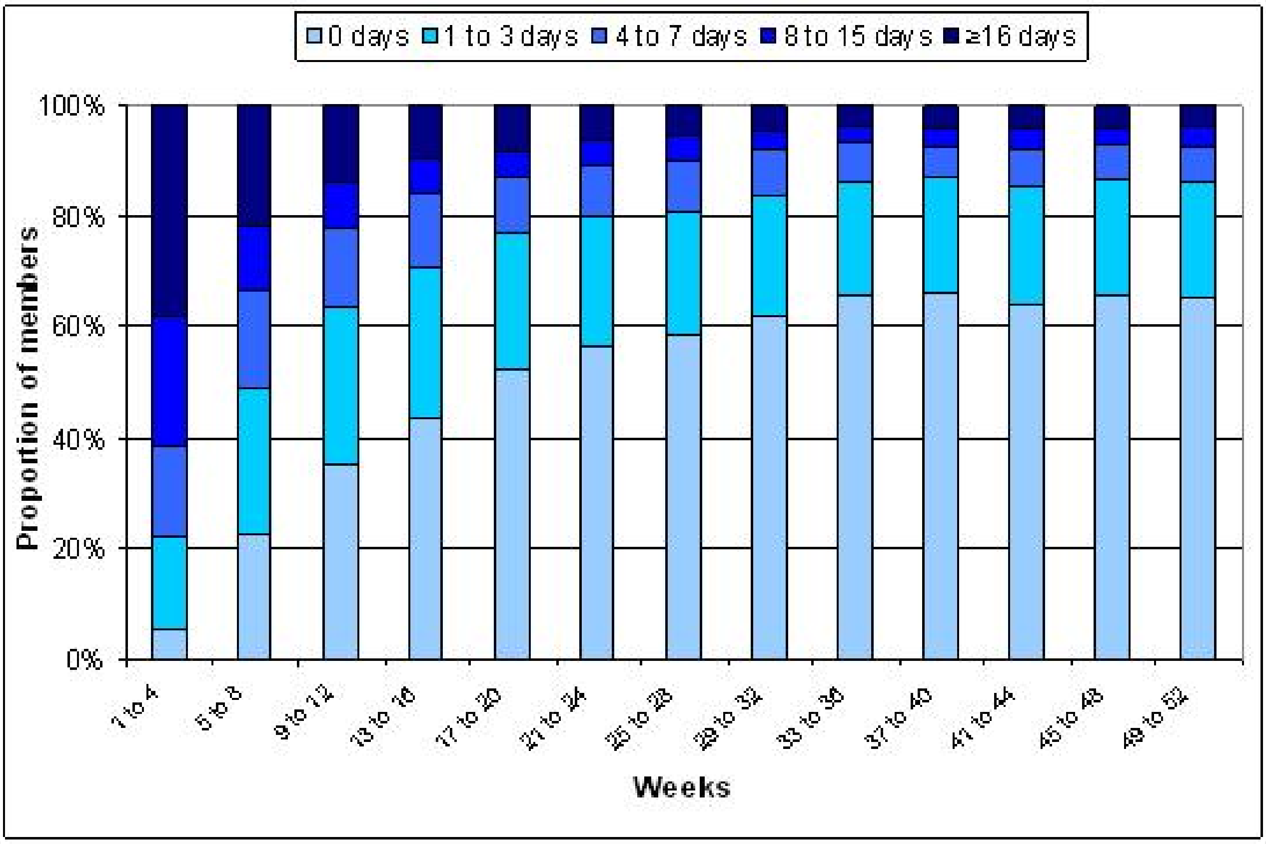


Figure 3. Website use from enrollment to 52 weeks among 52 week subscribers



Dropout Attrition

Figures 4 and 5 present dropout attrition curves for 12- and 52 week subscribers respectively. Of the 6943 participants who subscribed to the program for 12 weeks, the retention rate was 97% at 12 weeks, with 238 participants (3%) dropping out over the 12 week period (Figure 4). For the 2656 participants who subscribed to the program for 52 weeks, the retention rate was 77% with 605 dropping out over the 52 week period (Figure 5).

Figure 4. Dropout attrition and nonusage attrition from enrollment to 12 weeks among 12 week subscribers

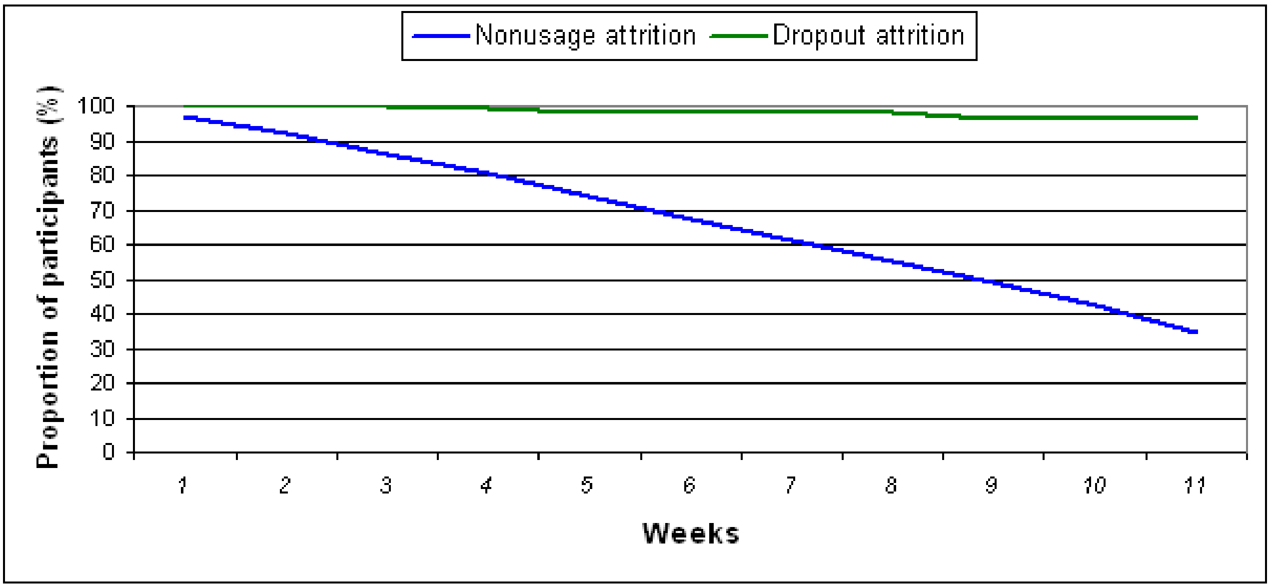
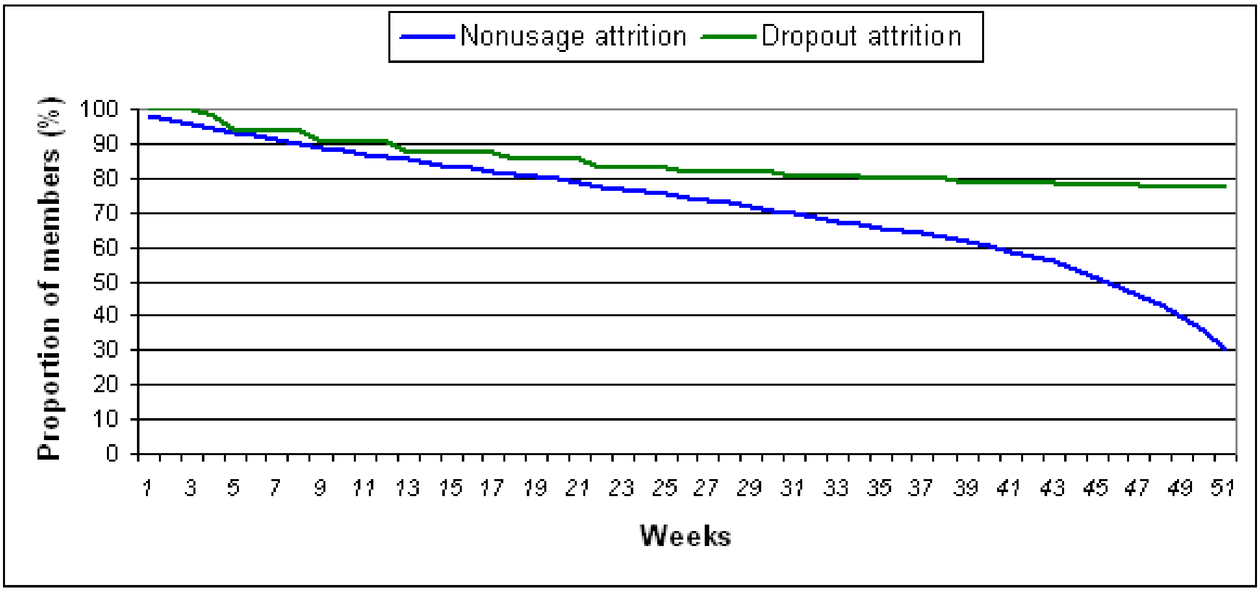


Figure 5. Dropout and nonusage attrition from enrollment to 52 weeks among 52 week subscribers



Nonusage Attrition

Figures 4 and 5 also present nonusage attrition curves for those who subscribed and completed a 12- or 52 week subscription, respectively. Of the 6705 participants who subscribed to and completed 12 weeks of the program, 35% (2317) of participants were classified as ”users” of the program at 12 weeks. The lowest proportion of participants stopped using the program during weeks 1 and 2. The proportion of participants who stopped using the program remained steady from week 3 to week 10 (6% to 7% stopped using per week) but increased during week 11 to 8%. Of the 6705 12 week subscribers, 50% (n = 3398) had become nonusers of the program by week 9 (Figure 4).

Of the 2051 participants who completed their 52 week subscription, 622 participants (30%) were “users” of the program at 52 weeks. The proportion of participants who stopped using the program remained steady from week 1 to week 44 (1% to 2% stopped using per week) but increased rapidly thereafter. By week 46, greater than 50% of the 52 week subscribers were nonusers of the program (Figure 5).

Predictors of Nonusage Attrition: 12 week Subscribers

Table 2 describes unadjusted predictors of nonusage attrition among 12 week subscribers from univariate analyses. In the multiple regression analysis (Table 2), skipping meals (hazard ratio = 1.12, 95% confidence interval (CI) 1.04 - 1.19, *P* = .001) and eating to ease emotional upset (hazard ratio = 1.11, 95% CI 1.04 -1.18, *P* = .001) were the 2 pretreatment characteristics found to significantly increase a participants risk of being a nonuser. Participants who exercised more than 1 day per week were at a significantly decreased risk of being a nonuser (hazard ratio = 0.76, 95% CI 0.72 - 0.81, *P* < .001). Participants who ate breakfast (hazard ratio = 0.88, 95% CI 0.82 - 0.95, *P* = .001) were also at decreased risk of nonusage, as well as participants aged 45 to 65 years (hazard ratio for 45 to 55 years of age = 0.83, 95% CI 0.73 - 0.93, *P* = .001; hazard ratio for 55 to 65 years of age = 0.80, 95% CI 0.66 - 0.99, *P* = .04).

Table 2. Risk of nonusage attrition for 12 week subscribers

Risk Factor	Unadjusted (n = 6705)		Adjusted (n = 6686)[d]	
	Hazard Ratio (95% CI)	*P*	Hazard Ratio (95% CI)	*P*
Gender				
Male	1.00 (reference)			
Female	0.85 (0.78 - 0.92)	< .001		
Age (years)				
18 to 25	1.00 (reference)		1.00 (reference)	
25 to 35	0.92 (0.84 -1.01)	.09	0.93 (0.85 - 1.02)	.12
35 to 45	0.92 (0.84 -1.01)	.09	0.93 (0.85 - 1.03)	.15
45 to 55	0.81 (0.72 - 0.91)	< .001	0.83 (0.73 - 0.93)	.001
55 to 65	0.77 (0.63 - 0.95)	.01	0.80 (0.66 - 0.99)	.04
65 to 75	0.54 (0.29 - 1.01)	.05	0.63 (0.34 - 1.17)	.14
Socioeconomic status (IRSAD decile) [a]				
1-2	1.00 (reference)			
3-4	1.04 (0.88 - 1.23)	.67		
5-6	0.97 (0.83 - 1.13)	.69		
7-8	1.01 (0.87 - 1.17)	.93		
9-10	1.03 (0.89 - 1.19)	.72		
Remoteness [b]				
Major cities of Australia	1.00 (reference)			
Regional Australia	0.97 (0.90 - 1.04)	.35		
Rural/remote Australia	1.17 (0.91 - 1.49)	.21		
BMI				
Healthy weight	1.00 (reference)			
Overweight	1.02 (0.92 - 1.14)	.66		
Obese	1.11 (1.00 - 1.24)	.04		
0 to 1 days	1.00 (reference)		1.00 (reference)	
2 or more days	0.74 (0.69 - 0.78)	< .001	0.76 (0.72 - 0.81)	< .001
Reason for eating				
To ease emotional upset	1.07 (1.01 - 1.14)	.01	1.11 (1.04 - 1.18)	.001
For the joy of it	0.99 (0.93 - 1.05)	.63		
To reduce stress	1.10 (1.03 - 1.16)	.002		
Out of boredom	0.98 (0.91 - 1.05)	.59		
Eating habits				
Fry foods	1.07 (0.99 - 1.13)	.07		
Use butter in cooking	1.06 (0.99 - 1.13)	.07		
Drink full sugar soft drinks	1.16 (1.09 - 1.24)	< .001		
Skip meals	1.23 (1.16 - 1.31)	< .001	1.12 (1.04 - 1.19)	.001
Drink tea or coffee with sugar	0.99 (0.94 - 1.05)	.84		
Eat breakfast	0.77 (0.72 - 0.82)	< .001	0.88 (0.82 - 0.95)	.001
Use low fat products	0.85 (0.79 - 0.90)	< .001		

Risk Factor	Unadjusted (n = 6705)		Adjusted (n = 6686)[d]	
	Hazard Ratio (95% CI)	*P*	Hazard Ratio (95% CI)	*P*
Keep snack foods in the house	1.03 (0.97 - 1.09)	.33		
Drink 6 or more glasses of water a day	0.92 (0.86 - 0.97)	.004		
1 or more health-related reasons for weight loss	0.97 (0.92 - 1.03)	.37		

[a] n = 6610

[b] n = 6611

[c] n = 6686 (all unadjusted)

[d] Stratified by gender

Predictors of Nonusage Attrition: 52 week Subscribers

Table 3 describes unadjusted potential predictors of nonusage attrition for 52 week subscribers using univariate analyses. In the multiple regression analysis (Table 3), eating breakfast (hazard ratio = 0.88, 95% CI 0.79 - 0.99, *P* = .04) was shown to be associated with reduced risk of nonusage attrition. Drinking tea or coffee with sugar was associated with increased risk of nonusage attrition among 52 week subscribers (hazard ratio = 1.23, 95% CI 1.11- 1.37, *P* < .001).

Table 3. Risk of nonusage attrition for 52 week subscribers

Risk Factors	Unadjusted (n = 2051)		Adjusted (n = 2043)[d]	
	Hazard Ratio (95% CI)	*P*	Hazard Ratio (95% CI)	*P*
Gender				
Male	1.00 (reference)			
Female	0.90 (0.78 - 1.04)			
Age (years)				
18 to 25	1.00 (reference)			
25 to 35	0.96 (0.79 - 1.16)	.66		
35 to 45	0.93 (0.77 - 1.16)	.45		
45 to 55	0.79 (0.63 - 0.97)	.03		
55 to 65	0.68 (0.49 - 0.91)	.01		
65 to 75	0.20 (0.02 - 1.44)	.11		
Socioeconomic status (IRSAD decile) [a]				
1-2	1.00 (reference)			
3-4	0.92 (0.71 - 1.18)	.49		
5-6	0.82 (0.66 - 1.03)	.08		
7-8	0.89 (0.72 - 1.10)	.29		
9-10	0.82 (0.66 - 1.01)	.06		
Remoteness [b]				
Major cities of Australia	1.00 (reference)			
Regional Australia	1.03 (0.91 - 1.16)	.66		
Rural/remote Australia	1.05 (0.64 - 1.71)	.89		
BMI				
Healthy weight	1.00 (reference)			
Overweight	1.02 (0.74 - 1.42)	.89		
Obese	1.04 (0.76 - 1.41)	.83		
Exercise level [c]				
0 to 1 day	1.00 (reference)			
2 or more days	0.70 (0.63 - 0.78)	< .001		
Reason for eating				
To ease emotional upset	0.98 (0.88 - 1.08)	.64		
For the joy of it	0.96 (0.87 - 1.07)	.46		
To reduce stress	0.93 (0.84 - 1.03)	.17		
Out of boredom	0.97 (0.86 - 1.10)	.62		
Eating habits				
Fry foods	1.12 (1.00 - 1.24)	.04		
Use butter in cooking	1.16 (1.04 - 1.29)	.007		
Drink full sugar soft drinks	1.12 (1.01 - 1.26)	.04		
Skip meals	1.22 (1.10 - 1.36)	< .001		
Drink tea or coffee with sugar	1.25 (1.13 - 1.39)	< .001	1.23 (1.11 - 1.37)	< .001
Eat breakfast	0.82 (0.73 - 0.92)	.001	0.88 (0.79 - 0.99)	.04

Risk Factors	Unadjusted (n = 2051)		Adjusted (n = 2043)[d]	
	Hazard Ratio (95% CI)	*P*	Hazard Ratio (95% CI)	*P*
Use low fat products	0.84 (0.75 - 0.93)	.001		
Keep snack foods in the house	1.09 (0.98 - 1.21)	.13		
Drink 6 or more glasses of water a day	0.93 (0.83 - 1.03)	.15		
1 or more health-related reasons for weight loss	0.90 (0.81 - 1.01)	.06		

[a] n = 2019

[b] n = 2019

[c] n = 2043 (all unadjusted)

[d] Stratified by exercise level

Discussion

This study is one of only a small number of studies [29,35-42] to follow a group of real-world participants of a Web-based weight loss program and is the first to comprehensively evaluate the prevalence and predictors of nonusage attrition in a large cohort. The study demonstrates a high prevalence of nonusage attrition and highlights the need for evidence-based strategies to reduce attrition rates. Notably, we found that a participant's age, as well as his or her eating and physical activity habits at enrollment can predict nonusage attrition.

The findings from this study are consistent with other studies that have demonstrated that individuals in the mid-to-older age group (45 to 65 years) are at decreased risk of nonusage [13,29,30]. People in this age group have lower levels of Internet access [43], spend less time using the Internet and are less likely to use user-generated sites than younger age groups [43,44]. However, their access and use of the Internet is increasing rapidly [43,44]. Therefore, this suggests that Web-based interventions may be well suited to the mid-to-older age groups.

The study findings suggest that people with poor eating or physical activity habits prior to enrolling in a commercial Web-based weight loss program are most likely to stop using the program. This includes participants who exercised less than 2 days per week, skipped meals, did not eat breakfast, drank tea or coffee with added sugar, or identified eating to ease emotional upset. This suggests that these at-risk individuals may require alternate or additional support to remain an active participant of Web-based programs, particularly in the short-term. Alternatively, it may be that the Web-based program in its current form did not engage this group of participants. A research priority is, therefore, to determine whether different or extra website features can improve website usage in this group of at-risk individuals.

This study highlights the importance of investigating nonusage attrition to accurately describe attrition rates. The retention rates for the commercial Web-based weight loss program of 97% after 12 weeks and 77% after 52 weeks were high in comparison with observational [29,37,40,41] and experimental [5] Web-based weight loss intervention studies, as well as all types of behavioral weight loss interventions [45]. However, as participants purchase a specific subscription plan and can only unsubscribe if they have special circumstances that prevent them from completing their subscription, the retention rates do not capture those participants who did not wish to continue using the program. The nonusage attrition at 12 weeks of 65% and at 52 weeks of 70% is higher than the dropout attrition rates and demonstrates that a number of participants do not continue to use the commercial Web-based weight loss program for the duration of their subscription. Use of the commercial website was consistent with other public health interventions delivered via the Internet, whereby use drops after the preliminary weeks of the intervention [17]. For both 12- and 52 week subscribers the nonusage attrition was steady throughout the majority of the intervention, but nonusage attrition increased slightly towards the final weeks of the intervention. This opposes a previous hypothesis that suggests that by the final phase of the intervention a stable user group should exist, resulting in less nonusage [4]. The pattern of nonusage attrition in this study is most likely an interplay of several factors that potentially impact nonusage attrition either positively (eg, cost of program, program features, and usability) or negatively (eg, no prompts or personal contact, self-directed nature) [4].

To our knowledge, only 2 other studies have investigated nonusage attrition rates in a Web-based interventions aiming to achieve weight loss [29,42]. The first, an observational study, described nonusage attrition rates for a physical activity focused Web-based program (MiLife) and found that 79% of participants were still using the website after 12 weeks [42]. The second study compared nonusage attrition rates among RCT and real-world participants of a Web-based intervention (Active-Online) to promote physical activity over an 18-month period. Greater than 50% of trial participants became nonusers after approximately 11 months and 1 month for the real-world participants [29]. This commercial Web-based weight loss program's nonusage attrition rates were superior to the real-world participants of Active-Online but higher than MiLife [29,42]. However, both Active-Online and MiLife incorporated strategies that have been previously proposed as factors that influence nonusage attrition [4]. One intervention was worksite based [42], which may have enhanced the networking and/or peer pressure and peer support, and, therefore, reversed the usual decline in nonusage [4]. A number of "push-factors" [4], including reminder emails and short message service (SMS) were utilized [29,42]; therefore, participants may have felt obligated to continue using the Web-based programs [4]. The use of accelerometers by participants in one of the studies to monitor physical activity levels [42] may have improved the usability of the program and, therefore, increased usage rates [4]. In comparison, the commercial Web-based weight loss program is primarily a self-directed intervention. This may have negatively impacted usage rates, as it made it easier for participants to stop using the program [4]. However, the participants paid a commercial rate to access the program, which has been previously suggested to positively impact usage rates [4]. As the cost of the program varied and was dependant on the length of subscription and whether a participant paid up front or in installments, the impact on nonusage may have varied. Therefore, the nonusage attrition rates reported in this study appear acceptable compared with previous studies, taking into consideration the existence of factors that may have impacted nonusage attrition.

Limitations

Potential limitations of this study include that only pretreatment characteristics were considered as potential predictors of nonusage attrition. It is possible that other factors such as satisfaction with the program, initial and ongoing weight loss, and external factors also influenced program use. However, the aim of this study was to determine whether it is possible to predict who will use the program at enrollment. Furthermore, although a large number of pretreatment characteristics were explored as potential predictors of nonusage attrition, the study could have been improved by including a larger range of pretreatment characteristics (eg, motivation and stage of change), as well as through the use of validated measures to more comprehensively assess eating and physical activity behaviors. In addition, the study did not track the use of all features of the commercial Web-based weight loss program (eg, weekly tutorials and menu plans), as these data were not available at the time of the study. This may have overestimated nonusage attrition rates. Furthermore, the methodology assumes that nonusage is a negative behavior. It has been suggested, however, that participants may consider Web-based interventions differently from other treatment options [3]. Participants who stop using the website may have achieved a positive outcome and, therefore, reduced the frequency with which they engage with the Web-based program [3]. Further research investigating participants' reasons for dropout and nonusage attrition and the impact of dropout and nonusage attrition on long-term weight loss is therefore required.

Implications

Adherence has been acknowledged as one of the main determinants of effectiveness [46]; therefore, strategies are required to improve nonusage attrition rates among Web-based weight loss program participants. Previous research [5], including research with this cohort [47], has demonstrated a significant correlation between the use of different website features (eg, log-ins, use of discussion forums, online diary entries, and self-monitoring of weight) and weight change. Therefore, there is potential to improve weight loss achieved by participants of Web-based weight loss programs by establishing effective methods to improve nonusage attrition, so that the majority of participants continue to use the website features in the long-term. As the mean weight change achieved by participants of this Web-based weight loss program after 12 and 52 weeks has been found to be clinically important and statistically significant [48,49], if strategies were successful in improving engagement, the public health impact could be substantial.

The findings from this study also highlight key pretreatment sociodemographic and behavioral predictors of nonusage attrition. The findings are similar to other weight loss [21,26-28] and Web-based intervention studies [30], whereby individuals most in need of treatment are less likely to complete and/or engage with the intervention. A number of previous Web-based intervention studies have investigated Web and non-Web-based strategies to improve website engagement including periodic prompts, incentives, self-monitoring, management of participant expectations, improving intervention usability, provision of feedback, as well as contact with service providers [2]. Given the self-directed nature of this intervention, the findings suggest clear evidence-based guidelines outlining the website use required to achieve significant outcomes may also improve nonusage attrition rates. One or a combination of these strategies could be provided to the participants who enroll in the program with the pretreatment characteristics predictive of attrition. However, we do not know the most appropriate strategy or combination of strategies required to improve the use of Web-based programs or whether the strategies required are consistent across population groups. In the future, such knowledge may be used as part of the enrollment process to ensure individuals enroll who are best suited to this approach and that they are provided with access to program features within the Web-based program that meets their needs. Therefore, a research priority is the development and evaluation of strategies to improve nonusage attrition rates in Web-based programs, including their impact on different population groups.

Conclusion

Previous research has identified optimization of participant retention and website use as key challenges for all Web-based interventions [2-4]. This study demonstrated the high prevalence nonusage attrition characteristic of Web-based interventions and, therefore, highlights the need for evidence-based strategies to improve website use. Researchers should investigate the use of new or additional intervention strategies among participants with the pretreatment demographic and behavioral characteristics that were found to independently predict nonusage attrition in this study.

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Conflicts of Interest

MJ Neve receives a postgraduate scholarship top-up from SP Health Co. CE Collins is a consultant dietitian to SP Health Co. PJ Morgan and CE Collins hold an Australian Research Council (ARC) Linkage project grant that is evaluating a weight loss program with SP Health Co.

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Abbreviations

BMI: body mass index
ISRAD: Index of Relative of Socioeconomic Advantage and Disadvantage
RCT: randomized controlled trial
SMS: short message service

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Original Paper

Biomedical Informatics Techniques for Processing and Analyzing Web Blogs of Military Service Members

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Abstract

Introduction: Web logs ("blogs") have become a popular mechanism for people to express their daily thoughts, feelings, and emotions. Many of these expressions contain health care-related themes, both physical and mental, similar to information discussed during a clinical interview or medical consultation. Thus, some of the information contained in blogs might be important for health care research, especially in mental health where stress-related conditions may be difficult and expensive to diagnose and where early recognition is often key to successful treatment. In the field of biomedical informatics, techniques such as information retrieval (IR) and natural language processing (NLP) are often used to unlock information contained in free-text notes. These methods might assist the clinical research community to better understand feelings and emotions post deployment and the burden of symptoms of stress among US military service members.

Methods: In total, 90 military blog posts describing deployment situations and 60 control posts of Operation Enduring Freedom/Operation Iraqi Freedom (OEF/OIF) were collected. After "stop" word exclusion and stemming, a "bag-of-words" representation and term weighting was performed, and the most relevant words were manually selected out of the high-weight words. A pilot ontology was created using Collaborative Protégé, a knowledge management application. The word lists and the ontology were then used within General Architecture for Text Engineering (GATE), an NLP framework, to create an automated pipeline for recognition and analysis of blogs related to combat exposure. An independent expert opinion was used to create a reference standard and evaluate the results of the GATE pipeline.

Results: The 2 dimensions of combat exposure descriptors identified were: words dealing with physical exposure and the soldiers' emotional reactions to it. GATE pipeline was able to retrieve blog texts describing combat exposure with precision 0.9, recall 0.75, and F-score 0.82.

Discussion: Natural language processing and automated information retrieval might potentially provide valuable tools for retrieving and analyzing military blog posts and uncovering military service members' emotions and experiences of combat exposure.

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KEYWORDS

Blogging; medical informatics; military personnel; information storage and retrieval; combat disorders

Introduction

Web logs ("blogs") have become a popular mechanism for people to express their daily thoughts, feelings, and emotions. Much of the information contained in blogs includes health-related themes, both physical and mental. The matters described in a blog post may be very similar to the information discussed during a clinical interview or psychological consultation. Therefore, blogs might contain information that could be important for clinical research, especially in the mental health field where stress-related symptoms are often difficult to ascertain or measure and where timely recognition is often key to successful therapy [1].

In the field of biomedical informatics, information retrieval (IR) techniques (such as automated indexing) and natural language processing (NLP) are commonly used to unlock information contained in free narrative-style text notes [2-4]. With a focus on blogs, these methods can support "infoveillance" [5] and assist the clinical research community to better understand feelings and emotions post deployment and the burden of symptoms of stress among US military service members. In this study, we sought to evaluate the potential for using available IR and NLP tools to unlock information in blogs related to US military service members' experiences and emotions of combat exposure by analyzing the blogs of the military personnel deployed during Operation Enduring Freedom/Operation Iraqi Freedom (OEF/OIF).

Methods

Blog Selection

The authors evaluated military blogs available on the Internet and manually selected 90 blog posts describing combat exposure according to selection criteria. Military blogs catalog Milblogging.com [6] lists over 2500 English-language military blogs and provides basic categorization functionality (sorting by location, time, popularity etc). Three authors (SK, MS, CB) independently used the ordered list of blogs from Iraq and Afghanistan in the period of 2002 to 2008 from this site and selected 1 to 3 blog posts from each site that (1) were in the English language, (2) contained a first person description of the events, (3) were not less than 5 sentences long, (4) were not written for business purposes (eg, news piece or military report), and (5) described concrete situations and events related to active duty.

Of the collected blog posts describing combat exposure, 50 were used for indexing and term weighting and 40 for the pilot evaluation and analysis.

Two of the authors (CB, MS) selected 60 blog posts from Milblogging.com conforming to the same selection criteria listed above except that they did not necessarily describe combat exposure. These 60 blogs were used as a control set during evaluation.

Indexing and Term Weighting

A "bag-of-words" representation was employed to analyze and categorize the blog texts. In this model, the word order is not taken into consideration, and each text is treated as simply a collection of words. Such text representation is used in most typical approaches to text classification [7].

Python version 2.6.2 [8] with Natural Language Toolkit (NLTK) version 2.0b6 [9] was used for data preprocessing and term weight calculation. Data preprocessing included tokenizing (breaking up the texts into separate words), stemming, and removal of "stop" words. Stemming is the process of reducing morphologically related words to their common base form. Alternate spellings were treated as unique words during the stemming phase. The stop word list was created in order to automatically discard common words, that is, stop words, that by definition do not have any combat-specific meaning (articles, prepositions, and words such as go, do, have).

Term weighting is a standard procedure used in automated indexing to assess the importance of individual words in a corpus of documents [10]. We used "TF*IDF" term weighting in order to evaluate word frequency distribution and assess the frequency of occurrence of the words related to combat exposure. In this approach, the indexing weight is a product of term frequency (TF) and inverse document frequency (IDF). TF is a measure of the frequency of a word across a set (corpus) of documents, and IDF is a measure of the frequency of a word within a given document.

Ontology Creation and Use

The resulting frequency distribution tables were reviewed by three authors (CB, MS, SK) in order to select the words relevant to combat exposure used in blog posts. Upon discussion and consensus from all authors, the list of relevant words was created. After that, the selected words were used in creation of a pilot ontology. An ontology is a way to create formal definitions of concepts by specifying semantic relationships between these concepts [11]. Creation of the ontology is an important step for future research as several open-source NLP suites have ontology-aware tools. Collaborative Protégé (version 3.4.4, build 579) [12], an ontology editor, was used to create and store the ontology.

The ontology was imported into General Architecture for Text Engineering (GATE) NLP framework (version 5.2.1, build 3581) [13]. GATE is one of several available open-source NLP tools. The ontology and word lists were used to construct ontology-based gazetteers: alphabetized word lists that are used by GATE for text analysis. The ontology annotation tool, Java Annotation Patterns Engine (JAPE) [14], was then applied to further refine text tagging. JAPE grammar is a set of (modifiable) rules that determine actions that are implemented during the annotation [14].

Pilot Evaluation

NLP performance was evaluated by an author (LP), who is an expert in the field of evaluation. Here, focus was on whether our system was able to identify blogs related to the deployment experience (and therefore of interest to the health care provider) from a larger set of texts. Selected posts from the combat exposure set and the control set were run through the GATE pipeline and at the same time reviewed by the fourth author (LP), who was previously unfamiliar with the ontology and word lists but who has had extensive experience in clinical work with military service members. The blog posts were categorized by this author into 2 groups: those that did and did not describe clinically relevant combat exposure. The results of the GATE pipeline on the same blog posts were then evaluated in reference to this clinical categorization (ie, the "expert standard"). Standard information retrieval metrics in biomedical informatics literature such as precision, recall, and F-score were used for the evaluation [15,16].

Results

After stemming and stop words exclusion, the indexing weights of all word stems in blog posts were calculated. We selected 263 word stems related to combat exposure out of those which had indexing weight above 0.1. The 20 most frequent word stems (those with the largest weight) are shown in Table 1.

Table 1. Most frequent word stems related to combat exposure

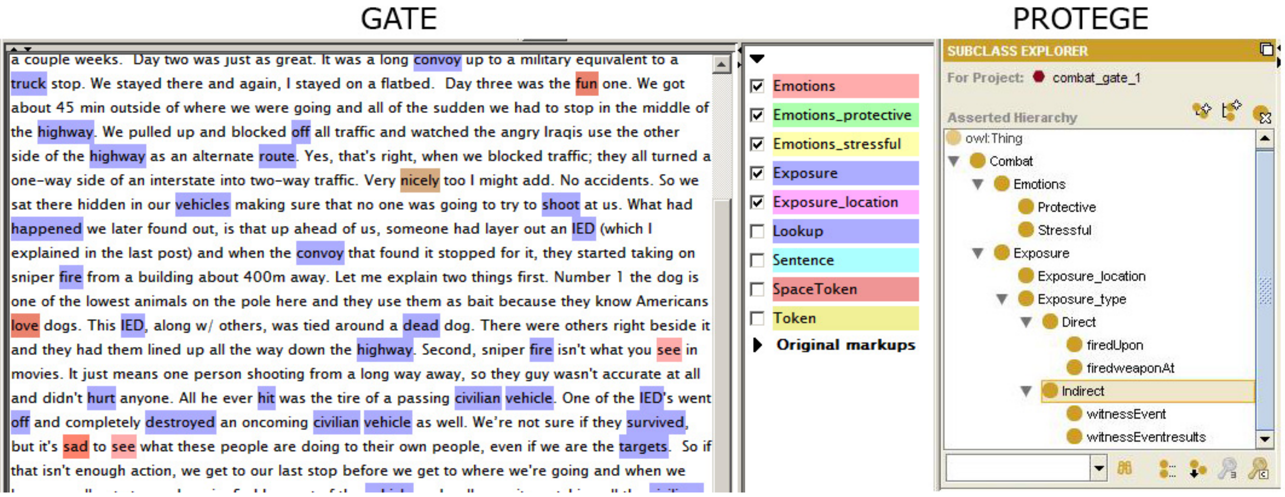
Word Stem	Weight	Index Document Frequency (IDF)
Explos	1.38	0.71
Mission	1.37	0.72
Truck	1.37	0.72
Soldier	1.24	0.82
See	1.20	0.85
Fire	1.17	0.87
Patrol	1.15	0.89
Vehicl	1.08	0.94
Hit	1.05	0.96
Attack	1.05	0.96
Stop	1.05	0.96
Deton	1.00	1.0
Bomb	0.97	1.02
Secur	0.91	1.07
Mortar	0.91	1.07
Deploy	0.88	1.10
Shot	0.84	1.12
Happen	0.81	1.15
Weapon	0.81	1.15

Combat Exposure Dimensions

Words related to combat exposure events had 2 different dimensions: (1) characteristics of the physical exposure itself such as firing a weapon, being attacked, or witnessing an explosion (eg, “explosion,” “bomb,” “shot”) and (2) feelings and emotions associated with the exposure such as being scared, feeling compassion (eg, “secure,” “hope”). The most frequent words were manually separated into the 2 categories. These dimensions were then incorporated into the ontology structure.

Within the ontology we created separate categories for the physical combat exposure and emotions associated with it. Under the exposure category, 2 subcategories were created: direct and indirect. We defined direct exposure as an active involvement in a combat situation (such as firing a weapon), while an example of an indirect exposure would be witnessing a combat-related event. We also created 2 subcategories for the emotions: protective (described by words such as “hope,” “safe,” “supporting”) and stressful (such as “scared,” “upsetting,” “nervous”). Figure 1 shows the ontology we created and how the ontology was used to annotate a sample blog in GATE. Note that on the left in Figure 1 is a GATE screenshot with color-coded ontology categories. The combat-related works in the text are annotated in accordance with the ontology (purple for physical exposure, and pink and brown for emotions). On the right in Figure 1 is a Protégé screenshot with ontology.

Figure 1. Use of ontology in GATE



GATE

PROTEGE

a couple weeks. Day two was just as great. It was a long convoy up to a military equivalent to a truck stop. We stayed there and again, I stayed on a flatbed. Day three was the fun one. We got about 45 min outside of where we were going and all of the sudden we had to stop in the middle of the highway. We pulled up and blocked off all traffic and watched the angry Iraqis use the other side of the highway as an alternate route. Yes, that's right, when we blocked traffic; they all turned a one-way side of an interstate into two-way traffic. Very nicely too I might add. No accidents. So we sat there hidden in our vehicles making sure that no one was going to try to shoot at us. What had happened we later found out, is that up ahead of us, someone had layer out an IED (which I explained in the last post) and when the convoy that found it stopped for it, they started taking on sniper fire from a building about 400m away. Let me explain two things first. Number 1 the dog is one of the lowest animals on the pole here and they use them as bait because they know Americans love dogs. This IED, along w/ others, was tied around a dead dog. There were others right beside it and they had them lined up all the way down the highway. Second, sniper fire isn't what you see in movies. It just means one person shooting from a long way away, so they guy wasn't accurate at all and didn't hurt anyone. All he ever hit was the tire of a passing civilian vehicle. One of the IED's went off and completely destroyed an oncoming civilian vehicle as well. We're not sure if they survived, but it's sad to see what these people are doing to their own people, even if we are the targets. So if that isn't enough action, we get to our last stop before we get to where we're going and when we

☑ Emotions
☑ Emotions_protective
☑ Emotions_stressful
☑ Exposure
☑ Exposure_location
☐ Lookup
☐ Sentence
☐ SpaceToken
☐ Token

Pilot Evaluation

We ran 20 randomly selected blog posts through our GATE pipeline and calculated the number of annotations (ie, the number of times words from our ontology were highlighted). For each document, the ratio of the number of annotations to the total word count (N_{ann}/N_{wc}) of the document was used as a measure of "richness" of the text in terms of the words related to combat exposure. We took the median of the ratios for all posts (4.95%) as a threshold. A given post was said to be recognized as relevant to combat exposure when the ratio N_{ann}/N_{wc} fell above the threshold and irrelevant if the ratio fell below the threshold.

Table 2. Classification of blog text by relevancy to combat exposure by expert opinion and by our GATE pipeline for which the threshold is 4.95%

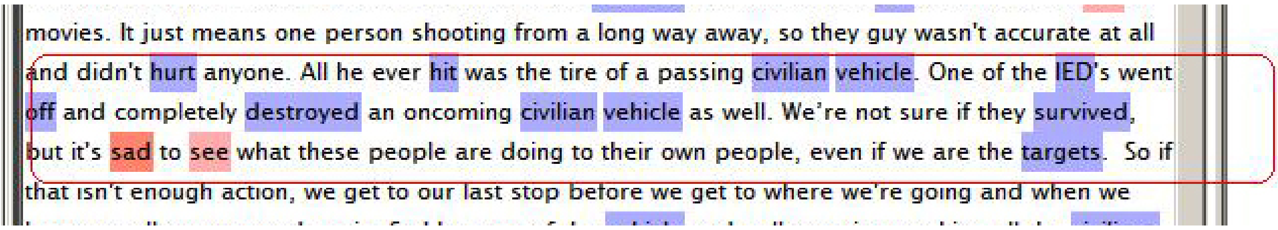
	Relevance of Text to Combat Exposure (Italics = Relevant, Nonitalics = Irrelevant)	
Post	According to Expert Opinion	According to GATE Pipeline (N_{ann}/N_{wc})
Post 1	*Yes*	4.59%
Post 2	No	*5.05%*
Post 3	No	4.31%
Post 4	No	4.18%
Post 5	No	2.80%
Post 6	No	4.46%
Post 7	*Yes*	*8.47%*
Post 8	No	3.03%
Post 9	*Yes*	*6.83%*
Post 10	*Yes*	4.84%
Post 11	*Yes*	*9.09%*
Post 12	*Yes*	*6.74%*
Post 13	*Yes*	*7.63%*
Post 14	No	4.73%
Post 15	*Yes*	*7.09%*
Post 16	*Yes*	*8.15%*
Post 17	*Yes*	3.81%
Post 18	No	3.44%
Post 19	*Yes*	*7.77%*
Post 20	*Yes*	*6.83%*

Compared to the expert opinion ("reference standard") our system returned 9 true positives, 1 false positive, 7 true negatives, and 3 false negatives. Precision is defined as (TP/(TP+FP)) and is the fraction of documents retrieved that are actually relevant to the search criteria. Recall is defined as (TP/(TP+FN)) and is a measure of sensitivity, ie, the fraction of all possible relevant documents in the test set that are retrieved. F-score is a harmonized mean of precision and recall, and provides an overall measure of the effectiveness of an information retrieval system. Our GATE pipeline performed with a precision of 0.9, recall of 0.75, and F-score of 0.82.

Examples

In the highlighted passage in Figure 2 many words related to combat exposure (purple) are found within 1 or 2 sentences of words related to emotions and senses (red, pink).

Figure 2. A section of an annotated blog describing the trauma of war

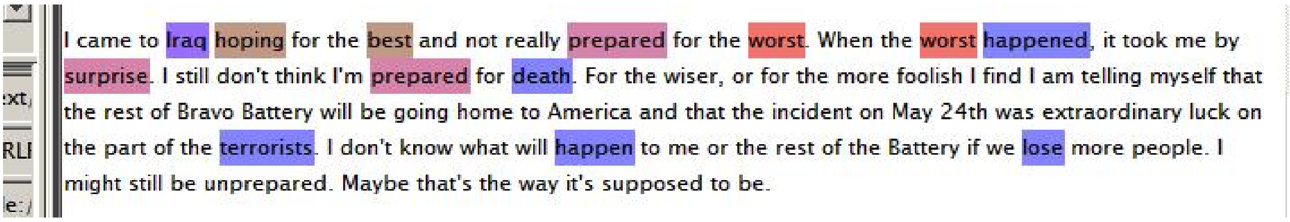


movies. It just means one person shooting from a long way away, so they guy wasn't accurate at all and didn't hurt anyone. All he ever hit was the tire of a passing civilian vehicle. One of the IED's went off and completely destroyed an oncoming civilian vehicle as well. We're not sure if they survived, but it's sad to see what these people are doing to their own people, even if we are the targets. So if that isn't enough action, we get to our last stop before we get to where we're going and when we

This paragraph presents an example of a specific traumatic factor: an attack against a soldier that injured innocent civilians instead.

Another example of the proximity of the words related to the 2 dimensions of combat exposure can be seen in the annotated paragraph in Figure 3. The purple labels mark the combat events and locations, while the red and brown mark the words from the emotions category.

Figure 3. A section of an annotated Web blog showing physical and emotional descriptors



I came to Iraq hoping for the best and not really prepared for the worst. When the worst happened, it took me by surprise. I still don't think I'm prepared for death. For the wiser, or for the more foolish I find I am telling myself that the rest of Bravo Battery will be going home to America and that the incident on May 24th was extraordinary luck on the part of the terrorists. I don't know what will happen to me or the rest of the Battery if we lose more people. I might still be unprepared. Maybe that's the way it's supposed to be.

This passage follows the description of learning that some of the fellow soldiers were killed during convoy and clearly shows the deep emotional response to this event.

Discussion

Findings

We identified 2 dimensions of combat exposure descriptions: physical and emotional. These have been incorporated into the ontology and given specific annotations in GATE. The results of the pilot evaluation show that even without taking context into account our pipeline was able to retrieve the relevant blog posts with relatively good precision and recall.

We found that many of the words related to concrete experience and emotional reaction occurred within one or two sentences of each other frequently pointed to the paragraphs in the text that described the most dramatic combat situations. This may be instrumental in text analysis and uncovering the burden of combat exposure. This finding will be important for future research that will include context-aware analysis.

Challenges

Blog texts are a heterogeneous and, at times, poorly structured text material. This distinguishes them from more structured texts like radiology reports and makes text processing more challenging. Apart from typos and spelling errors, there are field-specific abbreviations, slang terms, and intentional spelling variants. For example, one of the commonly seen words was an exclamation "Boom!" that described an experience of sudden loud sound, such as explosion; this word came in many different shapes, such as "BOOM," "Boooom," and "Bo-o-om." One of the commonly encountered words was an abbreviation IED, which stands for improvised explosive device; this word was also often misspelled ("IOD," "IUD" etc). The analysis of context (such as negation and word proximity) in blogs will also be more difficult because of poor structure and the informal nature of the blog text.

Limitations

Although we found the bag-of-words weighting approach to be useful in discovering the vocabulary used by blog writers to describe combat situations and experiences, the adequacy of this approach for blogs remains a point of discussion. The bag-of-words approach is restrictive as it does not allow analyzing words in context. Thus, semantic ambiguity is difficulty to address with this approach. Other researchers have found similar limitations to this type of approach due to issues such as scarcity of data [17]. However, a potentially more informative context-aware mechanism ("rich bag-of-words") is not possible to construct without a domain-specific vocabulary that we will be able to create using the results of the basic bag-of-words algorithm. This work is the first step toward creating a vocabulary for future context-aware tools.

There are other important limitations to this work. First, the generalizability of the sample may be questioned because of an important selection bias: by analyzing the blogs one can only know the experiences and opinions of people who have blogs. This is especially concerning in military blog analysis, because not every soldier at all times has access to the Internet even if they desire to have a blog and are allowed to do so by their commanding officers. Nevertheless, blogs can be used as a general measure of combat stress and may also be used to help identifyand quantify novel stressors specific to modern wars (for example, IEDs and suicide bombs). Another issue is that blogs represent a form of retrospective self-report and are by nature less reliable than the more objective methods of external surveillance such as videotaping or clinical interview. The external methods, however, are rarely available at the battlefield or are too expensive to be considered. Moreover, the consequences of combat stress may differ in their severity depending upon the attitudes and predeployment neurocognitive functioning of the person who experienced it [18].

By analysis of the blogs it was not possible to reliably identify the authors of the blogs who were active duty soldiers. In fact, the nature of the “blogsphere” is such that one cannot be sure whether the author of the blog really exists or is a fictional character. In addition, accurate assessment of temporality is a challenge in blogs. It is not always clear when the soldier has described a particular experience, whether it was right after the events or after some time upon recollection. However, given that a blog post describes actual combat events from the first person, it is still possible to use this blog post in the analysis, because the language used is similar. An additional issue found was that a portion of the blogs retrieved by Internet search seemingly conforming to the search criteria and using military language proved to be descriptions of the video game experience. It is thus essential to design an NLP system that accurately identifies these posts as being negative for combat exposure.

Another limitation is that the type of content and the personal details that are discussed in the blog may differ substantially from those mentioned during a person-to-person clinical interview.

Possible Alternatives

Our approach to blog analysis was based on lexicons and ontologies created manually, which is both time-consuming and domain-specific. An alternative to this could be unsupervised or semisupervised approaches that have been applied to online reviews and blogs analysis [19]. Other alternatives to the GATE pipeline are possible, such as Unstructured Information Management Architecture (UIMA) [20], which is also open source.

There are ways to analyze natural text without creation of an ontology. However, ontologies play an important role in knowledge management and data integration [21]. Having the data structured by way of ontology will help us in the future research that will involve optimization of the existing algorithm and development of context-aware analysis. Many available open-source NLP systems now include ontology-aware tools; creation and development of the ontology will make the knowledge obtained from our study transferable.

Possible Applications and Future Research

In the course of our study, we have encountered a multitude of blog posts of the military genre that had nothing to do with combat exposure. Selecting the relevant posts manually was a lengthy and tedious task. Our GATE pipeline, especially when evolved into a more context-aware tool, could be used for automated selection of blog posts (or diary entries, or even physician’s notes) that discuss combat exposure from all available text data. This can be instrumental in clinical work as it may help therapists and researchers to concentrate on the text material relevant to the combat exposure.

Our present work is a first step toward creating a more comprehensive context-aware algorithm that can be used for large-scale blog text categorization and analysis. Without the context analysis (such as negation, word order, and proximity) and more sophisticated software framework, it will not be possible to analyze thousands of documents or correctly classify them by combat exposure descriptions.

When developed to the point where the analysis of many thousands of documents is possible, an application such as ours could be used as a training tool for psychiatrists who are working with military personnel. It is also possible that an NLP application like this one may be used in clinical work to provide clinicians with text material discussing combat exposure and deployment-specific traumatic factors.

Future research is needed to demonstrate possible correlations between a person's descriptions of his or her wartime experiences in their blog with the ensuing symptoms or disorders. Focus groups and medical records analysis could be used for this purpose. The information obtained from military blogs may also be used during the focus groups to facilitate discussion and elucidate difficult or unusual subjects.

We conclude that available open-source natural language processing and automated information extraction tools may be instrumental in the analysis of free text contained in blogs. Analysis of military blog posts available on the Internet may help uncover the military service members’ emotions and experiences of combat exposure.

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Conflicts of Interest

None declared

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Abbreviations

GATE: General Architecture for Text Engineering
HSRD: Health Services Research and Development
IED: improvised explosive device
IR: information retrieval
IDF: inverse document frequency
JAPE: Java Annotation Patterns Engine
NLM: National Library Of Medicine
NLP: natural language processing
OEF/OIF: Operation Enduring Freedom/Operation Iraqi Freedom

TF: term frequency
UIMA: Unstructured Information Management Architecture

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Original Paper

Development and Evaluation of the Personal Patient Profile-Prostate (P3P), a Web-Based Decision Support System for Men Newly Diagnosed With Localized Prostate Cancer

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Abstract

Background: Given that no other disease with the high incidence of localized prostate cancer (LPC) has so many treatments with so few certainties related to outcomes, many men are faced with assuming some responsibility for the treatment decision along with guidance from clinicians. Men strongly consider their own personal characteristics and other personal factors as important and influential to the decision. Clinical researchers have not developed or comprehensively investigated interventions to facilitate the insight and prioritizing of personal factors along with medical factors that are required of a man in preparation for the treatment decision.

Objectives: The purpose of this pilot study was to develop and evaluate the feasibility and usability of a Web-based decision support technology, the Personal Patient Profile-Prostate (P3P), in men newly diagnosed with LPC.

Methods: Use cases were developed followed by infrastructure and content application. The program was provided on a personal desktop computer with a touch screen monitor. Participant responses to the query component of P3P determined the content of the multimedia educational and coaching intervention. The intervention was tailored to race, age, and personal factors reported as influencing the decision. Prepilot usability testing was conducted using a “think aloud” interview to identify navigation and content challenges. These issues were addressed prior to deployment in the clinic. A clinical pilot was conducted in an academic medical center where men sought consultation and treatment for LPC. Completion time, missing data, and acceptability were measured.

Results: Prepilot testing included 4 men with a past diagnosis of LPC who had completed therapy. Technical navigation issues were documented along with confusing content language. A total of 30 additional men with a recent diagnosis of LPC completed the P3P program in clinic prior to consulting with a urologist regarding treatment options. In a mean time of 46 minutes (SD 13 minutes), participants completed the P3P query and intervention components. Of a possible 4560 items for 30 participants, 22 (0.5%) were missing. Acceptability was reported as high overall. The sections of the intervention reported as most useful were the statistics graphs, priority information topics, and annotated external website links.

Conclusions: The P3P intervention is a feasible and usable program to facilitate treatment decision making by men with newly diagnosed LPC. Testing in a multisite randomized trial with a diverse sample is warranted.

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KEYWORDS

Prostate cancer; decision making; computer-assisted; pilot study

Introduction

There is a growing body of evidence that men with a recent diagnosis of localized prostate cancer (LPC) conduct the treatment decision-making process by strongly considering their own personal characteristics and other personal factors [1-7]. Recently diagnosed men must often assume some responsibility for the treatment decision together with guidance from clinicians. The participation of patients with cancer in making decisions about treatment is promoted by virtually all interested parties including professional societies, researchers, and clinicians. Information widely available via the Internet, though of variable accuracy, has helped to hasten a new dynamic between patient and clinician. Because no other disease with the high incidence of prostate cancer has so many alternative treatments with so few certainties related to outcome, many men are faced with assuming some responsibility for the treatment decision along with guidance from clinicians.

Yet clinical researchers have not comprehensively investigated interventions to facilitate the gaining of insight and the prioritizing personal factors as well as the decision making that are required of a man with a diagnosis of LPC. Decision support technologies provide much needed information to patients, but (1) focus solely on medical factors considered relevant by physicians (eg, histology, comorbidity, and age), (2) fail to customize the information to the personal characteristics of the patient [8-10], or (3) depend on interventions that have never been rigorously tested in randomized trials with diverse samples [2,11,12]. The goal of this ongoing program of research is to improve the decision-making experience for men with LPC by highlighting personal characteristics and factors that men bring to the treatment decision: their desired level of participation in decision making, the importance of potential outcomes and complications, current symptoms, priority information topics, the influence of others, race/ethnicity, and self-perception of age.

This research was informed by O’Connor’s Decision Support Framework (DSF) [13]. The framework is most appropriate for health care situations in which careful deliberation is required because of many uncertainties and value-sensitive risk/benefits and for which the deliberation phase (deciding) requires substantially more effort than the implementation phase (undergoing a particular management strategy or therapy). The DSF is organized by (1) determinants of decisions, (2) decision support interventions, and (3) evaluation of both the process and outcomes of the decision support. Since our research team had documented the determinants, that is, the personal factors brought to the decision by men with LPC [1,7], we were poised to engage in the second step, designing the support intervention and evaluating the process.

In this paper, we report the iterative development and initial evaluation of a tailored Internet patient decision support system, the Personal Patient Profile-Prostate (P3P), in which all of these factors are assessed and addressed. The research aims included the following system requirements: (1) specifications of use cases, (2) application architecture and content, (3) usability, and (4) feasibility.

Methods

Preclinical Design Overview

An iterative development approach was employed, beginning with the development of use cases (see Multimedia Appendix 1) by members of the research team. Within these cases and through contextual inquiry with potential users and investigators (including content and informatics experts), we used a structured process for identifying end users, requirements, and application content. In addition to gathering end user requirements, we closely adhered to National Cancer Institute’s recommendations about appropriate user interface design [14]. The application was initially implemented in 2004. Detailed methods are presented below with respect to the preclinical design phase, with methods grouped by architecture, query, and intervention content.

Application Architecture

The application architecture for P3P utilizes an open source Web software platform and provides for a flexible survey environment [15]. The survey environment also enables the overlay of interventional content The design employs a modular, extensible approach built on the generalized storage and display of survey instruments. All survey content associated with a specific instrument is stored in a database, and “assessments” can be compiled from multiple survey instruments. Each survey instrument is represented as a reusable object containing questions, possible answers, and control logic. The software retrieves these objects and displays them to the user, recording answers as well as metadata such as time stamps and navigation information. A survey editor allows researchers to make changes to the content and the sequence of questions without software modifications. The survey framework also includes a patient manager to enter patient demographics and manage the patient data associated with a specific administration of an assessment in a clinical setting.

The Web application was implemented using the PHP language and MySQL database on a Linux/Apache server, a development platform commonly known as "LAMP” [16]. All user interface components were implemented as dynamic server-side pages. Surveys were presented using templates, making it simple to adapt the system to conform to user interface guidelines and to a variety of device characteristics. Touch screen monitors were utilized to display and access the P3P program. This hardware, along with the navigational design of the program, eliminates the use of a mouse and scrolling. Keyboarding is not required but is available for optional open-ended items. User interface widgets (radio buttons, checkboxes, and navigation buttons) can be resized to work well with touch screens via a simple configuration option.

Application Content

Profile Query Component

The purpose of the profile query was to gather the input necessary for the tailored intervention component. The P3P opening screen introduced the participant to the nature and purpose of the intervention, that is, to help make "the best choice for you," providing information and guidance to understand the participant's personal concerns. In addition to demographic characteristics, the following valid and reliable instruments were presented in the query component of P3P in order to generate the intervention (Table 1). All instruments were adapted for the touch screen by presenting 1 item per screen, with the exception of some items from the Expanded Prostate Cancer Index Composite Short Form 6.2002 (EPIC-SF) that were logically presented next to each other (see below). Additional questionnaires were presented to the patient during the query component which were outcomes of using the P3P tailored intervention in a future randomized trial, and we thought best to pilot test the inclusion of instruments to measure state anxiety [17] and decisional conflict [18]. Finally, we included an acceptability assessment [19]. Reading grade level of the application's internal content was calculated using the Flesch-Kincaid measure for an average of 7.6 (SD 1.6) and ranging from 5.4 to 10.0. Skipping questions without answering was allowed.

Table 1. Variables and questionnaire results used to generate the P3P tailored intervention

Variable	Questionnaire
Sociodemographic characteristics	Demographic data form
Influential personal factors	Personal Profile [7]
Information preferences	Patient Information Program [20]
Decisional control	Control Preferences Scale [21]
Symptoms	EPIC-SF [22]

Personal Profile

The Personal Profile was developed by the investigators based on the earlier qualitative work [1] and was designed for and used with 260 men during a descriptive quantitative study of the personal factors that influence men's treatment decisions [7]. Face validity and test-retest reliability of the Personal Profile have been established [7]. The profile contains ranking of the following personal factors with regard to influence on the decision or importance to the decision: influential people (spouse/partner, family member, coworker, friend, and celebrity), influential outcomes (bladder, bowel and sexual function, and expected survival) and personal characteristics (confidence in the doctor, age, work, and recreational activities). Each of these item responses was listed as "no influence," "a little influence," "some influence," or "a lot of influence."

Control Preferences Scale and Information Priorities

The Control Preferences and Informational Priorities were the 2 components of the Patient Information Program (PIP) developed by Davison and colleagues [20]. The first component of the PIP uses the Control Preferences Scale modified by Davison [23] to elicit patients' preferences for control over treatment decision making. The second component of the PIP focuses on identifying priority information topics and is based on a paper and pencil survey previously developed and validated by Davison in samples of men newly diagnosed with prostate cancer.

Expanded Prostate Cancer Index Composite Short Form 6.2002

Prostate cancer-targeted symptoms were assessed using the 4 prostate-targeted symptom domains developed by Wei and his colleagues [22]: Sexual, Hormonal, Urinary, and Bowel. Each scale of the EPIC-SF includes a function subscale and a "bother" item. In P3P, the final item of the EPIC-SF, assessing the patient's perception of "how big a problem" for 5 hormonal symptoms, was displayed in a matrix on 1 screen.

Outcome Measures (Did Not Create an Intervention Component)

Anxiety

Anxiety was measured with the 20-item State component of State-Trait Anxiety Inventory (STAI) [17], which is also known as the Self-Evaluation Questionnaire.

Decisional Conflict

The Decisional Conflict Scale (DCS) [18] measured the conflict inherent in the treatment decision encountered by the men in the sample. Of the subscales of the DCS, 2 (Uncertainty and Factors-Contributing-to-Uncertainty) are appropriate for use before or during decision-making and the third (Effectiveness of Decision Making) for use after the decision has been made.

Intervention Component

Immediately after a participant had completed the query component, the P3P intervention was delivered to him in 5 distinct sections. First, the participant was shown a screen that listed the levels of decisional control preference with the earlier selected level highlighted. The participant was then instructed to play the video clip matching the selected control level. Next, the 4 priority categories of "information needed today" that were ranked highest in the Patient Information Program component were displayed as brief narrative text on-screen summarizing the priority topic, and a full page teaching sheet was printed for each topic. Third, a statistics tutorial was displayed utilizing the highest ranked influential outcome: survival, bladder, bowel, or sexual function. The screen included explanatory text and an exemplar percentage chart such as 17 frowning faces and 83 smiling faces in a rectangular matrix of 100 faces.

The fourth section began with a screen containing a menu of topics covering the influential factors that had been ranked as having some or a lot of influence on treatment decision making. When viewed, each topic included a brief narrative description of the issue and a corresponding video clip depicting a patient discussing the topic with a physician. Finally, an option to explore 4 reputable, informational prostate cancer websites [24] to which an annotated guide and links were provided was presented as the final intervention component. The clinicians on this investigative team reviewed the websites for current information.

Table 2 summarizes how the intervention was tailored to the patient's personal profile and provides links to screenshots in the Multimedia Appendices.

Table 2. P3P intervention customization by the patient's personal profile

Patient Query Component	Internal Algorithm	Intervention Delivered to Patient
Prostate cancer information priorities: • Stage of disease • Prognosis • Treatment options • Side effects • Home self-care • Impact on family • Sexuality • Social activities • Family risk	• Patient was presented 36 paired comparisons of 9 information topics and selected from each pair the topic of greater priority to him to receive information • The top 4 most highly prioritized were calculated.	• Information relevant to the top 4 priorities was briefly summarized on-screen. • At the end of the intervention, the patient received printed teaching sheets on each topic.
Demographics: • Date of birth • Self-reported race	• Patients' ages were categorized as under 60 or 60+ years of age. • Patients self-identified as white, black, or other (Asian, Native American).	• Videos featured a patient actor close to the patient in age and matched for race as below; those reporting "other" or skipping the race item were offered intervention content tailored to white patients.
Preferred role in the Treatment decision (Control Preferences Scale)	• Patient selected response option: 1 or 2 (active role) 3 (shared role). 4 or 5 (passive role) • The preferred role was highlighted in the intervention text and video, (Multimedia Appendix 2).	• Text and video coaching customized to patient's race was offered for a patient to express his preferred role. • In the video, the doctor acknowledged the patient's preference (Multimedia Appendix 3). • The patient was offered the opportunity to view the text and video for other control preferences.
Influential People: • coworkers • friends outside work • spouse/partner • other family members	• Patient selected option for how much influence these people had as he considered his treatment choices: (1) no influence (2) a little influence (3) some influence (4) a lot of influence. • For each reported to have "some influence" or "a lot of influence," the intervention offered text and a video coaching the patient to tell his doctor.	• Text and video coaching were offered for the patient to express who were the influential people in his decision process. • The doctor in the video acknowledged the importance of these influential people and helped the patient compare his own views and situation to those of influential people (Multimedia Appendix 4). • At the end of the intervention, the patient printed the teaching information with "fill in the blank" text he could use to prepare for the exam visit.
Influential outcomes: • survival • bladder function • bowel function • sexual function	• For each of these treatment outcomes, the patient selected how much importance or influence it had on his decision: (1) no influence (2) a little influence (3) some influence (4) a lot of influence. • The outcome rated most influential was used as the example for teaching about statistics. • In the case of a tie between outcomes, the example was selected randomly from those rated most highly influential. • For the outcomes rated "some influence" or "a lot of influence," the patient was offered text and video coaching.	• Text and a graphic illustration taught numeracy skills useful to understanding statistics about possible outcomes. • The example provided was highly salient to the patient (Multimedia Appendix 5). • Text and video coaching customized to age was offered for the patient to express the influential factors in his decision process. • The doctor in the video acknowledged the importance and helped the patient understand the relative likelihood of each treatment option's impact on these factors (Multimedia Appendix 6). • At the end of the intervention, the patient printed the teaching information with "fill in the blank" text he could use to prepare for the exam visit.

Patient Query Component	Internal Algorithm	Intervention Delivered to Patient
Current symptoms: (EPIC questionnaire) • urinary • bowel • sexual	• Each symptom domain included an overall impact item. • For each item where the patient responded that the symptom is a “moderate problem” or a “big problem,” the symptom was listed on the intervention menu page to learn more about (Multimedia Appendix 7).	• Text and video coaching customized to race was offered on each symptom the patient experiences as a problem. • In the video, the patient reported his symptom and the doctor offered to help him understand how different treatments might impact his symptoms differently (Multimedia Appendix 8). • At end of the intervention, the patient printed the teaching information with “fill in the blank” text he could use to prepare for the exam visit.
Useful links	Not customized–the same content was offered to all patients.	• Links to 4 highly rated professional websites offering general information about prostate cancer.

Acceptability

At the completion of the program, aspects of patient acceptability (easy, understandable, enjoy, helpful, time, value of information, and overall satisfaction) were measured for the entire P3P with the Acceptability E-scale, a 1 to 5 scale anchored by 1 = not easy at all (for example) to 5 = very easy (for example) [19]. We added 1 item, “value of information,” to our previous scale. An additional set of investigator-developed usefulness queries was presented using a similar 1 to 5 scale and focused on the unique sections of the intervention.

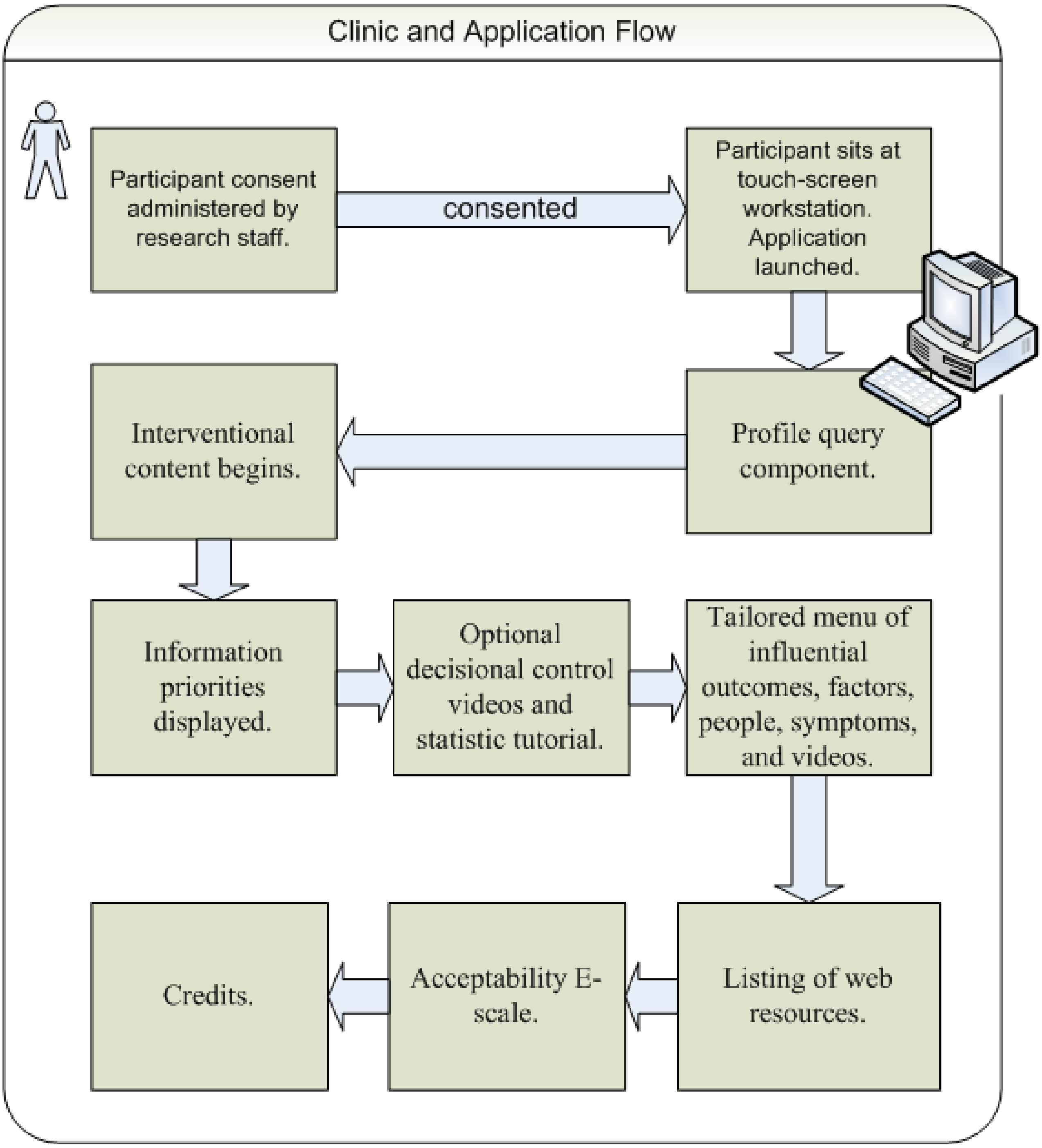
Prepilot Usability Testing in Proxy Patients

The University of Washington Human Subjects Division approved all study procedures and materials. In all, 4 English-speaking men who were at least 6 months post-prostate cancer treatment were recruited from a university-based prostate cancer clinic practice to test the usability of the P3P program. Each consenting participant was asked to complete the P3P prototype using a touch screen monitor and desktop computer in an informatics laboratory at the University of Washington, School of Nursing. Simultaneously, an audio-recorded cognitive clinical interview [25], also known as the “think-aloud” method [26], was conducted by a graduate nursing student (author JW). The purpose of this usability testing was to asses how men interacted with the technology and to identify problems with the interface and/or content. The subjects were asked to “think-aloud” as they went through the questions and the intervention on-screen in order to understand their experience of the system.

Clinical Pilot Testing

A total of 32 English-speaking men with newly diagnosed LPC who sought consultation at the University of Washington Medical Center’s Prostate Oncology Center were invited to participate by clinic nursing staff. Of these, 30 men provided informed consent and were enrolled by a research team member. Participants used the program on a touch screen monitor with a full-size keyboard connected to a desktop computer in the center’s patient education room. The team member was waiting in an adjacent room and available for assistance if needed and made summary notes of each participant’s session including any usability issues reported, feedback offered, and whether a spouse or partner viewed the program with the participant. The participant then proceeded to the consult visit with 1 or more prostate cancer specialty physicians within an hour of using the intervention. Figure 1 displays the clinical and application flow.

Figure 1. Clinical and application flow



Analysis

Usability testing data from the prepilot were analyzed descriptively with quantitative content analysis [27]. In addition, the following quantitative measures were used for the clinical pilot results: completion time, data completeness, and acceptability scores. The questionnaire results will be reported elsewhere.

Results

Prepilot

The program and cognitive interview took 1 to 1½ hours to complete. The interviews were audio-recorded and transcribed verbatim. Table 3 lists the tasks and observations and responses from the testing. Minor edits were made to the P3P program based on these formative findings.

Table 3. Summary of participants' responses and observations during prepilot usability testing (N=4)

Goals	Task	Observations and Responses Regarding Content and Technical Aspects of the Program (n for Each Observation)
Overall ease of use	Page navigation: Understand and follow navigation instructions	Technical: Expectation of auto advance vs use of "next" button (3) Progress bar meaning unclear (3) Dislike of required scrolling on certain screens (due to resolution of personal computer monitor used in testing) (2)
Complete query component	Understand and answer each item of each scale	Content: Confusion between "ethnicity" and "race" (2) Doubt was expressed regarding the ability of most patients to identify a treatment preference after the biopsy and before the appointment to review options (3) Request for brief explanation of treatment options before query component (1) The phrase "home self-care" confusing (3) Wording of information priority pairings led participants to believe the same item was repeated (4) Difficulty recalling which section was which when asked to evaluate the various sections (4)
Receive customized education/coaching component	Open, understand, and review sections	Technical: Unclear how to proceed after video clips (4) Double clicks used to open menu items when single clicks were adequate (1) Content: Information and content valuable (4)

Clinical Pilot

Of the 30 participants, 26 (87%) completed query and intervention components of the P3P program in less than 1 hour (mean 46 minutes, SD 13 minutes, range 16 to 69 minutes). The sample had a mean age of 61, ranging from 45-74. Missing data were minimal: 15 participants answered every one of the 152 items, 8 men skipped 1 item (0.6%), and 7 men skipped 2 items (1.3%). Of a possible 4560 items for 30 participants, 22 (0.5%) were missing. All participants watched the tailored video clip describing the identified decision control preference, and 7 men watched additional clips representing other control preferences. In all, 10 men viewed a video clip from the menu of personal factor results. The majority, 28 of the 30 men, viewed at least 1 set of text and graphic statistics tutorials about survival, incontinence, impotence, or bowel disturbance.

Overall acceptability of P3P was calculated as high (Table 5). At least 67% of the sample chose a 4 or 5 on each of the acceptability items

Participants reported on the usefulness of the specific intervention components viewed (Table 6). Over half of all participants who viewed each component reported usefulness at 4 or 5 on the 5-point scale. In all, 5 participants did not have time to access or chose not to view the additional websites.

There were no significant relationships between age, education, or work status and any usefulness outcome (data not shown). Many verbal questions/comments were made by participants regarding future home access to the program. Many participants also said that the information would have been more useful a few days prior to the consult with the urologist. Participants reported perceived time pressure in the clinic to finish viewing all components before being called in to see the physician. Additional comments were written by 6 men; of these, 5 offered critiques of wording or display in the program, and 1 man endorsed the content on family impact.

Research team member notes were available for 23 of 30 sessions and indicated 2 usability problems: 1 participant was unsure how to navigate away from an informational prostate cancer website pop-up linked from the intervention, and another did not know how to print teaching sheets at the end of the program. An additional 3 men were noted to have trouble hearing the videos. Also, 13 men were reported to have viewed the intervention together with a spouse or partner, while 10 did not.

Table 4. Demographic characteristics of participants (N = 30)

	n	%
Ethnicity		
Hispanic/Latino	0	0
Missing	2	6.7
Race		
White/Caucasian	29	96.7
American Indian/Native Alaskan	1	3.3
Married/partnered	24	80
Work status		
Working (full-time or part-time)	17	56.6
Not working (retired or unemployed)	13	43.3
Annual household income		
≤ US $35,000	4	13.3
US $35,001-55,000	4	13.3
US $55,001-85,000	7	23.3
≥ US $85,001	15	50.0
College graduate	23	76.7
Home Internet access	29	96.7
Frequent computer user	25	83.3
Primary health insurance		
Private	22	73.3
Medicare	7	23.3
Missing	1	3.3
Number of weeks since biopsy		
< 4	9	30.0
4 and over	21	70.0

Table 5. Overall P3P Acceptability (N=30)

Item	Mode	Mean (SD)
Easy to Use	5	4.8 (.41)
Understand questions	5	4.7 (.52)
Time to complete	5	4.5 (.78)
Enjoy program	5	4.0 (.98)
Helpfulness of program	5	4.0 (1.0)
Value of Information	4	3.7 (1.0)
Overall satisfaction	5	4.1 (.92)

Table 6. P3P intervention component usefulness

Component	n	Mode	Mean (SD)
Statistics graphs	30	5	3.8 (1.6)
Control preference graph	30	3	3.8 (1.1)
Priority information topics	29	5	3.7 (1.3)
Video clips	30	3	2.8 (1.2)
Websites	25	5	4.0 (1.2)

Discussion

The P3P was successfully developed, tested, and deployed in an academic medical center urology clinic by an interdisciplinary research team. The acceptability and usefulness scores plus verbal and written comments have given us areas with which to further revise and develop the program.

There was a high level of interest in participating. Travel logistics were cited by the 2 men who did not participate as the primary reason for not enrolling. This problem together with comments requesting access to the program a few days before the options review visit indicated a strong need for home access to the intervention.

Men may also have been more likely to view the menu items with which they were the least familiar, notably statistics. Only 10 men were able to, or chose to, view the video clips providing coaching on how to speak with one’s doctor regarding influential personal factors. We are uncertain as to why the other 20 men did not view the video clips although this could be explained by lack of time or misunderstanding of the screen instructions or menu display. The men may have been constrained by time at the completion of the program since they immediately went into their clinic visit with the urologist. There is some evidence from a subsequent cognitive interview study of African American men using P3P [28] that the navigation of the menu display for the video clips was not readily apparent.

Methods of evaluation applied in this study have been used by other health technology evaluations of tailored intervention in 15 healthy women relevant to preventing osteoporosis [29] and 13 Hispanic family caregivers relevant to health promotion [30]. Findings of all these trials indicate that performance usability testing in settings that mirror the intended use setting can successfully identify areas and functions of the applications that require modification. Patient-centered decision support technologies posted on the Internet or provided in larger electronic health systems that have not been exposed to rigorous usability testing are inherently suspect for poor generalizability and potential end user dissatisfaction at best, or poor uptake and disuse, at worst.

The reported acceptability of this tailored decision aid is comparable to that of other electronic, Web-based applications developed by this research team and colleagues. The electronic self-report assessment for cancer (ESRA-C) is a screening assessment for patients with all cancer diagnoses shown to be efficacious for improving clinician patient communication [31]. Wolpin et al [32] reported similarly high levels of acceptability for the ESRA-C application including 342 ambulatory patients with cancer who had completed the program at 2 time points. Intervention websites in health care have included quantitative acceptability measures typically developed by the researcher as study-specific scales or item sets and which have not been validated. For example, DiLorio and colleagues [33] reported the success of a Web-based self-management program for epilepsy from participants’ perspectives with regard to overall satisfaction and component-specific satisfaction. While we were unable to compare the scores because the instruments varied somewhat, the approach was feasible in both studies and both differentiated satisfaction with various program components. Furthermore, our scale for user self-report of satisfaction and acceptability has been tested for reliability and dimensionality. Tariman et al [19] analyzed a sample of 627 respondents and reported that the Acceptability E-scale was found to have a consistency coefficient of .76, good item-to-item and item-to-scale correlations, and was unidimensional.

A large team of researchers recently developed the International Patient Decision Aid Standards Collaboration instrument (IPDASi) [34] as a means to evaluate decision support technologies. While the P3P contains each of the 9 applicable dimensions, a quantitative scoring of P3P has not been conducted using the IPDASi.

Our pilot findings are limited by the evaluative scope of the study, namely feasibility, usability, and satisfaction with a new decision support system. Our participants were fairly well educated with most household incomes in the 4th or 5th quartile for the region and predominately white, precluding generalization beyond this group of men. However, the results have guided the redesign and deployment of P3P for testing in a multisite, randomized trial with a diverse sample [35]. The new application is accessible from remote (home) locations on varied hardware and software.

In conclusion, our preliminary evidence suggests that the P3P is a useful and acceptable decision support system that feasibly can be deployed in a clinical practice setting. The program enables men with early stage prostate cancer to identify and understand the personal issues and factors that influence a treatment decision and coaches men to articulate those issues and factors to the consulting physician.

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Conflicts of Interest

None declared

Multimedia Appendix 1

Personal Patient Profile-Prostate (P3P): Use case in urology

[PDF file (Adobe PDF File), 49 KB - jmir_v12i4e67_app1.pdf]

Multimedia Appendix 2

Screenshot of CPS video highlighted for patient's selection

[PDF file (Adobe PDF File), 184 KB - jmir_v12i4e67_app2.pdf]

Multimedia Appendix 3

Decisional control video: Active participation

[PDF file (Adobe PDF File), 651 KB - jmir_v12i4e67_app3.pdf] [WMV file (Windows Media Video) 6,144 KB - jmir_v12i4e67_app3b.wmv]

Multimedia Appendix 4

Influential people video: Coworker

[PDF file (Adobe PDF File), 635 KB - jmir_v12i4e67_app4.pdf] [WMV file (Windows Media Video) 9,216 KB - jmir_V12i4e67_app4b.wmv]

Multimedia Appendix 5

Screenshot of a statistics teaching text/graphic page

[PDF file (Adobe PDF File), 254 KB - jmir_v12i4e67_app5.pdf]

Multimedia Appendix 6

Influential outcome video: Bladder

[PDF file (Adobe PDF File), 451 KB - jmir_v12i4e67_app6.pdf] [WMV file (Windows Media Video) 9,216 KB - jmir_V12i4e67_app6b.wmv]

Multimedia Appendix 7

Screenshot of an EPIC urinary domain item

[PDF file (Adobe PDF File), 49 KB - jmir_v12i4e67_app7.pdf]

Multimedia Appendix 8

Screenshot of a current symptom coaching page

[PDF file (Adobe PDF File), 152 KB - jmir_v12i4e67_app8.pdf]

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Abbreviations

DSF: Decision Support Framework
ESRA-C: electronic self-report assessment for cancer
EPIC-SF: Expanded Prostate Cancer Index Composite Short Form 6.2002
IPDASi: International Patient Decision Aid Standards Collaboration instrument Personal
PIP: Patient Information Program
P3P: Personal Patient Profile-Prostate

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