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Randomized Controlled Trial of an Internet-Based Versus Face-to-Face Dyspnea Self-Management Program for Patients With Chronic Obstructive Pulmonary Disease: Pilot Study

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Abstract

Background: People with chronic obstructive pulmonary disease (COPD) continue to experience dyspnea with activities of daily living (ADL) despite optimal medical management. Information and communication technologies may facilitate collaborative symptom management and could potentially increase the reach of such interventions to those who are unable to attend face-to-face pulmonary rehabilitation or self-management programs.

Objective: The purpose of this randomized study was to test the efficacy of two 6-month dyspnea self-management programs, Internet-based (eDSMP) and face-to-face (fDSMP), on dyspnea with ADL in people living with COPD.

Methods: We randomly assigned 50 participants with moderate to severe COPD who were current Internet users to either the eDSMP (n = 26) or fDSMP (n = 24) group. The content of the two programs was similar, focusing on education, skills training, and ongoing support for dyspnea self-management, including independent exercise. The only difference was the mode (Internet/personal digital assistant [PDA] or face-to-face) in which the education sessions, reinforcement contacts, and peer interactions took place. Participants returned to one of two academic clinical sites for evaluation at 3 and 6 months. The primary outcome of dyspnea with ADL was measured with the Chronic Respiratory Questionnaire. Secondary outcomes of exercise behavior, exercise performance, COPD exacerbations, and mediators, such as self-efficacy and social support, were also measured. A satisfaction survey was administered and a semistructured exit interview was conducted at the final visit.

Results: The study was stopped early due to multiple technical challenges with the eDSMP, but follow-up was completed on all enrolled participants. Data were available for 39 participants who completed the study (female: 44%; age: 69.5 ± 8.5 years; percent predicted forced expiratory volume in 1 s: 49.6 ± 17.0%). The fDSMP and eDSMP showed similar clinically meaningful changes in dyspnea with ADL from baseline to 3 months (fDSMP: + 3.3 points; eDSMP: + 3.5 points) and sustained these improvements at 6 months (fDSMP: + 4.0 points; eDSMP: + 2.5 points; time effects $P < .001$; group by time $P = .51$). Self-reported endurance exercise time ($P = .001$), physical functioning ($P = .04$), and self-efficacy for managing dyspnea ($P = .02$) also showed positive improvements over time in both groups with no significant differences with respect to program modality. Participants who completed the study reported favorable satisfaction with the programs.

Conclusions: Although there were numerous technical challenges with the eDSMP, both dyspnea self-management programs were effective in reducing dyspnea with ADL in the short term. Our findings will need to be confirmed in a larger randomized trial with more mature Web and personal digital assistant tools, use of a control group, and longer follow-up.

Trial registration: clinicaltrials.gov NCT00102401, http://www.webcitation.org/5X8CX4gLC

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KEYWORDS

Dyspnea; pulmonary disease; chronic disease; self-care; self-efficacy; health behavior; health education; exercise; monitoring; Internet; cellular phone; telemedicine; randomized controlled trial; Personal Digital Assistant (PDA)

Introduction

Despite optimal medical therapy, people living with chronic obstructive pulmonary disease (COPD) continue to experience persistent dyspnea (shortness of breath) with their activities of daily living (ADL) and therefore must engage in the long-term tasks of self-management. Self-management has been defined as an “individual’s ability to manage the symptoms, treatment, physical and social consequences and lifestyle changes inherent in living with a chronic condition” [1]. Most interventions that support self-management are based on key principles of social cognitive theory [2] and are generally focused on increasing patients’ confidence in their ability to manage their illness and resulting symptoms by providing (1) relevant education so patients understand how their perception and behaviors can affect how much an illness interferes with their lives, (2) specific skills training and problem solving techniques, (3) goal setting and self-monitoring, and (4) sustained reinforcement of lifestyle changes [1,3-5].

Alternative care models, such as disease or care management programs, have been tested and shown to have some success in improving health outcomes in other diseases such as diabetes [6-8] and congestive heart failure [9,10], but programs for patients with COPD are yet to be implemented widely [11-13]. Pulmonary rehabilitation is a comprehensive evidence-based approach to supporting patients with COPD [14,15]. However, due to reimbursement policies in the United States, these programs are generally of short duration and may not be accessible to many patients because of distance, scheduling, and eligibility requirements. Thus, convenient and easy access to resources for self-management education, skills training, and ongoing support remains a notable challenge for patients with COPD and their caregivers. More recently, the pervasive increase in various forms of information and communication technology in everyday life provides a natural avenue and perhaps a partial solution for health providers to reach out to more patients and provide seamless support across the illness trajectory. Findings from a number of studies in the last several years have shown the positive impact of information and communication technology on health promotion and disease management activities in both healthy and clinical populations [16-22].

We previously tested a face-to-face dyspnea self-management program that combined individual education on strategies to decrease dyspnea with a home walking prescription, symptom monitoring, and telephone reinforcement by a nurse and found that this program decreased dyspnea with ADL over the long term [23]. The question remained whether an Internet-based program with similar components could bring about the same outcomes with greater reach to those who are not able to attend face-to-face programs. With the exception of a previous report on the feasibility and acceptability of engaging a small sample of patients with COPD in a nurse-facilitated, Web-based dyspnea self-management intervention by our group, there have been no other published studies on the use of the Internet for self-management support in this clinical population [24].

The purpose of this study was to extend our previous investigation by comparing the efficacy of the Internet-based dyspnea self-management program (eDSMP) with a face-to-face dyspnea self-management program (fDSMP) on the primary outcome of dyspnea with ADL in patients with moderate to severe COPD over a longer period using a randomized design. Secondary outcomes included exercise behavior, exercise performance, and COPD exacerbations. We hypothesized that the difference in changes in the primary outcome of dyspnea with ADL, measured by the Chronic Respiratory Questionnaire (CRQ), would not be greater than the minimal clinically important difference of 2.5 points between the two groups.

Methods

Study Design

We conducted a randomized, repeated measures (0, 3, and 6 months) pilot study to compare the effects of an eDSMP to an fDSMP in patients with COPD. The trial took place at two academic medical centers, University of California San Francisco, and University of Washington, Seattle. This research study was approved by the institutional review boards at both study sites and was registered with ClinicalTrials.gov (NCT00102401).

Participants

Participants were recruited from a combination of Web-based and non-Web-based sources. Recruitment announcements were sent to various email distribution lists and online support groups for patients with COPD and older adults. Email postings were sent via a Web vendor intermediary who produced decision-support content for patients with COPD. Other recruitment activities included chest clinic referrals, letter mailings to university clinic patients with a COPD-related diagnosis, announcements at Better Breathers support groups and pulmonary rehabilitation programs, and newspaper advertisements.

The inclusion criteria were (1) a diagnosis of COPD and being clinically stable for at least 1 month; (2) spirometry results showing at least mild obstructive disease defined as post-bronchodilator forced expiratory volume in 1 s (FEV1) to forced vital capacity (FVC) ratio < 0.70 with FEV1 < 80% predicted, or FEV1/FVC < 0.60 with FEV1 > 80% predicted; (3) ADL limited by dyspnea; (4) use of the Internet and/or checking email at least once per week with a Windows operating system; (5) oxygen saturation > 85% on room air or ≤ 6 L/min of nasal oxygen at the end of a 6-minute walk test. Participants were excluded if they (1) had any active symptomatic illness (ie, cancer, heart failure, ischemic heart disease with known coronary artery or valvular heart disease, psychiatric illness, or neuromuscular disease); (2) participated in a pulmonary rehabilitation program in the last 12 months; or (3) were currently participating in > 2 days of supervised maintenance exercise.

Randomization and Procedures

An investigator who was not involved in the day-to-day study operations generated the randomization sequence using the SPSS version 14.0 (SPSS Inc, Chicago, IL, USA) random sequence generator feature and placed the randomization in separate sealed opaque envelopes. The randomization scheme was stratified by the two clinical sites in blocks of six to ensure balanced allocation to the two treatment groups. Since registration and access to the Web questionnaires on the vendor-supported website required designation of a treatment group early in the baseline visit, the study nurse opened the randomization envelope during the first half of the visit. While the study nurse was privy to the treatment assignment, participants were not informed of their assignment until the visit was complete.

Baseline assessments included spirometry, completion of Web questionnaires, and 6-minute walk tests. Spirometry was performed using a Koko spirometer (Pulmonary Data Services, Louisville, CO, USA). Pulmonary function tests were used only to compare the severity of disease measured by airflow obstruction between the groups. At the end of the baseline visit, the study nurse introduced the personal digital assistant (PDA), a Blackberry 680, to the eDSMP participants; they were encouraged to play an electronic game on the PDA to increase their comfort with the device since it would be used to record their real-time symptom and exercise data. Participants assigned to fDSMP did not receive a PDA. All participants returned to the clinic within 1 week for an initial face-to-face dyspnea and exercise consultation with the study nurse coach and continued to participate in their respective intervention programs for the next 6 months. They returned to the medical center at 3 and 6 months for testing by study staff who were not involved in the intervention. Individual semistructured interviews were conducted either in person or via telephone at the final visit by the evaluation staff or investigators (HQN and VCK) who were not directly involved in the intervention.

Dyspnea Self-Management Programs

Theoretical and Technical Framework

Major concepts from social cognitive [2,25], self-management [26], and pathophysiological [27] theories as well as our previous work on dyspnea self-management [23,28,29] provided the underlying framework for the dyspnea self-management program. Specifically, the dyspnea self-management program was comprised of education and skills training for dyspnea management, including individualized tailored exercise planning, self-monitoring of respiratory symptoms and exercise, and personalized reinforcement and feedback for exercising and the use of dyspnea self-management strategies. These programs were proposed to increase self-efficacy for exercise and dyspnea management. This improvement coupled with social support and possible physiological changes was hypothesized to ultimately reduce dyspnea with ADL and allow the dyspneic patient to increase his or her functional performance. Both programs were designed to provide similar content and “contact” time for ongoing reinforcement and support and differed only in the mode of delivery (Table 1). The eDSMP incorporated technological enhancements to support earlier recognition of worsening symptoms through real-time monitoring, more prompt feedback, and convenient access to information and support, which were hypothesized to attenuate the possible disadvantages of decreased face-to-face contact.

We used a vendor-supported, Web-based application that was configured to our study specifications for the eDSMP [30] (see Multimedia Appendix).

Table 1. Dyspnea self-management program components

Core Components	fDSMP	eDSMP
1. Dyspnea and exercise consultation (1-1.5 hours)	Individual face-to-face	Individual face-to-face Training on website and PDA
2. Endurance (4 times/week, 30 min/session) and arm strengthening (3 times/week) exercise program	Unsupervised independent exercise	Unsupervised independent exercise
3. Collaborative self-monitoring of exercise and respiratory symptoms and reinforcement of dyspnea management strategies (weekly in month 1; biweekly in months 2-6)	Paper diaries Reinforcement telephone calls (5-10 min)	PDA and Web diary Reinforcement emails
4. Structured education of dyspnea management strategies, skills training, and peer interactions (six 1-hour sessions)	Paper modules Face-to-face group sessions	Interactive Web modules Live group chat sessions Bulletin board

Dyspnea and Exercise Consultation

All participants returned to the clinic within 1 week of their baseline visit to participate in a 1.5- to 2-hour face-to-face consultation with an advanced practice nurse who specialized in either general adult or pulmonary medicine. The goal of the consultation was for the study nurse to establish rapport with the participant and to understand his or her current level of exercise and experience with dyspnea through motivational interviewing techniques [31]. An individualized exercise plan was developed with the participant, and actions that could be taken to prevent and manage future COPD exacerbations were discussed. The eDSMP participants were provided with a detailed paper help manual on how to navigate and use the website tools and their PDA. They received training on how to use the website to access the education modules, self-monitoring tools, and communication tools using the clinic computer. They also received training on how to record their daily exercise and symptoms using the PDA.

Exercise Program

During the consultation visit described above, the nurse and participant together developed an individualized exercise plan that was based on the participant's baseline exercise performance, dyspnea at the end of a 6-minute walk test, oxygen saturation, stage of exercise motivational readiness, and exercise preferences. The home-based exercise program included a combination of endurance (walking, cycling, or swimming) and arm strengthening (biceps curls, triceps curls, side arm raises, and upper arm raises) exercises. All participants were encouraged to complete endurance exercises at least 4 times per week for 30 minutes per session and arm strengthening exercises at least 3 times per week. They used a modified 0- to 10-point Borg scale [32] to gauge their dyspnea as a proxy for exercise intensity and were instructed that they should feel at the end of their exercise that they could not have gone further. Participants who were more disabled were encouraged to perform their exercises in smaller 10-minute increments.

Collaborative Self-Monitoring and Reinforcement

The eDSMP participants submitted real-time information about their symptoms (dyspnea, sputum, sputum purulence, symptoms of a cold, wheezing, and cough) and exercise (mode, duration, and worst dyspnea) via the PDA (Figure 1) or website. The fDSMP participants completed paper diaries and mailed them back weekly to the study office. Participants in the eDSMP group were encouraged to communicate their exercise goals and progress to the nurse by using a Web-based goal-setting tool (Figure 2), whereas the fDSMP group set exercise goals during the telephone calls. The nurses reviewed this information to provide individualized feedback and reinforcement to participants regarding their use of dyspnea management strategies and exercise progress via email (eDSMP) or telephone (fDSMP), weekly for the first month and then biweekly for the next 5 months. These contacts were designed to be as similar as possible for the two groups. One difference was that automated email alerts were sent to the study nurses based on real-time symptom (worsening of symptoms from usual) and exercise (reports of not performing exercise for at least 3 consecutive days) data that the eDSMP participants submitted. There were no such alerts for the fDSMP participants.

Figure 1. PDA exercise and symptom queries (eDSMP group)

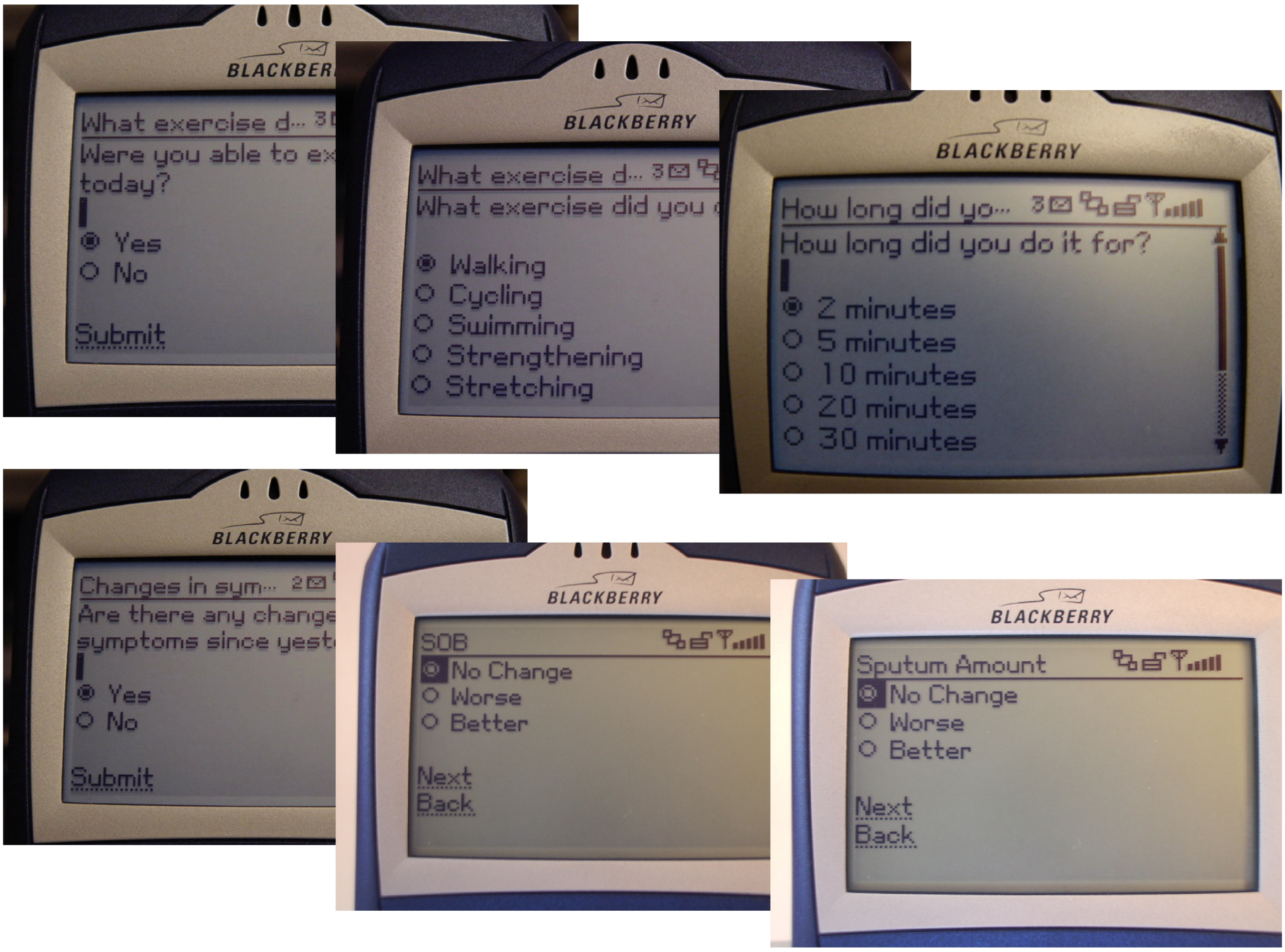

Figure 2. Exercise goal setting (eDSMP group)

Structured Education Sessions and Peer Interactions

All participants received education on shortness of breath (SOB), breathing strategies to reduce SOB, exercise and SOB, modifying activities to reduce SOB, coping with SOB and stress, and medications to manage SOB and COPD flare-ups. The eDSMP group accessed Web-based education modules, while the fDSMP participants were given a paper copy of the modules on these six topics. The Web modules, which were written at the 8th grade level or lower, also had nondigitized audio, pictures, and animations. The content from these modules was reinforced by study nurses during six weekly live chat sessions with participants from both clinical sites (eDSMP) or face-to-face meetings at the medical centers (fDSMP). These education sessions were designed to encourage peer interactions and mutual support.

Outcome Measures

Primary Outcome

Dyspnea with ADL was measured with the CRQ-Dyspnea subscale, which has been validated in previous studies [33,34]. Participants chose five activities that were most important to them and were asked to rate the severity of dyspnea with these activities on a 7-point Likert scale ranging from “extremely short of breath” to “not at all,” with higher scores indicating less dyspnea. The benchmark for a minimal clinically important difference in mean scores is 2.5 [35]. Participants rated their dyspnea for these same activities at 3 and 6 months. We tested the concurrent validity of the Web-based CRQ-Dyspnea questionnaire by having 21 participants complete a paper version within one to seven days of the first administration during the baseline visit. While the individual responses for the five CRQ-Dyspnea questions were variable ($r = 0.62$), total scores were comparable (Web version: 15.7 ± 5.6 vs paper version: 15.1 ± 5.5).

Secondary Outcomes

Stage of Motivational Readiness for Exercise

Participants selected their readiness for exercise from a list of five descriptions (precontemplation, contemplation, preparation, action, and maintenance) [36].

Exercise Behavior

Participants were asked about the frequency and duration (5-, 10-, 20-, 30-, 40-, 60-minute increments) of endurance (walking, cycling, swimming), strengthening, and stretching (yoga, tai chi) exercises for a typical week during the last 4 weeks [24,37]. Total minutes per week with each type of exercise were calculated by multiplying the exercise frequency by session time in minutes.

Exercise Performance

Exercise performance was assessed using the 6-minute walk test. Subjects inhaled two puffs of a bronchodilator before the test. After standardized verbal instruction, two 6-minute walk tests were performed approximately 30 minutes apart on the same day in a hospital corridor [38]. Oxygen saturation, heart rate, and ratings of dyspnea were measured before and after both tests. The test with the greater distance was used in the analyses.

Health-Related Quality of Life

The CRQ and Medical Outcomes Study Short-Form 36 (SF-36) were used to measure disease-specific and general health-related quality of life (HRQOL), respectively. In addition to the dyspnea scale, the 20-item CRQ measures other components of disease-specific HRQOL, including fatigue, emotional functioning, and mastery (self-efficacy). The SF-36 has 36 questions that relate to nine distinct components of overall health and two composite measures of physical and mental functioning. Higher scores reflect better HRQOL for both instruments.

Acute COPD Exacerbations

Acute COPD exacerbations were defined as an increase in any two major symptoms or an increase in one major and one minor symptom for at least two consecutive days and accompanied by a change in the medical regimen [39,40]. Major signs and symptoms included dyspnea, sputum volume, and sputum purulence; minor ones included symptoms of a cold (nasal discharge or congestion), wheezing, and cough. Participants provided daily ratings of these signs and symptoms either in the written logs (fDSMP) or their PDA (eDSMP) based on the following scale: no change, worse, or better [41,42].

Mediators of Treatment Effects

Knowledge

Knowledge of strategies to manage dyspnea was measured by a 15-item multiple choice and true/false questionnaire that was adapted from previously published instruments [43]. Internal reliability of the instrument was .72.

Self-Efficacy

Self-efficacy for managing dyspnea was measured using a single question with a 0- to 10-point response scale: “How confident are you that you can keep your shortness of breath from interfering with what you want to do?” [37].

Perception of Support

The information and emotional subscale of the Medical Outcomes Study Social Support Scale [44] was used to measure general perceived support. Questions related to exercise-specific support were modified from previous work [45] to assess participants’ perception of support from study nurses, family and friends, and health providers to either initiate or maintain an exercise program using a 7-point Likert scale ranging from “strongly agree” to “strongly disagree.”

Program Preference

Many participants volunteered their preference for either the fDSMP or eDSMP during the telephone screening. However, they were formally asked their preference during the dyspnea and exercise consultation by the study nurse.

Usage

Due to the configuration of the vendor’s Web server log files, we were unable to obtain detailed navigation information for each participant. We were, however, able to obtain proxy usage measures by virtue of timestamps recorded whenever eDSMP participants logged exercise and symptom data, set exercise goals, posted to the bulletin board, or participated in the chat sessions. Technical issues were documented and compiled.

Satisfaction

Participants were asked about their satisfaction with specific components of the eDSMP (13 items) or fDSMP (9 items) and their overall satisfaction with the programs using a 3-point scale (“not at all satisfied” to “very satisfied”). The evaluation staff or lead investigators (HQN and VCK) who were not directly involved with the interventions conducted semistructured interviews with participants at the end of the study. Participants were asked to provide feedback on what aspects of the program were most or least helpful for managing their dyspnea and how the program could have been done differently to support self-management. Probing questions were used to remind participants of the four major intervention components. Other questions were asked during this interview; however, a description of these questions is beyond the scope of the paper.

Statistical Analyses

Independent *t* tests for continuous variables or chi-square and Fisher exact tests for categorical variables were used to compare baseline characteristics between the two groups. For all primary and secondary outcomes and mediators, we conducted repeated measures analysis of variance (ANOVA) tests that had one between-subjects factor— treatment group, with two levels (fDSMP and eDSMP)—and one within-subjects factor— time, with three levels (baseline, 3 months, and 6 months). This design allowed for testing the main effect of time, the main effect of treatment group, and the interaction of treatment group by time. We incorporated intent-to-treat principles whereby, for the participant who missed follow-up at 3 months (n = 1), baseline values were used, and for the participant who missed the follow-up at 6 months (n = 1), 3-month data were used. The intent-to treat analyses led to results that were comparable to those conducted using the available data only; therefore, results of the intent-to-treat analyses are reported. Since this was a pilot study with a relatively small sample size and all analyses of secondary outcomes were exploratory, we did not adjust the alpha levels for testing multiple outcome variables. Rather, we simply present the actual *P* values for each test. We did not examine differences in the outcomes between the two clinical sites since the samples were too small for meaningful comparisons. All statistical analyses were performed using SPSS version 14.0.

Results

Participants

A total of 173 prospective participants were screened from April 2005 to July 2006 across both clinical sites. As shown in Figure 3, 50 participants were randomized to either the eDSMP (n = 26) or fDSMP (n = 24) arm after 123 participants were excluded (89 were not eligible, 18 refused to participate, and 16 were lost to contact). The investigators stopped the study early due to the cumulative technical and usability challenges that peaked when three consecutive eDSMP participants had multiple difficulties accessing the Web application and subsequently withdrew. All enrolled participants were followed through 6 months according to the study protocol.

Figure 3. Subject flow

Participants who dropped out after randomization (n = 11; 36% due to technical difficulties) were similar in age, education, employment status, distance from home to the respective clinical site, pulmonary functioning, disease severity (measured by the BODE composite index, which includes body mass index [BMI], FEV1, dyspnea, and 6-minute walk test) [46], stage of readiness for exercise, and treatment group preference compared to those who remained in the study. However, those who dropped out tended to be female (73% vs 44%, *P* = .09) and current smokers (27% vs 8%, *P* = .08), reported no musculoskeletal problems (0% vs 31%, *P* = .04), rated themselves as having advanced computer skills (55% vs 26%, *P* = .14), and were less likely to have participated in any face-to-face support groups (0% vs 28%, *P* = .05) or previously attended pulmonary rehabilitation (9% vs 44%, *P* = .04) compared with those who completed the study.

Participants in both treatment groups were similar on all baseline characteristics, suggesting that randomization was successful (Table 2). Approximately 66% of the sample expressed a preference for one of the two dyspnea self-management programs. There were notable differences between the groups in the proportion of participants who had a preference for either the fDSMP or eDSMP. Compared with only 25% of participants randomized to the fDSMP group who reported a preference for their assigned program, half of the participants randomized to the eDSMP group reported a preference for their assigned program (*P* = .01).

Table 2. Sample baseline characteristics*

	fDSMP (n = 20)	eDSMP (n = 19)	Total (n = 39)	Dropouts (n = 11)
Demographics				
Age, years (mean ± SD)	70.9 ± 8.6	68.0 ± 8.3	69.5 ± 8.5	67.3 ± 10.0
Female	9 (45%)	8 (39%)	17 (44%)	8 (73%)
Caucasian	20 (100%)	18 (95%)	38 (97%)	11 (100%)
Education				
High school or some college	8 (40%)	10 (50%)	18 (46%)	5 (45%)
College or more	12 (60%)	9 (50%)	21 (54%)	6 (55%)
Not currently employed or currently disabled or retired	15 (75%)	13 (72%)	28 (72%)	6 (55%)
Living situation: with spouse or other	13 (65 %)	12 (63%)	25 (64%)	6 (55%)
Currently smoking	1 (5%)	2 (11%)	3 (8%)	3 (27%)
Distance to clinical site, km (mean ± SD)	13.1 ± 15.7	20.4 ± 18	16.6 ± 17	10.4 ± 11.8
BMI, kg/m^2 (mean ± SD)	27.7 ± 6.4	29.4 ± 5.9	28.5 ± 6.2	26.2 ± 4.2
Disease Severity				
FEV1/FVC (mean ± SD)	0.46 ± 0.11	0.49 ± 0.14	0.47 ± 0.13	0.48 ± 0.13
FEV1 % predicted (mean ± SD)	50.3 ± 17.6	49.0 ± 16.8	49.6 ± 17.0	52.8 ± 18.2
GOLD stage				
Mild/moderate	10 (50%)	9 (47%)	19 (49%)	5 (45%)
Severe/very severe	10 (50%)	10 (56%)	20 (51%)	6 (55%)
BODE composite score (mean ± SD)	2.8 ± 2.2	2.5 ± 1.5	2.7 ± 1.9	2.1 ± 1.6
Supplemental oxygen	5 (25%)	6 (33%)	11 (58%)	2 (18%)
Comorbidities				
Cardiovascular (HTN and CAD)	10 (50%)	9 (50%)	19 (49%)	4 (36%)
Musculoskeletal (arthritis and other pain)	8 (40%)	4 (22%)	12 (31%)	0 (0%)[†]
Previous pulmonary rehabilitation	8 (40%)	9 (47%)	17 (44%)	1 (9%)[†]
Computer/Internet Skills				
Self-rated computer skills				
Beginner	2 (10%)	4 (21%)	6 (15%)	2 (18%)
Intermediate	14 (70%)	9 (47%)	23 (59%)	3 (27%)
Advanced	4 (20%)	6 (32%)	10 (26%)	6 (55%)
Computer use, years (mean ± SD)	5.6 ± 2.7	5.7 ± 2.8	5.7 ± 2.7	6.4 ± 2.9
Hours on the Internet per week, median (range)	9.5 (1-25)	15.0 (1-90)	14 (1-90)	12 (2-35)
Participate in online support groups	2 (10%)	5 (28%)	7 (37%)	1 (9%)
Other Characteristics				
Motivational readiness for exercise				
Precontemplation/contemplation	6 (30%)	8 (42%)	14 (36%)	3 (27%)
Preparation	8 (40%)	6 (33%)	14 (36%)	5 (46%)
Action/maintenance	6 (30%)	5 (28%)	11 (28%)	3 (27%)
Treatment group preference[‡]				
fDSMP	5 (25%)	7 (39%)	12 (31%)	4 (50%)

	fDSMP (n = 20)	eDSMP (n = 19)	Total (n = 39)	Dropouts (n = 11)
eDSMP	4 (20%)	10 (50%)	14 (36%	3 (38%)
No preference	11 (55%)	2 (11%)	13 (33%)	1 (12%)
Outcome expectation of dyspnea self-management program[§]				
Very/extremely	11 (55%)	11 (58%)	22 (56%)	5 (46%)
Quite	3 (15%)	6 (32%)	9 (23%)	4 (36%)
Fair	6 (30%)	2 (10%)	8 (21%)	2 (18%)

[*] Values are number (%) unless otherwise stated. BMI, body mass index; FEV1/FVC, forced expiratory volume in 1 s/forced vital capacity; GOLD, Global Initiative for Obstructive Lung Disease; BODE, body mass index, airflow obstruction, dyspnea, exercise; HTN, hypertension; CAD, coronary artery disease.

[†] $P < .05$ (dropouts vs participants).

[‡] $P = .01$ (fDSMP vs eDSMP).

[§] “How much do you think this program (eDSMP or fDSMP) will assist you in managing your shortness of breath?” (1- to 6-point Likert scale: “not at all” to “extremely”).

Outcomes

Primary Outcome: Dyspnea with ADL

While there was a significant main effect of time ($P < .001$), the lack of a significant group by time interaction ($P = .51$) indicates that the trajectory of change in dyspnea with ADL over time was not different between the two programs (Table 3). Participants in both programs showed similar clinically meaningful changes in dyspnea with ADL from baseline to 3 months (fDSMP: + 3.3 points; eDSMP: + 3.5 points) and, for the most part, sustained these improvements at 6 months (fDSMP: + 4.0 points; eDSMP: + 2.5 points).

Table 3. Comparison of treatment effects: dyspnea, exercise, exercise performance, and HRQOL*

	fDSMP (n = 20)	eDSMP (n = 19)	Group *P* Value	Time *P* Value	Group × Time *P* Value
Primary Outcome					
CRQ-Dyspnea with ADL (score range: 5-35)[†]					
Baseline	15.9 ± 5.4	18.8 ± 6.2	.14	< .001	.51
3 Months	19.2 ± 5.8	22.3 ± 4.6			
6 Months	19.9 ± 6.2	21.3 ± 6.0			
Secondary Outcomes					
Exercise stage of change: action or maintenance					
Baseline, no. (%)	6 (30%)	5 (26%)	-	-	-
3 Months, no. (%)	14 (70%)	16 (84%)			.47[‡]
6 Months, no. (%)	15 (75%)	12 (63%)			.85[‡]
Endurance exercise (total min/week)					
Baseline	77 ± 113	89 ± 102	.22	.001	.99
3 Months	141 ± 100	173 ± 130			
6 Months	121 ± 81	128 ± 111			
Strengthening exercise (total min/week)					
Baseline	21 ± 46	11 ± 29	.54	< .001	.61
3 Months	56 ± 66	53 ± 70			
6 Months	53 ± 59	34 ± 37			
6-Minute walk test (m)[§]					
Baseline	406 ± 150	436 ± 92	.22	.70	.05
3 Months	386 ± 157	450 ± 91			
6 Months	394 ± 165	456 ± 91			
CRQ-Fatigue (score range: 4-28)[†]					
Baseline	16.1 ± 4.4	17.1 ± 5.3	.29	.03	.13
3 Months	16.6 ± 4.8	19.4 ± 4.1			
6 Months	17.7 ± 5.2	18.3 ± 4.4			
CRQ-Mastery (score range: 4-28)[†]					
Baseline	20.4 ± 5.2	21.7 ± 3.2	.35	< .001	.98
3 Months	22.3 ± 5.8	23.6 ± 2.9			
6 Months	22.4 ± 5.5	23.6 ± 3.7			
CRQ-Emotional functioning (score range: 7-49)[†]					
Baseline	33.4 ± 8.0	35.9 ± 7.2	.33	.38	.98
3 Months	34.6 ± 8.7	36.8 ± 7.5			
6 Months	34.5 ± 8.6	36.8 ± 7.8			
CRQ-Total score (score range: 20-140)[†]					
Baseline	85.8 ± 18.9	93.5 ± 15.7	.19	< .001	.60
3 Months	92.7 ± 22.5	102.1 ± 15.6			
6 Months	94.5 ± 22.6	99.9 ± 16.8			

	fDSMP (n = 20)	eDSMP (n = 19)	Group *P* Value	Time *P* Value	Group × Time *P* Value
SF-36 Physical composite (score range: 0-100)[†]					
Baseline	32.8 ± 8.5	37.3 ± 7.0	.07	.04	.99
3 Months	35.3 ± 11.0	41.0 ± 7.9			
6 Months	35.2 ± 10.6	39.9 ± 7.6			
SF-36 Mental composite (score range: 0-100)[†]					
Baseline	51.8 ± 9.9	49.7 ± 10.1	.70	.31	.47
3 Months	52.2 ± 11.7	52.8 ± 9.6			
6 Months	53.5 ± 11.6	51.3 ± 10.0			

[*] Values are mean ± SD unless otherwise stated. CRQ, Chronic Respiratory Questionnaire; ADL, activities of daily living; SF-36, Medical Outcomes Study Short-Form 36.

[†] Higher scores are better.

[‡] Chi-square test.

[§] For the eDSMP group, n = 18.

Secondary Outcomes: Exercise Behavior, Exercise Performance, HRQOL, and Acute Exacerbations of COPD

A majority of participants in both groups advanced in their stage of readiness for exercise with up to 84% reporting that they were in either action or maintenance at 3 months (see Table 3). This was consistent with changes in total duration of endurance exercise per week from baseline to 3 months, + 84 mins (eDSMP) and + 64 mins (fDSMP), and at 6 months, + 39 mins (eDSMP) and + 44 mins (fDSMP). However, exercise performance as measured by distance covered during the 6-minute walk test declined in the fDSMP and increased in the eDSMP over time with a marginal group by time difference ($P = .05$).

Total scores on the CRQ, reflecting disease-specific HRQOL, improved over time for participants in both the eDSMP and fDSMP ($P < .001$). There were also positive changes in the SF-36 physical composite scores over time for both groups ($P = .04$). Neither of the programs had an impact on the SF-36 mental health composite score.

There was a total of 11 acute exacerbations of COPD in 10 participants, captured either through the electronic or paper diaries or obtained during the telephone or email follow-up contacts. The short study duration and heterogeneous disease severity across participants made it unrealistic to capture enough events for group comparisons.

Mediators of Treatment Effects: Knowledge, Self-Efficacy, Perception of Support, Program Preference, Usage, Technical Issues, and Satisfaction

There were small improvements in participants' already high baseline knowledge of dyspnea management strategies at 3 months, which was sustained at 6 months ($P < .001$), with no group differences over time ($P = .68$; Table 4). Participants in both programs improved their self-efficacy for managing dyspnea ($P = .02$) with no group by time differences. These positive changes were also captured in the CRQ mastery subscale ($P < .001$; see Table 3). Perception of general social support did not appreciably change ($P = .42$) or differ between groups over time ($P = .68$). However, participants reported that they agreed or strongly agreed that they received the support from the study nurses needed to either start or maintain their exercise programs (3 months: fDSMP, 91%; eDSMP, 100%; 6 months: fDSMP, 90%; eDSMP, 100%).

Table 4. Comparison of mediators of treatment effects: knowledge, self-efficacy, and perception of support*

	fDSMP (n = 20)	eDSMP (n = 19)	Group *P* Value	Time *P* Value	Group × Time *P* Value
Knowledge					
Dyspnea knowledge (score range: 0-15)†					
Baseline	12.5 ± 2.3	12.6 ± 1.8	.49	< .001	.68
3 Months	13.3 ± 1.6	13.8 ± 1.0			
6 Months	13.8 ± 1.5	14.1 ± 1.0			
Self-Efficacy					
Self-efficacy for managing dyspnea (score range: 0-10)†					
Baseline	4.6 ± 2.4	4.7 ± 2.3	.18	.02	.34
3 Months	5.5 ± 3.3	6.8 ± 2.3			
6 Months	5.0 ± 3.6	6.7 ± 2.6			
Perception of Support					
Perception of general social support (score range: 0-100)†					
Baseline	68.9 ± 37.2	62.2 ± 27.6	.64	.42	.68
3 Months	65.2 ± 31.7	64.0 ± 24.3			
6 Months	70.9 ± 31.0	66.4 ± 27.1			
Perception of exercise support from research staff ‡					
3 Months			-	-	-
Strongly agree, no. (%)	13 (65%)	14 (74%)			
Agree, no. (%)	5 (26%)	5 (26%)			
6 Months			-	-	-
Strongly agree, no. (%)	16 (80%)	13 (68%)			
Agree, no. (%)	2 (10%)	6 (32%)			

*Values are mean ± SD unless otherwise stated.

†Higher scores are better.

‡At 3 months, n = 19 for fDSMP group.

Approximately 38% (n = 15) of the participants were randomly assigned to their preferred program; 28% (n = 11) were assigned to their nonpreferred program. The remaining 13 participants expressed no program preference. Comparisons across these three groups (concordant, discordant, nonpreferential) on the binary outcome of change in the CRQ-Dyspnea of at least + 2.5 points showed no differences among the groups in the proportion of participants who met this clinically important improvement threshold at 3 or 6 months (*P* = .40 and .39, respectively). Participants who preferred the eDSMP tended to be younger (65 ± 8 vs 72 ± 7 vs 72 ± 9 years, *P* = .06), lived further away from the clinical site (24 ± 21 vs 15 ± 16 vs 11 ± 9 km, *P* = .12), and rated their computer skills as advanced (43% vs 17% vs 15%, *P* = .05) compared to those who preferred the fDSMP or had no program preference, respectively; there were no other notable differences across the preference groups.

A majority of the technical issues for the eDSMP had to do with access to the study website. Participants had to install proprietary security software plug-ins in order to access the site. Five participants had at least two pop-up blocker software programs on their systems and required remote assistance from the vendor's technical support staff to disable the programs. Three participants expressed concerns about disabling their pop-up blocker software and security vulnerabilities when accessing the site with the Internet Explorer browser; the site was not accessible with non-Windows-based operating systems or other Web browsers. One participant required almost 5 hours of technical support from the vendor before she could access the site. Participants commented during the exit interview that the decreased accessibility, slow loading of the Web application, and security concerns discouraged them from using the site more regularly.

There were also notable usability challenges with the wireless-enabled PDA and unreliable wireless coverage [47]. Participants had to complete 16-30 unique actions on the device to submit an exercise or symptom entry. When asked about the least helpful component of the study, one participant commented, "The most annoying was the blackberry [PDA]. If you exercised three different ways, for example, cardio, weights, and stretching, you had to go back through the symptoms questionnaire for each type of exercise." Another commented that he changed his reporting behavior once he learned of the branching logic for the symptom surveys: "I would answer 'no change'; it was too bothersome to report change since I would then have to go through each of the screens." Inconsistent wireless coverage was also problematic: "The PDA did not allow me to document [my data] when I left the city. The technical glitches need to be fixed. It worked well when it worked."

The numerous technical problems decreased participant engagement with the Web and PDA tools, and this was reflected in the number of Web log-ins and the exercise and symptom entries via the website and/or the PDA (Table 5). The exercise goal-setting tool and bulletin board were seldom used by eDSMP participants. One participant who was initially interested in using the bulletin board for peer-to-peer communication expressed his disappointment: "The bulletin board—no one uses it to ask questions." Only two eDSMP participants used the exercise goal-setting tool more than five times. When probed about use of specific tools on the site, one participant commented, "I never remembered to do the goal setting or graphing on the website."

A total of 77 and 122 exception alerts were generated based on lapses in exercise entries or reports of worsening symptoms from usual, respectively. Most fDSMP participants (80%) attended all six face-to-face education sessions (5.8 ± 0.6 sessions), while more of the eDSMP group (96%) participated in at least six online chat education sessions (6.2 ± 2.0 sessions). The number of email and telephone reinforcement follow-ups was comparable between groups.

Participants in both groups were most satisfied with the initial face-to-face interviews (Table 6). Use of the PDA and peer interaction received the lowest ratings by the eDSMP group. Mean ratings of overall satisfaction were only slightly lower in the eDSMP compared to the fDSMP group.

Table 5. Usage statistics over 6 months for eDSMP

Usage Parameter	Mean ± SD (Range)
Website log-ins	59 ± 34 (20-151)
Exercise goal setting	4 ± 6 (0-25)
Exercise entries	156 ± 80 (51-338)
Symptom entries	137 ± 48 (17-229)
Exercise exception alerts	4 ± 5 (0-17)
Symptom exception alerts	6 ± 6 (1-20)
Reinforcement emails	14
Education sessions	6.2 ± 2.0 (0-11)

Table 6. Satisfaction with the dyspnea self-management program*

	fDSMP (n = 20)	eDSMP (n = 19)
Initial face-to-face interview	2.9 ± 0.31	2.8 ± 0.48
Education sessions	2.7 ± 0.71	2.4 ± 0.78
Educational materials	2.6 ± 0.68	2.6 ± 0.50
Exercise goal setting	2.6 ± 0.59	2.4 ± 0.70
Exercise and symptom self-monitoring	2.5 ± 0.69 (paper log)	2.1 ± 0.73 (PDA) 2.4 ± 0.69 (website)
Receiving exercise prompts on PDA	N/A	2.4 ± .51
Reinforcement (telephone vs email)	2.7 ± 0.66 (telephone)	2.6 ± 0.50 (email)
Interaction with peers	2.2 ± 0.86	1.9 ± 0.80
Assistance with managing acute exacerbations of COPD	2.3 ± 0.73	2.4 ± 0.78
Overall program	2.7 ± 0.47	2.6 ± 0.51

*1 = not at all satisfied, 2 = quite satisfied, 3 = very satisfied. Values are mean ± SD.

Discussion

We found that older adults with moderate to severe COPD showed clinically and statistically meaningful improvements in dyspnea with ADL as a result of participating in either a 6-month, face-to-face (fDSMP) or an Internet-based (eDSMP) dyspnea self-management program. These changes were consistent with overall increases in the mediator of self-efficacy for managing dyspnea and in the secondary outcomes of self-reported exercise endurance time and physical functioning. This is the first study we are aware of that employed a randomized design to test the effects of a technology-enhanced dyspnea self-management intervention for patients with COPD.

This study builds on our previous published findings with the fDSMP [12,23] and, more recently, the eDSMP [24]. Our overall goal is to be able to offer two comparably effective programs to broaden the reach to help more patients with COPD manage their dyspnea. As such, both programs were designed to provide similar content and contact time and only differed with regard to the mode that was used for education, collaborative self-monitoring, reinforcement, and peer interaction. It is noteworthy that participants in the eDSMP experienced reductions in their dyspnea despite considerable technical and usability challenges with our Web-based desktop and PDA application. The eDSMP participants who completed the study generally reported a positive experience with the program, especially their interactions with the study nurses, despite the technical challenges with accessing the website and using the PDA. These findings suggest that the "active ingredient" of the eDSMP probably had less to do with the technology and more to do with the ongoing feedback and focused motivational support on dyspnea self-management they received from the nurses via email and during the online educational chat sessions. We hypothesize that the initial face-to-face dyspnea and exercise consultation was also probably critical in fostering a positive relationship between eDSMP participants and study nurses.

For participants who were able to log their exercise and symptoms using their desktop computer or PDA, the study nurses could review this information in real time and provide feedback and encouragement. Even for those who had trouble with either the website or PDA, the nurses showed a genuine interest in the participants' well-being and consistently used motivational techniques to reinforce their confidence in self-management of dyspnea, including regular exercise. We believe that these positive nurse–patient collaborative interactions that were not dependent on the Web application and primarily occurred asynchronously via email increased the eDSMP group's engagement in exercise and consequently provided a positive impact on the perception of dyspnea similar to that of the fDSMP. Our observations are in line with findings from other behavioral studies of Internet-based physical activity and weight loss interventions. Those programs in which participants corresponded with and received regular feedback from a human counselor had increased treatment adherence that resulted in more robust outcomes [20,21,48,49]. Tate et al [21] tested the efficacy of a self-directed Internet weight loss program compared with a similar program that was supplemented with behavioral counseling either from an automated expert system or a human counselor. While weight loss was comparable between the two active arms at 3 months, the group that received feedback from a live counselor had significantly greater weight loss at six months. The study by Wing and colleagues [20] suggests that an Internet-based weight maintenance program, which included use of human counselors, was as effective as a face-to-face program in decreasing the number of participants who regained weight. Earlier studies of Internet-based behavioral interventions that did not include face-to-face contact or interactions from a human interventionist had weak effects [50,51]. Interestingly, a recent study of healthy middle age and older adults showed that those who received automated physical activity counseling advice via telephone had similar improvements in self-reported physical activity over 12 months compared to the group that received human advice [52]; both groups received an initial in-person exercise counseling session with a trained health educator.

A number of the participants in the current study reported that they enrolled in the study because they desired to "stay accountable to something or someone" and that they would be less likely to exercise if they were not "monitored." This theme was also reported in a recent study of an Internet-based physical activity program with healthy adults [53]. These observations may reflect the attitudinal characteristics specific to participants who seek out and volunteer for these types of research studies. An important question to address in future studies is whether this sense of accountability and commitment could be maintained with less resource-intensive approaches. Although there are no published cost-effectiveness analyses of Internet-based behavior change interventions, it would seem that interventions like our dyspnea self-management program, which include an empathetic and caring health provider, could perhaps reach more patients; however, they may be no more cost-effective than face-to-face programs. Economic evaluations of different models of Internet-based interventions for chronically ill older adults will need to be conducted before such resource-intensive interventions can be scaled up to the population level.

Patient-centered models of care suggest that health care should be "tailored" to the individual and provided in accordance with their values and preferences [54]. Thus, it is particularly important that investigators testing different delivery channels assess participant preferences and examine whether these preferences actually moderate participation and response. The study nurses observed that some participants preferred certain aspects of both programs (ie, telephone calls rather than email, but chat room rather than in-person education sessions). We measured participant preferences and found that concordance between program preference (eDSMP or fDSMP) and program assignment did not result in greater improvements in the primary outcome of dyspnea. A weakness of our study and others that test for interactions between delivery channel preferences and improvements in outcomes is the small sample sizes. Future studies will need to be adequately powered to examine how individual preferences, perhaps measured at different times during the study, modify participant engagement in the intervention and affect outcomes. In addition, a greater understanding of the factors that shape participants' preferences for different modes of communication may help to identify mechanisms that increase acceptability, participant engagement, and retention.

Limitations

Several limitations must be considered in interpreting our study findings. While the results are encouraging, it is important to note that due to significant technical and usability challenges, which for the most part could have only been resolved with a complete redesign of the Web and PDA application, it was necessary to stop the study early. We nevertheless gleaned important insights from this pilot study on the role of information and communication technologies in supporting collaborative self-management with older chronically ill patients and methodological issues that would have to be addressed with such clinical studies in the future [55].

Since the primary study outcome is a symptom and can only be derived through self-report, we have to assume that what we captured was the best representation of participants' dyspnea experiences. While changes in dyspnea with ADL for both groups were accompanied by changes in other conceptually similar self-reported measures (eg, self-efficacy for dyspnea management and physical functioning), we did not observe improvements in a more objective indicator—distance covered during a 6-minute walk test. These observations are similar to that of our earlier study of the fDSMP in which dyspnea with ADL decreased but with only small changes in exercise performance [23]. However, the findings are in contrast to pulmonary rehabilitation programs in which exercise performance usually improves in conjunction with reductions in dyspnea with ADL [15]. Based on our theoretical framework, the dyspnea self-management programs could be acting through a different pathway to reduce dyspnea with ADL (eg, increased confidence, cognitive reframing, or activity modification instead of increased fitness, which is typically associated with higher intensity supervised exercise training interventions).

It is possible that study participants desired to impress the investigators by responding favorably to the self-reported measures. We doubt that this was the case. Approximately one third of the sample was already in the active or maintenance stage of exercise and reported engaging in an average of 83 minutes of exercise per week at baseline, which is surprisingly comparable to a recent report on a large sample of patients with COPD [56]. With such relatively high levels of physical activity, one might expect a regression to the mean, but instead, endurance and strengthening exercise increased in both groups to levels that met or exceeded public health guidelines for physical activity [57]. Moreover, we worked with participants to incorporate upper extremity strengthening exercises that theoretically would improve dyspnea with ADL. These exercises may not necessarily have an impact on walking performance. Many ADL involve arm activities, and in COPD, upper extremity activities produce substantial dyspnea. Regardless, it will be important for future studies to include objective assessments of free living physical activity since this is one parameter that can easily be triangulated with self-report [58].

Due to the technical and usability challenges with the Web and PDA application and differential participant attrition, we terminated the study before reaching our sample target. The absence of a significant group by time effect in the changes in the primary outcome of dyspnea could be due to insufficient power. Nevertheless, the differences in the dyspnea change scores between the two programs were small and not of the magnitude that would meet the accepted benchmark for a clinically significant difference. Future studies will need to confirm whether these two programs can indeed produce and sustain such benefits beyond 6 months and are superior to a control intervention.

Study participants were primarily Caucasian and generally well educated, reflecting the demographics of early Internet adopters [59]. These characteristics make the findings less generalizable to the broader population of COPD patients. Although we excluded participants who had completed pulmonary rehabilitation within the last 12 months, 42% of the participants had previously participated in pulmonary rehabilitation. This reflects a sample that is generally more engaged and motivated since only a small percentage of patients with COPD ever participate in pulmonary rehabilitation [56].

Conclusion

Despite these limitations, this is the first study we are aware of that employed a randomized design to test the effects of a technology-enhanced dyspnea self-management intervention for older patients with COPD. The study included objective verification of disease severity with spirometry and exercise performance testing, which are often absent from eHealth studies. The sustained improvements in dyspnea with ADL over repeated measurements reflect the specificity of the intervention, that of dyspnea management. If future studies confirm that the two programs can effect significant improvements in dyspnea with ADL and secondary health outcomes, the potential for use in the continuum of self-management interventions is enormous (eg, symptom management for patients with other cardiopulmonary diseases or those with mild disease who are not eligible for pulmonary rehabilitation, a "booster" for graduates of these programs, or as palliative care for those who are too ill to participate in face-to-face programs).

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Conflicts of Interest

None declared.

Multimedia Appendix

Selected PDA and website screenshots

[PPT file (Microsoft Powerpoint), 4.3 MB - jmir_v10i2e9_app1.ppt]

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Abbreviations

ADL: activities of daily living
BMI: body mass index
BODE: body mass index, airflow obstruction, dyspnea, exercise
COPD: chronic obstructive pulmonary disease
CRQ: Chronic Respiratory Questionnaire
eDSMP: Internet-based dyspnea self-management program
fDSMP: face-to-face dyspnea self-management program
FEV1: forced expiratory volume in 1 s
FVC: forced vital capacity
PDA: personal digital assistant
SF-36: Medical Outcomes Study Short-Form 36
SOB: shortness of breath

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Original Paper

Patients’ Engagement With “Sweet Talk” – A Text Messaging Support System for Young People With Diabetes

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Abstract

Background: Guidelines for optimizing type 1 diabetes in young people advocate intensive insulin therapy coupled with personal support from the health care team. “Sweet Talk” is a novel intervention designed to support patients between clinic visits using text messages sent to a mobile phone. Scheduled messages are tailored to patient profiles and diabetes self-management goals, and generic messages include topical “newsletters” and anonymized tips from other participants. The system also allows patients to submit data and questions to the diabetes care team.

Objectives: The aim was to explore how patients with type 1 diabetes interact with the Sweet Talk system in order to understand its utility to this user group.

Methods: Subjects were 64 young people with diabetes who were participating in the intervention arms of a randomized controlled trial. All text messages submitted to Sweet Talk during a 12-month period were recorded. Messaging patterns and content were analyzed using mixed quantitative and qualitative methods.

Results: Patients submitted 1180 messages during the observation period (mean 18.4, median 6). Messaging frequency ranged widely between participants (0-240) with a subset of 5 high users contributing 52% of the total. Patients’ clinical and sociodemographic characteristics were not associated with total messaging frequency, although girls sent significantly more messages unrelated to diabetes than did boys (P = .002). The content of patients’ messages fell into 8 main categories: blood glucose readings, diabetes questions, diabetes information, personal health administration, social messages, technical messages, message errors, and message responses. Unprompted submission of blood glucose values was the most frequent incoming message type (35% of total). Responses to requests for personal experiences and tips generated 40% of all the incoming messages, while topical news items also generated good responses. Patients also used the service to ask questions, submit information about their self-management, and order supplies. No patients nominated supporters to receive text messages about their self-management goals. Another option that was not used was the birthday reminder service.

Conclusions: Automated, scheduled text messaging successfully engaged young people with diabetes. While the system was primarily designed to provide “push” support to patients, submission of clinical data and queries illustrates that it was seen as a trusted medium for communicating with care providers. Responses to the newsletters and submission of personal experiences and tips for circulation to other participants also illustrate the potential value of such interventions for establishing a sense of community. Although participants submitted relatively few messages, positive responses to the system suggest that most derived passive support from reading the messages. The Sweet Talk system could be readily adapted to suit other chronic disease models and age groups, and the results of this study may help to inform the design of future text message support interventions.

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KEYWORDS

Diabetes mellitus; adolescent; eHealth; social support; text messaging

Introduction

Diabetes is a condition requiring considerable self-management of diet, exercise, and medication use, and this can be challenging for children and adolescents. Recent guidelines on the management of type 1 diabetes recommend that young people should be offered intensive insulin therapy in conjunction with a package of care including emotional and behavioral support [1,2]. However, increasing the frequency of direct clinical contact is costly, and young people can fail to engage with conventional group-based support activities [3,4].

Emerging information and communications technologies have considerable potential to aid patients with long-term conditions, and young people with diabetes report using many of these to serve their information and support needs [5]. For example, analysis of messages submitted to online diabetes forums suggests that adolescents use these in order to obtain social support, information, advice, and shared experience [6].

Text messaging via mobile phones has become an integral component of teenage culture in many parts of the world, providing an inexpensive, portable, and widely available form of communication [7]. Over a third of US teenagers and 80% of UK teenagers reported using text messaging in national surveys published in 2005, and these figures are undoubtedly increasing [7,8]. The medium is increasingly being used to deliver health care information, reminders, and lifestyle interventions and has obvious potential to engage young people with diabetes [9].

For these reasons, we developed the “Sweet Talk” system, which delivers tailored motivational messages to young people with type 1 diabetes using text messaging. In a randomized controlled trial, this was shown to have positive effects on diabetes control, self-efficacy, and adherence, and user questionnaires indicated high patient acceptability [10]. However, understanding how such complex interventions work requires an appreciation of how they are adopted and used by their intended targets. While the Sweet Talk system was primarily designed to deliver passive “push” support to patients, its capacity to allow them to submit or reply to messages presented an opportunity to explore these issues. This paper describes an analysis of patients’ interactions with Sweet Talk that sought to inform our understanding of how users integrate such systems into their daily lives, the elements that they engage with the most, and any unexpected uses.

Methods

Description of the Sweet Talk System

Sweet Talk is a novel intervention for supporting young people with type 1 diabetes through text messaging. The intervention is informed by social cognitive theory, which states that health behaviors are influenced by self-efficacy, or the belief in one’s ability to perform actions that will influence outcomes [11], which, in turn, is influenced by goal setting and social support [12,13]. The system was designed to deliver a unique form of push support [14], in contrast to conventional support groups and websites where users have to actively access a site to read messages [15], thus favoring motivated patients and potentially enhancing health inequalities [9,16,17]. The system contains a database of text messages, including information, tips, and reminders categorized according to the main diabetes self-management tasks of insulin injections, blood glucose testing, healthy eating, and exercise. Messages are automatically scheduled based on patient profiles (age, gender, and treatment regimen) and personal diabetes self-management goals created at each clinic visit (healthy eating, exercise, insulin injections, and blood glucose testing). Such personalization appears fundamental to behavioral support interventions [18-20]. Patients receive a weekly text message reminder of their personal goal and a daily text message from the database, thus receiving either one or two messages daily. In addition, patients receive occasional text “newsletters” relating to topical issues and asking questions about their own diabetes self-management routine. They are encouraged to send in messages containing information or questions related to their diabetes self-management. Patients’ ideas and responses that are felt likely to be of general interest are forwarded anonymously to the whole group in order to develop a sense of community among the participants while avoiding the risks of unmoderated peer-to-peer networks, such as the sharing of health-harming practices and text bullying [7,21,22]. The different message types are explained further in a previous paper describing the development of the system [14]. Since Sweet Talk aims to motivate effective self-care, it may also be regarded as a type of “persuasive technology” [23]. Figure 1 represents the theoretical model of the intervention, and a screenshot of the Web-based interface is shown in Figure 2.

Figure 1. Theoretical basis of the Sweet Talk intervention

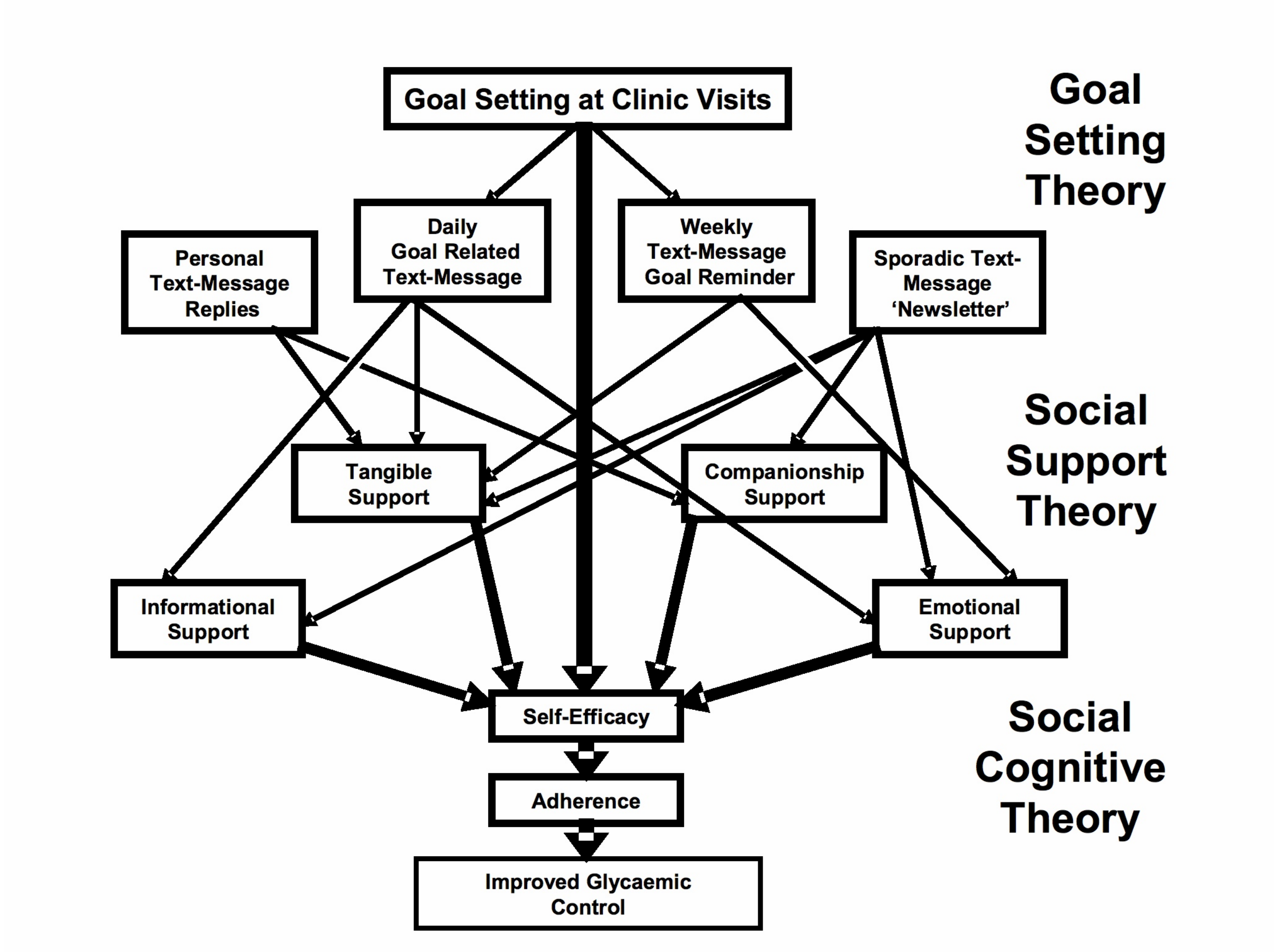


Figure 2. Screenshot of Sweet Talk

Wednesday 22 October 2003 | hi Victoria

Hi Victoria.

Welcome to sweettalk home. From here you can manage all aspects of the sweettalk project.

The trial has been running for 386 days.

In the people section you can find details about all of the patients.

You can edit and create new profiles on all your patients, manage goals, schedules, friends and family.

People profiles

You have **65** patients

You have **18** active patients (patients who have responded in the last two weeks).

There are **47** inactive patients

In the messages section you can edit and create schedules (including event messages and schedules) and goals.

The messages are associated with people in order to send them.

Messages

There are **2** scheduled messages to be sent

There are **13** newsletters waiting to be sent

In the time section you can see ALL incoming and outgoing messages. You can also see messages scheduled to be sent in the future.

Time

29288 messages have been sent

1099 messages have been received

2 messages scheduled to be sent

In the place section you can edit, create and check clinic locations and other places for which contact details are useful.

Use the scheduling function 'events' to send place related information to people.

Place

There are **6** clinic locations

Subjects and Procedures

The subjects were 64 boys and girls aged 8-18 years with type 1 diabetes participating in the intervention arms (Sweet Talk plus conventional therapy n = 33; Sweet Talk plus intensive therapy n = 31) of a three-arm clinical trial during a 12-month period between October 2002 and March 2004.

Written informed consent was obtained from patients and their families, and the study was approved by The Tayside Committee on Medical Research Ethics. Participating patients received a pay-as-you-go mobile phone and a £10 phone card, and incoming text messages to the Sweet Talk system were free of charge. Mobile phones could also be used for personal use. Patients allocated to Sweet Talk were given an information card highlighting the messages that they could expect to receive and suggestions of how they could use the system (Figure 3).

Figure 3. Sweet Talk information card

Sweet talk

support for kids with diabetes

+27 838 8911 999880

Please don't use Sweet talk for urgent stuff; ring the diabnet nurse or the kids' ward instead!

to you you'll get the following messages

ideas every day or so about your chosen goals

daily messages to help you lookafter your diabetes

reminders about birthdays or your Clinic appointments

newsletters about SweetTalk

thanks messages when you send Sweet talk an idea

answers to your SweetTalk questions

to Sweet talk you can send these sorts of messages

send in a number to record your most recent BG level.

send in a txt to ask a question

02.02.1970 anniversary mum
11.04.1973 birthday jo
Sweet talk can send you reminders of birthdays and anniversaries

friend 07896543657 jo
if you want a friend to help you, we'll send them txts about your goals.

Quantitative Methodology

All of the text messages sent to and from the Sweet Talk system were recorded over the 12 months of the study. This produced observational data on messaging patterns, which could be triangulated with patient clinical and demographic data, as well as message transcripts. Post-hoc analyses for associations between message content and demographic variables were undertaken using chi-squaretests for categorical variables and analysis of variance (ANOVA) for continuous variables.

Qualitative Methodology

Message transcripts were analyzed by VF using the constant comparative method in order to generate descriptive themes [24]. This process was facilitated by Nvivo textual analysis software (QSR International, Doncaster, Australia). AG independently analyzed 10% of the messages in order to validate the themes identified by the first rater, and inconsistencies were resolved through discussion. Further verification was achieved through team-based review of identified themes and representative raw data by VF, AG, and CP. Transcripts were then content-analyzed by VF according to these thematic categories [25].

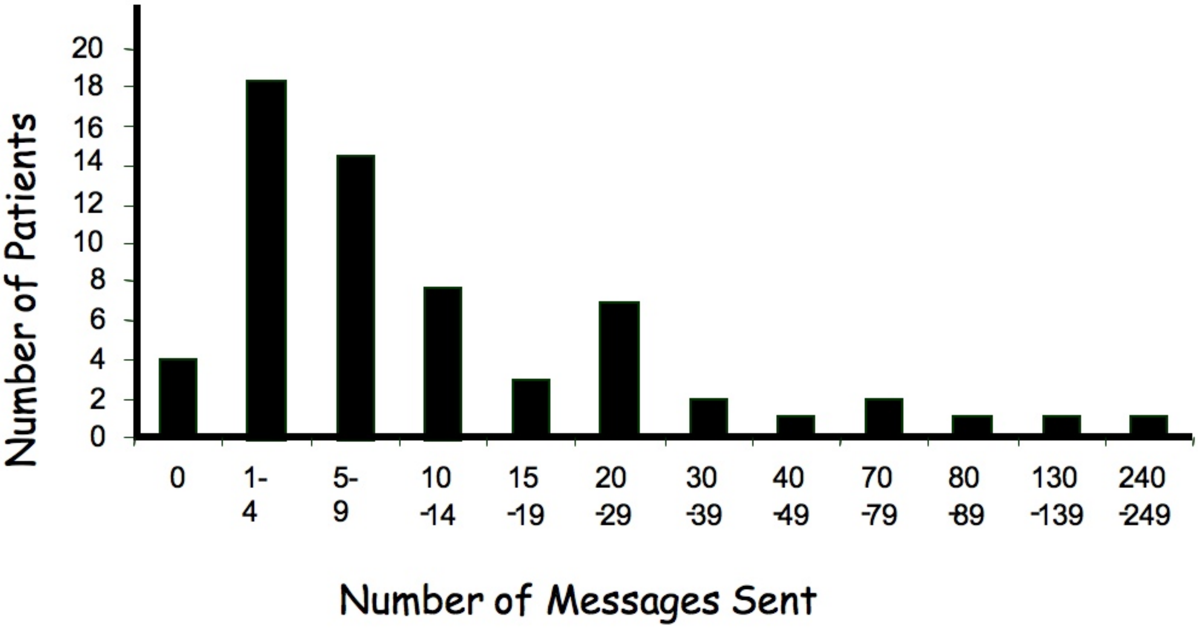
Results

Frequency of Patient Interactions With the Text Messaging Service

All but 4 of the 64 patients allocated to the Sweet Talk intervention submitted one or more text messages during the 12 months of the study. A total of 1180 messages were submitted, representing an average of 18.4 messages per patient. However, total messaging varied widely between individuals, from 0 to 240 (median 6), and the distribution was skewed by 5 patients who contributed 52% (614/1180) of the messages (Figure 4). A significant proportion of these messages were from 2 boys who sent in very regular blood glucose readings, comprising 338 of the total 1180 messages received (29%).

No participants took the opportunity to use the birthday reminder service or to nominate family or friends to receive patients' goal reminders so that they could act as personal supporters—two options offered on the information card (see Figure 3).

Figure 4. Number of messages sent to Sweet Talk during the 12-month study



Association Between Messaging and Patient Characteristics

There were no associations between the total number of messages submitted to Sweet Talk and patients' social or clinical demographics, including age, gender, duration of diabetes, insulin regimen, HbA_{1c} (glycosylated hemoglobin), or social deprivation score, all determined using ANOVA for the continuous variables and chi-square tests for the categorical variables ($P > .05$). Post-hoc analyses for associations between message content and demographic variables identified one significant association with gender: females sent significantly more messages containing information and questions unrelated to diabetes (females: mean 1.53 ± 2.51; males: 0.09 ± 0.30; $P = .002$).

Patients who had expressed positive attitudes toward Sweet Talk in a user survey [10] were no more likely to have submitted messages to the system than those who had not. Patients sending messages to Sweet Talk received a higher number of personalized responses ($r = .521$, $P = .01$).

Text Message Themes

The content of the text messages that patients sent to Sweet Talk fell into 8 broad thematic categories covering blood glucose readings, diabetes questions, diabetes information, personal health administration, social aspects, technical messages, message errors, and message responses. Illustrative text messages are shown in Table 1. The total exceeds 1180 because 77 messages were coded into more than one category.

Table 1. Main themes from patient-submitted text messages

Theme	No. (%)	Example
Blood glucose tests	418/1180 (35)	“This morning my blood was sitting at 5.7”
Diabetes questions	74/1180 (6)	“Is it ok 2 do nova rapid just before or after a lantus injection?”
Diabetes information	50/1180 (4)	“I hav managed 2 change my injection site 4 a few days now! =)”
Personal health administration	63/1180 (5)	“Could i have a onetouch ultra meter because went through the wash on holiday”
Social messages	75/1180 (6)	“I slept over at 2 friends houses.it was great,it was my first time”
Technical messages	86/1180 (7)	“Its hard 2 send txts bak 2 u cuz this fom dosnt get coverage.”
Message errors	19/1180 (2)	“Nyt Nyt Dad”
Responses to Sweet Talk messages	472/1180 (40)	“More hard coz of parties & sleepovers” (Txt in and let us know what ur doing in the holidays - do holidays make it easier or more difficult to control ur blood sugars?)”

Blood Glucose Testing

Messages containing blood glucose values accounted for 35% of all messages (418/1180). Of these, 56% (232) followed the advice to submit blood glucose values alone (see Figure 3), while the remainder incorporated these values within text. Two boys contributed to 81% of the total blood glucose text messages sent.

Diabetes Questions

Messages containing questions related to some aspect of diabetes self-management made up 6% (74/1180) of all messages. Sweet Talk appeared to provide an opportunity for obtaining information between clinic visits and to send questions that patients may have found difficult to ask in a clinical setting (eg, “Cld DiaBT’s get their belly pierced”). Text messages containing diabetes questions were further categorized into topic themes, as illustrated in Table 2.

Table 2. Examples of diabetes questions submitted by patients

Topic	No. (%)	Example
Blood glucose	16/74 (22)	“my bg's hav bin runnin a bit higher than usual for the past couple of weeks cos of exams. Any tips on how i can get them back to normal?”
Exercise	4/74 (5)	“Im finding it difficult 2 find the time 2 exercise with my exams being so near what should i do?”
Insulin	8/74(11)	“Is it ok 2 do nova rapid just before or after a lantus injection?”
Diet	7/74 (9)	“What can i have to eat when my Friends are having sweets?”
Pump	11/74 (15)	“Wen ur in the bath or shower, wot hapens if anythng gets in2 the infusion set even with the clip on?”
Carb counting	5/74 (7)	“Hi quick question. Does popcorn count as Carbs? What effectwill it hav on my bg's?”
HbA_{1c}	2/74 (3)	“Could u tell me my hb1ac result that i was tested 4 on tuesday at montrose?”
Goals	1/74 (1)	“Can you tell of my goal because i cant remember what i wrote on the sheet”
Emergency	1/74 (1)	“I got ketones…. bloods r up …. HELP!”
Other	19/74 (26)	“Cld DiaBT’s get their belly pierced”

Diabetes Information

Messages containing information about a patient’s own diabetes self-management or health status accounted for 4% (50/1180) of all messages (eg, “I hav managed 2 change my injection site 4 a few days now! =)”). Sweet Talk also provided an outlet for expressing frustration with their diabetes. One “emergency” message was received: “I got ketones bloods r up HELP.” This message was sent despite clear instructions on the information card that the Sweet Talk system was not intended for this use and that patients should continue to use our emergency help line. Telephone follow-up revealed that the patient knew this but simply wanted to know what would happen if he sent a message of this kind.

Personal Health Administration

Patients were encouraged to use the Sweet Talk system as an easy method of contacting the diabetes team with any requests. Of the total messages, 5% (59/1180) contained requests for supplies such as insulin pump consumables, blood glucose meters, and insulin travel authorization letters (eg, “Could I have new meter because it went through the wash on holiday”) and requests for information about clinic appointments (eg, “Hi, can you please tell me when my next clinic appointment is. Thank you”).

Social Messages

Messages of a social nature made up 6% (75/1180) of patients’ incoming messages. Although not directly related to diabetes, these messages provide insight into how patients integrated the system into their daily lives and its value as a source of social support (eg, “Just ate an ice-cream and done a dual wave. Off to colosseum!” and “Happy xmas 2 every1 at 9wels ”). Post-hoc analyses for associations between message content and demographic variables identified gender differences: females sent significantly more messages containing information and questions unrelated to diabetes (females: mean 1.53 ± 2.51; males: 0.09 ± 0.30; *P* = .002).

Technical Messages

Messages about technical aspects of the Sweet Talk system accounted for 7% (86/1180). Of these, most were related to difficulties with message transmission and cost of the messages (n = 55). A further 18 messages indicated problems with the content of the Sweet Talk messages, highlighting failures in message personalization or not understanding the messages (eg, “I keep getting messages about injections but I’m on the pump”).

Message Errors

Of the total messages, 19 (2%) appeared to have been sent to Sweet Talk in error (eg, “Nyt nyt Dad”).

Responses to System-Generated Messages

Messages that were sent by patients in direct response to a Sweet Talk text message made up 40% (472/1180, Table 3). Of these, the sporadic text message newsletters generated the most responses (40%, 190/472). For example, one message that asked patients what symptoms they got when their blood sugars were running high provoked responses such as “I get thirsty and a dry throat when I’m high. I also can get a bit moody.” The four newsletters that triggered the greatest flurry of responses had updates on diabetes research, raised the issue of a chocolate manufacturer offering tokens for sports equipment, and reported about a film star and a soap opera character with diabetes. The remaining messages were in response to the daily scheduled messages (30%, 142/472), personal messages (25%, 118/472), and the weekly goal reminder (5%, 22/472). There was a significant correlation between the number of messages patients sent to Sweet Talk and the number of individual response messages they received (*r* = .521, *P* = .01).

Table 3. Patient responses to Sweet Talk system messaging

Type of Message	Number of Patient Messages	System Message	Patient Message
Scheduled	142	Have u tested today?	“Yes i have been 2.9 4.5 & 5.5”
Goal reminder	22	ur goal is 2 eat less sugary things 2 get ur bloods down!	“I no i am tryin’”
Newsletter	190	Txt in and let us know what ur doing in the holidays - do holidays make it easier or more difficult to control ur blood sugars?	“More hard coz of parties & sleepovers”
Responsive mode	118	Re: question about infusion set – the cannula is self sealing, so with or without clip nothing can get in.	Question: “Wen ur in the bath or shower, wot happens if anything gets in2 the infusion set even with the clip on?” Response: “Really? That’s good, its been at the bak of my mind 4 ages!”

Discussion

Principal Findings

While the primary intended function of Sweet Talk was to deliver passive support to patients, most participants in this study took the opportunity to submit messages to the system. Analysis of these messages has provided insight into the ways users may adapt text messaging interventions to best serve their needs. Although average messaging frequency was low, there was wide variation among participants, with most messages submitted by 5 power users. No associations were found between total messaging frequency and clinical or psychosocial measures. The content of patients’ messages fell into 8 broad categories covering submission of blood glucose readings, questions about diabetes treatment or lifestyle, information about diabetes self-management, personal health administration such as supply re-ordering, social messages, technical messages, messages sent in error, and responses triggered by a scheduled Sweet Talk message. Unprompted submission of blood glucose readings was most common, followed by messages submitted in response to a system-generated message. Of the latter, those suggesting that patients share tips and frustrations about diabetes self-management generated the most responses. Diabetes news items also stimulated many responses. Females sent significantly more text messages of a social nature, unrelated to diabetes, than did males. No participants took the opportunity to nominate family or peer supporters to receive their goal messages or used the birthday reminder function.

Limitations

While the generalizability of the results is limited by the fact that only 5 users accounted for the majority of the messages, most participants interacted with the system during the study. This is consistent with observations of diabetes chat rooms, where only a minority of users post messages but the remaining lurkers read and benefit from other peoples’ messages [17,26]. In a user satisfaction questionnaire, reported separately, most participants indicated that Sweet Talk had helped them to look after their diabetes and that they wished to continue receiving messages at the end of the study period [10].

The lack of association between messaging frequency and clinical or psychosocial measures may reflect our choice of scoring systems, which were largely diabetes centered. Assessing personality measures such as neuroticism, extraversion, openness, agreeableness, and conscientiousness [27] may have revealed important associations and should be considered in future studies assessing the uptake and use of such interventions.

Implications for Practice

The formative data generated by this study have helped to further our understanding of the fit of this technology with users' needs, to challenge our pre-existing ideas about how it might support young people, and to generate ideas for refining the service.

Patients' interactions with the system suggest that many valued the opportunity to engage in reciprocal communication, although not all participants chose to take advantage of this. Patients who more frequently submitted questions to the system inevitably received more individual responses, illustrating how motivated patients may obtain more personalized services despite efforts to design equitable technology-based support interventions.

Submission of blood glucose readings was the most common type of message, supporting results of studies indicating the potential for remote disease monitoring [28]. Using Sweet Talk to request supplies and enquire about appointments also has potential to increase efficiency through avoiding the telephone tag that can occur when health professionals and patients try to communicate between clinic visits [29]. The volume of text messages sent by patients over the year of the study was low, and minimal health professional time was required for correspondence with patients. This is consistent with studies of email consulting, which did not show the expected unmanageable burden of correspondence [30].

Newsletters containing information about topical aspects of diabetes or reports about public figures with the condition may have stimulated responses through reinforcing the sense of community and boosting self-esteem through identification with respected role models. Studies of disease-specific websites and chat rooms indicate that it is the information and companionship components that are most valued by patients [17,26].

Sweet Talk appears to have provided a forum for patients to ask personal or embarrassing questions that they may have felt unable to ask at a clinic visit. This is compatible with research demonstrating the value of computer-based interventions for encouraging disclosure of sensitive information, such as mental health problems [31].

Females' greater use of the system for social messaging accords with studies of mobile phone and chat room use [6,17,32]. However, social messaging represented far fewer interactions in this study (4%) than in a previous telephone support study by our group, in which it accounted for the majority of talk time [33], possibly reflecting teenagers' preference for verbal over written communication for social interaction [8].

While ongoing parental and peer support for diabetes self-management is important for optimizing glycemic control in adolescence [34-36], none of the participants in this study took the opportunity to nominate family or friends to receive messages related to their diabetes goals, which contrasts with results in other areas such as smoking cessation [37]. This may have been due to inadequate advertisement or explanation of the concept, lack of interest, or a concern that it would place patients under unhelpful pressure. A previous study in which children's blood glucose readings were sent to a parent's mobile phone showed that while this promoted a sense of reassurance in some children, in others it generated a feeling of surveillance and reduced their sense of personal control [38].

Future Research

Our qualitative and usage data illustrate both individual differences in patients' propensity to interact with the system and the multiple potential utilities that such complex interventions may provide. Further research to explore patterns of use in different age and clinical groups would be valuable, as would studies of the personal and contextual factors influencing the adoption of such technology.

Inviting patients to join the editorial board of similar text messaging interventions will help to ensure the appropriateness of message content and delivery schedules as well as identify users' expectations for reciprocal messaging and the likely implications for practitioner time.

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Conflicts of Interest

None declared.

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Original Paper

Therapist-Assisted, Internet-Based Treatment for Panic Disorder: Can General Practitioners Achieve Comparable Patient Outcomes to Psychologists?

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Abstract

Background: Mental illness is an escalating concern worldwide. The management of disorders such as anxiety and depression largely falls to family doctors or general practitioners (GPs). However, GPs are often too time constrained and may lack the necessary training to adequately manage the needs of such patients. Evidence-based Internet interventions represent a potentially valuable resource to reduce the burden of care and the cost of managing mental health disorders within primary care settings and, at the same time, improve patient outcomes.

Objective: The present study sought to extend the efficacy of a therapist-assisted Internet treatment program for panic disorder, Panic Online, by determining whether comparable outcomes could be achieved and maintained when Panic Online was supported by either GPs or psychologists.

Methods: Via a natural groups design, 96 people with a primary diagnosis of panic disorder (with or without agoraphobia) completed the Panic Online program over 12 weeks with the therapeutic assistance of their GP (n = 53), who had received specialist training in cognitive behavioral therapy, or a clinical psychologist (n = 43). Participants completed a clinical diagnostic telephone interview, conducted by a psychologist, and a set of online questionnaires to assess panic-related symptoms at three time periods (pretreatment, posttreatment, and 6 month follow-up).

Results: Both treatments led to clinically significant improvements on measures of panic and panic-related symptomatology from pretreatment to posttreatment. Both groups were shown to significantly improve over time. Improvements for both groups were maintained at follow-up; however, the groups did differ significantly on two quality of life domains: physical ($F_{1,82} = 9.13$, $P = .00$) and environmental ($F_{1,82} = 4.41$, $P = .04$). The attrition rate was significantly higher among those being treated by their GP ($\chi^2_1 = 4.40$, $P = .02$, N = 96).

Conclusions: This study provides evidence that Internet-based interventions are an effective adjunct to existing mental health care systems. Consequently, this may facilitate and enhance the delivery of evidence-based mental health treatments to increasingly large segments of the population via primary care systems and through suitably trained health professionals.

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KEYWORDS

Panic disorder; anxiety; Internet; mental health; general practice; cognitive behavioral therapy; email

Introduction

Projections indicate that by the year 2020 mental health and neurological disorders will account for 15% of the global burden of disease [1]. Such worldwide estimates are comparable in Australia, with mental illness accounting for 13% of total disease burden [2] and 1 in 10 Australian adults reporting that they suffer from a long-term mental or behavioral problem [3].

Despite the high prevalence, up to 40% of people experiencing a mental health problem do not receive any mental health care within a given 12-month period [4]. Typically, when treatment is sought, general practitioners (GPs) are the first, and often only, point of contact [5,6], with a recent Australian national survey finding that psychological problems account for 7.8% of GP visits [7]. Seeking help from a GP confers a number of advantages over other mental health professionals, such as psychologists and psychiatrists, in that GP visits are more accessible, affordable, and less stigmatizing [8].

In an attempt to address gaps in mental health care service provision in Australia, and in recognition of the critical role GPs play in service delivery, the government has expanded the number of Medicare (Australia's universal health care system) rebate items for mental health consultations, and, in 2001, introduced the Better Outcomes in Mental Health Care (BOiMHC) initiative. The BOiMHC initiative includes educational activities and financial incentives to improve the capacity of GPs to deliver evidence-based psychological interventions such as cognitive behavioral therapy (CBT) [9]. Although the initiative has been welcomed by the health industry and consumers, difficulties in service provision remain. For example, GPs often lack the time and necessary resources and support mechanisms to deliver appropriate psychological interventions to their patients, such as clinical supervision [10]. Consequently, not all GPs and/or regional divisions of general practice choose to participate, thereby creating inequitable patient access. As such, it is important to consider alternative models of delivering effective, evidence-based therapy, particularly for use in primary care. One promising and emerging service delivery modality is the Internet.

Internet-Based Therapy

Internet-based therapy (eTherapy) typically involves the interaction between a consumer and therapist (eTherapist) via the Internet [11] and incorporates the use of a structured Web-based treatment program for consumers to access in conjunction with eTherapist assistance (usually by email) [12]. Approximately 84% of Australians have access to the Internet [13]; consequently, eTherapy programs offer a unique opportunity to deliver evidence-based mental health treatment, without the need for intensive therapist involvement, to large underserved segments of the population.

Over the past decade, Internet-based treatments have been found effective for a variety of physical health conditions and mental health disorders, such as headache [14], encopresis [15], tinnitus [16], depression [17], and posttraumatic stress symptoms [18]. Based on existing research, the psychological disorder most effectively treated via the Internet is one of the most common anxiety disorders—panic disorder.

Panic Disorder

Panic disorder affects approximately 1.3% (with agoraphobia, 2.4%) of the Australian population annually [5]. It is characterized by recurrent unexpected panic attacks and is commonly associated with other anxiety disorders [6], depression [19,20], increased risk of suicide [19], and substance and alcohol abuse [20]. Its incidence among people attending general practices has been estimated to be as high as 1 in 12 [21].

CBT is a well established and highly effective treatment for panic disorder (with or without agoraphobia) [22]. The efficacy of CBT for panic disorder appears uncompromised when patients have comorbid depression [23] and when it is transferred from controlled research settings to real-world clinical settings [24]. Although CBT is effective for people with panic disorder, it typically averages 12 hours of face-to-face treatment with a mental health specialist [25]. Furthermore, there are major barriers to accessing expert assistance, including a scarcity of skilled therapists, long waiting lists, high cost, illness symptoms, comorbid conditions, sociodemographic factors, psychological distress, and consumer fears regarding the stigma of a mental health referral [26,27]. These barriers particularly disadvantage people in regional and rural areas where travelling time and distance are an added burden [28].

Internet-based treatments largely address all of these barriers, and, indeed, panic disorder has been effectively treated via the Internet in a number of countries including Sweden [29-31] and the United Kingdom [32]. In Australia, one Internet program for panic disorder, Panic Online (PO), has been developed and extensively evaluated over the past decade.

Panic Online

Clinical trials have shown that PO, when paired with human support via email (provided by psychologist), is clinically superior to information-only control conditions or other forms of manual and telephone-based therapy [33,34]. PO has also been found to be credible and satisfying to participants [34], and outcomes are unaffected by level of education [35]. Furthermore, a recent exploratory study indicated that PO has the potential to be highly cost-effective [36]. Additionally, PO was recognized by the National Institute of Clinical Studies [37], and notably in a recent meta-analysis, it attained the largest effect size for an Internet-based treatment for a clinical mental health disorder [38].

To our knowledge, PO has not previously been trialled with professional support beyond that of a psychologist, except our own study [39]. This paper reports on the full dataset from a study for which preliminary findings from a limited dataset have been published previously [39]. Given the central role that GPs have in the health system, the aim of the present study was to extend our current understanding of PO’s efficacy by examining participant outcomes when the program is supported by a GP in a traditional face-to-face consultation in comparison to eTherapist assistance.

Methods

Participants

A total of 193 people registered for the study, and after 97 were excluded on the basis of inclusion/exclusion criteria, a total of 96 individuals ultimately commenced treatment as part of this study: 43 were recruited into the PO plus psychologist support via email (PO+P) group and 53 into the PO plus face-to-face GP (PO+GP) group.

In total, 132 BOiMHC-trained (CBT-trained) GPs registered to participate in the study, of which 37 actively referred the 53 PO+GP patients and treated participants as per the standardized protocol. Seven psychologists (6 females; 1 male) were employed as eTherapists for the PO+P group and as assessors for both groups.

Measures

This study utilized three assessment phases (pretreatment, posttreatment, and 6-month follow-up after treatment). Each assessment included a clinical interview conducted over the telephone by a psychologist and the completion of a set of self-administered questionnaires accessed via the Internet. Recent studies have shown that the majority of validated paper-and-pencil questionnaires generally retain their psychometric qualities and produce equivalent results when administered in an online format [40,41].

Anxiety Disorders Interview Schedule-IV

The Anxiety Disorders Interview Schedule-IV (ADIS-IV) is a semistructured clinical interview designed to permit differential diagnosis among anxiety and mood disorders and to screen for other major disorders (eg, substance abuse, psychosis, somatoform disorders). It includes the “number of panic attacks in the last month” (PAMTH). The ADIS-IV has good-to-excellent reliability and validity [42]. In the present study, the ADIS-IV was used to determine eligibility and participant diagnosis at each assessment phase.

Anxiety Sensitivity Profile

The Anxiety Sensitivity Profile (ASP) [43] is a 60-item questionnaire measuring the extent to which respondents are fearful that anxiety-related sensations will have harmful consequences. Respondents rate, on a 7-point Likert scale, the extent to which they agree that the sensations described would lead to a bad outcome. The ASP has high test-retest reliability [43].

Depression Anxiety Stress Scale

The Depression Anxiety Stress Scale (DASS) [44] is composed of three 14-item subscales measuring depression, anxiety, and stress. The extent to which a variety of symptoms were experienced within the prior week is rated on a 4-point Likert scale. Alpha coefficients have been reported at .91, .84, and .90 for the depression, anxiety, and stress subscales, respectively [44].

Mobility Inventory

The Mobility Inventory (MI) [45] is a measure of agoraphobic avoidance behavior, comprising 27 items. Participants indicate, on a 5-point Likert scale (1 = never avoid to 5 = always avoid), the degree to which they avoid a variety of places or situations when they are alone (MIA) and accompanied (MIB). Acceptable psychometrics have been reported for the MI [45-48].

Panic Disorder Severity Scale

The Panic Disorder Severity Scale (PDSS) [49] consists of seven items rated on a 5-point Likert scale (0 = not at all to 4 = most severe). The PDSS is designed to assess the severity of seven dimensions of panic disorder (panic attack frequency, panic attack distress, anticipatory anxiety, agoraphobia fear and avoidance, interoceptive fear and avoidance, occupational impairment/interference, and social impairment/interference) and associated symptoms. The seven items are summed to derive a total score ranging from 0-28, with higher scores reflecting greater symptom severity. The PDSS has excellent interrater reliability and good validity [49].

Treatment Credibility Scale-Modified

The Treatment Credibility Scale-Modified (TCS-M) [50] measures respondents’ attitudes to the credibility of a nominated treatment (in this study, either PO+P or PO+GP). Respondents rate five items on a 10-point scale (0 = not at all to 10 = very much) with respect to how credible they consider their allocated treatment to be after having read a brief rationale and description of the treatment. Higher scores reflect greater levels of perceived credibility.

World Health Organization Quality of Life-BREF

The World Health Organization Quality of Life-BREF (WHOQOL-BREF) [51] is a 26-item questionnaire developed from the original WHOQOL 100-item questionnaire. The WHOQOL-BREF covers four domains: physical health (eg, sleep, pain), psychological health (eg, self-esteem, concentration), social relationships (eg, social support, personal relationships), and environment (eg, physical safety, financial resources, recreation).

Procedure

Study Design

The present study employed a natural groups design open to all Australian residents who met the inclusion criteria (detailed below). Participants who were referred to the program by their GP were allocated back to their GP for treatment and were therefore in the PO+GP group. Participants who self-referred to the program (eg, found it via Web surfing, word-of-mouth) were allocated to receive PO supported by an eTherapist and were therefore in the PO+P group.

Recruitment

The study was advertised to the general public via participating GPs, Australian mental health websites, and local and national media. Study volunteers could register their interest on the PO website.

GPs were recruited in Victoria, South Australia, and New South Wales via BOiMHC-accredited training programs. Participating GPs were sent a project information package and subsequently were contacted by a research officer (either in person or via telephone) to discuss research protocols, PO program components, the manner in which PO was to be used, and the expected role of the GP and patient in the study. Additionally, regular consultative support was provided by the research officer throughout the duration of the study.

Inclusion/Exclusion Criteria

To be included in the study, participants were required to be Australian residents, have computer access, be 18 years or over, be fluent in English, have a primary diagnosis of panic disorder (with or without agoraphobia; as determined via the clinical telephone interview), and to agree not to undertake any other type of therapy for their panic disorder during the study. The request to refrain from other treatments did not cover the follow-up period. At post-assessment, all participants but one (whose data were removed from the analysis) had refrained from other treatments, as measured by self-report.

People were excluded if they reported a seizure disorder, stroke, schizophrenia, hyperthyroidism, organic brain syndrome, heart condition, or chronic hypertension as these are confounding variables with independent associations with panic attacks [52]. People were likewise excluded if they had commenced taking medication in the previous 12 weeks or were not stabilized on their medication dose since this has the potential to confound any treatment effects found for PO.

Assessment

Study registrants were contacted by a psychologist who conducted a screening interview to determine whether they met the exclusionary criteria. When exclusionary criteria were met, volunteers were advised of the reason they could not participate and were referred to alternative services as appropriate. When exclusionary criteria were not met, an explanatory statement and consent form were emailed. Upon return of consent, a full clinical diagnostic assessment was conducted via telephone using the ADIS-IV, which took, on average, 90 minutes. Our interrater reliability for this procedure was .93. Following this, participants completed a set of online questionnaires. Upon assessment completion, participants were emailed a username and password with instructions on accessing the PO program. Posttreatment and follow-up assessments (clinical telephone interview and online questionnaires) were conducted at the end of week 12 and 6 months later. Psychologists did not provide therapy for any participant they assessed.

The Panic Online Program

PO is a 12-week eTherapy program consisting of an introductory module, four learning modules, and a relapse prevention module. The program includes treatment methods commonly used in standard CBT for panic disorder, including instructions for controlled breathing, progressive muscle relaxation, cognitive restructuring, and interoceptive and situational exposure. Downloadable audio of isometric and progressive muscle relaxation and sequential photographic slide shows for two graduated exposure in vivo exercises (going to the supermarket and driving a car) were provided. An adjunct stress management program was also available to all participants (see Richards et al [34]). Information and guidance throughout the program were standardized across participants.

Panic Online With Psychologists (PO+P)

Communication between participants and psychologists occurred via email. No limitations were placed on email frequency; however, the assigned eTherapist was instructed to initiate contact if he or she had not received communication from a participant for approximately 1-2 weeks. On average, per participant, eTherapists sent 15.29 emails (SD 9.26; n = 31) and spent 378.62 minutes (SD 264.43; n = 29) emailing participants throughout the 12-week treatment. On average, each eTherapist provided support to 7.17 (range 2-19) participants.

Panic Online With General Practitioners (PO+GP)

Following assessment by a psychologist, participants allocated to the PO+GP condition were asked to make an appointment with their GP for their first PO consultation. The GP was then informed by the assessor that the patient could commence treatment. GPs and participants were encouraged to consult regularly (approximately once per week) throughout the treatment duration, while participants were using PO between consultations. On average, participants saw their GP (in a face-to-face consultation) 7.14 times (n = 31) throughout the 12-week treatment.

Statistical Methods

An independent groups *t* test was conducted to assess treatment credibility. Three repeated measures multivariate analysis of variance (MANOVA), an analysis of covariance (ANCOVA), and an independent groups *t* test were performed to analyze data from this study. MANOVA was conducted to reduce the possibility of type II errors. The first repeated measures MANOVA examined panic symptoms and included the following: clinician-rated panic disorder and agoraphobia severity (as indicated by the ADIS-IV), PAMTH, ASP, and PDSS scores. The second MANOVA examined negative affect and included the three DASS subscales of depression, anxiety, and stress. The final MANOVA examined quality of life and included three of the four WHOQOL-BREF domains (physical, social, and environmental). Lastly, an ANCOVA was conducted to analyze the WHOQOL-BREF psychological domain using the pretreatment assessment score as the covariate. This was analyzed separately as there was a significant difference in the pre-assessment treatment scores between the two groups.

Results

Participant Characteristics

In addition to their primary diagnosis of panic disorder, 75 participants were also assessed with clinical levels of agoraphobia (30 in the PO+P group and 45 in the PO+GP group). See Table 1 for a summary of participant characteristics. At pretreatment assessment, 52% of participants were taking medication (19 in the PO+P group and 31 in the PO+GP group). Table 2 provides a breakdown of medication frequencies at pretreatment assessment. Over half of the sample (n = 56) received a secondary clinical diagnosis at pretreatment assessment. Table 3 provides a breakdown of the frequencies of clinically significant comorbid conditions at pretreatment.

Table 1. Characteristics of participants at pretreatment assessment, by group

	PO+P			PO+GP			Total		
Characteristic	No.	Mean	SD	No.	Mean	SD	No.	Mean	SD
Age (years)		43.5	12.4		38.7	10.9		40.9	11.8
Education (years)		12.7	2.8		12.9	2.8		12.8	2.8
Gender									
Male	10			10			20		
Female	33			43			76		
Medication									
Yes	19			31			50		
No	24			22			46		
Primary diagnosis									
Panic disorder	13			8			21		
Panic disorder with agoraphobia	30			45			75		
Clinically comorbid condition at pretreatment assessment									
Yes	22			34			56		
No	21			19			40		
Previous mental health treatment (inpatient/outpatient)									
Yes	20			29			49		
No	23			24			47		

Table 2. Medication frequencies at pretreatment assessment, by group

Drug Class*	PO+P	PO+GP	Total
SSRI	1	14	15
Benzodiazepine	9	4	13
SNRI	5	2	7
SSRI + Benzodiazepine	2	4	6
Tricyclic antidepressant	1	2	3
Tricyclic antidepressant + SSRI	1	–	1
SSRI + SNRI	–	1	1
Benzodiazepine + SSRI + Antipsychotic	–	1	1
SSRI + Antipsychotic	–	1	1
RIMA + Benzodiazepine	–	1	1
Anticonvulsant + Benzodiazepine + Antipsychotic	–	1	1
Total	19	31	50

*SSRI, selective serotonin reuptake inhibitor; SNRI, selective noradrenaline reuptake inhibitor; RIMA, reversible inhibitor of monoamine oxidase type A

Table 3. Clinical comorbid condition frequencies at pretreatment assessment, by group*

Disorder	PO+P	PO+GP	Total
Generalized anxiety disorder	5	17	22
Depression	9	13	22
Social anxiety disorder	5	15	20
Specific disorder	9	9	18
Dysthymia	4	9	13
Posttraumatic stress disorder	1	6	7
Hypochondriasis	2	4	6
Obsessive compulsive disorder	–	4	4
Alcohol dependence	1	2	3
Substance abuse	–	1	1

*Some participants were assessed as having multiple clinical comorbid conditions.

Attrition

Attrition was defined as participants who withdrew, for reasons either known or unknown, from the research trial. The overall attrition rate for this study was 42.7% (41/96): 37.2% (16/43) and 47.2% (25/53) for the PO+P and PO+GP groups, respectively. This difference was not significant (χ^2_1 = .60, *P* = .41, N = 96). Attrition from the treatment and follow-up phase was also examined separately. Overall attrition from pretreatment to posttreatment was 28.1% (27/96), with 16.3% (7/43) dropping out of the PO+P group and 37.7% (20/53) from the PO+GP group. Fisher exact test revealed that significantly more participants in the PO+GP group dropped out of the treatment (χ^2_1 = 4.40, *P* = .02, N = 96). A further 14 participants (14.6%) were lost from the study between posttreatment and follow-up assessment. The overall attrition rate from posttreatment to follow-up by condition was 20.9% (9/43) for the PO+P group and 9.4% (5/53) for the PO+GP group; this difference was not significant (χ^2_1 = 1.68, *P* = .15, N = 96). Table 4 provides reasons for attrition.

Table 4. Reasons for attrition, by group

Reason	PO+P	PO+GP	Total
Unknown	9	9	18
Lost contact	1	4	5
Commencing face-to-face counselling	1	2	3
Computer problems	1	2	3
Personal issues (nonspecific)	2	1	3
GP difficulties		2	2
Cured		1	1
Health problem	1		1
Housing crisis	1		1
Language difficulties		1	1
Moved state		1	1
Personal issues (mental health)		1	1
Pregnancy		1	1
Total	16	25	41

Data Properties and Treatment

This study utilized intention-to-treat analyses. That is, pretreatment assessment scores for participants discontinuing their involvement during treatment were carried forward and used in both the posttreatment and follow-up assessments (11 for the PO+P group; 21 for the PO+GP group). Fisher exact test revealed no difference between the groups (χ^2_1 = 1.52, *P* = .19, N = 96). A further 16 PO+P and 13 PO+GP posttreatment assessment scores were carried forward and used in the follow-up assessment. The difference was not significant (χ^2_1 = 1.26, *P* = .19, N = 96).

Nonnormally distributed dependent variables were transformed to satisfy normality assumptions. The DASS depression subscale and the MIA required a square root transformation, and PAMTH required a logarithmic transformation.

One-way analysis of variance (ANOVA) tests were conducted on all measures to test for pretreatment differences between groups. A significant pretreatment difference was found in the WHOQOL-BREF psychological domain, with the PO+P group reporting greater quality of life for this domain in comparison to the PO+GP group (Table 5 and Table 6). However, no differences were found between the treatment groups for any other measure (see Table 5). Furthermore, no significant pretreatment assessment differences were detected for age ($F_{1,94}$ = 4.09, P = .05), gender (χ^2_1 = .08, P = .62, N = 96), agoraphobia (χ^2_1 = 2.36, P = .09, N = 96), medication use (χ^2_1 = 1.42, P = .22, N = 96), presence of clinically significant comorbid condition (χ^2_1 = 1.16, P = .22, N = 96), years of education ($F_{1,81}$ = .10, P = .75), or previous inpatient or outpatient treatment for a mental health condition (χ^2_1 = .35, P = .54, N = 96).

Results of evaluation of normality assumptions, homogeneity of variance-covariance matrices, and linearity were satisfactory. Additionally, Bartlett's test of sphericity was conducted to confirm that the dependent variables in the MANOVA groupings were correlated at the $P < .05$ level. A multivariate outlier was detected in the panic symptoms MANOVA grouping and was subsequently removed due to its impact on the mean.

Table 5. *F* ratios and *P* values from pretreatment assessment ANOVA

Variable*	*F*	*P*
DASS depression	$2.52_{1,89}$	.12
DASS anxiety	$0.72_{1,89}$	.40
DASS stress	$1.60_{1,89}$	.21
WHOQOL-BREF physical	$3.61_{1,87}$	.06
WHOQOL-BREF psychological	$6.09_{1,87}$	.02
WHOQOL-BREF social	$1.94_{1,87}$	.17
WHOQOL-BREF environmental	$2.73_{1,87}$	.10
MIA	$0.41_{1,84}$	.53
MIB	$0.31_{1,83}$	.58
PAMTH	$0.38_{1,94}$	.54
ASP	$0.03_{1,88}$	.86
PDSS	$1.75_{1,86}$	.19

*DASS, Depression Anxiety Stress Scale; WHOQOL-BREF, World Health Organization Quality of Life-BREF; MIA, Mobility Inventory alone; MIB, Mobility Inventory accompanied; PAMTH, panic attacks in the last month; ASP, Anxiety Sensitivity Profile; PDSS, Panic Disorder Severity Scale.

Treatment Outcomes

Treatment Credibility

An independent samples *t* test revealed no significant differences between the groups for perceived treatment credibility prior to treatment (t_{82} = 1.96, P = .05).

Panic Symptoms

For the panic symptoms grouping, repeated measures MANOVA revealed no significant interaction between time (pre, post, follow-up) and group (PO+P, PO+GP) or group main effect. However, a significant main effect for time was found from pretreatment to posttreatment assessment. Examination of the univariate tests for time and associated means revealed a significant decrease on all seven measures. Means and standard deviations are presented in Table 6, multivariate results in Table 7, and univariate results in Table 8.

Table 6. Means and standard deviations for treatment outcome measures at pretreatment, posttreatment, and follow-up treatment assessments, by group

	PO+P			PO+GP		
Variable*	No.	Mean	SD	No.	Mean	SD
Clinician panic disorder rating						
Pre	43	6.17	1.25	53	6.29	1.29
Post	43	3.43	2.03	53	4.29	2.30
Follow-up	43	3.02	2.42	53	3.84	2.65
Clinician agoraphobia rating						
Pre	43	4.07	2.80	53	5.13	2.35
Post	43	2.16	2.22	53	3.65	2.52
Follow-up	43	2.40	2.34	53	3.40	2.69
PAMTH						
Pre	43	6.33	7.99	53	9.85	14.83
Post	42	2.67	5.48	53	4.27	8.12
Follow-up	42	1.86	2.98	53	4.35	7.93
PDSS						
Pre	38	14.62	4.40	50	16.05	5.45
Post	38	9.71	5.65	52	12.00	6.24
Follow-up	38	9.59	5.96	50	11.73	6.36
ASP						
Pre	39	3.45	1.31	51	3.40	1.42
Post	41	1.88	1.64	51	2.58	1.62
Follow-up	41	1.83	1.61	52	2.50	1.59
MIA						
Pre	41	2.15	.93	45	2.26	.88
Post	39	1.78	.87	40	2.11	.91
Follow-up	37	1.76	.88	44	2.03	.87
MIB						
Pre	41	2.55	1.09	44	2.67	.95
Post	39	2.14	1.08	42	2.36	.95
Follow-up	37	2.16	1.12	45	2.34	.93
DASS depression						
Pre	41	12.24	9.83	50	16.45	12.86
Post	40	7.15	9.76	51	13.52	12.90
Follow-up	41	7.24	9.48	50	12.33	12.54
DASS anxiety						
Pre	41	17.46	10.10	50	19.24	9.80
Post	40	10.28	10.73	51	14.56	10.60
Follow-up	41	10.23	10.33	50	13.64	10.43
DASS stress						
Pre	41	19.26	10.35	50	21.98	10.06
Post	40	12.23	10.84	51	17.24	11.79
Follow-up	41	12.59	10.97	50	16.24	11.51
WHOQOL-BREF physical						

Variable[*]	PO+P No.	PO+P Mean	PO+P SD	PO+GP No.	PO+GP Mean	PO+GP SD
Pre	40	59.05	16.81	49	51.59	19.60
Post	37	69.53	13.85	50	58.54	21.13
Follow-up	38	70.43	14.08	48	57.92	20.94
WHOQOL-BREF psychological						
Pre	40	50.48	18.05	49	41.07	17.76
Post	37	60.47	17.94	50	49.83	18.48
Follow-up	38	60.96	17.45	48	48.83	19.75
WHOQOL-BREF social						
Pre	40	55.00	25.09	49	47.19	27.21
Post	37	61.49	22.85	50	52.17	27.12
Follow-up	38	61.18	22.87	48	50.61	27.64
WHOQOL-BREF environment						
Pre	40	63.38	16.92	49	57.65	15.76
Post	37	67.00	15.01	50	60.58	15.76
Follow-up	38	67.62	15.76	48	60.44	15.27
Treatment credibility						
Pre	39	40.59	7.57	45	37.47	7.02

[*] PAMTH, panic attacks in the last month; PDSS, Panic Disorder Severity Scale; ASP = Anxiety Sensitivity Profile; MIA, Mobility Inventory alone; MIB, Mobility Inventory accompanied; DASS, Depression Anxiety Stress Scale; WHOQOL-BREF, World Health Organization Quality of Life-BREF.

Table 7. Effects from the repeated measures MANOVA and ANCOVA analysis between groups*

	Time Effect				Group Effect				Treatment × Time			
Variable	F	*P*	Partial η^2	β − 1	F	*P*	Partial η^2	β − 1	F	*P*	Partial η^2	β − 1
Panic symptoms												
Post	$10.28_{7,52}$	.00	.58	1.00	$1.65_{7,52}$	.14	.18	.62	$1.16_{7,52}$	.35	.14	.45
Follow-up	$2.16_{7,58}$	.05	.21	.77	$.90_{7,58}$	.52	.10	.35	$.87_{7,58}$	.53	.10	.34
Negative affect												
Post	$18.04_{3,86}$	.00	.39	1.0	$1.69_{3,86}$	.48	.06	.42	$.80_{3,86}$	.50	.03	.22
Follow-up	$.53_{3,86}$	.66	.02	.16	$.53_{3,86}$	.10	.07	.52	$1.15_{3,86}$	.33	.04	.30
Quality of life												
Post	$15.40_{3,82}$	.00	.36	1.00	$1.95_{3,82}$	.13	.07	.49	$.98_{3,82}$	.41	.04	.26
Follow-up	$.58_{3,80}$	.63	.02	.17	$2.97_{3,80}$	.04	.10	.68	$.01_{3,80}$	1.00	.00	.05
WHOQOL-BREF psychological												
Post					$2.16_{1,83}$	.15	.03	.31				
Follow-up	$.00_{1,80}$	.95	.00	.05	$2.89_{1,80}$	.09	.04	.39	$.23_{1,80}$	.63	.23	.08

[*] Panic symptoms MANOVA includes clinician-rated panic disorder and agoraphobia severity, PDSS, and PAMTH; negative affect MANOVA includes DASS subscales of depression, anxiety, and stress; quality of life MANOVA includes WHOQOL-BREF physical, social, and environmental domains.

Table 8. Effects from univariate tests

Variable	Time Effect				Group Effect			
	F	*P*	Partial η^2	$\beta - 1$	F	*P*	Partial η^2	$\beta - 1$
Pretreatment to Posttreatment								
Panic disorder	$69.49_{1,58}$	.00	.55	1.00				
PAMTH	$29.91_{1,58}$	.00	.34	1.00				
ASP	$35.37_{1,58}$	.00	.46	1.00				
PDSS	$50.14_{1,58}$	.00	.46	1.00				
Agoraphobia	$37.23_{1,58}$	.00	.39	1.00				
MIA	$15.16_{1,58}$	.00	.21	.97				
MIB	$21.79_{1,58}$	.00	.27	1.00				
DASS depression	$41.18_{1,88}$	.00	.32	1.00				
DASS anxiety	$47.98_{1,88}$	.00	.35	1.00				
DASS stress	$44.66_{1,88}$	.00	.34	1.00				
WHOQOL-BREF physical	$45.91_{1,84}$	.00	.35	1.00				
WHOQOL-BREF social	$9.98_{1,84}$	.00	.11	.88				
WHOQOL-BREF environmental	$12.07_{1,84}$	.00	.13	.93				
Posttreatment to Follow-Up								
WHOQOL-BREF physical					$9.13_{1,82}$	.00	1.00	.85
WHOQOL-BREF environmental					$4.41_{1,82}$	.04	.05	.55

[*] PAMTH, panic attacks in the last month; ASP, Anxiety Sensitivity Profile; PDSS, Panic Disorder Severity Scale; MIA, Mobility Inventory alone; MIB, Mobility Inventory accompanied; DASS, Depression Anxiety Stress Scale; WHOQOL-BREF, World Health Organization Quality of Life-BREF.

Negative Affect

For the negative affect grouping, repeated measures MANOVA revealed no significant interaction between time and group or group main effect. However, a significant main effect for time was found from pretreatment to post treatment assessment (see Table 7). Examination of the univariate tests for time (see Table 8) and associated means (see Table 6) revealed a significant decrease on all three DASS subscales.

Quality of Life

For the quality of life grouping, repeated measures MANOVA revealed no significant interaction between time and group. However, a significant main effect for time from pretreatment to posttreatment assessment and a significant main effect for group from posttreatment to follow-up assessment were found (see Table 7). Examination of the univariate tests for time (see Table 8) and associated means (see Table 6) revealed a significant positive change on all three domains from pretreatment to posttreatment. Examination of the univariate between-subject effects from posttreatment to follow-up revealed a significant difference between the groups for the WHOQOL-BREF physical and environmental domains. The mean scores for both domains (see Table 6) showed that the PO+P group experienced a slight improvement, whereas the PO+GP group showed a slight decrease from posttreatment to follow-up.

WHOQOL-BREF (Psychological)

An ANCOVA was conducted on the psychological domain of the WHOQOL-BREF from pretreatment to posttreatment and posttreatment to follow-up. No significant differences were detected (see Table 7).

Panic-Free Status and High-End State Functioning

Panic-free status and high-end state functioning were examined at posttreatment and follow-up assessment. Panic-free status was defined as zero panic attacks reported during the month immediately prior to the assessment. At posttreatment assessment, panic-free status was achieved by 52.4% (22/42) of the PO+P group and 50.9% (27/53) of the PO+GP group; this difference was not significant ($\chi^2_1 = .00$, $P = 1.00$, N = 95). At follow-up, 52.4% (22/42) of the PO+P group and 47.2% (25/53) of the PO+GP group were panic free, but this difference was also not significant ($\chi^2_1 = .09$, $P = .68$, N = 95).

High-end state functioning was defined as being panic free and having a clinician-rated panic disorder score ≤ 2. At posttreatment assessment, 28.6% (12/42) of the PO+P group and 26.4% (14/53) of the PO+GP group achieved high-end state functioning, but this difference was not statistically significant

(χ^2_1 = .00, *P* = .82, N = 95). At follow-up, 47.6% (20/42) of the PO+P group and 32.1% (17/53) of the PO+GP group achieved high-end state functioning, but again, the difference was not significant (χ^2_1 = 1.77, *P* = .14, N = 95). However, for the PO+P group, the increase in high-end state functioning from posttreatment to follow-up was significant (t_{41} = −2.44, *P* = .02).

Discussion

The purpose of the current study was to investigate whether the established efficacy of PO was affected by changing the form of therapist assistance from email support provided by psychologists (eTherapists) to face-to-face support provided by GPs, and, further, whether treatment improvements were maintained. The results of this study support findings from several previous studies examining Internet programs in primary care [53,54] and demonstrate that evidence-based eTherapy programs could be a valuable tool for GPs managing patients with mental health conditions.

The recommended treatment for panic disorder includes CBT, medication (antidepressants and/or benzodiazepines), or a combination of both [55]. However, there are difficulties associated with each form of treatment. Barriers such as accessibility, waiting lists, cost, and stigma inhibit access to CBT experts [26,27], and use of pharmacotherapy is often complicated by side effects, compliance, and other health considerations [56]. Furthermore, medication use in comparison to CBT treatment does not appear to result in sustained recovery beyond discontinuation [56,57]. Consequently, investigating other methods of delivering cost-effective and clinically effective treatment is important to address the growth of mental health disorders both in general practice and the wider community.

In this study, PO (whether supported by eTherapists or face-to-face GPs) led to significant improvements in panic attack frequency, depression, anxiety, stress, anxiety sensitivity, agoraphobia avoidance, and quality of life. Improvements were maintained at follow-up, with the only significant differences occurring on the WHOQOL-BREF physical and environmental domains. It is beyond the capacity of this study to ascertain definitively why the groups differed on these particular measures. It is possible to speculate, however, that the different dissemination processes (email vs face-to-face) created disparate learning experiences between the groups, resulting in the PO treatment information being used and retained in different manners. Further, while the groups did not significantly differ on any pretreatment assessment sociodemographic measure, the PO+GP group did have a higher degree of comorbidity and proportion of participants on medication. Consequently, it is possible that this study inherently measured two different cohorts.

Surprisingly, attrition from treatment was significantly higher for the PO+GP group. A number of possible reasons can be hypothesized. First, there was variation in the level of support throughout the duration of the trial. While participants in the PO+GP group were encouraged to regularly access their GP throughout treatment, this was not a requirement, and GP visitations could not be reasonably regulated within this study. By contrast, participants in the PO+P group were able to email their therapist as often as they wished, and their therapist was required to respond within 24 hours. Second, greater effort and planning are required to attend a medical practice in comparison to writing an email. Consequently, participants in the PO+P group may have experienced a greater level of continuous support and encouragement to adhere to the treatment. It is also worth noting that while treatment credibility was not significantly different between the groups, it did near significance, with the PO+P treatment appearing to be viewed more favorably than the PO+GP treatment. Finally, it is not known whether the content of GP visits focused specifically on panic disorder or incorporated consultation on other unrelated ailments. However, in comparison to other Internet-based studies [14,16], attrition overall in this study was relatively low.

It is noteworthy that the proportion of participants achieving high-end state functioning in both groups continued to increase from posttreatment to follow-up and that for the PO+P group, the increase was significant. These results not only support the durability of PO to maintain treatment outcomes but also indicate that it has the capacity to continue to have benefits beyond treatment completion.

Limitations

There are several methodological issues and limitations to note. The primary limitation of this study was that it used a nonrandomized, natural groups design. Consequently, we can not speak to the direct comparability of these two treatments, and it is possible that the groups differed in ways not considered within this study. It should also be mentioned that all participating GPs were trained in delivering CBT. It is unknown whether non-CBT-trained GPs would achieve similar outcomes. This issue would benefit from further investigation as the accessibility to the program would be increased substantially if the evidence base indicated that all GPs were able to effectively support patients using the program. As discussed earlier, the treatments differed in terms of the supportive communication modality employed. This factor may have affected attrition and was not investigated. A final issue relates to PO access. Unfortunately, participant usage statistics (eg, number of times accessed PO, duration of time spent on PO) were not available. Consequently, it is possible that one group may have spent a proportionally greater period of time accessing and/or reading the PO material and therefore achieved and sustained greater benefits.

Implications

A number of implications for policy and practice can be derived from this study. While it is anticipated that there might be reluctance to adopt eTherapy into general practice [58], this study has demonstrated the capacity of evidence-based programs, such as PO, to aid GPs in the management of mental health disorders, such as panic disorder, and achieve sustained outcomes, making them an invaluable tool. However, at present, there is no specific Medicare and/or private health insurance rebates on such services. Furthermore, there is need for appropriate educational and financial support within primary care to integrate these programs within existing public health systems.

Conclusions

This study demonstrates that when panic disorder sufferers are provided with accessible online treatment protocols, CBT-skilled GPs can achieve sustained patient outcomes comparable to best-practice treatments delivered by psychologists. Further research will be required to evaluate Internet-based programs for other mental health conditions and with non-CBT-trained GPs. Nevertheless, this study provides strong evidence that the use of Internet-based programs is an effective adjunct to existing mental health care services and may enable the delivery of evidence-based treatments to increasingly large numbers of patients via primary care with the support of suitably trained health professionals.

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Conflicts of Interest

None declared.

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Abbreviations

ASP: Anxiety Sensitivity Profile
BOiMHC: Better Outcomes in Mental Health Care
CBT: cognitive behavioral therapy
DASS: Depression Anxiety Stress Scale
GP: general practitioner
MIA: Mobility Inventory alone

MIB: Mobility Inventory accompanied
PAMTH: panic attacks in the last month
PDSS: Panic Disorder Severity Scale
PO: Panic Online
WHOQOL-BREF: World Health Organization Quality of Life-BREF

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Original Paper

Evaluation of Internet-Based Technology for Supporting Self-Care: Problems Encountered by Patients and Caregivers When Using Self-Care Applications

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Abstract

Background: Prior studies have shown that many patients are interested in Internet-based technology that enables them to control their own care. As a result, innovative eHealth services are evolving rapidly, including self-assessment tools and secure patient-caregiver email communication. It is interesting to explore how these technologies can be used for supporting self-care.

Objective: The aim of this study was to determine user-centered criteria for successful application of Internet-based technology used in primary care for supporting self-care.

Methods: We conducted scenario-based tests combined with in-depth interviews among 14 caregivers and 14 patients/consumers to describe the use of various self-care applications and the accompanying user problems. We focused on the user-friendliness of the applications, the quality of care provided by the applications, and the implementation of the applications in practice.

Results: Problems with the user-friendliness of the self-care applications concerned inadequate navigation structures and search options and lack of feedback features. Patients want to retrieve health information with as little effort as possible; however, the navigation and search functionalities of the applications appeared incapable of handling patients' health complaints efficiently. Among caregivers, the lack of feedback and documentation possibilities caused inconvenience. Caregivers wanted to know how patients acted on their advice, but the applications did not offer an adequate feedback feature. Quality of care problems were mainly related to insufficient tailoring of information to patients' needs and to efficiency problems. Patients expected personalized advice to control their state of health, but the applications failed to deliver this. Language (semantics) also appeared as an obstacle to providing appropriate and useful self-care advice. Caregivers doubted the reliability of the computer-generated information and the efficiency and effectiveness of secure email consultation. Legal or ethical issues with respect to possible misuse of email consultation also caused concerns. Implementation problems were mainly experienced by caregivers due to unclear policy on email consultation and the lack of training for email consultations.

Conclusions: Patients' and caregivers' expectations did not correspond with their experiences of the use of the Internet-based applications for self-care. Patients thought that the applications would support them in solving their health problems. Caregivers were more reserved about the applications because of medico-legal concerns about misuse. However, the applications failed to support self-care because eHealth is more than just a technological intervention. The design of the applications should include a way of thinking about how to deliver health care with the aid of technology. The most powerful application for self-care was secure email consultation, combined with a suitable triage mechanism to empower patients' self-awareness. Future research should focus on the effectiveness of such Web-based triage mechanisms for medical complaints and on the development of interactive features to enhance patients' self-care.

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KEYWORDS

Internet; technology; primary care; access to information; electronic patient-provider communication; self-care

Introduction

Internet-based technology has become increasingly important for promoting access to care and self-care management [1-3]. Particularly, systems that combine high-quality information with interactive components for self-assessment, decision support, or behavior change have the potential to reduce costs while maintaining the same or achieving better quality of care [2,4]. This means that technology can respond to an increasing demand for care in the aging society.

What has become widely accepted is the value of Internet-based technology to deliver health care irrespective of time and place, and the enhanced access to care for people from underserved areas [1,3]. Notwithstanding the better services, a relevant question is whether these Internet-based applications can support patients or consumers in controlling their own health behavior, and secondly, whether they can facilitate the quality of health care.

Recognizing that patients are interested in managing their own health, the industry is exploring ways of encouraging them to be more in control of their own health and health care [5]. Initially, health care innovations were mainly market-driven products delivering information that may not benefit patients. Currently, innovative Web-based technologies in health care that have interactive components, such as an “ask the doctor service” (via secure email consultation) [1] and self-tests, are evolving rapidly [6]. The use of the Internet is no longer restricted to information retrieval but enables patients to manage their own health proficiently and at their own convenience by means of such interactive components for self-care.

When self-care is the focus of Internet-based technology, we need to evaluate more thoroughly what people can do with the self-care applications. How do they evaluate their own health condition with self-assessment tools, what do they feel and think while communicating with a system about their ailment, and what do they expect from computer-generated self-care advice? A qualitative evaluation study is thus needed to achieve insight into the process of consulting Internet-based applications for medical support and to determine which health care functions can be delegated to Internet-based health care systems [2].

To date, evaluations that take user perspectives into account as well as the appropriateness and meaningfulness of interactive components to support self-care are scarce [2,7]. The aim of this study was to determine user-centered criteria for successful application of Internet-based technology for supporting self-care. To this end, we evaluated the use of three Internet-based applications in primary care that have various features for self-care (eg, self-test, digital triage) and electronic patient-caregiver communication (free text or question-and-answer form).

In wanting to observe the contribution of various interactive components to support self-care, we focused on the user-friendliness of the applications [2,3,8,9], the quality of care provided by the applications [2,10], and the implementation of the applications in practice [11].

Methods

Description of Internet-Based Applications for Self-Care

We evaluated three commonly used Internet-based primary care applications in the Netherlands: Medicinfo (M) [12], Praktijkinfo (P) [13], and Dokterdokter (D) [14]. These certified applications are based on ISO 9000:2000 standards [15] and use encrypted software for secure exchange of information. Users have to log on with a user ID and password. Patients have free access to all three applications.

The applications have multiple components for self-care so as to appeal to a wide range of users, thus underlining that patients will differ in their needs for self-care. In all three applications, patients can search for self-care information about their health complaint by means of a digital medical encyclopedia with alphabetically ordered lists or online health brochures. Two applications, M and D, provide self-care tools that can be used for various purposes: obtaining information about the possible causes of a health complaint, and checking the necessity of a doctor’s visit and getting (self-care) advice for nonurgent health complaints.

For the first purpose, application M provides a so-called Symptom Scan. This self-test consists of a questionnaire about specific health symptoms and generates a bar chart showing the probabilities of medical causes for a certain disease or injury.

For the second purpose, M and D provide a digital triage function that consists of a symptom-driven question-and-answer system for filtering urgent complaints and for providing fully automated diagnosis and advice. The digital triage is intended to prevent unnecessary visits to the doctor. Patients have to label their health complaint either on alphabetically ordered lists (M) or on a virtual body (D). Subsequently, they have to run through the questions and answers related to the identified problem. In the event of urgent symptoms, the triage application generates advice to visit a doctor. In the event of nonurgent issues, it generates tailored self-care advice.

All three applications offer the possibility of secure email communication between patient and caregiver. The P and D applications provide online encounters between patient and general practitioner (GP) but require a pre-existing relationship. Patients of M can consult 28 specific health experts anonymously. With M and P, patients can consult a caregiver in their own words (free text). With D, patients first have to run through a question-and-answer system (digital triage) before being able to pose their question in their own words. Questions have to be answered within 24 hours, and caregivers receive a reimbursement for each Web consultation.

Recruitment of Participants

Fourteen caregivers participated in this study, including GPs, physicians specializing in communicable diseases, and a psychologist. All caregivers were current users of one of the Internet-based care applications. Participating caregivers were recruited by email by the systems' providers and used their practice website and email to recruit patients. A total of 14 patients agreed to participate. Eligible patients were at least 18 years old, Dutch speaking, and had experience with using one of the Internet-based applications.

Scenario-Based Tests Combined With In-Depth Interviews

We used scenario-based tests combined with in-depth interviews to describe the use of the Internet-based applications and the accompanying user problems. Trained observers watched users communicating with the interface of the application while doing simulated tasks and thinking aloud [16]. The test consisted of six "what if" scenarios (see Multimedia Appendix) representing health complaints related to self-limiting diseases. All scenarios were tested by physicians. Patients were instructed to read a scenario out loud and to imagine that they were in the situation described. Caregivers, on the other hand, were instructed to answer patients' questions. The participants' activities were recorded with audio-visual equipment. The tests were carried out at the participants' home or workplace. Each test lasted about 90 minutes.

Data Analyses

Two researchers independently identified user problems from the verbal reports of the scenario-based tests. Repeated or reworded descriptions of the same problem were only counted once. Agreement on categorization of the problems was high [17], both for the patient problems (Cohen's kappa = 0.95) and the caregiver problems (Cohen's kappa = 0.87). In the event of disagreement, researchers discussed the categorization of the problems in order to reach consensus. All of the 358 identified user problems were categorized as quality demands for supporting self-care by technology [10]:

1. Problems with user-friendliness: referring to technical and design features (presentation of information) that are relevant to the use of the applications
2. Problems with the quality of care: referring to patient-caregiver communication and self-care advice generated by the application, especially the responsiveness of the applications [18,19]
3. Implementation problems: referring to the incorporation of the applications into daily practice and to policy issues concerning email consultation

Results

The results present the problems observed while using the applications for self-care aims. The results section is split into two parts: the first addresses patients' use of the applications and the problems experienced, and the second addresses caregivers' use of the applications and the problems experienced with handling patient requests. To indicate the main problems, a full overview is given for each.

Patient Problems

Searching for Self-Care Information

By means of digital medical encyclopedia with alphabetically ordered lists of medical terms, patients could seek self-help information about their health complaint. Patients experienced difficulties in finding information. The navigation structure of the website (home page) appeared troublesome for patients trying to find the information they were looking for. For instance, the search options were not equipped for finding the right information quickly and also provided irrelevant or useless results. As patients wanted to retrieve health information with as little effort as possible, and the applications did not meet this need, they opted for a search engine, such as Google, to find the right information.

> *Because I can't find a "search function" and the structure of the menu is unclear, it means that I have to carry on scrolling. For me, that's a big enough reason for quitting this site. It's just too much bother, and I'm someone who uses the Internet on a daily basis.* [P13]
>
> *With Google, you get the right answer straight away. It's much faster than this. I can't ask my question here. I have to search.* [P8]

Semantic shortcomings hindered the search process because the search options used medical terms that were not defined or explained, which meant that patients could not match their health complaint with the terminology offered.

> *I read "muscular weakness." Now what is muscular weakness?* [P10]
>
> *Lots of difficult words. Better information about what it is would be handy.* [P3]

Comprehension problems arose because the virtual body of the application did not provide sufficient information for labelling a health complaint. Patients had to click on the body to label their complaint in order to get more information. However, patients were not accustomed to describing their complaint via the labels of a virtual body, and they were not able to label ailments like tiredness, insomnia, and mental problems. The possibilities offered by the medical encyclopedia were often irrelevant and/or too general to be helpful for self-care.

> *I expect the ABC [medical encyclopedia] to comprise both physical and mental problems. I am now looking for sleep disorders, but that isn't my main problem. Apparently I first have to make a diagnosis about what's wrong with me before I can search further.* [P7]
>
> *I was expecting more of a medication advice. This information just deals with common solutions. I find that general knowledge.* [P5]

Interpreting Computer-Generated Self-Care Advice

Via self-tests and digital triage features, patients could receive fully automated self-care advice to identify the possible causes of a health complaint or to decide whether a doctor's visit was necessary.

M provides a so-called Symptom Scan, a self-test to gather information on the possible causes of a health complaint. The self-test can be consulted for four health complaints: dizziness, chest pain, headache, and tiredness. It consists of a list of questions about specific symptoms. The self-test generates a list of probabilities of medical causes for a certain disease or injury; for example, a test for headache resulted in a 96% chance of migraine, a 1.1% chance of a brain tumour, and a 0.1% chance of meningitis.

Patients had difficulty interpreting the results of the Symptom Scan. It was unclear to them how they should interpret a percentage of 0.1. Is this chance negligible or is it a realistic 0.1% chance of meningitis? As the system failed to provide further information on this, a doctor still needed to be consulted. The system thus did not provide the security the patient was seeking or support the patient in his or her self-care demand. In certain cases, the test results even evoked fear. This was due to the fact that most of the presented terms were related to injuries and diseases instead of common conditions. Furthermore, patients noted that in many cases the questions of the self-test were irrelevant or incomplete. The consequence of this was that patients lost confidence in the Symptom Scan and no longer took the results of the test seriously. Besides this, the patients appeared to have insufficient expertise to answer the Symptom Scan's questions; consequently, the results did not coincide with the patient's complaint.

> *It doesn't help me much. A percentage of 0.3—I have no idea what that means. In my opinion, those questions were totally irrelevant.* [P6]

Patients could check the necessity of a visit to the doctor by means of a symptom-driven question-and-answer system (digital triage). Patients felt that they were referred to a doctor too quickly. Consequently, the advice to visit a doctor was not always taken seriously, particularly in the case of an apparently less serious health complaint, like a cough. Moreover, the generated advice frightened patients when they were told to visit a doctor after answering only a few questions.

> *Sounds ominous: "Contact your GP." I would prefer some explanation why that is necessary.* [P8]

What do patients expect from computer-generated self-care advice? The question-and answering system (digital triage) seemed appealing to patients because of its ability to adjust to personal characteristics (ie, patients fill in their personal symptoms and the system responds to their personal data). The fact that patients have to fill in personal information results in an expectation of tailored health care advice. However, patients found the self-care advice to be insufficiently tailored to their specific needs; it was no different from the general information available in public health leaflets or encyclopedia. Consequently, patients attached greater importance to personal advice from a caregiver, whether through the Internet or from a doctor's visit.

> *I am quite interested in what it comes up with, whether it's identical to what has been said before [in the medical encyclopedia] or if I will be given more specific information on my current symptoms.* [P11]

Furthermore, patients found that the digital triage function did not yield as much as expected. The number of questions they had to answer on an ailment was not in accordance with the perceived severity of their health problem. For example, for a problem like a cough, patients had to answer about 50 questions before they received advice on what to do (application D). Patients found the number of questions disproportionate to their complaint. With more a complex health problem, such as tiredness, patients had fewer objections to a greater number of questions because they understood that more questions are needed if a complex problem is to be considered.

> *That cough question, it takes you 15 minutes to run through all the questions, whereas you might just as well have picked up the telephone.* [P2]

Formulating Health Complaints via Email

Patients faced problems describing their health problem; mental health problems were especially difficult to verbalize. In these cases, patients were already heading for a doctor's visit during their email consultation. One of the applications (P) requires patients to classify their complaint under a category such as shoulder complaint or headache before they can pose a question to their GP by email. These rubrics appeared insufficiently tailored to the language patients used for verbalizing their complaint.

> *It's quite tricky, having to categorize your question. Look, if you have cystitis, it's not so difficult. But if you think you've got a pain in your stomach, or are constipated, those kinds of things are difficult to classify.* [P13]

Patients also found it difficult to decide what kind of information a caregiver needs in order to be able to answer their questions. The completeness of information given to a caregiver depended on the type of interaction with him or her. In the event of a pre-existing relationship, patients anticipated the GP's knowledge about their medical history (information about their personal situation and activities that had already been undertaken to solve the health problem). When consulting an unknown caregiver, patients gave as much information as possible about their personal situation and health problem, often accompanied with information about the actions they already had undertaken. By doing so, patients took into account the fact that the caregiver could not pose a counterquestion because of the lack of feedback features. With application M, patients can consult several clinical experts for advice on a specific health problem; however, it appeared to be difficult for patients to choose the right expert for their complaints (eg, they found it difficult to select an expert for a complaint of headache).

Implementation of Applications in Practice

Patients were not trained to use the self-care applications. Moreover, they had no idea whether use of the applications would continue to be free in the future. Due to lack of training or education, not all features of the applications were used, such as the possibility for patients to store the information generated by the applications (P and D) in a patient file. The structure of the websites seemed so unclear that all kinds of features to document and upload information were overlooked.

Overview of Patient Problems

Table 1 presents an overview of the problems patients experienced while they were observed using the applications' features for controlling their health. Problems were categorized into quality demands for supporting health care through technology. Patients experienced 260 problems in total. They faced problems mainly with the quality of care provided via the Internet-based applications. The information was insufficiently tailored to patients' needs, and language (semantics) appeared one of the main obstacles to providing appropriate and useful self-care advice. Problems with the user-friendliness of the applications were mainly related to navigation features, such as inadequate search options and unclear presentation of information; the menu on home pages failed to enable patients to find the information they were looking for. Implementation problems occurred because of vagueness concerning regulations about free access and lack of training on how to use the applications for solving health-related problems.

Table 1. Overview of patient problems (N = 260)

Quality Demand	Identified Patient Problems
User-friendliness (n = 106, 40.8%)	Navigation problems: Lack of a search engine Lack of an adequate search option Unclear navigation structure; hyperlinks were nonexistent or useless Unclear or unattractive layout of Web pages No features for printing information
	Technical problems: Software bugs Drop-down menus or back buttons failed
Quality of care (relevance, comprehensibility of information; responsiveness) (n = 146, 56.1%)	Problems with relevance of information: Information provided by the digital medical encyclopedia was too general to be useful Information provided by the virtual body was too limited to be useful Self-care advice insufficiently tailored to personal needs
	Problems with comprehensibility of information: Semantic mismatch between system and users because of unclear medical terms and lack of features to verbalize a problem in their own vocabulary Self-care advice hard to interpret Self-care advice frightening
	Problems with responsiveness: Caregiver used more than prescribed response time to answer patients' questions
Implementation (policy, training) (n = 8, 3.1%)	Lack of education: Underuse or misuse of applications because of lack of education Uncertainty about regulations for using Internet for self-care

Caregiver Problems

Identification of Patients

In the event of a pre-existing relationship between a patient and caregiver, the caregiver first looks up the name and date of birth of the patient in order to identify him or her. Next, the caregiver looks for additional information in his or her own patient record. Although caregivers authenticate the patients by checking the personal data, they still have concerns about the service being misused (ie, they might receive requests from unknown patients who were using the account of a patient already on file). In case of anonymous email encounters, caregivers were also aware of the risk of not knowing the patient. With application M, they are trying to curtail this by asking all patients approaching them for an email consultation to fill in a health statement first. To this end, patients must answer questions specifically selected with regard to what the caregiver needs to know as well as the health risks the patient might run. In this way, the caregiver can soon see in an overview how or where he or she must adjust the advice to the situation of the unknown patient. All the questions have to be answered with "No" if a patient desires an email consultation. The health statement does not eradicate all risk, however.

> *Because that's the last thing you want, right? That they leave with wrong advice but then it turns out that we did ask the question only that they didn't answer it, that they thought, "Oh, it's not a problem," which later turns out to be one after all. That's the drawback of not knowing somebody and still advising them on the basis of a health statement that they have had to fill in themselves.* [C7]

Interpreting Patient Requests

For the P and D applications, email communication is only possible with registered patients. In this way, it is clear to the caregiver who is asking the question. For M, the people asking the questions are anonymous, which means the caregiver has no background information on the person concerned. However, to be able to give a more personal or tailored answer, it is necessary to have background information or a medical history.

> *It can be difficult sometimes. You only have a smidgen of background information about somebody, whereas with real-life contact you can see how someone reacts. When you say something and the message does not come across at all, someone starts to look vague or something, then you can try to explain it again in a different manner, but this way you just don't see anything, so it's difficult. If someone hardly gives background information, you have to keep your advice rather general, but when somebody imparts a good deal of background information, your answer can be more exhaustive.* [C7]

With application D, caregivers received a history of the patient's health problem via the questions and answers from the digital triage system. Although the caregivers valued the medical history questionnaire differently, they remarked that it offered many advantages when interpreting the patient request. In their opinion, it offered a lot of information that helped to understand the complaint or the problem better and thus allowed them to distinguish important alarm signals. On the other hand, the medical history questionnaire appeared insufficiently capable of analyzing the health complaint to result in clear advice. It took too long to filter the relevant information.

> *Look, if all I can see is "No" everywhere [answer indicating nonurgent symptoms], I am inclined to stop reading all the answers and overlook the "Yes."* [C6]

Answering Patient Requests

Aware that their written answers can have legal consequences, caregivers take great care with the formulation of their answers to patients. Moreover, with the absence of a clear protocol for communicating online with patients, caregivers also worry about the quality of care. With application M, caregivers are alert to mentioning that their advice could be a possible indication of the cause of the complaint, but that it is not a diagnosis.

> *Well, I'm always on my qui vive, so as not to write things down in the file that could later be used against me in court, shall we say. So I tread cautiously with the formulation of a number of things.* [C5]

> *You can give general advice. You can always do that, but you have to incorporate a kind of safety device by saying "Oh, in a number of cases, there will be exceptions." And that's why we are constantly pleading for a quality protocol for these kinds of things, and that protocol must comprise three elements: expertise of the person manning the desk—it must be someone with considerable experience; there must be a certain guarantee that the questions will be answered within a certain time limit; and the third, and that is the trickiest of them all, is that you must try to give answers that are safe, and...if you think "There's a risk here," you must also clearly communicate that with..."If you want to be sure, you must make an appointment."* [C9]

With application D, the digital triage generated a standard advice (ready-made answer) based on an ICPC code. In the Netherlands, the International Classification of Primary Care (ICPC) is accepted as a standard for coding and classifying health complaints, symptoms, and health disorders in primary care [20]. In most cases, the generated ICPC code did not correspond with the caregiver's expectations. Sometimes an ICPC code could not even be generated and the caregivers themselves had to allocate a code, which was not always easy due to lack of relevant medical information. Moreover, the ready-made answers did not correspond with the professional beliefs of practising medicine and, as a consequence, they were changed or reformulated (ie, geared more to the personal and/or medical characteristics of the patient).

> *It's just too general. I have to rewrite things quite often. And not all questions from patients refer to an illness. I remember someone asking me once about genetic research. That's not a medical problem. Things are not always run-of-the-mill.* [C8]

Documentation of Patient Requests

The system's features, like sending attachments and archiving patients' questions and answers, were hardly used due to a lack of education about the usage of the applications. Furthermore, despite most caregivers wanting to know how patients acted on their advice, two of the applications (M and D) did not offer a feedback feature. Caregivers thus emphatically advised patients to visit a caregiver in case of doubt about their health problem.

> *I find it quite difficult at times, when I get so little feedback on how my answer has been interpreted. Was it successful or not?* [C7]

> *It's true it's difficult, because you're not given any feedback. If the patient doesn't react, fine, but if that leads to mistakes being made, that's a pitfall.* [C9]

The medical records of caregivers' patients could not be integrated with the documentation system of the Internet-based applications. Although patients' demographics and medical histories could be saved, caregivers did not use this functionality because they found it inconvenient. All notes on an email consultation, including date and content, were made in their own medical records.

> *At this moment I still don't have the option to look at information coupled to my medical record. And no link to your own record is inconvenient.* [C11]

> *If something really special has to be recorded, then I would do so in my medical record. I regard this [application P] merely as a means of communication, whereby I do not feel the need to document patient information.* [C13]

Implementation in Practice

Caregivers faced difficulties with the incorporation of email consultation into daily practice. The Internet-based care applications were not compatible with the patient administration systems already in use, and email consultation usually takes place outside of office hours. Moreover, caregivers were ignorant about the conditions (rights and obligations) of email consultation. Directives for the use of electronic patient-caregiver communication were unavailable or unclear about the care delivery process and the definition of a pre-existing relationship. Caregivers wondered whether a personal encounter was required before an online encounter and about the definition of the first personal contact. Moreover, they expected greater inspection from government on the influence of health care insurers regarding privacy. They also felt the need for an unambiguous view on the admission of email communication for anonymous contact between patient and caregiver. Caregivers are of the opinion that the rate of a Web consultation (€4.50) is too low. They think that although email consultation can be an added value to regular care because access to care could be enhanced, they would restrict its use to simple nonurgent health complaints and to known patients.

Overview of Caregiver Problems

Table 2 presents an overview of problems faced by caregivers while using the applications for handling patient requests. Caregivers experienced 198 problems in total. About half of the problems concerned the user-friendliness of the applications, such as unclear navigation structures and lack of feedback or documentation possibilities. Quality of care problems concerned laborious answer procedures, the nonprofitability of email consultation, and legal or ethical problems with respect to possible misuse of email consultation. Implementation problems occurred due to unclear policy on email consultation and the lack of training for email consultations. Caregivers found the applications too time consuming because these systems could not be integrated with their existing patient information system or medical records.

Table 2. Overview of caregiver problems (N = 198)

Quality Demand	Identified Caregiver Problems
User-friendliness (n = 101, 34.8%)	Navigation problems: Unclear navigation structure, hyperlinks lacking or useless Lack of feedback features Lack of documentation features Unclear answer procedures/formats
	Technical problems: Software bugs
Quality of care (n = 43, 37.9%)	Nonprofitability* of email consultation: Requests from patients still required personal contact with a caregiver
	Concerns about a higher chance of interpretation difficulties: Carefulness with formulating answers to patient requests, such as being extremely careful when formulating the answer because of possible legal consequences
	Concerns about a higher chance of misuse: Requests from unknown patients through using the account of known patients
Implementation (n = 54, 27.3%)	Unclear regulations about email consultation: Lack of a transparent protocol for email consultation Unclear regulations about prerequisites for using email consultation Lack of quality inspection of email consultation applications Insufficient reimbursement for email consultation
	Lack of education and training: Underuse or misuse of applications because of lack of education
	Interoperability of systems: Applications could not be integrated with the existing patient information system or medical records
	Concerns about patient equity of access: Concerns about the risk of widening of the gap between those who have access to new technology and those who have been excluded

*Profitability: the degree to which the health service can be delivered in a quick, effective, and economical manner.

Discussion

Patient and caregiver expectations did not correspond with their experiences with the use of the Internet-based applications for self-care. Patients thought that the applications would support them in solving their health problems, that they would guide them on a “problem-solving journey on the Internet” by consulting various interactive components that would enable them to make informed decisions about their health condition. Caregivers were more reserved about the applications because of medico-legal concerns about misuse. However, the applications failed to support self-care because eHealth is more than just a technological intervention. The design of the applications should include a way of thinking about how to deliver health care with the aid of technology [21]. The applications provide various interactive components disconnectedly, so users themselves have to find out which feature will be convenient and profitable for what purpose. In terms of diffusion of innovations [11], we know that only very motivated people will persist.

We aspired to determine user-centered criteria for Internet-based applications for self-care. We focused, therefore, on quality demands for interactive health communication applications as formulated in prior studies [2,11]: user-friendliness, quality of care, and implementation. Based on our results and prior studies, it can be concluded that technology should be simple and easy to use, in line with end users' ways of thinking and behavior with respect to solving health problems via technology. Moreover, to develop or improve Internet-based applications for self-care, language and comprehensibility of information are important content criteria. Self-care support applications should match the vocabulary of the users and the language of the medical systems. This requires rethinking the presentation of information for self-control via the Internet. From the perspective of caregivers, the applications failed because of their inability to store medical data in the patient records already in use. The adoption of a new technology depends on the presence of an adequate infrastructure or other technologies that cluster with the innovation [11].

What health care functions can be delegated to Internet-based health care systems? We evaluated three applications with various components for self-care, such as symptom-driven question-and-answer systems, self-tests for preliminary evaluation of the urgency of a health complaint, and email consultation services for electronic patient-caregiver communication. Patients appreciated email communication more than the other components because they preferred convenient access to a high level of personalized health care. Digital triage was insufficiently geared to their expectations and was more medico-technology driven than user centered. The applications have multiple components for self-care to appeal a wide range of users, but without a thorough analysis of how people think and frame their problems, how they expect to be responsible for their own care and decisions, and what they need to support this self-care, the components might well result in an overload of information. People get lost on the Internet, so personal assistance is needed. In our opinion, we feel that the organization of patient-centered care expectation management is a prerequisite to delivering health care through technology.

Despite these shortcomings, we believe the applications have the potential to mature. The findings of our study are consistent with the results of previous studies [2,3,22-28]. For instance, the study by Car and Sheikh [24] presented key features for optimal email consultation, such as ease of adoption; combining new technology with existing ones; user-friendliness; easy to set up, manage, and use by doctors and patients; integration with existing medical records; and archiving and logging. These key features should therefore be addressed in the development of new Internet-based self-care applications. According to the Institute of Medicine [10], care needs to be customized according to patient needs and values, which we also found in our study. Problems related to quality of care resulted from patients' inability to formulate their complaints as a health problem. The applications should be designed to solve this semantic problem by providing an adequate search engine and by avoiding the use of medical jargon. Moreover, the systems were incapable of delivering personalized and tailored health care, which seems one of the most important requirements for high-quality patient care. In order to improve the quality of care, applications should be designed to meet the most common types of need, but should also have the capability to respond to individual patient choices and preferences [10]. The Kerr et al study [2] identified quality criteria for Internet interventions for long-term conditions. The user-generated criteria relating to information content, presentation of information, language, and interactivity (tailored and personalized advice, question-and-answer functionality) correspond with the findings of our study in the sense that the absence of these criteria impeded self-care.

This correspondence in study findings illustrates that Internet-based technology in health care is evolving throughout the world and that it encompasses comparable quality demands. Although the impact of Internet-based technology may not be fully clear until diffusion becomes widespread, explorative studies such as this one can give insight into the requirements necessary for widespread use in the future.

The use of scenario-based tests combined with in-depth interviews proved to be a powerful method for describing and identifying user problems and for supporting the re-design processes of the Internet-based applications for self-care. From prior studies [4,29], we know that such a qualitative approach provides reliable and meaningful data for developing and implementing Internet-based technology for supporting self-care. Moreover, the use of the scenario-based tests provided patients and caregivers with the opportunity to learn about the functionality of the applications and how to use them more efficiently, and it gave them more confidence in the utility of the Internet-based technology.

Notwithstanding the relatively small size of our sample, which limits the generalizability of our results, we now have more insight into the requirements for successful Internet-based technology for supporting self-care. The aforementioned criteria on user-friendliness, quality of care, and implementation of the technology are key elements in creating an efficient and effective Internet consultation process. To foster widespread use of Internet-based technology, like electronic patient-caregiver communication and self-assessment via the Internet, the needs of end users should be the starting point for the development of such applications [29-31]. In order to prevent the risk of providing inaccurate or inadequate advice, self-assessment tools that are neither efficient nor effective should not be part of eHealth services. The most powerful application for self-care is email consultation, combined with a suitable triage mechanism to empower patients' self-awareness.

There will be ongoing demand for evaluation of eHealth services. Future studies should focus on the possibilities of self-care via Web-based triage systems combined with email communication to create awareness of illness and to make timely care possible and feasible. These systems should be interoperable with electronic health records and tailored to particular usage (ie, users with comparable disease profiles).

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Conflicts of Interest

None declared.

Multimedia Appendix

Scenarios used in the study

[PDF file (Adobe PDF), 68 KB - jmir_v10i2e13_app1.pdf]

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Original Paper

Assessing Patient Attitudes to Computerized Screening in Primary Care: Psychometric Properties of the Computerized Lifestyle Assessment Scale

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Abstract

Background: Computer-based health-risk assessments are electronic surveys which can be completed by patients privately, for example during their waiting time in a clinic, generating a risk report for the clinician and a recommendation sheet for the patient at the point of care. Despite increasing popularity of such computer-based health-risk assessments, patient attitudes toward such tools are rarely evaluated by reliable and valid scales. The lack of psychometric appraisal of appropriate scales is an obstacle to advancing the field.

Objective: This study evaluated the psychometric properties of a 14-item Computerized Lifestyle Assessment Scale (CLAS).

Methods: Out of 212 female patients receiving the study information at a family practice clinic, 202 completed a paper questionnaire, for a response rate of 97.6%. After 2 weeks, 52 patients completed the scale a second time.

Results: Principal component analysis revealed that CLAS is a multidimensional scale consisting of four subscales (factors): (1) Benefits: patient-perceived benefits toward the quality of medical consultation and means of achieving them, (2) Privacy-Barrier: concerns about information privacy, (3) Interaction-Barrier: concerns about potential interference in their interaction with the physician, and (4) Interest: patient interest in computer-assisted health assessments. Each subscale had good internal consistency reliability ranging from .50 (2-item scale) to .85 (6-item scale). The study also provided evidence of scale stability over time with intraclass correlation coefficients of .91, .82, .86, and .67 for the four subscales, respectively. Construct validity was supported by concurrent hypotheses testing.

Conclusions: The CLAS is a promising approach for evaluating patients' attitudes toward computer-based health-risk assessments.

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KEYWORDS

Computers; scale; psychometric; screening; risk assessment; family practice

Introduction

The use of computer interactive technology in health care settings is on the rise. Many studies report using patient-administered computer programs for health-risk assessments [1-4] as well as for preventative health education in clinical settings [5-7]. Interest is particularly growing in computer-based health-risk assessments for which patients complete a computer survey privately during their waiting time. The interactive program then prints a risk report for the clinician and a recommendation sheet for the patient at the point of care.

Such computer-based health-risk assessments can facilitate meaningful communication between clinicians and patients by saving the clinicians' screening time for thorough risk management and by allowing the patients to self-reflect on their risk profile before the medical consultation.

Many practical implications have also been recognized for computer-based health-risk assessments. At the organizational level, the advantages include speed and efficiency, accountability, quality improvement, and cost containment [8]. At the individual level, convenience to providers and patients includes tailored testing, accuracy of responses, unobtrusive means of branching or skipping questions, instant feedback on risks and referrals to clinicians and patients, and aids to diagnosis [9]. Technological advances, such as touch-screen, mobile, hand-held tablet computers, have amplified the utility of computer-based health-risk assessments. Such interactive computer technology has great potential in primary care settings where provider time is constrained due to a multitude of presenting health issues and preventive needs of patients [10].

However, user attitudes toward interactive computer technology are important when considering applications. In 1986, Nickell and Pinto developed a computer attitude scale for the general population [11]. Despite good psychometric properties [12], this scale has limited applicability in the physician-patient context due to specific communication patterns between health care providers and patients. While computer attitude scales have been developed and evaluated for physicians [13,14] and other health care providers [15], reliable and valid scales for general patients are lacking [16]. Further, little knowledge exists about scale reliability over time [16].

In our review of the literature on computer-based health-risk assessments, two scales were identified as potentially applicable to general patient populations. The first scale was developed by Lucas in 1977 and tested among patients visiting specialized clinics in hospital settings [17]. This 22-item scale tapped patient attitudes toward different types of clinical encounters, including computer-assisted visits, in-person visits, and ideal health care visits. The assessments used a semantic differential technique whereby participants rate each item on a bipolar scale with contrasting adjectives at the extremes, such as hot and cold [18]. The Lucas scale was subsequently used by others in a primary care setting [2]. Yet this scale is difficult to apply in today's world of globalization, given different interpretations of adjectives by respondents of diverse ethnocultural backgrounds. Further, scales based on a semantic differential technique are lengthy and, hence, of limited use in time-pressed clinical settings.

Addressing some of these concerns, Skinner developed a short 14-item Computerized Lifestyle Assessment Scale (CLAS) in 1993 [19]. First drawing on an initial study of family practice patients [2], a large pool of items was generated through group discussions with patients and providers about the pros and cons of computer-based health-risk assessments. This list was reviewed by the research team, and the final pool of items was established through consensus among the team members. An easy to comprehend Likert-type scale was used whereby participants are asked to express their level of agreement or disagreement for each item. Given the centrality of decisional balance (ie, extent of pros compared to cons) in health behavior theories and research, the CLAS focuses on patient perceived benefits and barriers toward computer-based health-risk assessments. Several studies grounded in the Transtheoretical Model and Health Belief Model demonstrate that preventive behaviors, such as cancer screening visits, improve when perceived benefits exceed perceived barriers [20,21]. Thus, assessment of the decisional balance of patients in relation to computer-based health-risk assessments is meaningful in establishing their acceptance of future use. Although CLAS is a theoretically informed scale for primary care patients, its psychometric properties have not been previously reported.

Lack of psychometric appraisal of scales may impede research and innovation to advance the field. Recent studies have begun to report patients' general reactions to the use of computer interactive technology. In 2000, Dugaw et al reported patients' overall acceptance of computerized medical history taking in an emergency department, with limited description of the measurement [22]. Likewise, recent randomized trials on computer-based health-risk assessments by Rhodes et al in a US hospital emergency department reported general reactions of patients, their recall of advice after a 1-month follow-up, and satisfaction with the visit [3,4,23]. Although information on patient satisfaction is important, it does not generate knowledge specific to technologically mediated patient concerns or facilitators in medical encounters. In 2006, MacMillan and colleagues reported patients' higher preference for computer-based screening for the risk of partner abuse compared to face-to-face inquiry. However, the preference measurement relied on three de novo questions about "ease," "like answering," and "private enough" [24]. The use of nonstandardized methods of measurement could lead to difficulties in assessing and interpreting results over time and across sites. At the same time, clinical adoption of computer-based health-risk assessments is dependent on the availability of reliable and valid knowledge about patient attitudes.

Considering the potential of CLAS, this study evaluated its psychometric properties as part of a larger research program on computer-based screening for lifestyle risks, including partner abuse, among female patients. Using standard procedures [25,26], the aim of this study was threefold: (1) to assess the dimensionality and/or latent constructs of CLAS, (2) to measure test-retest reliability and internal consistency of the instrument, and (3) to provide initial evidence on its construct validity.

Methods

The study was conducted at a multidisciplinary family practice clinic affiliated with a teaching hospital in Toronto, ON, Canada. The study was approved by the hospital research ethics board as part of a research project on prevalence of partner abuse; details are provided elsewhere [27].

Participant Recruitment

All adult female patients with an appointment were eligible to participate if they were at least 18 years of age, could speak and read English, and could provide informed consent. The study participants were recruited in 15 days over a period of three consecutive weeks in February of 2004. On recruitment days, all adult female patients with appointments were given a brief letter of invitation by the clinic receptionist at the time of arrival. These potential participants were then approached in the waiting area by a recruiter to confirm their eligibility and inquire about their interest in the study. Willing participants were taken to a separate room in the clinic, unaccompanied by family or friends, where they completed the survey after giving informed consent. At this time (T1), participants were also asked to consent to a subsequent contact after 2 weeks (T2) to administer the CLAS a second time. Participants sealed the survey in the provided envelope before returning it to the recruiter. Then, participants received health brochures (domestic violence, cancer, and heart health) with telephone numbers for domestic violence counsellors and the assaulted women's helpline.

Measurement

The survey included the CLAS, which is a 14-item scale that covers patients' positive and negative perceptions about computer-based health-risk assessments [19]. Participants read a vignette about such a "computer survey" (Textbox 1) and rated each CLAS statement on a Likert-type scale of 1 to 5 (strongly agree, agree, not sure, disagree, strongly disagree). Other sections in the survey gathered information on sociodemographics (age, marital status, country of birth, years lived in Canada, highest education completed, employment status, and income), health (self-rated health, partner violence, and number of visits to family practice), exposure to computers (access and use), comfort in completing the survey, and English language abilities (see Table 1 for details).

Textbox 1. Vignette

> We would like to know your opinion about a computer survey of patients. This survey is completed by patients on a computer before seeing their family doctor. The computer survey asks questions about lifestyle and health risks such as smoking, stress, conflict in relationships, and safety. The questions appear on the computer screen one by one. The patient answers by touching one of the options on the computer screen using a non-ink pen. Patients do not type or use any computer parts but only touch the screen to give answers. This computer survey uses simple day-to-day language of 5th grade reading level. The computer system prints (1) a summary of patient health risks for the doctor to review, and (2) an information sheet for the patients about their reported health risks. *What is your opinion about such computer-based health-risk assessment of patients before seeing a family doctor*?

Sample Size

The aim was to recruit a sample of 200 participants. As CLAS included 14 items, a sample of 200 was expected to generate an adequate subject-to-variable ratio of 14:1 to derive latent constructs. For factor analytical approaches, Gorsuch (1983) and others recommend a subject-to-variable ratio of five when the communalities are high and there are many variables for each factor [28,29]. If these conditions are not met, then a subject-to-variable ratio of 10 is recommended [28]. Others suggest that a sample of 150 should be considered sufficient when the factor analyzed solutions have several high loading markers (> 0.80) [30]. Our sample size is fair in meeting both of the established requirements (minimum sample size and sample size per item) for psychometric studies.

Data Analyses

The CLAS items [19] were reverse coded prior to analyses so that 1 referred to "strongly disagree" and 5 to "strongly agree." All analyses were conducted using Statistical Package for Social Sciences (SPSS) version 12(SPSS Inc, Chicago, IL, USA). Preliminary statistical procedures examined distributions of the individual items (eg, means, standard deviations, skewness, and kurtosis) and evidence of ceiling or floor effects. The quality of data was evaluated by percentage of missing responses, which were low; hence, we used the case deletion in subsequent analyses. The sampling adequacy was assessed by the Kaiser-Meyer-Olkin test.

Prior to reliability and validity analysis, we examined the latent structure of the scale. The latent constructs of the CLAS were examined by employing principal component analysis (PCA) [31,32]. The number of latent constructs or factors was determined using scree plots and the criterion of eigenvalues greater than 1.0. We considered three-factor, four-factor, and five-factor solutions with varimax rotation. Salient loadings were defined using a critical value of 0.38 [28].

The scale reliability was estimated by both internal consistency and test-retest reliability of the subscales. To examine homogeneity of items or internal consistency, item-total correlation [33] and change in Cronbach alpha coefficient upon item deletion were used [34]. For test-retest reliability, intraclass correlation (ICC) from a two-way random effects model was executed [35]. We also compared T2 participants to the remaining participants at T1 with respect to characteristics measured at T1 to assess the potential to generalize the reliability findings.

After factors were derived and reliability established, construct validitywas investigated. For this analysis, we tested hypotheses that were based on existing literature. Further details on the hypotheses are presented in the Results section under construct validity. The hypotheses were tested by using Pearson product moment (r_p), point biserial (r_{pb}), or Spearman rank (r_s) correlation analyses, as appropriate.

Results

Participants

Among 361 women approached, 212 eligible women received the study details in privacy, 207 provided written consent (response rate 97.6%), and 202 returned the completed surveys. Participants had a mean age of 45.3 years (range 19 to 86) and 36% were immigrants, with the top two groups from Europe and Asia (Table 1). Almost 75% of the participants were in a current intimate relationship, and 77% had at least university education. Nearly 64% were currently employed and reported annual household income of at least Can $40,000; 87% of the participants had access to computers, and 66% used one every day. Self-perceived health was rated as "good" on a scale of one to five with a mean of 3.2 (SD 1). The mean number of visits to the family practice during the last year was 4.6 (median 3.5; mode 1; range 0 to 30).

Table 1. Sociodemographic characteristics (N = 202)

Variable	No.	%
Age (years), mean (SD)	201	45.3 (15.4)
Current marital status	202	
Married or common law or intimate		74.9
Separated or divorced or widowed		13.9
Single, not in relationship		11.4
Country of birth: Canada	129	63.9
If immigrant: years lived in Canada	71	
Less than 10 years		23.9
11 to 20 years		16.9
More than 20 years		59.2
If immigrant: country of birth	72	
Europe		36.1
East or South East Asia or South Asia		29.1
West Indies, Latin America, or Caribbean		20.8
Middle East or West Asia		6.9
Africa		5.6
Highest education	201	
Less than high school		3.0
High school, some or complete		19.9
University or higher, some or complete		77.1
Current employment	201	
Full-time or part-time		64.2
Unemployed		13.9
Retired or on disability		21.9
Household annual income (Can $)	181	
Less than 20,000		15.5
20,001 to 40,000		19.9
40,001 to 60,000		20.5
More than 60,000		44.2
Access to computer at home or work	200	87.0
Use of computer in the last month	200	
Every day or two to three times a week		81.5
Once a week or once a month		6.5
Not at all		12.0
English ability,[*] mean (SD)	201	4.5 (0.87)
Survey comfort level,[†] mean (SD)	199	4.0 (1.2)

[*] Scale of 1 to 5: 1 = poor, 2 = fair, 3 = good, 4 = very good, 5 = excellent.

[†] Scale of 1 to 5: 1 = very uncomfortable, 2 = uncomfortable, 3 = not sure, 4 = comfortable, 5 = very comfortable.

Table 2. Item summary statistics and Pearson correlations

Item[†]	% Miss[*]	Mean[‡]	SD	Skewness	Kurtosis	Item Correlation													
						1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. Routine	1.0	3.93	0.86	-0.74	0.62	1													
2. Lifestyle	0.5	3.67	0.94	-0.73	0.39	.58	1												
3. Save time	2.0	3.73	0.92	-0.64	0.55	.62	.47	1											
4. Better assess	1.0	3.28	0.84	-0.07	0.17	.54	.43	.50	1										
5. Comfortable	1.0	3.92	0.85	-0.86	0.93	.60	.52	.41	.34	1									
6. Trusted	2.0	3.36	0.94	-0.33	0.02	.47	.33	.37	.42	.59	1								
7. Confidentiality	0.5	3.30	1.14	-0.17	-1.06	-.08	-.05	-.80	-.06	-.24	-.29	1							
8. Certain information	0.5	3.39	1.12	-0.24	-0.78	-.14	-.04	-.15	-.04	-.22	-.26	.47	1						
9. Mistakes	1.0	2.63	0.84	0.51	0.27	-.18	-.16	-.14	-.27	-.39	-.41	.41	.38	1					
10. Less time	2.0	3.35	0.99	-0.34	-0.41	-.06	.02	.16	-.02	-.19	-.13	.25	.17	.26	1				
11. Personal touch	1.0	3.38	1.19	-0.14	-1.12	-.32	-.24	-.20	-.30	-.34	-.32	.28	.40	.43	.40	1			
12. Another doctor[§]	0.5	2.13	0.98	0.98	0.92	-.35	-.28	-.30	-.33	-.47	-.27	.29	.26	.42	.32	.50	1		
13. Answer honestly[§]	1.5	4.42	0.68	-1.36	3.36	.40	.19	.32	.23	.50	.28	-.07	-.19	-.20	-.12	-.20	-.35	1	
14. No pat info[§]	4.5	4.26	0.70	-0.97	2.15	.35	.19	.19	.20	.25	.23	-.04	-.03	-.06	-.06	-.06	-.12	.34	1

[*] % Miss, % missing response.

[†] Full item statements are provided in Table 3 and Table 4.

[‡] Scale of 1 (strongly disagree) to 5 (strongly agree).

[§] Skewed items.

Item Descriptive Statistics

The item means and standard deviations were acceptable, while three items were skewed (Table 2). These items were transformed and PCA was executed with and without transformations. As the two PCAs were similar in factor structure and factor loadings, we report PCA without transformed items in this paper. Sampling adequacy was indicated by a Kaiser-Meyer-Olkin test value of .82 and the absence of ceiling or floor effects. The factorability was indicated by correlation and partial correlation matrices.

Factor Structure

On conducting the PCA, the first 10 eigenvalues were 4.7, 2.1, 1.1, 1.0, .85, .76, .69, .53, .50, and .44. Four factors emerged with eigenvalues greater than or equal to one, accounting for 63.7% of the total variance. Based on the scree plot, either a three-factor or four-factor solution was indicated. We considered three-, four-, and five-factor solutions, and the four-factor solution yielded the most interpretable results. A summary of the PCA with varimax rotation is presented in Table 3. The factors were named Benefits, Privacy-Barrier, Interaction-Barrier, and Interest. Three- and four-factor solutions were also compared for the internal consistency of the derived subscales. Although the Privacy-Barrier and Interaction-Barrier factors merged into one factor upon forcing a three-factor solution, the internal consistency of the subscales was higher in the four-factor solution than in the three-factor solution. This internal consistency comparison was based on the reliability coefficients adjusted for the length of the subscales [33].

Table 3. Summary of principal component analysis with varimax rotation

Item	Factor Loadings				h^{2*}
	Benefits	Privacy -Barrier	Interaction -Barrier	Interest	
1. Computers will help doctors with routine lifestyle questions	.79				.74
2. The computer is a good way to ask lifestyle questions	.79				.65
3. It would save doctors time.	.78				.65
4. Doctors will make better assessments with such computer systems	.74				.60
5. I would feel comfortable answering questions on a computer	.58				.61
6. Computers can be trusted	.54	(.41)†			.51
7. I would worry about confidentiality		.82			.69
8. I do not want certain information about me on the computer		.81			.69
9. Too many mistakes will be made with computer		.60	(.39)†		.55
10. Doctors would spend less time with patients			.81		.71
11. There will be loss of personal touch of a doctor			.69		.67
12. I would find another doctor			.63		.57
13. I would want to read patient information sheet				.80	.67
14. I would answer honestly				.74	.62

*h^2 refers to communalities.

†Item shared loading between factors above the critical value.

Variances accounted for by the four identified factors (Benefits, Privacy-Barrier, Interaction-Barrier, and Interest) after the rotation were 33.6%, 15.0%, 8.0%, and 7.2%, respectively. The item “Computers can be trusted” in the first factor (Benefits) shared loading (.41) with the second factor (Privacy-Barrier) above the critical value of .38. Also, the item “Too many mistakes will be made with computer” in the second factor (Privacy-Barrier) shared loading (.39) with the third factor (Interaction-Barrier) above the critical value.

The Benefits factor consisted of six items with factor loadings ranging from .79 to .54. The items loading on this factor cover perceived benefits toward the quality of medical consultation and means of achieving the benefits. The Privacy-Barrier factor consisted of three items dealing with patient concerns about privacy, with loadings ranging from .82 to .60. The Interaction-Barrier factor consisted of three items covering patient concerns about interference in the interaction with the physician, with loadings ranging from .81 to .63. Although the Interest factor consisted of only two items, both items had strong factor weightings (ie, .80 and .79). The stability of this factor was also apparent during execution of the five-factor solution. Both items of this factor continued to load together while the fifth factor consisted of one item pulled from the Interaction-Barrier factor.

Reliability

To estimate internal consistency reliability, we considered the following criteria for each subscale: (1) an item-total correlation of at least .3 for all items, (2) no increase in the Cronbach alpha coefficient if an item was deleted, and (3) general acceptability of the item means and standard deviations. All three criteria were met for the subscales (Table 4).

Table 4. Internal consistency of the subscales

Item	Mean (SD)*	Corrected Item-Total Correlation	Cronbach Alpha if Item Deleted
Benefits: Cronbach alpha .85			
1. Computers will help doctors with routine lifestyle questions	3.9 (0.87)	.77	.80
2. The computer is a good way to ask lifestyle questions	3.7 (0.94)	.62	.83
3. It would save doctors time.	3.7 (0.91)	.61	.83
4. Doctors will make better assessments with such computer systems	3.3 (0.85)	.59	.83
5. I would feel comfortable answering questions on a computer	3.9 (0.85)	.66	.82
6. Computers can be trusted	3.4 (0.95)	.57	.84
Privacy-Barrier: Cronbach alpha .70 (alpha .81†)			
7. I would worry about confidentiality	3.3 (1.1)	.53	.54
8. I do not want certain information about me on the computer	3.4 (1.1)	.52	.55
9. Too many mistakes will be made with computer	2.6 (0.84)	.46	.64
Interaction-Barrier: Cronbach alpha .67 (alpha .80†)			
10. Doctors would spend less time with patients	3.4 (0.99)	.42	.66
11. There will be loss of personal touch of a doctor	3.4 (1.2)	.56	.47
12. I would find another doctor	2.1 (0.97)	.49	.57
Interest: Cronbach alpha .50 (alpha .75†)			
13. I would want to read patient information sheet	4.3 (0.70)	.34	–
14. I would answer honestly	4.4 (0.63)	.34	–

*Scale 1 to 5: strongly disagree, agree, not sure, agree, strongly agree.

†Adjusted reliability coefficient, adjusted to compare to scales with six items.

The Cronbach alpha coefficients for the four subscales Benefits, Privacy-Barrier, Interaction-Barrier, and Interest were .85, .70, .67, and .50, respectively. There was no increase in Cronbach alpha if items were deleted from the first three subscales. This analysis did not apply to the Interest subscale as it had two items only. The item-total correlation for the subscales Benefits, Privacy-Barrier, and Interaction-Barrier ranged from .77 to .57, .53 to .46, and .52 to .44, respectively. We also calculated the reliability coefficients adjusted for the length of subscale [33], given that the number of items loading on the subscales varied and that Cronbach alpha is sensitive to number of items. The adjusted reliability coefficients were .81, .80, and .75 for the Privacy-Barrier, Interaction-Barrier, and Interest subscales, respectively, where adjustment was made to assume six items as for the Benefits subscale. This analysis assumes that the new items would be similar to the old items with respect to content and reliability.

Scale reliability over time was assessed with the test-retest data (n = 52). At T2, 52 patients were successfully reached out of 145 T1 participants who consented to the second contact. The reduced participation at T2 was due to (1) the study requirement that the second administration of the CLAS occur within 2 weeks of the first administration, and (2) the fact that many patients were difficult to reach because they had provided telephone numbers at work. The T2 participants were similar to the other T1 participants (n = 150) on sociodemographic characteristics, including age, country of birth, number of years lived in Canada, education level, employment status, income, English language abilities, access to computers, computer use in the last month, relationship status, experiences of intimate partner violence, number of visits to family practice, and perceived health. However, the T2 participants were less likely to be employed than participants who consented but could not be reached for second contact (χ^2_2= 7.0, $P < .05$). The time between T1 and T2 contacts averaged 16 days (SD 2.6, median 15, mode 15). The ICC analysis based on a two-way random effect model gave coefficients of .76 for the overall scale and .91, .82, .86, and .67 for the subscales of Benefits, Privacy-Barrier, Interaction-Barrier, and Interest, respectively. As the CLAS is a multidimensional scale, the test-retest reliability of the subscales was higher than the test-retest reliability of the overall scale.

Construct Validity

To evaluate validity of the derived constructs, several hypotheses were formulated based on a literature review. We hypothesized that the Benefits factor would be positively associated with participants’ frequent use of computers as greater familiarity with computers is likely to increase peoples’ comfort and perceptions of the benefits [2]. Also, we hypothesized that patients with poorer health would perceive the benefits of computer-based screening as high due to the limited time available for lifestyle inquiries during their routine health care visits. As computer-based screening has been found specifically beneficial for socially sensitive issues [2-4,36-39], it was hypothesized that participants reporting victimization by intimate partners would perceive the benefits as high. Existing studies report that patients are likely to perceive barriers in using preventive health services if they have low socioeconomic status or are immigrants [40,41]. Accordingly, it was hypothesized that the Privacy-Barrier and Interaction-Barrier factors would be positively associated with participants' non-Canadian-born status, low household income, unemployment, and lesser years of education. We also hypothesized that the Interest factor would be significantly associated with less use of computers and older age.

The hypotheses were tested by correlation analyses. The Benefits factor was positively associated with poorer self-perceived health and intimate partner victimization (r_p = .15, P = .03; r_{pb}= .19, P = .02) as hypothesized. However, it was not significantly associated with the use of computers, in contrast to our hypothesis. To explore further, we examined the mean scores of the Benefits subscale by participants' frequency of computer use in the last month. Participants who used computers every day or two to three times a week somewhat agreed with the Benefits (mean 3.7, SD 0.67), while participants who used computers once a week or once a month (mean 3.5, SD 0.50) or not at all (mean 3.6, SD 0.67) seemed to neither agree nor disagree with the Benefits.

As hypothesized, the Privacy-Barrier and Interaction-Barrier factors had positive significant associations with participants' non-Canadian-born status (r_{pb}= .19, P = .006; r_{pb}= .22, P = .001), low household income (r_p= .23, P = .002; r_p = .21, P = .004), and lower use of computers (r_s = .16, P = .03; r_s = .18, P = .01). Furthermore, older age at the time of immigration had a positive association with both the Privacy-Barrier and Interaction-Barrier factors (r_p = .27, P= .02; r_p = .28, P = .02). The Interaction-Barrier factor also had significant associations with participants' unemployment status and lesser years of education (r_{pb} = .16, P = .03; r_s = .18, $P < .01$). The Interest factor had significant positive associations with older age (r_p = .16, P = .03) and less use of computers (r_s = .14, P = .04).

Discussion

The CLAS has demonstrated good preliminary psychometric properties and shows promise as a tool for assessing patient attitudes toward computer-based health-risk assessments. Each of the four latent constructs or derived subscales of the CLAS had good internal consistency that exceeded the recommended threshold of 0.7 [42] after adjusting for the number of items. Furthermore, the multidimensionality of the CLAS highlights different clusters of barriers perceived by patients in the use of interactive technology, namely privacy and interaction with physicians. This study also provides much needed initial evidence of the scale stability over time through test-retest analysis. This is important as some researchers and health care interventionists aim to assess patient attitudes toward computer-based health-risk assessments before and after new initiatives.

Implications

The use of a psychometrically validated scale is an essential element in facilitating clinical and policy decisions about the application of computer-based health-risk assessments. This is of particular importance for sensitive health risks and conditions where superiority of computer-based risk assessments over personal interviews is already well documented with respect to patient disclosure of socially sensitive information. These health risks and conditions include behaviors related to sex, alcohol, drugs, HIV, and violence [2-4,36-39]. A similar link is demonstrated in our study as a positive association between women's victimization at the hands of their intimate partner and the Benefits subscale. Literature shows that women experiencing partner abuse seldom spontaneously disclose it to health care providers [43,44], who frequently fail to detect victims of abuse due to time pressure, priority of acute problems, and discomfort [45,46]. At the same time, clinicians' questioning about abuse is the most significant predictor of women's disclosure [47]. Computer-based screening matches abused women's preferences for "direct questioning," and it has limited dependency on physician time. Above all, it is a nonjudgmental and anonymous way of asking about socially sensitive health risks. Perhaps it explains why abused women in our study perceived higher benefits of the computer-based screening. Our future work will test the computer-based screening intervention in a family practice setting for the detection and disclosure of partner abuse.

The findings also highlight the complex nature of human behavior. Study participants perceived barriers in two distinct ways: barriers regarding privacy and barriers regarding interaction with physicians. At the implementation level, this underscores the need to measure both domains to understand and thereafter address effective use of computer-based health-risk assessments. At the theoretical level, this distinction is novel to the original conception of the scale. Possibly, patient attitudes have taken specific forms with the increasing use of computers. Recent studies reveal that use of the Internet for health information influences the way people relate to physicians, make medical decisions, and access health services [48,49]. In 2007, a telephone survey with 2479 Canadians examined their attitudes toward electronic health information and their privacy [50]. The survey found that 9 out of 10 people perceived the use of electronic health information as integral to the provision of high-quality care but had mixed confidence about the protection of health information. Future research should further examine the domains of privacy and interaction barriers in the use of computer-based health-risk assessments. Other studies report that patients' perceptions toward computer-based lifestyle assessments are positively increased after they are provided the actual experience [2,19].

Our post hoc analyses indicate that study participants who were immigrants or had lower socioeconomic status perceived more barriers. This raises two critical questions: (1) Is this an extension of the "digital divide?", and (2) What does it mean for implementation? The term "digital divide" stems from research and refers to "decreased access to information technologies, particularly the Internet, for racial and ethnic minorities, person with disabilities, rural populations, and those with low socioeconomic status" [51] (p 449). The digital divide requires vigilance when using certain health information technologies, such as the Internet [52,53]. In contrast, computer-based health-risk assessments in health care settings bridge the digital divide because these programs provide tailored health information to the patients at the point of care. They may play a positive role in addressing patients' unequal access to health information and care—an anticipated impact similar to telemedicine [54].

Limitations

Several limitations of this study should be noted. The CLAS predominantly measures the decision-making aspect of human behavior, though it has relevance for research on explaining and changing behavior regarding computerized assessments. Future studies should explore other aspects such as patient self-efficacy and cue-to-action. The construct of Interest would also benefit from further conceptual development. Further, our analysis of the construct validity is post hoc in nature. Many of the correlations were not strong even when significant. This is possibly due to our convenience-based use of a larger survey to select variables which in turn had a more distal than proximal relationship with the CLAS constructs. Although we found support for most of our hypothesized relationships, the Benefits subscale was not associated with the participants' use of computers, contrary to our hypothesis. The study sample was relatively more educated than the average general population, and 87% of the participants had access to computers at home or work; almost a similar proportion reported using the computer every day or at least two to three times a week. Perhaps frequent use of computers makes people think critically about their advantages and disadvantages, leading to a cautious assessment of their benefits. On other side, it is also possible that computers have now become part of our everyday life and their benefits are taken for granted, reducing the level of perceived benefits seen a few years ago. Future research with larger samples should examine this further and establish the construct validity with a priori selection of variables. Also, it will be important to conduct a classic multitrait-multimethod study in which the four constructs on the CLAS are assessed via different methods (eg, peer ratings, behavior observations). This type of study will provide evidence for both convergent and discriminate aspects of the CLAS construct validity.

Caution is warranted regarding the generalizability of our study findings. We evaluated psychometric properties of the CLAS with female patients only. A future study involving both men and women is needed to ensure its applicability to all patients visiting primary health care settings. Further, patients were recruited from a single site. However, the collaborating clinic had several physicians and served a large number of diverse patients with estimated annual visits of 50,000. The study obtained a high response rate and, reassuringly, the participants were similar to females residing in Toronto in terms of immigration and marital status [55,56]. At the same time, study participants had relatively higher levels of income and education than the general population. The test-retest results of our study may have limited generalizability as participants in the second administration of the CLAS were more likely to be unemployed than the rest of participants. Nevertheless, the two groups were similar for all other sociodemographic and health-related variables that were measured. Further research is needed with a heterogeneous sample as an important next step to advance the generalizability of the scale.

Conclusion

This study of patients in a family practice setting advances our understanding of the properties, applicability, and generalizability of the CLAS. This is an important improvement over previous assessments of other scales that relied on samples of convenience or were not specific to patient populations. Furthermore, the phrasing of items in the CLAS is expected to allow people from different ethnocultural backgrounds to reply in a meaningful way, unlike some other existing scales. At the same time, future research with a heterogeneous sample is needed to enhance its generalizability by gender and socioeconomic status while examining the utility for low and high users of computers. In conclusion, this study is a step toward facilitating research and interventions for promoting patient acceptance of computer interactive technology.

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Conflicts of Interest

None declared.

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Abbreviations

CLAS: Computerized Lifestyle Assessment Scale
ICC: intraclass correlation
PCA: principal component analysis

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Original Paper

The Impact of Inaccurate Internet Health Information in a Secondary School Learning Environment

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Abstract

Background: Patients in the United States commonly use the Internet to acquire health information. While a significant amount of health-related information is available on the Internet, the accuracy of this information is highly variable.

Objectives: The objective of the study was to determine how effectively students can assess the accuracy of Internet-based material when gathering information on a controversial medical topic using simple keyword searches.

Methods: A group of 34 students from the science magnet high school in Houston, Texas searched for the terms “vaccine safety” and “vaccine danger” using Google and then answered questions regarding the accuracy of the health information on the returned sites. The students were also asked to describe the lessons they learned in the exercise and to answer questions regarding the strength of evidence for seven statements regarding vaccinations. Because of the surprising revelation that the majority of students left the exercise with inaccurate information concerning the safety and efficacy of vaccines, these same students participated in a follow-up study in which a fact-based vaccine video was shown, after which the assessment of student knowledge was repeated.

Results: Of the 34 participants, 20 (59%) thought that the Internet sites were accurate on the whole, even though over half of the links (22 out of 40, 55%) that the students viewed were, in fact, inaccurate on the whole. A high percentage of the students left the first exercise with significant misconceptions about vaccines; 18 of the 34 participants (53%) reported inaccurate statements about vaccines in the lessons they learned. Of the 41 verifiable facts about vaccines that were reported by participants in their lessons-learned statement, 24 of those facts (59%) were incorrect. Following presentation of the film, the majority of students left the exercise with correct information about vaccines, based on their lessons-learned statement. In this case, 29 of the 31 participants (94%) reported accurate information about vaccines. Of the 49 verifiable facts about vaccines that were reported by participants, only 2 (4%) were incorrect. Students had higher correct scores in the “strength of evidence” exercise following exposure to the video as well.

Conclusions: Allowing students to use the Internet to gain information about medical topics should be approached with care since students may take away predominantly incorrect information. It is important to follow up conflicting information with a solid, unambiguous message that communicates those lessons that the instructor deems most important. This final message should be fact based but may need to contain an anecdotal component to counter the strong emotional message that is often delivered by inaccurate Internet sites.

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KEYWORDS

Health education; health informatics; popular medicine; vaccines

Introduction

Use of the Internet for the acquisition of health information in the United States is widespread and growing [1]. Whether looking for information about disease symptoms or treatment options, health consumers see the Internet as an important tool for gathering health information. One benefit of the Internet is its potential to provide current and timely sources of health information in ways that traditional print resources cannot. This is extremely important in the health domain since information may change rapidly and currency of information can be very important. The Internet also provides health consumers with a wide range of no-cost material that is easy to access. Printed materials carry acquisition costs in terms of both time and money and may be difficult to obtain for those who are not health professionals, leading consumers to use the Internet [2]. Clearly, the advantages of obtaining health information via the Internet make it an attractive source for the average health consumer.

Unfortunately, these advantages do not come without some cost. Because information is available quickly, it can be transient in nature, and excellent sources found today may not be available for use again in the future. While there are many sources on the Internet, the accuracy of all these sources may not be the same. Worse, the accuracy of specific content is difficult to ascertain quickly and easily. This means that consumers of Internet health information must have good scientific literacy to be able to sift thorough copious amounts of information and make an informed choice about which to keep and which to discard. Because of this abundance of information of unknown accuracy, consumers of this information typically employ a number of different strategies to aid them in their efforts [3].

For many health issues, there is widespread agreement in the medical community about the proper course of action (eg, how to treat a minor cut). In other situations, there may be different opinions about the correct course of treatment (eg, angioplasty vs coronary artery bypass) based on the specific medical facts of a particular case or how an individual patient presents. These kinds of differences are understandable and are inherent in the practice of medicine. Other topics, however, while enjoying widespread agreement in the mainstream medical community, are still the source of significant controversy due to the efforts of some outspoken groups and individuals. The Internet provides these groups a strong voice by allowing them to share their views in a manner similar to sources of medical information that are generally accepted as authoritative. On the Internet, medical information from trusted sources like the American Medical Association or the National Institutes of Health must compete with information from groups and individuals who may not be trained in the field or who may interpret data in unscientific ways that support their particular viewpoints. Even the best Internet search engines do not return results in the order of authenticity or trustworthiness of the source, and the brief descriptions that are included in search results do not provide sufficient information for a consumer to make a well-informed assessment of the accuracy or reliability of the site [4]. This makes finding and evaluating this type of health information on the Internet particularly difficult [5].

Information about vaccines falls into the category of medical topics that have a high degree of controversy between the mainstream medical establishment and groups who disagree with the generally accepted lines of thought. For the most part, vaccines are considered to be one of the most important medical advances, eradicating or significantly reducing mortality from a host of now-preventable diseases. When administered according to well-established protocols, vaccines are considered both safe and effective. Their impact in developing countries is especially important since many diseases that are relatively rare in the developed world still claim large numbers of lives [6]. Despite the scientific evidence that illustrates the benefits of vaccines, there are a number of groups who espouse the contrary view that vaccines are actually harmful and may cause, rather than prevent, disease [7], and the number of parents in the United States who choose not to vaccinate their children continues to grow [8].

As part of an effort to teach students to gather and evaluate health information, we developed an exercise that had them seek out information about vaccines using the Internet as their primary data source. The goal of this research was to determine how effectively students could assess the accuracy of Internet-based material when gathering information on a controversial medical topic using simple keyword searches. Based on this teaching experience, we make suggestions about the design of instruction material for similar exercises.

Methods

Methods for the Search Exercise

A group of 34 juniors and seniors from the science magnet high school in Houston, Texas (Milby Science Institute) were recruited to participate in the study. In the United States, magnet schools are schools that draw academically talented students from a wide geographic area to allow them to focus on a specific concentration of study, like music, science, or mathematics. Participants were volunteers from an advanced science class at Milby. There were 17 males and 17 females. Although ethnicity data were not collected from the participants, Milby is comprised of 94% Hispanic, 4% African American, 1% Asian, and 1% White students. Although Milby is predominantly Hispanic, its minority enrollment is similar to that of the Houston Independent School District as a whole. The Houston Independent School District is the seventh largest public school system in the nation, and with almost 200,000 students, is the largest in Texas. Its student body is 60% Hispanic, 28% African American, 8% White, and 3% Asian. At Milby, 79% of the students are classified as economically disadvantaged, as defined by the federal guidelines for participation in the free/reduced-price lunch program, and this percentage is identical to the Houston Independent School District as a whole. This demographic is representative of that found in most large urban educational environments.

Table 1. Accuracy judgments of sites that were returned by the Google search for "vaccine danger"

Search Result Position	Site URL	Google Title Description	Accurate?
1	www.know-vaccines.org/parent.html (http://www.webcitation.org/5YKI9b32b)	Know Vaccines – Contact Information	No
2	www.nccn.net/~wwithin/vaccine.htm (http://www.webcitation.org/5YKIKHZTF)	Vaccination Information & Choice Network - Vaccine/Vaccination	No
3	www.cbsnews.com/stories/2003/08/21/eveningnews/main569522.shtml (http://www.webcitation.org/5YKIW0Ycm)	Military Mute On Vaccine Danger?	No
4	www.909shot.com/History/Newsletters/nlr1296.htm (http://www.webcitation.org/5YKIcRpCq)	The Vaccine Reaction	No
5	www.shirleys-wellness-cafe.com/vaccines.htm http://www.webcitation.org/5YKIiwNgh)	Vaccines Warning: Are they really safe and effective?	No
6	www.shirleys-wellness-cafe.com/petvacc.htm (http://www.webcitation.org/5YKIo2L58)	Danger of Pet Vaccination - Vaccinosis - adverse reaction to ...	No
7	www.thinktwice.com/multiple.htm (http://www.webcitation.org/5YKIuVzbs)	ThinkTwice Global Vaccine Institute: Multiple Vaccines. Danger!	No
8	www.veteransforpeace.org/Military_mute_on_082103.htm (WebCite not available)	Military Mute on Vaccine Danger?	No
9	www.mercola.com/forms/vaccine_teleconference.htm (http://www.webcitation.org/5YKJDuxJl)	The Danger of Vaccines, and How You Can Legally Avoid Them	No
10	educateyourself.org/cn/infantimmunizationweek14apr05.shtml (http://www.webcitation.org/5YKJIvWaw)	National Infant Immunization week	No
11	www.shirleyswellnessnews.com/n/n11-02.htm (http://www.webcitation.org/5YKJNehtW)	Shirley's Wellness Café Newsletter	No
12	Inquirer.gn.apc.org/rubella2.html (http://www.webcitation.org/5YKJa9ElJ)	Gambling with Rubella Vaccine	No
13	www.909shot.com/Articles/gnspriva.htm (http://www.webcitation.org/5YKJyv8RA)	Vaccination Nation	No
14	www.cbsnews.com/stories/2004/03/01/eveningnews/main603284.shtml (http://www.webcitation.org/5YKK4FTBM)	Military Vaccine Flattens GI, 17	No
15	Bmj.bmjjournals.com/cgi/eletters/316/7129/446 (http://www.webcitation.org/5YKK9vPQH)	Bmj.com Rapid Response for Masters and Beyreuther, 316(7129)446-448	Yes
16	www.eczemavoice.com/forum/messages/270/441.html?1041724527 (http://www.webcitation.org/5YKkX1cYE)	Eczema Voice	No
17	Society.guardian.co.uk/publichealth/story/0,,588304,00.html (WebCite not available)	SocietyGuardian.co.uk | Society | New claims of vaccine danger	Yes
18	www.geocities.com/heartland/8148/vac.html (http://www.webcitation.org/5YKkhJnNU)	Be informed about vaccines	No
19	http://www.advancedhealthplan.com/mothersday.html (http://www.webcitation.org/5YKl0YaP7)	Mothers day Proclamation Original by Julia Ward Howe.	No
20	www.whale.to/v/tebb/ap7.html (http://www.webcitation.org/5YKl3ani5)	Compulsory Vaccination in Bombay	No

Table 2. Accuracy judgments of sites that were returned by the Google search for "vaccine safety"

Search Result Position	Site URL	Google Title Description	Accurate?
1	www.vaccinesafety.edu/ (http://www.webcitation.org/5YKlm91Os)	Institute for Vaccine Safety (IVS)	Yes
2	www.vaccinesafety.edu/thi-table.htm (http://www.webcitation.org/5YKonwPOM)	Institute for Vaccine Safety – Thimerosal Table	Yes
3	Vaccines.net/newpage114.htm (http://www.webcitation.org/5YKlyCebp)	Vaccine Safety	No
4	www.cdc.gov/nip/vacsafe/ (http://www.webcitation.org/5YKndg6d3)	NIP: Vacsafe/Overview (main Page)	Yes
5	www.cdc.gov/nip/menus/vacc_safety.htm (http://www.webcitation.org/5YKoLsNzP)	NIP: Menus/Vaccine Safety	Yes
6	www.909shot.com/ (http://www.webcitation.org/5YKmwGu3k)	National Vaccine Information Center	No
7	www.immunize.org/safety/ (http://www.webcitation.org/5YKmzAt57)	Vaccine safety information form IAC	Yes
8	www.who.int/immunization_safety/en/ (http://www.webcitation.org/5YKn2I3N0)	WHO | Immunization safety	Yes
9	www.fda.gov/Fdac/features/095_vacc.html (http://www.webcitation.org/5YKn6l54C)	How FDA works to insure vaccine safety	Yes
10	www.vaccines.net/newpage114.htm (http://www.webcitation.org/5YKn9dNpn)	Vaccine Safety	No
11	http://www.fda.gov/fdac/features/2001/401_vacc.html (http://www.webcitation.org/5YKnCG307)	Understanding Vaccine Safety: Immunization Remains Our Best ...	Yes
12	www.nap.edu/readingroom/books/vaccine/ (http://www.webcitation.org/5YKnFCzoa)	Vaccine Safety Forum	Yes
13	www.hhs.gov/nvpo/vacsafe.htm (http://www.webcitation.org/5YKnjRzqe)	CDC National Vaccine Program Office: Vaccine Safety	Yes
14	www.who.int/vaccine_safety/ (http://www.webcitation.org/5YKnmfn9c)	WHO | Global Advisory Committee on Vaccine Safety (GACVS)	Yes
15	www.mercola.com/2003/jan/15/vaccine_benefits.htm (WebCite not available)	Vaccine Safety and Benefits Not Scientifically Proven	No
16	www.vaccineinformation.org/safety.asp (http://www.webcitation.org/5YKnzOd7C)	Vaccine Safety	Yes
17	news.bbc.co.uk/1/hi/health/3640898.stm (http://www.webcitation.org/5YKo2JmE8)	BBC NEWS | Health | Study backs safety of MMR vaccine	Yes
18	pediatrics.about.com/cs/immunizations/a/vaccine_safety.htm (http://www.webcitation.org/5YKo5Eb1S)	Understanding Vaccine Safety	Yes
19	www.iom.edu/report.asp?id=25184 (http://www.webcitation.org/5YKoCXBgt)	Vaccine Safety Research, Data Access, and Public Trust – Institute…	Yes
20	www.Michigan.gov/documents/Vaccine-Safety_7192_7.pdf (WebCite not available)	Vaccine Safety	Yes

The study was reviewed and approved by the Institutional Review Boards at Rice University and the Houston Independent School District. Since all but four of the participants were under the age of 18 (median age 17 years), all of the participants and their legal guardians gave written informed consent. The students were financially compensated for their participation in the assessment activity and were debriefed about the purpose of the study at its conclusion.

Participants were not told the purpose of the study, but rather that they were “helping to assess the suitability of assignments for ‘Bioengineering and World Health,’ a new course for high school students.” The students were asked to search for the terms “vaccine safety” and “vaccine danger” using the Google search engine and then to answer a number of questions regarding the accuracy of the health information on the sites. The students were in the same room when the data were collected, but they worked alone on their own computer. We judged the accuracy of the sites on a simple, single dimension: sites that argued that vaccines were inherently dangerous were judged to be inaccurate (not evidenced based), while sites that argued that vaccines were generally beneficial were judged to be accurate (evidenced based). Sponsored links were excluded from the analysis. We then compared that to the students’ assessments based on their answers to the following question: “Do you think that the sites that pop up on the two searches contain accurate health information? Why or why not?” This question forced the students to make a collective assessment of the accuracy of the sites they had just viewed. Table 1 lists the sites that were returned by the Google search for “vaccine danger,” and Table 2 lists the sites returned for “vaccine safety.” In both tables, the list of sites is in the same order as that returned by the search engine.

At the end of the assessment exercise, the students were asked to write down what they learned from the assignment, and approximately half of the students (n = 17) also filled out a survey that had questions regarding the strength of evidence for seven aspects of vaccinations. These questions required the student to indicate the level of scientific evidence supporting each statement based on the information the students collected. This survey included the following statements: (1) Vaccines have contributed to the eradication of certain diseases; (2) Diseases had already begun to disappear before vaccines were introduced because of better hygiene and sanitation; (3) Vaccines prevent childhood deaths; (4) Vaccines cause autism; (5) Vaccines cause diabetes; (6) Vaccines prevent epidemics; and (7) Vaccines weaken the immune system.

Methods for the Video Exercise

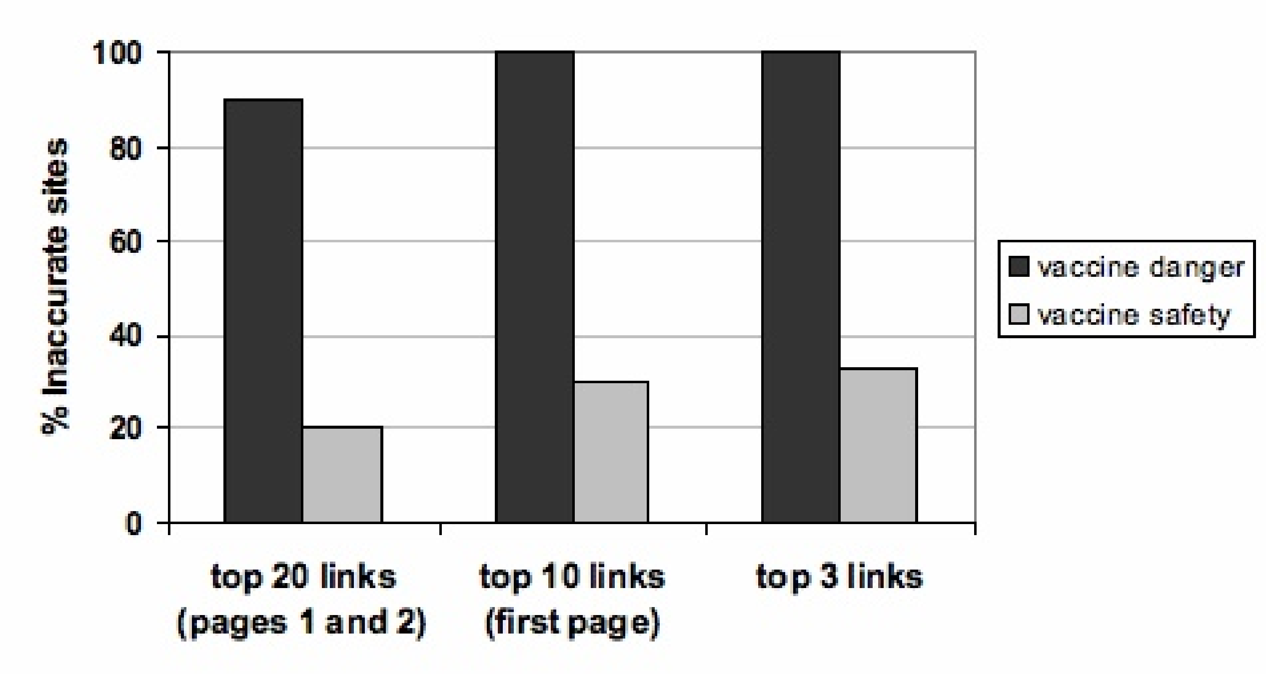
Because of the surprising (and troubling) results from the search study, these same students were invited to participate in a follow-up study in which a video from the Children’s Hospital of Philadelphia’s Vaccine Education Center entitled “Vaccines: Separating Fact from Fear” was shown [9]. This short, 27-minute film addressed common misconceptions about vaccines and answered each misconception with a fact-based answer. The follow-up study was conducted within 7 days after each participant’s initial visit, and 31 of the original 34 students were able to participate. When the students were asked to participate in this follow-up study, they were simply told that their participation in assessing another module of the course was desired. After watching the video, the students were again asked to write down what they learned from the assignment and to complete the same questionnaire that inquired about the strength of evidence for seven aspects of vaccinations. Simple *t* tests (2-tailed, alpha = .05) were conducted to assess if the responses to the strength-of-evidence questions were different following the video exercise.

Results

Results From the Search Exercise

Combining the search results for both search terms (vaccine danger and vaccine safety), it was found that 22 of the 40 links (55%) in the first two pages (40 total search results across both search terms) were inaccurate. Frequently, users restrict their exploration of search results to the first page of results that are returned [10], and this increases the percentage of inaccurate sites to 65% (26 out of 40 links). In a study of how people search for health-related information on the Internet, Eysenbach and Köhler showed that the first three links on a search results page account for approximately 80% of the subsequent click-throughs [11]. Using this measure, 67% (27 out of 40 links) of the sites returned from the Google search were inaccurate. Figure 1 shows the percentage of inaccurate sites for three different levels of search results (2 pages, 1 page, and top 3 links) for each of the search terms used in the study. The percentage of sites found to be inaccurate for the Google search using our simple decision rule is consistent with results reported by Abbott [12]. Clearly, the probability of encountering inaccurate information is very high given the content of the sites that are most likely to be looked at following a search. In fact, if a user searched the term “vaccine danger” only, the first page of search results would have contained no accurate sites.

Figure 1. Percentage of inaccurate sites for three different levels of search results



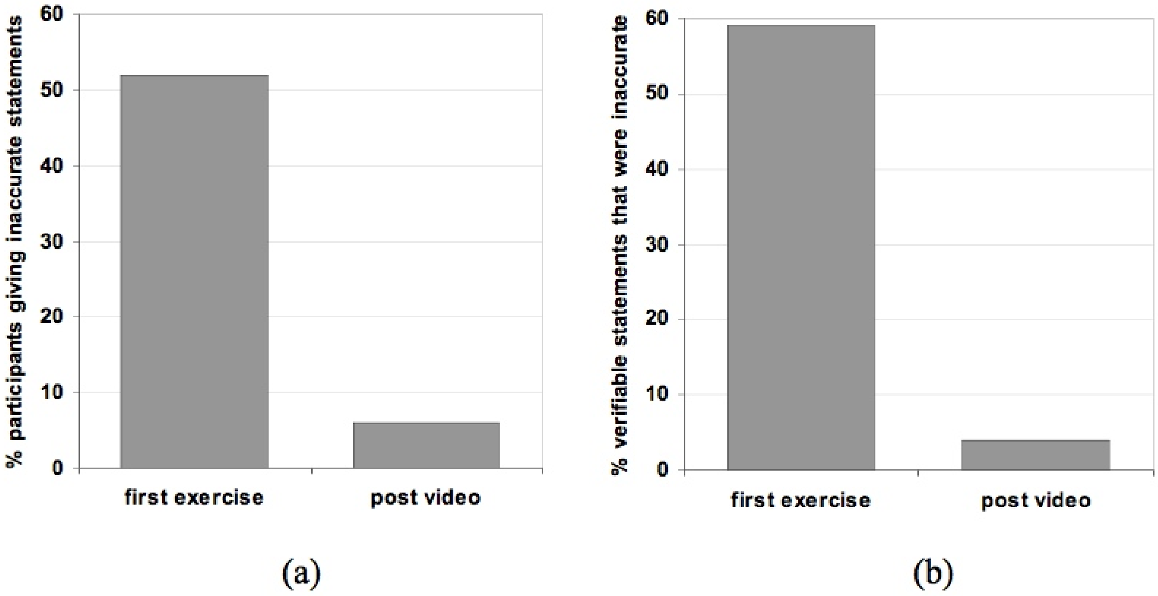
Student assessment of the accuracy of the returned sites indicated that 20 out of 34 participants (59%) thought that the sites were *accurate* on the whole, while 9 out of 34 participants (26%) thought that the sites were *inaccurate* on the whole. Only 5 students out of the group of 34 (15%) thought that site accuracy was mixed, with some sites being accurate on the whole and others not. These results are consistent with the results of a Pew Research study [13] that found that 52% of those visiting health websites believe that almost all or most of the information is correct.

A high percentage of the students left the exercise with significant misconceptions about vaccines, based on an analysis of the lessons-learned question they were asked to complete following their search. In this exercise, 18 of 34 participants (53%) provided inaccurate statements about vaccines. Of the 41 verifiable facts about vaccines that were reported by participants in their lessons-learned answers, 24 facts (59%) were *incorrect.* These incorrect facts included statements such as “vaccines can cause diabetes,” “vaccines can cause other diseases later in life,” and “children are diagnosed with autism due to a number of mandatory vaccines.”

Results From the Video Exercise

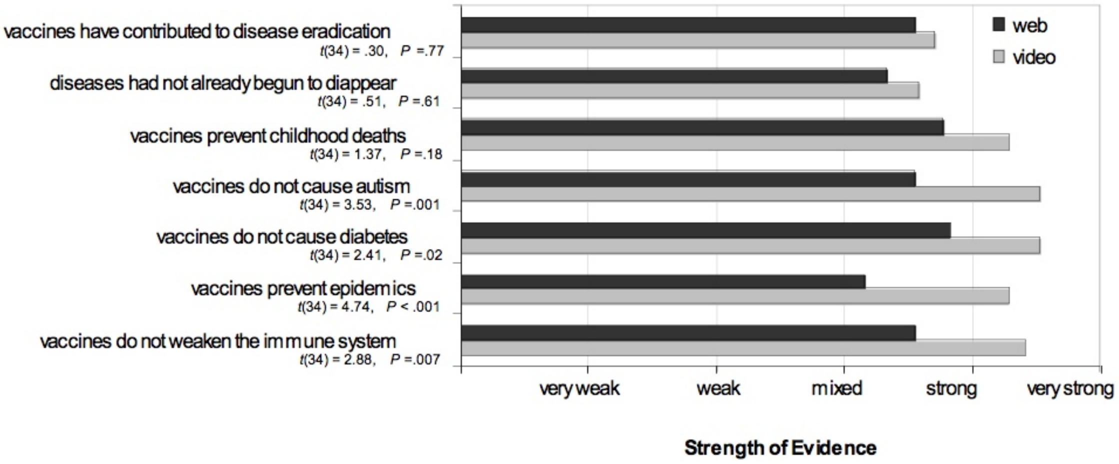
After completing the second portion of the study, where students watched a film refuting vaccine myths, the majority of students left the exercise with correct information about vaccines, based on their short lessons-learned statement. In this case, 29 of the 31 students (94%) reported accurate information about vaccines. Of the 49 verifiable facts about vaccines that were reported by participants in their lessons-learned answers, only two (4%) were incorrect (Figure 2).

Figure 2. (a) Percentage of students who gave inaccurate statements in the first exercise and after the video; (b) percentage of inaccurate statements given by students in the first exercise and after the video



Most of the facts reported by the students after the second study centered on the idea that vaccines did not cause other diseases and that while there were certainly risks associated with vaccines, the benefits far outweighed these risks. Following the presentation of the film, students also scored significantly higher (alpha = .05) on most of the questions regarding the strength of evidence for the statements about vaccine facts (Figure 3).

Figure 3. Average response to questions about the strength of evidence for statements about vaccines (dark bars are scores collected after the Web search exercise; light bars are scores collected from the same participants following the video exercise)



Discussion

Principal Results

These results show that even high school students with a science-focused education have a difficult time distinguishing trustworthy medical sites from untrustworthy ones, even though the majority of the information found in these searches is, in fact, inaccurate. Further, the lessons they report learning tend to reflect the most inaccurate information they encountered.

The tasks performed by the students in this exercise are similar to the information- gathering tasks performed by countless consumers of Internet health information every day, and many of these consumers (about 90 million in the United States alone) find medical information hard to understand [14]. Considering the fact that the majority of the information found by these searches on this particularly contentious health topic was *inaccurate* and that over half of the people who visit health websites tend to believe that the majority of the information they find there is *accurate* [13], it quickly becomes evident that there may be significant inaccuracies in the information that people take away from their efforts to gather information on health-related issues.

The problem is of particular concern in an educational setting. It is obviously undesirable to have students engage in Internet-based, information-gathering exercises if they leave the classroom with learnings that are the exact opposite of the intended message. The majority of the students in this exercise initially took away information about vaccines that was substantially incorrect. Their primary misconceptions were that that the risks associated with vaccines outweighed the benefits and that vaccines actually caused, rather than prevented, many diseases. These lessons were reported by the majority of the students even though the intent of the exercise was to teach students about the importance of vaccines in improving health. Given the potentially negative consequences of having students walk away with such erroneous health information, it is important to consider how to best guard against this undesirable outcome.

Guiding Student Internet Use

The easiest method to insure a specific outcome would be to simply restrict the websites that students are allowed to use during the course of completing an exercise in class to those sites that are deemed reputable and accurate by the instructor. For example, in the exercise described in this paper, the instructors could have directed the students to sites known to be accurate, such as the National Institutes of Health and the World Health Organization, to find information regarding vaccines. While this approach will likely yield the desired immediate result of getting accurate information to the students, it could potentially reinforce the students' idea that health information on the Web is generally accurate, when in fact the opposite appears to be true. It also fails to train students to think independently about the accuracy of information they find—a skill that is very important in later endeavors involving any information acquisition.

Another potentially simple way to steer students to accurate sites would be by identifying reputable medical sites through the use of "trusted authority" rating systems. These systems work in a fashion similar to the association of a business with the Better Business Bureau or to the ratings of products by an independent organization like Consumers Union. While these systems enjoy widespread adoption in certain domains, the Internet does not currently have a widely accepted trusted authority. Gagliardi and Jadad [15] and Pandolfini and Bonati [16] provide an overview of Internet rating systems. The fundamental flaw with rating systems on the Internet, however, is that there is no central controlling authority. This means that sites are not required to have their content reviewed or rated, and rating systems are not required to be proven valid or impartial. Because the use of rating and review systems is still haphazard, this method of steering students to accurate content is likely insufficient as well.

In the past, health information was often obtained through intermediaries, which were trusted figures like doctors and nurses. The rise of the Internet has given information seekers the chance for greater autonomy through the use of so-called apomediaries [17,18]. Unlike a traditional intermediary, who is a gate-keeper of information, apomediaries help a user find information. The Web itself is, of course, one form of apomediary, but generally the apomediation takes the form of advice given by other users on the Web by way of site recommendations, blogs, or even topic-specific information. This apomediation allows the information seeker to get information from a number of sources and exercise judgments about the credibility of the sources based on the collective preponderance of evidence they have encountered. If the apomediaries are deemed trustworthy in the eyes of the user, then this method can be beneficial, provided that the information supplied by the apomediaries is, in fact, accurate.

Ideally, students and consumers of health information should be trained to critically evaluate the information they find on the Web [19,20]. This can be a complex undertaking [21] because people use a variety of methods to determine the trustworthiness of a site. One method is the slow buildup of trust in a site through extended use [22]. This is a common technique for the selection of trusted news sites [23]. While the trust model may be effective, it is a lengthy process and does not lend itself well to the acquisition of knowledge for which the user desires to access only once. Further, it does not aid in the recognition of reliable sources based on the results of an Internet search.

In a search environment, users must quickly sort through various search results to make a determination of what information they are going to use (ie, information they place provisional trust in) and what information that they are going to discard (ie, information that they have deemed to be untrustworthy). Users employ a number of heuristics to make this initial determination, and, unfortunately, most of the techniques used have little to do with the actual content. One of the most common heuristics is design feature analysis [24], in which users gauge trustworthiness based on the physical design attributes of the site. However, Kunst and colleagues [25] have shown that in the Internet realm there is little correlation between the physical design attributes of a site and the reliability of the information contained on that site. Even if the physical attributes of the site follow presentation guidelines specific to medical information websites [26,27], the correlation remains low [25,28]. Another dimension related to page style is the use of scientific jargon in the presentation of the content. The use of scientific jargon in the presentation of medical information tends to increase the degree to which consumers are persuaded by the material [29]. Since both accurate and inaccurate sites tend to use similar language, a site's use of medical jargon is probably not helpful in assessing the validity of the site.

Other dimensions of the heuristic analyses include the assessment of the source based on the degree to which the author is viewed as an authority. Name or title recognition is one way users make this assessment. The validity of this technique has not yet been established in the literature, but it is a technique that is commonly employed by users [11,30]. Interestingly, the authority of the source appears to be greatly discounted in the presentation of personal anecdotes. If information has high face validity, users may ascribe more trust to the source than would be warranted upon close inspection of the facts. Some students in this exercise reported that the inclusion of personal stories and testimonials on the websites was highly compelling. Surprisingly, these students also reported that the opposite was true as well: sites that had an abundance of information that was presented in an authoritative, business-like fashion (often in the form of links to peer-reviewed material) were viewed as *less compelling*. It is not known how compelling websites change the trust equation, but data from these participants suggest that anecdotal information carried significant weight since this information was very likely to be reported by the students when they described what lessons they had learned from the exercise. The technique appears to be equally effective for the presentation of accurate information as well. The film used in the follow-up session, while factually accurate and produced by a reputable organization, contained a significant number of stories and anecdotes by parents whose children were protected by vaccinations. The film used a trusted authority (a doctor) to lead the narrative, but his fact-based presentation was always accompanied by an anecdotal story presented by a “real person.” Thus, the establishment of emotional appeal, even for the presentation of fact-based evidence, appears to be of high importance.

Conclusions

This paper presents a cautionary tale about using the Internet as an instructional tool for controversial medical material. Letting students use the Internet to gain information should be approached with care since students may come away with an incorrect message. While restriction of unstructured Internet activities may be the simplest solution, it does not train the students to use this valuable resource with a critical eye outside the classroom. It is very important to follow up conflicting information, like that commonly found on the Internet, with a solid, unambiguous message that communicates those lessons that the instructor wants the students to take away. This final message delivered to the student should be fact-based, but may need to contain an anecdotal component to counter the strong emotional message that is often delivered by inaccurate sites [31].

Instructors also need to insure that the intended message of the lesson is the one that students have actually retained over the course the instruction. By demonstrating to the students that health information on the Internet is highly variable in its accuracy, and that attributes that commonly influence trust (eg, authority figures, physical design, URL name) may not be good predictors of site accuracy, instructors can help students begin to develop the critical analytical skills necessary to assess the accuracy of Internet information. By presenting both accurate and inaccurate sites for the students to evaluate, the instructor can ensure that not only are the students leaving the classroom with the right information for the specific lesson at hand, but that they also leave a bit more prepared to make these critical evaluations in the real world when they become actual consumers of health information.

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Conflicts of Interest

None declared.

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Original Paper

Self-Reported Differences in Empowerment Between Lurkers and Posters in Online Patient Support Groups

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Abstract

Background: Patients who visit online support groups benefit in various ways. Results of our earlier study indicated that participation in online support groups had a profound effect on the participants' feelings of "being empowered." However, most studies of online patient support groups have focused on the members of these groups who actively contribute by sending postings (posters). Thus far, little is known about the impact for "lurkers" (ie, those who do not actively participate by sending postings).

Objective: In the present study, we explored if lurkers in online patient support groups profit to the same extent as posters do.

Methods: We searched the Internet with the search engine Google to identify all Dutch online support groups for patients with breast cancer, fibromyalgia, and arthritis. Invitations to complete an online survey were sent out by the owners of 19 groups. In the online questionnaire, we asked questions about demographic and health characteristics, use of and satisfaction with the online support group, empowering processes, and empowering outcomes. The online questionnaire was completed by 528 individuals, of which 109 (21%) identified themselves as lurkers.

Results: Lurkers (mean age 47 years) were slightly older than active participants (mean age 43 years, $P = .002$), had a shorter disease history (time since diagnosis 3.7 years vs 5.4 years, $P = .001$), and reported lower mental well-being (SF 12 subscore 37.7 vs 40.5, $P = .004$). No significant differences were found in other demographic variables. Posters indicated visiting the online support groups significantly more often for social reasons, such as curiosity about how other members were doing, to enjoy themselves, as a part of their daily routine (all $P < .001$), and because other members expected them to be there ($P = .003$). Lurkers and posters did not differ in their information-related reasons for visiting the online support group. Lurkers were significantly less satisfied with the online support group compared to posters ($P < .001$). With regard to empowering processes such as "exchanging information" and "finding recognition," lurkers scored significantly lower than posters. However, lurkers did not differ significantly from posters with regard to most empowering outcomes, such as "being better informed," "feeling more confident in the relationship with their physician," "improved acceptance of the disease," "feeling more confident about the treatment," "enhanced self-esteem," and "increased optimism and control." The exception was "enhanced social well-being," which scored significantly lower for lurkers compared to posters ($P < .001$).

Conclusion: Our study revealed that participation in an online support group had the same profound effect on lurkers' self-reported feelings of being empowered in several areas as it had on posters. Apparently, reading in itself is sufficient to profit from participation in an online patient support group.

(J Med Internet Res 2008;10(2):e18) doi:10.2196/jmir.992

KEYWORDS

Online support groups; patients; lurkers; empowerment; breast cancer; fibromyalgia; arthritis

Introduction

Studies have suggested that patients who use online support groups benefit in various ways [1-10]. Results of our earlier study indicated that participation in online support groups had a profound effect on the participants' feelings of "being empowered" in several areas. Empowering outcomes mentioned by participants were being better informed; feeling confident with their physician, their treatment, and their social environment; improved acceptance of the disease; increased optimism and control; and enhanced self esteem and social well-being [11].

Most studies of online support groups for patients have focused on the members of these groups who actively contribute by sending postings (ie, posters). However, it is assumed that a considerable number of patients use online support groups in a passive way. Thus far, it is not known if those who do not actively participate by sending postings, the so-called lurkers, profit to the same extent from participating in online support groups as posters do.

Although little is known about lurkers in online patient support groups, some studies have been conducted on lurkers in other online communities. Opinions about lurking and lurkers vary considerably. On the one hand, lurking is considered negative behavior. Smith and Kollock [12] describe lurkers as "free-riders": they use the resources of online groups without giving back to them. Others consider lurking as acceptable and even beneficial. Many groups encourage lurking because in this way potential new users get a feeling for how the group operates and what kind of people participate in it [13,14]. Lurking can be desirable for very busy groups; if all subscribers to a group were to participate actively, it could cause repetition of queries and result in an overload of postings [15].

Study results indicated that lurking rates are highly variable: 0% to 99% [15-18]. Nonnecke and Preece [17] reported an average of 45.5% of lurkers in health-related online support groups.

Only a few studies have examined lurkers' motives and experiences. In those studies, the participants were asked to indicate the reasons why they lurked instead of actually participating in the online communities. Reasons mentioned were concerns for privacy, no need to post, need to find out more about the group before participating, respect for others' time and attention restrictions, no skills to make the software work, and no "click" with the group dynamics or a poor fit with the group [13,14,19,20]. Lurkers mostly indicated that they participated in an online group in order to receive information. In contrast, posters mentioned reasons such as to offer expertise, enjoy oneself, entertain others, build a professional relationship, tell stories, participate in conversations, make friends, get empathic support, and be a group member [13,14]. Nonnecke et al [14] also investigated possible differences in attitudes between lurkers and posters. Results showed that lurkers were less positive with regard to their online support group than those who post.

Although the above-mentioned studies provided us with valuable information concerning the characteristics of lurkers, little is known about the impact of lurking in online support groups [4]. Moreover, the previous studies focused on a wide range of online communities in which topics were discussed relating to the government, organizations, health, and e-commerce. It is unclear whether these results can be generalized to online patient support groups. In the present study, we therefore explored if lurkers in online patient support groups profit to the same extent as posters do. In addition, we explored to what extent lurking patients differed from posting patients with regard to demographic characteristics and usage and satisfaction with the online support group.

Methods

Sample and Procedure

We focused our study on online support groups for patients with breast cancer, fibromyalgia, and arthritis. We chose to explore these three groups because of the contrast among the illnesses (life-threatening, unexplained, and chronic disabling, respectively). We searched the Internet using the Google search engine to identify all Dutch online support groups for patients with breast cancer, fibromyalgia, and arthritis. In total, we found 20 groups. The online support groups differed in size and extent of activity; in the most active public support group under study, several hundred messages were exchanged daily, while in the least active support group, only 30 messages were exchanged during the last month. In total, 6 support groups under study were private groups to which we as researchers had no access. Therefore, we could not verify the number of messages exchanged in these groups.

Contact was established between the first author and the Web owners of the groups. The purpose of the study and methodology were explained to the Web owners. In addition, they were asked if they had any comments on the online questionnaire. We then asked the Web owners of these groups for permission to invite the participants to fill out our questionnaire. The Web owners of 19 groups (7 breast cancer, 6 fibromyalgia, and 6 arthritis) supported our study. In order not to intrude in the online support groups as researchers, we asked the Web owners of these 19 groups to send a posting in which participants were invited to fill out our online questionnaire. Criteria for inclusion were listed in the postings. The participants had to state that they had been diagnosed with breast cancer, fibromyalgia, or arthritis and had engaged passively or actively in online support groups. The medical diagnoses of the respondents were not verified with their physicians. Participants who were willing to fill out our questionnaire were invited to visit a Web page which provided information about our study and contact details of the first author. In total, 593 participants responded to our request. Obviously, a response percentage is not available due to the fact that it is not known how many patients participated in the online support groups under study. Of these participants, 65 filled in only the questions concerning their background and were thus not included in the data analysis, leaving 528 respondents. Of these respondents, 109 (21%) identified themselves as lurkers, which we defined in line with Preece et al [13] as “members who had never contributed a posting to an online group.”

Instruments

Demographic and Health Characteristics

The respondents were asked to provide information about demographic characteristics such as age, sex, education, and diagnosis. Health-related quality of life was assessed with the SF 12, version 2. Standardized scores were calculated for physical and mental well-being, varying from 0 (poor well-being) to 100 (excellent well-being), with a mean of 50 and a standard deviation of 10 in the general population of the United States [21].

Use of and Satisfaction With the Online Support Group

Respondents were asked to indicate when they started visiting the online support group, how frequently they visited it, how long a visit lasted, and for what reasons they turned to the online support group. Lurking was measured with one single dichotomous item: “Did you ever contribute a posting to an online patient support group?”

The questionnaire also contained one item to measure general satisfaction with the online support group: “In general, how satisfied/dissatisfied are you with the online support group?” Respondents could answer on a 5-point scale that ranged from “very dissatisfied” (1) to “very satisfied” (5).

Empowering Processes

On the basis of the results of an earlier qualitative study [11], 29 items were formulated that described the empowering processes that took place in the online support groups. In all items, we asked for the frequency with which certain events happened in the online support group. Respondents could answer on a 4-point scale that ranged from “seldom or never” (1) to “often” (4). “Exchanging information” was measured with 9 items (alpha = .88). “Encountering emotional support” was measured with 12 items (alpha = .95), which was based on the Social Support List – Interaction [22]. “Finding recognition” was measured with 4 items (alpha = .70). “Helping others” was measured with 2 items (alpha = .82). Finally, “Sharing experiences” was measured with 2 items (alpha = .87).

Empowering Outcomes

On the basis of the results of an earlier qualitative study [11], 38 items were formulated that described empowering outcomes from participation in online support groups. All items had the format of a statement that began with “Through my participation in online support groups….” Respondents could answer on a 5-point scale that ranged from “completely disagree” (1) to “completely agree” (5). “Being better informed” was measured with 4 items (alpha = .85). “Feeling more confident in the relationship with their physician” was measured with 11 items (alpha = .91). “Improved acceptance of the illness” was measured with 5 items (alpha = .90). “Feeling more confident about the treatment” was measured with 5 items (alpha = .89). “Increased optimism and control over the future” was measured with 8 items (alpha = .76), partially based on the revised Illness Perception Questionnaire [23] and on the Dutch version of the Mastery Scale [24]. “Enhanced self-esteem” was measured with 3 items (alpha = .93), partially based on the Dutch version of the Rosenberg Self-Esteem Scale [25]. Finally, “Enhanced social well-being” was measured with 2 items (alpha = .70).

For an overview of the items belonging to all the above-mentioned constructs, see the Multimedia Appendix. For each construct, a mean total score was calculated.

Data Analysis

The data were analyzed with the statistical software package SPSS 12.0 (SPSS Inc, Chicago, IL, USA). Differences in continuous variables between the posters and the lurkers were tested by means of Mann-Whitney U tests and differences in categorical variables by chi-square tests. In the data analysis, we excluded the respondents only if they were missing the data required for the specific analysis. Because of the great number of comparisons conducted, statistical significance was assumed when alpha < .01.

Results

Demographic and Health Characteristics of the Posters and Lurkers

Lurkers were somewhat older and were more recently diagnosed compared to posters (Table 1). No significant differences were found in sex, marital status, education, employment status, or type of diagnosis. Lurkers had a poorer mental well-being than posters. No significant differences between posters and lurkers were found in the physical component of the SF12.

Table 1. Demographics and health characteristics of posters and lurkers

	Posters[*]		Lurkers		χ^2 (df)[†]	Mann-Whitney[‡]	*P* [§]
	No.	%	No.	%			
Sex					.000 (1)[‖]		1.00
Female	392	94	102	94			
Male	27	6	7	6			
Age in years (posters: n = 416, lurkers: n = 109)						18291.50	.002
Mean (SD)	43 (10.4)		47 (9.9)				
Minimum	17		19				
Maximum	73		75				
Marital/relationship status					.094 (1)[‖]		.76
Single	88	21	25	23			
In a relationship	331	79	84	77			
Education					2.24 (2)		.33
Low	129	32	42	39			
Middle	170	42	43	39			
High	111	27	24	22			
Employment status					1.33 (2)		.51
Paid job (> 20 hours)	128	31	39	36			
Paid job (≤ 20 hours)	54	13	11	10			
No job	234	56	59	54			
Diagnosis					.745 (3)		.86
Breast cancer	166	40	48	44			
Fibromyalgia	95	23	22	20			
Arthritis	97	23	24	22			
More diagnoses	61	15	15	14			
Time in years since diagnosis (posters: n = 385, lurkers: n = 96)						14382.50	.001
Mean (SD)	5.4 (6.1)		3.7 (4.6)				
Minimum	0		0				
Maximum	51		21				
Well-being (SF 12) (posters: n = 355, lurkers: n = 52)							
Physical well-being, mean (SD)	36.4 (11.6)		37.5 (9.9)			8294.50	.24
Mental well-being, mean (SD)	40.5 (6.4)		37.7 (5.8)			6960.50	.004

[*] No. is the number of respondents per item. Percentages are given with the total number of respondents per question as denominator (due to nonresponses, denominators may vary from question to question).

[†] Chi-square values are Pearson chi-square values with degrees of freedom in parentheses.

[‡] Mann-Whitney U value.

[§] *P* value for chi-square tests and Mann-Whitney U tests comparing posters and lurkers.

[‖] Chi-square values are Pearson chi-square values with continuity correction.

Use of the Online Support Groups by Posters and Lurkers

The lurkers participated for a significantly shorter period of time compared to the posters (Table 2). Lurkers visited the online support groups significantly less frequently than the posters did. Most of the posters (64%) indicated that they visited the support group daily, compared to 27% of the lurkers. There was no significant difference between the posters and the lurkers concerning the duration of the visit to the online support group.

Lurkers and posters differed significantly with regard to some of the reasons for visiting the online support groups. Posters indicated visiting the online support groups significantly more often for social reasons, such as curiosity about how other members were doing, to enjoy themselves, as a part of their daily routine, and because other members expected them to be there. Lurkers and posters did not differ with their information-related reasons to visit the online support group.

In general, the lurkers were significantly less satisfied with the online support group compared to posters.

Table 2. Use of the online support group by posters and lurkers

	Posters[*]		Lurkers		χ^2 (df)[†]	Mann-Whitney[‡]	*P* [§]
	No.	%	No.	%			
Number of years participating in an online support group (posters: n = 389, lurkers: n = 94)						13456.00	< .001
Mean (SD)	2.3 (2.1)		1.6 (2.1)				
Minimum	0		0				
Maximum	9		9				
Frequency of visits to online support group					75.756 (5)[‖]		< .001
More than once during a day	140	35	6	7			
About one time during a day	121	30	18	20			
More than once in a week	96	24	28	31			
About one time in a week	31	8	19	21			
More than once in a month	0	0	0	0			
About once in a month	6	2	7	8			
Less than once in a month	6	2	12	13			
Duration of visits to online support group					3.560 (3)		.31
Less than 10 minutes	94	23	30	29			
10 minutes to 30 minutes	237	58	50	49			
30 minutes to 1 hour	57	14	18	18			
More than 1 hour	21	5	4	4			
Reasons for visiting the online support group							
Because I'm curious how other members are doing	244	58	34	31	24.298 (1)[¶]		< .001
It's part of my daily routine	202	48	15	14	40.992 (1)[¶]		< .001
When I have a question about my disease	180	43	36	33	3.131 (1)[¶]		.08
To enjoy myself	157	38	15	14	21.070 (1)[¶]		< .001
When I heard new information about my illness	125	30	25	23	1.698 (1)[¶]		.19
When I have a lot of symptoms	92	22	20	18	.475 (1)[¶]		.49
When I feel lonely	92	22	15	14	3.106 (1)[¶]		.08
When I get new symptoms	106	25	27	25	.000 (1)[¶]		1.00
After visiting a doctor	61	15	6	6	5.609 (1)[¶]		.02
Before visiting a doctor	43	10	3	3	5.226 (1)[¶]		.02
Because other members expect me to be there	50	12	2	2	8.830 (1)[¶]		.003
General satisfaction with the online support group (posters: n = 375, lurkers: n = 63), mean (SD)	4.3 (0.79)		4.0 (0.65)			8652.50	< .001

[*] No. is the number of respondents per item. Percentages are given with the total number of respondents per question as denominator (due to nonresponses, denominators may vary from question to question).

[†] Chi-square values are Pearson chi-square values with degrees of freedom in parentheses.

[‡] Mann-Whitney U value.

[§] *P* value for chi-square tests and Mann-Whitney U tests comparing posters and lurkers.

[‖] The assumption of chi-square concerning the minimum expected cell frequency (5 or greater) has been violated. Therefore the answer option “more times a month” has been left out of this analysis.

[¶] Chi-square values are Pearson chi-square values with continuity correction.

Empowering Processes

With regard to all empowering processes, lurkers scored significantly lower than the posters (Table 3). The processes that were reported the most frequently in the online support groups by both lurkers and posters were “exchanging information” and “finding recognition.”

Table 3. Mean scale scores processes for posters and lurkers

	Posters		Lurkers		Mann-Whitney[*]	P [†]
	No.	Mean (SD)	No.	Mean (SD)		
Exchanging information (1-4)	411	3.0 (0.54)	99	2.8 (0.59)	15560.00	< .001
Finding recognition (1-4)	387	2.9 (0.54)	73	2.5 (0.67)	9720.50	< .001
Sharing experiences (1-4)	387	2.8 (0.85)	73	1.9 (0.93)	6233.00	< .001
Encountering emotional support (1-4)	405	2.3 (0.74)	86	1.5 (0.61)	6272.50	< .001
Helping others (1-4)	387	2.3 (0.71)	73	1.6 (0.63)	6463.50	< .001

[*] Mann-Whitney U value.

[†] *P* value for Mann-Whitney U tests comparing posters and lurkers.

Empowering Outcomes

Table 4 shows that lurkers did not differ significantly from posters with regard to the empowering outcomes, with the exception of “enhanced social well-being.” The lurkers experienced the outcome of “enhanced social well-being” significantly less often compared to the posters. The empowering outcome that was experienced to the strongest degree by both posters and lurkers was “being better informed.”

Table 4. Mean scale scores outcomes for posters and lurkers

	Posters		Lurkers		Mann-Whitney[*]	P [†]
	No.	Mean (SD)	No.	Mean (SD)		
Being better informed (1-5)	373	3.7 (0.76)	61	3.6 (0.66)	9403.50	.03
Enhanced social well-being (1-5)	359	3.4 (0.96)	52	2.8 (0.76)	5603.50	< .001
Feeling more confident in the relation with their physician (1-5)	369	3.4 (0.72)	58	3.3 (0.60)	10248.00	.60
Improved acceptance of the disease (1-5)	365	3.3 (0.91)	56	3.1 (0.92)	9001.50	.15
Feeling more confident about the treatment (1-5)	365	3.2 (0.79)	57	3.1 (0.79)	9112.50	.13
Enhanced self-esteem (1-5)	359	3.2 (0.94)	52	3.0 (0.83)	7790.00	.05
Increased optimism and control (1-5)	361	3.2 (0.59)	52	3.1 (0.64)	8268.00	.16

[*] Mann-Whitney U value.

[†] *P* value for Mann-Whitney U tests comparing posters and lurkers.

Discussion

Principal Findings

To the best of our knowledge, this study is the first to empirically examine differences in perceived empowering outcomes between lurkers and posters. Our study revealed that, with the exception of the empowering outcome “enhanced social well-being,” participation in an online support group had the same profound effect on lurkers’ feelings of being empowered in several areas as it had on posters. Apparently, the mere reading of postings from others in online support groups can be beneficial for patients. Therefore, lurking in online support groups might be seen as a form of bibliotherapy. The idea of bibliotherapy is that well-being can be improved by reading self-help books or stories in which people can identify themselves with others [26]. Other studies have found evidence for online bibliotherapy; it has been shown to be effective in reducing depression [27], increasing self-management ability [26], and treating panic disorders [28].

Lurkers and posters did differ, however, with regard to the empowering outcome of “enhanced social well-being.” Fewer lurkers than posters reported that participating in an online support group led to a rise in their number of social contacts or to a decrease in loneliness.These results did not surprise us because it seems to be impossible to achieve new social contacts by lurking in an online support group.

In contrast to the empowering outcomes, we did find differences between lurkers and posters concerning the empowering processes executed in the online support groups. These differences not only appeared when focusing on processes that cannot be executed as a lurker, such as "helping others," but also with processes such as "finding recognition." These results are in line with the study results of Bane et al [29], who found indications in their study that lurkers in an online weight management group were less likely to see the group as a source of support and that it was less likely for them to find another group member with whom they could socially compare themselves.

An explanation for the significant difference between lurkers and posters with regard to the process "exchanging information" can, in our opinion, be linked to one of the frequently mentioned advantages of online support groups, namely that patients have the opportunity to request and receive informational support according to their personal needs and preferences [30]. Although lurkers have the option to read the information posted by others, they do not take advantage of the option to ask questions with specific concern for their own personal situation.

Our study indicated that lurkers were less satisfied than posters with the online support group. These results are in line with results of earlier studies that found that the majority of lurkers were significantly less enthusiastic than posters about the online group they participated in [13,14]. Nonnecke et al [14] suggested that lurking might even be a result of dissatisfaction with the online group, although they did mention that it is not clear whether lurking behavior causes dissatisfaction or whether dissatisfaction with the online group results in lurking.

This study also provided some insight into the demographic characteristics of lurkers in Dutch online support groups. The demographic populations of lurkers and posters were similar in this study with the exception of age. Lurkers were somewhat older compared to those who post. These results might indicate a relationship between a lack of computer skills and lurking since elderly people are in general less familiar with computers. In addition, one of the respondents to our questionnaire illustrated this problem: "I gave up trying to contribute a posting to [name of online support group]. I just cannot find out how to…."

Finally, the results of our study showed that lurkers are active for a significantly shorter period of time in the online support groups compared to the posters. This might indicate that among the lurkers, there are indeed new users of the online support groups who first want to get to know the group before they start posting. This phenomenon is referred to in the literature as "de-lurking" [20,31].

Several researchers have focused on methods to speed up the process of de-lurking, for example, by fostering receptive participation and by making the learning about the community and the first experiences as pleasant as possible [31] or by providing clear usability instructions [13]. The present study, however, indicates that for lurkers themselves it is not really necessary to de-lurk because they profit to the same extent from participating in online support groups as posters do. This does not mean that we encourage lurking. Lurking may be a problem for online patient support groups if there are few or no participants who contribute postings. According to Nonnecke et al [14], lurking is especially a problem for new online groups that do not yet have a sustainable group of active contributors. Silent online groups cannot survive because there is so much on offer on the Internet that people do not return to these groups [13].

In addition, this study showed that lurkers do not profit to the same extent as posters with regard to the outcome "enhanced social well-being" and that lurkers had a poorer mental well-being. These results might suggest that posting improves social or mental well-being. However, because we do not have baseline information about social and mental well-being at the time a patient joined an online support group, we cannot draw any conclusions about the causality of this relationship.

Limitations of the Present Study

The findings of this study are limited by the relative small percentage of lurkers (21%) included. Although a response percentage is not available, we presume that the percentage of lurkers active in the online support groups under study is higher than 21% when we consider the study results of Nonnecke and Preece [17], who reported an average rate of 45.5% of lurkers in health-related online support groups.

In addition, a considerable number of participants only partially completed the questionnaire. To examine whether there was selective attrition, we compared those respondents who completed the questionnaire with the respondents who did not complete the questionnaire on crucial aspects, such as whether they were posters or lurkers (data not shown). This analysis showed that lurkers did not complete the questionnaire significantly more often than posters. Since the questions on empowering outcomes were at the end of the questionnaire, this might mean that those lurkers who did not feel empowered simply did not respond to the respective questions. However, we can also think of other viable reasons. According to Preece et al [13], lurkers usually do not have the inclination to respond to questionnaires. Therefore, it can also be expected that lurkers more often than posters decide not to complete a questionnaire. This might especially be the case if a questionnaire is of considerable length, such as the one used in our study.

Thus, the participants who chose to complete the online questionnaire are not necessarily representative of all lurkers and posters participating in online support groups for patients with breast cancer, fibromyalgia, and arthritis.

Finally, it should be taken into account that the results are self-perceived outcomes. Participants themselves estimated to what extent they profited from participation in online support groups. This does not prove that they truly profited from participation. Although this study provided us with relevant insights into the empowering outcomes as experienced by the posters and lurkers, a randomized controlled trial or a longitudinal study is required to evaluate whether posters and lurkers are truly empowered.

Conclusion

Earlier studies showed that patients can profit from participation in online patient support groups. Our current study suggests that this not only applies to those patients who actively participate by sending postings, but also to those patients who only lurk in online patient support groups. Apparently, the use of online support groups, even if it consists of merely reading postings by others, might be beneficial for patients. Physicians should therefore acquaint their patients with the existence of online patient support groups since these groups offer the surplus value of patient expert information compared to regular medical information.

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Conflicts of Interest

None declared.

Multimedia Appendix

Original Questionnaire (in Dutch)

[PDF file (Adobe PDF), 148 KB - jmir_v10i2e18_app1.pdf]

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Original Paper

Comparison of Use and Appreciation of a Print-Delivered Versus CD-ROM-Delivered, Computer-Tailored Intervention Targeting Saturated Fat Intake: Randomized Controlled Trial

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Abstract

Background: Computer-tailored health education, a promising health education technique, is increasingly being delivered interactively, for example, over the Internet. It has been suggested that there may be differences in use and appreciation between print and interactive delivery of computer-tailored interventions, which may influence information processing. This may especially be the case for women, older people, and people of lower socioeconomic status. Knowledge about differences in use and appreciation could help in choosing the appropriate delivery mode for a particular target audience.

Objective: The study investigates a content-identical, computer-tailored intervention addressing saturated fat intake delivered via print or CD-ROM. We analyzed consumer use and appreciation of the feedback information and explored whether possible differences exist among gender, age, and education subgroups.

Methods: Healthy Dutch adults (18-65 years), none of whom were under treatment for hypercholesterolemia, were randomly allocated to receive a computer-tailored program on CD-ROM (n = 151) or in print (n = 141). At baseline, data were collected on gender, age, and education level. One month post-intervention, data were collected on the use (feedback information read, saved, discussed) and appreciation (trustworthiness, perceived individualization, perceived personal relevance, and user-friendliness) of the feedback. Statistical analyses on the use and appreciation items were performed using chi-square tests and independent-samples *t* tests.

Results: After exclusion of individuals with missing values, a total of 257 and 240 respondents were included in the analyses of the use outcomes of feedback read and saved, respectively. The results indicate that among the total population, the print feedback was read more often than the CD-ROM feedback (95% vs 81%; $P = .001$) and saved more often than the CD-ROM feedback (97% vs 77%; $P < .001$). Similar results were found among the gender, age, and education subgroups. After exclusion of individuals who did not read the information and those with missing values, a total of 208-223 respondents were included in the analyses of the use outcome of feedback discussed and the appreciation items. The personal relevance of the print feedback was rated higher than for the CD-ROM-delivered feedback (0.97 vs 0.68; $P = .04$), but the effect size was small (0.28). These differences in personal relevance were also seen among women (1.06 vs 0.67; $P = .04$) and respondents aged 35-49 years (1.00 vs 0.58; $P = .03$), with moderate effect sizes (0.38 and 0.44, respectively).

Conclusions: Despite the possible advantages of interactive feedback, the present study indicates that interactive-delivered feedback was used less and perceived as less personally relevant compared to the print-delivered feedback. These differences in use and appreciation of delivery modes should be taken into consideration when selecting a delivery mode for a specific subgroup in order to optimize exposure.

Trial Registration: ISRCTN 01557410; http://www.webcitation.org/5XMylWleH

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KEYWORDS

Computer; Internet; tailoring; process evaluation; demographic differences; diet; nutrition education

Introduction

Computer-Tailored Health Education

Computer-tailored health education delivers individualized information matched to an individual's characteristics [1,2] and is a promising health education technique, particularly for (print-delivered) nutrition education [3]. The Internet is increasingly being used for the delivery of computer-tailored interventions. There are many features that make the Internet an attractive medium of delivery, such as the instant and continuous availability, the possibilities for interactivity, and the possibility to provide immediate feedback [4,5]. Another potential advantage is that larger numbers of people can be reached for lower cost, as compared with print-delivered interventions [4,6,7].

There also may be disadvantages of providing computer-tailored interventions over the Internet: it may be more difficult to read or process information from a computer screen [8,9], it may require more effort to receive the computer-tailored feedback (ie, starting the computer and the program), and people may be less likely to save and re-read interactive-delivered feedback [8]. Furthermore, it has been suggested that specific groups, such as people of lower socioeconomic status, women, and older people, will not be reached with interventions over the Internet because they may have more difficulty with and less interest in using interactive media [10-14].

On the other hand, some previous studies have shown that persons from lower socioeconomic groups have more interest in computer-tailored feedback compared to generic information [15-17]. In addition, the possibility of incorporating multiple mediums on the Internet to convey the information could reinforce comprehension for less-educated individuals [18]. Even though it has been suggested that there may be differences in use between print- and interactive-delivered computer-tailored interventions, the evidence to demonstrate this is still limited. The aim of the present study is to examine differences in use and appreciation of an identical-content, print-delivered versus interactive-delivered, computer-tailored intervention.

Knowledge about differences in use and appreciation could help in choosing the appropriate delivery mode for a particular target audience.

Information Processing and Delivery Mode

Use and appreciation of an intervention are important factors to study since they are prerequisites for active information processing [19,20]. Active information processing is necessary for finally achieving changes in determinants and behavior [20]. Information processing starts with attention to the message [19], which can be operationalized as reading the information. The channel through which the information is provided is one of the factors that may determine attention to the message [19]. Attention to the message may be more easily achieved when the information is provided in a readily readable format or when it is provided via a medium that the receiver likes or knows how to use [13,21].

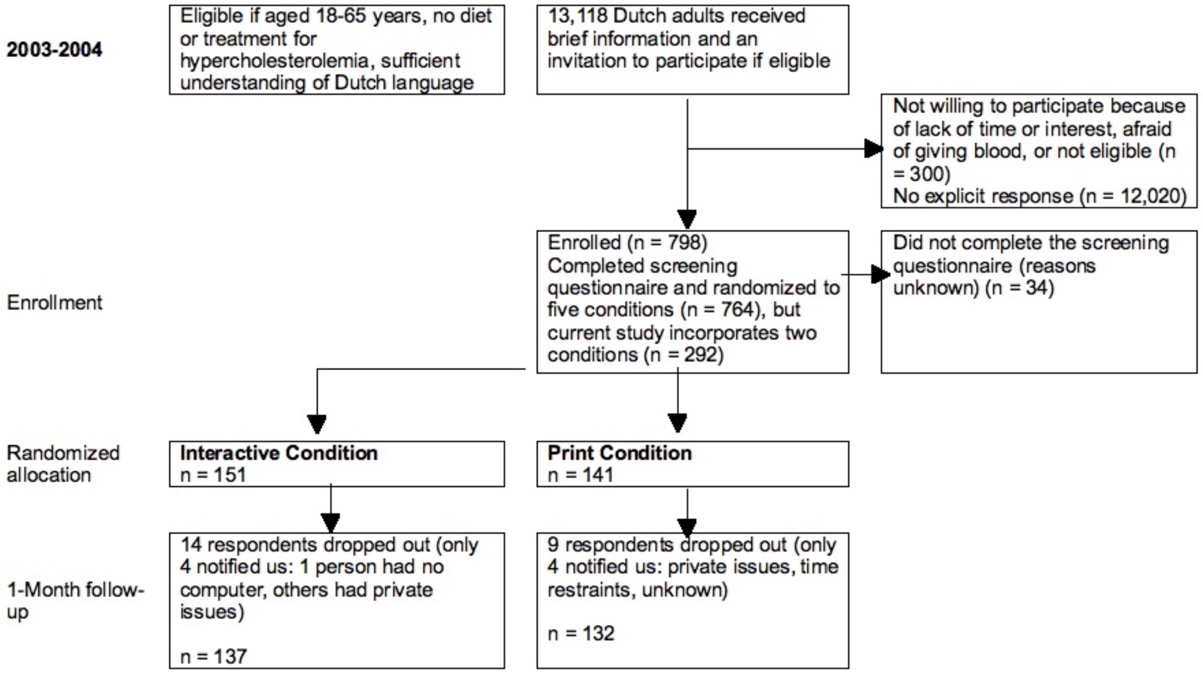
Active information processing not only involves attention to the message, but also thoughtful consideration of the information content. Reading, saving, and discussing the information with others may be indicators of active information processing. Furthermore, information is more likely to be attended to and actively processed when it is perceived as interesting, personally relevant, and individualized [22-26]. In a study by Oenema and colleagues, perceived personal relevance and individualization were identified as mediators of the effect of a computer-tailored intervention [26].

Even though, based on theory, indicators of use and perception of personal relevance are important for achieving intervention effects, these factors may be different for print and interactive deliveries: the medium may determine attention and access to the message [19], as well as the ability and willingness to actively process the information [13,27].

Only two previous studies have compared use of print- and Internet-delivered interventions with identical content [28,29]. Both studies reported higher recall and use of the print materials compared to the materials delivered through the Internet. In the current study we will evaluate a broader set of indicators for use and appreciation and perceptions of personal relevance between a print-delivered and an interactive-delivered, computer-tailored, nutrition education intervention with identical content aimed at reducing saturated fat intake. These interventions were found to be equally effective in reducing saturated fat intake in the short term, but only the effects of the print-delivered tailored feedback were maintained in the longer term [30].

The current study specifically examines whether there are differences in use (information read, saved, discussed with others) and appreciation (perceived personal relevance, perceived individualization, trustworthiness, user-friendliness) between print computer-tailored advice and interactive computer-tailored advice. These differences were examined for a mixed population and for gender, age, and education subgroups. A CD-ROM was used to deliver the interactive, Web-based intervention, enabling people who did not have Internet access to use the program.

Figure 1. Subject recruitment and retention flowchart



Methods

Design and Recruitment

This study is part of a larger randomized controlled trial with five study arms. The current study uses data from two of the study arms for secondary data analysis: computer-tailored dietary saturated fat reduction feedback delivered on CD-ROM (n = 151) or delivered in print (n = 141). Approval for the research project was obtained from the Medical Ethics Committee of Erasmus University Medical Center, Rotterdam, The Netherlands. All participants gave written informed consent after receiving written information about the study. Volunteers for the larger intervention trial were recruited from among employees of nine large companies and inhabitants of two neighborhoods in the Rotterdam area (2003-2004). A total of 798 adults volunteered to participate, none of whom were on a prescribed diet or under treatment for hypercholesterolemia. Participants completed a baseline paper-and-pencil screening questionnaire and were subsequently randomized by computer to one of the two intervention conditions (Figure 1).

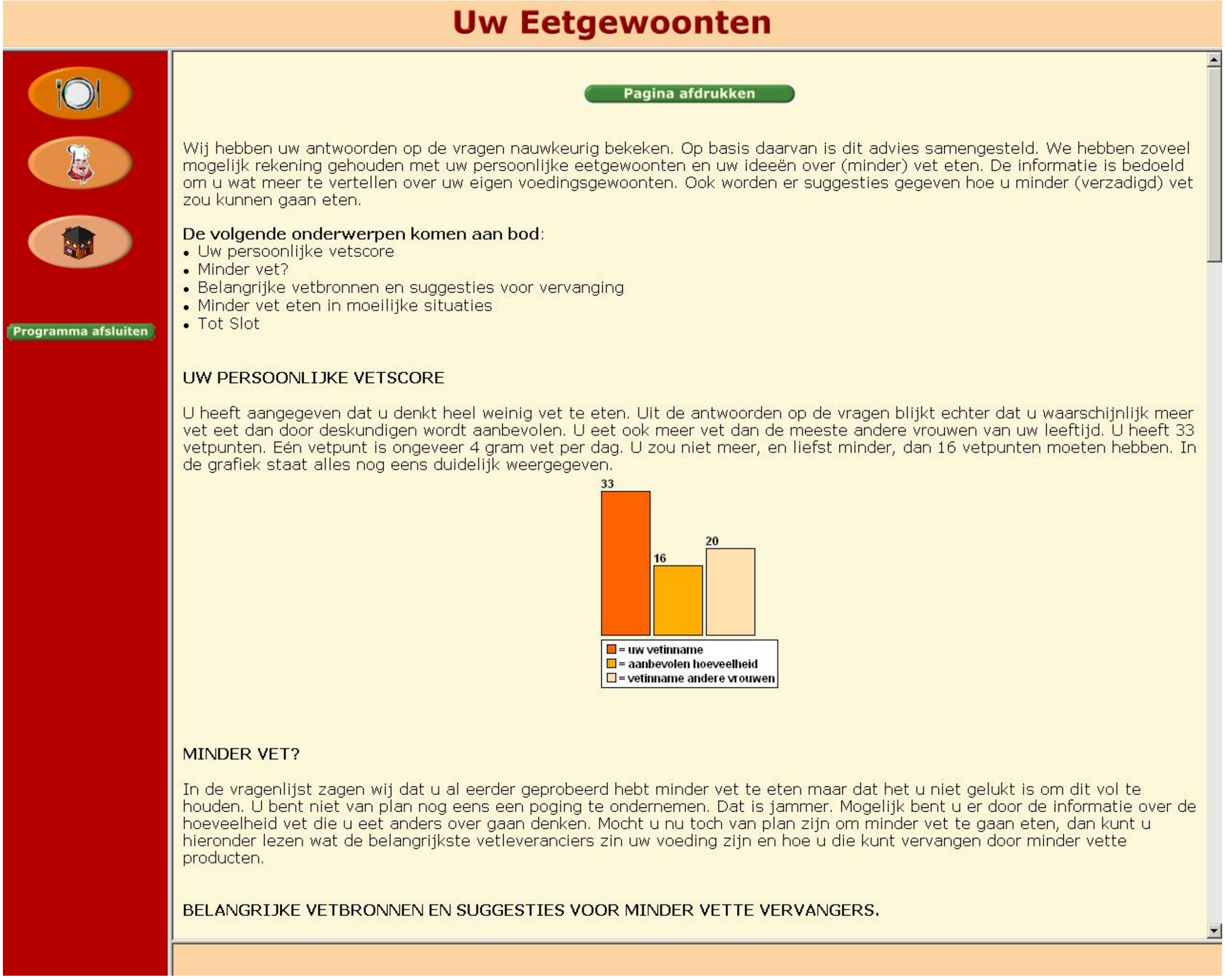
Computer-Tailored Interventions

The tailored feedback in the current study incorporated feedback on personal saturated fat intake, social-comparison information, motivational feedback, practical product feedback addressing the most important sources of fat in the person's diet, information on low-fat alternatives, and self-efficacy-enhancing feedback for difficult situations as derived from an individual assessment. The content of the computer-tailored program (screening questionnaire and feedback) was identical for the two intervention conditions, only the delivery mode was different, as described below. Details of the computer-tailored feedback are described elsewhere [30].

CD-ROM Condition

In the CD-ROM condition, the computer-tailored feedback was programmed as a series of Web pages (questionnaire, feedback messages), then stored on a CD-ROM. The program started with a home page explaining the nature and goal of the program and how it should be used. Immediately after completion of the screening questionnaire, the individualized computer-tailored information appeared on screen (Figure 2). Low-fat recipes for appetizers, main courses, and desserts could be searched from a recipe page. It was possible to print and save the feedback, but the program did not automatically do this. Respondents were asked to use the program on a computer with Internet Explorer 5.0 or higher and to use it in the same week they received the CD-ROM.

Figure 2. Example of part of the feedback delivered on CD-ROM



Wij hebben uw antwoorden op de vragen nauwkeurig bekeken. Op basis daarvan is dit advies samengesteld. We hebben zoveel mogelijk rekening gehouden met uw persoonlijke eetgewoonten en uw ideeën over (minder) vet eten. De informatie is bedoeld om u wat meer te vertellen over uw eigen voedingsgewoonten. Ook worden er suggesties gegeven hoe u minder (verzadigd) vet zou kunnen gaan eten.

De volgende onderwerpen komen aan bod:
- Uw persoonlijke vetscore
- Minder vet?
- Belangrijke vetbronnen en suggesties voor vervanging
- Minder vet eten in moeilijke situaties
- Tot Slot

UW PERSOONLIJKE VETSCORE

U heeft aangegeven dat u denkt heel weinig vet te eten. Uit de antwoorden op de vragen blijkt echter dat u waarschijnlijk meer vet eet dan door deskundigen wordt aanbevolen. U eet ook meer vet dan de meeste andere vrouwen van uw leeftijd. U heeft 33 vetpunten. Eén vetpunt is ongeveer 4 gram vet per dag. U zou niet meer, en liefst minder, dan 16 vetpunten moeten hebben. In de grafiek staat alles nog eens duidelijk weergegeven.

MINDER VET?

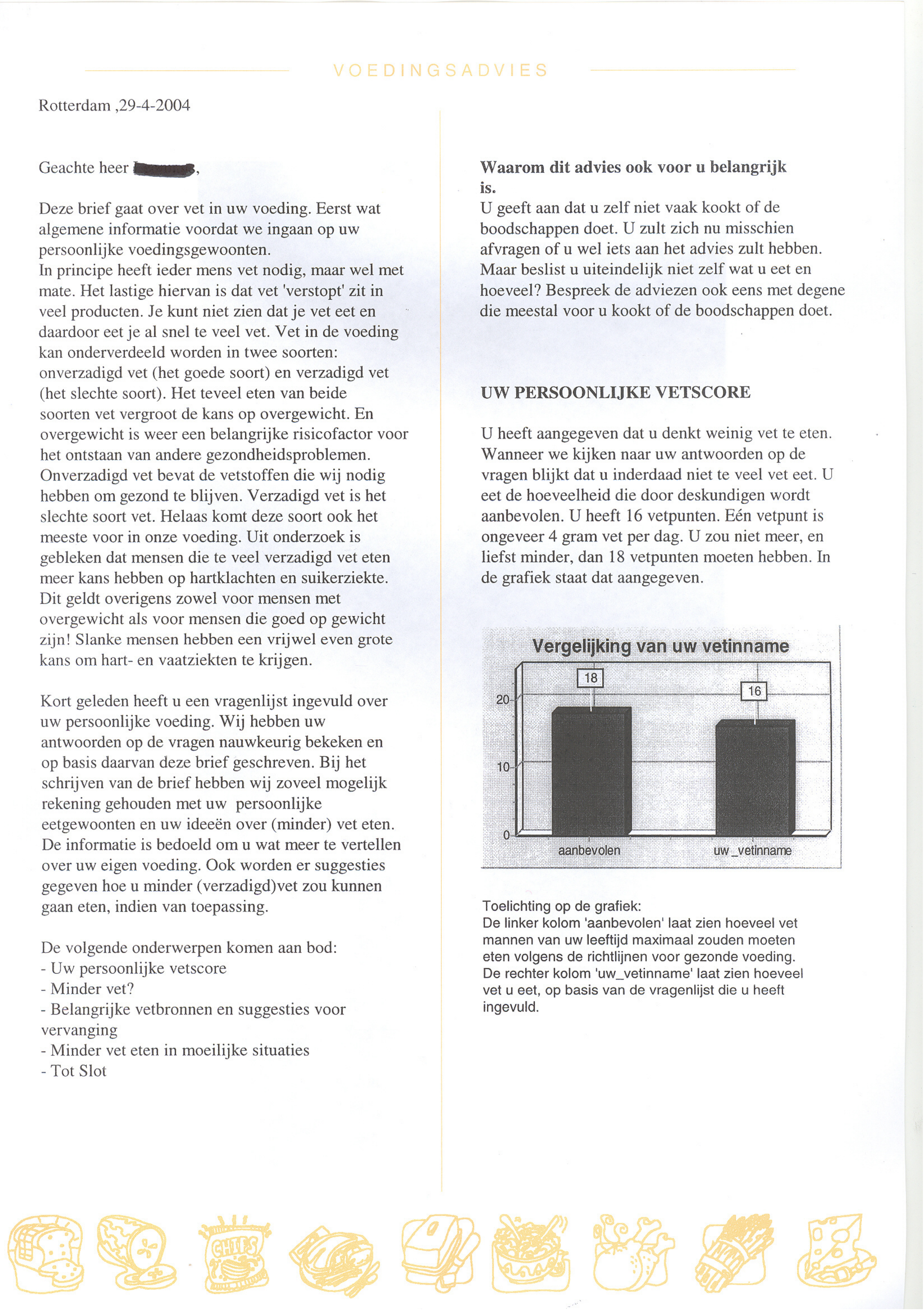
In de vragenlijst zagen wij dat u al eerder geprobeerd hebt minder vet te eten maar dat het u niet gelukt is om dit vol te houden. U bent niet van plan nog eens een poging te ondernemen. Dat is jammer. Mogelijk bent u er door de informatie over de hoeveelheid vet die u eet anders over gaan denken. Mocht u nu toch van plan zijn om minder vet te gaan eten, dan kunt u hieronder lezen wat de belangrijkste vetleveranciers zin uw voeding zijn en hoe u die kunt vervangen door minder vette producten.

BELANGRIJKE VETBRONNEN EN SUGGESTIES VOOR MINDER VETTE VERVANGERS.

Print Condition

The tailored information in the print condition was generated from the results of a baseline paper-and-pencil questionnaire. The questionnaires were scanned and imported into a computer-tailoring program that generated individualized computer-tailored printed feedback letters of 1.5-4 pages (Figure 3). Depending on their preferences, respondents received recipe suggestions for low-fat appetizers, main courses, or desserts. The feedback letters were sent to the home address of the respondent within 2 weeks of the time the study team received the completed questionnaire.

Figure 3. Example of part of the feedback delivered in print



VOEDINGSADVIES

Rotterdam ,29-4-2004

Geachte heer [redacted],

Deze brief gaat over vet in uw voeding. Eerst wat algemene informatie voordat we ingaan op uw persoonlijke voedingsgewoonten.
In principe heeft ieder mens vet nodig, maar wel met mate. Het lastige hiervan is dat vet 'verstopt' zit in veel producten. Je kunt niet zien dat je vet eet en daardoor eet je al snel te veel vet. Vet in de voeding kan onderverdeeld worden in twee soorten: onverzadigd vet (het goede soort) en verzadigd vet (het slechte soort). Het teveel eten van beide soorten vet vergroot de kans op overgewicht. En overgewicht is weer een belangrijke risicofactor voor het ontstaan van andere gezondheidsproblemen. Onverzadigd vet bevat de vetstoffen die wij nodig hebben om gezond te blijven. Verzadigd vet is het slechte soort vet. Helaas komt deze soort ook het meeste voor in onze voeding. Uit onderzoek is gebleken dat mensen die te veel verzadigd vet eten meer kans hebben op hartklachten en suikerziekte. Dit geldt overigens zowel voor mensen met overgewicht als voor mensen die goed op gewicht zijn! Slanke mensen hebben een vrijwel even grote kans om hart- en vaatziekten te krijgen.

Kort geleden heeft u een vragenlijst ingevuld over uw persoonlijke voeding. Wij hebben uw antwoorden op de vragen nauwkeurig bekeken en op basis daarvan deze brief geschreven. Bij het schrijven van de brief hebben wij zoveel mogelijk rekening gehouden met uw persoonlijke eetgewoonten en uw ideeën over (minder) vet eten. De informatie is bedoeld om u wat meer te vertellen over uw eigen voeding. Ook worden er suggesties gegeven hoe u minder (verzadigd)vet zou kunnen gaan eten, indien van toepassing.

De volgende onderwerpen komen aan bod:
- Uw persoonlijke vetscore
- Minder vet?
- Belangrijke vetbronnen en suggesties voor vervanging
- Minder vet eten in moeilijke situaties
- Tot Slot

Waarom dit advies ook voor u belangrijk is.

U geeft aan dat u zelf niet vaak kookt of de boodschappen doet. U zult zich nu misschien afvragen of u wel iets aan het advies zult hebben. Maar beslist u uiteindelijk niet zelf wat u eet en hoeveel? Bespreek de adviezen ook eens met degene die meestal voor u kookt of de boodschappen doet.

UW PERSOONLIJKE VETSCORE

U heeft aangegeven dat u denkt weinig vet te eten. Wanneer we kijken naar uw antwoorden op de vragen blijkt dat u inderdaad niet te veel vet eet. U eet de hoeveelheid die door deskundigen wordt aanbevolen. U heeft 16 vetpunten. Eén vetpunt is ongeveer 4 gram vet per dag. U zou niet meer, en liefst minder, dan 18 vetpunten moeten hebben. In de grafiek staat dat aangegeven.

Toelichting op de grafiek:
De linker kolom 'aanbevolen' laat zien hoeveel vet mannen van uw leeftijd maximaal zouden moeten eten volgens de richtlijnen voor gezonde voeding.
De rechter kolom 'uw_vetinname' laat zien hoeveel vet u eet, op basis van de vragenlijst die u heeft ingevuld.

Measurements

Gender, age, and education level were assessed in the baseline questionnaire. A categorical variable was created from age (≤ 34 years, 35-49 years, 50-65 years) [13]. Highest level of completed formal education was measured using one question in which seven education categories were distinguished (from elementary school to university degree) [31]. The categories were then collapsed into a three-level education variable (lower = lower secondary education or less; medium = upper secondary or post-secondary non-tertiary education; higher = college or university training).

At 1 month post-intervention, the outcome measures (use and appreciation items) were assessed. The questions were introduced by explaining that nutrition advice referred to either the advice delivered by a printed letter or by CD-ROM. Use was assessed with the following yes/no items: "I have read the complete nutrition advice"; "I saved the nutrition advice"; and "I discussed the nutrition advice with others." Appreciation was assessed using a 5-point scale (from −2 = strongly disagree to +2 = strongly agree): "I perceived the nutrition advice as trustworthy"; "The nutrition advice addressed my personal dietary habits"; "The nutrition advice was of personal relevance for me"; and "The nutrition advice was user-friendly." Appreciation questions were adapted from the process questionnaire as proposed by Brug and colleagues [23] and have been successfully used in previous studies [25,26].

Statistical Analysis

Equality of the study groups at baseline was examined with chi-square tests (gender, education) and an independent-samples *t* test (age). Differences in use and appreciation outcomes between the intervention conditions were analyzed with chi-square tests (feedback read, saved, and discussed) and independent-samples *t* tests (trustworthy, perceived individualization, personal relevance, and user-friendliness). Respondents with missing values were excluded from the analyses. The "discussed" variable and the appreciation items were analyzed only for those respondents who confirmed they had read all the information. Finally, in order to compare the size of the difference in appreciation items between the print and the CD-ROM group, we calculated the effect sizes as the standardized differences in group means by dividing the difference between the conditions by the pooled standard deviation. Effect sizes were categorized as small (0-0.32), moderate (0.33-0.55), or large (> 0.55) as defined by Lipsey [32]. The analyses were performed for the total group, and, based on the literature [13], we decided a priori to conduct stratified analyses in specific subgroups based on gender, age, and education category. All analyses were conducted in SPSS version 11 (SPSS Inc, Chicago, IL, USA).

Results

Population Characteristics

Among the respondents (n = 292), 46% were male, the mean age was 43.9 years (SD 10.3), 22% fell in the lower education level, 34.4% in the medium education level, and 43.6% in the higher education level. There were no significant differences in gender, age, or education level between the two conditions.

Use of the Computer-Tailored Information

As shown in Table 1, the print-delivered feedback was read more often than the CD-ROM-delivered feedback according to self-reports among the total population ($P = .001$) and among women ($P = .003$). This was also the case for participants in the 50-65 year age group ($P = .01$; Table 2) and for participants in lower and higher education levels ($P = .04$ for both groups; Table 3).

The print-delivered feedback was reported to be saved more often than the CD-ROM-delivered feedback among the total population ($P < .001$), men ($P = .02$), women ($P < .001$), the ≤ 34 year and 35-49 year age groups ($P = .001$ for both groups), and medium- and higher-educated respondents ($P = .001$ for both groups).

Less than 50% of those who reported to have read the tailored information discussed it with others.

Table 1. Use and appreciation of the print- and CD-ROM-delivered, computer-tailored intervention, by gender

	Total Study Group				Men				Women			
Use (yes/no)	**Print, No. (%)**	**CD-ROM, No. (%)**	***P*** [*]	χ^2_1	**Print, No. (%)**	**CD-ROM, No. (%)**	***P*** [*]	χ^2_1	**Print, No. (%)**	**CD-ROM, No. (%)**	***P*** [*]	χ^2_1
Read[†]	122/129 (94.6)	103/128 (80.5)	.001	11.73	53/58 (91)	45/57 (79)	.06	3.53	69/71 (97)	58/71 (82)	.003	9.02
Saved[†]	120/124 (96.8)	89/116 (76.7)	< .001	21.42	51/55 (93)	40/52 (77)	.02	5.25	69/69 (100)	49/64 (77)	< .001	18.23
Discussed[‡]	50/114 (43.9)	38/94 (40)	.62	0.25	25/48 (52)	16/40 (40)	.26	1.28	25/66 (38)	22/54 (41)	.75	0.10
Appreciation (−2 to +2)	**Mean ± SD**	**Mean ± SD**	***P*** [§]	**ES**[‖]	**Mean ± SD**	**Mean ± SD**	***P*** [§]	**ES**[‖]	**Mean ± SD**	**Mean ± SD**	***P*** [§]	**ES**[‖]
Trustworthy[‡]	1.28 ± 0.96 (n=120)	1.26 ± 1.02 (n=102)	.89	0.02	1.34 ± 0.88 (n=53)	1.33 ± 0.90 (n=45)	.97	0.01	1.24 ± 1.03 (n=67)	1.21 ± 1.11 (n=57)	.88	0.03
Perceived individualization[‡]	1.12 ± 1.01 (n=121)	1.01 ± 1.08 (n=102)	.45	0.11	1.04 ± 0.98 (n=53)	1.13 ± 0.97 (n=45)	.63	−0.09	1.18 ± 1.04 (n=68)	0.91 ± 1.15 (n=57)	.18	0.25
Personal relevance[‡]	0.97 ± 0.98 (n=119)	0.68 ± 1.11 (n=102)	.04	0.28	0.85 ± 1.02 (n=52)	0.69 ± 1.10 (n=45)	.47	0.15	1.06 ± 0.95 (n=67)	0.67 ± 1.12 (n=57)	.04	0.38
User-friendly[‡]	0.99 ± 1.07 (n=121)	1.09 ± 1.04 (n=102)	.50	−0.09	1.00 ± 1.06 (n=53)	1.33 ± 0.88 (n=45)	.10	−0.34	0.99 ± 1.09 (n=68)	0.89 ± 1.11 (n=57)	.65	0.09

[*] *P* value derived from Pearson chi-square test.

[†] Only cases without missing values are included in analyses; therefore, numbers in denominators differ from numbers in Figure 1.

[‡] For the analysis of the variables discussed, trustworthy, perceived individualization, personal relevance, and user-friendly, only respondents who indicated they had read the information and without missing values were included in the analysis.

[§] *P* value derived from independent-samples *t* test.

[‖] Positive effect size (ES) in favor of print; negative ES in favor of CD-ROM; ES can be categorized as small (0-0.32), moderate (0.33-0.55), or large (> 0.55).

Table 2. Use and appreciation of the print- and CD-ROM-delivered, computer-tailored intervention, by age group

	≤ 34 Years				35-49 Years				50-65 Years			
Use (yes/no)	**Print, No. (%)**	**CD-ROM, No. (%)**	***P***[*]	χ^2_1	**Print, No. (%)**	**CD-ROM, No. (%)**	***P***[*]	χ^2_1	**Print, No. (%)**	**CD-ROM, No. (%)**	***P***[*]	χ^2_1
Read[†]	22/23 (96)	26/30 (87)	.27	1.23	64/69 (93)	44/54 (82)	.06	3.60	36/37 (97)	33/44 (75)	.01	7.92
Saved[†]	22/22 (100)	17/30 (57)	.001	12.71	65/66 (99)	40/51 (78)	.001	12.57	33/36 (92)	32/35 (91)	.97	0.00
Discussed[‡]	8/20 (40)	10/25 (40)	1.00	0.00	30/61 (49)	17/40 (43)	.51	0.43	12/33 (36)	11/29 (38)	.90	0.02
Appreciation (−2 to +2)	**Mean ± SD**	**Mean ± SD**	***P***[§]	**ES**[‖]	**Mean ± SD**	**Mean ± SD**	***P***[§]	**ES**[‖]	Mean ± SD	**Mean ± SD**	***P***[§]	**ES**[‖]
Trustworthy[‡]	1.18 ± 1.01 (n=22)	1.31 ± 0.97 (n=26)	.66	−0.13	1.35 ± 0.90 (n=63)	1.23 ± 1.02 (n=43)	.54	0.13	1.23 ± 1.06 (n=35)	1.27 ± 1.10 (n=33)	.87	−0.04
Perceived individualization[‡]	1.05 ± 1.13 (n=22)	0.88 ± 1.24 (n=26)	.64	0.14	1.22 ± 0.91 (n=63)	1.05 ± 1.00 (n=43)	.35	0.18	0.97 ± 1.11 (n=36)	1.06 ± 1.06 (n=33)	.74	−0.08
Personal relevance[‡]	0.81 ± 1.03 (n=21)	0.35 ± 1.23 (n=26)	.18	0.40	1.00 ± 0.94 (n=62)	0.58 ± 0.96 (n=43)	.03	0.44	1.00 ± 1.04 (n=36)	1.06 ± 1.12 (n=33)	.82	−0.06
User-friendly[‡]	0.68 ± 1.21 (n=22)	1.23 ± 1.03 (n=26)	.10	−0.49	1.00 ± 1.03 (n=63)	0.98 ± 0.99 (n=43)	.91	0.02	1.17 ± 1.03 (n=36)	1.12 ± 1.11 (n=33)	.86	0.05

[*] *P* value derived from Pearson chi-square test.

[†] Only cases without missing values are included in analyses; therefore, numbers in denominators differ from numbers in Figure 1. [‡] For the analysis of the variables discussed, trustworthy, perceived individualization, personal relevance, and user-friendly, only respondents who indicated they had read the information and without missing values were included in the analysis.

[§] *P* value derived from independent-samples *t* test.

[‖] Positive effect size (ES) in favor of print; negative ES in favor of CD-ROM; ES can be categorized as small (0-0.32), moderate (0.33-0.55), or large (> 0.55).

Table 3. Use and appreciation of the print- and CD-ROM-delivered, computer-tailored intervention, by education level

	Lower Education				Medium Education				Higher Education			
Use (yes/no)	**Print, No. (%)**	**CD-ROM, No. (%)**	***P*** [*]	χ^2_1	**Print, No. (%)**	**CD-ROM, No. (%)**	***P*** [*]	χ^2_1	**Print, No. (%)**	**CD-ROM, No. (%)**	***P*** [*]	χ^2_1
Read[†]	29/30 (967)	22/28 (79)	.04	4.47	43/46 (94)	35/43 (81)	.08	3.00	49/42 (94)	46/57 (81)	.04	4.45
Saved[†]	27/28 (96)	23/25 (92)	.49	0.49	46/46 (100)	31/39 (80)	.001	10.42	47/50 (94)	35/52 (67)	.001	11.52
Discussed[‡]	10/25 (40)	8/18 (44)	.77	0.09	20/43 (47)	13/32 (41)	.61	0.26	20/46 (44)	17/44 (39)	.64	0.22
Appreciation (−2 to +2)	**Mean ± SD**	**Mean ± SD**	***P*** [§]	**ES**[‖]	**Mean ± SD**	**Mean ± SD**	***P*** [§]	**ES**[‖]	**Mean ± SD**	**Mean ± SD**	***P*** [§]	**ES**[‖]
Trustworthy[‡]	1.29 ± 1.01 (n=28)	0.95 ± 1.33 (n=22)	.32	0.29	1.37 ± 0.82 (n=43)	1.34 ± 0.68 (n=35)	.87	0.04	1.20 ± 1.06 (n=49)	1.36 ± 1.07 (n=45)	.49	−0.15
Perceived individualization[‡]	1.14 ± 1.06 (n=29)	0.82 ± 1.14 (n=22)	.31	0.29	1.23 ± 0.84 (n=43)	1.11 ± 0.90 (n=35)	.55	0.14	1.00 ± 1.12 (n=49)	1.02 ± 1.18 (n=45)	.93	−0.02
Personal relevance[‡]	1.18 ± 1.02 (n=28)	0.77 ± 1.15 (n=22)	.19	0.39	1.07 ± 0.70 (n=42)	0.94 ± 0.91 (n=35)	.49	0.16	0.76 ± 1.13 (n=49)	0.42 ± 1.20 (n=45)	.17	0.29
User-friendly[‡]	1.14 ± 1.03 (n=29)	1.00 ± 1.19 (n=22)	.66	0.13	1.07 ± 0.99 (n=43)	1.17 ± 1.01 (n=35)	.66	−0.10	0.84 ± 1.16 (n=49)	1.07 ± 0.99 (n=45)	.31	−0.21

[*] *P* value derived from Pearson chi-square test.

[†] Only cases without missing values are included in analyses; therefore, numbers in denominators differ from numbers in Figure 1. [‡] For the analysis of the variables discussed, trustworthy, perceived individualization, personal relevance, and user-friendly, only respondents who indicated they had read the information and without missing values were included in the analysis.

[§] *P* value derived from independent-samples *t* test.

[‖] Positive effect size (ES) in favor of print; negative ES in favor of CD-ROM; ES can be categorized as small (0-0.32), moderate (0.33-0.55), or large (> 0.55).

Appreciation of the Computer-Tailored Information

Trustworthiness, perceived individualization, and user-friendliness were not significantly different between the print condition and the CD-ROM condition. However, the CD-ROM condition was rated as more user-friendly by men (*P* = .10) and respondents ≤ 34 years (*P* = .10), with a moderate, though not statistically significant, effect size.

Results showed a statistically significant higher perceived personal relevance for the print condition compared to the CD-ROM condition among the total population (*P* = .04), women (*P* = .04), and the 35-49 year age group (*P* = .03), with effect sizes that can be categorized as small (among total population) to moderate (among women and 35-49 year age group). In addition, the print condition was rated as more personally relevant by the ≤ 34 year age group (*P* = .18) and the less educated respondents (*P* = .19), with moderate, though not statistically significant, effect sizes.

Discussion

Principal Results

The results of this study indicate that there are differences in the use and appreciation of a print-delivered versus CD-ROM-delivered, computer-tailored intervention. The differences were mainly in favor of the print-delivered intervention. The print feedback was read and saved more often than the CD-ROM feedback (some specific subgroups excepted), and the print feedback was perceived as more personally relevant in the total study group and in some of the subgroups, with small to moderate effect sizes.

Surprisingly, the print-delivered feedback was rated as more personally relevant. Personal relevance is considered to be a core characteristic and a potential working mechanism of computer-tailored interventions [16,17], and, in the present study, both interventions had the same level of personalization and individualization. Apparently, it is not only the feedback itself that is related to the perception of personal relevance, but also the delivery mode through which the information is distributed. Perhaps the immediate feedback on screen after completion of the questionnaire (in the CD-ROM condition) versus the time lag between returning the questionnaire to the researchers and receiving feedback (in the print condition) influences this perception. The receipt of a personalized mailed letter might also enhance relevance. Another explanation may be that participants had expected more personal relevance from a computer program in which they had to complete questions first.

Comparison With Prior Work

Our study is unique in evaluating a broader set of indicators for use, appreciation, and perception of personal relevance between a print-delivered and an interactive-delivered, computer-tailored intervention with identical content.

The finding that the print-delivered feedback is read and saved more often than the CD-ROM-delivered feedback is in line with expectations and findings from previous studies [8,9,28,29].

Information sent through print media may be more easily available and accessible and easier to read and save [8,9]. Our results not only indicate that the subgroups suggested in the literature (women, less educated respondents, and older respondents) use the CD-ROM less than print, but also that this is the case for men and higher-educated and younger respondents. However, we do not know why participants in the CD-ROM group did not read the information. Having to use a computer and start a program may have been a barrier in terms of the time, effort, or planning that would be needed to use the program and generate the feedback. For another segment of the participants, lack of motivation or skills to use interactive media may have been a reason [13,21]. This could have been the case for women, older persons, and less-educated persons.

Vandelanotte et al found that people over 40 years compared to those younger than 40 years preferred an intervention delivered in print over an interactively delivered intervention [25]. However, it has also been found that even though people had indicated they preferred to receive an intervention over the Internet, they nevertheless did not access this intervention [29].

The findings of this study add to the evidence regarding differences in use of interactive and print-delivered interventions with identical content [28,29] and provide important new insights in appreciation and perceived relevance of the information. Findings from this and previous studies suggest that interactively delivered interventions as used to date may be less successful in attracting attention and may be less suited to facilitate active information processing compared to print-delivered computer-tailored information. Efforts are needed to increase use, appreciation, and active information processing.

Limitations

The present study provides descriptive data. Further studies should explore if personal relevance and reading level mediate differential effects between print-delivered and interactive-delivered tailored feedback. Additionally, less-educated people and those older than 65 years were underrepresented or not included in this study. Although the intervention could be provided over the Internet, in this study it was delivered on a CD-ROM.

In this study we conducted a lot of tests without correction for multiple testing, which may increase the risk of false positives in the outcomes of the analyses. However, due to subgroup analyses, the number of participants was rather small in some analyses, which may have caused lack of power to detect significant differences, even when there was a moderate effect size. Reducing the P value to correct for multiple testing would increase the risk of false negatives. Therefore, we reported the uncorrected P values and the effect sizes of our different outcome measures. We evaluated the significance of differences using a significance level of $P < .05$. Effects can also be evaluated using a more conservative significance level of $P < .01$ to approach correction for multiple testing. In addition, the moderate effect sizes may provide an indication of differences that might become statistically significant when analyzed in larger groups.

Further, this study compared two delivery modes on aspects of use and appreciation that are relevant for both modes (ie, in both cases, for information processing, the information should be read, saved, and perceived as personally relevant). However, using this approach, we may have missed important aspects for use and probably appreciation of the information or the program that are more sensitive to specific characteristics of interactive media. Future process evaluation studies could use more extensive and specific instruments.

Conclusions

Interactive computer-tailored feedback appears to be read and saved less than print-delivered feedback and perceived as less personally relevant, especially among certain subgroups. These differences in use and appreciation of the computer-tailored intervention delivered through print or interactive delivery modes can be taken into account when selecting a delivery mode for a specific subgroup in order to optimize exposure. Future studies should explore methods to improve exposure to and use of interactively delivered computer-tailored information.

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Conflicts of Interest

None declared.

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Original Paper

An Exploration of Factors Related to Dissemination of and Exposure to Internet-Delivered Behavior Change Interventions Aimed at Adults: A Delphi Study Approach

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Abstract

Background: The Internet is an attractive medium for delivering individualized, computer-tailored behavior change interventions to large numbers of people. However, the actual numbers of people reached seem to fall behind the high expectations. Insight into factors that determine use of and exposure to these Internet interventions is important to be able to increase the reach and improve exposure.

Objective: The aim was to identify potentially important factors that determine whether adults visit an Internet-delivered behavior change intervention, extend their visit, and revisit the intervention.

Methods: A systematic, three-round Delphi study was conducted among national and international experts from Internet intervention research and practice, e-marketing/e-commerce, Web design, and technical website development. In the first round, 30 experts completed a structured, open-ended online questionnaire assessing factors that were, in their opinion, important for a first visit, an extended visit, a revisit and for effective promotion strategies. Based on the responses in this first questionnaire, a closed-ended online questionnaire was developed for use in the second round. A total of 233 experts were invited to complete this questionnaire. Median and interquartile deviation (IQD) scores were computed to calculate agreement and consensus on the importance of the factors. The factors for which no consensus was obtained (IQD > 1) were included in the third-round questionnaire. Factors with a median score of six or higher and with an IQD ≤ 1 were considered to be important.

Results: Of the 62 experts invited for the first round, 30 completed the questionnaire (48% response rate); 93/233 experts completed the second-round questionnaire (40% response rate), and 59/88 completed the third round (67% response rate). Being motivated to visit an Internet intervention and perceiving the intervention as personally relevant appeared to be important factors related to a first visit. The provision of tailored feedback, relevant and reliable information, and an easy navigation structure were related to an extended visit. Provision of regular new content and the possibility to monitor personal progress toward behavior change were identified as important factors to encourage a revisit. Primarily traditional promotion strategies, like word-of-mouth by family and friends, a publicity campaign with simultaneous use of various mass media, and recommendation by health professionals, were indicated as effective ways to encourage adults to visit an Internet intervention.

Conclusions: This systematic study identified important factors related to the dissemination of and exposure to Internet interventions aimed at adults. In order to improve optimal use of and exposure to Internet interventions, potential users may need to be motivated to visit such an intervention and the information provided needs to be personally relevant. Furthermore, several (technical) aspects of the intervention itself need to be taken into account when developing Internet interventions.

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KEYWORDS

Internet; Internet interventions; health behavior change; dissemination; exposure; Delphi study

Introduction

The Internet has dramatically changed the possibilities for communication, including communication about health behavior and behavior change [1]. The Internet is a very attractive medium for the delivery of behavior change interventions since it provides the option of delivering sophisticated versions of individualized, computer-tailored interventions and holds the promise of reaching large numbers of people [2-5]. However, the actual reach of Internet-delivered behavior change interventions seems to lag behind this high expectation [6,7]. Evidence from efficacy trials indicates that actual use of and exposure to the assigned intervention content is low [8,9], and when implemented in real life, exposure rates may be even lower [10,11]. In addition, exposure to the intervention content is not always optimal. It has been demonstrated that it is difficult to sustain visitors' loyalty to an intervention over an extended period of time [12,13], which may result in premature attrition from a session or in non-use of follow-up sessions. Furthermore, people tend to spend only a limited amount of time assessing the program [14], which makes optimal exposure to the intervention content unlikely. Loyalty to the program over an extended period of time may not be necessary for all Internet interventions or for all people using them since not all Internet interventions require extensive or repeated use of all the offered content [15,16]. However, for all Internet interventions at least some exposure to the intervention content is needed to initiate a process of behavior change. An increase in the number of people reached and improved exposure to Internet-delivered behavior change interventions are needed to be able to achieve optimal implementation of interventions after they have been evaluated to be efficacious [6,9].

The importance of focusing attention not only on intervention efficacy but also on dissemination, reach, and exposure in achieving public health impact is emphasized in the RE-AIM (Reach, Efficacy, Adoption, Implementation, and Maintenance) framework [17]. To be able to improve dissemination and exposure rates of Internet-delivered behavior change interventions, it is important to identify factors that enhance or inhibit these rates since such factors have to be targeted when attempting to improve dissemination and exposure [18]. The present study investigates factors related to dissemination of, use of, and exposure to Internet-delivered behavior change interventions among adults.

Access or use of the Internet is not likely to be a barrier to accessibility of Internet interventions these days since penetration rates of home Internet access and Internet use are high. Various factors have been related to Internet or Internet intervention use, for example, differences in motivation, skills, and availability of computer facilities [9,19]. It has been suggested that to increase the number of first time and extended visits, it is necessary to ensure reliability and credibility of the source or provider of the intervention [20,21]. The information structure has been found to be related to the use of information, with less structured websites tending to prematurely lose visitors [13,22,23]. Also, the amount of detail and elaboration of the information has been related to the length of time people process the intervention information [12]. Furthermore, it has been suggested that a static website that does not change over time may not attract revisits to interventions designed for multiple visits [4]. The use of email to encourage revisiting an intervention seemed to have some effect on revisits, but not on encouraging new users [7,24]. Even though some potentially important determining factors have been suggested in the literature, these factors have not been studied in a systematic way, which is the aim of the present study.

In this study we defined Internet-delivered behavior change interventions (or Internet interventions) to include those interventions that are aimed at the primary prevention of chronic disease by promoting healthful behaviors. Examples are interventions that promote healthful dietary, physical activity, and safe sex practices, discourage alcohol consumption, or encourage smoking cessation or sun protection behavior. Although these are very different topics, similar issues regarding exposure to and use of the content are likely to apply for all these interventions.

Dissemination and use of Internet interventions can be considered a process of diffusion and adoption of the intervention. Therefore, we used the Diffusion of Innovations Theory proposed by Rogers as the theoretical background for this study [18]. According to this model, characteristics of the user, the source (ie, the provider of the intervention), and the innovation (in this case the intervention) are important in the process of dissemination and adoption. Characteristics of the users include personal characteristics, such as gender and age, but also individual cognitions regarding use of Internet interventions, including attitudes, subjective norms, perceived behavioral control, and intention as derived from the Theory of Planned Behavior [25]. Furthermore, perceived possibilities and barriers to use of an intervention may play a role. Potentially important characteristics of the source are the perceived credibility and reliability. Characteristics of the intervention include the complexity (the degree to which the Internet intervention is perceived as difficult to understand and use), the trialability (the degree to which it is possible to experiment with the intervention before adopting it completely), and the relative advantage of the intervention (the degree to which the intervention is perceived to be superior to the idea that it replaces) [14,18]. In this study the term "dissemination" was used for the activities that the developers or providers have to undertake to bring the intervention to the attention of potential users. Dissemination was regarded as being distinct from exposure since the first is more related to activities of providers and the latter to the behavior of potential users. We conceptualized the process of visiting an Internet intervention and being optimally exposed to its educational content as consisting of three distinct phases that are potentially determined by different factors: (1) a first visit, in which a potential user has to decide to go to a website and see what it entails, (2) extending the visit, in which a user has to decide whether to continue his or her visit and be exposed to (part of) the content, and (3) revisiting the Internet intervention, in which the user has to decide to make a return visit to the intervention.

To assess the potential factors related to use of and exposure to Internet interventions, we conducted a three-round Delphi study. The specific aim of this study was to identify the (1) factors that are associated with dissemination of and exposure to (first visit, extended visit, and revisit) Internet interventions aimed at adults, and (2) extent to which experts agree on the importance of these factors.

Methods

A three-round Delphi study was conducted with international experts from health promotion research, e-marketing/e-commerce, Web design, and technical website development. A Delphi study is a technique particularly suited for generating ideas about topics on which scientific knowledge is scarce. The technique allows for including experts from all over the world, guarantees anonymity of responses that may make the experts respond more freely, and is aimed at reaching agreement on the important issues [26-28]. The first round of the Delphi study was aimed at identifying potential factors of dissemination, first visit, extended visit, and revisit of an Internet intervention. The aim of the second and third round was to determine the importance and achieve agreement on the importance of the factors identified in the first round. The Delphi study was conducted over the Internet using online questionnaires. It was part of a larger study in which factors of dissemination and use of Internet interventions in adolescents were investigated. In the first round of the study, experts were asked to indicate factors that would be important for adults as well as for adolescents. In the second and third rounds, experts had to provide separate responses for adults and adolescents. The entire Delphi study was carried out within 3 months (October to December 2006). The results regarding adolescents are published elsewhere [29].

Participants and Procedure

A total of 62 prominent experts in Internet intervention research and practice, e-marketing/e-commerce, Web design, and technical website development from around the world were invited for the first round of the Delphi study. The ratio of experts from each field was set to 30:10:10:10. The highest number of experts was chosen to be from health promotion research and practice since we expected that these experts would have the broadest insight into the effectiveness of dissemination strategies and the factors related to a first visit, an extended visit, and a revisit. Criteria for choosing key experts in the first round were the following: (1) they were first authors of key scientific publications in the area of eHealth and eHealth promotion, and (2) they had written multiple scientific articles regarding this topic. People were also included if they were active members of editorial boards of leading journals in health promotion and the Internet and had published in these areas or journals. Representatives of e-marketing/e-commerce and ICT (information and communication technology) companies (eg, Web designers and developers) were selected on the basis of publications, our own network, and by asking the responders to provide names of other experts in their field.

This list of experts was extended to 233 persons (aim was 250) to be invited for participation in the second round of the study. The criterion for selection was being first author of a scientific paper or abstract on the topic of Internet interventions. Names of first authors were retrieved through a literature search in PubMed, PsycINFO, and Web of Science (between 2000 and 2006), and first authors of abstracts published in proceedings of relevant national and international conferences (eg, Society for the Internet in Medicine [MEDNET 2005 and 2006] and International Society for Behavior Nutrition and Physical Activity [ISBNPA 2004-2006]) were added to the list. Experts from the field of e-marketing/e-commerce and ICT were mainly found through our own network and by referral from experts in the first round. The experts who responded in the second round (n = 88) were invited to participate in the third round.

The experts were invited to participate in the study and each subsequent round by means of an email. In this email, the purpose and procedure of the Delphi study was explained and a link to the questionnaire was provided. Invitees were reminded once by email to complete the first-round questionnaire and twice to complete the second- and third-round questionnaires. The questionnaires were pre-tested by experts in the fields of health promotion research and e-marketing.

Measurements

First Round

The first-round questionnaire was a structured questionnaire with an open-ended answer format. Participants were asked to list all the factors that, according to their expertise, (1) are essential for successful dissemination of Internet interventions, (2) determine whether a person will visit an intervention for the first time, (3) determine whether a person will stay long enough on a website to meaningfully engage in the educational content, and (4) determine whether a person will revisit a website. A sample question was “What are, according to your expertise, factors that determine whether a person will visit an Internet-delivered behavior change intervention for the first time?” The respondents were asked to suggest factors related to the user, the source, the Internet intervention itself, the physical and social environment, and any other important factors. The questionnaire started with a definition of all concepts used (eg, what we defined as factors, Internet-delivered interventions, behavioral topics addressed in these interventions, and dissemination).

Second Round

The second-round questionnaire had a closed-ended answer format and included all the unique factors that had been mentioned by the experts in the first round, except for those that were general health education principles not unique to Internet interventions (eg, the intervention is based on scientific knowledge, the information should be understandable) since these are basic principles for state of the art health communication interventions for which no rating of importance and consensus is needed. The questionnaire consisted of 82 statement items (see the Multimedia Appendix) presenting factors related to the (potential) visitor, the source, and the Internet intervention itself for a first visit, extended visit, revisit and for dissemination. The experts were asked to indicate how important they thought each of the factors were on a 7-point Likert scale (1 = not important, 7 = extremely important) for adults and adolescents separately. Apart from determinants of dissemination, the experts in the first round mentioned many factors that were, in fact, ways to promote Internet interventions. Therefore, we included a list with 23 strategies for promoting an Internet intervention. The experts were asked to choose the five strategies they thought were most successful for promoting an intervention among adults. This list of promotion strategies appeared in random order for each of the respondents.

Third Round

The third-round questionnaire contained the items (48 in total, see the Multimedia Appendix) of the second-round questionnaire for which no consensus was obtained (interquartile deviation [IQD] > 1). The answering scale for each item now included information on the median score and IQD for that item as determined in the second-round questionnaire. The experts were asked to re-rate their answers on the same 7-point Likert scale in the light of this new information.

Data Analysis

All the responses to the first-round questionnaire were listed, and similar responses were grouped together to reduce the number of factors. The remaining list of potentially important factors was included in the questionnaire for the second and third round, except for the factors that were general health education principles.

In the second round, following the standards for analyzing data from a Delphi study, the median scores were calculated to determine agreement on the importance of the statements. Also, the IQDs were calculated to determine consensus among the experts on the importance of the statements [26,30]. On a 7-point Likert scale, an IQD ≤ 1 can be considered as good consensus and means that more than 50% of all opinions fall within one point on the scale [28]. Items with a median ≥ 6 (very or extremely important) and an IQD ≤ 1 were considered as important factors. The dissemination strategies were analyzed by means of multiple response analysis.

In the third round, median scores and IQDs were calculated for the items included in the third-round questionnaire. SPSS 11.0 (SPSS Inc, Chicago, IL, USA) was used for all the statistical analyses.

Results

Participants and Response Rates

In total, 30 of the 62 experts we approached completed the questionnaire in the first round (48% response rate; Table 1). Participants were primarily from health promotion institutes (64% response rate) and health promotion research (50% response rate); 93/233 respondents completed the second-round questionnaire (40% response rate), and 59/88 completed the third-round questionnaire (67% response rate). Three participants resigned from participation in the third round due to time constraints, and two could not be contacted again since they had not provided contact details in the previous questionnaire. Reasons for nonparticipation and dropout of the other experts are not known, although some reported lack of time or interest.

Table 1. Response rates in the Delphi study

Discipline	First Round			Second Round			Third Round		
	No. Invited	No. Responded	%	No. Invited	No. Responded	%	No. Invited	No. Responded	%
Health promotion research	32	16	50	155	65	42	62	41	66
Health promotion institutes	11	7	64	20	10	50	10	8	80
e-Marketing and communication	9	3	33	24	6	25	6	4	67
Technical implementation	10	4	40	34	10	29	10	6	60
Unknown	–	–	–	–	2	–	–	–	–
Total	62	30	48	233	93	40	88	59	67

Measurements

First Round

All factors unique for Internet interventions identified in the first round are listed in the Multimedia Appendix. This list is composed of factors that were mentioned by individual experts (eg, using modular approach, an enjoyable and rewarding experience in the first visit), as well as factors that were brought up by several of the experts (eg, tailored/individualized content, word-of-mouth by family and friends, the credibility of the source). More factors were mentioned for a first visit and an extended visit than for a revisit. The factors mentioned under dissemination were mainly ways to promote an intervention, such as word-of-mouth, commercials on TV and radio, and email.

Second Round

With respect to the first visit, 4 of 17 items pertaining to the potential visitor (sufficient Internet skills, experience with using the Internet, motivation to visit the intervention, perceived relevance of the intervention) and 2 of 9 items pertaining to the

Internet intervention (instant use, easy navigation structure) had a median score ≥ 6 (Table 2). Consensus was reached for three of these items.

Regarding an extended visit, 5 of 9 items related to the visitor (eg, wants to improve behavior, experiences the use as rewarding, appreciates tailored feedback), 0 related to the source, and 12 of 23 items related to the Internet intervention (eg, displays personal progress, provides brief registration procedure, free of charge) had a median score ≥ 6 (Table 2). Consensus was reached for 10 of these items.

With respect to revisiting an intervention, 4 of 5 items regarding the visitor (receiving a reminder, committed to revisit, wants to improve behavior, positive experience with previous visit) and 5 of 10 items pertaining to the Internet intervention (new content, monitoring progress, experienced previous visit as easy, rewarding, and enjoyable) had a median score ≥ 6 (Table 2). Consensus was reached for all these items, indicating that the majority of experts agreed that these were important factors for revisiting.

None of the strategies for dissemination had a median score ≥ 6 (see the Multimedia Appendix).

Overall, consensus (IQD ≤ 1) was reached for 34 items in the second round. Most items that reached consensus were related to revisiting an intervention (10 of 15 items). The least consensus was achieved for dissemination of interventions (1 of 7 items).

Table 2. Results of the Delphi study per item (second and third round) with a median score ≥ 6 (full list of results including items with lower scores can be found in the Multimedia Appendix)

Questionnaire Item	Second Round			Third Round		
	No.	Median†	IQD	No.	Median†	IQD
I. How important do you think each of the following factors are in determining whether a person will make a first visit to an Internet-delivered behavior change intervention?						
A. Whether the potential visitor						
- has sufficient skills to use the Internet	89	6	1.5	59	6	1
- has experience with using the Internet	88	6	1	_*	–	–
- is motivated to visit a behavior change intervention provided through the Internet	88	6	1	–	–	–
- perceives the Internet intervention as relevant for himself/herself	84	6	1	–	–	–
B. Whether the Internet intervention						
- can be used instantly without downloading special software by the potential visitor	83	6	2	56	6	0
- has a navigation structure that appears to be easy to use at first sight	83	6	2	56	6	0
II. How important do you think each of the following factors are in determining whether a person will stay on an Internet-delivered behavior change intervention long enough to actively engage in and process the educational content provided in the intervention?						
A. Whether the visitor						
- knows in advance how long it will take to go through the whole intervention	80	6	2	56	6	1
- wants to improve his/her behavior in relation to the topic of the Internet intervention	80	6	1	–	–	–
- perceives the topic and content of the entire Internet intervention as being personally relevant	79	6	2	56	6	0
- experiences the use of the Internet intervention as rewarding	80	6	1	–	–	–
- likes receiving (tailored) feedback on the answers he/she provided on questions	80	6	2	56	6	1
C. Whether the Internet intervention						
- displays personal progress through the program (eg, progress bar, page numbers)	78	6	1	–	–	–
- provides the opportunity for a visitor to stop at any moment and to proceed at a later time	79	6	1	–	–	–
- has an aim that is clear to the visitor	79	6	1	–	–	–
- provides information that appears reliable to the visitor	78	6	1	–	–	–
- provides information that is easy to understand for the visitor	79	6	1	–	–	–
- provides information that is perceived to be useful for the visitor to help him/her in changing behavior	77	6	2	56	6	0
- has a tone of voice that is appealing to the visitor	78	6	1	–	–	–
- has an easy-to-follow navigation structure	78	6	2	56	6	0
- provides tailored feedback	77	6	1	–	–	–
- provides tailored feedback which is perceived as relevant to the visitor	77	6	1	–	–	–
- provides behavior change information that seems achievable to the visitor	77	6	2	56	6	0
- can be used free of charge	77	6	2	55	6	0
III. How important do you think each of the following factors are in determining whether a person will revisit an Internet-delivered behavior change intervention?						
A. Whether the visitor						
- receives a reminder to revisit the Internet intervention	76	6	1	–	–	–
- is committed to revisiting the Internet intervention	76	6	1	–	–	–
- wants to improve his/her behavior in relation to the topic of the Internet intervention	76	6	1	–	–	–
- had a positive experience with the previous visit to the Internet intervention	76	6	1	–	–	–

Questionnaire Item	Second Round			Third Round		
	No.	Median†	IQD	No.	Median†	IQD
B. Whether the Internet intervention						
- provides new content on a regular basis	76	6	1	–	–	–
- provides the possibility for a visitor to monitor his/her progress in changing behavior	76	6	1	–	–	–
- has previously been experienced as easy to use by the visitor	76	6	1	–	–	–
- has previously been experienced as rewarding by the visitor	76	6	1	–	–	–
- has previously been experienced as enjoyable by the visitor	76	6	1	–	–	–

[*] Dashes indicate that consensus was obtained on the item in the second round and, for that reason, was excluded from the third-round questionnaire.

[†] All items were scored 1-7 on a 7-point Likert scale.

The ways to disseminate Internet interventions that were indicated most often were word-of-mouth by family and friends (58.1%), a publicity campaign with the simultaneous use of various mass media (58.1%), and recommendation by health professionals (52.7%; Table 3).

Table 3. Strategies of Internet intervention dissemination (N = 74)

Dissemination Strategy	No.	%
Word of mouth (eg, by friends and family)	43	58.1
Publicity campaign with simultaneous use of various mass media	43	58.1
Health professionals (eg, general practitioner, physical therapist)	39	52.7
TV and radio programs (eg, talk shows, consumer programs)	31	41.9
Commercials on TV and radio	28	37.8
Articles in magazines and newspapers	25	33.8
Links to the Internet intervention at other websites	20	27.0
Involvement of people who belong to the target group	20	27.0
Advertisements on websites visited by the target group	19	25.7
Face-to-face contact	18	24.3
Email	17	23.0
Banners of the Internet intervention on other websites	14	18.9
Nonmedical professionals (eg, worksite health promoter)	14	18.9
Advertisements in magazines and newspapers	12	16.2
Advertisements on relevant products (eg, cigarette packs, milk cartons)	10	13.5
Free publicity (eg, postcards, brochures, bulletin board postings in libraries or hospitals)	9	12.2
Use of virtual guides to direct people to the Internet intervention (eg, in chat boxes)	8	10.8
Telephone calls	7	9.5
Forums on the Internet	4	5.4
Other ICT channels (eg, MSN Messenger, AOL Instant Messenger)	3	4.1
Distribution of flyers at exhibitions and other public events	2	2.7
Distribution of flyers door-to-door	1	1.4
SMS (Short Message Service)	0	0.0

Third Round

The median scores of the items included in the third-round questionnaire did not differ from the second round. Consensus was achieved for 45 of the 48 items (IQD ≤ 1; see Table 2). No consensus was achieved for positive expectations of behavior change interventions delivered through the Internet (relating to first visit), whether the user has to provide sensitive information, or the option of a trial before starting the intervention (related to extended visit). These three factors had a median score < 6.

Discussion

Summary of Findings

This Delphi study is among the first systematic explorations of potentially important factors related to the dissemination of and exposure to Internet-delivered behavior change interventions. The study is unique in its focus on factors related to a first visit, an extended visit, and a revisit and by taking into account the characteristics of the potential users (in this case, adults), the source, and the intervention itself. In particular, factors related to the potential user, such as motivation and perceived personal relevance, were identified as important factors (median score > 6; IQD ≤ 1) related to a first visit. With regard to an extended visit (ie, staying on the intervention long enough to meaningfully process some of the content), many more factors related to the intervention itself were identified as important. The intervention needs to provide tailored feedback and relevant and reliable information and be clear and easy to use. The experience with the intervention in the previous visit, the inclination to change the behavior targeted in the intervention, the provision of new content, and being reminded to visit the intervention were regarded as important factors for a revisit. Apart from the factors that were rated as very important or extremely important, most of the other factors that came out of the first round reached consensus and were rated as somewhat important or important (median score 4-5). This means that these factors (listed in the Multimedia Appendix) also need to be taken into account when attempting to improve use and exposure to Internet interventions.

Interpretation of Findings

The existing knowledge on factors that enhance or inhibit optimal use of and exposure to an Internet intervention mainly relate to characteristics of the intervention itself. In this Delphi study we used the Diffusion of Innovations Theory [18] as a theoretical framework, and therefore, we also considered characteristics of the user and the source as potentially important factors associated with adoption. In contrast to previous studies, credibility and reliability of the source were not identified as very important factors for visiting an Internet intervention or extending a visit [20,21]. With respect to characteristics of the potential users, motivation to visit the intervention and perceived personal relevance of the intervention were identified as important factors. The finding that motivation is an important factor is intuitive since visiting an Internet intervention for the first time, extending the visit, and revisiting the intervention can be considered as specific behaviors that can be explained by the Theory of Planned Behavior [18]. According to this theory, motivation is the determinant most proximal to behavior. The present study did not, however, provide information about factors underlying the motivation to visit an Internet intervention, such as attitudes, subjective norms, or perceived behavioral control [18]. This is possibly due to the breadth of topics addressed in this study or that the study was performed among experts and not among the actual users of Internet interventions. Nevertheless, motivating people to visit an Internet intervention seems to be important.

The provision of personalized feedback seems to be a key element related to an extended visit to an Internet intervention. This finding underlines what has been previously suggested in the literature. Computer tailoring has been identified as a very promising health education technique and the Internet, as a suitable medium for delivery of computer-tailored interventions [31,32]. Furthermore, if the computer-tailored information is iterative and provides new information and information about the users' progress, it might also encourage people to revisit the intervention [3,4,33-35].

Not only are motivation and personal feedback important, but the way in which the information is presented was also identified as an important factor for extending a visit and revisiting an Internet intervention. The navigation structure of the intervention must appear attractive and easy to use, as has been stressed before by Danaher et al [22]. Also, the intervention itself must look attractive at the very fist encounter (within 50 ms since an opinion about visual attractiveness is formed that quickly) [23]. Furthermore, the information obtained needs to be experienced as enjoyable and rewarding, but visitors must also find it usable and easy to understand [36].

An important factor to encourage people to revisit an Internet intervention that is designed for multiple visits is the provision of new content on a regular basis as there may be no need to return if the website does not change over time [4]. To make a revisit attractive, different aspects can be added to make the intervention less static, such as providing iterative tailored feedback or indicating what can be expected in a next visit. Another way to attract people to revisit the intervention is by reminding them, for example through email.

The communication channels most often indicated as potentially effective dissemination strategies were the more traditional channels such as word-of-mouth by family and friends [12], a publicity campaign with simultaneous use of various mass media, and recommendation by health professionals. Also, "old fashion" promotion strategies such as a publicity campaign, TV and radio commercials and programs, and articles in newspapers were seen as effective. The more novel channels, such as SMS, instant messaging, and banners on other websites, were hardly selected as important channels for dissemination.

Limitations

There are some limitations to the study that need to be mentioned. We tried to incorporate experts from several disciplines as well as technical and marketing backgrounds. However, experts from technical and marketing backgrounds were underrepresented and responded less in the second and third round. Thus, the factors that were identified are more strongly based on the expert opinion of health educators and health promoters, and important factors from the technical and marketing field may have been missed. However, consensus was reached for most of the factors, which indicates that there were hardly any differences in the responses of experts from the various fields. Response rates in the various rounds ranged between 40% and 67%. Even though these response rates seem quite low, they are comparable to those found in other Delphi studies [26]. The low response rates may be due to the time investment that was required from the experts. They were asked to complete two or three questionnaires within 3 months. The low response rates may have resulted in the inclusion of a select group of experts, which may have introduced bias. We expect, however, that potential bias due to this selected sample is limited since the experts who participated provided a large variety of potentially important factors and saturation seemed to have been reached. Nevertheless, we cannot completely rule out the possibility that potentially important factors may have been missed. Most nonrespondents did not give a reason for not responding, but those who did mostly reported lack of time.

The Diffusion of Innovations Theory [18] and, within that, the Theory of Planned Behavior [25] that we used as a framework may not have been a complete fit for the present study and may have prevented us from looking at other potentially important factors. Another limitation may be that we tried to get information about various aspects of the process of visiting and revisiting an intervention. This breadth of topics may have been at the expense of the depth of information. The fact that mainly general factors were identified, such as “motivation” or “a rewarding experience,” and not factors that constitute motivation or a rewarding experience may be an indication of this. However, the aim of the present study was to gain a broad insight.

The results of the present study provide information about important factors for a first visit, extended visit, and a revisit that apply to most Internet-delivered behavior change interventions but that are not really intervention specific. Furthermore, not all factors identified in the present study may be equally applicable to all Internet interventions aimed at the primary prevention of chronic disease. That is because there is huge variety in the type of Internet intervention (low-intensity interventions without follow-up to very intensive interventions with up to 1 year follow-up), behavior targeted in the intervention, behavior change strategies applied, and so on. Therefore, for each intervention, the most applicable factors have to be chosen.

Conclusion

In this systematic exploration of potentially important factors determining whether adults visit an Internet-delivered behavior change intervention for the first time, extend a visit, and revisit the intervention, a number of factors were identified that can be taken into account when developing new Internet interventions. Further determinant research is needed to confirm the findings of this study and to identify important exposure-related factors from the perspective of the potential users.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix

Results of the Delphi study per item (second and third round)

[PDF file (Adobe PDF), 108 KB - jmir_v10i2e10_app1.pdf]

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Abbreviations

ICT: information and communication technology
IQD: interquartile deviation
SMS: Short Message Service

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Original Paper

Real World Use of an Internet Intervention for Pediatric Encopresis

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Abstract

Background: The Internet is a significant source of medical information and is now being shown to be an important conduit for delivering various health-related interventions.

Objective: This paper aimed to examine the utility and impact of an Internet intervention for childhood encopresis as part of standard medical care in a “real world” setting.

Methods: Patients diagnosed with encopresis were given a Web-based information prescription to use an Internet intervention for pediatric encopresis. A total of 22 families utilized the intervention between July 2004 and June 2006. A chart review and phone interview were undertaken to collect user characteristics; defecation-related information, including frequency of soiling, bowel movements (BMs) in the toilet, and amount of pain associated with defecation; and information on computer/Internet usage. Three questionnaires were used to examine the utility of, impact of, and adherence to the Internet intervention. Program utilization was obtained from a data tracking system that monitored usage in real time.

Results: Overall, parents rated the Internet intervention as enjoyable, understandable, and easy to use. They indicated that the Internet intervention positively affected their children, decreasing overall accidents and increasing child comfort on the toilet at home. Of the 20 children who initially reported fecal accidents, 19 (95%) experienced at least a 50% improvement, with a reduction of accident frequency from one fecal accident per day to one accident per week. Although it is not clear whether this improvement is directly related to the use of the Internet intervention, patient feedback suggests that the program was an important element, further establishing Internet interventions as a viable and desirable addition to standard medical care for pediatric encopresis.

Conclusions: To our knowledge, this is the first time a pediatric Internet intervention has been examined as part of a “real world” setting. This is an important step toward establishing Internet interventions as an adjunctive component to treatment of pediatric patients in a clinical setting, particularly given the positive user feedback, possible cost savings, and significant potential for large-scale dissemination.

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KEYWORDS

Internet; behavioral intervention; encopresis

Introduction

The Internet has become a vital source of health care and medical information. Approximately 113 million Americans have searched for health-related information on the Internet [1], and a majority of children and adolescents are now online [2]. Parents are more likely to use the Internet than are nonparents, with 83% of adults with a child using the Internet compared to

60% of adults without a child at home [3]. While the vast majority of health-related websites are informational [4,5] a growing number of sites provide health interventions that patients can use to self-treat or use in conjunction with face-to-face treatment [6]. Such Internet interventions are typically behaviorally based treatments that have been operationalized and transformed for delivery via the Internet. They are usually based on empirically validated, face-to-face interventions and are enhanced by graphics, animations, audio, and video. These interventions are generally interactive, highly structured, self-guided or semi-self-guided, personalized to the user, and tailored to provide follow-up and feedback [7].

There is a growing literature on the feasibility and efficacy of Internet interventions for a variety of pediatric disorders, including body image/disordered eating [8-11], weight loss, nutrition, physical activity [12-17], encopresis [18], asthma [19,20], smoking [21,22], pain [23], and traumatic brain injury [24-26]. While studies have shown that Internet interventions can be used to successfully treat a diverse set of pediatric disorders, “real world” use of these interventions (defined as patients being given access to these programs as part of their clinical care as opposed to part of a research study) has not been examined.

In the real world, Internet interventions will likely be sought out directly by consumers or prescribed by a clinician. Clinicians can direct patients and families to Internet interventions using a Web-based information prescription. An information prescription is a “prescription of focused, evidence-based information...to manage a health problem” [27]. We have previously shown that 65% of individuals (77% who receive an email reminder) will visit a website specifically prescribed by their clinician [28]. There are no data, however, that show how patients use and react to the prescription of an Internet intervention within a “real world” setting.

Between 1.5% and 7.5% of children suffer from encopresis [29]; 25% of visits to pediatric gastroenterology clinics [30] and 3% of visits to general pediatric clinics are due to encopresis [31]. In this paper, we examine the utility and impact of an Internet intervention for pediatric encopresis prescribed as part of standard medical care for patients seeking treatment for encopresis at a pediatric gastroenterology clinic in a major medical center. To our knowledge, this is the first attempt to examine the prescription of a pediatric-based Internet intervention as part of standard medical care. It is important to note that this was not a randomized controlled trial, but rather an attempt to examine the use of an Internet intervention as part of clinical care (not as part of a research study) by retrospectively reviewing medical records and conducting phone interviews. While outcome data on defecation related variables were collected and are reported here, improvements in this area cannot be directly attributed to the Internet intervention. Rather, this study examines the users’ perceived impact of the prescribed intervention in the context of their standard medical care.

Methods

Patients

Patients included families with an encopretic child seen at the Pediatric Gastroenterology Clinic at the University of Virginia Children’s Hospital. All children had a documented diagnosis of encopresis, as noted in their medical record, and had been given access to the pediatric encopresis Internet intervention as part of treatment.

Procedure

As part of treatment, the pediatric gastroenterologist seeing the children (SB or JS) provided families with a Web-based information prescription directing them to U-CAN-POOP-TOO, an Internet-based intervention for childhood encopresis (described below). The family provided the gastroenterologist with their email address, and an email message was sent to them with instructions on how to begin using the program.

Patients were seen between July 2004 and June 2006 and were contacted for an interview between June and August 2006 (conducted by KA). This interview occurred anywhere from 2 months to 2 years following their appointment. Relevant patient data were available from the Internet intervention data tracking system (usage data) and medical charts. Consent was obtained at the beginning of the phone interview. This protocol was approved by the University of Virginia Health System Institutional Review Board.

Measures

Data came from three sources: (1) medical charts, (2) the U-CAN-POOP-TOO data tracking system, and (3) a phone interview. The medical chart provided basic demographic and descriptive information, including patient characteristics, contact information, and diagnoses. It also provided history and frequency of soiling, frequency of bowel movements (BMs) in the toilet, and amount of perianal pain the child experienced during defecation. The U-CAN-POOP-TOO data tracking system contained usage statistics of the Internet intervention for each patient, including the number of completed program components.

During the phone interview, the parents were asked questions about the following: additional user characteristics (eg, school grade, developmental delays), retrospective and current bowel-related information (frequency of accidents, BMs on toilet, and pain ratings), and computer/Internet use (how often an individual uses a computer and the Internet as well as their comfort level with both). Three structured questionnaires were completed during the interview. The phone interview also included open-ended questions about what parents believed were the most helpful and least helpful components of the program. The three questionnaires, developed mostly for this interview, included the following:

1. U-CAN-POOP-TOO Utility Questionnaire: This inquired about the extent to which the parent and child found the program useful, enjoyable, understandable, and easy to use. There are 10 items, 8 requiring responses on a 5-point scale from 1 (“not at all”) to 5 (“very”), and 2 items asking what

the most and least helpful aspects of the Internet program were. For the 8 Likert scale items, the alpha coefficient was .69, indicating good internal reliability. It was administered to all parents who had used the U-CAN-POOP-TOO program.

2. U-CAN-POOP-TOO Impact Questionnaire: This asked parents to rate how much they perceived the program helped their child. There are 25 items, and responses are on a 5-point scale from 1 (“not at all”) to 5 (“very”). Parents could also respond with a 0 to indicate that the item was not relevant to them. To establish internal reliability, the items were broken down into five categories, including physical symptoms (alpha = .88), comfort (alpha = .80), worry/mood (alpha = .65), school/social support (alpha = .94), and cost/time (alpha = .64).The questionnaire was administered to all parents who had used the U-CAN-POOP-TOO program.
3. Internet Intervention Adherence Measure: This measure attempts to identify obstacles that interfered with the patient completing the program. Obstacles are categorized as Internet/computer/technical issues, personal/family issues, intervention-general issues, and intervention-specific issues. Patients are asked to respond to the 35 items on a 3-point scale from 1 to 3, indicating whether that obstacle had “no part,” “a little part,” or “a major part” in why they stopped using the program. The measure was administered to patients who stated that they stopped using the U-CAN-POOP-TOO program for some reason other than that their problem was “resolved.” This is an expanded and more detailed measure to the one we used in a previously published paper examining barriers to following through with a Web-based information prescription [28].

Internet Intervention for Pediatric Encopresis (U-CAN-POOP-TOO)

The U-CAN-POOP-TOO program (Figure 1) was developed for the treatment of pediatric encopresis and has been found in a randomized controlled trial to be an effective addition to standard medical care [18]. The child-focused program targets primarily 5- to 12-year-olds, but it was designed to be used by the child and parent(s) together. Using graphics and animation, detailed information is presented through intensive and engaging tutorials. Users are educated about anatomy, physiology, and pathophysiology of digestion (Anatomy Core); clean-out and laxative treatments (Medication Core); and behavioral techniques for treatment of encopresis (Behavior Core). The three core modules of the program (Figure 2) take 60 to 90 minutes to complete, and all users are instructed to review them during the first week. New modules are assigned each week based on a follow-up assessment the user completes about their child’s status. Not all modules are necessarily viewed by all users; only those modules identified as relevant are assigned and encouraged to be reviewed. However, all modules can be viewed by all users. The follow-up is comprised of 17 to 20 questions, depending on the week. The system contains a total of 22 modules, each which takes 5 to 10 minutes to review. See Ritterband et al (2003) for a more detailed description of the program [18].

Figure 1. Screenshot of the “Welcome” page of U-CAN-POOP-TOO

Figure 2. Screenshot of the “Welcome” page of U-CAN-POOP-TOO

Statistical Methods

Descriptive statistics of the 22 subjects included in the data analysis were first computed, including gender, race, age, and education as well as developmental delays, accident history, and the age of the child when toilet training was completed. Repeated-measures analysis of variance and correlations were calculated to examine changes in the main bowel-related variables of interest. Cure and success rates were also computed. Additional descriptive statistics were computed to explore program usage patterns by patients. To examine the impact of computer/Internet usage specifically, a composite *z* score was created for each patient by combining the patient’s email and Internet usage. This composite *z* score was generated by computing a *z* score for each patient by comparing him or her to the overall group mean on each variable (number of standard deviations from the overall mean). The email and Internet *z* scores for each person were then averaged to calculate the composite score. Pearson correlations were computed between the computer/Internet usage *z* scores and the initial to follow-up change scores. Descriptive statistics were calculated based on parents’ responses to the measures of perceived utility and helpfulness of the program, as well as perceived obstacles to completing the program. Finally, responses to the open-ended questions about the least and most helpful aspects of the program were reviewed for clear themes.

Results

Patient Characteristics

Between July 2004 and June 2006, 46 patients seen in the pediatric gastroenterology clinic for encopresis were provided the U-CAN-POOP-TOO Web-based information prescription. Figure 3 shows the flow of patients: 10 patients could not be reached by phone or email for the interview; of the remaining 36 patients, 3 did not provide consent, 3 stated that they never received the initial email with their personalized log-in information, 5 never logged on, and 3 logged on but never viewed any of the intervention material. No subsequent data were collected on these patients. This resulted in 22 patients (13 males and 9 females). See Table 1 for a summary of patient characteristics.

Figure 3. Flowchart of patient enrollment

Table 1. Patient characteristics (N = 22)

Characteristic	
Gender	
Male	13 (59%)
Female	9 (41%)
Race	100% Caucasian
Age	
Range	5 years, 1 month to 12 years, 11 months
Mean (SD)	8 years, 10 months (2 years, 3 months)
Education	
Range	kindergarten to 5th grade
Median	3rd grade
Developmental delays*	3 (14%)
Accident history (duration of encopresis), mean (SD)	44.73 months (26.27 months)
Age of toilet training, mean (SD)†	33.62 months (12.86 months)

*These were based on self-report and were identified as “mild neuromotor processing abnormality,” “fine motor skill problems (in occupational therapy),” and “cerebral palsy.”

†Indicates missing data from initial chart review (N = 21).

Bowel-Related Statistics

Three main bowel-related variables were examined for the initial period and the follow-up period: (1) the number of fecal accidents over a 2-week period, (2) the number of BMs passed in the toilet over a 2-week period, and (3) the average amount of perianal pain experienced during defecation over a 2-week period, based on a 3-point Likert scale from 0 (“none”) to 2 (“a lot”). The initial period was the 2 weeks before the children were enrolled in the program, and the follow-up period was the 2 weeks immediately before the phone interview.

The number of accidents decreased from 13.86 (SD 10.40, median 13.00) during the initial period to 2.14 (SD 2.21, median 1.00) during the follow-up period ($F_{1,21} = 27.29$, $P < .001$). No significant changes were found for the number of BMs in the toilet ($F_{1,20} = .01$, $P < .93$) or the amount of pain the child experienced during defecation ($F_{1,17} = 2.84$, $P < .12$). These results are summarized in Table 2.

Table 2. Initial to follow-up bowel-related statistics (N = 22)

	Initial (Chart Review) Mean (SD)	Follow-Up (Interview) Mean (SD)	*P*
Accident frequency (per 14 days)	13.86 (10.40)	2.14 (2.21)	.001
BMs in toilet (per 14 days)	14.62 (10.68) (N = 21)*	14.82 (8.65)	.93
Pain on defecation	.56 (.78) (N = 18)*	.14 (.47)	.12

*Indicates missing data from initial chart review.

While all patients included in the analyses had a diagnosis of encopresis, two of the 22 patients reported no accidents in the 2 weeks prior to using the system. These same two patients continued to be accident free during the follow-up period. Of the remaining 20 patients, 10 (50%) reported having no more than one accident in the 2 weeks prior to the phone interview. Four patients (20%) were considered “cured” by indicating that they had no accidents during the follow-up period. All but one of the 20 patients (95%) had at least a 50% reduction in accident frequency from the initial to interview period. The median reduction was 7.5 accidents in 2 weeks, supporting the notion that these were substantive improvements.

The number of fecal accidents in the 2-week initial period did not predict the number of accidents at the follow-up period. That is, there were no significant correlations between initial and follow-up periods for accident frequency ($r = .05$, $P < .84$, N = 22), BMs passed in the toilet ($r = .27$, $P < .24$, N = 21), or amount of pain with defecation ($r = −.10$, $P < .71$, N = 18), suggesting that the severity of the symptoms at the time of enrollment did not relate to how much the patient benefited from treatment.

U-CAN-POOP-TOO Use Statistics

Of the 22 patients who used U-CAN-POOP-TOO, 18 (82%) completed all three assigned cores (main treatment components). All 22 patients completed the Anatomy Core; 20 completed the Medication Core; and 18 completed the Behavior Core. A total of 12 patients (55%) completed one follow-up, four (18%) completed a second and third follow-up, and two of these four (9%) completed more than three follow-ups. Modules were individually assigned based on responses to follow-ups; however, patients had access to all the modules. The average number of modules completed was 7.23 (SD 9.64); 14 patients (64%) completed at least one module.

There was significant variability in the amount of time elapsed between when patients were initially given access to U-CAN-POOP-TOO (between July 2004 and June 2006) and the time the phone interview was conducted (between July and August 2006). To examine whether time alone may have been a significant factor in terms of reported encopretic symptoms, patients were divided into three time-based groups with an attempt to make cell sizes roughly even: (1) those enrolled between July 2004 and June 2005 (N = 5), (2) those enrolled between July 2005 and December 2005 (N = 7), and (3) those enrolled between January 2006 and June 2006 (N = 10). No differences were found among these three time groups for changes in accident frequency ($F_{2,19} = 1.93$, $P < .18$), BMs in the toilet ($F_{2,18} = 1.54$, $P < .25$), or pain experienced during defecation ($F_{2,15} = 1.57$, $P < .25$).

Computer/Internet Use

The 22 families reported checking their email 13.18 times per week (SD 14.03) and using the Internet 10.39 hours per week (SD 10.15). On average, they indicated their comfort level using the Internet to be 2.64 (SD .73) on a 5-point scale ranging from 0 (“not at all comfortable”) to 4 (“I’m an expert”). A total of 15 of the 22 families (68%) had high-speed Internet access at home, six (27%) had dial-up access, and one was unsure about the connection speed. The above variables (computer/Internet usage, Internet comfort, and connection speed) were examined to determine whether they affected outcome. No significant correlations were found between computer/Internet usage and the change from initial to follow-up period for accident frequency ($r = .09$, $P < .69$, N = 22), BMs passed in the toilet ($r = .38$, $P < .09$, N = 21), or amount of pain associated with defecation ($r = .08$, $P < .76$, N = 18). Internet comfort and connection speed were also not significantly correlated to changes in any of the bowel-related outcome variables (r values ranged from −.17 to .27; P values ranged from .25 to .59).

Utility of U-CAN-POOP-TOO

In general, parents reported favorable reactions to U-CAN-POOP-TOO. They tended to like the program (mean 4.62, SD 0.50, N = 21) and found it understandable (mean 5.00, SD 0.00, N = 20) and easy to use (mean 4.62, SD 0.74, N = 21). They also believed that their child liked the program (mean 4.05, SD 1.28, N = 21) and found it understandable (mean 4.32, SD 0.89, N = 19) and easy to use (mean 4.47, SD 0.77, N = 19). Those who responded “not applicable” to items on the U-CAN-POOP-TOO Utility Questionnaire were not included in the analysis for that item (explaining the varying sample sizes). In addition to questions about enjoyment, comprehension, and ease of use, parents were also asked what they believed were the most helpful and least helpful components of the program. They found the tutorials about anatomy and pathophysiology to be one of the most helpful aspects of the program. They also liked that the program was geared toward the child, but that it was comprehensive and nonjudgmental. No clear themes emerged from the “least helpful” question.

Impact of U-CAN-POOP-TOO

The U-CAN-POOP-TOO Impact Questionnaire was administered to examine how much the parents believed the program affected outcome. Those who responded “not applicable” were not included in the analysis for that item. On average, 19 out of 25 items (76%) were rated at least “somewhat helpful,” and no item was described as “not at all helpful.” On the 1- to 5-point scale, average responses ranged from a low of 2.33 (the program helped reduce the number of times parents had to remind their child to use the bathroom) to a high of 4.2 (the program helped the child feel more comfortable using the toilet at home). See Table 3 for a listing of individual items.

Table 3. U-CAN-POOP-TOO Impact Questionnaire

Question: How much did the U-CAN-POOP-TOO program help (from 1 “not at all” to 5 “very”)	No.*	Mean (SD)
Physical Symptoms		
Decrease the number of overall accidents	17	3.71 (1.21)
Decrease the number of accidents at school	14	3.43 (1.28)
Decrease the number of accidents at home	16	3.56 (1.26)
Increase the number of times your child goes to the bathroom on his/her own	17	2.94 (1.39)
Reduce the number of times you, the parent, had to remind them to use the bathroom	18	2.33 (1.46)
Decrease the use of diapers during the day	7	3.00 (1.29)
Decrease the use of diapers during the night	5	2.80 (1.20)
Increase number of BMs in the toilet	17	3.65 (1.27)
Your child have less pain with defecation	9	3.44 (1.13)
Improve your child’s appetite	9	3.33 (1.41)
Reduce your child’s stomach pain	12	3.17 (1.19)
Comfort		
Your child feel more comfortable using the toilet at home	20	4.20 (1.01)
Your child feel more comfortable using the toilet at school	15	2.67 (1.59)
Your child feel more comfortable using the toilet out (restaurants, mall, etc)	16	2.69 (1.66)
Worry/Mood		
Reduce your child’s worry about something ‘bad’ happening when s/he is on the toilet	10	3.20 (1.40)
Reduce your child’s worry about having a BM; ie, worried about pain or stool not coming out	10	3.50 (1.08)
Reduce your child’s worry about having accidents	16	3.50 (1.16)
Improve your child’s mood (happier, more confident)	17	3.41 (1.18)
School/Social		
Increase school attendance	3	3.00 (1.73)
Improve school performance	7	3.00 (1.41)
Improve participation in sports and social activities, like scouts, visiting friends, religious groups	13	2.46 (1.20)
Improve peer relationships/friendships	14	3.00 (1.18)
Improve relationships with family	17	3.59 (1.37)
Related Cost/Time		
To what extent do you believe this Internet intervention helped reduce the number		
…of visits with your doctor/doctor’s office?	14	3.07 (1.27)
…of phone calls with your doctor/doctor’s office?	14	3.14 (1.70)

[*] Those who responded “not applicable” were not included in the analysis for that item (explaining the varying sample sizes).

Adherence

Of the 22 patients examined, 16 indicated that they stopped using the program for some reason other than that their problem was “resolved.” They were administered the Internet Intervention Adherence Measure, the questionnaire used to identify obstacles to using the program. Based on the responses, only two items had a mean score of 2 or greater (on a 1- to 3-point scale). They were “I just forgot [to go to the website]” (mean 2.00, SD 0.89) and “I didn’t have time in my schedule” (mean 2.06, SD 0.85). Notably, these were the same top two obstacles identified in our previous study examining the use of Web-based information prescriptions [27].

Discussion

This paper examined the utility and impact of an Internet intervention for childhood encopresis provided as a Web-based information prescription in a “real world” situation. Based on parent participant report, there was an almost universal belief that the system had a substantive and positive effect on their child. When parents were asked to rate their perception of the impact of the Internet intervention, they indicated that the Internet program helped decrease the number of accidents and increase the child's comfort in using the toilet at home. Parents also believed that the system helped reduce their child's physical symptoms of encopresis and level of worry, improved their child's mood, and increased and improved their child's school and social activities. Additionally, parents believed that U-CAN-POOP-TOO helped reduce the number of calls and visits to their doctor, implying that there may be cost reductions with the use of the program.

Accompanying improvements in defecation-related variables were reported, including a marked decrease in fecal accident frequency from the initial to follow-up period in this sample of patients. However, it cannot be determined if this improvement is directly attributable to the Internet intervention due to the major limitation of not having a control group. This precludes reaching a definitive conclusion as to whether the Internet intervention caused the improvement. Yet, while the lack of a control group makes it impossible to state that the intervention led to the observed improvements, parents clearly indicated that they believed the program played an important and substantive role in their child's success.

Other Limitations

In addition to the lack of the control group, there are some other limitations with this "real-world" analysis that should be considered when interpreting these results. Parents articulated two difficulties in answering certain questions during the phone interview. Parents frequently stated that they had difficulty differentiating whether or not a certain outcome (eg, reduced number of accidents, improved school attendance) was due to the medications/laxatives their child was taking or due to U-CAN-POOP-TOO. More often than not in these cases, parents tended to assign most or all of the credit to the medication, making the findings reported here more conservative. Parents also noted that the questions did not take into account a change (decrease) in the volume of the accidents. Some parents stated that there was improvement but that this was not reflected in their answers as their child was still having accidents (just smaller accidents).

Another limitation of this paper relates to who was given the Web-based information prescription and the patients who were ultimately included in the analyses. Patients were not systematically identified or consecutively selected; instead, the physician used his own judgment as to whether a patient would be appropriate for receiving the Web-based information prescription. This judgment was based on the presentation of the family related to issues such as disorganization, apparent motivation, and readiness to change. This certainly limited the number of patients included but fits more appropriately with the notion of a "real world" prescription in that clinicians will likely provide Web-based information prescriptions to those whom they believe would benefit as opposed to providing it to everyone. It is not known what proportion of the overall clinic might have been deemed to benefit.

The final group used in the analyses was relatively small and all were Caucasian. These issues make it inappropriate to generalize these findings to a larger or more diverse population. Also, two of the 22 patients were not actually having accidents in the 2 weeks immediately prior to using the Internet intervention. They did, however, have a diagnosis of encopresis and reported accidents prior to this 2-week period. There is also an issue regarding the difference in time when patients used the program. Some patients accessed U-CAN-POO-TOO as long as 2 years before the interview, while others accessed it as recently as 2 months prior. However, in all the subanalyses conducted to examine this issue, no differences were found in any of the primary variables among groups of patients separated by varying enrollment dates.

Finally, not everyone who was given access to U-CAN-POOP-TOO used the program. Those who stopped using it for reasons other than resolution of their child's encopresis identified lack of time and forgetfulness as two of the main barriers. This is consistent with our previous findings showing these as two of the most common barriers to families following through with Web-based information prescriptions [28]. However, it is important to reiterate that even given the number of patients who stated that they stopped using the system prior to the resolution of their problem, most of those had at least a 50% reduction in accident frequency. In addition, they indicated that the program had a substantive impact on symptom reduction. It is also worth noting that these patients might have appeared as "dropouts" in a clinical trial, but their perception is that the program made a difference in their care.

Conclusions

This paper has important implications for the treatment of pediatric health problems using Internet interventions. These results indicate that parents believe Internet interventions can be helpful to their children outside of clinical trials. Although an increase in the development, testing, and use of Web-based applications is already occurring [32-34], this study lends additional support for the importance of this work. Given the potential for cost savings and the capability of large-scale dissemination of Internet programs, their appeal is obvious. While testing of the feasibility and efficacy of these types of interventions is increasing [35], this is, to our knowledge, the first "real world" study documenting patients' perceived impact and utility of an Internet intervention in a pediatric population. Additional feasibility, efficacy, and real-world effectiveness studies are necessary to increase acceptance of Internet interventions and clearly establish their usefulness in the treatment of a variety of pediatric disorders.

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Authors' Contributions

LR designed the study and wrote the manuscript. KA carried out the protocol, contacted all patients, and helped draft the manuscript. FT participated in the design of the study and provided substantial editing of the manuscript. JM performed the statistical analyses and helped edit the manuscript. DS provided help in editing the manuscript. DC participated in the design of the study and provided help in editing the manuscript. JS participated in the design of the study and provided help in editing the manuscript. SB participated in the design of the study and provided help in editing the manuscript. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

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Abbreviations

BM: bowel movement

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Original Paper

Supporting Emerging Disciplines with e-Communities: Needs and Benefits

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Abstract

Background: Science has developed from a solitary pursuit into a team-based collaborative activity and, more recently, into a multidisciplinary research enterprise. The increasingly collaborative character of science, mandated by complex research questions and problems that require many competencies, requires that researchers lower the barriers to the creation of collaborative networks of experts, such as communities of practice (CoPs).

Objectives: The aim was to assess the information needs of prospective members of a CoP in an emerging field, dental informatics, and to evaluate their expectations of an e-community in order to design a suitable electronic infrastructure.

Methods: A Web-based survey instrument was designed and administered to 2768 members of the target audience. Benefit expectations were analyzed for their relationship to (1) the respondents' willingness to participate in the CoP and (2) their involvement in funded research. Two raters coded the respondents' answers regarding expected benefits using a 14-category coding scheme (Kappa = 0.834).

Results: The 256 respondents (11.1% response rate) preferred electronic resources over traditional print material to satisfy their information needs. The most frequently expected benefits from participation in the CoP were general information (85% of respondents), peer networking (31.1%), and identification of potential collaborators and/or research opportunities (23.2%).

Conclusions: The competitive social-information environment in which CoPs are embedded presents both threats to sustainability and opportunities for greater integration and impact. CoP planners seeking to support the development of emerging biomedical science disciplines should blend information resources, social search and filtering, and visibility mechanisms to provide a portfolio of social and information benefits. Assessing benefit expectations and alternatives provides useful information for CoP planners seeking to prioritize community infrastructure development and encourage participation.

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KEYWORDS

Dental informatics; Internet; faculty, dental; education, dental, continuing; education, dental, graduate

Introduction

Science as a Collaborative Activity

Over the centuries, science has developed from a solitary pursuit into a team-based collaborative activity and, more recently, into a multidisciplinary research enterprise [1-3]. The increasingly collaborative character of science, mandated by complex research questions and problems that require many competencies, is evidenced by the creation of large research networks that share data or jointly use unique instruments. Barriers to such networks have been lowered by the advent of the Internet, which can provide an underlying electronic infrastructure for large collaborative efforts. Disciplines such as astronomy would not have developed as rapidly without joint construction and use of billion-dollar facilities; disciplines such as genomics cannot quickly advance without cross-correlating output data using a jointly developed sequence archive.

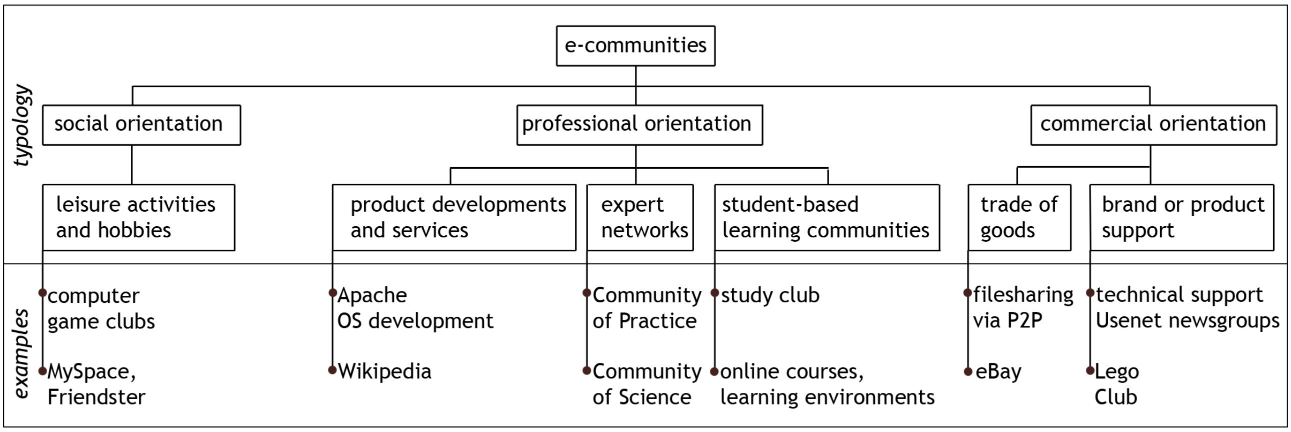
Biomedical research follows this trend closely, due in large part to federal funding initiatives such as the National Institutes of Health (NIH) Roadmap, which encourages the formation of multidisciplinary research teams as outlined in its “Research Teams of the Future” theme [4]. Recently, the NIH funded 12 institutions under its Clinical and Translational Science Awards (CTSA) program, which is designed to accelerate the transfer of results from basic science to clinical practice—an inherently multidisciplinary goal. Some of the awardees are trying to advance the science of doing science through collaboratively developed electronic applications, transforming their academic research centers into communities of science [5].

Typology of e-Communities

However, the emergence of e-communities is not limited to multidisciplinary research teams but can be observed in many different contexts. E-communities have long been used to support collaboration among professionals and researchers [6-8]. More generally, e-communities are often created to facilitate interaction between people with similar needs, problems, or goals [9,10]. Considerable research has been devoted to characterizing these communities, making it possible to conceptually identify and describe pathways that can accelerate their emergence in the field of biomedical research.

E-communities can be characterized according to social, commercial, or professional orientation [11] (Figure 1). Social e-communities, such as MySpace [12], Friendster [13], and Facebook [14,15], evolve around leisure activities or hobbies. These communities originally consisted primarily of social software tools allowing members to meet new people. Commercial e-communities like eBay, which provides a platform for auctions among its worldwide community of 168 million members [16], focus on facilitating the marketing and selling of goods. Professional e-communities are formed around shared professional interests and can broadly be divided into entities focused on product development and services, expert-based knowledge networks, or student-based learning communities [17]. Examples of product- or service-based e-communities are the 75,000 contributors to the online encyclopedia Wikipedia [18] or the 2014 active developers [19] who work on Apache, an open source software product that has claimed 67% of the Web server market [20]. Expert-based knowledge networks, also referred to as communities of practice (CoPs), seek to expand, develop, and document existing knowledge by facilitating interaction between practitioners and researchers interested in a field.

Figure 1. Characterization of e-communities (derived from [11])



Communities of Practice

CoPs focus on one domain of knowledge and the accumulation of knowledge and expertise in this domain over time [21]. For instance, CoPs allow education professionals to support one another and enhance teaching [7,22]. An example of such an e-community is the Multimedia Educational Resource for Learning and Online Teaching (MERLOT) [23]. Organizational CoPs support efficiency and learning among knowledge workers [24]. According to Johnson, who distinguishes CoPs from traditional organizations, research communities have members with “different levels of expertise…simultaneously present,” allow for a “fluid peripheral to center movement that symbolizes the progression from being a novice to an expert,” and support “completely authentic tasks and communication” [25]. CoP participants receive new factual information, solutions to problems, and learning and insight [26]. Tapped In, for instance, allows isolated education professionals to support one another’s teaching efforts [7], and Math Forum promotes communication among researchers, practitioners, administrators, and students interested in the study and teaching of mathematics [22]. These benefits are derived from information that is socially embedded, existing in the context of interpersonal and group interaction, unlike the neutral authority-based information found in traditional sources such as journal literature [27].

Compared with the research performed on social and commercial e-communities and on professional e-communities focused on product development or services or on learning, research on CoPs lags behind. A thorough search for literature evaluating how well these systems facilitate the initiation of collaborations yielded no results. Judging from anecdotal evidence, systems of this type currently do not play a significant role in helping researchers establish collaborations. However, it is this type of e-community that is crucial for the transformation of biomedical research. Little is known about how socially embedded benefits can be exploited for the formation of CoPs. However, this is what programs like the CTSA aspire to, advancing science through communication among scientists from different fields with disparate primary research agendas. The research described in this paper focuses on the role e-communities can play in the genesis and growth of new or loosely formed fields or disciplines.

Case Study: The Dental Informatics Online Community

The field examined in this case study is dental informatics (DI), which, unlike its parent discipline, biomedical informatics, can still be characterized as a nascent discipline [28]. Bridging different disciplines, DI is similar to other emerging disciplines such as pharmacogenetics and consumer health informatics. DI, which can be defined as the application of computer and information science to improve dental practice, research, education, and program administration [29], faces major challenges to establishing itself [28,30]. These challenges are similar to those of other emerging disciplines and include, for instance, a small, slowly growing number of geographically dispersed, experienced, trained researchers and the absence of a dedicated professional infrastructure such as a society or standing annual conference [31]. Therefore, DI seems to be an appropriate context for a study of how to overcome the characteristic challenges and hasten the development of emerging disciplines through collaborative electronic applications.

To these ends, a global e-community, the Dental Informatics Online Community (DIOC), is being established (Figure 2). Supported by an electronic infrastructure, the DIOC’s three project charges are as follows: (1) encouraging and supporting the formation of partnerships and collaborative projects in DI, (2) promoting the development of DI resources, and (3) disseminating research results and best practices. Ideally, the DIOC can provide a dedicated professional home for DI researchers and serve as an open, common, and worldwide forum for all individuals interested in the field.

Figure 2. Screenshot of Dental Informatics Online Community (DIOC) home page

The Virtual, Global Community
for Anyone Interested in Dental Informatics
Funded by the National Library of Medicine

This community will help you to find resources in the dental informatics and dental technology field as well as connect you to other people to share ideas, problems and research opportunities. Become a member!

Search the DIOC Website, Member profiles and Publication Archive

What is Dental Informatics?

Project Directory Released. As of December 2007, the new Project Directory is avaialbe. The goal of the Project Directory is to allow members to display what projects they are working on, find collaborators, and learn about possible funding opportunities.

Member Directory Released. As of November 2007, the new Member Direcotry is availabe. The goal of the Member Directory is for people interested in Dental Informatics to share information about themselves including their research, interests, location, publications, funding, cooperation partners, and even a recent picture.

Learning Center Released. As of November 2006, the Learning Center is available. Please explore this resource which serves as starter for everyone new to dental informatics. The FAQ-like format allows you to navigate easily to the questions you always wanted to ask. Let us know if you can't find the answer to your question!

New Publication Archive. Have you ever had problems trying to find research papers about dental informatics? Our archive contains over 950 papers related specifically to dental informatics.

Become a member. Members of the DIOC can get notified about new developments in the field, can add information to DIOC, can leave comments on all pages, update their personal profile and access other members' profiles, and add keywords to papers in the archive. Members are not restricted to a specific discipline, association membership, nationality or qualification, and membership is free. Register here.

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Informatics in the UK
Spring 2007: Professor Kenneth Eaton releases a special issue of UK Health Informatics Today containing multiple articles about Dental Informatics.

Release
Nov 13, 2006: Release of the first two interactive modules of the DIOC after extensive development work.

NLM Grant
Dec 9, 2005: With a priority score of 129, the G08 application has been selected for funding by the National Library of Medicine.

AMIA Support
Jan 31, 2005: American Medical Informatics Association continues support for DIOC by providing $2,000 seed funding.

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Challenges for New Communities of Practice

The DIOC, like any other new CoP, first needs to attract and retain a critical mass of participants by, for instance, widely advertising the expected benefits of participation. Unlike traditional information systems, a CoP depends on volunteers to provide content. Thus, after attracting participants, CoPs need to foster active participation. Studies of participation demographics in multi-user communities and social networks have found that between 46% and 82% of users are lurkers who never contribute [32]. While participation inequality cannot be entirely overcome, it must be recognized and addressed in order to achieve a reasonable diversity of contributing sources. On the other hand, legitimate peripheral participation should not be discouraged [33]. Even if the highly active core of members is the most crucial source of information, a viable e-community needs a steady flow of members with a range of commitment levels—peripheral and moderately engaged as well as highly active. CoPs generally strive not to encapsulate their members but instead to help them succeed outside the community. An external orientation is crucial because the DI research community has a responsibility to educate the wider dental community about DI's scope and potential contributions.

The first step in attracting participants to a new CoP and then transforming many of them into active contributors is to determine the information needs of the target audience. There is general recognition that a needs assessment is the first step in any project that aims at providing useful information for a specific target audience [34-36]. While there is a large body of literature on the information needs of clinicians and health consumers, very few studies target the specific information needs of nonclinical biomedical researchers. The Faculty BurdenSurvey, evaluating the workload of university researchers, has shown that scientists spend 42% of their research time filling out forms and attending meetings. The results also reveal researchers' struggles to find research partners and hire research personnel [37]. A distinguishing feature of researchers' information needs is that they are not limited to bibliographical information or textbook facts, but also include knowledge about research infrastructure in such areas as funding, policy, and the training pipeline. Early studies show that scientific research is communal, reflecting a strong network of interconnected scientists who use formal and informal channels of information exchange [38-40].

This analysis leads to three main research questions:

1. Which information resources do researchers currently prefer to use?
2. How can their current professional relationships be described?
3. What are their expectations of a CoP, and how are these influenced by factors such as amount of participation necessary for a sustainable e-community and level of involvement in funded research?

The answers to these questions can assist with outlining the basic requirements for an e-community whose goal is to accelerate the emergence of a new discipline. While other successful e-communities could partially be used to model the DIOC, creating a community for a field in its formative stages requires more than just copying and pasting features and functions of e-communities for well-established disciplines. Thus, a needs assessment of prospective members was undertaken.

Methods

Instrument

A review of the literature did not identify an existing instrument suitable for determining information needs and expected benefits. Thus, our first task was to develop such an instrument. Informal interviews with a convenience sample of four active DI researchers suggested some common information needs and revealed a strong desire for peer communication. Problems they identified with finding information sources as well as information needs identified in published studies were used as the starting point for an original survey instrument. These initial items were then developed and refined using Dillman's Tailored Design Method [41] and principles from Thinking about Answers [42]. The survey design, delivery, and responses are reported here according to the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) [43]. The final draft included 22 questions and was tested in a two-step process:

1. An expert group (three DI faculty [TKS, HS, TPT], three medical librarians [PMW plus two others], one business school faculty member [BSB], and one business school doctoral student [XW]) provided qualitative feedback. As a result of their evaluation, two questions were dropped, 12 were revised, and the texts of the preamble and email invitation were altered.
2. Nine volunteers from the target population participated in an evaluation using the Retrospective Thinkaloud protocol as suggested by Sudman at al [42]. This method avoids many of the pitfalls of concurrent narration such as disturbing the normal process of thinking about the answers. Volunteers received the survey ahead of time via email as an MS Word (Microsoft Corporation, Redmond, WA, USA) document with instructions not to open it before a 30-minute phone interview, during which we did the following:

- asked them to answer one survey question at a time
- engaged them in a short follow-up discussion after each answer
- inquired about the methods used to arrive at each answer
- logged their answers, problems, or comments
- solicited final comments and general suggestions

Evaluation of phone interview data resulted in further revision of seven of the 20 survey questions: in four cases, wording was not sufficiently comprehensive; in three, questions were too specific; in two, questions were misinterpreted. In addition, two more questions were eliminated, and two questions were combined into one.

The final version of the survey instrument included 17 items that were presented on one screen: five demographic questions, including current position; one question on expectations regarding the DIOC; six questions regarding professional relationships; and four questions about information-seeking behavior. There was also a general comments section at the end of the survey.

Three question formats were used. Two questions were open-ended, asking for extended text input; five questions were open-ended, with short answers such as age; and nine questions provided multiple-choice options. The question regarding participants' expectations branched differently depending on whether or not they had already signed up for the DIOC; those who had signed up were also asked how they had learned about it (see the Multimedia Appendix).

The study was approved by the University of Pittsburgh's Institutional Review Board in May 2006.

Target Population

To increase the likelihood that the survey would provide representative data encompassing the needs of all people interested in DI, the composition of the prospective target audience was first determined. In addition to including clusters of people easily accessed through established gatherings such as the American Dental Education Association (ADEA) TechnoFair, an annual teaching technology showcase event of dental educators, we wanted to cover the possibility of unanticipated subgroups that might have their own membership or meeting organizations. To that end, we analyzed a set of 620 Medline abstracts identified for a 2003 study [31]. The combined approaches identified 12 distinct recruitment groups (Table 1).

Table 1. Distribution of target population across interest/source groups

Group Description*	Email Addresses, No.	Survey Respondents, No. (%)
Personally approached at AADR, ADEA 2006	113	28 (24.8)
Authors of 620 DI papers	910	58 (6.4)
AMIA DI working group member list	44	13 (29.5)
IMIA DI working group member list	133	24 (18.0)
Bioinformatics researchers with dental interest	11	3 (27.3)
ADEA TechnoFair authors (2004, 2005, 2006)	369	48 (13.0)
Current DIOC members	211	92 (43.6)
2003 DI conference participants	82	15 (18.3)
MLIS community	110	6 (5.6)
MLA (randomly selected 385 of the 3850-member directory)	385	6 (1.6)
280 funded informatics researchers (randomly selected 100)	100	1 (1.0)
9000 funded dental researchers (randomly selected 300)	300	14 (4.7)
Total	2768	–
Total after eliminating duplicates	2609	–
Total after eliminating duplicates and validating	2303	256† (11.1)

*AADR, American Association for Dental Research; ADEA, American Dental Education Association; DI, dental informatics; AMIA, American Medical Informatics Association; DIOC, Dental Informatics Online Community; MLIS, Master of Library and Information Science; MLA, Medical Library Association.

†Total number of respondents is smaller than sum of group respondents because some individuals belong to more than one group.

Email addresses for individuals in the groups were obtained using two main approaches. Where member directories for organizations such as the American Medical Informatics Association (AMIA) DI working group were accessible, addresses were extracted directly from them. If member directories were not accessible, names and institutional affiliations were extracted from other publicly available sources; for example, current email addresses of the authors of 620 known DI papers from Medline [31] were obtained by manual search of their respective institutional websites. Duplicate email addresses within each group were eliminated.

At the time of the survey, the DIOC website had been operating and accepting registrations for 6 months. Although many DIOC features were not yet functional, 211 people had registered after finding the site either through publicity or their own search. These individuals were also invited to participate in the survey.

All 2768 email addresses in the combined groups (see Table 1) were entered into a database (MySQL version 5.0.18; Sun Microsystems, Santa Clara, CA, USA). Duplicate entries were eliminated, but all information about group association was retained. In this intermediate collection, there were 2609 unique email addresses.

It was incidentally noted that after merging the 12 groups, there were only 158 duplicate addresses, indicating a very shallow overlap among target audience sectors. The majority of people who had not signed up for the DIOC (2354, 98.1%) belonged to just one of the sampled organizations; 40 were members of two organizations, and 5 belonged to three organizations. Among the 211 DIOC members, 136 (64.4%) did not belong to any other organization; 61 belonged to one other organization, 11 belonged to two others, and 3 belonged to three others. These observations are consistent with the common characterization of DI as a diverse but somewhat fragmented community. Overall, then, the sample seemed to include both a very small core of widely active participants and a large body of peripherally involved individuals.

In order to calculate a more accurate response rate, we tried to filter out nonexisting email addresses by programming an add-on to Sendmail (version 8.13.1; Sendmail Inc, Emeryville, CA, USA) and emailing the invitations from the server it ran on (Linux 2.6.9, Red Hat 3.4.5/Apache 2.2.0; Red Hat Inc, Raleigh, NC, USA; Apache Software Foundation, Forest Hill, MD, USA). The add-on program recorded and flagged 306 email addresses as nonexistent. After this process, 2303 unique email addresses remained. However, it was not possible to detect email accounts that, while technically operational, had been abandoned by users. As a result, the response rates reported here are biased low.

Delivery Format

A Web-based format was chosen for the survey instrument because it significantly reduces turnaround time compared with mail surveys [44]. Because the goal is to establish an online community, concerns about Web-based surveys being biased toward computer users were not a significant issue [45]. All data were stored on a state-of-the-art administered server with LAMP architecture.

Invitations to complete the survey were emailed and included a unique access code to prevent both duplicate entries and completion by people who were not part of the target audience. Prospective participants were informed of how long the survey would take, who the investigators were, and that the data would be used for scholarly purposes only. Incomplete surveys could be submitted by respondents since no validation of user entries was performed. Thus, response rate for each question was different, as reported in the survey results below.

The initial invitation was emailed on June 1, 2006. A reminder was sent on June 14, 2006, and a final reminder was sent on July 10, 2006. No incentives were provided to any respondents.

Data Analysis

After the survey closed on August 10, 2006, all response data in the MySQL database were exported to an MS Excel (Microsoft Corporation, Redmond, WA, USA) spreadsheet stored on a secure local file server. The majority of the survey questions required quantitative responses and could thus be analyzed with little or no additional manipulation. The open-ended questions regarding expected benefits of the CoP were coded into categories by two raters [BB, HS]. After agreeing on a 14-category coding scheme, both raters independently coded all individual responses. Disagreements on coding for specific items were resolved through discussion.

Analysis of the data included descriptive characterization of information-seeking and collaboration-related needs, examination of differing expectations within meaningful subsets, and identification of respondent clusters with distinctive expectations for a research-oriented online community. Comparison of the subsets was based on chi-square tests of difference in the relative proportions of the reported expectations. A two-step cluster analysis (implemented in SPSS version 15.0; SPSS Inc, Chicago, IL, USA) was used to determine the degree of homogeneity in benefit expectations. This exploratory procedure uses comparisons of individual responses (in this case, the benefits expected by each respondent) to identify sets of similar individuals. Examination of relative scores and *t* test results were then used to determine the specific benefits or benefit combinations that distinguished one cluster from the others.

Results

Response Rate and Demographics (Questions 12-17)

The response rate of 11.1% (256/2303) is based on the validated, unique email addresses. Of the 211 individuals already signed up as DIOC participants, 92 (44% of group and 36% of all respondents) completed the survey (see Table 1).

On average, respondents were 46.4 years old, had held their current title for 7.9 years, and had been at their current institution for 11.6 years. The 249 respondents to the question on country of residence reported living in 30 different countries (Table 2). A plurality held academic positions of varying rank; many of the others identified themselves as students, dental practitioners, or scientists (Table 3). To assess the representativeness of the respondents, we compared their main professional activity with our initial target group association using Pearson correlation. We found no significant correlation between the respondents' main professional activity and their initial target group association ($P < .05$).

Table 2. Distribution of respondents' country of residence (partial list, only countries mentioned at least three times)

Country	No. (%)
United States	139 (54.3)
Germany	15 (5.9)
Canada	10 (3.9)
United Kingdom	7 (2.7)
Netherlands	7 (2.7)
India	6 (2.3)
Australia	4 (1.6)
Sweden	4 (1.6)
Italy	4 (1.6)
Japan	3 (1.2)
Missing responses	7 (2.7)
Total number of respondents	249 (97.3)
Total	256 (100)

Table 3. Distribution of respondents’ academic positions (partial list, only positions mentioned at least twice)

Academic Position	No. (%)
Full professor	36 (14.1)
Associate professor	35 (13.7)
Department chair/CEO/director	25 (9.8)
Postgraduate student	21 (8.2)
Dental practitioner	18 (7.0)
Scientist	17 (6.6)
Consultant	13 (5.1)
Administrator	11 (4.3)
Librarian	7 (2.7)
Dean	6 (2.3)
Predoctoral student	3 (1.2)
Dental hygienist	2 (0.8)
Missing responses	25 (9.8)
Total number of respondents	231 (90.2)
Total	256 (100)

Information-Seeking Behavior (Questions 1, 2, 5, 6)

Table 4 shows that electronic resources dominate as information sources for the target audience when asked, “How often do you use the following information sources when trying to find professional information?”

Table 4. Use of information sources*

Information Source	Frequently, No. (%)	Sometimes, No. (%)	Never, No. (%)	Total
Medline (via Ovid, PubMed, EMBASE, Web of Knowledge, or other database provider)	196 (80.3)	35 (14.3)	13 (5.3)	244
Internet search engines (Google, Yahoo, Lycos, etc)	186 (83.4)	35 (15.7)	2 (0.9)	223
Online journals (e-print, full-text archives of print journals, etc)	184 (78.6)	48 (20.5)	2 (0.9)	234
Print journals	114 (47.5)	117 (48.8)	9 (3.8)	240
Books from your personal collection	103 (44.4)	113 (48.7)	16 (6.9)	232
Conferences, lectures, etc	94 (40.7)	134 (58.0)	3 (1.3)	231
Researchers within my institution	89 (38.7)	115 (50.0)	26 (11.3)	230
Researchers from other institutions	70 (30.7)	143 (62.7)	15 (6.6)	228
Books from/in libraries	61 (26.3)	137 (59.1)	34 (14.7)	232
Bibliographic databases such as… Cochrane Database of Systematic Reviews or other Cochrane Library components	61 (26.5)	93 (40.4)	76 (33.0)	230
Newsletters	60 (26.0)	127 (55.0)	44 (19.0)	231
National or local media (newspapers, television, etc)	51 (22.0)	114 (49.1)	67 (28.9)	232
Other information source: which?	48 (60)	32 (40)	N/A	80
IEEE Xplore	20 (9.4)	41 (19.3)	151 (71.2)	212

*Responses to the following question: “How often do you use the following information sources when trying to find professional information?”

Asked about the existence and use of an institutional library, 213/251 respondents (84.9%) indicated that they have access to one, and 194 (91.1% of those indicating access) do use it either physically or virtually.

There were 162 responses to an open-ended question regarding the manner in which the respondents find out about research funding. Funding resources were identified mostly through visits to known funding agencies' websites, frequently those of NIH. Next in frequency were various forms of intra-institutional notification; personal communication, including not only formal contact but also informal word of mouth; and use of general Web search engines. Among the 16 resources that were categorized as aggregating services, Community of Science was mentioned most often.

Professional Relationships (Questions 3, 4, 7-9)

Respondents were asked about collaboration, with collaborator defined as "co-author, co-investigator, consultant to a specific project" (Question 3). During the previous 12 months, 193 respondents had, on average, worked with 10 collaborators. Table 5 summarizes collaborator origins.

Table 5. Origin of collaborators during the past 12 months (multiple selections were permitted)

Options for Origin of Past Collaborators	No. (%)
Come from my department	179 (92.7)
Come from other institutions with faculty specializing in my area of interest	173 (89.6)
Come from my institution, outside my department	172 (89.1)
Are people with whom I have collaborated in the past	170 (88.1)
Are people with whom I have conducted relevant research	133 (68.9)
Are people whom I met at conferences, conventions, etc	119 (61.7)
Are people to whom I was introduced to by a colleague	111 (57.5)
Other	38 (19.7)

When asked where they usually find research assistants (Question 4), most of the 248 respondents reported getting help from inside their institution (mentioned 86 times, 34.7%), from past helpers (mentioned 74 times, 29.8%), or from inside their department (mentioned 69 times, 27.8%) rather than from recruitment services within (mentioned 43 times, 17.3%) or outside (mentioned 26 times, 10.5%) their organization.

On average, respondents attend five professional meetings per year (based on 245 respondents to Question 7). Relevance of the meeting agenda to one's general research interests, relevance to particular research projects, and potential for networking with fellow researchers were the crucial criteria used in deciding meeting attendance (Table 6). Less important were whether the conference featured an esteemed researcher and the availability of funding to support attendance.

Table 6. Factors influencing conference attendance*

Factor	Very Important, No. (%)	Somewhat Important, No. (%)	Not Important, No. (%)
Relevance of agenda to my general research interests	168 (65.6)	51 (19.9)	7 (2.7)
Relevance of agenda to a particular research project	122 (47.7)	85 (33.2)	14 (5.5)
Conference features an esteemed researcher	48 (18.8)	121 (47.3)	49 (19.1)
Likelihood of attendees' research interests coinciding with my own	82 (32.0)	108 (42.2)	31 (12.1)
Networking with fellow researchers	109 (42.6)	90 (35.2)	21 (8.2)
Availability of funding to support attendance	88 (34.4)	73 (28.5)	60 (23.4)
Ability to present my own work	92 (35.9)	91 (35.5)	37 (14.5)
Other	34 (13.3)		
Missing responses	7 (2.7)		
Total number of respondents	249 (97.3)		
Total	256 (100)		

*Responses to the following question: "To what degree do the following factors influence whether you attend a particular conference or not? (Rate the factors.)"

Respondents were asked if they belonged to specific dental and informatics organizations (Question 9). They could augment their response by entering up to three additional organizations; 130 respondents (56.3%) belonged to the International Association for Dental Research (IADR), 97 (42.0%) to the American Dental Education Association (ADEA), and 77 (33.3%) to the American Dental Association (ADA). A total of 88 respondents were members of one of the listed organizations, 59 of two organizations, and 30 of three organizations. The most common write-in choices were European dental research and medical specialty organizations.

Expectations for the DIOC (Questions 10, 11)

Participants who had already signed up for the DIOC were asked about what kinds of benefits they expected from their involvement. Those who had not signed up were asked how they thought an e-community might help them with their research; 64% (164/256 respondents, both groups combined) reported at least one type of expected benefit. The two raters coded the individual responses on a 14-category coding scheme (Kappa = 0.834), concentrating on how benefit expectations related to (1) the respondents' willingness to participate in the DIOC and (2) how this willingness was related to involvement in funded research (Figure 3).

DIOC Versus Non-DIOC Participants

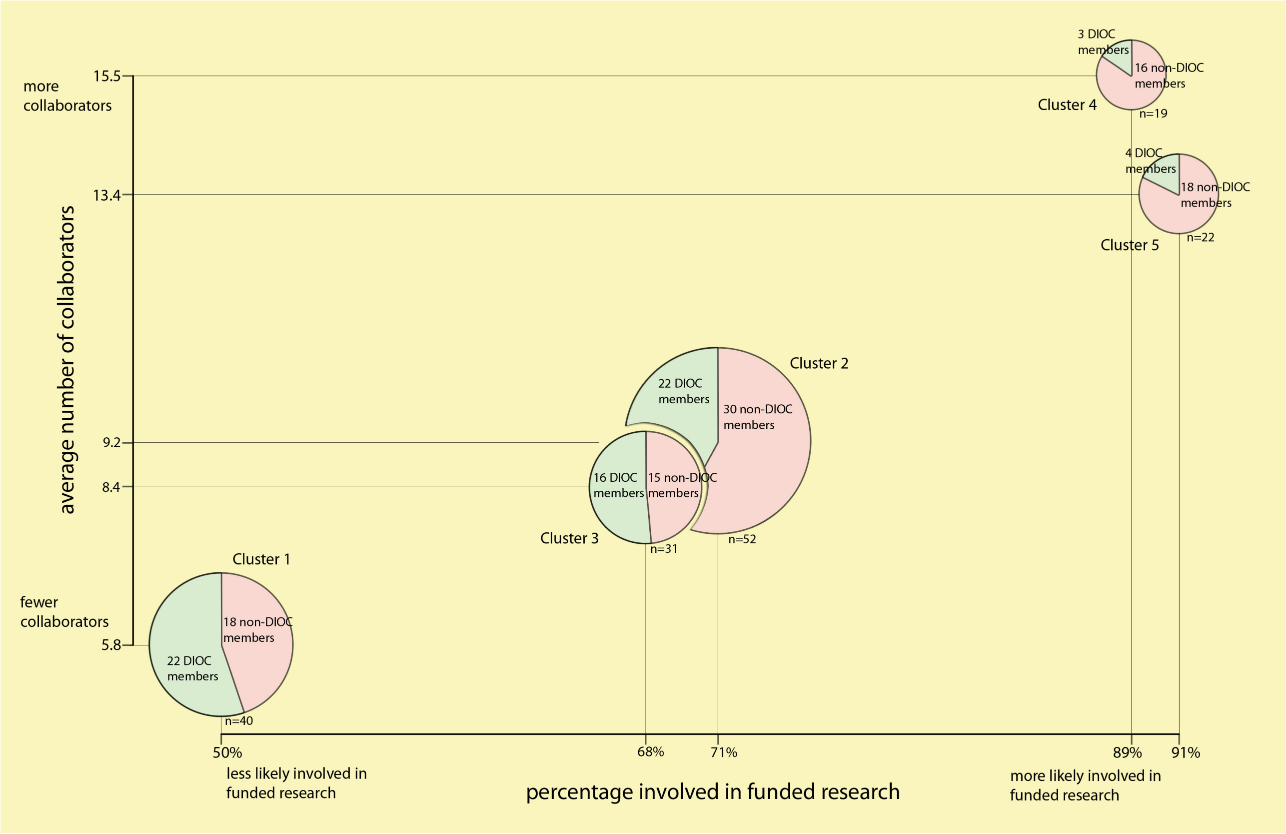
Individuals who had already signed up for the DIOC tended to expect more specific benefits from the community than those who were not yet registered, including general information, identification of experts, networking with peers, advocacy support, and career development (Table 7). However, there may have been confounding factors such as the different question construct (see Multimedia Appendix for the survey instrument) and the fact that DIOC members were primed by reading the goals of the community when they initially signed up.

Table 7. Comparison of expected benefits mentioned by different groups

Benefit Category	DIOC Membership			Research Funding			Total, No. (%), (n = 164)
	Non-Member, No. (%), (n = 97)	Member, No. (%), (n = 67)	*P* *	Funded, No. (%), (n = 115)	Not Funded, No. (%), (n = 49)	*P* *	
Information Benefits	72	63		93	42		135
General information	38 (39.2)	47 (70.1)	< .001	56 (48.7)	29 (59.2)	.15	85 (51.9)
Funding information	18 (18.6)	4 (6.0)	.02	20 (17.4)	2 (4.1)	.02	22 (13.4)
Specific topic	10 (10.3)	7 (10.4)	.59	12 (10.4)	5 (10.2)	.60	17 (10.4)
Teaching materials	4 (4.1)	2 (3.0)	.53	3 (2.6)	3 (6.1)	.25	6 (3.7)
Data sharing	2 (2.1)	3 (4.5)	.33	2 (1.7)	3 (6.1)	.16	5 (3.1)
Social Benefits	45	69		74	40		114
Peer networking	21 (21.6)	30 (44.8)	.00	35 (30.4)	16 (32.6)	.46	51 (31.1)
Identification of potential collaborators and/or research opportunities	19 (19.6)	19 (28.4)	.13	30 (26.1)	8 (16.3)	.12	38 (23.2)
Advocacy support	2 (2.1)	9 (13.4)	.01	5 (4.3)	6 (12.2)	.07	11 (6.7)
Expert identification	1 (1.0)	6 (9.0)	.02	2 (1.7)	5 (10.2)	.03	7 (4.3)
Participation in the field	2 (2.1)	5 (7.5)	.10	2 (1.7)	5 (10.2)	.03	7 (4.3)
Instrumental Benefits	3	8		7	4		11
Career development	1 (1.0)	7 (10.4)	.01	4 (3.5)	4 (8.2)	.19	8 (4.9)
Recruiting	2 (2.1)	1 (1.5)	.64	3 (2.6)	0 (0.0)	.34	3 (1.8)
Other Benefits	23	11		26	8		34
Uncertain	17 (17.5)	3 (4.5)	.01	18 (15.6)	2 (4.1)	.03	20 (12.2)
Unclassifiable	6 (6.2)	8 (11.9)	.16	8 (7.0)	6 (12.2)	.21	14 (8.5)
Average number of benefits cited per respondent	0.87	1.64		1.24	0.99		

[*] Determined by chi-square analysis.

Figure 3. Benefit clusters



Funded Versus Not Funded Research

The approximately 70% of respondents who participate in funded research were significantly more likely to expect the DIOC to be a source of funding information and opportunities (see Table 7). Number of collaborators, an indicator of research involvement, was positively correlated with the expectation that the DIOC might provide information about funding opportunities (Spearman correlation = 0.164, *P* = .049) and recruiting (Spearman correlation = 0.184,*P* = .03). By contrast, individuals not participating in funded research were more likely to expect the DIOC to help them with expert identification and opportunities to participate in the field.

Active researchers were significantly more likely than non-researchers to express uncertainty concerning the potential benefits of participation in the DIOC. Number of collaborators was also positively correlated with the likelihood of a respondent reporting uncertainty (Spearman correlation = 0.229, *P* = .01). Tenure in current position was negatively correlated with expectations of receiving general information benefits (Spearman correlation = −0.18, *P* = .03).

Benefit Clusters

Overall, the most frequently expected benefits from participation in the DIOC were general information (eg, exchange of ideas, keeping well informed), mentioned by 51.9% of respondents; peer networking (eg, finding colleagues with same interests), mentioned by 31.1%; and identification of potential collaborators and/or research opportunities, mentioned by 23.2%. Two-stage cluster analysis revealed five identifiable clusters, each associated with a distinctive collection of benefit expectations (see Figure 3):

- Cluster 1: General information
- Cluster 2: General information and social benefits (collaboration, peer networking, etc)
- Cluster 3: General information and peer networking
- Cluster 4: Uncertainty
- Cluster 5: General information and collaboration opportunities

General information benefits were widely mentioned across all clusters, but responses regarding social benefits varied. While 58% mentioned some type of social benefit, the cluster analyses suggest that some individuals seek general information alone, while others expect general information combined with peer networking and collaboration opportunities.

In addition to reflecting specific combinations of benefits, the clusters were also distinguished by the characteristics of the individuals associated with them. Individuals in Clusters 1 and 2 tended to have fewer collaborators, be less likely to be doing funded research or using online search resources (Medline, Cochrane Library), and be more likely to have signed up for the DIOC. By contrast, members of Cluster 4 were proportionately more likely to be participating in funded research and to have a higher number of collaborators. Members of Cluster 5 were more likely to have a higher number of collaborators, more likely to be doing funded research, and less likely to have signed up for the DIOC.

Knowledge About the DIOC

Of the individuals who had already signed up for the DIOC, 36/91 respondents (40%) learned of it via an Internet search engine, 26 (29%) received an electronic announcement, 19 (21%) heard about it during a conference, and 22 (24%) specified other sources. Respondents were allowed to select multiple responses for this question.

Discussion

Principal Findings

Any online community must attract a critical mass of involved participants if it is to be sustainable. Individual researchers develop expectations about the benefits of involvement, and these benefit expectations play a significant role in their satisfaction with, commitment to, and, ultimately, participation in an e-community [46]. While information needs continue to figure prominently in expectations, researchers are increasingly seeking support for the social aspects of information use and tools that support formation of collaborative relationships. Understanding benefit expectations (both on their own and in the larger socio-informational context) and developing technical infrastructure and resources to meet them are critical to facilitating biomedical research with CoPs.

Information Needs and Implications for Community Design

Up-to-date information resources are a foundational element of any planned CoP. Access to a variety of timely information was often mentioned as a desirable benefit of involvement in the DIOC by individuals across all clusters. The DIOC's planned information stores, including general information about DI as well as more specific resources such as a project directory, address this need.

The ideal is for community participants to generate a significant proportion of information resources themselves in such forms as detailed personal profiles, postings to the project directory, and tags, comments, and other annotations. But it may be difficult to quickly attain and then sustain such a goal to a degree that satisfies researchers accustomed to immediate access to plentiful and readily available traditional library resources—not to mention the abundant, if unvetted, resources of the Web. In addition, a CoP needs to offer an attractive breadth and depth of material without creating an undue content creation burden on each participant. Thus, DIOC planners may need to allocate ongoing funds for creation and maintenance of information resources to augment content created by participants, such as a mix of searchable databases and interactive features that can accommodate the anticipated range of user expectations and behavior. Whether this challenge exists for research-oriented CoPs in general is a question for future research.

Just as respondents judge the value of a conference or meeting by how well its topic matches their interests or has particular relevance to a specific research project, potential CoP participants see information resources as an indication of the fit between community activities and their own needs and interests. However, since any one individual is likely to be interested in only a fraction of the available material, CoP architectures and interfaces must include targeting and filtering capabilities. For example, CoPs should aggregate timely information about funding opportunities relevant to their prospective audiences and automatically alert users to new funding opportunities in a targeted manner. These notifications need to match user subject interests and accommodate user preferences [47-50].

Social Information Use and Implications for Community Design

The high degree of reliance on personal communications and word of mouth (mentioned 34 times out of 162 responses) indicates that even with electronic alerts and Internet searches, personal communication remains a significant source of information about funding opportunities for our respondents. This finding matches the results of earlier studies regarding the information-seeking behavior of dentists [51].

To support social information seeking and sharing, CoPs need infrastructure for both direct communication (such as document sharing and referrals) and indirect information sharing (via collective tagging or public annotation of informational items). CoPs also should provide contexts such as message boards and forums in which individuals who lack well-developed interpersonal networks can observe and participate in group discussion. Allowing CoP members to annotate, comment on, and discuss information will not only add value to the CoP, but will also encourage the building of trust and knowledge in the community, which are important elements in the development of computer-mediated interaction [52-54].

Collaborative Relationship Needs and Implications for Community Design

Discipline- and research-oriented CoPs need to support professional relationships among members, enabling individuals to find potential collaboration partners and to form and maintain relationships. Our respondents' collaborations originated almost equally from inside and outside their own departments and institutions, substantiating the findings of Griffith and Miller [39]. The global character of the DIOC makes it a potential site for forming collaborations outside members' local institutions.

One key aspect of relationship formation is visibility. Increasing the visibility of individuals, their interests, and their intentions helps catalyze effective professional relationships. Each CoP member should be able to create and maintain a profile accessible to all, enabling subscribers to construct and develop verifiable identities within the community [52]. Profiles should not only include interests, location, collaboration partners, and publications, but should also point to information contributed to the CoP as a trace of the subscriber's activity. A project directory and a research opportunity exchange will help members learn about each others' current activities, find help for their own projects, and join projects in early stages as collaborators.

In addition to forming collaborative relationships with other individuals or other participant subgroups, individuals also want to develop and maintain awareness of what the overall community is doing. Emerging disciplines usually do not support a standing professional meeting, but CoPs can provide at least a partial substitute for that aspect of scholarly activity and for the networking opportunities generally available at traditional professional meetings. As mentioned above, it is hoped that the DIOC will substitute for a standing DI conference and serve as a professional home for researchers who primarily dedicate their career to this emerging discipline, allowing virtual affiliation without travel. Again, closely linked project and people directories that let members learn about ongoing projects and who is responsible for them are key resources.

Online Communities as Part of a Complex Socio-Informational Ecology

Respondents with higher numbers of collaborators and involvement in funded research were more likely to express uncertainty about the benefits of participation. They were more likely to mention general information and collaboration opportunities as expectations, while those with fewer collaborators and no funded research participation mentioned social benefits such as expert identification and advocacy support. These differing profiles, coupled with the significant negative correlation between tenure in an organization and the expectation of general information benefits, underscore the fact that academic online communities such as the DIOC are competing with individuals' own environments—their networks, institutions, and other immediately available resources.

Unlike traditional information systems, which are typically seen as the only, or at least the primary, source of information of a particular type within an organization, CoPs operate within a much broader, highly competitive social-information ecology. CoPs compete with individuals' own local resources, so persuading time-pressured researchers to move from habitual exclusive reliance on known resources to exploring new tools and techniques in the interest of improving long-term productivity is a key challenge [5].

Individuals uncertain about benefits were proportionately more common among those who had not signed up for the DIOC ($P < .05$), highlighting the need to clearly demonstrate the benefits of participation during the recruitment process. In general, CoP planners faced with competition and potential users' ambiguity need to consider the benefit stream visible to individuals approaching the community for the first time. They should provide an immediate payoff and participation incentives for first-time members of all types, with collaboration opportunities for those wanting a social context and straightforward information benefits for those whose expectation of social benefits is lower.

However, in complex ecological systems, attempting to "win" simply by direct competition can be a costly approach that often fails. The CoP planner should look for ways in which the presence of related resources and systems supports the goals of the community. For example, the use of online information sources by DI researchers, the emergence of the Internet as an important tool for dentists [55], and the advent of Google as an important clinical information resource for physicians [56] can be seen as either a competitive threat or an opportunity. Individuals' reliance on online searching creates several positive externalities that CoP planners can take advantage of. CoPs can use state-of-the-art user interface design and search technology that is already familiar to the target group (eg, similar to those of Google or PubMed). Application programming interfaces and other affordances already provided by such applications can facilitate integration into the presentation of CoP resources. Lastly, the presence of a developing ecology of information sources and social computing tools allows CoP planners to incorporate resources and capabilities into a community without bearing the full cost of development and maintenance.

Taken together, these results characterize both the promise and the challenge of academic online communities. On the one hand, CoPs present clear benefits for individuals who are more isolated, less connected, and lacking in access to local institutional resources; these participants can, in return, increase the diversity and impact of an otherwise fragmented discipline such as DI [57,58]. On the other hand, they do require contribution of resources by their members if they are to provide substantial ongoing benefits [59]. Contribution in the form of participation creates a stronger and more valuable community. But ability and willingness to contribute are, in part, dependent on one's local environment [60]. Thus, academic e-communities such as the DIOC face a paradox: the individuals best qualified to contribute to them are the least likely to see them as providing resources or benefits beyond those already available in their own professional milieus.

Yet the structure of the clusters in the DI community suggests a possible solution. By building a base of commonly valued information resources and providing individuals with the ability to pick and choose the nature of their social engagement with the community, the DIOC can provide an infrastructure that brings together a diverse group of individuals with complementary needs. Identifying the interlocking contribution-benefit pairs allows them to be addressed, and leveraged, during implementation [61]. Frameworks and strategies for identifying and working with complementary pairing of contributions and benefits should be pursued in future studies of CoPs.

Limitations

A response rate of 11.1% is low but within the expected outcome range [62] given the fact that many of the email addresses used came from sources of unknown update status such as academic department home pages. The validation process eliminated some but not all of the invalid addresses. Thus, the reported response rate, while more accurate than it would have been without address validation, is likely to be an underestimate of the true response rate. Because a part of the results focuses on DIOC members, one needs to consider the influence of our earlier announcements as well as the material provided to the members on the preliminary website during sign-up. The specific language used in the marketing—"get involved…communicate with peers…disseminate research results…formation of research and education partnerships"—may have skewed baseline expectations.

Data about current position and country of residence show that respondents were well distributed across the spectrum of the intended target audience. The results seem to reflect the fact that interest in DI is spread among many different countries and pursued by people in various academic and clinical positions.

However, it is possible that the selection of 12 target audience groups might not be entirely inclusive.

Some of the general comments made on the concluding survey question ("Is there anything else you'd like to tell us?") criticized our US-centric view. While it is true that most of the professional organizations listed as choices for membership were US-based, the results of our pilot tests did indicate predominance of US respondents. However, a pro-US bias might have influenced question constructs and results.

This study relied on self-reported data, which may be incomplete and/or incorrect. For instance, respondents might have unperceived information needs that they did not report [35].

Conclusions

We were able to assess the information needs of dental informaticians, researchers, educators, clinicians, and other interested parties. Data on expected benefits of a CoP for DI were collected and evaluated, allowing compilation of requirements for the creation of the DIOC.

The survey itself has increased the awareness of the DIOC project. Casual observation has shown that DIOC registration spiked in the wake of the various survey invitations and reminders.

Future work should focus on validating the instrument used in this study as well as carefully applying our findings to other emerging biomedical research fields such as consumer health informatics.

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Conflicts of Interest

None declared.

Multimedia Appendix

Survey instrument, including branching differences

[PDF file (Adobe PDF), 81 KB - jmir_v10i2e19_app1.pdf]

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Abbreviations

CoP: community of practice
CTSA: Clinical and Translational Science Awards
DI: dental informatics
DIOC: Dental Informatics Online Community
NIH: National Institutes of Health

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